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THE JOHN J. LYNCH, MD CENTER FOR ETHICS

Rounding with the Editor

The In Practice Collection*

*All author credentials listed in the bylines of the articles in this special collection reflect the credentials that were submitted when the articles were originally published.

ROUNDING WITH THE EDITOR

A Decade of Volumes on the Horizon

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 9, Number 3 of the Journal of Hospital Ethics (JoHE). This issue marks a milestone for JoHE; it is the last issue before JoHE embarks on its 10th volume. Over the years, many have asked if we would publish again some of the case analyses that have appeared in JoHE. To celebrate this achievement, we decided to present here our first compilation of past case analyses.

We have worked to consider the best way to produce such a publication. At times when Christian (Carrozzo, JoHE's Managing Editor) and I have talked about what form such a publication might take, we simply hadn't arrived at the format we thought would be best, until now. In planning this celebratory issue, we immediately recognized that it was the perfect vehicle for accomplishing our goal of publishing a past collection. We hope you enjoy reviewing so many of the cases from JoHE's past as we approach our 10th volume. This is also a good time to look back a bit…

Only a few of our readers know how JoHE began. But anyone who knows Nneka Sederstrom, the second director of what was then the Center for Ethics at Washington Hospital Center, can likely guess where this story is going. At that time, the Center was comprised of Sue Edwards, Jack Lynch, our Medical Director (and Associate Director of the Washington Cancer Institute, also at the Washington Hospital Center), Nneka, and me. One morning, out of the blue, Nneka shares with me that she was considering the idea of starting a clinical ethics journal and wanted to know my thoughts. I replied that it would be a great idea if we had the bandwidth to manage such a thing. At the time, we simply didn't, so we shelved the idea for the time being. Of course, anyone who knows Nneka knows her ideas are not squashed so easily.

About a couple months later, Nneka tells me, "Well, I've got leadership's commitment for the needed resources for the journal. Will you be its Editor-In-Chief?" To this, I replied emphatically that I would not, that I knew nothing about publishing save for the glimpses gathered from publishing my own journal articles and promptly left her office. By the time she asked again I had warmed to the challenge, and I agreed. I have been grateful ever since. Serving as the journal's Editor-in-Chief all these years has been a great pleasure and honor.

This brief origin story leaves out years of climbing up a steep learning curve, including many attempts to hire contractors to handle one or more aspects of the journal's needs and help fill my knowledge gaps. That included mighty efforts by Leslie LeBlanc, my dear friend and colleague who then was the Managing Editor (and all-around Duomo) at *The Journal of Clinical Ethics (JCE).* The Center, JoHE, and everyone at our hospital owe a great debt of thanks to our medical librarians who have donated and continue to donate countless hours to the journal; we can't thank them enough. And we have benefited greatly from all the contributions made by our Editorial Advisory Board members. This brief history also leaves out many afternoons with Nneka, expletives deleted, complaining that my knowledge base was simply insufficient to run this journal and her patience and tolerance of these bursts of exhaustion. Her unwavering confidence in me is just evidence of her secret administrative 'sauce.'

Enter Christian Carrozzo. Christian truly rescued JoHE from the jaws of defeat. Although he didn't have any more experience running a journal than I did, he applied himself in such a way as to catch up and then far surpass my know-how, mastering virtually all aspects of producing and running a journal. Since his advent, JoHE has truly grown into the professional publication that we believe meets that of any other journal in the field. Although JoHE has always had a unique model that differentiates it from more traditional medical ethics journals, we have prided ourselves on being written for the practicing clinician. There has always, also, been a heavy emphasis on the inclusion of hypothesized and/or composite cases.

Over time, while not losing these unique characteristics, JoHe (primarily at Christian's suggestion), has evolved. At the outset, JoHE was intended mostly for MedStar-wide consumption. Now our features come from a wide range of national and international authors, article length limitations have expanded, and JoHE routinely publishes original studies. Our case analysis structure and presentation architecture has become more elastic. All of these changes have increased JoHE's utilization by academics, both faculty and students. One of Christian's perhaps most important initiatives, resulting from discussions with George Agich, one of the founders of the International Conference for Clinical Ethics and Consultation (ICCEC), is JoHE's publication of the proceedings of the ICCEC meetings since 2016. ICCEC is the only group devoted specifically to advancing the art of clinical ethics consultation, internationally. In addition, JoHE has also published the peer-reviewed work produced by visiting scholars associated with Christian's neuroethics work at the Lynch Center.

This brief summary sketch gives our dear readers a narrowly open window into the history of the first decade of volumes for JoHE. We certainly have enjoyed putting this case collection together (named the "In

Practice Collection" in honor of the standard section in JoHE devoted to case analyses). This decade of volumes has been a labor of love. We look forward to the next decade and we hope you do, too.

Sincerely,

Evan

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The In Practice Collection

Is Surrogate Assent Enough for Physicians to Shift a Dying Patient's Care to Comfort Measures Only?

Chee M. Chan, MD, MPH

Abstract:
Mrs. C is an 86-year-old woman with dementia and dehydration, brought to the hospital by her youngest daughter. The patient is bedridden with contractures and skin breakdown. After admission to the ICU, her condition has worsened. The decision that has to be made most immediately is about hemodialysis, which none of the physicians want to start. Their clinical preference is to institute a general plan of care that calls for comfort measures only. The patient has 3 daughters and has been living with the youngest for the last few years. After additional discussions, the youngest daughter has overtly assented by nodding in agreement, which is ethically sufficient. What level of agreement should be necessary for a physician to believe that he or she has permission to proceed with a treatment plan?

PRESENTATION

Mrs. C is an 86-year-old woman with dementia and dehydration, brought to the hospital by her youngest daughter. This daughter has been her live-in caretaker for the last several years. Over this period of time, the patient has been slowly declining and when she presents to the hospital, she is unresponsive and breathing shallowly. The patient has had dementia for several years and is now unable to communicate. She is unable to recognize any of her 3 daughters and does not interact with her environment. She has to be hand-fed, weighs only 92 pounds, and has significant comorbidities, contractures, and the beginnings of bedsores in several places. The daughters report that none of them have ever spoken with their mother about her medical care preferences.

After admission to the Intensive Care Unit (ICU), the patient needs a central line because her peripheral line, placed in the Emergency Department (ED), has failed and the team has been unable to establish other access. Over several hours, Mrs. C's condition shows no improvement. Her sodium level is 105, her creatinine is 4, her heart rate is in the 30s, and her blood pressure is 80/60. Despite adequate hydration, the patient has no urinary output and needs dialysis for renal failure. The medical team needs informed consent to order dialysis, if that is going to be the direction of care.

By this time, the patient's 2 other daughters have arrived at the hospital. The fellow has already conferred with the hospital's nephrologist and the patient's community internist. She and the attending physician sit down with all 3 daughters and the fellow explains the whole situation. She begins by carefully describing Mrs. C's medical condition and all the complications that have developed. She tells the daughters that the doctors have attempted to treat the condition that initially brought their mother to the hospital—her dehydration—but that doing so is complicated as a result of her overall deconditioned state. The fellow states in a kind but firm way that the dehydration is not the main problem, turning the conversation toward attention to their mother's failing kidneys.

The fellow, after summarizing the many medical problems Mrs. C has, explains that it is time to make some long-term decisions. The fellow repeats that the patient's failing kidneys right now are the main problem, but states that the clinical team does not believe that focusing on the kidney problem makes the most sense for their mother. Instead, the physicians believe that the best treatment plan for Mrs. C is to stop aggressive curative interventions and focus only on the patient's comfort as the most humane approach. The fellow tells the daughters that the medical team believes the patient is dying and that her doctors agree that the best approach is to shift to a care plan that does only those things that will keep her comfortable.

Although 2 out of the 3 sisters, albeit hesitantly, agree that shifting to comfort measures only would be the best plan, the youngest says, "I can't make that decision now." When the sisters try to talk with her, she just silently cries. The discussion continues for several minutes, and the fellow attempts again to obtain consent for comfort measures only. This time the youngest daughter remains silent.

The meeting is concluded, with the fellow wondering how explicit the caregiving daughter needs to be, especially given that she initially had expressed reluctance, for the physicians to believe that there is reasonable agreement among everyone in favor of comfort measures only. The fellow asks the attending physician about the difference between consent and assent. The attending replies that it should not be necessary to give explicit consent. To make assent ethically acceptable, however, the youngest daughter must at least overtly concur with the physician's recommendation.

After providing all 3 sisters the benefit of conversation with the hospital chaplain and clinical ethicist, the fellow and the attending physician meet with the daughters and review the situation again. The caregiving daughter is crying, but when the fellow asks them if they agree to a plan of comfort care only, all 3 nod their heads in agreement.

Original Publication: Vol 3, No 1 (2012)

CLINICAL ETHICS RECOMMENDATION AND CHART NOTE

Ethics History: Patient is an 86-year-old woman with dementia who presents to the ED with de-hydration. The patient is bedridden with contractures and skin breakdown. After admission to the ICU, her condition has worsened. The decision that has to be made most immediately is about hemodialysis, which none of the physicians want to start. Their clinical preference is to institute a general plan of care that calls for comfort measures only.

The patient has 3 daughters and has been living with the youngest for the last few years. At first, the 2 older daughters agree that their mother's care plan should shift to comfort measures only; the youngest says she is not ready to make that decision. After additional discussions, the youngest daughter has overtly assented by nodding in agreement, which is ethically sufficient.

Issue: What level of agreement should be necessary for a physician to believe that he or she has permission to proceed with a treatment plan?

Recommendation: The resources of the hospital should be provided to assist these daughters through this difficult time. Overt assent should be considered ethically sufficient for shifting to comfort measures only.

REASONING

Whether assent, as opposed to explicit consent, is sufficient as ethical justification for a physician to withhold and/or withdraw life-extending technologies has not been well explored in the professional literature. In a search of PubMed, the electronic source for citations in medicine, discussions of assent are primarily related to pediatric research or research with adults lacking decisional capacity sufficient to provide their own informed consent.

Although the literature on withholding and/or withdrawing life-extending technologies is much richer, when searching the PubMed database for articles addressing assent to withhold dialysis, no articles were found.

A recent article, however, mentions assent in the section titled, "Recommend Against CPR."[1] In this important section discussing when to recommend for and when to recommend against and not offer cardiopulmonary resuscitation (CPR), the authors state "… Assent to this recommendation," i.e., the recommendation not to perform CPR, "would then allow the physician to write a do-not-attempt-resuscitation order." We absolutely agree with this position on CPR and believe that it should be applied to any life-extending technology that no longer provides benefit to the patient.

It is not uncommon to have a family member who is reluctant to explicitly consent to a do-not-resuscitate order (DNR) or to resist withholding/withdrawing life-extending technologies of any variety. Some are reluctant because they believe it means giving up all hope or that by consenting to withholding or withdrawing life-sustaining interventions, their loved one will not be appropriately treated in other ways. Regardless of the reason, there are data suggesting that pressuring family members to explicitly consent in these situations may be of harm to them. In a study of the subjective experience of surrogates who authorize a DNR in New York State, when surrogates are required to give written consent, researchers found that doing so can produce negative emotions in the surrogate, including guilt, ambivalence, and internal turmoil.[2] Convincing, also, is a meta analysis showing that approximately one-third of surrogates have a negative emotional reaction to making such decisions.[3] These negative reactions can last for months and, in some cases, years.

We consider it a flaw in the way informed consent is practiced today to require explicit consent to these decisions about how to care for dying patients. Insistence on requiring families to give explicit consent to a shift from aggressive life-extending treatment to a plan of comfort care only is, for some family members, tantamount to the family member causing his or her loved one's death. Better is the slightly different approach presented in the Blinderman et al. paper.[4]

Since the development of the modern ICU, the pendulum has swung between the extremes of ethical acceptability for the physician's prerogative to withhold or withdraw life-extending technologies to the belief that patients and families ought to control decision making about the use of such interventions.[5] Although standards of practice have evolved toward giving the decision-making authority to patients and families, it is now time to consider revising end-of-life (EOL) practices in acute care hospitals. [6,7]

The American Medical Association (AMA) has issued Opinion 8.20 regarding invalid medical treatment. It offers this clear guideline: "Treatments which have no medical indication and offer no possible benefit to the patient should not be used."[8] Although some may disagree with whether, in this case, dialysis provides clinically meaningful benefit, this AMA statement provides strong professional support for physicians practicing good EOL care, including allowing assent to serve as concurrence with such good care.

In sum, it is our experience that when family members disagree with a proposed plan of care, particularly when it has to do with EOL care, most often they will speak up. Even when they do not explicitly say anything, their hesitations are felt. As a result of our experience and the mounting data about potential harm to family members, we believe that, in many cases, assent should be sufficient. In this case, the assent of the youngest daughter, as evidenced by her nod, should be ethically sufficient for the physicians to shift the patient's plan of care to comfort measures only.

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Balancing the Risks and Benefits of Interventions for Pregnant Patients With Acute Psychosis

Eric Rafla-Yuan, MD; Michelle T. Nguyen, MD; Angel C. Robinson, MD, MPH; Kathryn J. Shaw, MD; Frank A. Chervenak, MD and Lawrence B. McCullough, PhD

Abstract:
A 25-year-old woman who is 8 months pregnant is brought to the emergency department with altered mental status. The medical team was concerned about next steps in management should the fetus continue to show signs of distress, since Ms. J was unable to provide informed consent for cesarean delivery. Some physicians and nurses on the obstetrics team worried that performing cesarean section without consent would be tantamount to assault and battery. However, other team members feared that a lack of intervention could lead to fetal demise, an outcome that they felt was ethically worse and unacceptable.

PRESENTATION

Ms. J is a 25-year-old pregnant woman who was brought to the emergency department by paramedics after being found wandering in a residential neighborhood appearing unkempt and having altered mentation. She had no identifying documentation or belongings on her person and was presumed to be homeless. During her exam she was able to state her name and reported that she was "8 months pregnant," but otherwise demonstrated disorganized thoughts and provided tangential or nonverbal responses. She was not able to provide any emergency contact information and her past medical, psychiatric, and social history were similarly unknown. After unremarkable laboratory testing including a complete blood count, comprehensive metabolic panel, thyroid markers, and urine toxicology, she was admitted to the inpatient psychiatric unit for acute psychosis.

While in the psychiatric ward, a fetal nonstress test (NST) was performed to obtain information on fetal wellbeing. Her initial NST was nonreactive with decelerations, which raised a possibility of fetal distress. Without stating why, she physically refused to cooperate with further fetal monitoring and repeatedly removed the external monitors from her abdomen. Ms. J appeared uncomfortable and paranoid, becoming increasingly agitated. She appeared to respond to internal stimuli and was not able to participate in discussions regarding her own care or that of her fetus. The psychiatrist performed a capacity assessment and determined that Ms. J did not have decision-making capacity. The psychiatrist then ordered emergent intramuscular injections of haloperidol and she was transferred to Labor & Delivery.

Upon arrival, the obstetricians resumed fetal monitoring and discussed whether Ms. J should be physically restrained if she became agitated again in order to prevent her from removing her external monitors. They were concerned about the next step in management should the fetus continue to show signs of distress because Ms. J was unable to provide informed consent for cesarean delivery. Some physicians and nurses on the obstetrics team worried that performing cesarean section without consent would be tantamount to assault and battery. However, other team members feared that a lack of intervention could lead to fetal demise, an outcome that they felt was ethically worse and unacceptable.

A social worker was consulted to help identify and locate any family members to serve as Ms. J's surrogate decision-maker; however, it was uncertain whether family members could be contacted in time if an emergent indication for cesarean delivery arose. Even if a surrogate could provide informed consent for a cesarean section on Ms. J's behalf, the obstetrics team had concerns about the safety of performing surgery on a physically agitated patient and discussed whether she should be restrained in this situation. The hospital bioethics committee was urgently consulted.

ETHICAL ISSUES

There are many unique ethical challenges involved in the care of pregnant women with acute psychosis due to illnesses such as schizophrenia, bipolar disorder, and substance use disorders. Decision-making capacity may be limited or completely impaired in these patients. Physicians are therefore faced with the dilemma of determining if a patient is able to give informed consent, and whether certain interventions for maternal and/or fetal benefit in the absence of informed consent are ethically justified.

Here, the primary ethical challenges are 1) does this patient have the capacity to make her own medical decisions and decisions regarding her fetus, 2) how should a surrogate decision-maker be identified when family members are unknown or unavailable, and 3) are interventions which follow the typical obstetric standard of care ethically justified in a pregnant patient who lacks decisional capacity due to psychiatric illness?

RECOMMENDATIONS

1. Perform regular capacity assessments and clearly document the results of the evaluation.

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2. Obtain psychiatric consultation to assist with impairing psychotic symptoms. In many cases, antipsychotics may provide benefit to both mother and fetus.

3. If involuntary fetal monitoring is being considered, a prior determination should be made if interventions without maternal consent, including cesarean delivery, would be undertaken in response to an abnormal monitoring result. If interventions in response to abnormal fetal heart tracings (FHTs) would not be justified or undertaken without maternal consent, involuntary fetal monitoring should be avoided.

4. Avoid use of restraints unless all other means of maintaining patient and staff safety have been exhausted. Use of restraints is likely to be traumatizing and worsen physical and mental health out-comes for both mother and fetus.

In this case, the bioethics committee recommendation agreed with the psychiatrist's assessment that the patient did not have decision-making capacity. Despite the patient's inability to provide consent, the bioethics committee also recommended she continue to receive antipsychotic medication in order to avoid restraints and possibly hasten recovery of her decisional capacity. The committee also asserted that if the patient demonstrated no change in decisional capacity upon reassessment after treatment with haloperidol, and if all efforts to identify a family member or close friend are exhausted, then her treating physicians may serve as a surrogate of last resort for medical decision-making.

