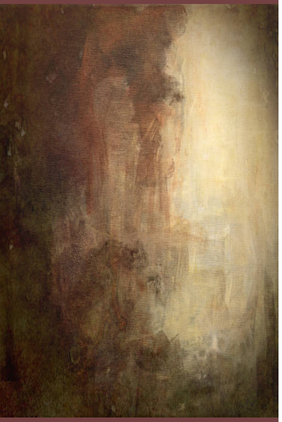

VOLUME 6
NUMBER 2
FALL 2019

JOURNAL OF HOSPITAL ETHICS

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The mission of the John J. Lynch, MD Center for Ethics at MedStar Washington Hospital Center is to help clinicians and other hospital professionals meet a standard of excellence in the care of our patients through education, training, consultation, policy development, and research in clinical ethics. Additionally, when appropriate, we address the ethical concerns of our patients and families directly. The MedStar Washington Hospital Center's bioethics program began in 1982. The John J. Lynch, MD Center for Ethics, subsequently established, is involved in over 300 clinical ethics consultations a year, as well as the development of internationally recognized bioethics conferences and education programming.

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CENTER FOR ETHICS
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JOURNAL OF HOSPITAL ETHICS

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The Mission of the Journal Remains the Same

Dear Readers,

Welcome to volume 6, issue number 2 of *JOHE.* We are very excited about this issue because it is the culmination of changes we've been planning for many, many months. The mission of the journal remains the same. We are only publishing about ethical issues that are relevant to hospital care, both practical and theoretical. Further, for the most part, features will continue to be shorter than standard, academic journals. Our preferred word count stays around 3500 words. Although our journal is an academic one, it is not a research journal, per se. We seek work that is presented in crisp, intellectually engaging, narrative. Our emphasis on scholarly justification and sound argumentation remains unchanged as does our rigorous adherence to our processes for double-blinded peer review.

But there are many perhaps subtle changes that we believe (as does our Editorial Advisory Board) will make *JOHE* a more useful, educational, and meaningful publication. On occasion, we may accept longer pieces. We are interested in pieces, every so often, that include well-researched data. We are now accepting articles "over the transom" as they say in publishing. ("Over the transom" comes from the old days when publishers' offices had heavy wooden doors with a window, or transom, at the top. Those transoms were usually open, and hopeful authors would throw manuscripts at the publisher through that open transom.)

Perhaps one of the most prominent changes is that we are no longer going to constrain the features and cases to a particular focus, as our journal always has in the past. This change is a result of editorial, intellectual, and logistical considerations. First, we have long been concerned that with only two (or previously three) issues a year (I here exclude our ICCEC Proceedings issue because it includes only ICCEC abstracts annually), subscribers might be paying for only one issue that is of real interest to them. That is, for example, we have in the past published an issue on psychiatry and an issue on neonatology. Well, if someone is only interested in one, or worse still, neither, one has subscribed with disappointment. By opening *JOHE* to work only constrained by its commitment to featuring articles relevant to hospital and clinical ethics, it is more likely that there will be something of interest in every issue for each of our subscribers.

As for the intellectual reason, it is much easier to solicit or accept articles and cases of excellence when prospective authors have a slightly broader set of boundaries. There are just more such pieces to choose from. Given that we are now accepting articles "over the transom," prospective authors do not have to guess about, or force their own interests and expertise into, specific topical domains. Also, as we continue our practice of soliciting pieces from particular potential authors, we don't have to focus within such tight margins ourselves, either.

Finally, regarding the logistics of producing *JOHE* while each of us has other responsibilities here at the John J. Lynch, MD Center for Ethics: opening up our content means that we have a better chance of being on time. We are so appreciative to our many, longstanding, and loyal subscribers who, over these many years, have been so patient. By cultivating and reviewing many works at the same time, we can now devote time to several issues, if not volumes, at once.

So, with no further ado: workplace violence is the focus of an article by Martinez, Cartner, and Herbst, an issue to which most of us, unfortunately, can relate. For example, given that the John J. Lynch, MD Center for Ethics is seated in MedStar Washington Hospital Center, in Washington, DC, a 926+ bed, urban, tertiary care, Level 1 Trauma and teaching hospital, when talking about workplace violence, we've unfortunately got a lot of it. According to an article in *Modern Healthcare*, whether it is verbal abuse or physical assaults, violence in the healthcare environment is rampant.[1] Quoting Tom Mihaljevic, MD, president and CEO of the Cleveland Clinic, "Daily, literally daily, we're exposed to violent outbursts. . . ."[1] In Mihaljevic's annual State of the Clinic speech, he called workplace violence a "national epidemic."[1] As data in an article from the U.S. Bureau of Labor Statistics make clear, during the period of 2011 through 2017, intentional injuries were experienced by healthcare and social assistance workers at a far faster rate than in construction, manufacturing, and all of private industry.[2]

Patients are overwhelmingly the perpetrators. This is totally unacceptable.

From an organizational ethics perspective, this means that, in addition to spending their days in difficult environments where they care for and meet the needs of the sick and vulnerable, healthcare providers are the most vulnerable to violence in the workforce. Various hospitals have instituted all sorts of anti-violence strategies such as panic buttons, badged-access-only in certain parts of the hospital, limited visiting hours, de-escalation training, metal detectors, increased police presence, security cameras, and emergency-preparedness training, to name some of the more common.

Development and implementation of violence-deterrence and avoidance programs, however, are tricky. Unlike other kinds of buildings, hospitals have to be open to easy access for patients in acute need and their families. So, the committees working on these matters are always trying, within the culture and architecture of particular hospital buildings, to find the best balance in maintaining open access with increased protections.

Turning from explicit threats of physical harms to matters of abusive and threatening language, the complexity in ethical responses becomes less clear. For purposes of space, let's take two conditions off the table: threats of violence that are empty threats, given the clinical status of the particular patient, and abusive or threatening language from decisionally impaired patients. Such threats of violence, at least in otherwise ethically sound environments, can be ordinarily rolled off the shoulders of staff. Because even if a patient is making threats, or actually behaving in physically harming ways toward hospital caregivers (eg, throwing urinals or food off a meal tray), such patients can be restrained. Here I focus only on abusive, but not physically threatening, behavior by the capacitated patient.

During the period of 2011 through 2017, intentional injuries were experienced by healthcare and social assistance workers at a far faster rate than in construction, manufacturing, and all of private industry.

What if the abuse is only verbally disgusting: lewd or racist? How much nontruly violent, obnoxious abuse must one take? This situation calls for different strategies for deterrence and avoidance than the kinds previously noted, to protect everyone in a hospital from truly violent patients (or family members).

For example, many of us are, or have long since instituted, moral distress rounds in various parts of the hospital. Most commonly, these focus on helping residents, fellows, and nurses work through difficult cases, often difficult deaths, that have left them shaken or deeply conflicted. But, especially with nurses, these moral distress rounds may include attempts to help these caregivers process the most common forms of miserable, obnoxious abuse: the sexist, racist varieties. Informal feedback indicates those who attend these moral distress sessions find them helpful. Nonetheless, thorough evaluation of such moral distress rounds has yet to be studied in well-designed research.

These topics are innovatively explored in our feature by Martinez, Cartner, and Herbst. With their focus on the ethics of discharging threatening, violent, and disruptive patients and family members, they start with scenarios with which many of us will be all too familiar. What is wonderful about this article is the degree to which the authors move from the world of policy to the impacts that policy outcomes can have, not only on patients and families in a particular hospital, but within a large hospital system.

Some of us reading *JOHE* today still remember when Arnold Relman, MD, the great Editor-in-Chief of the *New England Journal of Medicine* from 1977-1991, started writing about the tectonic shifts in medicine that were the result of runaway costs, and the response to those costs: managed care. Relman, rather, advocated for improvements in care that he saw centered around the hospital model of the Mayo Clinic, for example. That is specialized and superior care in a multilayered system, in which physicians were salaried employees. Today, we live in a world in which sprawling hospital systems are common place. The article by Martinez, Cartner, and Herbst makes us think about this kind of structure in relationship to a problem that most of us simply think about at a per-patient/per-encounter level. Perhaps they are right; carefully crafted policy may be the best bulwark against violent and abusive patients.

Turning to our feature that illuminates traumatic brain injury (TBI) in one family, these stories paint a damning picture of the medical professionals' and insurers' disinclination to incorporate new information about TBI into what might be lifesaving, or at minimum life-transforming, but in either case expensive, treatment. Griffin and Anhalt tell stories about family members who suffered what many would consider life-ending or at least lives of permanent dependence. But in two circumstances, patients were transferred to neurorehabilitation programs that specialized in TBI, rather than going the "regular" route to short-term rehabilitation, and then, likely, on to a nursing home for long-term care until their death. These separate efforts resulted in both patients returning to full and active lives. The efforts needed by family and friends to get the patients to these specialized neurorehab facilities, however, seem unfair. While one senses that this family appears particularly privileged and thus unusually well-equipped to mount such efforts, the more average, or especially the impoverished among us, seem unlikely to make use of such rarified facilities. And so, within the new field of neurorehabilitation, we see the same injustices embedded in them that are evident in so many other parts of medicine. To be sure, that does not reduce their importance to the lives of those who do get within their doors when needed.

Such specialized facilities have been a boon to the needs of persons with other kinds of injuries. There are rehabilitation facilities that specialize in backs or joints or are designed for cardiac rehab post heart attack. The history of specialization is invariably one of professional and payor resistance. But the stakes here are very high. Yes, with less-than-state-of-the-art rehab for backs or knees or hearts, life may be shorter or less comfortable, but less-than-standard-of-the-art brain rehab has a high risk of consignment to long-term care in which the "care" part of long-term care can be pretty thin. That is why this article that recounts the seeming pile-up of TBIs in one family who, lucky for them, seemed up to the task of figuring things out at the highest level of medical excellence, is an eye-popping tale. The article points us to making sure that if any of us or our family members have TBI, we know what the rehab possibilities are and how to explain them to our physicians when they don't appear to be as aware.

Which brings us to the piece by Conners and Janda, which examines a different brain problem, that of intracranial hemorrhage (ICH). There are equally eye-popping similarities with the previous article. The main point of the article is that one must advocate to give a patient every reasonable chance to be heard. Conners and Janda call on clinicians, especially, to be careful and intellectually open to seeing what may or may not be present in the spirit of giving patients the best chance at meeting their best functional level.

The last article in this issue of *JOHE* welcomes John Banja as an invited author to our inaugural section devoted to the Program for Neuroethics and Clinical Consciousness at the John J. Lynch, MD Center for Ethics. The founder of the Program, Christian Carrozzo, who is the Senior Editor of *JOHE*, provides an introduction to the Program and this special article on page 112.

In all, we hope that you will find the many changes in this issue to be satisfying and educational. As always, but especially about these shifts towards a slightly different *JOHE*, we would love to hear your thoughts.

Sincerely,

Evan

Evan G. DeRenzo, PhD
Editor-in-Chief

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How Should Integrated Healthcare Systems Anticipate and Respond to Patient-Associated Violence?

Aida F. Martinez, BS, Joel Cartner, BA, JD, and
Jennifer L. Herbst, JD, MBioethics, LLM

INTRODUCTION

The relationship between a patient and a healthcare provider is built on mutual trust, and respect is vital for optimal patient outcomes. There is an expectation that care is provided until both patient and provider agree to its conclusion. If, however, the relationship is compromised, such as in instances of violent or threatening behavior, earlier than expected termination of the therapeutic relationship may be appropriate. Healthcare is inherently intimate, and both patients and providers are vulnerable. While violence is certainly not condoned, it can be reasonably anticipated by healthcare professionals and healthcare systems.[1,2]

For the purposes of this article, we understand violence in this context to be any language or action exhibited by a patient, surrogate, or visitor that is disruptive, insulting, inappropriate, or abusive and that subjectively or objectively threatens the safety of healthcare providers and/or patients. Violent behavior may be the intentional or unintentional result of a prior diagnosis, a current medical concern, or a previous (often negative) experience in healthcare; or it may stem from personalities, characteristics, or differences between individuals. The following three scenarios provide examples of how healthcare-related violence might occur.

SCENARIO ONE

Charles had a history of hypertension and type 2 diabetes mellitus that led to chronic kidney disease that required hemodialysis three times a week for three hours each visit. Charles suffered a myocardial infarction and was admitted to the hospital. Three days into his stay, his care team determined that he was stable enough to receive a round of hemodialysis. Charles provided consent, and indicated that he had regularly received hemodialysis before this admission and was familiar with the process. The team attempted to contact his previous nephrologist, to no avail. Charles inquired as to when he might go home. The physician explained that he would be discharged once his cardiac and renal functions were stable. During the session, Charles became progressively agitated and ripped out the intravenous lines and tubing used, well before the session was complete. When Charles removed the tubing, his blood sprayed over instruments, the floor, and, to a lesser extent, on the staff and the other patient in the room, which put Charles and others at risk of injury and possible infection. The staff were increasingly anxious and concerned for their personal safety and ended the dialysis session. Charles adamantly refused additional treatment from the hospital staff and demanded to be discharged. In the electronic medical record, the care team documented Charles's behavior, concerns about the safety of the other patient in the room, and concerns for their own safety. The care team sought to transfer Charles to another hospital, but no beds were available. Against medical advice, Charles left the hospital. Because of the red flag in his electronic health record, no outpatient clinic in the healthcare system will treat Charles in the future.

SCENARIO TWO

Penelope was a 12-year-old girl who was badly injured in a motor vehicle accident. She survived and had to receive weekly physical therapy (PT) sessions to aid in her recovery and reduce her pain. The outpatient PT clinic was located on the first floor of the hospital where Penelope received her care immediately after the accident. At one of the PT sessions, Penelope's mother Jessica became agitated and anxious when she observed her daughter's pain in moving through the exercises. Jessica interrupted the therapy and yelled at the physical therapist. This became so distracting that Jessica was asked to exit the room. She refused, security personnel were called, and Jessica and Penelope were escorted out of the building. As she left, Jessica threatened the staff of the PT clinic with physical harm "if you ever hurt Penelope like that again." The clinic and the hospital had a "zero tolerance" policy in place, and Jessica's threats were documented in Penelope's electronic health record. Jessica might not be allowed to return. She provided transportation and consent to PT on Penelope's behalf. If Jessica cannot return to the clinic and hospital, it is not clear how Penelope will receive the PT she needs.

