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Moral Distress: *A Growing Problem in the Health Professions?*

BY CONNIE M. ULRICH, ANN B. HAMRIC, AND CHRISTINE GRADY

In the insightful and provocative book *Final Exam*, noted author and liver transplant surgeon Pauline Chen chronicles her medical education and some of the ethical dilemmas physicians face in practice.¹ She describes a hierarchal and often authoritative system of care, reflecting upon the frailties of care providers as well as patients. Though she does not explicitly use the term, Chen implicitly describes the impact of *moral distress* on health care quality, providers' ability to meet professional and ethical obligations, and subsequent provider satisfaction and retention.

Moral distress, as defined by Andrew Jameton in 1984, is the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints.² Others have noted the psychological and physical burdens resulting from moral distress.³ Today, nurses and their colleagues face ethical issues that seem more complex and more frequent than when Jameton coined the term twenty-five years ago. Although moral distress was originally conceptualized to address ethical issues in nursing, all health care professionals tackle morally relevant questions pertaining to the "rightness" or "wrongness" of decisions, treatments, or procedures, while feeling powerless to change situations they perceive to be morally wrong. Providers frequently say things

like, "It's not my job to speak out; no one will listen anyway," or, "This doesn't make any sense; why are we continuing to do this?," or "I want to tell the patient to run."

A case drawn from practice shows the anger, guilt, and moral compromise that health care professionals may experience in situations of moral distress. A thirty-five-year-old woman, Ms. Adams (all names and identifying details have been changed), had been diagnosed with acute lymphocytic leukemia that proved resistant to all standard and experimental chemotherapy regimens. She was divorced, uninsured, and had four young children. Previously hospitalized for fungal pneumonia and sepsis that was compounded by a low white blood cell count from experimental treatment, Ms. Adams returned to the emergency room with abdominal pain, nausea, and vomiting. She was readmitted and diagnosed with a pancreatic abscess and small bowel obstruction; she developed intractable pain and pancytopenia—a form of anemia requiring daily transfusions. She was not a candidate for surgery at this time because of her debilitation.

Ms. Adams and her family met with the team to discuss her options. She refused hospice care in lieu of continuing aggressive treatments like experimental chemotherapy, believing that she would "be healed and pull through this ordeal." She said that after her blood counts recovered, she wanted to go home to spend time with her children. She chose to remain a "full code" rather than agree to a do-not-resuscitate order. Her parents told the oncology fellow, "She is a fighter and would want to try anything to save her life."

Jane, Ms. Adams's primary nurse, struggled to accept these decisions. She had already seen several primary care patients suffer through medically futile chemotherapy. Jane empathized with her patient's desire to keep fighting for her children, but she doubted Ms. Adams would leave the hospital alive.

A week later, Ms. Adams again developed sepsis, along with blood in her urine, confusion, rapid breathing, and system failure. Jane asked, "Why are we providing false hope to Ms. Adams and her family? This seems senseless. I feel like I'm inflicting unnecessary suffering on her." The fellow agreed, saying he was also troubled and would not choose this type of treatment for himself or his loved ones. He believed hospice would be the best option for Ms. Adams, but told Jane that his job was to do everything he could to keep her alive, since he must follow his attending physician's orders and the family's wishes.

Ms. Adams died two weeks later in the intensive care unit, never making it home to see her children. Her case raises several morally distressing events frequently encountered in daily patient care—feelings of powerlessness, miscommunication, missed opportunities for meaningful end-of-life discussions, confrontational dialogue, implicit deception, and value conflicts related to "hope-driven treatment."⁴ Jane and the oncology fellow felt guilt, sadness, and anger. They were concerned that they had failed their patient on several fronts: first, by offering her treatments that they knew would not help her and would only give her toxic side effects; second, by honoring

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choices that they would have rejected for themselves; third, by failing to discuss palliative care and hospice options until the patient was too debilitated to return home and spend time with her children; and finally, by failing to confront the attending physician, who refused to discuss end-of-life care with his patient in a meaningful way.

Chen notes that physicians—especially those less experienced or in training—can view “dying [as] a personal failure and withdrawing treatment [as] the declaration of defeat.”⁵ In this case, the oncology fellow decided that his easiest choice was to simply follow orders; yet by doing so, he created more suffering, both for his patient and for himself. While providers are expected to respect the autonomous right of patients to determine their own best interests, they are not obligated to provide medically futile care. As Edmund Pellegrino and David Thomasma state, “no one can make health professionals do what is thought to be harmful to patients.”⁶ However, there is no clear point at which a provider can override patient autonomy when he or she is concerned about life-sustaining treatments. When does treatment become more burdensome than beneficial, and who determines that? Empirical evidence suggests that providers face mounting pressures from administrators, colleagues, patients, and families. They question futile treatments, encounter unethical and unprofessional practices, and become emotionally exhausted, frustrated, and disillusioned with their professional practice.⁷ Certainly, we need to diminish the untoward effects of moral distress.

