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# Communication Strategies and Cultural Issues in the Delivery of Bad News

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## ABSTRACT

**Good communication is a fundamental skill for all palliative care clinicians. Patients present with varied desires, beliefs, and cultural practices, and navigating these issues presents clinicians with unique challenges. This article provides an overview of the evidence for communication strategies in delivering bad news and discussing advance care planning. In addition, it reviews the literature regarding cultural aspects of care for terminally ill patients and their families and offers strategies for engaging them. Through good communication practices, clinicians can help to avoid conflict and understand patients' desires for end of life care.**

## INTRODUCTION

INTERACTING WITH PATIENTS facing life-limiting illness can be a rewarding experience. Yet, for many clinicians, it also remains one of the most challenging aspects of their work. Few physicians, including specialists, receive formal training during residency about communication, and even doctors who routinely deliver difficult news admit that they are unsure of their ability to properly perform this task.[1–3] Cultural and ethnic differences further complicate matters, and astute clinicians recognize that communication with each patient and family is a unique experience.

In this paper, we present a narrative review of the evidence for general communication strategies as well as specific communication techniques to be used during the delivery of bad news and discussions of end-of-life treatment decisions. In addition, we also explore the role of culture and ethnicity in end-of-life communication. The primary sources for communication strategies for delivery of bad news came from prognostic discussions in oncology and the intensive care unit (ICU). The literature base is currently developing, and the quality of evidence overall remains moderate to poor. While there is a developing literature showing the benefits of specific communication interventions, much of the information about general communication strategies, communication of bad news, and cultural preferences for care comes from focus group studies, patient surveys, and expert opinion.

To clarify the level of evidence, we have used the Strength of Recommendation Taxonomy (SORT)[4] to grade the level of evidence of specific communication recommendations summarized in Tables 1–3. SORT is a measure of the quality of patient outcome oriented evidence. "A" level grading represents consistent evidence from two or more high quality studies, including randomized controlled trials, cohort studies, and systematic reviews. "B" level evidence represents inconsistent or lesser quality studies, including cohort

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studies and case series. "C" is evidence based on expert opinion or general practice.

## PRINCIPLES OF GOOD COMMUNICATION

Several general skills improve communication between patients and clinicians in all settings. These include preparing oneself for the encounter, creating a supportive environment, using appropriate nonverbal behaviors, and expressing empathy.[5–7] Advance preparation is important; health care providers should have a working knowledge of potential areas of discussion prior to talking with patients to avoid being caught by surprise or appearing uninformed. When possible, the physical setting for patient encounters ought to be private, quiet and comfortable.

Despite the hectic nature of one's schedule, patients do not want to feel rushed and nonverbal techniques such as sitting down, making eye contact, intently focusing on the patient or family and not looking at one's watch can help create the perception of ample time and convey empathy.[8,9] While many physicians experience empathy with patients, it is crucial that it is openly communicated to the patient, as even short demonstrations can decrease patient anxiety.[10] Patient concerns should be elicited through the use of open-ended questions, focusing on psychological aspects of the illness, summarizing, and clarifying areas of poor understanding. Using closed-ended or leading questions, premature advice, and focusing on physical aspects of disease tends to inhibit disclosure, and these should be avoided.[9]

With good communication, patients report better outcomes, greater satisfaction, improved understanding, enhanced adherence to treatment and decreased litigation.[11–15] In contrast, poor communication can be devastating for patients and families, affecting their psychological adaptation to an illness.[16–18] Therefore, the use of good communication is especially important in the delivery of bad news.

### *Patient-centered communication*

Patient-centered communication describes an approach in which attention is placed on establishing partnerships with patients, exploring and establishing common ground, understanding psychosocial factors, and understanding how the patient experiences their illness.[19,20] Both verbal and nonverbal behaviors help to facilitate information exchange, build trusting partnerships with patients, decrease unnecessary utilization of health care resources, and facilitate recovery from illness.[19] While some patients prefer biomedical focused discussions, patient-centered communication

TABLE 1. LITERATURE STANDARDS FOR BREAKING BAD NEWS AND GRADES BY SORT TAXONOMY[4]

| *Recommendation* | *Grade* |
|---|---|
| In general, patients desire information about their diagnosis, treatment, and prognosis. | B |
| Clinicians should ask patients how much they want to know before giving information. | B |
| Clinicians should explore cultural issues in an open-ended dialogue with patients and families to ensure they are appropriately addressed. | B |
| If patients desire, family members should be present during discussions of medical care. | B |
| During discussions of bad news, clinicians should explore patients' emotional cues through empathic statements. | B |
| Bad news should be given in an area free from distractions, and with appropriate time allotted. | B |
| A clinician who is an expert about the patient's condition should provide the information. | B |
| Physicians should use appropriate body language during discussions, including removing obstructing objects. | C |
| Clinicians should limit the amount of information provided, giving no more than three pieces of information without a break. | C |
| Clinicians should meet frequently with patients and families. | B |
| During discussions about care at the end of life, clinicians should elicit patient goals, values, and desires for care. | B |
| Only professional medical interpreters should be used, unless it is unavoidable. | B |

