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## *At the Bedside*

# Fourteen Important Concepts Regarding Moral Distress

*Edmund G. Howe*

### ABSTRACT

I suggest that we may want to strive, over time, to change our present professional-cultural view, from one that sees an expression of moral distress as a threat, to a professional-cultural view that welcomes these challenges. Such an effort to better medicine would not only include dissenting clinicians, but patients (and their loved ones) as well.

In this issue of *The Journal of Clinical Ethics*, in "Harnessing the Promise of Moral Distress: A Call for Reorientation," Alisa Carse and Cynda Hylton Rushton discuss moral distress.<sup>1</sup> They define distress as "the troubled call of conscience, an expression of fidelity to moral commitments seen as imperiled or compromised," and discuss how clinicians' experience of distress may reflect underlying strengths. In this introduction I will elaborate on these themes as they apply to moral distress more widely. I will use a much expanded definition of moral distress to maximize the degree to which clinicians can use these concepts to most help their patients and themselves. The definition and scope of moral distress I will discuss will be any distress that results from conflicting values, to any extent.

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**Edmund G. Howe, MD, JD**, is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics*. The opinions or assertions contained herein are the private views of the authors and are not necessarily those of the AFRRI, USUHS, or the Department of Defense. The funders had no role in study design, data collection, and analysis, decision to publish, or preparation of the manuscript. Conflicts of interest: none.

### MORAL DISTRESS: SOME CORE CONCEPTS

#### **Moral Distress as an Alarm**

Freud famously said that our dreams are the royal road to understanding our unconscious.<sup>2</sup> Moral distress may work in much the same way; it may alert us to moral conflicts that exist outside our conscious awareness. As Carse and Rushton state, "The experience of moral distress is not itself a symptom of moral deficiency or failure; it is a sign that one is attuned to ethical pressures or concerns, 'an alarm signal when a conscientious person is required to practice in challenging contexts.' " Without these alarms and the awareness they may bring, we may go forward without recognizing underlying moral conflicts. If they are not addressed, they may pose greater harm. If we can identify them earlier on, we may be able to resolve them in a earlier and much more beneficial way.

Even patients' expressions of nonverbal distress may enable clinicians who detect this distress to change their behavior. Here is an example: Dworetz reports that some pregnant women who are carrying a fetus that has died, or are carrying a fetus whom they know will die soon after birth, want to give birth so that they can hold the infant, even if only for a very short time.<sup>3</sup> They may cherish this experience for the rest of their lives. Their clinicians may not anticipate this, and may urge the mothers to have an abortion. The mothers may or may not comply. Even if they do not comply, they may long, and deeply, resent this advice. Some women who experienced this have formed groups for themselves, and for women who are currently going through the same experience.

Suppose a clinician advises a woman who is carrying a fetus that has died, or is dying, to have an abortion. Even if this “alarm” is nonverbal, the clinician will be able to change tack. The clinician could say, for instance, “On the other hand, some mothers want very much to hold their baby after the baby dies, or when they know the baby will soon die. They may cherish this experience forever. Do you know what you would want?” While this may not seem realistic, it illustrates how seeing moral distress as an alarm can bring about change. The example also illustrates how picking up on expressions of moral distress may, over time, improve the quality of medical care. The conflicting values here are between clinicians who initially, paternalistically, urge a woman to have an abortion versus clinicians who respect a woman’s autonomy to a greater degree by indicating that she has two options.

When patients or family share feelings of moral distress, we can thank them immediately, even in front of colleagues. That way, people who have spoken up will know that at least one person appreciates they shared a concern, even if others do not. A broader definition of moral distress that I am discussing goes beyond Carse and Rushton’s more narrow definition. I am suggesting that clinicians routinely imagine the possibility that there may be values in conflict underlying any patient’s or colleague’s show of distress. Only by inquiring may we determine whether their distress stems in part or whole from a moral conflict—or that it does not.

**Moral distress due to unfairness.** There are many sources of moral distress, but one may be exceptionally important clinically: unfairness. Being able to recognize unfairness may help clinicians better their practice. Persons who believe they have been dealt with unfairly may be more likely to reject rational reasoning. They may feel the perceived unfairness has violated some part of them in a deep-seated way. This is consistent with recent findings from some neurophysiological brain studies.<sup>4</sup>

Here are some examples. A patient was raped, but it was not having been raped that most embittered her. She had had therapy following the trauma, and she believed that she had mostly recovered. What continued to enrage her was the fact that she couldn’t, in any way, pursue or achieve justice. She thought rather obsessively about ways that she might seek revenge.<sup>5</sup> She did not take revenge. The man who raped her continued to go free, because the conditions of his raping her were not those for which he could be criminally convicted, or even brought before the court.<sup>6</sup> A second example involves a less-violent unfairness. A medical student grew up in a family with little income. His mother bought food

for the family with food stamps. When he entered medical school, he witnessed classmates playing games on their computers during lectures. He felt his rage triggered each time. “They are so ungrateful,” he would say. “I find myself hating every one of them.” I provide a second, less-serious example to show how even a small degree of unfairness may cause a felt reaction that is disproportionately large.

