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# RHODE ISLAND MEDICAL JOURNAL



## SPECIAL SECTION MEDICAL ETHICS

GUEST EDITOR: THOMAS A. BLEDSOE, MD, FACP

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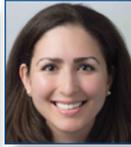
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# Medical Students Analyze Complex Ethical Issues Observed in Clinical Rotations

THOMAS A. BLEDSOE, MD, FACP  
GUEST EDITOR

This issue of the *Rhode Island Medical Journal* features ethically complicated cases identified and analyzed by medical students at Brown University during their third-year clinical clerkships. These cases were selected by a core group of students from over 120 papers submitted by their classmates and provide a unique view into the process of professionalization of medical students. In medical situations that practitioners see every day, the medical students identify issues that are ethically complicated (and sometimes deeply morally troubling). What can we learn from their ethics analyses of these situations?

All medical students at Brown participate in six semi-structured small-group ethics seminars during their clinical rotations with the twin goals of learning to recognize the ethical tensions in all medical encounters and to develop the skills to critically analyze those tensions and find solutions that work for both the members of the health-care team and the patient and family. These medical students, being incompletely professionalized, have a tremendous ability to call out injustices and to identify approaches that do not adequately respect patient autonomy. They see “solutions” that may result in harm to patients while attending to others’ goals and motivations, issues that might well be “swept under the rug” by busy practitioners. With medicine increasingly being delivered by teams in a hierarchical environment, it is likely that ethical concerns of some members of the team are left unaddressed. Learning to identify and address those concerns is a third goal.

Each of the cases presented in this issue was originally identified and analyzed by a student. Each presentation and formal analysis presented here was written collaboratively by the original submitting student and other students



From the cover: International code of medical ethics adopted by the 3rd General Assembly of the World Medical Association, London, 1949.

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in the core group. Practical ethics in the real world requires an action plan that is ethically defensible. Even choosing to do nothing is a choice that requires justification. As such, the formal analysis that follows (by these student authors) is intended to both identify a “best” path forward and to present an ethical justification for it. Members of the Rhode Island Hospital Ethics Committee were then asked to provide additional commentary on the cases as submitted. Some of these Ethics Committee commentaries were provided by 4th year students who had spent the previous 2 years as invited committee members.

In reviewing these cases, the reader will be challenged to decide whether to allow a psychiatrically ill patient to refuse major surgery, how to account for cultural issues in a patient who

may (or may not) have paranoia, what to do about a patient with widely metastatic peritoneal cancer who sells the opiates she gets from the hospice doctor but certainly suffers from severe pain, or whether to continue a surgery when a patient clearly asks the surgeon to stop. If you are conflicted about the “best” path forward after reading these cases, don’t despair, as the conclusions of various consultants are also more often than not conflicting as well.

We hope that these cases stimulate the readers’ interest in and attention to the ethical tensions in their day-to-day clinical work, and that the students’ approach to these situations will be helpful in both addressing and mitigating the ethical tensions in the readers’ clinical work.

**Author**

Thomas A. Bledsoe, MD, FACP, Clinical Associate Professor of Medicine, Alpert Medical School of Brown University.

## Alpert Medical School Teaches Clinical Ethics

THOMAS A. BLEDSOE, MD, FACP

There are as many methods of *teaching* medical ethics as there are of *doing* medical ethics. Despite some degree of standardization across other disciplines within the science of medicine both in the material to be taught and the methods of teaching (pedagogy), clinical ethics education is largely a “home-grown” product in most medical schools. National organizations like the American Society of Bioethics and Humanities have ethics education interest groups but have not developed formal curricula in these areas. Within the house of Medicine, similarly, professional organizations have published ethics guidelines and manuals but these are usually specialty or sub-specialty specific with little attempt or success in identifying and publishing common standards or methods of imparting these professional ethics to students.

Often, medical ethics education is attached to or incorporated into courses that teach general professionalism in the context of teaching the skills of medical interviewing or physical examination. For example, some boundary issues and standards of professional behavior might be appended to teaching about taking a sexual history or specific physical exam maneuvers. In these schools, ethics education is seen as part of the process of professionalization with the hope that professional ethics will be absorbed and then adopted by the students before they get to their more comprehensive clinical training. (Of course, once their clinical rotations get started, they are at risk of being more forcefully swayed into other approaches by the “hidden” curriculum<sup>1</sup> that they pick up informally from colleagues, more senior medical students, house officers, faculty and others who work in health care.)

In some schools, ethics education is taught by philosophers who are more observers of the medical profession than practitioners of it. A particularly complicated or challenging situation that is originally based in an actual case is presented, and then the details of the case are twisted like a Rubik’s cube with a series of “what-if” questions in an attempt to glean the underlying ethical principle in the case.

Many but not all medical schools do teach medical ethics using the approach of “principlism” developed by Beauchamp and Childress and first presented in their book *Principles of Biomedical Ethics* originally published in 1979.<sup>2</sup> Most clinical medical students are able to recite “the big 4” principles of Autonomy, Beneficence, Non-maleficence and Justice while making the mistake of thinking these 4 are presented

as a hierarchy (with autonomy at the top), that this approach can help one decide what to do and that there are only four principles to remember.

### METHODS OF MEDICAL ETHICS

There are actually many different ways of “doing” medical ethics.<sup>3</sup> A relatively simple approach is to use **virtue ethics** and simply ask, “What would a good doctor do?” when faced with an ethically complicated situation. While running the risk of circularity and begging the question of “what makes a good doctor,” this approach is often surprisingly useful. We all have had or have heard about physicians who behave in exemplary (or less than exemplary) ways and some model of ideal behavior is usually close at hand. Another approach is to use **casuistry** or case-based ethics. Like the philosophers mentioned above, this approach starts with the presentation of a case and proceeds with a discussion intending to identify the “best” approach to the situation. Cases that are similar or different in ethically relevant ways are then examined in an effort to identify the aspects of the case that are most ethically relevant while also looking for underlying ethics tenets that are strong enough to stand up in different but similar situations. The hope is that by deciding the best course in this case, the practitioner will have also identified a strategy that will be a useful guide in other ethically similar cases in the future.

The tools of **feminist ethics** can be used to attend to those whose interests are often discounted. **Communitarian ethics** seeks the approach that results in the best outcome for the community (which contrasts with the (mistaken?) approach often taken which allows *individual autonomy* to assume a dominant role in directing behavior).<sup>4</sup>

While many approaches to medical ethics ask the question from the physician’s or practitioner’s perspective, at Brown we tend to lean more heavily on a technique called deliberative bioethics.

### DELIBERATIVE BIOETHICS

Now more than ever, the practice of medicine has become a “team sport,” so the question for the physician is less “what should I do?” and more “What should *we* do?” and that “we” entails the involvement of others.

In a paternalistic model of care delivery, the “we” is the patient and the physician: Using paternalism the physician decides what is best for the patient. As such, the question “What should we do?” is actually “What should I do to (and for) you, the patient?” In a hierarchical practice environment, the physician may consider and then decide on the best approach and inform the rest of the team what has been decided. In this way, akin to medical paternalism, “What *should* we do?” becomes simply “What *will* we do?” as the physician uses authority to direct the team’s actions.

Using a model of shared decision-making, this “What should we do?” seeks to incorporate the values of the patient *as understood by the patient* in an effort to attain a philosophically rich, autonomy-respecting model of shared decision-making by incorporating medical facts, medical science and practical wisdom *and* both patient’s and physician’s goals and values.

Similarly, the approach of **deliberative bioethics** rests on the premise that the “best” approach from an ethics standard is the one that seeks to maximize the goals and values of all of those involved. Included would be conversation about the worthiness and prioritization of conflicting motivations which may be intrapersonal or interpersonal. This approach mirrors shared decision-making between physician and patient.

Ethics is about theories of right action and deliberative bioethics requires the participants to present defensible reasons for one action or another. Gutman and Thompson, in discussing deliberative democracy, have stated that “citizens and officials must justify any demands for collective action by giving reasons that can be accepted by those who are bound by the action.”<sup>5</sup> Similarly, in deliberative bioethics, other members of the medical team and members of the patient’s social circle have a right to the same types of reasons.

Gutman and Thompson have presented four characteristics of ethical reasons that must be present for this approach to succeed.<sup>6</sup> First the reason must be accessible or comprehensible. Second the reason must be moral, i.e., general and therefore applicable to all in similar situations. Third, the reason must be revisable. The very process of entering into ethical deliberation requires that one is willing to revise one’s position, if presented with an adequately compelling argument. Finally, the reason must be respectful. As Gutman and Thompson state, “much moral disagreement will persist even among good-willed and intelligent people” so entering into deliberative bioethics one accepts the possibility that consensus may not be possible. That said, deliberative bioethics seeks to understand and then balance these types of reasons with the goal of a *shared decision* about the best path forward *together*.