REASONING

Providing care when decision-making capacity is compromised by acute psychiatric illness is further complicated in pregnancy by the additional pressures of time constraints and fetal considerations. This case reviews ethical calculations for the risks and benefits of interventions for pregnant women who are impaired by psychotic symptoms and may be unable to provide consent for routine or emergency obstetric treatment. Evaluation of decisional capacity is a fundamental initial step in determining the treatment course for a pregnant patient whose ability to provide consent is suspected of being impaired by psychosis, with a framework for this process previously established and reviewed.[1-3]

A thorough psychiatric evaluation may provide valuable information regarding the severity and nature of the psychotic illness and any possible interference in decision-making. A thorough understanding of the patient's disease course will aid the determination of next steps for clinical care, as decision-making capacity of a psychotic patient may not be permanently impaired, but instead fluctuate over time. Symptoms stemming from a recent drug ingestion may resolve after a short course of supportive treatment, while symptoms that are severe and chronic in nature may not be expected to meaningfully improve in time for a woman to participate in time-sensitive decisions. Collaboration with a psychiatric consultant may be required to gather requisite data needed for informed ethical decisions.

Decision-Making About Intrapartum Management For a Patient Without Decision-Making Capacity

The ethics and law of decision making for patients who lack decision-making capacity have become very well established.[4, 5] When a clinically appropriate assessment of lost decision-making capacity has been made and documented in the patent's record, the team should seek authorization of recommended clinical management from the legally designated surrogate. Typically, applicable law provides a list, starting with a court-appointed guardian, then spouse and other family members, close friend, and surrogate of last resort, usually one or two physicians. The team should consult organizational policy. Uncertainties should be addressed to organizational legal counsel.

Two consensus ethical and legal standards should guide surrogate decision-making. The first is the substituted judgment standard, a decision based on a reliable identification of the patient's relevant values, beliefs, and preferences. When the surrogate is not able to meet this standard, the best interests standard applies. This standard is a function of clinical judgment about medically reasonable clinical management, which the surrogate should authorize. In cases such as this, it is not uncommon that no family member or other legally designated surrogate such as a close friend can be identified. Applicable law usually provides for a surrogate of last resort, often two physicians. These surrogates may not be able to meet the substituted judgment standard. The best interests standard will then apply: when cesarean delivery should be recommended in rigorous clinical judgment, it should be authorized.

Organizational leaders should assure that decision-making policies are complete and clear. The ethics and law of surrogate decision-making are so well understood that policy should stipulate that seeking a court order is not required.

INTERVENTIONAL CONSIDERATIONS

Pharmacological Intervention

Antipsychotics may be useful agents in restoring the decisional capacity of psychotic patients, and their use towards these aims fulfills the ethical obligations to autonomy and both maternal and fetal beneficence. Antipsychotic treatment may promote the mother's ability to adequately care for herself and appropriately care for her developing fetus before and after birth. Additionally, reduction in symptoms and improvement in reality testing may increase the mother's ability to participate in the delivery process, which respects her agency and reduces the risk of a traumatic birth experience. Left untreated, maternal psychiatric illness increases infant mortality and morbidity through numerous avenues.[6] Thus, administration of antipsychotic agents may improve both maternal and fetal outcomes. Concerns with psychotropic medications may center on the mother's inability or refusal to consent to treatment and any potential teratogenic effects on the fetus. While involuntary medication administration may infringe on the autonomy of the mother, antipsychotics may concurrently promote autonomy by restoring capacity and competence.[7, 8] When possible, medication should be offered voluntarily in an oral formulation before involuntary administration. Regularly scheduled medication is preferred over a pattern of continuous emergent dosing, as it is likely to be more effective and less traumatic.

Notably, numerous recent studies have not found an increased risk of congenital malformations with exposure to antipsychotics, and a single dose is generally considered low risk.[9, 10] Risks of other side effects in the mother and fetus are typically dose-dependent, so the minimal effective dosage should be pursued. Haloperidol is often preferred for first-line treatment of acute psychosis in pregnancy because of its longer record of established safety data and lower side effect burden.[8, 11] As psychosis in pregnancy often represents a psychiatric and obstetric emergency, a psychiatric consultation is warranted to assist with medication recommendations and need for further psychiatric treatment.

Fetal Monitoring

Fetal monitoring is a relatively benign, low-risk assessment tool that imposes no harm to the pregnant woman or the fetus. Nonstress testing (NST) is a form of antepartum fetal monitoring that can provide clinically useful information about fetal oxygenation and acid-base status. Ethical dilemmas surrounding involuntary fetal monitoring do not typically stem from NST itself, but from the lower positive predictive value of nonreactive NSTs (with or without variable decelerations) and the potential harms associated with aggressive or invasive interventions which may be performed in response to these results. Outcomes of fetal heart tracing (FHT) abnormalities vary widely, and the overall clinical efficacy of fetal monitoring in predicting and preventing adverse fetal outcomes, whether it is performed in the context of an antepartum NSTs or continuous fetal monitoring for a laboring patient, remains controversial.[12-14]

If involuntary fetal monitoring is being considered, a prior determination should be made if interventions without maternal consent, including cesarean delivery, would be undertaken in response to an abnormal monitoring result. Beneficence-based obligations to perform fetal monitoring may vary depending on the presence of preexisting comorbidities or obstetric conditions associated with a higher risk of neonatal morbidity or mortality (e.g., poorly controlled diabetes, hypertensive disease, fetal growth restriction, or oligohydramnios). If interventions in response to abnormal FHTs would not be justified or undertaken without maternal consent, involuntary fetal monitoring should be avoided.

Physical Restraints

Risks of restraints are higher for pregnant patients than the general population. The American College of Obstetricians and Gynecologists (ACOG) recommends against physical restraints because of the increased risk of maternal venous thrombosis, interference with the physician's ability to evaluate complaints (such as abdominal pain or vaginal bleeding), interference with the physician's ability to respond to emergencies (such as eclamptic seizures, shoulder dystocia, and hemorrhage), and interference with normal labor and delivery.[15] Use of restraints is also associated with marginalized social groups, is experienced as dehumanizing, and may inject coercion into the physician-patient relationship.16 Thus, for most cases of psychosis in pregnancy, physical restraints do not promote maternal or fetal beneficence and are contraindicated unless all other means of maintaining patient and staff safety have been exhausted.

Patients with a history of mental illness may have become pregnant as a result of unwanted or even forced sexual intercourse. To prevent physical resistance and the use of physical restraints, in the event of indicated cesarean delivery, sedation should be administered. The patient in our case did not physically resist intramuscular injections of haloperidol. Being touched, much less having surgery performed, may trigger a strong reaction. Psychiatric consultation can help to manage such sequelae.

CONCLUSION

Pregnant women with acute psychosis pose ethical challenges to physicians that are well understood in the ethics and law of surrogate decision making. Organizational policy should guide care teams, with the sustained support of organizational leadership. For these patients, treatment of psychotic symptoms can provide substantial maternal and fetal benefit, and psychiatric consultation may not only assist with symptom management, but also provide information useful for ethical decision making.

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Ethical Considerations in the Risk-Benefit Analysis for Patients With Diminished Capacity

John Tuohoy, PhD and Jeffery T. Young, MD

Abstract:
Ms. Y is a 64-year-old woman who presented to the Emergency Department (ED) with chest pain, shortness of breath and a history of fainting. Ms. Y receives cardiac catheterization for a more precise evaluation of the aortic valve, as well as to assess any narrowing of the coronary artery, and likely undergo aortic valve replacement surgery. Ms. Y told the clinician she was not interested, but would take her vitamins and be fine. When the clinician explained that her prognosis without surgery was not good, Ms. Y indicated that toxins were poisoning her. Upon assessment, the psychiatric team determined that Ms. Y lacked sufficient capacity, due to a psychotic illness, to make her own decisions regarding her aortic stenosis, her psychiatric illness, and related treatment recommendations. Ms. Y continued to decline all interventions and requested to leave the hospital.

PRESENTATION

Ms. Y is a 64-year-old woman who presented to the Emergency Department (ED) with chest pain, shortness of breath and a history of fainting. She consented to admission to a medical unit. She was diagnosed with aortic stenosis, presumably severe. The clinician recommended that Ms. Y receive cardiac catheterization for a more precise evaluation of the aortic valve, as well as to assess any narrowing of the coronary artery, and likely undergo aortic valve replacement surgery. Ms. Y told the clinician she was not interested, but would take her vitamins and be fine. When the clinician explained that her prognosis without surgery to replace the aortic valve was not good, Ms. Y indicated that toxins were poisoning her home. When pressed for details she was non-specific, except to say that to avoid the toxins she had been living in her car and in hotels for the past several months. Concerned that she lacked capacity to give informed consent, the staff suggested Ms. Y remain in the hospital to receive appropriate psychiatric evaluation, to which she readily agreed. Upon assessment, the psychiatric team determined that Ms. Y lacked sufficient capacity, due to a psychotic illness, to make her own decisions regarding her aortic stenosis, her psychiatric illness, and related treatment recommendations. Ms. Y continued to decline all interventions and requested to leave the hospital.

Ms. Y allowed the care team to contact her family, a brother and sister. After she again refused all interventions, the family indicated to the care team that they felt there was an obligation to save Ms. Y's life by performing the cardiac catheterization and subsequent valve replacement, even without her consent. In their view, Ms. Y was a danger to herself because of her delusion about toxins, and they believed she needed to be held in the hospital if necessary and be treated. At the very least, the family believed the care team should try to modify Ms. Y's delusions. They stated that they would sign any necessary consent forms, even if that meant they had to obtain legal guardianship.

For their part, the cardiac surgeons were reluctant to move forward without the cooperation of the patient. Although they were not confident that good postoperative management was possible with a patient unlikely to cooperate, they wondered if they should go ahead with the surgery anyway, given the risks posed by her condition if not addressed surgically. The surgeons were not sure whether not operating was abandonment of a vulnerable patient, or if doing surgery without her cooperation was justified given that it might be harmful. The psychiatric team recommended a trial of antipsychotic medication, which the patient adamantly refused. Injectable medication was considered, but it was anticipated that she would require restraint for administration. The treatment team's assessment was that the patient would be frightened by physical restraints and that the ensuing stress could precipitate a cardiovascular event. After listening to one another's concerns, the care team and Ms. Y's brother and sister agreed to seek assistance from the bioethics consult team.

BIOETHICS RECOMMENDATION AND CHART NOTE

On the recommendation of the bioethics consult team and the care team, the patient's family agreed on the use of a decision-making algorithm (**Figure 1**, on the following page) developed for ethically managing patients who are unable to give informed consent and are refusing recommended treatment. Once a lack of capacity has been determined, the algorithm helps surrogates and health care providers consider the potential safety or feasibility impact of a lack of cooperation on the risk-benefit equation. Similarly, the algorithm also helps surrogates and providers consider the potential negative impact of forced treatment on the patient's personhood, and to balance that consideration as well in the risk-benefit analysis.

REASONING

Many patients cannot grasp the significance of their illnesses or give adequate consideration to the medical options presented to them. They lack decision-making capacity, and reliance on surrogates is necessary.[1] When providers and surrogates consider the risks of a procedure or treatment, the focus tends to be on such

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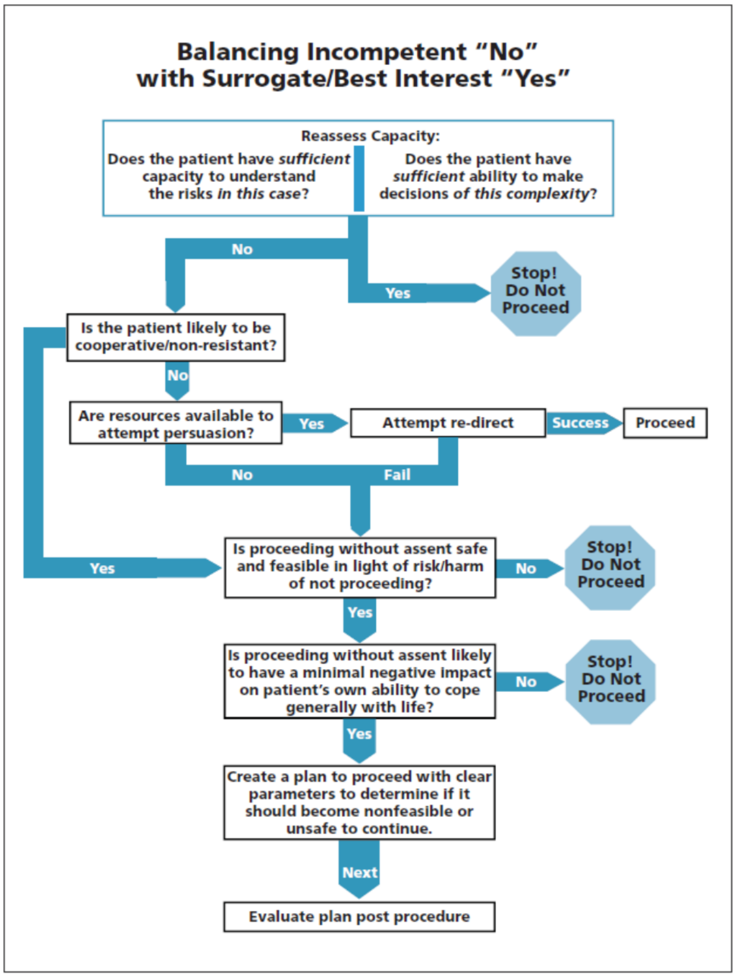

Figure 1

surgery, or on potential side effects of medication, including weight gain or depression. In this article, we call attention to additional potential risk in the form of suffering or harm that may arise in patients who are unable or unwilling to cooperate, and on potential suffering or harm that patients may experience as a result of treatment being forced on them.

An algorithm that raises key ethical concerns an help find this ethical balance between not doing enough and causing unintentional harm. The algorithm proposed here reflects the ethical conviction that respect for a patient as a person means treating individuals as autonomous persons.[2] If the person has diminished capacity, not only does he or she deserve the opportunity for treatment to be considered, additionally careful consideration of the inadvertent but potentially harmful side effects of treatment is required.[3] The values of patient-centered care may help us understand the many ways a patient may suffer or be harmed by challenging us to appreciate the patient's world view, values, preferences, and expressed needs "through the patient's eyes" and to work in partnership with the patient.[3]

Harm may not only be caused by the physical or emotional side-effects of treatment, but also from the potential adverse impact that may occur if a patient resists or refuses to cooperate with treatment, including, for example, post-operative rehabilitation. In addition, a patient may be harmed by the experience of forced treatment. Assuming that a previously impaired patient regains capacity, it cannot be taken for granted that the now-capacitated person will agree with and be thankful for the treatment forced on him or her during the period of incapacity. The patient's "personhood" may suffer harm by forced treatment, and this injury may not be healed simply by restoration of capacity.[4] The proposed algorithm begins with a team oriented assessment of the patient's capacity to make health care decisions. Due to the complexity of cases such as this one, this assessment should be performed by a psychiatrist, to determine whether this patient has:

1. communicated a choice; **2.** demonstrated a sufficient understanding of the illness, treatment options, risks, and benefits of the proposed treatment and alternatives; **3.** demonstrated sufficient ability to deal with the complexities of this particular situation and its potential consequences; and **4.** explained his or her decision in such a way that a logical basis for it may be discerned.[5]

The patient should be given every possibility to demonstrate sufficient capacity necessary, in light of the potential benefits and risks of his or her situation, before moving toward the substituted judgment of a surrogate. Maintaining the patient, family, treatment team alliance is paramount as these challenging issues are worked through. Depending on the requirements or standards of particular jurisdictions, a judge ultimately may need to determine whether capacity is impaired and, if so, to appoint a surrogate. If sufficient capacity exists, informed refusal should be respected. In this case, the use of the algorithm reaffirmed that Ms. Y did not possess sufficient capacity to make the decisions needed in this situation.

When sufficient capacity does not exist, the algorithm recommends an assessment of whether the patient is likely to be cooperative or non-resistant. If the answer is "no," avenues of persuasion and treatment should be sought, in an effort to allow the procedure to ethically proceed, on the assumption that cooperation will help ensure success and not introduce additional risks inherent in cases involving non-cooperative or combative patients. If the patient is unlikely to cooperate or to be at least non-resistant, or if there are no persuasive influences that can be successfully brought to bear, as was the case with Ms. Y, the algorithm recommends assessing whether proceeding without patient cooperation is safe and feasible. If the surrogate and clinicians determine that the risk of a lack of cooperation together with all the other risks carries such hazard as to outweigh the benefits of the procedure, the procedure can be ethically omitted. The ethical principle of not doing harm to a patient (nonmaleficence) should be respected whether or not a patient lacks capacity. If proceeding without assent or cooperation is determined to be safe and feasible, the algorithm then recommends a final assessment: What is the likely harm that may come to the person of forced treatment, or what is the likely impact on the patient's ability to cope with life generally?

