symposium article

Patient-centered care: the key to cultural competence

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Much of the early literature on ‘cultural competence’ focuses on the ‘categorical’ or ‘multicultural’ approach, in which providers learn relevant attitudes, values, beliefs, and behaviors of certain cultural groups. In essence, this involves learning key ‘dos and don’ts’ for each group. Literature and educational materials of this kind focus on broad ethnic, racial, religious, or national groups, such as ‘African American’, ‘Hispanic’, or ‘Asian’. The problem with this categorical or ‘list of traits’ approach to clinical cultural competence is that culture is multidimensional and dynamic. Culture comprises multiple variables, affecting all aspects of experience. Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality. Culture is therefore a very elusive and nebulous concept, like art. The multicultural approach to cultural competence results in stereotypical thinking rather than clinical competence. A newer, cross cultural approach to culturally competent clinical practice focuses on foundational communication skills, awareness of cross-cutting cultural and social issues, and health beliefs that are present in all cultures. We can think of these as universal human beliefs, needs, and traits. This patient centered approach relies on identifying and negotiating different styles of communication, decision-making preferences, roles of family, sexual and gender issues, and issues of mistrust, prejudice, and racism, among other factors. In the current paper, we describe ‘cultural’ challenges that arise in the care of four patients from disparate cultures, each of whom has advanced colon cancer that is no longer responding to chemotherapy. We then illustrate how to apply principles of patient centered care to these challenges.

Key words: patient, care, communication, culture

five ‘cultures’

Four 65-year-old patients with stage IV colon cancer present to the medical oncology clinic to discuss treatment options. All have extensive lung metastases and malignant pleural effusion causing shortness of breath. Their cancers have progressed despite extensive chemotherapy.

The first patient is a Kuwaiti Muslim woman who is covered from head to toe in a burka. She is accompanied by her oldest brother, her husband, a sister, and one of her sons. Her brother intercepts the Arabic interpreter in the hallway to ask that we not disclose the diagnosis of cancer or any other bad news.

The second patient is an American Jewish woman who is experiencing rapid respiratory deterioration from pulmonary involvement. We discuss goals of care, and we recommend transitioning to palliative care, since additional anticancer therapy is likely to be risky and ineffective. She and her husband are determined to continue chemotherapy to ‘keep fighting and go down swinging’. They view death as failure.

The third patient is a US Viet Nam veteran from rural Mississippi who wears a camouflage hat, Harley Davidson T-shirt, and worn military fatigue pants. He has post-traumatic stress disorder, smoked heavily until he became short of breath, and drinks 6–10 beers per day. I ask him: ‘What is your understanding of your illness?’ He replies in a deep southern drawl: ‘Doc, I know I am pretty bad. I just don’t want to take stuff that’s going to make me more sick.’

The fourth patient is an African American man who is admitted to the hospital with cancer-related fatigue. He is confined to bed the majority of the day. He was the sixth of nine children in a family with limited means, and he was the first to attend college. He served on the law review of a prestigious east coast law school. Before retirement, he worked as a lawyer in a large firm specializing in business transactions. He is receptive to the idea of transitioning to palliative care without anticancer therapy, but his daughter is adamantly resistant to such a change. She is angry no matter what we say or do. The patient initially agrees to ‘no code’ status, but she convinces him to remain ‘full code’. His daughter says ‘I am sure the good Lord will save my father. We have to keep praying for a miracle.’

Both of us have seemingly little in common with the above patients. I (DEE) am a Caucasian American Jewish middle-aged medical oncologist whose grandparents immigrated to America a century ago to escape anti-Semitism in Eastern Europe. I was raised in an upper middle class household. None of my grandparents went to college, but all their children and grandchildren did. I (WB) am a fourth generation Caucasian male from Irish American stock who grew up in a middle class Catholic neighborhood. Unlike the Kuwaiti woman, neither of us speaks Arabic nor visited Kuwait. Both our wives and
the ‘dos and don’ts’ or ‘list of traits’ approach to cultural competence in the clinic

What does the literature on ‘cultural competence’ tell us about how to care for these four patients, seemingly from very different cultures? Much of it focuses on the ‘categorical’ or ‘multicultural’ approach, in which providers learn relevant attitudes, values, beliefs, and behaviors of certain cultural groups. In essence, this involves learning key ‘dos and don’ts’ for each group. For instance, ‘People from country A think establishing direct eye contact is bad luck’, or ‘People of ethnic group B are distrustful of the US health care system.’ Literature and educational materials of this kind focus on broad ethnic, racial, religious, or national groups, such as ‘African American’, ‘Hispanic’, or ‘Asian’.

