



A Case Study of Moral Distress

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Moral distress occurs when an individual's moral integrity is seriously compromised, either because one feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome. Recurrent situations of moral distress can lead to the "crescendo effect," with buildup of moral distress and moral residue in care providers. This article analyzes a case that led to moral distress in a health care team. Themes of moral distress are identified, and strategies are offered to help clinicians manage such cases. Institutional resources such as ethics committees and palliative care teams can be helpful in dealing with moral distress if they are knowledgeable about the phenomenon.

KEY WORDS

bioethics, moral distress, NICU, palliative care

Moral distress occurs when an individual's moral integrity is seriously compromised, either because one feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome^{1,2} (L. D. Wocial, personal communication, October 24, 2013). Moral distress is a relational experience shaped by multiple contexts, including those of the work environment.³ This compromised moral integrity gives rise to emotionally distressing responses that may range from avoidance, frustration, anger, and guilt to physical symptoms.^{1,4,5} Moral distress shares some emotionally distressing responses with other syndromes, such as burnout, compassion fatigue, or posttraumatic stress disorder. However, unique to moral distress is the experience of having one's moral values or obligations compromised or allowing them to be compromised.² As a result, moral distress can cut to the heart of one's view of oneself as a moral professional and moral person.

A related but distinct phenomenon is that of moral residue. Webster and Bayliss⁶ defined moral residue as the emotional residual that remains from experiences of

moral compromise; this residue is lasting and powerful because action or inaction has resulted in threatening or betraying core beliefs and values that help define oneself.

Moral distress is by definition a subjective experience, because professionals differ in their core values and obligations. Each professional has a personal set of values based on family background, religious tradition, and life experience that lead to distinct perspectives. Because these are deeply held views, differing perspectives are challenging to reconcile, particularly in areas where there is no societal consensus on the "correct" moral action (as can be the case regarding treatment at the end of life). In addition, each health profession has a code of ethics that specifies core obligations and values informing the profession. Studies reveal wide variability in moral distress levels within and across professional groups: whereas registered nurses and other health care professionals (HCPs) engaged in direct patient care have higher moral distress statistically than do physicians or HCPs not in direct practices, some physicians/HCPs have higher moral distress than do registered nurses.⁷⁻⁹ High levels of moral distress correlate with perceptions of poor collaboration, a poor ethical climate, and less satisfaction with care quality. Regardless of discipline, clinicians with high moral distress are more likely to have left a previous position or are considering leaving their current one.⁷⁻⁹

The strong emotions characteristic of moral distress challenge health care teams to work together to recognize moral distress and support each other in problematic situations. Consider the following case. This case represents a composite of numerous cases the author has experienced over the past decade of working with morally distressed clinicians.

The Case of Baby C.

Weighing about 750 g, baby C. was born at 25 weeks' gestation at a rural hospital. In his first week of life, he had a severe intraventricular hemorrhage (grade 4) with resulting hydrocephalus. Baby C.'s parents were called to the hospital and told about the intraventricular hemorrhage. They were offered the option of withdrawing treatment, as at that point he was on a ventilator. His mother compared this option to "putting an animal down," and the parents refused. The parents said they understood the risk of disabilities and that he would have significant problems, but that was acceptable to them.

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At 2 weeks of age, baby C. was transferred to an academic medical center with a large neonatal intensive care unit (NICU) for ongoing management of his hydrocephalus and after he developed necrotizing enterocolitis (NEC) that required extensive surgery. He has continued to remain in this NICU for the last 4 months. Baby C.'s course has been complicated, with periods of stabilization in some organ systems and deterioration in others. Currently, he is able to breathe on his own. Initially, he was too small for a ventriculoperitoneal (VP) shunt, so a ventricular reservoir was placed that requires tapping every other day to remove accumulated cerebrospinal fluid. Although there was a plan to insert a VP shunt, it was put on hold when further surgery was required for the NEC; now, a VP shunt is not an option. He will need a ventriculoatrial shunt for long-term management of his hydrocephalus, which requires frequent revisions with growth.

After repeated surgeries for his NEC, baby C. now has short bowel syndrome and will require total parenteral nutrition indefinitely. He is not a candidate for a bowel or liver transplant because of his neurological status. Neurologically, baby C. does not have a functioning cortex and is most likely cortically blind. He very rarely opens his eyes and has little spontaneous movement. Recently, he has demonstrated some "jittery" movements that may indicate early cerebral palsy. Given all these complications, being able to send the infant home is unrealistic in the short term, and perhaps the long term as well.