Whatever may be the objective assessment of the patient's clinical best interest, the patient still will be required to cope with what has happened. Here the insights of surrogates are essential. The clinical outcome may be that patients like Ms. Y benefit from treatment in the form of mitigation of illness or survival as a result of forced treatment. The ultimate reality, however, may be that we create a situation of human suffering if the patient's quality of life is substantially diminished, or the patient is harmed by the treatment.[5] If at this point the surrogates agree that the impact of proceeding with treatment on the patient's ability to cope with life in general will be a negative one with likely personal suffering, which is assessed to be more important than the estimate of benefit that is expected to come from treatment, it is ethical for the care team to recommend and the surrogates to agree to not proceed with the proposed treatment. On the other hand, if it is concluded the impact will be minimally negative or only negative for the short term, it can be ethically appropriate to create a care plan to proceed. Such a plan should entail checks and measures to ensure that previous assessments, such as that the procedure can be performed safely, were accurate. It may be necessary to withdraw from a care plan for which clinicians or surrogates misjudged the good.

After careful consideration of the concerns in this algorithm, a consensus was reached by the care team and surrogates that it would be best to try to manage this patient medically, without surgery, as best as possible. Within hours, she experienced a cardiac arrest while hospitalized, received CPR, was intubated and admitted to the intensive care unit (ICU). After emergency treatment, stabilization, and extubation, she requested to be discharged from the ICU, adding "if surgery means going through anything like that," she was definitely not interested. This reflection on her experience suggested to the care team and surrogates that she was capable of appreciating the harm that could come from major surgery that might very likely include a repeat experience of intensive care treatment and intubation, and was helpful in re-affirming the care team and family's conclusion that not forcing surgery was in her best interest.

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Beyond Ethical and Legal Borders: The Case of a Complex Factitious Disorder

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Abstract:
This article presents the case study of Charlie, a person who suffers from factitious disorder (FD) imposed on self (previously called Munchausen syndrome), a serious psychiatric condition. As described in the Diagnostic and Statistical Manu-al of Mental Diseases (DSM-5), individuals with this disorder intentionally fabricate physical or psychological symptoms for medical attention with no obvious gain. It is extremely difficult to care and accompany patients with factitious disorder. As Wong and Detweiler mention, "Many clinicians remember their first Munchausen syndrome case as if they were seeing medicine through a distorted prism and struggle with residual conflicting thoughts, as the clinical and ethical implications can be challenging."3 Clinicians may unknowingly do harm by prescribing unnecessary tests, medications, and procedures (e.g., narcotics, surgeries) with the associated risks and iatrogenic consequences of being in a hospital for so long. Once it is known that the patient suffers from FD, reactions are ambivalent even perhaps negative, as Denis and Denis outline.4 Some may be reticent to admit that the patient is lying or cheating, some may avoid the issue altogether or just prefer to err on the side of prudent belief and treat accordingly. How then should we respond to Charlie's manifestations of suffering?

INTRODUCTION

As described in the Diagnostic and Statistical Manual of Mental Diseases (DSM-5), individuals with factitious disorder (FD) imposed on self intentionally fabricate physical or psychological symptoms for medical attention with no obvious gain. Deceptive behaviors may include exaggeration, fabrication and induction of injury that causes others to perceive them as more ill, impaired, or injured. An individual with FD may, for example, add blood to a urine test or ingest a substance to falsify laboratory test results, deceptively report abnormal episodes (e.g., dizziness or seizures) or symptoms, physically injure themselves or induce an illness (e.g., by injecting fecal material to produce an infection) to convince others that treatments, even invasive surgeries, are needed. Patient with FD primarily have somatic concerns and present in medical rather than mental health settings with persistent levels of anxiety and distress about being sick. They may or may not have co-morbid physical conditions or other psychiatric disorders which makes diagnosis difficult.[1,2]

Charlie is a 50-year-old woman who sought medical attention for an array of physical ailments. Her symptoms seemed somatic in nature. Our ethics team first encountered Charlie and her husband, her silent sentinel partner always at her side, in August 2017 in the cardiology department of Hospital A. She had been hospitalized for over a month complaining of heart palpitations and digestive symptoms. She was refusing to eat (at least in front of the staff) because of reported allergies and food intolerances and an irritable bowel. Worried and determined to help Charlie, the medical team ordered an impressive number of medical exams, from blood and urine analyses to more invasive diagnostic tests. The medical team was unanimous; nothing could explain her physical symptoms and a discharge was anticipated. Charlie refused the discharge and requested a feeding tube, claiming she was not able to eat otherwise. The team suspected that perhaps she was suffering from anorexia and offered her psychological support, which she refused. After many discussions, the team concluded that a gastrostomy was not indicated and that there were no further medically indicated reasons for her to stay at the hospital. She was discharged. As Charlie was discharged against her wishes, the emergency department was informed not to hospitalize her again unless she presented with a new condition that wasn't already examined. As suspected, a few hours later, Charlie appeared at the emergency department claiming she was not able to eat. She was offered psychological help which she refused again and left.

Several weeks later, the ethics service was called by an internist at Hospital B who was struggling with a complex case. This hospital was one of four hospitals served by the same group of ethicists. As the internist described her struggles with her patient, the ethicist recognized that it was in fact Charlie. She had been admitted shortly after she had been discharged from Hospital A. By the time the ethics service was involved, Charlie had undergone an impressive number of medical exams from various areas of specialty, which, just as in Hospital A, did not identify any treatable physical malady or explain her reported symptoms. The team's suspicion of the presence of a factitious disorder was becoming stronger. It was decided by the medical team, which included a psychiatrist, that the same approach as that of Hospital A's would be appropriate: offer her psychological help (which she refused) and discharge her. However, Charlie insisted on having a feeding tube placed. She was discharged, and the emergency department was also informed.

Charlie and her husband came back less than 24 hours later but she was not admitted. Given the last two hospitalizations, it was expected that Charlie would present at yet another near-by hospital that same night seeking medical attention and hospitalization. The same pattern would follow; admission and repeated scans and laboratory tests, exposing her to considerable risks if she could convince a physician to install a feeding tube

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because the health care team refused to do so. The judge did not allow the feeding tube to be placed. As Charlie again refused to be discharged, Hospital D obtained a court order to have her transferred by ambulance to her local hospital which was Hospital C. She was well known at that hospital because of previous long-term hospitalizations. The diagnosis of factitious disorder was already on the table of possible afflictions, but because Charlie refused access to her medical records, this information and other health in-formation was unknown by Hospitals A, B, or D. Upon arrival, she was evaluated by a psychiatrist. He pro-posed to admit her in the psychiatric ward, which she refused, but he concluded that she was competent to make her own decisions. She was discharged immediately and offered to be seen at home as an out-patient by a psychiatrist. She refused again.

Several months pass during which the ethicists did not hear about Charlie to find out that she was hospitalized in Hospital E. There, she convinced a physician to perform a gastrostomy. She then returned to the emergency department of Hospital C with a new pattern. Every night around midnight, she presented to the emergency department with her husband and would be registered and triaged as low priority. At first, and for several weeks, whenever called to see the emergency physician, they would ask for examinations to be performed. Faced with refusals from medical staff, Charlie and her husband would wait all night in the waiting room but would leave in the morning before seeing a physician. Before leaving the premises, they would stop at the cafeteria to eat. According to the emergency staff, they would often stay and sleep in the emergency room without disturbing anyone. On the odd days they were not present, they would go to another emergency department across town where they would reproduce the same pattern.

Finally, the ethics service at Hospital C organized another meeting which included many teams within the hospital, including emergency, internal medicine, psychiatry, and the chief medical officer. It was decided that the couple would be confronted and questioned to find out how the hospital could possibly offer better services. So, in the middle of the night at the emergency department, the couple was approached by a clinical ethicist and a physician. The couple refused to talk and left the emergency department in a hurry. They were not seen again. Where and how is Charlie doing today is unknown.

Caring in the Distortion

It is extremely difficult to care and accompany patients with factitious disorder. As Wong and Detweiler mention, "Many clinicians remember their first Munchausen syndrome case as if they were seeing medicine through a distorted prism and struggle with residual conflicting thoughts, as the clinical and ethical implications can be challenging."[3] One distortion exists within the doctor-patient relationship since one of the implicit premises of that relationship is that both parties collaborate honestly with one another to reach an appropriate plan of care for the patient. This principle is so fundamental that it becomes a challenge for clinicians to integrate FD’s intrinsic distortion as part of the relationship. Another distortion touches on the general goals of medicine to do good and avoid harm. Clinicians may unknowingly do harm by prescribing unnecessary tests, medications, and procedures (e.g., narcotics, surgeries) with the associated risks and iatrogenic consequences of being in a hospital for so long. Once it is known that the patient suffers from FD, reactions are ambivalent even perhaps negative, as Denis and Denis (2016) outline.[4] Some may be reticent to admit that the patient is lying or cheating, some may avoid the issue altogether or just prefer to err on the side of prudent belief and treat accordingly. In our discussion with the clinical teams, the question came up as to whether Charlie is suffering “for real” or is lying for medical attention. The answer to this is never straightforward as FD is a disorder that compels a behavior due to suffering and results in additional suffering because of the behavior. As Denis and Denis state, patients lie because they suffer and suffer because they lie, and the will to lie is, from the patient’s perspective, is not necessarily appreciated as it is often pathological.[4]

How then should we respond to Charlie’s manifestations of suffering? Taking an initial medical history to assist with diagnosing leads to a spiral of tests, consultations, and exams only to conclude after days or weeks of hospitalization that nothing can be appropriately diagnosed and thus no interventions are medically indicated. In many cases it would seem that psychiatric approaches could be indicated care options but are systematically refused by the patient. Even when the disorder is known to be factitious, a crying wolf puts physicians on the edge since no physician wants to be the one who overlooks a serious but treatable pathology (e.g., appendicitis) from which the patient is actually suffering and may die. With collaboration distorted, along with trust, the core of the therapeutic alliance is at stake and empathy suffers.

Is it even possible to implement a partnership relationship with Charlie? In addition, it becomes evident that we might be harming Charlie through undesired side-effects and iatrogenic consequences by enabling Charlie to remain in this vicious cycle. For example, because of her long hospitalization, she was extremely weak from lack of exercise and presented signs of biochemical alteration from too many blood tests and other examinations. She claimed that her legs had neurological issues that made her too weak to walk. She refused physiotherapy and preferred to use a wheelchair. She was prone to infection because of her gastrostomy tube and claimed to be scared to eat by mouth. The clinical team now further suspects that she has become dependent on narcotics. Shouldn’t something be done to protect her from (self) harm?

Caring While Maintaining Confidentiality?

Another major ethical and legal obstacle is the patient's right to privacy and the duty of professionals to respect all confidential information shared by patients. Usually, confidentiality serves the higher purpose of maintaining trust within the therapeutic alliance. This trust is essential for patients as otherwise they would not have a privileged and protected safe space to be able to share or reveal sensitive information that is necessary for proper diagnosis, appropriate treatment, and caring. For Charlie, this space is compromised. She mistrusts the clinical team and is mistrusted by the clinical team once FD is suspected. More so, important medical information is purposely omitted by the patient when, for example, Charlie is seen by a health care team for the first time. When health care professionals work with partial information it hinders their obligation to provide medically safe and appropriate care. Over and again, she undergoes unnecessary examinations with health care teams who struggle to piece together a diagnosis tabula rasa as if starting from nothing or for the first time with only partial information from the patient, a process Charlie underwent in every hospital.

Differentially diagnosing FD requires time and collaborative efforts. Charlie systematically refused to consent to the medical team having access to her medical records from other hospitals which in-and-of-itself was considered suspicious. In our case, only after consultation with an ethics team that covered many of the hospitals visited by Charlie did the pattern become more obvious; Charlie was not aware that some of these hospitals shared a common regional electronic medical record system. When a patient's physical integrity is at risk (e.g., unnecessary invasive surgery with lasting consequences), is it justifiable to bend the rules of confidentiality? Confidential grey zones do exist and, practically speaking, in many cases strict confidentiality seems extremely difficult given the nature, specificity, and complexity of this case. Maintaining strict confidentiality does not seem in Charlie's best interest when defined in terms of the prevention of her self-harm.

Caring With a Concern for Justice

The feigning of symptoms by a patient leads also to very long hospitalizations and the non-appropriate use of medical resources along with their associated cost.[5] From a social justice perspective, in a universal health care system, as mentioned in the Code of physicians, there is a duty to use health care resources judiciously.[6] Resources are limited and access to professionals and health care services should not be wasted. Charlie underwent an impressive number of scans, exams, and engaged quite a few medical specialties during their attempts to diagnose her. Not to mention, Charlie mobilized hundreds of health and legal professionals. Whether any of this helped her is unclear.

Caring and Not Abandoning the Patient

How do we maintain an appropriate level of empathy for such patients? Caring and not abandoning is certainly a struggle. At some point and after a long stay in a hospital, suspicion of FD creates an odd dynamic that leaves little space for empathy and opens the door to reject Charlie. In their interactions with her, professionals question whether she knows that the medical team is aware that her condition is factitious and are challenged by considering whether they should confront her on her "lies" and, if so, how. Healthcare professionals can also become exhausted over what seems to be a therapeutic dead-end and a vicious circle. Feelings of being deceived, even if deception is understood as an essential aspect of FD presentation, may lead to complete detachment and avoidance. Loss of meaning and an uncaring stance may overwhelm professionals and deeply undermine empathy.

Further, the diagnosis of factitious disorder can carry a stigma, and by extension Charlie might be subject to discrimination. Will she be treated differently, not taken seriously or perhaps ignored? Will her psychological well-being be overlooked over her physical complaint?[7]

CONCLUSION

Is contemporary medicine capable of treating someone like Charlie? Despite all of the time she spent hospitalized and attempts to connect with her, she seemed only to accept treatments (e.g., gastrostomy) that would perpetuate her fundamental illness (FD) and refused care that the team thought would help her physically and mentally (e.g., physiotherapy, psychological and psychiatric support, routine home care to avoid hospitalization, and ER).

Charlie's case resulted in quite a bit of distress and helplessness among several healthcare professionals. The ethics team played an essential role in building spaces for moral understanding and support to struggling clinical teams attempting to care for Charlie. One recommendation that emerged was the importance to have a clear, concrete, and coherent plan of care for Charlie that would help channel her anxiety for medical attention. This plan included her pain being managed, scheduled routine home visits and easy access to a team composed of 3 designated physicians: a psychiatrist, an internist, and a family physician in an out-patient setting. The objective was to avoid chaotic emergency room visits and her wandering from hospital to hospital. Such care would be orchestrated by a single health professional (the family physician with assistance from the psychiatrist and the internist) across institutions for coherence and efficacy. This would also help Charlie not feel abandoned, a major concern in caring for an FD patient. She would have direct access to the same health professionals with whom she would, in time, build a trusting relationship. This trust could be a powerful element capable of convincing Charlie to share confidential information (e.g., medical records from other institutions). This professional would additionally engage Charlie in a way that would delicately point out incoherencies in her discourse but without making her flee to another institution. Furthermore, this person would coordinate all additional health and social services if needed. The second objective that emerged was the need to help teams find meaning in caring for Charlie. It may be helpful to discuss ways to engage and remain meaningfully empathetic with her by shedding light on her underlying psychiatric condition, even if she refused treatments that would seem beneficial, and even if she continued to fabricate symptoms and seek inappropriate medical treatment.

One question that was considered was whether clinical ethicists from different institutions should share general information about Charlie, namely the possibility of her having FD to awake suspicion earlier in her pattern. As discussed above, clinical ethicists might find themselves on a tightrope with respect to confidentiality across institutions, given they are also tasked with providing consultations to institutions that do not share an electronic medical record system. After all, they are not only witnesses to the misuse of resources, but also the willingness of at least some clinicians to provide harmful, nonindicated interventions that could compromise Charlie's physical integrity. To say nothing meant also that ethics support and intervention could not facilitate a coherent course of action or really help Charlie. In our opinion, confidentiality as a general rule has exceptions. Is it breaking confidentiality when, after a while, Charlie's pattern becomes clear given how many institutions had become involved in her care? Also, in a public health care system, borders be-tween institutions are mainly administrative and region-ally delineated. Many initiatives already exist to merge health data within larger hospital systems as well as across institutions, especially in relation to laboratory results for better and more efficient care. We argue that the concept of confidentiality should follow and be interpreted clinically and not administratively. As mentioned by Caselli et al., early identification of a factitious disorder by a multidisciplinary team can save precious time, reduce harm from inappropriate treatment and self-harm, and save resources. Finally, in our situation, we considered that the benefits of building and sharing a coherent care plan outweighed the potential harms of breaching certain confidential information.

Perhaps this was a necessary step for Charlie to begin a healing process or at least obtain safer care as well as personalized and adapted support for her complex condition.

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End-Stage Surgical Status After Repeated Foreign Body Ingestion

Madison S. McCarthy and Thomas A. Bledsoe, MD

Abstract:
Repeated foreign body ingestion is common in patients with Borderline Personality Disorder (BPD).[1] The treatment of foreign body ingestion in these patients has historically been challenging given the nature of repeated ingestion and limited treatment options, yet end-stage surgical status as a result of repeated ingestion in this psychiatric condition is less common and all the more challenging to treat.[2] In this case, we report on a clinical ethics consultation in which a 40-year-old patient with Borderline Personality Disorder and an extensive history of repeated foreign body ingestion presents after ingesting 10 nails and is determined to have the prognostic status of being both end-stage psychiatrically and end-stage surgically. End-stage, in the context of this case report, is when a patient no longer has elective or emergent medical interventions as an available option of treatment. Particularly, we focus on the novelty of end-stage surgical status in Borderline Personality Disorder and discuss the ethical tension in determining a patient to be end-stage psychiatrically and the provider associated distress with no longer being able to offer medical treatment options. Based on the framework of the case, we also provide general ethical recommendations for managing patients with a lack of medical options secondary to psychiatric disease.

