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*At the Bedside*

# Harmful Emotional Responses that Patients and Physicians May Have When their Values Conflict

*Edmund G. Howe*

## ABSTRACT

One of the most difficult decisions a clinician may face is when, if ever, to decline what a patient wants, based on the clinician's own moral conscience. Regardless of what the clinician decides, the outcome may be deeply emotionally painful for both parties, and the pain may last. I will discuss this pain, how it occurs, and what we can do to try to reduce it before, during, and after a conflict arises. Approaches include explaining how we are like the patient or doctor, that no one is perfect, and that what we *do* is not who we *are*.

In this issue of *The Journal of Clinical Ethics*, several authors discuss the extent to which doctors should give their individual moral values priority over the moral values of patients or patients' family members, and, if doctors should do this, how they should do it. The articles focus particularly on the opinion that the American Medical Association's Council on Ethical and Judicial Affairs (CEJA) has written on these questions.<sup>1</sup>

The AMA opinion suggests that physicians continue to do as they have been doing, and continue

to do now; that is, physicians should act in accordance with their deepest moral beliefs. If they do this, however, they should continue to inform patients and their families about the services they could expect to receive, but which their doctor won't provide, because of their doctor's individual moral beliefs. The doctor may refer patients to other care-providers, but, if doing this would compromise the doctor's moral convictions, the doctor still must tell patients how they can gain access to these services.

The latter two alternatives are especially controversial. Udo Schuklenk states in "Accommodating Conscientious Objection in Medicine—Private Ideological Convictions Must Not Trump Professional Obligations," in this issue of *JCE*, for example, "If you believe that abortion is akin to murder, it does not quite amount to a reasonable compromise that you should be obliged to pass a pregnant woman on to a colleague whom you know will commit what you consider a murderous act."<sup>2</sup>

BJ Crigger explains in "Thinking about Conscience," also in this issue of *JCE*, that controversies arose while the members of CEJA wrote the opinion.<sup>3</sup> She states that it can be expected, therefore, that many readers may disagree with it.

Indeed, this is the case. Schuklenk is a leading example. He asserts, for instance, that unjustifiable harm will result when physicians assign priority to their individual moral consciences. This, he says, would "subject eligible patients seeking help from a medical professional, *qua* professional, to the va-

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garies of this professional's idiosyncratic views of the universe." Schuklenk gives a chilling example of a harm he believes illustrates his contention: today in Italy, he asserts, "about 70 percent of gynecologists conscientiously object to performing abortion." He says that "this is arguably a major factor in the staggeringly high back street abortion rates in that Roman Catholic country."<sup>4</sup>

Schuklenk asserts further that the harm that can be brought about when physicians refuse to treat reflects a moral error on the part of the AMA. He cites Robert Baker, whom he regards as the "United States' pre-eminent historian of medical ethics." Baker, Schuklenk states, sees the AMA as an organization that "abdicated its role as moral conscience of the profession."

In the future, the AMA opinion might draw a distinction between objections that are religiously based and those that are morally based. In other contexts, this has led to discussion of whether a physician's religious views are "main stream" or are idiosyncratic.

Perhaps, in some instances, objections based on conscience shouldn't be accorded moral weight, an outcome that Schuklenk would favor. An example is patients who want to change their gender. Some physicians will not treat these patients, based on the physicians' moral and/or religious beliefs. To not treat them, however, may be as deeply problematic as not treating patients based on their gender, sexual preference, or ethnicity.

An important question any refusal to treat raises is: How this will affect the patient? It may be that, due to the risk of harm that such a refusal may cause, doctors who know that they will face such conflicts could choose, far in advance, to not enter fields where these problems will arise.

The present practice of physicians' refusing to treat, based on their own moral consciences, may not change in the near future. This is especially likely under the new AMA opinion. Still, there may be ways for physicians to better accommodate patients' decisions regarding treatment, based on physicians' own moral views, than they do now.

Physicians could initially regard their patients' values as having a moral weight that is similar to, or equal to, their own. As Martha Nussbaum wrote, following John Rawls: "The reasonable citizen does not try to enforce her own comprehensive doctrine through law, out of recognition of the burdens of judgment and a related respect for her fellow citizens."<sup>5</sup> Doing as Nussbaum suggests may reduce the burdens that acting unilaterally may bring. She notes that it might be reasonably expected that people will

differ on important life matters and values; because of this, a Rawlsian social justice perspective, a spirit of mutual respect, would suggest that it is most reasonable for those whose views are in disagreement to propose "fair terms of cooperation."<sup>6</sup> Doctors who pursue maximally reconciliatory and accommodating ends may further three important values: treating patients with greater respect, reducing harm to themselves, and interacting with greater equality.

Patients and doctors who experience the moral impasses described in the AMA opinion may experience emotional or moral burdens as a result. Whether physicians decide to follow their own consciences or the moral views of their patients, there may be harmful, long term effects for patients and physicians. The most harmful emotional response patients and physicians may experience is shame: painful self-consciousness about inferiority, failure, and defeat.<sup>7</sup> Shame can be psychologically toxic<sup>8</sup> because it reduces self-esteem, and those who feel shamed may lose their capacity to enjoy life, sometimes for many years. Anthropologist Ashwin Budden states, "clinical theorists acknowledge that, in practice, shame is often difficult to detect, . . . because it gets buried in tendencies to withdraw, in language styles, and in distortions of memory, only to resurface in clinical symptoms, maladaptive behaviors, and somatic distress."<sup>9</sup>

The risk that shame will be hidden, remain buried, and then express itself in tendencies to withdraw are of special importance to this discussion. During moral disagreements on the ward between patients and doctors, for example, both may experience shame and then express it by withdrawing. They may then distance themselves from each other. If this distancing occurs during their initial discussions, it may prevent the parties from being able to share in decision making.

Many of us have witnessed or experienced extreme examples of this effect. I have written in these *JCE* pages, for example, of family members blocking the door to a patient's room or surrounding the patient's bed to protect the patient from clinicians, and of a grandmother who threw herself over her grandson's body to protect him from clinicians whom she knew had different moral views than her own. These examples represent patients' loved ones responding primarily with anger. In these instances, the greatest harm to them may be feelings of being isolated and alone. These memories may persist, and haunt them.

In light of the potential for these very bad outcomes, we might ask the following two questions: Should physicians give priority to their own moral

values? If they should, how should they go about doing this?<sup>10</sup> I will not provide answers, but rather will describe the most serious possible emotional harms to which patients and physicians may be exposed. I will suggest some ways in which other clinicians who observe these emerging negative effects may, both during the conflict and after, try to help.

Fortunately, we have clues as to how to best approach the challenging task of intervening that may help conflicting parties, or at least reduce some of the tension. Terri Traudt, Joan Liaschenko, and Cynthia Peden-McAlpine, in their article "Moral Agency, Moral Imagination, and Moral Community: Antidotes to Moral Distress," in this issue of *JCE*, present approaches that nurses in the intensive care unit (ICU) have used when they encounter moral disputes.<sup>11</sup> In this remarkable study, nurses report that they do not feel the degree of moral distress that might be expected, and most importantly for our purposes here, they describe why and how. Thus, in this article, I will discuss the shame that moral conflicts may engender and some approaches we may take to reduce incidents of shame for patients and doctors, on the wards and after.

### SHAME CAUSED BY MORAL INJURY

Moral injury may come about when our doing what is right is blocked by a person in authority (or by ourselves) in a high-stakes situation. The moral injury may create feelings of guilt, shame, and/or anger, and may result in "numbing."<sup>12</sup> This numbing may occur when patients and doctors reach a moral impasse that triggers doctors to make the kinds of decisions the AMA opinion considers. The increased distance between doctors and patients caused by this numbing may harm both of them, in the short run and in the long run.

In the short run it may prevent them from reaching an agreement, or at least from being able to maintain mutual respect and to genuinely care about each other. In the long run, it may dampen their capacity to experience joy in their lives. Of the emotions guilt, shame, and anger, it is shame that may be, by far, the most destructive.<sup>13</sup> For example, Bruce Bower notes, shame may "render individuals especially prone to moving from suicidal thoughts to actions" due to "self-hate triggered by extremely distressing experiences."<sup>14</sup> In their research on guilt and shame, Toni Schmader and Brian Lickel found that shame may cause persons to feel "ashamed," "humiliated," "disgraced," and "embarrassed."<sup>15</sup> Practically, shame exists when people feel bad about what they or others have done and then believe that this reflects

badly on what kind of persons they are. As experts in this area, Ulrich Orth, Matthia Berking, and Simone Berkhardt found, shame involves a "negative evaluation of a central aspect of the self. . . ."<sup>16</sup> "The self-esteem system," they continue, "reacts with a significant drop. . . ."<sup>17</sup> Schmader and Lickel state, more simply, that persons who feel shame feel that they are "somehow flawed."<sup>18</sup> Jonathan Shay states that when persons feel less good about themselves, it may "deteriorate" their "character."<sup>19</sup> People who experience shame infer that what they *did* (or that another did) reveals some immutable truth about who they *are*, at their core. This belief, as I shall explain, is always mistaken, and such erroneous inferences are sources of shame that we may be able to help others undo.

When we recognize the emergence of shame (or its existence after it occurs) we may be able to beneficially intervene. As noted above, persons may withdraw when they feel shame. Schmader and Lickel found that feelings of shame may predict "avoidance motivations . . . not . . . aimed at solving intergroup conflicts."<sup>20</sup> More than anything, then, we may be able to help prevent such avoidance and distancing from occurring, and, by doing this, allow patients and doctors, *together*, to have better results.

### HOW SHAME MAY OCCUR WHEN MORAL CONFLICTS ARISE

Several harms may affect patients and doctors when a moral conflict arises. These harms may differ, and differ substantially, depending on whether doctors follow their own moral views, as the AMA opinion allows, or they deny their own moral views and go along with the views of their patients. In either case, patients and physicians may feel shame and be gravely harmed.

I will first discuss the shame that may occur when doctors adhere to their own values and do not assist patients in the ways that patients want. I will then discuss the harms that may ensue when doctors go against their own values to assist their patients. As a paradigmatic example of a moral conflict, I will use an example presented several years ago in *JCE*, in which the authors stated their belief that obstetricians should not attend planned home births, because they see home births as posing additional and unnecessary risks to infants.<sup>21</sup> This conflict illustrates the negative outcomes that may arise when there is an irreconcilable conflict in doctors' and patients' moral beliefs.

Moral conflicts like this are not uncommon, and it is not uncommon that they remain unresolved. In

this issue of *JCE*, Thaddeus Mason Pope and Kristin Kemmerling write, in “Legal Briefing: Stopping Non-beneficial Life-Sustaining Treatment Without Consent,” that these kinds of conflicts remain intractable to intensive communication and mediation in approximately 5 percent of disputes regarding medical futility.<sup>22</sup> Pope and Kemmerling discuss a law that was introduced in Virginia, but was not passed, which would have given a physician who holds moral views that are intractably different than the patient’s 14 days to find another doctor to comply with the patient’s request. A physician who could not do this in the allotted time could then impose his or her moral views on the patient. It is well worth imagining the pain that patients and loved ones would experience at this point.

That a physician would be given discretion not only in what she or he would choose, but also in finding another physician, illustrates how wide the gap may become between doctors’ and patients’ capacities to enact their moral views. It may suggest too the need for the AMA and other medical bodies to adopt more robust *limitations* in their guidelines to enhance uniformity in the U.S. states.

What might such limitations be? One is the extent to which patients and doctors have an existing relationship. Later in this article, I will consider the example of an obstetrician who is opposed to home delivery who is meeting with a pregnant woman for the first time. At the other extreme is the example of a doctor who has cared for a patient for some time and suddenly learns that the patient, who has come to be placed on a respirator, wants to discontinue it, knowing he or she will die, and the doctor objects to the discontinuation. In this second instance, the doctor could apologize to the patient for not having foreseen earlier that this situation could occur (if foreseeing it was possible), and then help the patient find another “route,” one that might help the doctor avoid feeling morally complicit—a risk that Schuklenk has said that should, ideally, be avoided.

A further possible limit might be whether we should give different ethical weights to religious versus moral objections. The question would then arise whether a physician’s religious objection is idiosyncratic; but even if a religious belief is “mainstream,” some stances may remain unjustifiable, for example, refusing to treat a patient who wants to change gender.

A final consideration is whether the nature of doctors’ specialties should make a difference, for example, psychotherapists. In these cases, therapists’ moral objections may exceptionally affect and impair the care they provide their patients.

An underlying question in all of these examples is the extent to which all careproviders are capable of changing their moral views. A well-known way to change a negative bias, for example, is to personally get to know those against whom one has a bias. This may work well for therapists, for example. This raises another question for clinicians: when they don’t know whether they can change their moral views, should they have their patients choose whether they would want to see another physician, or wait to see whether they, themselves, can change? The answer may depend on the extent to which the physicians’ incompatible moral view is “reasonable” or not.

### **Harms to Patients and Doctors When Doctors Follow the AMA Opinion**

*Harms to patients.* Many of the harms that arise when a doctor refuses to give a patient a treatment the patient wants are self-evident. As Schuklenk relates, women who are unable to find a doctor to perform an abortion may seek out an unsafe back street abortion. Another example would be that of a mother who chooses to deliver her infant at home without assistance and whose baby is then born with severe complications that would not have occurred if she had chosen a hospital delivery, assisted by her obstetrician. This could occur because, for instance, there are complications that arise during the birthing process that obstetricians using equipment available only in a hospital can treat, but could not treat with the more-limited equipment they could bring to a patient’s home. Frank A. Chervenak and colleagues state, for example, that this is the main concern that underlies their opposition to attended planned home births.<sup>23</sup>

The last case is a “worst-case” example, as the mother’s emotional pain may be greatly increased knowing she went against the advice of her obstetrician. Perhaps she disagreed with her obstetrician’s assessment that delivery at home posed greater risks than a hospital delivery. She might have disagreed on empirical grounds, believing that the risks posed by a hospital birth should be the only value at stake. She might feel profound regret that she had heard her obstetrician’s advice and disregarded it.

Even when infants who are born at home do not experience problems, however, mothers (and fathers) who go against their doctor’s advice may be affected by what the doctor said and did, as the doctor informed the parents, at least implicitly, that their decision to not deliver in the hospital was (in the doctor’s view) morally wrong. Most of us believe that doctors commonly choose to enter medicine to help

others. These parents would also know that their doctor refused to help deliver their infant in a way that the doctor could have agreed to help. The parents would know, then, too, that their doctor refused to help when she or he could have agreed to help, even though the doctor knew that, in this instance, his or her refusal *could result in very serious harm to the infant*. And that this possible harm could have been prevented if the doctor had been willing to help deliver at home.

Given this, the parents' response may primarily be anger. This anger may in part, however, be due to their unconscious need to protect themselves from the more devastating feelings of self-doubt and shame that may result from knowing they willingly chose to go against their obstetrician's advice.

The parents may ever after doubt their capacity to make the best choices for their child, although they may have believed that they could do this before. This new self-doubt is the essence of shame. Said simply, the parents may lose respect for themselves and even feel self-loathing. Their self-doubt may cause them to place less value on what they want for their child, and themselves, in the future.

Such negative effects may underlie some points made in the articles in this issue of *JCE*. Schuklenk provides one excellent example:

I have taught bioethics for a number of years in a large health sciences faculty. Invariably, among the dentistry students in any given year, there were a fair number of students who explained their choice of profession with their moral objections to abortion. However, *many also did consider it unprofessional to burden future patients with their personal convictions on this subject matter.*" (Emphasis added.)

Armand H. Matheny Antommara offers a second example in "Conscientious Objection: Widening the Temporal and Organizational Horizons," in this issue of *JCE*:

Within this frame, the AMA opinion neglects the issue of physicians explaining the basis of their objections to patients. While discussing the basis may facilitate the mutual sharing of perspectives, some patients have objected to their physicians raising this issue or the way they presented it. One patient, for example, described her physician as launching into a lecture about her need to rethink things after having asked him to prescribe birth control pills.<sup>24</sup>

Doctors may make moral judgments like this and communicate that they believe that patients or par-

ents are making less-than-optimal moral judgments. If they do not say this explicitly, they may imply it. They may even state this knowingly, in the hope of convincing parents or patients to comply with what the doctors believe is morally right. An example is that of a couple who had given birth to an infant with Tay-Sachs disease, and the child, just a few years later, was dying.<sup>25</sup> (Infantile Tay-Sachs is a rare genetic disorder that causes progressive deterioration of nerve cells and usually death by the age of four or five.) At every oral feeding the child was at risk of aspirating food into his lungs and then painfully coughing and quite possibly dying from a fatal lung infection. As it was, he coughed from saliva going into his lungs often while eating. The question arose whether he should have a feeding tube inserted, which would have allowed him to live a little longer, but, at the same time, in his doctor's view, would prolong his suffering.

The boy's parents wanted to have a feeding tube inserted to allow their son to live longer. The child's doctor told them that wanting this was selfish. In response, they changed their minds. They decided to let their child die, and reported that the doctor's telling them they were selfish was a critical factor in persuading them. (This may raise the general question of whether doctors should tell others that they are selfish. For example, obstetricians who are unwilling to attend planned home births might say this to parents who are considering it—that the parents are acting selfishly. If they do say this, they should "soften" it and place it in context by adding that they could imagine, if they were in the parents' position, that they might want what the parents want. If the doctors do say this, it must be genuine. Yet, it might be preferable, or even ethically mandatory, to say nothing like this at all.)

The answer to this question has been and presumably should be "no," even though, and despite the fact that saying this could, as in the above case, possibly enhance parents' and patients' autonomy. Why might this not be best approach and not be justifiable? A first reason is, of course, that the doctor's judgment may be wrong. Accordingly, parents and patients may respond with rage, although the parents in this case did not. A second reason—the one I am emphasizing—is based more on the emotional vulnerability of parents, patients, and most, if not all of us: our emotional vulnerability to feeling shame may not, in the vast majority of cases, "allow" it.

This risk to persons, as to these parents, may be increased due to the fears and doubts they already have. Their feelings may already be emotionally

“primed” to being harmed. They then may be exceptionally vulnerable to shame. I am reminded of this vulnerability in regard to research performed by Stanley Milgram in the early 1960s.<sup>26</sup> In the research, an authority figure told research participants, who had been brought in off the street, to administer increasingly painful shocks to a person sitting in a chair, when that person gave the wrong answer on a test. (The seated person was an actor who did not actually receive the intended shocks, but who did flail and scream when the research participants turned up a dial and pushed a button.) Milgram met with me and other medical students in the early 1960s. He pled with us to take to heart what his findings conveyed. He implored us, based on his findings, to never unthinkingly do harm just because we were told to do so by an authority.

The irony (to me, a very sad one) is that, based on this research, Milgram was later seen by many as morally flawed, when he had sought just the opposite. The reason for this later judgment is critical to our present concerns: that is, the research participants later indicated that they had gained self-knowledge from the experiment, namely that their capacity to harm another was much greater than they had known. Milgram came to be criticized for having changed the research participants’ views of themselves without having forewarned them that this might occur. The research participants might forever experience shame, as a result. The feeling that they were less moral than they thought might be like the implicit feedback that parents might infer from their obstetrician’s refusal to assist in their planned home birth. That awareness might be with them and haunt them for the rest of their lives.

*Harms to physicians.* Doctors who decide to go against a patient’s wishes may be harmed as well. An example to illustrate this could again be obstetricians who say that they won’t participate in planned home births. They may say this because doing so would pose, in their view, unnecessary and avoidable risks to a baby. Parents who want their doctor to attend a home birth may differ in how they interpret the studies regarding the relative risks to infants, and/or they may see other values as warranting some moral weight.

Obstetricians who feel they must turn down parents’ requests may feel moral distress, especially if they came into medicine to help people. They would not be helping others, in the parents’ view. These obstetricians might believe they will help more babies, overall, by furthering the degree to which parents agree to deliver their baby in a hospital. But these parents, rather than appreciating the

obstetrician’s viewpoint, might only feel (and express) their wrath. The doctors might feel shame because they did not succeed in convincing the parents to deliver in the hospital. Doctors often are—and should be—perfectionists in their work. Having this need is essential when they “work up” and treat patients. It may be necessary to save lives. But this tendency may extend too far. When it does, doctors may have unrealistic expectations that they can succeed perfectly. This erroneous belief is a flawed cognition that is most likely to result in persons coming to feel shame. They may also feel shame, believing that their colleagues will judge them, or even that they will be sued.

What might be the outcome of doctors’ feeling they have failed? They may feel shame, and this shame may be “primed” by their feelings of fear. The obstetricians, like the parents, may defend themselves against their feelings of fear, consciously or unconsciously. In turn, the doctors may feel only anger toward the parents, and blame them, and their anger and blame may be, in part, their minds defending them from feeling shame. During ongoing discussions, these responses may make the doctors more rigid, and, over the longer run, make them more distant. Thus, their responses of shame may harm both patients and doctors. As we shall see, ICU nurses and other careproviders may be able to help doctors and patients avoid this.

### **Harms to Patients and Doctors, Even When Doctors Go Along with What Patients Want**

*Harms to patients.* Using this same example, if parents deliver at home and their baby is harmed because they did, the parents may feel profound regret. Further, even when their baby is fine, if parents know their obstetrician disagreed with their choice to birth at home, they may feel new and unprecedented self-doubt regarding their capacity to make moral judgments regarding their child. On the other hand, if their physician attends the planned home birth, the parents still may be harmed. Knowing that their doctor has agreed to help, against his or her own values, the parents may still experience new self-doubt. More than this, perhaps, the physician may feel guilt and anger toward the parents. The physician may even feel shame. The physician may, as discussed previously, then become distant. This distancing may harm the parents more than it does the doctor. The doctor may, for instance, withdraw due to feeling shame and then dread further interactions with the parents.

A recent study reports the frightening possible adverse effects of this kind of distancing on some

patients.<sup>27</sup> In this study, psychiatrists' charts were reviewed to see whether there were signs suggesting that doctors were distancing themselves from their patients. A positive correlation was found between doctors' write-ups that indicated signs of distancing and the likelihood that a patient would end his or her life. This study dramatically and sadly shows the possible increase in negative outcomes when doctors distance themselves. If physicians feel shame, the risk that they will knowingly or unknowingly distance themselves increases. It is patients who will most likely suffer when this happens.

*Harms to physicians.* When values conflict, doctors may choose not to act on their own beliefs. They may do this primarily to not impose on patients the negative outcomes that could occur. Obstetricians might attend planned home births for this reason, for example, even though they oppose home delivery. They might do this to decrease the risk to a newborn, even though the obstetricians feel that it is morally wrong for parents to allow such risk to their baby. Obstetricians could also attend home births, despite having opposing views, because they want more than anything to preserve the patient/physician relationship. They might realize—and realize rightly—that this end, especially over the long run, is more important than any other.

To illustrate the costs to physicians' emotions that such a decision may bring about, I will go somewhat "far afield" to discuss a conflict that parents of children who are subjected to bullying at school may undergo. The parents may believe that they have no choice but to report the bullying to the school authorities, but their child may plead with them not to report it. Parents who are placed in this bind may find it excruciating. If the parents do not report the bullying, it may continue, whereas if they do report it, their child may lose trust in them.<sup>28</sup> This example may mirror, in an important way, the moral bind that physicians find themselves in when they have to decide whether or not to follow their own moral views. If, for example, they go along with the views of parents or patients, when those views conflict with their own, the feeling that they are doing wrong may not "go away."<sup>29</sup>

Physicians in these circumstances may feel resentment, and they may feel numb and distance themselves from the patient. This may be very harmful to the patient; as noted above, distancing has been found to be a risk for suicidal patients. Clinicians' moral struggles in treating suicidal patients may be much like parents' struggles when they must decide whether to report that their child has been bullied. Clinicians who treat suicidal patients may have to

decide whether to hospitalize a suicidal patient involuntarily. The responses of suicidal patients are complex. They (like most or even all of us) may be more emotionally vulnerable than we suspect.

This is illustrated by a fellow physician and friend who gave me permission to tell her story. In fact, she urged me to do this so others might know what occurred with her, and how it could occur with others. She was taking a medication that was well known for producing a "suicidal side-effect." She suddenly noticed that she felt suicidal. She knew that this was a side-effect and sought help. The doctor whom she saw did, she said, "everything right." She told him that she was quite sure she wouldn't take her life, but even as she said that, she felt that she would. She said she knew it, but to succeed in taking her life, she couldn't tell the doctor about it. She felt driven to take her life and to lie to him, even though, especially as a doctor, she knew that her feeling suicidal was nothing more than a side-effect, and thus, if she could stay alive for long enough, the side-effect would go away. Thankfully, she did not take her life.

But her experience shows why clinicians who care for these patients may feel in such a bind when a patient doesn't want to be admitted to the hospital. The angst of physicians in this situation is, in some ways, akin to that of obstetricians who try to decide whether to attend a planned home birth. They may feel highly conflicted and feel angst, regardless of which way they choose. They may have no escape from feeling shame because, no matter what they choose, they may erroneously believe that somehow they should have been able to do better.

It is no wonder that two highly renowned psychiatrists, John Maltzberger and Dan Buie, refer to what clinicians may feel toward some suicidal patients as "counter transference hate."<sup>30</sup> This feeling is not, of course, what the clinicians would want to feel or believe that they should feel. Doctors who have individual moral beliefs that strongly clash with their patients' moral beliefs may feel that they are in a similar bind. They may feel shame, distance, and dread, regardless of what they choose to do.

Given this, what might be an optimal approach for physicians to take when they first meet a patient with whom they anticipate they may have a moral conflict? Here is a generic example. A physician might say, "Good morning Ms Alfred, I am Robert Jones. It is a pleasure to meet you. I am taking the opportunity to meet and talk with you this morning, as I do with all new patients, to introduce myself and to say, briefly, a few things about myself and my practice. My approach may or may not be

different than what you've experienced, but I hope you will feel at ease and comfortable. I want you to know that although I am speaking first this morning, this is most likely the only time that the conversation will be about me, unless you ask a direct question. Okay, I assume that since I practice [XXXX], that you are here for that reason?"

After Ms Alfred responds, the doctor could say: "The relationship that I have with you is most important to me. I hope it is a relationship we will build together, based on trust and open conversation. This is part of the reason I am introducing myself. I want you to know that if you choose to be my patient, I will always endeavor to provide you the very best medical care I can. Since I have only a general understanding of why you are here, nothing that I say is in response to or in judgment of you personally, except for my expression of building a relationship based on trust and open communication. I sincerely hope that you hear me in that way. In the interest of trust and openness, I must explain that if you are seeking a physician-partner who will provide [YYYYY], I will not be your best choice. You may not have come here for that reason. I will say more, if that is a conversation you want to have, but this is completely up to you. I want to be clear that my reasons for my practice choices may be mistaken and wrong, but this is the best I can do. And, since I value your trust above all else, I wanted to begin by disclosing this. I hope I have not put you on the spot or caused you to feel uncomfortable, although I understand this conversation risks doing just that. If I did, I sincerely apologize. What happens next is completely up to you. I am happy to discuss any of this with you—or none of it, if that is your choice. You are welcome to stay, but I will understand if you decide to leave. Whatever you decide, I want you to find a physician whom you can trust and with whom you feel most comfortable. Shall we go on?"<sup>31</sup>

This is one optimal interaction when meeting a patient for the first time for physicians who do not feel, in good conscience, that they can offer a particular health service. Further consideration of what might be optimal approaches in other situations when conflicts may arise—for example, when a patient and physician already have an established relationship—may lead to better outcomes.

#### **APPROACHES THAT MAY ALLOW BETTER RESOLUTIONS**

##### **Limiting Occurrences of these Impasses**

One possibility that is preferable is for doctors to take measures to reduce the likelihood that such

conflicts will occur. Some of the authors published in this issue of *JCE* discuss this; for example, Antommaria relates an argument made by Holly Fernandez Lynch, that state licensing boards should be responsible for compiling and publicizing lists of physicians who are willing to provide particular treatments and of physicians who refuse to provide the treatments, and for assuring that there are a sufficient number of willing physicians.<sup>32</sup> This approach may or may not ultimately be optimal. It could, it would seem, help limit the problem that Schuklenk brings up in the paradigmatic negative example he uses of women who undergo back street abortions in Italy and other Roman Catholic countries that outlaw the procedure.

There are two other examples that are useful to further illustrate this approach. The first is that of a Jehovah's Witness patient who needs immediate surgery but is unwilling to accept blood. Some surgeons may be willing to operate under this condition. Others are not. If, then, hospitals surveyed surgeons beforehand to find out who would be willing to operate and who would not, it may save patients' lives. In the future, hospitals could quickly locate surgeons who are willing to do this kind of surgery.<sup>33</sup>

Another example that may be more commonplace is that of internists who are attending physicians. Some of these doctors feel an exceptional commitment to the sanctity of life, and may not be willing to give sedative meds to patients who have decided to go off a respirator and end their lives. The sedative meds may spare patients from suffering due to air hunger, but the meds may also reduce the patients' respiratory drives, so that the patients will die when they otherwise might have survived for some time off a respirator.<sup>34</sup> Attendings who are opposed to giving sedative meds for this reason may come onto a ward on which such a terminal event has already been arranged. These doctors may feel that they have no other moral choice than to order that the terminal event be stopped, at least until they can review the decision themselves, and then seek optimal arrangements so that the meds can be administered by another doctor.

The result of this postponement may be, of course, catastrophic. The patient and family may have been preparing themselves for this end, only to have it be most traumatically delayed. To try to help prevent this from occurring, hospitals might have policies in place to help avoid it. If such a terminal event is planned, for instance, the hospital could take special precautions to ensure that the attending doctors coming newly onto the ward will know this well in advance.

In the same way that hospitals can set new policies based on conflicts that occur, members of ethics committees (and all careproviders) should be aware that their work may not end when an ethical conflict has been resolved. Like these hospitals, they may want to ask, once a conflict has ended, how in the future such a conflict might be prevented.

### **Intervening When We Encounter a Conflict and Sense Others May Be Experiencing Shame**

The dilemmas that nurses and others may encounter on an ICU ward are easy to imagine. Doctors may, for example, believe that further treatment is futile, but the patient and family may have the opposite view. This may be more likely now that physicians in some hospitals have policies “backing them” in making this determination. Of course clinicians may also, at the far other extreme, want to keep a patient alive at all costs, and this too may cause nurses and others no end of moral distress.

What the ICU nurses report in the article by Traudt, Liaschenko, and Peden-McAlpine in this issue of *JCE* is remarkable. The authors report that, generally, the nurses do not feel moral distress, and the authors report on the approaches the nurses use that may help the nurses fare as well as they do. The approaches may help any careprovider encountering similar conflicts. We may use these approaches to try to defuse the kinds of warring interactions we have been considering. We may not enable the various parties to a conflict to agree on a desired outcome, but we may be able to mitigate the residual rancor that otherwise could occur. This especially might be indicated, for the reasons I have given above, when we see that patients or physicians who are in conflict are feeling shame.

### **The Nurses’ Approaches**

The authors of this study summarize the nurses’ approaches in this way:

The nurses consistently approached the moral issues embedded in their daily work in a caring manner with a primary focus on loyalty to their patients and a willingness to challenge hierarchies. They held themselves accountable for their actions and did not fail to act because of either external or internal constraints. The practices of (1) self-awareness, including accountability for self and one’s skill, and (2) advocacy fostered their ability to work through these constraints.

Several key aspects of this summary warrant discussion. I shall use some of the nurses’ own words

to convey what they did. One ICU nurse says of her colleague, “I want her to know I’ve got her back.” The foreknowledge and assurance that a colleague will be on our side may be more critical than anything else in these situations. This is because it may go a long way to help us to feel safe, and we are then able to attend more fully to our patients. Our thoughts and feelings will be less distracted by our own concerns. Such unconditional trust in another can help a patient or careprovider overcome shame, if that person has come to feel shame during or after a warring interaction. Seeking out another with whom we feel safe and being able to share a feeling of shame may provide immediate and long-term emotional relief. A community with whom we can debrief and find support can be the most important asset careproviders can have.