SCENARIO THREE

Keith was brought to the emergency department (ED) by ambulance. He was well known to the ED staff and was considered a "frequent flyer" due to his multiple admissions for alcohol intoxication. On this admission to the ER, Keith was belligerent and addressed the nurses and physician with obscene, abusive, and insulting language and tone. The providers felt uncomfortable and threatened by his behavior, but behavior like this was common in the ED, and so they just "dealt with it." Keith was placed in a room to sober up. Keith's girlfriend Allison soon arrived at the ED and demanded to see Keith. The ED's policy of limiting visitors to 10 minutes was enforced, but Allison refused to leave Keith's side. She yelled expletives at the staff as they entered the room and she was physically removed by security personnel. The nurses warily checked on Keith's vitals to ensure that he was stable, vigilant to any violent outbursts from him as well. Keith stated that he wanted to leave the hospital as soon as possible, and the staff conceded to this. As soon as he was alert and no longer intoxicated, Keith was prepared for discharge. The ED staff felt that Keith would soon return with alcohol intoxication, and were not surprised when this occurred two weeks later.

Some argue that healthcare providers, by dint of their training and the social expectations of the profession, are obligated to care for patients, even when providers experience violence or abuse, and that violence should be expected.

ANALYSIS

These scenarios illustrate instances of violent, abusive, or threatening behavior towards providers or staff that originated with a patient, a visitor, or surrogate decision maker. In two of the cases, the therapeutic relationship was terminated before the patient's clinical needs were resolved because the care team felt unsafe, uncomfortable, and disrespected. In the last case, repeated abusive behavior was tolerated because it was expected, and care was provided, although somewhat reluctantly. Was termination of the therapeutic relationship or discharge of the patient ethical?

PROVIDERS HAVE GOOD REASON TO WANT TO BE SAFE

While it is perfectly reasonable to want a safe workplace, the physical vulnerability inherent in healthcare means that violence is often experienced and perhaps should be anticipated.[3,4] Vulnerability without trust can trigger defensive behavior. For some, defensive behavior means a fight. For others, defensive behavior means flight, or otherwise removing themselves from the situation. For still others, it means freezing in place—remaining immobilized until the threat or violence passes. Individual professionals, practices, hospitals, and healthcare systems must work through conflicts between patients and healthcare providers.[5,6]

Historically, physicians could terminate therapeutic relationships with violent patients with few consequences and little scrutiny, especially in the outpatient setting, where health concerns are less acute than they are in most inpatient hospital settings and the availability of nonclinical personnel such as public safety, social work, patient relations, or patient advocates is lower. Termination has been ethically justified for difficult patients, which may include violent and abusive patients, as well as those who are so needy that they "could seriously compromise the physician's ability to provide the care needed by his or her other patients."[7] While physicians have been discouraged from declining care for patients whom they may personally dislike or do not adhere to medications, these patients can be unfairly perceived as "difficult," similar to those who present actual threats of violence.[7,8] Some argue that healthcare providers, by dint of their training and the social expectations of the profession, are obligated to care for patients, even when providers experience violence or abuse, and that violence should be expected. Many healthcare providers have assumed this responsibility.[9,10]

POLICY MUST REFLECT THE CONSOLIDATION OF HEALTHCARE SYSTEMS AND PROVIDE GUIDANCE TO PROVIDERS

In the past, some individual professionals and practices may have been willing and able to tolerate a wider range of behavior, either because the burden of any non-adherent or abusive patient would be borne primarily by the individuals, or there was an implicit code of silence when violence was concerned.[11] Increasingly, though, healthcare is no longer provided by unaffiliated individuals and practices, but rather by larger groups and systems, as a team-based endeavor that involves participation across disciplines and settings.[12,13,14] At present, 90% of careproviders are considered to be highly or super concentrated, defined by the number of providers within the same metropolitan area; 90% of insurers can be described in the same way.[14] Within the same metropolitan area, the vertical and horizontal consolidation of services aims to expand an organization's ability to more efficiently offer more services to more patients across various care settings.[15,16] Ideally, such integration allows the systemic coordination of various specialties to address the multiple needs of patients.

While a provider may still maintain some discretion on whether to invoke a patient termination policy, healthcare system dynamics can add a sense of heightened responsibility and consequences for the system far beyond that of a single professional. With the increased consolidation and integration of healthcare and patient records, a decision to terminate a care relationship with a patient because of violence (whether the patient's, a surrogate's, or a visitor's) may prevent the patient from accessing care anywhere else in the system except the emergency department, and then only if the patient presents with a qualifying medical emergency. Because of the potential systemwide implications of a termination decision and the grave care consequences that a hasty or wrongful decision may have on a patient, healthcare systems should create a policy for termination decisions that protect patients against unfair treatment, act in patients' best interests, protect staff and institutions from unsustainable burdens, and better inform system design.[17]

SYSTEM-RELATED PROMISES CREATE ETHICAL OBLIGATIONS TO SUPPORT PROVIDERS AND PATIENTS

Healthcare systems, due to their large size and manifold components, are complex. Due to these complexities and their at times nebulous arrangement, new and significant ethical challenges are raised by organizational mergers, acquisitions, and integration. While traditional business ethics has been proposed to guide these new issues, the fundamental nature of healthcare requires that justice (which may be perceived as secondary or unnecessary for many businesses) be considered a primary ethical principle that must be upheld by the healthcare system.[18] As DeGeorge argues, a hospital is more than merely a physical facility, but rather is an organization that should act rationally when it "chooses between alternatives, and affects human beings." As such, a hospital has a moral obligation to the human beings that its decisions and actions impact. Additionally, hospitals are established for the primary purpose of the good of patients, and, for this reason, the well-being and care of patients are of principal concern.[19] Because hospitals have a legal obligation to stabilize all who come in with a medical emergency and to ensure the safe discharge of all patients,[20] they are less able to terminate a therapeutic relationship without consequences than outpatient clinics. Hospitals the have expertise and resources to treat the most acute emergent patients. To do this, they tend (more than outpatient clinics) to have more resources for the most complicated patients.

Healthcare systems must obtain revenue to run effectively, provide all of the services that patients require, and compensate those who provide those services. They are also responsible for providing adequate care. Day-to-day operations include taking care of patients and providers. The needs of patients and providers differ; namely, patients need access to adequate healthcare, while providers need an environment in which they have access to the resources that are needed to administer adequate healthcare. Systems make promises to both providers and patients. Providers are guaranteed professional environments that are free of harassment and disruptive behaviors that are safe and healthy, environments of dignity and respect.[21,22,23] Patients are assured treatment without discrimination, delivered in a safe environment.[24,25] Healthcare systems pledge effective communication and access to bioethics committees, and to protective and advocacy services.[26] Patients who make a complaint or who register a grievance are promised that they will receive a written reply and that actions will be taken by the hospital to "make things better."[27,28] Visitors are allowed, unless their presence infringes on the safety of others, and patients are expected to be respectful toward and considerate of staff and other patients.[25,28] As a result of these promises, and considering their moral and ethical obligations, healthcare systems have an obligation to support both providers and patients to prevent or de-escalate conflicts that could result in termination that may, in turn, result in a denial of all but emergency care.[29]

Because hospitals have a legal obligation to stabilize all who come in with a medical emergency and to ensure the safe discharge of all patients, they are less able to terminate a therapeutic relationship without consequences than outpatient clinics.

THE BEHAVIOR OF PATIENTS, SURROGATES, AND VISITORS MAY BE DUE TO REASONS BEYOND THEIR CONTROL

The literature on the termination of patients from hospitals often describes violent or difficult patients as manipulative, destructive, or otherwise abrasive, and often conflates non-adherent and high-conflict patients with violent patients.[30,31] But there is an ethically relevant distinction between nonviolent, difficult patients and patients who threaten the safety of others: while nonviolent, difficult patients affect the therapeutic relationship, patients who threaten others call forth a moral obligation to protect oneself and others.

To the extent that a patient has deliberately sought care from a clinician and continues to have decision-making capacity, the therapeutic relationship may be seen as one of dependency (ie, clinicians are dependent upon patients for information and patients are dependent upon clinicians for care) and asymmetry (ie, patients know far more about their own symptoms, values, and priorities, and clinicians know far more about clinical practice and judgment, available resources, and relevant healthcare system norms and policy). The ethics of care in these circumstances is committed to human flourishing (both of patients and members of the care team) or beneficence, and universally condemns exploitation and hurt (of either patients or members of the care team) or nonmaleficence, and expects patients and members of the care team to work toward these commitments. When patients lack capacity, however, it is only reasonable that they carry less personal responsibility for the human flourishing of the care team. Even so, "violence violates the values on which the practice of care rests," and replaces mutual recognition with alienation. Should there be violent activity, members of the care team and patients are likely, and reasonably, to shift from a focus on care to a focus on risk and control.[32,33]

Difficult behavior in the clinical setting is not idiopathic. The use of the term "difficult" to describe patients often disregards underlying issues of poverty, implicit bias, and ableism.[34,35,36] As a result, any policy for a hospital system should recognize that "hostility, anger, depression, anxiety, and even noncompliance are common reactions to difficult circumstances, even among the psychologically healthy and typically well-adjusted."[29] Without policies and resources, ad hoc determinations to terminate therapeutic relationships may exacerbate existing health disparities for members of communities that are already underrepresented or vulnerable, especially when these decisions do not distinguish between difficult but nonviolent behavior and active threats and acts of violence.

Thus, comprehensive guidance to ethically, justly, and effectively prevent and manage violent behavior is needed. It is preferable to implement a systemwide policy, including education and training on the prevention of violence[37] rather than leave providers and staff members individually responsible for navigating possible termination of care and alternatives to termination of care. Policy that deals with ethical or moral questions may not have a single solution that is applicable across every controversy. Instead, policy must be created to find a reasonable answer, agreed upon by the stakeholders involved.[38] Decisions made in healthcare systems affect more than a single patient, and policy must be written to reflect this by involving in the input of more than one individual provider.[39] Providers, patient relations staff or patient advocates, hospital staff, social workers, healthcare system ombuds, ethics committee members, and even patients, among others, should be included to write and revise policy for a healthcare system's prevention of and response to violence. The patient's perspective is indeed important; the complexities of healthcare systems require a focus on justice for patients and the ethical duty to provide just and fair access for patients, as well as transparency as to how this access is regulated. The involvement of patients (whether current or former patients) to draft and revise system policy will improve the likelihood that the content, procedures, and implementation of the policy reflect care for all of the stakeholders in the system.[40,41] The inclusion of patients supports the ethical concept of respecting patients' autonomy, as they would be able to participate in shared decision making regarding their healthcare.[42]

Historically, individual physicians have generally been expected to send patients notice of termination in writing 30 to 60 days prior to the termination date, and have been encouraged to provide a list of alternative providers from whom patients may seek care.[43,44] These established legal and ethical guidelines are useful in considerations of the dyadic patient-physician relationship. However, when violent behavior occurs within a consolidated and integrated healthcare system, in which multiple participants care for a patient, termination guidelines should recognize their implications for community health and social justice.[45] We present a draft policy that: (1) recognizes the ethically different considerations between difficult but not violent behavior and actual threats and violence; (2) reflects the different roles and relationships between providers, patients, surrogates, and visitors; and (3) leverages the resources and expertise that are available in most hospital settings (which now often act as hubs in integrated health systems) for the benefit of all of the stakeholders in the system (see figure 1).

TERMINATION MAY HAVE PREVIOUSLY UNFORESEEN CONSEQUENCES FOR PATIENTS IN HIGHLY CONCENTRATED AND INTEGRATED HEALTHCARE SYSTEMS

Unlike termination from a single physician's care, termination from a consolidated and integrated systems, especially systems that have a widespread geographic reach and shared electronic health records, can result in the effective denial of all care other than that provided in an emergency department.[46] Let's return to Charles in the first scenario. There has long been a recognized subset of patients who receive dialysis who severely disrupt the treatment of other patients, which occasionally rises to the level of presenting a threat to the physical safety of those who provide their care.[47,48,49] Charles's disruptive behavior put him at risk for termination by his healthcare system, and this risk would be compounded if the healthcare system adopted a strict "zero tolerance" policy for patient violence that included identification in the electronic health system.[50] Zero tolerance policies have been used in the contexts of criminal justice, education, and immigration.[51,52,53] While they are perhaps well intended to protect staff and others, these policies tend to exacerbate historic injustices and community tensions rather than prevent the undesired conduct. Coupled with the characteristics of consolidated healthcare systems as discussed above, and the large geographical area these systems cover, such a termination could prove dire for patients who are most likely to be perceived as violent or merely difficult.[54]

Should Charles's care be terminated by the entire system or network, there would be detrimental effects to his care: without treatment he would die, and treatment would only be available if he presented to an emergency department in crisis. This is not ideal, medically or economically. An alternative policy approach would consider Charles's perspective and seek to understand the cause of his