Table 2. Useful Communication Techniques and Grades by SORT Taxonomy[4]

| *Technique* | *Example* | *Grade* |
|---|---|---|
| Acknowledgement | Naming of an emotion or communication barrier.<br>"It sounds like you're angry." | C |
| Exploration | A probe for more information.<br>"Tell me more." | C |
| Empathy | Expressing understanding of another's experience.<br>"I can't imagine how difficult this is for you." | C |
| Legitimation | A statement which normalizes or validates an opinion or emotion.<br>"Most people would feel the same way." | C |
| Summarize | Rephrasing and confirming what has been said.<br>"Let me make sure that I've heard you correctly…" | C |
| "Firing a warning shot" | Alerting the patient or family to impending bad news.<br>"Mr. Smith, I've looked at your father's lab results, and I'm afraid I have some bad news." | C |
| "I wish" statements | A statement that allows alignment with a patient's desires, but implicitly acknowledges that it is not likely to occur.<br>"I wish we had a way to make him better." | C |
| Delivery of no more than three pieces of information before pausing for a break | "Your father is very weak, and has not been eating or drinking in the past several days. Unfortunately, I don't think that he is going to recover and be able to eat on his own. He will likely continue to decline and become less responsive over the next few days."<br>"I've just shared a lot, are you still with me?" | C |

is preferred by most patients.[21] In general, the techniques outlined in this paper facilitate a patient-centered approach to clinician–patient communication.

## DELIVERING BAD NEWS

Bad news is "any information that adversely alters one's expectations for the future,"[22] or "news that results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received."[23] Both definitions recognize that bad news is subjectively determined and may be perceived differently, depending on one's personal experience. The delivery of bad news has a lasting effect on patients' and families' recollections of a medical encounter.

### *Who should deliver the news?*

Most health care providers participate in breaking bad news, and interdisciplinary teamwork helps prevent discrepancies in information and aids in identification of patient needs.[24] Physicians are tasked most frequently with delivering bad news, with surgeons, oncologists, and critical care doctors delivering bad news more often than general internists.[25,26]

Because of their close role with patients, nurses are often called upon to answer questions regarding prognosis and treatment, and are identified by patients as a primary source of information and emotional support.[26,27] Nurses serve a vital function as liaisons between patients and physicians. In one study, lung cancer nurse specialists met separately with patients following bad news discussions, and wrote physicians notes summarizing these encounters. Nearly all of these physicians found the notes provided useful new information.[28]

Social workers also facilitate such communication. They often arrange meetings, negotiate with decision makers, and provide essential services, such as interpreters.[29,30] Some have suggested that social workers help instruct patients on how to talk with doctors and be present when bad news is discussed.[31,32]

### *Health care providers responses to the delivery of bad news*

Providing bad news is stressful, even for professionals who routinely deliver it.[33,34] In workshops for oncology fellows, bad news was frequently identified as a psychologically difficult task[35] and physicians report greater satisfaction delivering positive information.[36] Providers who feel more comfortable with

Table 3. Working with Interpreters and Grades by SORT Taxonomy[4,257–259]

| *Recommendation* | *Grade* |
|---|---|
| Only professional medical interpreters should be used, unless it is absolutely unavoidable. | A |
| Clinicians should meet with interpreters prior to family meetings to discuss the planned discussion. | C |
| Physicians and interpreters should agree on cues to signal stopping points or discuss how much can be said before pausing for interpretation. | C |
| Before starting, all participants should be introduced. | C |
| Interpreters should sit near the patient, but avoid obstructing the interaction between the patient and clinician. | C |
| Physicians should speak in the second person ("Do you have pain?") and interpreters should speak in the first person ("I will give you medicine for your pain"). | C |
| Physicians should speak directly to the patient and should look at the patient while they listen to the interpreter, as if it is a normal conversation between only the clinician and the patient. | C |
| Clinicians should use nonverbal communication, and respond to nonverbal cues by the patient to establish empathy. | C |
| Checking frequently for comprehension is important to ensure understanding. | C |
| If an exam is needed, clinicians should ask the patient if it is okay for the interpreter to stay. | C |
| Following the interview, the clinician should meet with the interpreter to discuss the meeting and clarify misunderstandings. In addition, if further interpretation is needed for the same patient, the same interpreter should be used. | C |

their communication skills report less job distress and clinicians with higher levels of personal accomplishment had less emotional stress and burnout.[37,38] Furthermore, oncologists' lack of an established rapport and inability to effectively deliver bad news to patients with cancer is a possible explanation for short courses of futile chemotherapy at the end of life.[39] Therefore, doctors who take the time to deliver bad news in a caring and professional manner not only emotionally support their patients in a difficult time, they are personally rewarded and may avoid unhelpful interventions.