Another ICU nurse describes how she goes beyond caring for herself to feel greater empathy for others. “Sometimes,” she said, “I think we’ve been through this so many times, but it’s always that person’s first time, so just go in, not being all-knowing. . . . I try to put myself in that family member’s shoes and not say too much. Not to give too much advice, but rather just empathize with how hard this must be.” Empathizing as much as we can in such situations is critically important. As psychiatrist Jodi Halpern notes, citing research results, “when doctors attune to patients’ cues nonverbally patients communicate emotionally laden topics and give fuller histories.”<sup>35</sup> When we encounter a patient or careprovider who is feeling shame, our nonverbal expressions may show that we believe that we are like the person we see before us, in the most essential ways. We know that we are like the person feeling shame, regardless of what that person has done.

Conveying that we know we are “like the other” is most important in enabling another to overcome shame and then model this acceptance in turn, becoming similarly unconditionally accepting of him- or herself. How then might we do this initially within ourselves? One way is to seek to identify, somewhere within ourselves, feelings that are similar to the ones the other person may be experiencing. Granted, when the other person has behaved exceptionally badly, this may be extremely difficult. Still, though, I believe that it is possible to do this. A hideous example would be a mother who, like Euripides’s Medea kills her children to gain revenge on an unfaithful husband; or a father, who kills his children to gain revenge on an unfaithful wife. These parents later feel the profoundest regret. This does happen.

Such desire for revenge is not a feeling with which most of us would want to identify. We might

believe that these parents are not like us. We may see them as sociopathic or as evil, but, in any case, not as persons worthy of dignity and respect.

But when we feel that others—patients or care-providers—are different from ourselves, our efforts may be limited in the degree to which we can help them. Still, it is most likely that we will be able to see some trait we have in common. Who among us has not, for example, felt some feeling, at least somewhat like revenge, when wronged by another? There is some evidence that the desire to retaliate may be more common in those with obsessive traits, but who living among us is without these traits—or at least vulnerable to having them when we have been bested by the wrong influences, or too much stress?<sup>36</sup> Experiencing this kind of feeling, even if it is fleeting, may be vivid enough for us to realize that we and the person who is feeling shame are similar.

It may be difficult to identify with another when we feel we can't find any common frame of reference. I recall in this regard, for instance, a time I interviewed a couple whose toddler had died when left alone in a swimming pool for what must have been little more than an instant. I interviewed them much like the doctor who interviewed my suicidal colleague: I did it "by the book." I asked all the right questions and left no key part of the history unexamined. Only years later did I wince when I recognized in a moment of epiphany how I had so absolutely failed to ever ask myself how these parents might have felt at that time—and indeed, perhaps felt always thereafter. I felt shame. I recognized that I hadn't stopped to try to imagine within myself their intolerable and unimaginable pain.

Our task, then, is to stop, and at least, like the second ICU nurse, to ask ourselves what it must be like to be the other person, even if we can't ever really know. The paradox is this. Even if we only try to do this, the effort, in and of itself, may generate empathy. Of course, to do this and succeed may hurt. Leston Havens, a psychiatrist known for his exceptional work with patients who have schizophrenia, often spoke of how hard this work was for him, and that it should be hard for others. To empathize, he said, *could* and *should* be painful.<sup>37</sup> The approaches described above by the two ICU nurses are, in large part, nonverbal, but may be, however, most important. Systems within our brains may tabulate others' nonverbal responses separately from verbal responses, perhaps to indicate to us the degree to which we should trust what is or isn't "said."<sup>38</sup>

The second nurse's approach was not to make statements, but to ask. Rather than confront patients and family members with views they might have

been missing, she asked them questions. This seems an ideal way to evoke change by genuinely promoting new thinking that avoids making others feel defensive. We can imagine that the nurse could steadfastly continue to ask questions until she felt that her task was done. Asking is a common approach, used for the same purpose, in psychotherapy. Therapists might seek to promote growth by asking, for example, "Could it be that . . . ?" Leston Havens, however, cautioned against therapists using such approaches routinely or repeatedly. Making such comments repeatedly, he said, is "risky: There is much to say for this, but unless it includes spontaneity the result is to deaden. . . ." <sup>39</sup> The point is that we cannot expect to achieve optimal rapport with patients by responding with rote phrases. The phrases may be empathic and help build our relationship with patients, but unless they reflect authentic concern, they may cause patients pain. Our responding by rote may cause patients to feel infantilized.

We might consider the nurses' approaches as similar to those of clinicians who do mediation. Just a brief look at some of the approaches mediators have used, that they have reported in *JCE*, will make this comparison more clear. One example is Edward Bergman's approach.<sup>40</sup> He, like the nurses, emphasizes steadfast advocacy. When an institution has implicitly supported a questionable policy, for example, he seeks to involve the institutional or departmental representative responsible. This may facilitate, at the very least, he says, feuding parties' having a greater understanding afterward.

Autumn Fiester also emphasizes asking.<sup>41</sup> She says, for example, that the questions she asks may unearth overlapping interests "despite what may be chasms of distance between stakeholders' differing initial positions." This may bring out new, shared truths without inadvertently driving stakeholders to become more firm in their original positions. When we wish to help those in disagreement to find common moral ground, however, Feister warns, we "must not come to any party's defense." This is because it may appear that the intervener is being judgmental. "Calling the speaker on what he or she has said may be implicitly "shaming."<sup>42</sup>

Haavi Morreim notes that the exact wording of questions is important. We must avoid expressing an implied criticism, but rather, we should frame our question as "an inquiry born out of genuine curiosity."<sup>43</sup> Morreim, like the ICU nurses, stresses the importance of expressing empathy. An honest expression of empathy for doctors, she says, such as recognizing the difficult position they are in, may enable them to feel more open. In addition, she de-

clares, it may help them to realize, and then possibly share, how distraught they are, and even their regret at having, in part, precipitated the situation.<sup>44</sup>

How might these approaches “work” in the conflict we have been discussing, an assisted planned home birth? Looking to respond to an obstetrician who does not want to encourage a home birth, we might say, “It sounds like you really want, above all else, what is best for the baby. It must be excruciating for you that the parents don’t see this as you do.” As Edward Bergman says, this may not solve the problem. It may, though, help the obstetrician and the parents end up feeling better toward each other and not feeling shame.

### **Approaches We May Use after these Deliberations**

After a conflict has ended, patients and doctors may feel residual shame for the reasons outlined above, but the shame may remain hidden, even to them. They may, for example, feel and express it only as anger. We may still be able to help both parties reduce their shame by asking them if they would like to discuss their experiences with us. If they will, there are three key approaches that we should keep foremost in our minds. All are implicitly what the ICU nurses and mediators do. These approaches have even been used effectively with those among us who revile themselves more than perhaps any others: as mentioned above, mothers (and fathers) who kill their own children.<sup>45</sup> These parents may later feel that they have no reason to live. How might they be helped to feel again that there is, or may be, some quality to their lives that will make living worthwhile? These are the same approaches that may help patients and doctors overcome the shame they feel.<sup>46</sup>

Among all of those we have considered who may most need these approaches are parents who disregard their obstetrician’s advice against home birth, only to have their child encounter serious problems that could have been prevented in the hospital. The first approach is to enable them to feel trust. They must know that those with whom they will share their shame will not judge them. This approach requires us to really feel that we are like those we hope to help, as discussed above. As Brené Brown states, having researched this endeavor for years, “Find someone who loves you, not despite your vulnerabilities but because of them.”<sup>47</sup>

This may seem like a big reach for any nurse or physician outside a therapeutic relationship. Further, if we haven’t previously “tested” a friend or colleague, sharing information that they might judge negatively might be a gamble. Still, I hope that most

of us have someone like this. I have been astonished, in this regard, often, by the degree to which just one colleague’s unqualified support can offset, and sometimes even wholly reverse, the despair that shame may create. One of the ICU nurses who is quoted states this implicitly when she says of her colleague, “I want her to know I’ve got her back.”

As Jodi Halpern states, an individual can quickly shift from shame to regain a much better sense of self, given the right interpersonal circumstances.<sup>48</sup> As Brené Brown put it, speaking of herself, “Shame dissipated the minute I realized that I wasn’t alone—that my experience was human.”<sup>49</sup> Shame is a painful self-consciousness about inferiority, failure, and defeat.<sup>50</sup> When a trusted person lends his or her support, it may prevent the shame from becoming entrenched. Shame that is not helped may bring about a type of posttraumatic disorder, one that reflects the absence of a possible recovery.<sup>51</sup>

What might a colleague say to a person that conveys such unconditional support? Perhaps the colleague could say something like, “You did the best that you could. There is nothing more that you could have done in this situation.” This may mean not only that the colleague couldn’t have done better, but also, on a deeper level, it may mean that the person who is feeling shame couldn’t have done better given the limits of the situation, or given how that person saw the situation at the time. A quintessential assumption we must make to be able to help others is that people do the things they do not because they are bad, but because they got something or other wrong. Then, whatever that thing was that they got wrong, perhaps that can be corrected. This belief must come from what might be called faith, although it is not necessarily a faith that is religious. That is, it cannot be concluded from what we can see. We can, though, perhaps, choose to have this attitude.

Another approach we might consider is to communicate that, regardless of what the person has done, no one can be perfect. Shame tells you, Brené Brown says, that “you’re not good enough and you should have known better.”<sup>52</sup> And so, “You’re officially a prisoner of . . . perfecting. . . .”<sup>53</sup>

The crimes of parents who kill their children are immense. But even those crimes may be seen as stemming from human imperfection. This is why, therefore, if we want to help people with their shame, we must see vulnerability as something that we all share, regardless of the shame’s source, and, indeed, its resulting extent.<sup>54</sup>

The third key approach is to help patients and careproviders who feel shame to distinguish between what they do and have done, and who they

are. *What they have done is not who they are.* It is their behavior. Brown states that, knowingly or unknowingly, we attach our self-worth to what we do.<sup>55</sup> If things don't go well, she says, we focus on what we have done and lose sight of who we are.<sup>56</sup>

If we are in a therapeutic role with a person who feels shame, we could work with the individual to try to discover, with that person, a new coping skill that the person needs and may lack. When we want to help a person who feels shame, we must, however, believe that, no matter what the person has done, she or he warrants the same respect we give to ourselves. This is because how each of us feels will affect the other. Havens may have said this best: "both minds indirectly affect the other . . . both minds will forever be changed. There is no other way. At the end of the interview, . . . two slightly different people emerge from the office, whether they are aware of this fact or not."<sup>57</sup>

For some of us, this may be impossible. For others, this conviction of mutual and identical worth will readily come. Is it possible that we can change our attitude, so that we can see this underlying good in others, that is necessary to help them overcome shame? Viktor Frankl would say "yes." He speaks of those in Nazi concentration camps who were comforted when other prisoners gave away their last pieces of bread. He says that they may have been few in number, but they offered proof that everything can be taken from us except for one thing: "the last of the human freedoms—to choose one's attitudes in any given set of circumstances."<sup>58</sup>

Such a change in attitude can't easily be inferred from ostensible evidence. This basic goodness underlying and within all of us, even when wholly hidden, can be difficult to infer from the behavior, for example, of a serial killer sociopath. That could be, however, a choice that we make.<sup>59</sup> Some of us come by this naturally. Others can *choose* to see those "worst among us" in this way.

The AMA opinion on physicians' exercise of conscience may reflect the possibility that clinicians may have values that they can't—and perhaps that they shouldn't—overcome. Conflicts arise because this may be as true for patients' values that they can't—and perhaps shouldn't—overcome. The challenge is for us to do what we can. This may be for us to help both parties feel as emotionally unscathed as they possibly can.

## CONCLUSION

My introduction to the articles in this issue of *JCE* has primarily examined the emotional effects

of doctors following (or not) the AMA opinion on physicians' exercise of conscience and the feelings of patients who will be affected as well. I have also addressed some of the ways that before, during, and after we encounter these conflicts, we may optimally respond. The most toxic emotion addressed that may come about due to these conflicts, for both patients and doctors, is shame. Patients may feel, like the participants in Milgram's research, that they are less morally sound than they believed they were. Doctors may feel that they should have done better, and then distance themselves from their patients.

I have discussed how, when we observe this shame, we may best proceed. Aside from exploring ways to prevent these conflicts from arising, we can assure patients and doctors who are affected that we are just like them, assure them that no one is perfect, and tell them that what they *do* is not who they *are*. We must to believe that those we try to help are, indeed, good.

## NOTES

1. "Opinion 1.1.7 Physician Exercise of Conscience," *Code of Medical Ethics* (Chicago, Ill.: American Medical Association, 2016). The opinion appears in full in figure 1 in BJ Crigger, S.L. Brotherton, P.W. McCormick, and V. Blake, "Report by the American Medical Association's Council on Ethical and Judicial Affairs on Physicians' Exercise of Conscience," in this issue of *JCE*, 27, no. 3 (Fall 2016).

2. U. Schuklenk, "Accommodating Conscientious Objection in Medicine—Private Ideological Convictions Must Not Trump Professional Obligations," in this issue of *JCE*, 27, no. 3 (Fall 2016).

3. BJ Crigger, "Thinking about Conscience," in this issue of *JCE*, 27, no. 3 (Fall 2016).

4. This example has exceptional meaning for me. The first rotation I took during my internship right after medical school was in obstetrics and gynecology. This was at Harlem Hospital in New York City and was before *Roe v. Wade*. The doctors on this service agonized at this time over how far they could go within New York State's laws to provide women abortions. They wanted to do this to the extent that they could, because they were all too aware of what was occurring and would continue to occur if they didn't. They knew that "backstreet" attempts, as Schuklenk states, would occur. As a result of this, more women would have uterine infections and then, perhaps, lose their capacity to conceive, and some might possibly even die.

My second rotation was in pediatrics. Here, children came in with lead poisoning caused by their eating flakes of lead-based paint within their homes. The treatment for this was to give them three shots of what is called a chelating agent three times in 24 hours to remove the lead from their blood. This meant that the children would get one such shot—from a painful, large-bore needle—at 2 a.m.

every night. After the first night, the children would know. Thus, they would stay awake until 2 a.m. every night thereafter, dreading this event. They would often, hearing a nurse and me coming, spring from their bed and run. I spent many nights, therefore, with a nurse, chasing them around the ward at that hour.

They would then be cured, but only until they ate lead paint again at home again. Then they would return to the ward for a retreatment four months later.

Thus, to be able to help these women and children maximally, I concluded, clinicians would need the help of the law to allow abortion and to outlaw lead-based paint. Therefore, I then applied to law school.

5. T. Brooks and M.C. Nussbaum, ed., *Rawls's Political Liberalism* (New York: Columbia University Press, 2015), 4.

6. *Ibid.*, 24.

7. A. Budden, "The Role of Shame in Posttraumatic Stress Disorder: A Proposal for a Socio-Emotional Model for DSM-V," *Social Science & Medicine* 69 (2009): 1032-9, 1033.

8. D.J. Robinaugh and R.J. McNally, "Autobiographical Memory for Shame or Guilt Provoking Events; Association with Psychological Symptoms," *Behaviour Research and Therapy* 48 (2010): 646-52, 651.

9. Budden, "The Role of Shame," see note 7 above, p. 1036.

10. Crigger asks the second question this way: "If physicians, being individual moral agents as well as members of an ethically freighted profession, should sometimes be able to follow personal conscience in the conduct of their professional lives, how are they to do so in a responsible, ethically acceptable way?" Crigger, "Thinking about Conscience," see note 3 above.

11. T. Traudt, J. Liaschenko, and C. Peden-McAlpine, "Moral Agency, Moral Imagination, and Moral Community: Antidotes to Moral Distress," in this issue of *JCE*, 27 no. 3 (Fall 2016).

12. J. Shay, "Moral Injury," *Psychoanalytic Psychology* 31, no. 2 (2014): 182-91, 182.

13. T. Schmader and B. Lickel, "The Approach and Avoidance Function of Guilt and Shame Emotions: Comparing Reactions Self-Caused and Other-Caused Wrongdoing," *Motivation and Emotion* 30, no. 1 (March 2006): 43-56, 54. See, also, U. Orth, M. Berking, and S. Berkhardt, "Self-Conscious Emotions and Depression: Rumination Explains Why Shame But Not Guilt is Maladaptive," *Personality and Social Psychology Bulletin* 32, no. 12 (December 2006): 1608-19; J.T. Maltzberger et al., "Traumatic Subjective Experiences Invite Suicide," *Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry* 39, no. 4 (Winter 2011): 671-93.

14. B. Bower, "Over the Edge: What Leads a Person to Move from Thinking About Suicide to Taking Action?" *Science News* 189, no. 1 (9 January 2016): 22.

15. Schmader and Lickel, "The Approach and Avoidance Function," see note 13 above, p. 47.

16. Orth, Berking, and Berkhardt, "Self-Conscious Emotions," see note 13 above, p. 1609.

17. *Ibid.*, 1615.

18. Schmader and Lickel, "The Approach and Avoidance Function," see note 13 above, p. 54.

19. Shay, "Moral Injury," see note 12 above, p. 182.

20. Schmader and Lickel, "The Approach and Avoidance Function," see note 13 above, p. 55.

21. F.A. Chervenak et al., "Planned Home Birth in the United States and Professionalism: A Critical Assessment," *The Journal of Clinical Ethics* 24, no. 3 (Fall 2013): 184-91. For a general discussion of the contexts obstetricians confront today, see L. Diamond-Brown, "The Doctor-Patient Relationship as a Toolkit for Uncertain Clinical Decisions," *Social Science & Medicine* 159 (2016): 108-15.

22. T.M. Pope, "Legal Briefing: Stopping Nonbeneficial Life-Sustaining Treatment without Consent," in this issue of *JCE*, 27, no. 3 (Fall 2016).

23. Chervenak et al., "Planned Home Birth," see note 21 above.

24. A.H.M. Antommara, "Conscientious Objection: Widening the Temporal and Organizational Horizons," in this issue of *JCE*, 27, no. 3 (Fall 2016).

25. "Death of a Child: Losing Adam," *NPR Driveway Moments 2*, K. Thompson, producer, 2004.

26. N.J. Russell, "Milgram's Obedience to Authority Experiments; Origins and Early Evolution," *British Journal of Social Psychology* 50, pt. 1 (March 2011): 140-62.

27. L. Westgate, B. Shriner, P. Thompson, and B.V. Watts, "Evaluation of Veterans' Suicide Risk with the Use of Linguistic Detection," *Psychiatric Services* 66, no. 10 (October 2015): 1051-6.

28. A poignant, fictional example is that of August, a child born with exceptional facial features, who is bullied. He refuses to tell his parents and plans to not return to school. "You're going to have to tell Mom and Dad why," Via, his older sister, tells him. "Via, it's okay," August says. "I know what I'm doing. I've made up my mind." P.J. Palacio, *Wonder* (New York, Knopf, 2012), 114-5.

29. Moral convictions may run deep. Consider, for example, Antommara's example in "Conscientious Objection," see note 24 above. He asks, "How should the owner of a physician practice respond, for example, to a nurse or medical assistant who generally administers injections, but who objects to administering depot medroxyprogesterone acetate (DMPA, a long-acting contraceptive injection drug—Depo-Provera)?"

30. J.T. Maltzberger and D.H. Buie, "Countertransference Hate in the Treatment of Suicidal Patients," *Archives of General Psychiatry* 30, no. 5 (May 1974): 625-33.

31. This hypothetical introductory conversation was written by Norman Quist as we were discussing, on 26 August 2016, how physicians might best respond if they knew that they might have a conflict when first meeting a patient. I am exceedingly grateful to Norman for sharing not only this passage, with which I concur, but for making numerous other comments and suggestions that have added greatly to this article.

32. Antommara, "Conscientious Objection," see note 24 above.

33. For another approach to this ethical conflict with Jehovah's Witness patients, see A. Pena, "Preventing the Predicable," *American Journal of Bioethics* 15, no. 1 (2015):

72-4.

34. R.D. Truog, D.W. Brock, and D.B. White, "Should Patients Receive General Anesthesia Prior to Extubation at the End of Life?" *Critical Care Medicine* 40, no. 2 (February 2012): 631-3.

35. J. Halpern, *From Detached Concern to Empathy* (New York: Oxford University Press, 2001), 93.

36. People with more obsessions and/or compulsions tend to be more prone to feeling a desire for revenge. Who among us lacks obsessional thinking or compulsive feelings? R. Fatfouta and A. Merkl, "Associations between Obsessive-Compulsive Symptoms, Revenge, and the Perception of Interpersonal Transgressions," *Psychiatry Research* 219 (2014): 316-21.

37. "... when an interviewer and a patient meet, their minds meet and interact... it is critical to understand the clinical gremlins that arise..." L. Havens, "Approaching the Mind in Clinical Interviewing: The Techniques of Soundings and Counterprojection," *Psychiatric Clinics of North America* 30 (2007): 145-56, 144.

38. The importance of nonverbal interactions cannot be overstated. Parts of the brain may specially process these responses. C.D. Frith, "The Social Brain?" *Philosophical Transactions of the Royal Society B: Biological Sciences* 362, no. 1480 (April 2007): 671-8.

39. L. Havens, "The American Impact on Psychoanalysis," *Psychoanalytic Quarterly Dialogues* 14, no. 2 (2004): 255-64, 259.

40. E.J. Bergman, "Identifying Sources of Clinical Conflict; A Tool for Practice and Training in Bioethics Mediation," *The Journal of Clinical Ethics* 26, no. 4 (Winter 2015): 315-23, 320.

41. A. Fiester, "Contentious Conversations Using Mediation Techniques in Difficult Clinical Ethics Consultations," *The Journal of Clinical Ethics* 26, no. 4 (Winter 2015): 324-30, 329.

42. *Ibid.*

43. E.H. Morreim, "Story of a Mediation in the Clinical Setting," *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016): 43-50, 47.

44. *Ibid.*, 45.

45. See, e.g., S.H. Friedman and P.J. Resnick, "Child Murder by Mothers: Patterns and Prevention," *World Psychiatry* 6, no. 3 (October 2007): 137-41, and D.G. West, S.H. Friedman, and P.J. Resnick, "Fathers Who Kill Their Children: An Analysis of the Literature," *Journal of Forensic Sciences* 54, no. 2 (May 2009): 463-8. For an example of how a therapists may work with such patients effectively, see M. Manjula, C.R. Chandrashekar and Filicide, "Extended Suicide: An experience of Psychotherapy with the Survivor," *Indian Journal of Psychiatry* 56, no. 2 (April-June 2014): 194-6.

46. Brown summarizes research on how to treat and overcome shame in lay language in B. Brown, *Daring Greatly* (New York: Avery, 2012).

47. *Ibid.*, 80.

48. Halpern, *From Detached Concern to Empathy*," see note 35 above, 117.

49. Brown, *Daring Greatly*, see note 46 above, p. 81.

50. Budden, "The Role of Shame," see note 7 above,

p. 1033.

51. *Ibid.*

52. Brown, *Daring Greatly*, see note 46 above, p. 63.

53. *Ibid.*, 64.

54. *Ibid.*, 35.

55. *Ibid.*, 63.

56. *Ibid.*, 64.

57. Havens, "Approaching the Mind in Clinical Interviewing," see note 37 above, p. 56.

58. V.E. Frankl, *Man's Search for Meaning* (Boston: Beacon Press, 2006), 65-6.

59. Simone Weil wrote, "at the center of the human heart, there's a longing for an absolute good. . . . The needs of a human being are sacred. . . . Whenever people are lonely and turned in on themselves, wherever there is sadness or ugliness, there are privations that need remedying." S. Weil, "Draft for a Statement of Human Obligation, 1943," in *An Anthology*, ed. S. Miles (New York: Grove Press, 1986), 202, 207, 210.

## **Features**

# **Moral Agency, Moral Imagination, and Moral Community: Antidotes to Moral Distress**

*Terri Traudt, Joan Liaschenko, and Cynthia Peden-McAlpine*

### **ABSTRACT**

Moral distress has been covered extensively in the nursing literature and increasingly in the literature of other health professions. Cases that cause nurses' moral distress that are mentioned most frequently are those concerned with prolonging the dying process. Given the standard of aggressive treatment that is typical in intensive care units (ICUs), much of the existing moral distress research focuses on the experiences of critical care nurses. However, moral distress does not automatically occur in all end-of-life circumstances, nor does every critical care nurse suffer its damaging effects. What are the practices of these nurses? What specifically do they do to navigate around or through the distressing situations? The nursing literature is lacking an answer to these questions. This article reports a study that used narrative analysis to explore the reported practices of experienced critical care nurses who are skilled at and comfortable working with families and physicians regarding the withdrawal of aggressive treatment. A major finding was that these nurses did not report experiencing the dam-

aging effects of moral distress as described in the nursing literature. The verbal communication and stated practices relevant to this finding are organized under three major themes: (1) moral agency, (2) moral imagination, and (3) moral community. Further, a total of eight subthemes are identified. The practices that constitute these themes and subthemes are further detailed and discussed in this article. Understanding these practices can help mitigate critical care nurses' moral distress.

### **BACKGROUND**

Moral distress has been recognized and studied for more than 30 years. The concept was first introduced in 1984 by philosopher Andrew Jameton, who defined it as the feeling experienced "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action."<sup>1</sup> Three years later, Judith M. Wilkinson extended Jameton's work by further exploring the phenomenon of moral distress as experienced by staff nurses working in hospitals.<sup>2</sup> She looked specifically at the kinds of cases that caused moral distress for nurses and discussed both the types of situations and moral frameworks involved.

The cases mentioned most frequently by the nurse subjects were those concerned with prolonging life. The moral issues mentioned most often were (1) harm to the patient in the form of pain and suffering and (2) treating persons as objects, or dehu-

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manizing them. Given these findings, it is no surprise that much of the subsequent nurses' moral distress research from 1987 forward focuses on experiences in critical care settings.

Patricia Rodney was one of the first to further moral distress research by examining the experience specific to nurses caring for dying patients in critical care settings.<sup>3</sup> The results of her study found "senselessness" to be a central theme of critical nurses' perspectives on prolonging the dying process. She found that these nurses experienced corresponding moral distress that resulted in feelings of resentment, frustration, and sorrow.

Continued studies confirmed that the majority of clinical situations reported to cause critical care nurses to experience moral distress were related to end-of-life care, and the highest levels of moral distress were found to be associated with providing aggressive treatment to patients who were not expected to benefit from that provision.<sup>4</sup> The reasons nurses felt futile care was provided included demands by patients' family members, the lack of timely or skilled communication, and the lack of consensus among the treating team.<sup>5</sup> In morally distressing situations related to the end of life, nurses described negative consequences for themselves, patients, and families. For the nurses, these negative consequences included psychological and physical exhaustion, decreased morale, and decreased job satisfaction.<sup>6</sup>

While previous studies acknowledged both the institutional and individual components of moral distress, there was little written that offered theoretical explanation of how these components were related. Elizabeth Peter and Jean Liaschenko studied moral distress within the context of feminist moral theory, concentrating on the work of Margaret Urban Walker and Hilde Lindemann.<sup>7</sup> Feminist moral theory sees morality as a set of socially embodied practices that occur between people as they account to each other. Walker described moral identity as an accounting of what a person responds to, takes responsibility for, cares for, and values.<sup>8</sup> Under this lens, Peter and Liaschenko described moral distress as "the response to constraints experienced by nurses specific to their moral identities, responsibilities, and relationships."<sup>9</sup>

Given the strong relationship between moral distress and aggressive end-of-life treatment, Peter and Liaschenko argued that the goal of healthcare should be one of healthcare professionals working together in a shift away from prolonging life at all cost to the relief of suffering.<sup>10</sup> This shift is challenging in a culture in which the boundary between not enough

treatment and too much treatment is difficult to establish.<sup>11</sup> Perceptions vary between physicians, nurses, and family members. More so than others, critical nurses accept the reality of death and are committed to making it as comfortable as possible, despite the "paradigm of curing" rather than a "paradigm of caring" that is prevalent in critical care environments.<sup>12</sup>

Critical care nurses have reported moderate levels of moral distress overall.<sup>13</sup> They cited organizational, professional, and emotional stressors.<sup>14</sup> Emotional stressors included value conflicts, lack of emotional support, and dealing with the suffering of patients and families. Professional stressors included lack of end-of-life competencies, difficulty communicating with families, and difficulty collaborating with the medical team. Organizational stressors included the lack of a palliative care approach, inter-professional mistrust and conflict, and lack of continuity in life support and treatment plans.

Moral distress has a negative impact on the healthcare work environment. One study found that one in three nurses experienced moral distress.<sup>15</sup> Another study found that nearly 50 percent of nurses have acted against their conscience in providing care to terminally ill patients.<sup>16</sup> Most critical care nurses do not feel their nursing education prepared them to provide quality care to the dying and their loved ones.<sup>17</sup>

Since not every critical care nurse experiences the damaging effects of moral distress, there is much to be learned from the reported practices of those who do not. Although rich in identifying the presence of moral distress in ICUs and its negative consequences for nurses, the literature is lacking in information about those nurses who manage to avoid or navigate through it. This article reports the second major finding of a study of experienced critical care nurses who are comfortable with dying patients, which described their communication with families and physicians to negotiate consensus on withdrawing aggressive treatment and shifting to comfort care.<sup>18</sup> This finding concerns the apparent absence of moral distress in the nurses. We document the specific practices reported by these experienced critical care nurses who were able to navigate around or through morally distressing situations.

## METHOD

### Research Design

Narrative research interprets the meaning of actions and events experienced by individuals or groups to describe why something happened as it

did.<sup>19</sup> An understandable plot or story line is achieved by linking together actions and events, organizing them into a schematic whole. The overall plot is constructed by highlighting common actions and events, identified as themes. A hermeneutic interpretive technique is used to analyze the data and create the story from narrative examples that construct the plots and themes.<sup>20</sup> These plots and themes explain the overall story. Narratives from reported practices are valuable for illuminating actual practices.

### **Participants and Settings**

A volunteer sample of 19 critical care nurses participated in the study. These nurses represented four ICUs located in a large teaching hospital in the midwestern United States, including neurological, medical, cardiovascular, and cardio-thoracic surgical units. The invitation to participate offered the options of self-nomination or peer-nomination. All participants were self-nominated.

Inclusion criteria for this study included a minimum of five years' experience, a work schedule of at least half time, being comfortable with dying patients and their families, and having excellent communication and pain and symptom management skills. The average age of these nurses was 48, and their critical care experience averaged 17 years. Of the 19 participants, 13 (68 percent) reported they had no education in death and dying. The remaining six participants (32 percent) reported they had education in death and dying through continuing education programs.

### **Data Collection**

Principal investigators collected the data between January and April 2012. All ICU nurses in the teaching hospital were invited to participate by letters in their mailboxes, and copies were also sent to them via email. The letter detailed the study and inclusion criteria and instructed interested nurses to contact the researchers by telephone to schedule an interview.

The data consisted of unstructured, audiotaped interviews conducted by the principal investigators that lasted approximately 90 minutes. Each participant was asked the following "grand tour" question: "Tell me about stories where you were able to negotiate with families and physicians to get everyone on the same page regarding withdrawal of aggressive treatment." In the interview process, particular attention was paid to the temporal structure of the narrative to gather sequenced narrative information.<sup>21</sup> The researchers followed the lead the partici-

pant provided, asking clarifying questions throughout the interview.

The research team used the consensual validation method<sup>22</sup> and unanimously agreed that the 19 interviews provided sufficient data to answer the research aim. This richness of the data was used as the criteria for ending data collection. The interview data provided ample material for numerous thick descriptions.

The audiotaped interviews were professionally transcribed into written text, and checked for accuracy of transcription. The written interviews were subsequently coded in ATLAS.ti, a computer software program designed to facilitate qualitative data analysis and research.

### **Ethical Considerations**

The institutional review boards at the researchers' university and the teaching hospital where the nurse participants were recruited approved the study. Participants provided written informed consent prior to their interview, and were paid an honorarium of US\$100 for their time. Each nurse was assigned a fictitious name for recording, transcription, and coding to ensure confidentiality. The de-identified transcripts were then stored in electronically encrypted files in a locked office.

### **Data Analysis**

The data were analyzed using a narrative, hermeneutic interpretive approach. The research team used the consensual qualitative research method, in which each researcher analyzes the data independently, followed by analysis by a team. The focus of the analysis is interpretive, and discussion moves between the original data and the emerging description of the plot and themes.<sup>23</sup>

In the interpretive process, it became clear that the nurse participants in the study did not demonstrate evidence of experiencing moral distress as described in the nursing literature. This subset of data was then further analyzed. The verbal communication and stated practices relevant to this finding were identified and categorized, first as plots, then abstracted to themes. Descriptions were written for each theme, and exemplars for each theme were selected to illustrate the descriptions. The actions and events that were interpreted as themes were identified and reported as three major themes and eight subthemes.

