Healthcare Professional Narratives on Moral Distress: Disciplinary Perspectives

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Most healthcare professionals can describe one or more clinical situations which left them feeling at best unsure and at worst troubled or distressed by the outcome or the decisions that were made for a patient. In some of these situations, healthcare professionals experienced moral distress because of their involvement in what they perceived as a morally undesirable situation. Moral distress is a phenomenon experienced by a wide range of healthcare professionals in a variety of settings. As described elsewhere in this book, although the term was first used to describe an experience of nurses, who often felt constrained by rules or hierarchies in healthcare facilities, healthcare professionals across the spectrum have experienced and described moral distress. Often, the themes and experiences of moral distress are similar and shared across healthcare professions, themes of lack of control, powerlessness, and unrealistic expectations. Yet, differences in context and role responsibilities influence and can result in dissimilar experiences of moral distress in healthcare providers with different roles and responsibilities. For some healthcare professions, the phenomenon of moral distress has not been named or recognized or has been called something else.

In this chapter, we have brought together the voices of multiple healthcare professionals to describe moral distress from their own perspectives. Nurses, physicians, a social worker, a chaplain, and a pharmacist, each provide thoughtful insights into how they understand and have experienced moral distress from their own disciplinary perspective. Two of the contributions found in Part 1 offer an academic survey of the literature, including the history and current thinking and research on moral distress in nursing (Davis and Fowler) and in social work (Fantus). The other contributions in this chapter collection found in Part 2 (in alphabetical order by Fins, Joy, Kruse and Burgart, Lindsey, Mooney, Uritsky) offer a more personal perspective on how they, as physician, psychiatrist, physicians, chaplain, pediatric nurse, and pharmacist, respectively, experience or witness moral distress in their practice. Many describe the confluence of disparate factors that result in or confound the experience of moral distress, and many describe the value of story-telling, sharing experiences, and thinking or acting together to convert distress-inducing situations into possible opportunities for growth and change.

Part 1 Contributors

Anne Davis and Marsha Fowler, Moral Distress in Nursing: Looking Back to Move Forward

Sophia Fantus, Social Work Perspective: Moral Distress

Part 2 Contributors

Joseph Fins, A Source of Moral Distress: The Corporatization of Medicine
Michelle Joy, Moral Distress: A Psychiatrist perspective
Katherine Kruse and Alyssa Burgart, Physicians' Experiences of Moral Distress and Burnout
Reverend Peggy Lindsey, A Chaplain's Perspective on Moral Distress
Kim Mooney-Doyle, Moral distress in pediatric nursing and research
Tanya J. Uritsky, Pharmacist's Perspective on Moral Distress in Palliative Care: A narrative

3.1 Reviews of Moral Distress in Nursing and in Social Work

3.1.1 Moral Distress in Nursing: Looking Back to Move Forward

Anne J. Davis and Marsha D. Fowler

3.1.1.1 Introduction

No moral issue is historically context-free, and that includes the issue of moral distress. Most discussion of moral distress reaches back to Jameton's [1] work *Nursing* Practice: The Ethical Issues. Here, Jameton identifies three categories of moral concern: moral uncertainty, moral dilemma, and moral distress. Moral uncertainty occurs when the nurse is unclear whether a difficult situation is moral in itself, and if it is, what values or obligations are being challenged. Moral uncertainty is amenable to ethics education and to professional socialization and education into the values of nursing. Moral dilemma occurs when the nurse faces a conflict of values or of ethical obligations, which presents alternative and conflicting courses of action. Ethics education is important here as well, as is participation in the community of moral discourse. Moral distress, in its original definition, "arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action." [1]. Moral distress is not amenable to ethics education; such education simply helps the nurse be clearer and more articulate about the nature of the distress, which is not a bad thing in itself. In moral distress the nurse has a degree of certainty about the right action to take and yet is obstructed from taking that action by the institutional constraints, later given some nuance and modified by Jameton to distinguish between internal and external constraints [2]. The *distress* of *moral distress* is not generated by discomfort intrinsic to the case circumstances. It arises from external, specifically institutional, barricades to morally right action, or to internal social and psychological factors such as fear of job

loss, self-doubt, timidity, trepidation, socialization against questioning medical orders, etc. What is important beneath Jameton's articulation of these three responses to moral issues is that his perspective was written from a nurses' point of view. The opening words of his work are

Nursing is the morally central health profession. Philosophies of nursing, not medicine, should determine the image of healthcare and its future directions. In its anxiety to control the institutions and technology of healthcare, medicine has allowed the central values of healthcare—health and compassion—to fall to the hands of nurses. Nurses thus supply the real inspiration and hope for progress in healthcare, and among health professionals, represent the least equivocal commitment to their clientele [1, p. xvi].

He is correct of course. While we are grateful for Andy's friendship and colleagueship over the decades, it is important to acknowledge how great a debt of gratitude nursing owes to him. Among the philosophers who were early into the rise of bioethics movement, Dr. Jameton was distinctive. While other philosophers were uniformly medically identified, Jameton encamped with nursing. He provided second wave nursing ethics (post-1965) with rigorous, groundbreaking, and creative scholarship.

Continuing research has given rise to a host of corollary terms including moral outrage, moral courage, moral resilience, moral residue, moral sensitivity, and more. There has been an escalation of interest, since 2010, in moral distress in the nursing research literature, across settings, roles, and even countries. Nursing databases such as CINAHL include research articles on moral distress from Canada, Ireland, Italy, the Netherlands, Brazil, Malawi, Australia, Greece, Turkey, Belgium, New Zealand, Switzerland, Iran, Jordan, Sweden, Israel, Uganda, and more. In short, moral distress in nursing circles the globe.

3.1.1.2 The Moral Milieu of an Institution: Predecessor Literature

In discussions of moral distress, greater attention is often accorded to the moral environment in which nursing is practiced. Canadian nurse-ethicist Storch and colleagues note:

Within Canada's fast-paced, ever-changing healthcare environment, providers are experiencing difficulty practising according to their professional ethical standards, leading many to experience moral or ethical distress. Limited attention has been paid to improvements in the ethical climate in healthcare settings in research focusing on nurses' workplaces. [3]

Storch points to the research neglect of workplace ethical climate. While she is correct regarding contemporary neglect of research on the moral environment of healthcare, there is a precursor literature that, for the most part, remains neglected as well. This literature has much to contribute to the elucidation of both the historical development of the concept of moral distress, its clinical expression, and its broader clinical, institutional, and social context that predates Jameton's definition.

For example, Davis and Aroskar's book *Ethical Dilemmas and Nursing Practice* [4], now in its fifth edition, devotes an entire chapter in each successive edition to social, institutional, and professional factors that make "being moral" difficult [4]. Several distinctive features in the first edition set it apart from prior and succeeding

literature. While Davis and Aroskar were not the first to point to institutional structures that affect the practice of nursing, they were to first to explicitly set it within an ethical nexus for analysis. In answering their question of whether or not nurses could be moral in their practice, they looked to broad social issues such as the social location of women and gendered social roles reinforced by institutional structures and embedded in law, as well as to the suffusion of American healthcare by a business model; to institutional issues, specifically to the nurse's competing loyalties to hospital, physician, and patient, but also to hierarchical structures of authority and communication; and to the historically rooted nurse—physician relationship with its sex-stereotyped roles, authority, communication, and medical paternalism. Here, Davis and Aroskar cite Leonard Stein's highly original work "The Doctor—Nurse Game," which had great explanatory power in its day, and still does to some extent [5–7]. Another distinctive feature is that Davis and Aroskar moved significantly beyond the "dilemma-based" and "principle-based" expositions of that day to look at the broader context of ethics in nursing. They maintain that

The overriding ethical issue for nurses, especially those working in hospitals, can best be described as one of multiple ethical obligations coupled with the question of authority... The physician has a special legal relationship with the patient, whereas the nurse's legal obligations vary according to a state's nurse-practice act. This fact makes nursing ethics more complex in clinical settings....Such issues as professional role, gender, education, public image, work environment, and status are central to nursing history and its present situation in which ethical dilemmas occur. [8]

Davis and Aroskar were not the first to deal with institutional constraints to nursing practice. For example, Marlene Kramer's [9] work Reality Shock: Why Nurses Leave Nursing presents her sociological research on the entry of new nursing graduates into nursing practice. She focuses on "the discrepancy and the shock like reactions that follow when the aspirant professional perceives that many professional ideals and values are not operational and go unrewarded in the work setting." [2]. She looks at "the seeds of discontent," that is, the effects of values discordance on new nurses and the value structure of the nursing profession against the value structure of bureaucratic healthcare that employs the nurse. She writes "the goal of adaptation in a reality shock situation is the creation of a viable habitat in which one can be productive, effective, and content for a longer and probably indefinite period of time." [9]. While Kramer's method is decidedly sociological, the cases that she cites demonstrate challenges to the nurses'-or nursing's-values and ideals; the cases are intrinsically ethical but not named as such. It is left to Davis and Aroskar to take these seeds of discontent and to exegete them as explicitly ethical in nature, and to set them within a larger social context beyond that of the particular healthcare institution.

