

Applying a Balm

Medicating the Patient to Treat the (Moral) Distress of Caregivers

Margaret M. Mahon, PhD, CRNP, FAAN, FPCN O Karen L. Barker, MSN, CRNP

Moral distress occurs when a nurse knows the right action but is impeded from taking that right action because of institutional constraints. Caring for patients who are dying might evoke distress, including moral distress. The distress from a difficult clinical situation is likely to permeate other areas of practice. In this article, 2 cases are used as a means to distinguish moral distress from other distress arising from clinical situations. Opportunities to alleviate distress include increasing knowledge, improved communication, enhanced collaboration, and development of institutional supports.

KEY WORDS

collaboration, distress, end-of-life care, moral distress, primary palliative care

Ithough originally described more than 30 years ago, moral distress has come to be recognized in scholarly and administrative realms as having a significant effect on health care providers' clinical work and personal lives. Nurses may be very aware of their own stress but not attribute it to moral distress. Distress, including moral distress, affects health caregivers insidiously across settings and across disciplines, thereby affecting the broader work environment. The following 2 cases describe the reliance on medicating the patient as a response to caregiver distress.

Moral distress is a response based on a believed right action impeded by

- institutional constraints (eg, policies, tradition);
- societal or cultural expectations (eg, decisions regarding life-prolonging therapies); and/or
- contextual factors (eg, feeling unsafe, inadequate staffing, poor team functioning, lack of administrative support). 1,2

Margaret M. Mahon, PhD, CRNP, FAAN, FPCN, is nurse practitioner, Pain & Palliative Care, Bethesda, Maryland.

Karen L. Barker, MSN, CRNP, is nurse practitioner, Pain & Palliative Care, Bethesda, Maryland.

Address correspondence to Margaret M. Mahon, PhD, CRNP, FAAN, FPCN, National Institutes of Health, 10 Center Drive, Bldg 10/CRC MSN 1517, Bethesda, MD 20892 (mimimahon@hotmail.com).

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Nurses' mental engagement with, and responses to incidents that might engender distress evolve over time. Understanding this process identifies opportunities for intervention.

CASE STUDIES

Mr Madison was a 78-year-old man with end-stage heart failure, who has been hospitalized 3 times in the past year. He was hospitalized with another heart failure exacerbation and again was started on inotropic infusions. Although he previously improved with inotropic therapy, his disease had become refractory. Mr Madison decided that he no longer wanted to come back to the hospital. The plan was to transfer him home, where he would receive hospice care with the support of his wife and children. The transfer was planned for 2 days hence. Milrinone was discontinued. Following discussion with the patient and his family, the goal for Mr Madison's care was changed to focus on end-of-life care. He had shortness of breath that was well managed with diuretic therapies, discontinuation of intravenous (IV) fluids, and low-dose opioids (hydromorphone 0.2 mg IV every 1 hour as needed; patient used 4-5 doses a day). He had lower extremity edema. Mr Madison was sleepy most of the time, but oriented when awake. He was weak and needed help with position changes, although he was able to, and enjoyed sitting in a chair at the side of the bed for hours. He has pain with transfers. Because "he is comfort care," Mr Madison's nurse planned to be aggressive about his symptom management. She requested and was given a range order with liberal opportunities for titration. She administered the opioid every 30 to 60 minutes, and the rate was increased rapidly. The nurse explained that she was trying to prevent suffering: "I have seen people suffer at the end of life, and that's not happening to my patient." Mr Madison appeared comfortable but becomes increasingly somnolent with increased opioid doses. He had previously denied pain except with movements. His dyspnea was well managed before any dose increase.