Baby C.'s parents live in a rural area without skilled home nursing support to manage his many problems. The parents have other children at home, and both parents work, so it is difficult for them to make the 3-hour drive to the NICU. Baby C.'s parents have a high school education and are members of a Protestant church in their community, although they do not attend regularly and do not profess a strong religious preference. Although they have some family support to provide care for their other children so that they can visit the NICU, no other family members have ever visited baby C. As time has gone by, baby C.'s parents have visited less frequently and for briefer periods. At present, they come only 1 or 2 times a week and show little bonding with their son. The parents decline participation in their infant's care and do not wish to hold him.

A few days after the most recent bowel surgery, the team met with the parents to review all that had happened. Baby C.'s mother seemed most surprised by the doctor's statement that baby C. wasn't going to be able to take

a bottle or see. The team gave his parents the option to "not do CPR or meds" if his situation worsened, but the father said that he felt that as long as baby C. was "fighting for his life" they should support him. If the team thought a time came when the baby was truly suffering, the parents said they would consider withdrawing treatment, but not now.

Moral distress has been building among many of the NICU staff caring for baby C. As one nurse stated, "baby C. is a vegetable. What is this family being told for them to think there is hope for any quality of life for him? Are we giving them false hope?" Some nurses, physicians, and respiratory therapists feel this treatment is all futile because baby C.'s profound neurological compromise means that he has no chance for a meaningful quality of life. Some staff believe that the infant is suffering—they are angry that aggressive treatment is continuing to be offered and are refusing to care for baby C. They note that such cases happen repeatedly on the unit. Some professionals are concerned about the use of resources for questionable benefit; the costs are being paid by Medicaid, and there is an acrimonious debate going on at the state level about the rise in Medicaid costs and who will pay for them. Other staff members feel overwhelmed and sad—these staff note that they keep their efforts focused on stabilizing each system and dealing with each clinical problem as it presents rather than look at the overall goals of care for this infant and what is being accomplished by all this treatment. The big picture is too painful. After a recent discussion, a resident noted, "We've not seen the forest for all the trees."

However, other team members state, "I can't see that he is suffering, and anyway, what can we do? Baby C. is breathing on his own, and his surgical wounds are healing." These professionals say, "We've lost the window of opportunity to withdraw treatment." One physician stated, "We have to tread very carefully here because of our societal mandate to treat these compromised infants aggressively—we can't have anyone think we are killing the baby." Other staff see such comments as reflective of the unit's culture of aggressive treatment in all situations.

Although institutional resources are available that would be helpful in providing guidance and support for the staff such as a pediatric palliative care team and an ethics consultation service, they have not been used for a variety of reasons. These include concern that the palliative care team would "take over" the case and that asking for an ethics consult would imply that the NICU team was "inadequate" and "not doing a good job."



COMMENTARY

Themes of Moral Distress

The first noteworthy characteristic of this case is that the experience of moral distress is not limited to nurses—physicians and other HCPs involved are also experiencing moral distress. Baby C.'s parents may be experiencing moral distress as well, but this discussion will focus on the clinician's experience. As noted, moral distress is not unique to any one discipline, and it is clear that multiple staff members from different professions are experiencing moral distress in this case. The powerful emotions of moral distress are seen in the varied reactions of the staff members. However, they are experiencing moral distress for different reasons, grounded in differing understandings of their obligations and the ethically appropriate actions needed. So one important implication is that members of this team need to name their moral distress and share their differing perspectives with one another. Nurses familiar with moral distress can help their colleagues recognize and understand the phenomenon rather than assume that the nurses are the only ones who are morally distressed. Such discussion can help each team member take a step back and begin to respond to what is happening in a more analytic and unified fashion, rather than be mired in their individual reactions.

Baby C.'s case demonstrates that the experience of moral distress is highly variable—some staff are severely morally distressed and argue against continued aggressive treatment, whereas others feel that the care provided to baby C. is morally appropriate, and they feel obligated to continue. Different views of whether the baby is suffering also give rise to differences in perceived moral obligation. As noted, differing values and understandings of their obligations mean that some individuals may respond to a case with moral distress, while others do not. However, the varied reactions in baby C.'s case are compromising this staff's ability to communicate, to come together, and to examine goals of care as they are evolving. The key challenge is to protect everyone's moral integrity in such situations, including the integrity of baby C.'s family, while forging a consensus on goals of treatment. Consensus building should include a child's parents as members of the team, but in this case, more frequent and clear communication with baby C.'s parents was required than staff have been able to achieve.