The problem with this categorical or ‘list of traits’ approach to clinical cultural competence is that culture is multidimensional and dynamic [1, 2]. Some people from country A avoid eye contact, whereas others do not. Some people of ethnic group B are distrustful of the US health care system, while others are not. According to the Oxford English Dictionary, ‘culture’ refers to the ideas, customs, and social behavior of a particular people or society. Anthropologists emphasize that culture is not a single variable but rather comprises multiple variables, affecting all aspects of experience [3]. Culture is inseparable from economic, political, religious, psychological, and biological conditions. Culture is a process through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants [3]. Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality [3]. Culture is therefore a very elusive and nebulous concept, like art.

‘Culture’ is a term that is vaguely conceptualized and inaccurately used in medical training and practice. Cultural concepts are often taught as being synonymous with race or as a catch-all, monolithic term to describe people who appear physically similar and are thought to have the same beliefs, values, and behaviors [4]. This multicultural approach results in stereotypical thinking rather than clinical competence.

For example, consider the 65-year-old Kuwaiti Muslim woman described above. What information does ‘Kuwaiti Muslim’ convey? Can we conclude she does not want to be informed about her condition just because her brother requests we not disclose her diagnosis or other bad news? Can we conclude she has lived in Kuwait her entire life, comes from a large family, and has not received higher education? She may live in Paris 6 months of the year, speak three languages, and work as a consultant for an energy company. She may have raised three children who were educated in the US. Lack of accountability for variations perpetuates stereotypes and diverts attention from accurately assessing individual patients and their families.

Each cultural group, such as Ashkenazi Jewish or African American, is not a monolithic, static group. In any multicultural society, each cultural group is constantly undergoing modifications and mixtures that make it different from the cultural group of origin. Consider the African American man with advanced colon cancer described above whose angry daughter adamantly resists his decision to transition off anticancer treatment. Is she distrustful, having read about the Tuskegee Syphilis Study and segregation, or simply grieving the impending loss of her beloved father, as she would regardless of her racial background? Is she from a religious faith that believes decisions about dying rest in God’s hands? Broad generalizations about culture are not clinically useful.

‘cross-cultural’ approach

A newer approach to culturally competent clinical practice focuses on foundational communication skills, awareness of cross-cutting cultural and social issues, and health beliefs that are present in all cultures. We can think of these as universal human beliefs, needs, and traits. This approach relies on identifying and negotiating different styles of communication, decision-making preferences, roles of family, sexual and gender issues, and issues of mistrust, prejudice, and racism, among other factors [5-13]. Table 1 summarizes a few models of effective cross-cultural communication and negotiation with key references. Table 2 lists cross-cultural clinical skills as defined by the Association of American Medical Colleges (AAMC).

Cultural competence has thus evolved from making assumptions about patients on the basis of their background to the implementation of the principles of patient-centered care [14,15]. In this model, communication skills such as exploration, empathy, and other techniques are the gateway to understanding patients’ needs, values, and preferences. Culturally competent providers expand this repertoire to include skills that are especially useful in cross-cultural interactions [16]. Excellent medical care thus combines sophistication in scientific knowledge with equally sophisticated communication skills to understand the needs of the individual patient, to address his/her feelings and concerns with sensitivity and compassion, and to educate patients about their choices in care [17].

Culturally competent medical practice describes a skill set that enables a physician to respectfully elicit from the patient...
Table 1. Models of effective cross-cultural communication and negotiation [25]

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<tr>
<th>Kleinman’s questions [12]</th>
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<tr>
<td>What do you think has caused your problem?</td>
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<td>Why do you think it started when it did?</td>
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<tr>
<td>What do you think your sickness does to you?</td>
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<td>How severe is your sickness? Will it have a short or long course?</td>
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<tr>
<td>What kind of treatment do you think you should receive?</td>
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<td>What are the most important results you hope to receive from this treatment?</td>
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<tr>
<td>What are the chief problems your sickness has caused for you?</td>
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<td>What do you fear most about your sickness?</td>
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<th>Table 2. Association of American Medical Colleges (AAMC) Cross-Cultural Clinical Skills</th>
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<tr>
<td>Knowledge, respect, and validation of differing values, cultures, and beliefs, including sexual orientation, gender, age, race, ethnicity, and class</td>
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<tr>
<td>Dealing with hostility/discomfort as a result of cultural discord</td>
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<tr>
<td>Eliciting a culturally valid social and medical history</td>
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<tr>
<td>Communication, interaction, and interviewing skills</td>
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<tr>
<td>Understanding language barriers and working with interpreters</td>
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<tr>
<td>Negotiating and problem-solving skills</td>
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<tr>
<td>Diagnosis, management, and patient-adherence skills leading to patient compliance</td>
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And family the information needed to make an accurate diagnosis and negotiate mutually satisfactory goals for treatment. The physician needs to ask questions that build trust necessary for the patient to confide in the physician. Finding out what matters most to another person requires more than outstanding communication skills. Caring for the patient also depends on an affinity for the patient [3]. Franz Kafka said ‘a born doctor’ has ‘a hunger for people’ [3]. The main thrust of cultural competence is focus on the patient as an individual, not a stereotype; as a human being facing danger and uncertainty, not merely a case; as an opportunity for the doctor to engage in an essential moral task [3]. If we were to reduce culturally informed care to one activity that even the busiest clinician should be able to find time to do, it would be to routinely ask patients (and where appropriate family members) what matters most to them in the experience of illness and treatment. Clinicians can then use that crucial information in thinking through treatment decisions and negotiating with patients [3].

