

Edmund G. Howe, "Families, Strangers, and Those Most Alone: Insights from Cultures, Including Our Own," *The Journal of Clinical Ethics* 24, no. 4 (Winter 2013): 311-22.

At the Bedside

Families, Strangers, and Those Most Alone: Insights from Cultures, Including Our Own

Edmund G. Howe

ABSTRACT

In this introduction to this issue of *The Journal of Clinical Ethics* (*JCE*), I will discuss the legacy of our recently departed friend and colleague, Edmund D. Pellegrino, MD. In this light, I will discuss three articles in this issue of the journal that provide insight into the cultures of China, Mexico, and the U.S., and propose alternative approaches for careproviders in the U.S. to include in their practice as they work with patients and family members at the end of life.

A dear friend has left us.

Edmund D. Pellegrino, MD, a most eminent physician and ethicist, recently has died. In the first part of this introduction, I shall say a bit about him, including who he was to me, referring to him as "Ed," as I think he would have liked.

I will then discuss three articles included in this issue of *The Journal of Clinical Ethics* that involve different cultures: China, Mexico, and the U.S. The influence of culture was one of Ed's core concerns.¹

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First, I will consider the importance of family to elderly Chinese-Americans, and the possibility that patients may not want to know when they have an incurable illness. Second, I will discuss a study that asked men from Mexico whether they would donate an organ to a stranger. Their answers may not reflect their culture, and whether they would actually do as they say may be open to question, but their responses challenge us to reconsider how we should treat strangers. Third, in a case from the U.S., a patient with a history of sexual "predatory" behavior toward children has a brain tumor that is probably operable. In addition to other questions, his plight raises a concern that I see as the most important of all. Namely, how, in the U.S., we treat those who are the most alone.

Finally, I will present the most difficult real case I ever encountered, that involves the influence of culture. It is one I put to Ed before 170 medical students. He preferred that format to giving planned presentations. I will tell what happened and how Ed responded.

DR. PELLEGRINO AND HIS LEGACY

When I was first asked to become editor-in-chief of *JCE* 25 years ago, Ed was the first person I called, to ask if he would be willing to be on our editorial board. He said yes.² After that, the other "leaders in ethics" whom I called accepted. They could not have

felt better when accepting than knowing that Ed was already aboard. I first met Ed when he was the president of Catholic University. I was in a group of faculty who sought Ed's insights on a plan to offer fourth-year medical students an ethics elective that combined the resources of our four schools—which we accomplished.³ I came to know Ed better still as I asked him each year to speak to medical students at the Uniformed Services University of the Health Sciences (USUHS), where I teach.

Ed instructed students, always, on the moral commitment that careproviders make from the moment they first offer to treat a patient. They make this promise, he'd say, when the patient is most vulnerable, and so this promise is not that of a "used-car salesman," and may involve self-sacrifice.

Ed shared, too, his "secret" for interviewing students applying to medical school. He asked them harder and harder questions until they didn't have an answer. If they told Ed "I don't know," they were "probably OK." But if they didn't, it was likely they weren't. Ed emphasized the all-importance of integrity, of doing what is right, even when "no one is looking." This captures who Ed was. It is this trait, his integrity that caused me, when I become stuck, to ask myself, "What *Ed* would do?"

Finally, I should add that Ed, while lecturing, would, without exception, spot a student not paying attention. He would leap up the stairs of the amphitheater, literally, even in his later years, until he reached the row the student was in. He'd wait there until the student noticed the silence and would look up. Each year, before he came to speak to my students, I would inform them he would do this. (I would say I was doing this to add to my "ethics cred.") To emphasize the benefits of providing prior information, I would assure the students, "*He will do this.*" Ed never proved me wrong.

LESSONS FROM THREE CULTURES

Of China, and of the Importance of Family

In this issue of *JCE*, Karen C. Chan, in "Challenges to Culturally Sensitive Care for Elderly Patients: A First-Generation Chinese-American Perspective," describes how Chinese cultural beliefs may differ from those in the U.S.⁴ She reports, for example, that confidentiality, as found in the West, is "foreign" in the East. She reports that families protect aged patients from hearing "bad news," and Chinese physicians often are willing to *lie* to patients when their family members request this. Chan reports that an ongoing effort, the ENABLE Project (the

Empowerment Network for Adjustment to Bereavement and Loss in End-of-life) in Hong Kong, is trying to change this, so that people there can adopt Western moral values. This makes some sense, because autonomy is very important. Yet there may be substantial compensatory gains from more traditional practices such as placing great importance on family. I will explore this, and what we might most learn from them.

The Importance of Family

Chinese parents, when they age, may accept their adult children making medical decisions for them. They may accept this even when they are competent and when their children's decisions differ from their own. Chan explains why: to these patients, there is nothing more important than maintaining good family relationships. The gains that patients may have from this value priority are hardly trivial. In my own psychiatric practice, I experience, as do other therapists, the harms that families can inflict. Adult siblings battle over who will get a dying parent's inheritance, and then they no longer speak to each other. Adult children may end contact with a parent, once they can, because the parent, verbally or even physically, continues to abuse them. (Ending contact may be the best choice they have.) Aged parents may not give adult children any information when they are hospitalized because they are afraid how their children might use this information against them. One aged patient said, for example, "My son might use this information to try to 'put me away'." (It was not a wholly irrational fear). On the other hand, I and other therapists see how families may benefit a patient most profoundly.

