Donna D. McKlindon, Pamela Nathanson, and Chris Feudtner, "Responding to Moral Distress and Ethical Concerns at the Intersection of Medical Illness and Unmet Mental Health Needs," *The Journal of Clinical Ethics* 28, no. 3 (Summer 2017): 222-7.

Cases and Analysis

Responding to Moral Distress and Ethical Concerns at the Intersection of Medical Illness and Unmet Mental Health Needs

Donna D. McKlindon, Pamela Nathanson, and Chris Feudtner

ABSTRACT

Some of the most difficult clinical ethics consultations involve patients who have both medical and mental health needs, as these cases can result in considerable moral distress on the part of the bedside staff. In this article we examine the issues that such consults raise through the illustrative example of a particular case: several years ago our ethics consultation service received a request from a critical care attending physician who was considering a rarely performed psychosurgical intervention to address intractable and life-threatening agitation and aggression in an adolescent patient for whom standard treatments had proven unsuccessful. We consider strategies that may be useful in addressing not only the ethical dilemmas or the clinical problems, but also the emotional, social, and moral distress that arise in delivering care in such complex cases, in which standard routine practices of care have been exhausted. In addition, we explore the processes that led to this situation and suggest ways to promote early recognition and intervention for similar cases in the future.

Donna D. McKlindon, MSN PMHCNS-BC, is Associate Director of the Department of Medical Ethics at the Children's Hospital of Philadelphia. *mcklindon@email.chop.edu*

Pamela Nathanson, MBE, is the Policy and Program Coordinator in the Department of Medical Ethics at the Children's Hospital of Philadelphia.

Chris Feudtner, MD PhD MPH, is the Director of the Department of Medical Ethics at the Children's Hospital of Philadelphia and is a Professor in the Department of Pediatrics and the Department of Medical Ethics and Health Policy at the Perelman School of Medicine, University of Pennsylvania, in Philadelphia.

INTRODUCTION

Ethical dilemmas are woven into the everyday fabric of pediatric healthcare. Among the most challenging cases are those involving patients who have both medical and mental health needs. These complex cases can generate feelings of moral distress within the healthcare team.

The concept of moral distress, as applied to nurses, was first described by Jameton in 1984, as the psychological disequilibrium that occurs when health professionals know, or believe they know, the ethically appropriate course of action to take, but are unable to carry it out because of obstacles that are present.[1] Contributors to moral distress have been identified as institutional constraints and their impact on nurses' ability to advocate for patients; the inability to influence medical decisions related to patients' pain and suffering; and a lack of recognition of one's expertise within the hospital power hierarchy.[2] Under these types of circumstances, acting in a manner that is contrary to personal and professional values undermines the individual nurse's integrity and authenticity as a person.[3] While much of the early literature focused on moral distress as

experienced by nurses, the concepts and their underpinnings have application for all healthcare providers.

By definition, complex care situations involving challenging medical and behavioral health needs beg the services of many consultants, including mental health professionals and ethics consultants. The practice of consultation routinely employed in healthcare settings may vary based upon a number of factors, including the nature of the consultation, the composition and skill set of the consult team, the specific request, and the level of urgency (real or perceived), as well as the culture of the organization. The process and outcome of any specific case can be greatly affected by who is asked to consult and how the consultation is managed.

In this article we will consider the intersection of ethical dilemmas and unmet mental health needs in principle and application. Utilizing a specific, complex case example to ground the discussion, we will examine the intertwined nature of these two issues, identifying the guiding principles, standards of practice, and skill sets recommended for addressing complex care cases.

THE CASE

Myles (a pseudonym) was a mid-adolescent male with severe intellectual disability and multiple complex medical and behavioral health conditions, including the need for a tracheostomy and ventilatory support. He had experienced numerous lengthy hospitalizations in several tertiary care pediatric hospitals during his lifetime. Guardianship and medical decision making had been assumed by the state several years prior to this hospitalization, and a guardian *ad litem* was appointed at that time. Myles had lived in several residential facilities, and immediately prior to this hospitalization was living in a small group home that had demonstrated an ability to manage his behavioral and stable medical needs.

