June 2017

Volume 19, Number 6: 515-634		
Peer-Reviewed CME Article: Medical Educ		518
Avoiding Racial Essentialism in Med Lundy Braun and Barry Saunders	iicai Science Curricula	3 10
Teaching Clinical Ethics at the Bedsi Essential Role of the Hospitalist	ide: William Osler and the	528
Matthew William McCarthy and Jose	eph J. Fins	
Moral Distress and Medicine	!	
From the Editor		
Moral Distress: A Call to Action		533
Subha Perni		
Ethics Cases		
How Should Resident Physicians Re	espond to Patients' Discomfort and	
Students' Moral Distress When Lea	rning Procedures in Academic	
Medical Settings?		537
Commentary by Bonnie M. Miller		
How Should Integrity Preservation	and Professional Growth Be	
Balanced during Trainees' Profession	onalization?	544
Commentary by Eli Weber and Sharo	on Gray	
How Should Physicians Respond W	hen the Best Treatment for an	
Individual Patient Conflicts with Pra	ectice Guidelines about the Use	
of a Limited Resource?		550
Commentary by Edmund G. Howe III		
What Should Physicians Do When T	hey Disagree, Clinically and	
Ethically, with a Surrogate's Wishes	s?	558
Commentary by Terri Traudt and Ioa	n Liaschenko	

Podcast

Strategies for Addressing Moral Distress:

An Interview with Dr. Elizabeth Epstein

The Code Says The AMA Code of Medical Ethics' Opinions Related to Moral Distress BJ Crigger	564
Medical Education Antecedents and Consequences of Medical Students' Moral Decision	
Making during Professionalism Dilemmas Lynn Monrouxe, Malissa Shaw, and Charlotte Rees	568
In the Literature	
Who Is Experiencing What Kind of Moral Distress? Distinctions for Moving from a Narrow to a Broad Definition of Moral Distress Carina Fourie	578
State of the Art and Science	
Initiatives for Responding to Medical Trainees' Moral Distress about End-of-Life Cases	585
M. Sara Rosenthal and Maria Clay	
Policy Forum	
What Is the Role of Ethics Consultation in the Moral Habitability of Health Care Environments?	595
Wendy Austin	292
Strategies for Promoting High-Quality Care and Personal Resilience	
in Palliative Care Katherine E. Heinze, Heidi K. Holtz, and Cynda H. Rushton	601
Medicine and Society	
Culture and Moral Distress: What's the Connection and Why	
Does It Matter? Nancy Berlinger and Annalise Berlinger	608
History of Medicine	
What Moral Distress in Nursing History Could Suggest about the	
Future of Health Care Andrew Jameton	617
Images of Healing and Learning Dirty Laundry: Drug Formulary Exclusions	629
, , , , ,	

631

June 2017, Volume 19, Number 6: 518-527

PEER-REVIEWED CME ARTICLE: MEDICAL EDUCATION

Avoiding Racial Essentialism in Medical Science Curricula

Lundy Braun, PhD, and Barry Saunders, MD, PhD

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Abstract

A wave of medical student activism is shining a spotlight on medical educators' sometimes maladroit handling of racial categories in teaching about health disparities. Coinciding with recent critiques, primarily by social scientists, regarding the imprecise and inappropriate use of race as a biological or epidemiological risk factor in genetics research, medical student activism has triggered new collaborations among students, faculty, and administrators to rethink how race is addressed in the medical curriculum. Intensifying critiques of racial essentialism are a crucial concern for educators since bioscientific knowledge grounds the authority of health professionals. Central ethical issues—racial bias and social justice—cannot be properly addressed without confronting the epistemological problem of racial essentialism in bioscience teaching. Thus, educators now face an ethical imperative to improve academic capacities for robust interdisciplinary teaching about the conceptual apparatus of race and the recalibration of its use in teaching both genetics and the more pervasive and urgent social causes of health inequalities.

Introduction

The need for US medical schools to improve teaching about racial inequalities in health and disease has become acute: it is an ethical responsibility. National protests against racial discrimination in police actions and beyond have had particular salience on college campuses. Because of the shifting terrain of premedical undergraduate education, in which students have been exposed to more history and sociology of medicine, current medical students are sometimes more aware than their professors of how racism manifests in medicine and medical education [1]—including the intensifying scientific controversies regarding human genetic variation [2].

Consequently, medical students are asking for increased diversity among faculties and trainees, commitments to improve educators' and fellow students' social and behavioral competence, and reduction of stigmatizing biases in clinical settings. In collaboration with interested faculty and administrators, students are also asking for deeper engagement with social and structural causes of persistent and widening health disparities [3–5]. And students are contesting a preclinical curriculum that merely documents racial health disparities (without explanation), offers presumptive explanations that are disproportionately biological, and deploys race uncritically as a biological or epidemiological risk factor.

These concerns (of course not limited to students, as there are important initiatives involving residents and faculty members as well) have an intrinsically ethical character, rooted in awareness of historical legacies of racialized vulnerabilities and ongoing social injustices in our country. Medical schools have an ethical responsibility to teach the social and <u>structural causes</u> of health inequality and to engage with the epistemological aspects of racial categorization (and would even if students were *not* asking!).

Many physicians and medical educators are confused about the meanings of race and feel ill-equipped to engage debates about race in the classroom or uncomfortable using race in clinical practice [1, 6]. The ethical obligation that medical educators now feel with new intensity, to improve pedagogies regarding race, must include revising how we use racial categories even in our descriptive bioscientific teaching—especially in genetics. Indeed, the rise of student activism at this historical moment is, in part, an outcome of the plethora of studies invoking genetic differences for racial disparities in health and disease [7]. Whether and how race is used or misused in genetics research and teaching is important because bioscientific knowledge is a key source of clinical authority. We thus must expand faculty capacities to teach about race with nuance and multidisciplinary awareness.

Racial Essentialism in Genetics and Other Medical Biosciences

The idea of innate differences among races has been foundational to science since the Enlightenment—and this idea persists in medical education and clinical medicine. For example, the idea of innate racial differences in lung capacity was first promulgated by Thomas Jefferson in his *Notes on the State of Virginia*. It took 50 years for his philosophical musings to acquire an empirical foundation in the hands of plantation physician Samuel Cartwright; the idea has since become deeply embedded in medicine globally [8]. Although poorly supported by accumulated evidence, pulmonary function tests are "corrected" for race [8]. Similarly, the idea of innate differences persists in laboratory tests for glomerular filtration rate that are also "corrected" for race in the US (but not everywhere) on the presumption that blacks by nature have higher muscle mass and therefore higher creatinine levels [9]. The medical literature on hypertension is rife with genetic explanations of the disease's higher prevalence among US blacks than whites,

although hypertension prevalence is higher in Spaniards, Finns, and Germans than in US blacks [10]. While a recent systematic review of genomic studies that focused on race and cardiovascular research indicates that the contribution of genetic difference among races is minimal at best [11], the eighth Joint National Committee on the Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC 8) guidelines for hypertension categorize treatment strategies by race [12]. Even in the case of tuberculosis, which was a highly racialized disease until the mid-twentieth century, when environmental explanations of its cause assumed dominance [13], genetic predisposition has reappeared in the biomedical literature as an explanation for blacks' greater susceptibility to the disease [14]. Finally, teaching about a monogenetic disease like cystic fibrosis (CF) often begs important social questions. As Wailoo and Pemberton have queried: How did we arrive at its standard introductory description (since the 1990s) as "the most common lethal genetic disease afflicting Caucasians" [15] from a previous time when we recognized its multiethnic distribution? How does the whiteness of CF shape performance of standard CF genetic screening batteries among other "races"? Beyond genetics, how important are social or environmental exposures or health care access in determinations of "racial" differences in CF outcomes?

Debates over Race, Genetics, and Knowledge Production

The recent call by an interdisciplinary team of scholars at the National Academies of Sciences, Engineering, and Medicine to convene a panel to consider how "to move past the use of race as a tool for classification" [16] is a timely articulation of the long-standing debate concerning the meaning of race in medicine. Yudell et al. argue for development of alternate approaches to using race in human genetics research and genetic explanations of health and disease. They join many other scholars in emphasizing that race is a sociopolitical, not a biological, concept [7, 11, 17, 18] and in raising concerns about biological conceptions of race that continue to inform biomedical research studies [19]. They note the analytic imprecision of race in genetic research as a proxy for ancestry [16]. The use of race in biomedicine is thus a consequential matter of knowledge production, one with important ethical ramifications.

The expansion of genetically oriented research on racial disparities devolves in part from the National Institutes of Health (NIH) mandate of the early 1990s to incorporate US census categories in NIH-funded research [20]. This mandate led to many important studies, summarized by the Institute of Medicine (now the National Academy of Medicine) in a 2003 report [21], which provided careful documentation of the depth and persistence of racial health disparities in the US. Yet, inattention to causal frameworks and the fluid nature of racial categories also had an unintended consequence [20, 22]. Research centered on genetic explanations of racial disparities in disease has expanded [2]—despite well-established and compelling, though still not fully developed, evidence that socioeconomic factors and structural policies such as segregation, resource allocation, and so on are the major causes of disparities [23, 24]. This research emphasis

on genetic explanations has been carried into the medical science classroom and into standardized national examinations [1].

To date, medical schools have responded to student activism primarily by developing curricular materials on implicit bias, usually measured by the Implicit Association Test (IAT), and its effects on medical decision making [25]. Indeed, clinician bias and preexisting preferences held by medical students for white and upper-class patients have been documented [26]. Faculties and administrators across the country have organized workshops wherein students and professors reflect on how unconscious bias affects clinical interactions [27]. Yet other zones in which to interrogate bias, such as the biomedical research that forms the knowledge base for medicine, the preclinical curriculum in which this is taught, and assessment methods, remain to be studied in depth. While illuminating for some aspects of the clinical encounter, the IAT assesses a limited psychological aspect of a complex social phenomenon. Measureable entities have a certain appeal, but the IAT cannot account for the many ways in which racism and other biases manifest structurally and work in institutional contexts.

Failure to resolve whether race is a social construct or a genetically bounded entity remains at the heart of tensions shaping curricular efforts on race [28]. To explore these tensions, some medical curricula are moving beyond implicit bias by including lectures or discussions on race as a social or biological concept and electives (many of them student driven), speakers' series, journal clubs, and book clubs exploring the complex history of race and racism in medicine and the clinic [29]. However, we believe that even these promising initiatives leave the key epistemological issues largely untouched: the structural, social, and cultural ways in which racism shapes our knowledge base in medicine and leads to health inequalities. Even if scientists and medical professors hold different views, which they undoubtedly will, they should at least acknowledge and incorporate such challenges to conventional thinking into their teaching. While it will be no simple matter to dislodge current investments in genetic explanations of racialized health inequalities, medical curricula will be morally enriched by educators' efforts to pursue appropriate uses of race in the medical context.

Challenges to Medical Education Reform: A Role for Humanities and Social Sciences

Simultaneous with the expansion of genetics research on race, scholars of race in the humanities and social sciences have contested the bioracial essentialist enterprise, offering nongenetic explanations of health disparities and uncovering the long history of problematic beliefs in biological races [8, 30-33]. Unfortunately, medical school faculties lack the disciplinary range of undergraduate faculties, and biomedical perspectives dominate the curriculum. There is nothing in the medical curriculum like the critical race theory that has flourished in legal studies since the late 1980s when some law schools, with more elective time and a long tradition of incorporating critical social theory and history into coursework, began integrating critical race theory into their curricula [34,

35]. The highly centralized and standardized curriculum in medical schools, however, is more constrained than that of law schools, in part due to the mandates of accrediting agencies.

Some medical schools have departments of social medicine, history, or medical humanities that foster critical discussions about race and social determinants. But many do not. Consequently, medical faculties competent to teach global race theory or critical scholarship on race and racism are limited. Most critical scholarship on social and historical contexts of race and health in the past decade has taken place in disciplines outside biomedicine—with limited dialogue with faculty in biological sciences or medicine [36]. With incoming medical students increasingly versed in humanities and social sciences perspectives on health and increasing representation of social concerns on national examinations, such as the Medical College Admission Test® (MCAT®) and the United States Medical Licensing Examination®, this is an important moment to reflect on possibilities of integrating interdisciplinary perspectives on race into medical bioscience education.

There is no quick fix to redirect the medical curriculum on racial health disparities from its current focus on genetic explanations to social and structural explanations. Indeed, given unique challenges presented by the medical curriculum, harmful profiling in the clinic can result if race is presented in a routinized way and students are not introduced to the nuances of the controversies over race in medicine [37, 38]. A curriculum that addresses racial disparities in a substantive way requires an intellectually engaging space where bioscience and clinical faculty and students can be introduced to the historical, sociological, and anthropological scholarship on race in medicine, its continuities and discontinuities.

While public health faculty can provide important expertise for addressing racism in medicine, public health schools face dilemmas similar to those of medical schools [39]. And, like medical students, public health student activists are responding to tensions between social understandings of health inequality and the biomedical framework [40].

Another major limitation to integrating critical perspectives on race into the medical curriculum is the dominant mode of student assessment. Geared to licensing examinations, multiple-choice assessment is inadequate for evaluating understandings of complex, controversial, and fluid relationships among race, racism, bodily difference, and health.

Conclusion

How should we in medical schools teach race, genetics, and health to health professionals with respect and care, when the topic invites radically different perspectives and even differing definitions and understandings of the concept of race

over time and from place to place? How should we approach curricular reform? Given extensive interdisciplinary scholarship on race and racism in medicine and the recent call by Yudell et al [16] for alternative approaches to the use of race in genetics research, medical science educators must now, at the very least, acknowledge and teach the controversy and avoid facile use of race as a "bioscientific datum" [41]. There is extensive curricular material from the fields of social epidemiology, medical anthropology, and sociology of medicine that examines the health consequences of racism. Medical schools need to draw on interdisciplinary university faculty to teach about the roots of structural racism. In a recent article calling for reform of health professions education, an interdisciplinary team of researchers underscore the urgent need to address how structural racism shapes medical institutions, including research and practices that focus on biological differences. Significantly, the authors argue that we need to "recognize racism, not just race" [42].

Emerging curricula drawing on social justice frameworks or "structural competency" are promising developments [43, 44]. First formulated in 2012 as a theoretical approach to rethink cultural competency education, structural competency focuses on educating students about the changing structural forces in society that produce health inequality and poor patient care [45]. From the perspective of structural competency, it would be possible to examine racial essentialism and remove it from medical teaching while retaining a focus on the health effects of racism and racialized social vulnerabilities, as student activists have so poignantly articulated [1, 29]. But this goal cannot be realized without commitments to interdisciplinary collaborations that engage, not simplify, the contemporary controversy over race, racism, and disparities. In an environment where questions, reservations, and opposition can be openly entertained, faculty and students should work together with members of the communities they serve to develop a richer knowledge base to interrogate the problematic history of race in medicine and the legacy of this history in the persistence of health inequalities.

Some tentative steps have been taken by students and educators, as discussed above. But we need to do much more. Given increasing attention to race in medicine and ongoing student activism, this is an exciting moment to renew the process of engaging the controversy, with the goal of improving health for all.

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PEER-REVIEWED CME ARTICLE: MEDICAL EDUCATION

Teaching Clinical Ethics at the Bedside: William Osler and the Essential Role of the Hospitalist

Matthew William McCarthy, MD, and Joseph J. Fins, MD

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Abstract

As the field of hospital medicine celebrates its twenty-first anniversary, we believe it is time to expand its mission to play an even greater role in medical education. Given hospitalists' proximity to students and clinical material, members of this growing cohort of physicians are uniquely positioned to teach normative reasoning, professionalism, communication, and medical ethics in real time to trainees on the wards. But, to do so, we must reimagine the role of the hospitalist in graduate and postgraduate medical education.

Introduction

William Osler's vision in 1903 of the hospital as a college revolutionized medical education by bringing clinical teaching from the lecture hall to the bedside [1]. By transforming the clinic into a classroom, Osler's Johns Hopkins experiment altered the course of American medicine [2]. But in the intervening century, we have seen an erosion in the scope of bedside teaching as the professoriate has gradually retreated from hospital wards to research laboratories and administrative positions [3]. In place of professors, we increasingly find hospitalists—specialists in inpatient medicine—who now provide the bulk of inpatient care for hospitalized patients and often serve as clinician-educators for medical trainees [4].

The mere presence of attending hospitalists discussing these issues with medical students and house staff would help overcome the "hidden curriculum" of medical training [6] and serve as a normative corrective to the ascendant primacy of evidence-based medicine. In short, the hospitalist can bring humanism to the bedside and validate topics such as professionalism and communication that are sometimes perceived as soft or marginal. But, to do so, we must reimagine the role of the hospitalist in graduate and postgraduate medical education.

Exploring Ethics in Real Time

In 2002, the American College of Graduate Medical Education (now the Accreditation Council for Graduate Medical Education) identified six core competencies for the practicing physician: (1) patient care, (2) medical knowledge, (3) practice-based learning and improvement, (4) systems-based practice, (5) interpersonal skills, and (6) professionalism [7]. Expanding on this list, the American Board of Internal Medicine enumerated three core principles related to professionalism: (1) the primacy of patient welfare, (2) patient autonomy, and (3) social justice [8]. But, based on our experiences, disagreement exists over how these principles can be measured, assessed, and taught to students.

As the senior educator on inpatient wards, the hospitalist has the potential to redefine medical education by exploring the ethical implications of medical decision making in real time. While some may argue that it is too time intensive to teach bioethics on rounds—Aristotle argued that only leisure makes philosophy possible [9]—there is reason to believe the process will actually save time and improve patient care.

The Hospitalist as Ethicist

From diagnostic decisions to discharge planning, the practice of hospital medicine is laden with ethical quandaries. On a daily basis, the hospitalist is confronted with issues of information disclosure, autonomy, and truth-telling, to name but a few. In our experience, few hospitalists have received formal training in clinical ethics; even fewer, we suspect, feel comfortable teaching trainees about their approach to these complex situations. A tremendous educational opportunity exists, and it should become a priority of hospital medicine to incorporate normative reasoning into the array of patient-centered clinical skills that are taught at the bedside [10]. While the details still need to be worked out, it's time to begin to reconceptualize the role of the hospitalist in medical ethics education in the twenty-first century.

Trainees should be taught to think beyond evidence-based treatments. By examining the legal, historical, and ethical precedents regarding seemingly mundane interactions with patients, they will be prepared to have more thoughtful interactions with their patients amidst the flurry of activity on the hospital wards. To do so, however, we should

establish a training mechanism. Hospitalists should have a grounding in bioethics and an educational ethos that fosters deliberation over <u>efficiency on rounds</u>. We believe this novel approach to medical education will also improve communication, patient satisfaction, and, most importantly, outcomes.