In this paper, we describe what we consider to be principles of ‘patient-centered cultural competence’ to guide busy clinicians in the care of vulnerable cancer patients, regardless of their race, nationality, religion, socio-economic status, education, or other background. We will focus on practical approaches relevant to the clinical encounter rather than system or political issues, such as those that lead to health disparities. These principles and related skills are summarized in Table 3.

**key elements of patient-centered cultural competence (summarized in Table 3)**

‘Please don’t tell my sister’

Let’s reconsider each of the four patients with stage IV colon cancer described at the beginning of this paper by applying key elements of patient-centered cultural competence to conversations with them. What is the best approach to address the 65-year-old Kuwaiti woman’s brother’s request for non-disclosure? First, we should acknowledge that a request for non-disclosure is not a ‘cultural’ phenomenon. Such requests are not uniquely ‘Kuwaiti’, ‘Middle Eastern’, or ‘Muslim’. Some people from Kuwait (or for that matter, Kentucky or Kurdistan) delegate all health-related discussions to family members, whereas others handle those discussions themselves. Regardless of country of origin, some people prefer not to dwell on bad news, whereas others want as much information as possible so they can plan for the future.

Second, most people generally understand the gravity of their illness even without being told details. The Kuwaiti woman knows her extended family did not travel with her by plane for 24 hours to the US to address a trivial health issue. She may only read Arabic and may therefore be unable to understand the words ‘Cancer Centre’ on the sign out front, but she nonetheless knows she has a serious health condition. Despite her knowledge, she may not want to discuss details or hear the word ‘cancer’.

What is the Kuwaiti woman’s brother really saying when he asks that we not disclose the diagnosis or any bad news? Finding out can be as simple as asking ‘What are your concerns?’ [18]. This approach is likely to resonate with her brother, because he, like everyone, has a profound need to be
Table 3. Principles of patient-centered cultural competence and relevant skills, phrases, and examples

**Foundational skills relevant to all principles (represented by the acronym 'PREP')** [30]

- Preparation: establish the right frame of mind and plan before seeing the patient
- Respect: show respect, since patients are vulnerable and need our assistance
- Environment: create a comfortable setting for the patient and family
- Presentation: represent the profession and the work we do

**Principles**

**Principle 1: Everyone has a profound need to be heard and to be understood.**

- Inviting the patient to tell the story of his illness is itself therapeutic.
- Exploring the patient’s concerns gets you tuned in to his agenda.
- Taking a personal history allows the patient to feel as if you are interested in him as a person, not only as a patient.

**Relevant skills, phrases, and examples**

- Listen attentively when the patient talks
- Explore: ‘Tell me more’
- Allow space (silence) in the conversation
- Use open ended questions
- Invite the patient narrative
  - ‘Please tell me what you understand about your condition.’
  - ‘What would you like to discuss today?’
  - ‘Tell me about your family.’

**Principle 2: All people really care about is being cared about**

- Telling the patient and her family you will treat them as if they were part of your family, and then doing so, builds trust and rapport.
- Responding to emotion with empathy allows a patient to feel you are tuned in to her.

**Relevant skills, phrases, and examples**

- Create the right atmosphere: be friendly, greet everyone in the room, sit at eye level
- Respond to emotion with empathy
  - ‘I wish things were different.’
  - ‘This must be very difficult for you.’
  - ‘I can see you were hoping for better news.’

**Principle 3: Family is an extension of the patient.**

Almost all people have a profound love for and loyalty to family, especially immediate family. Asking a patient about his family opens an emotional window.

**Relevant skills, phrases, and examples**

- Acknowledge the work of the family:
  - ‘I am impressed by the love between you and your family.’
  - ‘You have done a great job supporting your wife through her treatment.’
- ‘What do your children understand about your illness?’
- Partner with patient and family

**Principle 4: Words can harm and words can heal** [20].

- As the cliché goes, ‘It is not what you say but how you say it.’
- Giving information in a way that a patient understands strengthens your connection to him.

**Relevant skills, phrases, and examples**

- Saying ‘there is nothing more we can do for you’ is inaccurate and harmful
- Saying ‘I wish we had better treatments for you. I think we need to focus on your quality of life and dignity’ is healing
- Be clear, avoid jargon, and keep explanations geared to the patient. People need the truth… delivered sensitively.
- Balance optimism with credibility

**Principle 5: Physical touch is a powerful force that can be destructive or healing**.

- If you are a man, do not extend your hand to a woman unless she extends hers first.
- If you do not know how to greet someone, simply smile and nod respectfully.
- Maintain modesty during the physical exam.