## CLINICAL MEDICAL ETHICS EDUCATION AT BROWN

At Brown, clinical ethics education is based on a balance between acquiring the ethics of the profession and the humility required to deliberate ethically with others, whether those others are classmates, patients and their families or other members of a healthcare team. This often requires doing extra work to better understand the perspectives and priorities of others with a goal of *shared decision-making*. As such, students are given an assignment in two of their clinical clerkships to identify and then formally analyze an ethically complex medical situation using assigned templates that encourage use of deliberative ethics.

In our experience with clinical ethics consultations, those involved are often at loggerheads over an intervention with both “sides” pretty sure they are making the right choice and that the others are mistaken. Surprisingly, the facts of the case are often not mutually agreed upon and this lack of a common understanding of the situation may have led to the divergent views on what should or should not happen. Even when the facts are clear to all, goals and values of the participants are often assumed and not adequately explored. Sometimes there is open hostility or disdain for the (assumed) goals of the other side. We have found that stepping back from questions about *interventions* and doing a more formal analysis of *goals* often yields an understanding and appreciation of the other and will frequently allow for respectful shared decision-making moving forward.

In the students’ medicine clerkship, they are asked to complete a 6-step ethics consultation template that mirrors what we use in clinical ethics consultation. In the first step, the facts of the case are presented including biologic, social and psychologic factors. As noted, in actual ethics consultations, what feels like a very complicated ethics dilemma is sometimes simply the result of a failure to communicate. The goal of step 1 is to have a common understanding of the situation before delving into more complicated issues of ethics. In subsequent steps, the student is asked to clarify the pending medical decision and then attempt to crystallize the ethics question. As ethics is often about obligation or permissibility, this may take the form of a “should” or “may” question.

Once the ethics question is posed, there is a conscious attempt to list out those involved in the pending medical decision and subsequent ethics question and then to delineate the needs, preferences, values and obligations related to the decision at hand of each of those involved. Some of these motivations will be readily apparent and some will require some background work. With an eye toward the actual medical decision and knowledge of the motivations of the various “players,” the student is then asked to balance the motivations against each other while also looking for commonalities. This balancing exercise is the crux of the ethics analysis. The final step in the analysis is a “preventive

ethics review" which seeks to learn from the very existence of this ethical dilemma: What could have been done differently in this or a similar case that would have mitigated the ethical tensions?

A slightly different tack is taken in the students' obstetrics and gynecology rotation. In this assignment, the students are also tasked with identifying an ethically complicated medical situation. The obstetrics environment is rich with conflicting motivations and interests and, with minimal prompting, the students present a fascinating array of cases to analyze. Once the case is chosen and presented, the students are asked to simply outline the competing considerations in the case and to put themselves into the role of attending physician and decide what their chosen path would be with supporting reasons for that action. Recognizing that others may well choose differently, they are then asked for the most compelling reasons why one might choose differently. Finally, as James Dwyer has written, there is a great danger in medical ethics in remaining silent<sup>7</sup> and the students are specifically asked to discuss what harms might ensue if they choose to keep their ethics concerns to themselves in the medical situations they have chosen to analyze.

It is our contention that there are ethical tensions inherently present in every medical encounter<sup>8</sup> and that physicians (and especially trainees) disregard those tensions at their own and their patients' peril. Attending to their own personal and professional ethics and also actively seeking to understand and incorporate the goals and values of their patients and colleagues into a model of shared decision-making is presented as an important element in their professional development.

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## Author

Thomas A. Bledsoe, MD, FACP, Clinical Associate Professor of Medicine, Warren Alpert Medical School of Brown University.

## Correspondence

Thomas A. Bledsoe, MD, FACP  
375 Wampanoag Trail  
East Providence, RI 02915  
401-649-4020  
Fax 401-649-4021  
[thomas\\_bledsoe@brown.edu](mailto:thomas_bledsoe@brown.edu)

# Risk-Benefit Evaluation for Surgery in a Patient with Psychiatric Complications

TRAM TRAN, BS; ANDREW M. TAREILA, BA; JEREMY MUDD, BA; YOUNG SEOL, SCB; CAITLIN RYUS, BA, MD, MPH; SUSAN L. MONTMINY, MPA, RN, BSN, CPHRM

## THE CASE

Our patient was a 56-year-old woman with bipolar disorder and chronic obstructive pulmonary disease who continued to smoke, and who presented to the ER with intermittent substernal chest pain. In the last year, she had had several similar episodes, with multiple presentations to the ED. Each time, she refused further evaluation and left the hospital against medical advice, reportedly “to smoke cigarettes.” At this visit an electrocardiogram revealed an inferior non-ST elevation myocardial infarction. She was admitted to the CCU for cardiac angiography, which revealed multi-vessel coronary artery disease. The cardiologists recommended coronary artery bypass graft (CABG) surgery.

During medical rounds, the cardiology team presented the results of the angiogram and treatment recommendations to the patient and her boyfriend. The team also discussed the risks and benefits of the CABG procedure, including medications the patient would start and continue daily, such as dual antiplatelet therapy and other important medications. She also declined nicotine replacement therapy, while becoming aggressive towards medical staff because she was not allowed to leave the hospital to smoke.

As she became increasingly agitated, she stated she was not reliable enough to take the daily medications after surgery and refused the surgery until she could go outside to smoke. Her agitation escalated into violent behavior towards staff and she began pulling out her intravenous lines. In response, the cardiac team called hospital security as well as a psychiatric consult to evaluate her capacity. The psychiatric team determined that she lacked capacity to make medical decisions due to her agitation, inability to make rational decisions, and behaviors that necessitated sedation. While she was sedated, discussions with her family revealed their anxiety about her prognosis and their strong desire for her to undergo CABG.

## THE ETHICS DILEMMA

Should the physicians perform CABG or pursue optimizing medical treatment of the patient’s heart disease and psychiatric disease?

## STUDENT ANALYSIS: (TT, AT, JM, YS)

In this case our patient has stated her clear refusal of CABG surgery. It may be argued that the care team should heed both her aversion to surgery and her refusal to adhere to the post-operative therapy prescribed. Although surgery may be indicated for this medical condition in an ideal candidate, the ethical principle of physician non-maleficence might prevent the physicians from taking this patient to surgery. She is a poor candidate for surgery due to her many risk factors, history of medical non-adherence, and significantly, her expressed intent to stop post-operative medications. In this instance, the anticipated harm of surgery, including significant morbidity or death, could outweigh the potential benefit of improved life expectancy, and surgery could easily be construed as causing harm.

The ethical principle of justice further supports not operating on this patient. Operating on this patient may well deprive others of needed care.<sup>1</sup> Surgical supplies, operating room time, and support personnel required to pursue this operation are expensive. The current healthcare landscape demonstrates that the number of patients with surgical needs will continue to rise while the pool of surgeons trained to treat them will fail to keep pace.<sup>2</sup>

There are, however, many arguments in favor of performing the surgery. It is the nature of medicine that some patients will respond to treatment more poorly than others. This is not, and has never been, a justifiable reason to withhold treatment from patients who do not or potentially will not respond as well. Researchers have rigorously studied the short- and long-term risks of CABG, resulting in many models to predict a patient’s risk based on individual characteristics.<sup>3,4</sup> That the surgery was offered at all indicates this patient could benefit from CABG even with her mental health comorbidities.

To respect patient choice, physicians have a duty to offer care that may reasonably improve patient health, even in the context of risk. A patient with decision-making capacity may decline the intervention. However, in this patient without decision-making capacity, the physician must work with a surrogate decision-maker when one is available.

The American Medical Association’s Principles of Medical Ethics states that physicians are responsible for helping surrogate decision makers use the “standard of substituted judgment” in medical decision-making. The standard obligates

the surrogate to mirror the patient's desires, including "the patient's views about life and how it should be lived," as well as "the patient's attitudes towards sickness, suffering, and certain medical procedures."<sup>5</sup> When our patient was previously thought to have capacity, she had explicitly stated that she was incapable of adhering to complicated treatment plans. Her surrogate decision makers have an obligation to adhere to these "attitudes towards sickness," despite their trepidation with the prognosis.

While the patient's family desires surgery to potentially prolong her life, she has proven time and time again to be non-compliant with physicians for evaluation and treatment of her heart disease. Again, many of these scenarios occurred when the patient was felt to have capacity for medical decision-making. The family argues that the patient's non-compliance is founded on her anxiety and that she would comply with treatments if given the opportunity. The patient, however, has not demonstrated this in past interactions with the healthcare system, specifically in her numerous departures from the Emergency Department against medical advice.

While physicians often determine optimum treatments based on risk-benefit modeling in complicated patients, these determinations are neither static nor permanent. Over time, physicians may get to know their patients and form different opinions of prognosis based on personal expertise with prior cases. In no way does a physician's past offer of a procedure remain open out of principle, especially if new information comes to light that negates the prior risk-benefit assessment. In this case, it behooves the treatment team to focus on optimizing medical and psychiatric treatment of the patient's heart disease and psychiatric comorbidities, before any attempt at surgical intervention.

#### ETHICS COMMITTEE ANALYSIS #1 (SM)

Analyses of these difficult cases benefit greatly from discussions among diverse members of the Hospital Ethics Committee. As Director of Risk Management, I tend to view ethical dilemmas in terms of risks and benefits.