Vaughn's research for her 1935 master's degree "dissertation" (thesis) *The Actual Incidence of Moral Problems in Nursing: A Preliminary Study in Empirical Ethics* is the first, pre-bioethics, ethics research that addresses moral issues in practice [10]. It is the first research that touches upon institutional strictures and conditions that trouble or fetter nurses. The object of her research was "to obtain, by means of diaries, the actual incidence of moral problems occurring among nurses." [10]. A total

of 95 nurses returned 288 diaries, kept over a period of three months, and that "yielded 2,265 moral problems" categorized using a modification of Lehmkuhl's classification of moral problems [10, 11]. Vaughn reports that she divided the data "into three general classes: moral problems, cultural problems, and questions that do not seem to imply problems. The morally-involved problems...exceed out of all proportion the balance of the material..." [10]. The vast majority of incidents or concerns recorded were in fact of a moral nature; the nurse-physician relationship was chief among all of the incidents reported. "The greater number of these involved questions of the propriety of the nurses making suggestions to the doctor regarding his orders, questions of loyalty to the physician, and doubts in matters of making hospital rounds with the doctor." [10]. More specifically these narratives included questions of the nurse's moral responsibility where physicians ordered wrong treatments, physicians made life-threatening mistakes, a physician declined to use gloves in multiple pelvic exams, a nurse recognizing a broken bone that the physician does not, and so on. In the recorded cases, nurses were aware of what was or was not an ethical issue and where the crux of the issue lay. That is, their uncertainty was not over the moral nature or content of the concern, or over what would be an appropriate moral outcome, but over how to proceed.

Vaughn uses Lehmkuhl's classification system:

...with some slight modifications. Lehmkuhl's "duties to state" was omitted and, for our purpose, "duties to the patient", "duties to the hospital", and "duties to the profession" supplied [11, page 19]

She thus incorporates but does not analyze some of the competing ethical obligations that Davis and Aroskar articulate some years later. Vaughn does, of course, predate the critical theories to which nursing ethics scholars have access today, specifically those that examine intersections of race, gender, and power.

Though hers is the first actual research, certainly nurses' distress over institutional practices, physician-related issues, and more predates Vaughn's work. In 1928, Sara Parsons writes in her ethics textbook, *Nursing Problems and Obligations*,

A nurse may find herself in an institution where she cannot respect her superior officers or approve of the policy of the institution; if so, she can hardly stay in such a place permanently without conforming to the objectionable ways or seeming to condone the malpractice of other officials....She must in all situations try to keep a clean-cut ideal of honor for herself [12, p. 109]

This position is mirrored in the 2015 ANA Code, though some have mistakenly believed that this hardline is new to nursing ethics. It is over 100 years old and enduring. The passage reads:

Nurses should address concerns about the healthcare environment through appropriate channels and/or regulatory or accrediting bodies. After repeated efforts to bring about change, nurses have a duty to resign from healthcare facilities, agencies, or institutions where there are sustained patterns of violation of patient's rights, where nurses are required to compromise standards of practice or personal integrity, or where the administration is unresponsive to nurses' expressions of concern. Following resignation, reasonable efforts

to address violations should continue. ... By remaining in such an environment, even if from financial necessity, nurses risk becoming complicit in ethically unacceptable practices and may suffer adverse personal and professional consequences [13, pp. 24–25].

Institutional constraints, including difficult relationships with physicians are noted in the nursing ethical literature from the 1870s onward. Isabel Robb, in *Nursing Ethics: For Hospital and Private Use* [14], devotes a section to the "relation of the nurse to the physician." In that section she acknowledges that some physicians are "incapable," and that

...if truth be told, there are rare instances in which the physician is unworthy of the respect both of nurse and patient, and the former, when she has gone through one such unsatisfactory experience, is fully justified in avoiding the care of patients under his charge....but although the nurse may be longsuffering...she is not expected to put up with unjust or rude behavior, and when she finds that, through no fault of hers and despite her best endeavors, she cannot work in harmony with the physician, she is fully justified in leaving the case as soon as an efficient substitute has been found to take her place. [14]

In Hirschman's typology of exit (leave), loyalty (stay), and voice (express concern) the historical weight of nursing's ethical literature, both heritage and contemporary ethics literature, is to attempt to make institutional change to improve the moral milieu or its policies, but where the institution is refractory to change—exit, or exit with voice [15, p. 54].

3.1.1.3 Shaping and Re-Shaping the Moral Milieu

As Davis and Aroskar note, effective moral navigation requires formal mechanisms for discussing ethical dilemmas as well as a socio-ethical culture that will foster discussion and action [8]. Intrinsic to this, of course, is a need for foundational ethics education. However, ethics education cuts both ways in that it assists in analysis and decision-making and can bring a clarity—that can make the issues even more acute and frustrating. The 2015 American Nurses *Association Code of Ethics for Nurses with Interpretive Statements* (Code) addresses the moral environment of nursing. It states:

Nurses are responsible for contributing to a moral environment that demands respectful interactions among colleagues, mutual peer support, and open identification of difficult issues, which includes ongoing professional development of staff in ethical problem solving. Nurse executives have a particular responsibility to assure that employees are treated fairly and justly, and that nurses are involved in decisions related to their practice and working conditions. Unsafe or inappropriate activities or practices must not be condoned or allowed to persist. Organizational changes are difficult to achieve and require persistent, often collective efforts over time. Participation in collective and inter-professional efforts for workplace advocacy to address conditions of employment is appropriate [13].

Beyond the immediate practice context, the Code looks to shaping the moral environment through regulatory and accrediting bodies, and professional associations. It states:

The workplace must be a morally good environment to ensure ongoing safe, quality patient care and professional satisfaction for nurses and to minimize and address moral distress,

strain, and dissonance. Through professional organizations, nurses can help to secure the just economic and general welfare of nurses, safe practice environments, and a balance of interests. These organizations advocate for nurses by supporting legislation; publishing position statements; maintaining standards of practice; and monitoring social, professional, and healthcare changes [13].

The Code also assists nursing in navigating obligations, at least in terms of prioritizing the nurse's commitment to the patient above other obligations. Provision two states: "The nurse's primary commitment is to the patient, whether an individual, family, group, community or population" [13]. The general conflict of obligations or values envisioned are those between nurse and physician, nurse and employer, nurse and nurse. At times, however, it will include a conflict of obligations or values between nurse and patient. The Code does provide a range of mechanisms for nurses to safeguard their own moral integrity without compromising patient care, such as withdrawing from situations where there is a conflict of interest, to engage in conscientious objection, to identify prior to employment limits to practice, and more.

3.1.1.4 Ethics Education and Enduring Issues in Nursing

There are enduring, structural, issues within nursing itself that are antecedents of moral distress. For example, multiple entry points in nursing disadvantage both the profession and individual nurses. As Donley notes,

Registered nurses are undereducated members of the healthcare team, when compared with physicians, social workers, physical therapists, pharmacists, and dieticians to name a few. Looking beyond the clinical environment, the nurse work force also lacks the educational credentials of persons in the business, investor, and insurance communities that now play significant roles in healthcare decisions. Under-educated members of the health team rarely sit at policy tables or are invited to participate as members of governing boards. Consequently, there is little opportunity for the majority of practicing nurses to engage in clinical or healthcare policy [16].

As has been called for decades, standardizing the entry level for nursing practice at the baccalaureate level and above would go a long way toward securing the nurse's place at the table, if one means of addressing moral distress requires nurse participation in clinical policy making.

Early modern nursing, 1870s to 1965, (that is, prior to the American Nurses Association 1965 position paper on nursing education [17]), viewed ethics education, the moral formation of the student, and the "tone" of the school and hospital (i.e., moral milieu), as important as clinical and scientific content. From 1900 to 1965, at any given point in time, there were from two to 11 textbooks on nursing ethics widely available to schools of nursing. These books were largely lost when nursing moved from hospital-based education into colleges and universities, and ethics education shifted from nursing schools into departments of philosophy or theology (or is lost altogether). This shift was concurrent with the rise in the field of bioethics, which nursing embraced, substituting it for the 125 years of nursing ethics that had developed [18, 19].

A second issue, then, is that participation in moral policy making requires ethics education, a persistent problem in contemporary nursing education. As central as ethics is to nursing practice, it is often treated as peripheral to the curriculum, to be squeezed in if there is space. It is also treated as if it were not an academic discipline in itself, but rather the domain of commonsense and conscience (or the domain of privatized personal opinion) that does not require formal knowledge or competence to qualify to teach it. Were the centrality of nursing ethics to the profession, to professional formation, and to professional practice to be reclaimed [19], nurses would be better equipped to face moral concerns in professional practice and to navigate them appropriately.

A third example of a structural issue within nursing relates to larger trends in higher education that affect nursing (and medical) education: the failure to educate nurses for "civic professionalism" in general but more strongly so with the corporatization of education and the mantra of "job ready, career ready" with a devaluing of a broader education that includes the liberal arts, the humanities [20]. The humanities, as a reflection upon human experience, equip learners to assess and challenge the social and political—and institutional—status quo. Sullivan, in *Work and Integrity: The Crisis and Promise of Professionalism in America*, claims that "the narrowing of professional claims toward the purely cognitive or technical in recent decades has contributed to the weakening of professionalism," [21] resulting in a decline in professional civic engagement, a loss of concern for the welfare of society, a decline in altruism and professional ethics, and the reconceptualization of the recipient as consumer of a commodity. In his work with Benner, they call for several changes to nursing education to move professionals away from technical and into civic professionalism, a move that would ultimately strengthen professional ethics for practice and ethical comportment [20, 22].

