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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.¹ 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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MORAL DISTRESS: SOME CORE CONCEPTS

Moral Distress as an Alarm

Freud famously said that our dreams are the royal road to understanding our unconscious.² 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.³ 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.⁴

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.⁵ 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.⁶ 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.⁷ 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.⁸ 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.⁹ 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."¹⁰

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."¹¹ 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.¹² 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.¹³ 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.¹⁴ 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."¹⁵ 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.¹⁶ 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.¹⁷ 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.¹⁸ 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?¹⁹ 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?”²⁰

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.”²¹ 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.”²² Many patients, Fins reports, improve like this. Sometimes it occurs “dramatically,” he says, “even decades after their original brain damage.”²³

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.²⁴ 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.²⁵

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.²⁶ 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.²⁷ 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."²⁸ 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.²⁹ 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.³⁰ 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.³¹ 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.³² 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.³³ 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.³⁴

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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Special Section on Moral Distress

Harnessing the Promise of Moral Distress: A Call for Re-Orientation

Alisa Carse and Cynda Hylton Rushton

ABSTRACT

Despite over three decades of research into the sources and costs of what has become an “epidemic” of moral distress among healthcare professionals, spanning many clinical disciplines and roles, there has been little significant progress in effectively addressing moral distress. We believe the persistent sense of frustration, helplessness, and despair still dominating the clinical moral distress narrative signals a need for re-orientation in the way moral distress is understood and worked with. Most fundamentally, moral distress reveals moral investment and energy. It is the troubled call of conscience, an expression of fidelity to moral commitments seen as imperiled or compromised.

It is crucial that we find ways to empower clinicians in heeding this call—to support clinicians’ moral agency and voice, foster their moral resilience, and facilitate their ability to contribute to needed reform within the organizations and systems in which they work. These objectives must inform creative expansion in the design of strategies for addressing moral distress in the day-to-day of clinical practice. We include suggestions about promising direc-

tions such strategies might take in the hope of spurring further innovation within clinical environments.

INTRODUCTION

The challenges of moral distress have become a rallying cry for clinicians and a focal point in the clinical ethics literature. Although the term “moral distress” was originally coined to refer to the anger, frustration, and suffering of nurses who felt their integrity was threatened by institutional pressures and constraints,¹ moral distress is now recognized as a growing reality across clinical disciplines and roles,² contributing to escalating rates of burnout and turnover, challenging recruitment, and imperiling the quality of patient care.³ An alarming number of clinicians report feeling besieged and disillusioned in healthcare systems that are riddled with moral failings they feel powerless to change. In this environment, moral distress is a pervasive problem, one that too often leads clinicians to experiences of helplessness and moral failure. Despite over three decades of research into moral distress, and widespread awareness of its costs, there has been little significant progress in effectively addressing its sources or diminishing its destructive impact.

There is no question that addressing moral distress will require multifaceted reform efforts, including vitally needed systems reforms.⁴ Our focus here is on the direct support and empowerment of clini-

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cians in cultivating ways of working with moral distress that can mitigate its detrimental consequences in day-to-day clinical practice. As we will explore, this will require individual effort but also organizational innovation. To date, strategies on this front have included enhancing education in ethical analysis, encouraging interdisciplinary training and collaboration, and expanding ethics consultation, mediation, and conflict resolution.⁵ These represent promising steps. At the same time, we believe the persistent sense of frustration, helplessness, and despair that still dominates much of the clinical narrative around moral distress signals the need for a basic re-orientation in the way we understand, think about, and work with moral distress, one that more fully recognizes and harnesses its positive promise and potential.

Most fundamentally, moral distress reveals moral investment and energy. It is the troubled call of conscience, an expression of fidelity to moral commitments seen as imperiled or compromised. Realizing the positive promise of moral distress will require finding innovative ways to empower clinicians in heeding this call—to support their moral agency and voice, foster their moral resilience, and facilitate their ability to contribute to needed reform within the organizations and systems in which they work. These objectives must inform creative expansion in the design of strategies for addressing moral distress in the day-to-day of clinical practice if we are to move beyond the sense of victimization, failure, and despair too often accompanying moral distress and better support clinicians' ability to practice with integrity. At the end of our discussion, we offer some suggestions about promising directions such strategies might take.

MORAL DISTRESS REVISITED

As the concept of moral distress has gained traction in clinical bioethics, it has been understood in diverse, and sometimes conflicting, ways.⁶ We understand moral distress broadly as anguish or anxiety tied to a sense of imperiled integrity. Sometimes moral distress entails a judgment that one has violated a core value commitment, failed to fulfill a fundamental moral obligation, or in some other significant way fallen morally short under conditions of constraint or duress. Moral distress is not, however, always tied directly to an experience of personal or professional moral failure or shortfalling. Sometimes it consists in uncertainty or anticipatory anxiety in the face of constraints, pressures, or moral concerns that are experienced as challenging to, or

threatening of, one's integrity.⁷ It can also involve situations in which one is concerned about being complicit in wrongdoing, or uncertain or anxious about contributing to, or supporting, an ethical lapse—perhaps on the part of an organization in which one works or with which one is affiliated. The sources of moral distress are diverse, as we will explore. They can be both social and institutional and, as is increasingly recognized, psychological, including notably the psychological “residue”⁸ of insufficiently resolved moral distress itself— affective states and emotions (for example, of anxiety, frustration, shame, anger) carried into new situations in ways that can diminish clinicians' moral resilience and responsiveness, leading to escalations of moral distress, now widely known as the “crescendo effect.”⁹ We will discuss the cumulative and dynamic nature of moral distress in some detail later. Crucially, moral distress emerges in the dynamic relationship between the individual clinician and the context in which he or she practices. Addressing moral distress will thus require an approach that constructively engages a multiplicity of relational, organizational, cultural, and psychological factors as they dynamically interact in supporting (or eroding) clinicians' moral agency and integrity in particular contexts.¹⁰

While much attention has been given in the literature to the negative impact of moral distress on the psychological well-being of clinicians and the quality of patient care, most fundamentally at stake in moral distress is the experience of effective moral agency, the sense of trust and confidence in one's ability to sustain integrity—to live and act with fidelity to one's own deeply held, enduring standards and value commitments, including those central to one's professional identity and role. The epidemic of moral distress invites us to think more fully about what is entailed in sustaining moral integrity in challenging conditions and how clinicians might be supported in doing so. As we will argue, moral distress is often an expression of moral integrity rather than a sign or symptom of moral failure. The challenges of moral distress point to the limitations of individual agency and control; we can do our best to act with utmost integrity and yet find ourselves disempowered and silenced—unable to effectively uphold the moral standards to which we are committed or to give effective voice to moral concern or protest. Too often when this happens, the moral distress experienced is inflected by a sense of personal deficiency and failure, despite the constraints and pressures encountered. It is therefore urgent that we think more fully, both about the distinctive kinds of chal-

lenges generating moral distress and about ways clinicians might be better supported and empowered in addressing these challenges.

To this end, we begin with reflections on an understanding of moral distress given especially systematic articulation in a recent analysis of moral distress by Thomas and McCullough.¹¹ While Thomas and McCullough's analysis is in many respects clear and insightful, it reinforces a troubling view of moral distress on which it is too readily associated with individual moral weakness and deficiency. It thus contrasts in stark ways with the understanding of, and approach to, moral distress we seek to characterize here.

Thomas and McCullough's "Taxonomy" of Moral Distress

In a recent analysis, Thomas and McCullough develop a "philosophical taxonomy" of what they call "ethically significant moral distress."¹² Their taxonomy represents one of the most systematic accounts of moral distress to date. On Thomas and McCullough's account, moral distress is a response to impediments encountered in clinical circumstances that incentivize *akrasia* or "moral weakness," introducing considerations of "self-interest" that "weaken the self-discipline and commitment to the care of others required by professional and individual integrity."¹³ These impediments fall along a spectrum: the more formidable the impediment, the higher the level of self-sacrifice required to act with integrity.

Impediments that "challenge" integrity can be withstood, given sufficient self-discipline. Impediments that "threaten" integrity introduce incentives that are powerful enough to "undermine" the self-discipline needed. Impediments that "violate" integrity are "so powerful that one finds oneself completely unable to do the right thing." In cases that "violate" integrity, "the self-discipline required to sustain the commitment to scientific, clinical, and moral excellence that define the healthcare professional's role" is "destroy[ed]."¹⁴ When clinicians are aware that they have acted in self-interest, "against considered moral judgment," they experience moral distress, which "manifest[s] psychologically" in a range of states, including "anxiety, frustration, anger," "burnout [and] depression," all of which can negatively impact the quality of patient care.¹⁵

In developing and defending their taxonomy, Thomas and McCullough expand on a case first presented by Epstein and Delgado.¹⁶ In the case, a patient in the intensive care unit (ICU) of an academic medical center who is suffering sepsis and multi-

organ failure goes into unstable ventricular fibrillation. The nurse and resident physician begin cardiopulmonary resuscitation (CPR) and are joined by medical interns who respond to the resuscitation attempt. It is believed that the patient is dying, so, at the request of the nurse, the resident calls the patient's family members. The family are directed to the waiting room. Given the patient's condition, the nurse believes CPR must stop so that its utility and the patient's wishes can be discussed with the family. The resident agrees, but continues to run the code, telling the interns to switch off in doing compressions "so everyone gets a chance to learn" and all will get some practice in a real code situation. The nurse attempts to intervene and stop the exercise, but is persistently overridden by the resident. The situation escalates as the resident physician continues the exercise and the nurse's intensifying efforts are dismissed. Finally, at her "wit's end," the nurse tries unsuccessfully to physically stop the resuscitation and, refusing to participate in the code, threatens to leave and call the nurse manager and attending physician who have authority to override the resident physician's orders.

In analyzing the case, Thomas and McCullough describe the nurse's integrity as initially "challenged" as she witnesses the code exercise undertaken on her dying patient, then "threatened" as her escalating efforts to intervene are ignored, and finally "violated" as she refuses to participate in the code and threatens to leave the scene. At this point, they write, the nurse is in full-blown moral distress; she confronts impediments to moral action so "formidable" that her "self-discipline" is "destroy[ed];" she has never before "abandoned her clinical duties, commitment to teamwork, or doing what is best for the patient."¹⁷

Thomas and McCullough don't specify what "self-interested incentives" are in play in this case, or why they believe the nurse's self-discipline is "destroyed." Perhaps they interpret the nurse's threat to leave the scene as a self-interested effort to soothe her own rattled emotions. If so, this is a troubling interpretation at best. Indeed, one might wonder why it is the nurse's conduct alone that is assessed, given the complex dynamics characterizing the situation. It is understandable, in one sense, as the example is intended to illustrate the spectrum of escalating stages of moral distress. The resident and others are a kind of "foil" used to generate an analysis of the nurse's escalating moral distress as it exemplifies the stages of Thomas and McCullough's spectrum.

But in focusing on the nurse without attending to other facets of the situation, Thomas and McCul-

lough effectively assign disproportionate moral responsibility to her, marking her as the locus of moral deficiency and weakness.¹⁸ This deflects attention away from a number of significant factors that are in play in the situation, including the power imbalance between the nurse and the resident physician, the authority of the resident physician over the medical residents and interns at the patient's bedside, the complete breakdown of effective communication within the "team," or the potential ways the resident physician's own conduct might be incentivized within the organization. It puts the focus of moral appraisal on the individual who is experiencing moral distress, rather than considering a broader array of relational and institutional factors that are contributing to moral distress.

Moreover, the description of the nurse as "abandoning" her patient because her "self-discipline" is "destroyed" frames her conduct as morally defective, tying her moral distress to her awareness of her own (alleged) moral deficiency. Thomas and McCullough's spectrum analysis is insightful in highlighting that moral distress can be a response not just to failures (or "violations") of integrity, but also to perceived challenges and threats to integrity. At the same time, framing the spectrum of moral distress itself in terms of *akrasia* or "moral weakness" reinforces a deeply problematic understanding of moral distress, one too often reflected in the sense of moral deficiency and failure that are felt by clinicians experiencing moral distress.

Consider a different understanding of the nurse's case, one that shifts the narrative. On this understanding, the nurse is not abandoning her patient or her team; she is resisting participation in what she sees as an ethical violation of her patient, protesting this violation, and attempting to do everything in her power to put an end to it. She is herself unable to succeed in protecting her patient because she lacks the institutional authority to override the resident's orders. In preparing to leave the scene, she is not seeking to soothe her own rattled emotions (her "distress"), but to locate staff with the requisite authority to protect her patient from further violation. Leaving is thus not an act of self-interest or a failure to undertake the "self-sacrifice" necessary to meet her clinical obligations; it is an attempt to meet her obligations—to act on her "considered moral judgment"—in a situation in which time is urgent, her own power and authority are limited, and her concerns and protests are ignored.

On this understanding, the nurse is attempting to cut moral losses in a challenging situation. No amount of self-discipline and willpower can secure

the outcome she deems morally optimal; nevertheless, she resolutely fights for her patient as best she can. In an important sense, her actions are an expression of her integrity, not a failure (or "violation") of integrity.

We can, to be sure, imagine the nurse might herself emerge from the resident's use of her patient to practice CPR feeling emotionally distraught about what she experiences as her own failure to effectively protect her patient. She might even feel as though she is "abandoning" her team in leaving the scene. Like many clinicians who struggle to effectively uphold their own moral standards in the face of pressures and constraints, the nurse's moral distress may carry a sense of personal moral failure and shame. But if so, this is troubling, for it would take insufficient account of what this case so poignantly captures, namely, the susceptibility of individual moral agency to the power and authority of others, the way others' treatment and regard can limit what we can effectively do, including the outcomes we can effectively achieve, and the moral concern and protest we can effectively voice.

We believe that this case signals a more general need for a complex understanding of the relationship of moral distress to moral integrity, one that recognizes that it is sometimes in acting with integrity that one experiences moral distress, precisely because one's powers are limited or one's efforts are thwarted or dismissed.

This is not to deny that moral distress can itself sometimes be a moral liability. Acute or unresolved moral distress can take a toll; it can diminish emotional and moral resilience, introducing significant internal, psychological impediments to moral responsiveness and integrity. Forms of "self-related distress" can also accompany moral distress and motivate self-protective action that may be harmful to patients. In their broader analysis of moral distress, Thomas and McCullough rightly highlight the well-documented negative repercussions of cumulative and escalated moral distress in generating painful states, including states of "anxiety, frustration, anger . . . burnout [and] depression," that can imperil patient care.¹⁹ While exertions of self-discipline and will can, on occasion, enable clinicians to power through states of suffering and distress in service to their patients, the kind of emotional and moral fortitude and resilience that are needed to sustain moral responsiveness and integrity in morally distressing environments cannot simply be willed "on a dime," but must be fostered and supported over time. As we will explore, the systems in which clinicians practice can play an important role both

in supporting and in eroding the clinicians' internal resilience.

In their positive recommendations, Thomas and McCullough highlight institutional and systemic sources of moral distress, urging healthcare leadership to implement institutional mechanisms for the ongoing review and reform of potentially integrity-imperiling "challenges and conflicts" that are created by organizational practices and policies; they also emphasize the need to clamp down on clinicians who, perhaps like the resident physician in their example, abuse their power and authority in ways that imperil their colleagues' ability to work with integrity.²⁰

These forms of organizational oversight and accountability can be essential in addressing sources of moral distress. They point beyond the individual clinician who is experiencing moral distress to the broader conditions generating the distress. At the same time, moral distress is not always a response to problematic organizational incentive structures or institutionally tolerated abuses of power or authority. Its sources also reflect the real and inescapable moral complexity of many clinical situations, including the fact that conscientious and thoughtful clinicians, patients, and families can struggle with uncertainty, feel constrained by the pressures and limitations of time and resources, and disagree about ethically appropriate interventions and optimal outcomes. We have good reason to expect moral distress to be an ongoing challenge in clinical practice, even when troubling incentive structures or abuses of power are not an issue.

In understanding and addressing moral distress, we must shift away from the prevailing negative narrative, in which moral distress is too often tied, at the individual level, to "moral weakness"; this reinforces a troubling tendency to regard moral distress as evidence of personal moral deficiency, an inability to withstand the challenges and demands of clinical work. 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."²¹ More fully understanding the challenges generating moral distress can help rehabilitate our relationship to it.

In the next section, we explore four challenges we believe are key: the experiences of moral powerlessness, frustration, and anger; of voicelessness and isolation; of diminished moral responsiveness; and of shame. We highlight the dynamic and cumulative character of moral distress, the way it can itself

diminish psychological and moral resilience, impairing the capacity of clinicians to respond with composure and clarity to new morally distressing situations, thereby compounding the experience of moral distress, and often, too, the sense of deficiency and shame in the mix. Making positive and lasting headway in addressing the crisis of moral distress will require finding ways to address these challenges.

THE CHALLENGES OF MORAL DISTRESS RECONSIDERED

Powerlessness, Frustration, and Anger

In a personal narrative, Susan McCammon, a surgical oncologist, describes her "helplessness and outrage . . . immense, and frightening in its unfamiliarity" when she learns that the institution where she practices has, in the wake of a damaging storm, "terminated" care for uninsured patients.²² McCammon questions this decision, moving up the "increasingly reticent and then elusive" line of authority, only to discover she is powerless to combat it. "While this decision was made by the administration," she writes, "its enactment was delegated to the physicians. Thus, not only were the physicians not involved in the decision to terminate their patients, they shouldered the burden of telling their patients that they would no longer be treated."²³

Carrying out a decision she deems immoral, McCammon bears the brunt of her patients' terror, grief, and rage. Like many clinicians, she must navigate a situation she has not designed, confronting choices resulting from institutional practices and policies she lacks authority to change. She is expected to acquiesce to, and carry out, decisions that are at odds with her own moral convictions. Continuing to work within the system is the price she pays to remain connected to her patients and true to her values of service. But it is a steep price, one McCammon experiences as morally compromising.

The experience of powerlessness, of being "caught" and pressured to do what one believes to be wrong, or impeded in meeting moral commitments one takes to be fundamental, is a key theme in narratives of moral distress.²⁴ This powerlessness has many faces—the nurses and physicians mandated by their hospital to treat a catastrophically brain injured child even when they believe doing so to be "cruel," who "observe their own hands engaged in what they perceive as the unconscionable act of harming a child"; the clinician so overwhelmed by her patient load she cannot provide what she regards as safe and adequate care;²⁵ the neonatal intensive care unit team that, for lack of

alternatives, releases a still fragile infant into a social environment it deems inadequate and perilous; the ICU nurse who lacks authority to stop a practice code that she believes is violating her dying patient.

When moral distress is tied to a sense of powerlessness, clinicians often feel helpless, frustrated, and angry, trapped in situations they are unable to alter or exit without undue moral cost.

Voicelessness and Isolation

The sense of powerlessness, frustration, and anger is often connected to an experience of voicelessness, especially when one's moral concerns are devalued or disregarded. Thomas and McCullough's ICU nurse protests, but her protests are ignored by her team and are dismissed by her superior. McCammon's questions and concerns about her institution's policies in the wake of the storm meet with administrative resistance and evasion. In a different kind of case, a clinician reflects on the "strong wall of silence" he experiences in response to administrative bullying and abuse, of the "fear of retaliation" that "prevents professionals from doing what is right—speaking up."²⁶

Even when no direct retaliation is feared, institutional hierarchies can have a profound impact. A nursing student describes obeying her teacher's commands to remain silent about an act she witnessed: "I finished out my rotation without a peep. But in doing so I feel I betrayed the people in my life who have mental illnesses. I betrayed the belief in human rights, which had led me to healthcare in the first place. And I betrayed the patients who come to that hospital seeking help and compassion and are instead treated like criminals."²⁷ The inability to give an effective voice to moral concern or to protest can be alarming and humiliating; if persistent, it often leads to silent suffering and a keen sense of moral isolation.²⁸

The contours of morally distressing situations are diverse: Clinicians may experience their integrity as imperiled by resource constraints, by others in authority, by conflicts with patients or colleagues that stymie resolution or progress, or by policies they lack the authority to override. Sometimes moral distress is an anguished response to direct participation in perceived wrongdoing under duress, such as providing painful treatments whose complications degrade the human body and prolong dying, sometimes to witnessing wrongdoing one lacks the power to stop. One may not, of course, be as powerless and voiceless as one believes oneself to be. But the experience of moral distress highlights our vulnerability, as individual moral agents, to the power and au-

thority of others, to systems that we neither design nor control, and to the way others' treatment and regard can limit what we can effectively do—including the moral concern and protest we can effectively voice.

Diminished Moral Responsiveness

The moral demands of clinical work can make the toll of moral distress especially poignant and concerning. Patients and their loved ones are vulnerable to the quality of the technical knowledge and skill of the clinicians who care for them, but also to the expressive quality of the care they receive—the sense that their experience of illness is understood and honored, and that those caring for them are respectful, compassionate, and trustworthy. Empathic understanding and communication can play critical roles in the discernment and responsiveness at the heart of the clinical excellence, enabling clinicians and patients to communicate effectively and to build and sustain the trusting alliances that are often essential for effective treatment.²⁹

More generally, navigating ethically challenging clinical situations requires an ability to detect and interpret the morally salient dimensions of the situation one is in; to identify justified responses to ethical challenges, even when they sometimes entail moral cost or compromise; and to execute action in an emotionally balanced, morally grounded, and compassionate manner.³⁰ Clinicians in whom these capacities are compromised may overlook morally salient factors, missing occasions for moral action. They may carry unreflective assumptions and projections into new situations, in ways that distort perception and impede their ability to sensitively track the impact of their decisions on patients and others, including clinical colleagues.³¹ They may find it difficult to work constructively with conflict or to engage collaboratively in forging shared resolutions to ethical challenges.

In clinical environments, the same factors that make moral responsiveness crucial make it difficult to achieve. Persistent exposure to suffering can lead to empathic overarousal and secondary trauma. Time pressure, exhaustion, uncertainty, conflict, and limited ability to effect desired outcomes often challenge emotional fortitude and resilience. A clinician who carries unresolved moral distress into the clinical encounter may find it doubly difficult to achieve the mix of flexibility, openness, emotional equanimity, and compassion called for. Negative emotional arousal can become overwhelming and unbearable, leading to self-protective patterns of "flight," avoidance and/or abandonment of patients, colleagues,

and others; “fight,” expressions of anger, contentiousness, cynicism, and other forms of aggression and resistance; and “freeze,” emotional disengagement, shutting-down, numbing, and disconnecting, sometimes in ways that produce a “robotic” task-orientation.³² All of these reactions can lead to conduct that is morally disengaged, even callous, risking communication breakdowns, entrenched conflicts, and damaged trust. Clinicians suffering from persistent moral distress often lament that they have “lost heart,” are “simply going through the motions,” or “just don’t care anymore.” In such conditions, one may also cease to see ethical avenues that are open and within reach, or grow numb to injustices or infractions of important principles.

Shame

Chronic, unmitigated, or repeated experiences of moral distress often generate an ongoing sense of deficiency—of what Sandra Bartky identifies as a form of shame, “manifest in a pervasive sense of personal inadequacy . . . a species of psychic distress occasioned by a self or a state of the self apprehended as inferior, defective, or in some way diminished.”³³ Crucially, shame need not entail the belief that one has done something wrong. Too often, clinicians feel shame when they are not able to resolve difficult situations, secure desired outcomes for patients, or prevent others’ wrongdoing. The experiences of moral powerlessness, frustration, and anger, of voicelessness and isolation can, if sustained, become manifestations of shame when they are tied to a sense of personal or professional moral deficiency. Conscientious clinicians may respond with especially acute shame to signs of their own diminished resilience, apparent in mounting disengagement or diminished responsiveness, considering these to be moral failings. Bartky highlights the “profoundly disempowering” drive for “secrecy and concealment” induced by shame, which can undercut the possibility of solidarity with others—even with those who may be struggling in similar ways—and further intensify experiences of helplessness and isolation.³⁴ Often in the grip of moral distress, especially when it is chronic or sustained, one becomes the victimized person, the “walking wounded,” as a sense of moral injury or grievance takes over. Experiences of helplessness, voicelessness, emotional depletion, and shame can induce a sense of loss and disillusionment—alienation from aspirations that once informed one’s professional identity and grounded engagement in purposeful and trusting collaboration with colleagues. It can be increasingly difficult to sustain confidence, courage, and hope.