### *Information needs of patients*

Patients perceive receiving bad news to be stressful, yet still desire information about their condition. Consistently across many studies, when asked about their wish to hear information about diagnosis, symptoms, treatments, side effects, and prognosis, the majority of patients indicate they want as much information as possible.[40–44]

Despite this preference, patients often do not express to clinicians their full desire for information. In one study of patients with advanced cancer, the use of open-ended questions during the interview revealed concerns about disease progression, symptoms, and the dying process that patients had previously felt were not answerable.[45] One of the areas that patients are least likely to ask about is prognosis.[46]

Patients and caregivers wish to hear a realistic assessment of their prognosis,[47] but may want this information presented in a positive manner.[42,48] For example, in women with recent diagnoses of breast cancer, information about the chance of cure was identified by more than 90% of women as very important, whereas information about the shortest time someone with cancer might live was very important to only 30% of patients.[49] In addition, qualitative estimates of prognosis are often perceived as more desirable than quantitative estimates.[42,46]

Despite the desire of most patients for prognostic information, some patients do not want full disclosure. Furthermore, patients often vary in their desire for prognostic disclosure over the course of illness, with many focusing on information about disease and treatment when first diagnosed, and prognostic information at later visits.[40,42,50] That said, as their disease progresses even further, fewer patients want to have explicit discussions about their prognosis. Therefore, at each point in time, clinicians should maintain a patient centered focus and clarify with patients how much information they want to know before discussing prognostic information.[46,51]

Family members often want to be involved in discussions of prognosis and bad news, yet the literature shows some patients want family present whereas others do not.[52–57] Alternatively, some patients may want bad news delivered to their family, trusting that their family will disclose to them what they feel is appropriate. It is important to respect patients' preferences, including who should be present and who should not, and to identify family dynamics regarding who will be involved in discussions, who will make decisions, and how consensus will be achieved.[52,53] Furthermore, patients and family members often have differing needs for information during bad news discussions. For example, in a study of terminally ill patients with cancer, family members were often interested in hearing about prognosis and what to expect as the disease progressed, whereas patients wanted information about daily living and symptom control.[58] Furthermore, caregivers often need information about day-to-day management and about what may happen at the time of death.[59] In some situations, given the disparate information being shared, it may make sense to have separate discussions, thus giving health care providers the opportunity to explore each individual's information needs.[59,60] In such situations, clinicians should provide consistent information to both parties and explore any desires by patients or families to shield or protect each other from prognostic information.[61]

### *Communicating prognosis*

Many patients, even those with end-stage disease, have not had prognostic discussions with their doctors, and often overestimate their prognoses.[50,62] Physicians are generally reluctant to discuss prognosis and prefer to discuss it only when patients bring it up.[63] Furthermore, many physicians worry about known inaccuracies in physician prognostication and prognostic uncertainty, and therefore withhold information until the patient is so close to death that accuracy is assured.[53,64] Even when discussions are held, a truthful assessment of their prognosis is often not given.[65,66] Although physician estimates of prognosis are more accurate than patient estimates,[67,68] physicians often communicate an overly optimistic prognosis, or only provide vague statements without a specific time estimate, even in patients who express a desire to hear the truth.[65,66]

Patients often do not understand common statistical terms or manipulate them to make them more positive.[44,48,49,69,70] One such example is the framing effect, in which patients are more likely to undergo interventions when outcomes are expressed in positive terms (such as percent survival) instead of negative terms (such as percent mortality).[71] Additionally, patients may change their preferences depending on the statistical terms employed, such as relative risk versus absolute risk.[72]

When prognostic uncertainty is expressed by physicians, patients often mistakenly place themselves in the most optimistic prognostic group.[44] Depressed patients, men, and those with less education are more likely to misunderstand their prognosis.[73–75] Patients who inappropriately believe in the curability of their cancer are more likely to choose alternative and aggressive treatments.[67,68,76] Of note, in such patients with advanced disease, there does not appear to be a survival difference in those who choose treatment directed toward cure compared with those that choose palliation only.[68]

### *The role of hope*

Many providers worry that being truthful about prognosis may contribute to a loss of hope.[77,78] While not supported by consistent evidence,[79] patients often feel that a loss of hope contributes to poor outcomes.[80] Indeed, healthcare providers, families, and patients rate the provision of hope as very important, even in situations involving a terminal prognosis,[32,43,56,60,81–84] and report increased stress when told that "nothing more can be done."[85] That said, providing hope does not mean that clinicians must do whatever is necessary to preserve the idea of treatment effect or cure.[47] At all stages of illness, clinicians can provide hope and a positive outlook even in the face of a poor prognosis. Such hope should be realistic, and focus on topics such as goals of care, symptom control, and supportive resources, rather than unrealistic expectations.[32,63,86] For example, terminally ill patients want reassurances that doctors will take care of them, not abandon them, and that they will not suffer.[60,87] Such practices are consistent with psychological hope theory, in which hope is defined in terms of selection of goals, identification of pathways, and motivation to attain goals. Patients with high hope are able to identify attainable goals, find alternative pathways, and summon the motivation and energy to achieve their goals. However, in situations in which the desired goals are unattainable, as in dying patients, it is beneficial to focus on alternative, attainable goals.[88] Providers can help patients realize these new goals and maintain hope by providing clear information, controlling symptoms, and maintaining functionality.[89]