An example is how parents can help an adult child who has severe psychiatric illness such as schizophrenia or bipolar illness. When the patient loses touch with reality, it may occur rapidly, and he or she may suddenly get much worse. Family members may discern this well before the patient does, can share this information with the patient, and thus the patient may be able to get the immediate care needed, and perhaps avoid hospitalization. If a patient can avoid repeated hospitalization, it may profoundly change his or her quality of life. Careproviders can also help families gain such skills to help patients do as well as possible. One example is that a patient with schizophrenia—like anyone else—may do much worse when family members are overly critical. Careproviders in China and in the U.S. have taught family members to "stop." In China, the rate of hospitalization of patients with schizophrenia is eight times less than it was.⁵

Family harmony may have protective, “preventative” benefits. There is evidence that children who grow up in close families may become more “resilient” or better able to cope with stress.⁶ The extent to which a family can affect its members has few limits. Family arguments may harm infants as they sleep!⁷ Family members may benefit a patient, particularly at the end of life. A remarkable and even surprising example is that a family may experience, together, a profound sense of meaning and emotional richness even when a parent has Alzheimer’s disease and “loses it” increasingly as he or she ages.

I think of a man whose mother has severe dementia. As she got worse, he became increasingly distraught. I told him what I had seen: that some adult children find and report that these days with their parents are the best days of their lives. Why? Because they find, in spite of what they expect, that, during this time, they feel an emotional closeness with their parents they never felt before. They interact, for example, by touching. They miss interacting verbally, but they can share that kind of closeness with other people. This man told me later that my telling him this somehow enabled him—and his mother—to change their lives very significantly. Somehow my telling him this enabled him to cherish what he *had* with his mother, rather than focus on what he and she had lost. He acknowledged, for the first time, that previously, throughout their lives, they had mostly argued. He now relishes each moment they still have together.

In these ways, Chinese patients may find family harmony especially rewarding. They may not have the same kind of personal autonomy we value in the U.S., but the priority they give to family harmony may be a substantial gain. This may be even more true for them because, like most people, their feelings are deeply allied with their cultural beliefs. As Greene says, people “are more committed to their ways of life than they are to producing good results.”⁸ In light of this, they may place greater value on the needs and wants of their family than on their own needs and wants, especially at the end of life. What, then, may be some clinical implications for careproviders practicing in the U.S.?

Clinical Implications

Patients’ choices, when dying, are limited. They may, for instance, be able to choose only between an experimental treatment that enables them to live longer but with more pain, or the standard of care that may result in their not living as long.⁹ Under these circumstances, they may want whatever their families would need or want, more than what they

need or want. This preference may be conscious or unconscious. Careproviders, here, as those in China, may find ways to follow what families decide. In China, patients may want this to a greater extent because it is part of their culture.

Should We Make It Easier for Patients to Make Decisions in their Family’s Interests?

There are essentially three ways that careproviders might further patients’ desires to meet the needs and wants of family members to a greater extent than we usually do. These are: (1) careproviders can “promote” this as an option when patients are competent; (2) careproviders can help family surrogate decision makers use this approach when patients are no longer competent; and (3) careproviders may give greater priority to meeting the needs and wants of family members when careproviders serve as ethics consultants.

1. *When patients are competent, careproviders can take the initiative to inquire whether patients might want to make decisions based on their family’s interests.* For example, in earlier issues of *JCE*, Jeffrey T. Berger has written about patients’ concerns that they not be a burden to family members: “A main concern of patients is not to burden their family members, and this concern often influences patients’ preferences for medical care. Types of burdens that are of concern to patients include emotional burdens, financial burdens, and physical burdens for relatives who directly provide care.”¹⁰ Given these concerns, careproviders may ask patients questions they usually might not think to ask. In addition to asking patients what they want, careproviders can ask patients if they want to discuss what they think their family members might want. To soften a possible harmful connotation of this question, careproviders can say, “I ask because some patients want to talk about these kinds of things, and some patients don’t.” Because, of course, if patients don’t want to talk about these things, it could imply that they care more about what they want than about what their family members need and want.

When patients are interested in discussing their family members’ needs and wants, it might be helpful for careproviders to provide an example. For instance, careproviders can explain that family members may have their own unique response to the patient’s illness: “Some family members can find great meaning in being with their parent at the bedside—being able to touch them. But other family members might find this emotionally excruciating, and avoid it, and they may feel guilty about it.”

A possible downside to this approach is that some patients might then think they should consider the feelings of their loved ones when they haven't. On the other hand, some patients may not consider these things before careproviders raise the issues explicitly, and, if careproviders don't, the patients may later regret that this didn't occur to them. Still other patients may struggle with these kinds of concerns on their own, and feeling alone can be the source of exceptional pain.

Being a financial burden on family members is a common concern. Careproviders might ask patients, "Would you want to discuss the concerns your family may have about money?" There may be a downside to beginning this conversation: it may imply patients *should* consider it. But, as above, unless careproviders ask, some patients may not consider it and later wish they had, or, if they do consider it, they may not feel able to discuss it with anyone.

Finally, careproviders can ask a more general question: "If you could no longer make decisions for yourself, would you want your family to make decisions for you based on what they think *you* would want, or that are based on what *they* would want?"

2. Empowering a surrogate decision maker.

When patients say what they really want is what family members would want, this can be stated in an advance directive. But even when patients put it in an advance directive, the person who is tasked with implementing the directive may not follow it. The implementer may reason, "The family's task is to say what the *patient* would want, not what *they* would want for themselves!" Given this, careproviders could suggest to patients who feel this way that they should not only put this in an advance directive, but should also tell whomever will make decisions for them that this is what they really want.

Careproviders can also tell the patient's surrogate decision maker how best to bring about what the patient wants, given current U.S. cultural values. Then, should the patient become incompetent, family members can say what *they* want, but present it as what they believe the *patient* would have wanted. Some may ask whether this is ethical, but, on a deeper level, this is what the patient had previously said he or she wanted.

In this way, careproviders can inform patients and families, early on, about how the U.S. system currently "works." That is, ethically—if not legally—families and other surrogate decision makers will be asked to say not what they want, but what the

patient would have wanted, and implementers may hesitate when family members say that what the patient would have wanted is what they, the family members, want. Some who question whether this is ethical might also assert that careproviders should instead try to change our present "system." But, for now, the approach I'm describing may be the only way that a patient and family members can both have what they want. Ethically, careproviders who use this approach are telling patients and family members the *truth*, and are alerting patients and family members about this truth early enough that they have time to make some choices—that is, while the patients can express their preferences.