We should give our full attention to patients and colleagues who experience moral distress due to what they believe is unfairness, regardless of how significant it is. When persons become upset, they may respond with an emotionally reactive fight-or-flight response. When they have this response, they may be much less open, and thus unable to hear another’s conflicting point of view.<sup>7</sup> As Carse and Rushton state, “In heightened states of emotion, we can hold on to convictions by selectively honing in on confirming evidence, while remaining immune to disconfirming evidence.” When a person experiences moral distress, the overall goal should be to resolve the distress including resolving the conditions causing it. Since rational argumentation may not work, what should we do when we see a person who is upset due to feeling moral distress?

**Maybe more effective than rational argumentation.** Since, once aroused, persons in moral distress are less likely to want—or even be able—to reason, we should seek to try to lessen their heightened arousal, regardless of our own moral views. Almost always, there is some sound underlying basis for the moral distress, even though the degree of the distress may not be justified. In these instances, we should note our agreement with that part of the distress, to seek some way that the other person will accept us as an ally, in the sense that we want to seek with the person to find a better resolution, from that person’s point of view. This may mean being willing to align ourselves with that person, and pursue together a resolution we both can accept.

John Gottman is regarded by many as the leading expert on treating troubled couples. He asserts that for couples to do well, they must have “a safe haven” before they begin to tell each other how they feel. As they say how they feel, Gottman says, they must always exchange validation for what the other says.<sup>8</sup> Persons who experience moral distress in medical contexts are not, of course, troubled partners, but Gottman’s guidelines may be as effective as any. When we act as an ally to a person in moral distress, we may want to regularly validate the sound points in what the person says. When we make a point, we can offer it tentatively and bring about exchanges of validation by asking the other person each time whether or not the other person agrees.

Coincidentally, this process may lead, in the end, to parties being able to more readily agree. Seeking to imagine how to validate another person's points, on which we may differ, may allow both parties to gain new insights in a way that offering counter arguments doesn't.<sup>9</sup> Other ways to form alliances, that do not involve confrontation with another person who may be experiencing moral distress, have been developed by clinical ethicists who provide medical mediation. *JCE* has presented many pieces describing these approaches. A counterintuitive example that goes against what most of us may believe—and do—involves responding to another person's anger. There may be no skill more important when responding to a person who feels morally distressed. For this reason I will highlight some core points made by Autumn Fiester, a leader in this field. As she points out, "Whether explosive or intimidating or quietly seething, anger is probably the most common impediment to fruitful dialogue." She states, "The facilitator needs to find the source of the negative emotions so the cause can be addressed and, hopefully, remedied." Her key point is that "Reconceiving . . . expressed anger . . . as a signpost of moral grievance assists in viewing the grievance as potentially . . . productive, and offers a fruitful avenue . . . towards a shared resolution."<sup>10</sup>

Another core intervention from mediation is to directly contact and involve those who have the authority to make the changes necessary to resolve the person's moral distress. I will consider specific examples, for example, the contexts in which rules may require exceptions, in the next section. Edward J. Bergman, also a mediator, noted in a prior issue of *JCE* that clinical conflict "will often require the inclusion of institutional or departmental representatives." Bergman continues that even when dialogue does not result in changes, mediation can promote "greater understanding" and "credible institutional commitment to a genuine balancing of competing concerns."<sup>11</sup> These approaches are only a beginning. In the last section of this article, I will describe an approach that may surpass any other in enabling us to form a sufficient alliance with others who feel moral distress, such that we can work together.

**Maybe ethically mandatory.** When others feel that injustice has occurred, there is another intervention that I believe we should regard as ethically mandatory. This response is based not on ethics, but compassion. Persons who believe that they have been subjected to rank unfairness may totally decompensate emotionally in ways that they haven't before, and thus may not be able to understand. They may fear, not without reason, that they are losing their mind. Given this, we may be able to reduce

their panic to an almost remarkable extent by informing them this little-known fact: namely that unfairness may indeed have such a profound effect. With this awareness, they may have at least a glimmer of an understanding of why they feel as they feel, and it may be enough to restore a belief that they can cope successfully.

### **Who May Feel More Moral Distress than Others?**

In their article in this issue of *JCE*, Carse and Rushton discuss a case first published in an article by Delgado and Epstein.<sup>12</sup> In the case, a patient in the intensive care unit (ICU) of an academic medical center who has sepsis and multi-organ failure appears to be dying, and the nurse caring for the patient and the resident begin cardiopulmonary resuscitation (CPR). The patient's family is called, and they are in the waiting room. The nurse believes CPR should stop, so that its utility and the patient's wishes can be discussed with the family. The resident agrees, but then begins an exercise in which interns practice doing compressions on the patient. The nurse tries to stop it. She is rebuffed and feels intense moral distress. In the next section, I will discuss whether the nurse's objections to the teaching were appropriate, in regard to medical teaching more generally. I will not discuss in any detail whether her attempt to stop it was the best way to proceed, and, by extension, how others in similar situations might best proceed.

There are well-established ethical criteria for answering these questions regarding what clinicians and others should do when they must make moral decisions immediately, as the clinicians had to decide in this case, when the nurse insisted they stop. These criteria for making decisions include, for example, the potential irreversibility of the outcome, and the relative probabilities and magnitudes of competing benefits and harms. In the case of the ICU nurse, it seems likely that those who were learning CPR by practicing on her dying patient would have had other opportunities to learn how to do CPR. Further, after objections to a practice are raised on the basis of moral distress, it should be mandatory that the objections be widely discussed. It may turn out that there are other grounds for the distress that clinicians detect, but they can't know initially whether this is the case. It may be that, from a discussion of the ICU nurse's moral distress, that a way of teaching would no longer be permitted. In this case, the fact that the patient's family were waiting nearby may be critical factor—and provide the final word on the matter. Informing the patient about this teaching opportunity beforehand (and well beforehand, if possible), as well as informing the family,

clearly are necessary to fulfil the requirements of several core values—respect for the autonomy of the patient and family; allowing them to spend their last moments together; respect for the relationships they have with their clinicians. These are values emphasized particularly by the care perspective.