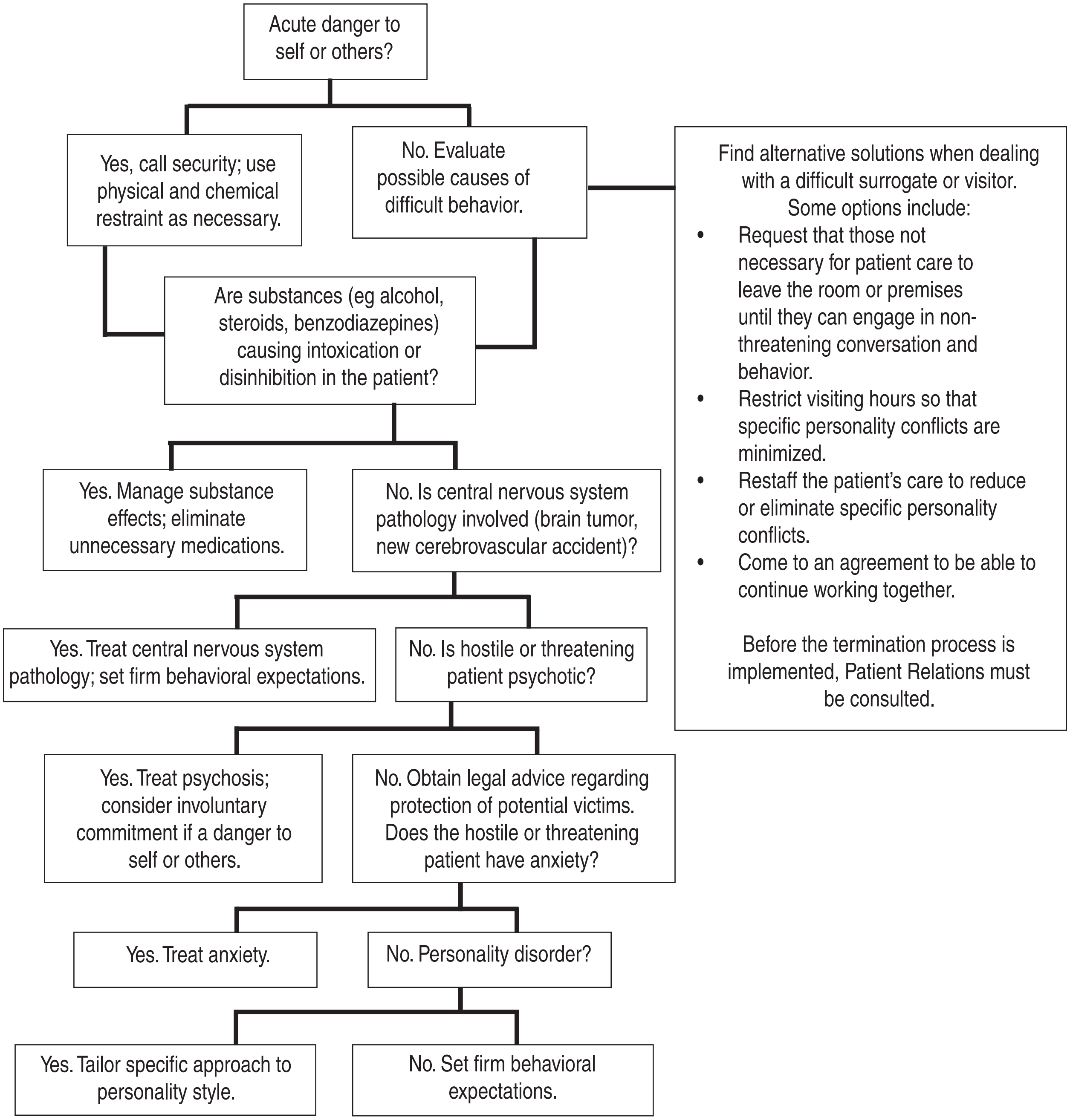

FIGURE 1. Adapted from Peteet JR, Meyer FL, Miovic MK. Possibly Impossible Patients: Management of Difficult Behavior in Oncology Outpatients. *J Oncol Pract.* 2011;7(4):242-246.

behavior, rather than merely punish it.[26] Charles could have a history of negative interactions with healthcare providers and feel misunderstood and vulnerable in healthcare settings. His discomfort might lead to feeling trapped during the hemodialysis process, and he might become so frightened and disturbed that the only solution he sees is to immediately end the dialysis and "escape" the situation. In other words, his defensive behavior might trigger a tendency to fight and flee.

The healthcare team met with Charles and came to understand his perspective. Charles and the providers decided to limit his hemodialysis treatment to 90 minutes instead of the typical three-hour session, to prevent the possibility of future violence. Although 90-minute dialysis sessions are not considered the usual standard of care (and would require documentation of a discussion with Charles), if Charles is able to remain calm during 90-minute-long sessions, this approach would allow continued treatment and not compromise the safety of providers and other patients. Perhaps in instances such as these, in which patients seek discharge against medical advice, there is ethical justification for discharge. Respect for the autonomy of patients includes the recognition that patients can choose to leave a hospital or outpatient clinic and terminate their own care, provided they have the capacity to decide. The question here is, what is the greater threat: putting other patients and staff in danger, or termination of care when a patient cannot consent and will not assent to any form of treatment?

Further investigation into the second scenario, which involved Penelope and her mother Jessica, revealed the ways in which social determinants of health can impact behaviors in healthcare. Jessica's pregnancy with Penelope was unintended, because she did not have ready access to family planning services in her community. Jessica grew up in a family marked by violence and alcohol abuse, which predisposed her to anxiety in adulthood.[55] When the staff sought to de-escalate the situation, they could have called a third party such as a patient advocate, chaplain, or social worker, in addition to security. Jessica could have been connected with resources to better manage her anxiety, whether clinically diagnosed or not, as she observed her daughter's PT sessions.[56] In this way, Penelope could continue to receive the therapy she needs.

Frequent use of the emergency department can present a challenge to providers and be disadvantageous to patients. Purported frequent flyers, more appropriately called "super utilizers,"[46] often have more underlying psychiatric, psychosocial, and substance abuse issues than members of the general public, which can complicate the provision of care. Furthermore, patients are unable to receive appropriate management of chronic conditions in the ED, which is equipped for acute and emergent cases. In the third scenario, Keith would have been better treated outside of the ED, where there would be support and resources to address his substance abuse and addiction.[46,57] Patients such as Keith are often dreaded by providers, as the behavior or emotional features they display often reflect an underlying psychiatric or personality disorder or subclinical trait that may complicate care. Most providers choose to continue to give compassionate care, based on their deep sympathy for patients' suffering. Challenging, violent or difficult patients such as Keith can push providers to their limits.[58]

It is critically important to address the concerns of the medical team and care providers in relation to these sorts of instances. A focus on the promotion of patients' health can help overcome some of these obstacles. An alternative to Keith's discharge, with the expectation that he would soon return, would be to recognize the possible psychosocial or behavior traits fundamental to his behavior. A change of focus to Keith as an individual, not solely as a super utilizer, with the involvement a social worker or case manager and outpatient services, could reduce his use of the ED. Furthermore, Keith's substance abuse issues would be more comprehensively addressed. When hospitals become part of larger integrated healthcare systems, these systems become increasingly responsible for the dearth of outpatient services, including when outpatient providers choose to deny or terminate difficult patients. There cannot be compliance with the Emergency Medical Treatment and Active Labor Act (EMTALA) when there is a zero tolerance policy for patients.

It may be ethical to use a zero tolerance policy in response to violence by patients' visitors. In general, visitors can support the healing process in hospitals. However, in instances of disruption or violence, as in the example of Allison, Keith's girlfriend, visitors may do more to harm than to help. Providers and staff, such as those in the ED, should not be required to endure violent behavior or language from visitors, simply due to their association with a patient.

Each of these proposed alternatives takes staff time and expertise that is often underrepresented in healthcare, especially in the outpatient setting, largely because de-escalation and mediation are skill sets more often seen in professionals and staff who are perceived to be nonclinical (ie, public safety, patient advocates, social workers, ombuds, chaplains, ethics consultants), and clinicians are often unable to bill and be reimbursed for training in these areas. These services are understood to be necessary at most hospitals because of the recognized legal obligation to care for every person who comes to the ED in crisis, but these skills are rarely a part of outpatient services based on the historic understanding that there is no affirmative duty for individual professionals to treat all patients. Given the promises that integrated healthcare systems make to the communities they serve (and the financial implications of driving more patients to the most cost-effective care setting), integrated healthcare systems may have new incentives to provide system-level public safety and patient support services to be used by inpatient and outpatient clinicians. A single policy that is applied across an entire healthcare system will ensure that violent behavior from patients, surrogates, or visitors is responded to in an ethical manner, which will protect the rights and access to healthcare of individuals as well as protect the safety of providers, staff, and the organization.

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Traumatic Brain Injury: Compassionate Care, Not Clinical Nihilism

Leslie C. Griffin, JD, PhD, and Carole S. Anhalt, JD

INTRODUCTION

Traumatic brain injury (TBI) affects millions of Americans every year. Its difficulty challenges physicians, family members, and patients in numerous ways, unique to every patient. Patients always suffer, and need extensive help and care from their families, friends, and medical personnel. In this article we combine our experiences as patient, family member, and friend to argue for compassionate, patient-focused medical care. All hospitals should provide reasonable neurologic recovery based on careful science and attentive listening, always with the hope that patients can do better with physicians' compassionate caretaking and a family's loving support.

THE FAMILY PERSPECTIVE

Ten years ago, I (CSA) got the first of two phone calls that changed my life. My elderly mother had fallen, as she had done what seemed to be a thousand times, but this time she sustained a TBI and was having to undergo emergency surgery to save her life. The incident happened around midday, but my sisters did not call me until almost midnight to tell me because "we didn't want to worry you." I was beyond angry and later found out that the rest of the family had been called by mid-afternoon. Mine was the last call made, even though I live the furthest away from my parents and would have the longest distance to travel.

When I arrived at the hospital the next day, my mother had already had emergency surgery and was stable. When I finally was allowed to see her, she looked like a shell of her previous self. She had bandages around her entire skull and two black eyes. Seeing my mother lying in a hospital bed terrified me. I wondered if I would ever get my mother back. Few injuries take humanity from a person as do those to the brain. TBI, as I later found out, changes everything.

When our whole family was able to talk with my mother's caregivers, the physicians seemed guarded when discussing their outlook for her recovery. The neurologists and neurosurgeon seemed to indicate that my mother would likely never function normally again, and that we might consider nursing home placement. The thought made me feel physically ill. My strong, fiercely independent mother was not going to be placed in nursing home. My dad, a plastic surgeon for more than 50 years, offered to stop practicing in order to care for her. My parents, married for more than 50 years (married the day before his medical school graduation), could never be separated, not even by TBI. The physicians' attitudes toward my mother's prognosis scared and angered me. I wondered, "People can recover from TBI, can't they?"

I now understand that the physicians' fatalistic attitude I witnessed concerning my mother's prognosis is a kind of "therapeutic nihilism."[1]

Norman Doidge, MD, who has written two books on neuroplasticity (the ability of the brain to heal after injury), calls the fatalistic attitude toward TBI "neurological nihilism," and argues that such attitudes are based on a longstanding view of the brain as a machine with fixed parts that cannot be repaired if they are broken.[2] "Localization," as this theory of the brain is called, has now been disproven, although a large percentage of physicians continue to believe it, leading to their fatalistic attitudes toward TBI. Ultimately, one of my mother's physicians discussed neurorehabilitation with my father. There was a very reputable neurorehabilitation center close to the hospital where my mother was taken for surgery. My mother underwent rehabilitation there for three months. Slowly but surely, her fiery personality and wit returned. Today, while she still has some memory problems and a slightly shorter temper than before, she has returned to be the rock of the family she always was.

Eight years after our nightmare with my mother ended, we got a second call that changed our family forever. This time, my brother-in-law, a renowned equestrian, had fallen off his horse, and the horse had landed on him, slamming his head into the ground. My mother called me to tell me that Allen[3] had been airlifted (as was she) to a trauma center. She was crying. She knew what the implications of TBI were, having been through it herself. I assumed that he would make a full recovery like my mother did, but it was not meant to be. Almost two years from the date of the accident, he died. Allen was 57 years old.

Allen lived in a major southeastern city. I assumed the physicians there would take great care of him because he was a major benefactor of the hospital where he was taken; but, in my opinion, he was not given optimal care. He was in a coma for weeks, and when he came out of the coma, he was immediately placed in a nursing home, where he languished until he died. Over the last year of his life, he experienced excruciating headaches and other problems that I now know are typical of TBI patients. His behavioral problems led to an order for electroconvulsive therapy (ECT). As a family member, I questioned the efficacy of ECT for someone whose brain was already injured, but I was advised by my family that his physicians thought it was the right course of action. In the last six months of his life, my parents (who had visited him often) remarked that he seemed to have lost the will to live.

Like Doidge, Fins discusses how physicians are nihilistic about TBI patients and their chances for recovery, and how this may lead to inappropriate do-not-resuscitate orders—and worse.

To my knowledge, Allen's physicians never advocated for neurorehabilitation. His physicians seemed to exude the same fatalistic attitude as most of my mother's physicians. I often wonder if he had been given the opportunity to properly recover from his injury. I also wonder if things could have turned out differently had his physicians been more optimistic about his diagnosis and ordered neurorehabilitation. Joseph J. Fins, MD, MACP, in his book, *Rights Come to Mind*, discusses how people who sustain severe TBI, like my brother-in-law, are often institutionalized in nursing homes, which typically do not have the facilities and infrastructure to properly care for them.[2] Like Doidge,[1] Fins discusses how physicians are nihilistic about TBI patients and their chances for recovery, and how this may lead to inappropriate do-not-resuscitate (DNR) orders—and worse.[2]

In my dissertation research, I read an article on the discharge of TBI patients. A nationwide inpatient sample from 2005 to 2010 reports only 6.8 percent of TBI survivors were discharged to inpatient rehabilitation.[4] This study reflects a physicians' practice patterns that are consistent with the neurological nihilism discussed by Doidge[1] and Fins[2] (and witnessed by my whole family). Such nihilistic attitudes toward TBI patients must change. Otherwise, many more people like my brother-in-law will die prematurely from TBI without the opportunity of recovery. Accurate prognostication matters, especially for TBI patients.

THE PATIENT'S PERSPECTIVE

All kinds of people suffer and study TBI. Last year I (LCG) read a moving story in the *Washington Post* about Rahul Desikan, MD, PhD, a scientist who studied brain disease and developed Lou Gehrig disease (amyotrophic lateral sclerosis—ALS).[5] He continued with his brain research even after his illness struck. When asked why, he gave a powerful answer: "I would turn my attention to other nonscience pleasures if ALS researchers and clinicians would stop using a 'one size fits all' treatment framework and embrace a personalized approach because no two ALS patients are alike."[5]

This is a profound insight that many patients recognize. Desikan needed a "personalized approach because no two ALS patients are alike."[5] Indeed, no two patients *are* alike, in relation to any disease. One size treatment does not fit all. Medical personnel should know this to be true. But, as Desikan wrote, even the best doctors, researchers, and their hospitals may forget this principle when they practice medicine. Patients experience this neglect. It is important that everyone—strangers, family, friends, medical personnel, and insurance companies—treat patients as distinct and unique individuals. This is especially important in the area of TBI, when, due to injury, the patient may seem missing instead of present, unresponsive instead of thinking.

TBI is a particularly difficult type of damage. I know this well because I survived it twice. In 1993 I was hit by a car while walking across the street with the walk sign indicating that it was safe. I had two brain surgeries to repair the damage. In 2016, a young man tried to murder me while I was out for an afternoon walk. He knocked me on my head, and I was left bleeding on the street.