Many of the key features of moral distress are evident in this case. Staff experiencing moral distress feel powerlessness and helpless to stop treatment that they think is ethically wrong. A number of root causes of moral distress identified in earlier research^{2,9} are present here (Table 1).

The case of baby C. demonstrates the tendency seen in many acute care settings for clinicians to continue to focus on physiological parameters, even as patients cannot be stabilized, and the original hoped-for outcomes become increasingly unrealistic. In ICU settings, aggressive treatment

TABLE 1 Root Causes of Moral Distress Seen in the Case of Baby C

• Following family wishes for continuing aggressive treatment when the provider believes that such treatment is not in the best interest of the infant
• Offering/providing aggressive treatment that is seen as futile and prolonging suffering
• Inappropriate use of resources
• Giving "false hope" to family members
• Inadequate information being given to family members to allow for fully informed consent
• Poor team communication

of each organ system is the primary focus of treatment and communication with patients and families. Although initially appropriate, situations where the damage to organ systems is too great to allow for meaningful recovery raise troubling questions. As one provider in baby C.'s case noted, "The big picture is too painful." However, the emphasis on stabilizing systems in the absence of considering the "big picture" of the overall goals of care can be confusing to parents, who may believe that the clinical reports they receive indicate that their infant is improving in a quality-of-life sense, not just in a biological system sense. After 4 months of intensive treatment, baby C.'s parents had unrealistic expectations regarding the health of their infant, because they were under the impression that baby C. would be able to see, have some cognitive function, and take a bottle. In the author's experience, it is not unusual that when HCPs keep the focus on improving laboratory values, blood gases, physical healing after surgery, and stabilizing various organ systems, that patients and families come to the erroneous conclusion that there is overall progress toward recovery and a meaningful quality of life.

Goals of Treatment

Examining whether the goals of treatment should switch to palliation should be incorporated into many plans of care earlier than it is but this is often difficult to accomplish in complex trajectories such as with baby C. Clear consistent communication with families and ensuring their partnership in decision making is critical in such cases. As the clinical picture changes and what constitutes a positive outcome changes, clinicians must help each other and patients and families adjust their focus and efforts from life prolongation to comfort and absence of suffering. For example, baby C.'s parents wanted to support their infant in "fighting for his life" but did not want him to suffer. Clinicians could have explored the parents' statements in more depth to better understand what they would see as a good outcome in light of realistic goals of care at each decision point in his



complicated trajectory. It should be noted here that problems can arise when parents want a futile treatment that has been offered and/or begun. Clinicians are not ethically obligated to offer or begin treatment they believe to be futile, nor are parents entitled to demand it. Early involvement of a palliative care team at the same time as aggressive interventions are being offered can help the transition from a life-prolonging focus to end-of-life care. In the case described, however, the pediatric palliative care team was poorly accepted by the NICU team, warranting reflection on both sides as to why this was so.

The 3 “Levels” of Moral Distress

Moral distress operates most often at multiple levels: the individual case, the team/unit, and the organization/system within which care is given. The need to develop strategies that go beyond a particular case to address unit and organizational levels is one of the reasons that moral distress is so difficult to address. In the case of baby C., all 3 levels are operating. Dealing with baby C.’s case alone will not address the recurring nature of such cases: the communication issues among interprofessional team members and between the team and parents, the unit’s culture with respect to aggressive treatment, and the organizational challenge of the relationship of the critical care team to pediatric palliative care resources. As a consequence of inadequate attention to this feature of moral distress, similar cases tend to recur and cause a buildup of both moral distress and moral residue, the so-called “crescendo effect”² (Figure). In the crescendo effect, difficult cases, if not resolved with explicit attention to moral distress, can leave providers with moral residue. As similar cases recur, the staff’s moral distress becomes progressively higher as the moral residue from previous unresolved cases builds in the provider. Each inadequately resolved case results in a second crescendo of moral residue. In the case of baby C., there is a clear sense of escalating moral distress over time as the issues continue; the crescendo effect can occur within a case as well as between cases. This phenomenon has been reported in nurses

and physicians but not in other providers, although it is just beginning to be studied.²

Resources Available to the Staff and Barriers to Their Utilization

It is unclear to what extent the unit’s clinical and administrative leaders are resources for the staff in managing their moral distress. However, this team has not yet achieved a consensus from their differing perspectives. Leaders need to work to support and safeguard the moral integrity of HCPs in their settings.¹⁰ Exploration of the leadership’s knowledge of moral distress and ability to develop strategies for supporting the staff’s moral agency may be needed.