The Cumulative Dynamic of Moral Distress

It is important to appreciate the cumulative and dynamic character of moral distress. Short-term, moral distress is associated with states of frustration and anger, but also of rage, grief, and guilt, among others. Longer-term consequences include anxiety, emotional exhaustion, depersonalization, burnout, depression, and a range of chronic physical ailments.³⁵ When unresolved or persistent, moral distress can erode resilience, leaving clinicians vulnerable to disruptive and disabling escalations of distress. Jameton distinguished “initial moral distress” from “reactive moral distress,”³⁶ the long-lasting painful emotions or “moral residue,”³⁷ carried in the aftermath of morally distressing situations. Empirical evidence reveals that when triggers of distress are repeated, or new morally challenging situations are encountered, the impact is often cumulative, elevating the residual baseline of somatic and emotional dysregulation, producing a “crescendo effect” that increases with intensity as new situations are encountered.³⁸ This is exacerbated when new distressing situations resemble earlier ones, thus activating memory, heightening the sense of frustration and powerlessness, and generating anxiety as one anticipates new distressing situations around the bend.

Crucially, moral distress does not always trace to discrete and identifiable crises or conflicts. It can emerge more insidiously, beginning with vague moral discomfort, or the dawning awareness, for example, that resource-driven pressure to cut corners and curtail costs—to discharge patients before they are ready or to perform interventions for which one is insufficiently trained—has become morally intolerable; or an anguished realization that the exhausting daily demands of one’s understaffed and under resourced facility have eroded the safety and quality of the care one is able to provide, and perhaps led to a loss of the sense of connectedness, generosity, and compassion once present in one’s work. While moral distress is sometimes triggered by identifiable crises and conflicts, it can also escalate more gradually, through a cumulative erosion of one’s sense of moral effectiveness and integrity. This is important because it can make it more challenging to notice and address moral distress before it escalates in destructive ways.

Whether dramatic or gradual, moral distress can itself disrupt composure, diminish resilience, and impede effective moral agency. It is an inherently cumulative, dynamic phenomenon that can spiral in destructive ways. This is a dynamic that we believe it is essential and possible to interrupt and re-

direct. Doing so will require recognizing and honoring the moral energy and investment revealed by moral distress so it can be worked with and directed in ways that support clinicians' moral empowerment and voice, and foster the psychological and moral resilience clinicians need in navigating the complex challenges of their work.

MOVING FORWARD: RE-ORIENTING OUR APPROACH TO MORAL DISTRESS

Despite the extensively documented costs of moral distress, it is possible to navigate morally distressing circumstances in positive and constructive ways. It is also possible to grow in the wake of morally distressing experiences—to find meaning, to reconnect to one's original commitments and aspirations, and to release the negative and destructive residue so often fueled by frustration, anger, despair, and shame.³⁹ Realizing these positive possibilities on a broad scale will require a re-orientation in the way moral distress is understood and worked with. In particular, we must find ways within clinical practice to more fully recognize, and harness, the positive promise of moral distress. We highlight the value of "moral resilience" in addressing moral distress, and urge a shift away from the harsh perfectionism that often informs understandings of moral integrity. Re-orienting our approach to moral distress will require practical recognition of the profound embeddedness of individual moral agency and both the real limitations on individual power and control this entails and the positive potential it represents. We must seek to empower individual moral efficacy and support individual integrity through creative innovation within clinical organizations and shared systems of practice.

Fostering Resilience, Supporting Integrity

Resilience is a concept that has gained traction in various disciplines concerned with managing the effects on individuals of adverse situations, including natural disasters, war, crime, and other potentially damaging and disabling experiences.⁴⁰ Generally, resilience refers to the ability to adapt to or recover, in healthy ways, from stress, trauma, loss, and other challenges, to be buoyant in adverse circumstances. A hallmark of *moral resilience* is the ability to restore or sustain integrity under morally challenging circumstances.⁴¹ Moral resilience entails *conscientiousness*—the diligent, resolute, and thoughtful ongoing effort to live in alignment with one's own principles and value commitments, even in the face of challenges and obstacles. Morally re-

silient individuals do not buckle under adversity or fear; they are buoyant, able to "bounce back," to recall their commitments and to re-orient themselves in ways that work constructively with the possibilities available, and in some instances to grow and learn from adversity. Morally resilient people draw upon inner strength and fortitude in encounters with moral adversity; they are also able to work effectively under conditions in which the possibility of moral adversity or threat is realistically anticipated. While moral resilience requires fortitude and perseverance, it is not simply or centrally a matter of individual exercises of discipline, willpower, or resoluteness, which are of limited value at best in navigating the kinds of integrity-challenging constraints and pressures that often generate moral distress.⁴²

Moral distress in all its forms confronts us with the brute limitations of our own power, authority, and control. To acknowledge limitation is to face, head-on, our vulnerability to the choices and conduct of others, and to institutional structures and policies and systems of practice that frame the situations in which we act. This requires abandoning what the philosopher Norman Care calls the "myth" of the "in-control agent."⁴³ This "myth" and the pressures to be "heroic" can render clinicians especially susceptible to moral distress. In morally challenging situations, it is crucial to accept that the effort exerted can be more important than the outcome achieved, and that compromising wisely can be integrity-preserving. Perfect fidelity to one's own principles and value commitments is simply not always possible. This is not to counsel moral complacency or apathy, but to emphasize the importance of thoughtful and principled consideration of the limits of our own power, control, and understanding. In a positive sense, sustaining integrity must, as Wendy Austin writes, "involve more than a single-minded focus on one's own moral agency." Especially in contexts that are inherently collaborative, as clinical contexts characteristically are, Austin writes, "being ethical . . . involves perpetual responsiveness to others," a "recognition of the messy . . . interdependence of decisions, interests, and persons."⁴⁴

In such contexts, exercising resilient moral agency is not centrally a matter of independent, individual effort, but of collaborative engagement in forging paths that are walked together, and shaped in ongoing ways through shared, collective effort. Moral resilience thus requires flexibility and responsiveness in the ongoing, conscientious process of interpersonal moral negotiation, a willingness to

revisit and reevaluate one's perceptions and choices with honesty and openness, and both awareness of, and self-compassion in the face of, the inherent finitude of one's own moral power and control. Yielding a perfectionistic, insular understanding of personal accountability and moral integrity is an important step in addressing moral distress.

This is not to deny that moral compromise can constitute moral self-betrayal, especially when it is significant or persistent, or that repeated limitation and constraint on our ability to act as we believe we ought can erode meaningful integrity, leading to a sense of moral deficiency and failure or troubling moral complicity, however hard we try to make the best of a bad situation. We need to dismantle the impediments to integrity in day-to-day clinical practice. This will require finding ways to empower clinicians and secure them meaningful moral voice in addressing the sources of their moral distress. It will also require devising innovative approaches that support clinicians' ability to work directly with their moral distress itself—with the somatic and affective dimensions of distress—thus bolstering their psychological and moral resilience. In what follows, we offer reflections about promising strategies we might take on each of these fronts. Our reflections are largely suggestive and programmatic; we make them in the hope that they will spur further thought, contributing to concrete innovation and experimentation within clinical environments.

Moral Empowerment, Moral Voice

As we have emphasized, moral distress is, most fundamentally, an expression of conscientious moral concern, of fidelity to moral commitments that are seen as imperiled or compromised. It is a troubled call of conscience. Heeding this call—sustaining integrity—under conditions of moral pressure, conflict, and constraint requires being able to stand for, and give voice to, one's commitments and values, choosing whether, when, and how to resist, protest their compromise, or speak for them—even in cases when moral disagreement persists or one's own position will not hold sway. Having a voice—being able to assert appraisals, raise concern, protest meaningfully, with background trust that one's perspective counts and can have an impact—is crucial to overcoming the sense of moral powerlessness and isolation so often tied to moral distress.

Understanding this can provide insight into how we might support clinicians' effective moral agency and integrity—namely, by creating safe and responsive environments in which clinicians can give voice to conscience in meaningful ways. We believe clini-

cal organizations and institutions can significantly mitigate moral distress by creating what Margaret Walker has (broadly) called “moral-reflective spaces,” in which clinicians are provided the opportunity to meet and explore the sources of moral distress in their day-to-day practice.⁴⁵ Crucially, these reflective “spaces” would be formally instituted and facilitated, with regular, designated times and places, providing ongoing (rather than crisis-driven or *ad hoc*) opportunities to engage in collaborative ethical reflection and exploration. They would provide a safe and responsive forum in which clinicians can speak to ethically troubling challenges, lodge concerns and suggestions, express moral anger, share stories, and propose reforms without fear of retaliation or other negative repercussions.⁴⁶ They would also invite clinicians across roles and disciplines into active engagement in thinking, querying, and reflecting together about the ethical challenges they encounter in their day-to-day work,⁴⁷ thus enhancing clinicians' understanding of diverse ethical perspectives and concerns as they are attached to distinct roles and responsibilities within clinical practice.⁴⁸

In meeting regularly on equal terrain to explore ethical challenges and concerns in an environment of curiosity, trust, and respect, clinicians representing different disciplinary and clinical perspectives might carry a more egalitarian sensibility of mutual respect and understanding back into the clinical “trenches,” feeling that their voices have been heard and valued and that their moral views can have an impact.⁴⁹

In addition to providing opportunity for shared ethical reflection and trust building, moral reflective spaces can be locations of valuable ongoing ethical skill-building, including skill in constructive moral reflection and communication. There is a standing risk that expressions of moral distress will be construed in a reductive way (both by speakers and hearers) as mere lamentations or reports of inner states—for example, of frustration, anguish, anger, discomfort—rather than as assertions of moral appraisal, concern, or protest. There is also a risk that both the conflicts generating moral distress and the solidarity arising from shared distress can lead to a damaging intensification of negative energy, a litany of reasons to feel hopeless, that further entrench resentment or deflate efforts to seek needed reform. We thus envision an important role for skilled facilitators in cultivating ongoing engagement in “narrative repair,” guiding the development of “counter stories”—through which themes of victimization, powerlessness, guilt, and shame might,

over time, yield to empowered discourse, in which integrity-preserving and restoring strategies are identified, energizing moral courage and hope.⁵⁰ It is also important to encourage movement beyond impoverished moral vocabularies or cryptic, shortcut, disguised claims—pleas and “complaints”—that get easily dismissed (“Why are we doing this?” “We’ve been down this road before.” “Nothing will ever change.”), so that observations and concerns are framed in ways that invite constructive and robust ethical analysis: What is ethically at stake here? What features of the situation are amenable to compromise and further exploration? What assumptions are we making? Are they true? What interim steps might we take to shift our understanding or change the situation? Crucially, clinicians’ expressions of moral distress would be offered into “a space of reasons” in which they could be explored—analyzed, contested, debated, emended, and checked against diverse perceptions and perspectives. They would be heard not as just laments, but as a call or appeal to others with whom there is hope of achieving greater shared moral understanding and alignment in practice. A crucial piece of this may involve the acknowledgment of moral anger, and the creation of space in which anger can be witnessed and constructively worked with in a respectful and safe context. A context like this might, for example, afford an opportunity for the ICU nurse, resident physician, and medical residents and interns in Thomas and McCullough’s case to carefully hash out and explore what happened in the practice-code situation, and identify ways to proceed, should a situation like that arise again.

The pragmatics of integrating such “spaces” into clinical environments is something that must be decided in the concrete, within actual organizations and institutions—and it will take experimentation. They might, for example, be integrated into daily clinical rounds, ongoing patient care conferences, morning reports or clinical hand-offs, regular, structured debriefing sessions, facilitated “ethics conversations,” or dedicated ethics rounds.⁵¹ What we are proposing would include an expansion of formal, facilitated, interprofessional ethical engagement beyond consultation models, making constructive and inclusive reflection an integral part of clinical practice. It would involve a shift away from a quandary-centered orientation that is tied to discrete and identifiable conflicts, crises, and choice points, to a more inquiry-based, open-ended, model of ethical reflection, that includes, but does not focus on, solution seeking and decision making. This, in turn, would invite the extension of ethical exploration to

include systemic issues—for example, power dynamics, communication breakdowns, interdisciplinary tensions, and other matters of practice and protocol that trigger moral distress in the daily life of clinical work.⁵² The emphasis would be placed on appreciating diverse ethical perspectives and orientations, thereby encouraging clinicians to examine their own ethical assumptions and biases, to extend their moral imaginations, and to develop comfort with the idea that there may be more than one interpretation of, and viable resolution to, the challenges they confront.⁵³ Especially if a premium is placed on achieving insight into others’ perspectives, rather than on agreement, there would be potential to enhance mutual understanding and develop both greater respect for complexity, and greater comfort with ethical uncertainty.

There is no question that “moral-reflective spaces” of the kind we are envisioning are best joined with broader reforms within healthcare practice and policy, which protect clinicians’ freedom to question and protest, empower and authorize clinicians to contribute to needed practice and policy reforms, and commit resources to the support of innovative ethical education and consultation.⁵⁴ While moral-reflective spaces represent just one piece of a bigger picture, we believe they hold significant promise as a way to help stem the escalation of moral distress. They would offer clinicians a consistent, ongoing opportunity to exercise constructive moral agency, to see themselves as members of a larger moral community that provides a safety net of support in response to morally distressing or ethically complex situations. Joining others in grappling with the sources of moral distress can enhance mutual understanding and respect and set a shared ground for proposing and experimenting with changes in practice and protocol. This can diminish the sense of helplessness, isolation, and despair so often tied to moral distress. More positively, such “spaces” would offer promising opportunities to harness the moral energy and investment revealed by moral distress, and direct it in ways that support clinicians’ empowerment and voice.

Tapping into the Promise of Mind/Body Connection and Mindfulness Practice

In addition to creating moral reflective spaces in which clinicians can speak to, and explore, sources of moral distress, we believe it is important to find ways to support clinicians’ ability to work constructively with their moral distress itself, with the somatic and affective states of “distress.” As noted above, moral distress can, if insufficiently ad-

dressed, disrupt composure, diminish resilience, and impede moral responsiveness. The ability to cultivate mental and emotional fortitude, to maintain greater inner stability and resilience, can be crucial in the face of morally distressing clinical realities that often lead to reactivity and outrage, numbness, and withdrawal.

We know, for example, that sometimes, when mired in heightened emotional states, we can be impeded in our ability to remain open and curious, able to engage in inquiry, reflection, or constructive exchange. We can feel stuck, and react with anxiety, anger, or fear that close down imagination and flexibility, and lead to narrow and rigid views of what is possible, obscuring creative, integrity-preserving compromises and unforeseen options. In heightened states of emotion, we can hold on to convictions by selectively honing in on confirming evidence, while remaining immune to disconfirming evidence. The capacity to identify the morally relevant aspects of a situation and to weigh their significance realistically, to give room to different moral perspectives, and to work flexibly, creatively, and collaboratively in envisioning possible ways forward can all be impaired.⁵⁵ Thus the ability to work skillfully with somatic and affective dimensions of distress is not just a way to address the physical and psychological “fallout” of moral distress, to secure greater well-being, it is also a way to strengthen moral efficacy and integrity, to foster capacities that ground the moral discernment and responsiveness that are at the heart of moral integrity.

We thus urge the development of approaches within clinical training and practice that offer clinicians ongoing ways to work skillfully with the emotional and somatic dysregulation generated by moral distress. Here we must experiment creatively. Among the strategies we believe hold great promise are techniques directed to cognitive, affective, attentional, and somatic awareness and self-regulation, including approaches derived from contemplative traditions used for stress reduction and resilience training. Mindfulness is an awareness of the present moment that emerges by purposefully paying attention to and not judging one’s unfolding experience.⁵⁶ Mindfulness practices to stabilize emotion and focus attention can enable clinicians to perceive the context of their moral adversity with more clarity, curiosity, and openness. “Awareness” practices can assist clinicians in recognizing emotional triggers and states of negative arousal, including symptoms of over-aroused empathy.⁵⁷

There is emerging evidence that mindfulness practices offer promising methods for the support

of psychological and moral resilience.⁵⁸ Research suggests, for example, that mindfulness-based interventions can decrease rumination and avoidance of experiences, enhance emotional stability, and help sustain equanimity under conditions of stress.⁵⁹ These changes, in turn, correlate with the reduction of anxiety and depression and the enhancement of positive emotions, including self-compassion.⁶⁰ Mindfulness, in tandem with skillful self-regulation of affect, can enhance clarity and composure, and enable clinicians to be more resilient and flexible in the fray of clinical pressures, less at risk of making clinically poor decisions aimed at alleviating their own distress, better able to address conflict, and more able to engage empathically with patients and colleagues.⁶¹ While some may doubt the practicality of integrating mindfulness practice and other contemplative approaches into clinical work environments, pointing to the already overwhelming work loads and time pressures clinicians juggle, we believe that finding ways to introduce insights and practices from contemplative traditions into the clinic can encourage the institutional creation of time and space for taking stock, for pausing. This can serve as a meaningful antidote to the sense of urgency that is so often a factor in moral distress.⁶²

It is also important to note that some forms of mindfulness practice, once learned, offer highly portable techniques clinicians can use to secure greater self-regulation and focus in just moments,⁶³ and that even brief mindfulness meditation training has been reported to have significant positive effects.⁶⁴ New approaches to building such capacities have been proposed⁶⁵ and, although further research is needed to evaluate their effectiveness, we believe these efforts hold significant promise as powerful, practical, and scalable means of fostering clinicians’ resilience in clinical environments.

CONCLUSION

While it is unlikely that moral distress can be eradicated, it can serve as a valuable catalyst for moral progress. What is needed are productive, integrity-preserving, growth-enhancing strategies for working with and channeling the moral energy and investment that moral distress reveals. There is no question that the positive strategies we recommend must be a part of a robust, ambitious, multifaceted endeavor—a “full-spectrum” approach to developing a culture of ethical practice across healthcare institutions, policies, and networks.⁶⁶

The challenges posed by moral distress in day-to-day clinical practice reveal the limitations of ap-

proaches within clinical ethics that are cognitively focused and organized around discrete crises and decision points. Although it is sometimes triggered by crises, moral distress can also escalate in gradual, more insidious ways, especially when it is rooted in deeper organizational and systemic challenges. As it consists of disregulated somatic and emotional states, moral distress shapes the way clinicians perceive, frame, and respond to moral problems. If not detected and worked with in an ongoing and proactive way, it often takes on a dynamic of its own. When it does, it can itself further disrupt moral composure, diminish compassion, and threaten clinical collaboration and trust. Too often, by the time an ethics consult, mediation, or other support resource is sought, moral distress has escalated precipitously; emotions are at their height, narratives and conflicts are locked in, and the patient, family, and treatment team have spiraled into full-blown crisis. The challenges of moral distress thus call on us to design interventions that are ongoing, proactive, and integrated into clinical practice in thoughtful ways.

Moral distress itself is not the enemy. If properly worked with, it can heighten awareness that an occasion calls for careful moral consideration and prompt fruitful reflection and action. It is essential that we find new ways to support the effective moral agency of clinicians, at all levels of power and authority, so they can stand for, and give courageous voice to, matters of conscience without fear of resistance, dismissal, or reprisal, and with realistic hope that their constructive protests and creative ideas will be heard and taken seriously. There is also an urgent need for the design of innovative approaches that will support clinicians' ability to work constructively with the somatic and affective dimension of moral distress, and to learn skills that can foster moral resilience and enhance moral efficacy. Constructively working with and redirecting the energy consumed by moral distress can help clinicians to restore their commitment to the people they serve, practice with moral integrity and compassion, and take action to reform the systems in which they work.

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Focus More on Causes and Less on Symptoms of Moral Distress

Tessy A. Thomas and Laurence B. McCullough

ABSTRACT

In this commentary on Carse and Rushton's call for reorientation of moral distress,¹ we state agreement with the authors that the discourse of moral distress should refocus on the moral components of integrity. We then explain how our philosophical taxonomy of moral distress,² mentioned by the authors, appeals to moral integrity. In this process, we clarify our taxonomy's appeal to Aristotle's concept of *akrasia*. We conclude by offering support of Carse and Rushton's challenge to organizations to strengthen moral integrity by fostering resilience.

Carse and Rushton's call for reorientation of moral distress is a welcome and important addition to the ongoing discourse of moral distress. They underscore the limited progress in effectively addressing moral distress that has resulted from an

incomplete understanding of the fundamental elements of moral distress. We agree that if one does not focus on what is *really* going on, the causes of moral distress, one will focus only on its symptoms. The latter is important work, to be sure, but it is not enough and, we fear, will prove inadequate in the long run. We therefore need to curtail our time, energy, and resources fixing the wrong problems with the wrong solutions.

In their appeal for the reorientation of the moral distress narrative, Carse and Rushton adopt our focus on the moral component of *integrity* as the main fundamental element of moral distress that is constantly stressed within a system, and call for reforms that support moral agency and moral resilience. We welcome their characterization of our focus on the *moral* in moral distress and our resulting philosophical taxonomy of moral distress as "the most systematic account to understanding moral distress."

Our proposed philosophical taxonomy of moral distress appeals to the core concept of moral integrity.³ In the current moral distress literature, too often the exploration of the underpinnings of moral distress has primarily focused on understanding the *distress* component of moral distress. The *distress* component of moral distress centers on the psychological responses (anxiety, anger, frustration, burn-out, *et cetera*) of those experiencing moral distress. The study of the psychological manifestations of

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moral distress is an important endeavor, since it is well documented that experiences of moral distress generate and involve tangible feelings and responses. However, focusing only on the psychological manifestations and the *distress* component of moral distress is to focus only on symptoms and not the underlying cause. A major accomplishment of our proposed taxonomy is to shift the focus back to the *moral* component of moral distress and thereby its causes. The moral component explicitly emphasizes the interconnection between moral distress and moral integrity; moral distress occurs when moral integrity is challenged, threatened, or violated.⁴ These, in turn, cause the psychological manifestations that are well documented in the moral distress literature.

Our taxonomy also appeals to Aristotle's concept of *akrasia*, usually translated as "moral weakness." Why do we sometimes do *precisely* what we ought not do? Moral philosophy has long debated the underpinnings of good and wrongdoing, and much of the scholarship documented is the deep analysis of Socrates and Aristotle's classical account. Aristotle understood *akrasia* to name the intrinsic tendency in some circumstances to act against one's considered right judgment and thus lose self-mastery. This can happen deliberately, when someone in authority uses his or her organizational power to force a healthcare professional to act against considered professional judgment. When resisting such power comes at a very high price, ordinary human beings may sometimes elect to lose self-control and go along, even though they know that they should not. This is not a matter of character, but of behavior and action that can damage character by damaging moral integrity.

Our taxonomy appeals to Aristotle's concept of *akrasia* to raise awareness of the powerful organizational forces that influence behavior and action. The awareness and/or mindfulness that behavior and action may generate discordant judgments in response to challenges, threats, and violations of moral integrity—thereby generating moral distress that manifests with significant psychological sequelae⁵—may help moral agents to better understand their experiences and to identify opportunities for improvement that are based on such mindfulness. Carse and Rushton thus misread *akrasia* as "moral deficiency and failure felt by clinicians experiencing moral distress," and "as evidence of personal moral deficiency, an inability to withstand the challenges and demands of clinical work." It is, instead, the ordinary human behavior of not acting heroically and, therefore, sometimes not having self-mastery.

In this view, Aristotle analogizes an akratic moral agent to "a city that votes for all the right decrees and has excellent laws, but does not apply them."⁶ We agree with Carse and Rushton that "sometimes in acting with integrity that one experiences moral distress" and the "experience of moral distress is not itself a symptom of moral deficiency or failure." We treat the experience of moral distress as a symptom of the challenges, threats, and violations to moral integrity that originate such behavior, and not in some character flaw. In this respect, the translation "moral weakness" is misleading.

In our view and embraced by the taxonomy, all moral agents have the capacity for moral integrity, but that capacity is sometimes limited by *akrasia* thus understood. It is a mistake to treat this as being morally deficient or a failing. Simply stated, the experience of moral distress occurs when an agent's fundamental sense of sound and strong moral integrity is challenged, threatened, or violated. Thus, being aware of inherent *akrasia* that potentially influences judgments, behaviors, and actions is not a negative narrative of moral distress as suggested by the authors. In fact, mindfulness of actions that are discordant with moral integrity may offer further understanding of the strong psychological manifestations of moral distress that include powerlessness, loneliness, and shame that express injury to moral integrity, and to that extent, loss of self-mastery. Such mindfulness can then guide a moral agent's judgment, behaviors, actions, and self-assessment before, during, and after a distressing situation.