### **Rigor**

Narrative researchers have argued for acceptance of the validity of collected evidence and interpreta-

tion that is foundational to narrative analysis. The purpose of validation is to convince readers that the research assertions are strong enough to be a basis for understanding human behavior.<sup>24</sup> The researcher is responsible for ensuring that the participant's own voice is heard and the narrative is not primarily the interviewer's creation.<sup>25</sup>

Yvonne S. Lincoln and Egon G. Guba proposed four criteria for establishing trustworthiness in a qualitative study: (1) credibility, (2) dependability, (3) confirmability, and (4) transferability.<sup>26</sup> In later writings, they established authenticity as a fifth criterion.<sup>27</sup> All five of these criteria were met in analysis of the data in this study.

In this study, trustworthiness was ensured by the audiotaped interviews and their verbatim transcription. The professionally transcribed interviews were reviewed and further checked for accuracy by the researchers. The group dynamic ensured reflexivity, the process of examining both oneself as the researcher and the research relationship. Research team members made sure that one another's preconceptions did not influence interpretation.

This study, by using the same interview guidelines, careful documentation in ATLAS.ti, and the use of memos, maintained dependability for an inquiry audit purpose. Inter-coder checks were established, and category lists and themes were developed and managed via ATLAS.ti. Based on the narratives, thick, vivid descriptions were constructed and followed by illustrative data. It is the thick description in the findings that allow transferability to like contexts. The researchers mutually agreed that a point of data saturation had been reached because the team was no longer finding new information relevant to the themes.

## FINDINGS

Enacting moral agency, exercising moral imagination, and fostering moral community were the major themes that described how experienced critical care nurses navigated around or through morally distressing situations while working with families and physicians regarding the withdrawal of aggressive treatment. The specific practices that constituted these themes include: self-awareness, advocacy, empathy, ascertaining what the patient would want, envisioning and facilitating possibilities for a good death, supporting relationships, managing conflict, and doing moral communicative work. These practices are non-sequential and are often circular. However, each is discussed separately in this article for the sake of clarity (see table 1).

### Theme One: Moral Agency

*Moral agency* is commonly defined as an individual's ability to make a moral judgment based on a commonly held notion of right and wrong and to be held accountable for their actions. Nurses in this study shared stories that demonstrated strong moral agency that facilitated positive outcomes for both patients and their family members. The nurses consistently approached the moral issues embedded in their daily work in a caring manner with a primary focus on loyalty to their patients and a willingness to challenge hierarchies. They held themselves accountable for their actions and did not fail to act because of either external or internal constraints. The practices of (1) self-awareness, including accountability for self and one's skill, and (2) advocacy fostered their ability to work through these constraints.

*Self-awareness.* To be self-aware is to be conscious of factors that influence one's thoughts, feelings, and actions so that one has a reasonable idea of how and why one thinks, feels, and acts as one does. The nurses in this study understood and were able to articulate what it was about themselves that contributed to their skill and comfort working with families and physicians regarding the withdrawal of aggressive treatment. They knew the work of nursing, knew how to get the work done, and understood what makes them skilled. They clearly articulated their roles and responsibilities as they and others understood them, and held themselves accountable for their actions. They benefited from their own experience as did others. There were two aspects to their self-awareness: accountability for self as a moral agent in general and as a nurse in particular, and accountability for their skill, discussed below.

*Accountability for self* was the first component of the nurse participants' self-awareness. These nurses articulated their understanding of what it

TABLE 1. Themes and specific practices

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1.	Moral agency
	• Self-awareness
	• Advocacy
2.	Moral imagination
	• Empathy
	• Ascertaining what the patient would want
	• Envisioning and facilitating possibilities for good death
3.	Moral community
	• Supporting relationships
	• Managing conflict
	• Moral communicative work

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means to be a nurse and their willingness to accept responsibility for whom and for what is under their care. The responsibility they accepted was for the (1) professional knowledge and skills necessary to be a competent nurse, (2) knowledge and understanding of their own moral values, and (3) knowledge of their emotions and how their emotions influence their actions. They knew the emotional work involved in caring for the dying and recognized the need to manage the difficulties of the work. They were concerned not only with their own ability to manage the stress and complexity of working with dying patients, but also with how their colleagues managed this work. One participant described her concern this way:

**Irene:** I sometimes feel like nurses are different from the rest of the public because of what we experience at the bedside. . . . It worries me. I feel like I have coped with it very well, but who are we missing that takes it home and can't figure out how to bring it in their heart or how to release it?

**Interviewer:** And what's the "it" you're coping with?

**Irene:** When you value life and it's ended . . . it's been a traumatic end and you're seeing this happen in front of your very eyes. You're caring for that patient and trying to make it [the death] the best possible way and then you wrap him in a body bag, you zip him up, and call transport to take him to the morgue. You continue to do your job. . . .

The nurses benefited from their own experience and learned from that of others. They accepted responsibility for their particular stance on end-of-life care and recognized that people held different views. They cited the virtue of "wisdom" and the qualities of "confidence," "maturity," and "sensitivity" as important personal traits in doing this work well. As one nurse commented:

It's all in maturity and sensitivity, and respecting that we all have different perceptions and values, and we don't always have the right to put them onto other people. That's hard and it takes a lot of wisdom. **[Irene]**

Not only did these nurses take responsibility for what they knew, they recognized what they didn't know, and knew how to get the information they needed to act. A participant displayed this awareness and understanding in stating:

You need to know what you know. You need to know what you don't know. You need to know

where to go to get the answers to the stuff you don't know. It's that simple. Nobody is ever going to have all the answers. . . . Just be able to recognize what you know and share it. And be able to recognize when you don't know and say "I don't know." Those are not dirty words.

**[Anne]**

*Accounting for skill* was the second component of the participants' self-awareness. Here they were not referring to their clinical skills, but rather to communicative skills such as listening, interpreting body language and emotion, timing, and word choice. Many attributed this practical wisdom to longevity in their position and unit and learning from repeated experiences. A significant part of this development was learning from one another through the mutual sharing of experiences that also included feedback. One nurse described it this way:

Having a comfort level, being very close to someone you don't know at that most intimate moment when you're with someone who is maybe taking their last breath, how did I learn to do that except for experience and time? I wasn't taught that [formally]. I had situations. . . . Talking out loud sometimes is how you learn and also, because I share a story that reminds me of a story you're telling, then we learn from each other. . . . We teach each other without knowing about it. We observe each other. **[Irene]**

*Advocacy.* For the nurses in this study, the practice of advocacy was central to their moral sense of self and thus their moral agency. Their advocacy included speaking to the family on behalf of the patient and speaking to the medical team on behalf of the family on end-of-life matters. In these situations, nurses reported advocating for their patients by challenging families, physicians, or both to consider a change of direction from aggressive treatment to comfort care. To accomplish this they listened carefully, skillfully asked questions about families' and physicians' understanding of the situation and goals of care, and provided information. This communicative work kept the biographical life of the patient and that person's suffering body at the center of concern. The following nurses stated the importance of keeping the focus on the biographical life of the patient when speaking on behalf of the patient to the family:

I will remind them [the family] that this is about what Mary the patient wanted and what kind of things did Mary do? Was she real active? Was she this? Was she that? What would she think

about being on a ventilator and in a nursing home for an extended period of time, if not for the rest of her life? [Anne]

Because you know, it is about family, but it isn't about family. It's about what is best for that patient. And I think a lot of times with family members, they're thinking about what's best for them. But I've always got to remember that you've got to think, "What is best for her?" What is best for her may not be what is best for you. Family members may want the mother to live forever, but that's not what's best for her and especially family members that have a little bit of guilt. [Elaine]

### Theme Two: Moral Imagination

*Moral imagination* is a moral agent's active attempt to consider what moral decisions to make and what action to take. Strong moral imagination was an attribute of the nurses in this study. For them, it was a moral imperative to envision possibilities for a "good death" for each individual dying patient. In the context of considering withdrawal of aggressive treatment, the stories they shared demonstrated their ability to discern various possibilities for acting and to envision the associated benefits and harms. The specific practices the nurses discussed around moral imagination were (1) empathy, (2) ascertaining what the patient would want, and (3) envisioning and facilitating moral possibilities for a good death.

*Empathy.* Nurses' empathy for the patient and the family was key in helping families to make the transition from aggressive treatment to comfort care. The nurses in this study demonstrated their ability to figuratively put themselves in another's shoes and skillfully reflect that perspective to the family. They frequently cited aggressive treatment situations in which they asked loved ones "How would you feel if . . . ?" and "What would you want done if . . . ?". They shared stories that demonstrated reflective listening (offering back the speaker's idea to confirm their own understanding), thereby building trust, respect, and a safe environment conducive to decision making. This empathetic communicative work was a moral imperative for these nurses. As one participant indicated:

It was a tremendous outlay of energy on my part, but a lot of times when I'm working I'm thinking, if these people were my family, what would I want someone to do for them? How much would you put yourself out? How much does somebody help the ones that you love at the end of their life? [Ruby]

Empathy was also important so that nurses would not get lost in the routine of their work in which death was a significant part. Another participant shared:

Sometimes I think we've been through this so many times, but it's always that person's first time, so just go in, not being all-knowing. . . . I try to put myself in that family member's shoes and not say too much. Not to give too much advice, but rather just empathize with how hard this must be. [Olivia]

*Ascertaining what the patient would want.* In a medical culture where respect for autonomy and shared decision making have replaced traditional paternalism, unilateral withdrawal of aggressive treatment by physicians is not the norm. Today it is more common for families to demand further aggressive interventions, even when such treatment is not in the patient's best interest. Under such circumstances, it was important to the nurses in this study to ascertain what the patient would want.

The concept of ascertaining what the patient would want must be situated in the context of the larger study, which examined the communicative work that nurses do with families and physicians regarding the transition from aggressive treatment to comfort care. None of the nurse participants told a story of advocating for continued aggressive treatment when either families or physicians wanted to withdraw treatment. All of their narratives demonstrated their conviction that withdrawal of aggressive treatment and support of as peaceful a death as possible was in the best interest of the patient. In this study, ascertaining what the patient would want was not about getting an answer to questions of a technical sense—Would your family member want to have CPR or not?—but rather about answers to questions of an existential sense—What would it mean for your family member to live "like this"? One nurse shared:

If I can't talk to the patient, I will talk to the family and say, "Have you had a discussion with your loved one regarding what they would want as far as ongoing care for medical things?" Very often they will say, "Well, they just want to live," or they'll say, "Yes, Mom has been very clear to me that she does not want to be on the ventilator again," . . . or whatever it may be. [Fran]

In helping families to explore the meaning of "like this," the nurses used knowledge of the patient's biographical life and deteriorating status in attempt to show families that continued aggres-

sive treatment would not contribute to their loved one's flourishing.

A major way of helping families was to relieve them of the responsibility for authorizing withdrawal of aggressive treatment by reassuring them that they were not acting on their own, but rather as an important voice for their now-voiceless loved one. One nurse shared how she defended her patient's best interests by reminding family members of their appropriate role in decision making:

I'm not asking them to decide what they would want; I'm asking them to tell me what they know the patient wanted. It's important to me to make that distinction for them because it's important that the decision made is about what the patient wanted and it also gives them some absolution, if you will, of responsibility for the decision that they need to voice. [Anne]

*Envisioning and facilitating moral possibilities for a good death.* The nurses in this study sought to ensure that their patients' lives ended well and that the patients' deaths were morally acceptable and emotionally comfortable for their families. The nurses saw alternate ways of viewing a patient's imminent death. They often challenged families and physicians to consider whether continued aggressive treatment was sustaining life or prolonging suffering. One participant stated:

I guess it's how you want to view it. Do you want to view it that we can prolong your life or that we can prolong your suffering? We [ICU nurses] view it, a lot of times, as we can prolong your suffering. We would, quite often, choose to end aggressive treatment much sooner than family members will. And even physicians sometimes too, just don't quit. They are so aggressive and the prognosis is so poor. [Natalie]

This presentation of an alternate view was important in helping families and physicians to come to a mutual understanding of what was happening to the patient. Working to provide a good death involved transitioning from hope for a cure or a miracle to realization that death was inevitable. It was a moral imperative for these nurses to help families remember their loved one's death as peaceful. The following participants shared how they worked to facilitate this and prepare families for the emotional work of grieving:

The first thing I think to do is make them [the patients] look like the last hour wasn't a struggle, breathing tube or bleeding or messy. . . . So the first thing we did we just got him washed up

and cleaned. I said to bring the family in and I had no words. I didn't have any words. I just said, I'm so terribly sorry. [Jenny]

If I'm insensitive or not paying attention, that is what they are going to remember about their family member's last days or last moments. Those moments are often imprinted in people's minds and I want that to be the very best situation it can possibly be. On our end I want to do everything to make it good. I want them to feel at peace about whatever is happening. [Maria]

### Theme Three: Moral Community

A *moral community* is a group of people working towards a common moral end. The nurses in this study indicated strong awareness of the importance of moral community and saw themselves as critical to the process of decision making regarding the withdrawal of aggressive treatment. For these nurses, the moral end sought was a good death for their patient. They thought it was important for physicians to share in the pursuit of this moral end. The nurses reported practices that recognized and positively utilized the relational nature of moral community. The specific practices they demonstrated relevant to moral community are (1) supporting relationships, (2) managing conflict, and (3) moral communicative work.

*Supporting relationships.* For the nurses in this study, relationships were central to getting their work done well. "Supporting" was a word used frequently as they described themselves, their roles, and responsibilities relative to forming and maintaining relationships that made a moral community possible. Recognizing the contributions of others to the care of the patient and family was a way to establish and preserve their moral community.

On patient and family support, one participant shared her perspective:

We always want to consider things through the patient; what the patient would decide for their self if they could. But they don't live in isolation; they live as part of this family. So I think this [supporting the family] is extremely important. [Fran]

Another shared her view on the importance of supporting her fellow nurses:

I want her to know I've got her back. There's nothing stupid she can say. I'm here for her. . . . I can't make everyone do things my way, and I wouldn't want that, because I don't think my way is always perfect. Wisdom is being able to

support, acknowledge, and give comfort to someone who is struggling or doubting what they said and feeling like they made a mistake and try to look at all the pieces to that and help them learn from it. **[Irene]**

Another shared the importance of supporting physicians:

I feel they [the family] deserve to hear a pretty good explanation from the physician, and then what I do is I let the physician take the lead, or I'll talk to the physicians and just say this is where we're at, and I'll just gently nudge them into that position. "Here you go, let me know when it's good for you to talk to this family." Then they do so, and what I do is support the physician. . . . I'll support the physician, and I feel that my role is to further educate them and answer their questions and concerns. **[Natalie]**

*Managing conflict.* In the complexity of health-care systems, conflict is inevitable, and this may be especially the case when the moral stakes are high. In spite of the inevitability of conflict, the nurses in this study did not view it as insurmountable and were skilled at staving it off or managing it to resolution. In the stories the nurses shared, the major underlying conflict was expressed as "Why are we doing this [aggressive treatment for a dying patient], and to what end?" This questioning directed the work of the moral community.

The nurse participants' narratives demonstrated their ability to recognize conflict, identify its source, minimize its impact, and manage the conflict to resolution. They continually worked to achieve and maintain positive relationships with families, physicians, and other team members. They saw communicative skill and patience as personal assets in conflict management. The conflicts were with families who did not want to acknowledge the deterioration and implications of the patient's condition, and with physicians who did not want to give up on aggressive treatment. The reasons for the conflict included differences in values between quality of life and quantity of life, the timing of withdrawal of treatment, and incongruent communication from different sources. Nurses described managing conflict as follows:

There are families who, if you try to talk to them about the reality of the illness, any deterioration, or anything that has to do with [the patient] not living, they just don't want to hear it. All they want to do is keep going no matter what, even though you have conversations with them

about quality of life. That gets difficult and they get angry. **[Bonnie]**

Usually the conflict is with the family or the physicians. A lot of times it is with the physicians. . . . I shouldn't stereotype, but sometimes they just don't want to let go. A lot of times they just want to avoid the issue. **[Elaine]**

The nurses shared examples of everyday practices that demonstrated their skill in minimizing impact and managing the conflict to resolution. Part of managing conflict is about understanding the reasons for actions and determining if they make sense. To achieve this, the nurses utilized the communicative skills of asking questions in an effort to understand the other person's perspective, and respectful listening. This communicative work enabled the nurses to protect and maintain relationships.

Situations of potential conflict, which are often the result of communication failure, were complicated by the common problem of families getting different information from different physicians. The nurses in this study were proactive in seeking resolutions by not being afraid to "speak up" regarding the problem and the need for resolution. A participant shared:

If the family expresses to me, "Gosh, we hear one thing from someone, one thing from someone else," I will tend to say, "I'm sorry. I'm going to get this clarified for you, so we can all get on the same page." Then I go straight to the physicians and say, "What's the plan? The family is confused. They are in a huge challenge." **[Jenny]**

Another study participant recognized that family members often need time to come to terms with the knowledge that their loved one is dying. She shared the value of patience in pro-actively managing potential conflict and "getting people on the same page":

How I deal with that basically is just to ask them why they feel the way they do and let them process it. Sometimes it takes two or three days for them to process. It's usually not just a process of "Okay, fine, yeah, we'll do that." It usually takes a while. We usually have a couple of conferences with the family, with the doctor, and bring in some other doctors, sometimes bringing palliative care into the conference. . . . I think the benefit from the conference is that everyone is together; everyone hears the same thing, and the doctors can answer the questions the family has. **[Elaine]**

*Moral communicative work.* A good death, one that is free from avoidable distress and suffering for patients, their families, and caregivers, is not possible without good communication. The nurses in this study demonstrated skill in moral communication: the verbal and nonverbal social interaction that enhances one another's understanding of the moral situations they are in and informs moral decision making and action. The nurses shared stories that demonstrated their skill in establishing rapport, preparing for conversations, asking questions, active listening, giving reflective feedback, being clear, and knowing when not to speak. The following quotes from participants in the study illustrate this work:

You start off with developing rapport. In the ICU, you have to do it quickly. If you develop rapport within the first few minutes of meeting somebody, it holds for the shift. You need to be able to build that trust right away. So you start with the family members, feel them out to see where they're at. "How are you doing with all this? Is there anything you'd like to talk about? What have the doctors been telling you about how things have been going?" . . . Then summarizing for them where the patient's at currently, like, "The patient came in really sick. This is what we're seeing right now," gently telling them the information. **[Pam]**

Wise nurses are good listeners, and they do more listening than speaking. Sometimes you can intervene without saying anything. Sometimes by being a good listener, the person all of a sudden comes up with a discovery of what they were looking for because they either see it in your face or they heard themselves say it out loud, and suddenly it opens a door to something else they think about. I see that quite frequently. Sometimes that is wisdom, knowing when to let someone make a discovery for him- or herself. **[Irene]**

## DISCUSSION

This study extends the nursing literature on moral distress by reversing the focus from the causes and implications for critical care nurses to the reported practices of those who do not appear to experience its damaging effects. Although not asked directly about moral distress, the nurses in this study—who are skilled at and comfortable working with families and physicians regarding the withdrawal of aggressive treatment—did not show evidence of experiencing moral distress in the midst of commonly distressing situations. These nurse par-

ticipants reported practices that appear to function as safeguards against its negative consequences. The narrative analysis of the stories they shared illustrates that experienced critical care nurses working with dying patients can navigate around or through distressing situations without the consequent moral distress by enacting moral agency, exercising moral imagination, and fostering moral community.

### Moral Agency

The first antidote for critical care nurses' moral distress is *moral agency*. The nursing literature speaks much of empowerment, but little of moral agency. Yet nurses *are* moral agents; they must have agency in order to influence relationships and outcomes in their workplace. We argue for replacing the concept and language of "empowerment" with that of "moral agency."

The concepts of empowerment and moral agency are not unrelated. However, empowerment implies authorization or permission to act, whereas agency implies self-directed capacity or choice to act. Clearly this difference has moral significance. The nurses in this study did not need to have their actions authorized or legitimated by others—they took responsibility and held themselves accountable and did not fail to act because of either external or internal constraints.

The critical care environment for this study did not appear to be unlike other ICUs where nurses have reported experiencing moral distress. Yet, the causes of moral distress reported in the literature were either not expressed or were overcome by the study nurses. For example, a frequent source of moral distress for critical care nurses that is cited in the literature is a lack of input on end-of-life decision making. The nurses in this study saw themselves as active moral agents with not just a key role, but in fact a responsibility to facilitate end-of-life discussions. They demonstrated skill in moral communication, the verbal and nonverbal social interaction that enhances understanding of moral situations, informs moral decision making, and facilitates moral action. They worked to establish and maintain moral communities, asserting themselves as essential to the process of decision making regarding the withdrawal of aggressive treatment and the actions necessary to foster a "good death," the moral end sought. (The nurses' descriptions of their work contributing to a "good death" was consistent with Marilyn J. Field and Christine K. Cassell's definition as "one that is free from avoidable distress and suffering for the patients, families and caregivers; in general accord with the patients' and families' wishes; and

reasonably consistent with clinical cultural and ethical standards.”<sup>28</sup>)

The nurse participants in this study shared common characteristics of what we have termed “accountability for self,” a component of self-awareness. The study findings demonstrate the relationship between self-awareness and what the feminist philosophical literature describes as moral identity. For Margaret Urban Walker, moral identity is an accounting of what a person takes responsibility for, responds to, is concerned about, cares for, and values—this *is* moral agency.<sup>29</sup>

The other component of self-awareness we termed “accounting for skill.” The nurses in this study were adept at this. Many attributed their skill to longevity in their position and unit and learning from repeated experiences, which they also shared with one another. Previous studies have reported correlations between years of experience and moral distress, but the findings are inconclusive.<sup>30</sup> In a 2005 study of critical care nurses, Ellen H. Elpern and colleagues found that intensity of moral distress increased with years of nursing experience.<sup>31</sup> This led the authors to speculate that with increasing years in the profession the cumulative effect of distressing experiences increased as well. On the other hand, Katherine A. Hinderer found that increased years of experience with patients’ deaths was a major element in critical care nurses’ coping skill.<sup>32</sup> Our study confirms Hinderer’s findings. We believe this is because the nurses were able to form and sustain moral communities, another antidote to moral distress that is discussed further below.

### Moral Imagination

The second antidote to moral distress in critical care nurses is *moral imagination*. Moral imagination requires not just the skill of being able to imagine various possibilities and their consequences, but the ability to morally evaluate the possibilities as well. This is not a new concept. P. Anne Scott defined moral imagination as “that aspect of the imagination that potentially becomes active in the moral agent’s attempt to consider what moral decisions to make.”<sup>33</sup> Mary C. Corley, drawing on Scott’s work, argued that nurses who have an acute moral imagination are more likely to have a high level of moral sensitivity and moral competence, and experience less moral distress.<sup>34</sup> This study supports Corley’s work and adds the specific practices by which moral imagination is demonstrated. These practices include empathy, ascertaining what the patient would want, and envisioning and facilitating moral possibilities for a good death.

Knowing the patient was absolutely critical to these nurses. Having empathy for the embodied suffering of the patient and knowing the biographical life of the patient were the ways they ascertained what the patient would want by helping families answer the question, “Would your loved one want to live *like this*?” When families can see the biographical life of their loved one being respected and honored by the transition from aggressive treatment to comfort care, the likelihood of a good death—the moral end that is sought—is made possible.

### Moral Community

Fostering *moral community* is the third antidote to the moral distress experienced by critical care nurses. A moral community is a group of people united by a shared common end with moral implications: in this case, the well-being of patients. Working for the well-being of patients by many people and groups requires sustained coordination of action across these people and groups. Relationships that allow for questioning, that can tolerate the expression of uncertainty, and that are frequently accompanied by strong affect are essential to coordinating this work. Recognizing the contribution of others and being able to call attention when these things are lacking reinforces the goal of the work and minimizes disruption of the work. The nurses in this study were expert in supporting relationships that foster a moral community.

It is important to note that communities typically reflect multiple ends, at least some of which will inevitably conflict. For this reason, managing conflict is an essential skill for working in a complex social world. Differing perspectives regarding end-of-life care are a major cause of conflict and moral distress in critical care nurses. The practice of managing conflict is intertwined with being a skilled communicator. A study that examined family members’ responses to making choices regarding the withdrawal of aggressive treatment found that conflict was the result of their unmet needs for information and communication.<sup>35</sup> The data suggest that a shift from aggressive treatment to comfort care was often perceived by patients’ family members as abrupt and unexplained, and contributed to conflict. The narratives shared by the nurses in this study support that finding. However, the study nurses utilized the communicative skill of asking questions and respectful listening in an effort to understand family members’ perspectives and needs in the face of decision making regarding the withdrawal of aggressive treatment, thereby minimizing the potential for conflict.

A study that described the stressors experienced by critical care nurses in providing end-of-life care found that professional stressors included difficulty in collaborating with physicians as well as difficulty in communicating with families.<sup>36</sup> The practice of moral communicative work is not only important to offsetting these stressors, it underlies every other specific practice previously discussed.

Feminist healthcare ethics recognizes the work of nurses as embedded in complex social networks including healthcare providers, patients, families, administrators, and others further organized under political and economic structures.<sup>37</sup> Historically, these networks have been structured in strict hierarchies that are marked by differences in power and knowledge. Today the emphasis is on teamwork in an attempt to reduce these hierarchical differences and recognize the contributions of all involved in patient care. As laudable as this effort is, we argue that the notion of a team and of teamwork lacks the moral connotation that health work deserves. The notion that healthcare environments are moral communities rather than hierarchical organizations has been increasingly recognized as imperative to good patient care and end-of-life decision making.<sup>38</sup> In terms of moral distress, this is particularly important in caring for the dying. We argue for replacing the concept and language of “teamwork” with that of “moral community.”

### LIMITATIONS

The study was limited because the practices identified were based on the participants' self-reporting rather than observed, real-time behavior. It was also limited by the participants' self-selection and lack of diversity. The study group was all female, with an average age of 48 years. The findings are not necessarily reflective of the demographics of a larger, more diverse ICU. Further, the study was limited to one midwestern teaching hospital in a major city.

### CONCLUSION

As medical technology continues to expand our capability to prolong life, extending the dying process is a potential complication. The line between too little and too much treatment is increasingly blurred. Continued attention to the consequent moral distress is necessary. Healthcare moral communities can benefit from the knowledge gleaned from this study and its implications for reducing moral distress in critical care nurses.

Given that few nurses in this study had formal education regarding death and dying, we believe their education had little impact on their ability to navigate around or through morally distressing situations. These nurses spoke a great deal of supporting each other and supporting newer nurses. This speaks to the value of mentorship.

A feminist moral perspective contributes two important insights. One is that moral issues do not stand outside of their social contexts. The problems of morality are embedded in everyday work. The second insight is that humans are intrinsically relational and interdependent, which emphasizes the significance of connection, sharing, and community.<sup>39</sup> A feminist lens supports a shift in thinking and language away from empowerment toward moral agency and from teamwork toward moral community. The advantage of this language is to highlight the morality that is embedded in day-to-day nursing work and the ways in which nurses understand their moral identity, relationships, responsibilities, and values.<sup>40</sup>

The findings of this study are valuable in providing illumination and exemplars for what expert practice in caring for patients who are transitioning from aggressive treatment to comfort care actually looks like. Because these practices are identifiable, we assume they are replicable. We suggest that interventions that are designed to mitigate moral distress use these concepts and language. The development of critical care nurses who are able to navigate around or through morally distressing situations can be achieved through mentorship in moral agency, moral imagination, and the fostering of moral communities.

### CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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# Towards a New Narrative of Moral Distress: Realizing the Potential of Resilience

*Cynda Hylton Rushton and Alisa Carse*

## ABSTRACT

Terri Traudt, Joan Liaschenko, and Cynthia Peden-McAlpine's study contributes to a much-needed reorientation in thinking about and working with the challenges of moral distress.<sup>1</sup> In providing a vital example of nurses able to navigate morally distressing situations in positive and constructive ways, and offering an analysis of the component elements of these nurses' success, the study helps identify promising directions we might take in addressing the epidemic of moral distress. It also invites important questions, concerning the challenges faced by clinicians who do not work in healthy "moral communities," who lack the ethical competencies, and who don't have the presumptive authority and recognition enjoyed by the seasoned clinicians studied here. We explore some of these questions, and suggest ways we might build on the insights of Traudt and colleagues' study.

What is it that enables some critical care nurses to navigate morally distressing situations effectively, aware of the ethical challenges they confront, but

without experiencing painful or disabling threats to their integrity or moral efficacy? Traudt, Liaschenko, and Peden-McAlpine's qualitative study published in this issue of *The Journal of Clinical Ethics* highlights the often-overlooked possibility that both morally distressing situations and moral distress itself can be skillfully engaged without detrimental effects. Their data begin to illuminate a "counter story" about moral distress that suggests that the negative consequences of moral distress are not inevitable if clinicians can work intentionally, skillfully, and in integrity-preserving ways with the ethical challenges they confront. Instead of reinforcing the prevailing narrative of moral distress, in which themes of victimization, powerlessness, and negative emotion prevail, the authors offer us a study of self-identified critical care nurses who exemplify forms of moral resilience and skill that enable them to navigate morally distressing situations in positive and constructive ways within their own clinical contexts. Their analysis of the component elements of these nurses' success offers valuable stimulation in examining those conditions both within individuals and within systems of practice that contribute meaningfully to the support of individual integrity and ethical practice in morally distressing circumstances.

The literature on moral distress provides extensive documentation of the negative impact of situa-

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tions that challenge the integrity of nurses and other clinicians. In part, this may reflect the focus of the instruments used to measure the frequency and intensity of moral distress, which have not included inquiry into the positive potential of moral distress, or the strategies and support conditions that clinicians themselves have found helpful, both in sustaining integrity in challenging contexts and in mitigating the damaging consequences of their moral distress.<sup>2</sup> While Traudt, Liaschenko, and Peden-McAlpine intriguingly suggest that the subjects of their study did not show evidence of moral distress, despite the “morally distressing” circumstances they confronted, it may also be true that at least some of the nurses in this study experienced moral distress—felt the challenges or threats to their integrity—but saw this distress as a signal of moral concern, a call of conscience, and were able to work strategically so as to preserve their integrity and well-being.<sup>3</sup> It is, in any case, critical that the self-chosen subjects in the study are seasoned and confident clinicians; and indeed part of the point of the study is to highlight the forms of competency these clinicians confidently deploy in addressing moral complexity and conflict. The study also, and crucially, highlights key characteristics of the nurses’ practice environments that supported their effective moral agency. At the same time, it leaves unexamined important challenges that arise for clinicians who may be less seasoned, less skilled, less confident, less supported by their practice environments, or who do, for a myriad of reasons, find themselves disrupted by moral distress.

Traudt, Liaschenko, and Peden-McAlpine organize their findings around three themes, each of which captures “antidotes” to moral distress: (1) “moral agency,” (2) “moral imagination,” and (3) “moral community.” These themes offer promising direction for dismantling the detrimental effects of moral distress, but they also raise further questions. Consider, for example, the first theme, of moral agency. The authors draw a distinction between “moral agency” and “empowerment.” Moral agency, they write, “implies self-directed capacity or choice to act,” whereas empowerment “implies authorization or permission to act.”<sup>4</sup> They suggest that the concept of “empowerment” is problematic, and should be replaced by a concept of “moral agency,” thereby highlighting the value of “self-direction” and “choice” in clinicians’ navigation of moral challenges. While we may well embrace the idea that nurses should own their own power and authority—power and authority formally granted them by their role as nurses, and secured by their license to prac-

tice—formal authorization alone is insufficient to secure the “authorization” needed to exercise effective moral agency and voice in the day-to-day of practice. It must also be secured through the community in which nurses practice. The narratives included in the study reveal critical care nurses who, in exercising “moral agency,” are already in significant ways “empowered” or “authorized” within their practice environments. They are formally authorized by the *Nursing Code of Ethics* to advocate for the interests of their patients, to address their suffering, and to speak on their behalf.<sup>5</sup> But more than this, they are, because of their recognized clinical and ethical competence, authorized as moral agents who enjoy influential impact and voice within their practice communities. Significantly, in its focus on moral communication and moral community, the study itself points to factors beyond the individual’s “self-directed capacity or choice to act” that are key in securing the respect and uptake needed for effective moral agency.