It is not uncommon for patients to be noncompliant with care; patients have the right to make testing and treatment choices, even if these choices appear poorly considered to the medical team. In this case, the team has determined that the patient does not possess the capacity to make her own medical decisions at the moment of crisis. While the psychiatric diagnosis of bipolar disorder may be clouding her ability to do so, at that moment it is the sedatives that are impeding her most. When a patient is deemed to lack capacity, a surrogate decision maker is needed. One of the health care team's jobs is to look for someone who is best positioned to know what the patient would have wanted if she could choose for herself. In cases involving chronic diagnoses, we would first inquire about an advance directive created during previous periods of lucidity. Absent that, in

Rhode Island, there is no law determining who can make decisions for the patient and function as a surrogate. In this case, it may be helpful to follow the guidance of the Rhode Island General Laws Uniform Anatomical Gift Act in determining who may act as the surrogate decision maker.<sup>6</sup> Not infrequently, there are situations in which a friend or clergy member may know the patient's wishes better than family. The surrogate decision maker must be informed that treatment should conform to what the patient would want based on written or oral advance care planning if available. If these preferences are not known, care preferences should be founded on evidence of what the patient would have chosen based on the patient's values, previous choices, and beliefs (substituted judgment) or, failing that, the best interests of the patient.<sup>7</sup>

Patients with psychiatric disorders that directly affect cognition may benefit from both a period of treatment and more intensive efforts at education, in order to optimize understanding of relevant information. Introducing a known and trusted confidante may also help the patient to make decisions consistent with his or her best interest(s).<sup>8</sup>

In this case, the "evidence" known thus far includes the fact that the patient chooses to live her life without pills. These have been seen as decisions on her part worthy of respect (did anyone try to compel her to take her outpatient medications?) and may represent her true wishes. At the same time, she has not expressed suicidal ideation. Other critical questions to ask include: "What is the bigger risk for the patient, not proceeding with the surgery or having it and taking anticoagulant medications inconsistently?" "Is there time to delay the surgery to allow her psychiatric medications to help her gain a more solid capacity?" The health care team's short-term solution of sedating her to avoid her leaving against medical advice is only that. Taking advantage of these chemical restraints to allow family to override a consistently expressed desire to forego surgery by the patient would be similarly difficult to defend from an ethical perspective. (Our Risk Management opinion in such a case would also suggest that such an approach carries significant legal risk.)

If there is time to delay the surgery, the clinical team should continue to work with the patient, the trusted patient confidante and the patient's outpatient providers, while continuing to educate her about the risks of avoiding surgery and the benefits of having it, seeking her consent.

#### ETHICS COMMITTEE ANALYSIS #2 (CR)

The patient in question is having an NSTEMI and CABG surgery is indicated. Without this surgery, she has a very high risk of severe morbidity and death. It has been determined that she lacks capacity for medical decision-making and her family would like her to undergo CABG.<sup>9</sup> However, all parties are concerned that she will be noncompliant with

her anticoagulant medication and continue to smoke. The question of whether to move forward with surgery will be based on the team's concern for noncompliance, essentially their assessment of her ability to care for herself. They must decide whether her noncompliance is of greater risk than forgoing the surgery altogether.

To perform a surgery and put her at risk for clotting raises the specter of violating the principle of non-maleficence even though serious clotting is not an inevitability. We don't know if or how often she will neglect to take her pills.

We have many other patients who end up in the cath lab after decades of artery hardening smoking, neglected diabetes, etc., yet we continue to provide treatments from of our duty of beneficence.<sup>10</sup> It would be neglectful to deny her the standard of care that we would provide to another patient who simply didn't declare as stubbornly and honestly about the likelihood of noncompliance. Doing so violates our obligation to beneficence as well as the principle of justice. Unlike transplant recipients, our patient does not have to prove herself to be capable of compliance.<sup>11</sup> Though cardiac surgery is expensive, her receiving a CABG does not mean someone else will not. She has been declared to lack capacity to decline care and CABG is the standard of care.

It is also quite possible that her mental health will improve and that she will become more capable of keeping up with daily medication. Perhaps an unjust distribution of resources left her incapacitated by psychiatric illness, and now facing denial of lifesaving surgery because she doesn't have the coping skills to take a daily medication. We can attempt to address the broader psychosocial context at play and mitigate her noncompliance with wrap-around services at discharge. It is our ethical obligation to serve and not abandon our patients, to perform the standard of care when possible, and to provide the opportunity for patients to recover from ailments of the body as well as the mind. For these reasons, the most ethically defensible course is to perform the CABG with the valid informed consent of her surrogate decision-makers, and to then work with the patient upon discharge to give her the best chance for health through her surgical recovery and beyond.

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## Authors

Tram Tran, BS, Alpert Medical School of Brown University, Providence, RI.

Andrew M. Tareila, BA, Alpert Medical School of Brown University, Providence, RI.

Jeremy Mudd, BA, Alpert Medical School of Brown University, Providence, RI.

Young Seol, ScB, Alpert Medical School of Brown University, Providence, RI.

Caitlin Ryus, BA, MD, MPH; Resident, Yale University Emergency Medicine.

Susan L. Montminy, MPA, RN, BSN, CPHRM; Director, Clinical Risk Management, Lifespan, Providence, RI.

## Correspondence

Andrew M. Tareila

Warren Alpert Medical School of Brown University

222 Richmond St.

Providence, RI 02903

Andrew.Tareila@brown.edu

# To Continue or to Withhold Opioid Analgesics? An Ethical Dilemma Involving a 63-year-old Cancer Patient Who ‘Broke the Pain Contract’

NICHOLAS LEMME, BS; BRYAN LEYVA, BA; RACHEL OCCHIOGROSSO, BS; YOUNG SEOL, ScB; JAMES M. BADGER, PhD; MARGARET MANNIX, PhD

## THE CASE

We present a 63-year-old woman with a history of poly-substance abuse, end-stage pancreatic adenocarcinoma and ten recent admissions for pain control. She re-presented with severe epigastric pain and anorexia. Prior to presentation, the patient's pain was controlled with opiates prescribed by a palliative care physician. This physician was no longer prescribing opiates because of a breach in the patient's pain contract: the patient was believed to be selling her opiates to support her methamphetamine addiction. At the time of previous discharges, she would be given a short course of opiates to last until the follow-up appointment. Despite this, the patient would return days after discharge complaining of severe pain and asking for or even demanding more pain medication. Upon each re-admission, even though the patient's toxicology screen was positive for methamphetamines, opiates were restarted. Per the chart, the patient had admitted that she was selling her pills to obtain illicit drugs. Consequently, during the patient's final admission, the patient's treatment team encountered an ethical dilemma.

## THE DILEMMA

Should the team again prescribe this patient opiate pain medication on discharge to treat her pain until outpatient care could be established *or* should treatment be withheld due to the knowledge of the patient's continued illicit drug use and selling of her prescription medications?

## STUDENT ANALYSIS (BL, NL, RO, YS)

The ethical dimensions of this case are complex, especially when one considers the fact that Rhode Island (RI) ranks first in the country in opioid-related deaths. Deaths from overdose have occurred from illicit drugs, prescription medication, and combinations of both. In 2016, there were 1,567 overdose case reports in RI, 336 of which resulted in death. This represents a 16 percent increase in drug-related overdose deaths since 2015. Although the rate of deaths caused by prescription drugs has leveled since 2009, deaths from illicit drugs are increasing.<sup>2</sup> In addition, overdose deaths caused by dual use of illicit drugs and prescription medication are up nearly a third since 2011.

Like many other states, the overdose crisis in RI began

with prescription drugs. Health-care providers, who are part of the reason for the opioid epidemic<sup>3,4</sup>, have an obligation to help to prevent opioid-related deaths by ensuring that those who are prescribed opioids are using them responsibly.<sup>5</sup> Model “pain contracts” typically include terms of treatment including risks and benefits of treatment, prohibited behaviors and points of termination, patient responsibilities, and rules for interacting with caregivers. Typically, contracts include statements that explicitly prohibit patients from giving (or selling) their prescription medications to anyone else, and discourage them from using any mind or mood-altering or illicit drugs while receiving treatment unless authorized by a physician.<sup>6</sup> Willfully prescribing opioids to this patient in the context of her untreated methamphetamine addiction carries risks beyond those of the opiates themselves. For example, providers run the risk of supporting the patient and others' illicit drug addiction, and thereby contributing to the state's opioid crisis. Since the patient is not complying with her end of the pain contract, this provider team may be well supported, under the ethical principle of non-maleficence, to terminate the contract and withhold treatment.