This approach exemplifies a subtle, wider-reaching guideline that is almost always applicable: that careproviders should, in general, tell patients and all of their loved ones all that they know that could be a factor in what patients and families will need to make the decisions that face them.¹¹ As a practical tool for determining when to do this, careproviders can ask themselves what patients and loved ones would know if they were specialists in the medical area in which the patient is ill, lawyers, and ethicists—all combined!

3. Options for ethics consultants.

Careproviders often serve as ethics consultants—formally or informally. When family members must make decisions for an incapacitated patient, one thing an ethics consultant can do is provide the family with legal information on how members of a family are prioritized as decision makers. When it is clear that an incompetent patient's preference was to meet family members' needs and wants, however, rather than provide family with legal materials, ethics consultants may instead encourage family members to discuss, together, what decisions should be made, so that all involved can come to agree on what *they* most want for the patient. I hope that the core justification for this is self-evident: when patients are not able to say what they would have wanted prior to becoming incompetent, such family discussion may be the best and only way with the greatest likelihood of bringing about what, at the deepest level, most patients would most genuinely want.

To repeat: the ethical presupposition underlying this approach is that it is what most patients, if asked, would probably want. Most patients will say that they would want what their family feels is best for *them*. Here is an example how this can, and has, been carried out. The patient was in a coma; he had untreatable cancer, with, at most, six months to live. The coma was caused by an infected abscess in a

nasal sinus that antibiotics weren't reaching. His careproviders thought surgery could drain the abscess sufficiently for the antibiotics to work. But even if surgery did work to the extent that the patient regained consciousness, no one could guess whether he would *want* to regain consciousness, because, regardless, he would die within a few months. His wife said "no" to the surgery, but his children said "yes." State law said the wife was the patient's highest "prioritized" surrogate decision maker, and she should say what she thought he would want. Of course, if her decision trumped, the children's task would be, if possible, to forgive her. But there was another route: the family could choose *together*—which is what they did. Encouraged by the ethics consultants (of which I was one), the family agreed the patient should have the surgery and a DNR (do-not-resuscitate) order. But, to everyone's surprise, before surgery, the antibiotics started to work, and the patient regained consciousness. He was able to say that he *wouldn't* have wanted surgery, and, in a few months, he died, as predicted.¹²

Should We Be Less Concerned than Usual about Being Sure Patients Really Know They Are Going to Die?

Chinese doctors, Chan relates, often don't tell parents they are dying, at their family's request. This raises several questions. For example, how do these patients, their families, and their doctors all fare in this kind of situation? This also raises the clinical question, particularly applicable to us in the U.S., of whether we should, in general, try to insure that patients know they are dying, to the extent that we do. For example, how much information should we give patients, and at what times? A specific context in which this conflict recently has arisen is in response to a legal requirement enacted in the State of New York—and elsewhere—in February 2011: the Palliative Information Act "mandates" that if a patient is diagnosed with terminal illness, the patient's careprovider must offer to give the patient full information regarding the patient's legal rights to palliative care and all other options.¹³

This law mandates what would seem to be optimal care. I recall, for example, how nurses at one hospital once contacted me and asked me to consult with all of the staff working in their specialty service, because the doctors were telling fatally ill patients only about the options of receiving the standard of care or of entering a research protocol. Physicians were not, the nurses said, telling patients about the option of palliative care. (I shall add that these patients had, in general, a fourth option: to

ask careproviders to "do nothing." Of course, I would ask a patient if he or she chose this option, "Why?")

But a risk here, for careproviders who follow this New York law, at least to the letter, is that they might give patients more information than they need or want, which may be harmful. It could "overload" them. Astrow and Popp, two physicians, strongly make this point: "What is needed in such cases is not simply information, but an appreciation for the profound anxiety everyone feels at the border between life and death. In asserting power over the way in which deep and troubling human questions should be addressed . . . the New York legislature seems likely only to generate cynicism. . . when . . . patients and their families are most in need of honesty, kindness and engagement."¹⁴ Elderly patients in China, Chan says, have an overriding reason to not want to know that they are dying: they believe if they discuss death, it may have unwanted consequences, even hastening their own death. In the U.S., patients may not want to have this information for other reasons. They may even simply just want to deny it. How hard, under these circumstances, should we "push"? Should we respect patients' denial more than we typically do now in the U.S.?

1. Asking patients how much they want to know.

One way careproviders can approach the question of how much patients want to know is to take the initiative to ask. This may be the best approach, but there is a risk that if patients don't want to know, and no one asks them whether they'd want to know if they are dying, it may let the "cat out of this bag."¹⁵ If patients haven't discussed it, and no one asks, the patients' preferences can only be inferred.

Adult children in or from China might have greater moral justification than we would in the U.S. for inferring that a parent would want them to decide whatever they think is best, since this is, as Chan tells us, already a common value for them. Recent research on "giving bad news" indicates that patients in the U.S.—as within any culture—differ. Some want all possible information, but many want less. The latter group may not want to know, for example, how much longer they are likely to live.¹⁶ And while some patients want all of the information they can get, as soon as they can get it, others want it in smaller doses, over time.

In general, patients often want specific information on how their terminal illness is likely to affect them. In providing this information, careproviders may want to avoid using vivid visual images, because these may be remembered differently than more abstract, verbal concepts. For instance, visual

images, if presented as “worst-case scenarios,” may continue to “haunt” patients to a greater extent.

Like all of us, patients may not know what they really want. For example, patients may feel, at first, they want all possible specific information, but later may feel they want only more general information.¹⁷ Given the different needs of different patients, and given that patients’ needs may change over time, perhaps the best way to meet patients’ needs is to say, each time, after providing some new information, “Is this enough information for you, for now?”¹⁸ This may be an optimal way for careproviders to provide information that leaves the decision of “how much information?” wholly up to patients.