The implications of ethical decisions should be discussed and dissected on ward rounds with the same rigor, enthusiasm, and attention to detail with which differential diagnoses are generated and treatments are rendered. We believe these impromptu didactic sessions will create more astute physicians who are better communicators. It is our hope that this novel educational ethos will lead to more satisfied patients and more thoughtful clinicians who are able to fully engage in shared medical decision making. But this will only work if we strengthen the ties between ethics and medicine; medical ethicists can (and should) be brought to the wards to broaden teaching opportunities during ward rounds. Conversely, hospitalists should have exposure to medical ethics, either formally or informally.

As clinicians, we have become quite good at making decisions and teaching others how to make them. But often we do not have a coherent moral framework that respects the goals and values of our diverse patients. Inconsistency in the approach to ethical decision making can lead to confusion among health care workers, patients, and students and may ultimately compromise the doctor-patient relationship [11]. Moreover, an important learning opportunity could be missed. A structured approach to these situations is an unmet normative need and, if taught properly, will provide a remarkable opportunity to enhance the quality of graduate medical education.

Conclusion

In his address to the New York Academy of Medicine in 1903, entitled "The Hospital as a College" [1], William Osler laid out a blueprint for graduate medical education and put forth a provocative claim: "Ask any physician of twenty years' standing how he has become proficient in his art, and he will reply, by constant contact with disease; and he will add that the medicine he learned in the schools was totally different from the medicine he learned at the bedside" [12]. As the field of hospital medicine celebrates its twenty-first anniversary, it seems fitting to ask what we have learned at the bedside of the patient and to examine how well hospital medicine has fulfilled Osler's vision of the hospital as college [4]. For as many changes as medicine has witnessed since Osler's day—including the rise of managed health care, subspecialists, evidence-based medicine, and electronic medical records—one constant remains: the ethical imperative to teach while providing humane care. It is this obligation on which all others are based and can be measured.

The properly trained hospitalist could be poised to make important contributions to the teaching of medical ethics and doctor-patient communication and thereby serve as an

antidote to the hidden curriculum. If these goals could be realized, we might be able to return to William Osler's original vision of the hospital as a college [1].

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FROM THE EDITOR

Moral Distress: A Call to Action

During medical school, I was exposed for the first time to ethical considerations that stemmed from my new role in the direct provision of patient care. Ethical obligations were now both personal and professional, and I had to navigate conflicts between my own values and those of patients, their families, and other members of the health care team. However, I felt paralyzed by factors such as my relative lack of medical experience, low position in the hospital hierarchy, and concerns about evaluation. I experienced a profound and new feeling of futility and exhaustion, one that my peers also often described.

I have since realized that this experience was likely "moral distress," a phenomenon originally described by Andrew Jameton in 1984 [1]. For this issue, the following definition, adapted from Jameton, will be used: moral distress occurs when a clinician makes a moral judgment about a case in which he or she is involved and an external constraint makes it difficult or impossible to act on that judgment, resulting in "painful feelings and/or psychological disequilibrium" [2]. Moral distress has subsequently been shown to be associated with burnout, which includes poor coping mechanisms such as moral disengagement, blunting, denial, and interpersonal conflict [3-7].

Moral distress as originally conceived by Jameton pertained to nurses and has been extensively studied in the nursing literature [8, 9]. However, until a few years ago, the literature has been silent on the moral distress of medical students and physicians [10-15]. Nevertheless, students and residents are particularly vulnerable to moral distress given the deeply hierarchical nature of medical training, a vulnerability that has only recently been recognized. A study I conducted with Matthew Baldwin and another medical student, Lauren Pollack, found that 90 percent of student respondents at a New York City medical school reported moral distress (Perni S, Pollack L, Dzeng E, Granieri E, Baldwin M, unpublished data, June 2016). This finding suggests that moral distress is prevalent in medical trainees. However, even when trainees graduate and achieve higher places in the medical hierarchy, they are likely frustrated and constrained by bureaucracy, policy, and resource limitations.

This issue of the *AMA Journal of Ethics* explores the concept of moral distress from the overlooked perspectives of medical students and physicians. Multidisciplinary experts, including philosophers, physicians, and nurses, have come together to interrogate the

meaning of moral distress and describe practical strategies and solutions for both alleviation of its burden and the transformation of medical education and culture.

Two articles in this issue focus on the evolution of the concept of moral distress in research and practice. Jameton reflects upon his initial description of moral distress, which, he argues, can result from resource challenges in delivering patient care within the context of a larger global movement for sustainability. Carina Fourie describes how the concept of moral distress has changed since its initial description, arguing that the definition has been broadened to include distress related to uncertainty as well as other groups of health professionals besides nurses. She argues that consideration and retention of the distinctions among varieties of moral distress and the types of professionals experiencing it is imperative for thorough study and targeted intervention.

Two articles focus on moral distress in the context of caring for the dying. In their response to a case of a resident faced with a family member demanding aggressive care that he believes only prolongs the patient's suffering, Terri Traudt and Joan Liaschenko argue for the <u>cultivation of virtues</u> such as trust, empathy, and humility as antidotes to moral distress. They also advocate the use of communicative practices and strategies within a moral community that promote common moral ends, which can include a "good death." Katherine E. Heinze, Heidi K. Holtz, and Cynda H. Rushton argue for universal <u>palliative care education</u> for clinicians, standardized but flexible palliative treatment protocols, measures to track clinician burnout, and investment in ethical practice environments to address moral distress in care of the dying.

Three articles focus on the importance of shared decision making in individual patient-physician encounters as a means of mitigating moral distress. In response to a case in which a physician feels conflicted about applying hospital guidelines that recommend using a reduced dose of a drug in scarce supply to treat patients newly diagnosed with bladder cancer, Edmund G. Howe III discusses the importance of transparency as a way to preserve the patient-physician relationship while relieving the physician's moral distress. Bonnie M. Miller, responding to a case of a student who feels conflicted about performing a procedure on an unwilling patient, argues that medical team members can respect the patient's right to autonomy by being transparent about the student's role. And Nancy Berlinger and Annalise Berlinger discuss moral distress that arises in situations in which unexamined "cultural" assumptions about a patient, family, or group might conceal larger structural problems or bias, arguing that students and clinicians should learn to think critically about such situations.

The remaining four articles focus on larger practical organizational solutions. Lynn Monrouxe, Malissa Shaw, and Charlotte Rees examine the implications of moral decision making for moral distress and argue for targeted <u>support for students</u> at three levels, including organizational support for reporting of substandard behavior. In their

commentary on a case in which a resident's professional value of preserving life conflicts with her attending physician's recommendation for palliative care for a dying patient, Eli Weber and Sharon Gray examine the role of medical trainees' <u>narrative identity</u> and avoidance of conflict in their moral distress and how case-based ethics education sessions can provide a solution. M. Sara Rosenthal and Maria Clay, founders of the "Moral Distress Education Project," discuss best practices for <u>reducing moral distress</u>, including debriefings and Schwartz RoundsTM. And Wendy Austin argues that <u>ethics</u> <u>consultation</u> can be a way to reduce moral distress and promote "morally habitable" organizational environments. Finally, in the podcast, Elizabeth Epstein discusses the <u>moral distress consultation service</u> that the University of Virginia created in response to this problem.

This issue thus examines the theoretical and practical implications of moral distress and is a first step towards creating a medical climate in which professional integrity is not at odds with personal integrity. Health care systems will need courage and leadership to cultivate open, reflective moral communities that interrogate the disconnect between our ideals and the realities of medical practice in ways that can alleviate individual moral distress as well as transform health care culture more broadly.

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ETHICS CASE

How Should Resident Physicians Respond to Patients' Discomfort and Students'
Moral Distress When Learning Procedures in Academic Medical Settings?
Commentary by Bonnie M. Miller, MD, MMHC

Abstract

In this scenario, a medical student, Lauren, experiences moral distress because she feels that learning to perform a procedure on a patient who requested not to be used for "practice" puts her own interests above the patient's. Lauren might also worry that the resident physician is misrepresenting her abilities. The resident physician could help alleviate Lauren's distress and align her interests with the patient's by more clearly explaining the training situation to the patient and seeking the patient's approval. Lauren might also manage the situation by assuring the patient of the resident's supervisory role. This article argues that trainees should have the opportunities to practice procedures and difficult conversations in simulated settings and that institutions should support a culture of "speaking up" to ensure patients' and learners' safety.

Case

Lauren is a medical student who is doing her clinical year rotation in neurology. She has never performed a lumbar puncture (LP), also known as a spinal tap, but a patient on the neurology inpatient service requires one for diagnosis. Her resident physician, Adam, suggests that she attempt to perform one.

Lauren is initially excited about this prospect, and Adam demonstrates to her the steps involved in this procedure. When Adam tells her, "It might cause some pain, but you have to make sure the patient is perfectly still," she begins to feel apprehensive.

Lauren and Adam go to see the patient, Mrs. Jones, together. Adam tells the patient that they will need to do an LP. The patient looks warily at Lauren and says, "Well, I don't want you practicing on me." Adam responds, "Don't worry. You're in good hands."

Lauren feels extremely conflicted. On the one hand, she feels as though she is practicing on the patient and could cause pain or a more serious consequence, since it is her first time ever performing the procedure. On the other, she knows that she needs to learn this important skill and that "practicing" in this manner is the only way to do so. She

wonders whether to tell the resident physician that she doesn't want to do the LP on this patient, given this particular patient's statement, but she is also concerned that opting out might prompt a negative response from the resident physician, who evaluates her.

Commentary

In his 1984 book, *Nursing Practice: The Ethical Issues*, Andrew Jameton used the term "moral distress" to describe what nurses experience when they feel powerless to carry out what they believe to be a morally correct course of action because of institutional constraints [1]. Moral distress subsequently has been identified in multiple professions including medicine, pharmacy, and respiratory therapy [2-4]. Repeated episodes of moral distress may result in burnout, withdrawal from direct patient care activities, job dissatisfaction, and attrition from the health care professions [2, 5]. It has also been implicated as a factor in empathy erosion in nurses, medical residents, and fellows [5, 6].

With their subordinate position in the health care hierarchy, medical students experience moral distress in response to many different situations, including witnessing or participating in provision of futile or nonindicated care or disrespectful behavior [7, 8]. Students might remain silent because they fear that voicing concerns could offend superiors and negatively impact their evaluations, as in Lauren's case. In addition, they may feel that it is improper or disrespectful to question their teachers' authority, or they might worry that they simply don't know enough to correctly interpret complex situations. In such cases, speaking up could expose their knowledge deficits, again leaving them vulnerable to negative judgments of potential evaluators. Their own uncertainty and reluctance to act may compound their distress and cause them to feel equally culpable for any harmful consequences to patients.

In this vignette, Lauren feels legitimate and laudable concern for her patient's well-being. The primacy of patient welfare and the ethical principle of beneficence demand that the care team always act in ways that put patient interests first [9]. Yet even before she enters the patient's room, Lauren begins to worry that if she performs the lumbar puncture, she would be putting her own interests as a student before those of her patient, who should always receive the best care possible. In this case, Lauren feels that the best care possible would be provided by the resident, who has greater experience and therefore would be less likely to cause harm. Her patient's stated concerns about being practiced on amplify her preexisting apprehension.

In addition, Lauren may feel that the resident's stating, "You're in good hands," unintentionally misrepresents her abilities. The fact that Lauren is inexperienced could increase the risk of pain or an unsuccessful first attempt at obtaining spinal fluid. The ethical principle of respect for patient autonomy demands that patients be fully informed of all benefits and risks if they are to make good decisions about their own care,

consistent with both their values and their risk tolerance. Even more fundamentally, honesty and integrity are foundational concepts of medical professionalism [9-11].

On the other hand, Lauren's most important obligation as a student is to develop the competencies needed for the safe, effective, and equitable practice of medicine. Medicine's social contract with society demands that Lauren return society's investment in her by acquiring the profession's specialized knowledge and skills and by using them in a way that benefits all patients [12]. In this framework, Lauren would not be completely self-interested in seeking appropriate learning opportunities. Thus, a tension develops between what may be best for the patient immediately in front of her and what is best for all of the patients that Lauren will care for in the future.

As the physician immediately responsible for this patient's care, the resident carries the primary responsibility for resolving the current dilemma. Ideally, given the scenario described, the resident would acknowledge his patient's concerns, sense Lauren's discomfort, and gently and diplomatically reframe the conversation in order to align the patient's best interests and her need for autonomy with Lauren's need to learn. For example, he could say:

Mrs. Jones, the good hands are both Lauren's and mine. Lauren is an excellent medical student who needs to learn how to perform lumbar punctures if she is going to provide the very best care to her own patients in the future. I have walked Lauren through the procedure and am confident that she will do a good job. However, there is a risk that with Lauren performing the procedure, you will experience more pain or that the initial attempt will be unsuccessful and I will need to undertake a second attempt. I will do everything possible to lessen these risks by directing her carefully and taking over if I feel she will cause you any harm, including excessive pain. In addition to the benefit you will gain from having this procedure, you will provide benefit to Lauren and her future patients. If you are uncomfortable with this plan, I will perform the procedure and Lauren will observe and assist.

This kind of communication expresses respect for the patient's moral agency and could help ease Lauren's distress because it provides a truthful description of the situation and shifts control of the care plan back toward the patient. The patient is now able to weigh her added risks against the added benefit gained from helping Lauren learn and can make a good decision consistent with her values.

If the resident physician does not recognize or accept his ethical responsibility, Lauren is left with several choices. She could simply proceed despite her concerns and discomfort, taking advantage of this opportunity to learn and avoiding any semblance of insubordination. Studies of moral distress show that students do indeed select this

option and may even <u>habituate</u> to these situations such that the experienced distress eventually diminishes [5]. Alternatively, Lauren could attempt to explain the situation to the patient herself:

Mrs. Jones, while I won't really be practicing on you, I am a medical student who needs to learn how to do this procedure if I am to become a good doctor. My resident physician is an outstanding teacher and has already instructed me on all of the steps. He will guide me, and if at any time he thinks that you might be harmed or that you are experiencing unusual pain, he will take over. There might be an increase in your risk of pain or the need for a second attempt, but with my resident physician directing me, that risk will be reduced. If you agree, I will be very grateful for your contribution to my education.

This sample statement seeks to express respect for both the patient and the resident physician.

If Lauren feels so uncomfortable that she cannot proceed, she can ask the resident physician if they can leave the room briefly so that she can explain her concerns: "Adam, I really appreciate your confidence in me, but with Mrs. Jones seeming so reluctant, I'm much more comfortable watching you this time. Then maybe the next time an opportunity arises, I'll feel more confident and prepared." By asking to leave the room for this conversation, Lauren would avert potential embarrassment for the resident physician and lessen her own fears about a negative impact on her evaluation. Her resident could then return to the room with a statement similar to the following: "Mrs. Jones, Lauren and I discussed the situation, and, given your concerns, I will perform the procedure and Lauren will observe and assist."

In reality, the types of conversations described above require poise and readiness that might be difficult to muster in the midst of evolving care episodes. Practice can help. Medical educators should anticipate such situations and provide opportunities for trainees to practice responses in controlled settings, through either role play or <u>simulation</u>. Ethical preparation is just as important as technical preparation in assuring that our trainees provide the best possible care to patients as they fulfill their obligation to learn.

Simulation technologies provide an important and increasingly available means of mitigating risk to patients. High-fidelity simulations exist for many procedures, including lumbar puncture [13]. Instead of "practicing" on her patient, Lauren could have practiced safely in the simulation lab while receiving feedback that would have allowed her to improve her technique. Although at some point a real patient would be her "first," Lauren would feel more confident and prepared after being coached in a simulated setting.

During their training and beyond, all doctors will perform procedures on patients for the first time. This circumstance is necessary not only for initial skill development but also for the advancement of medicine. In the late 1980s, an entire generation of practicing general surgeons had to relearn gall bladder removal with the introduction of laparoscopic cholecystectomy [14, 15]. Even the patients of experienced physicians found themselves being the "first." However, by informing patients of trainees' roles and by doing everything possible to mitigate risks of potential harm, physicians and students can actively learn while still protecting patient welfare, thereby aligning their own interests and those of the public with those of their individual patients.

The tension between what is best for a single patient and what is best for all patients plays out at the institutional level as well. While academic health centers have a moral responsibility to train a highly competent physician workforce, thereby returning society's investment, they have an equally strong moral obligation to provide the highest quality care to every individual patient while respecting each patient's autonomy [16]. The resulting conundrum cannot be easily reconciled. Training involves a trajectory over time. Patients as a group must inevitably participate in the training of future physicians by accepting care from trainees who are not yet at the top of the learning curve, even if patients as individuals exercise their right to refuse such care. While simulation helps, ultimately there is no other way for physicians to become fully competent than to care for real patients. Institutions must manage the tension between learners' and patients' needs by ensuring that patients are clearly informed of the system's educational mission and its implications for their care; by respecting each patient's autonomy in decision making; by providing adequate supervision for trainees; and by providing alternative learning resources, such as simulation, that allow safe practice and reduce the risks in being the "first" patient [17].

Finally, we should do our best to nurture a culture of safety in our academic health centers in which speaking up is viewed as a moral action taken in the best interest of patients and not an act of insubordination [18]. Realizing this cultural change would require that faculty members at the top of the hierarchy receive training to accept these messages graciously, with the understanding that a "speaking up" culture advances all academic missions. It also would require the support and role modeling of committed and enlightened leaders, along with strict enforcement of antiretaliation policies.

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ETHICS CASE

How Should Integrity Preservation and Professional Growth Be Balanced during Trainees' Professionalization?

Commentary by Eli Weber, PhD, MA, and Sharon Gray, BSN, PHN, RN

Abstract

People can experience moral distress when they regard themselves as expected to pursue a course of action they believe to be morally wrong. However, beliefs that give rise to moral distress are sometimes underdeveloped. Experiences of moral distress are not uncommon for medical trainees, who are still in the process of forming their professional identities and whose identity-constituting beliefs might therefore be subject to ongoing revision. Thus, it is important for health professions training programs to incorporate case-based ethics education sessions into their structure to help identify and alleviate trainees' moral distress, provide ethics education, and create a "safe space" for trainees to talk openly about moral concerns related to clinical practice. Such opportunities are crucial to the professional growth of trainees.