It is important, however, to remember that controlled substance agreements exist not to punish patients who do not act in accordance with physician goals, but rather to allow personalized patient counseling and promote shared decision-making about the risks and benefits of opioid use.<sup>7</sup> The use of these agreements as an enforcement tool only serves to further stigmatize patients with chronic pain and erodes their access to healthcare.<sup>8</sup> Moreover, such usage is frequently ineffective, as patients with legitimate needs for pain medication (as in this case of a patient with pancreatic cancer) can often easily acquire pain medication from other physicians. In this view, it is the role of the physician to build a therapeutic alliance with the patient, instead of effectively forcing her to switch providers to obtain the same outcome of receiving her required pain medications or being left without treatment of *either* her pain *or* her methamphetamine addiction. Such handoffs of patients only cause discontinuities in care, leading to suboptimal management and poor patient-doctor relationships.

Physicians should have a goal of respecting patient autonomy while seeking to optimize outcomes. This means allowing the patient to define what the best goals are, even if they may be at odds with medical opinion. This is especially true

in the realm of oncology and palliative care, where patients are faced with a deeply intimate choice and can make a wide variety of decisions about their goals of care. While physicians should not endorse or become complicit in decisions that harm a patient's health, such as abusing methamphetamine, they must also respect the patient's freedom to decide to continue such actions. It would be more productive to establish a trusting relationship with the patient and explore the patient's motivations for using methamphetamine and encourage treatment, rather than attempting to forcibly reduce her access to methamphetamine by withholding important and indicated medical therapies.

Additionally, this case was noteworthy because it illustrated the competing demands under which physicians are often placed – specifically, balancing the physician's obligation to the patient with the obligation to society. Clearly, the sobering facts surrounding the explosive rise of prescription and illicit opioid abuse epidemic illustrate that physicians and other public health professionals have an ethical obligation to ensure that any opiates provided are in the smallest dose possible and used appropriately. However, in patients with legitimate and ever-changing needs such as this patient, it is very difficult to advocate for cessation of opiate prescriptions even with the suggestion that this patient may be using these prescriptions inappropriately. Ultimately, we recommend a compromise solution such as a discharge with appropriate home follow-up in which a visiting provider could provide medication in small amounts frequently, while continuing to monitor the patient's pain needs. This would minimize the risk that the opioids are sold or exchanged. This setup would give the patient, suffering from a devastating illness, the opportunity to have more of a focus on quality of life at the end of her life.

There is concern that discharging patients from a pain practice serves to further stigmatize them and deny care to those most in need. Pain contracts are an important tool to establish a physician-patient relationship but can become ethically fraught if a patient violates the terms of the agreement and the physician then feels bound to remove them from their practice. This situation may be further complicated if a patient's objectionable actions may have been influenced by their disease itself. A team-based approach that is mindful of community and outpatient resources may prove to be helpful to find creative solutions to continue to ensure appropriate treatment for patients who may struggle to have access to care. This case illustrates the degree to which decisions to continue care or discharge a patient from a practice are individualized and heavily influenced by the details of each patient's case. The specter of the opioid crisis suggests that more attention needs to be given to any possible instance of opioid abuse, but particularly in end-of-life cases, individual physician judgment should take precedence to ensure compassionate and ethical care.

### ETHICS COMMITTEE ANALYSIS #1 (JB)

This case study illustrates a healthcare provider's ethical conflict of wanting to minimize the potential harm of prescribing opioids to a patient who acknowledges active drug diversion while addressing her legitimate need for pain management due to underlying abdominal cancer. The patient was described as seeking recurrent acute care hospitalizations for pain control but, upon discharge, would sell her prescribed opioids to purchase methamphetamines. The patient has a diagnosis of cancer and presumed methamphetamine use disorder. Compton<sup>9</sup> reports that there is a lack of evidenced-based guidelines for the management of chronic pain in patients with a history of addiction.

Although the patient has the autonomy (right) to make her own decisions about the use of prescribed opioids, this right can be overruled by a provider's concern that a requested treatment is ineffective, can cause harm to the patient or others, or is contrary to existing laws.<sup>10</sup> The provider's intent is to provide pain relief for the patient. To continue to prescribe opioids knowing that they are being diverted for illicit drugs is neither minimizing harm nor providing therapeutic benefit for the patient. In fact, the patients' diverting of opioids places others at risk and is illegal behavior. Kotalik<sup>11</sup> believes the opioid prescriber shares with the patient an ongoing ethical responsibility for the proper use of the drug.

From an ethical standpoint, the prescribing physician should stop prescribing opioids and refer the patient for substance use treatment.<sup>12</sup> Ideally, the patient would be seen by a hospital-based substance use team and referral for treatment could be arranged in coordination with on-going medical follow-up. Use of methadone or suboxone would not be indicated as the primary drug being abused is methamphetamines. Chang and Compton<sup>13</sup> strongly believe that untreated addiction results in poor functionality and subsequent poor pain outcomes. Once the methamphetamine use is controlled then use of opioids could be re-considered in conjunction with continued substance use treatment. For patients with a short-life expectancy, deferral of opiate prescribing may not be an option. The question then becomes how to safely manage acute/chronic pain needs. Realistically, there are only two viable options. First, that patient could be admitted to an inpatient hospice unit where the focus of care would be on comfort. Alternately, the patient could have home hospice based services with a designated caregiver who would dispense opiate medication.

### ETHICS COMMITTEE ANALYSIS #2 (MM)

This complicated patient case identifies several ethical challenges. Do drug users deserve to be treated autonomously? Does someone with a personality disorder have that right? Can a provider ethically refuse to provide narcotic treatment for someone with cancer pain? The two principles of

autonomy and beneficence can be applied as helpful lenses with which to consider all aspects of the case.

Caring for this woman respectfully necessitates considering her wishes. However, her history of cocaine and methamphetamine abuse is important. She has an increased risk of opioid abuse due to this history and has now explicitly told providers that she is not taking prescribed pain medication. It is in her best interest – the physician is guided by beneficence – to refuse to prescribe opioids and to offer alternative pain management strategies. While at first pass it may seem rash (i.e., to make treatment decisions based on a patient's addiction, not to mention her non-adherence), this is widely considered a “best practice” when considering opioid prescribing.

When considering the patient-provider relationship, both parties ostensibly want a trusting one. The patient has been truthful in admitting sale of her medication. The provider is bound to use that information to guide her care. Further, the provider should be similarly honest with the patient. At this point, his or her role can focus on clear and open communication: review of the risks of illicit drug use, explain treatment options, review the risks of undertreated pain and discuss non-opioid alternatives. Previous providers terminated the relationship due to poor adherence; doing so again would not be for her own good (previous terminations did not improve her course). Considering the patient autonomous – *truly* autonomous and capable of engaging in treatment discussions rather than seeing her as a meth addict – could lead providers to in-depth care planning discussions suggested above. While she has been honest about what she did with previous prescriptions, she has not been clear or transparent regarding her motives. The physician can present him or herself as honest and forthright and attempt to elicit a reciprocal response from the patient.

Much of this assumes the provider is motivated to expect more from the patient, a difficult task after a frustrating treatment course. She has not followed recommendations and has potentially put one's medical license at risk by selling her medication. She may be emotionally labile and dramatic. She has terminal cancer and cancer-related pain and is using methamphetamines – ultimately disheartening! The provider should seek peer consultation and acknowledge disappointment about the patient's decisions thus far. It is imperative to do so in order that non-medical judgments about the patient's psychosocial background do not influence the physician's medical recommendations. Maintaining compassion and respect for non-compliant patients is a challenge and in this case doing so involves withholding of opioids.<sup>14</sup>

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## Authors

- Nicholas Lemme, BS; Alpert Medical School of Brown University, Providence, RI.
- Bryan Leyva, BA; Alpert Medical School of Brown University, Providence, RI.
- Rachel Occhiogrosso, BS; Alpert Medical School of Brown University, Providence, RI.
- Young Seol, ScB; Alpert Medical School of Brown University, Providence, RI.
- James M. Badger, PhD; Clinical Associate Professor of Psychiatry and Human Behavior, Alpert Medical School of Brown University, Providence, RI.
- Margaret Mannix, PhD; Assistant Professor of Psychiatry and Human Behavior (Clinical), Assistant Professor of Pediatrics (Clinical), Alpert Medical School of Brown University, Providence, RI.

## Correspondence

Nicholas Lemme, BS  
 Warren Alpert Medical School of Brown University  
 222 Richmond Street, Providence, RI 02903  
[nicholas\\_lemme@brown.edu](mailto:nicholas_lemme@brown.edu)

## Does Doctor Know Best? Cultural competence is patient-centered care

KIRA NEEL, BA; LAURA A. DEAN, BA; NICOLE A. NEGBENEBO, BS; BONNIE B. O'CONNOR, PhD; NICHOLAS WARD, MD

### THE CASE

Ms. M is a 77-year-old American Indian woman with a history of multiple myeloma who presents with severe back pain. Imaging reveals five new, in addition to four known, spinal compression fractures. She is otherwise healthy. Her physical exam is notable for tenderness to palpation along the lumbar and thoracic vertebrae.