If careproviders suggest to a patient who is seeking information, “Let’s wait until later,” the patient may feel pressured respond, “OK.” It is important for patients to have all the control that they can, especially when they lack control due to a terminal illness. When careproviders want to advise waiting until later to provide information, at most they might suggest, “Perhaps it might be wise to wait to discuss some more specific questions until a later time, because, right now, it is most likely that they will never arise. What do you think?”¹⁹ Careproviders could share this further rationale: “If we discuss this now, and these concerns never do arise, our discussing these concerns now will cause you unnecessary worries.”

Alternatively, careproviders could opt to give a patient more information only when he or she asks for it. This approach, however, has a downside: it may discriminate, in its effect, between patients who ask for information and those who, for some reason or other, don’t ask. It may not be ethically justifiable to discriminate between the two groups, based on this difference.

2. *Giving patients hope.* When and the degree to which careproviders should try to convey hope may, for somewhat analogous reasons, differ among patients. Some patients may still want all possible information, even when there is “no hope for cure,” and they may lose trust in their careproviders if careproviders don’t openly tell them everything they can. Careproviders who seek to overcome this risk could urge patients to feel “other kinds of hope,” such as hope that the patient can leave a good memory with others, or of dying with dignity. For some patients, hope that they won’t be soon dying, though, is the only kind of hope they want. Careproviders who know this may give hope in some ways that are literally truthful and yet allow such hope. They may tell a patient, for example, that some patients “defy

the odds.” Still other patients may want a hope of a cure, yet want the truth—that will destroy this hope—at the same time. Careproviders’ task may then be paradoxical.²⁰ For example, a patient was dying of cancer. He told every careprovider he saw that he wanted all possible information. He later told me he’d “quit” his oncologist because he asked him what he could do to prolong his life, and this oncologist had said truthfully but bluntly, “Nothing.”²¹

Of Mexico, and of the Kindness of Strangers

In this issue of *JCE*, Joshua S. Baru, Brian P. Lucas, Carmen Martinez, and Daniel Brauner describe their study of 59 hospitalized men who were “undocumented, Hispanic immigrants” in “Organ Donation among Undocumented Hispanic Immigrants: An Assessment of Knowledge and Attitudes.”²² First, the authors asked the respondents whether they would be willing to donate an organ to a stranger. Then, the authors told the respondents that if they needed an organ transplant in the U.S., they most probably wouldn’t get one. Finally, they asked the respondents whether they would still be willing to donate an organ to a stranger. Three-quarters said they still would. This finding has important implications for careproviders for two reasons.

First, it exemplifies how the respondents in the study would extend their altruism beyond family members and good friends. Some might see this as going beyond what a person should be willing to do. That these men said they would be willing to extend such a gift to strangers may, however, represent a more ethically enlightened, *global* perspective to which, now, we all should aspire.²³ That many in the U.S. and elsewhere feel the same way as the men in this study is, at the very least, something careproviders should know. This awareness could, in some cases, change what careproviders do here in the U.S.²⁴

Second, these findings suggest that our willingness to give to others is not based in reciprocity, as many believe. The principle of reciprocity is used in game theory to understand how people may act to benefit themselves maximally, especially over the longer run.²⁵ Reciprocity may be used to support many clinical judgments, for example, when a mother agrees to undergo fetal surgery mostly for the sake of her fetus, or when family members continue to care for a loved one even though it causes them emotional or physical harm. When a person chooses to give without an expectation of reciprocity—like the Hispanic patients who said they would donate an organ if it was needed, with no expecta-

tion of receiving a donated organ, if needed—we may respect their gift more than one made with the expectation of some kind of repayment.

Third, the responses of the Hispanic men have far-reaching implications for careproviders who treat patients “eye to eye.” That is, when careproviders tell patients an unpleasant truth, it may *not* damage their relationship with patients. When careproviders are honest and forthcoming, it may strengthen the relationship. It is something most patients will deeply appreciate.

For example: some hospitals require its mental health careproviders to obtain a signature on a “no-suicide contract” from suicidal patients, even though there is evidence that this policy may be quite harmful, overall, because patients may feel “distanced” when careproviders ask them to sign, and so they may be more likely to commit suicide. One of my colleagues had a patient who balked at signing such a contract. He asked, “Why?” My colleague replied that she guessed the hospital required her to request a signature because the hospital thought it would be better, legally, to protect *itself*. She said she disagreed and thought it was harmful to patients. The patient thanked her profusely for telling him this. He said that this caused him to trust her even more.

Of the U.S., and of Those Who Are Most Alone

In “Surrogates and Extra-Familial Interests,” in this issue of *JCE*, Ralph Baergen and William Woodhouse consider the case of a patient who has physical and cognitive impairments that are most likely due to a brain tumor that could be removed.²⁶ The patient has been confined to a wheelchair and has lived in an institution for years. If the tumor is removed, the patient may become legally competent, and be able to resume independent living. If he can, though, there is a problem: he has a history of pedophilia, and he may resume being a danger to children. The patient’s sole living relative is a younger sister, who has children. She is afraid that if she takes “responsibility” for him, he may harm them, as he harmed her when she was a child.

This case raises a number of important issues. First, there is a concern for the sister that may not be obvious: she could make the difference in whether or not the patient gets surgery. If she doesn’t consent to it, will she suffer a great deal of guilt? Others who have another’s fate in their hands may suffer in this same way. Thus, one concern is whether, in some way, the greater society should try to attend to this difficulty. That is, is there some way that society can take responsibility for such patients, so that

when a family member can’t take responsibility—in this case, the sister was asked to approve the surgery and arrange for supervision for the patient afterwards—society can? This approach extends our caring for loved ones to caring for strangers—like the men from Mexico, who said they would be willing to donate an organ to a stranger.

A second, greater question is how anyone could possibly consider not providing surgery to this patient, when it seems likely that surgery would help restore his competency and his “freedom.” Typically, in our society, we do not hesitate when surgery could restore a patient’s mental capacity. We typically do all that we can to help patients. Perhaps, in part, for this patient, some of us might not provide surgery because it would allow us to remain *passive*.