PRESENTATION

Ms. Smith is a 40-year-old patient with an extensive history of ingesting foreign bodies secondary to Borderline Personality disorder, Post-Traumatic Stress disorder, and Impulse Control disorder presented to the emergency department at an urban tertiary-care hospital upon referral by her primary care provider after another ingestion.

Ms. Smith has a decades-long history of psychiatric illness, which has been documented extensively in her medical record since 2001. She has an estimated >100 psychiatric-related admissions with a majority of them being related to foreign body ingestion. Ms. Smith has also had over 35 surgical procedures since 2015.

Of note, Ms. Smith has had a varied history of suicidality. For example, in 2018, it was documented that the patient ingested pills and was actively attempting to obstruct treatment in hopes of taking her own life. In 2021, the patient had two significant ingestions, although neither were reported by the patient to be a result of suicidal behavior. The second ingestion was attributed to being triggered by depression, whereas the first admission was not documented to be attributed to a specific event.

When Ms. Smith was admitted in 2021, she was sent to the emergency department by her primary care provider (PCP) after reporting severe abdominal pain and nausea without vomiting. Upon presenting to a local hospital, she was transferred to a higher level of care given her acuity. Ms. Smith did not have any notable stressors, although she reported to not feel like herself and to have skipped two days of medication. After going to the emergency department following her PCP's recommendation, a foreign body ingestion of 10 nails that had occurred 9 days prior was discovered, and the patient was subsequently admitted to an internal medicine ser-vice.

Diagnostic imaging revealed the 10 nails located within the small bowel loops of the abdomen, at least one in the duodenum, and an unspecified number in the jejunal loops of the left abdomen. Gastroenterology planned to only endoscopically intervene on the patient if nails appeared in the duodenum. A repeat CT scan showed that the nails had migrated towards the duodenum and the patient subsequently underwent an esophagogastroduodenoscopy (EGD) for retrieval. Two nails were identified in the proximal second portion of the duodenum, which left behind two 2mm lesions and distally, a 5mm linear ulceration.

The surgical and psychiatric services were also consulted. Upon initial evaluation, the surgical team signed-off on the patient, citing that "given the multiple operations this patient has required in the past for ingested foreign bodies, she has a hostile abdomen that even if an operative intervention were warranted would likely carry with it risks that outweighed the benefit. As such, this patient is no longer a surgical candidate whatsoever as there is no surgical intervention that would prove beneficial either now or in future occurrences of ingested foreign body."

At one point during the admission, a senior attending, who had operated on Ms. Smith several times previously, wrote a longer note detailing the thought process that resulted in eventually declaring this patient to no longer be a surgical candidate. Given the degree of risk of another open abdominal procedure, the senior surgeon was saddened by her condition but interestingly, not ethically conflicted in his decision to not offer another procedure and to actively recommend against such an intervention by another surgeon at their, or another, institution.

Of all the consulting providers, the psychiatry service had the benefit of knowing Ms. Smith for the longest amount of time. The service noted that she had already seen a variety of providers and undergone treatments spanning over two decades, none of which had resulted in any notable remission from repeated foreign body ingestion, therefore perpetuating the eventual state of her lesion-filled abdomen. The patient was agitated and uncooperative for the majority of her admis-

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sion. However, she was deemed by the psychiatry service to have full decision-making capacity.

ETHICAL ISSUES

The clinical ethics consultation was requested primarily to evaluate the ethical implications and defensibility of not offering further surgical treatment options given Ms. Smith's repeated ingestions and overall state of her abdomen. Furthermore, the ethics consultation also helped to evaluate future psychiatric recommendations for the patient given the patient's history and the determination of limited treatment options. Although several services consulted on this patient's case, these questions were best explored through the intersection of the primary medical team's decision-making with the psychiatric and surgical services' decision making. The psychiatry service had confidence in their decision to consider this patient end-stage as a result of her repeated ingestions, which resulted in her end-stage surgical status. Similarly, the surgical service also had confidence in their decision to declare this patient to no longer be a candidate for surgical intervention. The ethics consult allowed for both the Committee and the providers to discuss the basis behind declaring this patient to be end-stage, and as a result, the lack of treatment options that follow such a declaration.

The moral distress that was most present in this consult was felt most acutely by the primary medical team. The lack of surgical options and advanced treatment options from this service and consulting services — in combination with the patient's relative youth and otherwise excellent health — was a source of significant distress.

To avoid further moral distress, the primary medical team strongly considered recommending the patient to seek care at another hospital, despite a senior surgeon consulting on this case actively discouraging intervention at another institution. The ethical node of whether or not recommending a patient to seek treatment at another hospital is appropriate, especially in the case of a patient deemed to have end-stage status, formed as a result of this distress and was the second issue discussed during this consult.

RECOMMENDATIONS

1. Declaring a patient to be end-stage status — and thus no longer a candidate for most medical interventions — is a tough decision, especially in the context of a middle-aged patient that is well-appearing. But, ultimately, this decision is at the discretion of the treatment team(s) and was rooted in what is medically indicated for the patient. The considerable surgical and psychiatric history that Ms. Smith had was well understood by the services and with the past and present circumstances in mind, we determined that such a declaration would be ethically appropriate.

2. Given limited treatment options and risk of death from perforation and other associated gastroenterological complications, the Ethics Committee suggested that the team consider referring the patient to a hospice care service. Upon further investigation, it was found that the patient could not be transferred to inpatient hospice care due to the ambiguity surrounding the patient's remaining life and overall lack of need for comfort measures given her overall feeling of wellness. The patient was also apathetic towards engaging in treatment including, but not limited to, palliative care or hospice care. The Committee recommended that the patient, in the absence of being followed by palliative care, be counseled to have a plan for palliative care services. If she was made acutely ill from complications of this most recent ingestion, the primary medical team hoped to consult palliative care to make them aware of the patient prior to this event in order to better facilitate care and reduce potential secondary moral injury.

3. The Committee advised against the primary medical team's desire to recommend that the patient present to another hospital given that it is unethical to defer a patient to seek emergent and/or inpatient-level care at another institution, especially when that care can be provided at the institution at which the patient is currently admitted.

REASONING

The Committee, much like the care team, found this case to be a challenging one given the competing ethical issues and lack of precedence. In 2014, only 15 case reports on deliberate foreign body ingestion in patients with personality disorders were found in the literature.[3] Yet, around 1500 patients die each year due to foreign body ingestion, of which 92% are estimated to be deliberate.[4] The recommendations were generated as a result of the facts given by the consortium of the treatment team, but in establishing them, we recognized and appreciated the burden held by the four treatment services involved in this patient's care.

The first recommendation, which was to determine the patient to be end-stage status, was the result of the evaluation of the patient's past medical history in the present circumstances. In the case of this patient, medical intervention was deemed to no longer be helpful to the patient, only harmful. Given that Ms. Smith was relatively well-appearing, despite the presence of foreign bodies in her abdomen, there was no other significant, medically indicated intervention other than surgery to retrieve the foreign bodies. However, her past medical history and known state of her abdomen made this not possible. Given this, the medical team's recommendation of declaring this patient to be of end-stage status was deemed ethically appropriate. The Committee recognized that the difficulty around this decision stemmed primarily from provider-associated moral distress.

The second recommendation, to introduce the patient to the palliative care team, was considered out of the norm of traditional inpatient medical practice. Often, clinical medicine tends to focus on therapeutic care and not palliation, which made this an unusual course of action. However, given the patient's unusual situation and imminent demise, the Committee felt that a palliative approach for her end-of-life care was the most ethical course of action for the patient.

The third recommendation required further clarification from the care team prior to evaluating its ethical appropriateness. The Committee felt that there were different ethical implications for telling the patient to seek care elsewhere in an emergency versus to gain a non-emergent second opinion, and therefore, asked the medical team's reasoning for wanting to recommend that the patient seek care at another hospital. In the case of this team, they hoped to advise the patient to seek care at another hospital in an emergent circumstance, which we felt as unethical.

This consult, unlike the majority of others seen by this particular Committee, was mostly about managing and evaluating the moral distress experienced by the providers taking care of this patient than the patient's own distress. Of note, this patient was not part of any committee-related ethical discussion, which made any direct discussion with the patient challenging. In the spirit of offering support, the Committee reviewed the ethical implications of the treatment team's medical recommendations, which ultimately led to reassuring the treatment team that their decisions were ethically appropriate, despite their challenging nature.

The patient, although not present for the consult, was seemingly accepting of the Committee's recommendations. She did not appear to be in distress following the consult.

In emergency department encounters following this admission and the ethics consult, she has declared herself to be DNR/DNI and has even offered to discuss the recommendations of this consult to her providers.

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When the Guardian Relinquishes Decision Making: Limited Capacity in the Legally Incompetent Patient

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Abstract:
Prior to this hospitalization, Mrs. L's primary care physician filed a report with the local Adult Protective Services (APS) agency. Upon review of the case, APS determined that Mrs. L had been a victim of elder abuse and neglect. Despite the emergently obtained guardianship order due to what APS reported of the patient's circumstances at home, and regardless of whether or not the patient actually did have the capacity to make a fully autonomous decision to go home, the primary medical team's assessment was that she did not, and they felt duty bound to discharge the patient somewhere they felt was going to constitute a safe discharge. This case presents several ethical considerations that were further complicated by the unusual legal situation of having a court appointed guardian wish to relinquish his court appointment so quickly. First, can a medically frail and socially vulnerable patient, in this case a victim of elder abuse and self-neglect, with at best questionable decisional capacity, make a seemingly unsafe decision to go back into a neglectful environment? Second, does the hospital staff have an obligation to refuse to agree with decisions of a questionably autonomous patient? Finally, who should be ultimately granted decision-making authority if a court-appointed guardian believes his ward has decisional capacity?

PRESENTATION

Mrs. L is a 66-year-old female with a past medical history of depression, lower gastrointestinal bleeding, coronary artery disease, cerebrovascular accident, hypertension, hyperlipidemia, implantable cardioverter defibrillator, severe malnutrition, and scabies presenting from home to a medium-sized community teaching hospital in Colorado for failure to thrive and neglect during the COVID-19 pandemic. She lived at home with her daughter and son-in-law. Her husband was deceased. She had a son whom she declined to involve in her medical care.

Prior to this hospitalization, her primary care physician filed a report with the local Adult Protective Services (APS) agency. Upon review of the case, APS determined that Mrs. L had been a victim of elder abuse and neglect. Through the county probate court, a legal guardian, Mr. K was granted emergency guardianship. Once this guardianship was established, APS agents went to the patient's home in order to bring her to the hospital for a medical evaluation; however, she refused to leave her home. The patient and family refused to cooperate, and APS ultimately required police assistance to remove her from her home. Several dogs were also removed by animal care and control because of the condition of the residence. Mrs. L was brought to the Colorado Community Hospital and Wellness Center via emergency medical services and was admitted for observation because of failure to thrive.

Mrs. L underwent a thorough evaluation by multiple medical specialists. Pulmonology was consulted for a 1.1 cm pleural based pulmonary nodule in the right upper lobe. The pulmonologist planned for an outpatient positron emission tomography (PET) scan to further evaluate. Gastroenterology was consulted for a 1.4 cm low-attenuation lesion of the right hepatic lobe. The gastroenterologist planned for an outpatient magnetic resonance imaging study to characterize the liver lesion. Oncology was consulted to evaluate both the lung and liver lesions. The oncologist was in agreement with the diagnostic evaluations being pursued by the other specialists. Cardiology was consulted for management of Mrs. L's coronary artery disease and no acute inpatient interventions were indicated. Palliative care was consulted to discuss goals of care, but Mrs. L refused to have a conversation with the palliative care provider. Physical and occupational therapy services recommended that Mrs. L be discharged to a subacute rehabilitation facility to continue receiving therapy services. However, she refused to be discharged to any facility and demanded to return home with her family.

Concerning the patient's capacity assessment by psychiatry, they found Mrs. L to be cooperative with a stable mood, normal affect, and without hallucinations, delusions, or preoccupations. She denied suicidal or homicidal ideations. She displayed a logical thought process with fair insight and her judgment was intact. Her recent and remote history was intact. The psychiatry service determined she was not a risk to herself or others and recommended outpatient treatment for a history of depression with anxiety and post-traumatic stress disorder. The guardian also thought the patient had capacity to decide whether to go to a rehabilitation facility or home. The primary care team at the hospital, however, thought the patient was not capacitated and letting her go home would be an unsafe discharge. At this point, the guardian requested bioethics become involved.

Upon interviewing with the bioethics consultant, Mrs. L was alert and oriented to person, place, time, and problem. She voiced understanding of her decline in physical health and recognized that she did live in a home cluttered with food waste and animal excrement. She had bought a farmhouse with her husband, however, after more than thirty years of marriage to celebrate their retirement. Shortly thereafter, unfortunately, her husband had died. After his death, her daughter and son-in-law had moved in with her. She appreciated the care they provided and agreed to having all the necessary

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home health supports her doctors were recommending. She just wanted to go home. The bioethics consultant discussed the patient with the guardian, focusing on psychiatry's assessment that the patient seemed to be capacitated enough to decide to go home. In the end, however, Mrs. L consented to go to the rehabilitation facility which resolved the matter for the hospital and the guardian. During the patient's stay, sadly, she died, and so never was able to return home.

ETHICAL ISSUES

Despite the emergently obtained guardianship order due to what APS reported of the patient's circumstances at home, and regardless of whether or not the patient actually did have the capacity to make a fully autonomous decision to go home, the primary medical team's assessment was that she did not, and they felt duty bound to discharge the patient somewhere they felt was going to constitute a safe discharge. This case presents several ethical considerations that were further complicated by the unusual legal situation of having a court appointed guardian wish to relinquish his court appointment so quickly. First, can a medically frail and socially vulnerable patient, in this case a victim of elder abuse and self-neglect, with at best questionable decisional capacity, make a seemingly unsafe decision to go back into a neglectful environment? That is, how decisionally intact must this patient be to decide to voluntarily participate in what appears to be an abusive situation? Second, does the hospital staff have an obligation to refuse to agree with decisions that seem to have a high likelihood of leading to the demise of an at most questionably autonomous patient? Finally, who should be ultimately granted decision-making authority if a court-appointed guardian believes his ward has decisional capacity?

RECOMMENDATIONS

1. Given the legal determination of Mrs. L's incompetence (de jure incompetence), and the subsequent appointment of a legal guardian, she is de facto incapacitated and so should not be permitted to make her own medical decisions.

2. Given that she is oriented currently to person, place, time, and problem, we encourage shared decision making with her legal guardian, and other members of the medical team, a process that might be thought to move towards using a best interests standard.

3. The patient's family has acted in a manner consistent with elder abuse and therefore, they have forfeited their legal status as her caregivers.

REASONING

This case is unique due to the several ethical issues coexisting in the presence of an unclear legal situation. First, we must address the ethics questions: can a medically frail and socially vulnerable patient with limited capacity reasonably decide to voluntarily return to what appears to be an abusive situation? Also, does the hospital staff have an obligation to refuse to aid and abet decisions that will assuredly lead to the demise of a patient? Over the last 50 years, the principle of autonomy has cemented itself as a fundamental ethical principle in medical practice as the field increasingly moves away from a primarily paternalistic disposition and a system in which physicians often did not see it as their responsibility to assure informed consent.[1,2] In theory, autonomy and paternalism are, in some ways, opposed. However, we suggest this case highlights their connectedness in ways that may be beneficial to the ethical contours of clinical practice via a best interest standard. Best interest decisions should be made based on the pain and suffering associated with an intervention, the potential for benefit, and complications that may result.[3] In all situations the guardian and the medical team have a duty to respect the patient's stated wishes and preserve autonomy to the highest degree possible but also make only what they consider a safe discharge.[4] In a system of practice that prioritizes autonomy, patients that retain the ability to provide limited informed consent for low-risk interventions (example: A moderately demented patient consenting for a blood draw but not having the capacity to consent to hemodialysis) could choose to put themselves in a situation that could lead to their own death. The UK's Mental Capacity Act of 2005 sets out how to make health, welfare, and financial decisions for a person 16 years or older who lacks decisional capacity:

1. A person must be assumed to have capacity unless it is established that he lacks capacity.

2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

This Act displays many similarities with the American Medical Association's code of medical ethics but goes further than the AMA code in specifying "unwise" decisions.[5] The implication being that those who retain capacity should be free to make unwise decisions.

However, those with limited capacity, those whose decisions conflict with the public interest, and those considered vulnerable for the sorts of reasons that could affect their decisional capacity, are subject to having their decisions overridden in what is argued to be their best interest.[6] Mrs. L may have retained capacity to understand minimally to moderately complex medical interventions, however, her incompetence ruling implies that she is not fully capacitated and therefore we have an obligation to prevent her from placing herself in harmful situations. It is through the best interest standard that the above recommendations are in support of the medical staff discharging Mrs. L to a rehabilitation facility to prevent her reentering a situation of neglect and abuse.

Cases in which a legally appointed guardian makes an effort to relinquish his or her guardianship so quickly as the guardian in this case are suspected to be rare. These circumstances present confusion for the medical team. Who should be granted decision-making authority if a court appointed guardian believes his or her ward has capacity after being found incompetent? In this case, the guardian's intention to relinquish his guardianship so quickly threw the medical staff into disarray related to who should be making medical decisions. With some legal, but no ethical precedent to guide our decision making, we argued that Mrs. L's de jure incompetence overrode any level of limited capacity and recommended that decision making, no matter how upsetting to the patient, remained with Mr. K until the court released him of his duty to his ward. With this recommendation he did consent to the patient's discharge to a rehabilitation facility. Had he chosen differently and placed the patient in a harmful situation, we believe this would have raised the following question: is hospital staff justified on the basis of a best interest standard, to reengage the court on behalf of the patient to remove a previously appointed guardian? In the American medical system this might expose the hospital network, a business entity, to legal liability and could bring an unfavorable community view of the hospital based on patient outcomes. This business risk does not outweigh the ethics benefit of providing a more protective spokesperson for a vulnerable individual in a perilous situation.