Ms Monroe was a 58-year-old woman with breast cancer with metastases to bones and lung. She had disease progression through 3 courses of treatment. She has become progressively weaker, and her functional status continued to decline; she spent most of her days in bed. Following her last round of chemotherapy, Ms Monroe was

admitted to the hospital with neutropenia and a cough. With a declining respiratory status, Ms Monroe was transferred to the intensive care unit and was intubated. Over the next 2 weeks, she became less responsive, even when off sedation. Ms Monroe had discussed "when it is time to stop" with her partner of 27 years. Several family meetings were held, and a decision was made to change the goals of care to a focus on a good dying. The patient was extubated; she appeared comfortable. Ms Monroe was still alive and comfortable several hours after extubation. The family started to express frustration. "Why isn't it over yet?" They approached several nurses with their concerns. The nurse taking care of Ms Monroe assured the family that they would aggressively work to prevent symptoms. Although the patient continued to appear comfortable, the nurse requested and was given an order for a continuous IV fentanyl infusion that was rapidly titrated from 25 to 100 μg/h, with hourly clinician boluses equivalent to the hourly IV rate.

DEFINING MORAL DISTRESS

Most health caregivers have been involved in a clinical situation that left them uneasy, upset, or frustrated. The nurse (or other caregiver) may have the vague sensation that something is not right or that the situation should have been handled differently. Although the initial response may be primarily emotional and somewhat vague, it is typically disturbing. This *ill ease* is often evoked by ethical dilemmas. In some cases, this unease represents moral distress.

Moral distress is the inability to implement what is believed to be the right action. Jameton³ distinguished moral uncertainty (not knowing the right thing to do), moral dilemmas (a clash between competing principles), and moral distress. He described moral distress in this way: "Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action." The definition has evolved over intervening decades, and several definitions have been used to guide research, theory, and practice. Prentice and colleagues⁴ wrote, "Moral distress refers to the anguish experienced when an individual makes a clear moral judgement about what action he/she should take but is unable to act accordingly due to constrains (societal, institutional, or contextual)."^{4(p701)} Jameton's³ definition captured the perceived helplessness that exists because of the perceived constraint of organizational factors. This inability to accomplish a goal causes emotional distress,⁴ which is a significant component of the experience of moral distress.

Taylor⁵ described moral distress as occurring when a nurse (or other professional caregiver) is "in an ethically challenging situation. They believe they know the right

thing to do, and yet something is preventing that right action from happening. It means I can't translate my judgement about what ought to be into reality. If I accept that situation, then I compromise my integrity." Because the nurse is unable to act, the effect of that immobility is personal compromise.

Moral distress among health caregivers is widespread. Moral distress exists in all professions, although to varying degrees and prompted by different circumstances. For example, the experience of moral distress for nursing students and medical students is similar, although the support received when reporting the experience may differ. Medical students may receive less support if they report their experiences of moral distress. Some nurses perceive their roles as replete with "conflicting loyalties and responsibilities." This may increase the risk of moral distress.

Moral distress is often expressed in terms of emotion and affect. The theme of "anguish or interior suffering" as a component of moral distress has been described by many who have written about moral distress. ^{11(p84)} Internal medicine residents and fellows described some of their medical interventions as "torture" causing "suffering." ^{12(p95)} Similar to nurses' experiences, many physicians have also described a sense of powerlessness, ¹³ because they were unable "to prevent harmful and futile treatments." ^{12(p95)} Providing futile interventions or therapies unlikely to benefit the patient has been cited as a cause of distress across disciplines. ^{8,14,15} The sense of an inability to influence the clinical situation often affects the evolution and perception of distress.

Dzeng and colleagues¹² described a perceived decisionmaking hierarchy that "descends from attending to resident to nurse, the consequent degree of moral distress experienced by trainees may be more similar to nurses than attending physicians.",12(p97) Those with more formal authority may remonstrate nurses with less authority even for voicing an opinion. 16 This notion of nurses at the bottom of a hierarchy, rather than as colleagues, reinforces perceptions of powerlessness (lack of empowerment) and the inability to control clinical situations. Nurses provide most direct patient care, but they often are not in a position to determine some of the care they provide or to affect goals of care or other, broader treatment decisions, even collaborating in or having input to decision-making processes.¹⁷ Nurses may feel powerless if they are unable to act in what they perceive to be the patient's best interest, and that powerlessness can cause moral distress. 18 That is, many nurses believe that they function outside extant institutional structures of power and decision making. While some of this is inherent in the roles of nurses, nurses' unique position vis-à-vis patients and families often provides nurses with important information on patient preferences, family stressors, or other factors that might affect care.