### *Culture and disclosure of bad news*

Maintaining hope even in the face of a poor prognosis is often culturally determined. Most white and African American patients expect to be fully informed of their condition and to use that information to make decisions about all aspects of their care.[90] On the other hand, if the patient belongs to a culture where the risks of truth-telling are generally seen to outweigh the benefits, then the emphasis may be on protecting the patient from full knowledge in order to maintain hope.[91–97] For example, for Bosnian immigrants, nondisclosure is seen as benevolent and protective[98] and traditional Navajo believe disclosure of truth causes bad outcomes.[99]

While the ethical issues surrounding communication of sensitive and difficult information are usually framed in terms of "telling" or "not telling" the truth, things are rarely so clear-cut. Patients from cultures where nondisclosure is the norm may expect and even want to know the "truth," but still may not expect that it will be told to them openly.[97,100] When interviewed, 23% of Japanese-speaking American patients preferred bad news be disclosed in a nonverbal manner,[100] and for Asian patients, direct statements, such as "you have widespread cancer" or "this cancer is incurable" may be seen as insensitive, rude, or uncaring.[97] If the patient comes from a culture in which the risks of truth-telling are emphasized, they may expect answers that are more euphemistic and indirect,[101] even to a straightforward question about prognosis.[101,102] Patients may wish to know the truth but expect to learn it through nonverbal means, through inference.[97] Here the difference is not only about whether to tell the truth, but also about what it means to tell. Learning the truth in a more indirect way may be seen as preferable because the ambiguity allows the patient the possibility of hope.[97,102]

Differences in patients can become complex, with variations within groups and immigrants who take on characteristics of their new country.[100,103] In Japanese immigrants to the United States, acculturation has increased their desire for truthful disclosure and decreased their desire for nonverbal communication of a poor prognosis.[100] In general, patients with less education, older age, and more advanced illness are less in favor of truthful disclosure.[104,105] While patients from many ethnic groups, such as Asian, Navajo, African, Central and South American, and Eastern European, may not desire full disclosure of prognosis,[90,99,106–110] treating patients as rigid members of cultural groups, with specified characteristics, is not a practical approach.[111,112] A potential method that was well received in one study, was the use of advance discussions while patients were healthy to determine the degree of truth telling they desired.[105] This allowed doctors to conform to patients' desires in a low-stress setting.

Given the complexities of discussing prognosis, no "one size fits all" approach can be expected to be successful in all patients. Rather, recognizing a physician's cultural bias, listening to patients and family, and engaging them in a dialogue and negotiation about preferences for truth disclosure, decision making, and family involvement offers respect for each patient's individuality and autonomy.[112,113]

Physicians must respect the desires of the patients for the type of information they seek, their desires to maintain hope, and the cultural norms each patient brings to the clinical encounter. Within these restrictions, physicians should provide an accurate and truthful prognosis within a range of time, acknowledging the existence of outliers, and maintaining hope.[85,114]

### *Discussing patient emotions and concerns*

Bad news conversations are laden with emotion for both patient and family. Dealing with patients' emotions helps to decrease anxiety, prevent depression later in the course of illness, and improve satisfaction.[16–18,52,85,114–117] Those concerned that dealing with emotions will take too much time can be encouraged by evidence suggesting that when emotional cues are missed, clinical interactions actually last longer.[7]

Patients who are most in need of discussing emotional issues are the ones least likely to spontaneously reveal their concerns, therefore placing more responsibility on the provider delivering the news.[118] In one study, patient self report of distress was negatively associated with physicians' detection of concerns.[119] Given the importance of addressing emotional issues and the reluctance of depressed or anxious patients to initiate discussions about these topics, the physician must work to develop an emotional trust with patients in which concerns can be discussed.[120]

### *Mechanics of delivering bad news*

Although the delivery of bad news is primarily a task of adhering to basic principles and techniques of good communication (Tables 1 and 2), several protocols have emphasized component steps that can help the learner achieve success.[121–123] Although they have face validity, there is limited evidence to support the impact of these protocols on patient care.[124–126] Many of the initial steps involve planning who will provide the information, who will receive it, where it will be given, and how much they want to know.