While the specific legal processes vary state to state in the United States, this case is generalizable and therefore the possibility of a similar issue arising elsewhere makes the legal complexities of this case worthy of a closer examination. But generally, to determine that a patient is incompetent to make their own decisions they must be incapable of taking proper care of themselves or their property or fail to provide for their family or other persons for whom they are charged by law to support. Once deemed incompetent, the court is tasked with providing a guardian capable of acting on behalf of the ward.[7] A guardianship order can only be granted or terminated during a court hearing. Mr. K was an experienced guardian responsible for multiple wards. He was familiar with this process and should have known he must continue to provide for Mrs. L until such time as the court receives evidence that the underlying condition justifying the guardianship has abated. Therefore, we believe it was a deviation from court protocol for the guardian in this case to attempt to invalidate guardianship over his ward before presenting the case to the court to decide. We are only able to detail his actions and are unable to comment on his reasoning for not following standard protocol. Mr. K did retain guardianship over Mrs. L until her death.

Unfortunately, as the American population continues to grow older, more socially isolated, and medically frail, we will likely begin to care for more patients with court-appointed surrogate decision makers.[8, 9] It is important to recognize that de jure incompetence does override de facto capacity for medical decision making. However, capacity exists on a spectrum and shared decision making and best interest standards can be utilized to maximize a patient's autonomy when a patient's limited capacity is not exactly clear and, with a high degree of certainty, will lead to increased suffering and bodily harm. Medical staff will face more situations in which a patient is deemed by a court to be incompetent but is found to retain limited decision-making capacity regarding low-risk medical treatments. In those situations, medical teams will need to be diligent in assessing capacity and not override the decisions of a capacitated patient. Hospital staff and health care providers in all medical specialties will need to be critically aware of local guardianship laws in order to know how to best support the autonomy of their patients.

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Who Should Be Determining the Code Status of a Dying Infant? Are We Expecting Too Much of Parents?

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Abstract:
Baby CE is an 11-day-old female who was born at 23 weeks and 5 days of gestation and is now in multi-organ failure. She is the surviving neonate of a twin pregnancy. She was designated Baby A in utero. Although this pregnancy was an in vitro fertilization of a single embryo, ultimately the mother was found to be carrying twins. At 18 weeks, the mother was found to have early cervical shortening, for which a cerclage (a ring or loop used to keep the cervix closed to prevent premature birth) was placed. Unfortunately, her cervical shortening worsened and she was admitted in her 22nd week of gestation to the labor and delivery unit. A neonatal intensive care unit (NICU) consult was performed. Both parents were in agreement that they desired a full resuscitation effort at delivery. Baby CE's mother went into labor at 23 weeks and 5 days. Now, on day 11 of life, the baby's course is not going well. The team explains that Baby CE has no meaningful expectation of survival and has signs indicating respiratory, cardiac, liver, and kidney failure. Baby CE's parents remain undecided as to whether they believe compressions ought to be performed. Some members point out that because many parents feel this decision is too burdensome, the team should not even be asking the parents anything at this point; they should simply tell them that resuscitation would not be attempted in the face of a cardiac arrest.

PRESENTATION

Baby CE is an 11-day-old female who was born at 23 weeks and 5 days of gestation and is now in multi-organ failure. She is the surviving neonate of a twin pregnancy. She was designated Baby A in utero. Although this pregnancy was an in vitro fertilization of a single embryo, ultimately the mother was found to be carrying twins. At 18 weeks, the mother was found to have early cervical shortening, for which a cerclage (a ring or loop used to keep the cervix closed to prevent premature birth) was placed. She was also started on 17-OH progesterone, a steroid hormone used to prevent pregnancy loss, in order to improve her chances of carrying the twins to full term.

Unfortunately, her cervical shortening worsened and she was admitted in her 22nd week of gestation to the labor and delivery unit. The maternal-fetal medicine team felt labor would very likely occur within the next week, so the mother received routine preterm medications, including betamethasone (a steroid with anti-inflammatory and immunosuppressive properties) to improve the lung maturity of the infants. A neonatal intensive care unit (NICU) consult was performed.

Because between 22 to 23 weeks of gestation is considered the edge of viability for a fetus until 24 weeks of gestation, parents routinely are given an option of whether they desire resuscitation efforts made on behalf of their infant. Thus, the neonatology team spoke with both parents at length about the risks of delivery at 23 weeks, including survival and the many complications that can occur during the NICU course due to prematurity. Based on data from the National Institute of Child Health and Human Development (NICHD), the twins had a 29% chance of overall survival, and only a 19% chance of survival without profound neurologic impairment. Despite these numbers, both parents, after hearing all the information and having a chance to have all their questions answered, were in agreement that they desired a full resuscitation effort at delivery.

Baby CE's mother went into labor at 23 weeks and 5 days. She had a spontaneous rupture of membranes, at which time her cerclage was removed and purulent drainage was noted coming from the cervical opening. The twins were then delivered via cesarean section. Baby B was stillborn. Baby A, named Baby CE, was successfully resuscitated and stabilized, weighing a mere 550 g (1 lb. 3 oz).

Baby CE's prognosis was grim at birth. She had a critical, though expected, course for the first 5 days of life. She required significant ventilator support and developed pulmonary interstitial emphysema. She was hypotensive, which required pressors for support, and ultimately received medical treatment for a patent ductus arteriosus (a congenital disorder wherein a neonate's ductus arteriosus fails to close after birth). She was hyperglycemic and required an insulin drip. She was found, by head ultrasound, to have bilateral grade 2 intraventricular hemorrhages. As is typical, she received blood transfusions and broad-spectrum antibiotics.

Day 6, however, was a turning point in the wrong direction. Baby CE had a pulmonary hemorrhage but managed to survive. She was coded with chest compressions and epinephrine. She required multiple blood products in order to be stabilized. She also required increased pressor support, and was found to have several new, extensive bilateral cerebellar hemorrhages. In addition, she was found to have a significant liver hematoma, which may have been secondary to the known physical trauma a code can induce.

During the night of her eighth day of life, Baby CE once again became severely hypoxic and bradycardic from a presumed pulmonary hemorrhage. Over the next several days, Baby CE's overall status worsened. The team was becoming increasingly uncomfortable continuing to provide life-extending therapy they felt was not indicated and would never help Baby CE.

Now, on day 11 of life, the baby's course is not

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going well. The NICU team, including a neonatologist, nurse, social worker, and chaplain, meets with the parents to discuss their concerns about Baby CE. The team explains that Baby CE has no meaningful expectation of survival and has signs indicating respiratory, cardiac, liver, and kidney failure at this time. Additionally, if she were to survive, she is expected to have profound neurologic impairment.

Baby CE's parents are quiet through much of the meeting, but express their faith that the NICU team will do everything they can to save their baby. The team explains that at this point they can continue to support Baby CE with the current management if that is the family's desire. They feel, however, that should she decline further, cardiac compressions and epinephrine no longer would be indicated. The team explains that cardiac compressions are generally not useful in the NICU, especially when the cardiac failure is a result of overall multi-organ failure. They point out that cardiac compressions can cause substantial trauma to infants. Baby CE's parents remain quiet, tearful, and undecided as to whether they believe compressions ought to be performed or not.

The NICU team is distraught at the end of the meeting; the team is uneasy with the parents' unwillingness to accept that resuscitative efforts are likely not in the baby's best interests. The NICU group knows that in some jurisdictions, including their own, a patient's or surrogate's permission is not needed for a physician to write an AND/LT (Allow Natural Death/Limited Therapy) order. The team involves other NICU physicians and senior nurses in a discussion about the care and ethical dilemmas surrounding Baby CE. Some members of the team feel that if cardiac compressions will not be helpful to the infant, then they should not be offered or provided. Other members feel that the parents' lack of agreement with the NICU physicians means that the NICU team should do everything possible, regardless of the potential harm and lack of expected benefit to the infant, to keep this infant alive, at least for now. Other members still are hopeful that with some additional time the parents will be able to accept the physicians' recommendation not to resuscitate. Some members point out that because many parents feel this decision is too burdensome — that to agree not to resuscitate would mean that they were giving up on their child, something they could never live with — the team should not even be asking the parents anything at this point; they should simply tell them that resuscitation would not be attempted in the face of a cardiac arrest. Having already lost 1 of their twins, this family may simply be unable to say that it is okay to stop resuscitative efforts. An ethics consult is requested to help determine the best course of action.

CHART NOTE AND RECOMMENDATIONS

Ethics consultation requested by neonatology intensive care unit (NICU) regarding an 11-day-old female infant born prematurely at 23 weeks and 5 days gestation and currently suffering multi-organ system failure. Ethics holds a discussion with the infant's primary physician and the rest of the NICU team in an effort to learn the specifics of the medical circumstances and to gather a comprehensive picture of the team's concerns in relation to the parents' inability to make a decision. Primary concerns of the team surround an ethical justification to act on what they feel is in the best interest of the infant in light of the parents' indecision. The NICU team wants to explore the ethics of the possible paternalism of making the decision about future resuscitation themselves. Further, the team is interested in the ramifications if the parents decide they want full coding efforts taken and the team remains opposed. Another concern is about whether asking them to essentially "give up" on their infant places an overwhelming emotional burden, which they are currently psychologically unfit to bear — how would the team know that and if they could determine that was the case, what should they do?

Subsequent to the team meeting, a separate conversation was had with the parents. The parents were still visibly distraught, though tranquil, having come no closer to making a decision themselves. They did, however, recognize the gravity of their infant's prognosis and were able to reasonably understand the futility and further trauma that would likely come as a result of additional resuscitative measures. They confessed to an inability to come to terms emotionally with making the finite decision to actually request measures not be taken. The father's last statement was, "We just can't tell them to stop, but they should do whatever they think is best." Ethics communicates the results of the meeting to the NICU team.

Ethics recommends that the physician, with at least 1 or 2 other members of the NICU team, meet with the parents to explain that if the baby codes (unless there is improvement in the baby from where she is right now), resuscitation will not be initiated—that is, if the baby's heart stops, that will be the way everyone knows it is time to stop.

REASONING

This case illustrates an often occurring and dilemmatic feature in a clinical ethics consultation involving parents of a dying infant—that is, when what is in the best interest of a patient is reasonably understood by all, but rendered emotionally unacceptable by family or loved ones. Often, some additional time is all that is needed for family members to negotiate the psychological resistance to coming to terms with what they are able to rationally accept. However, just as often, family members simply cannot bear the weight of making such a decision no matter how long they are given, or the time to lengthily reflect is simply not available given the clinical circumstance.

Sometimes, it may be best that the medical team refocuses around the cessation of the demand for a decision, rather than continuing to insist. Sometimes the insistence itself is ethically objectionable. Often, just taking the proper steps to gain the parents' understanding and acceptance that, without a definitive position from them, the medical team will do what they believe is in the patient's best interest. Often, the relief associated with not having to make a decision of this significance, and thus carry the moral distress and emotional weight related to the choice, is often all that may be unconsciously sought by parents and/or other family members suffering through the tremendous anxiety that comes with such a responsibility.

Identifying this complex state of mind in family members is no easy task. Clinicians ought to be mindful, however, of communicative signs that indicate a person's acceptance or resignation to the clinical circumstance. The removal of the absolute requirement for parents and/or other family members to make a decision may be needed in order to reduce said anxiety and allow these individuals the ability to release the guilt associated with making this difficult decision.

Palliative Care and Chronic Psychiatric Disorder

Paul Noufi, MD

Abstract:
A 28-year-old male patient is recently diagnosed with colon adenocarcinoma with metastases to the liver. The patient is homeless and found to be at very high risk of opiate use disorder relapse and of opiate diversion. The palliative care provider agrees to continue the prescription with the condition that the patient follow-up concomitantly with a substance use disorder (SUD) specialist. Is the palliative care provider coercing the patient to a treatment for the sake of getting appropriate pain management? The patient did not show any evidence of loss of capacity to make the decision to get SUD treatment on his own; is the clinician infringing on the autonomy of this patient?

PRESENTATION

Mr. X is a 28-year-old male patient with a medical history of recently diagnosed colon adenocarcinoma with metastases to the liver. His past psychiatric history is significant for stimulant and opiate use disorder and a questionable history of bipolar disorder or of a personality disorder.

Mr. X is homeless, with a very low socioeconomic status and a difficulty with acquiring basic needs and over-the-counter medications. He is a freelance musician and most of his income comes from occasional musical performances. His social support is minimal with mainly one sister who provides long-distance support and one friend who "helps out sometimes." There is a pervasive history of interpersonal difficulties leading to frequent challenges and estrangements. Early on in his medical follow-up, the patient expressed deep fears of being abandoned during this escalating and serious illness.

When the patient is admitted for the first time to the hospital for evaluation of his adenocarcinoma and for deliberation on his treatment plan, the palliative care team is consulted for management of his neoplasm-related abdominal pain. During the first encounter with the palliative care provider, the patient is immediately triggered and becomes verbally aggressive and closed-off to any intervention or verbal de-escalation, leading to an early interruption of the assessment. However, in an attempt to break the patient's cycle of self-fulfilled prophecies of persistent abandonment, the provider continues and eventually succeeds in establishing rapport with the patient, enough to persuade him to subsequently continue follow-up in the outpatient palliative care clinic.

The patient is found to be at very high risk of opiate use disorder relapse and of opiate diversion. However, his severe neoplasm-related pain requires a prescription of opiates for improvement of quality of life. A plan is established with the patient to increase the safety of the prescription. This includes a weekly prescription of a limited number of opiate doses, a weekly urine drug screen (UDS) with the agreement that substances other than cannabinoids are not expected to be detected, and a bimonthly in-person evaluation in the palliative care as well as oncology clinics.

For a while, the patient is maintained on opiate treatment with a good response of his pain and is regularly following up with his oncologist and receiving chemotherapy. His UDS is persistently negative for stimulants and non-prescribed opiates. Mr. X is expressing deep gratitude for the care he is receiving and is hopeful about his treatment.

Six weeks into his follow-up, a UDS is positive for amphetamines. Mr. X explains that this is a "one-time-only" relapse in the context of severe fatigue secondary to his chemotherapy regimen. The palliative care provider agrees to continue the prescription with the condition that the patient follow-up concomitantly with a substance use disorder (SUD) specialist, for which a referral is provided.

Unfortunately, after this incident, Mr. X starts skipping appointments and demanding unreasonable or non-feasible changes to his appointment timings. The referral to the SUD specialist is never completed. During one of his outpatient appointments, a code BERT (behavioral response team) is called because of staff safety concerns due to verbal and physical escalation while attempting to schedule his next appointment. The UDS results are inconsistently provided with an occurrence of detection of stimulants.

The palliative care team is at a loss as to how to best manage Mr. X. His chronic psychiatric condition is affecting his ability to adhere to the outpatient clinic prescription and to other safety precautions implemented in the clinic. His behavior poses a risk not only to himself, but also to staff members and to other clinic patients. At the same time, his neoplasm-related pain continues to require opiate treatment to be controlled. The providers are faced with Mr. X's clear distress and deeply rooted fears of abandonment but, unfortunately, he is starting to "break" an agreed-upon prescription contract that guarantees his safety and that of his environment. The agreement also guarantees the professional safety of the prescriber.

ETHICAL ISSUES

Is the palliative care provider coercing the patient to a treatment that he is not interested in for the sake of getting appropriate pain management? The patient did not show any evidence of loss of capacity to make the decision to get SUD treatment on his own; is the clinician

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infringing on the autonomy of this patient?

In addition, the provider is also considering his own motivations to recommend SUD treatment. Does he have a right to coerce this patient in order to maintain his own professional interests and the safety of his clinic and of the staff he works with?

What is the right of this patient to appropriate palliative management and quality end-of-life care and where does that right end?

RECOMMENDATIONS

Consider a multidisciplinary meeting involving bioethics, palliative care, and consultation- liaison (CL) psychiatry where the provider can express his concerns and discuss his motivations with other team members. The CL psychiatrist and the palliative care provider can discuss the challenges encountered in the treatment of this patient and complement each other's expertise to look beyond matters of simple capacity to make decisions and address the real underlying distress.

Consider continuing regular follow-up in the palliative care clinic with the agreement to discontinue opiate treatment and only provide alternative pain management methods until re- evaluation. This might help alleviate the fear of abandonment that the patient is experiencing, and ensures that the patient continues to receive appropriate medical follow-up and treatment. If follow-up will occur in the clinic, the teams ought to make sure that they have a safe plan with clear boundaries and conditions.

Alternatively, if the decision is to discharge the patient from the clinic, the palliative care provider ought to make sure that abandonment does not occur by providing the patient with outside options to continue receiving treatment. This might include continuing the prescription with the primary oncologist if they feel comfortable providing it or referring the patient to other palliative care clinics that have a different setting, conditions for follow-up, or an embedded SUD specialist among their team members.

REASONING

It is evident in the medical literature that there exists a clear disparity in the provision of end-of- life care for patients with severe and chronic mental illness as compared to the general population.[1] This is particularly true in patients with a past or current history of SUD.[2] These disparities stem from multiple factors, including but not limited to stigma, socioeconomic factors, and a lack of clear guidelines or resources for the management of these complicated cases. With these patients in general, as in the specific case presented here, the provider wants to make sure that he offers quality care with no involuntary bias, while still ensuring safety for both the patient and the medical staff.