For example, [A] is a new employee in a group practice. [A] finds out that his/her boss [B] has the office manager overbill for services provided by [A] in order to cover office overhead costs to pay ancillary and co-employee salaries. [A] knows that this is not the right thing to do and acknowledges the situation is now challenging his/her moral integrity. [A] wants to speak to the office manager and to [B] about this situation, to seek clarity and express dissent to [B]. [A] does not know if other colleagues are aware of the overbilling practice, and is concerned that speaking up will risk immediate job termination and labeling as a non-team player. [A] feels powerless and lonely. [A] reflects that he/she usually speaks up when he/she sees injustice, but also recognizes that the consequence of following through with usual behavior is higher than prior experiences. [A] decides to wait for six months before committing to a particular course of action: speak up or remain silent.

While Carse and Rushton reiterate the importance of focusing on the moral integrity component

of moral distress in their prelude, they are at risk for falling into the trap of psychologizing *moral* distress. Subsequently, their reconsideration of moral distress falls short. Emphasizing powerlessness, voicelessness and isolation, diminished moral responsiveness, and shame echoes the psychological manifestations of moral distress that have already been identified. These four aspects presented by Carse and Rushton have been well documented in the literature.⁷ This psychologizing of moral distress and its resultant focus on its affective symptoms distracts focus on their causes, the *moral* in moral distress. Loss of conceptual clarity impedes the task of reconsidering moral distress that Carse and Rushton propose to undertake.

While it likely impossible to eliminate moral distress altogether, it is possible to curtail some of its dangerous effects on individual healthcare professionals and on healthcare organizations. To this end, Carse and Rushton make the important contribution of identifying innovative practical strategies to address moral distress. The strategies accounted for by the authors appear to focus on bolstering support of the moral agent and preserving moral integrity within complex organizations and their cultures. Organizations formulate mission statements to embody the values of an organization. The mission statements usually include what leadership expects and discourages, as well as what leadership rewards and punishes. Organizational culture influences what leadership tolerates and, crucially for prevention of moral distress, what leadership should not tolerate if it is committed to the sustained moral integrity of healthcare professionals in the organization and thereby to patient safety and quality care. Leadership should tolerate neither the causes of moral distress nor their psychological manifestations.

Carse and Rushton call for healthcare organizations to focus on fostering resilience features and supporting the moral integrity of their clinical staff by creating healthier workspaces. To create a healthy work environment that emphasizes moral empowerment and moral voice, the authors encourage facilitated reflection and narrative sharing in the day-to-day clinical realm. We agree that facilitated discussions/debriefs can invite different frameworks to improve moral understanding and perceptions. Such a focus on moral reflection may empower clinicians to use shared ethical language and maintain the healthy workspace environment needed to improve team dynamics. Additionally, encouraging mindfulness practice can further deepen each moral agent's connectedness to his or her individual goals, val-

ues, and feelings, and identify larger connectedness to the organization and colleagues. All these potential interventions, when focused on the causes and the symptoms of moral distress, have the potential to promote resilience, which is essential for sustained moral integrity as a powerful antidote to moral distress.

NOTES

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Using Moral Distress for Organizational Improvement

James E. Sabin

ABSTRACT

Moral distress is a major problem for nurses, other clinicians, and the health system itself. But if properly understood and responded to, it is also a promising guide for healthcare improvement. When individuals experience moral distress or burnout, their reports must be seen as crucial data requiring careful attention to the individuals and to the organization. Distress and burnout will often point to important opportunities for system improvements, which may in turn reduce the experience of distress. For this potential virtuous cycle to happen, individuals must be able to articulate their concerns without fear of retribution, and organizational leaders must be able to listen in an undefensive, improvement-oriented manner.

INTRODUCTION

It's a mark of creative ideas that once we understand them, they often seem obvious. Just so with Carse and Rushton's crucial insight—that if we interpret moral distress properly we will see that it is not just a problem to be dreaded but also a promising guide for improving healthcare.¹ Their insight accords with the Japanese aphorism about quality

improvement: “Every defect is a treasure.” Moral distress is serious health system defect. It is a source of demoralization for massive numbers of health professionals and a major cause of turnover, especially among nurses, where the phenomenon was first described by Andrew Jameton in 1984.²

Paradoxically, the nursing profession's admirable ideals make nurses uniquely vulnerable to moral distress. Nursing students are selected in large part for their patient care values, and nursing education strengthens their capacity for empathy with patients and families. For the past 15 years, the Gallup poll has found that nurses are rated highest among all surveyed professions for their honesty and ethics!³ As Rushton writes elsewhere,⁴ in the hospital environment where they “practic[e] at the point of care, nurses are intimate witnesses to the pain, suffering, and hope of the people they serve.” In their caretaking roles, nurses are perilously poised between the patients and families they empathize with and the hospital systems that give them directives – whether in the form of “doctor's orders” or “policies and procedures.” As a result, when the health system fails to alleviate pain and suffering and disappoints patients' hopes, nurses suffer along with their patients. Jameton defined this suffering as moral distress, a condition that “arises when one knows the right thing to do, but *institutional constraints* make it nearly impossible to pursue the right course of action.”⁵

In this commentary I will focus on how the organizational settings within which moral distress oc-

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curs can, at one extreme, intensify the individual clinician's experience of moral distress, and at the other, harness its promise for health system improvement.

STRENGTHENING MORAL RESILIENCE

In Carse and Rushton's view, the starting point for harnessing the promise of moral distress is moral resilience within the individual staff member. Except in paradise, organizations inevitably create frustrations for the staff. Resilience allows us to bounce back. If I frame my workplace distress as a call for quality improvement, I'm less likely to feel like a disempowered victim and more likely to undertake moral activism. Carse and Rushton identify two pathways to heightened moral resilience—individual self-strengthening through such means as mindfulness practice and eschewing perfectionism, and creation of "moral-reflective spaces."

For persons whose temperaments support the move from distress to advocacy, strengthening resilience is the most direct path to achieving the positive potential of moral distress. I agree with Carse and Rushton that for some clinicians, mindfulness practice can foster this transformation.⁶ But for those for whom activism does not come naturally, and my guess is that this is a substantial number, focusing on the individual's response to moral distress risks adding one more burden for persons who already feel overwhelmed. If clinicians believe that resilience will immunize them against moral distress, and that mindfulness practice will make them resilient, they may frame moral distress as their own "fault," and blame themselves for the experience. If I blame myself for distress that is actually caused by a system problem, I deprive the system of feedback that could lead to improvement of quality.

With regard to "moral-reflective spaces," Carse and Rushton explain that "joining with others in grappling with the sources of moral distress can enhance mutual understanding and respect, and create shared ground for proposing and experimenting with changes in practice and protocol." One example of a "moral-reflective space" is Schwartz Center Rounds, in which clinicians discuss the social and emotional aspects of their clinical practices. Schwartz Rounds are conducted in more than 425 healthcare organizations in the U.S. and Canada and more than 120 in the United Kingdom.⁷ Another is Balint Groups, in which physicians and other clinicians meet to discuss challenging situations, with the primary focus being the clinician-patient relationship.⁸

I've participated in Schwartz Rounds and Balint Groups, and have experienced firsthand how these kinds of moral-reflective spaces of can invite exploration of clinical experience, including experience of moral distress, in an atmosphere of mutual support. Venues of this kind can strengthen resilience and the voice of clinicians as potential catalysts for change.

But voice is only half of the equation. For voice to be effective, the organization must be prepared to listen!

THE DIFFERENTIAL DIAGNOSIS OF MORAL DISTRESS

Not every subjective experience of moral distress arises from defects in the health system. Some people tilt towards feeling mistreated and victimized. And sometime distress arising in other areas of life shows up as workplace distress. If you never whined as a child, you're in a minority. Fables tell us about a princess who is so sensitive that she can't sleep if there is a single pea under 20 mattresses. There are risks in assuming that moral distress means the organization must change (false positives), but even more serious risks in not taking moral distress seriously enough (false negatives).

When I was recruiting physicians to work at the not-for-profit Harvard Community Health Plan HMO (HCHP), I tried to assess this dimension of personality by direct inquiry. I emphasized that while I liked working at HCHP, no organization was perfect, and moments of disagreement and distress with aspects of how the organization functioned were inevitable. What was the applicant's experience with this kind of situation? Does the applicant tend to feel victimized? Had she or he been an effective advocate in the past? This wasn't a foolproof method, but it is important to discuss Carse and Rushton's "moral resilience" in advance, just as it is important to discuss side-effects when prescribing a medication.

MORAL DISTRESS AND BURNOUT

Interestingly, while the *nursing* literature is replete with articles about "moral distress," the *medical* literature is comparably replete with articles about "burnout." My hunch is that moral distress and burnout are closely related phenomena, but labeled and conceptualized differently in accord with factors of hierarchy and perhaps of gender. "Distress" is associated with a structurally more subordinate position, like that of nurses, who are expected to

follow “doctor’s orders” and the “policies and procedures” of the organizations in which they work. Physicians have historically been more autonomous. “Burnout” sounds like the exhaustion that a runner might feel at the end of a race. I speculate that burnout from what is experienced as excessive or misguided demands and encroachment on autonomy is a more acceptable conceptualization for a profession that has been accustomed to seeing itself as the leader. Historically the nursing profession has been more female, and the medical profession has been more male, adding an element of gender to the alternative ways of conceptualizing work-related dysphoria.

LEADERSHIP’S RESPONSE TO MORAL DISTRESS AND BURNOUT

In 1957, Chairman Mao Zedong launched a campaign to “let a hundred flowers bloom and a hundred schools of thought contend” to encourage intellectuals in the Peoples’ Republic of China to recommend improvements in governance. The intellectuals obliged. But when Mao saw the torrent of criticism, he reversed course and jailed many of the critics.⁹ So much for voice in post-revolutionary China!

Openness to working with moral distress requires leaders to overcome the natural human tendency towards defensiveness that Chairman Mao illustrated so dramatically. Moral distress frequently includes an element of accusation of the organization and its leaders. I experienced this shortly after starting the role of Associate Medical Director at HCHP in 1980. In making rounds at a facility I was responsible for, I came upon a physician and nurse, both Caucasian. They were discussing their work, and said to me, “The doctors and the nurses are the new N—— [“N word”]!” I was shocked, and my reflexive response was defensive—“That makes me the new plantation owner.” They said they didn’t mean anything personal, but by failing to draw them out on the sources of their distress, my defensiveness cost me an opportunity to work constructively with their experience. If I could redo that experience I would: (1) tell myself—“Don’t take this personally—find out what they are reacting to!” and then (2) ask “Wow—that’s a strong reaction—what are the key things that lead you to feel that way?”

Just as distressed staff may need support from others and techniques like mindfulness to transform moral distress into constructive activism, organizational leaders need to undergo a similar process to transform themselves into receptive, improvement-

mindful listeners. Overcoming defensiveness takes hard work. But giving voice to moral distress accomplishes nothing without a listener who is influenced by it!

Empathic listening to what morally distressed staff members say doesn’t require agreeing with their advocacy. The fact that staff members are distressed by the organization’s policies and procedures doesn’t mean that they are right and the policies and procedures are wrong. But even if leaders are not going to change the factors that have caused the distress, they should listen with empathy, provide an undefensive explanation of the rationale for the *status quo*, and make a good faith effort to mitigate the negative impact on the staff.

The Mayo Clinic has been a leader in studying and responding to staff distress. While their published work focuses on “burnout” in physicians, their perspective is just as applicable to “moral distress” in nurses as well. According to the Mayo CEO and the Director of the Program on Physician Well-Being, “Mistakenly, most hospitals, medical centers, and practice groups operate under the framework that burnout and professional satisfaction are solely the responsibility of the individual physician . . . [in reality] reducing burnout and promoting engagement are the shared responsibility of individual physicians and health care organizations.”¹⁰

The very fact of creating a program focused on physician well-being reflects a management decision that burnout is a serious problem requiring a systemic approach to prevention and amelioration. Individual physicians are expected to identify ways in which the program can be improved. Leaders are expected to listen and respond. Mayo Clinic teaches us that dealing constructively with moral distress and burnout requires collaboration between the distressed individuals and the organization.

The most comprehensive approach to organizational ethics to date is found in the Veterans Health Administration Integrated Ethics program.¹¹ The program explicitly asks organizational leaders to foster a culture in which staff can articulate their concerns: “In a healthy organization, leadership creates an environment where open communication is welcome and encouraged. Employees can speak up without fear of having their comments held against them. In a ‘morally safe environment,’ staff is less prone to unethical behavior.”¹² When employees identify a significant “ethics gap,” they are expected to bring it forward, and the concern may generate a formal ethics quality improvement project.¹³ As at the Mayo Clinic, leaders are expected to listen and respond. Clinicians and patients will be well-served

if organizations follow the VA's wise recommendations.

CONCLUSION

An emerging literature, to which Carse and Rushton make an important contribution in this journal, links individual clinicians' experience, organizational leadership, and quality improvement in a potentially virtuous cycle. When individuals experience moral distress or burnout, their reports must be seen as crucial data requiring careful attention to the individuals and to the organization. As Carse



and Rushton demonstrate, distress and burnout will often point to important opportunities for system improvements, which may in turn reduce the experience of distress. For this potential virtuous cycle to happen, individuals must be able to articulate their concerns without fear of retribution, and organizational leaders must be able to listen in an undefensive, improvement-oriented manner.

As I thought about how to conclude this commentary, a series of images such as the *pas de deux* in ballet came to mind, all involving interactive dualities. Perhaps the most fitting is the ancient Chinese concept of Yin and Yang, as a way of conveying that organizations, like conversations, can only thrive if vigorous voice and empathic listening are both present.

NOTES

The artwork used to depict Yin and Yang is in the public domain.

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Looking at the Positive Side of Moral Distress: Why It's a Problem

Elizabeth G. Epstein and Ashley R. Hurst

ABSTRACT

Moral distress, is, at its core, an organizational problem. It is experienced on a personal level, but its causes originate within the system itself. In this commentary, we argue that moral distress is not inherently good, that effective interventions must address the external sources of moral distress, and that while there is a place for resilience in the healthcare professions, it cannot be an effective antidote to moral distress.

In their article, “Harnessing the Promise of Moral Distress: A Call for Re-Orientation,” Carse and Rushton refocus our collective attention on the need for multifaceted strategies to address moral distress in day-to-day clinical practice.¹ While we heartily agree with their call and believe that sustained attention to practice and research that impact clinical practice is certainly needed, we are concerned that their arguments re-orienting moral distress back towards the self (as opposed to the system) are problematic in two ways. One, their re-orientation asks that moral distress be cast in a more positive light—

being morally distressed serves as reassurance that the clinician is morally attuned. We agree that morally distressed clinicians are morally attuned, but the experience of being morally distressed is not a necessary condition for moral attunement or for its awareness. Additionally, calling moral distress a positive, for whatever reason, obscures that moral distress fundamentally is a grave problem within a system. Two, part of their call is that moral resilience can be an effective antidote to moral distress—that re-orientation to resilience will allow clinicians to let go of their “perfectionistic” and “heroic” tendencies, be less likely to “buckle under adversity or fear,” and be less morally distressed. These suggestions give us pause because the ability to convince healthcare organization administrators to take clinicians’ moral distress seriously is predicated on the fact that moral distress is a serious systems problem—an alarm bell that some aspect of the situation has gone awry, not that staff are under-resilient. And, although early in their article Carse and Rushton rightly decry the clinician-blaming implied when moral distress is equated with moral weakness, their call for clinicians to learn to be “buoyant,” not to “buckle” under to morally adverse situations, and to make lemonade from their morally distressing lemons continues the clinician-blaming they wish to avoid.

We argue that moral distress is a phenomenon of the industry. It is experienced on a personal level,

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but it reflects systems-level problems. As such, a systemic commitment to addressing the common sources of moral distress is the necessary cure. There is a place for resilience, in that it may help clinicians tolerate the problems, separate self from the problems, or bring problems forward, but, in the end, resilience cannot cure moral distress. In this commentary, we offer some insights on the systemic nature of moral distress based on our experience as moral distress consultants, and we expand on the potential place for resilience in the context of moral distress.²

MORAL DISTRESS IS A SYSTEMS PROBLEM —NOT A POSITIVE

At a recent annual conference of the American Society for Bioethics and Humanities, several colleagues were gathered in a hotel lobby discussing a presentation on moral distress they had just heard. One physician told of her frustration at the lack of administrative attention to a persistent problem at her institution that negatively impacted patient care. She turned to the others and said, “Moral distress is exactly what I’m experiencing. How many times must I bang my head against the wall before I just stop trying? When am I going to learn that I will not be heard?” This physician’s statement draws attention to some of the key background conditions of moral distress; lack of voice, external causes, and moral hazard (being made to bear the burden of another’s decisions), and each of these conditions draws attention to why moral distress cannot be couched as a positive sign, but is and must remain a systems problem to be solved, not merely endured.

LACK OF VOICE

The problem this physician and others face is not that they lack moral agency or are unaware of the wrongness of situations. Clearly, this physician is highly aware of the wrongness and is willing to speak up. The problem is that she has a legitimate claim to know that what is happening is wrong and is not being heard by those with the power to evaluate and fix the situation. This is not a problem with her, but with the system that does not hear her or value her potential as a useful informant or co-operant. We agree with Carse and Rushton when they state, “Having a voice—being able to assert appraisals, raise concern, protest meaningfully, with background trust that one’s perspective counts and can have impact.” However, having a voice goes beyond trust that one’s perspective counts. Having a voice

requires a corresponding act of the party with power—an act of hearing. And by hearing, we mean not only listening, but being willing to evaluate and address the situation given what is heard.

EXTERNAL SOURCES OF MORAL DISTRESS

The key sources of clinicians’ moral distress are fairly consistent. Following the family’s wishes to continue life support measures that are not in the best interest of the patient, witnessing a diminished quality of patient care due to poor team communication, watching patient care suffer due to a lack of careproviders’ continuity, working in conditions where staffing levels are unsafe, working with colleagues who are not as competent as care requires, and providing less than optimal care due to pressures from administrators to reduce costs have been shown, over and over, to be the root causes of moral distress for physicians, nurses, social workers, chaplains, and others.³ All of these sources reflect problems of healthcare systems such as unclear avenues of communication, power structures that inhibit frank dialogue about clinical problems, resource shortages, fear of litigation, and scheduling or staffing routines that undermine accountability. Further, all of these sources clash in some way with professional obligations such as to reduce risk and harm, to avoid unnecessary suffering, to respect patients’ dignity, to work as a team for the sake of the patient. And because clinicians must take care of patients in this milieu, their ability to carry out what is in the best interest of patients is, at times, difficult, and optimal care may be compromised. Clinicians understand the realities of healthcare—resources are scarce, multiple opinions are involved, and sometimes what they see as best for patients may be unachievable. Clinicians are also able to recognize when the system is unnecessarily failing them or their patients. It is these situations, and the resultant feeling of being trapped in having to do something that violates professional obligations, that is so problematic. And, although positive changes can and do occur in response to these situations, they reflect a core negative state, not a positive challenge.

MORAL HAZARD

Moral hazard occurs when the one making decisions does not bear the burden of those decisions.⁴ Administrators who decide to cease providing oncology care for patients who cannot pay for it do not bear the burden of that decision, but patients surely do, as do the clinicians who are left to explain the

mess to patients.⁵ A physician who decides to continue to aggressively treat a patient, despite the disagreement of the rest of the team, does not bear the burden of carrying out the orders, but the residents and nurses surely do: “I got put in the middle . . . the nurses coming to me and saying why are we doing this and . . . I was quite opposed to doing anything to begin with . . . yet the [attending] is saying to do another thing.”⁶ Administrators in Winnipeg, Manitoba, who ignored pediatric intensive care nurses’ concerns about a surgeon’s professional competence did not bear the burden of that decision, but the 12 children who ultimately died as a result of that incompetence surely did.⁷

This is not to say that there must be consensus on every decision or that administrations should not make unpopular decisions. In fact, thank goodness for the clear-minded administrators who are able to make well-informed (even if unpopular) decisions based on a varied set of data. And thank goodness for the keen eye of the attending physician who sees a ray of hope that the team does not see (yet), for this wisdom has certainly saved many a patient’s life. The problem is that administrators, physicians, nurses, and other healthcare providers do not practice in a vacuum or disconnected silo, but in a moral community—“a group of people united by a shared common end with moral implications; in this case, the well-being of patients.”⁸ To function as a moral community is to acknowledge the impact of decisions on others, and to recognize that the insight and expertise of team members makes for better decision making and better patient care.

Given that moral distress arises from external factors, involves a lack of voice despite those voices having a legitimate claim to be heard, and tends to be felt by those carrying out another’s decision, moral distress is an alarm bell that there are problems with what is happening at the patient, unit, or organization level, and not problems with clinicians’ goals, expectations, or values. The presence of moral distress should, therefore, serve as the impetus to demand systematic change. That one can use moral distress as a reason for change does not alter the nature of moral distress as an unalloyed negative. We need not recast moral distress in a positive light to see that good can come from those whose internal moral alarm bell caused them to raise their voices against morally wrong situations. Their acts of resistance should be celebrated, but that they had to resist in the first place should not. The positive promise Carse and Rushton desire comes from organizational interventions to resolve moral distress, not from the experience of moral distress itself.

MORAL RESILIENCE AS POSITIVELY STATED CLINICIAN-BLAMING

In the beginning of their article, Carse and Rushton offer a thoughtful critique of Thomas and McCullough’s taxonomy of moral distress;⁹ highlighting that their taxonomy misattributes moral distress to individual moral weakness, and misperceives moral distress as a failure of personal moral resolve and self-discipline. We readily agree with their critique. Carse and Rushton also underscore that experiencing moral distress is the sign of an attuned conscience, not a weak will. We agree. However, their subsequent call for enhanced moral resilience in clinicians in response to morally distressing situations, whether acute or cumulative, is problematic. Although they avoid calling morally distressed clinicians weak or lacking in moral resolve or self-discipline, Carse and Rushton’s positively framed language of moral resilience can have a similar impact—blaming the clinician for not bucking up, not being buoyant, or not looking at morally distressing situations as a growth opportunity. Learning to reframe situations to see previously unseen potential avenues or even positive aspects is a valuable tool and skill. Unfortunately, the language of fortitude and perseverance that Carse and Rushton associate with moral resilience echoes the traditional “keep a stiff upper lip” or “suck it up” ideologies foisted for so long on clinicians, which much of the recent research on moral distress is trying to undo. Therefore, our concern is that in attempting to affirm clinicians’ moral antennae for detecting moral distress, we are careful not to gloss over the wrongness of the situation or send the message that a way to address moral distress is to be more resilient, when the root causes of moral distress are external and system-oriented and have nothing to do with inner resolve.

This is not to say that resilience has no place in confronting moral distress. It does. But resilience born out of naming moral distress as categorically wrong is very different than resilience born out of being encouraged to “bounce back” from it. To avoid clinician-blaming, we must empower them with language that fully reflects the wrongness of the situation they are experiencing. And as with other injuries, we must avoid trying to move them through the recovery process from moral injury too quickly. “Buck up” and “bounce back” language can encourage clinicians to cover up or hide their moral injury, instead of naming it and taking actions necessary to recover from it. Strategies for helping clinicians to re-enter the trenches after a moral injury are abso-

lutely essential. But an overly positive spin on resiliency, in light of its myriad of contemporary usages and definitions, runs the real risk of labeling those who do not buck up or bounce back as morally weak.

This blaming concern is further highlighted by Carse and Rushton's claim that clinicians make themselves vulnerable to moral distress by being "perfectionistic" or "heroic." Here, the clinician-blaming is direct. They argue that if clinicians can learn to accept their inability to change a situation and accept compromise, they will be less morally distressed and may even find that they were being unreasonably perfectionistic and morally self-righteous. The moral distress they describe here is considered to be self-inflicted, which is addressed if clinicians relax their moral rigidity and listen to other perspectives. Being open to other perspectives and listening within one's moral community are incredibly important actions, which can positively impact a clinician's experience of a difficult clinical situation. These acts may indeed help address the experience of moral distress by showing clinicians they are not alone in their moral distress, that others feel the same way, that they may be mistaken about or missing important information related to the situation, or that there is indeed more grey than first thought about the situation, lessening their sense that there is a clear right and wrong. But to link moral distress, as Carse and Rushton argue, with clinicians' perfectionism and their need to be heroic shifts the source of moral distress to the shoulders of clinicians, and not on the shoulders of the system where it belongs.

The value of moral distress consults (as we have seen) or other opportunities to discuss and reflect on difficult clinical situations (as Carse and Rushton suggest) is that they create a moral space to learn more about the situation, be informed by other's views, and, especially for clinical leaders, understand the impact their decisions are having on others (moral hazard). None of this, however, is dependent on or directly related to clinicians first relaxing their moral integrity.