Power differences occur across health care settings, not only, for example, between some physicians and nurses, but also between providers and patients, administrators and clinicians, and health caregivers and support staff.⁵ The fact of a power differential often affects the development and persistence of moral distress.

The perception of clinical power, that is, the perception of one's ability to influence the course of clinical care, appears to be a key factor in the occurrence of moral distress. Browning¹⁹ explored the relationship between nurses' perceptions of empowerment and moral distress. She found that the intensity of moral distress experienced by critical care nurses was high; however, the frequency of moral distress was lower. In a review of 19 articles, Oh and Gastmans¹⁰ found that although the incidence of moral distress was low, the experience of moral distress was moderately intense. These authors also pointed out that moral distress does not end when the engendering event is over. Rather, the effects of moral distress persist and may be cumulative. The impact of moral distress may persist for years.²⁰ Nurses who felt more empowered described experiencing moral distress less frequently. 10 Howe 16 proposed that accepting one's helplessness (ie, powerlessness) may be beneficial when facing moral distress.

Jameton's³ definition of moral distress remains a foundation for current work in theory and practice. Although moral distress is an intensely individual experience, many authors, starting with Jameton, have addressed the notion of institutional constraints. That is, the rules or structures of an institution prevent implementation of a believed right action. As Hamric and Epstein²¹ wrote, "Moral distress is almost always a symptom of underlying unit, team, or system problems...."21(p133) Thus, although often perceived as a problem for the individual, the causes of moral distress are rooted far outside any single clinical encounter. Robaee and colleagues^{22(p3)} found that nurses believed "perceived organizational support" was low, and moral distress was high. It is important to note, however, that the authors found no relationship between perceived organizational support and moral distress.

Although ethical or moral distress can occur in a range of types of cases, moral distress is more likely to be experienced in cases in which the patient's care is deemed to be futile or not beneficial, often occurring at the end of a patient's life. ^{10,12,19,23} Moral distress may occur more often when caring for vulnerable populations. ⁹ Interestingly, nurse midwives have also described distress when recommendations for interventions they believe not necessary or beneficial are made, such as medications administered to hasten labor. ²⁴ A patient's dying is often replete with moral challenges, not the least of which concerns decisions regarding the benefit or futility of sustaining specific therapies.

Weber²⁵ suggested, "Sometimes one's moral distress may be due to an error in one's assessment of the morally distressing situation."25(p247) Furthermore, not all emotional distress arising from patient care is necessarily moral distress. Emotional tumult may occur in a situation in which there are no institutional impediments to implementing the "right" patient care. In other cases, the nurse's knowledge of the situation and perception of what is "right" may lead to interventions that reflect the nurse's beliefs or perceptions of an independent action, rather than an accurate or complete comprehension of the patient's clinical status. These distressing situations may arise when the perceived suffering comes not from the patient, but rather from the patient's loved ones, from the nurse, or from other caregivers. Factors affecting nurses' distress when a patient is dying is a common exemplar of what manifests as moral distress.

PATIENT AND FAMILY TRIGGERS OF NURSING DISTRESS

In both of the cases described previously, the nurses were distressed by the possibility of patient suffering and, in Ms Monroe's case, by family distress. The nurses caring for these patients believed that the means to prevent patient or family distress was with the use of opioids. In both of these cases, the nurses wanted to alleviate the perceived distress, so they obtained orders for the higher doses of opioids that they felt compelled to deliver.

Moral distress occurs when the nurse (or other caregiver) has the knowledge, skills, and abilities to take correct actions but feels unable to follow through because of institutional constraints. Although the nurses in each of these cases experienced distress, it does not meet both requirements for moral distress. In distress, including moral distress, there is often a dimension of weighing competing goods. An ethics dimension is often present in distress. Viewing the clinical situations more broadly interpreted provides ways that nurses' distress can be alleviated in the present and avoided in the future.