I was fortunate: Strangers saw me and called the police. An ambulance took me to the hospital. The police arrested my attacker. Friends noticed I was missing and searched until they found me in the hospital. They looked at my durable power of attorney, which was on file in the state of Nevada, and called my brother.[6] My brother, Joe Griffin, flew into town and made medical decisions for me. I always tell my students that young, healthy people can face unexpected medical trauma.[7] Things go better if you have your documents in place. Medical personnel should remind patients of this whenever possible. They should also seek to follow the patient's directives when the patient arrives, documented, at the hospital. The more time you spend on medical care before you need it, the better it will be once you do.

While I was still in the hospital and unaware, one of my law school colleagues, Stacey Tovino, JD, PhD, argued with my health insurance company. The insurers wanted to send me to rehabilitation, concluding that there was not much left to my intellectual abilities. Instead, Tovino wanted me to be moved to a particular hospital that was devoted to brain injury. She was able to get me there through her persistence as a health lawyer. My brother took me to that hospital; he flew with me to another state for treatment. Tovino later wrote an article explaining that insurers do not always have patients' best rehabilitation in mind.[8] Patients and their advocates often need to argue with insurers for patients to receive the best care, and it is often a long and difficult struggle. Fortunately, my insurance company covered most of my treatment. That is not true for everyone. In 2018, Americans borrowed $88 billion for healthcare. Many skip treatment entirely because of its cost.[9] That is not a patient-friendly situation. In general, it is urgent that healthcare becomes more accessible and affordable for everyone.

I remember, well, being conscious at the hospital. All I wanted was to go home. No one seemed concerned about challenging my mental development. Instead, they wanted me to follow the routines given to everyone else. They wanted to keep my hopes from getting too high.

Some of my medical treatment contradicted the ideal that the patient always comes first. The literature about patient-reported outcomes (PROs) reports that PROs improve medical care because they take the patient's experience and needs into account.[10] Numerous articles tell medicine to fit patients' stories into the record, not to merely follow new forms and technology.[11] Technology can achieve great things, but following it too closely, while ignoring other aspects of care, can be dangerous. Eric Topol, MD, in his book, *Deep Medicine*, quotes Hippocrates from 2,000 years ago: "It is more important to know what sort of person has [a] disease than to know what sort of disease a person has."[12] Then, Topol adds, "We physicians have long known that patients know their body and that we need to listen to them."[12]

Abraham Verghese, MD, MACP, has explained how growth in technology has left doctors focused on the "iPatient" instead of the real patient. He reminds readers that, in the traditional approach to medicine, "the body is the text, a text that is changing and must be frequently inspected, palpated, percussed, and auscultated."[13] Often, he notes, his students lack real clinical skills because they spend too much time on the technological aspects of medicine. My brain slides looked hopeless to many physicians, and some drew negative conclusions from them. Nonetheless, I kept communicating that I would be okay. I was right. I am healthy and back at work. This patient had confidence in her body, but some caretakers were unwilling to listen to her, rather than their interpretation of her imaging slides.

Many medical personnel emphasize how important it is to focus on the patient. Ghazala Sharieff, MD, MBA, corporate director of physician outreach and medical management at Scripps Health in San Diego, and clinical professor at the University of California San Diego, recently explained "What Putting Patients First Really Looks Like."[14] She describes her "One Thing Different" program, which asks all personnel to do one thing different every day at work. She argues that "health care needs a culture change from one where we too often treat patients as though we are doing them a favor to a culture that places their needs at the center of everything we do." She describes personnel who started telling patients "You are in really good hands," or who just practiced saying hello to one another.

I know how important the patient-focused experience is. In my experience, physicians told me or my family members twice that I had only two possible futures: death or permanent life in a brain-care institution. Medical personnel rarely listened to me or gave me encouragement. As John Tingle, distinguished lecturer at Birmingham Law School, Birmingham, UK, notes, "Good communication is an essential prerequisite for good and safe patient care."[15] Communication is central to medicine, but doctors often become persuaded that TBI may take the ability to communicate away from patients. Doctors often would not listen to my belief that I would become better.

Communication can be affected by biased outlooks and stereotypes toward patients. Studies now regularly explain that medical personnel's treatment of patients suffers from all forms of discrimination: racial, ethnic, gender, the poor, the elderly, disabled, LGBTI, and the overweight. "The medical community is increasingly recognizing that doctors' biases—based on race, gender, obesity or other factors—can harm patients' health."[16] Our country's history of slavery *still* results in blacks and whites being treated unequally.[17,18] Physician burnout may lead to bias.[19] Many authors urge medical programs to teach students to deal with individuals instead of stereotypes, and to treat everyone like a full and distinct human person and not like the subject of a technical study.

Sometimes we learn the most from scientists and physicians who unfortunately have become patients. Fifty years after being an intensive care patient, Edward Viner, MD, reflected that he could distinguish easily one nurse from another. Some nurses cared deeply, and others did not. That made a difference to Viner's care. Viner said the compassionate nurses made a difference and helped him heal. Two doctors tell Viner's story in their recent book, *Compassionomics*. Their scientific research indicates that compassion has a positive effect on patient care. It also keeps medical personnel from burnout. Their research taught them that "Science points to compassionate care as a powerful, evidence-based therapy that is essentially cost free."[20] Despite the freedom and success that compassion brings, however, their study also points to its erosion in healthcare. Compassion is not expensive or time-consuming. And it works. Yet, in this day and age, many practitioners avoid it. We have much to learn from physicians who know how to help patients through compassionate brain care.

AUTHORS

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Have We Been Mistaken About Intracranial Hemorrhages All Along?

Lisa M. Conners, DO, and Paul H. Janda, DO, JD

Arguments in favor of early decisions to limit treatment or recommend withdrawal of care in the setting of intracranial hemorrhage (ICH) claim to mitigate prolonged suffering and avoid costly treatments that are felt to be futile.[1] However, variances or inaccuracies in prognostication as well as physicians' preconceived notions about quality of life and futility of care complicate the matter and raise ethical concerns. In the specific setting of intracranial hemorrhages, the prognosis conveyed to a patient's family can often be overly pessimistic, leading to withdrawal of care and a self-fulfilling prophecy. Studies report that many patients with ICH who are felt to have a poor prognosis may in fact have a reasonable neurologic outcome when treated aggressively.[2]

According to traditional prognostic models, the most important variables when prognosticating patients with ICH are the Glasgow Coma Scale (GCS) at presentation, and hematoma volume. Most studies report a 30-day mortality rate of greater than 90% in those with ICH volume of greater than 60 cm^3 or GCS less than or equal to eight. Other poor prognostic factors include intraventricular hemorrhage, hydrocephalus, active bleeding or expansion of the hemorrhage, midline shift, hyperglycemia, marked hypertension, advanced age, and widened pulse pressure. A 2001 study by Becker et al investigated physicians' biases and preconceived notions about futility of care, as well as variances in prognostication of patients with intracranial hemorrhage. The authors found that many patients who were predicted to have a poor outcome had a reasonable neurologic outcome when they were treated aggressively. The study found that the most important factor in the patients' outcome was the aggressiveness of the treatment provided.[2] At first glance, this study may appear outdated, however the principles argued are still relevant and applicable to this discussion today, as the foundations of prognosticating the outcome of patients with intracranial hemorrhages continue to rely on the computerized tomography (CT) scan as well as the neurologic exam, which have not changed in the last few decades.

Becker et al retrospectively studied 87 patients with non-aneurysmal supratentorial intracranial hemorrhages. Of the 87 patients, 30 died, although care was withdrawn in most (23 of 30) of those patients. Withdrawal of care invariably lead to patients' death, which raised concerns that withdrawal of care in ICH may lead to self-fulfilling prophecies and bias predictive prognostic models, since withdrawal of care invariably lead to patients' death in all cases, and negated all previous clinical and radiographic prognostic factors.[2]

Traditional prognostic models predict a mortality rate of greater than 90% in those with hematoma volume of more than 60cm^3 or initial GCS of eight or less. In Becker's study, 27 patients met these criteria, 18 of whom died prior to discharge. Support was withdrawn in most of those cases (12 of 18), which invariably lead to patients' death. Interestingly, of the nine that survived to discharge, six (66.7%) were discharged to a rehabilitation facility, implying a favorable neurologic outcome and reasonable level of functioning and independence. Based on traditional prognostic models, this subset of patients had an expected mortality rate of greater than 90% and overall poor prognosis. This raises the concern that a significant number of patients with supratentorial ICH are being inappropriately poorly prognosticated based on available predictive models.[2]

In the specific setting of intracranial hemorrhages, the prognosis conveyed to a patient's family can often be overly pessimistic, leading to withdrawal of care and a self-fulfilling prophecy.

As part of their study, Becker et al distributed surveys to neurologists and neurosurgeons to investigate physicians' biases and preconceived notions about the futility of care in the setting of ICH. Eight neurosurgeons and 23 neurologists responded to the survey. Clinical condition, radiographic findings, medical comorbidities, patients' age, and affected hemisphere factored into their decision regarding whether they would recommend aggressive measures or withdrawal of care. The surveys presented four case reports and later compared their expected prognosis by the responders with the actual patients' outcomes following aggressive care.[2]

The first patient was a 58-year-old female with diabetes who was found unresponsive with a GCS of eight. Imaging showed a 74cm^3 left parieto-occipital hemorrhage with extensive intraventricular hemorrhage. There was no midline shift. Several surgeons who were surveyed would have recommended surgical decompression. Only one respondent would have recommended withdrawal of care. The patient had received aggressive medical management without surgical intervention and suffered several complications during her hospitalization. She had a modified Rankin Score (mRS)[3] of five at six-week follow up, denoting severe disability and the inability to ambulate or care for herself.[2]

The second patient was a 32-year-old female with a history of substance abuse who was found down with a GCS of six. A CT scan showed a 139 cm^3 right centrum semiovale intraparenchymal hemorrhage with 20mm midline shift, effacement of cisterns, and uncal herniation. Nearly one-third of the study respondents stated they would recommend withdrawal of care based on the patients' presentation and imaging. In the actual course of events, the patient underwent an emergent hematoma evacuation and, surprisingly, her mRS at six-week follow up was three, signifying that she required some assistance with her care, but was able to ambulate without assistance.[2]

The third patient was a 75-year-old woman with a history of coronary artery disease and breast cancer, found unconscious with a GCS measure of seven. Imaging was notable for a 139 cm^3 right frontal intraparenchymal hemorrhage with 10mm subfalcine shift and intraventricular extension. About 50% of the survey respondents stated they would recommend withdrawal of care in this patient. During the course of events, the patient underwent a hematoma evacuation and, at six-week follow up, her mRS was three, again denoting moderate disability, although she was able to ambulate without assistance.[2]

The fourth and final patient scenario described a 42-year-old female with a history of alcohol and intravenous drug abuse who was found obtunded. She was taking warfarin following a recent mitral valve replacement. A CT scan showed a 103 cm^3 right frontal intraparenchymal hemorrhage with intraventricular extension, 9mm midline shift, and uncal herniation. Her GCS at presentation was three. Not surprisingly, more than 50% of the survey respondents stated they would have recommended withdrawal of care, given traditional prognostic models. Interestingly, the patient underwent an emergent hematoma evacuation, and her neurological status significantly improved. At six-week follow up her mRS was only three, signifying that she was able to ambulate independently. Based on traditional prognostic models, she had a very poor predicted prognosis, with an expected mortality rate of greater than 90%.[2]

These patient scenarios highlight the discrepancies between expected neurological outcome, based on traditional predictive models, and patients' actual outcomes when aggressive measures were taken. Overall, the scenarios also indicate significant variances in prognosticating ICH between healthcare providers. The respondents stated that the level of function at which they felt worthy of using aggressive treatments was an mRS of four, denoting moderately severe disability (persons are unable to walk without assistance and are unable to attend to their own bodily needs without assistance). However, in three of the four patient scenarios, prognosis was predicted to be significantly worse than the actual outcome, raising concerns that physicians' biases regarding the appropriate level of care and the futility of care may inappropriately increase mortality in patients with ICH. Another study found that early decisions to limit care in these patients was associated with a doubling in the short- and long-term risk of death from all causes.[4] Becker et al argue that including patients in studies in which care was withdrawn invariably obscures the data and leads to a self-fulfilling prophecy. Their study suggests that when aggressive measures are taken, many patients who are predicted to have a poor outcome may in fact have a reasonable neurologic recovery.[2] Overall, there are very little data on this subject, as conducting a placebo-controlled study in which some patients are denied aggressive care while others are treated would be unethical. Additionally, withdrawal of care skews the results, as many of these patients require stabilization during their acute phase but recover over the long term. Based on the experiences of many practicing neurologists, and the data available, more investigation on this topic is crucial.

AUTHORS

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Introducing First-Year Dual-Degree Medicine and Public Health Students to Ethics and Professionalism

Samuel A. Kareff, MD, MPH, Meaghan McNulty, MD, MPH, FACP, Kenneth W. Goodman, PhD, and Gauri Agarwal, MD, FACP

INTRODUCTION

Various medical governing bodies stress the role of the hidden curriculum in transmitting key ethics and professionalism topics in medicine and public health to learners.[1] A growing body of research suggests that more active forms of instruction, including case-based scenarios[2] and objective structured clinical examinations,[3] may be useful in conveying such values. Given that ethics and professionalism are not standardized in all health-related curricula, more attention to interventions targeting these crucially important topics is necessary.[4]

Our resource focuses on the explicit instruction of ethics and professionalism values to first-year dual-degree medicine and public health students. While the foundations of ethics and professionalism are broad within both of these fields, we aim to highlight values and/or conflicts that are applicable to both areas of study. Previous studies report that small-group instruction is formative in exposing students to the hidden curriculum.[5] Therefore, we aim to build on this knowledge to determine whether a team-based-learning (TBL) style is equally applicable.

METHODS

A group of clinician-educators, an ethicist, and an upper-level medical student implemented this TBL session during the first week of the medical curriculum for dual-degree medical and public health students in a course entitled Introduction to Medical Professionalism (IMP). The IMP course introduced learners to various aspects of the medical profession, with a specific emphasis on ethics and professionalism. The course departed from the traditional TBL format, and did not require students to prepare prior to the session. The facilitators were familiar with some key concepts of bioethics instruction and were provided a faculty guide. We administered the TBL to an incoming class of 54 dual-degree medical and public health students. Some learners might have had previous instruction in ethics and professionalism topics (eg undergraduate bioethics study), but no learners had received any type of formal instruction in these topics from the University of Miami's graduate schools of health sciences. The study was reviewed and approved by the University of Miami Institutional Review Board prior to its initiation.