For his most recent admission, Myles presented to the hospital with increasing respiratory distress requiring ongoing ventilatory support. The admitting diagnosis was respiratory distress and autism with aggression toward others and self-injurious behaviors. Care was provided on a unit where most of the children are mechanically ventilated. A primary focus of the unit is the education of families in anticipation of discharge of the child to home or to a long-term care facility, and, of note, the unit staff did not have training or experiential expertise in addressing severe behavioral health concerns.

Myles was nonverbal with very minimal sign language capacity. He had an estimated IQ of 20. He was ambulatory and enjoyed interactive activities such as blowing bubbles and water play, liked to be sung to, and had several favorite videos. Myles received physical therapy, occupational therapy, respiratory therapy, and child life services. Behavioral health services were provided by the state, and included weekly visits by a behavioralist and in-hospital observation for four hours per day, four times per week, provided by a state-funded therapeutic staff support worker.

Myles had an extensive history of mental health concerns. Both prior to and during this hospitalization, he had frequent episodes of agitation, self-injurious behavior, and aggression toward others, resulting in the use of behavioral management restraints and sedating medications. Hospital policy allowed the use of restraints under these circumstances; but less restrictive measures must have been exhausted prior to their use. Several medications had been tried in an attempt to address Myles's care needs, including his sleep cycle, agitation, and aggression, all with insufficient success. Following extensive consultation with the psychiatry service, the team determined that no additional medication options were available.

The medical team had identified three major goals of care for Myles: (1) medical stabilization, (2) behavior management in order to provide for the safety of the patient and staff and to minimize or eliminate potential injuries, and (3) optimization of the care environment by arranging for appropriate disposition to a facility able to manage Myles's medical and behavioral health needs.

INITIAL ASSESSMENT BY A PSYCHIATRIC MENTAL HEALTH ADVANCE PRACTICE NURSE

Early in Myles's hospitalization, a psychiatric-mental health advance practice nurse (PMH-APN) responded to a request to review the use of behavioral management restraints for aggressive behavior and threat to self and others. As a member of the restraint and seclusion committee, the PMH-APN was responsible for oversight and review of all uses of behavioral management restraints, and in this capacity provided ongoing education and communication regarding restraint episodes to staff and unit leadership. In addition, the PMH-APN was asked to provide support and guidance to the staff who were caring for Myles related to addressing the complex care needs of the patient and accompanying staff distress.

The assessment completed by the PMH-APN identified the following six areas of concern:

1. Patient behavior management (agitation/aggression): Myles's aggression/self-injurious behaviors had resulted in multiple episodes of restraint to protect himself and others. Staff characterized his agitation and aggression as being unpredictable in nature and difficult to anticipate, as it was not easy to identify and/or read his cues. As a result, Myles had no consistent behavior management plan in place, and the strategies employed by the staff to communicate with him were not effective. Finally, Myles had an extremely disrupted wake/sleep cycle that was not amenable to medication management.
2. Staff's response to and interactions with the patient: Frequent restraint use and staff injury led to a great potential for moral distress and posttraumatic stress disorder responses among staff. Some staff were frightened of the patient, and, if they were injured while providing care, had difficulty returning to care in any capacity as a direct careprovider or as an assistant. The behavioral healthcare needs of the patient exceeded the skill set of the staff and conflicted with the primary focus of the care setting.
3. Optimization of the care setting: The care team needed to develop an appropriate plan of care involving collaboration between psychiatry, psychology, nursing, and critical care medicine, with a focus on a consistent plan of care and approach.
4. Disposition: Myles was considered to be medically stable, even though he was ventilator dependent. The inpatient care team agreed that an acute care hospital was not an optimal care environment for this adolescent, but the team had difficulty finding a facility that could adequately provide for both the patient's medical and behavioral care needs.
5. Organizational oversight: Systems level considerations included safety risks, length of stay, availability of and access to resources, and a complicated plan for continued care after discharge.
6. Advocacy: Myles was a ward of the state with an assigned guardian *ad litem*. Because he had no family present, the staff caring for Myles served as his only on-site advocates, and therefore felt a heightened level of responsibility for his care.

Through this assessment, the PMH-APN highlighted many important aspects of care and organizational concerns that needed to be addressed. The overriding sense of moral distress on behalf of the careproviders who were directly caring for Myles was palpable and certainly took its toll.