While we have principally addressed the antecedent and extant literature that looked toward external constraints to moral action, internal constraints to moral action exist as a source of moral distress. Sullivan, drawing heavily upon the work of Benner, supplies one corrective approach to those internal constraints by suggesting ways in which to reshape nursing education. He writes that

...the essential goal of the professional school must be to form practitioners who are aware of what it takes to become competent in their chosen domain and equip them with the reflective capacity and motivation to pursue genuine expertise. In the case of nursing, for example, this would mean studying and understanding the changing conditions of practice, as illuminated by history and the social sciences, alongside the study of the field's particular knowledge base in the physical sciences. ...Identification and formation of skillful ethical comportment must be the organizer of competence and inspiration of expert work [21, 22]

Professional formation, developed competence, reflective capacity, motivation for expertise, sociopolitical understanding; knowledge of history, physical, and social sciences; disciplinary knowledge and expertise...are all to the end of "identification and formation of skillful ethical comportment as the organizer of competence and inspiration of expert work."

3.1.1.5 Various Critiques of Moral Distress

As a concept, moral distress, for all its currency and favor, is not itself without controversy. In their provocative article "'Moral Distress' – time to abandon a flawed nursing construct?" Johnstone and Hutchinson posit major—fatal—flaws with the concept of *moral distress*. They write: Essential to the theory of moral distress is the assumption that such a state of distress in fact exists. Much of what has been written about moral distress, however, involves little more than an appropriation of 'ordinary' psychological and emotional reactions (e.g. frustration, anger, anxiety, dissatisfaction) that nurses may justifiably feel when encountering difficult ethical issues, disagreements and conflicts in the workplace. Whether these reactions necessarily constitute 'moral' distress, however, is debatable [23, p. 10]

Vaughn's diary cases would seem to support Johnstone and Hutchinsons's contention regarding specifically *moral* distress. The 2265 cases represent a variety of psychological responses to moral situations, but not *moral distress* per se. Indeed, the nurses seem to be particularly morally hale and hardy.

Johnstone and Hutchinson also address the issue of nurses' moral decisionmaking competence. They write:

Linchpin to the theory of moral distress is the idea that nurses know the right thing to do but are unable to carry it out. This idea is highly questionable on at least three accounts: first, it assumes, without supporting evidence, the unequivocal correctness and justification of nurses' moral judgments in given situations (rarely are the bases of the nurses' moral judgments revealed, and rarely is it admitted that nurses might be mistaken or misguided in their moral judgments, or that their moral judgments may be just plain wrong) ...[23]

Vaughn's cases contravene Johnstone and Hutchinson in that the 2265 cases do not generally present situations where right and wrong are unclear, uncertain, or truly in question (e.g., a physician instructs a nurse to deceive a patient, a nurse is ordered to falsify a patient record, the nurse is sexually harassed by the physician, and the like). These are cases of *moral failure*, not moral uncertainty. In the overwhelming majority of Vaughn's cases the *right* and the *good* are crystal clear; what is uncertain is *moral navigation* in the situation.

While it is possible to separate psychological and moral distress in practice, little conceptual work has been done on the actual distinction. For example, Noelle, at 24, was terminal from cystic fibrosis and after one-too-many end-of-life struggles, requested to be extubated. Extubation and her death within minutes was cause for psychological distress and grief for the loss of a long-time patient, but not for moral distress. Granted, the values of respect for the patient's wishes, and the odiousness of prolonging or even enhancing suffering in the face of ineluctable terminality were hardened values in this case. Previous to this instance, however, when the physician ignored Noelle's enduring, stated position, and intubated her anyway, the nurse was beset by both psychological and moral distress. While it may not be possible to do so, the failure to distinguish between psychological and moral distress runs the risk of conflating the two so that all psychological distress is labeled moral distress.

As noted above, ethics education can simultaneously clarify and aggravate moral distress. In Fowler and Mahon's 1979 research, students educated in clinical bioethics were able accurately to identify and parse actual moral issues and dilemmas in their clinical practice. But, having acquired the necessary ethical knowledge and analytical skill, they consequently articulated a level of *moral outrage* (as I had termed it). This was not distress, in the sense of moral suffering, moral impotence,

oppression, or even victimization. Rather it was moral outrage borne of knowledge and ethical decision-making skill—strength and empowerment—not weakness and powerlessness [24].

McCarthy and Gastmans, [25] McCarthy and Deady, [26] Johnstone and Hutchinson [23] Peter and Liaschenko et al. [27] and others have provided trenchant critiques of the concept of moral distress as it has developed since 1984. Given that contemporary nurses find the concept of moral distress to have explanatory power, and given that the concept itself is problematic, Peter makes this observation:

It may be that moral distress has made the social-moral space of nursing expressible in a way that many other concepts have not, with moral distress acting as window through which nurses can identify and describe the ethical nuances of their experiences. The problem may be, however, that we have asked too much of this concept by attempting to articulate more about the nature of nurses' ethical lives than it can reliably hold which has led to confusion regarding the meaning of moral distress and an over-emphasis on nurses' weaknesses as opposed to their strengths. My first recommendation, therefore, is that we also highlight alternative concepts in nursing ethics or develop, adapt, or borrow new ones that speak to the social-moral space of nurses. It is not that moral distress is no longer relevant, but we need to expand our understanding through additional concepts that help us understand the ethics of nursing work with its frequent proximity to patients or clients and its political positioning in a variety of settings. After all, the social-moral space of nurses does not just generate distress; it also opens opportunities to improve the well-being of patients because nurses are often in the position to provide and coordinate care in a way that recognizes patients as unique people [28].

It seems, then, that three things are needed. First, the very concept of moral distress needs to be subject to greater conceptual rigor and development. Second, nursing must address internal constraints of moral action, particularly those aspects of nursing professional formation and education that shape nurses' apparatus for ethical analysis and decision-making and equip and strengthen them for moral navigation in the contemporary healthcare system. Third, nursing as a profession, through its professional associations must continue to engage in social criticism and sociopolitical activism for social change, not simply on behalf of those who need advocacy, but for the larger social good that encompasses human health, rights, dignity, well-being, and flourishing. That social good includes the natural world in which humanity is situated; בלוע ווקת (tikkun olam), for the repair of the world, for the healing of the world. Here we would concur with Jameton's extension of the concept of moral distress to encompass inter-connectedness, respect for all life, equality, and modesty of consumption [29]. Greater attention needs to be paid to the consanguinity of humanity; its place in and responsibility for the larger social, political, and physical environment; and the rights of the non-human world over against humanity. As the current (2015) Code of Ethics for Nurses with Interpretive Statements notes,

Social justice extends beyond human health and well-being to the health and well-being of the natural world. Human life and health are profoundly affected by the state of the natural world that surrounds us. Consistent with Florence Nightingale's historic concerns for

environmental influences on health, and with the metaparadigm of nursing, the profession's advocacy for social justice extends to eco-justice. Environmental degradation, aridification, earth resources exploitation, ecosystem destruction, waste, and other environmental assaults disproportionately affect the health of the poor and ultimately affect the health of all humanity. Nursing must also advocate for policies, programs, and practices within the healthcare environment that maintain, sustain, and repair the natural world. As nursing seeks to promote and restore health, prevent illness and injury, and alleviate pain and suffering, it does so within the holistic context of healing the world [13, p. 37].

We call for greater rigor and clarity for the concept of moral distress, but also for its extension beyond our own anthropocentric distress.

3.1.1.6 Conclusion

In the end, enduring issues affecting nursing cannot finally be extracted from the larger, encompassing social-structural issues that surround nursing, issues that play out in clinical moral concerns of the nurse. Baer et al note that

Identity questions about who the nurse is, what constitutes nursing responsibilities, and what society and the profession can or should expect from nurses are governed by nurses' ever-present desire for power and authority over their work, a yearning that marks every human endeavor. Changing hierarchies within nursing and the social forces that determine nursing's position in society reflect ongoing debates about how the system operates, who changes it, upon whose authority such change is predicated, and ultimately who brings proposed changes to fruition. Nursing's expanding knowledge base raises further questions about what constitutes nursing knowledge, who owns it, who exercises it, and finally who benefits from it? [30].

Over the past century and a quarter much has changed for nursing though for each generation it may seem not enough. And yet, women acquired the vote and the end of coverture and gained some authority in society, including gaining access to legislative positions; nursing education has been standardized in terms of accreditation, and has moved from hospitals into colleges and universities; nursing students have ceased to be the hospital staff, and nursing faculty shifted from physicians to nurses; graduate education has been developed in nursing, including the doctorate; nursing wages have become salaries and have increased to livable income and nurses were brought under labor law; laws have grown to undergird advanced nursing practice; nursing has a seat at the table of commissions, boards, and policy bodies, even if only in token; healthcare teams have become more collaborative and cooperative, even where it remains to be fully realized; the proportion of women in medicine and men in nursing have increased, but not equalized; the National Institute of Nursing Research has been founded as a division of the National Institutes of Health (https://www.ninr.nih.gov); federal funding for nursing education and research has increased; nursing research and evidence-based practice have grown; ethics education in nursing has advanced in its rigor and analysis, though it is not fully and uniformly implemented in curricula by faculty with formal ethics competence; and more. Gains have been made; gains are yet to be made. For whatever gains are yet to be made, nursing is, nevertheless, in a stronger position within the healthcare community of moral discourse, and in a firmer position from which to navigate moral distress with strength, rigor, and vigor.