Beyond these comments, I wish primarily to ask why this ICU nurse, and not other clinicians, objected to practicing CPR on the patient. This leads to broader questions: Who may feel moral distress most intensely? Who may feel moral distress before others do? How can we, like this nurse, be better able to see and bring up these moral conflicts? I suggest, as Carse and Rushton do, that those who can see and bring up these conflicts may be best regarded as having a gift. They may be able to feel the pain of others to a greater extent. They may also, or alternatively, be more perceptive and/or intellectually open, although these greater capacities may also be, for them, a liability. They may hurt more because of the pain, vicarious though it is, that they can feel.<sup>13</sup> These gifted persons, who see pain more than most of us do, may have, in addition, the courage to alert us to what they and they alone see. This may alert us to better medical practices over time. This can only enhance the quality of the care that we provide.

Our conclusion from this would seem to be unequivocal: If circumstances permit, we should thank people immediately when they bring their moral distress to our attention. We owe them nothing less than to express to them our utmost and heartfelt appreciation. Some of us may view our colleagues who feel others' pain, and alert us to it, as, at worst, "bleeding hearts," and, at best, as unrealistic. But these colleagues may actually be more realistic than we are; they may see others without blinders, or they may not yet have come to deny what they once saw. That is, they may not have adjusted to the ever-present pain they witness by emotionally detaching or somehow rationalizing away its significance. Detachment may help them carry out some medical functions, but it may be at the cost of their becoming less aware of, and responsive to, patients' feelings.

Clinicians who have the greatest authority may rebuff colleagues like the ICU nurse for speaking up. Alarming, clinicians in authority may see or "project" the limitations they have as being within their colleague who speaks up. They may do this without knowing that they are doing it, because it helps them to avoid recognizing such deficiencies within themselves. They may also not feel the pain of recognizing that they have these deficiencies. Such scapegoating of others may cause long-lasting harm. And the harm may be compounded, because

when one clinician voices moral distress to a group, as the ICU nurse did, that person is changed by voicing it, and every member of the group will be changed by it too—in some way.

After a clinician voices this kind of distress, he or she may no longer "fit" in the group. Even if the peg remains square, the hole in which it once fit may have become rounded. Clinicians on a team—like the team learning CPR—who are challenged by a colleague—like the ICU nurse—may feel threatened, because their colleague saw an ethical problem, and brought it to their awareness, that they either didn't see, or couldn't see. The team members may then, consciously or unconsciously, want to defend themselves from this painful new self-awareness. They may want, and only want, to strike back; as I noted above, people who feel they have been wronged may respond by feeling a desire for revenge. They may want to strike back to defend themselves, in part or in whole, because they don't recognize that they feel hurt for their patients. Medical students are often taught they must learn to not take patients' pain home with them.<sup>14</sup> Most somehow learn to do this. There may be, though, a price, about which they are unaware. Their unconscious mind, protecting them, may not allow let them see patients' pain. It would be too painful for the clinicians.

Returning to the needs of those who express moral distress: they may not have developed this capacity for detachment. Some clinicians practice for years and never do. They may admit it, however, to other clinicians they trust, often only behind closed doors. Although they have not acquired a capacity for detachment, they have been taught and have accepted that they should be able to be detached and thus *should* be detached. Since they are not detached, they may feel shame. This shame may be, though, wholly unwarranted. It may be that, rather, they are and *should feel* luckily gifted. Their unwarranted feeling of shame may be not only ethically inappropriate and unjust; it may represent and reflect an erroneous bias held and put forth by the medical profession and its culture: that practitioners should be emotionally detached. They should not, for example, cry in the presence of their patients in response to the patients' pain.

Given this, we should regard clinicians who are not detached as more likely to be gifted. We should take most seriously what Elizabeth G. Epstein and Ashley R. Hurst write in their article in this issue of *JCE*, "Looking at the Positive Side of Moral Distress: Why It's a Problem."<sup>15</sup> They state, "thank goodness for the keen eye of the attending physician who sees a ray of hope that the team does not see (yet)." Ideally, in my view, we should not only thank a person

who expresses feelings of moral distress at once, explicitly, and loudly, so that any clinicians with us can hear it. Then those on our team will know where we stand. Moreover, perhaps the person voicing his or her views, like the ICU nurse, will not stand alone. This in itself may lead all of us on a path toward a new medical culture, as I alluded to previously. This new medical culture would be one in which dis-senting patients and colleagues would be welcome. And we would then be working together better, to better the practice of medicine.