**Principle 6: Non-verbal cues are powerful**

People transmit as much or more information by non-verbal cues as they do by words.

**Relevant skills, phrases, and examples**

- Be perceptive and adaptive. Strong emotions, such as fear, sadness, pain, and anxiety, are usually obvious.
- Address the patient’s suffering immediately if they obviously appear to be in pain.
- Establish eye contact with the patient that is commensurate with their eye contact with you. If they avert your gaze, establish less eye contact.
is often useful to ask your sister with great respect and compassion, just as I would exploring the brother carefully to his concerns and validate them. Saying request for non-disclosure as a golden opportunity to listen speak to her. Please show her compassion. 

This latter approach builds trust and rapport and shows we are essentially inseparable. You obviously love your sister a great deal. I love my sister, so please be sensitive about how you hear and understood. He is most likely to reply something like 'I am concerned my sister will not be able to handle the stress of knowing she has cancer. I am afraid she will simply give up.' Many people believe that informing the patient of a terminal diagnosis may hasten death [19]. He may also reply 'I am her older brother, so I have a responsibility to look out for her wellbeing.' This scenario illustrates how patient and family are essentially inseparable.

A request for non-disclosure represents both a challenge and an opportunity. We should resist the temptation to argue about patient autonomy, privacy laws, and other regulations. The patient and family should have as much control over the situation as possible. The following adversarial approach can be very damaging: 'You know we have rules about patient autonomy in this country. We need to fully inform your sister about her condition.' A better strategy is to recognize the patient’s and her family’s fear, and respond accordingly with empathy: 'I can understand how stressful this must be for you and your family. You obviously love your sister a great deal.' This latter approach builds trust and rapport and shows we care [20]. In the final analysis, all people really care about is being cared about, which is a variation on Peabody’s advice to Harvard medical students in 1925: ‘The secret of the care of the patient is in caring for the patient.’ [21]. The patient’s brother is not literally saying ‘Do not tell her,’ but is saying in essence ‘I love my sister, so please be sensitive about how you speak to her. Please show her compassion’. We should view his request for non-disclosure as a golden opportunity to listen carefully to his concerns and validate them. Saying ‘Tell me more’ and allowing for silence in the conversation solidifies the relationship by allowing her brother to be heard. Beyond exploring the brother’s concern, we might also ask ‘What do you think she already suspects about her illness?’ Finally, reassuring her brother by sincerely saying ‘I promise to treat your sister with great respect and compassion, just as I would my own sister’ builds trust and rapport.

When discussing sensitive information with the patient, it is often useful to ask ‘How much would you like to know about your illness?’ [19] or ‘Would you prefer I discuss your diagnosis with you, or with your family?’ [22]. While it is true that in times of uncertainty patients and families rely on the expertise of the physician, it is also true that most patients want to be informed and take part in decisions about their health care. While some cultures may defer to the expertise of the doctor almost all of the time, asking about their involvement communicates respect and caring.

Thus an important communication axiom has to do with monitoring one’s own reactions to cultural disparities. As physicians, we may feel the family is unnecessarily intruding into our relationship with the patient. Nonetheless, a rigid approach that insists that our own local cultural norms be followed can subvert the ultimate goal of providing excellent patient care. Most patients and their families ultimately understand the practical and emotional value of full disclosure, but they wish to receive information incrementally and sensitively. Some families prefer to disclose sensitive medical details to patients in their own ways and at their own pace. We can then assess the patient’s understanding later with exploratory questions and careful listening. Approaching requests for non-disclosure with an open, curious, and compassionate attitude builds trust and rapport, and results in more effective communication over the trajectory of illness.

doctors have feelings too

There are times when clinicians legitimately feel uncomfortable discussing sensitive information with family members or other designees rather than directly with the patient. For instance, consider a patient (not described above) with locally recurrent rectal cancer who delegates all detailed discussions about his condition to family members. The multidisciplinary team decides to offer pelvic exenteration followed by adjuvant chemotherapy and possibly radiation if surgical margins are involved. Treatment will result in a colostomy, urinary