CONCLUSION

Carse and Rushton's call to refocus on strategies to address moral distress in day-to-day clinical practice is a positive one. But their call focuses primarily on how an individual should handle moral distress (that is, by enhancing moral resiliency) when moral distress is a systems problem that mere perseverance and fortitude cannot solve. Their recast-

ing of moral distress in the positive glow of personal resiliency reads too much like a coach sending an injured player back into the game for the good of the team, but at the expense of the player. The gravity of moral distress should not be downplayed as a step towards addressing it. Instead, recognition of its fundamental negative nature should be preserved. This does not mean there are no short-term strategies for addressing the personal experience of moral distress while attempts at systemic change are sought. These strategies, however, are rooted in teams, not individuals. Team meetings to develop goals for pain management while a family comes to grips with a difficult outcome may be enormously helpful for staff. Patients with complex discharge needs may require regular multidisciplinary meetings with clinicians, risk management, administrators, case managers, and social workers to effect an appropriate plan. Although resilience is generally good for clinicians, it is not the cure, either in the short or long term, for moral distress.

NOTES

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Moral Distress: Conscious and Unconscious Feelings

William J. Winslade

ABSTRACT

In analyzing moral distress, perhaps greater attention should be given to the possible implicit sources of feelings of distress, as well as explicit sources.

Moral distress emerges for health professionals when, for example, ethical conflicts arise about patient care, interprofessional interactions, or hospital policies and practices. Several moments of moral distress erupt in the example of the nurse whose resident permits interns to practice cardiopulmonary resuscitation (CPR) on a dying patient, discussed by Thomas and McCullough,¹ and referenced by Carse and Rushton.² The nurse feels angry, frustrated, ignored, and prevented from carrying out her professional responsibilities.

In my brief comments I will focus on the nurse's conscious feelings rather than the moral issues.

The nurse believed that she should intervene to allow the family in the waiting room to be with their dying relative. She was frustrated and angry when the resident ignored and disregarded her request to stop the CPR practicing by the interns. Her anger

erupted when she grabbed the resident's arm to get his attention and to get him to respond to her.

One might think that the nurse should have sought help from the nurse manager or the attending physician. Her conscious feelings were intensified as she tried to go it alone.

In conflict situations we are all vulnerable to conscious feelings as well as repressed or unconscious emotions that contribute to moral distress. Next I will speculate from a psychoanalytic perspective about possible repressed or unconscious emotions that may have influenced or intensified the nurse's feelings of distress.

From my experience as a psychoanalyst I have learned to be alert to the influence of repressed or unconscious emotions. From a classical Freudian perspective one might wonder whether the nurse's anger was intensified by repressed or unconscious hostility because she had been ignored or her opinions disregarded in her personal or professional past experiences. According to Freudians we are all vulnerable to hostile feelings toward persons who exert unjustified power and disregard or ignore our personal or professional autonomy.

A different psychoanalytic perspective is based on the self-psychology associated with the work of Heinz Kohut. For years Kohut utilized classical Freudian techniques. After several former patients returned for further psychoanalysis because they felt that something was still unresolved, Kohut devel-

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oped a new clinical strategy. Rather than hostility, Kohut found that many patients suffered from unconscious feelings of deprivation, being cheated, or being left out in some significant way. Suppose the nurse in her private life had been deprived of an opportunity to say good-bye to a dying relative or had not been able to attend the funeral. Such a previous experience might help to explain her reaction to the resident and the CPR episode. One of my former analysands, at age four, lost his 14-year-old look-alike brother to a congenital heart defect. His parents did not permit him to attend the funeral. And the father became melancholic after the teenager's death. The father not only withdrew from the family but also suffered from a cardiac condition from which he died after a long, declining illness.

My patient felt left out when his brother died and he was deprived of a close relationship with his father. Perhaps the nurse had some personal experience of being left out, ignored, and her feelings of being disregarded made her particularly sensitive to the resident's lack of response to her. Perhaps her attempt to "go it alone" was rooted in some previous experience, in which she was frustrated because of being ignored and prevented from fulfilling her professional responsibilities. Although I can only speculate why the nurse felt distress and acted as she did, it would not be surprising that both conscious feelings and unconscious or repressed feelings of deprivation may have influenced her behavior. This nurse, like all of us, may not realize that our personal or professional behavior may be influenced by unconscious or repressed emotions of which we are unaware of at the time.

Perhaps in analyzing moral distress, greater attention should be given to implicit as well as the explicit source of the feelings of distress. However, we must be cautious about ascribing unconscious feelings to a health professional who is experiencing moral distress. We are all vulnerable to the influence of as-yet undiscovered sources of unconscious emotions that influence our conscious feelings. But we should also be cautious about over-interpreting conscious feelings as if they must always be a product of repressed or unconscious emotions.

NOTES

1. T.A. Thomas and L.B. McCullough, "A Philosophical Taxonomy of Ethically Significant Moral Distress," *Journal of Medicine and Philosophy* 40 (2015): 102-20.

2. A. Carse and C. Rushton, "Harnessing the Promise of Moral Distress: A Call for Reorientation," in this issue of *JCE*, vol. 28, no. 1 (Spring 2017).

Features

When Not to Rescue: An Ethical Analysis of Best Practices for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care

Nancy S. Jecker and Arthur R. Derse

ABSTRACT

It is now a default obligation to provide cardiopulmonary resuscitation (CPR), in the absence of knowledge of a patient's or surrogate's wishes to the contrary. We submit that it is time to re-evaluate this position. Attempting CPR should be subject to the same scrutiny demanded of other medical interventions that involve balancing a great benefit against grievous harms.

INTRODUCTION

Within hospitals in the United States, cardiopulmonary resuscitation (CPR) carries the unique status of being the only intervention that is automatically used unless a patient or surrogate explicitly refuses it or, uncommonly, if the treatment team determines it is contraindicated. Outside the hospital,

the response to sudden cardiac arrest is also unique: trained bystanders, if they are available, administer medical treatments while waiting for emergency medical responders to arrive. The underlying assumption governing the current approach is that everything that can be done should be done to save a person's life.

We propose fundamental changes to our response to sudden cardiac arrest. Both inside and outside the hospital, health professionals should refrain from the practice of resuscitating victims of cardiac arrest at any cost and regardless of outcome. Instead, the value of rescue should be placed in a broader context of other priorities within cardiac care. The goals of (1) helping the greatest number of people and (2) protecting the normal opportunities open to individuals—that is, capabilities and functioning that contribute to people's ability to participate in the social, political, and economic life of their society and to carry out their own plans and goals—should be the guiding ethical principles. The probability of medical success should also be a central consideration in determining whether or not to resuscitate. In disaster situations, when the need for rescue exceeds a society's capacity to respond, patients should be prioritized using triage. In every rescue attempt, our goal should be patient-centered, focusing not on physiological survival alone, but instead on an outcome in which individuals can

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benefit and can experience and appreciate their own lives.

THE DUTY TO RESCUE VICTIMS OF SUDDEN CARDIAC ARREST

The current default position within cardiac care is to prioritize the rescue of individuals who are in immediate peril, while tolerating social disparities in risk for cardiac disease and disability. This is reflected in the *2015 American Heart Association Guidelines Update for CPR and ECC* (emergency cardiovascular care) (hereafter, the *2015 AHA Guidelines*), which state, “Without objective signs of irreversible death (for example, decapitation, rigor mortis or decomposition) and in the absence of known advance directives declining resuscitative attempts, full resuscitation should be offered.”¹ The *2015 AHA Guidelines* place nearly absolute weight on the value of responding to a person who is in need of one kind of medical attention. We recommend replacing the *2015 AHA Guidelines* with a set of twin guidelines that better align our response to cardiac arrest with ethical requirements and patient-centered values:

1. Give priority to preserving normal opportunities for individuals and
2. Emphasize rescuing individuals for whom there exists a reasonable probability of medical success.

We agree with those who hold that the appropriate principle of distributive justice for setting priorities within a healthcare system is a principle that protects equality of opportunity.² Preventing and treating sudden cardiac arrest (SCA) with effective healthcare services contributes to preserving the normal opportunities of individuals, as the services preserve individuals’ ability to function in society and to realize their plans and goals. Prioritizing normal opportunities leads us to reject the *2015 AHA Guidelines*, which require full resuscitation efforts in the absence of obvious signs of irreversible death. Rather than emphasizing survival alone, our approach also emphasizes safeguarding the normal opportunities of individuals. We approach obligations to victims of cardiac arrest from a social and institutional perspective that shifts the focus away from an individualistic application of beneficence toward values—such as social justice and promoting the public good—that relate to the distributional and aggregate implications of rescue. Considering distributional and aggregate implications of rescue leads us to focus attention on establishing policies and ethical guidelines for which the probability of medical success is a major factor.

Historical and Cultural Influences

The original indications for attempting closed-chest CPR were based on the expectation that the procedure would result in a relatively healthy patient, for example, after acute myocardial infarction (MI).³ The procedure is now employed for a wide variety of conditions beyond otherwise healthy patients that include permanently unconscious patients, irreversibly demented patients, and patients in the last moments of a fatal disease. CPR is attempted by nonmedical as well as medical personnel; “in the field” as well as in medically controlled environments; by trained and nontrained bystanders; in nursing homes, airports, sports arenas; and upon persons of every age and social group, from the well-conditioned school athlete to the severely impaired nursing home resident.

Lay bystanders who perform emergency CPR may be unaware of the tragic time gap of vulnerability between the cerebral cortex and brainstem;⁴ while the cortex can sustain just four to six minutes of anoxia, the brainstem can survive 15 to 20 minutes before it is irreparably destroyed.⁵ Witnessing the rapid arrival of emergency medical personnel only 10 minutes after calling 911, laypeople may be amazed at this astonishing feat; yet they may not realize that, for the victim and family, CPR may be the prelude to a long and agonizing trajectory of permanent unconsciousness. The victim may survive only to join the estimated 10,000 to 25,000 permanently unconscious adults and 4,000 to 10,000 permanently unconscious children housed in hospitals and nursing homes across the U.S., many of whom are victims of failed CPR.⁶

We recognize that because attempts at CPR are carried out in so many different settings and circumstances, outcomes are not easily measured and compared. Despite the absence of a strong empirical database, attempting CPR has become so embedded in medical practice that it is the only intervention that requires the informed consent of a patient *not* to do. It is a default obligation in the absence of knowledge of a patient’s or surrogate’s wishes to the contrary. We submit that it is time to re-evaluate this position. Attempting CPR should be subject to the same scrutiny demanded of other medical interventions, such as potentially toxic cancer chemotherapy, that involve balancing a great benefit against grievous harms.⁷

The psychological impulse to rescue is a strong motivating factor that drives the allocation of resources toward rescue. When an identifiable victim is at risk of death, we are inclined to respond and to attempt to save the individual. Thus, as Jonsen framed it, we “throw a rope to the drowning, rush into

the burning buildings to snatch the entrapped, dispatch teams to search for the snowbound.”⁸ Yet this psychological impulse may or may not have ethical backing in particular situations. Among the ethical challenges created by rescue situations is that yielding to a duty to rescue in each and every case of apparent need would lead to an impossibly expensive system. At the same time, yielding only in a narrow range of cases would seem unfair to those not rescued.⁹ That a patient is in imminent peril does not, by itself, suffice to show that there is a duty to intervene. If a chance for a successful outcome is virtually nonexistent, or if the quality of the outcome to be achieved by an intervention falls well below a threshold that is considered minimal, the intervention should not be attempted, even if it is abundant and readily available.¹⁰ Patient advocacy does not support “doing everything”; rather, it justifies helping the patient. When an intervention fails to offer a patient any significant benefit, the claim that one is “rescuing” or attempting to “rescue” the patient is dubious. This labeling obscures the morally egregious features of what one is doing; as Jecker has noted, “A more honest telling might be: harming the patient, wasting resources, feeding false hope, disregarding professional standards, failing to show courage, being seduced by technology, neglecting to focus on palliative care, being co-opted by the family, refusing to acknowledge medicine’s limits, denying a patient’s impending death.”¹¹

This more honest telling reveals that when an intervention does not offer any significant benefit to a patient, the harms associated with the intervention are not offset. The ethical principle of nonmaleficence, or “do no harm,” represents the first duty of the clinician and provides a basis for a duty to refrain from using nonbeneficial medical interventions.¹²

In rescue situations when there is a reasonable prospect of benefitting the patient, a major factor that should be taken into account is the probability of medical success. What constitutes a “reasonable” prospect of benefit can be determined by appealing to the threshold proposed for quantitative futility, which mirrors the threshold used in the statistical evaluation of clinical trials. In the statistical evaluation of clinical trials, if an intervention produces its desired effect in only one in 100 cases, this is not considered significant, because it occurs so infrequently that it may be due to chance. Likewise, if the likelihood of medical benefit from a particular intervention is just one in 100, that is not considered significant and qualifies as quantitatively futile.¹³ While focusing on the probability of medical

success has a utilitarian aspect, it also appeals to a deontological imperative to come to the aid of the most medically needy individuals. Individuals who are in imminent peril and can be helped need our aid, while those whose medical conditions cannot be improved do not have any “need” for medical interventions.¹⁴ In response, it might be argued that refraining from acting when a patient faces imminent peril would have deleterious effects on careproviders’ compassion, or on patients’ and families’ trust. Our response is that genuine compassion is not demonstrated simply by using medical interventions, but rather by responding in a manner that helps the patient.

In the context of limited resources or limited dollars to pay for healthcare, society may ethically choose to place higher priority on nonrescue services. For example, in cardiac care, using CPR in the field to attempt to rescue a patient who has suffered a cardiac arrest and has been anoxic for an extended period may have less societal priority than investing in basic scientific and clinical research aimed at effectively preventing SCA. In situations of resource or fiscal scarcity when society chooses to limit the resources available for cardiac rescue, health professionals are responsible for carrying out society’s mandate and foregoing the rescue of an identifiable victim.¹⁵ Gaming the system by making an exception for one’s own patient violates ethical principles of justice and fairness.¹⁶ Nonetheless, for careproviders, patients are “up close and personal,” and call forth strong moral responses of compassion and respect for the individual. Although persons who are not one’s patients may be affected by decisions made at the bedside about the allocation of scarce resources, these persons are not identifiable, and represent what some have called “statistical lives.”¹⁷ From a utilitarian or social justice perspective, the distinction between an identifiable life and a statistical life is ethically irrelevant: a life lost or preserved is still a life. Yet it is psychologically challenging for careproviders (and others) to regard the lives of identifiable patients as being on par with statistical lives.

While these considerations are relevant throughout medical care, they bear special relevance to cardiac care. SCA is the most common cause of death in the U.S. Incidences of mortality and morbidity can be reduced by providing emergency medical services to victims of out-of-hospital cardiac arrest (OHCA) by calling 911, and by providing emergency services to victims of in-hospital cardiac arrest. By the time a patient is experiencing SCA, however, there is an overwhelming probability of death. An

estimated 91.6 percent of all patients with SCA due to atrial fibrillation (afib) and 82.3 percent of patients with SCA due to ventricular fibrillation (vfib) who are treated outside the hospital do not survive.¹⁸ For in-hospital cardiac arrest (IHCA), survival is only slightly better, with overall rate of mortality following IHCA of 84.1.¹⁹

Improvements in outcomes for both IHCA and OHCA have been modest over the past 25 years. Although some aspects of resuscitation care have improved over time, such as increased CPR by bystanders and shortened times to defibrillation, these trends appear to be offset by the clinical features of patients who present with SCA, such as increasing age and the decreasing proportion who present with vfib.²⁰ Much of the data related to in-hospital CPR outcomes are extrapolated from out-of-hospital data, and consensus recommendations by the AHA regarding improving outcomes following in-hospital SCA note a lack of evidence that is specifically focused on in-hospital SCA.²¹ Thus many of the *2015 AHA Guidelines* for improving outcomes associated with in-hospital SCA are extrapolated from data on out-of-hospital SCA. Further research focusing on in-hospital SCA are needed to improve recommendations in this area.

It has been argued that OHCA is treatable and that the prospect of improving outcomes is demonstrated by the nearly 500 percent difference in survival rates across communities in the U.S.²² Someone who suffers a cardiac arrest in Seattle-King County has a 62 percent chance of survival; by comparison, in U.S. cities such as New York and Chicago, survival rates are in the single digits.²³ The example of Seattle-King County demonstrates the possibility of achieving better outcomes and suggests the importance of conducting research to identify the factors that contribute to successful out-of-hospital CPR. Since OHCA occurs in more than one out of every 1,000 U.S. citizens each year, it represents an important area for research that is aimed at improving the quality of care. Thus, one promising strategy for saving more lives would be to prioritize investments in basic scientific and clinical research that are aimed at improving the quality of resuscitative care.²⁴

An alternative strategy to reduce the incidence of cardiac death and morbidity would be to invest in preventive and/or public health measures that focus “upstream” on reducing the incidence of SCA in the general population. For example, mortality and morbidity may be reduced by using cardiac medications and devices in high-risk populations; raising awareness of SCA and sudden cardiac death

(SCD) among the public, patients, and healthcare professionals; identifying, in advance, patients who are at greatest risk; reducing barriers to SCA care; and reducing disparities in SCA care and outcomes, for example, by improving reporting, planning, and performing best practices related to IHCA and OHCA. Such interventions tend to have higher yield than rescue interventions that take place post-SCA, as they cost less and benefit a larger population.

Evidence that investment in research and prevention yield benefits comes from the U.S. National Institutes of Health (NIH) Post-Resuscitation and Initial Utility in Life Saving Efforts (PULSE) workshops. The PULSE conferences developed recommendations that include establishing a consortium of resuscitation researchers, whose research is aimed at improving the outcomes of resuscitation. The resultant Resuscitation Outcomes Consortium (ROC) has conducted studies of the effectiveness of promising new therapies during the past decade. For instance, ROC reported the value of early defibrillation by bystanders using an automated external defibrillator (AED), and the value of bystanders performing CPR and immediately summoning emergency medical services (EMS), with the rapid arrival of EMS and implementation of EMS-based protocols for resuscitation. ROC reports that the burden of out-of-hospital SCA (and traumatic injury) is similar to that of major heart attack or heart failure. ROC has also reports that cardiac outcomes have improved in ROC-participating communities. Finally, ROC reports those therapies that are ineffective, allowing resources to be used in pursuit of more beneficial therapies.²⁵ All told, ROC may be a successful example of a coordinated and collaborative approach toward the allocation of federal resources in support of research on potentially lifesaving treatment for cardiac arrest. More research efforts of this kind will be needed to make a lasting and significant difference in the treatment of SCA.

Ethical Justification

Individual beneficence. The ethical backing for foregone rescue under certain defined conditions begins with recognizing that there is no ethical duty incumbent upon individuals to rescue a stranger in peril, even though there may be a strong psychological inclination to help. The arguments of those who claim otherwise are not ultimately persuasive. The most frequently cited normative basis for an individual obligation to rescue is *beneficence*, or the obligation to do good.²⁶ Beauchamp and Childress, for example, claim that individuals have a general obligation of beneficence that applies to rescuing

strangers, provided that certain conditions apply.²⁷ These conditions attempt to weigh the likely benefits of rescue against the risks or sacrifice on the part of the rescuer by requiring that: (1) the stranger, Y, is at risk of significant loss of or damage to life or health or some other major interest; (2) an action by the rescuer, X, is necessary, singly or in concert with others, to prevent this loss or damage; (3) X's action singly or in concert with others has a very high probability of preventing the loss or damage; (4) X's action would not present very significant risks, costs, or burdens to X; and (5) the benefit that Y can be expected to gain outweighs the harms, costs, or burdens X is likely to incur. Singer has likewise argued that there is a general duty of beneficence incumbent upon individuals that holds until we reach a level at which we would sacrifice something of comparable moral importance.²⁸ Singer, who is utilitarian, argues that an individual obligation to rescue arises in situations when rescue is likely to produce more benefit than harm.²⁹

The problem with assigning individuals a duty to rescue based on general beneficence is that it is overly demanding.³⁰ It requires performing acts that we would ordinarily regard as supererogatory, not obligatory. Thus, we are ethically justified in pursuing our own projects and activities, even though such pursuits are based on *agent-relative* reasons, that is, reasons that apply only to us as individuals and do not matter much, or at all, to others. More formally expressed, an agent-relative reason is one in which the general form of the reason includes an essential reference to the person who has it.³¹

A further problem with grounding a duty to rescue on general beneficence is that the distribution of burden falls disproportionately on those individuals who happen across persons in peril, rather than being distributed more fairly and evenly among society at large. These concerns suggest a need to move beyond beneficence and to consider the question of whether society as a whole has an obligation to help those in imminent peril.³²

Societal beneficence. Even if it is not morally incumbent upon an individual to provide aid to a stranger in imminent peril, there is nonetheless a collective obligation on the part of the wider society. Rescue obligations are generally coordinated at a societal level for purposes of efficiency. This approach ensures that the whole community collectively shares the burden of rescue, rather than having the burden fall disproportionately and arbitrarily on an individual who happens, by chance, to come across a victim.³³ In the treatment of cardiac arrest, the more specific question arises: What is society's

collective obligation to recognize and carry out rescue obligations in the field, for example, by funding and implementing emergency medicine systems to provide such services? The answer to this question requires a society to weigh the opportunity costs of prioritizing rescue compared with other possible investments. Approaching a duty to rescue from a social and institutional perspective shifts the focus away from the individualistic application of beneficence toward values—such as social justice and promoting the public good—that relate to distributional and aggregate implications of rescue.³⁴ That first responders, including fire, police, and ambulance services, are supported by tax dollars suggests that a collective obligation is generally recognized. Moreover, that everyone in the U.S., regardless of insurance status, ability to pay, or other factors, has a legal right to emergency medical treatment through the Emergency Medical Treatment and Labor Act suggests that a societal obligation to provide care to persons in emergent situations, now established in law, reflects the ethical consensus that treatment of medical emergencies by facilities that have emergency departments should be available to all.³⁵

The ethical basis for a societal duty to rescue can be found, not by appealing to individual beneficence, but instead by invoking values such as social justice and promoting the public good. Although there is no obligation on the part of individual bystanders to rescue a person in imminent peril, there is a generally recognized obligation on the part of all members of a society to contribute to public systems that provide rescue.³⁶

To examine the ethical basis and limits of a collective duty to rescue, it is instructive to consider whether or not there is such a duty in moderate trade-off situations, that is, situations when there is a moderately good chance of a successful outcome, but rescue would be costly. One position holds that a *justice-based* societal duty to rescue exists only if we would agree to such a duty from behind a *veil of ignorance* (discussed below).³⁷ From behind a veil of ignorance, what we would choose to do if there was an opportunity to be rescued that was not a “long shot,” but moderately good, albeit costly? Would we forgo moderate rescue opportunities to invest in alternatives that would have a higher yield, such as basic scientific and clinical research? We submit that we would place higher priority on preventing SCA, for example, by instituting public health measures, offering preventive medical care, and investing in basic scientific and clinical research measures. These alternative resource investments would potentially benefit more patients in the future, and thus

carry a much higher yield, than rescue attempts that offered only a moderate chance of success. The basis for this claim is that, under a veil of ignorance, deliberators would give priority to protecting fair, equal opportunity.³⁸

Ethics in emergency situations. In rescue situations, when multiple individuals require immediate aid and available resources are limited, clinicians use triage to prioritize patients in a fair and systematic manner. This occurs not only in mass casualty situations, such as during natural disasters when a surge of patients overwhelms the capacity of local systems, but also in emergency departments on busy nights when patients are cued according to triage criteria. Triage places priority on saving the greatest number of lives, assuming that each life saved represents a net gain.³⁹

Kipnis distinguishes *disaster triage*, which is supported by utilitarian principles, from other forms of triage, such as *clinical triage* and *battlefield triage*.⁴⁰ Whereas clinical triage gives priority to patients who are imminently dying, battlefield triage prioritizes persons who have minor injuries and aims to return them to battle (combining considerations of medical benefit with social worth factors). In contrast to both clinical and battlefield triage, disaster triage distinguishes three groups. First are the so-called “walking wounded.” Second are those who have sustained serious injuries yet who can be treated with relatively simple procedures. Third are individuals who have serious injuries who require relatively complex and risky interventions to meet their medical needs. Disaster triage assigns priority to the middle group, that is, to persons who have serious injuries that can be improved with relatively simple procedures, but who will not improve without aid. Disaster triage focuses exclusively on medical factors, as clinical triage does, but is distinct because it considers both medical urgency and the likelihood of medical benefit.