3.1.2 Social Work Perspective: Moral Distress

Sophia Fantus

3.1.2.1 Introduction

As members of multidisciplinary healthcare teams, hospital social workers are often held accountable in assuming responsibilities that are, at times, outside their clinical scope and professional expertise and skill-set. For instance, tasks may range from administrative duties and discharge planning, to therapeutic support and case management [31, 32]. Moreover, social workers uphold competencies in problemsolving, patient advocacy, as well as issues pertaining to social justice and ethical practice. As a result, social workers may be called upon during times of increased stress and ethical conflict to assist in resolving disputes between patients, families and healthcare teams [33-35]. Accordingly, social workers' occupational roles across hospital settings may trigger reactions of moral distress, discerned as individual responses to resolved ethical dilemmas that have compromised one's moral integrity and professional code of ethics [36, 37]. However, limited research has investigated the experiences of moral distress in social work [35]. A lack of theoretical and empirical scholarship has created difficulty in naming, addressing and subsequently mitigating social workers' moral distress. However, explicating sources of moral distress in social work is imperative to inform practice, education and research. Importantly, this commentary will elucidate how moral distress may transpire for hospital social workers.

3.1.2.2 Limitations in Empirical Scholarly Work

The concept of moral distress has primarily been explored in nursing and medicine to identify how withdrawal or administration of treatment, end-of-life care and patient treatment decisions may trigger reactions of moral distress [38, 39]. Findings have shown that nurses report high incidences of moral distress, often associated with: (1) the administration of aggressive and/or futile treatment; (2) working conditions, including staff shortages, budgetary concerns and increased workloads; (3) power differentials and hierarchies within the healthcare system and across healthcare professions; and (4) issues of self-doubt, fear and an inability to complete tasks [25, 40–42]. Thus, a broad range of individual, interpersonal, and systemic factors trigger experiences of moral distress may have deleterious consequences on the quality of patient care, effective job performance, as well as one's satisfaction and engagement with work [43–46].

More recently, comparative scholarly work has started to emerge investigating non-direct vs. direct care professionals' experiences of moral distress [47–50].

Notwithstanding the importance of such research, social work participants often comprise smaller samples when compared to participants working in nursing or medicine. Consequently, this engenders obstacles in performing cross-discipline analyses; the ability to recognize nuanced discrepancies between direct care practitioners and allied health professionals is difficult. Understanding professional differences is important to identify, address, and mitigate moral distress across disciplines.

In both empirical and theoretical social work scholarship, moral distress has not yet been adequately differentiated from other deleterious experiences. For instance, *burnout* and *occupational stress* are ubiquitous terms in social work practice and may have similar root causes as moral distress (including workloads, relationship conflict and resource constraints). Yet, burnout and occupational stress do not necessarily arise from morally comprising and ethically conflictual situations; rather, they are responses to general occupational constraints and pressures rather than inherent value conflicts [51–54]. Moreover, concepts such as *disjuncture, ethics-related stress* and *professional dissonance* have started to emerge in scholarship to elucidate issues that, at the forefront, seem quite comparable to moral distress. However, the inconsistent and arbitrary language used to describe these experiences subsequently hinders: (1) the ability to effectively address and identify deleterious consequences arising from moral distress; and (2) the synthesis of empirical scholarly research to establish evidence-based practices to mitigate experiences of moral distress.

DiFranks's study [55] investigated social workers' (n = 206) disjunctive distress, when beliefs in the professional code of ethics are discordant from (and not reflected in) behavior. Survey items included: (1) there have been times when I have had to compromise my professional integrity in my job settings; (2) I have experienced frustration because managed care and bureaucratic constraints often require termination before the client has been able to change; (3) I feel stress at work because I am not always able to help people in need with their personal problems and help them improve larger social issues; (4) I experience stress because of the conflict between my individual clients' interests and my agency's interests; and (5) I feel increased stress because, at times, my professional integrity has been compromised by practice realities. Although these items may support moral distress in social work, what remains unknown is whether these instances are the result of value conflicts from ethical dilemmas.

Similarly, a study conducted in Scotland looked at criminal justice social workers' (n = 100) *ethical stress*: comprising both disjunctive distress and ontological guilt [56]. The concept of ontological guilt refers to the accrual of regret that develops from acting in conflict with one's individual values and ethics; social workers may feel that they are not always able to help their clients. Moreover, Taylor [57] investigated *professional dissonance*, the discomfort that stems from conflict between professional values and expected occupational tasks. In consequence, ethics-related terminology presented in social work scholarship has elicited confusion in how to discern the concept of moral distress from other ethically challenging occurrences. This has important implications for social work practice, policy and education.

3.1.2.3 Moral Distress in Social Work

Although ubiquitous in medicine and nursing scholarship, the concept of moral distress has been inadequately explored in social work. As social workers' roles do not involve concrete decision-making with direct medical interventions and treatments, moral distress may transpire in entirely unique ways. Interpersonal relationships, advocacy, problem-solving and mediation are imperative skills that are a critical part of a social worker's hospital role. For instance, in a recent study on moral distress, ancillary staff (n = 7; 24%) (including four social workers, two chaplains, and one case manager) reported that moral distress transpired from "familyto-family discordance" more frequently than physicians (n = 6; 21%) and nurses (n = 16; 55%). Participants described that "working through family dynamics and psychosocial-spiritual barriers, occasioned frequent interactions with family members and patients that could create moral distress" [47, p. 826]. Similarly, Ulrich et al. [50] looked at ethics-related stress (a negative outcome of moral distress) by showing how social workers and nurses (n = 1215) reported feeling powerless when dealing with ethical issues, overwhelmed at ethical decision-making and increased job difficulty on account of ethical issues.

Few studies have exclusively investigated (and labeled) moral distress in social work. A recent study in Finland [49] specifically examined reactive moral distress. Reactive moral distress, or moral residue, results from recurrent moral distress that intensifies and escalates over time [25, 38]. This study assessed: (1) work-related mental well-being; (2) acting in accordance or in conflict with professional values; and (3) encountering insufficient resources, such as budget constraints and unmanageable workloads. Among respondents (n = 817), 77% felt that they were often unable to do their work as well as they would like, 36% felt that they were often forced to work in a way that conflicted with their professional values, and 18% experienced impaired work-related mental well-being at least a few times a week [49]. The authors suggest that participants who experienced less moral distress reported enthusiasm, inspiration, pride and resilience in their work more than those who experienced greater moral distress. However, a limitation with this study is that not all items/situations presented were indicative of moral distress.

Additionally, an Israeli-based study looked at moral distress among 216 social workers in long-term care facilities [58]. The authors administered a survey to social workers with items, such as: (1) I acted in a way which has been in contradiction to my professional beliefs due to pressures by the institution's management; (2) I confronted the staff when I perceived their behavior as being in contradiction with the best interests of the residents; and (3) there were situations in which I felt that my professional obligation to the residents was in contradiction with the financial interest of the institution [58]. Although findings reported low levels of moral distress among participants, this is perhaps indicative of the relevancy of survey items. Without utilizing a standardized validated measure, such as the Moral Distress Scale [59] or the Moral Distress Scale-Revised [60], it is important to consider how moral distress was conceptualized among social workers.

3.1.2.4 Root Causes of Moral Distress in Social Work

The root causes of moral distress for hospital social workers may operate across four distinct levels: (1) interpersonal clinical interactions, (2) working conditions, (3) power differentials, and (4) professional competencies, skills, and ethics [61].

Clinical interactions may be associated with end-of-life care and advance care planning discussions [62–64]. Social workers often uphold responsibility to advocate for patients and families if a patient refuses treatment, withdraws from futile care, or dismisses the healthcare team's advice and/or recommendations. Although conflict may ensue across the multidisciplinary team and the social worker may not agree with the resolved course of action, the social worker's responsibility is to advocate for the patient's wishes. The social worker may thus be in a position of disagreement with either the medical team or the patient's choice in treatment. Consequently, social workers "not only carry responsibility for moral decision making exercised at the higher levels of the public administration, but they also carry responsibility for their own moral decision making on the individual level, in their face-to-face encounters with their clients" [49, p. 88].

Working conditions can include budgetary constraints, staff shortages, and unmanageable workloads [65–67]. Funding shortages may result in discharge planning that may trigger moral distress [45, 68]. Organizational constraints may lead social workers to carry out discharge plans that conflict with their professional and personal ethics. This may intensify when the patient does not have the proper supports, finances or networks in place after discharge. Thus, when a social worker knows that the patient requires additional assistance, support and routine care that may not be adequately managed or implemented, and yet the hospital has required her to be discharged, this may result in moral distress.

Power differentials may reflect limited job autonomy and hierarchical power imbalances that place social workers in sometimes ethically compromising situations. Clinical social workers are members of multidisciplinary teams, yet they often lack control and autonomous decision-making in their workloads, patient care, and resource allocation [69]. Social workers may be hesitant or uncertain in how to confront occupational conflict, perhaps owing to disempowerment and shame [70, 71], a lack of supervision [56, 72, 73], and the overwhelmingly female-dominated profession of social work [74]. When social workers continuously feel unable to challenge the resolved ethical decision (often due to power differences), they become silent; social workers describe themselves as being omitted from ethical decision-making and patient treatment plans [75]. Poor collegial support, inadequate supervision, and a lack of inclusivity and collaboration with social workers may foster moral distress.

Professional Competencies, Skills, and Ethics can result in the manifestation of moral distress when social workers either feel as though they do not have the competencies or skills to perform their occupational role or there is conflict between their job performance and their professional code of ethics [55, 76]. This may be a result of role conflict (conflicting demands of their job) or role ambiguity (lack of clarity in expectations). As colleagues may not completely understand the range of social work skills and competencies, this often leaves social workers responsible for

tasks that are not in their job description. Role ambiguity and conflict may influence social workers' *self-perceived competence*, the "subjective evaluation of the person's skills and abilities to perform well" [75]. In a study among 591 social workers in the state of New York, participants' higher levels of self-perceived competence were associated with lower levels of emotional exhaustion and symptoms associated with burnout. The author posits that lower levels of self-perceived competence may impact one's ability to effectively resolve and react to one's job performance [75]. A lack of self-perceived competence may have consequences on workplace relationships and the perceived ethical climate, and in turn important consequences on how moral distress transpires across social work professionals.