The study also helps us to identify the ways in which many clinical contexts diverge from ideal conditions, inviting us to ask what challenges exist for clinicians who do not enjoy the forms of presumptive authority and recognition, who don’t work in healthy “moral communities,” and who lack the ethical competencies of these seasoned clinicians. Individual moral agency is a necessary foundation, but cannot alone ensure that one is able to contribute meaningfully and constructively—in a way that is heard by others and can have constructive impact—in complex moral situations. We need to examine the complex interplay between individual capacity and effort and other, more environmental cultural factors in play, and to acknowledge the root causes of moral distress that may lie in actual disempowerment, a lack of moral authority, and voice. There are very real constraints on nurses’ moral agency—imposed by policy, by professional codes, and by patients, families, and colleagues. The next step is to work with a new paradigm that acknowledges these factors and creates multifaceted strategies to leverage individual agency, address system contributions, and shift the culture of practice in ways that can enable nurses to practice with integrity.

Consider a second recommendation these authors make, to replace the focus on teamwork with a focus on “moral community.” It is an open, and intriguing, question whether the paradigm of “moral community” might hold more promise than that of “teamwork” in guiding the efforts needed to create an ethical culture of practice within clinical organizations—efforts that will ultimately need to include

all “stakeholders” within clinical institutions—leadership, managers, and front line clinicians—if we are to significantly address the impediments to integrity in day-to-day clinical practice.<sup>6</sup> In considering this recommendation, we must soberly acknowledge the realities, including the power and gender dynamics, the pervasive depletion and burnout reflecting clinicians’ despair and discouragement, and the external organizational pressures often impacting clinicians’ moment-to-moment practice.

Working with the paradigm of moral community might, for example, invite a more robustly moral understanding of the collaborative dimensions of clinical practice. Teams are often hierarchically structured by virtue of the diverse roles of those configuring them. Approaching clinical teams as “moral communities” might encourage norms of mutual respect and mutual understanding, and highlight virtues that can counteract hierarchical dynamics, thus encouraging more inclusive and mutually respectful collaborative processes. It might also encourage clinicians to think not just in pragmatic terms, gauging success in terms of solution-generation and goal-achievement within the clinical unit, but in terms of the moral “health” of the shared work of the clinical unit itself.

While problem solving is an essential part of clinical practice, there might be a focus as well on the moral health of the practice itself, as a shared undertaking. Imagine, for example, a forum in which members of the interprofessional team—nurses, doctors, social workers, chaplains, and administrators—come together weekly to explore ethically complex cases using evidence-based triggers that systematically flag moral distress risk factors. Once cases are identified, collaborative, interprofessional processes would be employed in forging integrity-preserving solutions in the midst of the inevitable organizational and clinical constraints. Understanding such forums as “moral communities” might encourage participants to engage in their work together in ways that seek to preserve the integrity of individual team members, but also, and importantly, the integrity and “moral health” of the interprofessional team.

Traudt, Liaschenko, and Peden-McAlpine offer us a rich and important model of moral communication and moral agency. Thus they capture that the kind of agency needed to navigate morally distressing circumstances is not found in paradigmatically solitary exercises of individual will or moral resoluteness; nor is sustaining integrity, on their implied model, a matter of achieving what one regards as the optimal moral outcome, or perfect alignment with and fidelity to one’s own moral commitments

and values. Rather, the authors recognize that moral agency is characteristically exercised in the context of deeply interconnected relationships, and that solutions to moral challenges must be forged collaboratively and carried out through collective effort. They highlight the role of “moral imagination” in this process—a skill that is central to the respectful, inclusive communication at the center of the nurse’s practice, that enables both higher levels of mutual understanding and more open and creative consideration of possible resolutions in the face of conflict and other moral challenges.

While a healthy moral process is important, it may nonetheless require moral compromises and trade-offs that can result in painful “moral remainders.” Consider the nurse in the intensive care unit (ICU) who must navigate a conflict between, on the one hand, respecting the preferences of her patient, whose chronic, debilitating condition makes him dependent on expensive healthcare technology but who views his diminished quality of life as acceptable, and, on the other, her obligation to be a good steward of limited resources in a context in which there is pressure to secure beds for patients who have a greater chance than this patient of benefitting from intensive care technology. Even if communication with the patient, the patient’s family, and the other involved clinicians is respectful, open, empathic, and inclusive, the nurse may carry an unsettling and morally distressing sense that she has not met important moral obligations, however the situation unfolds. Nurses routinely struggle to balance alignment with their own moral commitments, the moral obligations of their profession, and the economic and legal priorities of their organizations with their primary obligation to privilege the interests of their patients. Moral distress can thrive in the midst of these conditions, despite individuals’ or teams’ best efforts. In the absence of skills in self-awareness, self-regulation, and ethical competence, nurses are more acutely at risk of disruptive forms of moral distress.

Notably, the nurses in this study demonstrate skills and competencies that are aligned with moral resilience. Moral resilience, the capacity to “restore, sustain or deepen integrity in response to moral complexity, confusion, distress or setbacks”<sup>7</sup> includes elements of self-awareness, empathy, perspective taking, reflective listening, and conflict negotiation. Crucial to moral resilience are also self-regulation skills that contribute to creating the conditions in which other dimensions of moral agency and moral imagination can flourish. Mindfulness, the awareness that arises by paying attention to the present moment without judgment and in service of self-

understanding and wisdom, is a skill that can be learned to support self-regulation, discernment, and well-being.<sup>8</sup> Current neuroscience research suggests that, with training in mindfulness techniques, people are able to release strong sensations and emotions more easily.<sup>9</sup> Whether the nurses in this study exercised mindfulness skills and techniques is unknown, as they were not explicitly thematized. The Mindful Ethical Practice and Resilience Academy (MEPRA), an ongoing study into the moral resiliency of nurses at the Johns Hopkins Hospital, includes ten minutes of daily mindfulness practice to support nurses' ability to be more grounded, nonreactive, and self-aware, capacities needed to sustain the kind of empathic understanding and communication central to constructive and compassionate ethical practice.<sup>10</sup> Additionally, experiential sessions exploring elements of ethical competence (ethical embodiment, perception, reflection, and behavior<sup>11</sup>), communication skills using high-fidelity simulation, and strategies for moral resilience are included. Preliminary findings suggest that, following the six-session program, there are significant gains in nurses' ethical competence and confidence. This suggests that educational approaches such as MEPRA and Clinical Ethics Residency for Nurses (CERN), which go beyond cognitive skills, may be highly valuable in the cultivation of ethical competence.<sup>12</sup>

This study is inspiring in capturing and analyzing components of practice that render nurses able to exercise effective moral agency in navigating ethically complex and demanding clinical situations in the ICU, especially at the end of life. While it is a tribute to how much might be possible within specific clinical units, there is a broader story that must be told if we are to take insight and inspiration from their findings. It is a story we can only tell if we attend to the challenges nurses confront, given their position within broader systems, including the often inevitable and deeply entrenched hierarchies of power and authority within clinical organizations and practice, the fact that actual communities of practice may be less than healthy, or may be acutely challenged by resource constraints, poor communication, and the like. The dynamic interplay between individual moral competence and the culture of clinical practice was the focus of a recent national state of the science symposium, "Transforming Moral Distress to Moral Resiliency in Nursing," co-sponsored by the Johns Hopkins University School of Nursing, the Berman Institute of Bioethics, and Wolters Kluwer Health/*American Journal of Nursing*.<sup>13</sup> This symposium sought to create recommen-

dations for developing individual capacities for addressing moral distress through the cultivation of moral resilience and cultures of ethical practice by focusing on clinical practice, education, policy, and research priorities. The report of the symposium will be disseminated in early 2017. Traudt and colleagues' study provides important insight and data to support a paradigm shift that leverages positive, integrity-preserving solutions to address the recalcitrant and growing problem of moral distress in clinical practice.

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**Special Section: Physicians' Exercise of Conscience:  
Commentaries on the AMA's Code of Medical Ethics**

**Report by the American Medical Association's  
Council on Ethical and Judicial Affairs on  
Physicians' Exercise of Conscience**

*BJ Crigger, Patrick W. McCormick,  
Stephen L. Brotherton, and Valarie Blake*

**EDITOR'S NOTE**

The AMA Council on Ethical and Judicial Affairs (CEJA) develops policy for the AMA and maintains and updates its *Code of Medical Ethics*.

CEJA's report on physicians' exercise of conscience was recently included in the AMA's *Code of Medical Ethics* as "Opinion 1.1.7, Physician Exercise of Conscience." For the reader's convenience, the opinion has been included as figure 1.

and respect for patients' self-determination. At the same time, as individuals, physicians are moral agents in their own right and, like their patients, are informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs. In some circumstances, the expectation that physicians will put patients' needs and preferences first may be in tension with the need to sustain the sense of moral integrity and continuity that grounds a physician's personal and professional life.

This article examines the implications for patients, physicians, and the medical profession when tensions arise between a physician's professional commitments and his or her deeply held personal moral beliefs. It offers guidance on when a physician's professional commitments should outweigh personal beliefs as well as when physicians should have freedom to act according to the dictates of conscience while still protecting patients' interests.

**ABSTRACT**

As practicing clinicians, physicians are expected to uphold the ethical norms of their profession, including fidelity to patients

The respect and autonomy that medicine enjoys rest on the profession's commitment to fidelity and service in the patient-physician relationship and on

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individual physicians' recognition that, in becoming members of the profession, they commit themselves to upholding its core ethical values and obli-

gations. Yet physicians are not defined solely by their profession. As individuals, physicians are moral agents in their own right and, like their patients, are

**Figure 1. AMA CEJA "Opinion 1.1.7, Physician Exercise of Conscience"**

Physicians are expected to uphold the ethical norms of their profession, including fidelity to patients and respect for patient self-determination. Yet physicians are not defined solely by their profession. They are moral agents in their own right and, like their patients, are informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs. For some physicians, their professional calling is imbued with their foundational beliefs as persons, and at times the expectation that physicians will put patients' needs and preferences first may be in tension with the need to sustain moral integrity and continuity across both personal and professional life.

Preserving opportunity for physicians to act (or to refrain from acting) in accordance with the dictates of conscience in their professional practice is important for preserving the integrity of the medical profession as well as the integrity of the individual physician, on which patients and the public rely. Thus physicians should have considerable latitude to practice in accord with well-considered, deeply held beliefs that are central to their self-identities.

Physicians' freedom to act according to conscience is not unlimited, however. Physicians are expected to provide care in emergencies, honor patients' informed decisions to refuse life-sustaining treatment, and respect basic civil liberties and not discriminate against individuals in deciding whether to enter into a professional relationship with a new patient.

In other circumstances, physicians may be able to act (or refrain from acting) in accordance with the dictates of their conscience without violating their professional obligations. Several factors impinge on the decision to act according to conscience. Physicians have stronger obligations to patients with whom they have a patient-physician relationship, especially one of long standing; when there is imminent risk of foreseeable harm to the patient or delay in access to treatment would

significantly adversely affect the patient's physical or emotional well-being; and when the patient is not reasonably able to access needed treatment from another qualified physician.

In following conscience, physicians should:

- (a) Thoughtfully consider whether and how significantly an action (or declining to act) will undermine the physician's personal integrity, create emotional or moral distress for the physician, or compromise the physician's ability to provide care for the individual and other patients.
- (b) Before entering into a patient-physician relationship, make clear any specific interventions or services the physician cannot in good conscience provide because they are contrary to the physician's deeply held personal beliefs, focusing on interventions or services a patient might otherwise reasonably expect the practice to offer.
- (c) Take care that their actions do not discriminate against or unduly burden individual patients or populations of patients and do not adversely affect patient or public trust.
- (d) Be mindful of the burden their actions may place on fellow professionals.
- (e) Uphold standards of informed consent and inform the patient about all relevant options for treatment, including options to which the physician morally objects.
- (f) In general, physicians should refer a patient to another physician or institution to provide treatment the physician declines to offer. When a deeply held, well-considered personal belief leads a physician also to decline to refer, the physician should offer impartial guidance to patients about how to inform themselves regarding access to desired services.
- (g) Continue to provide other ongoing care for the patient or formally terminate the patient-physician relationship in keeping with ethics guidance.

informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs. In some situations, the expectation that, as healers, physicians will put patients' needs and preferences first may come into tension with a physician's own need to sustain the sense of moral integrity and continuity that grounds his or her personal and professional life. In such situations, physicians must decide whether and how personal conscience should guide their professional conduct.

Preserving an opportunity for physicians to act in accordance with the dictates of their conscience is important for preserving the integrity of individual physicians and the medical profession. Ethically sound patient-physician relationships and the practice of medicine as a moral activity rest on trust in physicians' personal and professional integrity. Thus physicians should have considerable latitude to practice in accord with well-considered, deeply held beliefs that are central to their self-identity. Nonetheless, both as individual moral agents and as members of a profession dedicated to promoting the welfare of patients, physicians have a responsibility to be thoughtful and deliberative in making such decisions.

### CONSCIENCE, INTEGRITY, AND DEEPLY HELD BELIEFS

When individuals speak of "acting in good conscience" or of acting in a way that preserves their "integrity," they are saying that they seek to align their decisions and actions with the deeply held beliefs that shape their self-identity as moral agents. As Martin Benjamin noted, to have integrity requires that "one's words and deeds generally be true to a substantive, coherent, and relatively stable set of values and principles to which one is genuinely and freely committed."<sup>1</sup> Those values and principles—which encompass not only religious beliefs, but also moral, social, and political values<sup>2</sup>—are central to individuals' understanding of who they are as individuals<sup>3</sup> and, for some, as professionals.

A claim to exercise conscience is underpinned by a claim that an act supports or violates one's integrity and deeply held beliefs. It does not rest on intuition or emotion, but requires that the individual carefully consider what is at stake for the patient, the profession, and the physician, and to be able to articulate how the values and principles that constitute the physician's identity-conferring beliefs justify acting one way or another. A claim to exercise conscience also requires a willingness to accept the consequences of that action.<sup>4</sup>

### PHYSICIANS' PROFESSIONAL RESPONSIBILITIES

Mark Wicclair wrote that, as a profession, medicine is dedicated to "a certain degree of altruism, or suppression of self-interest when the welfare of those [it serves] requires it."<sup>5</sup> Physicians' freedom to practice medicine within the bounds of their conscience must be considered in light of their professional responsibilities to their patients.

With certain exceptions, physicians are free to choose whether and with whom to establish a patient-physician relationship.<sup>6</sup> Thus a physician must provide emergency care unless another qualified health professional is available. However, physicians may decline to provide care for any individual patient so long as the decision is not based on the patient's race, religion, sexual orientation, disease status, or other reason that would constitute discrimination against a class or category of patients.<sup>7</sup>

Having once taken on the care of a patient, physicians have a further duty not to abandon the patient, encompassing obligations not to neglect the patient and to "support continuity of care."<sup>8</sup> While a physician may ethically withdraw from a case, he or she must notify the patient of the intent to withdraw sufficiently in advance to allow transfer of care to another physician.<sup>9</sup>

### CONSCIENCE AND PROFESSIONAL PRACTICE

In some circumstances, physicians may find the dictates of their conscience do not align with their professional obligation to provide care in keeping with a patient's medical needs and in light of the patient's values, preferences, and goals for care. Moral tension may arise when physicians are asked to provide an intervention that they believe is inconsistent with or would outright violate their deeply held beliefs, and, thus, compromise their integrity. These situations should be distinguished from cases in which physicians refuse to provide care on grounds of clinical judgment and recognized professional standards.

Moral tension can also arise when conscience dictates that the physician provide an intervention or service that is medically permitted but is prohibited, as Wicclair notes, "by law, institutional rules, employer policies, and so forth."<sup>10</sup> For example, when a physician feels morally obligated to prescribe emergency contraception or to care for patients regardless of their immigration status, in violation of hospital policy, law, or professional ethics.<sup>11</sup>

In resolving situations of moral tension, a physician must balance preserving his or her integrity with the interests of the patient, future patients, and the medical profession. Even so, as Joel Frader and Charles L. Bosk wrote, “being a conscientious medical professional may well mean at times acting in ways contrary to one’s personal ideals in order to adhere to a general professional obligation to serve patients’ interests first.”<sup>12</sup> These obligations may arise more frequently when a physician works in a location or medical specialty in which access to care and referral options are limited. Or it may mean structuring one’s practice to avoid, to the greatest extent possible, situations in which one would be asked or expected to provide care that creates significant challenges to one’s moral integrity.

Patients, the public, and fellow professionals must be reasonably able to expect that physicians will uphold the fiduciary responsibilities of the profession and will, in general, provide legally available, medically permitted interventions or services in keeping with patients’ medical needs and values, preferences, and goals for care. Physicians should use great restraint in deciding to act contrary to that general expectation.

### RESOLVING OR REDUCING MORAL TENSION

For physicians facing situations of moral tension, determining how best to preserve integrity in discharging their professional ethical obligations to patients calls for thoughtful deliberation that takes into account a variety of factors. These include considerations of whether there is an established patient-physician relationship, medical need, and the burdens a decision to act in conscience will pose for the patient, the physician, and others. A physician’s decision to act in conscience has ramifications at all levels of patient care: providing interventions or services, informing the patient about treatment options, and referring the patient elsewhere for care.

### Patient-Physician Relationships

In some instances the patient and physician will share deeply held beliefs, and it is unlikely that situations will arise in which a physician would feel compelled to act in conscience in a way that is contrary to the patient’s values and preferences. However, physicians cannot predict that they will share deeply held beliefs with all of their patients or with any one patient all of the time. A physician who knows that there are specific interventions or services he or she cannot provide “in good conscience”

has a responsibility to make that clear to prospective patients before entering into a patient-physician relationship with them.<sup>13</sup> Before a patient-physician relationship is established, the physician’s discretion to exercise conscience is at its greatest. Simply disclosing that certain services are not available is not always sufficient; how clearly the physician states his or her position, how well the patient understands the disclosure (and its implications for future care), the nature of the patient’s needs (for example, emergency care), and whether another healthcare professional is available to provide care are also important factors.

### Medical Need, Timeliness, and Alternatives

Medical need also constrains physicians’ freedom to act according to conscience. Patients must rely on physicians’ professional knowledge and skill and must trust that physicians will be dedicated to promoting patients’ welfare.<sup>14</sup> The more immediate a patient’s medical need, the more he or she must trust the physician, and the stronger a physician’s fiduciary obligation must be to fulfill that trust. Physicians have the least latitude to decline to provide care that is morally objectionable to them when that care is medically needed, unless the needed care is available to the patient elsewhere in a timely fashion.<sup>15</sup> Conversely, physicians have the greatest latitude to decline to provide care when that care is elective, is available elsewhere, and a delay in obtaining it will not unduly compromise a patient’s well-being or cause a patient to experience financial, medical, psychological, or other harm.

### Harms and Burdens to Patients

The likelihood and degree of possible harm to a patient similarly constrain physicians’ freedom to act on the grounds of conscience. Harms to patients can come in a variety of forms and may include physical harms, harms to dignity (as when the physician fails to respect the patient and disregards the patient’s values and preferences), and psychosocial harms.<sup>16</sup> In this respect too, the greater the likelihood that acting in conscience will harm the patient, the less discretion a physician has, particularly when the harm in question is serious and imminent. Some harms, such as death or permanent injury, may be so significant and foreseeable that a physician’s exercise of conscience is not justifiable.

Physicians should also consider other burdens that acting according to the dictates of conscience may impose on patients. Burdens can range from the inconvenience of having to go elsewhere for care that is readily available, to more significant chal-

lenges when a patient's access to care is limited by constraints on services in the local healthcare system or such patient-specific factors as health literacy or access to transportation. Time, distance to care, cost, or other logistic burden might be so severe as to outright bar the patient from obtaining necessary care. Again, the more significant the burden, the more physicians should temper their exercise of conscience in the interests of patients' welfare. By the same token, a minor inconvenience to a patient should not mean that a physician is compelled to act against deeply held personal beliefs. Yet physicians must be sensitive to the fact that what may initially seem to be a minor harm or burden could constitute a significant barrier to care for a patient, depending on the patient's individual situation.

### **Harms and Burdens to Physicians and Others**

When a physician chooses to act according to conscience, it can have implications for other healthcare professionals. Not being able to conduct one's life in keeping with deeply held beliefs can lead to moral distress,<sup>17</sup> as one has fundamentally compromised one's integrity and lost self-respect.<sup>18</sup> The moral and psychological harm for the individual physician can be compounded if moral distress adversely affects his or her ability to provide high-quality care.<sup>19</sup>

Yet prohibiting physicians from exercising their conscience altogether may deter some individuals from becoming physicians in the first place or from pursuing certain specialties. It may lead a physician to become callous, disrespectful toward patients with diverging beliefs, or cavalier in upholding personal and professional commitments, thus potentially compromising the care provided to patients and putting a strain on the trust of patients and the public in the personal and professional integrity of physicians.<sup>20</sup>

Exercise of conscience can affect the care provided to patients at the institutional level as well. When a physician declines to provide an intervention or service on the grounds of conscience, the burden falls to others to ensure that preserving individual integrity does not disrupt practice or compromise patient care or the functioning of an institution.<sup>21</sup> Permitting individual physicians to exercise conscience without constraint can likewise damage professional relationships with colleagues who either do not share a physician's deeply held beliefs, or who find other ways to resolve moral tensions between their beliefs and the expectations of their profession. Finally, while patients and the pub-

lic must trust the moral integrity of physicians, permitting physicians to freely exercise their conscience may, paradoxically, cause patients and the public to fear that physicians may not uphold the commitments expected of them as professionals.

### **THE PROBLEM OF MORAL COMPLICITY**

When a physician participates in an action that is in tension with his or her deeply held beliefs, he or she may feel complicit, in some measure, in moral wrongdoing. As Edmund Pellegrino noted, complicity involves "[sharing] in the guilt of an ethically improper act" by virtue of one's level of involvement with that act.<sup>22</sup> It is concerned with how participating in another party's immoral action (or inaction) violates one's own moral integrity.<sup>23</sup>

The degree to which an individual's action (or inaction) implicates him or her in a moral wrong depends on the individual's "moral distance" from the wrongdoer and/or the act, including the degree to which the individual shares the wrongful intent.<sup>24</sup> If one facilitates a moral wrong, but intended a morally licit purpose, then one is not morally complicit in the wrong. Moral distance also involves the extent to which one's action can be predicted to facilitate a moral wrong.<sup>25</sup>

Other factors that influence moral complicity include the severity of the immoral act,<sup>26</sup> whether one was under duress in participating in the immoral act,<sup>27</sup> the likelihood that one's conduct will induce others to act immorally,<sup>28</sup> and the extent to which one's participation is needed to facilitate the wrongdoing.<sup>29</sup>

For physicians, the question of moral complicity arises when they facilitate in some manner the accomplishment of an end they believe to be morally wrong. For example, a physician who declines to provide an intervention or service, such as abortion, on grounds of conscience must still grapple with whether to inform the patient about the objected-to option and whether to refer the patient to another physician who will provide the intervention or service. (A physician who is unwilling to forgo life-sustaining treatment may similarly worry that he or she is complicit in wrongdoing with respect to informing the patient about the option to forgo care or transferring the patient to another physician who is willing to withhold or withdraw such care.) Physicians must grapple with the degree to which their actions will compromise their feelings of moral integrity—some physicians may be able to

justify some provisions of care but not others, based on their level of complicity, even if the care implicates similar moral questions (for example, the sanctity of life). It may be the case, as one example, that a physician can reconcile choosing not to participate in abortion with providing emergency or other contraception. Yet in all circumstances, whatever the dictates of conscience, physicians must recognize and fulfill their other, continuing professional ethical obligations to patients.

### **Duty to Inform**

The duty to provide patients with the information they need to make well-considered decisions about their care is the embodiment of respect for patients' autonomy and is one of a physician's most fundamental professional obligations. As previously noted, physicians have a duty to present medical facts accurately,<sup>30</sup> including the risks, benefits, and costs of treatment alternatives,<sup>31</sup> and not to withhold information from patients.<sup>32</sup>

Providing information about treatment options that the physician sincerely believes are morally objectionable or about how a patient might obtain an objected-to treatment elsewhere is morally distant from what a physician's deeply held beliefs tell him or her is wrong. Providing information is sufficiently distant that the risk to a physician's integrity is outweighed by the professional obligation to inform, given the strong ethical importance of informed consent.<sup>33</sup> Physicians can avoid any taint of complicity by notifying prospective patients prior to initiating a patient-physician relationship about interventions or services that conscience prohibits the physician from offering.<sup>34</sup>

### **Duty to Refer**

The matter of physicians referring patients to physicians who will provide an objected-to intervention or service is more challenging. Physicians have an ethical duty not to abandon their patients and to provide for continuity of care.<sup>35</sup> While these ground an obligation to refer a patient when a physician cannot or will not provide the needed care, referring a patient for care that violates the physician's deeply held beliefs is clearly less morally distant from the objectionable act than is providing information.

Determining whether or how to refer requires that a physician consider the medical need, risks, and burdens to the patient of referring or not referring, and the likely impact of the physician's decision on colleagues and others. The greater the like-

lihood or severity of harm, the stronger is a physician's duty to facilitate, in some way, a patient's access to needed care, even in the face of becoming in some measure complicit in doing what the physician believes is wrong. Conversely, when there is little risk of harm, the weaker is the duty to facilitate access to the objected-to intervention or service. Physicians may have a heightened duty to refer a patient in the context of an established patient-physician relationship.<sup>36</sup>

Physicians have a number of options to discharge the duty to refer, ranging from something as simple—and morally distant from wrongdoing—as providing a toll-free number or local hospital number to the patient to inquire about services, to something as formal as referring a patient to a specific physician or institution.<sup>37</sup>

Physicians may also avoid (or at least minimize) their moral complicity by terminating the patient-physician relationship and encouraging the patient to find another physician who is better able to meet the patient's needs.<sup>38</sup> However, terminating the relationship is ethically permissible only when the timeliness of care is not a factor and the physician adheres to the ethical guidelines set for terminating a relationship, including providing needed care until the patient is transferred to another physician and ensuring that the patient's records are made available to the new physician.<sup>39</sup>

## **PROTECTING PATIENTS, PRESERVING INTEGRITY**

The freedom to maintain moral views and to act on them is central to a pluralist, democratic society.<sup>40</sup> Physicians, no less than patients, should be able to expect that they will be respected as moral agents. There is reason to think that preserving the opportunity for physicians to act according to the dictates of their conscience may, as Douglas White and Baruch Brody said, "yield better overall medical quality by fostering a diverse workforce that possess integrity, sensitivity to patients' needs, and respect for diversity."<sup>41</sup> In determining whether and how to exercise their conscience, physicians have a responsibility—rooted in their own status as moral agents and their commitments as medical professionals—to deliberate thoughtfully about the implications of their decisions for the well-being of patients and others and to seek ways to resolve or reduce moral tension that will not unduly compromise the physician's moral integrity nor disproportionately burden patients.

**MEMBERS OF CEJA WHEN OPINION 1.1.7  
WAS ADOPTED BY THE AMA IN NOVEMBER 2014**

Patrick W. McCormick, MD, MBA, chair  
Stephen L. Brotherton, MD, vice chair  
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**NOTES**

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# Accommodating Conscientious Objection in Medicine—Private Ideological Convictions Must Not Trump Professional Obligations

*Udo Schuklenk*

## ABSTRACT

The opinion of the American Medical Association (AMA) Council on Ethical and Judicial Affairs (CEJA) on the accommodation of conscientious objectors among medical doctors' aims to balance fairly patients' rights of access to care and accommodating doctors' deeply held personal beliefs. Like similar documents, it fails. Patients will not find it persuasive, and neither should they. The lines drawn aim at a reasonable compromise between positions that are not amenable to compromise. They are also largely arbitrary. This article explains why that is the case. The view that conscientious objection accommodation has no place in modern medicine is defended.

## INTRODUCTION

The thorny issue of conscientious objection accommodation in medicine is back on the agenda, and not just in the United States. Just slightly north, in Canada, religious doctors' groups are taking provincial regulatory bodies to court in order to establish that their members are well entitled to the accommodation of their conscience-based objections to participation in Canada's medical aid-in-dying

regime.<sup>2</sup> Guaranteed patients' access to this service takes a back seat to concerns about doctors' individual feelings on the subject. This is so, despite the fact that the Canadian Medical Association, as well as existing legislation in Quebec, define medical aid in dying uncontroversially as a medical procedure.<sup>3</sup> Why are we typically going out of our way to ensure that the accommodation of conscientious objectors is guaranteed, regardless of the impact this has on patients' access to care? The long and short of it is that we are traditionally so accustomed to taking conscience claims made by doctors sufficiently seriously that there is little debate about the normative justifiability of conscience accommodation policies. This shows both in the AMA's "Opinion 1.1.7, Physician Exercise of Conscience"<sup>4</sup> itself, as well as in the helpful backgrounder prepared by BJ Crigger and colleagues.<sup>5</sup> (The full text of the AMA opinion is included as figure 1 in that article). Both lack a plausible ethical or professional justification for why society ought to accommodate conscientious objectors in medicine. That being said, the AMA opinion is in line with the AMA's historical embrace of what Robert Baker called "a laissez-faire conception of ethics, according to which physicians should be free to follow the dictates of their personal moral responsibilities."<sup>6</sup> Not coincidentally, Baker, the pre-eminent historian of medical ethics in the U.S., described the AMA as an organization that "abdicated its role as moral conscience of the profession."<sup>7</sup>

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### CONSCIENTIOUS OBJECTION ACCOMMODATION AND THE “INTEGRITY OF MEDICINE”

The AMA opinion claims that the protection of individual conscience accommodation is “important for preserving the integrity of the medical profession.” While it is not unusual for such policy statements not to provide reason or evidence and to rely solely on the authority of the issuing organization or institution,<sup>8</sup> it is nonetheless surprising that this claim is followed by “thus physicians have considerable latitude to practice in accord with well-considered, deeply held beliefs that are central to their self-identities,” as if that followed logically from the initial unsubstantiated claim. If anything, we have reason to suspect that conscientious objection accommodation would have the opposite effect, namely to subvert the integrity of the profession. It would subject eligible patients seeking help from a medical professional, *qua* professional, to the vagaries of this professional’s idiosyncratic views of the universe. It is worth noting that this claim is not repeated in the article by BJ Crigger and colleagues. They focus their attention on the alleged need to accommodate conscientious objectors in order to protect their individual integrity. That clearly is not the same as claiming that the profession’s integrity would be at risk if individual conscientious objectors were not accommodated.

#### “CONSCIENCE” CLAIMS— MUST THEY BE REASON BASED?

Remarkably, the AMA opinion assumes that it is self-evident what “conscience” is, because no attempt is made to define the central concept of the document. Crigger and colleagues offer us a reasonable attempt at conceptualizing “conscience,” but we cannot be sure that that is actually an interpretation shared by the AMA. Crigger and colleagues mistakenly think that there is a need for conscientious objectors to show that their beliefs are deeply held, and that these beliefs do not “rest on intuition or emotion,” a view mirrored by the AMA opinion. They also expect that “the physician be able to articulate how the values and principles that constitute the physician’s identity-conferring beliefs justify acting one way or another.” Crigger and colleagues are not alone in believing that objectors ought to have a reasonable case when they demand accommodation. That conscientious objectors would have to be able to provide reasons for their accommodation request seems obvious to most people.

Many authors have arrived at a similar point of view, and they have tried to develop reasonableness criteria that objectors ought to meet.<sup>9</sup> However, and here reality meets theory, when it comes to, for instance, religious beliefs, it is practically impossible for any doctor to demonstrate that her or his professed beliefs are based on anything other than intuition and emotion.<sup>10</sup> Worse, we would have reason to be skeptical about the conviction claims made by religious conscience objectors, because the odds are not negligible that literally they do not believe what they claim to believe.<sup>11</sup> That matters quite a bit, given that the overwhelming majority of conscience-based objections are of a religious nature in the United States, but also in Europe, and I suspect elsewhere.<sup>12</sup> Unlike what Crigger and colleagues seem to think, today’s conscientious objection protections are designed in such a way that objectors do not have to show that their convictions are based on something more reasonable than “intuition or emotion.” The reason for this is that the courts, and legislators, rightly, refuse to take a stance on the typically religious convictions that purportedly motivate these objections.