In the above trifurcation, we agree with Kipnis’s proposal that society should employ principles of disaster triage in crisis situations by giving limited resources first to persons who can benefit from relatively simple procedures. In cardiac care, for example, those who are most critically ill and who can benefit from less-intensive resource investments should be given priority over those who are similarly endangered but who require more costly and risky interventions. So too, those who will survive and function reasonably well without immediate medical attention should receive lower priority than individuals who are critically ill and can benefit from relatively small investments of scarce re-

sources. We urge caution, however, and emphasize the point that this approach assumes, as a background condition, the just distribution of resources to different areas of medical care. For example, it assumes that the needs of individuals in rescue situations have already been weighed against the value of other health investments, such as preventive medicine and public health measures.⁴¹

In summary, because SCA is the most common cause of death in the U.S., relative to other diseases, it merits higher priority. When seeking to reduce the mortality and morbidity associated with cardiac disease, it is ethically important to weigh the duty to rescue the individual victim of SCA against other values, such as preventive and public health measures that will benefit a larger group.⁴² More research is needed to better understand the effectiveness of both SCD treatment and prevention to ensure the best possible use of finite resources. Our call for moderation in rescue challenges the *2015 AHA Guidelines*, which state, “Without objective signs of irreversible death (for example, decapitation, rigor mortis or decomposition) and in the absence of known advance directives declining resuscitative attempts, full resuscitation should be offered.”⁴³

Having placed rescue in the broader context of allocating scarce healthcare resources, we turn next to the ethical principle of justice to explore more directly the guidance that it gives in setting priorities within cardiac care broadly.

JUSTICE IN THE ALLOCATION OF SCARCE HEALTHCARE RESOURCES

Although careproviders are trained to make healthcare decisions focusing on benefitting the individual patient for whom they are providing care, medical decisions represent more than the choices of individual careproviders and patients. Healthcare decisions occur in the context of institutional, cultural, legal, financial, and other contextual features. One of the central contextual features affecting healthcare is resource constraints.⁴⁴ Constraints on healthcare resources include both resources and fiscal limits. Resource constraints arise due to limits in the raw materials required to make a healthcare service available. For example, there are more patients with end-stage cardiac disease than there are cadaver organs available. Resource limits also reflect workforce shortages. For instance, the American College of Cardiology reports that currently there is a deficit of approximately 1,700 general cardiologists in the U.S.; at the current rate, the deficit will increase to 16,000 by 2025.⁴⁵

Fiscal constraints exist because there is a finite amount of money available at any given time to pay for healthcare services. In 2014, for example, the U.S. spent 17 percent of its gross domestic product (GDP) on healthcare.⁴⁶ It could be argued that the U.S. ought to spend more or less on healthcare, yet the percentage of GDP a nation spends is limited. Not only is money itself a scarce commodity, societies also choose to invest in many social goods other than healthcare, such as national defense, public transit, police, and fire safety. Moreover, government spending on healthcare diverts funds from other health-producing services, such as education and environmental quality. Thus, even if we cared only about health, it would not be prudent to invest all of our society's resources in healthcare services.⁴⁷ What percent of GDP would it be "prudent" for the U.S. to spend? Different approaches to answering this question include assessing the nation's spending by comparing it to similar countries; considering the process of political decision making; asking how much a country should spend to attain a particular level of health; and using a budgetary approach, in which desired health status changes are identified and a determination of what needs to be purchased to achieve those goals is made.⁴⁸ Whatever approach we use to make this determination, it is important to underscore that there is no apparent correlation between higher spending on healthcare and improved health outcomes. Thus, the U.S. spent more per person on healthcare than 12 other high-income nations in 2013, yet it had the lowest life expectancy and some of the worst health outcomes for this group.⁴⁹ What drives U.S. spending may have less to do with quality and more to do with a "business culture," in which medical care is seen primarily as a revenue stream, resulting in costs ratcheting up without any discernible improvement in quality.⁵⁰

Distributive Justice

In the context of resource and fiscal scarcity, *distributive justice* becomes a central ethical consideration. Distributive justice refers to the problem of devising normative standards for allocating healthcare services when there are not enough resources or money to provide the services to everyone who stands to benefit. In the bioethics literature, discussions of distributive justice often focus primarily on individuals who are already experiencing a medical problem and are seeking access to medical services. With this framing, the ethical question becomes: How should we distribute particular healthcare services to medically needy patients who stand to benefit from those services? When we allocate

limited resources in this way, we assume that allocation has already taken place at many other levels: to healthcare as a whole; among different categories of services within healthcare; and within a particular healthcare category, to different types of services. Framing distributive justice with a focus on patient selection involves what has been called a *medical paradigm of justice*.⁵¹ A medical paradigm is concerned with individuals who are already sick, that is, who have developed a medical condition and are at the end state of medical need. With a medical paradigm, we seek an answer to the following justice question: According to what criteria should a medical treatment be distributed among multiple patients who stand to benefit?

When we allocate resources within a medical paradigm of justice, standards of *formal justice* and *material justice* apply. Formal justice requires treating ethically similar cases similarly. Thus, when characteristics that are ethically irrelevant become a basis for distributing a medical treatment, the standards of formal justice are violated. For example, the National Registry of Cardiopulmonary Resuscitation Investigators report that Black patients with IHCA were significantly less likely to survive to discharge than White patients, with lower rates of survival observed during both immediate resuscitation and post-resuscitation periods. Other studies have found significant sex-based disparities in risk of SCD,⁵² and racial differences in survival after IHCA.⁵³ In the U.S., there is evidence that both Blacks and women under utilize implantable cardioverter-defibrillator (ICD) therapy.⁵⁴ These findings are at odds with principles of formal justice, because race and sex are not ethically relevant bases for distributing cardiac services.

Whereas formal justice has a procedural focus, material justice has a substantive focus. Material justice purports to tell us exactly which cases are similar and which are different in ethically relevant respects. For example, material justice criteria may call for allocating healthcare resources on the basis of factors such as the likelihood, length, or quality of medical benefit; resources required; the cost of treatment; or the imminence of death. It has been argued on material justice grounds that, other things being equal, CPR should be provided to patients who have a higher probability of rapid and full recovery before it is provided to patients who have a lower probability of rapid and full recovery.⁵⁵

Medical Justice

There is general acceptance within the medical profession that physicians should distribute limited

treatments based solely on potential medical benefit, without regard to nonmedical factors. Thus rationing that is based on other factors, such as social worth, chronological age, or lifestyle choices are not the province of the physician. Medical justice identifies the primary responsibility of healthcare professionals to be acting in the best interests of their patients. Thus, physicians owe the ideal of service to anyone in need who can benefit from medical treatment; as Schneiderman and Jecker argue, “Although as citizens in society, physicians can and should contribute to social health policy decisions, at the bedside of an individual patient they should avoid making unilateral rationing decisions.”⁵⁶ Ideally, the field of medical justice would be noncomparative, and physicians would provide—or not provide—interventions without comparing the potential medical benefit of treating one patient against the potential medical benefit of treating another patient. Medical benefit encompasses a range of considerations, including the likelihood, length, and quality of medical benefit; the urgency of medical need; and, in some instances, the resources required by a particular patient.⁵⁷ This position gains ethical support from a variety of sources. First, rationing by healthcare professionals has adverse effects, such as undermining trust in the careprovider-patient relationship. Furthermore, society at large, not the careprovider, has the ethical and political mandate to make decisions regarding rationing and allocating resources. Finally, historical traditions of ethics in medicine require, for example, that physicians swear allegiance to patients’ welfare by following that method of treatment which “according to my ability and judgment I consider for the benefit of my patients,” and “abstain from whatever is deleterious and mischievous” (the Hippocratic Oath).⁵⁸

Although careproviders are ethically limited to distributing scarce healthcare resources on the basis of potential medical benefit, a society may impose limits based on both medical and nonmedical factors. Thus, in contrast to medical justice, *social justice* has a broader range of acceptable criteria. Healthcare professionals have a duty to uphold societal decisions regarding the allocation of healthcare, rather than attempting to “game the system” to benefit their own patients. This is because formal justice requires “playing by the rules” of an agreed upon policy, rather than seeking an exception for one’s own patients.⁵⁹

Societal Justice

The principle of *societal justice* gained traction during the 1960s, when physicians enlisted com-

mittees of laypersons in unprecedented ways to assist with the selection of patients for the then-scarce resource of kidney dialysis.⁶⁰ Although some referred to these committees disparagingly as “God squads,” the goal of delegating rationing decisions to a lay committee reflects an important ethical point: rationing decisions properly rest with society, not physicians (or other health professionals). In contrast to medical justice, societal justice is comparative. Societal justice draws distinctions among different individuals and groups and allocates scarce resources on both medical and nonmedical grounds.⁶¹

Even when healthcare resources are allocated in a way that conforms to standards of formal and material justice, other justice concerns may remain. To the extent that society can improve the social conditions that can put populations at greater risk of disease and disability, considerations of justice are at stake. What has been called a *social paradigm of justice* focuses on the source of medical problems, that is, on how a person’s need for healthcare services arose in the first place. Social determinants, such as lack of education, food insecurity, living in poverty, living in an unsafe neighborhood, or belonging to minority racial or ethnic group, are established factors that place populations at risk for medical conditions and early death. This level of allocation focuses on the allocation of resources between different types of services within a single healthcare category; that is, how much of society’s scarce resources and money should be devoted to public health measures that are designed to reduce the risk of cardiac disease within a healthy population? A social paradigm of justice frames questions of justice in terms of social factors that place people at increased risk of disease, injury, or early death. According to a social paradigm, the central question regarding justice is: How can we modify or prevent risk for disease, injury, or early death?⁶²

In cardiac care, for example, a risk within a population can vary depending on geographical location. As noted above, a victim of SCA in Seattle-King County has a far higher chance of survival than a similar victim in Chicago, which would demonstrate that societal decisions and human actions may contribute to, and may exacerbate, a medical crisis. Risk within a population also varies based on racial or ethnic group. For instance, in the U.S., Latinos and Blacks are at higher risk than Whites for OHCA arrhythmias associated with a poor prognosis. This may reflect delayed response time due to the reduced likelihood of receiving assistance from bystanders in neighborhoods that are primarily Latino, Black,

poor, or non-English speaking. Public interventions to increase the administration of CPR by bystanders and to improve health outcomes in neighborhoods that are at heightened risk may for SCA reduce this disparity.⁶³ When social and political choices put some groups at greater risk for disease and disability, to focus exclusively on the endpoint of health-care distribution—as medical justice does—gives us, at best, a partial picture. It leaves out the question of how the disease and disability arose in the first place, that is, a question of who becomes sick and why.

SETTING PRIORITIES

Finding the Elusive Middle Ground

A helpful way to think about setting priorities may be to frame this as making a choice to benefit one or the other of two hypothetical types of individuals, As and Bs. Suppose As are much sicker or much more disabled than Bs, and suppose it is possible to measure the units of benefit that can be given each individual, for example, in quality-adjusted life years (QALYs) or some other unit of measurement. Many believe that if a treatment can deliver equal benefit to As or Bs, we should prioritize helping As, who are worse-off from the beginning.⁶⁴

Although utilitarian approaches (such as cost-benefit and cost-effectiveness analyses) tend to be neutral in according priority to much sicker As over healthier Bs, many would prioritize rescuing the more needy over the less sick and less disabled. Similarly, many would be willing to forgo some extra benefits for the healthier Bs to provide greater benefits for the As. Yet even though they may favor the As, most people may tend to reject giving the As full priority.

By setting up a choice about rescue in this comparative way, it is more clear what is at stake in the *2015 AHA Guidelines* to rescue all victims of SCA in the field unless they show overt signs of death. What is at stake is that resources that might have been used in other, more effective ways are no longer available. The question thus may be framed as follows: How much priority should we give to A-type patient populations, rather than to B-type patient populations?

This example illustrates the deeper tension between *consequentialist moral reasoning*, on the one hand, and *nonconsequentialist reasoning*, on the other hand. Consequentialist reasoning focuses exclusively on producing the best consequences over all. By contrast, nonconsequentialist moral reasoning emphasizes duties that hold irrespective of con-

sequences. The requirement in the *2015 AHA Guidelines* to begin CPR on all victims of OHCA reflects a nonconsequentialist approach. It suggests that whatever the consequences, there is an absolute duty to attempt to rescue an individual in peril. By contrast, those who endorse prioritizing nonrescue measures, such as public health and preventive medicine measures to reduce harm to persons who might become sick, appeal to consequentialist considerations and the idea of producing the best consequences for the population as a whole.

The distinction between consequentialist and nonconsequentialist reasoning is also evident in the standpoints of health professionals versus the wider society. Health professionals tend to emphasize a duty to help their particular patients, irrespective of harms and benefits to others. By contrast, the standpoint of the wider society tends to highlight the greater good served by preventing harm to a much larger number of individuals. Determining the relative priority of cardiac prevention versus rescue requires addressing the best balance between consequentialist and nonconsequentialist moral reasoning. We submit that the most ethically defensible resolution is one that avoids extreme positions, that is, rejects placing absolute priority on either treating victims of SCA or reducing risk of future cardiovascular events in a population. We thus reject the *2015 AHA Guidelines* for essentially universal provision of CPR and ECC unless refused by the patient, and support instead a policy that limits CPR to OHCA based on material justice standards such as the likelihood, length, and quality of medical benefit.

While there is no satisfactory theoretical justification for an intermediary position, there is a justification based on considered judgments about particular cases. Although we draw on general normative approaches to articulate normative rules and principles, actually prioritizing principles when they are in conflict requires considering the circumstances and cases that characterize the debate. The choice between type-A persons and type-B persons in the above example helps us to see the justification for giving some weight to non-utilitarian considerations, such as rescuing the victims of SCA, but also illustrates, in a concrete fashion, the value of not giving absolute priority to rescue.⁶⁵

Another way to frame priorities in terms of concrete choices in particular cases is to consider which justice principles would be selected in hypothetical situations by parties under a veil of ignorance, mentioned above.⁶⁶ This heuristic device requires us to imagine that we are deprived of all knowledge

of particular facts about ourselves and do not know how our choices will affect us personally. In this way we are prevented from tailoring choices to our own advantage and must consider the possibility that we might be in the position of those who are least well-off with respect to whatever rule or principle is chosen.

One possible principle is a utilitarian one that distributes goods to create the greatest net balance of satisfaction. This tends to favor giving near absolute priority to public health measures that benefit a much larger population of individuals rather than giving priority to rescue, which primarily benefits just the individual SCA victim. Yet from the perspective of the veil of ignorance, a utilitarian principle would be rejected, because no one has a reason to agree to a personal disadvantage to produce a greater net balance of happiness or pleasure. Instead, behind a veil of ignorance, deliberators would be inclined to give priority to protecting fair, equal opportunity. This requires prioritizing healthcare services that prevent, cure, or compensate for deficiencies in the normal range of opportunities that are open to individuals.⁶⁷

With an emphasis on safeguarding opportunity, we propose the following ranking of priorities within cardiac care:

1. Modifiable risk factors that curtail normal opportunity,
2. Rescue with a moderate chance of successful outcome,
3. Rescue with a low likelihood or quality of successful outcome.

1. Modifiable Risk Factors that Curtail Normal Opportunity

The highest priority should be to address modifiable risk factors that carry the potential to profoundly curtail normal opportunities. For example, medication to control blood pressure, and public health measures, such as programs that improve diet and exercise in a population, have a much greater potential impact on the health of a population compared to the provision of healthcare services to treat people who are already sick. In ranking prevention first, parties in the original position might reason along the following lines. Although disease processes are the immediate cause of SCA, societal choices also contribute to the incidence of SCA in a population, and to morbidity and mortality post-SCA. Failing to reduce the incidence of SCA, when effective means to do so exist, violates standards of justice and illustrates what has been called *passive injustice*. Passive injustice consists of the refusal to

prevent harm from occurring when prevention can reasonably be done.⁶⁸ The surest way to safeguard normal opportunity is to prevent mortality and morbidity from occurring in the first place. Intervening after cardiac disease takes hold is a more costly and potentially less effective means of protecting normal opportunity.⁶⁹

2. Rescue with a Moderate Chance of Successful Outcome

The next priority should be rescue attempts for which there is a moderate chance of successful outcome. In moderately successful rescue, there is a moderate chance of restoring normal functioning, or something close to normal functioning. The justification for focusing on a moderate chance of success might be as follows. Although rights to equal opportunity give us claims on others for appropriate forms of healthcare, these claims are limited. The principle of justice does not extend to every rescue situation, and justice favors measures that try to prevent the need for medical rescue over those that attempt to rescue. We have some obligations due to the principle of justice to protect opportunity, but rescue should not be seen as the highest or sole priority.⁷⁰ Parties who are behind a veil of ignorance would see an exclusive focus on medical care for individuals who are in a crisis situation as having the unfortunate effect of diverting public health resources away from the primary obligations of justice, which are to prevent disease. Society has an obligation to protect the public good, in addition to its obligation to help individuals who are in a crisis situation. Addressing both duties requires seeking a proper balance. As Hodge and Gostin note, "Perhaps no duty is more fundamental to American Government than protecting the public's health."⁷¹ The duty to protect the public's health is based on utilitarian principles of avoiding harm and creating the greatest good for all members of society. This approach must be balanced against the rights of individuals in rescue situations.⁷²

3. Rescue with a Low Likelihood or Quality of Successful Outcome

The lowest priority should be assigned to the rescue of SCA victims when the likelihood or quality of outcome associated with the rescue intervention is poor, but not futile. Within this category, those outcomes that cost more would be placed behind those that cost less. The ethical justification for this ranking is discussed in more detail below. An important challenge to our proposal is that prioritizing a high likelihood and quality of outcome may

disadvantage vulnerable populations, such as racial minorities and members of lower socioeconomic groups, who have predictably poorer outcomes than their counterparts. In response, we reiterate the importance of combining an emphasis on outcome, with a high priority on research that is intended to reduce health disparities and improve outcomes for disadvantaged populations. There is currently no national database that tracks the incidence, outcomes, and various factors associated with cardiac arrest. We support the Institute of Medicine's recommendation to develop a national registry to track cardiac arrest events and make information about the incidence and outcomes of cardiac arrest publicly available.⁷³ We also support greater investment in basic science and clinical research in this area. Despite the prevalence of cardiac arrest in the U.S., federal research dollars devoted to resuscitation research are less than other diseases and conditions that occur with similar frequency in the U.S. population.⁷⁴ Once greater investment and research are developed, we support evidence-based strategies to reduce disparities in cardiac arrest outcomes.

CONCLUSION

In summary, we propose fundamental changes to the current approach to SCA. When setting priorities in cardiac care, the highest priority should be placed on interventions with the greatest chance of preserving normal opportunity for individuals. Priority should also be placed on helping the greatest number of people and on selecting interventions that have the greatest likelihood of benefitting patients. The AHA should base its guidelines for rescuing victims of SCA not simply on the individualistic application of beneficence—a medical justice model—but also on social justice and promoting the public good. The distributional and aggregate implications of rescue provide an appropriate ethical context for setting priorities in cardiac care.

Our arguments appeal to a combination of normative concepts and principles. We appeal to beneficence to argue that physicians do not have an ethical obligation to attempt rescue when there is virtually no chance of helping a patient. We invoke the principle of fair, equal opportunity when resources are allocated among different areas of cardiac care. We call upon a utilitarian-based principle of triage when resources are allocated among multiple individuals in disaster situations. Finally, we distinguish medical and societal justice to support the distinct ethical duties of individual careproviders versus society.

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A Framework for Ethical Decision Making in the Rehabilitation of Patients with Anosognosia

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ABSTRACT

Currently, the number of patients diagnosed with impaired self-awareness of their own deficits after brain injury—anosognosia—is increasing. One reason is a growing understanding of this multifaceted phenomenon. Another is the development and accessibility of alternative measurements that allow more detailed diagnoses. Anosognosia can adversely affect successful rehabilitation, as often patients lack confidence in the need for treatment. Planning such treatment can become a complex process full of ethical dilemmas.

To date, there is no systematic way to deal with different aspects of anosognosia rehabilitation planning. This is the first article to present a framework for ethical decision making in establishing rehabilitation plans that are focused on increasing patients' self-awareness of their own deficits after brain injury. It concentrates especially on addressing the ethical dilemmas that may arise, and describes stepwise procedures that can be applied to distinct theoretical approaches, as well as diagnostic and rehabilitation methods. To show the flexibility of the use of this framework, alternative approaches are discussed.

INTRODUCTION

Anosognosia is a broad term that signifies a lack of awareness of observed deficits following brain injury.¹ It is also described as a multifaceted phenom-

enon that can take different forms.² It can be found in any neurological deficit due to brain damage.³ Hence, a wide spectrum of methods should be available for individualized treatment planning.

Planning rehabilitation after brain damage begins with diagnosis, followed by distinguishing the scope and aims of treatment, making decisions concerning the types of treatment and methods to be used to achieve the stated goals, and planning assessment of the outcomes of treatment. Each of these steps should involve discussions with patients and possibly the patients' relatives.

Many approaches and methods have been established to achieve these goals and may be found in review articles.⁴ Therapists may choose approaches and methods that best address the patient's needs. For patients with anosognosia, however, the issue is more complex. Patients may not accept the diagnosis, understand the need for rehabilitation, or want to undertake the suggested treatment. Thus, an ethical problem of establishing the need for treatment arises. Lately, ethical decision-making models have been used to decide whether to treat a patient or not.⁵ "Should treatment be administered against the patient's will?" should be not the only question at that point; additional fundamental questions emerge, for example, "Even if patients agree to undertake a treatment when they are not motivated to do so, can treatment be as effective as it should be?" And more importantly, "What can and should therapists do in such cases?"

This is the first article to provide a framework for an ethical decision-making process in anosognosia rehabilitation planning for patients with acquired brain injury. It fills a gap in addressing the ethical issues that arise during the process of establishing rehabilitation in this population and provides clinicians with a structured, stepwise procedure for planning rehabilitation for patients who show different symptoms of anosognosia. The model is flexible, and alternative methods are described.

A FRAMEWORK FOR ETHICAL DECISION MAKING IN ESTABLISHING A TREATMENT PLAN FOR ANOSOGNOSIA

The framework for ethical decision making described here is a stepwise procedure to use in rehabilitation planning for patients with brain damage and impaired awareness of their own acquired deficits. It includes the following four steps,:

1. The therapist's theoretical background and practice framework,
2. Obtaining informed consent and establishing a therapeutic alliance,
3. Diagnosis,
4. A rehabilitation plan.

1. The Therapist's Theoretical Background and Practice Framework

1.1. Establish One's Own Clinical Practice Regarding Specific Theoretical Approaches

There is now no consensus definition for anosognosia. Theoretical approaches continue to evolve based on new empirical evidence. Several key explanations exist that make it possible to systematize knowledge and provide a basis for rehabilitation planning. It is important for clinicians to clarify their own perspective, allowing them to establish and systematize their own practice using particular approaches. Therapists should have a repertoire of theoretical approaches from which to choose, depending on the needs of the patient. Several clear-cut concepts of anosognosia are presented below.

Prigatano and Schacter suggested that impairments in self-awareness may take different forms and may have an organic, cognitive, and/or psychological bases.⁶ Lesions in specific areas of the brain may cause particular impairments in self-awareness regarding deficits. When the affected areas of the brain regenerate, full unawareness of deficits may change into partial unawareness of deficits. Depending on patients' pre-morbid personality characteristics, they engage in psychologically defensive or nondefensive strategies to deal with the consequences of their ill-

ness and current situation. Therapeutic interventions should take into account both cognitive and psychological factors to holistically address the impairment of self-awareness in a particular patient.

Vuilleumier reports that anosognosia is the result of deficits in higher order processes that integrate sensory inputs with bodily representations and action planning/abnormal motor intention.⁷ Marcel and colleagues⁸ add that anosognosia is the result of a defective process of "discovering" the loss of a function through observation or indirect means, supporting Levine's discovery theory.⁹ In other words, impaired self-awareness reflects a combination of proprioceptive mechanisms and cognitive deficits.¹⁰

The *pyramidal model of awareness* divides self-awareness into three interdependent but hierarchical levels. Applying this model to anosognosia, *intellectual awareness*, at the bottom of the pyramid, is the knowledge that there are specific deficits in one's function.¹¹ Moving up one level, *emergent awareness* enables one to monitor one's own performance and to recognize errors while executing a task. At the top of the pyramid, *anticipatory awareness* allows one to predict the occurrence of difficulties regarding specific types of tasks in the future.