Patients want information from an expert, but the exact person often depends on the type of bad news being delivered. For example, patients with cancer prefer to have a knowledgeable specialist provide them with the most up-to-date treatments and information.[32,56,57,60,85,127] In contrast, families of trauma patients value most the ability to answer questions, rather than seniority of the person giving the news.[128] Usually, the person most involved in the patient's care or with the most established, trusting relationship is best situated to deliver bad news.[53,60]

Most patients prefer that discussions occur in a private location, free from distractions, and with a clinician who has the appropriate amount of time available.[56,57,85,114,128,129] When families sense that a conversation is rushed, they report decreased satisfaction,[82,127–130] whereas increased frequency of meetings and proportion of family speech during meetings with providers increases satisfaction.[131,132]

Conversations should occur in person, but the relative importance of physician positioning, layout of the room, and physical contact varies across studies. In all cases, body language, such as being seated and establishing eye contact, should be used to convey empathy and establish trust.[56,82,114] Yet, the optimal amount of physical closeness is controversial. Sitting next to the patient appears to be unnecessary.[47,56,133] Physician touch has the potential to convey hope and express caring, yet not all patients are receptive.[47,84,114,134] In one survey, women desired physical contact more than men,[128] whereas in another, patients with acquired immune deficiency syndrome (AIDS) noted the benefit of touch more often than other groups.[84] Ultimately, one must gauge each patient individually, be aware that some patients may not welcome consolation by touching, and recognize that forced gestures are not desired.[47,55,56,84,128,133,134]

Clinicians should begin the bad news discussion by assessing the patient and family's understanding of the medical situation.[135] This ensures a shared understanding between the two parties, and provides the opportunity for correction of misconceptions.

Even though patients and families are generally interested in obtaining as much information as possible, the variability of preferences suggests that clinicians should ask patients and families how much they want to know before delivering bad news. If possible, this step is best completed at an earlier time, prior to the actual delivery of news.[136]

Families report that bad news information should be conveyed in an honest, straightforward, and caring manner that is not too blunt.[47,56,57,60,82,114,127–130,137,138] For example, in interviews about prognostic disclosure, patients often wanted information presented sensitively, making sure they were prepared, and delivered in a way that maintained hope.[82] In addition, patient satisfaction is higher when information is given at the patient's pace and at the level of detail they desire.[56,60] A good rule of thumb is to give only three facts at a time before pausing for a break and specifically checking for understanding. Patients and families place value on checking for comprehension,[32,43,53,114] and emphasize that there should be time throughout the discussion to ask questions and have an appropriate discussion of topics that are not clear.[47,56,57,128,133]

Supplementary information, including written material, may help decrease anxiety, improve patients' knowledge and retention of information, and satisfaction with encounters.[55–57,139,140] Yet, within written materials, some patients have reported that graphic displays enhance the negative aspects of bad news.[42,48] Providing audio recordings of clinical visits has improved patient satisfaction in some studies, but may be detrimental for people with very poor prognoses, as listening to the recording painfully relives the experience of hearing the bad information.[47,55–57,141–144] In one randomized trial, patients with poor prognoses who had been given audiotapes of the bad news clinic visit showed greater distress at 6 months than patients who had not received an audiotape.[141]

At the end of the discussion, physicians should summarize the information and make a plan for future care. While family meetings to discuss bad news often do not provide a definite clinical direction, at the conclusion of the discussion, a plan for interim care and further meetings should be established.

## ADVANCE CARE PLANNING

### *Advance directives*

Doctors and families must often determine what interventions and treatments an incapacitated patient would prefer. In one study, less than 5% of ICU patients were able to communicate with doctors at the end of life.[145] Advance directives, created to assist in these scenarios, have demonstrated limited effectiveness.

One problem with advance directives has been their low prevalence; it has been estimated that less than 25% of the general population has executed such documents.[146,147] Even in at-risk populations, such as end-stage renal disease or geriatric patients, the penetration remains low.[146,148–151] Doctors are frequently unaware of advance directives that may exist, or do not have them available when needed.[152] When advance directives are present, they often are not detailed enough to affect medical decision making.[153,154] Despite their promise, advance directives have been shown to not have an impact on the cost of medical care,[155] or the frequency of life support interventions.[156] They are rarely associated with discussions between patients and physicians,[157] and do not increase levels of discussion between doctors and patients.[158]

Another concern is that decisions based on advance directives by surrogate decision makers often do not correspond to the decisions or values of the patients themselves.[159,160] In a meta-analysis on this topic, surrogates were accurate in only 68% of cases.[161] Information about accuracy is difficult to interpret, as both physicians and surrogate decision-makers tend to be accurate in extreme cases, such as those involving very promising or very dire prognoses, but are frequently wrong in more complex cases, such as those involving dementia, or those with a small, but definable chance of recovery.[162] Surrogate decision-makers are often no more accurate in predicting desires of patients than models using actuarial data.[163] Furthermore, in a study of hypothetical clinical scenarios in which physician decisions might conflict with patient preferences for treatment, physicians made decisions in conflict with the advance directive in 65% of cases, highlighting the difficulty of making decisions strictly based on these documents.[164]

To increase the accuracy of advance directives, many experts encourage doctors and family members to discuss patients' preferences at the time an advance directive is created. While some studies have shown a benefit in having such discussions,[159,162] they have generally not been shown to be effective.[165,166] In one trial, patients and surrogates were randomized to one of five conditions (no advance directive, or scenario or value-based advance directive with and without discussions with their surrogate). Surrogate predictions of treatments in nine hypothetical scenarios were not improved either with the use of an advance directive or discussions of treatment.[166]