The first thought in this case is that the autonomy of the patient ought to be respected, especially given the patient is displaying decision-making capacity on his SUD treatment at the time of the assessment. However, the autonomy of the patient is not unlimited. The issue here stems more from the safety risk than from the mental illness itself. This case could be framed as a conflict between the two ethical principles of autonomy (for Mr. X) and justice (safety and safe options for all persons involved). While healthcare providers strive to support their patients' autonomy, clear boundaries should continue to be strictly implemented to prevent risk of violence in the healthcare setting.[3] In the absence of these boundaries and safety insurances, one also wonders if and how the provider can continue to provide high quality care when he himself feels threatened or coerced into a treatment plan that becomes driven by the patient's dynamics.

While compassion is a powerful skill that clinicians should foster, it is also important to keep in mind that it remains very different from empathy. Providers ought to be mindful and self-aware of this difference and of their own biases as they try to provide the best care that is suited to the needs of the patient. These considerations should always be thought of alongside a necessary requirement to protect the staff. On a systemic level, more studies are needed to further understand the challenges faced in the provision of end-of-life care to patients with mental illness, and to address them in a more evidence-based fashion.

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When Religion Enters Into Informed Consent and Decision Making

Sander H. Mendelson, MD

Abstract:

Mr. J is an 88-year-old male, retired lawyer, with a long history of Type II diabetes, hypertension, coronary artery disease, and advanced congestive heart failure. He is now hospitalized with congestive heart failure that is very difficult to control. The consulting cardiovascular surgeon is not in favor of implanting an LVAD in this patient. Mr. J tells his physician that he is a devoutly practicing Jew. Mr. J is ready to quote to any listener the Biblical and Talmudic bases of his views: the importance of life as a foremost value, the religious imperative to do everything to care for oneself medically, and the responsibility of the physician to heal. The primary ethical tension is that the patient, who is fully capacitated, wants to take the risk of a possibly technically feasible, technologically aggressive procedure for an expected minimal life extension. The physicians do not want to place an LVAD, believing that it is likely to do more harm than good. The decision making is complicated further because the physicians are hesitant to deny a capacitated adult making this request on the basis of his religious beliefs.

PRESENTATION

Mr. J is an 88-year-old male, retired lawyer, with a long history of Type II diabetes, hypertension, coronary artery disease, and advanced congestive heart failure. He is now hospitalized with congestive heart failure that is very difficult to control. He seems alert and well spoken. He requests that every effort be employed to extend his life, including use of advanced technology in cardiac support. The patient states that he has already done his own research and knows that there is the prospect of implanting a Left Ventricular Assist Device (LVAD). Mr. J is adamant that he wants this intervention if it will prolong his life, even by a few weeks or months.

The consulting cardiovascular surgeon is not in favor of implanting an LVAD in this patient. The surgeon and the consulting teams have made that clear, explaining that not only does the procedure itself have risks, but the postoperative maintenance is substantial. Further, the surgeon has told the patient that LVADs have not been shown to be of benefit in persons of his age and disability.

Mr. J tells his physician that he is a devoutly practicing Jew. He explains that it is his religious belief that every day of life is important, and according to the dictates of his religion he is to seek every opportunity to continue living. He is willing to take any risk if there is a chance his life will be prolonged. Mr. J is ready to quote to any listener the Biblical and Talmudic bases of his views: the importance of life as a foremost value, the religious imperative to do everything to care for oneself medically, and the responsibility of the physician to heal. He is determined to make his own decisions based on his rights of self-determination.

His wife died 5 years ago and he has 2 adult daughters. Mr. J lives alone and prides himself on his independence. These adult children, however, live close by with their families, whom Mr. J sees regularly. He is close to these children and their spouses and adores his grandchildren. One daughter supports her father's decision. She is willing to take care of him when he will not be able to care for himself. The other daughter has seen her father go through so much and does not want to see him suffer through another debilitating procedure and then die.

They call in their rabbi who agrees that Judaism places prime value on human life. But the rabbi confirms that Jewish practice does not require one to try every technologically feasible procedure, especially if the procedure is risky. While Mr. J's request is consistent with Jewish teaching, the rabbi states that the full implementation of life-preserving measures may not apply in a case such as his.

Mr. J was formally assessed psychiatrically, just to make sure that his mental status is unclouded. The psychiatrist assessed the patient as capacitated. The report stated explicitly that the patient appreciates the potential risks and benefits of implanting the LVAD and what having the LVAD might mean for his life.

CHART NOTE AND RECOMMENDATION

Ethically relevant patient history: Patient is an 88-year-old male with Type II diabetes, hypertension, coronary artery disease, and advanced congestive heart failure. The patient is requesting implantation of an LVAD. His physicians believe that placement of an LVAD is not in this patient's best interest medically, although they think that technically it could be done. They consider the patient's condition such that although placement might extend the patient's life, such extension is expected to be minimal. They believe also that any life-extending benefit will be outweighed by the expectation of the burden of postoperative care and, ultimately, harm and suffering at the very end of this man's life.

The patient is requesting this technology on the basis that it is required of him as a practicing Jew. The patient's own rabbi has said that, although seeking life extension through this means is consistent with Jewish practices, it is not religiously mandatory, and not mandatory in this case.

The patient has two daughters who differ on what

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each thinks is best for their father. The supportive daughter has said she will take her father into her home, if and when necessary.

ETHICAL ISSUES

The primary ethical tension is that the patient, who is fully capacitated, wants to take the risk of a possibly technically feasible, technologically aggressive procedure for an expected minimal life extension. The physicians do not want to place an LVAD, believing that it is likely to do more harm than good. The decision making is complicated further because the physicians are hesitant to deny a capacitated adult making this request on the basis of his religious beliefs.

RECOMMENDATIONS

Explain to the patient, family, and rabbi that the physicians here are not willing to place an LVAD because they believe it is likely to produce more harm than good. If the patient persists, staff should advise and assist the patient to be transferred to a physician elsewhere who would agree to place an LVAD. (It is acknowledged that finding such a solution is unlikely.) In the meantime, staff should continue to discuss the issue with the patient, family, and rabbi. Have Jewish clergy available to this patient and involve palliative care to assist the patient in understanding the various alternatives to the LVAD.

REASONING

Physicians do not have any duty or obligation to offer or carry out nonbeneficial, ineffective, or futile care.[1] This seemingly straightforward ethical norm is, however, difficult to practice. Nonetheless, it is the best way to practice medicine, even when it is difficult in the care of individual patients.

That this patient is capacitated can be expected to cause consternation. Some physicians may believe that they are expected to do whatever a capacitated patient wants on the basis of the principle of autonomy, which supports patient self-determination. But patient autonomy does not extend as far as to encroach on physician integrity and the physician's obligation to offer only sound medical care.

That this patient has put forward his religious belief as the basis of his request for the LVAD also has the tendency to stop physicians in their tracks. Health care providers ought to respect a patient's beliefs and values. Nonetheless, a patient's religious beliefs ought not to cause a physician to provide nonbeneficial care. The former does not automatically trump the latter. Instead, physicians ought to be respectful of religious beliefs but not use that as a reason to acquiesce to a patient's request for nonbeneficial treatment.

Physician integrity and professionalism rests on competence in making sound medical judgments. When patients request nonbeneficial care, regardless of the reasons, provision of nonbeneficial care ought to be resisted.

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Shared Decision Making in the Presence of COVID-19 and the Absence of Families

Lynette Cederquist, MD; Biren Kamdar, MD; and Alex Quan

Abstract:
For families and surrogates of patients suffering from COVID-19, the pandemic has made nearly impossible the ability to see their loved ones in the hospital day-to-day. Families and surrogates may now be more hesitant to voice their preferences and concerns, or mistrust of the medical profession on the part of members of the public that may simmer under the surface under ordinary conditions, may be quicker than usual to boil over. Both extremes may compromise the spirit of shared decision-making in medicine.1 Hence, with families absent, providers may find it necessary to adopt a more clinician-directed approach to decision-making. Once a COVID-19 positive patient enters a hospital, and viral spread mitigation policies separate patients and families, it is critically important that physicians be skilled at having end-of-life conversations with families that do not insist that they make decisions to shift to comfort measures only. Skill in these difficult conversations at the highest level is demonstrated when physicians bring families along gradually.

PRESENTATION

Mrs. C was 47 years old. She was brought by ambulance to her community hospital emergency room, where she was diagnosed with hypoxic respiratory failure secondary to COVID-19. After being emergently intubated, she had a pulseless electrical activity (PEA) arrest, requiring 17 minutes of cardiopulmonary resuscitation (CPR). Spontaneous circulation was restored and the patient was stabilized for transport. She was subsequently transferred to the closest tertiary care hospital where brain imaging revealed severe anoxic brain injury.

As had been the case since the beginning of the COVID-19 pandemic, to attempt to prevent the spread of the coronavirus, the hospital – like every hospital around the country - had initiated a restricted visitation policy. Essentially, patients cannot have visitors unless the patient is assessed to be imminently dying. Because Mrs. C was relatively stable, she was not so assessed even though her kidneys were now beginning to decline. The reason for the visitation restriction was explained several times to the patient's husband and adult children. The family was updated regularly by the Intensive Care Unit (ICU) team. Although the team, including the patient's ICU attending physician, regularly described to the family that the patient was not awakening from her arrest and that her kidneys were now failing, nonetheless, the family requested, then insisted, on continued, full life-sustaining treatment, including initiation of dialysis if it became needed.

Over a period of a week or more, multiple goals of care conversations were conducted, including vide-o conferences to demonstrate the patient's devastating neurologic injury. On hospital day 20, the ICU attending physician, the patient's resident, and nurse practitioner, joined by the hospital's clinical ethics consultant, held a teleconference with the patient's spouse and adult children. Acknowledging the impossible situation facing the family, the physician summarized prior conversations, including comments that continued life sustaining treatment was not producing any improvement in the patient's condition and was therefore not providing the patient any benefit. The team sensed that the patient's husband was moving towards a willingness to shift to comfort measures only, when the resident decided to step in and, unfortunately, made things worse. The resident said that the team didn't want to make the patient suffer.

With that, the most suspicious of the adult children said, "I thought you said our mother's brain was so bad that she wasn't able to communicate or appreciate anything around her," to which the resident responded with, "that's right."

Perhaps because of an apparently deep religious faith, the son then responded with, "I could understand what you mean if you had said that you want to make sure our mother isn't experiencing any pain. She might have pain and not be able to express it. But to suffer, I think, our mother needs to have much more awareness than you have told us she has." Immediately, the resident recognized his mistake. Suffering is a conscious human phenomenon. A patient who lacks consciousness in light of an anoxic brain injury cannot suffer.

Fortunately, this ICU attending was experienced at having residents make this mistake and skilled at getting out of the bind that the inexact usage of the word 'suffer' can produce. He side stepped quickly and replied in a way that honored the son's awareness of the profound difference between suffering and physical pain. He said, "Yes, we don't think the patient can be suffering as you so rightly point out. For that, we are all deeply grateful. Rather, we are concerned that the slower and more drawn-out her death might be is likely to produce more complications that might cause her actual pain or discomfort."

The attending then raised the issue about restrictive visitation policies while also expressing just how difficult the situation had become for the team, as well. He explained that when all could agree that, sadly, the time had come to shift Mrs. C's care to a plan focused exclusively on her comfort and letting nature take its course, two family members at a time would be allowed into the hospital to say their good-byes. Communicating the

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distressing aspects of Mrs. C's situation as also affecting the team resonated with the family. The next day, the husband called and requested firm recommendations from the ICU team, resulting in a change in status to Do Not Resuscitate (DNR) and a no-escalation order. The patient continued to deteriorate, and two days later the ICU team called the husband, telling him that he and the patient's children should come in if they felt they needed to do so. The team explained that the patient's blood pressure was becoming unstable and that they believed the patient was now actively dying. The family decided, however, that it would be too much for them. Because the patient had been transferred, the family now lived many hours away. It was unrealistic for them to make the trip.

The attending, with deep compassion, emphatically but gently assured the family that the patient would die comfortably which she did only a few hours later. Thus, by being very careful not to rush the husband or force him to explicitly agree to remove the patient's life-support, these sad conversations were allowed to progress at a pace that carefully brought the family along. By simply explaining to the family – and not asking anything of them – that it would not be in the patient's best interest to pound on her chest and likely break her ribs when her heart stops, the terrible implications could be processed appropriately by the family. By taking an unhurried approach, the attending guided this bereft, physically separated family, through an end-of-life process in which the family could feel that the decision-making had been shared.

Because this husband didn't feel rushed, he was able to trust the ICU team to facilitate a peaceful death for his wife. The hospital chaplain was summoned. The technology was arranged so the hospital chaplain and the family could pray together. With tranquil music playing, the patient died, a nurse holding her hand as she slipped away.

Once a COVID-19 positive patient enters a hospital, and viral spread mitigation policies separate patients and families, it is critically important that physicians be skilled at having end-of-life conversations with families that do not insist that they make decisions to shift to comfort measures only. Skill in these difficult conversations at the highest level is demonstrated when physicians bring families along *gradually.* Only this allows families to feel that their beloved family member died in peace, a feeling of comfort to survivors of this terrible pandemic.

ETHICAL ISSUES

Navigating Shifts in Shared Decision Making

For families and surrogates of patients suffering from COVID-19, the pandemic has made nearly impossible the ability to see their loved ones in the hospital day-to-day. Combined with media coverage exalting the efforts and expertise of first-line providers donned in PPE, the balance of power that the movement of shared decision-making has sought may be more off-kilter. Families and surrogates may now be more hesitant to voice their preferences and concerns, or mistrust of the medical profession on the part of members of the public that may simmer under the surface under ordinary conditions, may be quicker than usual to boil over. Both extremes may compromise the spirit of shared decision-making in medicine.[1] Hence, with families absent, providers may find it necessary to adopt a more clinician-directed approach to decision-making.

In cases where the family or surrogate do assert decision-making via substituted judgment, without the ability to visually appreciate the severity of their loved one's illness, families may be inclined to request non-beneficial and/or excessive treatments, propagated by unrealistic hopes of recovery. Therefore, a cycle of non -beneficial treatment and unrealistic hope may perpetuate, leaving providers in a quandary and possibly exposing patients to unnecessary pain and/or suffering with the continued use of life-extending technologies that are not providing clinically meaningful benefit.

The family in this case initially adopted a stance of unrealistic hope, requesting aggressive life-sustaining therapy. However, once the family recognized that the physician and nurses were the few people able to see and touch the patient, and because the clinicians updated the family without asking removal of life-extending technology, the family hesitantly but increasingly built a trusting relationship with the doctor and nurses. This shift in trust empowered the provider to frame decision-making and information sharing in a more clinician-directed manner while at the same time elucidating and honoring the family's wishes and values.

Shared Decision-Making and End-of-Life Discussions via Telephone or Videoconference

Because of the virus mitigation, visitor restriction policies, ICU physicians are experiencing the challenges of shared decision-making via virtual medicine. Mortality in patients requiring mechanical ventilation due to complications from COVID-19 has been reported to be as high as 76% and 97% in patients under and over age 65, respectively, making remote end-of-life discussions an increasingly common occurrence.[2]

Updating families or delivering bad news over virtual communication raises concerns about the situation or environment the recipient is in to engage in critical care discussions. Virtual communication places inherent constraints on a provider's ability to judge family or surrogate's emotional states or reactions regarding the information being conveyed. Monden, Gentry, and Cox outline five phases for effectively delivering bad news: preparation, information acquisition, information sharing, information reception, and response.[3] However, on the virtual platform, ability to manage these communications may be jeopardized. Without knowing the exact situation or environment in which the information will be received, and without being able to anticipate, witness, and respond to emotional responses, the provider can never feel fully prepared for a conversation, or anticipate the outcome. Following-up with a patient's family after end-of-life discussions begin may sometimes require numerous requests to communicate virtually in a short span of time, possibly intruding or infringing on the family's personal space and risking deterioration in clinician rapport with family. Thus, it can be emotionally taxing for both family and the providers to hold conversations about illness, death, and dying on a virtual platform.

In the absence of family at bedside, it is incumbent upon providers to be circumspect about how clinician-directed their actions can and should be.[4] They should be aware of the inherent limitations of communicating virtually and make every effort to engage the patient, family, or surrogate early, just as they should if they were present at the bedside. On the other hand, when the patient, family, or surrogate look to the provider to take on a more unilateral role given family absence, the clinicians should accept that responsibility. Kon and colleagues described a sliding scale of shared decision-making which allows an ethically supportable shift towards a more clinician-directed approach to decision-making when patients and families prefer such an approach.[5] If agreed upon, this approach may prove valuable in guiding providers and families struggling to navigate complicated situations and end-of-life decisions imposed by the COVID-19 pandemic.

RECOMMENDATIONS

1. Before any conversation with the family and the physicians, please give the family time to see and talk to the patient through use of video technology.

2. During the provider/family conversation, rather than asking the family what they know (and put them through the stress of being put on the spot), know ahead of time what the patient's condition was when the team updated the family last and start from there.

3. Ask, "Is there anything that I just said that is different from your understanding?" – and allow enough silent time for more timid family members to speak-up.
4. Then update the family as to the patient's status.

5. When finished, please ask if the family has any questions or concerns so far – again, allowing for enough silence to give family members time to speak-up.

6. Then move – slowly and gently – to a factual, neutral presentation of what is the best expectation of the treating team.