That we may find it easier to remain passive in morally stressful situations is explored in a well-known thought problem called the trolley question. A trolley is headed toward five people on the tracks, who are tied up and unable to move. You are next to a lever, some ways away, and, by pulling the lever, you can make the trolley switch to a different set of tracks and avoid the five people up ahead. But there is one person stuck on the other track. Which option will you pick: do nothing and allow five people to be killed, or pull the lever and allow one person to be killed?²⁷ Research indicates that most of us would find it more difficult to actively pull the lever and kill another human being, regardless of the number of lives it would save. Studies using f-MRI brain imaging report that a new part of research participants’ brains lighted up when they considered how, to act morally, they should actively respond in such situations.²⁸

But, as a society, it is abhorrent for us to even merely consider not providing surgery to the patient in the article by Baergen and Woodhouse. Such a response is the opposite of what Ed Pellegrino would have prescribed: taking right initiatives when we should. A broader, more invidious implication, however, is that we might be discriminating against others without being aware of it.

Why might we find it so easy, in this instance, not to act? The answer is, for me, personally painful—and it should be—because my first reaction when I read this case was to think of the welfare of the patient’s sister and her children: What would most benefit them, or do them the least harm? I probably felt negatively toward the patient because of what he had done. Based on this, it makes sense to ask ourselves how often we prejudge others, based on our own visceral responses to them, without knowing we are doing this.

Here is another example of how stigma may blind-side us to our own biases, from a recent annual meeting of the organization concerned with human research protections in the U.S. It concerns research now being conducted strictly according to U.S. policies on protecting research participants.

Great human suffering is created by persons' addictions to various chemical compounds. A current attempt to mitigate the power of addictive substances is to find a medication that lessens the pleasant effects of these substances. Researchers need to test the effectiveness of medications with human participants, but since the participants must use the new medication in combination with the addictive substance—for example, cocaine—there is a danger that participants who have not used the addictive substance previously may become newly addicted through its use during the research study. So researchers seek out participants who have used the addictive substance before.

But researchers also need to recruit participants who are “clean,” that is, who state they are not currently using the addictive substance, and test accordingly. Another criterion is that participants must state that they currently, genuinely, aren't interested in treatment, because it would be wrong to not give participants treatment if they did want it, and the research does not currently include treatment.

At this major research meeting, one presenter, Edward Nunes, reported on a small study in which people who were not current users of an addictive drug were given a medication called ketamine, used as an anesthetic.²⁹ Ketamine recently has been found to profoundly reverse some patients' depression, but it is only effective for a short time. In this study, “former” drug users who had previously said they did not want treatment for their addiction were given ketamine. Some cried. Some expressed, for the first time, how much they regretted their previous drug use, and that they wanted to change.

David Strauss, Nunes's co-presenter, asked whether we too easily believe participants in addiction studies when they say they do not want treatment. On some other level, beyond their awareness, perhaps they do. Strauss is concerned that we too easily accept what these research participants tell us about not wanting treatment, possibly because we have negative attitudes toward them, based on their past drug use. Both Strauss and Nunes suggest, as a different, ethical approach, that we add treatment components to current “nontreatment” protocols, such as motivational interviewing.³⁰

Could such a possibly negative view of people with addictions bias our judgment, without our

knowing, so strongly that we can act invidiously, as individuals as well as members of a whole society? In the same way, is it possible we have a negative bias against people who abuse children sexually, such as the man with the brain tumor who needs surgery? Such people are among those who are most alone. Considering these things can add a great deal to the number of things that we *might* do to help them. Edward H. Khantzian, a psychiatrist, says what in our lives is “worst” is not that we can suffer. What is worst, he says, by far, is that we can suffer *alone*.³¹

“ED PELLEGRINO'S CASE”

The case I asked Ed about was the following real one. A small group of civilian careprovider volunteers were staffing a medical clinic in a rural area of a foreign country. A man who lived in this rural area brought in his teenage daughter who needed immediate, lifesaving surgery. The man said that his daughter could only have the needed surgery if the surgeon was female. Unfortunately, there was only one, male surgeon at the medical clinic.

The staff had heard about a similar situation at a rural clinic not far away. There, a man brought in his daughter, whose body and face were badly burned. The father forbade any male careprovider to be in the operating room while his daughter was in surgery. Their only surgeon was male, and he performed the operation. The staff told father this. The daughter survived surgery, but, when she was released, the young woman's family killed her, throwing her out of the car when it was going full speed.³²

The law in this country proscribed this, but crimes like this continued to occur.

The staff in the case I presented to Ed performed the surgery behind closed doors, and then lied to the father about who had been in the operating room during surgery. Ed said he would not have lied. He said that he believed in discussion based on mutual respect. When moral views are in conflict, he wrote, “some extensive dialogue is in order.”³³ This approach of “respect and negotiate” is, generally speaking, the expected “first rule,” and Ed's skills at this were second to none.³⁴

Ed did not say, after saying he wouldn't choose to operate and lie, what he would do if this failed. I suspect he would have called in the local authorities to protect the daughter, and, thereafter, to do whatever was necessary to continue to protect her life, even if this would have meant bringing her back to the U.S., and even though this would have ripped her from her culture and all of the family and friends she had known.

Ed wrote that “never killing” was the “most fundamental” of all of the absolute moral values, although “never lying” was important, as well. “Deception,” he said, “leads to mistrust and anger when the truth becomes known, as inevitably it will be.” He wrote, too, about the current “international scene,” and stated, in regard to it, that the “inherent dignity” of all humans is the moral foundation of what we owe to each person.³⁵

I suspect Ed’s success in negotiating ethical conflicts with patients might have been due, in no small part, to his integrity, which was apparent to others. For example, he said that in decades of clinical practice he had never asked a patient to accept being treated by a student he was supervising and had the patient refuse. This position, to respectfully negotiate, he shared at USUHS with literally thousands of students. When these students now ask their patients whether they can do procedures “on” them, rather than presume they have permission, as most care-providers almost always do, this may be due to Ed.