The United States Supreme Court wrote on the subject,

What principle of law or logic can be brought to bear to contradict a believer’s assertion that a particular act is “central” to his personal faith? Judging the centrality of different religious practices is akin to the unacceptable “business of evaluating the relative merits of differing religious claims” . . . it is not within the judicial ken to question the centrality of particular beliefs or practices to a faith, or the validity of particular litigants’ interpretation of those creeds . . . courts must not presume to determine the place of a particular belief in a religion or the plausibility of a religious claim.<sup>13</sup>

The courts have correctly noted that there is no way to test the reasonableness of these convictions, so, what matters, in law, is that someone says that she or he holds particular views, ideally Christian views, because we are familiar with those traditions in liberal Western democracies. For all practical intent and purposes, that is the state of intellectual affairs with regard to the accommodation of conscientious objectors in medicine. It seems an exercise in futility for U.S.-based proponents of reasonableness criteria, such as Robert F. Card<sup>14</sup> or Crigger and colleagues, to argue for particular standards an objector must meet when it is clear that your average religious objectors cannot meet those standards, and

when it is clear that the highest court in the U.S. has already rejected that approach.

### WHY ACCOMMODATE CONSCIENTIOUS OBJECTORS?

This brings us to the crux of the matter. Some of the guidance pieces of the article by Crigger and colleagues fall into place once we accept their premise that conscientious objectors have a moral claim to be accommodated. It is then that we can engage in the activities they (and the AMA opinion) engage in, namely to draw up principles or policies that should govern conscientious objectors. However, it is far from clear that that is the appropriate response to accommodation claims. Incidentally, the conceptual problems mentioned earlier come back to haunt Crigger and colleagues throughout their article. I will return to this later in this commentary.

A fair number of authors have argued over the years that the starting point of both the article by Crigger and colleagues as well as the AMA opinion is mistaken, and that we should not accommodate conscientious objection claims.<sup>15</sup> I, too, have argued that we have no sound moral reason to do so.<sup>16</sup> This is not the space to present these arguments in great detail again, but in a nutshell, here they are: People join the medical profession (and particular specialties within it) voluntarily. In fact, they often compete vigorously for scarce medical school places. They know that their profession's scope of practice is ultimately determined by society, the very same society that provides these professions with a monopoly on the provisions of services that fall within that scope of practice. Medical practice is invariably changing over time and so is the societal understanding of what forms part and parcel of that monopoly practice. Doctors cannot credibly claim that the addition of a new professional service is irrelevant to their obligations, because they did not sign up for a deal that included that particular service. In fact, they decided knowingly to join a profession the scope of practice of which was beyond their individual control.

It could be argued that doctors had reason to assume that conscientious objection accommodation would be available to them in case of the addition of services with which they might disagree. This argument is also flawed, because conscientious objection accommodation itself is a policy issue that is bound to be subject to change. A number of European countries, for instance, including Sweden, Finland, and Iceland, have done away with conscientious objection accommodation in the context of

abortion, with no negative consequences for the profession's service delivery.<sup>17</sup>

As I have put it elsewhere, the upshot of this argument is this:

It remains unclear why untestable conscience claims from privileged professionals who voluntarily join a particular profession, and who have been endowed by society with a monopoly on the provision of particular procedures, should be accommodated, given that this toleration subverts the very objectives the profession is designed to achieve. This does not deny anyone the right to hold any number of private religious or moral beliefs, as they see fit and as they choose to hold. What we are denying is that professionals are entitled to subvert the objectives of the profession they voluntarily joined by prioritizing their private beliefs over the professional delivery of services to the public, especially when they are monopoly purveyors of those services.<sup>18</sup>

### CONCEPTUAL PROBLEMS IN THE AMA OPINION

The AMA opinion seems to conflate private beliefs and professional personas or roles when it states that doctors "are not defined solely by their profession," as if that mattered. The opinion then proceeds to making the already alluded to unsubstantiated claim about the integrity of the medical profession being at risk if doctors' private views are not accommodated. The opposite is likely the case. Patients do not visit their doctors as private individuals with private, deeply held beliefs, they visit doctors as professionals, and they have every reason to expect uniformly professional services across the profession and between professionals. Conscientious objection accommodation does away with all of that, and as a result, it does away with medical professionalism while prioritizing doctors' idiosyncratic private convictions (or, more precisely, these doctors' untestable claims about the substance and meaning of those convictions) both over their professional obligations, but also over the care of patients and health outcomes. Conscientious objection accommodation today, for all practical intents and purposes, prioritizes the protection of the religious conscience over the care of patients. To name just one example, in Italy today about 70 percent of gynecologists conscientiously object to performing abortion. This is arguably a major factor in the staggeringly high back street abortion rate in that Roman Catholic country.<sup>19</sup>

### DOCTORS' MEDITATIVE EFFORTS TRUMP PROFESSIONAL OBLIGATIONS TO PATIENTS

The AMA opinion offers a laundry list of issues doctors should consider when they ask for conscientious objection accommodation, but none of that matters practically, and all of it is introspective. None of the criteria proposed are designed to be tested by the profession, regulatory bodies, or the courts. Part of the reason for this is, as mentioned earlier, that the courts will steer clear of asking for "reason" or "rationality" when it comes to the substance of conscientious objection. That, in turn, reduces these suggestions to a meditative activity as far as objecting doctors are concerned. Patients would be at the receiving end of this meditation lottery. It is disappointing that that is apparently the best a professional association such as the AMA can envisage on this subject.

The skeptical reader might wish to give the opinion's (a) to (g) list a critical trial run. With the exception of (a), "Thoughtfully consider whether and how significantly an action (or declining to act) will undermine the physician's personal integrity, create emotional or moral distress for the physician or compromise the physician's ability to provide care for the individual or other patients,"<sup>20</sup> there is not a single guidance point that would force doctors to explain themselves. However, professionals are accountable for their actions to the societies that gave them monopoly provider status with regard to the provision of scope-of-practice services. The AMA opinion amounts to a "give it some thought" kind of bullet point list addressed at individuals who have already decided that their private ideological convictions are of greater significance than their professional obligations to patients. To ask a "professional" with such a mentality to "be mindful of the burdens their actions may place on fellow professionals,"<sup>21</sup> among other exhortations, seems, frankly, no more than a throwaway line.

Having already conceded the broader point, namely that medical professionals are entitled, *qua* professionals, to decline to provide professional services on untestable private conscience claims, the AMA opinion even concedes what is, in many jurisdictions, considered a compromise position. The compromise position accepts that objecting doctors do not have to provide professional services within their scope of practice, in non-emergency situations, on their conscience say-so, but they must transfer patients, without further ado, to a colleague who they know will provide the requested service. This compromise is not a compromise that objectors would

consider a reasonable compromise. If you believe that abortion is akin to murder, it does not quite amount to a reasonable compromise that you should be obliged to pass a pregnant woman on to a colleague whom you know will commit what you consider to be a murderous act. Guidance point (f) of the opinion instead makes clear that doctors objecting to such transfers, too, would be well entitled to refuse even that giving of information.<sup>22</sup> All of this is deemed to be sound professional advice, against the backdrop of these doctors' unaccountable meditative efforts.

### RANDOMNESS OF WHAT OBJECTIONS SHOULD BE ACCOMMODATED

The AMA opinion, having failed to establish why we ought to accommodate conscientious objectors in the medical profession, fails necessarily, too, when it tries to draw defensible policy lines with regard to the kinds of conduct that objectors should be able to get away with, versus behavior that would be unacceptable. The only concession to patients' interests in the opinion is that doctors must provide care in emergency circumstances, hence their conscience views apparently can be disregarded then. There appears to be some very limited concern by the authors of this document for patients' access to care after all. However, that is roughly where they think the inconveniencing of doctors' idiosyncratic private beliefs should end.

Crigger and colleagues argue that while doctors may decline to provide services to particular patients, doctors must not be motivated by a patient's "race, religion, sexual orientation, disease status, or other reason that would constitute discrimination against a class or category of patient." Presumably this is so because such a motive would be unreasonable. I wholeheartedly agree with their apparently existing AMA opinion, but none of this follows from their view on conscientious objection. On what ground would racist doctors, who belong to an Aryan Nation church, be denied the accommodation of their conscientious objection requests when it comes to patients of particular racial groups that their religion (or other ideology) tells them they must not touch? After all, what matters is that they strongly feel that that is what their religion (or other ideology) requires of them, and that they want to do the right thing by their religion (or other ideology). It is all a very deontological affair, like much of what drives the case for the accommodation of conscientious objectors in the first place. There is nothing by way of argument that can be deployed by conscien-

tious objection accommodationists that does not result in arbitrary policy.

Liberal Western democracies, depending on their constitutional arrangements and the power of institutionalized Christianity, have drawn policy lines in different areas, but none of those are a logical, foreseeable consequence of conscientious objection accommodation itself. Why should a female Muslim psychiatrist not insist that she only speak to her male patients through her *niqap*, and be accommodated? The only reason she would have trouble getting her accommodation request granted today, in liberal Western democracies, is that the statutory bodies or courts are unfamiliar with the ideology she has chosen. In the same way that society denies racist doctors the conscience accommodation that they might seek with regard to patients from certain “races,” they could deny accommodation to doctors who ask for conscience accommodation with regard to abortion or the *niqap*. That this does not occur is likely a consequence of the continuing respect for particular religious convictions and not for others. That, however, is incompatible with a secular state’s neutrality when it comes to conscience views.

#### **WHAT IF FUTURE CONSCIENTIOUS OBJECTORS DID NOT JOIN THE PROFESSION?**

Crigger and colleagues express concern that certain individuals might not join the medical profession if their conscience claims were not readily accommodated. They assume that that is a problem. However, a more plausible reply to this concern would be: “So what?” A lot of people choose not to join the medical profession for any number of reasons. I have a strong tremor in my hands that would prevent me from performing a whole range of professional medical services. It seemed obvious to me that I should not burden patients or fellow professionals with a limited scope of practice approach to professional services and instead leave that profession to those equipped to provide the full range of services that fall within that specialty’s scope of practice. Strangely, when it comes to persons who, prior to joining a profession, make a considered choice to adopt beliefs that would prevent them from delivering the scope of services the profession was established to deliver, Crigger and colleagues decry the supposed loss to the profession, were such individuals unable to join the profession due to the lack of accommodation. I think we ought to celebrate an individual’s decision not to burden future patients and professional colleagues with their idiosyncratic

beliefs by not joining a profession that the scope of services one finds objectionable.

I have taught bioethics for a number of years in a large health sciences faculty. Invariably, among the dentistry students in any given year, there were a fair number of students who explained their choice of profession with their moral objections to abortion. However, many also did consider it unprofessional to burden future patients with their personal convictions on this subject. Hence their decision to study dentistry instead. *Contra* Crigger and colleagues, there is no evidence to suggest that the delivery of quality medical services would suffer if such budding medical doctors decided to pursue other career opportunities. If anything, we should be concerned about the facts from a survey of 2,000 doctors in the U.S.: the authors state that 54 percent of doctors surveyed believe that a supernatural being intervenes in patient care, and that “the religious beliefs and practices of physicians also strongly influence the ways physicians interpret their clinical observations and the empirical data.”<sup>23</sup> Crigger and colleagues then go on to express concerns about “callous, disrespectful” doctors’ unprofessional behaviors, a matter unrelated to the question of whether people with strongly held personal beliefs that affect their ability to perform their professional functions should join such a profession in the first place.

#### **LAST BUT NOT LEAST—THE LAW**

What is the relationship of the argument and analysis presented thus far and the law? As noted earlier, conscientious objection accommodation has been provided for in many a jurisdiction and court cases, so is it not reasonable for professional associations to provide guidance points to professionals wanting to make use of their legal rights? A professional who chooses not to provide professional services due to a judgment call that is not professional, but deeply personal, engages by definition in unprofessional conduct. That remains true even if that professional happens to be legally entitled to such conduct. Professional associations should provide no ideological backing for such unprofessional conduct. They arguably ought to admonish their members to behave professionally at all times, while on the job. Support for conscientious objection accommodation does the opposite.

#### **CONCLUSION**

The AMA opinion provides conscientious objectors with a convenient document to point to when

asking for the accommodation of any objection, bar the provision of professional care during emergency circumstances. I wonder how a group of authors working for a patient lobby organization, rather than the AMA, would have approached the very same issue. It is doubtful that their hypothetical “opinion” would look anywhere close to the AMA “Opinion 1.1.7, Physician Exercise of Conscience.” What I find most puzzling, when reading this opinion and similar documents issued by doctors’ lobby organizations such as the British Medical Association or the Canadian Medical Association, is that there is this pretense that the concerns expressed in these documents have to do with protecting medical professionalism, when they constitute the exact opposite. These documents go out of their way to protect a privileged group of monopoly provider professionals who do not wish to provide the services that they contracted to provide to the public. Professional associations, such as the AMA here, reduce themselves to nothing other than ordinary trade unions lobbying for their members’ interests. That is not objectionable, but it would be helpful if they were at least more transparent about their objectives.

#### NOTES

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23. F.A. Curlin, S.A. Sellergren, J.D. Lantos, and M.H. Chin, “Physicians’ Observations and Interpretations of the Influence of Religion and Spirituality on Health,” *JAMA Internal Medicine* 167 (2007): 649-54.

# Professional Ethics, Personal Conscience, and Public Expectations

*Claudia E. Haupt*

## ABSTRACT

Examining to what extent physicians are, or ought to be, defined by the profession when giving advice to patients, this commentary seeks to offer a better understanding of the potential conflicts that the American Medical Association's (AMA's) "Opinion 1.1.7, Physician Exercise of Conscience," addresses.<sup>1</sup> This commentary conceptualizes the professions as knowledge communities, and situates the physician-patient relationship within this larger conceptual framework. So doing, it sheds light on how and when specialized knowledge is operationalized in professional advice-giving. Physicians communicate the knowledge community's insights to the patient. Thus, departures from professional knowledge as a matter of the professional's personal conscience are appropriately circumscribed by the knowledge community.

The AMA's "Opinion 1.1.7, Physician Exercise of Conscience" declares: "Physicians are expected to uphold the ethical norms of their profession, including fidelity to patients and respect for patient self-determination. Yet physicians are not defined solely by their profession." The aim of this commentary is to probe to what extent physicians are, or ought to be, defined by their profession when they give advice to patients. Examining that question

leads to a better understanding of the interests affected when, as the opinion describes it, "at times the expectation that physicians will put patients' needs and preferences first may be in tension with the need to sustain moral integrity and continuity across both personal and professional life." Three sets of interests intersect in such situations: those of the profession, those of the individual professional, and those of the patient. Sometimes, the tension among them must be resolved in a way that requires the individual professional to put the patient's interests and the profession's expectations first. But sometimes, when value judgments or moral questions are at issue, no amount of specialized training makes the professional more competent to offer professional insights. It is therefore important to understand how and when specialized knowledge is operationalized in professional advice-giving.

## PROFESSIONALS AS MEMBERS OF KNOWLEDGE COMMUNITIES

As a starting point, it is helpful to clarify the role of the individual professional within the profession. The professions are best understood as knowledge communities, that is, communities whose main reason for existence is the generation and dissemination of knowledge.<sup>2</sup> The most important feature of the professions—although the concept of "profession" itself is contested—is their

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knowledge-based character. As Daniel Halberstam noted, while individual professionals “may differ in their individual judgments about particular issues, their role as professionals traditionally implies their subscription to a body of knowledge that is shared among their peers.”<sup>3</sup>

As a result of training and practice, professionals acquire common knowledge and experience, and they draw on a shared body of knowledge in order to solve similar problems.<sup>4</sup> Their common understandings allow for the generation and exchange of insights within the knowledge community. Given the shared knowledge and understandings of this knowledge, members of knowledge communities have shared notions of validity and a common way of knowing and reasoning. Within the profession, the acceptance of professional insights will depend on the rules established by the profession.<sup>5</sup> The current state of the art within the profession provides the foundation for the individual professional’s advice, and current debates within the profession influence what counts as a defensible professional position. The knowledge community, moreover, shares certain norms and values that constitute their professional norms.<sup>6</sup> The relationship between the knowledge community and the individual professional, thus, is defined by their common knowledge. The normative corollary can be found in the law of professional malpractice, in which the standard of care against which the professional’s advice is measured is determined by the profession itself: exercise of the profession according to the degree and skill of a well-qualified professional. The knowledge community thus determines the benchmark against which the individual professional’s liability is assessed. In this way, the individual members of the profession are bound together by the knowledge community.<sup>7</sup>

### **Professional Expectations**

This relationship between the individual professional and the profession leads to certain expectations. The knowledge community’s and the professional’s interests are reciprocal when it comes to dispensing professional advice. The knowledge community’s interest lies in having the individual professional render accurate, comprehensive advice. Correspondingly, the individual professional has an interest in communicating the message according to the standards of the profession.<sup>8</sup> Because of these reciprocal interests, the proper site for conscience formation and negotiation of accommodations is located within the profession. The AMA’s opinion on physicians’ exercise of conscience is one such

effort. Health law scholar Elizabeth Sepper notes that “physicians’ conscientious judgments must be rooted in shared professional norms.” The result is that arising “conflicts manifest themselves between a patient’s values and the values of the profession as a whole, rather than one doctor’s values.”<sup>9</sup>

While there is no claim to superior competence regarding value judgments *per se*, the knowledge community is able to assess value judgments in light of its shared knowledge. Within its internal discourse, it can assess the effect of value judgments on professional knowledge and advice-giving by the individual professional. This tracks Sepper’s observation that “each physician must seek to maintain professional integrity, not only personal beliefs. One’s fellow physicians serve as a—or perhaps the—referent moral community.”<sup>10</sup> As a result, justifications for departure from professional consensus should originate within professional norms and ethics.

Multiple links tie the individual professional back to the knowledge community. Halberstam notes that the professional “is understood to be acting under a commitment to the ethical and intellectual principles governing the profession and is not thought of as free to challenge the mode of discourse or the norms of the profession while remaining within the parameters of the professional discussion.”<sup>11</sup> The malpractice liability regime, as already mentioned, likewise assumes this connection in imposing the profession’s standard of care on the individual professional. Professionals may be held liable for “unprofessional” advice, that is, advice that fails accurately to communicate the knowledge community’s insights.<sup>12</sup> Professional malpractice liability holds the individual professional to follow the standards of the profession. It ensures that the professional’s advice accurately communicates the knowledge community’s insights within the professional-client, or physician-patient, relationship. On the flip side, “unprofessional” advice is unprotected. Thus, Alex Stein writes, “[a] doctor commits malpractice when he treats a patient in a way that deviates from the norms established by the medical profession.”<sup>13</sup> It is thus the knowledge community that determines the standard of care.

### **Public Expectations**

Patients seeking professional advice will reasonably expect that they will receive competent and comprehensive professional advice in accordance with the profession’s insights. That is to say, patients expect that they will access the entire body of knowledge that constitutes the state of the art in the field.

The physician-patient relationship—like any professional-client relationship—is typically characterized by an asymmetry of knowledge; patients seek a physician's advice precisely because of this asymmetry. The very reason a physician's advice is valuable to patients is thus predicated on the knowledge the physician possesses and clients lack.<sup>14</sup> The nature of this relationship gives rise to fiduciary duties.<sup>15</sup> The client's interests are only served if the physician communicates professional knowledge that is accurate (under the knowledge community's current assessment), reliable, and personally tailored to the specific situation of the patient. To bridge the knowledge gap, and to ensure the protection of the patient's decisional autonomy interests, the physician has to communicate to the patient all information necessary to make an informed decision.<sup>16</sup>

### THE BASIS OF PROFESSIONAL ADVICE

Given these expectations, what justifications underlie valid professional advice? As just mentioned, patients seek a physician's advice because they want to access a useful body of knowledge that physicians possess but patients lack. This asymmetry of knowledge is the very reason a professional's advice is useful to the patient. In order to solve the patient's problem, the patient depends on accurate and comprehensive professional advice. Yet sometimes the physician may depart from, or refuse to deploy, the full range of professional knowledge for various reasons. We might think of them as outliers from professional knowledge.<sup>17</sup> And these outliers' advice may be distinguished by looking at the justifications underlying the advice that departs from professional consensus.

Outliers within knowledge communities whose disagreement is based on alternative assessments within the range of the profession's shared ways of knowing and reasoning are part of the knowledge community. Their advice constitutes good professional advice so long as it reflects defensible findings based on the profession's agreed-upon standards for evaluating professional knowledge. Generally, we want to encourage this type of outlier, because new ways of thinking advance the field and may gain the status of core knowledge. Consider, for instance, the increased acceptance of the medical benefits of marijuana, once considered an outlier position. But outliers whose disagreement is premised on rejecting the shared ways of knowing and reasoning that tie the profession together due to external, including religious, beliefs place themselves outside the knowledge community.

### Professional Knowledge

Professional knowledge is not monolithic, and there is a range of opinions that count as good professional advice.<sup>18</sup> The knowledge community's shared ways of knowing and reasoning limit the range of acceptable opinions found within them.<sup>19</sup> From a legal perspective, the law of professional malpractice and the law governing the admissibility to expert testimony traditionally take this into account.

As Robert Post has pointed out, "Malpractice law protects the vulnerability of clients by requiring professionals to maintain strict standards of expert knowledge."<sup>20</sup> In other words, malpractice liability ensures that the professional's advice accurately communicates the knowledge community's insights within the physician-patient relationship. The tort regime has developed the doctrine of "respectable minority" or "two schools of thought," available as defenses against claims of malpractice in many jurisdictions, to acknowledge the fact that there often is not one single correct answer.<sup>21</sup> The doctrine states that "Where two or more schools of thought exist among competent members of the medical profession concerning proper medical treatment for a given ailment, each of which is supported by responsible medical authority, it is not malpractice to be among the minority . . . who follow one of the accepted schools."<sup>22</sup> Ultimately, it is up to the knowledge community to determine what constitutes good advice.

The law of evidence bases the admissibility of expert knowledge on various factors, depending on the jurisdiction. In all jurisdictions, however, the common factor concerns methodology. Courts governed by *Frye v. United States* defer to the scientific community by asking whether there is "general acceptance in the particular field,"<sup>23</sup> while courts governed by *Daubert v. Merrell Dow Pharmaceuticals, Inc.*,<sup>24</sup> are asked "to judge science by the standards that scientists deploy in judging science."<sup>25</sup> This mirrors the knowledge community's shared notions of validity and common ways of knowing and reasoning upon which valid professional advice should be based.

### Exogenous Bases

But sometimes, professional advice may not be grounded in these shared notions of validity and common ways of knowing and reasoning. Pharmacists who believe that abortion is a grave moral wrong and therefore refuse to advise on the availability of certain forms of birth control they consider abortifacients, for example, do so based on a personal religious belief that is not the result of a

reinterpretation of professional knowledge by means of a shared methodology. Physicians, likewise, may have a political, philosophical, or religious disagreement with the profession. Justifying departures from professional knowledge and limiting otherwise available advice based on such exogenous reasons places professionals outside of the knowledge community. Instead, religious or other exogenous justifications form the basis for the professionals' advice. If patients do not receive full information, they may not know what is being withheld, or even that any information is being withheld.<sup>26</sup>

Furthermore, patients do not know what is contested professional knowledge and what is not. They may encounter a professional who, for religious reasons, will not provide advice on certain treatment options or medications. But the justification for omitting this information will not be based on professional knowledge. Patients, however, in order to make an informed decision, must reasonably be able to expect that professional advice will be based upon reasons internal to the knowledge community rather than individual, exogenous justifications for departure.

Could this information deficit be cured by disclosure? Advice-giving physicians could tell patients that the advice they dispense is limited. The state might even require that any professional whose advice departs from the knowledge community's insights, due to exogenous justifications, provide such a disclosure.<sup>27</sup> In principle, such disclosure will inform patients of the limited scope of professional advice. However, in practice, there is a significant filtering problem. Imagine doctors informing patients that, due to their religious faith, they will only dispense advice consistent with their faith. Even if patients are of the same faith, it is at least questionable whether it will be obvious to patients which advice is left out. Just as professional knowledge communities are not monolithic, faith communities are not monolithic. But even if disclosure puts patients on notice, professionals are still potentially not communicating the full range of professional knowledge. As the AMA's opinion notes, physicians must "make clear any specific interventions of services the physician cannot in good conscience provide because they are contrary to the physician's deeply held personal beliefs, focusing on interventions or services a patient might otherwise reasonably expect the practice to offer." In light of public expectations and the autonomy interests of patients, physicians nonetheless ought to provide comprehensive advice on the full range of available professional knowledge.

## THE LIMITS OF PROFESSIONAL KNOWLEDGE

Knowledge communities have specialized expertise, based on shared understandings of their field's knowledge. The knowledge community has a superior understanding of issues directly related to its core knowledge. But only the knowledge community's specific insights matter. Deference is thus awarded to core knowledge, not to peripheral interests, such as purely economic interests of the profession not based on professional expertise.<sup>28</sup> Likewise, no amount of specialized training by itself makes a professional more competent to render general value judgments on moral issues unrelated or only tangentially related to professional insights. For example, professional determinations based on medical expertise can be made regarding the total and irreversible cessation of all brain functions ("brain death") and its diagnostic criteria. However, it is a value judgment whether this medical diagnosis constitutes the end of life of the individual. This is a matter of ethical, philosophical, and religious dimension beyond medical expertise.

## CONCLUSION

Physicians' primary allegiance ought to be to their patients, on the one hand, and to their professional knowledge community on the other. They are the conduits through which the knowledge community's insights are transmitted to patients. A critic might object that this understanding places the membership in a profession above other constitutive aspects of a physician's identity. I do not mean to suggest that all other aspects of a professional's identity are secondary, and this is particularly true for the professional's religious beliefs. But the focus here is on the role of knowledge communities and the role of the advice-giving professional within the physician-patient relationship. In this position as conduit between the knowledge community and the patient, within the physician-patient relationship, the individual rendering professional advice is a professional first. And departures from professional consensus as a matter of personal conscience of the professional are appropriately circumscribed by the knowledge community, such as in the AMA's opinion on physicians' exercise of conscience.

## NOTES

1. "Opinion 1.1.7, Physician Exercise of Conscience," *Code of Medical Ethics* (Chicago, Ill.: American Medical

Association, 2016), included as figure 1 in BJ Crigger, S.L. Brotherton, P.W. McCormick, and V. Blake, "Report by the American Medical Association's Council on Ethical and Judicial Affairs on Physician's Exercise of Conscience," in this issue of *JCE*, 27, no. 3 (Fall 2016).

2. C.E. Haupt, "Professional Speech," *Yale Law Journal* 125, no. 5 (March 2016): 1150-547.

3. D. Halberstam, "Commercial Speech, Professional Speech, and the Constitutional Status of Social Institutions," *University of Pennsylvania Law Review* 147, no. 4 (April 1999): 771-874.

4. Haupt, "Professional Speech," see note 2 above, p. 1250-1.

5. *Ibid.*, 1251.

6. *Ibid.*

7. *Ibid.*, 1242.

8. *Ibid.*, 1251.

9. E. Sepper, "Doctoring Discrimination in the Same-Sex Marriage Debates," *Indiana Law Journal* 89, no. 2 (Spring 2014): 703-34.

10. *Ibid.*, 735.

11. Halberstam, "Commercial Speech," see note 3 above, p. 834.

12. C.E. Haupt, "Unprofessional Advice," *University of Pennsylvania Journal of Constitutional Law* (forthcoming, 2017).

13. A. Stein, "Toward a Theory of Medical Malpractice," *Iowa Law Review* 97 (2012): 1209-12.

14. Haupt, "Professional Speech," see note 2 above, p. 1271.

15. Halberstam, "Commercial Speech," see note 3 above, p. 845.

16. Haupt, "Professional Speech," see note 2 above, p. 1271.

17. C.E. Haupt, "Religious Outliers: Professional Knowledge Communities, Individual Conscience Claims, and the Availability of Professional Services to the Public," in *Law, Religion, and Health in the United States* ed. I.G. Cohen, H.F. Lynch and E. Sepper (Cambridge, U.K.: Cambridge University Press, forthcoming, 2017).

18. Haupt, "Unprofessional Advice," see note 12 above.

19. Haupt, "Professional Speech," see note 2 above, p. 1251.

20. R.C. Post, *Democracy, Expertise, and Academic Freedom: A First Amendment Jurisprudence for the Modern State* (New Haven, Ct.: Yale University Press, 2012), 47.

21. Haupt, "Unprofessional Advice," see note 12 above.

22. *Chumbler v. McClure*, 505 F.2d 489, 492 (6th Cir. 1974).

23. *Frye v. United States*, 203 Fed. 1013, 1014 (App. D.C. 1923).

24. *Daubert v. Merrell Dow Pharmaceuticals, Inc.*, 509 U.S. (1993).

25. C.B. Mueller, "Daubert Asks the Right Questions: Now Appellate Courts Should Help Find the Right Answers," *Seton Hall Law Review* 987 (2003): 1007.

26. J. Morrison and M. Allekotte, "Duty First: Towards

Patient-Centered Care and Limitations on the Right to Refuse for Moral, Religious or Ethical Reasons," *Ave Maria Law Review* 9, no.141 (2010): 148-9.

27. C.M. Corbin, "Compelled Disclosures," *Alabama Law Review* 65, no. 1277 (2014): 1340-51.

28. Stein, "Toward a Theory of Malpractice," see note

## Who Judges Harm?

*Nadia N. Sawicki*

### ABSTRACT

The American Medical Association's (AMA's) "Opinion 1.1.7, Physician Exercise of Conscience" attempts to help physicians strike a reasonable balance between their own conscientious beliefs and their patients' medical interests in an effort to minimize harms to both.<sup>1</sup> However, some ambiguity still remains as to whether the severity of harms experienced by physicians and patients is to be assessed externally (by policy makers or by a professional body like the AMA), or internally by the subjects of those harms. Conflicts between conscientious physicians' self-assessments of the moral harm associated with various actions and the AMA's external assessments of such harms are likely to lead to challenges in the implementation of some provisions of its opinion. This commentary argues, however, that provisions (b) and (e) of the opinion, which describe the information physicians should provide about their own scope of practice and about the existence of controversial procedures, are less likely to conflict with physicians' subjective assessments of moral harm, and therefore will face fewer challenges in implementation.

The AMA's "Opinion 1.1.7, Physician Exercise of Conscience" is grounded in the principle that physicians have a responsibility to engage in sincere and nuanced moral analysis when balancing their

own conscientious convictions against their patients' interests. In a climate of increasingly polarized public debate, this modest foundational principle deserves emphasis, lest the sound bites of commentators with absolutist agendas crowd out individual actors' critical assessments of their own moral responsibility.

The AMA opinion and the commentary on the opinion by members of the AMA Council on Judicial and Ethical Affairs (CEJA),<sup>2</sup> who wrote the opinion, reference the professional, personal, and social harms that can arise if healthcare providers are denied the opportunity to live and practice in accordance with their deeply held beliefs, as well as the harms that patients can suffer if their access to healthcare services is limited as a result of a careprovider's conscientious objection. But one ambiguity that still remains is who, in such situations, is entitled to make judgments about the relative severity of these harms.

Consider the types of conflicts that may arise as a result of this ambiguity. When a physician who opposes abortion maintains that transferring the medical records of a patient seeking abortion is morally impermissible because it constitutes complicity with an immoral act, must we defer to the physician's determination? Or can professional bodies, employers, policy makers, or patients deem the transfer of the patient's records too "morally distant" from the act of abortion to constitute a harm to the

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physician? Likewise, when a patient claims that she is burdened by having to travel overnight and miss work for an elective abortion because her local providers refuse to perform the procedure, must we defer to her assessment of the severity of the harm she will suffer? Or can policy makers, professional societies, or physicians make their own determinations of what constitutes a burden of access? Could they potentially even conclude that limiting access to elective medical procedures can never constitute a harm to patients?