She is being treated in the hospital only for her pain. She has declined orthopedic consultation and chemotherapy. Ms. M is appropriately alert and conversant. The primary care team deems her capable of medical decision-making. Nevertheless, she repeatedly voices concerns that the government and the hospital are conspiring against her and her people, intentionally poisoning them and trying to kill them. She insists that no one in any hospital ever has her interests at heart and see her as a vehicle for scientific experimentation, her current care team included. She is not even convinced that she either has multiple myeloma, or that if she does, that it will prove fatal. She states, "Doctors would never tell white people it's fatal for them."

At the time of her diagnosis months ago, she declined any intervention, and she continues to deny the severity of her disease. Presented again with evidence supporting treatment for symptomatic improvement as well as disease modification, she remains strongly opposed to any such treatment.

### THE ETHICS DILEMMA

Ms. M carries a deadly diagnosis. However, she distrusts the findings and suggestions offered by those caring for her. Ms. M's situation puts in tension her well-established right to autonomous decision-making about her health and the obligation of beneficence on the part of the team. Her physicians must determine what is "best" for this patient – or if such a decision is even theirs to make.

### STUDENT ANALYSIS (KN, NAN)

The central issue of Ms. M's dilemma is a pervasive current of institutional and historical racism, discrimination and maleficence towards Native Americans and communities of color. At first mention, this woman's claims could be written off as the ideas of a conspiracy theorist. However, Ms. M's resistance to allopathic treatment is justified based

on historical context.<sup>1</sup> A review of medical history reveals a sordid past of forced sterilization, coerced experimentation, and intentional infection with incurable diseases.<sup>2</sup> Beginning in the 15th century, smallpox was spread throughout American Indian tribes as a form of ethnic genocide.<sup>3</sup> Later, physicians with the Indian Health Service (IHS) performed non-consensual total hysterectomies and tubal ligations on women without their consent.<sup>4</sup> The IHS also tested new drugs on American Indians in the name of research.<sup>5</sup> The hepatitis trial vaccine program in South Dakota involved giving experimental hepatitis A vaccines to American Indian children. As incentives to participate in the program, they offered free diapers to families and candy to children.<sup>5</sup>

This history seeded a distrust that contributes to worse health outcomes. American Indians/Alaskan Natives are more likely than non-Hispanic whites to experience a delay between cancer diagnosis and cancer treatment.<sup>6</sup> American Indians who perceive discrimination in the clinic are less likely to complete treatment for chronic disease.<sup>7</sup> This cultural dissonance can undermine even the best intentions.<sup>8</sup> In order to alleviate this distrust – and subsequent substandard care<sup>9</sup> – we must acknowledge and educate ourselves about the systemic and historical racism that continues to alienate many patients.

Critics will suggest this places an undue burden on physicians but ignoring Ms. M's concerns is disrespectful and has not worked. Recent literature suggests that medical curricula can and *should* confront the systemic inequities perpetuated by generations of oppression.<sup>10</sup> With such training, doctors will develop a more nuanced understanding of patients' values and concerns, enabling equitable decision-making that honors both autonomy and beneficence allowing future generations of physicians to feel confident in the practice of anti-racist cultural competence, delivering improved outcomes for all patients.

### ETHICS COMMITTEE COMMENTARY #1 (NW)

This case describes a patient who is making decisions that the medical team feels are wrong and not in her best interest. Worse still, these decisions will prevent her from getting life-saving care and the reasoning seems unsound (and perhaps insane). The question is what to do next. The principle of autonomy dictates that we respect her decisions and the

principle of beneficence dictates that we not allow her to harm herself because of a possible mental illness affecting her ability to make these decisions.

Determining when a patient has capacity to make decisions can be complex and unrecognized “incapacity” may be common in adult medical patients.<sup>11,12</sup> In general, patients tend to fall roughly into three categories. The first category (no capacity), is patients who have a definable, clear-cut, major mental illness and we deem them unable to make medical decisions. The second group is comprised of patients who are clearly of sound mind, fully grasp the consequences of their decisions and choose an approach that goes against conventional medical wisdom or societal norms (i.e. Jehovah’s Witnesses). The third group is more difficult (capacity unclear). There are occasionally patients who seem to pass the test for mental health using our usual, often cursory bedside tests (do you hallucinate? What day is it? Do you understand what will happen if you don’t do this? etc.) but seem to lack insight into the consequences of their actions or present such an unusual set of reasons that suggest to the team that they may have some low-grade (or masked) psychiatric condition or cognitive deficit. What happens next in this case depends on the category to which our patient belongs.

Because of this, a lot hinges on the student’s sentence, “The primary care team deems her capable of medical decision-making.” Given the import of these decisions, the radical nature of the patient’s stance, and almost paranoid beliefs (suggestive of schizophrenia) it is important that this be delved into in much detail, perhaps with more psychiatric consultation. For the purposes of this discussion however, we will take as given that the patient does not have a major psychiatric illness. If this is the case, there is actually not much that the team can do. The team should make every effort to engage the patient and her family in discussions about her reasons. While there is a chance that short-term emotions, misconceptions, or poor advisors are influencing her and a different decision may be made, this patient’s decision may stand after such engagement.

Ultimately then, there are not many options in a case like this. Were the team to decide that the best decision was to pursue therapy against her will, what would happen next? If she held to her decision, they would have to force therapy on her. This may require physical and or chemical restraint. How successful would weeks of intense therapy be with a patient who does not cooperate? Practically, this would be very difficult. By causing harms *and* violating her autonomy (capacity having been established), such a course would have two ethical “strikes” against it, and would be hard to defend.

## ETHICS COMMITTEE COMMENTARY #2 (BO’C)

*“I have lived a long time with the white people and I know what they do. They are people who are very kind to anyone who is ready to do whatever they wish.”* Sarah Winnemucca

(1844–1891), Northern Paiute educator, activist, and author.

This case demonstrates the critical importance of cultural and historical issues to possible resolution of an ethical dilemma, and to accurate diagnosis of a patient’s state of mind.

Ms. M will know of the several-hundred-year history of abusive practices on the part of Anglo-European “officialdom” with respect to American Indian tribes and Nations.

Health care for Native Americans has since 1955 been the responsibility of the Indian Health Service (IHS), an agency of the federal government. The IHS has been rife with inadequate care and abuses of patients. Our patient or her daughters might well have been at risk or even been victims of this malfeasance.

In light of these facts, declarations of intentions “to help you” may be received with skepticism if not outright disbelief and mistrust. This history puts Ms. M’s mistrust of medical advice in a light of rationality and self-protection

Is Ms. M perseverating, or is she being vigilant in guarding her own safety? Is she engaging in “conspiracy theories” (implying some irrationality), or is she responding reasonably to a well-documented history of threats from “officials” and healthcare professionals to Native American patients, especially women? Is she ignorant of her diagnosis/prognosis, or is she taking precautions against allowing others who may have their own agendas to define her likely outcome and her treatment options? Should we work to redirect this patient’s concerns, or to redirect our own understanding of where she is coming from?

We cannot accurately diagnose Ms. M’s mental status or accurately interpret her rationales without some non-medical, but clinically relevant knowledge. Without this information, we cannot confidently defend as ethical any decisions regarding whether to attempt to override her autonomy (always ethically dicey, for *any* adult patient with decisional capacity) in refusing medical treatment for her diagnosis of multiple myeloma.

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### Disclosure

The views expressed in this article are the opinions of the authors and do not necessarily reflect the views of the Warren Alpert Medical School of Brown University.

### Authors

Kira Neel, BA; Alpert Medical School of Brown University, Providence, RI.

Laura A. Dean, BA; Alpert Medical School of Brown University, Providence, RI.

Nicole A. Negbenebor, BS; Alpert Medical School of Brown University, Providence, RI.

Bonnie B. O'Connor, PhD; Professor emerita of Pediatrics, Alpert Medical School of Brown University, Providence, RI.

Nicholas Ward, MD; Associate Professor of Medicine, Alpert Medical School of Brown University, Providence, RI.

### Correspondence

Kira Neel

Alpert Medical School of Brown University

222 Richmond Street

Providence, RI 02903

[kira\\_neel@brown.edu](mailto:kira_neel@brown.edu)

# Balancing Patient Autonomy, Surrogate Decision Making, and Physician Non-Maleficence When Considering Do-Not-Resuscitate Orders: An Ethics Case Analysis

NABIL MEHTA, BSE; SAMANTHA ROCHE, BS, MPH; ELISABETH WONG, BA; ABASS NOOR, MD; KATHRYN DECARLI, MD, MBE

## CASE SUMMARY

Ms. Smith, a 64-year-old woman, presented to her PCP with diffuse abdominal pain, nausea, and constipation. She had a history of chronic lower back pain and multiple back surgeries for which she had an implanted intrathecal morphine pump. She was referred to the hospital for an esophago-gastroduodenoscopy and colonoscopy, both of which were unrevealing. After the procedures, Ms. Smith felt “miserable” and lethargic and was subsequently admitted to the hospital for observation. The admitting physicians verbally confirmed her code status as DNR/DNI.