The session was allocated two hours. We administered a pre-test of three preclinical scenarios that highlighted key tensions in ethics and/or professionalism inherent to the fields of medicine and/or public health. The pre-test did not formally qualify as a Readiness-Assessment Test and did not require advanced preparation. The learners had 15 minutes to complete the pre-test, and then the facilitator used a PowerPoint presentation to instruct the learners on several key tenets of medical and/or public health ethics and professionalism for 45 minutes.

Learners were then offered three scenarios that alluded to tensions between medical and/or public health ethics in a preclinical context. Scenario 1 described a fellow dual-degree student who used stimulants in the library bathroom to prepare for an upcoming test. Scenario 2 focused on a student who routinely offered to drive his fellow classmates around, despite a history of seizure disorder and a decision not to inform anyone of that medical history. Scenario 3 examined a student's cell phone use while in a simulated clinical encounter.

The 54 learners were divided into six groups of eight and one group of six, and began the interactive portion of the TBL session. The groups were given 15 minutes per scenario to discuss their impressions of the cases, and to integrate their new knowledge from the PowerPoint presentation and confer with their colleagues regarding their own impressions (see table 1). Finally, group representatives shared their collective answers openly with the facilitator and the rest of the learners. Learners were asked to select one ethics and professionalism tenet and defend its applicability in a scenario.

The facilitator provided immediate verbal feedback to create links to the PowerPoint presentation, to ensure that each group's conclusions were considered by all of the learners in the classroom environment. For example, if a learner cited an ethics tenet without adequate supporting evidence from the scenario, the members of another group were asked how they might support that tenet. Once a cogent argument was presented by at least one representative from each group, the facilitator allowed discussion of the next scenario, until all three scenarios were thoroughly discussed. An example facilitation schema follows below.

OUTLINE FOR THE TBL SESSION

Session Objectives

1. Identify at least one ethics or professional value at play in preset clinical scenarios.
2. Describe the importance of an ethical or professional value.
3. Defend the group's choice to the facilitator with clear supporting evidence.

Notes to facilitators

Administer pre-test to students for 15 minutes, followed by delivery of the PowerPoint material for 45 minutes. Divide the learners into groups of six to eight students. Divide students by "counting off" to ensure that learners who are acquainted with each other will be divided among the TBL groups.

Instruct the learners to discuss only the first scenario for 15 minutes and to pick a group representative.

The facilitator should then obtain a commitment from the group representative for the first question in the scenario that reflects the group's consensus before proceeding to the next question in the scenario. For the second question, the facilitator should ask the group representatives their thoughts on conflicting actions and/or ethics and professionalism tenets.

If necessary, the facilitator may refer to the PowerPoint presentation that immediately preceded the TBL to give learners examples of ethics and professionalism values they may use.

SCENARIOS WITH SUGGESTED TOPICS FOR DISCUSSION

Scenario 1: Adderall Use in the Library Bathroom

You walk into the medical school library bathroom and encounter another second-year medical student. She, like the rest of your classmates, is very anxious about the upcoming Respiratory exam. You see her pop an orange and white pill, which you recognize as Adderall, into her mouth and then wash it down with some water from the sink. She notices your presence and brushes off the encounter, declaring, "I swear I'd flunk this Respiratory exam if it weren't for Addy!"

What Do You Do in this Situation? This scenario is to facilitate discussion regarding the inappropriate use of medication for personal gain.

TABLE 1. Session outline (2 hours total):

Session portion	Duration
Pre-test	15 minutes
Didactic session (PowerPoint presentation) and creation of TBL groups	45 minutes
Scenario 1	
Break out	15 minutes
Discussion	5 minutes
Scenario 2	
Break out	15 minutes
Discussion	5 minutes
Scenario 3	
Break out	15 minutes
Discussion	5 minutes

Learners might express a variety of actions they might take in this scenario, including talking to the student, offering help with study habits, confronting the student, encouraging her to obtain services, or do nothing.

Which ethical or professional values must you take into consideration? Learners might name various values, including patient safety, professionalism, integrity, privacy/confidentiality, honesty, or duty to report. Unacceptable answers include more generic statements such as, "This is not a legal use of medication," or "It's just the right thing to do."

Learners might express a variety of actions they might take in this scenario, including talking to the student, offering help with study habits, confronting the student, encouraging her to obtain services, or do nothing.

Scenario 2: Driving Classmates with a Seizure Disorder

While studying late one night in the medical school library, your study partner (a fellow first-year medical student) has a brief lapse of consciousness related to complex partial seizures, a form of epilepsy. You start packing up to take him over to the emergency room, but he insists on staying at the library. He admits to having had seizures in the past, but he has not had one in more than 18 months. He explains that, as soon as he was seizure-free for 12 months, he got his driver's license back, and was not about to go back to a life of public transportation and Uber. Your friend insists that you stay quiet about the seizure, but you know that other classmates often catch a ride with him. You are uncertain about what to do. Should you uphold your classmate's privacy or inform his friends and the medical school administration of the situation?

What Do You Do in this Situation? The scenario is intended to facilitate discussion regarding a perceived threat to public safety and a duty to warn, given knowledge of such information. Learners might express a variety of actions they might take in this scenario, including convincing the student to self-report, informing the student of the health risks of driving with seizures, explaining external effects such as liability to the student, seeking advice from friends and/or administration, or doing nothing.

Which ethical or professional values must you take into consideration? Learners might name various values, including public safety, duty to report, privacy/confidentiality, autonomy, or professionalism. Unacceptable answers include more generic statements such as, "This is the student's decision at the end of the day," or "I have to protect other drivers on the road."

Scenario 3: Cell Phone Use During a Clinical Encounter

While rounding with physician preceptors in the hospital, students take turns performing physical exams on the volunteer patients and should be observing the exams conducted by peers. Although all students are informed that the use of cell phones or other personal devices is unacceptable during these sessions, a student routinely checks his email when other students are conducting their exams. He feels like this time is useful for him to catch up on email.

What Do You Do in this Situation? This scenario is intended to facilitate discussion regarding the demands of professionalism in a collegial environment versus distractors from "the real world." Learners might express a variety of opinions about this scenario, such as a (dis)respectful, rude, or negative impact on others' learning, as well as a variety of actions, such as give constructive feedback, report to the physician preceptor, or do nothing.

Which ethical or professional values must you take into consideration? Learners might name various values, including respect for patients, students, or the preceptor; professionalism; or honesty. Unacceptable answers include more generic statements such as "That's just rude and I wouldn't tolerate it," or "This is acceptable as long as it does not affect me."

RESULTS

We analyzed results from the TBL using Kirkpatrick's pyramid level 1 (reaction). All six

TBL groups successfully fulfilled objectives one through three (as stated in table 1) in this TBL scenario, as demonstrated by their abilities to identify an ethics and professionalism value at play, describe its importance, and defend their choice with supporting evidence to the session facilitator. In addition to the immediate feedback provided by the facilitator, we collected students' evaluations of this TBL resource. Comments obtained from this feedback ranged from "excellent" or "good" (75 percent) to "poor" (8 percent).

We previously had conducted this TBL in a different format utilizing the same three scenarios as both a pre-test and a post-test. In this format, no group discussion took place by the time the facilitator delivered the PowerPoint presentation. Although the method of delivery was slightly changed year to year, we grouped the feedback of 94 learners in the course of two years of this TBL iteration. We analyzed and compared the learners' pre- test and post-test data quantitatively and qualitatively to determine the efficacy of the format before converting to the TBL model. Qualitatively, we observed that learners' reactions to the concept of "ethics principles" varied from the unfamiliar (eg ensuring a support system was present) to quite nuanced (eg no confidentiality was required, given the lack of a patient-careprovider relationship) in the pre-test. This differed from the post-test, during which most students successfully listed ethics and professionalism values, such as those introduced in the PowerPoint presentation. There were numerous statistically significant changes when we used confidence intervals (CIs) to measure the magnitude of group changes, rather than *p* values, to detect significant differences in group means. Tables 2, 3, and 4 give examples of these changes in learning.

DISCUSSION

This TBL adds to the growing literature regarding ethics and professionalism instruction for medical and other health science students. Although there is no gold standard for ethics and professionalism instruction, discussion-based teaching, particularly in a TBL format, may be more effective than traditional didactic instruction.

Several domains achieved statistical significance throughout the students' performance. For example, some of the key themes that facilitators hoped to reinforce, such as patient safety in Scenario 1 (Adderall use), and patient autonomy in Scenario 2 (driving with seizure disorder), were successfully instructed, given the students' citation of these ethics principles in the post-test. These tenets are crucial in understanding an individual clinician's responsibility in treating a single patient, as well as a public health practitioner's competing goals while formulating population health goals. Unfortunately, not all of

TABLE 2. Scenario 1: Adderall use in the library bathroom (*n* = 94; 95% CI = +/- 2.01%)

	Pre-test		Post-test			Pre-test		Post-test	
Actions taken	*n*	%	*n*	%	Ethics principles	*n*	%	*n*	%
Seek to understand student's reason*	42	44.7	48	51.0	Patient safety/inappropriate use of medication*	31	33.0	37	39.4
Offer help with study habits	12	12.8	14	14.9	Professionalism	23	24.5	22	23.4
Confront the student	10	10.6	11	11.7	Integrity	14	14.9	15	16.0
Do nothing	11	11.7	9	9.6	Privacy/confidentiality	11	11.7	9	9.6
Approach nonjudgmentally	11	11.7	9	9.6	No principle cited	9	9.6	7	7.4
Counsel students on risks	5	5.3	8	8.5	(Patient) autonomy	8	8.5	7	7.4
Encourage student to seek help	4	4.3	2	2.1	Honesty	6	6.4	8	8.5
Submit physician incident report	4	4.3	2	2.1	Duty to report	5	5.3	8	8.3
Seek advice from administration*	4	4.3	0	0.0	Respect	5	5.3	7	7.4
Other	3	3.2	2	2.1	Other	4	4.3	3	3.2

* Indicates a statistically significant change between pre- and post-test according to the 95% confidence interval.
Other actions taken included ensuring the student had a support system and talking to others. Other ethical principles included paternalism.

the key themes achieved statistical significance, such as professionalism in Scenario 3 (cell phones in a clinical space). This could be the result of ineffective didactic emphasis, or perhaps might indicate cultural changes regarding technological adaptation in the clinical sphere. Future iterations of this introductory intervention might tackle these tensions more directly.

We recommend this TBL and other similarly dynamic ethics and professionalism instruction methods, given their broad applicability and high rates of positive reception by medical students. The hidden curriculum will remain one of the most fundamental methods of transmission of key ethics and professionalism behaviors to medical students. Nevertheless, more explicit supplementation of these pillars of ethics and professionalism appears to be efficacious. Should future iterations of this TBL be studied, we recommend conducting these (or other previously studied) scenarios in a more "traditional" manner, such as comparison of case and control cohorts (ie, half of the learners receive the intervention and the other half does not). This might lend more credence to the efficacy of this intervention in molding dual-degree students' attitudes and knowledge regarding key pillars of ethics and professionalism. We also recommend the inclusion of nontraditional docents, such as

TABLE 3. Scenario 2: Driving classmates with a seizure disorder (*n* = 94; 95% CI = +/- 2.01)

	Pre-test		Post-test			Pre-test		Post-test	
Actions taken	*n*	%	*n*	%	Ethics principles	*n*	%	*n*	%
Convince the student to self-report	40	42.6	40	42.6	(Public) safety	66	70.2	67	71.3
Inform of health risks	19	20.2	16	17.0	Duty (to do no harm) (to report)*	49	52.1	54	56.3
Explain external effects, including liability and dilemma*	10	10.6	22	23.4	Privacy/confidentiality*	29	30.9	36	38.3
Seek advice from administration*	20	21.2	7	7.4	Autonomy*	11	11.7	20	21.3
Seek advice from friends*	3	3.2	12	12.8	Professionalism	7	7.4	4	4.3
Do nothing	2	2.1	1	1.0	No principle cited	3	3.2	3	3.2
Other	4	4.3	2	2.1	Other	7	7.4	5	5.3

* Indicates a statistically significant change between pre-test and post-test according to the 95% confidence interval.
Other actions taken included telling the friends in question about the seizure disorder. Other ethical principles included integrity, honesty, and, interestingly, not confidentiality because there is no patient-provider relationship between the two students.

TABLE 4. Scenario 3: Cell phone use during clinical encounter (*n* = 94; 95% CI = +/- 2.01)

	Pre-test		Post-test			Pre-test		Post-test	
Actions taken	*n*	%	*n*	%	Ethics principles	*n*	%	*n*	%
Take action*	47	50.0	62	66.0	Respect for patients	43	45.7	45	47.9
Do nothing*	38	40.4	27	28.7	Respect for students*	39	41.5	44	46.8
Disrespectful	28	29.8	25	26.6	Professionalism*	38	40.4	29	30.9
Give constructive feedback	26	27.7	25	26.6	Respect for preceptor	16	17.0	19	20.2
Rude	9	9.6	10	10.6	Respect (in general)	12	12.8	9	9.6
Negative impact on others' learning	6	6.3	5	5.2	No principle cited	6	6.4	8	8.5
Other	4	4.3	2	2.1	Other	11	11.7	11	11.7

* Indicates a statistically significant change between pre- and post-test according to the 95% confidence interval.
Other actions taken included issuing a physician incident report. Other ethical principles included altruism, the golden rule, honesty, and integrity.

hospital ethics committee staff, to conduct such an intervention.

There are a few limitations of our resource that merit discussion. Our TBL took place during a general introduction course that was placed at the very beginning of our dual-degree program's curriculum. Other institutions that have no such course or that launch more traditional preclinical courses immediately may have difficulty finding an adequate time and place to deliver such a TBL. We recommend partnering with other institutions to deliver this important TBL at an opportune session and location separate from the rigors of information-dense preclinical courses.

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CASE 1

Locked-In Syndrome and the Glasgow Coma Scale

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: **1 2 3 4**

PRESENTATION

Mr. Roitman is a 57-year-old man who arrived at the Emergency Department (ED) after suffering a stroke and collapsing in the square of his apartment community. Mr. Roitman remained conscious and was found by three children who were playing in the square at the time of his collapse.