If we demand that physicians take potential harms into account when they engage in moral deliberation about how they choose to practice medicine, any ambiguity about how these harms are to be measured will lead to dramatic (and likely self-serving) variability in the outcome of the moral calculus. Therefore, the AMA opinion and the CEJA commentary ought to at least engage with the question of how harms to physicians and patients should be assessed, and ideally establish consistent and ethically sound guiding principles for the assessment of such harms. However, the commentary appears to give significant deference to patients' self-assessments of harm, while instead making external judgments about "moral distance" in evaluating harms to physicians—a contrasting set of positions for which the CEJA gives no principled defense.

In discussing the connection between conscientious refusal and harm to patients, the CEJA commentary refers to physicians' duty to "promot[e] the welfare of patients," to "provide care in keeping with a patient's medical needs and in light of the patient's values, preferences, and goals for care," and to consider whether a treatment refusal will "unduly compromise a patient's well-being or cause a patient to experience financial, medical, psychological, or other harm." The commentary notes that "harms to patients can come in a variety of forms," and that physicians should "be sensitive to the fact that what may initially seem to be a minor harm or burden would constitute a significant barrier to care for a patient, depending on the patient's individual situation." Taken together, these statements indicate that harms to a given patient are identified by reference to that patient's values and preferences, and that physicians ought to give some degree of deference to a patient's self-assessment of harm.

With respect to the evaluation of harms experienced by physicians, however, the CEJA takes a less deferential approach. It asserts that "physicians should have considerable latitude to practice in accord with well-considered, deeply held beliefs that are central to their self-identity;" and refers to moral

distress, compromised personal integrity, and loss of self-respect as consequences of an inability to practice in this way. But when discussing issues of moral complicity, the commentary concludes that "The degree to which an individual's action (or inaction) implicates him or her in a moral wrong depends on the individual's 'moral distance' from the wrongdoer and/or the act," and appears to give little deference to physicians' own perspectives on moral distance. In subsequent sections, the commentary seems to establish conclusive positions on what types of acts are more or less "morally distant," and therefore more or less likely to cause harms associated with moral complicity. "Providing information about treatment options" that the physician finds morally objectionable, according to the CEJA commentary, is "morally distant" enough from providing the treatment itself that "the risk to physician integrity is outweighed by the professional obligation to inform." Providing a referral for such care, in contrast, "is clearly less morally distant from the objectionable act[;]" while merely providing a phone number is more "morally distant." The definitive way in which these conclusions about moral distance are presented suggest that there is some objective way to assess degrees of moral complicity. But the CEJA, unfortunately, provides no justification for reaching its own conclusions about the severity of complicity-related harms.

The AMA opinion could have dictated that harms on both sides are to be assessed subjectively (or internally) by the subjects of those harms; alternatively, it could have established objective (or external standards) about the severity of harms suffered by patients and physicians in various contexts. Instead, without sufficient ethical analysis in the CEJA commentary, it seems to apply different approaches to different types of subjects—reaching its own conclusions about the severity of harm to physicians in cases of moral complicity, while at the same time suggesting deference to patients' perspectives on access-related harms. This position is particularly surprising given that the opinion was adopted by a professional medical body that is likely to have greater expertise in assessing the harms that result from limitations on access to medical care than in evaluating moral culpability within the context of individual belief systems.

Some physicians whose conscientious convictions limit the types of medical care they provide will surely dispute the AMA's assessment of the moral distance (and therefore moral harm) associated with various actions. Any potential disagreement between conscientious physicians and the pro-

fessional body that purports to represent them will thus lead to challenges in the implementation of AMA opinion.

The starkest example of the difficulty that may arise in implementing the AMA opinion when self-assessments and external assessments of moral harm conflict is in the context of physicians' referrals. Provision (f) provides that, in general, physicians should provide patients with referrals for treatments the physicians do not offer. However, it also explicitly recognizes that some physicians' deeply held beliefs might prohibit referral; thus, it offers an alternative option, suggesting that such physicians instead provide patients with "impartial guidance . . . about how to inform themselves regarding access to desired services." But because the opinion does not acknowledge that some physicians may find this alternative equally objectionable (or advise those physicians on how to proceed), the possibility of conflict remains.

Luckily, the AMA opinion also presents two recommendations that are less likely to conflict with physicians' self-assessments of moral harm, and are therefore likely to result in fewer challenges in implementation. These are provisions (b) and (e), relating to the information physicians provide to their patients about their own scope of practice and about relevant treatment options to which those providers object on grounds of conscience.

Provision (b) provides that before entering into a relationship with a patient, a physician with conscientious objections "make clear any specific interventions or services the physician cannot in good conscience provide . . . focusing on interventions or services a patient might otherwise reasonably expect the practice to offer." Even fully crediting conscientious physicians' subjective assessments of moral distance, complicity, and harm, this provision is unlikely to be problematic. In my extensive research of this issue, I have been able to find no principled argument in support of the claim that such a simple notification requirement would render physicians morally complicit in objectionable conduct and thereby cause them harm.<sup>3</sup>

Moreover, even in the most widely publicized modern example of conscientious objection to medical care (albeit in the corporate context), no such argument has been made. Since the 2010 passage of the Patient Protection and Affordable Care Act, religiously affiliated employers have steadfastly objected not only to the act's mandate that they provide contraceptive coverage under their insurance policies, but also to its notification provisions.<sup>4</sup> Notably, however, their objections to the notification

provisions are grounded not in the requirement that they simply identify themselves as religious objectors, but in the fact that this self-identification necessarily triggers the government's use of the employers' own benefits infrastructure to facilitate objectionable contraceptive coverage.<sup>5</sup> According to the petitioners in *Zubik v. Burwell*, "If all the government wanted from petitioners were to know that they want to opt out of the contraceptive mandate, then this litigation would have ended the day it began."<sup>6</sup> Surely, if there were an argument to be made that mere notification of one's conscientious objections to specific types of medical treatment rendered one morally complicit in the objectionable care itself, that argument would have been aired before the Supreme Court rendered a hotly disputed opinion on this issue in the context of corporate objections.

Provision (e) further provides that physicians should "Uphold standards of informed consent and inform the patient about all relevant options for treatment, including options to which the physician morally objects." The commentary by Crigger and colleagues justifies this requirement on the grounds that informing patients about such treatments is "morally distant" enough "that the risk to a physician's integrity is outweighed by the professional obligation to inform[.]" While there is likely a great deal of variation in physicians' perspectives on moral complicity, the conclusion by Crigger and colleagues—that the moral harms associated with informed consent are limited—is not likely to conflict significantly with conscientious physicians' self-assessments of moral harm.

In a 2007 study published in the *New England Journal of Medicine*, 8 percent of physicians surveyed responded that a doctor who objects to a procedure on religious or moral grounds is not obligated "to present all possible options to the patient, including information about obtaining the requested procedure" when discussing treatment options with a patient.<sup>7</sup> However, these survey results may not be sufficient grounds to conclude that individual physicians balancing their own conscientious beliefs against their professional obligations to patients will in fact refuse to comply with the AMA's informed consent provisions now that they are in effect. First, the survey question asks physicians not just about informed consent, but also about providing patients with "information about obtaining the requested procedure," which is more closely akin to a referral conversation. Secondly, physicians' responses to a survey about general professional obligations do not predict how those physicians would respond to an actual case of conflict with their own patient—par-

ticularly if physicians take seriously the AMA's expectation that they engage in nuanced ethical self-analysis when faced with conflicts of conscience.

Finally, from a more substantive perspective, research suggests that even those with highly conservative religious perspectives may not actually oppose an informed consent requirement. For example, although the United States Conference on Catholic Bishops' (USCCB's) "Ethical and Religious Directives for Catholic Health Care Services" provides that physicians are not morally obligated to present information about treatment alternatives that are not "morally legitimate,"<sup>8</sup> some ethicists operating in the Roman Catholic tradition interpret physicians' informed consent obligations under the USCCB's "Directives" to permit (or even require) disclosure of controversial medical treatments.<sup>9</sup> Ronald Hamel, former senior director of ethics for the Catholic Health Association of the United States, has argued that the USCCB's "Directives" should be interpreted to require full disclosure of "all factually relevant information" to patients.<sup>10</sup> "While some will disagree," Hamel writes, "the full disclosure of medically appropriate or indicated options, factually relevant information—including direct abortion—in difficult obstetrical situations can and should occur, within certain parameters."<sup>11</sup>

Even though some conservative perspectives support full informed consent in such contexts, individual physicians may still oppose the AMA's conclusion that the provision of informed consent is not morally burdensome. For these physicians, there may be alternative means of satisfying the goals underlying provision (e). As I have written elsewhere, patients could be put on notice of the existence of treatment alternatives by way of a lesser disclosure duty.<sup>12</sup> Under such a limited disclosure model, physicians would be required to explain that while an objectionable intervention exists (by either referencing the intervention by name, or by speaking generally) it is not available due to their conscientious objection. Physicians would not, however, be required to provide any details about the intervention's medical benefits, risks, or mechanisms of action.<sup>13</sup> Notably, I have been unable to identify any scholarship offering a principled defense of the position that physicians risk being complicit in immoral behavior if they merely inform patients of the existence of morally objectionable but medically relevant treatments.<sup>14</sup> While such a limited disclosure would not fully satisfy provision (e) of the AMA opinion, it might be offered as an alternative (akin to the referral alternative) to help resolve any remaining tension between physicians and the AMA

regarding the moral harms associated with informed consent.

In conclusion, the AMA opinion and the CEJA commentary do not adequately discuss the question of how harm to patients and to physicians ought to be assessed. As a result of this omission, and the fact that the AMA appears to set an objective external standard about moral harms to physicians associated with different types of conduct, it is likely that there will be challenges to the implementation of the AMA opinion (particularly the referral provisions). That said, the AMA's objective approach to assessing moral harm to physicians is likely to be less problematic in the context of provisions (b) and (e), which require that physicians provide patients with information about the physicians' own limitations on practice, and about the existence of medically appropriate treatments. While objections may still arise, I expect that physicians who take to heart the AMA's expectation that they carefully consider the balance of harms when making ethical judgments about appropriate medical practice are unlikely to oppose these modest notification requirements.

#### NOTES

1. "Opinion 1.1.7, Physician Exercise of Conscience," *Code of Medical Ethics* (Chicago, Ill., American Medical Association, 2016).

2. BJ Crigger, S.L. Brotherton, P.W. McCormick, and V. Blake, "Report by the American Medical Association's Council on Ethical and Judicial Affairs on Physicians' Exercise of Conscience," in this issue of *JCE*, 27, no. 3 (Fall 2016). The AMA opinion is reprinted as figure 1 in this article.

3. See N.N. Sawicki, "Mandating Disclosure of Conscience-Based Limitations on Medical Practice," *American Journal of Law & Medicine* 42, no. 1 (1 January 2016): 121-4.

4. Current federal regulations require that employers seeking religious accommodation from the mandate either file a self-certification form with their third-party administrators, or notify the U.S. Department of Health and Human Services of their objection to the mandate. The notification provisions also require that employers identify their insurance issuers or third-party administrators in order for the government to facilitate contraceptive coverage by the employers' existing insurance companies. 26 *C.F.R.* § 54.9815-2713A(b)(2)(B). "Final Rules Regarding Coverage of Certain Preventative Services," 80 *Fed. Reg.* 41318 (July 14, 2015), finalized as 26 *C.F.R.* § 54.9815-2713A.

5. See generally, "Briefs for Petitioners" in *Zubik v. Burwell*, 2016 WL 93988 (U.S. Jan. 4, 2016); *East Texas Baptist University v. Burwell*, 2016 WL 93989 (U.S. Jan. 4, 2016).

6. "Briefs for Petitioners" in *East Texas Baptist Uni-*

versity v. Burwell, 2016 WL 93989 (U.S. Jan. 4, 2016), at \*38-39. See also “The Little Sisters of the Poor’s Brief on the Interim Final Regulation,” *Little Sisters of the Poor v. Burwell* (No. 1:13-cv-02611-WJM-BNB), 2014 WL 4489994, at \*2, FN2 (10th Cir. Sept. 8, 2014) (“The Little Sisters have never objected to merely identifying themselves so that the government can leave them alone.”).

7. F.A. Curlin, R.E. Lawrence, M.H. Chin, and J.D. Lantos, “Religion, Conscience, and Controversial Clinical Practices,” *New England Journal of Medicine* 356, (8 February 2007): 593-600, 593 and 597 (reporting “a cross-sectional survey of 2000 U.S. physicians from all specialties”). An additional 6 percent of respondents reported that they were undecided on this issue.

8. Directive 27 provides that “Free and informed consent requires that the person or the person’s surrogate receive all reasonable information about the essential nature of the proposed treatment and its benefits; its risks, side-effects, consequences, and cost; and any reasonable and morally legitimate alternatives, including no treatment at all” (emphasis added). U.S. Conference of Catholic Bishops, “Ethical and Religious Directives for Catholic Healthcare Services,” 5th ed., 17 November 2009, <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>, p. 20.

9. See R. Hamel, “Early Pregnancy Complications and the Ethical and Religious Directives,” *Health Progress* 48 (May-June 2014) (discussed below); M.R. Panicola and R.P. Hamel, “Conscience, Cooperation, and Full Disclosure: Can Catholic Healthcare Providers Disclose ‘Prohibited Options’ to Patients Following Genetic Testing?” *Health Progress* 52 (January-February 2006) (arguing that under Roman Catholic doctrine, “good moral reasons exist for providing patients with all factually relevant information, including that related to prohibited options”); P.A. Tully, “Morally Objectionable Options: Informed Consent and Physician Integrity,” *National Catholic Bioethics Quarterly* 8, no. 3 (Autumn 2008): 491-504, 491, 502 (arguing that physicians seeking to comply with the USCCB’s “Directives” ought to inform patients about the existence of objectionable options and explain their moral objections); A. Lustig, “Conscience, Professionalism, and Pluralism,” *Christian Bioethics* 18, no. 1 (2012): 72-92, 87-8 (arguing that public disclosures by pharmacists of their refusal to offer contraceptives “may be viewed as the necessary costs of conscientious action.”).

10. Hamel, “Early Pregnancy Complications,” see note 9 above, pp. 50-1.

11. *Ibid.*, 50.

12. Sawicki, “Mandating Disclosure,” see note 3 above.

13. From the perspective of patients’ access, this alternative is clearly suboptimal, because it would impose upon patients the burden of finding new providers who will provide information and treatment. However, this is a required burden even under provision (e) in its current form. Moreover, this burden is no greater than the burden patients currently experience in states with strong legislation protecting conscientious objection by medical pro-

viders. For further discussion of this issue, see Sawicki, “Mandating Disclosure,” see note 3 above, p. 87.

14. Indeed, even the text of USCCB’s Directive 27, which states that informed consent only *requires* disclosure of “morally legitimate” treatment alternatives, would not seem to *prohibit* this limited disclosure alternative. USCCB’s “Directives,” see note 8 above, p. 20. See also Tully, “Morally Objectionable Options,” see note 7 above, pp. 502-3 (explaining why complicity doctrine would not bar mere disclosure of morally impermissible options).

# Action Steps and Solutions for Physicians' Exercise of Conscience

*Eliza Blanchard and Lynn Stoller*

## ABSTRACT

Conscience can influence physicians' interactions with patients in myriad ways and, by extension, can influence the interactions and internal dynamics of a health care team. The AMA's opinion around physicians' exercise of conscience appropriately balance the obligations physicians have to their patients and profession, and the rights of physicians as moral agents to exercise their conscience.<sup>1</sup> While the opinion is an effective starting point, further guidance is necessary to clarify the process by which physicians should identify, manage, and, if necessary, report their conscientious refusals to patients, supervisors, or colleagues. In addition to laying out a proposed process for identifying and managing issues of conscience, this article will use relevant and timely examples to help clarify how a physician could apply this process in an instance of conscientious refusal.

## INTRODUCTION

Conscience can influence physicians' interactions with patients in myriad ways and, by extension, can influence the interactions and internal

dynamics of a healthcare team. The AMA's opinion around physicians' exercise of conscience appropriately balances the obligations physicians have to their patients and profession, and the rights of physicians as moral agents to exercise their conscience. The opinion emphasizes many important nuances, including the difference between refusing to participate in a certain procedure, such as abortion or providing death-hastening drugs, and refusing to treat a certain patient because of that patient's race, gender, sexual orientation, gender identity, religion, or other protected class or identifier. The first is allowable under the dictates of physician conscience; the second constitutes discrimination, which is usually illegal and always unethical.<sup>2</sup>

Another important nuance recognized by the AMA's opinion is whether patients can access the care they wish to receive elsewhere, in a non-burdensome way that does not require them to travel a significant distance, spend a significant amount of money, or delay or compromise the quality of their care. Physicians are more likely to have the right to refuse to provide care when patients can access that care elsewhere than if patients cannot access the care elsewhere, or if doing so would be significantly burdensome. In this way, patients' right to the care they wish to receive can often be balanced with the physician's right to conscience, without leading to precedent in which patients can lose their ability or right to access necessary medical care.

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In spite of the strengths of the AMA opinion, further guidance is necessary to clarify the process by which physicians should identify, manage, and, if necessary, report their conscientious refusals<sup>3</sup> to patients, supervisors, or colleagues. In addition to laying out a proposed process for identifying and managing issues of conscience, this article will use relevant and timely examples to help clarify how a physician could apply this process in an instance of conscientious refusal.

### RECOGNIZING IDENTITY

The AMA accurately points out that “physicians are not defined<sup>4</sup> solely by their profession. They are moral agents in their own right and, like their patients, are informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs.”<sup>5</sup> This point may seem self-evident, but in our work training physicians and physicians-in-training in religio-cultural competence,<sup>6</sup> physicians often express the perspective that they are defined—at least in their interactions with patients—solely by their professional role. Too many times physicians don’t take into account the extent to which they are formed by their social identities such as race, gender, sexual orientation, socioeconomic status, veteran status, immigrant status, or religion. They often think of themselves as value- and culture-neutral, responding to a patient’s values and culture without their own coming into play. In reality, the goal of religio-cultural competence is that patients receive competent care that takes into account their religious and cultural beliefs and practices, and are not negatively impacted by their physician’s religious and cultural beliefs and practices. In other words, the values and perspective of the physician should not prevent patients from making healthcare decisions that are in line with their own values and perspective on what is right for them, and from having those decisions honored as long as it is legal to do so.

The first step to managing conscience in the care of patients, then, is to recognize that physicians are in fact themselves “informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs,” and that these social identities may impact what care a physician is or is not comfortable delivering to patients. Once these social identities have been recognized and acknowledged in an encounter with the patient, physicians can begin the process of managing these identities to ensure the provision of culturally competent patient care.

### TYPES OF OBJECTIONS AND ASSOCIATED ACTIONS

It is also important for physicians to identify when they conscientiously object to providing certain care and when they object to providing care for reasons other than conscience. Objections to providing care can be divided into the following categories:

- *Personal preference*: Personal religious, spiritual, moral, and/or cultural preferences. An example might be a physician who objects to a family who wishes to perform an exorcism on the grounds that the physician personally believes it is silly or inconvenient. She/he does not have safety concerns and does not conscientiously object to the practice, in that she/he does not find it to be morally or ethically wrong. Instead, the physician’s cultural norms may cause her/him to think the exorcism will not have an impact; it makes the physician uncomfortable; and the physician would prefer not to be involved.
- *Professional integrity*: Core professional and legal roles, responsibilities, and obligations. An example might be a physician who objects to a Jehovah’s Witness couple who refuse to let their child with sickle-cell anemia receive a blood transfusion. The physician might object to treating this patient in accordance with the family’s preferred treatment plan on the grounds that doing so would violate the physician’s ethical and professional obligations to the patient.
- *Personal conscience*: Core moral and/or religious beliefs regarding what is right or what is wrong. An example might be a physician who objects to a patient’s request to terminate a pregnancy. The physician would be experiencing a conscientious objection if she/he thinks that participating in the procedure would be a violation of her/his personal and religious beliefs regarding the sanctity of life, and that the physician would be unable to live with her- or himself if she/he participated in this procedure.<sup>7</sup>

Understanding what type of objection they are experiencing can help physicians to identify which action steps to take next. If the physicians’ objection is based on personal preference, they can likely accommodate a patient’s request in spite of their discomfort, or suggest a compromise that helps to mitigate any inconvenience caused by the request, while still fundamentally honoring it.<sup>8</sup> If the physicians’ objection is based on professional integrity, they can consult hospital resources such as a lawyer, patient

advocate, and ethics committee to receive guidance as to whether following the patient's request actually would constitute a legal or ethical violation. They can also find out more about the patient's request and respectfully share more about why they object, with the goal of either reaching a compromise or, if all else fails and the action the patient is requesting is not legal, refuse to continue care.<sup>9</sup> Finally, they can suggest alternative methods when possible—for example, the possibility of a bloodless transfusion for a Jehovah's Witness patient. It is important to keep in mind that while alternatives should be explored, not all alternatives will be acceptable to all patients, even those who share a religious affiliation—for example, Jehovah's Witness patients may differ in which blood products they are and are not willing to accept.

Another example of this might be female genital cutting. This practice is not legal in the United States, so physicians who are asked to perform such a procedure could neither do so, nor transfer the patient to another physician. The best option in this type of situation is to educate the individual requesting the procedure on the potential harms resulting from this procedure and the fact that it is illegal, but in a respectful way so that the patient or family do not stop seeking healthcare.<sup>10</sup>

Physicians who object to providing care based on their personal conscience should follow a different type of action plan. They should inform their supervisor of any conscientious objections to providing care that they have, as soon as possible.<sup>11</sup> This might mean telling a supervisor when an objection arises in the course of caring for a specific patient; but it might also mean pro-actively telling a supervisor about any conscientious objections to providing types of care. For example, Jewish physicians who do not believe that brain stem death constitutes death, and know that they would conscientiously refuse to remove artificial nutrition or hydration from a patient who has been declared brain stem dead, should notify a supervisor of this objection before an emergency situation develops in which this objection may pose problems for a patient or family. This type of notification might happen at different stages, depending on the specific objection and how well the physicians are able to anticipate the objection ahead of time, based on the type of care they provide. Some physicians may have a deeply held objection to a procedure that they anticipate being asked to perform in the course of their work, and can pro-actively notify a supervisor as soon as they begin their job. Other physicians may not be fully able to anticipate which situations or

procedures they object to until the situation arises or the procedure is requested. Since religiosity is fluid and flexible, the procedures that physicians object to may not be static throughout their time in practice. Again, physicians should notify supervisors if a procedure they used to object to is now acceptable to them, or *vice versa*.

Even when a conscientious objection is invoked, physicians should ensure that they inform patients of all available medical options, without trying to sway the patient in the direction that they prefer. If necessary, physicians should refer or transfer care to another physician, if there is a physician who is available to care for that patient and if transferring care is not onerous to the patient (that is, if the patient does not have to travel to a faraway healthcare facility or spend more money to receive care from the non-objecting physician).

Some physicians may object to referring a patient to another institution or careprovider when the patient can access care that the physician finds immoral, on the grounds that even making the referral makes the physician morally complicit. While we are sensitive to this type of objection, we believe that physicians must communicate with their patients about their healthcare options and make referrals, if necessary, in order to help patients access the care that they choose. Issues of physicians' conscientious refusal involve a balance between the rights of physicians and the rights of patients, and we believe that refusing to tell patients about their healthcare options or refusing to allow patients to access those options goes too far in infringing on patients' rights. While physicians do have the right to conscientiously refuse to provide certain care, they do not have the right to stand between patients and the care they wish to receive, either by failing to provide patients with information about what type of care is available to them, or by refusing to transfer care to another physician who will provide that care. Physicians, as professionals, have obligations to their patients as well as to their own moral and religious beliefs. We believe that transferring care enables physicians to uphold both sets of responsibilities, whereas failing to inform patients about their options or to transfer care accordingly does not uphold physicians' responsibilities to their patients.

### CONSCIENTIOUS REFUSALS IN PRACTICE

Conscientious refusals are often discussed in cases related to abortion; contraception; caring for lesbian, gay, bisexual, or transgender patients; or aid in dying and other end-of-life contexts. In our work,

however, we have seen another example in which conscientious refusals can come into play: in cases when a woman does not want to know her medical diagnosis and wants her husband, father, or son to receive her medical information and make healthcare decisions on her behalf. Cases of this type came up with particular frequency when we conducted an in-depth assessment of cultural competence in Israeli healthcare. Given the United States' increasing rates of immigration, and racial, ethnic, and religious diversity, many physicians in the U.S. likely have seen, or will see, similar cases themselves. This case helps to illustrate how a physician can experience a conscientious objection based on values such as gender equality, self-determination, or a professional commitment to a patient's autonomy and informed consent.

The first step a physician should take if asked by a female patient to follow this treatment plan would be to assess what social identities are coming into play. The patient could be informed by social identities such as religion and national origin, since many religions and cultures may have the practice of having the eldest man in the family make medical decisions. For the physician, social identities coming into play might include gender (that is, a female physician who worries the patient and family don't think a female doctor can be competent) or national origin (that is, self-determination and individuality tend to be considered core American or Western values, so having a patient who prefers communal decision making may be less familiar or accessible).

Once physicians think through which social identities are coming into play, they should determine which type of objection they are experiencing. Physicians could be experiencing an objection based on personal preference, on the grounds that they personally would never choose to have their healthcare decisions be made by someone else, and that communicating through the patient's husband instead of the patient will be inconvenient in that the healthcare team cannot ask the patient basic questions related to her care and comfort without going through the patient's family member. Should this be the case, physicians should treat the patient in spite of their personal disagreement with the patient's preference and establish which decisions, if any, the patient is willing to make to help minimize inconvenience (for example, the patient may not want to make larger decisions about her treatment, but may be comfortable making day-to-day decisions regarding whether she needs another aspirin).

Physicians might be experiencing an objection based on professional integrity, because informed consent is generally considered a core legal and ethical component of patients' autonomy in the U.S., and physicians may therefore be unsure whether they are legally or ethically allowed to follow the patient's husband's treatment decisions rather than the patient's. In this instance, the physician should consult with the hospital's legal team and ethics committee to establish whether the patient's request is both legal and ethical. The ultimate answer to this question would depend on the exact request being made, but we generally find that choosing not to make further healthcare decisions is also a form of exercising autonomy, and that honoring such requests is generally legal, ethical, and an important part of providing culturally competent care. Often we find that, in the U.S., autonomy is collapsed with informed consent, such that patients are only acting autonomously if they have been fully informed as to all of their treatment options and then make a decision accordingly. However, as Daniel Fu-Chang Tsai notes, respect for autonomy can be defined more broadly as "patients' . . . right to voice their medical treatment preferences, and physicians' . . . concomitant duty to respect those preferences."<sup>12</sup> Using this definition of autonomy indicates that a patient who wishes to have her family make decisions on her behalf has, in fact, voiced a preference for her medical treatment, and that physicians should respect her preference.

Finally, physicians could be experiencing an objection based on personal conscience if, for example, gender equality is of deep importance to them and if they think they would be upholding an immoral patriarchal structure if they do not inform the patient of her diagnosis or ask her about treatment decisions.<sup>13</sup> If physicians truly believe they could not conscientiously care for this patient, they should transfer care to another physician who is comfortable providing this care. They should not, however, tell the patient about her diagnosis against her will or otherwise prevent her from receiving care in the way she has chosen, in accordance with her beliefs and values.

## CONCLUSION

The recommendations described in this article are meant to expand on the important opinion outlined by the AMA and to provide concrete action steps for physicians to help them recognize and manage the impact of their identities in the provision of culturally competent care for patients. We

hope that these recommendations and examples will showcase how to resolve conscientious objections in ways that recognize the moral agency of individual physicians while maintaining their professional obligations to provide care to patients in accordance with the patient's, rather than the physician's, beliefs, values, and preferences.

#### NOTES

1. "Opinion 1.1.7., Physician Exercise of Conscience," *Code of Medical Ethics* (Chicago, Ill.: AMA, 2016).

2. There are federal laws protecting against discrimination in public accommodations on the basis of race, color, religion, national origin, and disability. There are no federal laws protecting against discrimination in public accommodations on the basis of sex. Some state and local governments have such laws, but what constitutes "sex" and "public accommodation" is not consistent. There are also no federal laws protecting against discrimination in public accommodations on the basis of sexual orientation or gender identity; 19 states and Washington, D.C., have such laws. B. Browning, "Sweeping LGBT Rights Bill to Be Introduced This Week," 21 July 2015, <http://www.advocate.com/politics/2015/07/21/sweeping-lgbt-rights-bill-be-introduced-week>.

In spite of the sometimes inconsistent legal status around discrimination in public accommodations, the AMA states that a physician can ethically decline to enter into a doctor-patient relationship with a patient if the "specific treatment" requested conflicts with the physician's religious, personal, or moral beliefs, but may not refuse to provide treatment to a patient "because of race, color, religion, national origin, sexual orientation, gender identity, or any other basis that would constitute invidious discrimination." "Opinion 10.05. Potential Patients," *Code of Medical Ethics* (Chicago, Ill.: AMA, 2016).

3. This article will discuss issues of conscientious refusal, but applauds the AMA for recognizing that conscience can lead to physicians' desire to intervene in violation of law, hospital protocol, or other policies.

4. The word "defined" comes from the AMA, so this article cannot comment on the intended meaning of that word. For the purposes of this article, however, we understand "defined" to mean that physicians do not see encounters with patients solely through a professional lens, but also have personal perspectives that may be informed by religion, culture, or other factors, and that these perspectives, as well as their roles as physicians, inform their encounters with patients, and in some cases lead to conscientious objections to certain medical procedures.

5. "Opinion 1.1.7, Physician Exercise of Conscience," see note 1 above.

6. The Joint Commission defines cultural competence as "The ability of health care providers and organizations to understand and respond effectively to the cultural and language needs brought by the patient to the health care encounter." The Joint Commission: *Advancing Effective Communication, Cultural Competence, and Patient- and*

*Family-Centered Care: A Roadmap for Hospitals* (Oakbrook Terrace, Ill.; The Joint Commission, 2010). The Tanenbaum Center would therefore define religio-cultural competence as "the ability of healthcare providers and organizations to understand and respond effectively to the religious and/or cultural beliefs and practices brought by the patient to the healthcare encounter."

7. K. Culhane-Pera et al., *Healing by Heart: Clinical and Ethical Case Stories of Hmong Families and Western Providers* (Nashville, Tenn.: Vanderbilt University Press, 2003).

8. Ibid.

9. Ibid.

10. American Academy of Pediatrics, "Policy Statement—Ritual Genital Cutting of Female Minors," *Pediatrics* 125, no. 5 (May 2010), <http://pediatrics.aappublications.org/content/pediatrics/early/2010/04/26/peds.2010-0187.full.pdf>

11. Culhane-Pera et al., *Healing by Heart*, see note 7 above.

12. D. Fu-Chang Tsai, "Personhood and Autonomy in Multicultural Health Care Settings," *AMA Virtual Mentor* 10, no. 3 (2008): 171-6.

13. It is important to note that conscientious objections do not have to be based in religious beliefs. In this instance, the objection is based on a sincerely and deeply held belief in gender equity. An objection to providing care should still be considered a conscientious objection if physicians could not live with themselves if they do not act in accordance with their beliefs, regardless of whether their beliefs are grounded in religion or in something else.

# Conscientious Objection: Widening the Temporal and Organizational Horizons

*Armand H. Matheny Antommara*

## ABSTRACT

The American Medical Association opinion “Physician Exercise of Conscience” is generally sound; its recommendations regarding notice, nondiscrimination, informed consent, referral, and non-abandonment are reasonable.<sup>1</sup> Within its focus on individual physicians’ duties to particular patients, it could also emphasize that physicians should only share the reasons for their objections if patients express an interest and that they should only share the reasons in a respectful manner. The opinion, however, neglects wider time frames and higher levels of organization. It could comment on physicians’ duty to form their consciences appropriately and to select specialties and practice settings that do not engender excessive conflicts. Given the number of physicians who are not self-employed and the role of law in establishing rights and responsibilities, the opinion could also address employers’, legislatures’, and courts’ obligations to balance protecting physicians’ integrity and assuring patients’ access to medical treatment. Addressing these wider perspectives would greatly strengthen the opinion.