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<td><strong>Principle 7: Spirituality is important to nearly everyone.</strong></td>
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<td>- One’s faith in a higher power often becomes increasingly important during times of duress and vulnerability. This can also be stated as ‘There are no atheists in fox holes.’</td>
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<td>- Validating someone’s faith shows respect and support.</td>
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<td>- Telling a religious person ‘we are praying for you’ is very therapeutic.</td>
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| **Principle 8: Allow the patient and family as much control as possible.** |
| - Focus immediately on the issue the patient is most concerned about. For instance, discuss results of restaging studies first if the patient is worried about them.  |
| - Negotiate the content and flow of the conversation to give the patient control over the meeting.  |
| - Respect patient’s needs and priorities as long as they are reasonable, and sometimes even if they are unreasonable.  |

| **Explore:**  |
| - ‘What role does spirituality play in your life?’  |
| - ‘How has faith helped you during challenging times?’  |
| - ‘Has your clergy been involved in your spiritual care during your illness?’  |
| - Respect: ‘I respect your faith. Faith is powerful medicine.’  |

| **Principle 9: Focus on the patient and allow for silence.** |
| - ‘Tell me more’ and allowing for silence in the conversation solidifies the relationship by allowing her brother to be heard. Beyond exploring the brother’s concern, we might also ask ‘What do you think she already suspects about her illness?’ Finally, reassuring her brother by sincerely saying ‘I promise to treat your sister with great respect and compassion, just as I would my own sister’ builds trust and rapport.  |

| **Principle 10: Empathy builds trust.** |
| - When discussing sensitive information with the patient, it is often useful to ask ‘How much would you like to know about your illness?’ [19] or ‘Would you prefer I discuss your diagnosis with you, or with your family?’ [22]. While it is true that in times of uncertainty patients and families rely on the expertise of the physician, it is also true that most patients want to be informed and take part in decisions about their health care. While some cultures may defer to the expertise of the doctor almost all of the time, asking about their involvement communicates respect and caring.  |

| **Principle 11: Respect patient’s autonomy.** |
| - The patient is in caring for the patient. The patient’s autonomy, privacy laws, and other regulations. The patient and family should have as much control over the situation as possible.  |

| **Principle 12: Validate others’ concerns.** |
| - We should view his request for non-disclosure as a golden opportunity to listen carefully to his concerns and validate them.  |

| **Principle 13: Respect patient’s privacy.** |
| - ‘Tell me more’ and allowing for silence in the conversation solidifies the relationship by allowing her brother to be heard. Beyond exploring the brother’s concern, we might also ask ‘What do you think she already suspects about her illness?’ Finally, reassuring her brother by sincerely saying ‘I promise to treat your sister with great respect and compassion, just as I would my own sister’ builds trust and rapport.  |

| **Principle 14: Respect patient’s confidentiality.** |
| - When discussing sensitive information with the patient, it is often useful to ask ‘How much would you like to know about your illness?’ [19] or ‘Would you prefer I discuss your diagnosis with you, or with your family?’ [22]. While it is true that in times of uncertainty patients and families rely on the expertise of the physician, it is also true that most patients want to be informed and take part in decisions about their health care. While some cultures may defer to the expertise of the doctor almost all of the time, asking about their involvement communicates respect and caring.  |
diversion, loss of erectile function, and possibly other serious side effects. Expecting the surgeon to take the patient to the operating room without first discussing considerable risks with the patient himself seems unreasonable. The best approach to such conversations is to be transparent. The treating team should have the right to tell the patient ‘I am uncomfortable offering this treatment unless you have at least a general understanding of potential risks.’ Transparency like this offered calmly and sensitively is usually well received, since it shows true caring and compassion for the patient. Information flow is ultimately a negotiated process [19].

when ‘Tell me more about your pain’ becomes ‘Is it sharp, dull, or throbbing?’

Allowing a patient to truly be heard requires assistance from an interpreter if the patient and provider do not speak the same language. Culturally competent health care organizations should provide professional language assistance services for predominant languages in the region. These services include bilingual staff and interpreters, at no cost, at all points of contact, in a timely manner, during all hours of operation [23]. Family and friends should not interpret, except at the request of the patient, since they sometimes hide sensitive or negative information. Telephone interpreters are about as accurate as face to face professional interpreters [24]. Face to face interpreters are nonetheless preferable for conveying sensitive information, such as bad news or consent for chemotherapy, when available.

Communicating effectively with a patient through an interpreter depends upon a few key strategies [22].

- Take a few seconds to establish rapport with the interpreter before meeting the patient.
- Discuss preferences with the interpreter. For instance, you may find it useful to say:
  - ‘I like to use very open ended phrases, like “Help me understand what your pain is like”, or “Tell me more about your pain”. Please follow this strategy rather than converting my open ended comments into a series of close ended questions.’
  - ‘Please let me know if you are not comfortable with my phrasing and why, so I can modify my statements accordingly.’
- Speak directly to the patient or family member, just as you would with someone who speaks your language, rather than referring to the patient in the third person. Speaking directly to the patient establishes a stronger connection.
-Speak in simple, brief phrases for clarity and avoid medical jargon or complex concepts. We want to make sure our words heal rather than harm.