Case

Reema is a medical student with strong beliefs about preservation of human life as a primary purpose of medicine. One of her patients is a 65-year-old man with metastatic lung cancer. The attending physician, Dr. Alnin, decides to have a conversation with the patient about hospice care. The patient asks about a new and expensive chemotherapy that he had seen advertised. Dr. Alnin recommends against this option, citing the patient's low likelihood of a positive response and minimal extension of the patient's life even with an optimal response. Hearing this, the patient decides to pursue hospice. Reema is distressed by this decision because she feels that the team is giving up on this patient. She does not tell anyone that she feels this way, however, because she is concerned about being evaluated poorly by Dr. Alnin if she expresses disagreement with her advice to the patient and his family.

Commentary

It is no surprise when we encounter a case of moral distress involving a medical trainee. Trainees are usually first-career professionals, still developing a sense of their personal and professional moral values and identities [1], and are highly dependent on <u>evaluations</u> by others for advancement opportunities. These circumstances place them in a vulnerable position, and, as a result, trainees might feel they cannot

risk <u>speaking up</u>, even when refraining from doing so seems contrary to their own developing professional identity.

This conflict between professional identity and perceived expectations is what we see in the case of Reema, who believes that her primary professional purpose, as a physician, is the preservation of human life. As a result, she is deeply troubled when she hears the attending physician with whom she is working, Dr. Alnin, recommend against additional chemotherapy and in favor of hospice for the 65-year-old patient with metastatic lung cancer. For Reema, recommending hospice care is tantamount to "giving up," and she disagrees with her attending physician's treatment plan as a result. However, it is not simply her disagreement with the attending physician's recommendation that is the source of her moral distress. In this case, Reema's moral distress is more nuanced. First, Reema has certain beliefs about what it means to be a physician—that a physician's purpose is to preserve human life even for patients with a poor prognosis for meaningful recovery and that hospice is akin to "giving up"—and these beliefs shape her personal and professional identity in a particular way. Second, Reema perceives that because she is a medical trainee, she ought not to voice her disagreement with the attending physician, as doing so may have negative professional consequences for her. As a result of these beliefs, Reema's moral distress is deeply paradoxical—in order to preserve her professional identity as a physician, she feels as though she must act in a manner that is contrary to her own core beliefs about that same professional identity.

Moral Distress and Identity-Constituting Beliefs

In order to better understand and, more importantly, address Reema's moral distress, we should first clarify two key concepts. Let's begin with the concept of moral distress itself. For brevity's sake, we will utilize a definition of moral distress that one of us (EW) has argued for elsewhere, which we believe captures the phenomenon better than most alternatives: moral distress is "a negatively-valenced feeling state where one perceives a conflict between what one is expected to do and what morality requires" [2]. This description captures, we believe, what's happening in Reema's case rather well. From Reema's perspective, there is a conflict between what she believes to be the right thing to do, which is to voice her deep disagreement with the attending physician's recommendations in this case, and the expectation that, as a resident, she should not question the attending physician's approach to patient care.

The other concept worth clarifying in this case is that of an "identity-constituting belief." This concept makes use of a narrative notion of identity, whereby one's sense of self is constituted, in part, by one's beliefs about oneself and one's place in the world [3, 4]. One's narrative identity is thus the means by which one makes sense of and finds meaning in the world [4]. An identity-constituting belief, then, is a belief that is fundamental to one's sense of self, one's place in the world, and one's purpose. Clearly, Reema's belief that the primary purpose of medicine is to preserve life is such a belief—

it defines her understanding of who she is as a physician and what makes her life and work meaningful. As such, perceived obstacles to Reema's ability to express this aspect of her identity are likely to be deeply distressing for her.

What Exactly Is Morally Distressing about Reema's Situation?

There are at least two aspects of Reema's moral distress that can be readily addressed in this case.

First, Reema's belief that recommending hospice and advising against further chemotherapy for this patient is contrary to the primary purpose of medicine is one that bears closer examination. Although we do not know what influenced the development of Reema's belief about the primary purpose of medicine, there is some reason to think that her belief itself is not fully developed (since she has no clinical experience beyond rotations) and that further exploration would help her better understand and develop her professional identity and beliefs. For example, her mentors might help her to explore why she regards hospice care as "giving up" rather than as an appropriate medical specialty that provides palliation and comfort at the end of life. Moreover, there has been some debate about how to characterize the purpose of medicine [5, 6], a debate of which Reema seems largely unaware. If Reema were asked, for example, to consider these various perspectives on the purpose of medicine, Reema might be prompted to question her presumption that promoting human life requires maximally aggressive care in all circumstances and that one must promote human life without regard for quality of life. A deeper discussion with Reema of the role and responsibility of physicians at the end of a patient's life, when all treatment modalities have failed to stem the disease, might also contribute to changing her perception that only maximally aggressive care is laudable care.

As a physician, Reema believes that she—and Dr. Alnin—should be aggressively working to prolong this patient's life, so keeping silent about a treatment plan that contravenes this goal feels like a betrayal of the self. Reema's distress is thus explained, in part, by the fact that she feels she cannot act in accordance with her identity-constituting beliefs in this case. Her moral distress, however, provides an opportunity for her to develop a more nuanced perspective about the purpose of medicine and the meaning of the obligation to preserve human life. If her mentors can help Reema develop a more nuanced belief about the purpose of medicine and thereby contribute to the development of her identity-constituting beliefs, her moral distress can perhaps be alleviated in the process.

The other aspect of Reema's moral distress that can be readily addressed in this case is her perception that she should keep silent. The concern that she might be evaluated poorly if she challenges the attending physician is understandable, especially given the vulnerable position that trainees find themselves in relative to attending physicians. But

the expectation that trainees should never <u>express disagreement</u> or challenge the recommendation of the physician is contrary to the moral virtues of courage, intellectual honesty, and truthfulness, which are regarded as physician virtues [7]. Cultivating these moral virtues should therefore be a component of medical training programs. Reema's still-developing professional identity is also an opportunity for her to cultivate these moral virtues and to incorporate them into her own conception of what it means to be a physician.

An Action Plan for Addressing Resident Moral Distress

Thus far, we've identified two factors that seem to be the source of Reema's moral distress: her belief that the primary purpose of medicine is to preserve human life—along with her fairly narrow interpretation of what this purpose entails in the clinical setting—and her perception that, as a resident, she is expected to refrain from voicing any disagreement with the attending physician's recommendations. We've also identified several reasons for thinking that Reema's moral distress has more to do with her lack of professional development than any barriers to doing what morality requires. We will conclude our discussion by offering an action plan for addressing these sources of moral distress. This action plan can be easily integrated into an existing medical training program, and it offers significant educational and team-building benefits to both trainees and the attending physicians who mentor them. As such, there are compelling reasons to adopt some version of this action plan into almost any medical training program, even apart from the benefits that follow from addressing trainees' moral distress and promoting their professional development.

The sources of Reema's moral distress can be addressed via an educational program devoted to case-based discussion with other trainees, facilitated by an ethicist. Such programs are already in place at several medical schools, and results have been consistently positive [8, 9]. Engaging trainees in case-based discussions of ethical issues promotes peer-to-peer learning, creates a sense of camaraderie out of shared experiences, and creates something of a "safe space" for trainees to express their views on the ethical aspects of difficult cases. In addition, such programs create the opportunity to further educate trainees on the ethical aspects of medicine, including the purpose of medicine and the moral virtues of a good physician. Such a program would no doubt have been helpful in a case like Reema's, as it would have provided her a venue to explore some of the implications of her beliefs about medicine and to receive guidance about how to cultivate a more nuanced perspective on what it means to be a seasoned medical professional.

Conclusion

An underdeveloped professional identity is a significant knowledge deficit for medical trainees—doubly so when they lack adequate opportunities for professional growth. Medical trainees are, we contend, significantly more likely to have an underdeveloped

professional identity in virtue of their early career status and, as a result, are more likely to experience moral distress of the sort presented in Reema's case. Professional growth—particularly of an ethical nature—is best addressed, we claim, by incorporating case-based ethics education into medical training programs. Such opportunities allow for trainees' underdeveloped beliefs about their personal and professional identity and the ethics of medicine to be explored and expanded upon, with support from their peers and guidance from an expert. In addition, they allow trainees opportunities to express their views regarding the ethical dimensions of patient care, which further stimulates and nurtures their professional moral development. By promoting dialogue about professional moral virtues and the ethical dimensions of patient care, not only trainees but all health care professionals are encouraged to give voice to their personal and professional values.

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ETHICS CASE

How Should Physicians Respond When the Best Treatment for an Individual Patient Conflicts with Practice Guidelines about the Use of a Limited Resource? Commentary by Edmund G. Howe III, MD, JD

Abstract

The case presents a physician's ethical conflict, due to limited resources, between his obligations to meet the needs of a community and those of his patient. Elements of the decision-making process (and who should make the decision) are discussed, including the limitations of what ethical reasoning can offer and risks of arbitrary outcomes. Additionally, potential benefits to physicians and their patients of discussing these conflicts, including reducing the physician's moral distress, are noted. I argue that physicians' abilities to make "right" decisions in such situations are limited, and I suggest ways in which physicians can try to preserve their relationships with patients.

Case

Dr. Ellis is an urologist at a community hospital. He treats several patients with bladder cancer who require treatment with Bacillus Calmette-Guérin (BCG) therapy. However, there is a current worldwide shortage of BCG due to manufacturing problems. There are no national policies in the United States governing the dispensation of BCG in the setting of a shortage, so a multidisciplinary task force was recently convened at Dr. Ellis's hospital in order to decide how the hospital should respond.

The hospital task force, of which Dr. Ellis is a member, voted unanimously to adopt guidelines similar to those adopted by other hospitals, namely, to offer a one-third dose of BCG for induction and maintenance courses up to one year. These guidelines are based on a randomized trial by the European Organisation for Research and Treatment of Cancer that showed no difference in toxicity between one-third dose BCG and full-dose BCG [1]. Notably, however, the lower dosage resulted in higher recurrence rates. Dr. Ellis and many of his colleagues also recently attended a urology conference where a study of patients eligible for treatment with BCG during the shortage was presented: 87 percent of patients had treatment regimens that did not follow the standard of care, but the recurrence rate was highest among those who required induction BCG therapy and those who received an alternative to BCG [2]. The presenters recommended prioritizing patients who need induction BCG therapy.

When Dr. Ellis returned from the conference, he saw a patient named Jaan that he has had a long relationship with due to his history of prostate problems. Jaan is a fairly healthy 61-year-old man who has just been diagnosed with bladder cancer requiring BCG therapy. Dr. Ellis is aware that from a population and organizational perspective, he should not recommend the full dose of BCG treatment for Jaan but believes that he might be at higher risk for recurrence of his bladder cancer if the alternative regimen is used.

Talking to a colleague about Jaan's clinic visit, he says, "I voted to implement the BCG guideline, but I believe this patient should get the full dose." His colleague advises, "Give him the full dose of BCG. The guidelines aren't mandatory; guidelines have legitimate exceptions. You have to do what is best for the patient in front of you." Dr. Ellis considers this advice, but later he thinks, "Making an exception for Jaan means other patients might not receive BCG at all. How do I know that, down the road, another patient might be as worthy of being granted an exception to the guideline as Jaan? If I grant too many exceptions, the guidelines I helped implement won't mean much." Dr. Ellis continues to consider what to do.

Commentary

This case raises critical questions regarding the conflict physicians might face when the interests of many patients whom they don't know clash with those of their own patients due to medical resources being limited. The specific questions I shall address here are what they should do when they face this dilemma and how they might best handle the moral distress it arouses. In addition, I shall raise another issue that physicians in this situation should consider: discussing this ethical quandary with the patient or patients whom they treat and whose interests are at stake. Physicians who take this approach of sharing their dilemma with patients might benefit these patients by preserving their relationship with them and might also reduce their own moral distress.

Should Jaan Receive Full-Dose BCG Therapy?

In this case, the ethical principle of justice, expressed as community-based utility of a limited resource for many, conflicts with the principle of beneficence for Jaan, a particular patient. Utility for all here involves trying to do the greatest good for the greatest number. This principle is routinely applied in disaster settings, as when large numbers of seriously injured patients must be triaged and treated [3]. The application of this principle, however, is not straightforward. During disasters, lines might have to be drawn, for example, between patients with more and less serious injuries. Physicians typically treat first the patients who are the most seriously injured but still treatable [4].

In this case, some of the ethical issues that might arise during disasters aren't present. There is no question, for example, regarding when, if ever, the hospital should change its triage criteria based on more patients with bladder cancer "arriving" over time than

initially expected. There is also no direct conflict between the value of possibly saving more patients' lives, on one hand, and that of relieving other patients' profound suffering, on the other. But the case still involves a trade-off. The hospital task force adopted guidelines that recommend prioritizing patients who need induction BCG therapy, which implies that treatment with BCG should be at the expense of those who need long-term maintenance therapy.

In this case, as in many ethically complex cases, it might be that ethical analysis is limited in the extent to which it can lead to solutions [5] and, in particular, answer or indicate unequivocally which of two competing, mutually exclusive actions is morally best. Reasonable persons may therefore continue to differ on how an ethical question should be answered because they have different views regarding which core or foundational value should prevail. When disagreement occurs, the preferable ethical question and thus ethical approach may be not *what* the decision should be but *who* should decide. In this case, then, Dr. Ellis faces two questions: If *he* makes the decision about whether to recommend full-dose BCG for Jaan, what should his decision be; and should he himself decide, or should he refer this decision back to the task force?

This emphasis on who should decide is common in many clinical contexts. Deciding to let a child's parents decide—whether, for example, to withhold or withdraw life-supporting treatment when it clearly will not benefit the child—is a path often chosen when a child is so seriously ill that death is imminent and thus there seems to be no sound ethical basis for deciding whether to maintain the child's life or to allow the child to die. We allow parents in this situation to make this decision in large part because they are the people closest to their children and will be most affected by what they decide.

The decision in this case—whether or not Dr. Ellis should recommend induction BCG therapy for Jaan—may be like the decision of whether to withhold or withdraw life-sustaining treatment for a child facing imminent death; it might be one about which reasonable persons could reasonably disagree. There might be no self-evident ethical solution that will emerge even after a most thorough, conscientious discussion. Thus, in this case, as in the case of the dying child, who should decide could be more important than what the decision is.

By making the decision himself, Dr. Ellis could take into account his feelings, which might add to the ethical quality of his decision. If he feels compassion for Jaan, for example, it might motivate him to try to achieve for Jaan an exceptional benefit that goes beyond the benefit to which most other patients would be entitled. Although making a decision solely on this basis might be unjust, Dr. Ellis's sense that this patient is suffering might be an intuitive clue that the patient is worse off than others and thus needs this benefit more. Conversely, if Dr. Ellis made this same decision based on feelings such as having a prior relationship with Jaan, it would be unjust.

There are several arguments against Dr. Ellis making this decision alone (or even with just the colleague whom he previously consulted). First, his decision could reflect conscious or unconscious personal bias [3, 6]. This bias could favor Jaan in that he is Dr. Ellis's patient, or it could work against Jaan in that Dr. Ellis might strive too much to avoid acting on the basis of favoritism. Second, other physicians' personal biases might differ for a plethora of reasons. One clinician might favor Jaan because Jaan is his or her patient, whereas another, more concerned about the risk of unjustly favoring his or her patient over others, might strive to avoid this risk. Whether Jaan gets induction BCG therapy thus might depend more on the extent to which his physician fears favoring him than on anything else. If, then, the therapy Jaan receives stems in any degree from the extent to which his physician feels this fear, Jaan's outcome—which could be life or death—would be arbitrary. Patients' outcomes should not depend on which clinician, with which personal biases, they just happened to have seen. If the risk of Jaan's outcome depending on his physician's personal bias can be reduced by some other approach, ethically, this other approach would be a better process for decision making.

Dr. Ellis might, for example, ask the task force to decide what dose of BCG Jaan should receive (recusing himself, as a task force member, from participating in the decision-making process). In deciding whether to consult the task force, Dr. Ellis must consider first that it has already spoken (by issuing guidelines). Why the task force decided what it did we don't know. The task force, however, only issued *guidelines*, not rules, as Dr. Ellis's colleague accurately points out—possibly for "political" reasons. The members may have wanted above all else to leave the physicians in their hospital still free to decide what they believed to be best for their own patients, arbitrarily factoring in the interests of other patients. If this was the task force's rationale, it might be less ethically justifiable than other rationales that give greater priority to what would be best for the greatest number of patients, whatever the decision would be in an individual case.

In any case, if Dr. Ellis consults the task force, the task force, in addition to deciding for Jaan, could influence the decisions of all clinicians facing this same decision. The task force could make clear that it intends for physicians like Dr. Ellis to use their discretion or that it more strongly believes that the guidelines it expressed should be followed. This is not to say that what the task force decides would be from some ethical standpoint or other "more right." Any person or institution as, for example, our Supreme Court, might, of course, make wrong decisions. We cannot assume that by referring a decision to the best body to make the decision that the decision-making body will get it right. Subjecting such questions to the best *process* might be, however, the best that we can do.

The task force, itself, of course, can also be biased. Its guidelines could, for example, represent too much the professional bias or biases of certain clinicians who value giving priority to public health or greater moral weight to utility—for example, saving more

persons' lives. If so, this professional bias might need correction by making the task force membership more inclusive. Such groups frequently include patient representatives and members of the community. Inclusion of lay members and at least one member not affiliated with the institution is required, for example, on institutional review boards (IRBs) [7].

Dr. Ellis can, of course, advocate for Jaan's receiving full-dose BCG therapy before the task force whether or not his recommendation reflects Dr. Ellis's own personal beliefs [8]. Why might he do so if this would betray his own personal convictions? Dr. Ellis might favor Jaan's being able to express and pursue his best interests, as Jaan sees them (to the degree that he can) over everything else. Dr. Ellis's assisting Jaan in pursuing his best interests, in addition to being ethically justifiable in itself, could also help preserve their relationship and relieve Dr. Ellis's moral distress, as we shall now see.

How Might Dr. Ellis Best Relieve His Moral Distress?

If Dr. Ellis feels constrained by the guidelines to make a decision that goes against Jaan's best interests, he might experience moral distress. Jaan might feel abandoned and betrayed. Their relationship and their feelings may be the key deciding factors in Dr. Ellis's decision if acting in Jaan's best interests and following the task force's guidelines have, as it were, equal moral weight. In cases involving a clinician's moral conscience, patients' and clinicians' competing commitments may in fact be regarded as having equal moral weight [9]. Below I suggest some ways in which Dr. Ellis might resolve his dilemma while relieving his moral distress.