The American Medical Association (AMA) opinion “Physician Exercise of Conscience” has a very

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discrete focus: individual physicians’ duties to particular patients. It articulates a variety of physicians’ obligations including notice, informed consent, referral, and non-abandonment. In circumscribing its focus in this way, the AMA neglects wider time frames and higher institutional levels. For example, physicians have obligations in forming their consciences, choosing their specialties and practice settings, and accepting the consequences of their actions. While the central problem is the potential conflict between protecting healthcare providers’ consciences and assuring patients’ access, solutions may need to be implemented at higher levels of organization within the healthcare system. While the AMA opinion is generally sound, the AMA should also address these broader issues.

The AMA opinion states that, at times, physicians’ deeply held personal beliefs that are based on diverse cultural, religious, and philosophical traditions may conflict with their professional obligations, that include protecting patients’ interests and respecting their self-determination. Note that this characterization locates the conflict within the physician instead of between physicians and patients. The AMA opinion argues that patients and society rely on physicians’ and the profession’s integrity, and physicians should have considerable discretion in resolving these conflicts. The AMA concedes that this latitude should not be unfettered and articulates a variety of constraints. These constraints generally focus on individual treatment decisions and

include nondiscrimination, informed consent, referral, and nonmaleficence.

Within this frame, the AMA opinion neglects the issue of physicians explaining the basis of their objections to patients. While discussing the basis of an objection to treat may facilitate the mutual sharing of perspectives, some patients have objected to their physicians raising such issues or the way they presented it. One patient, for example, described her physician as launching into a lecture about her need to rethink things after having asked him to prescribe birth control pills.<sup>2</sup> Minimally, physicians should not berate or demean their patients. Being attentive to the power differential within their relationship, physicians should assess patients' interest in this information and should not force it on patients who are not interested.

### WIDER TIME FRAMES

In their report on the AMA opinion published in this issue of *The Journal of Clinical Ethics*, some members of the AMA Council on Ethical and Judicial Affairs (CEJA), note that their primary focus in writing the opinion was on individual physicians making decisions about their interactions with particular patients.<sup>3</sup> For example, they state that in situations in which physicians' personal integrity and professional obligations conflict, "physicians must decide whether and how personal conscience should guide their professional conduct." They distinguish between decisions based on intuition or emotion and those based on deliberation.

The AMA opinion does address some broader temporal issues. It argues that careproviders have an obligation to notify prospective patients in advance of interventions or services they are unwilling to provide. It also, interestingly, contends that obligations to patients increase with the duration of the relationship. (While establishing a physician-patient relationship is a clear threshold, it is not clear in what way the duration of the relationship is ethically relevant.) Finally, the opinion emphasizes that, when physicians terminate a relationship, they should make the patient's records available and provide needed treatment until the transfer is complete.

The AMA opinion could more forcefully address physicians' obligations in forming their consciences and selecting their specialties and practice settings. While one is morally obligated to act with integrity, one's action can be immoral if one's fundamental beliefs are wrong. An individual with racist beliefs may, for example, act with integrity, but nonetheless immorally, in discriminating against a member

of a minority group. This is one of the bases for prohibiting discrimination. It is essential that individuals develop sound, fundamental moral beliefs, and that protections of conscience should exclude unethical beliefs.

Physicians have substantial discretion in selecting a specialty and practice setting. These choices may influence the likelihood and severity of conflicts between maintaining integrity and assuring access. For example, physicians who are morally opposed to abortion, sterilization, and contraception are more likely to encounter conflicts as obstetricians/gynecologists than as orthopedists. If such individuals become obstetricians/gynecologists, they are more likely to encounter conflicts in rural, small group practices than in urban, Roman Catholic institutions. Physicians have some affirmative obligation to reduce the likelihood of conflicts. Specifying and enforcing this obligation is, however, difficult.

In addition to issues that precede particular decisions, there are also issues that succeed them. Some careproviders may refuse to perform actions that violate their conscience even if the refusal results in harm to patients. In such circumstances, the AMA acknowledges that physicians have an obligation to accept the consequences. The AMA, however, does not state what these consequences may or should be. They might include malpractice litigation by the patient or disciplinary proceedings by the state medical board. Causing the death of or permanent injury to a patient could justify revoking a physician's license.

### HIGHER LEVELS OF ORGANIZATION

In addition to a broader temporal horizon, the AMA should also address higher levels of organization within the U.S. healthcare system. A fundamental issue in this debate is how to protect both physicians' consciences and patients' access. This may best be accomplished at higher levels in the healthcare system. Holly Fernandez Lynch, for example, argues that state licensing boards should be responsible for compiling and publicizing lists of willing and refusing physicians and for assuring a sufficient number of willing physicians.<sup>4</sup> While the AMA mentions the institutional level, it does not discuss institutions' or the government's roles and responsibilities.

The article by CEJA members appears to focus on self-employed physicians who are in solo or small group practices. It, for example, makes reference to "structuring one's practice."<sup>5</sup> Within this framework,

the AMA opinion states physicians should “Be mindful of the burden their actions may place on fellow professionals.”<sup>6</sup> It, however, does not address what obligation these fellow professionals have to allow colleagues to act in accordance with their consciences. For example, must careproviders be willing to work to allow their colleagues to participate in annual or weekly religious observances? It also does not address how physicians’ employers should address their employees’ claims of conscientious objection. How should the owner of a physician practice respond, for example, to a nurse or medical assistant who generally administers injections, but who objects to administering depot medroxyprogesterone acetate (DMPA, a long-acting contraceptive injection drug—Depo-Provera)? Addressing employers’ obligations would have provided the AMA the opportunity to discuss claims made by members of other professions, such as nurses.

It should, however, be noted that a significant minority of physicians are not self-employed. The AMA’s own 2014 study of physicians’ practice arrangements found that 32.8 percent of physicians worked directly for a hospital or in a practice with at least some hospital ownership, and that 49.2 percent of physicians were not owners of a practice.<sup>7</sup> One of the questions is, to what degree are employers obligated to accommodate employed physicians’ objections? The extremes, again, are unreasonable; employers should be willing to take *de minimus* actions, but should not be required to endure undue hardships. Defining what constitutes a reasonable accommodation is context-dependent.<sup>8</sup>

Physicians’ ability to act according to their conscience may be conditioned by state or federal law. “Conscience clauses” vary in terms of what types of individuals and institutions are covered, beliefs are protected, treatments are addressed, and immunities are provided. Some legislation, for example, covers pharmacists and insurance plans in addition to physicians and hospitals, and some include physician-assisted suicide in addition to abortion and sterilization. Statutes also do not consistently address situations in which patients are likely to suffer harm. Some recent proposals to expand protections are very broad and include counseling and referral within their definitions of healthcare.<sup>9</sup> Conscience clauses should appropriately balance the protection of physicians and patients.

Protection against discrimination is currently an important legislative and judicial issue. While the AMA opinion is clear that physicians have an obligation not to discriminate, it could be clearer that the dignitary harms caused by discrimination are

sufficient to constrain physicians’ freedom to refuse to provide particular treatments to only certain categories of patients, for example, in-vitro fertilization to gay, lesbian, bisexual, transgender, or unmarried couples, based on their core moral beliefs.

## CONCLUSIONS

Within its restricted frame, the AMA opinion reiterates sound and generally accepted recommendations regarding conscientious refusal. Even within its focus on physicians, it should consider wider time frames and higher organizational levels. Physicians have duties in forming their consciences and have some obligations in selecting their specialties and practice settings. The resolution of the potential conflict between physician’s integrity and patients’ access generally requires developing institutional responses and will be shaped by regulation and legislation.

## NOTES

1. “Opinion 1.1.7., Physician Exercise of Conscience,” *Code of Medical Ethics* (Chicago, Ill.: AMA, 2016). The opinion is reprinted as figure 1 in BJ Crigger, S.L. Brotherton, P.W. McCormick, and V. Blaha, “Report by the American Medical Association’s Council on Ethical and Judicial Affairs on Physicians’ Exercise of Conscience,” in this issue of *JCE*, 27, no. 3 (Fall 2016).

2. “When Doctors Play Judge,” Anderson Cooper 360° Blog, 12 November 2007, <http://www.cnn.com/CNN/Programs/anderson.cooper.360/blog/2007/11/when-i-go-to-doctor-i-expect-him-or-her.html>.

3. Crigger, Brotherton, McCormick, and Blake, “Report by the American Medical Association’s Council on Ethical and Judicial Affairs,” see note 1 above.

4. H.F. Lynch, *Conflicts of Conscience in Health Care: An Institutional Compromise* (Cambridge, Mass.: MIT Press, 2008).

5. “Opinion 1.1.7, Physician Exercise of Conscience,” see note 1 above.

6. *Ibid.*

7. “New AMA Study Reveals Majority of America’s Physicians Still Work in Small Practices,” *AMA News Room*, 8 July 2015, <http://www.ama-assn.org/ama/pub/news/news/2015/2015-07-08-majority-americas-physicians-work-small-practices.page>.

8. M.R. Wicclair, *Conscientious Objection in Health Care: An Ethical Analysis* (Cambridge, U.K.: Cambridge University Press, 2011).

9. M.S. Swartz, “‘Conscience Clauses’ or ‘Unconscionable Clauses’: Personal Beliefs Versus Professional Responsibilities,” *Yale Journal of Health Policy, Law, and Ethics* 6, no. 2 (2006): 269-350.

# Thinking about Conscience

*BJ Crigger*

## ABSTRACT

The path to consensus about physicians' exercise of conscience was not linear. It looped back on itself as new insights illuminated earlier deliberations and in turn led to further insights. In particular, coming to agreement about physicians' responsibility in regard to referral charted a route through many course corrections.

By now, Dear Reader, you're aware that the American Medical Association (AMA) Council on Ethical and Judicial Affairs (CEJA) recently developed guidance in the vexed matter of physicians' exercise of conscience. Should physicians ever be allowed to hold the dictates of personal conscience about the commitments they take on as members of the medical profession and the expectations both colleagues and patients hold of them? Is it important for the profession to acknowledge the standing of its members as moral agents in their own right and respect their need to preserve physicians' identify-conferring values? How should physicians balance responsibility to deeply held personal beliefs and responsibility to the values that inform their profession?

Over the two years of CEJA's deliberations, these questions were of great moment among council members, who differed sharply in their individual views at the outset. Ultimately, however, members came together around a position all could endorse, albeit with greater or lesser degrees of individual disappointment in the result—to borrow from the philosopher Martin Benjamin, the council reached what members deemed an “integrity-preserving compromise.”

Reaching “yes” in answer to the first two questions above was relatively straightforward. The greater part of the council's attention thus was devoted to thinking through that third question. CEJA began by seeking to identify “acts of conscience” that all could agree would be unacceptable on the part of a physician: for example, no physician who has the requisite skill should ever decline to provide care in an emergency, or impose care over the reasonably informed refusal of a patient who has decision-making capacity, on the grounds of individual conscience. From there it moved on to thinking about what would be ethically permissible in the realm of physicians' exercise of conscience.

If physicians, who are individual moral agents as well as members of an ethically freighted profession, should sometimes be able to follow personal conscience in the conduct of their professional lives, how are they to do so in a responsible, ethically acceptable way? For the council, the crux of the mat-

ter was whether physicians who invoke conscience have an ethical responsibility to refer the patient, and if so, the nature and scope of that responsibility.

Deliberation on referral opened in earnest at the council's June 2011 meeting, with members positing what they labelled the "perform~refer~inform" continuum. That is, they suggested, faced with a tension between professional expectations and personal belief, physicians have the opportunity to fulfill the professional expectation (perform), to refer the patient to another healthcare professional who will fulfill the expectation (refer), or make the patient aware of all relevant treatment alternatives (inform).

The council felt it had adequately considered the "perform" endpoint within its discussion of the boundary conditions that defined some acts of conscience that would be unacceptable for a member of the profession of medicine and so turned its attention to the "inform" endpoint of the continuum. CEJA disposed of this in relatively short order as well, concluding that the well-established professional duty of informed consent requires physicians always to inform patients about all medically relevant options, irrespective of whether specific treatment alternatives or clinical services conflict with the physician's deeply held personal beliefs.

In beginning to think about the "refer" point of the continuum during this meeting, CEJA broadly parsed the notion between two possibilities, transferring a patient to establish a new relationship with another healthcare professional for the purposes of all care to be delivered going forward, versus referring a patient to another professional for the limited purpose of receiving a specific intervention or service. And there the matter rested until CEJA reconvened.

When the council returned to the question of referral at its next meeting (in August 2011), the issue of complicity emerged as central concern. That is, the council asked, does a physician who refers a patient for a specific intervention that the physician finds personally morally objectionable become complicit in a moral wrong? If the answer to that question is "yes," can the profession (and patients) legitimately expect physicians to compromise their personal moral integrity?

A first attempt to address these questions led the council to draw further distinctions with respect to referral; namely, distinguishing what they identified as "formal" and "informal" referral. By "formal" referral, CEJA had in mind referring a patient to a specific healthcare professional who will provide the problematic service. By "informal" referral, the

council meant to capture a more amorphous category of behavior, for which the index example was directing a patient to a healthcare institution at which the problematic service is available. The sensibility articulated in this distinction is that complicity could be considered a problem of degree.

Discussion of complicity continued into CEJA's subsequent meeting in October 2011 and beyond. As discussion progressed, the notion of harm to patients began to be layered over considerations of possible (moral) harm to physicians, morphing into a more encompassing focus on burdens to patients over CEJA's meetings in February and June 2012. Among the factors discussed in varying depth over time as relevant to forming an understanding of possible harms or burdens to patients were whether services that were morally problematic from the physician's perspective were medically necessary or elective, or were or were not time sensitive. In turn, discussion of burdens to patients led to questions about burdens to the physician, including the depth or severity of threat to deeply held beliefs, and on into questions about the impact of a physician's action in conscience on colleagues or the community.

Other considerations that emerged through this lens of "burdens," such as the availability of services otherwise in the community, whether the physician's action would have a discriminatory effect, or whether the physician had an existing relationship with the patient, also played back into conversations on previous topics, inviting additional reflection and refinement in these areas.

By the time CEJA began reviewing an actual draft of its report in August 2012, these deliberations had led to proposed recommendations that were extensive and highly specific. With proposed language in hand, however, several members argued that issues around referral had not yet been resolved satisfactorily. It would take ongoing conversation through another two meetings to achieve a formulation with which all members were sufficiently comfortable to allow CEJA to submit the report to the AMA's House of Delegates in June 2013.

Responses from the AMA's House of Delegates prompted further reflection on how the council could best frame guidance on referral (and in some instances other provisions) through a further three iterations before CEJA's report and recommendations were finally adopted in November 2014.

Thus CEJA's conversation on this topic evolved through several stages as council members identified and debated factors relevant to physicians' exercise of conscience, at times circling back to earlier provisional conclusions in the light of subse-

quent discussions. Throughout, multiple themes were woven into discussion of any given topic, and the council's sense of how to lexically order various considerations fluctuated over time as conversation highlighted different threads in the complex tapestry that was the overall report.

This may give the false impression that CEJA's deliberations were organic, free form, *ad hoc*, if not even undisciplined. To a certain extent conversations were indeed spontaneous, but always within a framework that had been roughly laid out at the inception of the work. Each council session was grounded in readings identified by staff and council members to help refine the provisional conclusions that were reached or to illuminate issues that were identified during the preceding session. The council's actual conversations were far richer than this brief description or the final report itself can do justice to, since both distill many hours of at times vigorous debate into a few meagre paragraphs.

The Council on Ethical and Judicial Affairs recognizes that its work is unlikely to satisfy every stakeholder fully. Some will take exception to its analysis; others will question the practicality of its recommendations. The council's goal is to take into account the interests and concerns of physicians, patients, and others in charting a navigable path through complex and potentially volatile issues in clinical practice.

#### **DISCLAIMER**

The views expressed here represent my personal reflections as a participant-observer and should not be attributed to members of the Council on Ethical and Judicial Affairs, individually or collectively, although I hope they would recognize their work process as I describe it here.

## Law

# Legal Briefing: Stopping Nonbeneficial Life-Sustaining Treatment without Consent

*Thaddeus Mason Pope and Kristin Kemmerling*

### ABSTRACT

In the United States, authoritative legal guidance remains sparse on whether or when clinicians may stop life-sustaining treatment without consent. Fortunately, several significant legislative and judicial developments over the past two years offer some clarity. We group these legal developments into the following seven categories:

1. Lawsuits for Damages
2. Amendments to the Texas Advance Directives Act
3. Constitutional Attack on TADA
4. Legislation Prohibiting Clinicians
5. Legislation Authorizing Clinicians
6. Cases from Canada
7. Cases from the United Kingdom.

### INTRODUCTION

For two decades, medical futility disputes have been one of the most frequent reasons for clinical ethics consultations. Consequently, it is no surprise that medical futility has been the subject of many

articles in *JCE*.<sup>1</sup> As is appropriate, clinicians and families eventually reach consensus in the overwhelming majority of these cases. Usually, the original parties reach agreement. Even when this is not possible, sometimes, the patient can be transferred to a new facility that is willing to provide the disputed treatment. Other times, the hospital is able to designate (or have a court designate) a new surrogate, by demonstrating that the current surrogate is not acting consistent with the patient's wishes or best interests. In either of these situations, by replacing one of the parties to the dispute, consensus is still achieved.

Clinicians and families cannot always reach consensus, particularly when the treatment requested is religiously motivated. Conflict in around 5 percent of medical futility disputes remains intractable to communication, negotiation, and mediation. In many of these residual cases, clinicians want to stop life-sustaining treatment, even though they have been unable to obtain the patient's or surrogate's consent. This approach is laden with ethical and legal uncertainty and risk. We lack authoritative guidance on whether or when clinicians may stop life-sustaining treatment without consent. Fortunately, several significant legislative and judicial developments over the past two years offer some clarity. We group these legal developments into the following seven categories:

1. Lawsuits for Damages

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2. Amendments to the Texas Advance Directives Act
3. Constitutional Attack on TADA
4. Legislation Prohibiting Clinicians
5. Legislation Authorizing Clinicians
6. Cases from Canada
7. Cases from the United Kingdom.

We have previously described and assessed the nature, prevalence, causes, and approaches to medical futility disputes.<sup>2</sup> We have also previously analyzed the legal rights, obligations, and risks of clinicians and hospitals that withhold or withdraw life-sustaining treatment without consent.<sup>3</sup> We will neither repeat nor summarize that material here. Instead, our goal is to update the reader on recent legal milestones. In this article, we focus on significant judicial and legislative developments from 2015 and 2016.<sup>4</sup>

### 1. LAWSUITS FOR DAMAGES

Perhaps the majority of medical futility cases adjudicated by the courts have been *ex ante* cases (that is, lawsuits that are filed before treatment is stopped).<sup>5</sup> These include many of the most famous and familiar cases, such as *Wanglie* and *Baby K*.<sup>6</sup> These cases typically take the following path. Clinicians judge that continued life-sustaining treatment is inappropriate and nonbeneficial. So, they recommend comfort measures only, but the patient's surrogate rejects that proposal even after the involvement of other institutional resources (such as ethics consultants, social workers, chaplains, and palliative care clinicians). Eventually, even though clinicians are unable to obtain consent for their recommended treatment plan, they announce their intent to unilaterally stop life-sustaining treatment. Many (perhaps most) patients' families accept or assent to such announcements, but some file lawsuits. In these lawsuits, the family asks the court to issue an injunction prohibiting the hospital from stopping life-sustaining treatment. The goal of *ex ante* cases is to keep the patient alive.

In contrast, *ex post* cases occur when a patient's family members bring a lawsuit after clinicians have already withheld or withdrawn life-sustaining treatment and the patient has died. The goal of *ex post* cases is to obtain monetary damages. While money cannot restore the patient's life, a verdict or settlement compensates the patient's family members for their legal injury.<sup>7</sup> Over the past two years, U.S. courts have issued two appellate opinions in *ex post* medical futility cases. One opinion is from the state

of Indiana and the other opinion is from the state of Connecticut.

The reader should remember that very few disputes result in written, published, appellate court opinions. While there have been only two appellate opinions in the past two years, that represents only the tip of a "lawsuit iceberg." Below the surface of this iceberg, more cases are pending in the trial courts. We offer two active, illustrative cases from Ohio.

#### Connecticut

In the summer of 2010, Helen Marsala was transferred to Yale New Haven Hospital after a lengthy stay in another Connecticut hospital. She had multiple organ system failures and was on a ventilator, dialysis, and artificial nutrition and hydration. On 24 July 2010, Yale clinicians changed Mrs. Marsala's status to comfort care only, over the objections of her family. Earlier, the hospital had repeatedly tried to get the family's consent for their recommended treatment plan. But ultimately the team consulted the ethics committee and proceeded without consent.<sup>8</sup>

Mrs. Marsala's family filed a lawsuit against Yale in August 2012. Clarence Marsala, her husband, asserted claims for wrongful death, loss of consortium, and medical malpractice. Mrs. Marsala's five children sued for intentional infliction of emotional distress (IIED) and negligent infliction of emotional distress (NIED). Specifically, they alleged that they suffered "serious, painful and permanent injuries" including: "(a) severe emotional distress; (b) loss of opportunity to say goodbye; (c) depression; (d) loss of sleep; (e) stress; (f) anxiety; and (g) pain and suffering."

In late 2013, a Connecticut Superior Court judge denied Yale's motion to dismiss the IIED claim.<sup>9</sup> The court ruled that a jury could find that "terminating a patient's life support with an awareness of her contrary wishes constitutes unacceptable behavior and would readily be considered extreme and outrageous."<sup>10</sup> But the trial court later dismissed the Marsala children's IIED and NIED claims. In late June 2016, the Connecticut Appellate Court affirmed.<sup>11</sup> Key to the court's analysis were limitations on "by-stander" IIED and NIED claims under Connecticut law. None of the children contemporaneously witnessed Yale's decision-making process and none was present when Yale made the ultimate decision to transition their mother to comfort care only.

Claims for NIED and IIED are typically the most successful in medical futility cases.<sup>12</sup> Therefore, the *Marsala* case stands out as an exception to a general

trend in which families have successfully asserted claims for NIED and IIED against hospitals that unilaterally withdrew life-sustaining treatment. Mr. Marsala is still proceeding against Yale on his claims for wrongful death, loss of consortium, and medical malpractice.<sup>13</sup> Trial is scheduled for November 2017. If he obtains a verdict or settlement, that will likely have a “chilling” effect on the willingness of other hospitals to stop life-sustaining treatment without consent.

### Indiana

In November 2007, Geraldine Siner was an 83-year-old, advanced dementia patient in the rehabilitation unit of Kindred Hospital following a stay in the intensive care unit (ICU) for aspiration pneumonia. To the hospital’s apparent consternation, the patient’s status remained “full code” (that is, she would receive all life-sustaining therapies in the case of a cardiac or pulmonary arrest—Mrs. Siner did not have a do-not-resuscitate order, or DNR, in her medical record).

When Mrs. Siner’s daughter, Kathy L. Siner, visited the patient at Kindred Hospital on 11 November 2007, she alleged that her mother became motionless and nonresponsive, but hospital staff delayed performing emergency procedures despite the fact that she was a full code.<sup>14</sup> Kindred Hospital alleged that Mrs. Siner never required resuscitation during these events.

Kindred Hospital’s ethics committee met and decided to override the Siner family’s decision, that the patient be a full code. Her treating clinicians made Mrs. Siner a “no code” (that is, she would not receive resuscitation). Following the meeting, Kindred Hospital informed Mrs. Siner’s family that they needed to find another hospital to care for Mrs. Siner, if they wanted her to be a full code.

In December 2007, the Siners transferred Mrs. Siner to Methodist Hospital, but it was apparently too late for Mrs. Siner to make a recovery. For weeks before the transfer, she had apparently received less aggressive treatment at Kindred. At Methodist, Mrs. Siner was treated for a collapsed lung, facial wounds, infection, and sepsis. She died there on 28 December 2007.

The Siner family planned to file a lawsuit. Pursuant to Indiana law, their case was first submitted to a Department of Insurance Medical Review Panel composed of three physicians. The purpose of this review was to determine whether Mohammed Majid, MD, and other hospital staff failed to comply with the appropriate standard of care. In January 2013, the review panel issued a unanimous decision find-

ing that there was sufficient evidence to support the conclusion “that the defendants failed to comply with the appropriate standard of care, and that their conduct may have been a factor of some resultant damages, but not the death of the patient.”<sup>15</sup> Following the decision, James Krueger, MD, one of the panel members, did an additional review of Geraldine Siner’s medical records and submitted an affidavit stating he incorrectly attributed the care in question to Majid. Krueger concluded that since a pulmonologist had been involved in Siner’s care, it was acceptable for Majid to defer to the pulmonologist’s judgment.<sup>16</sup>

In May 2013, the Siners filed a lawsuit against Kindred Hospital, Mohammed Majid, and others. They alleged that the defendants’ inadequate treatment of Mrs. Siner, as a result of the unilateral DNR order, led to damage that could not be reversed. Apparently, the Siners did not name the Indiana University Pulmonary and Critical Care Service as a defendant, because its treatment was recommended as a result of Mrs. Siner’s designation as a “terminal patient” by her attending physician. Alternative treatments such as tracheotomy and intubation were not deemed appropriate for terminal patients.

Late in 2013, the defendants moved for summary judgment. Both Kindred Hospital and Majid cited the opinion of the Department of Insurance Medical Review Panel, as well as Krueger’s affidavit, in their motions. The defendants argued that Krueger’s affidavit shifted the burden of proof to the Siners to show that sufficient evidence existed to establish an issue of material fact regarding the defendants’ role in causing Mrs. Siner’s injuries. The defendants also argued that the medical review panel’s opinion was too speculative in nature to establish that their actions were sufficiently related to Mrs. Siner’s injury to be the cause of her injury. The Siner family responded to these motions with additional affidavits from two doctors: Lawrence Reed, II, MD, and Timothy Pohlman, MD. The trial court found that these additional affidavits did not address causation and granted the defendants’ motions based on the absence of expert testimony to establish a claim for medical negligence.

On appeal, the Indiana Court of Appeals set out to determine whether the trial court erred in holding that the Siner family failed to produce evidence to establish an issue of fact regarding the defendants’ role in causing Mrs. Siner’s injuries.<sup>17</sup> The court of appeals discussed Pohlman’s affidavit, which the trial court determined did not contain testimony about causation. The court of appeals concluded that the trial court erred, because Pohlman’s affidavit dis-

cussed how the collapsed lung, infections, and sepsis were likely the result of Kindred Hospital's refusal to treat under the unilateral DNR order.<sup>18</sup> For example, Pohlman discussed how Mrs. Siner suffered from septic shock at the time of her intake at Methodist Hospital, and how Kindred Hospital failed to treat her according to the Society of Critical Care Medicine's Surviving Sepsis Guidelines because of her DNR order. The court of appeals reversed summary judgment for Kindred Hospital, because Pohlman's affidavit established a genuine issue of fact for causation.

In April 2016, the Indiana Supreme Court vacated the court of appeals' decision and reversed the trial court's grant of summary judgment to both Kindred Hospital and Majid.<sup>19</sup> Chief Justice Loretta H. Rush discussed the heavy factual burden on moving parties to negate the existence of any genuine issue of fact for any element of the claim. A "unanimous opinion of a medical review panel" in favor of the movant would usually be enough to shift the burden to the nonmoving party, but Mrs. Siner's case still involved disputed facts.<sup>20</sup> Specifically, the affidavits submitted by the defendants pertained solely to the issues related to pulmonary care and failed to address all of the injuries alleged by the Siner family. Kindred Hospital and Majid failed to negate the Siner family's claim, and material issues of fact were still in dispute. Summary judgment was inappropriate. By reversing the grant of summary judgment, the Indiana Supreme Court will allow the case to proceed to trial. It is set to begin 4 December 2017 in Marion County Superior Court.

## Ohio

*Marsala* and *Siner* are the only two U.S. medical futility cases from 2015 and 2016 that resulted in appellate opinions. But they are hardly the only medical futility conflicts to reach the courts. While they have not yet been adjudicated or settled, patients' families have filed other lawsuits. For example, the family of Edna Moomaw is continuing to litigate a \$2.5 million medical malpractice and wrongful death lawsuit against Summa Health System and several individual clinicians in Akron, Ohio.<sup>21</sup> Ms Moomaw was an 89-year-old woman who had been taken to Summa Akron City Hospital for a heart attack on 15 December 2012. On 20 December, Summa clinicians entered a DNR/comfort care only (DNR/CCO) order. This normally requires the consent of the patient or a surrogate. Ms Moomaw died on 22 December.

Ms Moomaw's family contends that clinicians entered the DNR/CCO order without her or their

consent. Although she was seriously ill, the patient had been insisting on full efforts to keep her alive. There is no evidence that Ms Moomaw had been determined to lack capacity. So, her directions were controlling. But even had Ms Moomaw been determined to lack capacity, her family would have been the authorized decision maker. Ms Moomaw's family denies that they discussed, much less authorized, the DNR/CCO order. The case is proceeding toward trial.

Interestingly, another family has also recently asserted medical futility claims against Ohio's Summa Health System. Minnie King had been a patient at Akron City Hospital in February and March 2013. She died there on 23 March 2013. In March 2015, Ms King's family filed a medical malpractice lawsuit against Summa and an individual clinician. They alleged that "Summa withheld or withdrew life-sustaining treatment from Minnie King, without consent, including taking away her medications, putting her on the palliative care unit, ordering hospice involvement, and making her comfort care only."<sup>22</sup> The court is now considering the hospital's motion for summary judgment. A jury trial is scheduled for December 2017.

## 2. AMENDMENTS TO THE TEXAS ADVANCE DIRECTIVES ACT

As the previous cases illustrate, removing a patient's life-sustaining treatment without consent entails a risk of liability in many states. To eliminate that risk, many clinicians and commentators have been calling for the establishment of special adjudicatory dispute resolution mechanisms to resolve intractable medical futility disputes. As a leading model to follow, policy makers in the U.S. and around the world have been looking to the conflict resolution provisions in the 1999 Texas Advance Directives Act (TADA).<sup>23</sup> Basically, TADA allows clinicians to stop life-sustaining treatment over a surrogate's objections, so long as the clinicians' own hospital review committee agrees.<sup>24</sup> So long as the clinician follows the specified process, the statute provides safe harbor legal immunity.<sup>25</sup>

While admired by many, TADA has proven extremely controversial. Over a ten-year period spanning five legislative sessions (2005, 2007, 2009, 2011, and 2013) state legislators introduced dozens of bills to amend TADA. Ultimately, none of these bills were enacted. As the 2015 legislative session began, it was clear that Texas legislators would again try to tackle TADA. The Texas Medical Association (TMA) observed: "In anticipation of another round of debates

over end-of-life care, TMA's work group dedicated to the issue will work to protect physicians' ability to do what's best [including the ability to decide unilaterally] for patients in their final days."<sup>26</sup> Indeed, defending TADA was part of the TMA's strategic road map for state advocacy initiatives. Other organizations similarly expressed interest in protecting, improving, or destroying TADA.<sup>27</sup>

Apparently, the sixth time was the charm. For the first time since 2003, Texas actually amended the "futility" provisions in the TADA. In March 2015, Representative Drew Springer introduced H.B. 3074. Basically, this legislation exempts artificially administered nutrition and hydration (AANH) from the scope of life-sustaining treatment subject to TADA's dispute resolution procedures. This special treatment is not surprising, particularly since the intense and prolonged international media attention on the legal dispute concerning Terri Schiavo, many state legislatures have tried to regulate AANH differently from other forms of life-sustaining medical treatment.<sup>28</sup>

Today, clinicians can continue using TADA to stop life-sustaining medications, mechanical breathing machines, and kidney dialysis treatment. But clinicians may not use TADA to stop AANH unless it would either not work at all or would directly harm the patient. The statute unpacks these exceptions, allowing clinicians to unilaterally withhold or withdraw AANH if it would: (1) hasten the patient's death; (2) seriously exacerbate other major medical problems not outweighed by the benefit of the provision of the treatment; (3) result in substantial irremediable physical pain, suffering, or discomfort not outweighed by the benefit of the provision of the treatment; or (4) be medically ineffective. It is important to note that clinicians may not stop AANH under TADA because of a patient's permanent unconsciousness or quality of life.