Two key resources for managing moral distress, the institution’s ethics consultation service and the pediatric palliative care service, were not utilized in this case. The availability of ethics consultation is not mentioned by any of the clinicians and may not be seen as a resource. There is wide variation in how ethics consultation services function. Although some ethics consultation services focus on individual cases, others take a broader view and know how to recognize and intervene in situations of moral distress. In particular, institutions that have dedicated ethics consultants with formal education are becoming increasingly aware of moral distress among staff, and ethics consultation may be helpful for situations of moral distress.

The pediatric palliative care service is also not seen as a resource to the staff caring for baby C., although for different reasons. There are 3 real problems here: the fallacy that the goals of palliative care and those of intensive care are in opposition, a palliative care team who is not perceived as being knowledgeable about moral distress and thus is not consulted and cannot help clinicians sort out this phenomenon before it crescendos, and a palliative care consultative service that is perceived as having a goal of “taking over” cases from the frontline clinicians.^{11,12}

With respect to the first problem, the overall goals of a patient’s care are individualized to that patient and of necessity change over time. They should not be determined based on the setting in which care occurs or the perspective of any one provider; rather, they are shaped by the clinical facts and contextual particulars that surround each patient and their family, the patient’s progress and responses to interventions, and the patient/family’s wishes. All clinicians, regardless of specialty or setting, share in the desire to maximize quality outcomes, so it is a concern when goals of critical care and those of palliative care appear to conflict. Increasingly, palliative care is becoming integrated into ICU settings so that palliative care clinicians are members of the ICU team to ensure that suffering and symptoms are addressed along with life-preserving aggressive interventions.

Second, palliative care teams should also provide support to all levels of staff and facilitate discussions of values

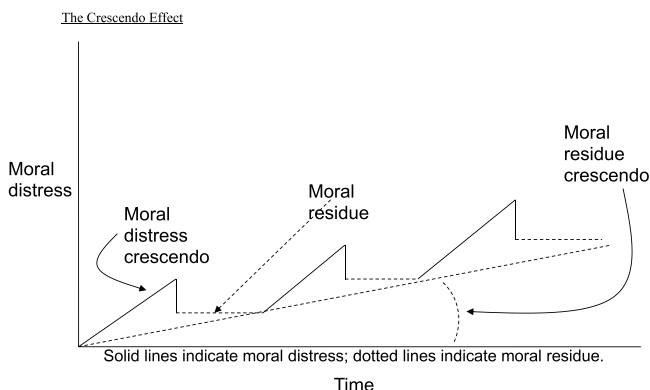


FIGURE. The crescendo effect. Source: Epstein and Hamric.^{2(p333)} Used by permission.



and goals of care, particularly around aggressive interventions and the likelihood that the overall goals for a patient's care can be achieved through these interventions. Knowledge of moral distress can be an invaluable aid to palliative care consultants as they try to tease out the differing values and obligations perceived by different team members and families and how those differences are creating conflict within a team. Finally, the goal of palliative care consultation is not to assume responsibility for the patient's care, unless that is specifically requested by the primary team. Rather, the consultation aims to support the primary caregiving team in any way that they would find helpful. Palliative care consultants can provide an additional perspective, suggest treatment strategies, and work to support patients, families, and caregivers through difficult conversations and choices.

Unfortunately, the lack of utilization of the 2 key resources of ethics and palliative care services in the case of baby C. is not unusual. In a recent editorial commentary on a study of improving the quality of end-of-life care in ICUs, Truog¹³ noted that only 8% of the patients in the study had a palliative care consult, and only 1% had an ethics consult. (Truog reported the referenced data after a personal communication with the authors of the following study: DeCato TW, Engleberg RA, Downey L, et al. Hospital variation and temporal trends in palliative and end-of-life care in the ICU. *Crit Care Med.* 2013;41:1405-1411.) Concerted education is needed on the benefits of these resources in helping frontline staff provide ongoing care in cases such as baby C.'s.