harnessing the power of touch

Physical contact has tremendous significance for anyone, especially when it occurs between a man and a woman. Physical contact, such as when greeting or examining a patient, is particularly sensitive when one or both people are religiously orthodox or socially conservative. Maintaining rapport and trust with the Kuwaiti woman presented above therefore requires tremendous skill and sensitivity, since she is covered from head to toe. The best approach to greeting this woman is to smile and nod respectfully and shake hands only if she extends her hand first. This general guideline is applicable to any encounter between a man and a woman. Of course, many professional, educated women throughout the world are comfortable shaking hands with men. However, one of the authors (DEE) has extended his hand to seemingly modern, American, professional women on multiple occasions only to find himself awkwardly grasping for air. In one case, the woman was a fellow physician who has lived in the US her entire life, but is an Orthodox Jew. In another case, the woman was the wife of a close colleague who is Christian who withheld her hand at a holiday party. Eye contact, while not literally constituting physical contact, is also highly significant. Some people avoid eye contact for a variety of reasons, ranging from personal preference to local social custom. When speaking to the Kuwaiti woman presented above (or any other patient), the best strategy is to calibrate your eye contact based on how much eye contact she establishes with you. After the interview, explain the importance of a thorough physical exam and set forth ground rules for the exam:

- ‘I need to examine you to make the best plan for your health care. Is that OK?’
- ‘I will make sure you are covered with a sheet the entire time to maintain modesty, and our nurse will be present the entire time. Your sister (or other family member) may sit in the exam room with you if you like. I may need to examine private parts of your body, but I will do so with sensitivity and as efficiently as possible to maintain your modesty. I will treat you as I would want my own family to be treated.’

The best strategy is to constantly arrange and rearrange sheets and gown to expose as little skin as possible at any time. These principles apply equally well to both genders and all cultures. I was relieved when my (DEE) own physician, who is a woman, followed these principles and talked me through the more sensitive parts of my annual physical.

‘I want to keep fighting and go down swinging’

Let’s reconsider the Jewish American woman and her resistance to transition to palliative care, despite the fact that additional anticancer treatment is very likely to harm her. She and her husband are apparently ‘in denial’ when they say ‘We want to keep fighting and go down swinging.’ Developing a strategy to care for her with compassion depends upon understanding their emotional state. Their denial is likely rooted in fear, sadness, anxiety, and anticipatory grief. We should also be in touch with our own understandable sadness and possible feelings of failure for not being able to cure her.

A common tendency is to try to convince them to transition to palliative care and become ‘no code’. However, this strategy is likely to yield resistance and ultimately fail. A better strategy is to allow the patient and her family to be heard and to seize
empathic opportunities. For instance, such a conversation might look like this:

Patient/family: ‘We want to keep fighting, go down swinging. We have fought this cancer long and hard, and we are not about to give up now.’

Doctor: ‘We never give up, and we always keep fighting any way possible, within reason. We will support you every step of the way. I respect your fighting spirit, and I am inspired by the love between you and your family. Let’s talk about a strategy to make sure you get the best care possible. First, please explain where you think you are in your illness.’ (This is an empathic and exploratory approach that validates and supports rather than tries to convince.)

Patient/family: ‘I know the latest treatment did not work like it was supposed to, but I want to keep taking more chemotherapy. I have young children, and I want to keep fighting for them. I know I can beat this.’

Doctor: ‘I respect your fighting spirit. What are your goals for taking chemotherapy?’ (This is again an empathic and exploratory approach. Additional questions may include ‘What do your children understand about your illness?’ or ‘How are your children doing under these difficult circumstances?’

Patient: ‘I want to be cured.’

Doctor: ‘I wish that were possible. What other goals do you have if your disease can’t be cured?’

The conversation proceeds in a natural free flowing fashion, with the doctor repeatedly exploring and validating concerns, beliefs, and goals, and offering empathy whenever opportunities arise. ‘Wish statements’ are also a powerful way of aligning with the patient and family while emphasizing the limitations of treatment. The patient and family do the vast majority of talking and eventually become tearful, which is a healthy response.

Patient [crying]: ‘I can’t bear the thought of dying from my cancer and leaving my children without their mother.’

Doctor: ‘I know that must be a scary thought. [Lengthy pause] I know this is not what you wanted to hear. I wish we had better treatments. I wish we could get rid of your cancer forever.’

Saying ‘there is nothing more we can do for you’ is not only a subtle form of abandonment, but is also inaccurate [24]. Helping a patient live life to its fullest at the end of life is extremely therapeutic. In contrast, saying ‘I wish we had better treatments for you. I think we need to focus on your quality of life and dignity’ offers a realistic assessment in an empathic and compassionate way.