### **SOME HARDER-TO-RESOLVE SOURCES OF MORAL DISTRESS**

The sources of moral distress are many. As Epstein and Hurst note, these include, for example, families who wish to continue life-support measures that are not in the best interest of patients, witnessing a diminished quality in patient care due to poor team communication, watching the care of patients suffer due to a lack of provider continuity, working in conditions where staffing levels are unsafe, working with colleagues who are not as competent as patient care requires, and providing less than optimal care due to pressures from administrators to reduce costs. These causes have, they add, “been shown over and over to be root causes of moral distress for physicians, nurses, social workers, chaplains, and others.” Some root causes are harder than others to clinically address. Recognizing this is so, and why, may help clinicians to feel less distress when they encounter them, and this understanding may reduce feelings of distress, often to what may seem a highly disproportionate extent. Knowing why the sources of moral distress are difficult to resolve may allow us to better understand why we may feel so frustrated or helpless. This greater understanding may benefit us, in much the same way that we can benefit persons who feel they have been treated unfairly, by acknowledging how devastating to their emotions and sense of well-being this may be.

### **Taking Our Needs, Sound in Themselves, Too Far**

Some of our needs are so important that we, as clinicians, may rightly consider them to be almost sacrosanct. Yet even these needs should probably, in most cases, have limits. But since we have been used to seeing these needs as almost sacrosanct, we may be reluctant to establish exceptions. This may cause problems “at the margins.” In this section I will discuss two such examples. A first example involves clinicians who are learning medicine. The ICU nurse’s protest is an example. Of course clinicians must initially learn medicine if they are to later

practice. The question is, at what point should we establish boundaries to respect patients.

A second example is the application of the principle of utility, which clinicians may, as they are teaching. This principle is, in some contexts, most valid and well-established. It is routinely applied, justifiably, for example, during disasters in which large numbers are injured. Utility maximizes consequences: by treating and triaging patients, based on the degree to which they will gain from treatment, it is a basis for treating patients equally. But there are grave limits to considering only utility. Yet, as when taking the importance of teaching too far, clinicians who are used to using utility, or want to use it for other reasons, may apply it too much, or too far. Thus I shall discuss some of the limitations to utility that we might build into our practice.

**When clinicians must learn.** In the case of the ICU nurse, we might imagine that the resident teaching CPR may have thought it was warranted to teach in this way. But some lines need to be drawn. In the past, such lines were sometimes not drawn, or at least not drawn early enough. A notorious example is medical students who learned to do pelvic exams by practicing on women who were under general anesthesia.<sup>16</sup> The women did not consent. Some clinicians continue to strongly believe that a patient in an academic hospital should not have a choice regarding who can learn to do procedures on the patient. Clinicians may argue that if a patient wants to gain from being in a teaching hospital, the patient should accept the possibly of added discomfort, if not greater harm, of students and clinicians who learn by doing procedures on patients. The continued presence of this argument reflects the presumed ethical priority of clinicians’ needs over patients’ autonomy. Even now I hear clinicians state this, adamantly. The presumption may be valid, and may ultimately benefit patients. But a more deeply seated problem is to presume it, without question.

It is now commonly recommended for medical students to introduce themselves to patients unambiguously, as medical *students*. They should not introduce themselves using unclear phrases, for example, “student doctor.” In the past, it was thought that somehow patients would know, on their own, that medical students wear short white coats and doctors wear long white coats. By assuming this, teachers and students may have been able to avoid any awkwardness in having to identify students as students. It may be another way that medical professionals favored their own interests over the interests of patients—and assumed the priority of this value, without question. Another example of how the teaching of medical students is granted a higher

priority than the needs and rights of patients may be that of the interns who were learning CPR on a dying patient while the family waited.

Medical students may discuss, in their medical and ethical training, what they should do when an attending or resident introduces them to a patient in a way that they shouldn't—as, for instance, a “student doctor.” Why should medical students go to such lengths to make sure that patients know their precise status when patients can't use the information to decide whether or not they will accept having a clinician-in-training, who is learning a new procedure, practice on them?

Informing patients without giving them a choice respected their autonomy, but giving them information without giving them a choice may leave them more frightened. Ed Pellegrino, a beloved and internationally renowned physician-ethicist, believed patients in an academic institution should have a choice. He also said that, as an attending, he had never had a patient say no to him when he asked whether a clinician-in-training could do a first procedure on the patient. How could this be? Ed explained that he would tell a patient that he would be there, looking over the trainee's shoulder. Thus, the trainee would be able to do the procedure, he said, almost as well as he would, himself—if not better, he might add with a grin. Ed was, as this example may indicate, a warm and endearing person. I can't imagine that I could turn him down. Ed held that the attending should be the one to ask a patient for permission. If the attending did not ask, it was unequivocally his or her moral mistake. To avoid the risk of even possibly being implicitly coercive, attendings should always indicate that they will, if a patient wants, make time for discussion.

I end this discussion of dilemmas in medical teaching with what may be the hardest example: clinicians doing a lumbar puncture—a spinal tap—on a newborn or infant for the first time. Trainees' skills in doing a first spinal tap (as well as later spinal taps) varies, and, by definition, they are less skilled than clinicians with more experience.<sup>17</sup> What should an attending advise a trainee to say to parents? Ed Pellegrino's view suggests an answer: the attending should be the one to speak to the parents.

Surely, as in all medical contexts that involve patients, medical practices should be transparent. Or should they? Might it be that there should be exceptions? I think of a clinician who informed me that sometimes, at his hospital, when a decision is made to withdraw a child from a respirator so that the child can die, the child's clinicians may, on their own, give the child sedative medication to help insure that the child won't suffer. The clinicians do

this because they fear that if they ask the parents for permission, they may say no. They may say no because the sedation could make the difference between the child continuing to survive after the respirator is shut off and the child dying. Parents may not want to give permission for clinicians to give the child medication that ends the child's life. Given this, should clinicians-in-training, about to do their first spinal tap on an infant, tell the parents it is their first, specifically? Or would it be kinder to just do the spinal tap with the parents not in the room, under the close supervision of their attending?