Many patients have expressed the desire for their family members to make medical decisions based on their own beliefs and needs at the time, rather than adhering strictly to the patient's advance directive. In a study of a subset of patients from the SUPPORT and HELP cohorts, greater than 70% in each subset indicated a preference for their surrogate and doctor to make decisions about resuscitation, rather than strictly following their advance directive.[167] In addition, in a study of 150 dialysis patients, only 39% of patients wanted strict adherence to their advance directive, while 61% wanted their family to have some choice in making decisions against their advance directive (19% "a little," 11% "a lot," and 31% "complete").[168]

Another difficulty with advance directives is the question of stability over time. Although patients' preferences are usually stable, some data suggest that they may change over time, including periods as short as 1–2 years.[169–172] In general, decisions regarding more severe conditions or prognoses (such as a coma with no chance of recovery), and those involving only minor debility tend to be more stable; while more moderate conditions (such as a stroke with a small chance of recovery) are more variable.[170,173] Further variability exists in regards to refusal versus acceptance of treatment. In a longitudinal cohort study of 2536 patients older than 65, treatment choices were followed for 2 years.[172] There was wide variability, but refusal of treatment was more stable than agreeing to treatment, with 66%–75% of treatment refusals showing stability while only 18%–43% of treatment requests remained the same. In multivariate analysis, hospitalization, increased depression, and loss of social support were associated with the desire for more treatment.

Despite the problems with advance directives and the difficulty with their use in patient care, physicians should not abandon them altogether. Rather, advance directives represent a useful tool for beginning advance care discussions regarding future care. In such advance care discussions, patients, family, and physicians should discuss a patient's values and goals of care, identify a surrogate decision-maker, and encourage regular communication regarding patient desires for care. Specific scenarios which are likely to occur can be discussed, but the overall discussion should focus on communicating information and sharing patient goals and values.[174–176]

### *Do-not-resuscitate (DNR) orders*

Preferences for DNR orders ought to be linked to the likelihood of survival after attempted resuscitation, yet there is considerable misunderstanding about these statistics. In nearly all studies, the overall chance of survival to discharge following an in-hospital resuscitation attempt is less than 15%[177,178] and in patients with significant comorbid illness, such as end-stage renal disease and cancer, the chances are even lower.[179–181] However, patients are likely to believe that survival is much higher. In one study of patients with heart failure, approximately one half were unaware of the possibility of anoxic brain damage, and 92% thought that the chances of survival to discharge was greater than 50%.[182] One potential source of misinformation is television, in which the chances of recovery after portrayed resuscitation greatly exceeds actual statistics.[183] When patients do receive accurate information about the outcomes of cardiopulmonary resuscitation (CPR), many change their decisions about resuscitation.[184,185]

Although most patients are interested in discussing code status with doctors,[185–187] very few do so.[145,182,188] In a study of patients with congestive heart failure (CHF), only 1 of 40 participants reported discussing code status, while 70% reported a desire to do so.[182] Quite often, physicians do not know the resuscitation preferences of their patients, and do not always understand the choices that patients make.[189,190]

When asked why they have not discussed DNR status with their patients, doctors state most frequently that they thought the patient was unlikely to suffer arrest during that specific admission.[191] In addition, many physicians report that they do not have enough time to discuss important topics with their patients, including DNR discussions.[33,64,192] As a result of this lack of communication, some patients who do not desire it experience attempted resuscitation.[193]

Discussions of code status have many of the same elements as discussing prognosis and bad news. Patients rate highly the provision of information, including prognosis, identification of emotional issues, and assurances of continued care.[194] Unfortunately, physicians often do not adhere to these principles and rush through discussions. In an analysis of "code status" discussions conducted by medical residents, only 13% discussed prognosis and only 10% discussed the patient's values.[195] Although many providers currently lack appropriate skills to discuss code status,[64,192,196] interventions designed to improve providers' overall communication skills, demonstrate improvement.[197–199]

## DECISION MAKING AT THE END OF LIFE

Decision making at the end of life is extremely difficult, partly because it is so foreign to most patients and families. In addition to the myriad medical situations that arise, cultural diversity creates even greater challenges for medical professionals. Through open communication and understanding, health care providers can ensure culturally competent care, provide needed information, assist decision making, resolve conflict, and hopefully enable a peaceful death.

### *Cultural competence and decision making at the end of life*

Patients come to the end of life within a framework of their culture and ethnicity, which influences attitudes toward end of life care. As of the 2000 census, 25% of the U.S. population was nonwhite and, in several large urban centers, whites were a minority.[200] Discussions of ethnicity and culture must acknowledge the tremendous variety within groups: a patient who recently arrived from El Salvador; a third-generation relative who speaks no Spanish; a white person who lives in the upper west side of Manhattan; a resident of rural Appalachia; someone in rural China or a resident of Hong Kong on academic fellowship to Los Angeles.

Ethnicity, or group affiliation, is one of a complex series of factors including socioeconomic status, gender, religion, life experiences, and individual psychology which influence the way patients and health care providers understand the experience of life threatening illness. Culture, or shared beliefs, provides a framework of expectations concerning communication with health professionals, the role of health professionals, family members and patients, the dynamics of decision making and the dying process itself.