The next morning, a nurse reported that Ms. Smith had been complaining of severe headache and leg shaking. Around 7 a.m., Ms. Smith was discovered unresponsive in her bed. She responded to naloxone and sat bolt upright, confused and agitated, swinging her arms and attempting to escape the bed. Given this vigorous response to naloxone, the team considered opiate overdose from a malfunctioning morphine pump as a potential etiology for the event. However, given the possibility of an intracranial hemorrhage or stroke, an urgent head CT was deemed necessary. It was clear that having the patient remain still for the scan would be a difficult task, especially as her combativeness persisted after receiving 2 mg of lorazepam. The team was hesitant to give more benzodiazepines in the setting of potential opiate overdose, especially since the patient’s code status was DNR/DNI and she could not be intubated if needed.

After reviewing the chart, the attending physician found it unusual that such a relatively healthy, young woman was not Full Code and explored this with Ms. Smith’s husband, her medical power of attorney. Mr. Smith explained that his wife had filled out an advanced directive with her PCP, delineating her wishes to be DNR/DNI, but that the document was at home. After a discussion of the implications of the DNR/DNI status, the husband clarified that Ms. Smith would want life-saving measures if there were a reasonable chance of recovery.

After the husband’s explanation of his wife’s wishes and despite the presence of an advanced directive, the team decided to change the patient’s code status to Full Code to allow more leeway in administering additional medications with the potential to cause respiratory suppression in the workup of this unresponsive episode. In this case, giving additional lorazepam could potentially be life-saving if the

CT showed a brain hemorrhage. On the other hand, the patient was clear in her DNR/DNI status prior to admission and had written documents expressing these wishes.

## MEDICAL STUDENTS’ ETHICS ANALYSIS (EW, SR, NM)

As Ms. Smith’s case demonstrates, despite tools such as advanced directives and powers of attorney, it remains difficult for patients to achieve prospective autonomy in regards to future care. This results in myriad ethical dilemmas. Many patients with DNR/DNI orders have conflicting wishes when queried with hypothetical scenarios. Additionally, medical details are impossible to predict which makes directives misleading and difficult to adapt.<sup>2</sup> Therefore, would it have been ethical to carry out Ms. Smith’s advanced directive since it was inflexible and presupposed unrealistic understanding on the patient’s part? Surrogate decision makers offer a plausible alternative since they can adapt to new details and information while keeping the patient’s values and wishes in mind. However, surrogate decision makers frequently make choices that do not align with what the patient would have decided in the same situation.<sup>3,4</sup> Given this, was it ethical for Ms. Smith’s husband to change her code status in the face of her acute condition and the need for potentially life-saving sedation? How should the balance between patient autonomy and physician non-maleficence be approached? To explore this dilemma, we consider the history and evolution of ethical issues related to DNR/DNI orders.

DNR orders were originally intended to restrict use of CPR for patients who had decided that the potential harms of resuscitation outweighed the potential benefits.<sup>5</sup> Primarily, these patients were nearing the ends of their lives, due to age or irreversible illness. As DNR orders became more common, many patients who did not wish to undergo CPR still chose to undergo procedures, including those requiring anesthesia or sedation, often for palliative purposes.<sup>6</sup> This created undeniable discomfort, particularly for anesthesiologists tasked with balancing the goal of achieving analgesia/amnesia against the potential for cardiovascular collapse inherent in administering anesthesia/sedation.<sup>6</sup> Subsequently, many anesthesiologists assumed the DNR order to be suspended during surgery, and this assumption was often made without the patient’s knowledge or input.<sup>7</sup>

Despite being employed by many organizations, the policy of automatically suspending DNR orders poses many ethical (and legal) issues, and certainly violates the principle of a patient's right to autonomy.<sup>8</sup> Of course, that is not to say that DNR orders should never be suspended.

On the role of DNR orders in surgery, Truog offered several reasons that may ethically justify suspending a DNR order in cases requiring anesthesia/sedation.<sup>6</sup> First, administering anesthesia/sedatives by nature involves the purposeful depression of vital functions followed by a skillfully planned "resuscitation"; therefore, any consent for anesthesia implies consent for the necessary resuscitation. Second, spontaneous cardiac arrest is notably different from an arrest that occurs "as the result of a therapeutic intervention" (i.e., respiratory depression from a drug overdose), as the latter is significantly more likely to be reversible.<sup>6</sup> We posit that these conditions applied to the administration of sedatives in the case of Ms. Smith, making it ethically defensible to suspend her code status for sedating her to obtain emergent diagnostic imaging.

Since the inception of DNR orders, conventions for physicians around respecting these orders have undergone substantial change. One approach towards a more ethical use of DNR orders has been for physicians to adopt a "procedural approach" to determining patients' preferences, perhaps recording specifically that a patient does not want ICU care or endotracheal intubation, for example.<sup>7</sup> An alternative "goal-directed approach" has been suggested, in which discussions of the patient's goals, values, and fears are used to inform the physician's decision of which procedures should be performed under which circumstances in real time.<sup>9</sup> This approach is accompanied by several challenges, perhaps the most significant of which is that it requires the clinicians making the decisions to have a nuanced knowledge of the patient's wishes. However, a goal-direct approach recognizes that it is impossible to represent the full range of scenarios that may arise over the course of care, particularly when anesthesia and sedation are involved, and offers the best opportunity for the patient to experience their desired outcome.

### ETHICS COMMITTEE ANALYSIS (AN, KDEC)

There are multiple options in this scenario: (1) treat the patient for suspected morphine overdose and do not obtain head CT, (2) administer medications needed to obtain head CT; if this results in respiratory compromise, proceed to intubation, (3) administer medications needed to obtain head CT; if this results in respiratory compromise, do not proceed to intubation.

If this patient's code status is an accurate reflection of her wishes, then it is not appropriate for the care team to place her in a position that risks need for intubation (option #3). Options #1 and #2 are both ethically consistent; the challenge lies in clarifying her wishes. The medical team's bias

towards a Full Code status for this relatively young and healthy patient has no bearing on her autonomy to refuse intubation. However, there is compelling information to suggest the patient's code status is not consistent with her actual wishes. Because she is unable to convey her wishes, we must rely on prior documentation, reach out to her PCP, and seek interpretation from her surrogate decision-maker.

The literature sets precedent that code status should not dictate care, but rather inform exploration with the health care proxy of specific medical situations. The spouse's willingness for this patient to be intubated should be taken into account because "research suggests that many patients do not expect surrogates to rigidly follow their traditional advance directives, but rather intend for surrogates to exercise judgment to determine the course of care when there is insufficient information available or for extenuating circumstances."<sup>10</sup> Silveira et al suggest we must "accept surrogate decisions as valid expressions of the patient's autonomy, even when those decisions conflict with the patient's written preferences."<sup>11</sup>

The PCP should play an important role in advanced care planning. Resources such as The Conversation Project<sup>12</sup> offer tools to achieve the widely called for goal "to transform advance care planning from the act of signing a form to a process."<sup>13</sup> However, plan as we may, "no prior discussion or documentation can anticipate all scenarios."<sup>14</sup> It is unreasonable to assume that this patient thought through the present case when she made her wishes known – but it is still possible she may have considered similar circumstances. If her spouse feels confident that she would accept possible intubation in this instance, it is reasonable for the medical team to move forward with CT scan, even if anesthesia is needed, and proceed to intubation should that become necessary.

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### Disclaimer

The views expressed herein are those of the authors and do not necessarily reflect the views of the Alpert Medical School and the Department of Medicine, Brown University.

### Acknowledgment

The first three authors contributed equally to this work.

### Authors

Nabil Mehta, BSE; Alpert Medical School of Brown University, Providence, RI.  
 Samantha Roche, BS, MPH; Alpert Medical School of Brown University, Providence, RI.  
 Elisabeth Wong, BA; Alpert Medical School of Brown University, Providence, RI.  
 Abass Noor, MD; Alpert Medical School of Brown University, Providence, RI.  
 Kathryn DeCarli, MD, MBE; Resident, Department of Medicine, Alpert Medical School of Brown University, Providence, RI.

### Correspondence

Elisabeth Wong  
 Alpert Medical School of Brown University  
 222 Richmond Street  
 Providence, RI 02903  
 Elisabeth\_wong@brown.edu

# Counseling Women on Long Acting Reversible Contraceptive (LARC) Use While Maintaining Reproductive Justice

CHRISTY GANDHI, BA; NEESHA NAMA, BA; NICOLE A. NEGBENEBOR, BS; NORIN ANSARI, MD, MPH; ELIZABETH MOTTA, BSRN

## THE CASE

A 32-year-old G7P5115 (seventh pregnancy, 5 live births) mother at 30-weeks of gestation was admitted with preterm labor for a trial of labor after cesarean section. Her first five deliveries were uncomplicated vaginal births that resulted in healthy babies; however, her sixth was an emergency C-section for preterm premature rupture of membranes and fetal distress. The infant was born premature, and did not survive. For this pregnancy, the patient was not adherent to prenatal care, only attending some prenatal appointments.