It would seem here that the ethically optimal course might well be to inform the parents and hope that some would say yes. The increased risk of serious harm to the infants should be minimal as it should be in all instances that involve clinicians' first-time learning. That some parents would say yes would not be unreasonable or uncaring, even though it involves a newborn.

***When the needs of the many may prevail.*** In their article, Carse and Rushton cite the “helplessness and outrage” that Susan McCammon, a surgical oncologist, felt when she learned that the institution at which she worked, in the wake of a damaging storm, was “terminating” care for uninsured patients. The moral distress McCammon felt was “immense.” We don't know why her institution adopted this policy. It may have been based on some application of utility. Regardless, this seems intuitively wrong. What we do know is that, for uninsured patients, it violated the principle of equity. This is probably what so enraged McCammon.

The core underlying factor that most likely distinguished patients who would be treated from those who would not was poverty; patients may not have had insurance because they could not afford it. Like the family of the medical student, they may have simply been poor. For those with decision-making responsibility, the use of utility may be particularly inviting. When deciding how to allocate limited resources, utility may be quantified, at least in theory. Quantified decisions may seem morally justified.

But giving sole, or even greatest, priority to the principle of utility may give short shrift to other values that should, in some contexts, warrant higher priority.<sup>18</sup> An example is justice for those worst-off. Justice may be harder to achieve because persons who are better-off may be less sensitive to the needs of those worse-off. Those who are better-off may be in the majority, and may make laws and policies. I will consider two kinds of worse-off patients to indicate possible exceptions to prioritizing the principle of utility. I will end the discussion with a contemporary policy conundrum that involves patients

who are worse-off. Clinicians who rely on the principle of utility more than they should is another example of over-applying a concept that is usually sound. The examples are meant to be paradigmatic of numerous others. Knowing this, we may better avoid such errors. The use of utility as an ethically all-overriding principle may be increasing. For example, some clinicians are now required to have 15- and even 12-minute follow-up patient visits, even in psychiatry. Mental health clinicians may be encouraged to see only patients who “really” still need mental health services. This is due to the large number of patients who currently need more care.

But which patients don’t “really need” care? I think of an aged adult woman who has greater than mild autism. My goal for her in working with me has been for her, for the first time, to ask me, “What do you think?” Now she has. She has also, for the first time, named an emotion she feels. I think too of a man I see who has a brain injury. He forgets a great deal, even from session to session. Outside our sessions he forgets, and then he feels shame. At each session, we undo his feelings of shame, and then, and only then, he is able to gain some relief from his feelings. These patients have made smaller, qualitative gains. Clinicians may feel moral distress when they feel pressure to sacrifice such smaller gains to help patients who are worse-off instead. Helping those worst-off first, even to a minor extent is, for example, a priority urged by Rawls.

In this respect, I think of a question raised on a larger, societal scale, namely, should patients with cognitive limitations not be eligible for organ transplant?<sup>19</sup> Many might agree a line should be drawn to exclude patients who are in a permanent vegetative state. But, for reasons I will discuss more in the next section, this may not be the case. What might be the optimal approach to patients with autism, memory deficits, and cognitive limitations? These patients may be seen as gaining less from treatment than others. When the issue arises, should there be a place for the John Rawlsian notion that sometimes the greatest priority should be accorded to bettering the lives of the worst-off? Might it be better, in some cases, to see whether it is possible to improve their quality of life, even when, in all other respects, it involves dis-utility?

### **Sustaining Lives as Opposed to Relieving Suffering**

Saving lives is paramount in medicine. This is nowhere more challenging than during a disaster. We may have to choose between saving more lives and relieving suffering. A value that is sound in itself, but which may be taken too far, is saving lives. This call may be exceptionally strong, but I will dis-

cuss, as a contrast, prioritizing the relief of suffering. Clinicians may be so intent on saving patients’ lives that they fail to recognize the extent of some other patients’ suffering, and thus the need to help them. The need to gain relief from their suffering may compete with the need to save others’ lives, as the example below most painfully depicts.

### **Saving a Life at the Price of Another’s Suffering**

The winter 2017 issue of *JCE* presented an emerging problem of immense ethical importance: how we can better meet the needs of patients with disorders of consciousness (DOCs). These patients may be aware, but have not been able to communicate with others, without medical assistance. As I indicated in that issue of *JCE*, as many as 41 percent of persons who previously would have been thought to be in a persistent vegetative state may not be. The actual figure may be higher. Patients who do not have awareness may heal. They may regain awareness for the first time after the onset of an illness or accident. Our relatively new knowledge that these patients may have some awareness now, or may regain awareness later, should cause us all quite significant moral distress. This is because the suffering these patients may experience, being aware but alone, may be much worse than most of us can imagine. As Joseph Fins, an expert on these disorders and a leading advocate for these patients asks, “Could anything be more isolating?”<sup>20</sup>

Let us try to consider, deeply, this loneliness. To do this, here is the example of two children who presented to a hospital with a condition called craniopagus. The children were connected at the head and their brains were inextricably intertwined. If one of the twins was to become fatally ill, as from sepsis or a bodily infection, both would die. Yet, it seemed to surgeons that, if this occurred, or before this occurred, the outcome of both children dying could be avoided. They could disconnect the body of the child whose body was dying from his head. This would save the life and brains of both children. This would leave, however, one child with a brain still aware, but possibly no means of expressing himself.