Cultural competence at the end of life is not about studying "different" cultures. Instead, it recognizes that end-of-life practices and attitudes are influenced by context, and that everyone brings their own cultural context to an encounter. In recent years, U.S. physicians and bioethicists have tended to emphasize the importance of respect for autonomy and individual rights, an informed consent model of decision making, and shared decision-making. Respect for cultural diversity involves recognizing that other values, such as maintaining family integrity, protecting patients from distress, and expectations for a more paternalistic or authoritative decision-making style may inform the choices of some patients. Furthermore, for many patients, fears about scarcity of medical resources have always been more relevant than fears about receiving excessive medical care.[201–205] Because participants in the medical encounter are coming from different contexts, cultures and experiences, they have different perspectives. Failure to recognize and explore these differences may lead to misunderstanding.

### *Family-centered and patient-centered decision making*

One key culturally based difference is between "family-centered" and "patient-centered" decision-making styles.[90] In many cultures family members are expected to make decisions for their loved one, rather than the patient exerting autonomy by choosing for themselves.[98,105,205,206] Indeed, in cultures in which full disclosure is not the norm, it is hard to see how patients could be expected to make medical decisions. In practice, however, families are usually involved in all aspects of decision making no matter what the cultural background, and the difference between a family-centered and patient-centered style is a matter of emphasis. Even in North America, where patient autonomy is paramount, surveys show that patients want to talk with their families about their desires, and have them involved in decisions at the end of life.[167,207–209]

One can frame the difference between these two styles of decision making in this way: are choices about medical care mainly the province of the patient, with the family responsible for supporting, persuading, and helping them decide according to what is best for the patient (patient-centered style); or are the medical choices a matter which is mainly the province of the family who are responsible for making choices which serve the good of the whole family, which includes but is not limited to the patient (family-centered style)? For Western patients, this often means that the patient is responsible for making medical decisions and autonomy is stressed, while for many Asian and Eastern European patients, the family is the preferred decision maker.[90,98,105,206] However, the situation is rarely clear-cut, with many Japanese families who have migrated to the United States preferring that family members make decisions regarding health care, while many Taiwanese patients with cancer state a preference to be informed of cancer diagnoses before their family members.[100,111] In addition, many African Americans prefer that family be involved in care at the end of life.[204] Often, education and experience with an illness or health care influences patients to favor autonomy.[90,99] Despite these differences, it is important to note that family often plays a close role, and even in those studies where patients stress autonomy, involvement of family is still important.[103,111]

Cultural obligations to family members, including the duty of children to care for, honor, and respect their parents, or "filial piety," may add even more complexity. Such obligations may be interpreted to mean doing everything possible to keep an elderly parent alive "even one more day."[205] Allowing the parent to die by removal of life support might be seen as indicating a lack of filial piety and bring disgrace on the family.[103] Conflicts occur when family insists that patients not be informed and not participate, or when family insists on treatments that the patient does not want. An elderly Korean woman may tell the nurse she is tired of getting chemotherapy and wishes she could go home and stop treatment. The next day her son insists on every possible treatment and the patient agrees. In this situation, health care providers may feel that the patient is being ignored and pressured unduly by her family, however, this may be a misunderstanding of the situation. The patient may expect or even want her family to make decisions, and feel that her own wishes about end-of-life care are less relevant than the good of the family as a whole.[205]

Family desires and culture may complicate completing documents such as advance directives and DNR orders. Caucasian patients, whose emphasis is on autonomy, are more likely to know about and have completed advance directives and DNR orders than African American, Hispanic, and Asian patients.[210–212] Factors predicting acceptance of advance directives include education level, prior experience with ventilators, availability of family, severity of illness, and age.[213]

Hispanic and African American patients note that there is less need for an advance directive due to expected family roles in medical decision-making.[214,215] Furthermore, in some faith communities, including white, African American, and Hispanic congregations, fear of being denied care is cited as a reason for not accepting advance directives.[216] Distrust of the medical system, as well as a strong faith in God are barriers to advance directives and DNR orders by African American patients.[215] Because of the belief in miracles and the conviction that only God can determine when a patient dies, African American patients are often reluctant to limit their medical treatment.[217] Unfortunately, even with a faith-based initiative to increase the use of advance directives, their use remains low.[215] However, despite the low use of advance directives in these communities, physicians should still discuss end-of-life care with their patients, keeping in mind that many patients may not want formal documentation of their preferences.