GROWING MORAL DISTRESS WHEN PROBLEMS WERE INEFFECTIVELY MANAGED

As the length of Myles's hospitalization stretched from weeks into months, several members of the healthcare team who provided care for Myles reported a growing sense of moral distress. A perceived lack of response on the part of the medical team, the hospital administration, and the behavioral health and child welfare agencies of the state, coupled with an inability to improve the care of the patient, manifested itself in part as a sense of helplessness among the staff. In the face of continued agitation and aggression and with no identified long-term plan of care, the staff's frustration grew.

The experience of moral distress—which typically also includes elements of personal emotional distress and the social stress of feeling either neglected by or in conflict with other members of the clinical care team—can have a great impact at the individual, team, and organizational level. An ethics consultant who is not experienced with or attuned to moral distress can potentially overlook this important aspect of consultation. In this case, the staff experienced moral distress related to perceived violations of duties, feelings of powerlessness to affect day-to-day care, lack of appropriate resources, safety concerns for the staff and patient, and the inability to establish an appropriate locus of care. The staff who cared for Myles believed that they knew what he needed, but felt powerless to make it happen.

Several members of the physician staff requested the exploration of psychosurgery (anterior cingulotomy) as an option for Myles to manage his agitation/aggression, thus perhaps broadening his options for placement. (Anterior cingulotomy, rarely used in the pediatric population, is a psychosurgery used to treat chronic pain, depression, and obsessive-compulsive disorder. The surgery involves disconnecting the thalamic and posterior frontal regions of the brain and damages the anterior cingulate region.) By proposing this unusual use of psychosurgery, the requesting physicians underscored the extreme nature of the care situation and the frustration level of the entire care team.

While not all of the ethical dilemmas or feelings of moral distress that arise from such cases result in ethics consultation requests, the way in which

these situations are defined and navigated can profoundly influence the experience of a patient and family, as well as of a staff.

THE ETHICS CONSULTATION

In the absence of an independent patient advocate with an ongoing presence in the hospital, a specific request for an ethics consultation came from physician members of the healthcare team, as the proposed psychosurgery represented an extreme, rarely implemented intervention with little evidence of a successful outcome. The process of consultation revealed the team's perception that the organization had not appropriately addressed the needs of this very complicated patient and of the staff caring for him. This sense of organizational inertia and ineptitude, as experienced by the healthcare team, led to a call for extreme measures in what was considered an extreme circumstance.

The questions posed during the ethics consultation included: (1) What is the right thing to do for this patient? Have we exhausted all options? Is psychosurgery an ethically permissible consideration? (2) How can Myles's best interests be protected? Who is responsible? How will his rights be maintained? (3) Is this an appropriate allocation of resources? This question applied both to the proposed surgical intervention as well as to planning for continued medical care after discharge. At the time of the request for the ethics consultation, Myles had been in the hospital for the better part of a year.

The PMH-APN involved with this case was also a member of the Ethics Consult Service (ECS). She was thus in a unique position as the ethics consultant to recognize and clarify the potential ethical dilemmas posed, understand the behavioral health needs of the patient, and assess the level and sources of moral distress experienced by the staff. In addition, the ECS brought to the discussion a neutral and objective ability to see the big picture, assess the available resources, and draw attention to the needs of the patient as well as those of the staff.

The ethics consultation involved mapping the case through detailed descriptions of past and present treatment interventions. Careful analysis revealed several unexplored or underdeveloped possibilities, which in turn had remained in the shadows because the care team was overwhelmed by the day-to-day care of the patient and did not have the optimal skill set, knowledge, or clinical experience required to access all of the potential resources to help think through and respond to the clinical challenges. The resulting recommendation from the ECS was that psychosurgery was not the only option remaining, and, therefore, until other options were vetted and tried, discussion of the ethical considerations specific to psychosurgery should be tabled.

The ethics consultation and the involvement of the ECS occurred well into the patient's hospitalization, and the mere act of requesting a consultation served to greatly increase organizational attention to the case. As a result of the increased attention and additional skills and experience brought to the table, several additional resources were committed to the care of the patient, many of which came about in response to the questions raised regarding protection of Myles's best interest and the appropriate allocation of resources. Additional interventions that had previously been overlooked included: (1) assessment by autism experts with identification of a plan of care; (2) a request for clinical expertise in a behavioral approach to care, resulting in plans to contract for consistent, trained, and competent behavioral support from an outside agency; (3) mobilization of internal and external resources aimed at facilitating the patient's discharge from the hospital (although a care facility had been identified early in the patient's hospital stay, the process of transition had been complex and slow); and (4) reinforced efforts to maintain engagement with the appointed guardian *ad litem* regarding decision making for Myles.