In addition to the AANH limitation, H.B. 3074 also clarified that TADA "does not authorize withholding or withdrawing pain management medication, medical procedures necessary to provide comfort, or any other health care provided to alleviate a patient's pain." Finally, H.B. 3074 added a requirement that a hospital provide the patient's surrogate with the portion of the patient's medical record related to the treatment received in the facility during the current admission or during the preceding 30 calendar days. By the end of May 2015, H.B. 3074 was passed by both the Texas House and Texas Senate. On 12 June 2015, the governor signed the enrolled bill. The amendment took effect on 1 September 2015.

While only H.B. 3074 was enacted, the Texas legislature considered five other bills to amend TADA in 2015. First, consistent with his track record for over a decade, Representative Bryan Hughes introduced H.B. 2984. Like many of Hughes's prior bills, this one would require that clinicians continue life-sustaining treatment until a patient is actually transferred to another facility. If the patient cannot be transferred, then the treating facility cannot withdraw life-sustaining treatment with the immunity provided by TADA.

With a pro-life agenda similar to Hughes, Senator Kelly Hancock introduced S.B. 1163. Similar to Hughes's H.B. 2984, Hancock's bill was not designed to improve the fairness of TADA. Instead, S.B. 1163 was designed to wholly eliminate TADA's dispute resolution provisions.<sup>29</sup> Instead of requiring treatment until transfer, like Hughes's bill, S.B. 1163 would have added a new statutory section that specifies two reasons on which a hospital review committee may not base a determination of medical inappropriateness. Specifically, it prohibits a hospital review committee from determining life-sustaining treatment to be inappropriate based on either:

(1) the lesser value the physician or professional, facility, or committee places on sustaining the life of an elderly, disabled, or terminally ill patient compared to the value of sustaining the life of a patient who is younger, not disabled, or not terminally ill; or

(2) a disagreement between the physician or professional, facility, or committee and the patient, or the person authorized to make a treatment decision for the patient . . . , over the greater weight the patient or person places on sustaining the patient's life than the risk of disability.

S.B. 1163 also specified that the only bases on which a hospital review committee may determine life-sustaining treatment to be inappropriate are: (1) physiological futility and (2) when "providing the treatment to the patient would clearly create a substantially greater risk of causing or hastening the death of the patient than would withholding or withdrawing the treatment."

Like S.B. 1163, Texas Representative Garnet Coleman's H.B. 4100 would also narrow the scope of a hospital review committee's discretion. Under H.B. 4100, a review committee could deny requested treatment only if it would: (1) threaten the patient's life, (2) seriously exacerbate other major medical problems not outweighed by the benefit of the provision of the treatment, or (3) result in substantial irremediable physical pain or discomfort not out-

weighed by the benefit of the provision of the treatment. H.B. 4100 would have also prohibited the review committee from determining medical appropriateness on the basis of “permanent disability, advanced age, gender, religious or cultural differences, or financial circumstances.”

In addition to specifying legitimate and illegitimate grounds for determining life-sustaining treatment to be inappropriate, S.B. 1163 offered four other amendments focused on procedural due process. First, the bill would extend the minimum notice of a hospital’s review committee meeting from 48 hours to seven days. Second, H.B. 4100 would extend the minimum period for transfer from ten days to 21 days. Third, it would require a hospital to offer a patient’s surrogate a patient liaison, quick access to the patient’s medical record, and an advisory consultation. Fourth, like S.B. 1163, H.B. 4100 would exempt AANH from the scope of life-sustaining treatment that can be refused.

Finally, Representative Patricia Harless introduced H.B. 2351. This bill would have required hospital review committees to adopt two types of policies: (1) “to prevent financial and health care professional conflicts of interest” and (2) “to prohibit consideration of a patient’s permanent physical or mental disability during a review.”<sup>30</sup>

In short, the battle over TADA has been largely fought between those who want to improve the fairness of TADA and those who are opposed to the very concept that hospitals and physicians should be authorized to stop life-sustaining treatment without the consent of a patient or a patient’s surrogate. The former have been thwarted in their efforts to improve TADA, because to improve it, is also to preserve it. For example, former Texas State Senator Bob Deuell was a significant force in improving TADA’s fairness. But since his bills still preserved hospitals’ rights to stop treatment, he was attacked by Texas Right to Life and was not re-elected.<sup>31</sup> As the 2017 legislative session draws near, familiar debates will again echo through the halls of the Texas Capitol.

### 3. CONSTITUTIONAL ATTACK ON TADA

While most opponents of TADA have attacked it in the state legislature, some have challenged TADA in the courts. Specifically, several lawsuits have alleged that TADA is unconstitutional, because it authorizes hospitals to deprive patients of their life without the procedural due process protections required by the U.S. Constitution.

For example, in 2007, Children’s Hospital of Austin planned to use TADA to withdraw life-sus-

taining treatment from Emilio Gonzalez, a 17-month old baby with Leigh’s disease. This incurable degenerative disorder destroys brain function and eventually results in the death of the patient. The baby’s mother filed a federal lawsuit alleging that the TADA process violated her son’s rights under the 14th Amendment to the U.S. Constitution.<sup>32</sup> But the case was dismissed because a similar lawsuit was already pending in a state court. The state case was also dismissed. No court ever ruled on the constitutional claims.<sup>33</sup>

But one constitutional challenge to TADA is now proceeding. In the fall of 2015, Christopher Dunn was a patient receiving life-sustaining treatment for a mass on his pancreas at Methodist Hospital in Houston, Texas.<sup>34</sup> Dunn had been “on ventilator support, unable to communicate verbally, sedated, largely unresponsive, and wholly unable to participate in health care or other decisions” since October 2015.<sup>35</sup> On 10 November 2015, following a hospital committee meeting, Methodist informed Dunn and his family that the facility planned to discontinue his life-sustaining treatment on 24 November 2015 pursuant to TADA.<sup>36</sup>

Ten days later, Dunn filed a petition for a temporary restraining order to prevent Methodist Hospital from ceasing his life-sustaining treatment on 24 November 2015. In his petition, Dunn raised a variety of issues about the constitutionality of TADA, including infringement of his right to procedural and substantive due process.<sup>37</sup> He argued that TADA infringed on his right to procedural due process under the 14th Amendment of the U.S. Constitution and Article I, Section 19, of the Texas Constitution, because: (1) the statute failed to provide adequate venue for Dunn to be heard regarding a critical medical decision; (2) failed to produce sufficient evidentiary safeguards against medical providers, leaving them free to make life-determining medical decisions with unregulated discretion; and (3) failed to provide a reasonable amount of time for a patient to be transferred. In essence, Dunn alleged that TADA is unfair to patients because it provides no opportunity for patients to be heard in life-altering medical decisions. Dunn also argued that his right to substantive due process was violated because TADA deprived him of a substantive privacy right to make his own medical decisions.

Dunn sought relief in the form of both a temporary and permanent injunction, as well as a declaratory judgment from the court stating that Methodist’s actions and planned discontinuance of treatment violated his right to due process. On 20 November 2015, the district court issued an order granting

Dunn's petition for a temporary restraining order, reasoning that Dunn would suffer immediate and irreparable harm if the injunction were not granted, because the likely result of withdrawing treatment would be death. The temporary restraining order required Methodist Hospital to cease and desist all efforts to remove Christopher Dunn's life support through 4 December 2015.<sup>38</sup>

In early December, Methodist Hospital filed a plea in abatement and answer to Dunn's petition. (A plea in abatement is a response that objects to the time, place, or mode of trying a case and seeks to suspend the case until a more appropriate time.) In this case, Dunn's condition prevented him from actively participating in his medical decisions, yet he was named as the plaintiff propelling the case forward. Methodist's plea in abatement argued that Christopher Dunn lacked the capacity to proceed with the lawsuit and requested that the case be abated until the issue regarding capacity was resolved. This would delay Dunn's suit until a guardian and legal representative were appointed or until Dunn was again able to act on his own behalf.

In its answer, Methodist objected to Dunn's petition in its entirety and argued that Dunn's only opportunity for relief required proof that, under TADA, there was a reasonable expectation that another physician or medical facility would be found that would honor the patient's directive.<sup>39</sup>

The court granted Methodist's plea in abatement pending the appointment of a guardian.<sup>40</sup> Christopher Dunn died on 23 December 2015.<sup>41</sup> The case's abatement status was removed in January 2016 and an order was issued substituting Dunn's mother, Evelyn Kelly, as plaintiff individually, and on behalf of the estate of Christopher Dunn. In February 2016, Kelly filed plaintiff's first amended petition with the court. The amended petition included the same constitutional claims that were laid out in Dunn's original petition, and included a new claim for intentional infliction of emotional distress, alleging that Methodist Hospital caused Kelly severe emotional distress when it informed her it would be withdrawing life-sustaining treatment resulting in her son's certain death in November 2015.<sup>42</sup> A trial date is set for 9 January 2017.

#### 4. LEGISLATION PROHIBITING CLINICIANS

The move in Texas to restrict the scope of TADA seems to be indicative of a broader trend to constrain and narrow clinicians' discretion to stop life-sustaining treatment without the consent of a patient or surrogate. We have described these as "red light"

laws, because they "stop" clinicians from proceeding with the treatment plan that they judge medically and ethically appropriate.<sup>43</sup>

For example, over the past two years, Kansas and Missouri have considered a basically identical version of "Simon's Law." The legislation was inspired by and named for Simon Crosier.<sup>44</sup> Crosier was born on 7 September 2010 with trisomy 18 (Edward's syndrome—a chromosomal abnormality with a very low rate of survival, due to heart abnormalities, kidney malformations, and other internal organ disorders). Crosier's mother discovered that her son's clinicians had placed a DNR order in his records without her knowledge or consent. Chromosomal disorders like trisomy 18 have long been deemed to be "incompatible with life." But the prospects for these children are actually far better than generally believed.<sup>45</sup>

Simon's Law is directed at patients who are under 18 years of age and has two parts. First, it requires healthcare providers to disclose their futility policies. "Upon the request of a patient or resident or a prospective patient or resident, a health care facility, nursing home or physician shall disclose in writing any policies relating to a patient or resident or the services a patient or resident may receive involving life-sustaining or non-beneficial treatment within the health care facility or agency." This probably applies not only to futility policies, but also to conscience-based objection policies.

The second part of Simon's Law prohibits clinicians from withholding or withdrawing the life-sustaining treatment from minors without the consent of at least one parent: "No health care facility, nursing home, physician, nurse or medical staff shall withhold life-sustaining procedures, food, medication or nutrition, nor place any restrictions on life-sustaining procedures . . . without the written permission of at least one parent or legal guardian of the patient or ward," and "no do-not-resuscitate order or similar physician's order shall be instituted either orally or in writing without the written permission of at least one parent or legal guardian. . . ."

While two states considered Simon's Law, neither enacted it. The Kansas bill was introduced in February 2016. It passed the Kansas Senate in March 2016, but died in a Kansas House committee in June 2016.<sup>46</sup> The Missouri bill was introduced in both 2015 and 2016, but failed to advance.<sup>47</sup>

In contrast to the Kansas and Missouri legislation, a Maine bill was enacted; L.D. 1117 was introduced in March 2015 and enacted by June 2015.<sup>48</sup> The new Maine law defines the situations under which the state Office of Child and Family Services

(OCFS) can withhold or withdraw life-sustaining treatment for children in its custody. There are two conditions: (1) OCFS may withhold or withdraw life-sustaining medical treatment if the parental rights of the child's parents have been terminated (for example, because of abuse or neglect), and OCFS determines that withholding or withdrawing life-sustaining medical treatment is in the best interests of the child;<sup>49</sup> (2) if parental rights have not been terminated, OCFS may stop treatment only with parental consent or with a court declaration.

Three other states considered or enacted related "red light" legislation over the past two years. Utah enacted a statute that prohibits health benefit plans from denying coverage for medically necessary treatment on the basis of life expectancy or the diagnosis of a terminal condition.<sup>50</sup> Oregon considered a bill that would require healthcare facilities to share futility policies within 12 hours of a patient's admission.<sup>51</sup> New York considered a bill that would amend the patients' bill of rights to require that a "patient's religious beliefs be respected with regard to withholding or withdrawing life-sustaining treatment."<sup>52</sup>

## 5. LEGISLATION AUTHORIZING CLINICIANS

While most of the recent bills addressing medical futility appear to be "red light" laws, there was at least one green light bill (that would authorize clinicians to stop treatment without consent). In January 2015, a Virginia delegate introduced a bill that would strengthen and clarify that state's long-standing futile care law.<sup>53</sup> The physician legislator explained that he wanted to clarify the law to say "a physician has the right to stop care that's medically and ethically inappropriate over the objections of the patient, family or advocate after a 14-day period of trying to transfer the patient to a doctor or hospital who will provide such care."<sup>54</sup>

Since 1992, Virginia law has provided that clinicians are not required to "render health care" that they "determine to be medically or ethically inappropriate." The statute further provides that if a "conflict remains unresolved the physician shall make a reasonable effort to transfer the patient to another physician who is willing to comply with the request." The physician must provide "a reasonable time of not less than fourteen (14) days to effect such transfer." During this 14-day period, the physician "shall continue to provide any life-sustaining care." This is a reasonable requirement that is commonly included in both healthcare decisions acts and institutional policies.

But the law is silent on what can be done once the 14-day time period ends. The 2015 bill would have added the following language to the statute. "If, at the end of the 14-day period, the physician has been unable to transfer the patient to another physician who is willing to comply with the request of the patient, the terms of the advance directive, the decision of the agent or person authorized to make decisions . . . despite reasonable efforts, the physician may cease to provide care that he has determined to be medically or ethically inappropriate." The bill was tabled in committee.

## 6. CASES FROM CANADA

In October 2013, the Supreme Court of Canada decided a medical futility dispute in favor of the patient's family. In *Cuthbertson v. Rasouli*, the court took a very strong approach.<sup>55</sup> As one Canadian law professor describes it, the court requires physicians to provide life-sustaining treatment even when it is "contrary to their conscientious professional discretion or contrary to the standard of care."<sup>56</sup> Patients or surrogates "can effectively demand treatment—even harmful treatment—by refusing consent to the treatment being withheld. That is, by requiring consent for withholding or withdrawing treatment, the Court created [an] entitlement to treatment."

The court's holding was later codified by the provincial medical board. In late 2015, the Ontario College of Physicians and Surgeons issued its policy on "Planning for and Providing Quality End-of-Life Care."<sup>57</sup> It provides that "a decision regarding a no-CPR order cannot be made unilaterally by the physician." If the patient or substitute decision maker disagrees and insists that cardiopulmonary resuscitation (CPR) be provided, physicians must engage in a specified conflict resolution process. "While the conflict resolution process is underway, if an event requiring CPR occurs, physicians must provide CPR."

The consequences and effects of the effect of the *Rasouli* decision have been even broader than expected. First, the decision only concerns the law in Ontario; since *Rasouli* is grounded in an interpretation of an Ontario statute, it has no direct legal effect in other provinces. Nevertheless, clinicians in other Canadian provinces have been "chilled" from standing up to families who demand healthcare services that the clinicians judged to be inappropriate life-sustaining treatment.<sup>58</sup>

Second, the *Rasouli* court allowed (and even encouraged) clinicians to use the Ontario Consent and Capacity Board (CCB) to resolve medical futil-

ity conflicts under *Rasouli*. The CCB is an “independent, quasi-judicial tribunal,” a “neutral, expert board” that replaces surrogates who fail to act in a patient’s best interests.<sup>59</sup> Under *Rasouli*, clinicians always need consent to stop life-sustaining treatment. But the CCB can get that required consent, if the surrogate is refusing consent that is inconsistent with the patient’s wishes or best interests.<sup>60</sup> But while clinicians had brought dozens of medical futility cases to the CCB before *Rasouli*, they brought almost none after. It appears this is because they are increasingly caving in to surrogate’s demands, even when they judge their demands to be medically and ethically inappropriate.<sup>61</sup>

On the other hand, while the volume of cases over the past two years may be lighter than before *Rasouli*, Canadian courts and tribunals have continued to adjudicate medical futility disputes. Indeed, in two recent cases, they have authorized clinicians to stop administering life-sustaining interventions even when requested by the patient’s family. One case comes from the Ontario CCB. The other case comes from the Quebec Superior Court.<sup>62</sup>

In *In Re SL*, the attending physician was concerned that many of the treatments being advocated by the patient’s surrogate would result in pain and discomfort to the patient.<sup>63</sup> The physician brought the case to the Ontario CCB. The CCB first determined that there was no evidence to suggest that the patient had ever expressed any wishes regarding treatment. Therefore, the CCB applied an objective best interest standard. The CCB noted that “this is an area that the Board found that deference should be given to the medical practitioner.” The CCB directed the surrogate to consent to the recommended treatment plan (palliative care only).

Unlike Ontario, Quebec does not have a CCB. But neither is it subject to the *Rasouli* rule that clinicians always need consent to stop life-sustaining treatment. Not subject to the limitations in Ontario, a Quebec court recently authorized clinicians to stop life-sustaining treatment over a surrogate’s objections.<sup>64</sup> In *University of Montreal Hospital v. WL*, clinicians felt that it was futile to continue mechanical ventilation and to continue feeding for Mr. L., who was in a vegetative state. Despite the objections of the patient’s sisters, the court authorized the hospital to stop any treatment except comfort care.

## 7. CASES FROM THE UNITED KINGDOM

In contrast to the limited judicial guidance in the U.S. and Canada, there is ample judicial guid-

ance in the United Kingdom. In 2015 and 2016, the courts issued more than a dozen decisions.<sup>65</sup> Almost all of these were of an *ex ante* nature. The questions posed were framed to especially address the appropriateness of life-sustaining treatments. Because these decisions are written and publicly available, they effectively help to move the social debate forward in a way that is beneficial to clinicians, patients, and citizens.<sup>66</sup>

## NOTES

1. E.g. T.M. Pope, “Legal Briefing: Medically Futile and Non-Beneficial Treatment,” *The Journal of Clinical Ethics* 22, no. 3 (Fall 2011): 277-96; T.M. Pope, “Legal Briefing: Medical Futility and Assisted Suicide,” *The Journal of Clinical Ethics* 20, no. 3 (Fall 2009): 274-86.

2. E.g. T.M. Pope and D.B. White, “Medical Futility and Potentially Inappropriate Treatment,” in *Oxford Handbook on Death and Dying*, ed. S. Younger and R. Arnold (Oxford, U.K.: Oxford University Press, 2016); T.M. Pope, “The Texas Advance Directives Act: Must a Death Panel Be a Star Chamber?” *American Journal of Bioethics* 15, no. 8 (2015): 42-4; T.M. Pope, “Medical Futility,” in *Guidance for Healthcare Ethics Committees*, ed. M.D. Hester and T. Schonfeld (Cambridge, U.K.: Cambridge University Press 2012), 88-97; T.M. Pope, “Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes,” *Saint Louis University Journal of Health Law and Policy* 3 (2010): 183-252; T.M. Pope, “Medical Futility Statutes: No Safe Harbor to Unilaterally Stop Life-Sustaining Treatment,” *Tennessee Law Review* 75 (2007): 1-81.

3. E.g. T.M. Pope, “Dispute Resolution Mechanisms for Intractable Medical Futility Disputes,” *New York Law School Law Review* 58 (2014): 347-68.

4. Brain death cases are a type of medical futility dispute because they involve a clinician-family conflict about the appropriateness of life-sustaining treatment. But because the legal analysis is so different, we do not address those cases here. We have addressed them before. T.M. Pope, “Legal Briefing: Brain Death and Total Brain Failure,” *The Journal of Clinical Ethics* 25, no. 3 (Fall 2014): 245-7.

Similarly, we do not discuss nonlegal developments. But we note that there are three new policies from professional organizations: “An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units,” *American Journal of Respiratory and Critical Care Medicine* 191, no. 11 (1 June 2015): 1318-30; G.T. Bosslet, “Defining Futile and Potentially Inappropriate Interventions: A Policy Statement From the Society of Critical Care Medicine Ethics Committee,” *Critical Care Medicine* 44, no. 9 (September 2016): 1769-74; A. Kon, “Shared Decision-Making in Intensive Care Units: Executive Summary of the American College of Critical Care Medicine and American Thoracic Society Policy Statement,” *American Journal of Respiratory and Critical Care Medicine* 193, no. 12

(15 June 2016): 1334-6.

5. T.M. Pope, "Involuntary Passive Euthanasia in U.S. Courts: Reassessing the Judicial Treatment of Medical Futility Cases," *Marquette Elder's Advisor* 9, no. 2 (2008): 229-68.

6. *In re: Wanglie*, No. PX-91-283 (Minn. Prob. Ct. Hennepin County June 28, 1991); *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993).

7. In addition to compensation, tort damages also (1) determine rights, (2) punish wrongdoers and deter wrongful conduct, and (3) vindicate parties and deter retaliation or violent and unlawful self-help. *Restatement (Second) of Torts* § 901, cmt. a (2005).

8. E. Stannard, "Seymour Man Sues Yale New Haven over Wife's Death, Says She was Removed from Life Support," *New Haven Register*, 31 July 2016.

9. *Marsala v. Yale New Haven Hospital*, No. AAN-CV12-6011711-S (Conn. Superior Court, Judicial District of Ansonia/Milford 30 Oct. 2013) (Judge Lee).

10. *Marsala v. Yale New Haven Hospital*, No. AAN-CV12-6011711-S (Conn. Superior Court, Judicial District of Ansonia/Milford 19 Mar. 2015) (Judge Tyma).

11. *Marsala v. Yale New Haven Hospital*, No. AC-37821, 166 CA 432 (Conn. App. 28 June 2016).

12. See Pope, "Involuntary Passive Euthanasia in U.S. Courts," note 5 above.

13. *Marsala v. Yale New Haven Hospital*, No. AAN-CV12-6011711-S (Conn. Superior Court, Judicial District of Ansonia/Milford) (Judge Tyma) (docket as of 15 August 2016), <http://civilinquiry.jud.ct.gov/>.

14. *Siner v. Kindred Hospital Ltd.*, No. 49A05-1404-CT-00165 (Ind. App. 9 Oct. 2014) (Appellate Brief).

15. This opinion was focused on the prolonged application of a CPAP (continuous positive airway pressure) mask that may have caused scarring and infection.

16. *Siner v. Kindred Hospital Ltd.*, No. 49A05-1404-CT-00165 (Ind. App. 9 Dec. 2014) (Appellee's Brief).

17. The court of appeals also addressed whether the involvement of Indiana University Pulmonary and Critical Care Service, an independent contractor, in Geraldine Siner's treatment removed potential liability for Kindred Hospital; and whether the medical review panel's opinion provided sufficient expert testimony to establish causation in the Siner family's medical negligence claim. The court of appeals discussed how the involvement of IU Pulmonary Care may remove liability pertaining to the CPAP mask, but would not be enough to invalidate all allegations in the Siner family's complaint pertaining to negligent care and injuries. Lastly, the court examined whether the medical review panel was sufficiently expert testimony for causation. The court held that the three-sentence opinion of the review panel failed to provide context sufficient to support a verdict, and was not enough to establish a genuine issue of material fact for causation.

18. *Siner v. Kindred Hospital Ltd.*, 33 N.E.3d (Ind. App. 2015).

19. *Siner v. Kindred Hospital Ltd.*, 51 N.E.3d 1184, 1186 (Ind. 2016).

20. Chief Justice Rush also discusses how the defendants' own submitted evidence created a genuine issue of

material fact, because the affidavit by Krueger created a conflict of evidence with the opinion of the medical review panel.

21. *Wagner v. Summa Health System*, No. CV-2013-09-4227 (Court of Common Pleas, Summit County, Ohio 2016).

22. *King v. Summa Health System*, No. 2015-03-1760 (Court of Common Pleas, Summit County, Ohio).

23. T.M. Pope, "Texas Advance Directives Act: Nearly a Model Dispute Resolution Mechanism for Intractable Medical Futility Conflicts," *QUT Law Review* 16, no. 1 (2016): 22-53; T.M. Pope, "Procedural Due Process and Intramural Hospital Dispute Resolution Mechanisms: The Texas Advance Directives Act," *Saint Louis University Journal of Health Law and Policy* 10 (forthcoming 2017).

24. *Tex. Health & Safety Code* § 166.046.

25. *Tex. Health & Safety Code* § 166.045.

26. Texas Medical Association, *Healthy Vision 2020*, 2nd ed., [https://www.texmed.org/uploadedFiles/Current/Advocacy/Healthy\\_Vision\\_2020/HV2020.pdf](https://www.texmed.org/uploadedFiles/Current/Advocacy/Healthy_Vision_2020/HV2020.pdf), pp. 17-8:

Legislation has been introduced over the past four legislative sessions that would instead require indefinite treatment with no provision for the physician exercising ethics or moral judgment. TMA has opposed these proposals because they would prolong unnecessary—and often painful or even torturous—are that cannot prevent but can only prolong death. They would also require physicians, nurses, and other health care professionals to provide medically inappropriate care, even if that care violates medical ethics or the standard of care. They also would set a dangerous precedent for the legislature to mandate the provision of physician services and treatments that may be medically inappropriate, outside the standard of care, or unethical.

27. E.g. J. Shannon, "Right to Life Groups Battle Each Other," *Examiner*, 12 March 2015.

28. J. Perry, "Biopolitics at the Bedside," *Journal of Legal Medicine* 28, no. 2 (2007): 171-92.

29. Texas Representative James Frank introduced H.B. 3414, the mirror companion to S.B. 1163.

30. The bill would allow consideration of a patient's disability, if it is "relevant in determining whether a medical or surgical intervention is medically appropriate." This is consistent with the rule under the Americans with Disabilities Act. E.g. *Glanz v. Vernick*, 756 F. Supp. 632 (D. Mass. 1991); *McElroy v. Patient Selection Committee of the Nebraska Medical Center*, No. 4:06-cv-03162-RGK-PRSE (D. Neb. 21 Nov. 2007), aff'd, No. No. 07-3877 (8th Cir. 9 Jan. 2009).

31. T. Stutz, "Sen. Bob Deuell Seeks to Stop Radio Ads Targeting End-of-Life Bill," *Dallas Morning News*, 15 May 2014.

32. *Gonzalez v. Seton Family of Hospitals*, No. 1:07-CV-00267-SS (W.D. Tex. 4 April 2007) (Complaint).

33. *Gonzalez v. Seton Family of Hospitals*, No. 86427 (Travis County Probate Court, Tex. 20 March 2007) (Complaint).

34. *Dunn v. Methodist Hospital*, No. 2015-69681 (Har-

ris County District Court, Tex. 20 Nov. 2015) (Petition).

35. *Dunn v. Methodist Hospital*, No. 2015-69681 (Harris County District Court, Tex. 2 Dec. 2015) (Plea in Abatement).

36. *Tex. Health & Safety Code* § 166.046.

37. This included a Section 1983 claim in which Dunn argued that he had been deprived of his rights as a result of Methodist Hospital's use of TADA to protect its decision to cease life-sustaining treatment.

38. *Dunn v. Methodist Hospital*, No. 2015-69681 (Harris County District Court, Tex. 20 Nov. 2015) (Order).

39. Methodist Hospital asserted that Dunn failed to prove that another facility or physician would accept him. The hospital also argued that the state constitutional claims in the petition fail, because the Texas Constitution does not provide a direct cause of action for infringement of constitutionally protected rights. Lastly, Methodist argued that Dunn's Section 1983 claim failed because the hospital would not qualify as a state actor and, in either case, it did not deprive Dunn of a liberty or property interest. The court did not rule on these arguments, as the issues were not asserted in the original petition.

40. *Dunn v. Methodist Hospital*, No. 2015-69681 (Harris County District Court, Tex. 4 Dec. 2015) (Order of Abatement).

41. D. Wray, "In Texas, a Hospital Ethics Panel—Not the Patient or Family—Decides Whether to End Care," *Houston Press*, 9 February 2016; "Chris Dunn Dies after Fight over Life-sustaining Treatment, Attorney Confirms," ABC13 Houston, 23 December 2015, <http://abc13.com/news/chris-dunn-dies-after-fight-over-life-sustaining-treatment-attorney-confirms/1133520/>.

42. *Kelly v. Houston Methodist Hospital*, No. 2015-69681 (Harris County District Court, Tex. 2 Feb. 2016) (First Amended Petition).

43. T.M. Pope, "Dispute Resolution Mechanisms for Intractable Medical Futility Disputes," *New York Law School Law Review* 58 (2014): 347-368

44. <http://www.simonismynane.com>.

45. J.D. Lantos, "Trisomy 13 and 18—Treatment Decisions in a Stable Gray Zone," *Journal of the American Medical Association* 316, no. 4 (2016): 396-8.

46. Kan. S.B. 437 (2016) (Committee on Federal & State Affairs).

47. Mo. H.B. 113 92015) (Kidd); Mo. H.B. 1915 (2016) (Kidd).

48. Me. LD 1117 (Cushing), enacted as Me. Pub. L. Ch. 187.

49. The statute provides that stopping treatment is in the best interests of the child "if the child is in a persistent vegetative state or suffers from another irreversible medical condition that severely impairs mental and physical functioning, with poor long-term medical prognosis, and the child would experience additional pain and suffering if life-sustaining medical treatment were administered."

50. Utah S.B. 271 (2015) (Bramble), enacted as Ch. 375, codified at *Utah Code* § 31A-22-644.

51. Ore. S.B. 524 (2016) (Knopp).

52. N.Y. S.B. 1054 (2015) (Hannon); N.Y. A.B. 3767

(2015) (Goldfelder).

53. Va. H.B. 2153 (2015) (Stolle).

54. E. Simpson, "Delegate Wants to Clarify Law on Treatment vs. Suffering," *Virginia Pilot*, 31 January 2015.

55. *Cuthbertson v. Rasouli*, [2013] 3 SCR 341, 2013 SCC 53.

56. H. Young, "Physician Conscientious Professional Discretion in Canada and the United Kingdom," 2016, [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2802776](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2802776).

57. College of Physicians and Surgeons of Ontario, "Planning for and Providing Quality End-of-Life Care," May 2016, <http://www.cpso.on.ca/policies-publications/policy/planning-for-providing-quality-end-of-life-care>.

58. D. Cape et al., "The Impact of the Rasouli Decision: a Survey of Canadian Intensivists," *Journal of Medical Ethics* 42 (2016): 180-5.

59. See note 1 above.

60. R. Cribb et al., "Stalemate: Deciding Life or Death," *Toronto Star*, 26 September 2014.

61. T. Blackwell, "Doctors More Reluctant to Clash with Families over End-of-Life Decisions in Wake of Supreme Court Ruling," *National Post*, 5 September 2014.

62. There have been five other recent Canadian cases. First, in British Columbia, the parents of Mary Jane Pierce obtained an injunction prohibiting clinicians from stopping life-sustaining treatment. But they had earlier signed over medical decision making to Child, Family, and Community Services. *Pierce v. Fraser Valley Aboriginal Children & Youth Society*, No. E152222 (B.C. Supreme Court, 11 Aug. 2015). Second, a Nova Scotia court dismissed an *ex post* damages lawsuit because the family failed to designate an expert witness. *Chan v. White*, 2014 NSSC 383 (Nova Scotia Supreme Court 24 Oct. 2014). Third, another lawsuit for damages is proceeding against Toronto East General. R. Cribb, "Family Sues Physician, Toronto Hospital over No-resuscitation Order," *Toronto Star*, 25 March 2015. Fourth, a medical board imposed discipline against Ontario physicians for writing a unilateral DNR order. *In re Complaint of Wawrzyniak re Chapman & Livingstone*, No. 95903 (College of Physicians and Surgeons of Ontario, 21 May 2015). Fifth, the Court of Appeal for Ontario affirmed a trial court's dismissal of a damages action related to the *Rasouli* case. *Salasel v. Cuthbertson*, 2015 ONCA 115.

63. *In re SL*, 2016 CanLII 46386 (Ont. CCB).

64. *Center Hospitalier de L'universite de Montreal v. WL*, 2014 QCCS 1864 (19 Mar. 2014).

65. These cases are collected at <http://thaddeuspope.com/medicalfutility/futilitycases.html>.

66. G.T. 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).