Opportunities to Diminish the Impact of Distress

To move forward from a difficult clinical case, one must be able to identify and isolate the distress. Responses to the clinical case that presents as a moving target are dynamic, changing as the case evolves. The ability to articulate one's discomfort is the start of the process of better clinical decision making.

Successfully decreasing distress is multidimensional and complex. Jameton²⁶ described multilevel approaches to addressing distress. Opportunities to decrease distress include improved knowledge about end-of-life care, better communication within and between professions, improved

collaboration, and institutional changes to support this improved patient care. The lasting benefit occurs when cases similar to these arise and are managed and processed, thus creating confidence in follow-through on the right action.

Knowledge

Inherent in Jameton's³ definition of moral distress is the notion that the nurse *knows* the right course of action. Prentice and colleagues⁴ wrote that in cases of "moral distress characteristically the right course of action is clear..." There are cases, however, where the "right course of action" is imprecisely defined, or nebulous.

Patients who are dying often experience symptoms such as pain, dyspnea, anxiety, delirium, and edema. Nurses with appropriate knowledge who care for patients who are dying anticipate how they will manage these symptoms. The American Nurses Association position statement, "Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life,"²⁷ was developed to provide concrete guidance on how nurses across settings and specialties can improve care of dving patients. Two of the recommendations are that nurses should "strive to attain a standard of primary palliative care so that all health care providers have knowledge of palliative nursing to improve the care of patients and families," and "All nurses will have basic skills in recognizing and managing symptoms, including pain, dyspnea, nausea, constipation, and others." Basic knowledge of care for the dying is a responsibility of *all* nurses. This is primary palliative care: that level of palliative care knowledge that all providers should have. 28 Recognition and management of physical symptoms are the core of this knowledge. Jameton³ wrote, "Competence lies at the heart of the concept of professionalism." ^{3(p80)} Primary palliative care is an essential competence.

As the nurses did in these cases, many nurses believe their role is to provide comfort at the end of life. ²⁹ Comfort is a vague term, although a universal goal. Unfortunately, many nurses lack the knowledge necessary to provide care of dying patients. 29-31 Nurses may not know or recognize common symptoms in people who are dying. As importantly, nurses may not recognize signs of dying and may label common changes (eg., agonal respirations, "seeing" people who have died, restlessness) as suffering. A lack of knowledge can contribute to nurses' distress, including moral distress. The discrepancy between the nurses' clinical assessment and knowledge of appropriate end-of-life care can cause distress. Nurses (and others) want to do something. If the patient is comfortable, if the dying is expected, then often the best the nurse can do is to monitor, but otherwise not to intervene, recognizing and allowing peaceful natural death.

A nurse may feel compelled to administer excessive doses of opioids if the nurse believes that dying inherently

involves suffering. If the nurse cannot identify when a patient does *not* have symptoms, or if the nurse acts only to *prevent* suffering, the nurse may administer more medication than is indicated based on the patient's actual symptoms, including opioids. The provider who acceded to the nurses' requests to increase the opioid dose and to decrease the opioid interval also wanted to do the right thing. Neither of these decisions, however, was based on what the patient actually needed.

The desire to ensure comfort is good. In the cases of Mr Madison and Ms Monroe, however, the nurses administered opioids that the patients did not need. The nurses believed they knew the right thing to do. The nurses' beliefs that the patients and family were suffering, or might suffer in the future, led to the nurses' suffering. To relieve their own suffering, the nurses used opioids to treat symptoms that had not occurred as a means to prevent future, potential suffering.

Nurses sometimes ascribe their reactions as resulting from moral distress, when instead the clinical decisions actually reflect a lack of knowledge. This "over treating," using opioids to treat the nurses' own suffering in the absence of the patient's physical suffering, may lead to the presumption that suffering is being prevented. Nurses must have current knowledge to allow the provision of excellent end-of-life care. Optimal knowledge and critical thinking can decrease distress.