The *comprehensive dynamic interaction model* is based on the concept of meta-cognition and explains the relationship between self-perception and performance of different tasks.¹² The interaction between meta-cognition and awareness is seen as dynamic. Increasing self-awareness is seen as a process of restructuring self-knowledge, in two interrelated aspects. The first aspect of self-awareness includes knowledge and on-line awareness. *Knowledge* refers to beliefs about self-efficacy that are based on previous experiences (stored in long-term memory) and one's sense of being able to effectively use one's cognitive skills when needed. *On-line awareness* refers to monitoring and self-regulation: constantly evaluating one's performance while executing tasks, and changing one's responses due to the demands of performing a specific task. The second aspect of self-awareness depends on the situation and task, and so deficits in this aspect of self-awareness may become evident in performing some tasks, but not others. Knowledge, beliefs, expectations, affective state, and on-line awareness are seen as being in constant interaction. Other factors also affect their interaction, such as fatigue and motivation.

In addition to anosognosia, *denial* is another form of unawareness that may be present in a variety of health-related diseases,¹³ and so the distinction between the two impairments should be made clear

and differentially diagnosed in each patient. In contrast to anosognosia, which has underlying neurological dysfunction, denial has psychological etiology.¹⁴ Prigatano and Klonoff describe patients' reactions that occur due to denial of illness as follows: preserved partial/implicit awareness of deficits, anger in response to feedback that indicates the impairment of particular function, and the presence of active struggle when patients perform an action that involves a deficient function.¹⁵ Patients with anosognosia lack information about themselves, are perplexed when they receive feedback that indicates a deficit, and show either willingness/indifference to feedback while performing an action that involves deficient function.¹⁶

1.2. Be Aware of One's Preferences, Specialties, and Weak Points as a Practitioner

The model presented here follows the American Psychological Association *Ethical Principles of Psychologists and Code of Conduct* (hereafter, the *APA Ethical Principles*) to conduct ethical analysis. "Principle A: Beneficence and Nonmaleficence" of the *APA Ethical Principles* states that clinicians are to benefit patients with professional treatments and avoid doing harm.¹⁷ This is especially important when clinicians provide a treatment that is intended to increase self-awareness in patients with brain injury. To provide high-quality services, clinicians should cultivate self-awareness regarding their own background and practice. Further steps for improvement as a professional include distinguishing one's own specialty and weak points as a practitioner.

1.3. Constantly Update One's Own Knowledge and Practice

Conscientious clinical practice requires therapists to take active steps toward constant self-improvement as professionals and as individuals. This conforms to "Standard 2.03: Maintaining Competence," in the *APA Ethical Principles*.¹⁸ Clinicians should review the current literature and participate in peer discussion. Actualizing their knowledge will help to update their own practice.

2. Informed Consent and Establishing a Therapeutic Alliance

Obtaining the informed consent of the patient and/or the patient's relatives is one of the first steps in the process of rehabilitation planning that may create ethical issues, especially for patients with anosognosia. Every patient has the right to be informed about the treatment proposed, to be able to make an informed choice regarding the suggested therapy.

Generally, patients may approve or reject suggested treatments based on their own cultural, religious, or socioeconomic status, or on some other individual basis. For patients with anosognosia, however, a proposed rehabilitation program may be rejected because they do not acknowledge the reason for treatment. Agreement between patients and clinicians on the course of treatment is part of establishing a therapeutic alliance, which is crucial to the success of the course and outcome of rehabilitation. It may be the basis for patients and clinicians to work together toward a set of goals.¹⁹

Therefore, the first step, before patients are asked to make a decision concerning treatment, is to evaluate their decision-making capacity. It is necessary, and a great challenge, to determine whether patients are even capable of giving informed consent. Clinicians may interview the patient or use a set of guidelines proposed by Grisso and Appelbaum to determine decision-making capacity, as follows:

1. The patient understands the given information,
2. The patient appreciates the given situation and the consequences,
3. The patient is able to reason about the treatment plan and options, and
4. The patient is able to express a choice.²⁰

Tunzi describes a strategy to evaluate patients' ability to make decisions using illustrative cases.²¹ More recently, Appelbaum elaborated on the guidelines and recommendations he made with Grisso.²² Based on the outcome of these evaluations, clinicians will learn whether the patient or a surrogate should make decisions regarding treatment. This is a part of a clinical decision-making model proposed by Jonsen, Siegler, and Winslade that is explained below.²³

2.1. When Patients Are Not Mentally Capable or Legally Competent to Make Decisions

After assessment, patients may be found to be unable to make decisions. Moreover, in rare cases, patients may be declared mentally incapable or legally incompetent by the courts. In those cases, surrogates must be chosen. Many state statutes describe how to designate a surrogate; when the courts are involved, they may appoint a surrogate. This is in line with "Principle E: Respect for People's Rights and Dignity," from the *APA Ethical Principles*, because choices concerning treatment should be made by patients or surrogates.²⁴ Beyond this, the following questions should be addressed as special, additional safeguards for patients:

1. Is this patient unwilling or unable to cooperate with medical treatment?

2. Is this patient's surrogate using appropriate standards (that is, the best interest of the patient) to make treatment decisions?

Even when a patient is not able to make decisions, a therapist must still provide substantial information about the proposed treatment to the patient and the surrogate. Then, the therapist must obtain assent from the surrogate, in accord with "Standard 3.10(b): Informed Consent," of the *APA Ethical Principles*.²⁵

2.2. Provide the Patient and Surrogate with All Pertinent Information

Prior to giving informed consent, patients should receive information about their assessment, about the nature and anticipated course of treatment, fees, the involvement of third parties, and the limits of confidentiality. Patients should also be encouraged to ask questions, and they should receive satisfying answers. This procedure addresses "Standard 9.03: Informed Consent to Assessment," and "Standard 10.01: Informed Consent to Therapy," of the *APA Ethical Principles*.²⁶

2.3. An Informed Decision Is Made by the Patient or Surrogate

After all of the parties involved (that is, the patient or surrogate and therapist) are clear on the specifics, the patient or surrogate chooses whether she or he is willing to work with the therapist and accept an initial working plan—or not.

2.3.a. The patient or surrogate consent. When consent is obtained, the therapist may continue with the working plan. The patient and his or her significant others should be enabled and encouraged to take an active role in the process of rehabilitation.

2.3.b. The patient or surrogate do not consent. After a clinician suggests the best method of treatment and, if possible, gives the patient alternatives to choose from, the patient has the right to accept or refuse proceeding with proposed methods, which might depend, for example, on religious views or cultural beliefs. Should the patient or surrogate refuse, the clinician should involve the patient or surrogate in further discussion to clarify the reasons for the decision and describe other possible methods that could be used. A clinician may choose a different method of treatment to adjust to a patient's or surrogate's preferences and expectations, and always keep in mind the goals of treatment. If consent is still not given, and the clinician does not have methods in his or her practice repertoire that are agreeable to the patient or surrogate, the clinician may choose to redirect the patient to another practi-

tioner or rehabilitation center that provides treatment methods that meet the patient's or surrogate's preferences and expectations. This conforms to "Standard 2.05: Delegation of Work to Others," in the *APA Ethical Principles*.²⁷ The therapist should assure that this situation does not negatively influence the patient in a physical or psychological way.

3. Diagnosis

3.1. Choice of Diagnostic Methods

Diagnostic methods should be chosen appropriately and individually for each patient. This addresses "Standard 9.02: Use of Assessments," in the *APA Ethical Principles*.²⁸ The following key points should be considered:

- The patient's medical condition,
- The patient's currently defined disabilities and cognitive deficits,
- The patient's currently defined intact functions,
- The patient's pre-morbid cognitive functioning,
- The patient's pre-morbid personality and psychological coping style,
- The presence and absence of persons who can provide knowledge about the patient,
- The theoretical background of the diagnostician,
- Available measures.

Anosognosia is most commonly assessed by comparing observed deficits with verbal self-reports by the patient.²⁹ Deficits are identified by a diagnostician, persons who know the patient, or both. The diagnostician observes the patient, evaluates neuropsychological test results, and consults the patient's medical history. Persons who know the patient can identify changes in her or his behavior through the comparison of the patient's current functioning with the patient's pre-morbid functioning.³⁰ To elicit a patient's verbal self-report, a structured clinical interview or questionnaire is typically used.³¹ A patient's pre-task and post-task verbal estimations of his or performance may also be used as a measure.³²

There is an alternative to a verbal report: by observing a patient perform a normal task, a clinician can estimate the number of corrections of errors and the patient's reactions (verbal and nonverbal) during and after the task as an indirect indication of the patient's impairment in self-awareness of her or his own functioning.³³ Less commonly used, VATA-m (a visual-analogue test for anosognosia for motor impairment) and VATA-l (a visual-analogue test for anosognosia for language impairment) are instruments that assess self-awareness for impairments.³⁴

Currently, a multi-modal approach to assessment of anosognosia is gaining popularity.³⁵

3.2. State the Diagnosis and Prognosis

An assessment should be finalized with a clear picture of a patient's deficits and intact functions. It is important to include the severity or phase of the impairments. Based on all of the information gathered, a prognosis should be made. The following questions should be addressed:

1. Is neuropsychological rehabilitation needed?
2. Is it the best option for this particular patient?
3. Are the deficits reversible?

3.2.a. If the answers to these questions are "yes."

A clinician then should ask, "What are the aims of rehabilitation?" A clinician should make clear the main goals and the partial steps needed to achieve the main goals. The goals should be realistic and individualized for each patient.

3.2.b. If the answers to these questions are "no."

A clinician should then ask, "What can the patient be offered?" When a patient will not benefit from treatment and/or a therapy will cause harm, the clinician should consider alternative options. Perhaps the therapy could be postponed? Or should a different type of therapy be offered, for example, family support, psychotherapy, or adjustment of the patient's environment (for example, to protect a patient with unilateral neglect—lack of awareness of one side of the body or lack of response to stimuli on one side—to prevent physical harm). This is in accord with "Principle A: Beneficence and Nonmaleficence," of the *APA Ethical Principles*.³⁶

4. The Rehabilitation Plan

The ethical considerations that arise in anosognosia rehabilitation planning are most evident in the phase after diagnosis, when a clinician develops a scope of rehabilitation to present to the patient or surrogate and to discuss it with him or her. There are three key questions to be addressed in this phase:

1. Is neuropsychological rehabilitation needed, and is it the best option for this particular patient?
2.
 - a. If the answer is "no," what should the patient be offered?
 - b. If the answer is "yes," what are the goals of rehabilitation?
3. How should these goals be achieved, taking into consideration the patient's preferences?

Developing a treatment plan is complex for patients with anosognosia. Due to a patient's symptoms, she or he may be not willing to undertake rehabilitation. Rehabilitation planning, at that point, becomes an ethical problem. There are several models for ethical clinical decision making that may be

used to plan treatment in an organized fashion and to ensure that ethical standards are followed. The following outline for developing a treatment plan for patients with anosognosia uses the *clinical ethical reasoning model* that was developed by Kaldjian, Weir, and Duffy:

1. Define the problem: The clinician identifies the cause of the dilemma. Here, for anosognosia, a neuropsychologist may suggest rehabilitation that concentrates on cognitive function, but the patient does not believe he or she needs to improve anything in his or her own functioning.
2. Gather and organize data: The clinician gathers information about the patient's case, that is:
 - a. Medical facts: The patient's condition, diagnosis, prognosis, cognitive and emotional status, decision-making ability, the benefits and burdens that may result from the recommended treatment, the probability that the goals of rehabilitation may be achieved.
 - b. Medical goals: The goals of rehabilitation.
 - c. Patient's goals and preferences: The patient's personal goals (based on his or her values and beliefs) are incorporated into the model of benefits and burdens, considering each of the options for rehabilitation.
 - d. Context: The personal status of the patient, which can influence her or his perception, preferences, and understanding of the rehabilitation options; also, the personal status of the clinician, that is, personal and professional obligations, moral standing, and socioeconomic circumstances.
3. Ask: "Is the problem ethical?" and interpret the problem in terms of whether it includes a question regarding moral values, norms, principles, *et cetera*. If the problem is of an ethical nature, examine the discrepancy in values that contributes to the problem.
4. Ask: "Is more information or dialogue needed?" Analyze the gathered data and incorporate additional information. Acquire a clear understanding of the patient's attitude toward the situation. It is important that the patient feels listened to and understood. When the patient does not convey his or her thoughts in a straightforward manner, discourse analysis might be helpful. Elaborate on ambiguous issues or new rehabilitation options, as this may resolve some of the problems. Dialog with the patient or surrogate until all of the issues are clarified.
5. Determine the best course of action, and support your position by referring to one or more sources of ethical values:

- a. Principles: Beneficence, nonmaleficence, respect for patient's autonomy, justice.
 - b. Rights: The rights of the patient as an individual and as a patient.
 - c. Consequences: Choose the best possible option in terms of the highest benefits and the lowest costs for the patient, the family, physicians, the hospital, *et cetera*.
 - d. Comparable cases: Find comparable previous cases and analyze them in terms of their resolution and the consequences of their implementation. That is, if a previous case was successful, it may be serve as a useful paradigm to follow in the current case.
 - e. Professional guidelines: Apply ethical codes of conduct.
 - f. Conscientious practice and the integrity of medical professionals: Redirect a patient to another specialist when you are not able to execute the rehabilitation plan, due to your own beliefs and moral values.
6. Confirm the adequacy and coherence of the conclusion: Check whether your conclusions are correct in terms of adequacy and coherence.³⁷

4.1. Learn from Previous Cases

If similar cases exist, review them for treatment options. If not, discuss the patient's case with colleagues, maintaining the confidentiality of the patient. A literature search may be helpful and provide appropriate treatment approaches.

4.2. Choice of Treatment Method

These considerations may be helpful in choosing a treatment approach, technique, and method:

- The patient's diagnosed cognitive and affective deficits,
- The patient's level of awareness of her or his own functioning,
- The patient's attitude toward his or her own illness and situation,
- The patient's pre-morbid personality and psychological coping style,
- The patient's intact cognitive and affective functioning,
- The theoretical background of the diagnostician,
- Available methods of rehabilitation,
- The context, that is, the personal status of the patient, which can influence his or her perception, preferences, and understanding of the rehabilitation options, as well as the personal status of the clinician, that is, his or her personal and professional obligations, moral standing, and socioeconomic circumstances.

There are several rehabilitation methods established for patients with anosognosia. These methods can be categorized using the following theoretical approaches regarding the patient's awareness of his or her own functioning:

1. Awareness as constituted of cognitive and psychological factors,
2. The pyramidal model of awareness,³⁸
3. The comprehensive dynamic interaction model,³⁹
4. Mixtures of approaches.

There are several techniques that can be used across the different approaches. Chittum and colleagues constructed individualized training packages for adult patients with brain damage.⁴⁰ They combined educational discussion with board games to teach patients about the cognitive and behavioral deficits that may follow brain damage.

Rehabilitation using a group format has been proposed by many authors. Ownsworth, McFarland, and Young described support group therapy combined with psycho-education.⁴¹ Lundqvist, Linnors, Orlenius, and Samuelsson developed a group therapy model composed of psycho-education, stress management, joint problem solving, and exercises focused on anticipating consequences.⁴² Goverover described a therapy focused on enhancing awareness and the use of strategies in activities of daily living.⁴³ Fotopoulou used exercises with third-person observation and self-evaluation, based on video recordings of the patient's performance of tasks.⁴⁴ Other rehabilitation techniques that may be incorporated into a treatment plan include: embedding, substitution, distraction, time out, natural facilitation, and the implicit recognition of deficits.⁴⁵

In addition, there are several well-established programs that incorporate different techniques aimed at the holistic improvement of patients. For example Malec, Smigielski, DePompolo, and Thompson designed the comprehensive day treatment program (CDTP).⁴⁶ The program was established within the Mayo Brain Injury Outpatient Program, which constitutes a series of community re-integrative programs.⁴⁷ The CDTP uses a group-oriented, comprehensive, integrated approach to rehabilitate patients with brain damage in post-acute stages.

4.3. Analyze Potential Treatment Options, Including Benefits and Risks

Taking into consideration possible alternatives, a clinician should analyze how each of option may benefit or possibly harm the patient. Creating a list of options, from the most to the least beneficial, may

be useful for a later discussion with the patient and significant others.

4.4. Address Outcome Measurement

The methods used in treatment should allow the reliable and valid measurement of outcomes. Do not use treatment methods that are similar to diagnostic measurements to track rehabilitation outcomes and that avoid checking practice effects.

4.5. Address Questions

Several important questions arise at this point:

- How do the chosen methods allow the patient to achieve the stated goals of treatment?
- Should psychotherapy be implemented?
- What is the probability of success?
- How can this particular patient benefit from the planned treatment?
- How can harm to this particular patient be avoided?
- What are alternative options in case of therapeutic failure?
- Are there plans and rationales in place, in case the treatment should stop?

4.6. Discuss Treatment Options with the Patient, Surrogate, and Significant Others

Therapists should take into account the patient's opinion at all times, including when deciding on a rehabilitation plan. With the patient, surrogate, and significant others (if they are involved in the process), set a final course for rehabilitation. A written plan is advisable, as it can be used to discuss progress with the patient during treatment. This approach corresponds to "Standard 10.01: Informed Consent to Therapy," in the *APA Ethical Principles*.⁴⁸

4.6.1.a. When consent is obtained. If the patient or surrogate agrees on the treatment plan, it can be implemented.

4.6.1.b. Encourage the patient to take an active part in the process of rehabilitation. During treatment, therapists should engage the patient in taking an active part in personalizing therapy and altering it due to the patient's current needs and circumstances, and to new opportunities, while keeping in mind the set goals. The therapist should track the patient's progress and discuss with him or her the outcomes of different methods.

4.6.2.a. When consent is not obtained. The patient or surrogate has the right to make a decision to end treatment at any time. It is better to discuss this before a treatment is initiated; that is why the patient or surrogate should be well informed at all stages of rehabilitation. If the patient or surrogate

does not agree to the treatment plan, treatment cannot be implemented.

On the other hand, a therapist can choose not to conduct rehabilitation for personal reasons. This is in line with "Standard 2.06: Personal Problems and Conflicts," of the *APA Ethical Principles*.⁴⁹ In addition, the therapist should closely monitor the attitudes of the patient or surrogate throughout the process of therapy. Involving the patient or surrogate in making further treatment decisions during therapy can prevent a patient from leaving therapy.

4.6.2.b. Redirect the patient to another therapist.

A clinician should prepare in advance how to support a patient, surrogate, and family should the clinician choose to redirect the patient to another clinician. It is optimal to redirect the patient to a therapist who will be suitable for the particular patient. This is in accordance with "Standard 2.05: Delegation of Work to Others," in the *APA Ethical Principles*.⁵⁰ Further recommendations may be found in section 2.3.b. of this article, above.

SUMMARY

Impairment in self-awareness is a downside for rehabilitation and turns planning for rehabilitation into a very complex process.⁵¹ In these situations, ethical decision making is indispensable. The clinical ethical decision-making model proposed by Kaldjian, Weir, and Duffy, reviewed above, represents a structured way of dealing with ethical problems in clinical settings.⁵² These authors suggest considering and weighing different rehabilitative options, in six consecutive steps.

In terms of diagnosis, anosognosia is usually considered when the patient's own ratings of functional abilities are higher than ratings by family members⁵³ and standardized neuropsychological testing.⁵⁴ A patient's ratings can be determined by several methods, including questionnaires, interviews, and pre- and post-task performance estimations. Structured interviews may be useful for patients with neglect of a half of their visual field, as it minimizes the possibility that their answers will be disturbed by the deficit. Questionnaires that include forms for different raters allow an estimation of a patient's self-awareness of deficits in comparison to his or her pre-morbid functioning (informant's rating), as well as to typical impairments in a patient's population (compared by the diagnostician). Through the use of questionnaires, anosognosia can be differentiated from other disorders, such as anosodiaphoria (indifference to the existence of a handicap) or denial.

Still, asking a patient to estimate her or his own performance prior to and after the execution of a task has its limits. It may exhibit a patient's ability to estimate his or her own abilities in general, rather than a lack of awareness of acquired deficits. Both interviews and questionnaires are verbal, which may limit their use with patients who are aphasic. When a patient has verbal deficits, nonverbal methods are advisable. Observation of a patient's behavior during a particular activity and his or her post-task reactions are then critically important. For example, in "jargon aphasia," a patient does not only verbally deny making language errors, but also does not correct them.⁵⁵ Further, some patients may deny their deficits but never initiate activity with the affected limb, or verbally admit a deficit, but act as if they are not experiencing any deficits.⁵⁶ Recently developed nonverbal measures that assess patients' self-awareness of deficits by using pictures may be helpful in such cases.

Because each of the described methods assesses a different aspect of anosognosia, a multi-modal approach is gaining popularity.⁵⁷ Ideally, the measures chosen for a particular patient should be resistant to the cognitive deficits he or she exhibits. Since no one such measure exists, the use of a set of measurements could minimize the confounding effects of cognitive deficits. Taking into account several sources of information provides an opportunity to address the issue holistically.

A common notion in psychology that is well worth considering in regard to anosognosia is that a mentally healthy person is in contact with reality and has an accurate perception of the self, but this may be applicable only to a point. As Taylor and Brown note, certain illusions are found in healthy persons (for example, viewing the self with an unrealistic optimism, viewing the self as changing for the better in the future, enhanced self-esteem or self-efficacy).⁵⁸ Such illusions may be adaptive for mental health and well-being, and may foster self-care, care for others, being happy, and engaging in productive and creative work. Ellis and Small add to this discussion by pointing out that defensive mechanisms such as denial of illness can occur without brain damage.⁵⁹ Given these observations, a clear picture of a patient's self-awareness of deficits should be established before any decisions about treatment are made. Distinctions should be made between impairments in self-awareness of deficits and pre-morbid personality characteristics. Holding certain illusions about oneself may be a psychological coping strategy in response to one's illness and current situation.

Once a diagnosis is made, a rehabilitation plan may be established that articulates major goals, as well as smaller steps to achieve those goals. Methods should be chosen that consider a patient's impairments, intact functions, predispositions, preferences, *et cetera*. The plan should be made in consultation with the patient and possibly relatives, so they may take an active part in the process. They should be made aware of their responsibilities and their importance in the success of the rehabilitation.

After informed consent is obtained from a patient or surrogate, treatment may be implemented. During the treatment, the patient and family should be kept updated on the patient's progress and attainment of rehabilitation goals so that they are informed at all steps of the therapy. The patient and possibly the family should take an active part in elaborating and individualizing the treatment as it progresses, according to the patient's needs, as well as to changing situations.

In conclusion, several key points should be kept in mind while implementing treatment for patients with anosognosia. First, ethical principles and standards must be met. This can be achieved by paying close attention to principles and standards throughout the process of rehabilitation and by addressing ethical questions at each step. Second, the patient as well as his or her significant others should take an active part in the process of rehabilitation and should be encouraged by the therapist to do so. Third, anosognosia may take different forms and should be diagnosed and treated with caution. As this is the case, a spectrum of methods should be available to the therapist, who should be well-informed about their use. Therapists should keep abreast of scientific news about this and related impairments to provide a high-quality service.

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Case and Analysis

Family Loyalty as a Cultural Obstacle to Good Care: The Case of Mrs. Indira

Shahla Siddiqui

ABSTRACT

What is the responsibility of the physician when a incapacitated patient assigns decision-making authority to a surrogate who does not act in the patient's best interest?

THE CASE

I first met Mrs. Indira when I was on consultation a number of months ago. It was the end of the day and I was annoyed when the phone rang and the junior surgeon requested that I go see a complicated patient for an anesthetic evaluation for a leg amputation. Each of these consults can take up to an hour and I was already exhausted.

The patient, Mrs. Indira, was in an isolation room due to her contagious infection—which would mean wearing protective gear (another five minutes gone!). The overwhelming stench of putrid flesh accosted me as I entered and tried to smile under my mask. She was a small, shy little Indian woman, in obvious pain, lying on her hospital bed, looking lost and worried. Her black hair belied her physiologic age, which seemed much more advanced. She smiled in a timid manner at me, recognizing me to

be a doctor. “Hi Mrs. Indira, I am here to speak to you about your operation,” I said, trying to sound cheerful. She remained silent as if she was assessing the situation and sizing up the threat. Fear was written all over her face. I had been told that she understood English perfectly, and so I didn't feel I needed a translator, however, I may have gotten it wrong. So I repeated myself, slowly, “I need to discuss with you the surgery, do you know about it?” Silence again.

I persisted, giving her my first name, my designation, my professional field, and also explaining how I had been asked to come see her. I was squirming inside and as uncomfortable about the interview as she was. I felt I needed to break the ice, and frankly I had nothing else to say, and so I rattled on. She avoided looking at me and pretended to focus on the glass of water at her bedside.