The children’s clinicians asked themselves, what would be preferable? To sever the head of one child so that they both could still live, or to allow both to die? In this rare and perhaps singular case, the clinicians answered that, put insensitively but accurately, no lives might be better than not-one-life-yet-not-two-lives. I do not know the outcome. The clinician who showed me the children’s skull x-rays and discussed the case with me wasn’t able to follow up on their outcome. The child who could have had just his brain could have been in a state much

like many persons with DOCs. They may have some awareness, but no way to express themselves.

This is the type of suffering that so concerns Fins and many others. Present technologies make it possible for some patients in DOCs to communicate, at least minimally. Additional patients, over time, may become slightly better. Fins reports the case of Maggie Worthen, age 21, who had a “cataclysmic stroke.”<sup>21</sup> Most thought she would remain in a vegetative state: her eyes would be open, but she would have no awareness of herself, others, or her surroundings. A “stunning breakthrough” occurred: she acquired the capacity for “some communication.” This was “real progress from where she had been.”<sup>22</sup> Many patients, Fins reports, improve like this. Sometimes it occurs “dramatically,” he says, “even decades after their original brain damage.”<sup>23</sup>

Our moral distress may be substantial at learning what patients with DOCs experience. Can we prioritize remedying their pain over an intervention that could save another patient’s life? The question, overall, is whether we may be so riveted to the goal of saving lives that we undervalue the need to relieve patients’ suffering, when the two needs compete. Worthen’s needs are a compelling example of how and why clinicians may want to consider giving priority to relieving the suffering of being aware but wholly alone. Meeting the great needs of the many patients with DOCs may require extensive efforts by clinicians, whose time is limited. A first response might be that we may want to take special care to not favor just one value or interest too much.

A second consideration is for those making decisions about these questions. As this dilemma illustrates, we are sometimes overwhelmingly helpless. Knowing we are sometimes helpless may, paradoxically, be a help. As noted above, in regard to people who feel were treated unfairly, and to clinicians who face hard-to-resolve issues, awareness of how difficult this decision making is may help us to avoid unrealistic expectations. Put simply, understanding one’s plight may be less painful than being helpless and not recognizing that this is the case.

***Bringing about a death that seems like murder.*** Carse and Rushton offer the example of clinicians who suffered great moral distress because they were treating a patient when they thought the treatment wasn’t warranted. Nurses and physicians were required by their hospital to treat a catastrophically brain-injured child, even though they believed doing this was “cruel,” that “their own hands engaged in what they perceive as the unconscionable act of harming a child.” This description is harrowing.

Clinicians may, quite rightly, want to treat patients with dignity. I am reminded of a concern raised

by Joanne Lynn, an eminent geriatrician and ethicist. She knew of the moral anguish that clinicians often experience when they must provide a treatment they believe is morally wrong. For example, clinicians may begin to emotionally detach from a patient who won’t agree to a DNR (do-not-resuscitate) order, even when they know the patient won’t do well.<sup>24</sup> A patient in this situation probably would prefer that his or her clinician not be emotionally detached. How can it be avoided? Perhaps clinicians could say that the disagreement about a DNR is causing them to feel emotionally detached. But they may, without knowing it, say this to vent anger toward a patient, and such anger can harm. On the other hand, the sharing might provide benefit; while saying this to a patient could be coercive, as it probably places pressure on the patient to request a DNR, this sharing might best respect and increase the patient’s autonomy. And, if the patient then requests a DNR, he or she could have a more meaningful and even intimate last several days, weeks, or months with the clinician, who would then be less likely to detach.

Patients may not want a DNR for many reasons. Perhaps they fear death. When we encounter people, whether patients or colleagues, who have exceptional concerns regarding death, we should keep in mind the uniqueness of death and how it may affect people in different and very deep ways. I think of a writer who published his view that one might fear death so much that one would rather die than continue to live with this fear. He took his own life.<sup>25</sup>

Another example illustrating the intensity of the feelings about death is that of a grandmother who threw herself over the body of her grandchild in his hospital bed, to protect him from clinicians. The boy had brain death, but his body was warm, since his heart was still beating. She believed, rightly, that the boy’s careproviders would declare him dead. In her view, he wasn’t. I used the word “murder” in the heading of this section to indicate the kind of response the grandmother might have to stopping treatment. It may be that in many, if not most, cases, stopping treatment can’t be avoided. The point I want to make is that we should ask patients and family members, as much in advance as we can, how we might reduce their future distress. Their distress may be emotional and moral. If so, we can pursue ways of reducing *both* sources of distress with them.

Here is one example of how we might, at least hypothetically, reduce the chance that a family will suffer a lifelong, pathological bereavement reaction to stop treatment, such as this boy’s grandmother. Many factors have been identified that may contribute to the disorder of lifelong, pathological bereavement. Most, such as the young age of a patient or

that it is a child who is dying, can't be altered. But one element can: the suddenness with which a person "subjectively perceives" that the patient has died.<sup>26</sup> Based on this, we may then be able to reduce loved ones' risk for deep grief by saying, as early on as possible, that the hospital has a policy that could support stopping treatment.