One strategy would be for Dr. Ellis to convey to Jaan his bind in this situation, especially since it is Jaan's interest that is most at stake. Dr. Ellis should not, however, ask Jaan to contribute to the decision by giving weight to what Jaan believes Dr. Ellis should do. If Dr. Ellis did so, he would be asking Jaan to consider sacrificing his own needs for other patients. Including Jaan in the decision-making process would most respect Jaan's autonomy but could also place Jaan in a most painful position. How could he not advocate for his own interest, unless he were motivated by altruism? On the other hand, this approach might be subtly coercive. Jaan might be inclined to state, contrary to his wishes, that he would sacrifice his own needs in order to be in Dr. Ellis's eyes a good person. The result of giving each patient like Jaan a say in the outcome might mean that those patients who are most self-serving would gain whereas those who are most self-sacrificing or susceptible to subtle coercion would lose out.

Dr. Ellis could also share with Jaan his rationale, why he believes he has only one choice—to follow the hospital guidelines—if he in fact believes this, and how truly sorry he is about this choice. If Jaan feels enraged, Dr. Ellis should support Jaan's reaction using recommended strategies for working with "difficult" patients [10]. He should then say that he understands: "I expect I would feel just like you, but perhaps feel even angrier."

He could further say that he would wholly understand if Jaan wants to see someone else and would ask no questions to save Jaan the pain of answering. Dr. Ellis could also offer to help Jaan find another physician if this is what he would like to do. Indeed, Dr. Ellis might have to provide a referral if he feels he cannot betray his own core beliefs. Moreover, Dr. Ellis, if making this decision himself, should explain why. This openness is paradigmatic of the openness regarding all other aspects of this decision that Dr. Ellis also should show and could include his even sharing with Jaan his fear regarding wrongly favoring Jaan on one hand or wrongly going too far to not favor his interests on the other. This sharing could increase mutual trust regardless of what Dr. Ellis feels he must do and could also help each, in this most painful situation, feel less alone.

Although Dr. Ellis might feel that he has failed Jaan, by making these offers and disclosures, he might feel *some* relief, knowing that this is the best that he can do for Jaan under these circumstances.

Conclusion

Physicians might not be able to find a best solution or process for resolving more difficult ethical dilemmas, such as how they should best distribute limited resources. They could, however, pursue a path that most respects and benefits their patients and themselves. Whatever they decide, they should have well-considered reasons. Their decisions should be based on ethical reasoning in addition to, and as checks on, what they might feel. They might feel compelled to favor their patients, for example, but they should not give this feeling sole or even overriding moral weight. In a given case, however, ethical reasoning might not determine which option is right. Doctors then may ask instead who should decide. Ethical reasoning can help us decide who should decide. An example is allowing some parents to decide for their children, as noted above.

Clinicians, should, in general, discuss their ethical dilemmas with their patients, to this extent at least making them shared. They should, if at all possible, hope to leave the hospital with their patients "hand in hand." This outcome may seem impossible if doctors in Dr. Ellis's situation make a decision that to any degree goes against the best interests of a patient like Jaan. They should seek to preserve their relationship with their patient in such instances, regardless. Patients like Jaan might understand their physician's dilemma, and the patient-physician relationship might then become even stronger.

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ETHICS CASE

What Should Physicians Do When They Disagree, Clinically and Ethically, with a Surrogate's Wishes?

Commentary by Terri Traudt, MA, MBC, and Joan Liaschenko, PhD, RN

Abstract

When patients' surrogates and physicians disagree about the appropriateness of aggressive treatment in intensive care units (ICUs), physicians can experience surrogates' demands as sources of moral distress. This article addresses the virtues and communication strategies needed to respond appropriately in such situations. Specifically, we offer a framework and language that rely on moral community to facilitate common ground and alleviate moral distress.

Case

Charlie is a resident in the intensive care unit (ICU). He meets a patient, a man who has a medical history of hypertension, atrial fibrillation, mitral valve repair, chronic kidney disease, and two failed kidney transplants. He developed kidney failure and subsequently progressed to shock and heart failure, requiring continuous dialysis and ICU care. He began to show signs of intensive care unit delirium very early on and refused surgical interventions.

The patient's wife, who was present in the ICU, was informed as he became increasingly delirious that her husband likely had limited time left, but she left the room during the discussion and refused to participate. Her husband rapidly decompensated. Nevertheless, she insisted on the continuation of intensive medical care. "Why does everyone keep talking about the negative?" she said. She refused palliative care involvement.

As the patient's ICU stay continued, he developed multiple ulcers all over his body and was unresponsive. He also developed gangrene of the leg and genitals and required a tracheostomy and percutaneous endoscopic gastrostomy (PEG) tube. Multiple conversations were held with the patient's wife about the futility of medical care at this point, but she said, "I believe in miracles, and everyone in the church is praying for him," and continued to push for aggressive care.

Charlie feels extremely conflicted. He believes that the patient is suffering greatly from continued intensive medical care, and that despite this approach's promise to prolong his

life, the patient's prognosis and quality of life (and possibly his experience of death) will not improve. He has the impulse to stop care, despite the wishes of the patient's wife. He wonders whether to stop writing orders for blood transfusions and antibiotics.

Commentary

Charlie is experiencing the classic symptoms of moral distress, which Andrew Jameton defined as the inability to execute what are "believe[d] to be ethically appropriate actions because of institutional constraints" [1]. This phenomenon is not uncommon in contemporary medical environments, particularly intensive care units [2]. One of the most common causes of moral distress is family or surrogate demand for continued aggressive treatment that will not provide medical benefit to the patient who is dying [2]. Charlie knows that continued medical interventions have the potential to prolong the patient's life but perceives the requested treatment simply as prolonging suffering. The first issue in this case is: How should he respond? This is not just a straightforward clinical question, but a moral one as well. As a moral question, the stance or attitude Charlie assumes towards his patient's wife is just as important as any specific words that he might say. We suggest that he begin with the important task of establishing trust.

Trust

<u>Trust</u> between clinicians and their patients and families is essential to moral health care practice. Charlie needs to secure his patient's wife's trust before she is ready to hear his perspective, which threatens her own. Charlie's trust is in his medical knowledge of and expertise in disease, prognosis, and treatment, but *her* trust is in the belief that a miracle will save her husband's life. Charlie clearly recognizes the medical fact that his patient is dying, but he must also recognize and feel what this means for the patient's wife.

There are different kinds of trust in health care [3]. It is safe to assume that most people trust that physicians as a group are competent—that is, that they have the knowledge and skills to diagnose and treat disease and injury. Patients and families completely rely on this level of trust. Equally important, however, is interpersonal trust. People do not automatically or necessarily trust physicians with their most intimate hopes and fears, who they are as a person. But when death threatens, things are different because "death asks us for our identity" [4]. In this situation, who one is as a person becomes central to the medical encounter. Thus, Charlie needs more than his medical expertise to gain the trust of the patient and the patient's wife. It is at this point that the virtues of empathy and humility—which we argue contribute to the establishment and maintenance of trust—assume significant moral import.

Empathy and Humility

Empathy. Margaret Urban Walker describes virtues as "linked capacities to attend, describe, inquire relevantly, feel appropriately, and respond reliably to situations of a

certain kind" [5]. In medical encounters involving dying patients, the clinician demonstrates the virtue of empathy in recognizing that impending death means a painful loss: for the patient, for the patient's loved ones, and for the health care staff. To empathize is to cross the barrier between self and other. For Charlie, it is to feel the great loss that her husband's dying is for this woman. Responding reliably is to treat the situation with the careful solemnity that it requires and to communicate accordingly. Good communicative practice is critical not only for the relay of medical facts but also because it conveys the empathic connection through both words and nonverbal gestures. If Charlie truly empathized with his patient's wife, he would feel her loss even in circumstances of disagreement.

Humility. The virtue of humility entails not assuming a superior stance towards others. In Charlie's situation, it means recognizing the power differential between himself and his patient's wife. Charlie's power lies in his knowledge of the workings of the human body, disease, and medical treatment and in the social status that comes with his expertise. The average person receiving ICU treatment and their loved ones have little of this knowledge. Humility in this case means that Charlie must feel, in spite of his superior medical knowledge, that he is also vulnerable to illness and death and therefore an equal participant in the human condition. In recognizing his own vulnerability, Charlie decreases the power differential between himself and his patient's wife, thereby nurturing trust.

Communication. In her writing on trust and suffering, philosopher Annette Baier states:

It is fairly obvious that some human-relations skills are part of what it takes to be a good physician, and that these cannot always just be grafted on to a good medical scientist, as an afterthought. Some aptitude for dealing with people should be a minimal requirement, not an optional extra, in a successful entrant to medical school [6].

We agree, and we further view the <u>communication</u> that it takes to express trust-establishing empathy and humility as not only legitimate but also essential work, indeed moral work. Terri Traudt et al. [7] describe moral communicative work as "the verbal and nonverbal social interaction that enhances one another's understanding of the moral situations they are in and informs moral decision making and action" [8]. In our view, the virtues of empathy and humility are necessary to doing this moral communicative work well.

Communication Strategies

The practice of these virtues and moral communicative work is the foundation of the second issue presented in this case: the question of which communication strategies physicians should use in situations in which being honest with family members means opposing their wishes. The first thing to note is that this communication takes place

within a moral community. A moral community is a group of people working together towards a common moral end [7]. In any health care setting, the moral end is the well-being of patients, which is commonly understood to be the restoration of health or the relief of suffering. In this case, to say that communicative work takes place within a moral community is to emphasize that many people who communicate with each other in various ways are involved in the care of this patient. It is when stakeholders' perceptions of the appropriateness of aggressive treatment are at odds with one another that moral distress can result.

When medical professionals agree that the patient is suffering greatly from continued aggressive treatment and that the patient's prognosis and quality of life will not improve, the goal becomes relief of suffering. In such circumstances, a "good death" becomes the moral end sought. The Institute of Medicine (now the National Academy of Medicine) describes a "good death" as "one that is: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" [9]. Charlie's challenge is to help his patient's wife see that the most appropriate goal of her husband's care at this point involves a shift from aggressive treatment to ensuring as good a death as possible.

Moral communicative work is hard work. However, specific practices that use the relational nature of moral communities can help the group to achieve common goals. A recent study of intensive care nurses who were skilled at and comfortable working with families and physicians in withdrawing aggressive treatment and who did not report experiencing damaging effects of moral distress common in such circumstances identified the following specific practices of moral communicative work: (1) establishing rapport, (2) preparing for conversations, (3) asking questions, (4) active listening, (5) giving reflective feedback, (6) being clear, and (7) knowing when not to speak [7]. We maintain that the trust-establishing virtues of empathy and humility are necessary to enacting these practices well. Although this particular study was with nurses, these specific practices can be of benefit to anyone involved in the care of dying patients.

While these important <u>communicative practices can be taught</u>, they are primarily learned by modeling skilled practitioners, just as virtues are not a matter of theoretical knowledge but must be cultivated. Both are fostered in moral communities by mentorship that can cross disciplines and other boundaries. For example, physicians can learn communication skills from a nurse or social worker or other member of the community. The extent to which Charlie has been mentored is not clear. Instructors should avoid the temptation to pull medical students from tough cases involving disagreement, thereby denying their students valuable opportunities to see them model appropriate behavior. A difficult patient or family member is often the case learners most need in order to develop empathy, humility, and moral communicative practices.

Conclusion

Good moral communicative work can help mitigate moral distress [7]. However, even the most virtuous and skilled communicator may not be able to move the patient's wife from her position. This could be the case even after ethics consultation resources have been utilized. When such a disagreement occurs, it is important to recognize and acknowledge that the moral community of caregivers might need to cope with the tragedy of providing aggressive treatment that prolongs a patient's suffering. For Charlie and others in his position, to carry on in this situation is to maintain empathy for the other, to forgive oneself for not achieving care goals, and to continue to do one's job well.

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THE CODE SAYS

The AMA *Code of Medical Ethics'* **Opinions Related to Moral Distress** BJ Crigger, PhD

The formal policies of health care institutions, as well as informal expectations and practices, can create moral distress for patients and health care professionals in a variety of ways. For example, financial incentives or tools intended to influence decision making can put patients' interests at odds with those of the institution or physicians who are employed by or have privileges within the institution. The AMA *Code of Medical Ethics* addresses situations that can create moral distress in several opinions.

Professionalism in Health Care Systems

Opinion 11.2.1, "Professionalism in Health Care Systems" [1], urges physicians in leadership positions in health care institutions to minimize the possible adverse effects of institutional policy and practice by ensuring, among other things, that policies "reflect input from key stakeholders, including physicians and patients" [2]. Physicians are further urged to ensure that incentives, if any, are designed in keeping with sound principles, implemented fairly so as not to disadvantage identifiable populations of patients, supported with appropriate infrastructure and resources, and minimize possible conflicts of interest among patients, physicians, and the institution. Opinion 11.2.1 also requires institutions to recognize that physicians' primary obligations are to their patients and to enable physicians to respond to the unique needs of individual patients, including "providing avenues for meaningful appeal and advocacy on behalf of patients" [3]. This opinion holds health care institutions responsible for monitoring the effect of incentives and policies and urges all physicians affiliated with an institution to hold leaders accountable for meeting these conditions for professionalism.

Transparency

Although <u>transparency</u> does not preclude moral distress, it can help mitigate the severity of distress that institutional policies or practices may cause patients or physicians. Several opinions stress the importance of transparency in health care. Opinion 11.2.4, "Transparency in Health Care" [4], acknowledges that health plans and other entities should inform patient-members about plan provisions that affect the availability of care and requires that individual physicians disclose incentives that could affect care as well as relevant treatment alternatives, whether or not they are covered by a health plan. This opinion calls on physicians collectively to advocate that health plans and institutions be transparent. Opinion 11.2.3, "Contracts to Deliver Health Care Services" [5], similarly

holds that physicians should assure themselves that their contracts with health plans or health care institutions permit them to disclose to patients information that may affect their care.

Finally, Opinion 10.7, "Ethics Committees in Health Care Institutions" [6], calls on ethics committees in faith-based institutions not only to uphold the principles to which the institution is committed but also to "make clear to patients, physicians, and other stakeholders that the institution's defining principles will inform the committee's recommendations" [7].

Exercise of Conscience

The *Code of Medical Ethics* also provides guidance for physicians who in good faith find they cannot adhere to institutional policy or practice in Opinion 1.1.7, "Physician Exercise of Conscience" [8]. Although this opinion focuses on situations that involve conflicts between patients' values and preferences and <u>physicians' personal moral commitments</u>, it is also instructive for situations in which physicians' commitments may be incommensurate with institutional values, policies, or practices.

Opinion 1.1.7 requires that physicians thoughtfully consider the implications of decisions to act (or decline to act) in accordance with "well-considered, deeply held beliefs that are central to their self-identities" [9]. Physicians should consider "how significantly an action (or declining to act) will undermine the physician's personal integrity, create emotional or moral distress for the physician, or compromise the physician's ability to provide care" [10]. Physicians should also be "mindful of the burden their actions may place on fellow professionals."

Contracts with Health Care Institutions

Opinion 11.2.3, "Contracts to Deliver Health Care Services" [5], calls on individual physicians to assure themselves that contracts with health plans or institutions minimize possible conflicts of interest and do not compromise the physician's own financial well-being or ability to provide high-quality care, for example, by setting unrealistic expectations about utilization of services. This opinion also urges physicians to enter into a contract only if it allows the physician to "exercise professional judgment," "supports physician advocacy on behalf of individual patients," and "includes a mechanism to address grievances" [11]. Physicians should negotiate to modify or remove terms that unduly compromise their ability to uphold ethical standards.

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MEDICAL EDUCATION

Antecedents and Consequences of Medical Students' Moral Decision Making during Professionalism Dilemmas

Lynn Monrouxe, PhD, Malissa Shaw, MSc, PhD, and Charlotte Rees, MEd, PhD

Abstract

Medical students often experience professionalism dilemmas (which differ from ethical dilemmas) wherein students sometimes witness and/or participate in patient safety, dignity, and consent lapses. When faced with such dilemmas, students make moral decisions. If students' action (or inaction) runs counter to their perceived moral values—often due to organizational constraints or power hierarchies—they can suffer moral distress, burnout, or a desire to leave the profession. If moral transgressions are rationalized as being for the greater good, moral distress can decrease as dilemmas are experienced more frequently (habituation); if no learner benefit is seen, distress can increase with greater exposure to dilemmas (disturbance). We suggest how medical educators can support students' understandings of ethical dilemmas and facilitate their habits of enacting professionalism: by modeling appropriate resistance behaviors.

Introduction

For many, medical school is a time of great stress. Indeed, a systematic review of research examining psychological distress in medical students suggests they suffer a high degree of depression and anxiety and greater psychological distress than the general population [1]. In this article, we consider medical students' distress, focusing on moral distress, i.e., emotional distress arising from the dissonance between one's ethical/moral beliefs and one's behavior, which occurs when one's actions are perceived as being limited by institutional constraints or unequal power relations [2-4]. By highlighting the concepts of professionalism dilemmas and moral decision making, we examine various types of dilemmas encountered by students, how they respond to those dilemmas, and any resultant moral distress they experience. Finally, we offer suggestions for how medical educators, working at the student, faculty, and organizational levels, can reduce or prevent students' professionalism lapses in the face of ethical dilemmas, thereby reducing their moral distress.

Professionalism Dilemmas

Although regulatory body professionalism codes apply to practitioners and medical students alike and students are taught professionalism during medical school, students often experience professionalism dilemmas. Such dilemmas arise in situations in which students witness and/or are asked to participate in professional lapses such as patient safety, dignity, and consent breaches [5] rather than in ethical dilemma situations typically encountered by health care professionals—in which decisions need to be made about life-sustaining treatment or the patient's best interest is in question. For example, a professionalism dilemma can be experienced by medical students when they witness senior clinicians jeopardizing patient safety through poor hygiene practices or disrespecting patient dignity through physically exposing patients' bodies for longer than necessary [2, 6-9]. Furthermore, medical students' seniors frequently request that they undertake activities during workplace learning that violate ethical principles, including examinations (sometimes intimate examinations) without valid patient consent and covering up mistakes, both of which potentially result in patient harm [2, 6-8, 10, 11]. Thus the dilemma students experience when witnessing professionalism lapses by seniors is whether to report such behaviors or turn a blind eye, and their dilemma when asked to participate in professionalism lapses is whether to comply with the request or resist [7]. Given the high degree of abuse that medical students report at the hands of their seniors within the health care workplace [2], resistance strategies need careful deliberation [8, 11, 12]. Thus, professionalism dilemmas require medical students to undertake some form of moral decision making.