Outcome

Six weeks after the time of this case presentation, baby C. contracted a central line infection that progressed rapidly to sepsis and multisystem instability. Baby C. was put back on a ventilator, and the parents were called in again. They agreed to withdraw aggressive treatment because the baby had no chance of improvement; once the ventilator was withdrawn, baby C. died. This case served as a catalyst for initiating discussions between the NICU's leadership and the pediatric palliative care service regarding how the groups could work together more collaboratively. Perceptions were shared, and plans were made to identify future patients/families who would benefit from earlier consultation.

Lessons Learned

This is a rich and complicated case of moral distress, with many intertwining elements at patient, team, unit, and organizational levels. While the resolution of this case was less than optimal in terms of addressing moral distress, baby C. did raise the staff's awareness of this phenomenon and the need to begin conversations about how to manage it. A number of strategies that can be useful in this case (Table 2) have applicability to other situations causing moral distress. This discussion will now move beyond baby C.'s

TABLE 2 Strategies to Address Moral Distress

1. Education of the interprofessional team to recognize and speak up about moral distress
2. Early, frequent, and consistent communication with patients and families
• Family meetings
• Clarify patient/family's understanding of the clinical situation and reclarify as needed
• Ongoing development of goals of care with patients and families
3. Have conversations about the ethical dimensions of care
• What ought we to do?
• Which obligation is primary?
• What are the goals of care? Have they changed? Do they need to change?
4. Build communication and collaboration among team members and with ethics and palliative care teams
5. Seek skilled facilitators to help the staff work through cases of moral distress
• Moral distress consultations that give attention to the 3 levels of moral distress
6. Debrief situations with a goal of preventing the recurrence of a similar case
• What were the early warning signs of moral distress, and how can we recognize them next time?
• What could we have done differently?
• How can we anticipate moral distress and intervene before the crescendo compromises provider integrity?
7. Strengthen the unit's ethical climate
• Interprofessional rounds
• Care conferences involving multiple disciplines
• Identify root causes of moral distress and develop strategies to address
• Target unit cultural elements needing improvement
• Develop administrative support in the face of organizational and systems problems
• Prioritize strategies
8. Be persistent
<i>Adapted from Epstein and Hamric² and Hamric et al.¹⁰</i>



case to a larger discussion of managing moral distress in clinical settings.

Initially, clinicians need to recognize and speak up about moral distress. It is noteworthy that many of the staff in the case of baby C. did not know that they were experiencing moral distress, much less that there was anything they could do about it. Education is an important place to start. Although it alone cannot decrease the incidence of moral distress, understanding the phenomenon and the importance of open and respectful discussion must occur before other strategies can be successful. Such education needs to include all caregiving disciplines, not just nursing.

Resilience and empowerment have been reported in 2 studies of moral distress. Harrowing and Mill¹³ studied Ugandan nurses participating in an HIV education program; this education helped the nurses feel more resilient and hopeful in managing their moral distress positively in the face of significant challenges due to inadequate resources. Browning¹⁴ found that higher levels of empowerment correlated with lower moral distress in a survey of critical care nurses. Collaboration, particularly active participation in end-of-life patient care conferences, related to higher empowerment scores. Both of these studies give clues to developing continuing education programs to help providers manage moral distress: Empowerment strategies and strengthening interprofessional communication and collaboration may be helpful.

Early, frequent, and consistent communication with patients and families can help build a climate of shared decision making and goal setting¹⁰ that can go a long way toward preventing moral distress. Challenges in communication with families and within teams are all too common in situations such as that of baby C. Major referral centers often receive patients who live some distance from the center. These patients and their families have had initial conversations with their initial caregivers that have left them with an understanding of the problems and necessary treatments that may differ from the views of the referral center clinicians. Establishing trust and determining what the parents understand so that the team can move forward together are important first steps. Key communication strategies in cases similar to baby C.'s could include conducting family meetings within the first 72 hours of admission and as needed and having families be present more frequently and for longer periods so they gain a realistic understanding of their infant's progress or lack thereof. If in-person visits are not possible, establishing communications through frequent phone conversations and designating one key clinician to communicate regularly with a designated family member may help keep families engaged, apprised of the patient's clinical course, and involved in decision making. As discussed, ongoing and clear articulation of the goals for each patient is necessary to ensure that team members speak with 1 voice.