7. Finally, proceed with team recommendations.

REASONING

The recommendations are written as they are to assist clinicians in developing a rapport and trusting relationship with a family whom the team has never met, and whom can only come into the hospital when they have agreed not to contest a shift to a 'no-escalation' or a comfort measures only plan of care. This is an incredibly difficult task. And there is little or no help for scripting busy and exhausted clinicians who are trying to have what, under ordinary circumstances, are among the most difficult conversations to have with families. These difficult conversations have now been made excruciatingly more difficult because they are being conducted remotely.

There is an emerging literature on how COVID-19 is providing the impetus for medical schools to expand their curricula related to telemedicine communication skills.[6, 7] There appears to be a focused and promising effort on the part of a Canadian group of family practice physicians to develop an approach to separating the concepts of physical distancing and social connectedness built on well-established understanding of relationships as the drivers of healing.[8] Scripted assistance for ICU physicians, however, working to come to a shared decision remotely with families about capping or withdrawing life-extending technologies is not yet available.

Like so many in the acute hospital setting, clinical ethicists are learning as this pandemic progresses. What is certain is that processes for engaging in shared decision-making will look quite different post-pandemic than they did pre-pandemic. The pandemic will almost certainly change how ICU physicians communicate with patients and/or families at the end of life.

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The Unbefriended Patient: An Ethical Balancing Act

Alexander Zhang, MD and Zahava Nilly Brodt-Ciner, MD

Abstract:
A 44-year-old man with untreated schizoaffective disorder is diagnosed with diffusely metastatic colon cancer. Inpatient psychiatry consultants confirmed that he lacked capacity for medical decision-making, and advised against initiating anti-psychotic medications due to concerns about intolerable adverse effects. He is unbefriended and neither a candidate for home hospice (lacking support at home), nor placement at a hospice-capable facility (being uninsured). Beauchamp and Childress' four principles have been widely applied in medical ethics. Though this model proves effective when patients or their proxies have the capacity to communicate their wishes, it is a more limited framework when patients are incapacitated and lack a proxy. The Four Box Model otherwise known as the Four Quadrant Model or Four Topics Approach, may aid physicians in the decision-making process when they are faced with these difficult situations.

PRESENTATION

K.N. was a 44-year-old man with untreated schizoaffective disorder who presented to the hospital with severe abdominal pain and was diagnosed with diffusely metastatic colon cancer. Despite education about his diagnosis, he demonstrated paranoid thinking about all offered treatments, including cancer-directed therapy and symptom management. He stated he expected to be cured and wished to go home. He was admitted to the internal medicine service and was seen by multiple specialists given the complexity of his case. Inpatient psychiatry consultants confirmed that he lacked capacity for medical decision-making, and advised against initiating anti-psychotic medications due to concerns about intolerable adverse effects.

K.N. had two sisters living out-of-state who initially agreed to serve as medical proxies and requested his code status be DNR/DNI. However, the sisters ultimately stopped answering or returning calls from the medical team, making him an unbefriended patient. While the primary team explored the option of applying for guardianship, his condition worsened. Due to the extent of his disease, the inpatient oncologists recommended a focus on comfort care. A palliative medicine consult was obtained, and hospice was recommended. However, he was neither a candidate for home hospice (lacking support at home), nor placement at a hospice-capable facility (being uninsured). He did not meet our institution's criteria for inpatient hospice, since he was refusing medications. Thus, he remained on the medical ward of our hospital.

As his condition deteriorated, he continued to refuse treatment. He developed signs of a bowel obstruction and frequently refused pain medication and antiemetics. The medicine team felt moral distress caring for him without adequate symptom control. A medical ethics consultation recommended respecting his refusal of medications and advised keeping the DNR/DNI in place. He passed away in the hospital after a 79-day stay.

ETHICAL ISSUES

Physician as the Decision Maker and Alternatives

Much of the difficulty in providing care for K.N. stemmed from the perceived conflict between the principles of autonomy, beneficence, non-maleficence, and justice.[1] Patient autonomy is the principle in which an individual has the right to make decisions regarding medical treatment regardless of its impact on their health. Beneficence states that every proposed intervention and decision should be performed with doing good in mind. The practice of non-maleficence requires that minimal harm should come about when attempting to achieve the desired medical outcome. And justice is achieved by ensuring that all decisions and treatment be offered to individuals regardless of the differences in their background. Limited evidence exists about how best to balance these principles in unbefriended patients, a uniquely vulnerable population.[1] Further, studies have shown that, while patients await guardianship, critical decisions often fall on the shoulders of physicians.[2]

Of particular difficulty in the case above were the decisions surrounding palliative treatment. For example, consider the act of administering an intravenous pain medication in an alert patient against their wishes. Would the medical team have to restrain the patient to do so? Such methods could cause the patient to have feelings of distrust, isolation, and psychological distress. Forced treatment could erode the relationship between the patient and medical team. And if no palliative care was provided, how would the medical team navigate caring for someone who was visibly suffering? In the case above, K.N. suffered from an untreated mental illness and was inconsistent in his decisions about symptomatic treatment and diagnostic testing. Unbefriended patients are often from vulnerable populations, such as the elderly, homeless, or mentally ill.[2] Primary mental illness or substance use disorders can impair decision-making capacity. These vulnerable populations have received increasing attention, yet there has been no national standardization of care for unbefriended patients.

The first line of defense is preventing a scenario in which a vulnerable patient becomes unbefriended. This can be accomplished by helping patients complete ad-

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vance directives or establish reliable surrogates ahead of time. The pitfall of this approach is that it won't protect some of the most vulnerable individuals, for example patients who rarely seek medical care, who are lost to follow-up, or who have poor health literacy. Survey estimates have shown that advance directives (AD) completion in the USA is between 2-30%.[3] Without ADs or reliable surrogates, decision-making for patients falls to the provider team. In these scenarios, providers must rely on their experience with the patient during their care. Unfortunately, this approach can lead to false interpretation of a patient's goals of care - time spent together may be short, and patients may be unable to articulate their wishes due to physical or psychological illness.

Coppola's study on the accuracy of surrogate predictions for this patient population show that primary care physicians and hospitalists had an accuracy of 0.66 and 0.64 respectively in terms of treatment decisions (compared to what the patient would have chosen).[3] Examples included treatment for Alzheimer's disease, emphysema, coma or stroke with poor prognosis, or cancer. Family surrogates were more accurate overall compared to physicians in most treatment decisions (this finding was statistically significant with a $p<0.05$). Family surrogates were typically found to make overtreatment errors (prediction that the patient would want treatment that the patient did not want), while primary care physicians consistently made undertreatment errors (prediction that the patient would not want a treatment that the patient did want). Hospitalists made both type of errors, however slightly favored overtreatment (overall difference in decision making was found to be statistically significant, with a $p<0.01$).[3] Coppola's team also studied the effect of advance directives on prediction accuracy. Only hospitalists' accuracy was improved with Health Care Directives (HCD) compared to no ADs, greatly decreasing overtreatment errors without increasing undertreatment errors. In the absence of ADs and family surrogates, physicians often have difficulty accurately choosing treatment options for patients without capacity. As Dr. Connor stat-ed, "providers live within the culture of medicine, a culture distinct from that of many patients. Studies comparing physician preferences, particularly around end-of-life issues, with those of the public demonstrate that doctors' values frequently differ from those of their patients." [2] This study highlights some of the many difficulties when taking care of unbefriended patients with regards to respecting beneficence and nonmaleficence.

To help in difficult situations such as this, resources such as ethics committees and court- appointed guardians can be utilized. Unfortunately, there is considerable variability in the expertise and availability of court-appointed guardians and the exact process of having one appointed will vary by legal jurisdiction. Additionally, non-patient-appointed surrogates can be even further removed in terms of awareness of patient preferences, potentially limiting their ability or comfort with making certain types of decisions.[4]

Four Box Model vs Four Moral Principles

Physicians sometimes find themselves the primary decision makers for acute or chronically ill patients who lack decision-making capacity. Though it is a moral and professional responsibility to uphold ethical medical care, the "right" decision can often be unclear. Beauchamp and Childress' four principles have been widely applied in medical ethics. This framework focuses primarily on the patient's perspective. Though this model proves effective when patients or their proxies have the capacity to communicate their wishes, it is a more limited framework when patients are incapacitated and lack a proxy. The Four Box Model otherwise known as the Four Quadrant Model or Four Topics Approach, may aid physicians in the decision-making process when they are faced with these difficult situations. [5-8]

The Four Box Model, though distinct from the four principles, incorporates much of the ideology of the latter into its tenets.

TABLE 1: The Four Box Model

1. Medical Indication	**2. Patient Preferences**
3. Quality of Life	**4. Contextual Features**

In considering Medical Indication, one utilizes the expertise of medical professionals to analyze the current clinical condition of the patient and advise the patient of the best course of action. This incorporates the tenets of beneficence and nonmaleficence by providing valuable information that allows patients and their families to make informed decisions about their care. The tenet of Patient Preference allows patients (with capacity) and surrogates to guide the course of care, thereby preserving their autonomy. With any illness, the goal of treatment is to improve a patient's perceived Quality of Life as much as possible. As this parameter can be very subjective in nature, care teams should be mindful of when to give and withhold treatment based on the patient's prognosis. Providing proper counseling to patients and their families in this regard naturally incorporates beneficence, nonmaleficence, and patient autonomy into practice. Lastly, each case must be considered based on the Contextual Features of the individual patient. While administering care, one should be cognizant of how the cost of care or the endpoints of management will impact their personal lives, cultural identity, and financial stability.

Dr. Teven and his team applied the Four Box Model in the setting of caring for burn patients.[7] These patients ranged from having minor injuries with good prognosis to being critically ill with uncertain prognosis. For patients who were incapacitated and unbefriended, Dr. Teven and his team found great utility in using this model when making decisions on the patient's behalf. Though eliciting patient preference was often difficult in these settings, Dr. Teven and his team were able to substantiate their decisions based on Medical Indications, predicted changes in Quality of Life, and Contextual Features. This enabled them to make the most ethically sound decision for their patients. Medical professionals intuitively use their experience and knowledge to guide care for incapacitated patients, but having an established framework that lends credence to their decisions may give many the confidence to take action during difficult situations. It can be difficult to contextualize Beauchamp and Childress' four principles, whereas the Four Box Model creates a readily applicable analysis process. As Dr. Sokol describes, "the four quadrants operate very close to the action, asking questions of immediate relevance to the case at hand," which may allow physicians to grasp the next best step more easily during an ethical dilemma.[6]

The Four Box Model is not without limitations. Despite being more grounded in the decision-making process, it does not offer any specific recommendations or guidelines. Especially in the care of complex medical patients at the end of life, as many unbefriended patients are, opinions on prognosis and the best course of action (in other words, the Medical Indications) can vary drastically between practitioners. As described in a qualitative study written by a clinical ethics committee in Singapore, many referrals to their team related to the "uncertainty about when to continue repeated treatment and when to put a stop to such treatment," as well as difficulty "in predicting the reversibility of the acute medical condition and the exact prognosis." [8] Since Patient Preference becomes uncertain once patients become incapacitated, it is important for primary care teams to begin goals of care conversations early, hope-fully preventing difficult ethical situations.

Quality of Life (QOL) as a tenet becomes a com-plex risk/benefit analysis when treating severely ill patients or those believed to be at the end of life. As previously described, the subjective nature of this tenet becomes a severely limiting factor with critically ill and incapacitated patients as several studies have highlighted important differences in patients' and clinicians' perception of patients' QOL.[9-11] Considering a patient's Contextual Features in medically complex patients, often the factors under deliberation are related to the loved ones' understanding and thus decision making. Elements like cost of care, caregiver burden, and guilt/grief lead to difficult ethical decisions that can run contrary to other tenets. A commonly encountered situation is when surrogate decision makers have difficulty coming to terms with the poor prognosis of their loved one and thus wish to "do everything" for them leading to overtreatment (with the false hope that this might change prognosis).

Though rare, physicians can find themselves in situations where they must make difficult medical and ethical decisions on behalf of an unbefriended patient who has not yet been appointed legal guardianship. We therefore believe that the utility and efficacy of the Four Box Model is a reasonable and easily applicable model for care teams to adopt.

TABLE 2: Four Box Model Analysis for Patient K.N.

Medical Indication	**Patient Preferences**
• Newly diagnosed, diffusely metastatic colon cancer with poor prognosis. • Chronic schizoaffective disorder with symptoms of psychosis. • Treatment options included chemotherapy with palliative intent vs. symptomatic control alone.	• Patient lacks capacity to make his own medical decisions. • No existing advanced directive. • Patient believes his health will spontaneously improve and wishes to go home. • Patient inconsistently requested or refused symptomatic treatment, such as analgesics and antiemetics.
Quality of Life	**Contextual Features**
• Without chemotherapy, patient expected to survive up to a few months. • With chemotherapy, patient would have a small chance of prolonging survival but would likely suffer side effects. • Symptomatic treatment could improve the quality of life and may prolong life as a result. • Due to the patient's poor understanding of his condition, the goals of care could only be judged by the medical team's reasoning. • Thus, the decision was made to forgo chemotherapy.	• Patient's family included a cognitively im-paired father and 2 sisters. • The sisters resided out of state and had initially been in regular contact with the team. Later in his care, they stopped answering or returning calls. • Patient had been lost to follow up multiple times and did not regularly see a physician. • Patient lacked insurance, limiting outpatient treatment and discharge options. • Patient did not meet requirements for hospice either in the hospital or upon discharge.

As demonstrated, many of the decisions that were made by K.N.'s medical team can be organized into the four categories. Additionally, this framework helps shift the ethical focus to objective measures of the patient's situation. Since one difficulty in caring for unbefriended patients can be the lack of information about subjective preferences, this objective analysis can be instrumental in caring for this population.

RECOMMENDATIONS

1. Prepare advance directives, discuss goals of care, and attempt to establish a surrogate as early as possible in or-der to prevent patients from becoming unbefriended. The process for guardianship should be started or researched early if the medical team realizes that a patient is at risk for becoming unbefriended.

2. If a patient is already unbefriended, acquiring insight into their preferences from any available source may be invaluable to future decision making. The responsibility of making medical decisions in the interim between loss of capacity and acquisition of a proxy/guardian often falls upon the care team.

3. A collaborative and multidisciplinary approach is often needed to provide unbefriended patients with the most effective and ethical treatment. Palliative Care and Medical Ethics teams are often able to provide an objective and expert opinion on situations unfamiliar to the primary care team.

4. Physicians should familiarize themselves with the resources available to them in their geographical region and medical system. Knowing the qualifying criteria and time required to become established in different programs are important variables in planning ahead.

5. The Four Box Model incorporates the widely accepted Four Moral Principles in a way that enables providers to feel more confident they are the doing the best for their patients, especially when their patients are incapacitated. By incorporating the four principles into a framework capable of integrating the medical professionals' knowledge and experience, the decision-making process in ethically fraught situations can become less mystifying.

REASONING

Vulnerable populations face many barriers to receiving the care they need; the unbefriended patient population exemplifying some of the most difficult situations clinicians and patients can face. Often, care teams lack information about patient preferences and may have had little contact with the patient and their proxies prior to patients becoming unbefriended. Many of these patients have limited care histories outside of their current admission and there is often little to no contact with individuals who know the patient well.

Prevention methods such as advance directives and official medical proxies established in the outpatient setting can significantly reduce the incidence of unbefriended patients. This will be most effective in patients who receive regular medical care, however is difficult to implement for those who have poor health literacy or rarely seek healthcare. For patients who only receive care in the acute setting, care teams should do their best to educate patients and to develop these directives as they can be instrumental in the patient's future treatment. The process can be time consuming and should be started early. When encountering unbefriended patients, medical professionals who have more frequent contact with these patients throughout the day, such as nurses, technicians, physical or occupational therapists, and social workers, often gather important insight into patients' preferences and should be regularly consulted in these situations. Medical Ethics committees and Palliative Care teams are also resources that should be included in an unbefriended patient's multidisciplinary care.

Frameworks such as the Four Box Model and the Four Moral Principles can be very useful while care teams are the acting surrogates. Unfortunately, at this time, there are few standardized resources to help navigate these difficult ethical situations; the care unbefriended patients receive can vary drastically between area codes and healthcare systems. As of now, the healthcare system in place makes it difficult for systemic changes to occur quickly, thus much of the responsibility then falls to multidisciplinary care teams to prevent or develop treatment plans for these patients. Applying the strategies above can help medical providers rise to this challenge in a fashion that is both ethically appropriate and medically indicated.

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Vaccination Decision Making of Involuntarily Committed Psychiatric Patients: A Clinical Case Series

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Abstract:
Involuntary civil commitment and treatment of patients with severe mental illness pose significant ethical questions when guardians of these patients authorize COVID-19 vaccination. Legally, involuntary commitment for psychiatric illness curtails personal rights to a degree that is rare outside the criminal justice system, so that a patient may receive treatment for a mental illness that poses putative danger to self or others . Once dangerousness is established to justify involuntary commit-ment, comes the question of treatment and care for severe mental illness and to what extent is medical intervention justified given the context of care. To illustrate the role of ethics committees, we present three chronological case studies to illuminate ethical issues arising from guardian-approved COVID-19 vaccination of involuntarily committed patients. Despite the benefit of the guardian's consent, patients may not assent to vaccination. Thus, these chronological cases explore whether psychiatric hospitals ought to vaccinate their inpatients against COVID-19 without assent, and how should they do so ethically, when civil liberties are already curtailed.