3.1.2.5 Implications for Social Work Education and Practice

Addressing the concept of moral distress in social work has important implications for both education and practice. Social work educators must learn to advance ethics coursework through distinguishing between ethics-related terminology, and addressing the manifestations of moral distress in social work. Identifying moral distress can perhaps help ready future social work practitioners to recognize and name these experiences, and address ways in which to mitigate deleterious consequences in their professional context. Discussing moral distress may also support multidisciplinary dialogue and conversation [35]. Utilizing common terminology may assist social work practitioners to seek supervision and support from other healthcare practitioners and to find common methods to prevent and resolve such conflict.

Future research is necessary to empirically understand how moral distress may transpire among social workers. Pilot studies can lead to the establishment of measurement scales to explicate specific items relevant to social workers' duties and responsibilities that may lead to moral distress. Furthermore, such pilot studies and validated measures can help further understanding of how moral distress differs from disjuncture, burnout, occupational stress and professional dissonance, and seek evidence-based practices to identify, discuss, and process the experience of moral distress.

3.2 Part 2: Healthcare Professional Perspectives

3.2.1 A Source of Moral Distress: The Corporatization of Medicine

Joseph J. Fins

Over the past decade, I have seen far less moral courage and the sort of professional autonomy that allows doctors speak out against what they may perceive as wrong or improper behavior. I focus on doctors, not to be physician-centric, but rather because there has been—in my view—a pronounced change in physician behavior in the three decades I have been in practice.

I have detected a decline in the sort of independence that docs were known for and that attracted many to the profession. This begs for an explanation and has implications for professional autonomy and its obverse when physicians feel a sense of moral entrapment and it is impossible to speak up or out.

This is a relatively recent change. There was a time when physicians prided themselves on their ability to self-regulate—whether they did so or not is another topic for another time. Physicians were emboldened by a sense of professional autonomy and discretion that allowed them to set their own moral compass and proceed in the direction they thought best and right. A downside of this hegemony was paternalism that fortuitously has been countered by the emergence of the patient's voice. But there was an upside to this sense of professionalism, the ability to express one's views as a physician. And with these articulations came a sense of empowerment that comes with having one's opinions heard, respected, and acted upon.

This professional prerogative has been eviscerated by many factors but one key sociological force has been the emergence of corporate structures of care that have tempered the power of the individual doctor and led to conformity and complacency. This becomes obvious if we contrast the private practitioner of yore with the hospitalist of today. The doctor in private practice a few decades ago was generally self-employed. Still a predominantly male profession, he was paid directly by his patients or their insurance companies. He was neither an employee of a managed care company nor the hospital and thus was independent of any financial pressures that they might exert. Indeed, the private practitioner in prior decades had power *over* the hospital as he was a source of patient revenue because he directed patients to one hospital or another depending upon where he chose to admit patients. If he was maltreated or censored in any way he could retaliate by redirecting this revenue stream and sending his patients elsewhere. This economic clout conferred power and the requisite independence which is sometimes needed to speak up.

Contrast this now quaint model with the modern hospitalist who is a full time employee of the hospital. His patients are assigned, and his patient load set, at the discretion of the hospital where he works. His wages are fixed, sometimes sweetened by a year-end bonus which is dependent upon efficiency and adherence to length of stay metrics. Any effort to counter hospital policies could imperil one's standing at the institution and potentially compromise one's employment, notwithstanding platitudinous standards about professionalism and accreditation standards.

These constraints are further compounded by the hierarchical nature of healthcare institutions with the decline of powerful departmental chairs and the rise of central administrators who control budgets and their chairs through the power of the purse. This diminution of professional sources of authority, a zero-sum game due to the rise of corporate power leads to further marginalization of clinicians who heretofore would air their grievances with their chairs.

While I am sure these compounding variables depend on the nature of each institution's leadership structure, there seems to be less recourse to professional channels of appeal thereby leading to moral distress and professional estrangement. Institutions that are mission driven by religious or secular attestations of purpose, in my experience, seem less prone to these distortions of professionalism. In the aggregate, conflicts of interest and the corporatization of practice can constrain patient advocacy and lead practitioners to feel torn between their obligations to their own families and those who are entrusted to their clinical care. This is a challenge for professionalism and can lead to moral distress. Increasingly, clinical ethicists are being called upon to use whatever institutional moral authority they have to provide a remedy and counterweight to these forces. Our advocacy echoes responses that may no longer be available to individual practitioners. Hopefully our efforts can do more than respond in individual cases and help corporate leaders of medicine appreciate that professionalism, as seen in the requisite autonomy of practitioners to be moral agents, is the healthcare system's greatest asset. If we lose that element of care, the loss will be priceless.

3.2.2 Moral Distress: A Psychiatrist Perspective

Michelle Joy

As I think of my job—my experiences as a psychiatric fellow, clinician, and forensic evaluator—I am first grateful. My work gives me a true sense of contentment and of appreciation, and I am keenly aware that I am very lucky to enjoy the work that I do. I hold the patients and evaluees that I see in high esteem. I intrinsically respect them. But beneath these interpersonal interactions, there exists a darker reality. It is the structure of society, the systems of care and incarceration. It is hierarchy and inequality. It can be confusing, difficult, and altogether distressing.

Working in community and forensic systems of care, you get the sense that psychiatry becomes an attempt to hold together the underfunded, under resourced, underdeveloped parts of society. And I don't mean the psychiatric care itself. You run abreast of poverty, food insecurity, homelessness, lack of access to healthcare, and limited education. And sometimes people are coming to you not because of the stresses of those situations—yes, that too—but literally and directly because of their needs. Psychiatry can become a route of access to social security disability payments. Psychiatry can be "three hots and a cot"—a colloquialism for food and shelter provided by the hospital (or even jail).

Frustration lies not with the individuals but with the dance itself. Suicidal becomes a code word for "I need something and can't be turned away." But how can you blame the person—subjecting themselves to intrusive questions, often medications, long waits of hours to days, loss of autonomy and privacy and freedom in admission to a psychiatric hospital.... The distress comes with knowing that this won't—and can't—be fixed with a pill. That there is no prescription a doctor can write to change society. But while wishing for more, for this person, for everyone, you try. You try to inspire hope, to validate struggles, to empathize with difficulties, and always to respect the individual.

And it can be hard. The dance goes on all hours of night and day; you do this first thing in the morning, at 3 in the morning, late at night. You can be yelled at, called names, or worse. You hope to avoid fecal smearing and assaults at all costs. But you remember that a lot of this exists beyond diagnosis. It is the desperate cry of people

in need, people without, people living in a rich and glamorous but wholly unequal society.

And too there is the trauma. Horrific stories of rape and torture, physical abuse, molestation during which you do your best to be present and honor survival.

And too there is the stigma. You know it from living life—see it on social media, hear it at dinner parties, receive it as mental health practitioners (always a joke to be had) or as people with diagnoses ourselves. You call and receive consults in which psychiatric comes to mean difficult, annoying, someone others don't want to deal with. And in quiet moments you realize that stigma is probably keeping many, many people from even making it to your door.

Also the discrimination. In a racist society, stories abound. A black man arrives late at night to discuss nightmares and fear after racial tensions in the military, his fear of white men, his fear he will retaliate. You realize there are no black providers to hold this space with him, and you try your best. A black child in a detention facility won't speak with you—despite your assignment to see if his case can be helped. You learn he is willing to speak with a black psychiatrist; you lament that no one is available. He falls down the roster. The transgender patient hears dead names, inappropriate pronouns, and "but have you had surgery?" all too often.

The system itself twists and turns and disappears behind layers of complexity. As a provider or a patient you try to grasp the complexities of insurance, referrals, prior authorizations, copayments, deductibles, sliding scales, waiting lists, appointment scheduling, refills, and more. And then you imagine attempting to navigate this without a phone. Without a home. Without money. Speaking another language. Lacking motivation. Distracted by hearing voices. With no one to help. Or care. In the forensic system the playing field is populated with attorneys, judges, plea bargains, evidence, probation, rights, and waiting. How to navigate is again the question.

And even within the services themselves, they glimmer then dart, a disappearing school of fish in a dark and infinite sea. Insurance will only pay for a short course of therapy. The dialectical behavioral therapy program won't take someone with an addiction. The trauma program will not accept someone who is suicidal. The early psychosis program only sees people within months of symptom onset—too late. The therapists regarded as the best charge hundreds of dollars per hour. The psychiatric facilities that treat complex medical problems close down. The medication has unbearable side effects. A treating provider has left the training program, the area, the field.

There are things we are forced—but are we?—to do that keep us up. Decisions we make. Protocols we follow. Involuntary commitment: did I save a life or traumatize someone, ensuring they will never again seek services? Malingering: was he really fabricating a story or was I just tired, frustrated, and resentful? "But the hijab must come off, it's a psychiatric emergency room, and we can't have anything someone could hang herself with." Do I have a suspicion of abuse, does this family require child protective services, or will that just be another stress and possible trauma? Declaring capacity to refuse treatment might mean capacity to accept death. Competency to stand trial means going forth with all the possibilities a guilty verdict might entail; not competent is waiting longer in jail. Will providing a diagnosis impair or empower? Should I suggest medications or therapy, neither or both? Because as much as the roles we fill ask for, insist upon, prediction, we are not fortune tellers or lie detectors. We hold no magical abilities and often operate with limited time and information. There are few lab tests or scans as ours is the world of words and stories.