Moral Decision Making: Ethics of Conduct, Character, and Duty

Rather than being a straightforward matter of doing the right thing, medical students' understandings of morally correct behavior differ from one individual to another [7, 13]. This is partly because moral judgments frequently concern decisions about behaviors that might entail some form of harm to another [14], and different individuals hold different perspectives about moral trade-offs (i.e., how to decide between two courses of action when the consequences of both have morally undesirable effects) [15]. It is partly because the majority of human behavior arises within a person-situation interaction [16]. Indeed, moral "flexibility" suggests that though we are motivated to do the right thing, any moral principle can bring forth a variety of context-dependent moral judgments and decisions [14]. Moral rules and principles are abstract ideas—rather than facts—and these ideas need to be operationalized and applied to specific situations [17]. Each situation will have different affordances highlighting one facet or another of any given moral value. Thus, when faced with morally dubious situations—such as being asked to participate in lapses of patient consent by senior clinicians during workplace learning events—medical students' subsequent actions (compliance or resistance) differ [10, 11].

We now further unpack how people react to the professionalism dilemmas they encounter by exploring different models of ethical judgments. There are two broad conceptualizations of ethical judgment: either we act according to the rules, laws, and duties that society lays down as being moral (ethics of conduct); or we act according to the type of person we think we are (ethics of character) [17].

According to the "ethics of conduct" perspective, it has been argued that, broadly speaking, people judge their actions by their conformity to a norm (deontology) or their consequences (consequentialism) [14]. In the ethics of deontology, the morality of an action is dependent upon the intrinsic nature of that action: there are *right* and *wrong* actions and the morally right thing to do is determined by duty or laws. Thus, undertaking intimate examinations on patients without valid consent is wrong as it goes against ethical and professional codes of conduct, regardless of the consequences. One form of deontology is principlism (based on the principles of autonomy, beneficence, justice, and nonmaleficence), which is often taught to medical students as a way of approaching moral decision making (see table 1) [18]. Principlism is a model of understanding one's duties in that it prescribes the way we should act on the basis of intersubjective agreements about morality.

Table 1. The four main concepts of principlism [18]

Respect for autonomy: respecting patients' rights to decide a course of action, so long as they have the capacity to consider and act on that plan.

Beneficence: both positive benefit and weighing benefits and risks for best outcomes.

Justice: the fair distribution of scarce health care resources and costs.

Nonmaleficence: typified by the phrase *primum non nocere*, first do no harm.

By contrast, in consequentialism the morality of an action is wholly determined by its *consequences*. Utilitarianism, whereby any act is judged on the basis of the total utility of that act, is an example of consequentialism [19]. Thus, undertaking intimate examinations on patients without valid consent may be acceptable according to a utilitarian position if the knowledge and skills obtained by the learner are used for the greater good [2]. The dual-process theory of moral judgment, which asserts that both affective and cognitive processes contribute jointly to moral decision making, relates to this concept of utilitarianism [19, 20]. When a moral decision has to be made, the dual-process theory suggests that our negative emotional reactions (i.e., prepotent emotions) inhibit a utilitarian decision [20]. For example, if the patient is *conscious*, the intimate examination is overtly coerced and could cause discomfort. However, if the prepotent

emotions are inhibited by the patient being *unconscious*, utilitarian reasoning tends to prevail, as the patient would be unaware of the exam and discomfort would be avoided.

Finally, virtue (character) ethics is a perspective including core concepts such as *arête*, *eudaimonia*, and *phronesis* (see table 2) [21]. Here, moral decision makers are not merely disembodied rational agents; rather they are individuals, shaped through their own experiences, and the master narratives they embody set the boundaries for what kind of persons they are and how they should act [22].

Table 2. The three main concepts of virtue ethics [21]

Arête: an embodied disposition to be virtuous (e.g., honest, compassionate, courageous), cultivated through experience and deliberate decision making. When taken to extremes these virtues can become "faults."

Eudaimonia: happiness or flourishing. Happiness is thought to depend on living a virtuous life. When one fails to be virtuous in one's actions, one might feel dissatisfaction, unhappiness, and even (moral) distress.

Phronesis: also known as practical (or moral) wisdom. Given that virtues taken to excess sometimes lead to failings, possessing the capacity to understand that some aspects of a situation are more essential than others is important. Phronesis is a type of wisdom that is drawn upon in practical decision making.

Having identified some of the ways in which individuals approach their moral decision making, we now consider the emotional impact of professionalism dilemmas for medical students whose actions run counter to their personal morals and consider how certain models of moral decision making are reflected in individuals' experiences of moral distress.

Moral Distress and Its Correlates

People who act against either their embodied moral code (virtue ethics) or normative rules (deontology) or who disregard consequences (consequentialist) may experience moral distress [3, 23]. Moral distress can occur solely in the moment in which a person feels upset or uncomfortable (classified as mild distress) [3]. However, sometimes distress continues for weeks or even months after an event (moderate distress) [3]. In extreme circumstances, distress is experienced many months or even years later (severe distress) [3]. Moral distress is different from other feelings (e.g., moral uncertainty or emotional distress) [23]. The distinction between emotional and moral distress is illustrated by the following example: "Psychiatric nurses may, for example, be

emotionally distressed while restraining a patient, but they are likely to become morally distressed only if they believe that restraining the patient is morally wrong" [24].

Historically, research investigating moral distress has focused primarily on the nursing context [25-30]. However, a recent review of health care professionals' moral distress identified the following correlates of higher levels of moral distress: perception that workplaces have poor ethical climates (among nonphysician health care professionals); poor nurse-physician relationships; low job satisfaction; low quality of care (among nurses but not physicians); intention to leave the job; lack of engagement at work; burnout; and, in acute care settings, working under 30 hours per week, lack of time for patients, and instrumental leadership [31].

Unlike the voluminous research on moral distress in nurses and nursing students, little research has been conducted with medical students. Wiggleton et al. [32] found that female medical students reported witnessing distressing dilemmas significantly more frequently than male medical students, although males tended to report experiencing greater distress than females with each dilemma they encountered [32]. In our questionnaire study of 2,397 medical students in the United Kingdom (UK), we found that males typically classified themselves as experiencing no distress, whereas females typically categorized themselves as experiencing distress [2]. Furthermore, moral distress demonstrated two distinct patterns: habituation, whereby students have a lower probability of experiencing moral distress the higher the frequency of occurrence of situations wherein they witness or participate in patient care being compromised for the justifiable purpose of their learning; and disturbance, whereby students have a higher probability of experiencing moral distress the higher the frequency of occurrence of lapses not directly beneficial to their learning (e.g., breaches of patient safety) [2]. The first finding suggests that when students justify their actions for their own learning (and thus for the greater good, per utilitarianism), their experience of moral distress is reduced. This finding is consistent with the dual-process theory of moral reasoning discussed earlier wherein negative emotions are suppressed, leading to more instances of such lapses. The second finding suggests that students' empathy for patients related to unjustified unethical events does not decline across their education, but remains steady [2]. Indeed, across many of our studies investigating students' dilemmas, students frequently reported experiencing distress during and sometimes up to a year after these events and narrated events with a great deal of negative emotion [2, 6-8, 11]. Having examined students' emotional reactions to their experiences of professionalism dilemmas, we now consider in greater depth students' actions in the face of their dilemmas and the reasons they give for such actions.

Professionalism Dilemmas: Acts of Resistance and Compliance

In an examination of 680 UK medical students' written narratives of their most memorable professionalism dilemmas (both witnessing and participating in

transgressions), Rees, Monrouxe, and McDonald found that 55 percent contained evidence of students' resistance to lapses, often detailing multiple acts of resistance [8]. The most common actions were verbally challenging the perpetrator directly; reporting the perpetrator; displaying concern for the wronged person (often the patient), both during (in front of the perpetrator) and following the incident (by staying behind or returning to the scene); and debriefing with a supportive person post-event. Rees and Monrouxe also examined 71 narratives of medical students who were asked by senior clinicians to undertake intimate examinations without valid patient consent to understand students' reasoning concerning why they complied or resisted and, if they resisted, how [11]. Only 18 percent reported resisting senior clinicians' requests to conduct intimate examinations without valid patient consent. Students cited multiple reasons for complying including, most commonly, their desire to fulfill their higher-order obligations to observe and perform, the strong climate of social acceptability (i.e., their peers and other seniors did not complain), their strong desire to learn, and their belief that doing so benefited the patient [11]. Reasons for resisting included the lack of consent, belief that the examination was inappropriate or unnecessary, and that features of the situation facilitated refusal (e.g., the request came from a less senior person) [11]. Furthermore, although this study did not specifically examine moral distress in relation to resistance and compliance, we have noticed how students' compliance with requests to perform consent-related professionalism lapses (across a wider range of consent dilemmas) can cause substantial upset for patients and distress for learners (as evidenced by their negative emotional talk), whereas positive emotional reactions and better protected patients can be seen within students' narratives of resistance [7].

Finally, analyzing over 2,000 health care students' written and oral professionalism dilemma narratives from multiple studies conducted in Australia, Sri Lanka, Taiwan, and the UK, Monrouxe and Rees [7] identified seven distinct modes of resistance: the most common acts comprised direct verbal resistance, directly raising concerns, and indirect verbal acts (e.g., when patient consent was coerced by their seniors, students directly addressed the patient to establish consent for their learning on them). Other acts of resistance included bodily acts such as students removing themselves from the scene of the lapse, drawing curtains to protect patient dignity, and washing hands/donning gloves when seniors did not [7].

As we can see, despite medical students learning within a hierarchical culture that justifies their involvement in professionalism lapses (which support a utilitarian model of ethical reasoning), they often have a desire to resist such participation. When resistance occurs, it can manifest in a variety of direct and indirect verbal and bodily acts. Resistance also contributes to students experiencing more positive emotional reactions.

Students' moral decision making and subsequent actions stemming from professionalism dilemmas can be influenced by external factors at the faculty and

organizational levels. It is to these we now turn as we discuss the implications of students' experience of professionalism dilemmas and subsequent decision making for the <u>training of doctors</u>.

Implications for Medical Education

Medical educators need to consider how best to support students' moral decision making in the face of professionalism dilemmas: whether to go along with lapses or resist them. We think that students need support at three levels: direct support for their learning, support for faculty development, and support for their institutions.

In terms of direct support for student learning, medical students need to understand their moral responsibilities by being aware of professionalism codes and the different ways in which ethical issues can be considered [7]. Although large-scale lectures can facilitate this goal, small-group interactive sessions with clinical facilitators appear to develop students' understanding of the ethical and professional complexity within which they are learning. Indeed, when considering students' understanding of what comprises professionalism, Wiggleton et al. have found that those who have experienced early patient contact and who are learning within small clinician-led interactive groups in which personal experiences are shared and professionalism issues are discussed demonstrate a more sophisticated and embodied understanding of what comprises professionalism than those learning predominately within a lecture-based curricula [33]. The latter students tend to focus on acting like a professional (e.g., through the clothes they wear, the way they talk), rather than embodying a strong sense of their professional self [33]. Furthermore, a number of students from lecture-based learning curricula commented on their learning at the end of the session and how they had participated in professionalism lapses without realizing they were ethically problematic. Finally, activities such as providing students with opportunities to share their professionalism dilemmas and share them with emotion [34-36], and to role-play idealized actions (i.e., how they wished they had acted), can empower students to recommit to their professionalism values and act on them in the future.

With respect to faculty development, medical educators need to ensure that clinical teachers are up-to-date with new professionalism policies and to increase these teachers' awareness of their positions as professionalism role models. Monrouxe and Rees [7] and Rees, Monrouxe, and McDonald [8] report that it is useful to share students' professionalism dilemma narratives with clinical teachers as part of formal faculty development in order to facilitate best practice.

Finally, organizations need to find ways to support staff and students' reporting of substandard behaviors. Such a joined-up approach to supporting medical students to become empowered, autonomous, and self-reflective moral decision makers would

enable them to choose the right action for the benefit of themselves, the profession, and patients.

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IN THE LITERATURE

Who Is Experiencing What Kind of Moral Distress? Distinctions for Moving from a Narrow to a Broad Definition of Moral Distress

Carina Fourie, PhD

Abstract

Moral distress, according to Andrew Jameton's highly influential definition, occurs when a *nurse* knows the morally correct action to take but is *constrained* in some way from taking this action. The definition of moral distress has been broadened, first, to include morally challenging situations that give rise to distress but which are not necessarily linked to nurses feeling constrained, such as those associated with moral uncertainty. Second, moral distress has been broadened so that it is not confined to the experiences of nurses. However, such a broadening of the concept does not mean that the kind of moral distress being experienced, or the role of the person experiencing it, is morally irrelevant. I argue that differentiating between categories of distress—e.g., constraint and uncertainty—and between groups of health professionals who might experience moral distress is potentially morally relevant and should influence the analysis, measurement, and amelioration of moral distress in the clinic.

Introduction

According to Andrew Jameton's influential definition, first published in 1984, moral distress occurs when a nurse "knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" [1]. According to this definition, moral distress occurs under specific conditions: there is moral certainty—the nurse *knows* the morally correct action to take—and there is something, commonly referred to as a "constrain[t]" [2] or "obstacle" [3], which prevents the nurse from being able to take the morally correct action. Although this definition and variants of it remain popular, there are at least two ways in which critics have attempted to broaden it. First, it has been argued that morally challenging situations that give rise to distress but which are not necessarily cases of certainty and constraint—such as those associated with moral conflict, moral dilemma, and moral uncertainty—should also be seen to result in moral distress [4, 5]. Second, moral distress is not restricted to the experiences of nurses; a range of health professionals, such as physicians, are being included in research on moral distress [6, 7].

While I have argued that we should broaden the definition of moral distress [4, 8], we need to guard against the neglect of morally relevant differences in the forms and experiences of moral distress. In this paper, I will highlight the significance of two sets of distinctions that might seem to be in danger of being blurred by broadening the definition of moral distress: first, categories of moral distress and, second, groups experiencing distress. Accepting a broader definition runs the risk of blurring these distinctions if moral distress is examined, measured, and addressed solely *as an aggregate*—in other words, as a sum or total. Regarding moral distress as an aggregate blurs what could be major morally significant features of distress, such as the unequal distribution of distress among groups of health professionals, because it would not take the experience of these different groups into account. These distinctions could be significant for identifying and ameliorating the specific causes and impacts of moral distress in the clinic.

What Is Moral Distress? The Difference between Narrow and Broad Definitions

For the purposes of this discussion, let's limit ourselves to the kind of moral distress that is experienced *by health professionals* in decisions taken about *patient care*, as this is the kind of moral distress often discussed within the clinical and nursing ethics literature [3]. Within these limits, and as a starting point for this analysis, moral distress can be described as a psychological response to morally challenging situations [4]. Jameton's definition [1], as well as many of the definitions used in the literature [3], can be viewed as examples of a type of narrow definition of moral distress because they limit moral distress to only one major kind of morally challenging situation—that is, situations in which a person is constrained from taking the correct action, as some obstacle (e.g., an institutional rule or a physician's decision) stands in the person's way [1, 4]. I will refer to these kinds of situations as cases of moral constraint. Advocates of the narrow definition of moral distress not only associate distress with moral constraint but also explicitly claim that cases of distress that stem from other morally troubling situations, such as a moral dilemma or moral certainty, are *not* moral distress [1, 4, 5].

I claim that Jameton's definition of moral distress should be seen as a definition of a category of moral distress, i.e., *moral-constraint-distress* (for short, *constraint-distress*) [4]. An example of constraint-distress is the distress felt by a nurse caring for a terminally ill child in a situation in which the parents insist on the child receiving aggressive life-extending treatment, although it is in the best interest of the patient for health professionals to stop treating her and to arrange for the provision of palliative care to avoid prolonging her suffering [1, 4]. Applying the terminology and form of the narrow definition to this case, we could say that the parents' decision is a constraint on the nurse's action.

While constraint is often treated as if it were a necessary condition of moral distress [1-3, 6, 9], I have argued that constraint-distress should not be considered the only form of

moral distress that is significant in the clinic [4]. I recommend adopting a broad definition of moral distress, which means recognizing that constraint is not a necessary condition of moral distress and that such distress can arise from morally troubling situations other than those of moral constraint. When health professionals experience distress due to a moral conflict, dilemma, or uncertainty, this should, I claim, also be referred to as moral distress [4]. Imagine that we change the previous example—the case of the child and the aggressive life-extending treatment—to reflect moral uncertainty. In this revised example, it is morally unclear both to the parents and the nurse which of the two actions—treatment or stopping treatment—should be taken, and the nurse experiences distress at the moral uncertainty of the situation. Instead of treating this distress as something other than moral distress, which Jameton has explicitly advocated [1, 9], I recommend that it be considered moral distress and that we call it a specific kind of moral distress—moral-uncertainty distress (for short, uncertainty-distress), as opposed to constraint-distress.

There are a few reasons why it is important to use a broader definition of moral distress rather than confining moral distress to constraint-distress as Jameton and others have done [4]. For the purposes of this paper, a particularly significant reason for using the broader understanding is the following: I assume that at least one reason, if not the primary reason, that we care about distress associated with morally troubling situations is because these situations are often likely to stem from or lead to violations of significant moral values—or both. It seems difficult to justify why we should then care only about those categories of moral distress that are related to constraint rather than those related to conflict or uncertainty if, indeed, these are also likely to stem from or lead to violations of the same or similar values.

There are at least three independent moral values that are relevant to moral distress: (1) the well-being of the patient, (2) the well-being of the health professional experiencing moral distress, and (3) the distribution of moral distress among groups of health professionals [8, cf. 10]. While values one and two are fairly intuitive, it might be helpful to specify that the distribution of distress could be unfair when greater burdens of distress are placed on particular groups of health professionals through no fault of their own [8]. If moral uncertainty, moral conflict, and moral constraint are all associated with moral concerns about the well-being of the patient and can all lead to psychological distress, why should that distress only be described as "moral" in the case of constraint? Additionally, if the well-being of health professionals and the distribution of moral distress are negatively impacted by any of these kinds of morally troubling situations, then why exclude cases of uncertainty and conflict from moral distress?

A concern that could be raised by advocates of the narrow definition of moral distress is that if we broaden the definition we might downplay the distinct experience of nurses, who are much more likely to experience constraint-distress, at least in comparison to

physicians, because they tend to have less decision-making power regarding patient treatment and thus are more likely to experience moral <u>constraint via others' decisions</u>. I suspect that one of the primary reasons why the definition of moral distress is often confined to constraint-distress is because of moral concerns about the "additional" burden of distress that might be experienced by nurses [4, 8, 11]. Any health professional could suffer distress due to concerns about patient care, which can lead to the well-being of that professional being negatively impacted. In these kinds of cases, only the moral values of patient well-being and professional well-being are likely to be violated. However, implicit in the possible objection to the broad definition of moral distress is the concern that certain groups of professionals, such as nurses, will suffer moral distress related not only to "typical" patient-care situations but also to the nature of their job and the constraints that they face as part of that job. In these cases, all three moral values are likely to be violated—patient well-being, professional well-being, and a fair distribution of moral distress among groups of health professionals.