The children called their parents, who then called emergency services. A parent of one of the three children who claimed to know Mr. Roitman and his family followed the ambulance to the hospital while they attempted to contact Mr. Roitman's mother. When Mr. Roitman arrived at the ED, both brain imaging (a CT scan—a computed tomography scan) and a toxicology test were ordered. Prior to any test results, Mr. Roitman went into cardiac arrest, was successfully resuscitated, and intubated. Although hemodynamically stable, Mr. Roitman was no longer conscious.

The toxicology report did not find any illicit drugs in Mr. Roitman's blood at the time of arrival, however, the CT scan revealed a significant intracranial hemorrhage (ICH) from rupture of the basilar artery that appeared to be spreading into the ventral pons. After he noted a clear toxicology, the unit's attending physician, Dr. Hayes, performed a Glasgow Coma Scale (GSC) assessment to determine Mr. Roitman's degree of consciousness, which resulted in a GSC score of 3 (E1V1M1): Dr. Hayes observed no involuntary eye movement, no verbal response, and no voluntary physical movement, which indicated a severe coma via the GSC. Given the pons involvement in helping to regulate certain autonomic functions, although Mr. Roitman appeared stable, the concern became one about whether his breathing and circulatory functions would continue if the hemorrhage should progress to his brainstem or damage the autonomic pathways that extend from the pons to the brainstem.

The accompanying parent of one of the witnessing children was able, finally, to contact Mr. Roitman's mother. She arrived that evening after

Mr. Roitman had been moved to the neurointensive care unit, and was visibly emotionally affected by the condition in which she found her son. It wasn't long before Dr. Hayes came to discuss her son's condition in clear, kind, appreciable detail. Mr. Roitman's mother, a 79-year-old woman, asked several questions about her son's neurological state, as the clinical explanation of what causes and constitutes a coma was unfamiliar to her. Dr. Hayes communicated that the CT scan had revealed a pontine hemorrhage—which, given its location, was considered to be a very serious active bleeding in the brain, often caused by nearby diseased blood vessels that sometimes harden and can eventually rupture if one's blood pressure is sufficiently elevated. After Dr. Hayes took the time to carefully explain her son's condition and the known causes of hemorrhagic strokes, Mrs. Roitman expressed understanding and informed the medical team that Mr. Roitman was not a drug user, to her knowledge, but that he smoked cigarettes daily, throughout his entire adult life. This had likely contributed to atherosclerosis and thus chronic hypertension.

Dr. Hayes then expressed that a further conversation regarding her son's code status would be an important and timely discussion, in case her son suffered another cardiac arrest while in a coma. Mrs. Roitman interrupted Dr. Hayes before he was finished speaking, and firmly expressed that under no circumstances would her son want to live in a coma with no foreseeable return to consciousness, and thus be "robbed of a meaningful existence," in his view. Moreover, Mrs. Roitman said, that having suffered such damage to his brain, if her son were to emerge from his comatose state and be cognitively disabled as a result, there was no doubt that her son would deny—unquestionably—that he wanted to live. After Mrs. Roitman considered what her son's wishes would be, she communicated to Dr. Hayes that a do-not-resuscitate (DNR) order should be put in place.

At this point, in the absence of any kind of relevant advance directive by the patient himself, Dr. Hayes felt that Mrs. Roitman, although devastated, had provided her most reasoned and honest opinion about her son's preferences. Dr. Hayes accepted the substituted judgment, and told Mrs. Roitman that he would order the DNR, and that she could return to her son's room to spend as much time with him as she liked.

Mr. Roitman's mother returned to her son and sat with him for some time. As she spoke with her sister, a neurologist, about the details of her son's condition, she kept a constant watch on him. Suddenly, she noticed what appeared to be some sort of movement near her son's eyes. She put down her phone and approached him for a closer look. When she did, Mr. Roitman appeared to blink, and his eyes moved up and down. She immediately ran out of the room to find a nurse. A nurse then immediately checked Mr. Roitman. His eyes were held partially open, but no repeated movement was seen. The nurse turned to Mrs. Roitman and told her that her son was in a coma, and that this disorder would not allow him to move his eyes. Mrs. Roitman was not satisfied with this answer and asked to urgently speak with Dr. Hayes. Dr. Hayes was not present, but was able to be reached via phone while other staff began to approach Mrs. Roitman in attempts to calm her. Another nurse, trained to assess clinical consciousness using the GSC, was instructed by Dr. Hayes to perform another evaluation. The nurse explained to Mrs. Roitman that she had been instructed to reassess Mr. Roitman's degree of consciousness. Mrs. Roitman understood, thanked the nurse, and stepped aside. However, after the second GSC, Mr. Roitman's responses remained the same and another score of 3 (E1V1M1) resulted from the evaluation. The nurse turned to Mrs. Roitman and expressed how very sorry she was to report that it appeared he remained in a coma, with no appreciable degree of improvement in his level of consciousness. Mrs.

Mrs. Roitman became emotional and told the nurse that she was certain that she saw her son's eyes move, and that "someone better do something about it, now!"

Roitman became emotional and told the nurse that she was certain that she saw her son's eyes move, and that "someone better do something about it, now!"

Because Mrs. Roitman felt that she had no other clinical recourse, she picked up her phone and called her sister back. She explained to her sister the eye movement she witnessed and what the medical team had concluded, to which her sister responded by asking if Mrs. Roitman knew how the team had assessed the coma. Mrs. Roitman explained that she recalled Dr. Hayes telling her about the "Glasgow test," and she believed this was the same test again performed by the nurse after Mrs. Roitman reported seeing her son's eyes move. Her sister then told Mrs. Roitman something she almost couldn't believe: the Glasgow test has been used for over 30 years and has been a great device for assessing consciousness when the disorder is thought to be either coma or vegetative state, and can even assess behaviors that indicate minimal consciousness. However, the Glasgow test cannot tell whether a patient is "locked-in," a disorder during which a person is fully conscious, but mostly paralyzed physically and unable to produce any voluntary motion other than that of blinking and vertical movement of the eyes. The Glasgow test does not test for *voluntary* eye movement nor eye tracking; its eye score ("E") regards only *involuntary*, reactive eye-opening movement. If Mr. Roitman was locked-in, the staff needed to do further tests. Blinking and vertical movement of the eyes might only happen sporadically, and might be difficult to determine. It might be that the bleeding had spread to the brainstem and Mr. Roitman would code, but, in the meantime, he might be "in there."

Immediately, Mrs. Roitman recalled telling Dr. Hayes that she was certain her son would want a DNR order to be put into effect given the situation. Not only might her son's neurologic condition be significantly different than the medical team believed it to be, but he might have been fully conscious and thus able, with proper interpretation, to communicate to his mother and medical team his own direct preferences for a DNR. She then told the nurse what she had learned from her sister, and insisted that someone do something. The nurse told her that Dr. Hayes refused to change the DNR order, based not on Mrs. Roitman's best understanding of what her son's wishes might have been, but due instead to his medical opinion that Mr. Roitman's continuing bleed would eventually reach his brainstem, which would predictably result in cardiac arrest via complete neurologic failure. The hospital resided in a jurisdiction wherein medically justified DNRs were legal, and did not require the agreement of a surrogate or family member, or even the patient, if the clinical condition could be said to be terminal, and the standard of practice, in terms of treatment, futile.

Mrs. Roitman was now beside herself and could not understand why Dr. Hayes would not consider the possibility that, while her son was still alive, he might be fully conscious. The nurse who performed the second GSC, and who spoke to Dr. Hayes regarding the DNR that was now considered unilaterally justified, expressed her own concern and called bioethics for a consultation.

ETHICAL ISSUES

The ethical question of how best to treat Mr. Roitman could only be answered after more medical facts were gathered. Locked-in syndrome is a difficult diagnosis to make, but if there was a possibility that Mr. Roitman was locked-in, that might have altered the care plan in significant ways—if not in the long run, perhaps at least in the immediate time frame.

To the ethicist, there seemed no logically sound reason for Dr. Hayes to have refused to consider that this diagnosis was a possibility. The ethicist needed to explore with Dr. Hayes his reasoning, and, perhaps, needed to advocate for re-examination of the patient, to see whether Mr. Roitman could be locked-in.

RECOMMENDATIONS

1. Re-examine Mr. Roitman for locked-in syndrome.
2. While the examination was pending, the DNR should be reversed, if requested by the patient's mother.
3. Do not have any end-of-life conversations in the patient's room.

REASONING

The recommendation for the ethicist to request more facts, ie, a further examination of the patient's disorder, regarded the possibility that the patient might be locked-in, which could influence the ethical analysis of the case, and, perhaps, could alter decisions about what might be best for Mr. Roitman at that time, and in the future. Locked-in syndrome is a rare disorder of consciousness (DOC) characterized by total paralysis of voluntary muscles in all parts of the body except for the remaining and limited ability to make eye movements.[1] Although the National Institute of Neurological Diseases and Stroke (NINDS) of the National Institutes of Health notes that this is a difficult diagnosis to make, in no small part because the voluntary eye movement of locked-in patients may be infrequent, locked-in syndrome means that patients can think and reason. Patients effectively retain their capacity for conscious experience; in clinical terms related to levels of consciousness, they retain their *awareness*. Thus, it is important to rule out this particular disorder before making decisions about what patients might want, in this case, at the end of life.

Although the disorder leaves patients paralyzed, and Mrs. Roitman indicated that if this were his physical condition he would not want to be sustained, Mrs. Roitman is still within her rights, if there is the possibility of communicating with Mr. Roitman about his clinical status and wishes for his future care, to request that every reasonable effort be made to determine if Mr. Roitman is able to make his own decisions.

If Mr. Roitman is able to communicate with his mother and clinical team members via the blinking or vertical movement of his eyes, it would be important to give him this opportunity. Seeking to understand what might be Mr. Roitman's thoughts at this time might change his medical management, which is why any reasonable evaluative effort to either ascertain that Mr. Roitman has locked-in syndrome, or does not, seems to be both medically and ethically appropriate.

This might mean that Dr. Hayes needs to find someone who can attempt to make this diagnosis if this is not a diagnosis he is skilled at making. If admitting to such inexperience is a barrier to Dr. Hayes's agreement to attempt to make such a diagnosis, Dr. Hayes needs to be able to admit this to himself, rather than dismiss the possibility out of hand. Perhaps Dr. Hayes simply does not think such a diagnosis in Mr. Roitman is a possibility. Nonetheless, every patient should be given a reasonable chance at attaining the highest functional level theoretically plausible in Mr. Roitman's condition, and there is no ethically acceptable reason for Dr. Hayes to ignore locked-in syndrome as a possibility. If it is a possibility, then it is Dr. Hayes's obligation to make, or consult another physician who could make, such a diagnosis.

If such an attempt is made and the diagnosis cannot be made, then Dr. Hayes will have done everything reasonable to give this patient the best chance of communicating his wishes. If Mr. Roitman is unable to do that, then perhaps at least he will be able to communicate with his mother. If the attempt to diagnose locked-in syndrome in Mr. Roitman fails, then his mother can be at peace that everything reasonable that could have been done has been done. If, however, a locked-in syndrome diagnosis can be made, then what seemed like ethically straightforward decision making prior to the diagnosis will need to be revisited.

The recommendation that nobody have any end-of-life conversations in the patient's room regards the possibility that, if the patient is locked-in and thus able to hear, think, and understand, overhearing such conversations could be highly traumatic to someone who is experiencing such a disorder and is thus unable to move or respond. That being said, if Mr. Roitman is experiencing locked-in syndrome, perhaps discussions in his presence regarding the fact that the team understands this to be a possibility could reduce any potential anxiety from which he might be suffering, given his condition and the inability to fully communicate to others his state of awareness. This should nevertheless be a carefully planned, clinical effort, with the priority being potential communication to the patient about very specific information, not a transient conversation about his care merely being held inside his room.

In the meantime, the DNR order should be lifted if the mother requests. Even though the patient is hospitalized in a jurisdiction that allows medically justified DNRs over the objection of family, such clinical discretion is often on firm ground only when a patient is actively dying, and a family requests clinically inappropriate intervention (eg, a patient has widely metastatic lung cancer and is in an actively dying phase and a family continues to insist that the patient be resuscitated). Here, in the face of uncertainty, there is still one possibility that should be determined before consigning this patient to a fully unconscious state, leading to certain death.

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CASE 2

Bad Behavior Toward Nurses: When is Enough, Enough?

Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: **1 2 3 4**

PRESENTATION

Mr. P was a 79-year-old male with a past medical history of end-stage kidney failure who had been on dialysis several years, which was started shortly after a diagnosis of congestive heart failure. He was not a candidate for advanced heart failure interventions and was slowly becoming increasingly demented. He was divorced and did not speak with his ex-wife. He had three children, two sons and a daughter; the daughter and younger son were involved in his care; the oldest son was estranged. Mr. P was admitted to a regular floor bed in the hospital for worsening heart failure.

After his admission, Mr. P made lewd comments to young female nurses who entered his room. When they leaned over Mr. P to provide care, he grabbed at them. The first approach to avoid these problems was to assign male nurses. In response, while Mr. P was not sexually inappropriate with them, he threw food and his urinal at them and yelled at them to leave his room. The team considered the use of soft restraints to prevent Mr. P from grabbing female nurses. Some team members, however, were opposed to the use of restraints for this purpose and preferred to try doubling up on staff, so that one nurse could try to prevent harm or abuse to the other by distracting Mr. P when his primary nurse had to move him or provide care. The nurse manager approved this approach during daytime hours, when there was a sufficient number of staff to double up, but at night the level of staffing was thinner and could not be stretched that far. A nurse contacted the ethics consultation service for a recommendation.

ETHICAL ISSUES

Historically, nurses have had to accept verbal abuse from patients, but tolerance for this kind of behavior is quickly evaporating. In today's modern hospitals, the safety of staff members is a priority. Given that this patient reportedly grabbed at female nurses when they attempted to care for him, his behavior could simply not be tolerated.

Thus, although it is always a patient's right to be treated with dignity and respect—a good to be accorded any hospitalized patient—Mr. P could not be allowed to put the nurses and himself at risk of harm. When it comes to verbal abuse, especially when the patient's dementia is sufficiently advanced to put in question his or her ability to inhibit bad behavior, it is less clear how to protect nurses from being subjected to offensive remarks and still allow them to provide the sort of care that the patient requires. A patient never has a right to be offensive. When a patient is too demented to control his or her own actions, it is difficult to provide a polite environment for staff and the patient and, at the same time, constrain the patient's offensive behavior.