CONCLUSION

This introduction focused primarily on Ed Pellegrino, on three different cultures, and what they might teach us. In her article, Chan describes how Chinese and Chinese-Americans hold their family members in high regard. We may find ways to do this more, here. We might do more to help patients who are at the end of their lives to do what their families want, if this is what the patients want. We might be less concerned when, having told patients the truth that they have a fatal illness, the patients act in ways that suggest they are denying this.

Baru and colleagues report that a majority of the Hispanic men they interviewed said they would donate an organ to a stranger, and that most of the men would do this whether or not they would be able to receive an organ transplant in the U.S. These men model altruism to which we all should aspire. Their willingness to donate, even after care-providers told them they probably would not receive an organ transplant if they needed it, indicates that care-providers may earn additional trust from their patients when they speak frankly with them.

Here in the U.S., Baergen and Woodhouse considered the possibility of not treating a man who needed brain surgery, who had a history of sexually abusing children. Perhaps it seems easier to do nothing for him, to remain passive, due to a society-wide moral blindness that exists beyond our awareness, based on bias against persons who harm children. Such considerations raise new questions regarding

our treatment of family members, strangers, and those who are most alone.

At the recent annual meeting of the American Society for Bioethics & Humanities (ASBH), outgoing society president Joseph J. Fins spoke of Ed Pellegrino as being like the renowned physician, Sir William Osler.³⁶ In this issue of *JCE*, in “On the *Lingua Franca* of Clinical Ethics,” Fins describes a case in which he asked a patient whether she would want to be “put under” general anesthesia for a week to see if her lungs might heal.³⁷ This was what Ed would have done: asking and doing what he believed would be medically best for his patient. At this ASBH meeting, Fins, with a colleague, discussed how they respond at Cornell when patients and families want treatments that might be considered futile. They explained that they don’t label treatments as futile, rather, they *negotiate* with patients and family members. They negotiate as long as they can, and only make a decision, if they must, for the remaining “1 percent.”³⁸

This is Ed.

NOTES

1. E.D. Pellegrino, “Intersections of Western Biomedical Ethics and World Culture: Problematic and Possibility,” *Cambridge Quarterly of Healthcare Ethics* 3 (1992): 191-6; E.D. Pellegrino, P.M. Mazzarella, and P. Corsi, *Transcultural Dimensions in Medical Ethics* (Hagerstown, Md.: University Publishing Group, 1992). See, also, T.L. Beauchamp, “Does Ethical Theory Have a Future in Bioethics?” *Journal of Law, Medicine & Ethics* 32, no. 2 (2004): 209-17.

2. I should acknowledge, here, on this 25th anniversary of *JCE*, my exceptional appreciation of Dr. Paul Beeson. Dr. Beeson wrote for us a most positive description of *JCE* for subscribers, prior to its publication. He was the author of a leading textbook in internal medicine at the time

3. J. Glover et al., “A Model for Interschool Teaching of Humanities During Clinical Training” *Journal of Medical Education*, 59 (July 1984): 594-6.

We hoped to put our resources together to offer medical students a fourth-year elective in which they would spend one week learning ethics at George Washington, Georgetown, and Howard University in D.C., and at the Uniformed Services University of the Health Sciences (USUHS) in Bethesda, Md. This rotation did come about and lasted for years. We went, then, in pairs, to other cities to share with other schools how they, too, might do this, but, to my knowledge, no other schools did.

4. K.C. Chan, “Challenges to Culturally Sensitive Care for Elderly Chinese Patients,” in this issue of *JCE*.

5. H.P. Lefley, “Cross-Cultural Perspective of Family Psychoeducation,” *Psychiatric Annals* 42, no. 6 (June 2012): 236-40.

6. Children who know the most about their families seem to have greater self-esteem. They can understand their difficulties in the context of their larger family system, and develop, as a result, a “more nuanced and less harsh” understanding of the challenges they face. A.M. Heru, “Families in Psychiatry: Narratives and Transmission of Resilience,” *Clinical Psychiatry News* 6-7, no. 9 (September 2013): 641.

7. A. Crawford, “Sleeping Infants Still Know When Mom and Dad Are Fighting,” *Smithsonian* 44, no. 6 (October 2013): 20.

8. J. Greene, *Moral Tribes* (New York: Penguin Press, 2013), 152-3.

9. They also do not know, of course, whether research or the standard of care will be better, because there is clinical equipoise: those careproviders who are the most expert are uncertain.

10. J. T. Berger, “Patients’ Concerns for Family Burden: A Nonconforming Preference in Standards for Surrogate Decision Making,” *The Journal of Clinical Ethics* 20, no. 2 (Summer 2009): 158-61, p. 158; J.T. Berger, “Patients’ Interests in their Family Members’ Well-Being: An Overlooked, Fundamental Consideration within Substituted Judgments,” *The Journal of Clinical Ethics* 16, no. 1 (Spring 2005): 3-10.

11. Policy and practice, here, might be inconsistent. This might, however, bring about the optimal end result. An example illustrating how this can be is having speed limits not strictly enforced: the speed limit may limit speeding, while the lack of enforcement frees police to do something else.

12. In this case, that the wife and family arrived at a decision that all could accept was additionally important because there were grandchildren. In other contexts, too, family members’ interests may warrant moral weight. See James Lindemann Nelson’s “Familiar Interests and Strange Analogies: Baergen and Woodhouse on Extra-Familial Interests,” for example, in this issue of *JCE*.

A current example, for instance, involves children who need scarce resources, such as drugs to treat their cancer, that are in too-short supply. After other criteria, such as medical utility, are exhausted, negative effects on *other* family members may be among the additional criteria that are considered.

13. N.Y. Pub. Health Law § 2997-c (Consol. 2013), AKA the “Palliative Care Information Act.” Discussed at a presentation by L.B. Solberg, “Empowering Terminally Ill Subjects through the Informed Consent Process,” at the Advancing Ethical Research Conference, jointly sponsored by PRIM&R (Public Responsibility in Medicine and Research) and Boston University in Boston on 9 November 2013. I wish to thank Lauren B. Solberg for alerting me to this issue and providing me this citation.