“Mrs. Indira, the surgeon has asked me to speak to you about the risk from anesthesia during your surgery. Can I please discuss this with you?” Again no response. I really wanted to tell her she was high risk: she had cardiac disease, diabetes, and renal failure. She needed an above-knee amputation from her sepsis, and she was already pretty sick. Without all this, she would surely die. She also needed to decide fairly quickly.

But yet something about her fear kept me from unloading all this on her without her active engagement. “Mrs. Indira. . .” I felt like I was addressing a stubborn school girl. “Do you want surgery?” I asked.

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“Ask my daughter,” she said softly, without looking at me directly. I had been told she had three daughters who did not visit her very frequently, as there was a wedding in the family very soon.

“I will discuss this with your family, but I need to let you know all the risks and benefits of the procedure. In the end the decision is yours,” I replied. “I, I cannot decide. You ask my daughter.” Again the silence, and then she shut her eyes as if dismissing me. That was the end of our encounter. She had made up her mind to defer her decision to her daughter, for whatever reasons, and there would be no discussion about it.

I silently left the room, puzzled and frustrated. I felt that she did have an opinion, that she was afraid, and that she wanted someone from her family, someone familiar to her, to help her cross this difficult journey with her and to guide her. And so she did what many women from the Subcontinent do, she let her fate rest with a loved one, trusting them to make a decision for her, that would be in her best interest. I was also aware that, as a mother of the bride, she didn’t want to burden her daughter at such an auspicious time by agreeing to a risky operation. Her pain and suffering was obvious, and, being educated, she probably knew that surgery was her best option, without which she might die.

I called her daughter on the phone, having documented the patient’s refusal to discuss the anesthesia risks. This daughter was the one getting married in a week’s time, and sounded busy and hassled. I introduced myself and explained why I had called. I told the high risk of the surgery, about the anesthesia, and the chance of a stormy postoperative course. I highlighted the risk of deferring surgery, as the mother might deteriorate from her sepsis.

She replied, “You know I am really busy, we have a wedding next week in the house. I cannot have the surgery done before the wedding you know, in case of complications. Who will deal with that? My mother knows all this and agrees.”

COMMENTARY

The ethical question here is, should a physician accept surrogate decision making when directed by the patient (driven by cultural or moral obligation or loyalty), and what happens when this decision is clearly not in the patient’s best interest?

Autonomous Decision Making and Family Loyalty

The influence of family loyalty on autonomous decision making has not been well explored in the literature.¹ In this case, we see a mother who is will-

ing to put up with excruciating pain for the sake of not disturbing her daughter’s wedding. Her own autonomy is tempered with feelings of responsibility (duty) towards her offspring. This self-sacrifice is not uncommon in both Western and Eastern families.² Might values such as loyalty influence autonomy to the extent that true choices are not stand-alone and unrelated? Should medical professionals take such choices at face value and disregard the nuances of such decision making? Individual independence is a cherished virtue and important in human development, but the boundaries of each individual merge at times with that of other beings and relationships. These shades of influence can affect autonomous decision making heavily.³

Individuals may have mental capacity, as my patient did, but her seemingly “unwise” choice of deferring her decision to her daughter did not stem from lack of understanding or lack of insight. It probably stemmed from a need to leave the burdensome decision of surgery to her daughter, whose plans she did not want to disturb. Her own safety and relief took a back seat to her need for loyalty and solidarity with her daughter’s happiness. In the face of such self-sacrificial behavior, what are the goals of care for the healthcare team? What of the doctor-patient relationship, which is based on a covenant of trust and the best interest of the patient?

Relational Autonomy and a Surrogate’s Responsibility

Feminist theory requires an examination of the context of the situation to come to a moral conclusion.⁴ It asks how a deed affects the person, the family, and those depending upon one another. In this case, in the mother’s mind, her decision for surgery could potentially disrupt her daughter’s happiness. But is this a misplaced belief? Could Mrs. Indira be persuaded that the surgery might result in a better outcome before the wedding, relieve her suffering, and prevent her untimely death?

If a patient willingly transfers her autonomy to a surrogate, what responsibility does the physician have to respect the decision? Does the principle of best interest dictate that the doctor override the decision and persuade the patient to undergo surgery for her own good? Is that likely the better option?

Cultural Influences

It is a challenge for physicians to balance, in a diverse society, cultural factors that influence a patient’s responses to medical issues, such as healing and suffering, in the physician-patient relationship.⁵ In this case, often a female patient from sub-

continental India, Pakistan, or Bangladesh will relinquish her decision-making rights to her family members, especially those responsible for her care and financial support.

Cultural diversity may affect the reception of “bad news,” advanced directives, and end-of-life care. Often families wish to shield patients from news of possible risks, and, at times, patients may refuse to hear such information.⁶ Is a patient exercising his or her autonomy by giving up this right?

In this case, the patient’s traditional role may have been to be docile, and she may have been accustomed to having others make important decisions for her. Should the decision that is made for her be a bad one, this cultural practice may hinder the delivery of beneficent medical care.

MALEFICENT DECISION MAKING BY FAMILY MEMBERS

Without judging the motivations behind Mrs. Indira’s daughter’s decision to defer surgery, it seems that the patient’s best interest was ignored. Mrs. Indira’s trust that her daughter would reach a feasible decision was overriding her concerns regarding her own safety. (Perhaps she thought that her daughter would defer the surgery, and she agreed with this decision, even at the expense of her own health.⁷) What is the role of a doctor in this close-knit family dynamic? Being a patient advocate, physicians at times find themselves to be in conflict with family members when a patient’s care is compromised. This usually happens when the said patient has no mental capacity.⁸ However, in cases such as this, when a patient willingly allows a family member to make a maleficent decision about her care, what steps should a physician take? Is there any legal recourse in such situations?

THE PHYSICIAN’S MORAL DILEMMA

As a result of all these factors, a physician may feel moral distress in the care of such a patient. If Mrs. Indira had left the decision to her physician, would it be easier to go ahead with surgery? Is there a conflict of values between the family and the physician? A physician may feel obliged to go along with a patient’s family (as a result of the patient’s desire to delegate the decision to surrogates), even though it may be an unwise decision. Others may feel that the “wrong” decision must be overridden, in the best interest of the patient.⁹ But performing a surgery (fraught with inherent risks) without the permission of the patient and relatives is not possible.

These frustrations can cause immense moral distress amongst clinicians.¹⁰

THE RESOLUTION OF THE CASE

The physicians tried to persuade the daughter to agree to surgery on the phone and also tried to engage the patient. However, Mrs. Indira continued to be passive and her daughter refused adamantly not to allow surgery until after the wedding. On the day before her wedding, Mrs. Indira deteriorated to the point of becoming comatose with septic shock, and her daughter finally arrived in the intensive care unit, and relented and agreed to the very high-risk amputation. The patient did not survive the operation, as her condition had become much worse and her organ failure had escalated due to the delay.

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Complexities in Caregiving: Comforts, Cultures, Countries, Conversations, and Contracts

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ABSTRACT

Providing medical care and planning for a procedure such as amputation may have different cultural contexts, based on patients' country, comfort, and contract with their physician. These contexts may create complexities for physicians as they interact with patients and caregiving relatives. Issues such as the personal choices of a caregiving relative may appear to unduly influence the decisions behind complex healthcare choices. We consider several possible scenarios in the background of the complex case presented in "Family Loyalty as a Cultural Obstacle to Good Care: The Case of Mrs. Indira," in this issue of *JCE*.¹

The patient-physician relationship dynamic sometimes evolves into a complex situation, leading to unsatisfying experiences for those who provide healthcare and those who receive it. In providing care for those who cannot make their own decisions, the involvement of a third party, such as a family member, while necessary, may introduce con-

flict, which is typical of a multipartite decision-making process. One such narrative is the case of Mrs. Indira, in this issue of *The Journal of Clinical Ethics*.² In our consideration of this case, we analyze Mrs. Indira's situation as third-party, blinded reviewers, and try to ask and answer various questions through imagined scenarios that may have led to the outcome described in the narrative. We feel that in such complex circumstances, many other factors, such as culture, country, and the clinician's role, may all add varying degrees of complexity, which may lead to incongruent decision making.

Briefly, as narrated in the article, Mrs. Indira is a presumably elderly (or middle-aged) woman, with a gangrenous foot that needs amputation. The anesthesiologist, while in the process of evaluating Mrs. Indira for a surgical decision (above/below knee amputation), was referred to a daughter by the patient, and a surrogate decision for going to immediate surgery was unduly influenced by the daughter's impending wedding. Due to postponement of the surgery, the patient developed further complications and died. The cultural influence of surrogate decision making, and a bias towards maintaining a wedding date to the peril of the patient's death, is elegantly described by the author in this article.

Both in the Eastern and the Western world, individuals and patients may make very surprising choices, sometimes in shocking contrast with the expectations of physicians. Shared decision mak-

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ing is a new concept of managerial medicine developing in Western countries, where clinicians objectively provide evidence to patients.³ Patients (and sometimes families) will make choices based on the data they receive from their careproviders. Computer algorithms and models are now being tried and deployed to facilitate their decision-making processes. The effectiveness of the algorithms and models in individual circumstances is still open to further, extensive study. Ideally, even in current practice, careproviders should objectively present data and facilitate patients' decision-making processes. Making decisions, such as evaluating the risks and benefits of amputation, the timing of the amputation, and the social events influencing the timing, present complex scenarios.

CHOOSING TO DIE RATHER THAN TO LIVE AS AN AMPUTEE

Did Mrs. Indira choose to avoid amputation deliberately, and perhaps consciously or subconsciously choose to die?

Life as an amputee is not easy. Even in Western countries—where citizens are protected by acts such as the American with Disabilities Act (ADA)—it is only in recent decades that life for disabled persons has become somewhat bearable. The ADA has ensured inclusivity for disabled individuals, with the provision of mobility-assisting devices, and the construction of many facilities that will not restrict activities of daily living. In low-middle-income countries and even in advanced economies such as Singapore, such provisions may not be taken for granted. Life as an amputee would be very challenging for an elderly person with limited resources and possibly in a strained family relationship. Thus, if Mrs. Indira lived by herself and would face serious dilemmas regarding her care in a post-amputation setting, she may have been reticent in her response to her doctor about a decision to have surgery. She may have used her daughter and her daughter's wedding as a ruse; the true, deeper reason might very well have been to avoid life as an amputee.

These reactions are not uncommon, even in Western countries. In a case report and review by Bhuvanewar and colleagues, the news of the possibility of amputation is often received by patients with a typical grief response, in which they undergo a phase of denial and depression.⁴ During this phase, patients often refuse to engage in a discussion of this possibility with their physicians. Something like this may have been the case for Mrs. Indira. Perhaps part of her response might have been bargaining: "I

am too tired; I don't want to go through the procedure." Was Mrs. Indira's citation of her daughter's impending wedding such a bargaining tool?

We have previously described common practices of surrogate decision making on behalf of Indian women.⁵ This may be especially prevalent among elderly women who are past child-rearing age. Sometimes this may be a fatalistic reaction, as in the case of Mrs. Gandhi, as described by Dewar and colleagues.⁶ A recent review covers broader cultural aspects of lifestyle and growing old among Indians.⁷

The psychological needs of a patient requiring amputation in India or South Asia has not been studied in depth. One study of amputees, focusing on males, all of them requiring amputation due to military service, reported that psychological interventions played a major role in improving depression, body image, and so on.⁸ Such interventions should be planned from the day of preparing a patient in the discussion of amputation (such as the pre-surgical evaluation stage). In the United States, in most tertiary care hospitals, this is done actively by physician-support staff—social workers and psychologist who engage the patient. This includes making a visit to the patient's home to evaluate the post-amputation readiness of the residence.

INDIRECT PHYSICIAN CONTRACTS AS IMPEDIMENTS TO ENGAGING PATIENTS

Another often overlooked, complex factor in physician-patient interaction is the nature of contracts with "third-party" physicians. In the case of Mrs. Indira, an anesthesiologist is conflicted about her role and the patient's decision-making process. Anesthesiologists engage with patients for brief periods of time (most of it is established when the patient is unconscious) to cover pre-surgical evaluation, to provide anesthesia care during the procedure, and to handle immediate post-operative recovery. Often times the direct caregiver, whom the patient identifies with as the careprovider, is the surgeon. Thus, the patient establishes a stronger, long-term, and direct contract with the direct caregiver—the surgeon. The role of the anesthesiologist is often relegated to secondary caregiving responsibilities. Brief and quick encounters with "second-degree" physicians (indirect contracts), such as anesthesiologists, often are not enough to establish the much-needed, deeper psychosocial rapport that is required to engage in dialogue and counseling towards making decisions such as amputation.

We have previously described that three physician specialties have such complex, indirect con-

tracts with patients: anesthesiologists, radiologists, and pathologists.⁹ Such indirect contracts can sometimes create certain conflicts and impediments in providing medical care. Teamwork among physicians is often required. (In the case of Mrs. Indira, this might be the surgeon and the anesthesiologist, along with a psychosocial counselor.) But this is very challenging to execute—to make optimal, congruent decisions in complex clinical situations, due to various limitations, in both Western and Eastern countries. In the case of Mrs. Indira, it led to conflicts in decision making, not only between the anesthesiologist and her patient, but also caregiving family members.

THE UNPREDICTABLE NATURE OF SUB-ACUTE AND CHRONIC HEALTH CONDITIONS

Decision making in acute settings, such as life-threatening emergencies, administration of cardiopulmonary resuscitation, or intubation, is sometimes easier than decision making for chronic health conditions. In the case of Mrs. Indira, the lack of immediate threat of complications possibly gave a false assurance to the care team, and presumably to the patient and her family members. Thus, in an alternate scenario, in which Mrs. Indira's daughter has a forthcoming wedding and her mother is involved in an acute event—such as a stroke, an accident, or a myocardial event—it might be easier to decide that an emergent surgical procedure is necessary, and it might be acceptable for events such as weddings to be postponed. However, when it is tough even for physicians to predict an outcome in a situation involving chronic illness, it is even more difficult for patients and family members to make healthcare decisions in the context of important life events such as weddings.

In an excellent review of this complex subject, Susan Watt compared two patients: Mr. Arthur, who has to make a decision about an acute health condition, and Mrs. Arthur, who has to make a decision about adjusting medication for a chronic condition.¹⁰ Interestingly, and as could be imagined also in Mrs. Indira's case, it was more difficult for Mrs. Arthur to make a decision regarding her chronic condition. Ironically, Mrs. Arthur (an imaginary patient, probably in a Western context) struggled with making a decision while planning around her niece's wedding. Watt's article nicely illustrates that making a decision about the treatment of a chronic illness (such as for Mrs. Arthur and Mrs. Indira) is more complex than it is for making decisions about an acute ill-

ness. In addition, the case of Mrs. Indira shows how personal/cultural scenarios such as weddings, as influencers of healthcare-related decisions, are not unique to Eastern cultures, but also are important factors throughout the world. It may appear that the daughter of Mrs. Indira acted with narrow and self-interested intent, but there may have been other nuances that influenced her decisions about her mother's health.

RACE, CULTURE, AND COUNTRY-OF-ORIGIN IDENTITY INFLUENCE PHYSICIAN-PATIENT RELATIONSHIPS

Comedian Russell Peters jokingly remarks that if he could choose, he would want to have a doctor who is "Black" and came from "the hood," because that doctor would be a survivor who had proved he could rise up against all odds, to become a doctor.¹¹

Consciously choosing a healthcare provider or a patient based on race and ethnicity is likely an uncommon practice. There have been some cases in which doctors have declared conflicts, and have withdrawn from providing medical care, based on faith: for example, a gynecologist who refuses to provide termination of pregnancy because he/she has pro-life beliefs.¹²

COMPLEX RACE RELATIONSHIPS ARE EXHIBITED IN SUBTLE WAYS IN COSMOPOLITAN ENVIRONMENTS

While there is absolutely no indication that a race/ethnic difference played any role in the relationship between Mrs. Indira and her treating anesthesiologist, anecdotal evidence indicates that such factors exist in similar situations. In a country such as Singapore, a very vibrant, diverse culture exists. There are conscious and unconscious biases and prejudices that exist at various levels between patients, their family members, and, less commonly, physicians.

Whether physicians exhibit such bias is less reported and possibly reflects their training and the value they ascribe to the care for human life (the Hippocratic Oath), irrespective of external factors. However, such constraints are not binding on patients. Can a conscious or unconscious bias by an Indian patient toward a Pakistani doctor in a Singaporean healthcare institution provide a substantial barrier to the establishment of a rapport, which could hinder an optimal decision-making process?

As discussed in a very recent article by Paul-Emile and colleagues in the *New England Journal of*

Medicine, patients in the U.S. may request the re-assignment of a physician (even if it is based on race!), and usually their requests are considered by the healthcare facility.¹³ Regulations facilitating or precluding such actions are hard to imagine, especially in other parts of the world. But physicians should be cognizant of such unconscious bias in the patients whom they care for, and try to accommodate their patients' bias without prejudice. This is with the moral intent of doing the right thing to heal the sick, even at the cost of hurt pride. After all, being a physician and providing care is a noble assignment.

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Law

Legal Briefing: New Penalties for Disregarding Advance Directives and Do-Not-Resuscitate Orders

Thaddeus Mason Pope

ABSTRACT

Patients in the United States have been subject to an ever-growing “avalanche” of unwanted medical treatment.¹ This is economically, ethically, and legally wrong. As one advocacy campaign puts it: “Patients should receive the medical treatments they want. Nothing less. Nothing more.”² First, unwanted medical treatment constitutes waste (and often fraud or abuse) of scarce healthcare resources. Second, it is a serious violation of patients’ autonomy and self-determination. Third, but for a few rare exceptions,³ administering unwanted medical treatment contravenes settled legal rules and principles. This “Legal Briefing” describes a central and growing role for the law. Specifically, courts and agencies have increasingly imposed penalties on healthcare providers who deliberately or negligently disregard advance directives and DNR (do-not-resuscitate) orders. I group these legal developments into the following five categories:

1. Five Types of Unwanted Medical Treatment
2. State and Federal Duties to Follow Advance Directives
3. *Doctors Hospital of Augusta v. Alicea*
4. Other Lawsuits for Ignoring Advance Directives
5. Administrative Penalties for Ignoring Advance Directives

INTRODUCTION

There is significant evidence that physicians routinely ignore patients’ preferences about life-sus-

taining treatment.⁴ Alarming, in two separate recent surveys, one-third of respondents reported that clinicians did not carry out a patient’s end-of-life wishes.⁵ Contrast another recent study of 200,000 long-term care residents in four Canadian provinces that reports a remarkably high compliance rate with DNR orders. Only one in 2,500 residents with a DNR order was resuscitated.⁶ One reason (although hardly the only reason) for this significant U.S. noncompliance is a widespread misperception among clinicians that one cannot get into legal trouble for doing “too much.”⁷ In 2013, I tried to bust this widespread myth and correct the misperception. I comprehensively collected and reviewed lawsuits and administrative sanctions to show that the risks of providing unwanted life-sustaining treatment are “not as rare, meager, and inconsequential as often depicted.”⁸

Unfortunately, clinicians continue to believe that it is “safe” to err on the side of saving or prolonging life, notwithstanding a patient’s own stated preferences.⁹ For example, in its 2015 report, *Dying in America*, the Institute of Medicine (IOM) observed that “adherence to patients’ advance directives” is negatively impacted by “concerns about malpractice liability.”¹⁰ Specifically, “physicians believe their liability risk is greater if they, mistakenly, do not attempt resuscitation than if they provide it against patient wishes.”¹¹

The IOM hastens to add that this “anxiety about being sued may not be based in fact.”¹² I want to substantiate this point. In this “Legal Briefing,” I up-

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date my research to report a persisting trend of civil and regulatory enforcement. Courts and administrative agencies have continued to impose penalties on healthcare providers who disregard advance directives and DNR orders. To be timely and relevant, I review significant legal developments from only the past 18 months.

1. FIVE TYPES OF UNWANTED MEDICAL TREATMENT

To adequately grasp the relevant context, it is useful to distinguish five relatively distinct types of unwanted medical treatment. In the first three, the treatment is probably unwanted because it has: (1) negative value—zero benefit but positive harm,¹³ (2) zero value—no benefit and no harm,¹⁴ or (3) low value—limited benefit and some harm.¹⁵ With these three, the value of the treatment is measured clinically and scientifically. In contrast, in the fourth type of unwanted treatment, (4) unknown value, the worthwhileness of the treatment is preference-sensitive. It might have high value for some and low (or no) value for others. Here, treatment is probably unwanted, not because of its limited physiological effects, but because robust survey evidence indicates that most patients would not want it. In these instances, patients never actually decided to reject the treatment, because they did not understand the risks, benefits, and alternatives. But, had the informed-consent process been adequate, patients probably would have rejected the treatment.¹⁶

The fifth type of unwanted medical treatment is materially different. In contrast to the first four types, now we really know that the treatment is unwanted. Here, patients have already explicitly and specifically (5) refused and rejected it. I focus on this type of unwanted medical treatment. I focus on cases in which two conditions are satisfied. First, patients had a DNR order or an advance directive that clearly refused and rejected a medical treatment. Second, clinicians administered that same treatment, notwithstanding the patients' prior instructions. While there are sometimes reasons to override advance directives,¹⁷ clinicians should normally follow them, especially when they are clearly applicable to patients' situations.

2. STATE AND FEDERAL DUTIES TO FOLLOW ADVANCE DIRECTIVES

Overlapping and redundant laws require clinicians to follow patients' advance directives. First, healthcare providers have been increasingly sub-

jected to civil liability for administering unwanted life-sustaining treatment.¹⁸ Many of these causes of action have been based on common law theories, including: (1) battery, (2) inadequate informed consent, (3) negligence, (4) intentional infliction of emotional distress, and (5) breach of contract. Other lawsuits have been based on statutes such as healthcare decisions acts and POLST (Physician Orders for Life-Sustaining Treatment) laws. Second, in addition to private lawsuits for money damages, care-providers have also been subjected to disciplinary and criminal sanctions for providing treatment without appropriate authorization.

Furthermore, neither this civil nor regulatory law has remained static. U.S. states continue to refine their cases, statutes, and regulations to better assure compliance with advance directives. For example, a 2017 New York State bill seeks to ensure there will be remedies in appropriate cases by adding "punishment provisions" and by specifically allowing for the "recovery of damages" for disregard of valid directives.¹⁹ In addition, the bill will prohibit careproviders from seeking and obtaining payment for such unwanted treatment.

A second 2017 New York State bill seeks to ensure that a surrogate's objection will not deter a care-provider from following the clearly expressed prior wishes of a patient.²⁰ The Family Health Care Decisions Act currently states that if a surrogate directs the provision of life-sustaining treatment, but the hospital or individual healthcare provider "does not wish to provide such treatment," then the hospital or individual careprovider nevertheless must either comply with the surrogate's decision, transfer the patient, or seek court review.²¹

While this provision is appropriate as applied to a dispute between a surrogate and a careprovider, it does not clearly or appropriately apply to a dispute between a surrogate and the patient, as evidenced by the patient's clear prior decision.²² The proposed amendment clarifies that the dispute resolutions for careprovider-surrogate conflicts do not apply when the hospital or individual healthcare provider is carrying out a patient's own prior decision.

3. DOCTORS HOSPITAL OF AUGUSTA V. ALICEA

I recently argued that precedential appellate court rulings on end-of-life treatment matters are critically important, because they often cast a large "judicial shadow" on medical care. I called these "landmark" cases. While rare, these publicly avail-

able rulings with reasons may provide much-needed guidance to clinicians and institutions.²³ In July 2016, the Supreme Court of Georgia issued just such a published and precedential ruling in a case concerning advance directive compliance: *Doctors Hospital of Augusta v. Alicea*.²⁴

Background

In November 2009, 89-year-old Bucilla Stephenson was living with her granddaughter, Jacqueline Alicea. When Stephenson completed an advance directive that month, she named Alicea her health-care agent. The advance directive specified that Alicea be “authorized to make all health-care decisions for [Stephenson], including decisions to provide, withhold, or withdraw artificial nutrition and hydration, and all other forms of health care to keep [Stephenson] alive.” The advance directive also directed, “I do not want my life to be prolonged if [among other conditions] I have an incurable and irreversible condition that will result in my death within a relatively short time.”

Stephenson’s advance directive did not specifically list or define the medical technology that she did or did not want used as part of her medical care. Yet, in addition to the written instructions, Stephenson repeatedly told her family members that “she was ready to go when the good Lord called her,” and said “when it’s my time, it’s my time, don’t prolong it.” Stephenson told Alicea specifically that “she did not want . . . to rely on a machine to have to live,” including a ventilator to breathe for her.