> *Thus, although it is always a patient's right to be treated with dignity and respect—a good to be accorded any hospitalized patient—Mr. P cannot be allowed to put the nurses and himself at risk of harm.*

RECOMMENDATIONS

1. For safety, when anyone cares for Mr. P within a certain proximity, he should be restrained. The choice of restraint should be that which causes the patient the least discomfort. The restraints should be released as quickly as safety permits.
2. Enlist the patient's children to attempt to reduce the inappropriate verbal output. That includes family meetings at the bedside to attempt to impress on the patient that he cannot speak lewdly or throw things at the nurses (although the restraints should be able to cut down on this behavior as well). Perhaps a schedule could be worked out for family to be present in the room as often as is possible and hopefully act as a deterrent against bad behavior.
3. Continue doubling of all nurses whenever reasonable for unit coverage.

REASONING

One reaction is to want to prevent this particular patient from admission to the hospital. That is not an ethically or legally viable solution. If the patient comes in through the Emergency Department (ED) and requires hospital admission, he must be admitted. The ethical norm is that a patient who needs care deserves care, regardless of how unpleasant or problematic that particular patient might be. The legal requirement comes from a 1986 federal law, the Emergency Medical Treatment and Active Labor Act (EMTALA).

EMTALA, known as the "anti-dumping" law, was designed to prevent a hospital's transfer of uninsured or Medicaid patients to a public hospital without, at least, a screen of the patient to ensure that the patient is stable for transfer. Hospitals have three main obligations under EMTALA:

1. An individual who presents at an ED must, at least, be screened for a medical emergency need. Examination and treatment cannot be delayed to verify insurance coverage or method of payment. EDs must post signs that notify patients and visitors of these rights.
2. If a medical emergency exists, treatment must be provided until the patient's emergency has been resolved or the patient is stabilized. If the receiving hospital does not have the capacity to treat the patient adequately, an "appropriate" transfer may then be made.
3. Hospitals with specialized capacities are obligated to accept transfers from hospitals that lack the ability to adequately treat a patient.

Clearly, barring a patient under these circumstances is not an option.

When a patient exhibits the behaviors described in this case, and after the staff talks to the patient, with and without family members present, if the patient is simply too demented or otherwise unable to retain any awareness of the unacceptability of these behaviors, for the patient's and staff's safety, the patient will have to be restrained when nurses are in close proximity. Understandably, some of the team members in this case might be uncomfortable using restraints for this reason. But if the behavior is bad enough to be dangerous to the patient himself or to those caring for him, and all other reasonable solutions have been attempted, restraints might be the only option able to maintain a safe environment for the medical team.

This use of restraints is supported by the National Institutes of Health. The NIH's educational materials, found on MedlinePlus, provide the guidance that "Restraints can help keep a person from getting hurt or doing harm to others, including their caregivers. They are used as a last resort."[1]

What is more difficult to control and less definitively addressed is this patient's lewd verbal behavior. Unfortunately, there is only so much one can do to stop patients from saying terrible things. And this is when enlisting the family may help.

The patient's children can't be there each time a nurse needs to attend to their father. Nevertheless, they might be able to arrange a schedule wherein their involvement in their father's care could be of great help to the caregivers, and increase the comfort of the patient. As an additional benefit, the children may gain a fuller sense of their father's mental and physical disabilities, which may pave the way for their greater understanding as his disease course progresses.

REFERENCES

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CASE 3

The Professionalism of Apology

Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: 1 2 3 4

PRESENTATION

Mr. Jenkins was a 64-year-old man with multiple sclerosis (MS) who came into the hospital because of altered mental status. Brought in by his wife of 48 years, who called 911 when she couldn't rouse her husband, Mr. Jenkins had had MS for the last six years and had declined rapidly in the last year or so. His wife had taken excellent care of him, with the assistance of their three adult children and the children's families, all of whom lived close by.

Mrs. Jenkins didn't notice the muscle contractions immediately seen by the ambulance personnel, who quickly identified that Mr. Jenkins was seizing. Mr. Jenkins was given multiple medications in an unsuccessful attempt to stop the seizures and intubated in the Emergency Department for airway protection.

Once in the hospital's intensive care unit (ICU), the team diagnosed that Mr. Jenkins was in convulsive status epilepticus. Convulsive status epilepticus means the patient has prolonged or repeated tonic-clonic seizures; seizures during which the patient loses consciousness, muscles stiffen, and jerking movements are usually seen. Status, as it is short-handedly referred to by clinicians, means that the patient has seizures that last five minutes or more, going from one seizure to the next without the patient regaining consciousness, a process that lasts at least 30 minutes.

Mr. Jenkins was in the ICU for more than a week. He was prescribed the maximum dosage of antiseizure medications, and when the medical team attempted to reduce the medications even slightly to see how Mr. Jenkins was doing, it was clear that he was still experiencing seizures. Prolonged status epilepticus is a sure sign for a poor cognitive outcome.

Mrs. Jenkins and her adult children took turns with him so that he was never alone, except during the very late hours of the evening into the early morning, because the ICU team insisted that the family go home to rest. Mrs. Jenkins sat daily, right up next to Mr. Jenkins's bed, with an arm draped over him as if to hold him in her arms, and stayed there and cried. The team kept the family informed with daily updates. Mrs. Jenkins and the children understood how critically ill Mr. Jenkins was.

The team physicians started, very gently, to approach the family with the possibility that Mr. Jenkins was not going to make it out of the hospital alive. Mr. Jenkins's children were there every day to support their parents, but were clear that decisions were to be made by Mrs. Jenkins. Although the children appreciated the gravity of the situation, they were resistant to consider the downstream implications of what had been happening.

Somehow, one of the junior residents told the wife that perhaps Mr. Jenkins could be trached and pegged (given a tracheostomy and percutaneous endoscopic gastronomy tube), and so be moved out of the hospital. The wife latched on to the possibility as an alternative to Mr. Jenkin's eventual death in the hospital.

Somehow, one of the junior residents told the wife that perhaps Mr. Jenkins could be trached and pegged, and so be moved out of the hospital.

Unfortunately, it is not possible to trach and peg a patient in status epilepticus for long-term care placement, but the resident who raised the issue lacked this knowledge. The resident thought that she might offer Mrs. Jenkins some hope. Unfortunately, this placed the senior resident and attending physician in a tough situation and they decided to call for an ethics consultation.

The responding clinical ethicist gathered the relevant facts and learned about the junior resident's mention of trach and peg. Because the ethics consultant did not have a medical or a nursing background (she was an attorney-ethicist), she didn't know that trach and peg in a patient with status epilepticus was not an option, but she had enough experience in end-of-life cases to ask whether surgery had already said that they would perform the procedure in question. When the answer is, "No, surgery hasn't been called yet," the ethics consultant asked the resident to please not have any more conversations with the family until surgery weighed in.

Within the hour, the resident texted the hospital ethicist that the surgeons said, "No, a trach and peg is not appropriate in a patient in status epilepticus and we will not perform either procedure." The team then had to manage an end-of-life discussion and take back an incorrectly proffered possibility for the use of a life-extending technology—a possibility that never existed in the first place.

ETHICAL ISSUES

The central ethical issue was that, because of a lack of knowledge, and perhaps because the junior resident was too emotionally uncomfortable in the face of Mrs. Jenkins's grief, the team likely harmed Mrs. Jenkins and her family when it unnecessarily added burden to their grief. Because of the mentioned trach and peg, ie, the offer of a possibly life-extending technology that was not actually possible, the family was put on an emotional roller coaster of heightened expectations, only to have those expectations dissolved. This is one of the most common ways clinicians cause families harm when a patient is actively dying: they raise possibilities before they have acquired the requisite information on whether what they offered can actually be provided. This can be characterized as a mistake in professionalism.

In performing all types of care, especially in end-of-life cases, clinicians must learn the difference between true compassion and simply acting from one's own need for self-soothing in situations of intense patient's or family's emotions. True compassion calls for the ability to put oneself in the place of someone who is suffering. True compassion calls for clinicians to be able to respond to the suffering of others in ways that will reduce or alleviate that suffering. If reducing or alleviating the suffering of deep, appropriately felt grief is likely to be unachievable, as in this case, offering words about how the team is keeping the patient free of pain and distress may be comforting. But, in this case, the resident's knowledge gap and possible lack of emotional experience resulted in setting unrealistic expectations and the need for the medical team to take back an option, and bit of hope, that were mistakenly offered.

RECOMMENDATIONS

1. The attending physician should meet with the wife and children to explain that an error was made in suggesting that a trach and peg was indicated as an option for Mr. Jenkins. The explanation should include why this was *never* a surgical option. Further, the attending should apologize for any additional distress this inappropriate suggestion may have caused the family.
2. The meeting should include the attending, the fellow if there is one, the senior resident, the patient's social worker, a hospital chaplain if requested, the patient's nurse, and the junior resident who made the erroneous suggestion. Once the attending has finished, the junior resident should apologize and state explicitly that the error was made because she didn't know that these procedures could not be performed in a patient with status epilepticus, and she, too, should apologize for any additional distress the error may have caused the family.
3. The attending should then conclude the meeting. The hospital chaplain and social worker should stay with the family as long as requested by the family.
4. There should be some time allowed before the next end-of-life conversation is started with the family, which would allow the family to recover from this unnecessary emotional burden.
5. To support the junior resident, and to help her learn from her mistake, rather than have her be left with the guilt of having made things worse, it would be useful for the attending physician, fellow, and/or senior resident to communicate and show their own compassion for her. To assist in that support, two resources could be recommended to the resident: a book, *Also Human: The Inner Lives of Doctors,*[1] and an article by Ann B. Hamric, John D. Arras, and Margaret E. Mohrmann, "Must We Be Courageous?"[2]

REASONING

The way residents are trained today in the United States is within the framework of the Accreditation Council for Graduate Medical Education (ACGME)'s Core Competencies.[3] In efforts to achieve excellence during residency, and throughout one's career in medicine and surgery, the Core Competencies guide the physician through the domains of medicine that not only set the baseline for technical and scientific competence, they are guideposts towards excellence in the *art* of medicine. The totality of skill in both competence and the art are what come together in the excellence and ethics of medicine. The ACGME's six Core Competencies are:

- Patient care
- Medical knowledge
- Interpersonal communications skills
- Professionalism
- Practice-based learning and improvement
- Systems-based practice[3]

For residents, the ACGME expects competency in all six areas to the level of a new practitioner. But even when these competencies have been met by the end of residency, these are domains that make medicine a profession. Maturity in all six areas is a career-long task for mastering the art of medicine. Mastery of the art of medicine is, arguably, what separates those physicians who are merely competent from those who are truly great.

In the ACGME Professionalism competency, residents are called on to show, "a commitment to carrying out professional responsibilities and an adherence to ethical principles." Residents must demonstrate:

> *Mastery of the art of medicine is, arguably, what separates those physicians who are merely competent from those who are truly great.*

- Compassion, integrity, and respect for others
- Responsiveness to patients' needs that supersedes self-interest
- Respect for patients' privacy and autonomy
- Accountability to patients, society, and the profession
- Sensitivity and responsiveness to a diverse patient population.

Achievement in this domain may be one of the most difficult, because it calls for more than development of skills. This domain calls also for well-shaped character. Professionalism calls for one to have a character marked by compassion and integrity.

Rather than a skill, compassion requires the physician to have the ability to consider the experience of those who are suffering, and to respond with kindness, decency, and the motivation to help. Maturity in emotional response often is what allows the physician to empathize with the suffering of others.

Empathy is the capacity or ability to put oneself in another's shoes. This is not the same thing as feeling sympathy. Sympathy, in this scenario, might be the emotional response of feeling pity or sorrow for the patient or his family. Knowing and acting on this difference is a refined, but critically important, distinction for the emotional maturation of a physician. Feeling sympathetic towards grieving families over the course of many clinical cases and years of practice can be crippling. On the other hand, feeling empathy for a grieving family, while feeling the positive emotion of compassion, can allow one to best understand what that suffering family might need to be soothed: ie, to be sufficiently objective to keep in mind what the range of possible remedies are allows one to keep emotions appropriately in check. It may be the case that learning to walk this emotional fine line allows a physician to maintain the decency needed throughout his or her career to continue to be fully present to the suffering of one's patients and families while protecting him- or herself from emotional overload, that can result in burnout.

Developing this professional ability calls one to become self-reflective; to identify when one is responding to one's own emotional distress (eg, saying that Mr. Jenkins can get a trach and peg when that is not actually an option), as opposed responding to a patient's and family's needs in a way that supersedes self-interest (eg, making sure the family knows Mr. Jenkins is not uncomfortable—if that can be accurately known). Self-awareness calls for experience in self-reflection. It is through self-reflection that a physician learns to quickly distinguish when he or she is making suggestions from selfish motives or from compassion in relation to the care and needs of the patient and family.

This self-awareness merges into another professionalism requirement of the ACGME Core Competencies, and the maturation of a great physician. This is when integrity and the need for an expressed apology come in. *Integrity* is the character inclination of soundness, completeness, incorruptibility, and firm adherence to a code of ethical behavior.

Once the team understood that the suggestion of a trach and peg was inappropriately raised by a team member, the senior member, ie, the attending physician, should model the appropriate behavior for the benefit of the team members. When that behavior potentially harms a patient or family, the attending should be forthright regarding what happened and apologize for the harm it may have caused.

Like the attending who must model responsible behavior for the rest of the team, the junior resident who made the mistake must learn to take responsibility for her mistakes. This is indicative of the ACGME requirement for residents that shapes the character of integrity of the physician and involves the Aristotelian virtue tradition of learning by doing. The more opportunities this resident has to take responsibility for her mistakes, the more she will be inclined to do so appropriately in future.

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"He's Not the Same Person Anymore": The Continuing Problem of Precedent Autonomy

John Banja, PhD

INTRODUCTION TO THE PROGRAM FOR NEUROETHICS & CLINICAL CONSCIOUSNESS, JOHN J. LYNCH, MD CENTER FOR ETHICS

The Program for Neuroethics and Clinical Consciousness (PNCC) at the John J. Lynch, MD Center for Ethics serves as a special research unit devoted to the intersections of philosophy, neuroscience, empirical psychology, and clinical neurology. Its mission is to contribute to relevant policy and practice, offer improved evaluations of decision-making capacity in disorders of consciousness, provide specialized analyses of clinical cases involving neurointensive care, and generate relevant interdisciplinary work, both theoretical and practical, in the form of peer-reviewed scholarship, conference presentations, and educational program development.