Communication

Distress of any type can be a very isolating experience. Further, poor communication can itself cause moral distress. Weiss and Fiester suggested that communication with families and among health care teams needs to evolve over the course of the relationship. Such communication would entail identifying expectations upfront, purposeful regular engagement, repetition of prior content, and updating information. Ongoing assessment of patient comprehension from the beginning is crucial. Good communication with patients and families, as well as with colleagues across disciplines, can alleviate distress. 33 If professionals share experiences of a patient's dying or concerns about whether a patient died well, isolation can be decreased. Taylor⁵ wrote that the most important thing that can be done is "to create a moral space and time to talk about" events that led to moral distress.

Some units engage in debriefing, a moment of shared silence, a short informal gathering, or another structured opportunity to acknowledge a patient's death, and the nurses' contribution to a patient dying well. Structuring opportunities for "formal and informal open forum discussion" serves to decrease the sense of isolation inherent in many people's experience of distress and a safe format in which to express feelings. Schwartz Center Rounds (http://www.theschwartzcenter.org/supporting-caregivers/



schwartz-center-rounds/) are a mechanism for structured, interdisciplinary interactions about distressing clinical situations. This interdisciplinary sharing can improve morale and allow care providers to maintain engagement with patients and even compassion. ¹³

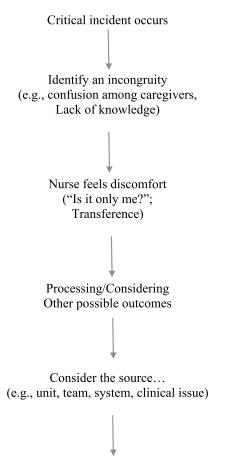
Thomas and McCullough³⁴ suggested that "a sustained commitment to moral excellence" can guide decision making and the management of conflict.^{34(p109)} A focus on moral excellence, or principles that guide the care under discussion, may provide some distance from the immediacy of any perceived conflict or distress. This provides an emotional separation from personalization in particular instances to a broader collective view ("it's not about me"). This shift in communication to fundamental principles may also provide not only a means to help with the current case, but also a foundation for future care that could engender distress.

Rushton³⁵ posited that the development of moral resilience would allow nurses to adapt to situations of moral distress. "In essence," she wrote, "moral resilience involves choosing how one will respond to ethical challenges, dilemmas, and uncertainty in ways that preserve integrity, minimize one's own suffering, and allow one to serve with the highest purpose." 35(p112) Identification of the highest purpose typically involves understanding both the overall goals of care for this patient ("What is the best we hope to accomplish? How will we get there? What should we do if we cannot achieve the best?) and processes of ethical decision making (integrating clinical facts with quality of life and patient preferences). No one person can identify and accomplish the highest purpose for any patient. Communication is a means to bring others' perspectives into planning for excellent patient care for this and future patients (Figure).

Moral resilience is not a choice: "I will be morally resilient." Rather, one develops the resources, both internal and external, that allow the development of options in response to ethical dilemmas, distress, and clinical uncertainty. The acquisition of knowledge and communication within an interdisciplinary team is the foundation of the process of becoming resilient.

Collaboration

Less collaboration has been linked with increased moral distress for nurses. ³⁶ Communication and collaboration are 2 sides of the same coin. True collaboration cannot occur without good communication. Although nurses often self-identify as the advocate for the patient, others involved in the care of each patient are also there to bring their knowledge, skills, and experiences to improve patient care. Palliative care is, by definition, interdisciplinary. Dying is a biological, psychological, spiritual, and interpersonal phenomenon. Working with clinicians across disciplines who can address each of these dimensions



Validate with colleagues/partners (e.g., bioethics, nurse leadership, interdisciplinary colleagues) **FIGURE.** Evolution of thinking: nurses' ethical decision continuum.

of care recognizes the breadth of the patient's life, as well as the patient's dying, and the family's evolving needs. This interdisciplinary, 360-degree assessment can decrease nurse isolation and thereby decrease distress. Collaboration is also an ideal means to address the American Nurses Association goals of comfort and excellent symptom management.