INTERSECTION BETWEEN ETHICS AND MENTAL HEALTH

The notion that combined mental health and ethics skills, education, and preparation can contribute positively to the process and outcome of ethics consultation is not new. Calvin P. Leeman described, through a case example, the need for ethics consultants to have training in the recognition of psychiatric issues and in interpersonal skills.[4] He recommended that these skills could be taught by psychiatrists, and also argued that psychiatric consultants themselves needed sufficient training in clinical ethics to recognize the ethical dimensions of many of their cases and to serve effectively on ethics committees and ethics consultation services. He suggested that psychiatric consultants should help other participants to develop greater psychological awareness and skills. Leeman stated that "the overall goal should be a comprehensive approach to patient care in which both psychiatric issues and ethical concerns are recognized and addressed."[5] Leeman concluded, therefore, that the most highly

effective consultants need to be versed in both ethics and psychiatry, so as not to miss a need for consultation that surely belongs in one of these domains.

In her 1993 article, "Keeping Moral Space Open: New Images of Ethics Consulting," Margaret Urban Walker stated, "the moral expertise of clinical ethicists is not a question of mastering codelike theories and lawlike principles. Rather, ethicists are architects of moral space within the healthcare setting, as well as mediators in the conversations taking place within that space."[6] She went on to say, "the ethicist's special responsibility is to keep open, accessible, and active (and if necessary to create and design with others) those moral-reflective spaces in institutional life where a sound and shared process of deliberation and negotiation can go on."[7] Similar responsibilities can be ascribed to mental health consultants, who aim to create an opportunity for open, reflective dialogue. In Myles's case, by creating space and time for discussion through the process of ethics consultation, the team was able to examine additional options and revisit previously discarded options in a calm and intentional manner. Mental health and ethics consultants working in collaboration may draw attention to perceived organizational gaps in care by creating a space for these difficult conversations and for care planning.

THE DENOUEMENT

With organizational acknowledgment of and response to this patient's unique care needs, and a renewed commitment to identifying the most appropriate locus of care, a multidisciplinary team, supported by ethics consultation and mental health resources, was able to identify a long-term care facility with resources and supports for Myles's medical and behavioral health needs and to prepare for his transition. His discharge took place approximately six weeks after the ethics consultation meeting.

GENERAL LESSONS LEARNED AND FUTURE PRO-ACTIVE STRATEGIES

This case prompted reflection by the individual staff members involved, the care delivery team as a whole, and the broader organization. The questions at each level were the same: What have we learned as a result of caring for this patient? and What can be done differently in the future?

Consultants, whether from mental health, ethics, or both, would benefit from being attuned to the potential intersection between these roles. In complex consultations, a consultant often serves in a dual role, responding to the staff's needs in addition to the needs of the patient and family. One strategy would be for a consultant to specifically name the moral distress exhibited by the staff, perhaps by incorporating a moral distress assessment tool, such as the one developed by Mary C. Corley and colleagues.[8] This assessment tool, potentially coupled with an ethical environment inventory such as the one developed by Charlotte McDaniel,[9] could prove useful in quantifying and documenting a staff's response, thus enabling consultants from both mental health and ethics to recognize and attend to these concerns promptly. Additionally, the use of these tools would help to create a framework for ethics consultation and the organization of the proposed interventions.

A review of the literature indicates that when careproviders perceive that there are ethical issues that they feel powerless to address, an open dialogue among patients, careproviders, and administrative personnel is warranted. Complex care situations, such as the case described here, that involve medical and psychiatric aspects of care and potential ethical dilemmas, are often accompanied by the experience of moral distress. Ethics consultations can often help patients and careproviders think through alternative strategies, utilizing an open and creative approach. An ethics consultation, provided by an individual who is skilled in medical ethics and mental healthcare, is one way to bring patients, family members, and members of the healthcare team to the table and open up a dialogue, creating the space and time to explore potential options to address the needs of all involved.