Most patients with advanced cancer or other incurable illness at the end of life are receptive to the idea of focusing on quality of life and foregoing cardiopulmonary resuscitation. Most of those who are initially resistant, like the woman described above, eventually become receptive with time and support. Often what they need is ‘permission’ to let go, especially when their family is pressuring them to continue treatment. Sometimes they need to discuss the issue of being a burden to their family. Leadership is the key to success in ‘code status’ conversations. Asking a patient or family ‘Do you want everything done?’ is often confusing, since they most likely do not fully understand what ‘everything’ entails. Presenting the decision as a choice between equivalent options is analogous to asking a contestant on a game show to choose randomly between two doors, one concealing a new car and the other concealing an old mule. Most patients will default with ‘Yes, I want everything done’ if they are not fully informed. We need to trust our training and judgment to help guide patients to make sound decisions on their own behalf. The conversation may sound like this:

Doctor: ‘I want to discuss a serious topic that I discuss with every patient who is seriously ill. Is that OK?’

Patient: ‘Sure.’

Doctor: ‘I want to discuss something called “code status”, or “heroic measures”. Have you heard of this? Do you know what I am talking about?’

At this point, many patients will acknowledge having read about and discussed resuscitation, and will immediately volunteer they do not want it but would rather die naturally when their time comes. The conversation may continue as follows for those who are undecided:

Doctor: ‘We have high tech machines in this hospital that are able to sustain peoples’ breathing artificially after they essentially die. When people with advanced cancer such as you end up on artificial life support machines like that, they almost never benefit and essentially always suffer. Most patients with incurable illness therefore opt to go (to the Lord) in peace when their time comes rather than die on a machine. What are your thoughts about this?’

Some people may consider this conversation coercive, since the doctor is making such a strong case against resuscitation. However, such recommendations are no more coercive than any other evidence-based recommendations. Nearly all patients at this point will forego resuscitation. A few more will need additional time to reflect on the topic and discuss it with family before they eventually agree to forego resuscitation. A small minority will never agree to ‘do not resuscitate’. Although the patient and family cannot force the treating team to offer mechanical ventilation if it is clearly not indicated, a very small minority of patients will nonetheless eventually die on a ventilator or shortly after being removed from one. We should not view these isolated instances as failures if we do everything in our power to provide our patients with the best care. Naturally, the conversation would look quite different for a patient who is not as tenuous and near the end of life as the four patients described above. We need to adapt sensitive conversations to the unique circumstances of each patient.

opening an emotional window

Let’s reconsider the US veteran described above who presents to the clinic alone, wearing clothing and non-verbal cues that
communicate independence, toughness, and stoicism. He says ‘Doc, I know I am pretty bad. I just don’t want to take stuff that’s going to make me more sick.’ This patient is seemingly ‘easy’, since he understands the reality of his medical situation and aligns with our goals for him. We need not convince him to forgo additional chemotherapy, which is likely to harm him. However, this seemingly ‘easy’ scenario is deceiving. His apparent stoicism actually masks depression due to uncontrolled pain. Strong emotions, such as fear, sadness, pain, and anxiety, are usually apparent by patients’ facial expressions and body language. However, sometimes they can be more subtle, so we need to be astute to detect them. The veteran is reluctant to take strong pain medicine, since he views doing so as a sign of weakness. He is an alcoholic, so he wants to avoid another addiction. He presents to clinic alone, since manifestations of post-traumatic stress disorder alienated him from his grown children, ex-wife, siblings, and anyone who was once in his inner circle. He still grieves his parents’ deaths. His mind returns frequently to the horrors of battle as a teenager in the distant jungles of Southeast Asia. He lives in isolation on a meager pension. This man’s camouflaged clothing and life experiences are no more or less ‘cultural’ than the Muslim Kuwaiti woman’s burka and religious faith.

How can we help this sad patient with his complex problems? We can neither cure his cancer nor ‘fix’ his psychosocial problems. The best strategy is to be alert for non-verbal cues and simply be present with him and show we care. The conversation may look like this:

Doctor: ‘You look very uncomfortable, like you are in pain. Tell me about that.’
Patient: ‘I’m fine, Doc.’

His stoicism masks his suffering, so we should address his suffering immediately. We gain little by rigidly pursuing a traditional history and physical exam while he is unable to attend fully to the task.

Doctor: ‘What are you taking for pain?’
Patient: ‘My primary doctor gave me some Percocet, but I ran out. I don’t like to take it, because I don’t want to get addicted.’
Doctor: ‘I understand. You do not want to get addicted.’

This ‘mirroring’ of what he just said simply shows we are listening and validates his concern. The next step is to explore and validate his concerns about addiction, reassure him that he may become tolerant but will not become addicted, and offer empathy whenever possible. The veteran eventually agrees to take strong analgesics to control his pain.

Doctor: ‘Let’s start by getting your pain under control. I will ask the nurse to give you some immediate acting pain medicine from our pharmacy over the next couple of hours. Then, we can talk again later if you feel better. If not, I may want to hospitalize you to get your pain under control. Does that sound like a good strategy?’