INTRODUCTION

Involuntary civil commitment and treatment of patients with severe mental illness pose significant ethical questions when guardians of these patients authorize COVID-19 vaccination. Legally, involuntary commitment for psychiatric illness curtails personal rights to a degree that is rare outside the criminal justice system, so that a patient may receive treatment for a mental illness that poses putative danger to self or others. As early as 1845, court opinions required that the degree of dangerousness to self or others be "great enough to justify such a massive curtailment of liberty."[1,2] Since the 1970s, dangerousness no longer needs to be imminent or entail violent behavior; rather, a person's risk to behave violently and cause injury to self or others can justify commitment.[3] In every state, inpatient commitment laws include component parts: mental illness, putative dangerousness, and need for treatment. Some states also include incompetence, deterioration, and grave disability.[3]

Once dangerousness is established to justify involuntary commitment, comes the question of treatment and care for severe mental illness and to what extent is medical intervention justified given the context of care. In a "principlist" grounded framework,[4] ethical care often prioritizes beneficence of the treatment over patient autonomy, with the hope that involuntary psychiatric treatment may itself restore patient autonomy. People with severe mental illness are often limited in decision-making so as not to have the capacity to weigh risks and benefits of a proposed treatment. Treatment could restore autonomy or a patient's rational judgement so that they may safely return to society, as outlined in Winick's concept of "therapeutic jurisprudence."[5] However, patients who are involuntarily committed should be allowed to make decisions for which they retain capacity and may be entitled to additional legal protections.[6] In some cases, involuntarily committed patients may have uncertain decision-making capacity. If a court finds that a patient is incapable of consenting to medical care, treatment, or service, a guardian, also known legally as the Guardian of the Person, is appointed to facilitate decision-making. The guardian has the right and authority to determine if refusal or consent should be made to "any" health care, treatment, or service, except for admitting the patient to an institution, or consenting to psychosurgery, electro-shock therapies, sterilization, or experimental treatment without the prior approval of the court.

Legally, the statutes of 19 states and the District of Columbia direct guardians to use a specific decision-making standard. Of these, 12 are best interest states, requiring a guardian to make decisions based on the guardian's belief of what is in the patient's best interest. Seven states direct guardians to use a "Self-reliance" standard which seeks to foster the patient's independence. Five states use a "Least restrictive alternative" standard which instructs that guardian to make decisions that minimize restriction of the person's decision-making agency.[7] Seven state statutes, such as that of New Hampshire, are silent or reference other standards like "Substituted Judgment" which directs guardians to substitute the patient's values and desires for their own. The Uniform Guardianship, Conservatorship and other Protective Arrangements Act, model legislation that reflects the ethical framework of the professional guardianship discipline, directs guardians to use a "Substituted Judgment" standard when possible and "consider the adult's previous or current directions, preferences, opinions, values, and actions to the extent actually known or reasonably ascertainable by the guardian." [8] No substantive difference in such standards exist when a guardian is a court-appointed stranger or a family member.

Given complex medical, ethical, and legal issues of decision making involving guardians, the care for patients with severe mental illness is rife with ethical con-

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cerns of providing medical interventions in an environment of the patient's limited autonomy. Thus, New Hampshire Hospital, a state psychiatric hospital, developed an ethics committee to promote constructive discussion about patient care and to facilitate resolution of conflicting ethical values. A permanent committee of the Medical Staff Organization, the Ethics Committee consists of at least two active members of the Medical Staff Organization, the hospital chaplain, plus representatives from nursing, social work, and administration. The Committee assists the organization in the development and review of policies and procedures and provides consultation regarding the ethical care and treatment of individual patients referred by treatment teams.

To illustrate the role of ethics committees, we present three chronological case studies to illuminate ethical issues arising from guardian-approved COVID-19 vaccination of involuntarily committed patients. Case 3 highlights the involvement of legal standards of decision-making. These three patients are assumed to receive significant benefit from COVID-19 vaccination.[9] They are less likely to have received vaccinations generally and are at greater risk for COVID-19-related complications, hospitalization, and death.[10,11] Severe mental illness positively correlates with environmental variables that are risk factors for COVID-19 infection: physical illnesses, homelessness, socioeconomic deprivation, and poor adherence to infection control. Admission to a psychiatric hospital may range from days to years; longer stays increase the risk of infection. Given increased risk for COVID-19 infection, morbidity, and mortality, the potential benefit of preventing infection through vaccination against COVID-19 is clear.[11,12]

Despite the benefit of the guardian's consent, patients may not assent to vaccination. Thus, these chronological cases explore whether psychiatric hospitals ought to vaccinate their inpatients against COVID-19 without assent, and how should they do so ethically, when civil liberties are already curtailed.

CASE 1

A 70-year-old woman was admitted from a nursing home on an involuntary emergency admission. Her psychiatric history was significant for schizoaffective disorder with paranoid delusions and hallucinations. Her medical history was notable for insulin-dependent diabetes, breast cancer in remission, and obesity. She had significant weight loss due to delusions about people trying to poison her food, water, and air. Her care was managed by a co-guardianship held by family members. During her hospitalization, she attempted to leave the hospital several times and refused medications and much of her food. Her weight recovered with guardian-ordered food. Her delusions developed to include a fixed belief that the COVID vaccine would kill her. When ready for discharge, she was accepted to a nursing home with a secure unit, on the condition she receive a COVID vaccination. Her co-guardians approved administration over the patient's objection to the vaccine. A team member wondered if the patient could surreptitiously be given the vaccine.

Nursing leadership consulted the Ethics Committee: Is it morally justified to vaccinate a patient against their stated wishes, and can deception be used to avoid the use of force?

ETHICAL ANALYSIS

Deception-based Vaccination

To address the idea of surreptitious vaccination without force, the Committee recognized how truth-telling is a paramount value in psychiatry.[13] Patients who lack capacity may not appear to be harmed by deceptive information, as they cannot use true or false information to decide. However, Potter writes, "medicating an uncooperative patient who does not understand what this medication is supposed to treat and whose risk to himself warrants medication by force is, at least arguably, morally preferable to a situation in which a cooperative patient has been tricked into taking a medication."[14]

While one may argue deception may spare harm to an individual patient, it can be detrimental to the public's trust in health professionals whose word needs to be believed for them to be effective. Psychiatrists must support involuntary patients' autonomy to the extent their capacity allows, even at the cost of open coercion. The Committee opined against deception on that basis.

Limited Rationality-based Vaccination

The patient had delusions that the vaccine was fatal. For the patient, it may have been traumatic to attempt to give her the vaccine against her wishes.

Declining a COVID-19 vaccine does not inherently demonstrate a lack of capacity; however, having delusions about a vaccine establishes the interference of psychopathology in impairing the patient's perception of reality and medical decision-making capacity.

In assessing whether vaccination aligns with patient values, a previous longstanding history of vaccination may serve as evidence that the patient's previously held personal values, such as a belief in vaccination, have been co-opted by a mental illness. Vaccination may be considered nonvoluntary. As Dominic Sisti wrote, "The concept of nonvoluntary psychiatric treatment recognizes that a patient may have held rational values that were co-opted by a mental illness."[15] For Sisti, involuntary treatment amounts to treatment over objection justified by imminent threat to a patient's or another's safety.

In this situation, there is an imminent threat of COVID-19 to the patient's safety. Thus, refusing a vaccination appears irrational. Discussion of the irrationality argument for imposing vaccination however ignores other aspects of voluntariness, such as previously expressed wishes to be treated in a crisis, or that the patient may have had a period of recovery in a mental state to which they would want to return.[15] The Ethics Committee decided against limited rationality as a justification for vaccinating the patient over objection.

Least Restrictive Alternative

Committee members also considered applying a least restrictive alternative: a similar ethical standard to the aforementioned legal standard that encourages clinical interventions which intrudes as little as possible on the patient's autonomy.[16]

Understanding what to avoid restricting is key; the preference to be vaccinated in a single moment is not the only element of the patient's volition. People choose to be vaccinated for various reasons, including the wish to end a pandemic, wish to protect their families, belief it is a civic duty, or a desire to remain healthy.[17] A patient's values can be obtained from collateral history such as vaccination records or a discussion with family and health practitioners.

Despite the staff's interest in seeking the patient's agreement for receiving the vaccination, there was no clear history that vaccination aligned with the patient's values, so the committee could not morally justify forced vaccination based on the ethical and legal priority of the least restrictive standard over other considerations, as discussed in Case 3.

The Ethics Committee recommended that the treatment team and guardian enlist others the patient may trust such as the chaplain and family to encourage her that the vaccine is safe and effective.

Thus, the patient met with family, and due to her strongly held religious beliefs, involved the chaplain, who shared position statements from various clerics encouraging vaccination. Neither of these actions convinced the patient to agree. The Ethics committee met again and continued to recommend applying the ethical principle of the least restrictive alternative. The treatment team and guardian could try to find alternative placements that did not require the vaccination. Ultimately, a nursing home with a secured unit that did not require vaccination was identified, and the patient was discharged accordingly.

CASE 2

A 62-year-old male with a past psychiatric history significant for schizoaffective disorder, bipolar type, and several prior hospitalizations was admitted on an involuntary emergency admission from his skilled nursing facility for aggressive, disorganized behaviors. He held numerous delusions, such as believing he was a famous artist. His medical history was significant for hypertension, hyperlipidemia, and hypothyroidism. During his admission, his sister, who is also his guardian, stated her desire for him to receive his COVID-19 booster. The patient had been previously vaccinated, and the booster was not required for safe discharge. The patient articulated twice he would accept the recommended immunization. However, when offered by a nurse with whom he was unfamiliar, he refused.

The patient's situation was brought to the attention of the Ethics Committee: Is it ethical to use a trusted messenger to encourage a patient to accept a medical intervention?

ETHICAL ANALYSIS

A prevailing belief among nursing staff was that the flu vaccine was not to be forcibly administered, even with guardian approval. This notion rested on the idea that the benefit of vaccinating against the flu did not outweigh the harm incurred by both patient and staff in forced vaccination. The idea of administering COVID-19 vaccination thus became a source of moral distress among the healthcare team, for which mitigation was necessary. Having chronologically followed Case 1, this case occurred as COVID-19 cases were rising across the country, raising concern for infection but not to a degree in which the risk of nontreatment was severe.

When considering the least restrictive alternative, the discussants of this case focused on why the patient's response to vaccination changed. Central to the analysis of this case are the approach of care ethics, which "emphasize relationship(s) as fundamental to being, eschew general principles, highlight the parent-child relationship as paramount, view moral responses as properly graduated, and identify emotions such as empathy, compassion, and sensitivity as prerequisites for moral response." [17]

In sum, care ethics seeks to promote the well-being of both caregivers and care-receivers by understanding how our beings and actions are enmeshed within a social context of relationships.

Recognizing that the patient was willing to discuss the vaccine with someone with whom he was familiar, the Ethics Committee recommended approaching the patient when he was less agitated and utilizing a trusted messenger, the nurse with whom the patient was familiar, as a least restrictive alternative. The use of a trusted messenger would not constitute coercion or deception, but an acceptable use of rapport. This strategy was successful, and the patient readily accepted the vaccine from the trusted nurse.

This second case demonstrates that the relationship of the nurse to the patient is fundamental. As Ida Jean Orlando described in the Nursing Process Discipline Theory, nursing requires investigating why patients behave in the way they do and what needs are unfilled.[18] This case relies on understanding the emotions of both patient and nurse and achieving of the nursing goal of meeting the patient's needs as well as mitigating moral distress at a time when it was not clear if the benefit of COVID-19 vaccination outweighed the harm incurred to both patient and staff from a forced administration of the vaccine.

CASE 3

A 66-year-old male with schizophrenia and experiencing homelessness was on an involuntary emergency admission after a release from prison. He presented with paranoia and failure to complete activities of daily living due to food-related obsessions. His medical history was significant for orthorexia, resulting in B12 deficiency. His guardian, a family member, approved psychiatric treatment including forced administration of long-acting injectable antipsychotics and was adamant that the patient be vaccinated for COVID-19. The patient was unsure about the vaccination as he believed COVID-19 may be a hoax. He believed the vaccine was "unnatural," unaligned with his health beliefs. The approval of forced administration by his guardian raised the question of whether forced administration was appropriate if least restrictive alternatives were tried and failed.

This case occurred later into the pandemic than previous cases; recent outbreaks in the hospital had created a sense of urgency with a heightened risk of disease and death. Effective treatments for COVID-19 were not yet available, and this patient had multiple risk factors for bad outcomes. Perceiving the possible need for forced vaccination, preemptive consultation with the legal department and review of the guardianship order revealed that "the right and authority [of the guardian] to determine if refusal should be made or consent should be given to any medical or other professional care, counseling, treatment, or service provided." This case was brought to the Ethics Committee: Should the clinical team honor a guardian's request to use coercion to administer the COVID vaccine to a patient against his will?

ETHICAL ANALYSIS

This case highlights the intersection of ethical and legal decision-making. The two attorneys consulted opined that the guardian has the authority to approve involuntarily vaccination. The committee's primary consideration, given the legal option rendered, was to ethically rely on the principle of beneficence. It considered that the worst outcome would be if a guardian lawfully requested the COVID-19 vaccine, the hospital failed to give the vaccine to the highly vulnerable patient, and the patient subsequently was infected with COVID-19 and consequentially died.

Given the guardian has the right to authorize the forced vaccination, which can be accomplished competently and with minimal physical risk to the patient by psychiatric staff accustomed to involuntary medication procedures and is the medically recommended treatment in the setting of a COVID wave, it would be difficult to justify not giving the vaccination.

An ethics committee may encounter a similar case with more challenging features, such as a different medical risk of vaccination inherent in the patient, such as prior reactions to vaccines, or complex history of patient-expressed wishes when not psychotic. An ethics committee may benefit from entering a dialogue with the guardian about the decision-making standard they used to decide to authorize the vaccination.

Given the complexities of the law, an ethics committee may choose to examine the legal limits to the decision-making powers of guardians. New Hampshire statutes do not direct a specific standard but the Office of Public Guardian, a nonprofit entity contracted with the state, relies on the Substituted Judgment standard as a matter of agency policy. State laws typically restrict substitute decision-making in areas deemed too personal for a guardian to exercise unregulated control, such as in the areas of sex, marriage, or birth control.[19] Likewise, vaccination being considered as a medical procedure is not sufficient for it to fall under the purview of guardian authority. Vaccination differs from most other medical procedures in that it does not treat a disorder of but alters physiology. Moreover, patients may never get the infection against which the vaccine protects, whereas medical treatment is for an existing diagnosis. Uncertainty around benefits, along with the possibility that society may consider vaccination too sensitive for the power of guardians to exercise their authority, casts doubt on guardian-authorized involuntary vaccination.

A guardian's power to authorize involuntary vaccination may have limits, but it may be permitted given additional oversight. For example, a New Hampshire guardian cannot authorize sterilization on his or her authority but may do so with the approval of a judge, who may limit the scope of a guardianship order on a case-by-case basis.[20]

Therefore, an option for an ethics committee faced with the complex task of weighing ethical considerations in such a case is to recommend that the clinical team seek judicial review of a vaccination request, to ensure that the guardian is not authorizing treatment outside their authority. The highest level of due process to protect the patient's legal rights amounts to the least restrictive imposition upon the patient's autonomy.

The Ethics Committee found the principle of beneficence paramount: the risks of a vaccine administration may be worth the lasting protection from the imminent threat of a severe disease in a high-risk congregate setting. However, the patient was discharged before the vaccination could occur. While ethics is not necessarily the same as law, and law is not necessarily same as ethics, this case illustrates how a contextually-driven dialogue between ethical and legal reasoning can inform clinical decision making.

DISCUSSION

Involuntary commitment inherently curtails personal rights to a degree not seen outside the criminal justice system. It carries the historical legacy of long-term institutionalization being used as a form of social control.[21] However, modern-day involuntary commitments seek to uphold due process and ethical values of autonomy, beneficence, non-maleficence, and justice while providing care. Court-ordered treatment can be viewed as "therapeutic jurisprudence" where the treatment is a means to an end and the individual regains their autonomy that was otherwise limited by untreated mental illness.[5]

Each of these cases highlights significant ethical questions whose answers depend on the context, including how acute the risk is perceived. The ethical principles of beneficence, autonomy, and non-maleficence, as well as the ethical virtue of truthfulness, were prioritized in answering these questions. Regarding beneficence, patients with severe mental illnesses have a greater risk of hospitalization and death due to COVID-19. The treatment teams and guardians believe that the benefits of the vaccines outweigh the risks for most such patients. Beneficence guides the treatment teams and the guardians to want to administer COVID-19 vaccines to highly vulnerable patients to prevent serious medical complications and deaths, especially with rampant viral transmission. Regarding autonomy, the probate court has found each patient to be legally incompetent to make appropriate medical decisions. Regarding non-maleficence, pursuing the least restrictive alternative guides the treatment teams, to try their best to find ways to encourage the patient to accept the vaccines with the least risk of patient injury. Ultimately, if efforts to employ less restrictive alternatives are ineffective and risk is perceived to a degree that the outcome of nontreatment is so severe, it may be legally and ethically permissible for the guardian to approve administration of the COVID-19 vaccine against the patient's wishes, which may be a lifesaving intervention during a pandemic.

The purposes and value of an ethics committee lie in the ability of an ethics-trained interdisciplinary team to engage in discussions regarding how treatment teams can ensure the best care possible that meets the needs of the patients, either articulated by the patient or their surrogate concerning a professional assessment of their behavior and history. The question to vaccinate patients in involuntary care is challenging and rife with ethical dilemmas. These cases demonstrate how ethics committees act as facilitators of constructive discourse of ethical values to foster consistent, value-based care.

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