Interdisciplinary education and collegial practice are two strategies that have been identified to decrease moral distress. They represent a commitment to seek common ground, garner mutual respect for individual roles, and promote discussion of meaningful ways to communicate and collaborate effectively about the ethical problems each group identifies.[10] Moving to increased collegiality and shared practice models may help alleviate moral distress by increasing a sense of shared responsibility and professional satisfaction. Recurring instances of moral distress can indicate underlying systemic problems of poor communication, inadequate collaboration, and perceived powerlessness, all of which must be addressed to develop and sustain a healthy work environment.[11] Incorporating these strategies into everyday practice is an important first step in preventing or alleviating moral distress.

Staff are often reluctant to request an ethics consult.[12] In this case, ultimately the suggestion of an

"extreme intervention" prompted a request for consultation. For this patient, who did not have an active advocate other than the staff, and whose care team expressed concern about their lack of expertise in behavioral health and who felt thwarted by early attempts to involve outside resources, a reluctance to request additional consultation may have reflected and exaggerated their sense of isolation and vulnerability. Ultimately, engaging an outside consultation prompted an additional review of the case at multiple levels of the institution. In retrospect, having a lower threshold for revealing the challenges in delivering care and asking for assistance may have resulted in attention being paid to this case and the mobilization of adequate resources, which may have expedited a move to an appropriate locus of care.

In follow-up discussions, the team who cared for Myles chose to use this case as a learning experience. The action of committing to regularly scheduled interdisciplinary care team meetings provided a natural forum for increased dialogue. By continuing to meet after Myles was discharged, the team was able to develop a realistic plan of care and identify adequately trained, contracted behavioral health staff in anticipation of his subsequent hospitalizations. In a more generalized way, the plan developed for Myles could serve as a template for early recognition and response to other complex care situations that involve patients with co-morbidities of medical and behavioral health needs throughout the organization. Such an approach would wisely include pro-active attention to the staff's needs. To this end, inclusion of a PMH-APN or another individual skilled in mental health and ethics in such planning would be beneficial.

Through collaboration, well-positioned and accessible mental health and ethics consultants could utilize their skills and strengths to improve care for patients and families, and in doing so uncover and address hidden moral distress. While moral distress cannot be eliminated, a systematic approach to assessment can develop new ways to respond to ethical conflict. When instituted on a regular basis, early recognition of and attention to moral distress goes a long way to support the development and maintenance of a healthy work environment, and to positively impact the care of patients and their families.

PRIVACY STATEMENT

Informed consent for permission to publish this case could not be obtained. Some details have been altered to protect the privacy of the patient.

NOTES

1. A. Jameton, *Nursing Practice: The Ethical Issues* (Englewood Cliffs, N.J.: Prentice Hall, 1984).

2. D.M. Huffman and L. Rittenmeyer, "How Professional Nurses Working in Hospital Environments Experience Moral Distress: A Systematic Review," *Critical Care Nurse Clinics of North America* 24, no. 1 (2012): 91-100.

3. C.H. Rushton, "Defining and Addressing Moral Distress: Tools for Critical Care Nursing Leaders," *AACN Advanced Critical Care* 17, no. 2 (2006): 161-8.

4. C.P. Leeman, "Ethics Consultation Masking Psychiatric Issues in Medicine," *Archives of Internal Medicine* 155 (1995): 1715-7.

5. Ibid., 1717.

6. M.U. Walker, "Keeping Moral Space Open: New Images of Ethics Consulting," *Hastings Center Report* 23, no. 2 (March-April 1993): 33-40.

7. Ibid., 38

8. M.C. Corley, R.K. Elswick, R.M. Gorman, and T. Clor, "Development and Evaluation of a Moral Distress Scale," *Journal of Advanced Nursing* 33, no. 2 (2001): 250-6.

9. C. McDaniel, "Ethical Environments: Reports of Practicing Nurses," *Nursing Clinics of North America* 33, no. 2 (1998): 363-72.

10. C.M. Ulrich, A.B. Hamric, and C. Grady, "Moral Distress: A Growing Problem in the Health Professions?" *Hasting Center Report* 40, no. 1 (January-February 2010): 20-2.

11. E.A. Epstein and A.B. Hamric, "Moral Distress, Moral Residue, and the Crescendo Effect," *The Journal of Clinical Ethics* 20, no. 4 (Winter 2009): 330-42.

12. E.J. Gordon and A.B. Hamric, "The Courage to Stand Up: The Cultural Politics of Nurses' Access to Ethics Consultation," *The Journal of Clinical Ethics* 17, no. 3 (Fall 2006): 231-54.