I am willing to concede that situations in which all three moral values associated with moral distress are being undermined are likely to have a special moral urgency, precisely because so many values are at play. However, this is no objection to broadening the definition of moral distress. It would only work as an objection to broadening the definition if doing so meant that moral distress was necessarily considered to be an aggregate. Moral distress would be treated as an aggregate if, for example, it were measured in such a way that no distinctions could be made between categories of moral distress such as constraint-distress and conflict-distress or between the different kinds of professionals experiencing moral distress, thus leading to particular concerns associated with constraint-distress and with nurses being overlooked. However, there is no need to treat moral distress solely as an aggregate even if one accepts a broader definition, and indeed there is good reason not to—because we will neglect important morally relevant features of moral distress if we do so. While I am claiming that there is enough in common between cases of moral conflict, uncertainty, and constraint that distress stemming from them should be referred to as "moral," I am not claiming that they should be considered to have precisely the same morally relevant features either.

Comparing Constraint-Distress and Uncertainty-Distress

Let's consider a brief moral assessment of the examples of constraint- and uncertainty-distress discussed in the previous section in order to highlight some of the specific morally relevant features that may be associated with them. As a reminder, these are the cases of constraint-distress wherein the nurse is constrained by the parents' decision to pursue aggressive treatment for the child and the cases of uncertainty-distress wherein the nurse is morally uncertain whether or not aggressive treatment should be pursued.

Take the first moral value identified in the previous section: the well-being of the patient. In the example of constraint-distress, the distress experienced is a signal that something has definitely gone morally wrong in terms of patient care; the treatment is not to the benefit of the terminally ill child (assuming the nurse is correct in his moral assessment of the case). Now compare this to the case of uncertainty-distress wherein the nurse experiences moral distress due to moral uncertainty—he might not know what is in the best interest of the patient because he is uncertain of the moral implications of his actions. The difference between the two kinds of moral distress, constraint and uncertainty, does appear to have moral relevance, although each stems from concern about a similar primary moral value—the well-being of the patient. If possible, additional action needs to be taken in cases of moral uncertainty so that the implications of interventions for patient well-being are determined before intervening. Unlike our case of constraint-distress, for example, this kind of case of uncertainty-distress may require an ethics consult to determine what the morally ideal course of action is likely to be.

The second relevant moral value is the well-being of health professionals. This value is relevant in the examples of both constraint-distress and uncertainty-distress; the well-being of health professionals is being undermined by their experience of distress, which can, in turn, have negative implications for the organization and the patient. For example, moral distress is associated with staff turnover intent [12]. What could be of further moral relevance and be fruitful for empirical research to determine is whether moral distress is experienced more acutely if it is of a certain category. For example, is constraint-distress more likely to negatively impact health professionals' well-being than uncertainty-distress because the health professional is blocked from being able to perform the correct action or the perceived correct action? Or does the experience of different kinds of distress tend to influence the same health professionals similarly? Here the answers to these empirical questions have moral relevance because if a particular category of distress is more harmful than another kind, then ameliorating the more harmful kind should be a greater priority, all other things being equal.

The third relevant moral value has to do with the distribution of moral distress among different groups of health professionals. We might find that certain kinds of health professionals, such as nurses rather than physicians, or those working for certain departments, such as the Emergency Department, or in certain specialties are more likely to develop moral distress. If this is the case, then they would carry a greater moral and psychological burden than other health professionals. As mentioned in the previous section, it seems reasonable that nurses on average would be more likely to experience constraint-distress than physicians because of their position in decision-making hierarchies [11, 12]. More research would need to be conducted to indicate which groups are most vulnerable and to which categories of distress they are most vulnerable; however, what is important to emphasize here is that making morally relevant

distinctions is related not only to the *categories* of distress experienced but also to *who* is experiencing the distress.

Conclusion

In this paper, I have highlighted the difference between a kind of narrow and a broad definition of moral distress. I claim that among the reasons why we should adopt a broad definition is that distress that arises from a variety of morally troubling situations related to patient care stems from and leads to similar violations of core moral values, and thus it would seem strange to single out only one of these types of situations—of certainty and constraint—as being wholly constitutive of moral distress. However, although there are primary moral similarities among these situations, there are also some additional morally relevant distinctions that should not be blurred by treating a broad notion of moral distress as an aggregate. In the final section of the paper, I emphasized how differentiating between categories of distress and the groups of health professionals experiencing distress is significant for determining morally relevant features of specific cases of moral distress.

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STATE OF THE ART AND SCIENCE

Initiatives for Responding to Medical Trainees' Moral Distress about End-of-Life Cases

M. Sara Rosenthal, PhD, and Maria Clay, PhD

Abstract

Moral distress frequently arises for medical trainees exposed to end-of-life cases. We review the small literature on best practices for reducing moral distress in such cases and propose two areas to target for moral distress reduction: medical education and organizational ethics programs. Students require training in end-of-life dialogues and truthful prognostication, which are not generally available without skilled mentors. But physician-mentors and teachers can suffer from lingering moral residue themselves, which can affect the teaching culture and student expectations. Finally, reducing unit moral distress that affects learners requires formal educational opportunities to debrief about difficult end-of-life cases and formal institutional mechanisms for effective clinical ethics consultation.

Introduction

Moral distress, initially defined by Andrew Jameton [1, 2], occurs in situations in which a person recognizes a moral problem but is constrained from acting on it or resolving it. In the case of medical students facing such a problem, internal constraints (e.g., feelings of powerlessness or insecurity from perceived low level on a team or in a hierarchy) as well as external constraints (e.g., legal or patient rights-based) prevent their taking action, resulting in moral distress and moral residue. Moral distress is not the same as feeling "sad" about a case or being vicariously traumatized by another's tragedy; rather, it occurs when the right action is identified but cannot be carried out. This is different than the limits of beneficence in patient care, in which all treatments for a patient at the end of life have been exhausted, leaving students feeling sad about a patient's death. Moral residue is a term initially defined by George C. Webster and Françoise E. Baylis as "that which each of us carries with us from those times in our lives when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised" [3]. Moral residue thus refers to the "lingering feelings" after the morally distressing event has passed [2].

Our analysis focuses on an emerging, yet critical problem facing medical education: moral distress in medical students unprepared for <u>end-of-life cases</u> and patient care

dilemmas in the adult setting [4]. Reducing moral distress for students in the end-of-life patient care context involves attending to two groups whose deficits contribute to a perfect storm: medical students who may feel powerless, insecure, and ill-prepared to navigate a difficult environment and role models and mentors who could have unresolved moral residue or who are unknowledgeable about how to help medical students address moral distress. So the first questions we must address are these: Who are the students? Who are their mentors? And, finally, who are the dying patients, and why might how they're treated trigger moral distress? We argue that failure to reduce rates of moral distress can lead to a variety of consequences and may even trigger or exacerbate depression, a recognized problem in medical school [5, 6].

Demographics: Students and Mentors

The incoming medical students for fall 2017 will be graduating in 2020. The vast majority of them will be admitted because of their academic performance and grades in the sciences [7]. Although in recent years there has been much more variety in medical school admissions criteria and openness to humanities majors, the typical applicant is still a science major [7–13].

In 2003, women comprised 50.8 percent of medical school applicants, but that figure had fallen to 47.3 percent by 2011 [14]; during the same period, the percentage of female medical school graduates rose from 45 percent to 48-49 percent [15]. It has even been suggested that there are "too many" women in medicine [16] because they tend to choose more family-friendly subspecialties (e.g., family medicine, internal medicine), leaving vacuums in more demanding specialties such as surgery. This pattern appears to reflect lifestyle choices that are not affected by health care systems, as the same trends are found in the United Kingdom [16], Canada [17], and Japan [18] as in the US. We know of no studies demonstrating whether women students are better equipped than male students to handle the end-of-life patient care context, although one study found they experienced less moral distress [4]. However, given that female medical students may not be seeing enough women in medical leadership roles due to a lag in organizational ethics policies surrounding promotion of females to leadership positions [19, 20], their moral distress may be exacerbated if they feel uncomfortable discussing it with male mentors.

Ultimately, mentors in medical education need to acknowledge that the strengths that got students into medical school (aptitude in math, science, and memorization) are frequently not the same skills that students need to get through medical school and become physicians in their own right. Invariably, the skills required to succeed in the profession, including empathy and communication, will need to be both modeled and taught, which is the ongoing process of exercising *clinical phronesis*, or practical reasoning [21, 22].

Who Is Teaching Medical Students?

Mentors in charge of training the next generation of physicians were trained in an era in which palliative care and clinical ethics education were rare offerings in hospitals [23], and thus they may be ill-prepared to help students with moral distress—particularly if they are themselves unfamiliar with or habituated to the phenomenon. Female mentors who trained in the 1980s and 1990s had very different, often negative, experiences due to their gender and might have learned to repress moral distress, becoming more numb to the triggers for it over time [24, 25].

Some mentors grew up in an era in which the 1978 satirical book, House of God [26], was seen as reality rather than fiction [27, 28]. The book centers on the dehumanizing process of medical residency, based on the author's own experiences as a resident at Beth Israel Hospital at Harvard Medical School in the 1970s, and became a "must read" because of its accurate descriptions of the grueling training environment. Many midcareer clinicians report increased burnout and increased emotional exhaustion [29], characteristics that have been associated with unresolved moral distress issues [30]. Moreover, mid-career mentors' differences from their students can pose challenges in addressing students' moral distress. The 1970s was an era in which diversity was virtually absent in medical schools; one report noted that minority students comprised 2.8 percent of total enrollment but 11-12 percent of the US population [31]. Baby boomer physicians also value complete dedication to work and "rigid approaches to patient care" [32], which might pose barriers to shared understanding and make it more difficult for students to discuss their moral distress with mentors. For all these reasons, there may be an insufficient number of appropriate mentors to help students with moral distress.

Who Are the Morally Distressing Patients in the End-of-Life Context?

When medical students have moral distress about end-of-life cases, it usually concerns the quality of life of the dying patient or the psychosocial circumstances surrounding the patient's death. Delayed decision making and delayed truth telling are the most common triggers [2, 33]. The patient population is heterogeneous, as are the many causes of death. However, the literature supports that the most frequent triggers involve the following types of cases:

1. Delayed end-of-life discussions. A common example in critical care involves patients on extracorporeal membrane oxygenation (ECMO) who are being "bridged to nowhere." In these cases, health care clinicians' reluctance to discuss death and dying leads to offering ECMO to poor patient candidates as a last resort. Families may consent to ECMO without really appreciating what it means. As a result, discussions about withdrawing from ECMO become delayed [34], creating moral distress in the unit.

- 2. Delayed or poor decision making. A common example involves incapacitated, unrepresented (i.e., unbefriended) patients waiting for guardianship. In such patients, end-of-life options are often delayed due to an overburdened guardianship system, which in many states, does not routinely consent to comfort care [35]. Patients might also have inauthentic surrogate decision makers who may not respect known patient preferences concerning end-of-life care.
- 3. Medically inaccessible or inappropriate care. Common examples involve families and patients requesting aggressive care that is either not financially feasible due to coverage problems or medically inappropriate because it does not offer benefit [36, 37].
- 4. Poor communication during notification of death determined by neurologic criteria. In many such cases, there is very poor understanding of how to talk to families about brain death, and there may be chaos at the bedside [38].
- 5. *Codes gone bad.* This involves misunderstanding about code status and what full code actually means [33, 39].
- 6. *Health disparity cases*. Such cases include patients presenting with end-stage diseases that are clearly preventable with proper primary care access [4, 40].
- 7. Patients with psychiatric problems, including end-stage addiction patients. Such patients can be violent towards nurses and health care professionals [41].
- 8. *Grieving family members*. Grieving can occur in either the adult or pediatric setting; however, in the latter, moral distress is pronounced because of the age of the patient and the suffering of the parents.

Reducing Moral Distress: Best Practices Solutions

Although the moral distress literature is still short on proven intervention strategies [42, 43], several strategies have been identified: discussion of issues and debriefing [44, 45]; an ethics consultation service and ethics rounds conducted by trained personnel to promote in-depth and personal conversations [44, 46, 47]; reflection, including mindfulness as a source of personal empowerment [30]; and peers and mentors to aid in the process of coping with moral distress [30]. The following organizational programs have been recommended to reduce moral distress within academic medical centers in which medical students are dealing with death and dying.

24/7 Clinical ethics consultation service. This model involves a 24/7 pager-responsive service in which trained clinical ethicists respond promptly to a request for consultation. Such services need to ensure that "anyone" can call a clinical ethics consult, and medical students should learn how to contact the service—in either their preclinical or their clinical years. In a typical ethics consultation, the ethicist reviews the case with relevant stakeholders; organizes multidisciplinary team meetings (e.g., huddles) or meetings, sometimes with families; and provides chart documentation and formal opinion notes in the chart with recommendations [48].

Preventative ethics rounding in targeted areas. Regular weekly rounding by either a clinical ethics team or a multidisciplinary team that includes pastoral care, social workers, and mental health care professionals should be done in ICUs or other units where end-of-life cases are common as a preventative ethics mechanism [49, 50]. Rounding permits early identification of potential dilemmas before they reach a crisis, planning goals of care discussions, identifying surrogates before a patient loses capacity, and so on. Chief beneficiaries of such rounding typically include nursing staff, residents, and medical students in their clinical years.

Moral distress debriefings. Some end-of-life cases leave the health care team with such profound moral distress and moral residue that there is a risk that the next similar case will have a "crescendo effect" [2], in which the moral distress intensifies with each repetitive situation. A debriefing involves a skilled facilitator (often a social worker or mental health care practitioner) who sits down with the team members and allows them to air frustrations and feelings [51]; medical students who were affected by such cases should be encouraged to participate.

Schwartz RoundsTM. This is a specific type of panel-based grand rounds that presents one difficult end-of-life case from the perspectives of the multidisciplinary team members looking after the patient and then invites audience feedback. The goal of such rounds is to discuss health care professionals' emotions rather than focus on the case from a medical science perspective. These are specific types of rounds that involve training and accreditation through the Schwartz Center for Compassionate Healthcare [52], and medical students at all stages should be encouraged to attend as a way to sensitize them and prepare for difficult cases.

Medical Education Initiatives

Stewards of medical school curricula should ensure that all physician-educators have opportunities to debrief about moral residue [4, 53], thus preparing them to serve as mentors to medical students and residents. These are, effectively, "train the trainers" programs. Physician-mentors should attend faculty development programs specifically aimed at equipping them with strategies to reduce learner moral distress, including open-communication strategies, facilitation skills for learners to debrief about "difficult" patients [54], the use of narrative ethics for self-reflection [55], an enhanced ethics curriculum [56], and peer-support programs [57]. Such initiatives also allow mentors to identify their own current or past experiences of moral distress, which can enable greater empathy and better communication with students.

Conclusion

Reducing students' moral distress in end-of-life cases is not of the "one solution fits all" variety. Strategies involve effective mentorship concerning end-of-life dialogues and

management of difficult cases as well as responsive clinical ethics services and training to support students, hospital staff, other trainees, and faculty, including medical education faculty who mentor students.

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POLICY FORUM

What Is the Role of Ethics Consultation in the Moral Habitability of Health Care Environments?

Wendy Austin, PhD, RN

Abstract

Ethics consultation has traditionally focused on the provision of expert guidance to health care professionals when challenging quandaries arise in clinical cases. Its role, however, is expanding as demands on health care organizations are negatively impacting their moral habitability. A sign of this impact can be seen in the moral distress experienced by staff and administrators, such that some leave their positions and their organizations. Ethics consultation, more broadly conceived, can be a major asset in ensuring that ethical practice is meaningfully supported, that moral distress is mitigated, and that the organizational environment is morally habitable.

Introduction

Moral distress is an inherent risk in contemporary health care practice with its complexity, rapid innovation, and unprecedented ethical quandaries. The provision of competent and compassionate care can be compromised by rising costs of health care and the organizational strategies enacted to address it, such as service rationing, streamlining strategies, and demands for "efficiency" [1]. Health care is thus a challenging environment for those striving to fulfill their moral obligations to patients, families, and the community at large. When real or perceived constraints inhibit health care professionals from acting on their moral responsibility in the way that they believe that they should, they can experience a deep sense of anguish and failure that, unless it is resolved, can remain to trouble them for years. Unresolved episodes of such "moral distress" can build to a crescendo and prompt professionals to resign their positions or even leave their fields entirely [2]. Health care leaders experiencing moral distress can feel inhibited in voicing their concerns about their decisions due to fears of being viewed as less than a team player [3]. However, research on health care leaders' moral distress is scarce [4]. The reality is that, if the weighty responsibilities of competent, compassionate care and treatment are to be borne without staff being overburdened by their responsibilities, health care organizations must be morally habitable so that space (literal and symbolic) exists for ethical reflection [5, 6]. What role might ethics consultation play in creating organizational conditions in which the inclusion, power, and trust necessary for authentic dialogue about ethical issues are fostered [6-8]? This question is explored here.

The Moral Habitability of Health Care Organizations

Moral distress has been attributed to lack of resources, human and material, manifested as unsafe staffing (i.e., inadequate number of health care staff or inappropriate skill mix of staff to provide safe, competent care) [9], equipment deficiencies, and lack of access to necessary treatments [10, 11]. Conflicts, whether between the patient or patient's family and the team or among the team members, are another cause [11]. For nurses, American [10] and Canadian [11] research shows that moral distress (its frequency and intensity) is correlated with poor quality of care, especially within an intractable, bureaucratic organizational system. It is morally distressing when organizational values are incongruent with those of one's discipline [12] or when there is a disconnect between the espoused values, beliefs, and attitudes of an organization and its actual customs and practices [13]. An example of both is when efficiency (defined in economic terms as maximizing value rather than as fulfilling the intended purpose) predominates over compassion within an institution, despite the latter appearing prominently in the mission statement.