The Department of Children, Youth, and Families (DCYF) removed her first child due to concerns of neglect. She elected to give each of her subsequent children to DCYF for placement and planned on giving this child to DCYF as well. The medical student assisted the patient in her labor and delivery room, discussing her current concerns about the delivery and her experience with birth control. She hadn't had "good experiences" with birth control in the past and had no plans for postpartum contraception. When asked if she was interested in preventing future pregnancies, the patient said, "No, I'm not." The student verified that the patient had correct information about birth control options. The patient acknowledged the information, saying that having a baby at this point was "no big deal." Other providers had explained the dangers of multiple pregnancies on her health, the potential negative outcomes for future unborn babies, the hardship of living in the DCYF system, and the ease of various birth control options. The medical student felt a professional obligation to address birth control options with the patient even though the patient was consistent in her lack of interest in starting a birth control method.

## THE ETHICS DILEMMA

Should reproductive health practitioners continue to discuss LARC use to women who repeatedly decline?

## STUDENT ANALYSIS (CG, NN, NN)

This provider-patient interaction highlights the tension between patient autonomy and medical beneficence. The reversibility, widespread access, and insurance coverage of long acting reversible contraceptives (LARCs) make these an attractive solution to prevent unintended pregnancies for women. The American College of Obstetricians and Gynecologists states that women have the "right to safe

childbearing with resources available to reduce maternal and infant morbidity and mortality" in their statement of policy for LARC use.<sup>1</sup> Although some may argue that this stance is paternalistic, the Hippocratic oath gives clinicians the responsibility to offer treatment to patients whenever possible.<sup>2</sup> Multiparity is a well-studied risk that has been linked to increased complications like placenta previa and low Apgar scores.<sup>3,4</sup>

Most would agree that unfettered access to reproductive choices is a worthy goal, perhaps especially for those caring for patients living in poverty. LARCs offer a solution to help break the vicious cycle of poverty by allowing women to exercise sexual autonomy without the financial implications of raising a child. The percentage of children born into low-income families has gradually been increasing in recent years.<sup>5</sup> Children in low-income families are more likely to be premature, have failure to thrive, and to later develop illnesses. This increases psychological, financial, and emotional stress on the family and poses a financial burden for the healthcare and social systems.

Physicians have a responsibility to care for their patients in ways that will benefit those patients long-term and also to consider the effects that those patients have on the healthcare system. Practitioners should help protect the system to ensure optimal care for all. Advocacy for contraceptive use is rooted in the passion to improve patient sexual freedom *and* healthcare costs. LARCs are safe, reversible options that should be presented to patients, especially those at higher social risk for unplanned pregnancies. Encouraging LARC use has significant benefits for both the patient and society as a whole.

However, concerns have been raised about whether efforts to expand access to long-term birth control methods limit the ability of marginalized women to exercise their right to reproduce.

It has been well documented that disenfranchised women have been forcibly sterilized. The Eugenics Board of North Carolina, established in 1933, oversaw the practice of involuntary sterilization of prison inmates and hospitalized psychiatric patients as a tool to combat poverty and welfare costs.<sup>6</sup> Welfare officials petitioned for sterilization of welfare recipients to control rising expenditures. Well-meaning contraceptive advocates during the Progressive era suggested promotion of contraception to control growing immigrant and poor populations.<sup>7</sup>

In the 1990s, a levonorgestrel-releasing implant was

aggressively marketed to poor women and women of color, especially in urban neighborhoods.<sup>8</sup> Several bills were proposed that provided financial incentives to female welfare recipients who agreed to use this method.<sup>9</sup> Judges have offered it as an alternative to jail time for women convicted of drug abuse during pregnancy.

Such coercive approaches are hard to justify. However, due to the convenient reversibility of LARCs, is it permissible to aggressively encourage LARC use for low socioeconomic and young women? A reproductive justice approach would involve the perfect balance between reducing barriers to LARC access, especially amongst those who have poor access to healthcare, while respecting a decision to *not* use these methods.<sup>5</sup> In the patient scenario presented, healthcare providers have a strong obligation to counsel the patient to adopt the use of LARCs because of her pregnancy history and social history, despite the patient repeatedly declining. Health providers should work to improve access to LARCs while respecting patient autonomy. This approach is tested in this case, in which the physician has a hard time convincing a patient that her reproductive choices are, in fact, “a big deal.”

#### ETHICS COMMITTEE ANALYSIS #1 (NA)

This patient has the right to decide whether or not she wants to use birth control. In this scenario, respecting her autonomy has a direct impact on others, namely her children who are now wards of the state. Yet, pushing a conversation on someone who is not willing or ready to listen is fruitless at best and paternalistic at worst. The medical team’s primary responsibility is the patient. There is a conflict between the student’s sense of responsibility to an unborn baby and desire to keep a patient happy through labor and delivery. While medical professionals try to act in the best interest of their patients, many decisions focus on what the doctor thinks is best, with less concern for a patient’s individual circumstances.<sup>10</sup> When the patient’s conception of “best” does not match the medical team’s, the resulting paternalism can be frustrating for all. Respect for autonomy requires that physicians remember that the patient willingly sought care and has the right to make her own decisions. Despite the concerns about the patient’s children, her autonomy with regards to birth control should be respected.

A conversation earlier in the pregnancy might have been tremendously helpful to understanding the patient’s choices, if possible. Contraceptive counseling in clinics has been associated with increased hormonal contraceptive use, and counseling regarding specific types of contraception has been associated with an increase use of those methods.<sup>11</sup> In a more relaxed setting, further questioning into the patient’s circumstances and motivations and a better understanding of her barriers and hesitations might have helped alleviate the frustrations of the medical student.

However, the medical student’s reach is limited to what she can do in the hospital. This much-needed conversation was not going to take place during the patient’s labor and

delivery, which the student likely realized. Similarly, the physicians on the team can only provide help to patients who want it. The best that an inpatient team can do is to meet the patient’s needs at the point of care and send her with as many tools as she can and is willing to carry.

#### ETHICS COMMITTEE ANALYSIS #2 (EM)

Ethical considerations for the medical student include the precarious position as a student observer and the potential to anger the birthing woman to the point of expulsion from the case. There may be a personal agenda from the medical student to prevent future pregnancies, based on sympathy for children who are adopted or living in the foster care system.

Each of these factors present ethical dilemmas and may be adding to moral fatigue for the medical student.

Should the student insist on having a conversation about birth control with the laboring mother? The ethic of respect for persons includes a commitment to the duty-based ethical principle of autonomy.<sup>12</sup> A birthing mother, with capacity, has a negative ethical right to be free of the pressure of listening to education that she does not want, and the health care team should respect this.<sup>13</sup>

However, the mother also has the positive right to competent care from the health care team, which includes education. The principle of fidelity establishes the responsibility of loyalty and trust between the patient and the providers.<sup>14</sup> In this case, there is conflict between the ethical duties to respect autonomy and maintain fidelity. Ranking and balancing the duty-based principles of autonomy and fidelity are best understood within the American cultural context of placing high value on autonomy.<sup>15</sup> Autonomy therefore becomes the prevailing or *prima facie* principle.<sup>16</sup> Additionally, it is unlikely that health promotion or birth control education efforts, during labor, would produce the hoped-for results.

Perhaps another health care team member at another time may be able to build a trusting relationship to advance optimal patient-centered options while providing respectful treatment of birthing mothers, particularly in cases of infant relinquishment.<sup>17</sup>

Finally, the medical student should consider the reexamination of her personal agenda in this case, in which she would like to prevent future pregnancies based on sympathy for children who are adopted or living in the foster care system and the assumption that future children will also be relinquished. The primary obligation must be to the birthing mother and the impact of multiple pregnancies on her physical and emotional health. Perceived prejudice by healthcare providers could negatively impact the health of the birthing mother. There is no definite information here that her previously relinquished children remain in foster care or that they have had difficult life courses. Additionally, there are legal and ethical limits to the scope of interference that can be unilaterally imposed on the birthing mother.

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## Authors

Christy Gandhi, BA; Alpert Medical School of Brown University, Providence, RI.  
 Neesha Nama, BA; Alpert Medical School of Brown University, Providence, RI.  
 Nicole A. Negbenebor, BS; Alpert Medical School of Brown University, Providence, RI.  
 Norin Ansari, MD, MPH; Intern, Yale New Haven Hospital, New Haven, CT.  
 Elizabeth Motta, BS, RN; Lifespan, Providence, RI.

## Correspondence

Christy Gandhi  
 Box G-9451  
 Brown University  
 Providence, RI. 02912-G  
[christy\\_gandhi@brown.edu](mailto:christy_gandhi@brown.edu)

## Putting the “No” in *Non Nocere*: Surgery, Anesthesia, and a Patient’s Right to Withdraw Consent

CLAUDINE YEE, BS; REBECCA S. HIMMELWRIGHT, BS; WALTER KLYCE, BA; TINA SANKHLA, MD; GEORGE P. BAYLISS, MD

### THE CASE

Ms. K is a 53-year-old G2P1 with Stage IIIA endometrial cancer who presented to the Women & Infants ambulatory surgical unit for a bilateral salpingo-oophorectomy and lymph node dissection. In the pre-operative unit, a resident reviewed the standard informed consent protocol with the patient, outlining the reasons for the procedure, the risks and benefits of proceeding, and the risks and benefits of doing nothing. The resident emphasized the necessity of surgery to stage the cancer and prevent further spread. Ms. K appeared anxious, but signed the consent form. The anesthesia team then proceeded with their evaluation, determining that she had hypertension, type 2 diabetes, an anxiety disorder, a BMI of 58.2 kg/m<sup>2</sup> and a Mallampati Class IV airway difficult for intubation. The team thus decided to proceed with an awake intubation, using video laryngoscopy to visualize the larynx with minimal sedation to reduce the risk of airway collapse. Ms. K agreed to the plan.