The *Journal of Hospital Ethics* is pleased to present the following new periodical section devoted to the PNCC. Our inaugural PNCC section invites the work of none other than the esteemed John Banja, PhD, of the Center for Ethics, Emory University. Banja tackles one of the most persistent philosophical questions surrounding neurointensive care—the problem of precedent autonomy.

Christian Carrozzo, MA
Founder, Program for Neuroethics and Clinical Consciousness (PNCC)
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MEATBALLS AND THE PROBLEM OF PRECEDENT AUTONOMY

In 2012, an interesting case appeared in the bioethics literature that involved the eating preferences of a resident at a long-term care facility.[1] Throughout his adult life and up until the onset of his Alzheimer's disease, "Oscar" had been a committed vegan, as was his wife. Upon admission to the facility, Oscar's wife made it clear that he was not to be served any meat, with which the staff had no problem. One day, however, Oscar was mistakenly served a plate of meatballs. He liked them so much that he demanded they be served at every meal. While the staff had no qualms about Oscar's meatball request and were prepared to comply with it, his wife was vigorously opposed. She argued that the values that defined Oscar's food choices up to the onset of his cognitive decline, ie, the values of "Oscar Then," must be respected and in place for the "Oscar Now." She argued that it would be an unconscionable violation of his dignity if those prior values that were central to his life were violated.

This case presents a less dramatic form of a dilemma that frequently confronts clinicians, especially in end-of-life scenarios. In these cases, families typically argue that their loved one's premorbid wishes—either for or against aggressive life-prolonging care—be honored. Either way, morally distressing situations can occur: Clinicians might resist complying with a request for very aggressive, "do everything" care if that treatment effort seems unreasonable, such as when death from a terminal illness is imminent.[2] Alternatively, clinicians might feel uncomfortable discontinuing life-prolonging care at a family member's request if a patient with serious cognitive disability seems to be tolerating his or her life reasonably well and has good longevity prospects, such as sometimes happens among patients in a minimally conscious state.[3]

The problem of the extent to which we should or shouldn't honor patients' premorbid wishes, especially when there are no formal and explicit advance directives but only imprecise declarations that families assert for the patient, recalls a famous debate beginning about 25 years ago between Ronald Dworkin and Rebecca Dresser. Dworkin coined the phrase "precedent autonomy" and robustly argued that, in cases like Oscar's when there is decent if not compelling evidence of the person's "critical" premorbid interests and wishes, those wishes must hold sway.[4] To do less would be to mock the individual's (precedent) autonomous rights, ignore various legal precedents and practices that enforce last wills and testaments, and, perhaps most of all, disregard the individual's (precedent) construction of his or her dignity. Alternatively and while not entirely disputing the importance of autonomy, Dresser's moral intuitions were more inclined towards beneficence and compassion.[5] She questioned the emphasis on autonomy and wanted to protect persons with severe cognitive disability from harming themselves, especially as they may have erroneously believed that their quality of life with disability would be intolerable or abjectly miserable.[6] Consequently, Dresser might well want to give Oscar Now the benefit of the doubt.

Precedent autonomy in Oscar's case invites at least two problems. The first is the metaphysical problem of identity: If a neurological event has irrevocably changed an individual such that he or she is no longer "the same" person he or she once was, why should we abide by the decisions the individual premorbidly made? If non-identity has resulted from Oscar's Alzheimer's disease such that Oscar Now is *essentially* different from Oscar Then, Oscar Now should not be harmed by the values of Oscar Then, because the latter no longer has the authority to dictate Oscar Now's preferences.[7] But Oscar's case is more complicated: His request for meatballs is problematic not only because it runs so contrary to his previous food preferences, but because it arises from his dementia. The discontinuity of the two Oscars is caused by his Alzheimer's disease, which in turn prompts us to question the validity of his meatball request. If Oscar Now could give rationally compelling reasons for his new predilection for meat, we wouldn't be troubled even if he seems very different from Oscar Then. But Oscar Now's ability to make decisions may be so compromised that it no longer compels our accommodation—which is what Dworkin would argue—such that we should revert to the decisions of Oscar Then. In what follows, I'll describe some responses to the problem and then discuss what cases like this one teach about moral decision making in general.

ATTEMPTS AT A RESOLUTION

However we philosophically construe the problem of identity—and there are many such constructions—it should be obvious that societies need a concept like it to make sense out of their citizens' social understandings and relationships. If we had no concept of persisting sameness through time, we'd be unable to honor living wills and last wills and testaments, attribute credit or blame to anyone, recall our past experiences, reliably recognize people and their intimates, and imagine and plan our futures. Without a social construction of sameness despite moment-to-moment change, our lives and social relationships would be incomprehensible.[8]

Philosophers have proposed various theories to explain identity, but space hardly allows for that analysis. Nevertheless, consider these three philosophical snapshots for explaining identity.

IDENTITY AS SUCCESSIVE PSYCHOLOGICAL STATES

This theory, inspired by the great 17th century political philosopher John Locke, holds that identity results from the way consciousness, and especially memory, integrates a person's mental states and activities backwards through time such that the person's "connectedness" constitutes his or her "self" the person's point of reference.[9] Locke argued that I would continue to be me even if my consciousness was transferred into someone else's body with that person's consciousness removed. Consequently, when the connectedness of one's psychological states is profoundly disrupted by some neurological event like a brain injury or the onset of dementia, one's identity can be lost. Thus, and on this account, one might say Oscar Now is an essentially different individual from Oscar Then. But because Locke also argued that the primary criterion of personhood and the decisional authority that comes with it require the possession of rational, thinking faculties, he'd almost certainly agree with Dworkin that the meatball request could, if not should, be denied. Deprived of his critical faculties, Oscar Now may simply have no decisional rights because he has no real autonomy.

IDENTITY AS MOMENT-TO-MOMENT BIOLOGICAL CAUSATION

This theory, labeled "animalism," entirely discounts psychological states as accounting for identity. Animalists argue that humans are essentially animals and that what accounts for human identity is the moment-by-moment, tightly coupled causational processes whereby their biophysiology generates new physical states that enable and account for our continuing existence.[10] Animalists contend that Lockean intellectual abilities are only a phase in the arc of a person's life. Thus, Oscar's cognitive decline is not identity changing, but an entirely common occurrence on life's way. One might argue that on this account, Oscar Now and Oscar Then are not essentially different or discontinuous. And to the extent that Oscar Now retains some degree of decision-making ability, animalists might opine, like the ethics committee that originally heard this case, that Oscar Now has simply "changed his mind" about eating meat and that his current wish to do so should be respected.

IDENTITY AS NARRATIVE

Suppose Oscar Then had occasionally said to his wife and friends over the years: "As you know, I am deeply opposed to killing animals so that they can be eaten. If the day ever comes when, because of mental decline, I can no longer recall or understand my opposition to eating animal flesh, I nevertheless want you to honor those values. Do not serve me meat even if I demand it." This is known in the bioethics literature as a "Ulysses contract"[11] (and I'll leave it to readers to explore why). Most people, including Dresser, not to mention Dworkin, might find this kind of declaration morally compelling because our cultural values, especially in the West, tend to honor highly explicit declarations of an individual's future desires and wishes.[12] Especially because our political traditions have emphasized individual liberties and freedoms, we respect the right of sufficiently rational adults to control their lives and to author the narrative that becomes their life story. And because Oscar has the most obvious claim to be the principal author of his narrative, it would be hard to comply with his meatball demand if Oscar had made a previous, detailed narrative that required its denial. Negotiating the problem without incident might require a canny chef to whip up a plate of vegan meatballs for Oscar, but that solution would leave us with other problems.

Negotiating the problem without incident might require a canny chef to whip up a plate of vegan meatballs for Oscar, but that solution would leave us with other problems.

Each of these philosophical responses is not without difficulty, but space does not allow for that analysis. Suffice it to say that philosophers have argued about these theories for decades, with none emerging a clear winner. In explaining sameness through time, each theory makes certain points that seem plausible, yet none are thought to be theoretically conclusive. And of course, there is nowhere to go to look to see which one is correct.

But even if we could settle on a theory of identity, we would then be faced with a second problem: deriving an "ought" from an "is." Since Scottish philosopher David Hume, many philosophers have argued that one cannot derive or infer moral propositions from factual claims and metaphysical claims (when they are understood as properly descriptive).[13] Such descriptions aspire to tell us what essentially is the case (in the realm of being or what is), while the former tell us what we ought to do. Consequently, even if we did settle on a theory of identity like Locke's successive psychological state theory, people might still argue that Oscar's meatball preference should be honored, even if he no longer possessed any rights authority due to his impaired cognition. They might invoke moral reasons based on compassion, or on respecting Oscar's inherent dignity (irrespective of his rights authority), or on alleviating care burdens imposed on the health professionals who care for Oscar—any one of which is independent of Locke's identity theory.

And yet, despite the classic is-ought dilemma, narrative identity theory may seem to bridge the gap between a descriptive metaphysics and ethics, perhaps because western societies embrace autonomy as both a metaphysical construct and an ethical principle. That is, the typical western rights holder is both an autonomous, self-governing being and an individual whose metaphysical nature demands our moral respect. Thus, many might find the hypothetical case for narrative identity made above—in which Oscar speculates on the possibility that he might suffer cognitive decline and explicitly tells his kin and friends that he would want no meat served to him in that event—an instance when the gap between is and ought closes. But as Christopher Buford has recently pointed out, narrative resolutions of precedent autonomy impose an immense "epistemic responsibility" on the individual.[14] The problem is, how realistic is it to think that many of us would be able to imagine ourselves in future contexts when our values become problematic? Even if we do imagine ourselves in future contexts, our declarations might still not be explicit enough, such as what happened in the tragic legal case of Michael Martin.[15]

In 1987, Michael Martin sustained a catastrophic brain injury that left him in a minimally conscious state. Although he could occasionally (but not reliably) recognize people and express preferences through grunts and gestures, he could not talk or perform any activities of daily living. After five years of neurological treatments, Michael's wife Mary pleaded that his gastric feeding be discontinued so that he be allowed to die. She argued that throughout her decades-long marriage to Michael, he often remarked that if he was ever catastrophically disabled and like "a vegetable," he would not want to live. Her request was opposed in court by Michael's mother and sister, and *In re Martin* proceeded to the Supreme Court of Michigan, which issued a ruling in 1995.[16] After hearing the evidence, the court ruled against Mary Martin, saying that while her evidence indicated that Michael wouldn't want to live in a "vegetative" state, he wasn't in a vegetative state, but was in a minimally conscious state (MCS). As such, Mary Martin failed to meet her evidentiary burden in convincing the court that Michael's premorbid declarations accurately envisioned the cognitive condition he was now in. Furthermore, Michael's caretakers noted that not only did he not appear to be in discomfort or pain, but that his occasional smiles suggested that he seemed to be tolerating his life in the MCS reasonably well, recalling Dresser's point that individuals sometimes mistakenly believe that a future condition of disability is unlivable or intolerable.

All of this is bewildering. For every moral argument recommending respect for Oscar's precedent autonomy, there may well be an equally good counterargument urging us to deny it. We are left without a satisfying resolution, principle, or precedent that settles the issue, other than the narrative account whose crystal-ball-like requirements may be beyond the cognitive reach of most persons. I shall conclude with some thoughts on this quandary.

TOWARDS A PRAGMATIC RESOLUTION

We might conclude by wondering why we think that a consensually approved resolution to a bioethical problem like precedent autonomy is always available, or lies in wait for some philosophical genius to discover. Perhaps it is because for most of the history of western moral philosophy, many people assumed that the moral universe resembled the physical universe in being bound by universal principles, laws, and theories.[17] So just like natural scientists, moral philosophers understood their job to be discovering the laws of the moral universe and showing how they apply to particular cases.

But suppose this "top down" model of moral decision making is mistaken. Suppose, instead, that rather than discover moral laws or principles, human societies instead encounter concrete and troubling situations and then create and put into practice responses to them—certain ones of which come to be called that society's "morality." Over the ages we test these strategies and revise, refine, or replace them in a seemingly never-ending struggle to deal more adaptively with life's challenges. Suppose, therefore, that morality isn't primarily the scholarly pursuit of abstract or intellectual principles that give us the right answers in cases like Oscar's, but, as Philip Kitcher put it, "an entirely human endeavor, a project begun by our remote ancestors tens of thousands of years ago and continuing indefinitely into the future. There is . . . only a central human predicament, from which we escaped by learning—imperfectly—to regulate our own conduct."[18] So, just as it has taken much of the 20th century to work out our moral practices around privacy, confidentiality, and informed consent, we shouldn't be surprised if it requires a similarly long stretch of time to develop consensually adopted approaches to the dilemmas of precedent autonomy and end-of-life policies.

In Oscar's case, we might try to convince his wife that as the scope of his pleasurable experiences contracts, it would not be morally objectionable to grant him the opportunity to choose what he eats. We might counter her arguments that doing so would be contrary to Oscar's lifelong vegan commitments by pointing out that the Oscar Now does not have the same interests and passions of the Oscar Then. Perhaps we can argue that because Oscar still has interests and preferences, albeit not as intellectually supported as was his veganism, his present decisions should be accommodated. But if his wife persists in her protests—perhaps threatening that Oscar's meat eating would alienate her from him—we might decide to fool Oscar with vegan meatballs, which would be problematic, since it tokens the use of deception as an allowable practice. Alternatively, we can side with his wife, tolerate and try our best to placate Oscar's tantrums over meatless meals if they occur, and patiently wait until his dementia advances to the point where he no longer has food preferences.

Ultimately, the Ethical Committee of the Swedish Board on Health and Welfare decided that Oscar had a right to "change his mind" about veganism, such that he should be served meatballs.[1] Yet that decision was later criticized for a reason that Dworkin would have approved: That Oscar actually lacks the cognitive ability to "change" his mind in a morally compelling way, ie, to evaluate the case for and against veganism with sufficient moral probity.[19] This only shows, however, that it will ultimately fall to us, rather than to philosophers, to resolve the problems our "human predicament" presents. Unfortunately, our solutions will often be far from perfect. But the bioethical practices and their supporting justifications that we adopt will also be the ones we bequeath to future generations. Let us hope they will at least be helpful.

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