When providers perceive ethical issues that they can do nothing about, an open dialogue among patients, providers, and administrative personnel is warranted. Interdisciplinary education and collegial practice are two strategies to decrease moral distress. For example, physicians and nurses can benefit from a common ethics course to exchange ideas and learn about each other’s professions and ethical philosophies. Helping students to develop an ethical skill set instills confidence that will allow them to exercise moral convictions when difficult patient care issues arise. In most settings, for example, nurses cannot initiate “do not resuscitate” discussions.⁸ However, Daniel Sulmasy and colleagues argue that nurses themselves feel capable of initiating these discussions, and that the majority of attending physicians they surveyed agreed that nurses should be permitted to do so.⁹

Moving to more open collegiality and shared practice models may help to alleviate moral distress by increasing a sense of shared responsibility and of professional satisfaction.

As the United States faces major nursing and physician shortages, interdisciplinary education and collegial practices would represent a commitment to seek common ground, garner mutual respect for each other’s roles, and discuss meaningful ways to communicate and collaborate effectively about the ethical problems each group identifies.

Recurrent situations of moral distress indicate underlying systemic problems of poor communication, inadequate collaboration, and perceived powerlessness that must be addressed if we are to minimize this phenomenon in clinical settings.¹⁰ Reducing moral distress calls for identifying efficient and effective mechanisms to support health care providers

who have limited time to focus on ethical issues but know that the intensity of these events lingers well beyond the occurrence. Many nurses feel the need for pastoral support to provide a comforting presence and listening ear when they experience moral distress. Chaplains and clinical ethics consultants can also intercede when value conflicts between two parties hinder a common goal.

As members of a health care community that the public trusts with their most morally significant treatment decisions, physicians, nurses, and other health care providers have an obligation to speak up about their ethical concerns for the patient’s welfare. Giving voice and

recognition to moral distress is the first step.¹¹ Ethical dialogue may provide a sense of resolve and reason to approaching difficult ethical questions that providers encounter when caring for those with complex health care needs. As Chen notes, perhaps we can then become the health care providers we always dreamed of being.

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Cryptic Coercion

BY ILINA SINGH

It's early evening and I imagine that below me, seventeen floors of this anonymous high-rise must be emptying out, workers spun from revolving glass doors into a twilight of routine responsibilities: traffic, transport, what to have for dinner. The eighteenth floor doesn't inspire ivy-covered fantasies about academic nightlife. Psychologists don't get that kind of real estate.

Here on the eighteenth floor, I am waiting for a child participant in my interview study on attention deficit hyperactivity disorder. There are lots of no-shows in this study. The staff smile at me and rush out, probably wondering why I appear to be guarding the door. I like to meet families as they

come in. I don't like them to be greeted by a locked door, to have to pick up the external phone and talk to me through the security system while their ears are still decompressing from the elevator ride. A child can't come into an interview relaxed when the family has had to pass through multiple screening barriers (parking garage, front desk, departmental door) simply to reach me.

George and his mother are late.¹ She apologizes; she went to the wrong building. George is small and lean, a ten-year-old boy of mixed race. He and his mother look exhausted and harried. They have already canceled one appointment with me; his mother felt they ought to attend today even though George has been at a school sports day all day and is hungry. She tells me he's been feeling a bit unwell, too, in the last few days—she is eager to talk about him.

We go into the briefing room and go over the consent forms. George is completely uninterested. I ask mum to engage George in the reading of the form, and she begins to read aloud to him. The language on the form has been rigorously scrutinized for accessibility by the university's institutional review board, but she struggles with it. Should I take over? I don't want to humiliate her. Instead, I launch into an explanation after she has read each item, as though this is the normal thing to do. George ticks the boxes signalling his consent. The last item says something like, "I understand the information on this form, and I want to participate in this study."

George says, firmly, "No."

"What do you mean?" his mother asks, clearly embarrassed.

He appears to waver. "I don't want to do it?"

"Yes, you do."

"I'm tired." His voice is so quiet I can hardly hear it.

"We've come all this way, and we promised this lady you'd talk to her."

I intervene, stressing to George that he does not have to do the interview if he doesn't want to. I tell them both that there will be no negative consequences if they don't participate. I am aware, though, that if George doesn't do this interview, a whole day of recruitment at this site will have been wasted. He is the only eligible child who has turned up on this day.

Mum begins negotiating with George: "You wanted that voucher, remember?"

I cringe. I don't know the technicalities of whether a participant who turns up for an interview but doesn't actually do an interview is eligible for the incentive. And the truth is that my budget for this study is very limited. But it doesn't matter; I have to intervene in maternal coercion. So I tell George he can have the voucher, and I tell his mum that I will pay her the participation fee. It's not a problem, I say; they can go.

George's gaze is moving haphazardly over the walls of the room, and I see it settle on the plate of cookies at the far end of the table. He hasn't seen them before. Normally I would have invited him and his mother to help themselves, but I've been distracted by the difficulties surrounding consent. He says, "Can I have a cookie?"

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