14. A.B. Astrow and B. Popp, “The Palliative Care Information Act in Real life,” *New England Journal of Medicine* 364 (19 May 2012): 1885-7, p. 1887.

15. Should careproviders or family members ask patients whether they would want to know if there are dying, it may convey to patients that they soon will die. Even when patients say, in reply, “No, I don’t want to know,”

they may sense, thereafter, that careproviders or loved ones are keeping information from them. This may diminish their trust, and then all involved may be carrying on a charade.

Care providers and family members may avoid this risk by asking such questions early enough that they do not know patients’ diagnosis or most likely outcomes. L. Van Vliet et al., “When Cure is No Option: How Explicit and Hopeful Can Information Be Given? A Qualitative Study in Breast Cancer,” *Patient Education and Counseling* 90 (2013): 315-22, p. 319.

Careproviders who plan to disclose such information should always ask who, if anyone, these patients would want to have with them. *Ibid.* See, also, P. Kirk, I. Kirk, and L.J. Kristjanson, “What do Patients Receiving Palliative Care for Cancer and their Families Want to be Told? A Canadian and Australian Qualitative Study,” *British Medical Journal* 265 (2004): 1343-9, p. 1347. Patients may prefer that a careprovider disclose information to them alone, or to when they are with their family, or they may want to have a loved one, *not a careprovider*, be the first to share this with them. S.J. Marwit and S.L. Datson, “Disclosure Preferences about Terminal Illness: An Examination of Decision-Related Factors,” *Death Studies* 26, no. 1 (January 2002): 1-20, p. 5.

16. Patients who want more information tend to be young, male, well-educated, from a rural background (perhaps because they are more familiar with death and are not religious.) Marwit and Datson, see note 15 above, p. 13. These patients may also be more comfortable with receiving more information when they have social support and tend, as a style of coping, to “monitor” as opposed to to “blunt” threatening information. Since news of imminent death is so unique, the role that these factors play may, in this particular context, still be uncertain.

On the other hand, patients may want and do better with more information when they have had a prior positive experience with death. Thus, careproviders should take a prior psychosocial history to determine this. *Ibid.*, 5. It may be, also, that patients with less education tend more to favor having their families with them when careproviders inform them. *Ibid.*, 15-16. In any case, careproviders have, it appears, tended to err by choosing too often to disclose such information to patients *alone*, without asking patients whether this is what they want. The effect has been to “delegitimize” the presence of these patients’ families, thus denying these patients and families what they may most need and want. *Ibid.*, 15.

As Chan points out, Chinese parents may feel more comfortable, though, talking with people who are *outside* of their immediate family. This may, be for example, because they sense, perhaps rightly, that their family members feel too close to them, and, thus, these discussions could be too painful for them. Chan, see note 4 above.

One mother from Australia who had cancer said, in regard to her children, for example, “what I haven’t done is asked them . . . what’s going to happen . . . I think they’ve taken it, in a sense, a lot harder than me . . . all I’m going to do is die. They’ve got to watch me die and then get on without me.” Kirk, Kirk, and Kristjanson, see note 15

above, p. 1348.

As this may be the case, careproviders might specifically ask patients whether, in addition or instead of sharing what they are feeling with only their families, they might also want the opportunity to speak on an ongoing basis with others, *outsiders*, who are not so involved.

17. J.R. Curtis et al., "An Approach to Understanding the Interaction of Hope and Desire among Individuals with Severe Obstructive Pulmonary Disease or Advanced Cancer," *Journal of Palliative Medicine* 11 (2008): 610-20.

18. Van Vliet et al., see note 15 above, p. 319. Currently, in response to this difference among patients that careproviders can't anticipate, many careproviders respond by what is called "pacing." They give out information gradually, over time. Kirk, Kirk, and Kristjanson, see note 15, above: "it is important to provide info on a regular basis, shift from 'cure' to 'palliation'," (p. 1343). It is unclear whether whether it is preferable, when careproviders tell patients how long they can expect to live, whether providing qualitative words or specific numbers is preferable. Van Vliet et al., see note 15 above, p. 315.

19. Van Vliet et al., see note 15 above, p. 318.

20. "Dependent on the meaning of hope for an individual, a paradox may exist if they also desire realism. . . . This paradox . . . may present one of the biggest challenges for professionals." S. Innes and S. Payne, "Advanced Cancer Patients' Prognostic Information Preferences: A Review," *Palliative Medicine* 23 (2009): 29-39, p. 36. Careproviders can give some patients hope by taking the initiative to point out ways in which patients and their families, for a time, can continue to live fully, if, and only if, this is actually the case. Van Vliet et al., see note 15 above, p. 317. In some case, this may involve careproviders pointing out what neither the patients nor their families have imagined. Patients may perceive this, however, as their careproviders not understanding the depth of their despair and/or, thus, their lacking in empathy. Careproviders may try to tailor their responses to the patients' and families' unique needs, using their intuition. This may, though, require greater interpersonal sensitivity than many careproviders are able to offer. *Ibid.*, p. 319. Moreover, even when careproviders have most exceptional interpersonal sensitivity, being able to intuit accurately what others want may be beyond what even then they can do. *Ibid.*, p. 319.

21. At the 15th Annual Meeting of the American Society of Bioethics & Humanities (ABSH), just concluded, Irene Ying, a physician, reported on three brain-imaging studies that suggested three *different* ways in which our brains may create denial, suggesting that this response maybe one acquired through evolution, because it is *adaptive*. She suggested, making clear that she was speculating, that patients may be able to both know that they are dying, but deny this, at the same time, so that it may be that careproviders should accept this more than they do now. I. Ying, "Therapeutic Doublethink: A Novel Concept to Ethically Justify Unrealistic Optimism in Patients with Advanced Cancer," presentation at the 15th Annual Meeting of the American Society of Bioethics & Humanities, held 24-27 October 2013, in Atlanta, Georgia. It is well-known by careproviders who are familiar with hypnosis

that people can hold contradictory, mutually exclusive beliefs at the same time. The contradiction, when in a trance, simply doesn't concern them.