There can be relational consequences to raising ethical issues in some organizations [13, 14]. One such consequence is to be "cut adrift." This evocative term was used by a participant in a moral distress study; this participant explained that it was fear of becoming a castaway that kept her silent [15]. She feared that her colleagues would regard her questioning of the ethics of a patient care situation as an indication that she was not a team player, "not one of us," and thus that she would lose valued collegial support. If avoidance or blaming is a cultural norm, staff might remain silent rather than risk being seen as deviant or as a troublemaker by asking, "Is what we are doing truly ethical?" When such cultural norms are in place, ethical questions tend not to get raised until a crisis occurs; unfortunately, when the crisis is resolved, change in the moral life of the organization might not happen and silencing can remain the norm [16].

Although health care leaders are obligated to establish structures and supports such that decision making and action are ethically grounded at the levels of clinical practice and <u>crisis response</u>, there may be insufficient attention given to making ethics integral to the everyday life of the organization [17, 18]. Developing and sustaining a morally habitable organization is an ongoing challenge, but it is one that must be met. As ethical consultation is the primary mechanism of doing so, its form and substance deserve a closer look.

Ethics Consultation

Ethics committees are the main approach to addressing ethical issues in hospitals in the US [19], although ethics consultation can take many forms. First, the individual ethics

consultant, with or without support of health care professionals with ethics training (a "hub and spokes" approach), provides guidance with regard to particular cases upon request [20]. Second, the capacity-building consultant focuses on training health care staff in ethics decision making, often using a particular framework [20]. Third, in a facilitation or team approach an ethics consultant (responsible for ethics analysis and framing), a facilitator (responsible for the process and ensuring procedures are followed), and, with luck, a recorder join other resource people and stakeholders to address an ethics issue [20]. Ethicists and ethics committees can and do play a role developing, implementing, and reviewing organizational policy [21]. They could, for example, initiate policy in the area of end-of-life care or prescribe prospective reviews of ongoing cases so that a 30-day intensive care stay would require an ethics review. An alternate response could be, as exists in some hospitals—particularly in intensive care units—to have weekly unit-based ethics rounds to reduce both patients' length of stay and clinicians' moral distress [22]. The best setup is likely for an organization to have several consultation options.

Regardless of the form ethics consultation takes, it seems profoundly important that its role goes beyond the provision of expertise for challenging cases. Ethics consulting needs to be an integral component in shaping and sustaining the moral life of a health care organization. It can, in all its forms, support staff and leadership in using the language of ethics and in cultivating their moral imagination, so necessary for understanding others' perceptions, beliefs, and worries [23]. The "moral sore spots" of the organization [24]—those problems and practices that are dysfunctional but so omnipresent that they have become accepted and unquestioned (e.g., a tendency across the organization to delay discussions with patients and families about personal directives; the low bar held by some physicians for informed consent)—will reveal themselves to an engaged ethicist who can help staff to move past resignation toward solutions [8, 25].

There is a role to be played in fostering interprofessional collaboration. Moral distress can occur when key decisions are made in a patient's treatment and care plan without input or discussion from the nursing or allied care staff assigned to carry it out [15]. Ethical issues offer opportunities for encounters in which staff can come to mutual understanding or rapprochement [26] through inclusive sharing of information, feelings, and outlooks. Such encounters need to occur between health care staff and organizational leadership as well. Experiences of moral distress can be mitigated if staff members comprehend the reasons why particular organizational decisions are made and have opportunities to share their concerns about the reasons offered with decision makers, such as those in administration. Ethics consultants could serve as facilitators of such opportunities. While ethical challenges will always be part of life in a health care organization, ethics consultation can thoughtfully address and resolve such challenges. The organization can be a liveable, ethical space.

Conclusion

Nearly a quarter of a century ago, the philosopher Margaret Urban Walker described health care ethics consulting in architectural terms: there is genuine technical expertise involved but, as with the creation of functional structures, also social and psychological knowledge and "aesthetic sensibility" [27]. Walker envisioned ethics consultants as having a sense of moral space, along with a sense of how and where it needs to be opened and structured within an institution. Ethics consultation can help create and sustain morally habitable health care organizations.

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POLICY FORUM

Strategies for Promoting High-Quality Care and Personal Resilience in Palliative Care

Katherine E. Heinze, PhD, RN, Heidi K. Holtz, PhD, RN, and Cynda H. Rushton, PhD, RN

Abstract

Palliative care (PC) clinicians are faced with ever-expanding pressures, which can make it difficult to fulfill their duties to self and others and lead to moral distress. Understanding the pressures that PC clinicians face and the resources that could be employed to ease their moral distress is crucial to maintaining a healthy PC workforce and to providing necessary PC services to patients. In this paper, we discuss recommendations related to two promising pathways for supporting PC clinicians in providing high-quality PC: (1) improving systemic PC delivery and (2) strategies to promote ethical practice environments and individual resilience. Enacting these recommendations holds promise for sustaining higher-quality and accessible PC and a more engaged PC workforce.

Introduction

Palliative care (PC) clinicians are faced with ever-expanding pressures, which can make it difficult to fulfill their duties to self and others. In 2008, more than 90 million Americans were living with serious illness, and this number was projected to double in 25 years [1]. PC clinicians are tasked with reducing the suffering of these patients and face daily challenges, such as treating patients with intractable pain, facilitating end-of-life (EOL) decision making, and collaborating with other health care specialists to ensure that PC is sufficiently integrated [2]. A recent survey found that PC physicians who were planning to leave the profession commonly cited burnout or dissatisfaction with their organization or practice as the reason [3], and another study found that high moral distress is linked to clinicians' intentions to leave their current position [4].

Moral distress has been described as "one or more negative self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that [one] perceives to be morally undesirable" [5]. PC clinicians have a duty to relieve suffering, but they also have a duty to follow the wishes of patients and their surrogates, which can lead to what PC clinicians view as furthering unjust patient suffering when, for example, aggressive acute care is pursued beyond the point at which its clinical benefits justify its risks [6]. Among nurses in critical care and oncology settings, moral distress has also

been linked to nurses' knowledge that PC is effective in relieving patients' suffering but is unavailable due to a deficiency of environmental, human, or material resources [6, 7]. Furthermore, in a recent survey the majority of physicians and nurses reported that the situations most responsible for their moral distress are (1) following families' wishes to continue life support when the clinician believes it is not in the patient's best interests and (2) initiating life-saving action that the clinician believes would only prolong death [4]. Without effective PC, patients might continue to receive aggressive acute care and suffer the associated pain and other symptom burdens. Although moral distress has been identified in PC clinicians, there is very little in this body of research that points to a solution to the moral distress epidemic.

Understanding the pressures PC clinicians face and the resources that could be employed to ease their moral distress is crucial to maintaining a healthy PC workforce and to providing necessary PC services to patients. We will discuss these goals in connection with two promising pathways for supporting PC clinicians in providing high-quality PC: (1) improving systemic PC care delivery and (2) strategies to promote ethical practice environments and individual resilience.

Improving Palliative Care Delivery

Improving integrated PC is critical because there are limited PC fellowship training programs for physicians in the US, with fewer than 250 graduates per year and an estimated shortage of 18,000 PC physicians [3]. To address the need for more integrated PC, many leaders, academics, and organizations have called for the institution of high-quality PC across the health care spectrum. Notably, the National Academy of Medicine released a landmark report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, in 2015 [8]. This report made specific recommendations for improving EOL and PC in the United States.

One of the primary recommendations of the report was to make PC a thread in health care education so that every clinician, regardless of specialty, would be capable of providing basic palliative care services. Currently, physicians and medical residents report that palliative care training is inadequate [9], and there is a common view among practicing clinicians that palliative care is only appropriate for patients who have stopped curative treatment, which prevents many patients who would benefit from PC from receiving it [10]. The nursing profession has made an effort to provide nurses with palliative care training through the End-of-Life Nursing Education Consortium (ELNEC), which has resulted in over 550,000 nurses receiving education in PC in 88 countries [11]. Despite the impact of the ELNEC program, there is still a need for more nurses with PC expertise, as suggested by the American Association of Colleges of Nursing recently releasing specific PC competencies for undergraduate nursing education [11]. Increasing palliative care knowledge across the health care workforce can improve communication between clinicians and patients, expand the number of patients who receive the range of

PC services—such as control of pain and other distressing symptoms and goal setting—and decrease both misinformation about PC and prominent sources of moral distress associated with end-of-life care [4, 10].

Furthermore, even though there is broad consensus that high-quality PC is necessary for patients with serious illnesses [8], there is a paucity of research on the specific patient outcomes that are necessary to achieve high-quality palliative care. In a recent review and meta-analysis, the authors concluded that the data do not support an association between specific PC processes and patient outcomes [12]. The National Academy of Medicine convened a panel of PC experts to propose specific components of high-quality EOL care (e.g., managing symptoms and emotional distress) [8], which could aid institutions and PC clinicians in planning and implementing PC programs and enable evaluation and data collection across health care systems.

Better understanding of these core components and the outcomes associated with them may lead to the incorporation of palliative care into routine treatment of serious illnesses as a matter of protocol, which could be particularly useful in the cancer setting [10, 11]. Oncology clinicians commonly use treatment protocols that map a course of treatment but allow for changes based on each patient's clinical course. Having a PC treatment protocol that operated in the same way could ensure that all cancer patients receive high-quality individualized PC along with their cancer treatment [13, 14]. Currently, patients with serious cancer diagnoses are underreferred for PC [15]; including PC earlier in the disease process is considered important for reducing patient suffering, clarifying goals of care [16], and reducing moral distress in clinicians [4]. An environment supportive of PC might also reduce the higher levels of moral distress experienced by clinicians trained in EOL care. For example, one survey of 592 interprofessional clinicians in a large tertiary medical center found that clinicians with specialized training in EOL care experienced higher moral distress than their colleagues who did not have this training [17]. While this finding might seem counterintuitive, the authors concluded that when clinicians are trained in providing high-quality EOL care, they likely become more aware of their obligations and duties to patients and their family members and therefore experience moral distress when they practice in a setting where it is not possible to fulfil these duties. Further research is needed to describe moral distress in clinicians in the context of high-quality PC and EOL care.

Promoting Ethical Practice Environments and Individual Resilience

While implementing high-quality palliative care may be an important tactic to address PC clinicians' moral distress on a systemic level, there is an urgent need to ensure that individuals have the <u>personal resources</u> to enact resilience on a day-to-day basis. The concept of resilience first emerged in the pediatrics literature to describe children who were able to thrive despite adverse circumstances [18]. Since its introduction, the concept of resilience has been studied in a diverse array of settings and populations [18].

Among health care workers, resilience-enhancing interventions have been demonstrated to have positive impacts on employee mental health and well-being, goal attainment, productivity, and performance [19]. And a recent pilot study conducted with PC clinicians found that a resilience-enhancing intervention was associated with reductions in perceived stress and improvements in perspective taking [20]. It stands to reason that when clinicians are more resilient, they are better able to attune to the needs of their patients and to provide more patient-centered, compassionate care [20].

The broad concept of resilience can be further tailored to the moral domain. Recently, the concept of moral resilience has emerged as a possible response to moral distress [21]. Moral resilience, or "the capacity of an individual to sustain or restore their integrity in response to moral complexity, confusion, distress, or setbacks" [22], might help clinicians to maintain their moral wholeness and continue to work in challenging circumstances even when the source of moral distress cannot be eradicated [23]. However, the association between moral distress and resilience is not well understood. In order to develop a robust scientific basis for moral resilience, it is necessary to define key concepts to test the hypothesis that moral resilience can reduce moral distress and other forms of moral suffering. Gaining a better understanding of the causal associations between moral resilience and moral distress is necessary to inform interventions to build moral resilience among PC clinicians and may result in increased well-being among PC clinicians and more engaged patient care.

Conclusion

PC clinicians have a moral imperative to care for others and to care for themselves [24]. There are currently many barriers to fulfilling these duties: systemically, the provision of high-quality PC is impeded by lack of training opportunities and lack of evidence-based outcomes data. On an individual level, PC clinicians may be plagued by moral distress that can lead to burnout, job dissatisfaction, or leaving the profession [25, 26]. In order to address these challenges, we offer two recommendations. First, PC programs that incorporate the core components of PC outlined in *Dying in America* should be implemented to ensure delivery of high-quality PC. PC research should also incorporate these core components so that results can be compared across studies. Furthermore, PC education components should be included in general education for all health care clinicians. Second, individual PC clinicians and health care organizations should invest in resources to mitigate the impact of moral distress and build ethical practice environments. More research is also needed to better understand moral resilience in the PC workforce. Enacting these recommendations holds promise for sustaining higher-quality and accessible PC and a more engaged PC workforce.

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MEDICINE AND SOCIETY

Culture and Moral Distress: What's the Connection and Why Does It Matter? Nancy Berlinger, PhD, and Annalise Berlinger, BSN, RN

Abstract

Culture is learned behavior shared among members of a group and from generation to generation within that group. In health care work, references to "culture" may also function as code for ethical uncertainty or moral distress concerning patients, families, or populations. This paper analyzes how culture can be a factor in patient-care situations that produce moral distress. It discusses three common, problematic situations in which assumptions about culture may mask more complex problems concerning family dynamics, structural barriers to health care access, or implicit bias. We offer sets of practical recommendations to encourage learning, critical thinking, and professional reflection among students, clinicians, and clinical educators.

Perceiving Difference and Communicating Uncertainty and Distress in Health Care Work

Culture is learned behavior, including ways of perceiving and thinking, shared among members of a group and from generation to generation within that group. This basic definition is reflected broadly in medicine, nursing, and other clinical professions [1]. Research from cognitive neuroscience suggests that humans are wired to produce culture, in that our brains developed to support social agreement and group collaboration [2]. Culture connects humans to one another in ways that include shared values, beliefs, and practices concerning illness and health. It is a fact of human experience, one that must be examined critically due to the potential consequences for patients of misunderstandings within a culture or concerning culture more broadly.

In health care work, "culture" can function as shorthand for a clinician's uncertainty or distress based on perceptions about difference or distinctiveness attributed to a group to which a patient, family, or patient population is perceived to belong. For example, when a clinician characterizes a patient's or surrogate's decision about a medical treatment as "cultural," without further detail this tends to mean that there is something about the decision that is unsettling to the professional, that the professional perceives this "cultural" something to be representative of a group, and that the professional perceives the decision maker to belong to this group. This article, by a health care ethicist and a practicing clinician, takes an interdisciplinary look at one common problem in health care

work: how "culture" may be used as an explanation for situations that produce moral distress.

"Culture" as Distress Code

Certainly, there are situations in which the specific content of a patient's health-related values, beliefs, preferences, or behaviors can and should be described with reference to culture. For example, religious commitments are one example of culture, which, for some people, include specific values or prohibitions concerning medical interventions, such as Jehovah's Witnesses' refusal of blood products. In all such cases, it is crucial for clinicians to understand the patient's values as they may inform her treatment and care; these values may or may not correspond to her religious commitments or to those of her family members [3]. A clinician may or may not personally agree with these commitments or be able to accommodate them in a health care setting, but he or she should recognize that they are important to the patient.

However, relying on the words "culture" or "cultural" as code to convey a clinician's *own* feelings concerning difference, uncertainty, and distress can be problematic in patient care. Perceptions can be misperceptions. Individuals are more than representatives of groups. Behaviors can be misattributed to groups.

Medical and nursing students and professionals who have read Anne Fadiman's 1997 book, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, a now-classic account of a medical team and a refugee family, are familiar with the consequences of using perceptions about cultural difference, including stereotypes about culturally different patients as noncompliant, as a placeholder for lack of understanding about the content of culturally specific, health-related behavior [4]. Fadiman's book is set in the 1980s in Merced, California, where Hmong refugees from Laos were resettled after years-long displacement following the Vietnam War. Most clinicians at the local hospital had little understanding of Hmong medical anthropology: their health-related beliefs, values, and behaviors. Fadiman describes a medical catastrophe—an anoxic brain injury sustained by a young Hmong child with epilepsy following a massive seizure—that may have resulted in part from professional culture. Clinicians' shared habit of thinking of the Hmong as noncompliant made it difficult for them to consider other possible explanations, such as medical error, for had outcomes.

More than a generation after the publication of Fadiman's book, medical and nursing educators aim to prepare professionals to work in a culturally diverse society and to recognize their own professions and institutions as cultures whose inevitable blind spots interfere with understanding a patient's or family's perspective. Fadiman's splendid book is often required reading in medical and nursing schools, and training in "cultural competence" has become standard in medical and nursing education at all levels [5-10].

These educational efforts emphasize respect for diversity and understanding of how cultural values may shape how people think and behave concerning health. They also aim to help clinicians recognize their own cultural commitments and to identify blind spots in their own perceptions about culture that may prevent them from seeing the effects of professional medical culture—such as shared but untested perceptions concerning the reasons for patients' behavior—on their interactions with patients, families, and communities. The evidence for the effectiveness of cultural competency interventions, however, is mixed [11].

Beyond education and training, students and clinicians should develop the habit of thinking critically, as a normal part of health care work, about situations in which references to the "culture" of a patient, family, or population may function as shorthand for their own uncertainty or distress. Figuring out whether a reference to "culture" is masking a stereotyped perception of a patient's health-related behavior is important, as is attention to why a clinician may reach for that word to explain his own perceptions of uncertainty or distress. This process of reflection on professional practice can start with these questions:

- 1. When I use the words "culture" or "cultural" in a clinical setting, what do I mean?
- 2. If I can't clearly describe what I mean:
 - (a) Do I lack relevant knowledge concerning health-related aspects of a patient's culture?
 - (b) Or am I using the word "culture" or "cultural" to stand for something else? If so, can I say what is troubling me?

Supervisors, role models, and clinician educators should call attention to unclear or euphemistic uses of the words "culture" or "cultural" in a care setting and encourage students and colleagues to explore what they think or perceive these words to mean in everyday use. For example, house staff, newly hired nurses, or participants in clinical ethics consultations or other case-based discussions may notice that, within a health care institution, a phrase such as "it's cultural" stands in for a shared perception of how some local patient population uses health care or makes treatment decisions. Noticing this is an opportunity for learning.

The following questions, when posed by clinical mentors and others responsible for supporting professional practice, can help clinicians look critically at professional and institutional norms concerning encounters perceived as cross-cultural:

What is the "cultural" something we perceive about this population?
 (a) What is its relevance to health?
 (b) How do we know this?

- 2. How should we respond when we encounter patient care issues that our professional (or institutional, depending on context) culture frames as "cultural"?
 - (a) Which "cultural" issues are we comfortable talking about?
 - (b) Which issues make us uncomfortable? Why?