Hospital Admission

Stephenson completed her advance care planning documents and discussions just in time. Two years later, on 3 March 2012, she was admitted to Doctors Hospital of Augusta. She was suffering from pneumonia, sepsis, and acute renal failure. Since she lacked capacity, Alicea’s agency was activated.

Alicea was a prompt and diligent health-care agent. She provided the hospital with a copy of Stephenson’s advance directive. She verbally instructed clinicians not to administer CPR (cardiopulmonary resuscitation), intubation, or mechanical ventilation. The hospital placed a copy of the advance directive in Stephenson’s medical record, but not behind the admission tab where clinicians could more easily see and review it.

First Intubation

Two days later, on 5 March, cardio-thoracic surgeon Phillip William Catalano asked Alicea for consent to drain fluid from Stephenson’s chest cavity

through a surgical thoracentesis. Catalano had not read the advance directive or the progress notes stating there was to be no intubation without calling Alicea.²⁵ Moreover, Catalano did not mention that the surgical thoracentesis would require intubation. Alicea consented, and Catalano performed the procedure. Stephenson was later extubated and taken off the ventilator. Neither Catalano nor any other clinician told Alicea that they intubated Stephenson or put her on a ventilator.

Second Intubation

Two more days later, on 7 March, Stephenson was experiencing respiratory distress in the early morning hours. The nursing staff was concerned that she would progress to respiratory failure. Around 4 a.m., the nursing staff called Catalano at home. Again, notwithstanding the advance directive and progress notes, Catalano decided to have Stephenson intubated and put on a ventilator to prevent her from going into respiratory or cardiac arrest.

A nurse urged Catalano to call Alicea before ordering the intubation. However, he rebuffed her, saying, “I’m not going to call her at six o’clock in the morning and scare the hell out of her. I’ll wait till, you know, she wakes up and then I’m going to call her and tell her what happened.” Later, explaining his thought process, Catalano testified: “If the family does not want her on the respirator, we can just pull the tube out . . . we can always undo it.” He further explained: “I really didn’t go into any of the code/no code/do not intubate/resuscitate. Save the patient’s life first and then we’ll do whatever it takes to make the family and that patient whatever [*sic*], but we can’t undo death.”

Catalano knew that Stephenson had an advance directive. He knew that Alicea was the designated health-care agent. Yet, without contacting Alicea for permission, Catalano directed the on-duty doctor to intubate Stephenson, explaining, “I don’t want her to die.” The on-duty doctor performed the intubation, and connected Stephenson to a ventilator. No clinician tried to contact Alicea before or after the intubation. Had they consulted Alicea before the intubation as she had directed, she would not have authorized the procedure.

When Alicea’s husband stopped by the hospital later that morning to check on Stephenson, he was surprised to see her on a ventilator. He called Alicea, who was shocked by the news. He also told her that the nursing staff could not find the advance directive. Alicea left work as quickly as she could, got a copy of the advance directive from home, and headed to the hospital. It took the nursing staff 15 to

20 minutes of searching to locate the hospital's copy of the advance directive. One nurse remarked to Alicea's husband, "Boy, somebody has really messed up. I found it."

Subsequent Treatment

When she arrived at the hospital, Alicea showed the advance directive to the supervising critical care physician and told him that the hospital had failed to follow Stephenson's wishes by intubating her and placing her on a ventilator, but that "since they put her on it, they had to take care of her."

Perhaps surprisingly to some, Alicea declined to have Stephenson extubated and the ventilator removed at that point. Instead, she chose to continue treatment for Stephenson. She also consented to other procedures, including the placement of a feeding tube, a bronchoscopy to remove pus from the airway, and a tracheostomy to provide an airway and to remove lung secretions. Stephenson remained in the ICU (intensive care unit) from 7 March until 14 March. At that point, Stephenson's kidneys were shutting down. Alicea authorized the removal of Stephenson's ventilator and the provision of comfort measures only from that point forward. Stephenson died on 17 March.

Lawsuit

In May 2013, Alicea filed a lawsuit against both Doctors Hospital of Augusta and Catalano. She alleged they contravened Stephenson's advance directive and acted contrary to the specific directions of her designated healthcare agent. The complaint further alleged that subjecting Stephenson to unnecessary procedures caused her pain, suffering, and emotional distress. Alicea asserted claims for (1) breach of contract, (2) inadequate informed consent, (3) ordinary negligence, (4) battery, (5) intentional infliction of emotional distress, and (6) breach of fiduciary duty. Notably, Alicea sought not only compensatory damages but also punitive damages, because the conduct was not merely negligent, but also egregious and unconscionable.

Trial Court

In April 2014, the defendants filed a motion for summary judgment, arguing that the Georgia Advance Directive for Health Care Act provided them immunity from liability. They contended that the GADHCA broadly immunizes healthcare providers for "failure to comply" with the directives of healthcare agents. Nevertheless, in May 2014, the trial court rejected the immunity argument and denied summary judgment.

The trial court held that immunity would apply on summary judgment only if all of the evidence (seven depositions and the medical record) showed that Catalano had acted in "good faith" compliance with the advance directive.²⁶ Instead, the evidence was far more mixed. It would also (if not better) support a finding that Catalano decided all by himself what was "right for the patient" and would only later check with the agent to tell her "what happened" and see if she wanted to "undo" the procedure already ordered. In short, Catalano was not acting in good faith reliance, in "honest dependence," on any decision that Alicea had made as Stephenson's healthcare agent. He made the treatment decision himself, exercising his own medical and personal judgment.

Court of Appeals

In June 2015, the Georgia Court of Appeals affirmed the trial court's denial of summary judgment to the defendants. The appellate court agreed that genuine issues of material fact existed regarding whether the defendants made a good faith effort to rely on the agent's directions and were thus entitled to statutory immunity.²⁷ The appellate court agreed that significant evidence showed that Catalano made the patient's healthcare decisions on his own, without relying in good faith on what the patient's agent (Alicea) directed.

Supreme Court

In July 2016, the Supreme Court of Georgia affirmed both lower court decisions denying the defendants' claims of immunity. Moreover, the court made two important observations. First, the court declared that a key animating purpose of the advance directive statute was to ensure that "it is the will of the patient or her designated agent, and not the will of the health care provider, that controls."

Second, the court determined that a core principle in the statute, reflected in many provisions, is that the patient and her agent may see a "real difference between passively allowing her life to slip away and requiring a loved one to make the affirmative decision to 'pull the plug' and halt life-sustaining measures like mechanical ventilation." Indeed, while it is a familiar refrain to bioethicists that there is no legal or ethical difference between withholding and withdrawing, the emotional and psychological differences have been well documented.²⁸

When she arrived at the hospital on 7 March, Alicea did not direct that Stephenson's ventilator be withdrawn immediately. Had Catalano followed the advance directive and had Stephenson died,

Alicea “would have understood that it was her time and God took her.” Yet, deprived of the opportunity to let nature take its course, Alicea consented to the continuing treatment until 14 March. Alicea drew a distinction between (1) never placing Stephenson on a ventilator and “let[ting] nature take its course,” and (2) taking the affirmative step of removing her from the ventilator now that she was already on it. According to Alicea, she then “had to make the decision that [she] wasn’t supposed to have to make.”

On the other hand, a jury could find that Alicea failed to faithfully fulfill her duties as agent, thereby failing to mitigate damages caused by the hospital’s breach. In other words, even if the hospital was wrong to intubate Stephenson and put her on a ventilator, that would have caused only a few hours of unwanted treatment. Instead, Stephenson was on a ventilator for more than a week because of decisions that Alicea made on her behalf, which were arguably inconsistent with Stephenson’s wishes.

Back at Trial Court

While the supreme court judgment sent a loud and clear message about advance directive compliance, it had a limited impact on Alicea’s lawsuit. It ruled on only one narrow issue that was presented procedurally in just one type of motion. The supreme court remanded the case to the Richmond County Superior Court, where it began. Alicea still had to establish liability on one or more of her claims.

Moreover, the defendants could have still argued (and could even have won) immunity. Yes, the trial court, the court of appeals, and the supreme court all agreed that the defendants were not entitled to summary judgment, because the evidence indicated that there was at least a disputed issue of fact as to whether Catalano acted with good-faith reliance on a decision made by Alicea. It would be a jury’s job to assess and weigh the conflicting evidence regarding Catalano’s good faith. While it seems unlikely, a jury could find that the defendants were entitled to immunity under the GADHCA. But the case might never get that far. In February 2017, the parties were engaged in settlement negotiations.²⁹

4. OTHER LAWSUITS FOR IGNORING ADVANCE DIRECTIVES

While the Georgia Supreme Court’s decision in *Alicea v. Doctors Hospital of Augusta* is the most significant legal development from the courts, families have been litigating other lawsuits against healthcare providers for ignoring advance directives and DNR orders. Three representative cases are from Maryland, Oregon, and California.

Maryland

In June 2013, Beatrice Weisman suffered a stroke that left her in the hospital. After weeks of worsening results, her family determined that “repetitive, painful, and intrusive medical interventions only served to prolong what was otherwise becoming a decreased quality of life.”³⁰ Therefore, on 7 August 2013, Weisman’s healthcare agent completed a Maryland MOLST form indicating that she did not want clinicians to resuscitate her if she coded.

Maryland MOLST (Medical Orders for Life-Sustaining Treatment) is a portable and enduring medical order form signed by a physician, nurse practitioner, or physician’s assistant.³¹ It contains orders about CPR and other life-sustaining treatments. MOLST orders can be based either on the consent of the patient or, if the patient lacks capacity, on the patient’s surrogate.³² MOLST orders must be honored by EMS (emergency medical services) medics and healthcare personnel in all healthcare settings.

While Weisman’s family prepared the right advance care planning documentation, Weisman’s MOLST failed to protect her from unwanted treatment. Just four weeks later, on 29 August 2013, clinicians at Maryland General Hospital (now part of the University of Maryland) performed CPR despite her express DNR instructions and against her wishes. Clinicians administered chest compressions, defibrillated Weisman three times, and injected her with epinephrine. Weisman was transferred to the ICU and later discharged home.

In July 2016, Weisman’s agent sued the hospital, asserting claims for: (1) assault, (2) negligence, (3) intentional infliction of emotional distress, (4) breach of contract, (5) breach of fiduciary duty, and (6) inadequate informed consent. The complaint alleges Weisman was “severely injured by the violent process.” She suffered “painful medical intervention at the end of her life in violation of her express wishes to the contrary,” and will “spend the remainder of her life in a condition repugnant to her values and wishes as to how and when she wanted to die.”

The complaint also focuses on the financial implications of the unwanted CPR. First, the hospital “ultimately charged” Weisman for medical services that she specifically advised “she did not want or were otherwise occasioned by [hospital’s] having ignored her express wishes.” Second, Weisman’s “artificially prolonged death” is “saddling her Estate as well as her extended family with enormous financial costs and other burdens.” Her family now spends “significant time, energy and resources,” alleged to amount to “tens of thousands of dollars per month” caring for Weisman because she cannot fully

care for herself. As of February 2017, the case is in an active discovery phase, with several depositions scheduled.

Oregon

The advance treatment instructions were clear and non-ambiguous in the Stephenson (Georgia) and Weisman (Maryland) cases discussed above. Yet, clinicians in those cases administered precisely the treatment that had clearly been specifically rejected. In contrast, the advance directive in a third case from Oregon was not so clear. Consequently, it was uncertain whether the patient's agent had the necessary warrant or mandate to make the healthcare decisions that he was making on the patient's behalf.

In June 2009, 56-year-old Californian Nora Harris was diagnosed with Alzheimer's disease. She drafted an advance directive directing that she did not want nutrition and hydration in an advanced state of dementia. Harris and her husband then moved to Oregon, because it had lower healthcare costs. In 2013, Harris's husband admitted her to Fern Gardens, a memory care facility.

In 2016, Harris's husband discovered clinicians at Fern Gardens were spoon-feeding Harris, contrary to her wishes (as he understood them). He tried to have the spoon-feeding stopped, but was overruled by the Oregon ombudsman for long-term care. So, he filed a lawsuit asking the court to order Fern Gardens to stop. He argued that "there was overwhelming evidence and testimony that she wouldn't want to be spoon-fed."

On 13 July 2016, Jackson County Circuit Court Judge Patricia Crain refused to issue the injunction.³³ The judge refused to order the nursing home to stop spoon-feeding Harris because the state ombudsman's office said that not helping her eat would be a violation of state law. Importantly, Harris's advance directive addressed only artificial nutrition and hydration. The advance directive never explicitly mentioned food and fluid by mouth. Therefore, the court never reached the question of whether the facility had to honor Harris's wishes. It was simply unclear what her wishes were. She now lacked capacity to express them. And Harris's advance directive was too vague to convey whether she would want help eating in her current state.

California

A fourth case was not brought against clinicians or facilities. Yet it involves a published appellate opinion that provides helpful guidance on advance directive compliance.

In 2011, Dick Magney completed an advance healthcare directive appointing his wife, Judith, as

his agent. In 2015 Magney was hospitalized with a serious heart infection. In consultation with the attending physician, Magney and his wife concluded that further treatment would not give him an acceptable quality of life. So, they pursued a palliative care treatment plan.

However, someone reported possible caretaker abuse to Humboldt County (California) Adult Protection Services. After a brief investigation, the County APS and public guardian sought to override Magney's advance directive by removing his wife as his designated agent and compelling medical treatment. The superior court granted the county's petitions. But two weeks later, the county withdrew its petition, after Magney's family presented a more complete medical picture.

The case concerns the family's entitlement to attorney's fees for having to litigate to enforce Magney's advance directive. The California Probate Code specifically provides that, in a proceeding under the Health Care Decisions Act commenced by a person other than the agent or surrogate, "the court may in its discretion award reasonable attorney's fees" to the agent or surrogate, "if the court determines that the proceeding was commenced without any reasonable cause."³⁴ The superior court denied these fees. But the court of appeal reversed.³⁵

The court of appeal concluded that the county lacked reasonable cause to commence the proceeding because its allegations of neglect were unsubstantiated. It observed that the county made an "appallingly inadequate evidentiary showing" and even deliberately misled the trial court. Furthermore, the court concluded that the county brought the petition because it determined that further medical treatment was in Magney's best interest. The court chastised the county for losing "sight of the fact that the Health Care Decisions Law does not provide a forum to debate the wisdom of a particular individual's health care choices." Absent a showing an advance directive is invalid or terminated, its instructions are controlling.

The language in the court of appeal's opinion was so strong, the Humboldt County attorney tried to have the opinion "de-published." But in January 2017 the Supreme Court of California denied this request.³⁶

5. ADMINISTRATIVE PENALTIES FOR IGNORING ADVANCE DIRECTIVES

Just as individual clinicians have duties to honor patients' treatment refusals, most healthcare facilities also have statutory and regulatory duties under U.S. state law to honor advance directives and re-

fusals of treatment. Furthermore, while state governments oversee the licensing of nursing homes, the U.S. federal government also has a significant role, because substantial Medicare and Medicaid dollars are used to cover nursing home care and services for the elderly and disabled. The U.S. Centers for Medicare and Medicaid Services contract with the states to monitor those nursing homes that want to be eligible to provide care to Medicare and Medicaid beneficiaries.

The states, usually through their health departments or departments of human services, have the responsibility for certifying a facility's compliance or noncompliance with quality and performance standards in Medicare and Medicaid regulations. Failure to comply with these duties can lead to fines and other sanctions. Three recent enforcement actions come from Connecticut, Florida, and Wisconsin.

Connecticut

In November 2015, the Connecticut Department of Public Health fined Miller Memorial Community for administering unwanted CPR.³⁷ Miller Memorial is a skilled nursing and rehabilitation therapy facility in Meriden, Connecticut. Its 93-year-old resident was admitted after a hospitalization for acute kidney injury. Upon admission, the resident and family members had requested a DNR order. However, employees did not enter the order into the nursing home's computerized physician ordering system. On 5 June 2015, clinicians found the resident without respiration or a heartbeat. They performed CPR and called 911. Shortly thereafter, paramedics intubated the resident and transported her to the hospital where she remained on advanced life support until she died.

Florida

The Florida Agency for Healthcare Administration imposed a \$16,000 fine on Jacaranda Manor nursing home after workers resuscitated a 75-year-old resident who had a DNR order.³⁸ The resident suffered from nearly 20 medical conditions, including chronic airway obstruction, a kidney disorder, and dementia. After being resuscitated and transported, the resident was placed in an ICU and had chest tubes inserted in his lungs.³⁹

Wisconsin

The Wisconsin Department of Health imposed a fine on Rock Haven nursing home in Janesville, Wisconsin.⁴⁰ A resident with an advance directive and DNR order was found on his bedroom floor,

nonresponsive. Facility staff initiated CPR despite the resident's wishes for no CPR. They called 911, but the paramedics were unable to revive the resident.

CONCLUSION

In one famous unwanted treatment case, a court observed that "unless health care providers . . . face consequences for ignoring or failing to follow a patient's directives, the public policy favoring these directives stands to be undermined."⁴¹ In this "Legal Briefing," I have aimed to establish that the prospect for enforcement and consequences is not as dismal as often depicted. At least when an advance directive is clear and pertinent, sanctions are more severe and more frequent than is commonly thought. This is one important starting point for changing clinicians' perceptions, and, consequently, clinicians' behavior.

NOTES

1. A. Gawande, "Overkill," *New Yorker*, 11 May 2015.
2. Campaign to End Unwanted Medical Treatment, "About Us," <http://endumt.org/about-us/>.
3. There are several exceptions to the normal requirement of informed consent. But most of these (like emergency and therapeutic privilege) are still premised on the notion that the administered treatment probably would be "wanted" by the patient. Some others (like conscience-based objection) are not.
4. T.M. Pope, "Clinicians May Not Administer Life-Sustaining Treatment without Consent: Civil, Criminal, and Disciplinary Sanctions," *Journal of Health and Biomedical Law* 9, no. 2 (2013): 213-96, 221-26; D.C. Leven, "Unwanted Medical Care and Treatment—Things You Can Do to Get Only the Care and Treatment You Want and to Which You Are Entitled," *NYSBA the Senior Lawyer* 8, no. 2 (Fall/Winter 2016): 15-21.
5. D.K. Heyland et al., "The Prevalence of Medical Error Related to End-of-Life Communication in Canadian Hospitals: Results of a Multicentre Observational Study," *BMJ Quality and Safety* 25, no. 9 (2016): 671-9; F.J. Freyer, "When You Die, Will Your Wishes Be Known?" *Boston Globe*, 12 May 2016.
6. S. Perry and C. Lawand, "A Snapshot of Advance Directives in Long-Term Care: How Often Is 'Do Not Done?'" *Healthcare Quarterly* 19, no. 4 (2017): 10-2.
7. Pope, "Clinicians May Not Administer Life-Sustaining Treatment without Consent," see note 4 above, pp. 248-59.
8. *Ibid.*, 260-96.
9. R.S. Martin et al., "The Effects of Advance Care Planning Interventions on Nursing Home Residents: A Systematic Review," *Journal of the American Medical Directors Association* 17, no. 4 (2016): 284-93; C.M. Burkle et

al., "Physician Perspectives and Compliance with Patient Advance Directives: The Role External Factors Play on Physician Decision Making," *BMC Medical Ethics* 13, no. 31 (2012).

10. Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington, D.C.: National Academy Press, 2015), 133.

11. *Ibid.*

12. *Ibid.*, 323.

13. Negative value treatment entails risk and harm with no corresponding medical benefit. This is often the result of intentional fraud for profit, for example, administering chemotherapy when the patient does not even have cancer. U.S. Department of Justice, "Detroit Area Doctor Sentenced to 45 Years in Prison for Providing Medically Unnecessary Chemotherapy to Patients," 10 July 2015, <https://www.justice.gov/opa/pr/detroit-area-doctor-sentenced-45-years-prison-providing-medically-unnecessary-chemotherapy>.

14. E.g., H.G. Prigerson et al., "Chemotherapy Use, Performance Status, and Quality of Life at the End of Life," *JAMA Oncology* 1, no. 6 (2015): 778-84.

15. E.g. *Medical Board of Australia v. Siow* [2016] SAHPT 1.

16. T.M. Pope, "Certified Patient Decision Aids: Solving Persistent Problems with Informed Consent Law," *Journal of Law, Medicine and Ethics* 45, no. 1 (forthcoming 2017); T.M. Pope, "Controlling the Misuse of CPR through POLST and Certified Patient Decision Aids," *American Journal of Bioethics* 17, no. 2 (2017): 35-7.

17. C.R. Bruce et al., "Navigating Ethical Conflicts Between Advance Directives and Surrogate Decision-Makers' Interpretations of Patient Wishes," *Chest* 149, no. 2 (2016): 562-7; E.K. Vig et al., "Responding to Surrogate Requests that Seem Inconsistent with a Patient's Living Will," *Pain and Symptom Management* 42, no. 5 (2011): 777-82.

18. See Pope, "Clinicians May Not Administer Life-Sustaining Treatment without Consent," note 4 above.

19. *N.Y. A.B.* 4274 (2017) (Gottfried).

20. Surrogates cannot update or amend a patient's advance directive. But when an advance directive is unclear or not clearly applicable to the present circumstances, the surrogate has discretion to interpret it.

21. *N.Y. Pub. Health L.* § 2994-f.

22. *N.Y. A.B.* 4019 (2017) (Pretlow).

23. G. Bosslet, M. Baker, and T.M. Pope, "Reason-Giving and Medical Futility: Contrasting Legal and Social Discourse in the United States with the United Kingdom and Ontario, Canada," *Chest* 150, no. 3 (2016): 714-21.

24. *Doctors Hospital of Augusta v. Alicea*, 788 S.E.2d 392, 299 Ga. 315 (2016).

25. Clinicians have a duty to check the chart for consent just as they have a duty to check the chart for contraindications to medications. E.g. *Parsons v. Northwestern Memorial Hospital and Northwestern Hospital Faculty Foundation*, 27 *Nat. J.V.R.A.* 5:C4, 2011 WL 10550300 (Cook County Judicial Circuit, Illinois 6 July 2011) (\$5 million jury verdict).

26. *Ga. Code Ann.* § 31-32-10.

27. *Doctors Hospital of Augusta v. Alicea*, 774 S.E.2d 114, 332 Ga. App. 529 (2015).

28. G.S. Chung et al., "U.S. Physicians' Opinions on Differences Between Withholding and Withdrawing Life-sustaining Treatment," *Journal of Religion and Health* 55, no. 5 (2016): 1596-606; M. Solomon et al., "Decisions Near the End of Life: Professional Views on Life-sustaining Treatment," *American Journal of Public Health* 83, no. 1 (1993): 14-23.

29. *Alicea v. Doctors Hospital of Augusta*, No. 2013-RCCV-00275 (Richmond County Superior Court, Georgia 13 February 2017) (offer of settlement).

30. *Weisman v. Maryland General*, No. 24-C-16-004199 (Baltimore County Circuit Court, Maryland 25 July 2016) (complaint).

31. "Maryland MOLST," <http://marylandmolst.org/index.html>.

32. *Code of Maryland Regulations* § 10.01.21.04.

33. *In re Harris*, No. 13-017-G6 (Jackson County Circuit Court, Oregon 13 July 2016) (order).

34. *Cal. Probate Code* § 4771.

35. *Humboldt County Adult Protective Services v. Superior Court*, 4 Cal. App. 5th 548, 208 Cal. Rptr. 3d 666 (2016).

36. *Humboldt County v. Superior Court*, No. S239048 (Cal. 25 Jan. 2017).

37. K. Farrish, "5 Connecticut Nursing Homes Fined Following Two Deaths, Lapses in Care," *New Haven Register*, 12 January 2016, <http://www.nhregister.com/article/NH/20160112/NEWS/160119858>; Centers for Medicare and Medicaid Services, "Inspection Report," 22 October 2015, <https://www.medicare.gov/nursinghomecompare>.

38. "State Fines St. Petersburg Nursing Home for Violating Resident's Do-Not-Resuscitate Order," *Tampa Bay Times*, 4 June 2014.

39. *Florida Agency for Healthcare Administration v. St. Petersburg Nursing Home LLC*, No. AHCA 2014-003053 (3 June 2014), <http://thaddeuspope.com/images/5407169.pdf>.

40. C.W. Idzerda, "County Nursing Home Rock Haven Moves Forward after State Violations," *Gazette Xtra*, 17 January 2016; Centers for Medicare and Medicaid Services, "Inspection Report," 7 April 2015, <https://www.medicare.gov/nursinghomecompare>.

41. *Anderson v. St. Francis-St. George Hospital*, No. C-930819, 1995 WL 109128, at *4 (Ohio Ct. App. 15 Mar. 1995).

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