But that world is a special one. It is a world of which many don't know hidden behind locked doors and privacy protections. But let it be known that despite its frustrations and flaws, it is a wonderful space to inhabit. We spend our days holding narratives, emotions, thoughts, and behaviors of most personal natures. I thank those individuals who share with me and hope that our system and society can work to increasingly improve the ways in which we can help those in need.

3.2.3 Physicians' Experiences of Moral Distress and Burnout

Katherine E. Kruse and Alyssa M. Burgart

Some physicians are unfamiliar with the term "moral distress," but upon hearing a description of the concept, they invariably realize they have personally endured moral distress or witnessed its aftermath. In the past decade, nursing literature has taken a deep dive into the study of moral distress, while medical literature has focused on the closely related issue of burnout [77]. Recently, the disciplines have converged and we have seen increased work on the interrelatedness of the concepts and of our professional experiences. Such studies bring to light the connection among moral distress, burnout, and depression, and their correlates: individual resilience, institutional moral climates and moral community. Nurses, physicians, social workers, other bedside providers, as well as hospital administrators, may experience moral distress [78]. The physician's role in modern healthcare carries specific professional expectations which are distinct from other roles. Our facets of responsibility are defined on several fronts: individual (patient expectations for a physician's care), societal (promotion of the public good), logistical (medical licensing requirements), legal (risk for malpractice claims), and personal (a physician's desire to be perceived by one's self and others as a "good doctor"). We may experience moral distress across the spectrum of professional life: the care of critically ill patients, working with challenging families, conflict with administrators, limited access to services and resources for patients, legal matters, policy constraints, among others. The effects of such stress do not stop with individual clinicians, and are implicated in harms to patients, such as medical errors [79].

Physician professional identity formation, anchored in the societal and professional expectations unique to our brand of medicine, leads to development of an exceptional sense of personal responsibility for our patients [80, 81]. By nature of our vocation we are held to a higher standard than non-medical professions, and patients insist we remain unblemished to gain and maintain their trust. Our contract with society expects that we serve as healers, guarantee our competence, be altruistic, act morally and with integrity, promote the public good, and be both transparent and accountable [82]. Armed with medical degrees and years of specialization training, the public requires physicians to be top notch diagnosticians and clinicians, but also scientists, teachers, and role models. We are expected to be both human (akin to our patients) and simultaneously superhuman heroes (capable of saving lives). The public barometer of success is no longer measured by accurate diagnoses or lives saved, but consumer ratings where those disgruntled with healthcare tend to be the most vocal.

Unmitigated duty to, and personal responsibility for, one's patient are nonnegotiable elements of physician practice. It is a duty and a privilege to care for the ill and dying, but can be burdensome as well. With this level of responsibility, even when we support team-based practice and a shared decision-making model, physicians often see ourselves as carrying much of the responsibility for ensuring individual patient outcomes. For many of us, the work for a patient doesn't end when we leave the hospital or clinic, as our patients remain on our minds throughout the day, sometimes even appearing in our dreams. This quest to serve each patient may become all-consuming. When coupled with the administrative tasks associated with practice, we are known for chipping away at time for personal care, making the achievement of an already nebulous work-life balance impossible. This trajectory sets physicians at risk for losing hold of the deeply rewarding and meaningful aspects of professional life.

Physicians frequently operate under the umbrella of a larger organization with its own priorities and obligations, which may conflict with the medical goals of individual patients or the best intentions of staff. When organizational values are noncongruent with those of physicians, morally distressing conflicts arise. Employers may mandate an unrealistic number of patients to be seen in one's clinic, leaving physicians to balance the fallout of one complex patient's needed care, leading to a waiting room full of irritated patients whose appointment times have long since passed. Physicians may also be expected to maintain Press Ganey patient satisfaction scores, which are themselves correlated with patient perception of sufficient time spent with the physician [83]. While in training, physicians anticipate spending their days providing direct patient care, but actually spend almost twice the amount time doing clerical work, and even more hours at home to complete it [84]. Some moral distress is unavoidable in our line of work and the risks for burnout will never be eradicated. Successful organizations acknowledge this reality and attentively foster a strong moral climate, nurture resilience, and balance demands on physicians so that we can forge ahead, rather than become disenchanted with the practice of medicine.

For some physicians, the combination of lofty expectations, a deeply ingrained professional integrity, low resilience, and untenable professional/institutional expectations create the perfect breeding ground for moral distress, burnout, and depression. Physicians who find and appreciate the deep meaning in their work are far less likely to experience moral distress and burnout. However, medical training does not require us to be emotionally healthy people armed with good coping abilities, resiliency, moral sensitivity, and ethical discernment skills, nor are such skills specifically nurtured in the arduous process of becoming a physician. Many physicians find themselves well trained in medicine, but woefully underprepared emotionally for its stressors. At the core of our calling to be doctors, sometimes lies both our greatest

strength and the seed of our undoing. Our drive to be the very best clinicians leads us to spend long hours caring for patients, voluntarily cutting into time with our families and personal interests. Self-care is so easy to cut from one's day, and we can end up emotionally and physically drained, hindering our moral sensitivity and perspective. Unregulated moral distress may lead to moral outrage, burnout, and acute secondary stress [85]. While it is tempting to see this as a personal problem, moral distress and burnout are associated with increased rates of medical errors, meaning that patients suffer as well. Some physicians' professional quality of life is so impacted that they leave practice altogether [86]. Physician burnout and depression are strongly correlated [87, 88], and some argue are one in the same [89]. Though it may initially sound dramatic, the string that connects these phenomena may be life threatening. An estimated 300–400 physicians commit suicide annually. This tragedy is not well understood, but is believed to be due to a combination of burnout and untreated mental illness [90].

3.2.3.1 Physician Narratives

As physicians and clinical ethicists, we navigate the murky water where clinical care and ethics converge. Sharing our professions' stories of moral distress is a wonderful way to open this important dialog. By acknowledging the difficult aspects of our work, we begin to prepare ourselves and our fellow clinicians to move past survival and create space to thrive in our work. To highlight moral distress in the clinical arena, our colleagues graciously shared their experiences:

Legal Rights in Organ Donation: Directed Donation

A heart failure specialist considers fair practices of organ transplant allocation.

I know it's [the family's] right [to give the organs to a specific person], but it feels really wrong. For the patient that gets the heart, if it's a good match, it's great, but it means someone who is really sick and may be top of the list, won't get it... and that person might die because they weren't lucky enough to have a friend die. It sounds sick, to say that... The UNOS system is supposed to make it so we don't have to be involved in the details of the donor. When the organ is directed, suddenly, the donor is much, much closer... It makes us all really uncomfortable.

Right to Information: International Medical Care

An international disaster relief physician struggled when practices around HIV were abruptly changed.

Our mission was a 'chronic emergency'... we had a strong presence and had been [in that city] for over five years... They had been testing for HIV and there was actually a way that we could request HIV medications on a case by case basis... But while I was there, we got an order from [the organization] to stop testing all together... we thought, even if we couldn't treat or continue the responsible care, we really felt that the patient had a right to know and definitely had a right to be tested. We were there to provide care. The test was simple and we had the time to do it. But this wasn't a pandemic, like ebola... it wasn't a crisis, so we could take care of every patient that came in front of us. I had a real problem with not being able to do the test for my patients.

Patient–Physician Communication: Gestational Carrier

An obstetrician uncomfortable with limitations placed on her communication with her patient.

I had a patient who was a gestational carrier for a couple... and because of the agreement with [the surrogacy organization] I was being told that I wasn't allowed to tell my patient about everything that was going on [a severe cardiac defect] with this being growing inside her body... Normally, I would have been able to do that... to talk about it, it's part of the relationship. You just want to take care of the person in front of you... Then [because of the disability] the parents didn't want the baby anymore... and the surrogacy organization basically stopped said 'we're done.' So then I thought, who's in charge now? Who gets the information about this baby? I just wanted to talk to her.

These examples provide a glimpse into physicians' morally distressing experiences. We encourage ongoing effort and focus on morally distressing events, both large and small, occurring in the practice of medicine. No matter the magnitude or flavor of moral distress, all merit respect and consideration [91]. The prevention and treatment of moral distress requires stepping back to examine the deep meaning that drives physicians to choose careers in medicine, the environment of practice, and what it takes to foster and support a morally robust community in which such physicians can thrive.

Moral distress takes many forms and can permeate every aspect of our professional lives. We have come a long way in recognizing moral distress and its connection to burnout as significant problems in medicine. Organizations across the country are making efforts to create better moral climates for all healthcare providers and patients. Acknowledging moral distress head-on, before it can smolder into burnout and depression, is one approach to ensure career longevity for those in the thick of it. When healthcare teams work together to address moral distress and burnout, we can make immense strides towards a more resilient moral community.

3.2.4 A Chaplain's Perspective on Moral Distress

Margaret Lindsey

I first became interested in moral distress when I was working as a chaplain at a suburban Chicago hospital and beginning the coursework for a Doctor of Ministry degree. I attended a conference on perinatal loss, heard a presentation about moral distress, and was hooked. What struck me immediately was how well suited chaplains are to respond to the problem. I had the good fortune, at the time, to be leading a series of seminars about medical ethics for the residents at our hospital, and I began to wonder if they shared the experience that I had just heard described as a nursing issue. I decided to make that question the focus of my doctoral research.