(This is a negotiated strategy.)
Patient: ‘Sure. That sounds fine.’

This patient knows his doctor cares about him, and he begins to trust his judgment. The patient returns to clinic two days later to continue the discussion:

Doctor: ‘How are you feeling today?’
Patient: ‘Much better.’

We need to get to know him better now that his pain is under control and he can attend to the conversation.

Doctor: ‘Good. I am glad to hear that. Tell me about your close inner circle of friends and family. Who is most important to you?’
Patient: ‘No one. I live by myself.’
Doctor: ‘Do you have children?’
Patient: ‘Yes. They’re grown, moved away, and busy with their own lives, jobs, and children. I don’t want to burden them with my problems.’

The doctor then takes a few minutes to learn more about the veteran’s relationship with his children, his wife, and other family members, validate concerns and regrets, and generally ‘ride the road’ with him. Almost all people have a profound love for and loyalty to family, especially immediate family. Asking a patient about his family opens an emotional window, even if those emotions are painful. It also moves the relationship with the patient from the technical plane of ‘what kind of chemotherapy can I offer’ to the interpersonal one, which to the patient feels like you are interested in them as a person. Conversations about family often precipitate strong emotions, such as crying, which is cathartic. We cannot ‘fix’ our patients’ alienation from loved ones, but we can at least be present, listen, and show we care.

The approach to a patient who remains on good terms with family members may look different. For instance, it is often useful to ask a patient who is approaching the end of life ‘Do your relatives know about your condition? When was the last time they visited you? Do they have plans to visit you soon?’ These types of questions communicate the seriousness of the prognosis in an empathic way without explicitly saying ‘You are going to die soon.’

there are no atheists in foxholes

Let’s reconsider the 65-year-old African American man whose daughter is resistant to palliative care and vows to ‘keep fighting’. Her anger and defiance during code status discussions are probably rooted in her love for him and the pain of imagining life without him, although they may also reflect her distrust of the medical establishment or his health care team. Asking the patient about his relationship with his daughter and her about her relationship with him can be very emotionally cathartic for both of them, if they are receptive to discussing such sensitive matters. His daughter invokes their strong religious faith to support her decision to reject a palliative approach. ‘I am sure the good Lord will save my father. We have faith in God. We want everything done, no matter what.’ One’s faith in a higher power often becomes increasingly important during times of duress and vulnerability. In other words, ‘There are no atheists in fox
hole. Nonetheless, the words ‘We want everything done’ can be very distressing for the health care team, since these words conjure up visions of patients languishing on ventilators for many days at the end of life. Nurses, doctors, and all providers suffer when patients suffer. Disagreement between providers and their patients and families over life sustaining measures at the end of life creates severe stress for everyone.

Many providers approach this challenge by trying to dissuade patients and families from heroic measures at the end of life using a factual or biomedical approach: ‘Studies have shown that patients with advanced cancer that is no longer responding to treatment essentially never benefit meaningfully from life support.’ While patients and families need accurate prognostic information in order to make well informed decisions, this factual approach is nonetheless ineffective for some patients and families who are highly emotional. The patient’s daughter in this case is sad and afraid and therefore not receptive to logic and facts. In this case, perhaps the better approach is to validate, explore, and empathize:

Doctor: ‘I respect your strong religious faith, which is strong medicine. This situation must be very difficult for everyone. What are your goals for treatment at this point?’

Patient/family: ‘We expect to be cured, of course. We will fight this to the end.’

Doctor: ‘I have the greatest respect for your fighting spirit and the love between you and your family. What is important for you if you are not cured?’

Patient: ‘To live as long as possible.’

Doctor: ‘And what will be important to you if you do not achieve long life?’

The doctor, the patient, and his family then engage in free flowing conversation during which the doctor supports, explores, and empathizes, but tries to avoid persuading. In most cases, the conversation gravitates toward a discussion of the importance of quality of life or balancing quality with quantity. However, a small minority of patients and their families never reach this epiphany despite guidance from providers. This situation is very challenging, since the prospect of placing a patient on a mechanical ventilator for their final days is horrifying to most of us. Nonetheless, we should recognize we may not be able to ‘fix’ this predicament, just like we cannot ‘fix’ most patients with advanced cancer. Even though patients and families technically cannot force us to offer heroic measures at the end of life, a small percentage of patients with advanced cancer will choose life sustaining measures despite our efforts. We should not view this as personal failure.

the golden rule

In the final analysis, we should treat our patients as we would want others to treat us during periods of vulnerability and fear. We need not memorize social customs, prevailing beliefs, or rules of engagement in order to take excellent care of people from all religions, ethnic groups, countries, and races. The key to cultural competence is patient centeredness built on respect, sensitivity, composure, partnership, honesty, astuteness, curiosity, and tolerance. All people really care about is being cared about.

disclosure

The author declares no conflict of interest.

references