### *Expectations regarding the doctor–patient relationship*

A shared decision-making model, in which patients are expected to participate in decisions about their care, is not the norm in all cultures.[106,218] In many countries, patients may expect physicians to assume a directive role, making decisions on disclosure of information and treatment.[98,219,220] Even in Western countries, where autonomy is stressed, many patients want the physician to decide on treatment course. Therefore, physicians should assess how much of a role patients desire in their care.[135,221–224]

Furthermore, patients from cultures with a more paternalistic medical style may misunderstand the intentions of physicians who are attempting to include them in decision making. For example, it is common in this country for oncologists to discuss the risks and benefits of chemotherapy with their patients in order to determine if it is appropriate to continue treatment. Patients unaccustomed to being included in this type of decision may interpret this as the oncologist telling them they must have chemotherapy. In situations like these, physicians may need to be more explicit about the fact that they are asking for input from the patient, and be willing to offer their opinion about the best course of action.

### Interpreters

One important need of all medical centers is adequate language interpretation. The use of family interpreters, although widespread (up to one third of clinical encounters) and perhaps inevitable, has been discouraged.[225–228] In studies of the use of family interpreters, family members frequently misinterpreted words and children interpreters frequently avoided topics dealing with bodily functions.[229] Furthermore, when *ad hoc* interpreters or family members do make mistakes, they are more likely to be clinically significant.[230]

The answer is not as simple as avoiding family interpreters and inserting licensed medical interpreters or "language lines."[231] If family members are expected to act as filters for all medical information, to ban them from this role without further discussion may lead to conflict. Furthermore, licensed interpreters are often trained to act as "voice boxes"; literally interpreting what is being said. They may or may not be prepared to, or empowered to, offer information about the cultural issues that may be involved in the discussion.[231] Cultural interpretation, as compared to literal interpretation, would include telling the health care providers which topics are taboo to discuss.[231] For example, if a test comes back indicating a non-English–speaking patient has cervical cancer, the English-speaking–only physician will need an interpreter to help convey this information. Prior to discussing this with the patient, it would also be helpful to know whether the patient is expecting to be told this sort of news directly, or whether it is acceptable in this culture to discuss the patient's reproductive organs in front of male relatives. Interpretation does not take the place of education about cultural issues—it is necessary but not sufficient. Whether a strict interpretation or cultural interpretation is used, communicating with a language discordant patient can be challenging, and general guidelines can facilitate this discussion (Table 3).

### Improvements in cultural care

Interventions to improve cultural awareness and provide culturally competent care include provider education, focus groups with patients, and programs to improve adherence to recommendations and health outcomes for specific cultural groups.[232–235] Empirical data on these interventions shows improvement in knowledge,[236,237] attitudes of providers,[236] patient satisfaction,[238,239] and improved patient outcomes.[233–235,240,241] The key to prevention of misunderstanding is education. Health care institutions need to be aware of the demographics of patients in their area, and provide community involvement in education of cultural aspects and desires for care of each of these groups. Focus groups with patients[242,243] and providers[244] can identify areas of concern, but providers must also recognize that patients may have beliefs that vary considerably from their cultural heritage. Physicians must also recognize their own beliefs and biases.[113]

### Conflict at the end of life

Conflict occurs during decisions to limit or withdraw care at the end of life. Data regarding the incidence of conflict between family and physicians is variable, with estimates ranging from 16% to 48% of cases involving end of life care.[245,246] For example, in an academic medical center study, conflict between staff and family was noted in 48% of cases and conflict between family members was noted in 24% of cases.[247]

Often, the source of conflict results from breakdowns in communication between physicians and family. In multiple studies of interviews with family members reporting conflict, lack of information is cited as a major factor in disagreements with clinical staff.[245,246,248] Family members desire more information and in one study of conflict no participants reported receiving too much information.[245] Families cite doctors' lack of acknowledgement of all family members, lack of privacy for family meetings, the need for information without medical jargon, lack of consistency of information across providers, and the need to feel listened to as key problems in communication.[245,248] Health care providers also cite difficulty in dealing with families, emotional issues, cultural differences, and prognostic uncertainty as barriers to effective communication at the end of life.[64,249]

The need for and benefits of improved communication are highlighted in recent work in ICU family meetings. Several studies have implemented communication interventions, including proactive case finding, ethics consultations, social worker support, and provision of information.[250–254] Such studies have shown several benefits to proactive communication, including increased proportion of DNR and comfort-only measures for high-risk patients, improved comprehension of treatments, and decreased length of both hospital and ICU stay. For example, an intervention consisting of a communications team for patients in the ICU felt to be at high risk for dying reduced ICU length of stay and costs of ICU care.[255]

These interventions demonstrate that good communication facilitates negotiations surrounding goals of care and emotionally difficult decisions. Improvement in communication, including discussions between providers, is vital for resolution of conflict at the end of life.[64,248] Providing a dialogue in which the concerns and decision-making styles of all parties are openly discussed, helps to increase discussion, resolve differences and establish trust.[103,231,256]

## CONCLUSION

Good communication, always challenging in health care, is especially difficult at the end of life. The complexities of different cultures and desires for different levels of involvement from patients and their families make communication tricky for even seasoned clinicians. However, by eliciting and respecting the patient and family's perspective, paying close attention to affect, and acknowledging emotional issues, healthcare providers can work to build collaborative, trusting relationships, avoid conflict, and give patients guidance on achieving their goals for care at the end of life.

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