22. J.S. Baru, B.P. Lucas, C. Martinez, and D. Brauner, "Organ Donation among Undocumented Hispanic Immigrants: An Assessment of Knowledge and Attitudes," in this issue of *JCE*.

23. "Altruism . . . eventually branched out beyond close relatives. . . . [Environmental stress is] not devoid of bonding power." R. Wright, *Nonzero: The Logic of Human Destiny* (New York: Vintage Books, 2000), 324 and 328. James Doty, a neurosurgeon, has founded and directs the Center for Compassion and Altruism Research at the Stanford Institute for Neuro-Innovation and Translational Neurosciences in Stanford, Cal. Strengthening our "compassion muscle," he says, to include "out-groups" throughout our globe is "how humanity is going to survive." E. Svoboda, "The Selfish Benefits of Compassion," *New Scientist* 220, no. 2939 (19 October 2013), 28-29, p. 29.

24. Transplant teams "have generally been suspicious" of living donors donating to strangers but "a majority of the public believe this is right." T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013), 55. See, also, A. Spital and M. Spital, "Living Kidney Donation: Attitudes Outside the Transplant Center," *Archives of Internal Medicine* 148 (May 1988): 1077-80; and C.H. Fellner and S.H. Schwartz, "Altruism in Disrepute," *New England Journal of Medicine* 284 (18 March 1971): 582-5.

25. D.L. Cohen, "Not Playing Games," *American Bar Association Journal* 99, no. 1 (January 2013): 25-6.

26. R. Baergen and W. Woodhouse, "Surrogates and Extra-Familial Interests," in this issue of *JCE*.

27. For a current overview and summary of studies in this area, see Greene, note 8 above, pp. 113-21.

28. J.D. Greene, R.B. Sommerville, L.E. Nystrom, and L.E. Darley, "An fMRI Investigation of Emotional Engagement in Moral Judgment," *Science* 293 (2001): 2105-8.

29. E. Nunes, "Panel X: Giving Drugs to Drug Users and Other Ethical Quandaries in Research on Substance Use," presentation at the Advancing Ethical Research Conference, jointly sponsored by PRIM&R and Boston University, Boston, on 9 November 2013.

30. D.H. Strauss, "Panel X: Giving Drugs to Drug Users and Other Ethical Quandaries in Research on Substance Use," presentation at the Advancing Ethical Research Conference, jointly sponsored by PRIM&R and Boston University, Boston, on 9 November 2013.

31. E.H. Khantzian, "We Are All at Least a Little Lost and Off-Putting: On Transformation," *Psychiatric Times* 30, no. 11 (November 2013): 37.

32. Young women in forced marriages who feel hopeless may commit suicide by self-immolation. H. Turner, "Literature Review: Afghanistan Women's Health Crisis, Health Service Delivery, and Ethical issues for International Aid," *Health Care Women International Journal* 27, no. 8 (September 2006): 748-59, p. 751. How many, if any, of these suicides are, in fact, murder, made to look like self-immolation, is open to conjecture. In 1997, six million Afghans had no access to medical care. *Ibid.* Touch

between men and women may be prohibited, and even the use of interpreters of the same sex is recommended. *Ibid.*, 754. “Humanitarian aid . . . may be all the medical care [these] people in some contexts . . . get.” *Ibid.*, 756. Doctors without Borders lost five staff in June 2004. They were shot and killed on a road. *Ibid.*, 756-7.

One local person said, “It is better that one person dies than the whole family of shame and disgrace. It is like a box of apples. If you have one rotten apple, would you keep it or get rid of it? I just got rid of it.” R. Husswini, *Murder in the Name of Honor* (Oxford, U.K.: One World Publications, 2012), 10.

Most honor killings occur in poor and uneducated populations where word of mouth spreads fast, and in rural populations, where economic hardship and daily struggles are the “rule of the day.” *Ibid.*, 43.

33. D.C. Thomasma and E.D. Pellegrino, “The Role of the Family and Physicians in Decisions for Incompetent Patients,” *Theoretical Medicine* 8, no. 3 (October 1987): 283-92, p. 285. “The difference between our view and that which argues for an absolute respect for patient wishes is that ours more explicitly rests on a dialogue about values.” *Ibid.*, 287. “The family can be seen as the object of the value the family holds. . . .” *Ibid.*, 287. “Our unconventional view of patient autonomy . . . incorporates respect for patient values logically prior to respect for current wishes or free actions.” *Ibid.*, 290. Would this girls’ prior values have included her preferring to die rather than to have a male surgeon operate? A Jehovah’s Witness patient might prefer death, but, then, this should be that patient’s view, not one imposed by a parent.

34. Building new relationships and non-coercive responses, rather than using power and coercion, enables people “to break out of the defensive private shells into which they [have] retreated, often out of fear.” H. Miall, O. Ramsbotham, and T. Woodhouse, *Contemporary Conflict Resolution*, 3rd ed. (Cambridge, U.K.: Polity Press, 2011), 40-4 and 53-4.

35. E.D. Pellegrino, “Some Things Ought Never Be Done: Moral Absolutes in Clinical Ethics,” *Theoretical Medicine and Bioethics* 26 (2005): 469-86, pp. 475, 480, 481, and 483. Ed dedicated this article to the memory of his colleague, David Thomasma. “I do not know whether he would have agreed with this approach,” Ed wrote. “But I do think he would consider a proposal for a modest retrieval of moral absolutes possible,” (pp. 470-1).

36. J.J. Fins, “A Tribute to Edmund Pellegrino and His Work,” plenary session at the 15th Annual Meeting of the American Society of Bioethics & Humanities, held 24-27 October 2013, in Atlanta, Georgia.