Why are chaplains so well suited to respond to the problem of moral distress? As I understand it, moral distress is a form of suffering, specifically spiritual, emotional, and moral suffering. It is a crisis of identity for the provider which threatens his or her sense of self as a moral being. It is a threat to the provider's integrity which may lead to a diminished sense of purpose and meaning in his or her work, and often results not only in a loss of job satisfaction but in a painful sense of having betrayed oneself and one's deepest convictions. Chaplains, as members of the clergy, have a fundamental responsibility to attend to the moral lives of those who are in their care. At the same time, it is our basic purpose, as chaplains, to ease spiritual suffering. Moral distress is a crisis that demands the fulfillment of that responsibility and of that purpose.

My research convinced me that moral distress was a universal experience among the medical residents with whom I worked. My conversations about the topic in our hospital's ethics committee eventuated in several other presentations to both nurses and medical staff, where I repeatedly heard the same thing. "Yes, that's my experience! I just didn't know what to call it. I still remember what happened with a patient, years ago. It was awful. Let me tell you about it." Sometimes there were tears. The pain lingered, and the moral residue clung. I discovered how common the experience was. My next challenge was to figure out what to do about it.

Most chaplains consider it their responsibility to care for hospital staff as well as patients and their families. We are trained to be good listeners and to facilitate healing conversations. As members of the clergy, we expect, and are expected, to keep confidences. In most hospitals, chaplains stand apart from administration and management and so are able to provide a safe haven for fellow staff members to discuss personal concerns, such as moral distress. Chaplains can address the issue, first of all, by providing education that describes and names the problem and by offering safe opportunities for providers to tell their stories.

Chaplains can also address the issue by supporting the efforts of providers who decide to work for change. As the American Association of Critical Care Nurses position statement, "The Four A's to Rise Above Moral Distress," suggests, the most adaptive response to moral distress may be to take action, but the risks and benefits of that action must be carefully considered. Chaplains are trained to facilitate decision-making, and so can offer assistance and support as providers assess the situation, evaluate their options, and determine their response. Chaplains can, and should, provide ongoing emotional and moral support as steps are taken toward change. In some hospitals, particularly faith-based ones where chaplains are seen as moral leaders, they may be well positioned to advocate for providers who work for change and justice within the system.

Many chaplains are trained in medical ethics, or serve on ethics committees, and may be able to offer insights from that training as providers grapple with moral distress. Most chaplains, as members of the clergy, have some basic education in ethics and some facility in analyzing ethical problems. Chaplains may, at times, address the issue by offering basic ethics education and proposing various models of ethical decision-making.

Much of my thinking on the topic, however, has been theological, and that, of course, is the unique perspective that a chaplain brings. For me, it's all about vocation. From my point of view, the most important question for a provider who is experiencing moral distress is ultimately "What is God calling you to do?" Of course not all chaplains are Protestant ministers, as I am, and not all providers are Christian. A more universal question might be "Who are you meant to be?" or "Who do you want to be?" or "Why did you choose this work?" Whatever source of motivation one appeals to, there is great power and hope in the recollection of that motivation, and in working one's way through the quagmire of moral distress in order to reclaim what

one once held dear. Although it seems a cruel twist of fate that those who are most sensitive about moral problems are also most vulnerable to moral distress, it is also the case that those who successfully wade through the muck emerge stronger. It takes courage and commitment, but is well worth the effort. There is much to celebrate if, in the end, the right thing is done for the patient and the provider's sense of self is restored. From this chaplain's perspective, moral distress is not just a painful problem, but a tremendous opportunity for spiritual, emotional, and moral growth.

Studies are beginning to show that providers from a wide variety of disciplines experience moral distress. In a 2013 study, Susan Houston and her colleagues at Baylor demonstrated its occurrence among a wide variety of healthcare professionals, including chaplains [48]. The chaplains in their study reported a high degree of intensity in their experience of moral distress, and a tendency to be most distressed by patient care situations that raised issues of social justice. It stands to reason that chaplains, who are charged with a particular responsibility for the moral well-being of others, would be acutely affected when their own moral integrity is threatened. It stands to reason, too, that chaplains, who are not just spiritual and pastoral caregivers but also religious leaders, would have a heightened sensitivity to issues of social justice and a consequent sense of responsibility. We chaplains are challenged by the moral distress we ourselves experience, just as our colleagues in other disciplines are. Will we notice it, learn from it, and grow?

My purpose in working with the residents at our hospital was to provide better pastoral care for them. As I became aware of this particular problem, I worked to find ways to ease the suffering they experienced, and to encourage their growth as individuals. That might be enough, by itself. But chaplains and other pastoral caregivers are increasingly aware of the systemic implications of our work, and my exploration of this topic has convinced me that our response to it, both as individuals and as institutions, has the potential to have a far greater impact. Might it not be that happy, spiritually healthy providers provide better care for their patients? What if more healthcare providers felt well-equipped to navigate the shoals of moral distress and work for positive change? Could it be that their efforts would lead to much needed improvements in our healthcare system and a better healthcare environment for us all? I'm betting on yes. As painful as the experience of moral distress can be, the opportunity it presents gives me hope.

3.2.5 Moral Distress in Pediatric Nursing and Research

Kim Mooney-Doyle

To cure sometimes; to relieve often; to comfort always.

As I embarked in a career as a pediatric oncology nurse, I knew that suffering and death would be part of the journey. I couldn't control that. I cannot control if a beloved child develops cancer, how they respond to treatment, whether they relapse, and if their disease causes their death. What I can control, however, is how I provide

care, how I teach others to provide care in this context, and the research questions I choose to investigate that may elucidate sources of child and family suffering, strength, and distress. I can work to minimize suffering and help children and families process life-threatening situations and decide as a family how they want to live life and how they want to die. I can try my best to be a source of sanctuary to children and families who live with life-threatening illnesses.

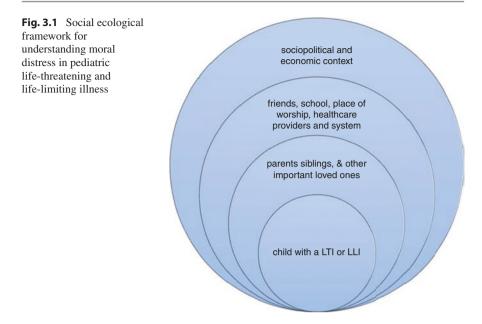
Without a doubt, one of the most life-giving aspects of working in pediatric healthcare is the relationships formed with children and their families. It is painful and confusing to see a child's symptoms mismanaged as they become more ill and death draws closer. It is painful to see families and clinicians have discordant views about prognosis and potential for cure. The pain that sticks with me, though, is the pain of seeing families not get what they need from the healthcare system or healthcare providers. This lack of support takes many forms: the single parent who is told that she cannot stay at the bedside of her sick child with the younger healthy sibling; the teenage girl and her mother whose complaints are blown off because they are deemed high-maintenance (and the child ended up in the intensive care unit); the mother who has one sick child in the hospital and other children at home and perceives that she is judged and "feels treated like shit" when she comes to the unit to see her child because she can't be at the child's bedside constantly; or parents who are judged by healthcare providers as "in denial" or "uninformed" for decisions they make about their child's care when the healthcare providers have incomplete information about the clinical or family perspective. Indeed, my moral distress as a pediatric nurse and researcher is rooted in the limitations of support provided to families; it is the lack of recognition of family moral distress.

Much of the recent literature on moral distress in pediatric healthcare providers describes the sources of this distress and how it varies among healthcare providers [92]. In addition, other literature points to ways in which moral distress can be minimized through innovative, interdisciplinary communication [93] or through instituting high-quality palliative care for children in a given unit [94], acknowledging the bidirectional relationships among pediatric healthcare providers, children, and their families. We influence the children and families we care for, and they influence us in return. Indeed, various disciplines experience moral distress for a multitude of reasons, situated in their given professional context, yet there are common themes throughout: providing care that seems futile or that causes harm; poor team communication; and discord between family and staff appraisal of a child's clinical situation. Yet, healthcare providers in these studies less frequently express concern about the way children and families are treated in the healthcare system or how children and families live with life-threatening illness and how they survive as a family unit. Also, parents, children, and other family members have had limited opportunities in the literature to express their own experiences of moral distress. It seems as though our concern about moral distress is more about us as healthcare providers and less about children and families. It seems as though we have forgotten that we get to leave the four walls of the intensive care unit or the oncology unit and, often, return to our healthy loved ones. Yet families are trapped in that existence, may not be able to fulfill the expectations they have established for themselves as parents, and may end up leaving the hospital without their child.

One of the greatest sources of moral distress described by pediatric healthcare providers is when a family desires and requests increasingly aggressive care, when the healthcare provider does not perceive it will be beneficial for the child. Yet, what rarely seems to be part of the conversation is how we, as pediatric healthcare providers, have a hand in creating this distressing situation. There is ample evidence in the pediatric oncology literature, for example, that parents and oncologists frequently have different prognostic expectations for a child's advanced cancer [95], that pediatric healthcare providers struggle with sensitive and difficult conversations about transitioning care in life-threatening illness [96] and that they fear diminishing hope and causing distress [97, 98], that there are communication gaps between healthcare providers delivered in a caring way [100]. Thus, illuminating the relationship between communication and moral distress for healthcare providers and families may be an important way to address the experiences of moral distress in pediatrics and mitigate its effects.