Distress is not unique to nurses. Patient care is improved by collaboration with colleagues across disciplines. Prentice and colleagues⁴ recognized that calls for collaboration as a means to alleviate moral distress are common; however, most who make this recommendation "[fail] to consider the ethical climate or capture the perspective of other health care professionals." Collaboration must include recognition of and appreciation for how inclusion of colleagues across professions and perspectives enhances patient care.

Institutional Solutions

Moral distress has been posited as an institutional-level problem.^{3,21} It is likely that other types of distress also have

institutional culture. Communication difficulties, which can exacerbate distress, are often an organizational concern that manifests in interpersonal communication. ^{1,2,37}

Nicotera and Mahon³⁷ have done extensive research into the concept of *structurational divergence*, "an institutional positioning at a nexus of incompatible meaning structures that creates recurrent conflict cycles."^{37(p92)} (Structures refer to the "rules and resources"^{38(p377)} of an organization. Rules that affect nurses' experience of distress, including moral distress, may be formal or informal.) Nicotera and Mahon³⁷ wrote, "*The problem causes the problem,* and, *no rule/resource exists to prioritize on structure over another.*^{37(p92)} In other words, in the cases of Mr Madison and Ms Monroe, a patient's dying created distress for a nurse, and the nurse lacked resources (including knowledge) to alleviate the distress. Because moral distress and other forms of distress are institutional or system issues, "interventions must be directed to root causes..."^{21(p133)}

Formal and informal structures influence the choices nurses make about how to address moral distress for themselves. Taylor³⁹ suggested identifying an ethically competent colleague who can support the nurse who encounters an ethically difficult situation. Ethical competence is different from being ethical. Ethical competence refers to specific knowledge and skills in the distinct discipline of ethics. A hospital ethics committee may be a resource for finding ethically competent nurses for additional support.

Helft and colleagues⁴⁰ described the development of unit-based ethics conversations to provide nurses with a space for open conversation about "ethically challenging situations.",40(p28) Unit-based ethics conversation facilitators were members of the ethics committee. Unit-based ethics conversations explicitly were not a mechanism to replace ethics consultation, although there was often overlap with content likely to be addressed by an ethics committee. Hamric and Epstein²¹ described the development of a moral distress consultation service that was eventually integrated into the hospital ethics consultation service. Browning and Cruz⁴¹ described their reflective debriefing protocol in which social workers intervened to provide regular moral distress debriefings with intensive care unit staff. The purpose of using these structured interventions to address moral distress was "not to eradicate moral distress, but to address it when it occurs and intervene early so that those providing care are empowered to act and know there are resources to help them in difficult situations before moral distress escalates.",21(p141)

CONCLUSION

Because end-of-life care is often complex, distress, including moral distress, is neither uncommon nor unexpected. Many resources exist to guide the provision of

excellent end-of-life care. Currently, too few nurses have adequate competence and confidence to provide end-of-life care; there has been a lack of promulgation of extant knowledge into prudent practice. Thus, nurses may make decisions that do not reflect patient needs, but rather their own. Nurses are responsible to acquire and maintain that knowledge in the same way that they do for any other specialty.

Communication and collaboration can decrease the sense of isolation that often accompanies distress and can enhance problem solving for patients' care. Interdisciplinary patient assessments, use of standardized tools, clinical skills to assess pain and other symptoms, and the opportunity to process through post-death debriefings can all benefit individuals and care teams.

Distress is not always negative. That nudge or niggling when nurses sense that "something is off" should be explored. "The answers to some difficult ethical dilemmas are often not black and white and should cause some distress and unease in both health care professionals and [patients and/or families]." Care for patients and families can be improved by awakening an awareness of the distress, naming it, and initiating a proactive action plan. This practice will support a positive ethical climate with appropriate clinical outcomes and less (moral) distress.

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