As we say this, we can make absolutely clear that there is no reason to believe that the policy would apply to their loved one. It may be that the family can hear the information without feeling too afraid, but at the same time, unconsciously if not consciously, begin to prepare for this possibility. They may begin to experience anticipatory grief at an earlier time. That may be best for them, for the same reason: undergoing grief at an earlier time may help them to not experience the patient's death as so sudden, later on. We may help the family the most at this time, however, by assuring them that if it does happen—unlikely though it is—that if the patient's clinicians would want to stop treatment, we will do all we can, with the family, to explore all of the ways in which they might be able to appeal a decision to stop treatment. Such reassurance at this time, early on, may help establish us as the patient's and family's ally. Later I will describe how important, in general, being an ally can be when patients or family members experience moral distress.

But the clinical point is straight forward. We should be most wary in applying one principle or value too far, even if it is a principle that we would typically prioritize. We should be wary of excluding other values that could warrant ethical priority, for instance, in these examples, being so involved in pursuing one goal that we fail to consider other, potentially helpful principles and values.

### Rules and the Law

Rules regarding medical care, most of us believe, are not made to be broken. We believe that rules should generally prevail and, when in doubt, we may err by following whatever rules might apply. We may, for this dubious reason, go too far. Likewise, laws may cause immense fear. If we break the law, we may go to prison. Also, we may seek to comply with laws to too great an extent. In this section, I will discuss some specific ways that we may respond to rules and the law that are likely to be harmful, and describe ways to help us to avoid these extremes.

**Obeying "the rules."** Rules may exert a tyranny that overrides both compassion and common sense. There are good reasons for this; rules may, for example, further consistency, help us treat others equally, move us to defer more to others who are duly authorized to make difficult decisions, and help

us reduce the risk of allowing persons in power to impose idiosyncratic, value-based decisions. Having rules may save us the work of having to create new rules. They may make what we do more transparent. But the price of following rules always, or too far, may be dear.<sup>27</sup> Carse and Rushton cite a likely painful example: a neonatal ICU team had to release "a still fragile infant" into an environment that seemed to be "inadequate and perilous." This allegedly occurred because there was a "lack of alternatives."<sup>28</sup> This may have occurred because there was a rule that those in authority believed they had to follow. Whether or not this is true, other examples aren't hard to find.

I recall, for example, a child who was hospitalized. He brought a fuzzy toy, to comfort him when he was alone. Having the toy with him was, however, against the rules of the hospital ward. The staff took the toy from him. He wailed. He didn't emotionally recover while on that ward. A somewhat parallel case involved a retired man, living alone, who was to enter a nursing home. He thought he could bring his cat, but then learned that he couldn't. In response to this news, he said that if he couldn't bring his cat with him, he would rather be dead. His careproviders almost admitted him involuntarily at this point, leaving the cat unattended. They almost did this because they weren't aware of any rule that allowed someone to go home with the patient to tend for his cat, for the short term, and then make arrangements for the care of his cat, in the longer term.

In the play *Wit*, a beloved friend climbs into bed to read a story with an adult patient who was dying. A medical school instructor uses the play, and this scene particularly, to teach her students. She reports the students initially feel discomfort because this represents breaking "the rules," but later, after discussion, the exercise seems to increase students' empathy.<sup>29</sup> This example from the play isn't farfetched. Not long ago, dogs were barred from visiting patients in the ICU. Now, in some ICUs, dogs can visit.

It is important, when assessing the merits of a rule and decide how far to extend it, to understand the rule's whys and wherefores. It may be that the rule itself is ethically suboptimal. This may be because those who made it placed unwarranted weight on some factor that didn't warrant such consideration, such as convenience or to avoid the greater difficulty of making decisions based on individual circumstances. For example, having one rule may confer dignity more invariably by accepting and insisting on bringing about, sooner rather than later, the death of some patients.

What might we do when we can anticipate the need for an exception to the rules? We can seek out

someone who most likely has the authority to grant an exception (or who can explain the rule). We can also alert patients as early on as possible that a conflict may arise, and indicate, as discussed above, that if this occurs, we will do all that we can to help them. We should do this regardless of our own moral views. I will discuss shortly why this is so.

**Obeying the law.** The possibility of breaking the law stirs deep-seated fears.<sup>30</sup> First, laws may have more than one meaning. An example is the phrase “to know.” Criminal defendants may be excused on the ground of insanity, for instance, only if they don’t know right from wrong. Likewise patients may be competent only if they know their options, including doing nothing. In both of these contexts, knowing may mean to only know literally or to understand in a deeper sense. Second, when the law is ambiguous, it may help to look to the law’s intent.

Third, laws that apply to medicine often are designed to help patients. If a law is unclear, and we try to help ourselves rather than our patient, we act at our own peril. A paradigmatic example is when a clinician asks a patient to sign a form on which the patient writes, that he or she won’t commit suicide. The clinician may do this to protect him- or herself. These contracts, however, don’t work, and may actually increase patients’ risk by distancing their clinician from them. Clinicians who know this should not ask patients to sign a contract, but rather should do what will most help their patients.

#### OPTIMAL APPROACHES TO PATIENTS AND FOR OURSELVES

I have shared a few ideas regarding how we may most help our patients, and ourselves, when we feel moral distress. I have suggested, for instance, that we regularly validate what patients say, and that we set realistic expectations for ourselves. There are, however, a few more general practices that may go further to help patients and ourselves.