Questions like these can supplement discussions of actual cases or of narratives encountered via readings, videos, or other media, with the goal of each being to sharpen clinicians' understanding of when a professional's reference to "culture" may convey professional or institutional distress or uncertainty about some aspect of the health-related behavior of a patient population. The cultural reference alone does not explain what the distressing problem is. Relieving moral distress, which is rooted in self-perceptions about right and wrong action and one's power to change a situation, involves articulating feelings so others can understand what "feels wrong" and the person experiencing moral distress can gain the critical distance needed to reflect on powerful intuitions and moral judgments [12].

Talking about culture is interesting, and understanding how a professional or institutional culture ascribes health-related behaviors to different patient populations can be enlightening. Reality-testing perceptions is important, so that patients, families, or populations are not stereotyped and structural factors (such as racism, poverty, and lack of health insurance) affecting behavior are not conflated with cultural norms. Simply blaming "the culture" for producing moral distress in clinicians is unlikely to help clinicians understand how to relieve this feeling or to make the most of their agency.

In addition to clarifying issues arising in individual cases, clinicians, mentors, and educators should resist <u>clichéd thinking</u> about culture. Generic references to "Asian," "African," "African-American," "Hispanic," "urban," or "rural" families; nonspecific references to religious teachings; and simplistic "East" versus "West" or "family" versus "autonomy" comparisons are common examples of clichés, which may contain some truth but rely on generalizations. In an immigrant nation such as the United States, and in other multicultural societies, health care professionals need substantive opportunities to learn about the cultures of the populations they serve and what patients and families can have in common cross-culturally—for example, when receiving bad news, facing difficult decisions, or considering obligations to older adults or to children. Whenever possible, organized teaching and learning opportunities about a specific patient population should include a member of that group who is well informed about health-related behaviors and how they can be informed by cultural norms.

Clarifying "Family Values"

Using "culture" as distress code often arises in decision making on behalf of a seriously ill patient, when a surrogate or other family member expresses a view framed in cultural terms, or when a professional perceives something "cultural" concerning a decision-making process. For example, a family member may tell a team member that withholding a diagnosis or prognosis from a sick person is appropriate within their culture. This type of culturally framed behavior may reflect agreements within a culture that family members should shield a sick person from the burden of this information and bear it themselves or a more specific belief that hearing bad news or talking about the possibility of death is inauspicious and will lead to a worse outcome. How should the professional respond?

Acquiescing to "what the family wants" would not be ethically sufficient if the patient has decision-making capacity or is capable of participating in decision making. In the United States and in other jurisdictions, the patient has legal rights, including the right to receive health information or to delegate this right to someone else. Therefore, clinicians need to find out how much the patient wants to know or prefers not to know. It would be a mistake to assume that the patient has no preferences and simply keep the patient in the dark.

Asking this family member, "Can you tell me more?" about a belief, value, or behavior that has been framed as cultural can help elicit concerns in a respectful way. This approach also begins a discussion about ethical obligations concerning disclosure. Enlisting the help of a chaplain, social worker, or other team member with strong communication skills (including an interpreter if needed) can be helpful. Clinical ethics consultation can also be helpful if uncertainty about how to talk with a patient about her preferences concerning health-related information, and how to explain to family members why it is important to clarify the patient's preferences, persists among bedside clinicians [3]. In such cases, an ethically sound outcome may include a patient expressing a preference for diagnostic or prognostic information to be disclosed to a family member or the patient expressing a preference to receive some or all information directly. Discussion might also reveal that the patient is already aware of her diagnosis and prognosis, even if she does not discuss this directly with her family.

Avoiding Cultural Explanations for Structural Problems

In addition to clichéd thinking, another problem with using "culture" in a general way—to signal distress or a problem—is that it may, as noted, misattribute a <u>structural problem</u> to the culture of a patient, family, or population. Structural problems for low-income workers, for example, may include lack of sick days, transportation, or child care. Ascribing no-shows to the patient's "culture" does not fix the problem. Professionals who observe access problems for some patient populations should ask:

- 1. What does our system look like from the perspectives of members of this population?
- 2. What barriers do members of this population face in connecting with us?
- 3. How can we learn from patients who have limited options?

The literature on the social determinants of health includes studies of structural problems affecting health care access or patients' ability to complete needed treatment [13]. Discussing an article from this literature may help clinicians, including medical social workers often responsible for working with patients to resolve access problems, to identify similar problems in their own setting, and, whenever possible, to identify structural solutions, such as more flexible scheduling or investments in care coordination so patients can receive services closer to where they live or work.

Culture and Bias

A third caution about using "culture" as a distress code is that perceptions framed in terms of "culture" can conceal implicit bias. In a widely reported 2016 study, preschool teachers who were asked to view videos of four well-behaved children and look for signs of behavioral problems tended to focus on boys, specifically, on the black boy [14]. The researchers concluded that heightened scrutiny of one child reflected implicit bias. The teachers' observations, measured via eye-movement tracking as well as their recollections when asked which videos they had focused on, suggested that their expectations of problem behavior were associated with race and gender.

Clinicians' shortcuts for identifying "problem" patients or "difficult" families might also reveal implicit biases concerning groups [15]. Health care professionals should understand the difference between cultural understanding that helps them respond to patients' needs and concerns and implicit bias expressed in "cultural" terms that can perpetuate stereotypes or obscure understanding. A way to identify biased thinking that may reflect institutional culture is to consider these questions about advocacy:

- 1. Which patients or families does our system expect to advocate for themselves?
- 2. Which patients or families would we perceive or characterize as "angry" or "demanding" if they attempted to advocate for themselves?
- 3. Which patients or families do we choose to advocate for, and on what grounds?
- 4. What is our basis for each of these judgments?

Conclusion

We are never done learning about culture in health care work. It is much too important to be relegated to a one-off training session or course. Health care professionals, especially those in teaching, mentoring, and supervisory roles, should make a practice of reflecting on and discussing their perceptions about the cultural components of patient care. In 2010, approximately 27 percent of physicians and surgeons and 15 percent of registered nurses in the US was foreign-born [16]; these clinicians thus bring additional cultural perspectives to cross-cultural encounters [16]. The diversity of the US health care work force is one of its great strengths. It presents a ready opportunity for mutual learning about culture—including professionals' perceptions and uncertainties concerning patients, families, and populations—and how these uncertainties can trigger moral distress. But diversity can also provide opportunities for self-reflection on how the different cultures with which professionals identify have shaped them.

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HISTORY OF MEDICINE

What Moral Distress in Nursing History Could Suggest about the Future of Health Care

Andrew Jameton, PhD

Abstract

The concept of *moral distress* was defined in 1984 as (a) the psychological distress of (b) being in a situation in which one is constrained from acting (c) on what one knows to be right. A substantial literature on the subject has developed, primarily in nursing ethics. The aforementioned elements of distress are applied here to areas of clinical and organizational significance: (a) distress from causing intimate pain during care of the dying, (b) constraints stemming from proximate and background challenges of health care organizations, and (c) changing perspectives on therapeutic technologies derived from global environmental perspectives. Although moral distress may be increasing in clinical settings, nursing advocates are developing positive ways to cope with it that can help clinicians in general.

Introduction

After its first use in nursing over 30 years ago, the concept of *moral distress* has proven applicable to a growing range of problematic situations. This essay outlines a few motifs in the development of the concept in nursing ethics and then considers some current applications of the concept. Starting with the bedside care of the dying, it sets moral distress in successively wider contexts, concluding with some morally problematic global environmental challenges that health care services will need to address during the next decades.

Coining a Concept

My 1984 book, *Nursing Practice: The Ethical Issues*, introduced moral distress as the experience of knowing the right thing to do while being in a situation in which it is nearly impossible to do it [1]. I was responding to students' stories related during classroom discussions of bioethical dilemmas, such as appropriate care for dying patients, limits to life support, and communication and decision making with patients and families. Some of the students were senior nursing clinicians. A few recalled with regret hospital incidents in which they were required to perform uncomfortable or painful procedures on patients when, in their experience, curative efforts were futile. A common flash point was the suctioning of patients on respirators who had been in intensive care units for weeks and

who were not going to live to discharge. Similarly, providing intensive care to premature infants with expectably poor outcomes disturbed some neonatal nurses [2].

Although standard bioethics texts at the time emphasized cognitive moral reasoning and appeals to abstract moral theories [3], nurses' ethical concerns were heartfelt. Thus, I thought it was important to address the emotional side of moral problems. In so doing, I shared the concerns of educators cultivating the moral development of clinical professionals [4–7]. Nurses were professionally concerned about the role of emotions in providing compassionate care to patients [8–11]. And feminist moral theory was foregrounding emotional factors in ethical theories based on care, compassion, and empathy [12, 13].

As originally conceived in *Nursing Practice*, the authority of nurses as professionals in organizations was also important to the development of the concept of moral distress. Feminist ethics stressed the equal moral standing of women with men, and nurses, in a traditionally women's profession, were building on a more than 80-year struggle to establish a fully autonomous profession with substantial control of their work [1, 14, 15]. The aspiration of equality encouraged nurses to assert their professional judgments and to confront others when they had objections [16, 17].

In situations in which nurses had ethical concerns, secondary ethics questions arose, generally falling under the rubric of "organizational ethics" [18, 19]. Assertive nurses wanting to speak with authority on ethical problems in a timely way faced questions and challenges [20]. Examples include: Should a nurse express doubts about the wisdom of a course of therapy? Whom should he or she first approach—the family? The attending physician? Other nurses? A nursing supervisor? If ethical questions recur, should he or she question persistently? What is a nurse's standing as a professional to raise ethical questions in a clinical context [21]? When is a medical order so problematic that an ethical nurse should refuse to cooperate [22, 23]?

Development of an Idea

Defining moral distress. A diverse literature about moral distress has grown [24, 25], which rightly notes the vagueness of the concept and its relationships to similar concepts [26-32]. Significant questions have arisen that reflect three facets of the definition:

1. What does the power of moral distress derive from? Why is it being labeled as "moral" distress and not simply as psychological distress? Are we really talking about something more like conscience, guilt, shame, or regret [27, 33]?

- 2. Is it really ever "impossible" to act? Isn't this something that depends on the perceptions of the nurse [26, 30, 34]? Or are there institutional factors that restrict ethical action by clinicians?
- 3. Do nurses really "know" the right thing to do, or is this simply about their opinion or firm belief [26]? Have moral judgments about the wisdom and aims of care shifted over time?

Increase and spread. A quick review of *PubMed* reveals that more articles about moral distress were published in the last three years ending 2016 than in the prior three decades, and a bibliometric analysis of articles published on moral distress between 1984 and 2013 revealed a sharp yearly increase in publications on the topic after 2011 [28]. The concept is spreading to other fields including pharmacy, social work, psychiatry, veterinary care, administration, long-term care, organ donation, surgery, palliative care, and managed care [28, 35, 36].

Growth in publication may simply reflect the natural spread of an idea or a trend in academic interest. But the scale of publication may also reflect an increase in the frequency, intensity, or extent of distress among health professionals [28]. I will take this possibility seriously here and in the remainder of the paper discuss some reflections on the rise in distress. Even if the literature proves to be misleading, it is worthwhile to reflect on potential causes of an increase in distress, since the discussion may suggest lines of research that prove fruitful in reducing the rates of distress.

Factors Contributing to the Spread and Increase of Moral Distress

If moral distress is indeed increasing and spreading to other fields, several explanations might plausibly be offered. The themes identified here grow out of *Nursing Practice's* paradigmatic case of moral distress—when a clinical professional is required to perform uncomfortable procedures on a patient during overextended terminal care. Each theme emphasizes one of the three facets of moral distress outlined in the previous section—the nature of distress, the possibility of action, and the extent of knowledge.

The nature of distress. Most people, including trained professionals, who work with the dying and those close to death react with feeling [37, 38]. A patient dying in a hospital setting seldom experiences an easy passage from rescue with the possibility of recovery to "comfort care only." So when patient, staff, and family are traversing the ordeal of a steepening rise in discomfort to eventually futile care, stressful ethical disagreement is common. In such circumstances, nurses conducting uncomfortable procedures are likely to experience distress [32]. Consequently, a compassionate response to clinicians' feelings will continue to be needed, whatever the frequency of other background issues of health care organizations.

Obstacles to moral action in health care organizations. If moral distress is increasing and spreading among health professionals, one simple explanation may be that many hospitals provide care at higher levels of acuity than in the 1980s. Moreover, morally distressed nurses often identify problematic incidents at the organizations in which they work [39]. Their views deserve respect, and, as some studies show, the frequency of distress is positively correlated with organizational problems [2, 28, 39, 40]. Such problems include short-staffing, inflexible policies, complex documentation, clumsy staff changeovers, poor communication, overly complex technology, mistakes, and other organizational and resource challenges [24, 25, 28, 41]. Some of these problems are local to the institution in which nurses work; others derive from broad challenges of the health services system. Background features, such as ownership by large organizations, profit-oriented management, and complex coding and record-keeping, are putting pressure on the professional autonomy of a variety of professions.

Finding solutions. There is a consensus in the research that moral distress is too frequent and that something should be done to alleviate it [42-44]. At one end of the spectrum, proposed solutions focus on the feelings of individual nurses and seek to comfort and heal them [45]. At the other, solutions address the topical content of the distress and so include organizational and policy measures intended to reduce the frequency of ethically problematic incidents [41, 46-49]. Many proposals combine elements of both. One approach is to support nursing staff in speaking to ethical issues. Some suggest encouraging nurses to be more resilient and courageous in speaking up [44]; others recommend improving nurses' ethical reasoning through education [50]. At another level, hospitals have created committees, such as moral distress consultation services, wherein problems can be discussed in depth [51-53]. Other approaches include involving staff in improvement of interdisciplinary communication and amending organizational culture [54, 55]. With or without institutional support, clinicians who identify distressing organizational problems can advocate creative ideas for improving their organizations and the health care system either within hospitals and clinics or by speaking publicly and in professional circles [14, 25, 41, 56, 57].

Looking Ahead: Larger Problems and Possible Solutions

At a third, more conceptual level—deeper, wider, and harder to discuss in clinical settings—perceptions of the global situation of human life on earth are changing in ways I will discuss below. Although at this point I cannot show that these concerns have begun to affect how clinical professionals feel about their work or challenges in it, I am willing to argue that these concerns ought to affect ethical judgments about clinical care. A good starting point for introducing these general concerns is the cost of care.

Changing moral judgments about health care costs. Two major concerns about health care costs are now converging. First, the financing and affordability of health care has been a public concern for a century. Many now regard health care as overly expensive and

health care spending as comprising a disproportionate share of the GDP [40, 58-60]. Second, concerns about the contribution of health care materials to <u>toxic waste</u> and other <u>environmental impacts</u> of health care have been growing for about two decades. Increasingly, health professionals and organizations are participating in greening programs to reduce the environmental damage done by health care [61-63].

Accelerating global change is adding weight to these financial and environmental concerns [64]. Levels of consumption in developed nations are decreasingly sustainable on a limited earth [65-68]. In the next decades, US per capita material and energy consumption needs to be scaled down to a terrestrial scale [66, 68, 69-71]. Since US health care already comprises a significant proportion of GDP, if the economy is to be scaled down, so must health care [72, 73]. It needs to be materially less ambitious, more modest, simpler, and more manageable [74].

Climate change. Climate change is emerging as one of the most—if not the most—significant long-term <u>risk to human health</u> and biodiversity [75-78]. The major health professions have expressed grave concerns about the health consequences of climate change [79-83]. And many health care organizations have begun to include clean energy, energy efficiency, and other climate change mitigation methods in their greening programs and building designs [84, 85]. Some health professionals are beginning to realize that in order for health care to adapt to environmentally driven shifts in long-term health risks, health services need to adapt to a potential global decline in population health status, climate refugees, disasters, and disruptions to the supply chain [73, 86].

Philosophical trends. As environmental practices enter hospitals, principles derived from environmental philosophy are being seen as increasingly applicable to health and health care [87-93]. A dominant message of environmental philosophy is that all humans are biologically interconnected in the great web of life [94-97]. This sense of interconnection is beginning to challenge the strong commitment to individual autonomy seen in traditional bioethics [3, 73, 98]. Technologically extensive and intensive care of the dying, as I observed above, is emotionally challenging to clinicians. It is also expensive and therefore environmentally costly [68, 99]. Thus technologically extending an individual's life is diminishingly meaningful in the face of the long-term need to maintain the human and nonhuman biosphere. Arguably, some of the proximate moral distress over technological dying reflects a changing moral perspective. It is likely that those who see things in this light will, to their distress, evaluate overtreatment more negatively than those around them.

Conclusion

As the literature indicates, moral distress may be spreading to medicine and other professions [28, 35, 36, 100-103]. This may reflect that a variety of health professionals are increasingly finding themselves in moral binds similar to those experienced by

nurses. By studying the literature on nurses' moral distress, physicians and other clinicians may learn something useful from nurses about coping with similar problems they may face now and in the future.

Current nursing thinking about moral distress is more positive than my 1984 formulation of the concept. It emphasizes that the cure for moral distress consists in taking action with others to tackle problems both great and small. A recent nursing symposium proposes to replace moral distress with *moral resilience* [44]. The intention of the rephrasing is to turn clinicians' awareness of problems into courage, cooperative speaking up, and persistent action to address the background problems that foster health care failures.

Yet we must consider that we might become even more distressed as we realize that solving the ethical problems of health care now urgently includes global social and environmental advocacy.

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IMAGES OF HEALING AND LEARNING

Dirty Laundry: Drug Formulary Exclusions

Artwork and caption by Katy Giebenhain, MA, MPhil



Figure 1. Detail of *Dirty Laundry: Drug Formulary Exclusions*, by Katy Giebenhain

Caption

Pharmacy benefit managers (PBMs) contracted by health insurance companies create lists or "formularies" of preferred medications they cover. In this artwork, information from such formulary lists supplied the source of the text. This practice of charging patients the full cost for medications, devices, or monitoring aids that are excluded from their health insurance companies' coverage plans undermines decision–making partnerships between physicians and patients. An ethically relevant irony explored here is that in the United States we seem to have more choice about, and access to, breakfast cereals and assault rifles than needed medications.

Editor's Note

Four lines of text appearing in *Dirty Laundry* are contextualized as follows: *Note to existing members*: *This formulary has changed since last year* and *Please bring this guide with you the next time you visit your doctor* and similar language appears in numerous web-based

sources of information about formulary lists. *If you choose to remain on your current medication, you may use any retail pharmacy and should expect to pay the full cost of those prescriptions* appears on the CVS/caremark[™] website [1]. *Please review the Formulary Drug Removals in the link below. This contains a list of drugs that will no longer be covered on your drug list. This means you will pay the full price if you continue with any of these drugs also appears on the CVS/caremark website [2].*

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