Another risk of these gaps in communication that may contribute to moral distress or result from moral distress is "othering" of parents and children who make decisions with which we do not agree. "Othering" is a process in which "a particular social group becomes defined or characterized in contrast to the dominant social group, usually with hierarchal undertones" [101]. As further described by Whitehead [101], "othering" allows those who perceive a wrong to "engage in a meaningful, therapeutic exercise that shifts their role from that of victim to that of judge. Doing so restores control in a situation that they are experiencing as extremely chaotic or senseless. They manage the chaos of their situation by reordering the occurrence of events in their lives, such that they refile themselves in the 'normal' pile that they are used to being a part of" (p.115). Thus, when pediatric healthcare providers feel they are participating in care they do not agree with or perceive as futile, they may perceive the parents making such decisions as "different" than themselves in order to process the situation, but with potentially dire consequences for the relationship. For example, when we, as healthcare providers, declare that we would never subject ourselves or a family member to stem cell transplantation, yet we have never had to make such a decision, we risk creating an artificial separation between ourselves and children/families. When confronted with a life-threatening illness, we might decide differently.

Eliciting sources of moral distress in families can prompt healthcare providers to see a multifaceted picture of family life in pediatric life-threatening illnesses. Understanding parents in the totality of their roles and situated within their given contexts provides windows into their decision-making and "re-goaling" [102] over time. An ecological perspective can elucidate moral distress within the context of pediatric life-threatening illness [103, 104] (Fig. 3.1). This perspective places the child at the center of various environments, nested within one another. Immediately surrounding the child are the parents and siblings and other close, intimate relationships. Surrounding the child and his or her loved ones is the community environment that encompasses school, friends and peers, healthcare systems and providers, place of worship, among other sources of support and service. Surrounding the



community that envelopes the child and family is the broader system that may not directly interact with the child and family, but influences their well-being. An example of this is the political context that supports legislation to provide concurrent curative and hospice care or family medical leave. Finally, all of these systems are situated within the broader culture that establishes norms and expectations (e.g., gender roles, family roles). These systems influence and are influenced by each other and change over time. Thus, this perspective recognizes that children and their families are the focus of our care and service and that there is a bidirectional relationship between children/families and healthcare providers. Yet, the ecological perspective reminds us that we are but one part, albeit an important (often life-sustaining) one, of a greater world that the child and family inhabits.

Using this perspective to elucidate the experiences of children and families in the context of serious, life-threatening illness, we can appreciate the various sources of stress and strength with which families contend, the meaning parents attribute to their child's illness and their role in being a parent, and the barriers families face trying to accomplish what they deem important [105]. We come to see that in order to feel as though they are "being a good parent to the ill child," [106, 107] parents may believe they should ensure their child has strong spiritual beliefs, may rarely leave the child's bedside for fear of missing a chance to ask the attending physician a question or having the child's needs unattended, or search the country for an open clinical trial. We also come to see the sources of conflict with which parents contend, such as ensuring healthy siblings feel loved and emotionally connected to the parent, which pulls them away from the bedside, financial distress because of lost wages or unanticipated expenses of hospitalization, parents' own emotional or psychological distress [108], or violence within their own homes or communities. Thus,

understanding the complex environments that families traverse demonstrates their own potential sources of moral distress and provides insights into behavior and decisions pediatric healthcare providers find challenging.

When we look beyond the action (or inaction) that has instigated our moral distress to the broader context in which parents or children make such decisions, our moral distress may be tempered because we see the situation from another angle that may challenge our initial moral judgement or provide insights into why parents make such decisions. This is similar to research by Laing et al. [109] in which digital stories by children with cancer and their families contributed to healthcare providers understanding of aspects of the cancer experience that were not discussed in a clinical encounter. Through the video, healthcare providers described diminished barriers between themselves and families; by "losing their healthcare provider role" participants in this study were moved by their common humanity with the children and families and perceived greater ability to connect with them [109]. Examining moral distress from an ecological perspective can unearth factors that influence our perceptions of moral distress; we can flip the microscope from the internal to the external. For example, when we change our focus from the distress and negative feelings we experience because a mother does not stay at the bedside of her sick child to understanding that the woman is living in poverty, has other children, and limited safe social support to care for those other children, our own moral distress may be alleviated. We may still find the situation of severe child and family poverty distressing and we may feel sadness for the involved family members and the child who is ill, but we may not feel a threat to our own integrity.

3.2.6 Pharmacist's Perspective on Moral Distress in Palliative Care: A Narrative

Tanya J. Uritsky

I have been a clinical pharmacy specialist working in a large academic teaching center for nearly seven years. I practice in palliative care, working with patients and families in great distress, facing big decisions, and looking for guidance from some of the best and brightest providers in the country, or even the world. They come here to get "fixed" as they often say. They come here because other places have not been able to meet their needs or make them better, but they heard we can do things that others cannot. Unfortunately, we cannot prevent the inevitable, sometimes we can delay it, but often not without consequence of long or frequent hospitalizations, significant pain and anguish. Although we aim to provide improved quality of life, it sometimes gets lost in the incredible push to preserve life. And I am ok with this, as long as it is informed and decisions are made based on "truths" as best as we know them, values are explored, and plans are clear but frequently revisited.

I have had one too many experiences where patients are told an intervention will "help." I really don't care for the word "help" in the medical world. What does this mean? I was working with a very sick patient who was told the chemotherapy would help him—the understanding of the patient's wife was that it would help

him have the chance to walk again, regain some function. The intent of the physician was that it would help preserve his organs in their current weakened and malfunctioning state at best, not improve his quality of life. While some may choose to continue in a weakened and debilitated state, that was not in-line with the values of this patient and his wife. From my position as a palliative care pharmacist, I inserted myself between the patient and the chemotherapy and was able to prevent this misalignment from happening. I explored the family's values and clarified with the physician's intent, which revealed the discrepancy in the plan for more chemotherapy. I then worked with the primary medical team and floor social worker to expeditiously establish comfort care for the patient in a preferred location as his health was rapidly declining. My pharmacist colleagues would have been the ones verifying the chemotherapy for this patient, not necessarily knowing much about the conversations or the values going in to the decision to give this medication to a very sick and dying man. I am empowered to try to sort this out as a member of the palliative care team; the unit pharmacists, however, are generally not so empowered.

This is exemplified in the hospital's transition to a new computer system. The pharmacists did not have access to any of the advanced care planning information despite the fact that it was accessible to other members of the medical team. It is presumed, even at the level of technology developers, that the pharmacist will verify a medication, something as major as chemotherapy, because it has been deemed appropriate on some "higher" level. The pharmacist is the medication specialist, with expertise that ranges from the molecular level through the level of interpreting the clinical impact of medications on patients. Pharmacists are on the front-lines; they do much of the counseling to very sick patients about potentially toxic medications and discuss their worries and concerns. Pharmacists may question the appropriateness of a medication order, but without access to patients' advanced care planning information and goals, the implied message is that our perspective does not matter. To rectify this and demonstrate that our perspectives do indeed matter, I worked to ensure pharmacists throughout the institution have access to this information. Unfortunately, the work continues as I don't know how many pharmacists even know they have access to this information, can use it in their clinical work, or feel empowered to do so.

In a different dimension on the above case, sometimes what is perceived as harmful is actually helpful in a way that is not so obvious to the entire healthcare team. I was involved in a case where the oncologist's idea of "help" was in alignment with the patient and his wife, but other members of the team were very distressed since the man was near the end of his life. The other members of the healthcare team had a difficult time reconciling their own values about what should be done with what the patient and his wife wanted and what the physician ordered. In exploring the wife's values, she needed to feel that she had done everything that could have been done—she needed to make every last effort possible to help her husband. It is distressing that chemotherapy was even offered, but I am certain the oncologist was trying to meet this need. This case demonstrates how it is essential to understand family values and the distress that would have lingered with his wife

long after this man's death if just one more thing wasn't done. If the pharmacist knows this, there is less strife around verifying the chemotherapy and more ability to offer consolation to the struggling team.

Along these lines, there is the idea that one is "just the pharmacist." The perceived role of the pharmacist can be limiting—as one who only knows the medications or who counts pills. With more and more clinical pharmacy presence on medical teams and with the robust therapeutics education of pharmacy school and post-graduate training, the pharmacist is poised to provide so much more. It has been my experience that providing support and symptom management for those in distress instills trust and this opens the door to explore patient values. Patients look to pharmacists as a trusted member of the team who is now their advocate. I have been involved in complex psychosocial and ethical situations, have led family meetings, have been at the bedside of a dying patient as a support to the family and the staff—all things that do not fit inside the traditional role of the pharmacist. Pharmacists need to be encouraged to get to know patients and advocate for them based on these interactions.

Then there are the moral considerations around stopping maintenance medications at the end of life or when patients have a life-limiting illness. These are crucial conversations and the emotional and psychological attachment that can be linked to the life-sustaining focus of many medications is often the crux of the challenge. The pharmacist is reliant on the prognostication of the providers as well as on their own experience in helping guide the patients and their families through this process. Having experience under my belt, I am less overwhelmed by these conversations, but pharmacists with less experience in this realm may experience distress around these decisions and conversations. As a result, they may be more likely to avoid these conversations or take a more general approach, leaving room for potential distress amongst themselves, the provider team, the patient and their family. Acknowledging this pivotal role of the pharmacist and offering ongoing education and support are essential to providing quality end-of-life care.

The presence of the pharmacist on the treatment team is strengthening and the role is different from specialty to specialty, and in various settings. It is important to acknowledge the areas of distress that may present themselves as this evolves and bring the pharmacist into the conversation about patient's hopes, dreams, and values.

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