#### Responding to Patients’ Moral Distress

We may have to wholly ignore our own moral values to help our patients to the greatest possible extent, as I have previously stated. We may have to do this, for instance, when we want to stop a patient’s treatment, but still try to help the patient or family appeal the decision to the degree that we can. When we do this, we may feel we are betraying our own values and selves. But this may not be the case, at all. Rather, we may be simply placing a patient’s or family’s right to pursue their own views above the particular content of our own views. The effect of our being committed to helping our patients, and

expressing this when a patient or family expresses moral distress, may go a long way to establish a solid ground on which all parties may seek to resolve the distress, together.

One further example. A patient of mine was dying. He wanted to call in numerous specialists in case there was some treatment that others had missed, but he lacked the physical strength to use the phone. His wife thought his contacting these other specialists was futile, and I agreed with her. Regardless, I encouraged her to make phone calls to the specialists for her husband, because I believed that he should be able to exercise his right to do so. She made the calls asking these specialists to come, as her husband was requesting, although none did before he died. He died, comforted and cradled in his wife’s arms. She supported his “rights” in this way by acting as he wanted when he could not do it for himself. Her doing this may well have made his last moment the best they could have been, and may have helped to make a most meaningful ending, for both of them, possible.

#### Reducing Our Own Moral Distress

I have discussed already the importance of having realistic expectations that one may be helpless and thus unable to resolve the present source of moral distress. Carse and Rushton also discuss this, quoting the philosopher Norman Care. This is, though, but one of the ways that we may most help ourselves when we feel moral distress. I will now discuss this and two other ways that may particularly be of help.

**Have realistic expectations.** Norman Care speaks of the “myth” of the “in-control agent,” holding that this myth exerts pressure on clinicians to be “heroic.” This myth may render clinicians more susceptible, he believes, to experiencing moral distress. In morally challenging situations, he states, clinicians should instead accept that our efforts may not effect much success. Compromising wisely, he says, can be integrity-preserving. This approach is most consistent with our helping our patients to pursue their rights. This effort may be the best we can do, whether or not we succeed.

**Share with a friend.** There are numerous approaches we can take that are self-soothing. Carse and Rushton discuss, for example, mindfulness. The goal of mindfulness is to disengage oneself from “strong attachment to beliefs, thoughts, or emotions” to achieve greater emotional balance and well-being.<sup>31</sup> Too much distress, as discussed above, may interfere with our optimal capacity for optimal moral reasoning. Mindfulness may, in addition to reducing moral distress, also increase our capacity to seek

and achieve better resolutions. Another most effective approach is to share our distress with a friend. This friend should be a person we can trust to not be judgmental. Merely sharing our distress may suffice. What may matter most is that we, like our patients, not feel alone.

I end this discussion with what I hope is an inspiring example, presented at the 2016 annual ASBH meeting.<sup>32</sup> Researchers reported on a study in which clinicians and parents of infants participated in, and observed, role-plays, in which clinicians told parents that they would resuscitate the parents' baby while the parents were present. (Infants were represented by mannequins in the role-plays.) The study sought to determine what clinicians could best say to parents in these situations. Parents were asked to imagine their reactions, as though the role-plays were real, so that they could provide useful feedback regarding how the clinicians in the study had done in the role-play.

During one role-play, one clinician suddenly believed that he should tell the "infant's" "mother" what was happening. At that point, the mother was standing several seconds away, walking in one corner of the room. The "father" was standing by the clinician's side as the clinician was trying to resuscitate the infant. The clinician spontaneously grabbed the hand of the father who was standing by him, and, taking the father's right index and middle finger, started pressing the father's hand up and down, so that the father could continue the resuscitation effort while the clinician went to speak to the mother. (One can resuscitate infants that small with two fingers.)

Most of the parents who were present observing the role-play marveled in response to the clinician's actions. The clinician had apparently instinctively sought to include both parents in the resuscitation, to help them and their baby to the greatest degree that he could. Some observers commented on whether the clinician should have involved the baby's father in this way, but whether he should have or not is not my point. My point in relating this scenario is that the father and the clinician were, at that moment, working together as partners, pursuing the goals that both shared of enhancing care for both the baby and the mother. This kind of united effort, even—and especially—when some are feeling and expressing moral distress, is the change in our medical culture that I am urging.

**If nothing else, help another.** I can find no better example than one presented during the Holocaust. Many Jewish inmates in concentration camps were starving, and did starve to death.<sup>33</sup> Some prisoners under these circumstances purposefully chose

a spot at the end of the food line when they were getting soup—not at the middle, not at the beginning. Those at the beginning of the line would get more chunks of food in their soup, which would be gone for those at the middle or end of the line. These prisoners wanted what little food there was to go to those who were worst-off, who were starving. It may be that people who experience moral distress now, like the concentration camp prisoners, will not be able to alter the circumstances that are causing their distress. They may, though, even if totally helpless in this sense, if nothing else, possibly still be able to help another.<sup>34</sup>

## CONCLUSION

I have addressed 14 points that we may want to consider when our patients or we ourselves feel moral distress. The end goal is to welcome and appreciate our patients and our colleagues who express their moral distress, rather than finding it threatening in any way.

## ACKNOWLEDGMENT

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