A related strategy is to increase explicit discussions of the ethical dimensions of care. The provision of health care to ill, injured, and vulnerable persons is a deeply moral practice. Yet it is commonplace that teams spend more time discussing clinical laboratory values and physiological responses to interventions than the underlying ethical rationale for their approaches. Too often, ethical discourse around particular cases is absent or pallid in clinical settings. Asking questions such as "What are our primary obligations to this patient and his family? What ought we to do at this point in his trajectory? What are the key quality-of-life issues with this baby, and how should they shape our care?" can assist providers to recognize their different values and perceived obligations. These underlying ethical mandates shape each provider's understanding of ethically appropriate decisions, and making this foundation explicit can facilitate discussions to craft an overall plan. Understanding the legitimate differences among colleagues and the need to safeguard patient/family and provider integrity even as we reach a consensus that may not satisfy all parties can help build team trust and respect, two critical ingredients of collaboration.

It is important to build collaboration between caregiving teams and institutional resources. Clinicians can sometimes see calling such resources as an admission that they cannot manage the patient situation rather than as consulting experts who can help with problem solving early in a case in order to prevent later problems. As problems escalate, some teams may adopt a "circle the wagons" approach that ignores such resources or even criticizes team members who want to use them.⁴ In such situations, moral distress steadily increases, making emotions more intense and further compromising the team's ability to problem solve. Identifying institutional resources and what they offer can be a helpful first step. In addition to ethics and palliative care services, some institutions have additional resources through social work, psychology, or chaplain services. Including an ethics or palliative care consultant on team rounds can build communication and trust that can lead to better use of resources. Staff can be challenged to question their own assumptions and biases as they listen to others, reflect on their language choices and behaviors, and get an objective perspective from someone outside the team.

The reader will note that these strategies require skilled facilitators knowledgeable about moral distress and the 3 levels at which it presents who can sensitively manage conflicting values and perspectives in ethically charged situations. In some clinical settings, particularly those outside academic medical centers, ethics consultations are managed by volunteer clinicians who may not be knowledgeable about ethics facilitation or moral distress. If skilled resources are not available, clinicians should request and expect that the institution will develop them.



Effective moral distress consultations can help staff name their moral distress and better understand the moral distress experienced by their colleagues; identify the recurring cases that are engendering moral distress and their root causes at clinical, team, and system levels; and develop and prioritize strategies to address each level.² Over time, the author and colleagues are finding that such consultations can empower staff, contribute to improved interprofessional teamwork, and lead to system changes that can minimize the damaging sequelae of moral distress and moral residue.

Debriefing is another strategy that can achieve the same goals. Effective facilitators can ask questions such as those listed in Table 2 and focus on strategies to prevent or minimize the recurrence of similar cases. Taking the time to develop plans for future cases can lead to earlier and more proactive approaches that can minimize the crescendo effect.

A number of strategies can be developed at a unit level to strengthen the ethical climate and deal with cultural elements that may give rise to moral distress. For example, interprofessional rounds and care conferences involving multiple disciplines can set an expectation of collaboration. Questions for unit leaders to ask themselves include the following: What are key unit cultural features that are giving rise to moral distress? What can we do about them? What are the organization problems for which we need administrative support to address? Where should we start?

Finally, persistence is an important virtue in dealing with moral distress. It takes time and sustained effort to sensitize providers, much less change unit and system cultures. Such changes require strong administrative leadership, particularly in the face of organizational problems and resistance from key stakeholders.

CONCLUSION

Moral distress is a complex phenomenon that, left unrecognized, can erode professional integrity and compromise moral agency in clinicians, regardless of discipline. Increased education regarding moral distress, its root causes, and consequences can begin a team's journey toward building an ethical climate within which patients, families, and providers collaborate to achieve optimal patient outcomes. Although moral distress cannot be eliminated, learning to manage it can empower staff, strengthen their moral integrity and resilience, improve teamwork, and eventually lead to organizational changes that protect and promote moral agency.

Palliative care teams can be a helpful resource for patients, families, and providers alike if they are familiar with moral distress and its interplay with moral residue. Strategies will require attention at individual, team/unit, and organizational levels and a commitment from administrative and clinical leaders to work together to address this damaging phenomenon. This work needs to become a priority to retain expert providers and prevent the crescendos of moral distress and moral residue too often seen in experienced clinicians.

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