The nursing staff then began preparing her for surgery, including inserting a peripheral IV for fluid and medication delivery. On the first failed attempt, Ms. K cringed. After the fourth unsuccessful needle stick, she became agitated and said, “I don’t want to do this anymore” multiple times. The crowd of IV nurses now assembled at her bedside reassured her and finally established access. The first medication through her IV was midazolam for mild sedation. She was then given pre-operative antacid but regurgitated half the solution. She was instructed to drink another cup, which she eventually swallowed through a steady stream of tears.

In the operating room (OR), the anesthesiologist began intubation. Despite the video camera attachment, the first few attempts were unsuccessful. She gagged multiple times and regurgitated fluid that obscured view of her airway. Over and over, she cried, “I don’t want to do this – I want to go home,” to which the anesthesiologist and nurses replied, “It’s ok, we’re almost there.” Finally, with a collective sigh of relief, the endotracheal tube was properly inserted. Medications for full sedation were administered and when the patient was fully sedated, the operation proceeded.

### STUDENT ANALYSIS (CY, RH, WK)

This case involves a patient originally deemed to have full capacity who has consented to potentially life-extending surgery. In the process of preparing her for the operation, she expresses reluctance with continuing, to the point of

specifically asking that the procedure be aborted. Many ethics analyses center on the presence or absence of proper informed consent; fewer discuss withdrawal of consent.<sup>1</sup> However, the right to withdraw consent remains a standard component of every informed consent protocol.<sup>2,3,4</sup> The UK Department of Health offers a useful paradigm for such situations: “A person with capacity is entitled to withdraw consent at any time, including during performance of a procedure. Where a person does object during treatment, it is good practice for the practitioner, if at all possible, to stop the procedure, establish the person’s concerns and explain the consequences of not completing the procedure.” It has in fact been deemed more than just “good practice” for the practitioner to stop the procedure – in a 2012 case, *Pallacovitch v. Waterbury Hospital*, the plaintiff sued on grounds of battery after her request to stop a blood draw was ignored.<sup>5</sup> In this case, the patient’s initial refusal occurred before medications which might interfere with her capacity had been administered. At that moment, pausing preparations for the procedure would have been safe and possible from a medical standpoint. Presuming that this patient was indeed attempting to withdraw her consent, the team would have been violating her basic rights to autonomy and self-determination as well as opening themselves to medicolegal culpability.

The argument could be made that the patient did not have capacity to withdraw consent. Evidence that decision-making capacity is intact includes the ability to understand the current situation, use relevant information, and communicate preferences supported by reasons.<sup>6</sup> The American Society of Anesthesiologists identifies groups of patients with “limited” decision-making capacity, including patients who can usually make decisions but whose decision-making capacity is temporarily altered. In these cases, physicians must use clinical judgment to determine a patient’s capacity, taking into account altering agents such as preoperative sedation and pain medication, as well as non-pharmacologic factors such as pain, panic, and shock. As previously mentioned, this patient’s initial refusal occurred before the administration of any medication. Perhaps, then, the clinical judgment of the team deemed that panic or pain diminished her decision-making capacity. However, should her mental state have been called into question, the team should have attempted to re-evaluate her capacity at that moment.<sup>7</sup> This would involve a complete stop in the procedure to allow thorough reassessment of the patient’s understanding of her current situation and rationale regarding her desire to

withdraw consent. Without such an evaluation, a determination that she lacked capacity would be hard to defend.

In this case, all members of the health care team ignored the patient's requests to stop the procedure in favor of continuing as originally planned. That choice could have been made for a myriad of reasons: not wanting to waste time and resources spent on preparing the operation, reluctance to delay a busy OR schedule, or interpretation of her statements as an expression of pain rather than withdrawal of consent. However, continuing a procedure in light of such statements is in direct opposition to basic ethical principles of autonomy and decision-making capacity.

### ETHICS COMMITTEE ANALYSIS #1 (TS)

This case presents an interesting, though unfortunately common, situation of a patient who consents for a procedure but then has second thoughts when she is experiencing physical discomfort. Considering usual practices and for the purposes of this analysis, we will assume that the patient was given a description of the operative plan and potential complications before signing the consent form. That said, no patient can ever be *fully informed* about what they may experience. Hearing a laundry list of possible complications and difficulties that "may" arise is a lot more palatable than actually experiencing the pain of multiple failed IV sticks, the nauseating taste of medication solutions, and the visceral discomfort of medical instruments being stuck down one's airway. The reality may end up being more than patients had initially thought they were agreeing to endure. Accordingly, while the pre-operative consent conversation is an important step in ensuring that we are respecting patient autonomy, we must also consider that a patient's wishes may change at any time and we must address their concerns as they arise.<sup>8</sup>

In this situation, when the patient verbalized "I don't want to do this anymore," taking the time to pause and address the patient's concerns would have been the best way to ensure respect of the patient's wishes if this could be done safely. This patient likely retained decision-making capacity at that point in time. Though the healthcare team was surely doing what they thought was in her best interest by continuing their attempts at starting an IV and later intubating the patient, ignoring her protests denied her the opportunity to be involved in decisions about her own care.

As the team may have assumed, it is very likely that the patient was just scared in those moments of discomfort and would have chosen to continue with the procedure if given the chance to have a discussion, but making this assumption without her input may risk a paternalism that undermines the patient's autonomy and ultimately her trust. Breaching autonomy could severely damage the doctor-patient relationship, discouraging her from seeking medical attention in the future and doing more harm than good in the long term. While the argument could be made that continuing the procedure was an act of beneficence by the healthcare

team, as the surgery was a vital component of her cancer treatment, it is not our place as healthcare providers to unilaterally make decisions on behalf of the patient, but rather to try to incorporate their values and ideals in shared decision making which is the basis for a strong doctor-patient relationship and improved healthcare outcomes.<sup>9,10</sup>

Taking the time to address patient anxieties when trying to make progress with a procedure can be very frustrating, especially when facing a busy day's schedule and considering the expense of OR time. But if a patient of sound mind clearly and repeatedly states that she would like to stop, I think we are ethically obligated to at least hit pause.

### ETHICS COMMITTEE ANALYSIS #2 (GB)

The vignette raises questions about autonomy, beneficence, non-maleficence. Was the patient's autonomy violated? The patient gave informed consent to both the surgical procedure and anesthesia. Informed consent involves providing the patient with information about the nature of the surgery, the expected benefits, possible risks and adverse events, alternative treatments to the surgery and consequences of not having the surgery.<sup>11</sup> It has become standard practice for anesthesiologists to consent patients for anesthesia with a separate consent process.<sup>12</sup>

Autonomy was preserved up until pre-operative discomfort made the patient cry out that she did not want to go through with surgery. The team may have assumed that this represented anxiety that would be overcome once the IV and endotracheal tube were in place and not an informed withdrawal of consent. But they did not assess that.

The principle of beneficence was upheld since the patient's chances of survival with the surgery seem greater than her chances without the surgery. Some authors have argued that beneficence should be seen as balancing the benefits against the risks.<sup>13</sup> We do not know whether the surgical consent as outlined above described the risks and the consequences of not doing the surgery.

The need to do no harm was observed in this case. While some might see continuing despite her cries as *causing transient* distress, the overall harm of cancelling the surgery would far outweigh the harm caused by continuing despite her anxieties. Admittedly, an effort to assess the patient's fear ahead of surgery and the risk of surgery in the morbidly obese<sup>14</sup> might have helped her understand and reduce her distress at the time of surgery.<sup>15</sup>

In summary, assessing the patient's anxiety as she was prepared for surgery may have allowed her more autonomy and reassured the team that it was justified in continuing with the procedure despite her initial protestations.

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## Authors

Claudine Yee, BS; Warren Alpert Medical School of Brown University, Providence, RI.

Rebecca S. Himmelwright, BS; Warren Alpert Medical School of Brown University, Providence, RI.

Walter Klyce, BA; Warren Alpert Medical School of Brown University, Providence, RI.

Tina Sankhla, MD; Warren Alpert Medical School of Brown University, Providence, RI.

George P. Bayliss, MD; Associate Professor of Medicine, Warren Alpert Medical School of Brown University, Providence, RI.

## Correspondence

Claudine Yee

Alpert Medical School of Brown University

222 Richmond Street

Providence, RI 02903

[Claudine\\_Yee@brown.edu](mailto:Claudine_Yee@brown.edu)