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Pediatric Behavioral Health Patients
“Boarding” in Emergency Departments

Across the nation, hospitals are seeing
an increasing need for psychiatric
care for children and adolescents that
is far outpacing available resources.
They come to the emergency depart-
ment (E.D.) for a variety of reasons,
many serious, including suicidal
ideation, hallucinations, or psychosis
and violent acting out. The inability
to discharge, transfer or refer younger
patients means longer E.D. and hospi-
tal stays without access to appropriate
treatment.

In Washington state, the “situation
is referred to as ‘boarding,’ where a
person living in a hospital emergency
room is in limbo, stuck in a unit ill-
suited to their needs until a long-term
psychiatric bed opens up.”¹ E.D.s
often don’t have “the staff, train-
ing or physical safety precautions”
to fully address their needs, nor can
they be discharged,² not only because
of unavailable inpatient beds but
also because of a lack of out-patient
resources.

In Maryland, behavioral health E.D.
patients experience an average delay
of 20 hours for discharge or transfer
with children and adolescents de-
layed twice as long as adults. In the
absence of available psychiatric beds
or outpatient resources for children
and teens, patients spend days, weeks
or even months “living” in the E.D.
Despite the clear need for additional

The Mid-Atlantic Ethics Committee
Newsletter is a publication of the
Maryland Health Care Ethics Committee
Network, an initiative of the University
of Maryland Francis King Carey School
of Law’s Law & Health Care Program.
The Newsletter combines educational
articles with timely information about
bioethics activities. Each issue includes
a feature article, a Calendar of upcoming
events, and a case presentation and
commentary by local experts in
bioethics, law, medicine, nursing, or
related disciplines.

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Editor

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resources, Maryland overall has only seen a 3% increase in psychiatric beds at general hospitals over a seven-year period, and some regions have actually lost beds. For example, Montgomery County has seen a drop in bed capacity for these patients over the same seven-year time frame, forcing some patients and families in crisis to seek treatment in nearby states.

There are many facets to this problem and likely many ways to address it. One clear need is for more psychiatric resources including more inpatient beds, better utilization of such beds and additional outpatient services. In early 2022, a state-wide psychiatric bed registry pilot was launched to alleviate the logistical burden of psychiatric placements, but it still faces many practical hurdles. Unlike Massachusetts and other states with high participation and effective bed registries, Maryland has not coordinated with its Medicaid Managed Care Organizations nor, like Virginia, has it codified minimum update frequencies into legislation. Despite repeated emphasis on the positive impact of community-based psychiatric resources and relationships, no existing or proposed plan has incorporated these pre-existing paths to care. The lack of hospital participation and inaccurate data simultaneously cloud the potential effectiveness of our system and illuminate the need for informed guidance from those impacted: patients, families, clinicians and institutions alike.

Besides the obvious clinical, financial and policy aspects of the problem, there are ethics issues at the heart of caring for these patients. Clinicians as well as hospital administrators are obliged by their codes of ethics and accepted principles to provide care to patients which is beneficial, avoids or mitigates harm, is carried out in a just fashion, and takes account of patients’ (or in the case of minors and others unable to decide for themselves, their decision makers’) perspectives.

The National Academy of Medicine (formerly the Institute of Medicine) has articulated a framework specifying 6 requirements for high quality care. It must be:

- **Safe**: Avoiding harm to patients from the care that is intended to help them.
• **Effective**: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).

• **Patient-centered**: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

• **Timely**: Reducing waits and sometimes harmful delays for both those who receive and those who give care.

• **Efficient**: Avoiding waste, including waste of equipment, supplies, ideas, and energy.

• **Equitable**: Providing care that does not vary in quality because of personal characteristics such as race, gender, ethnicity, geographic location, and socioeconomic status.

The current situation deprives many patients of all ages of behavioral health care that meets these aims because the conditions necessary to accomplish that care do not exist or are severely constrained. While patients bear the primary burden of this lack of adequate resources and timely care, the situation also leads to caregivers’ moral distress, i.e., discomfort related to a gap between what the doctors, nurses and others know to be the appropriate care for the patient and their inability to provide it due to institutional or systemic factors they can’t control. Unresolved or persistent moral distress can lead to moral injury, a more damaging psychological state associated with poorer quality of care, depression, burnout and suicide among clinicians. Its prevalence and severity had been significantly aggravated by the COVID-19 pandemic, and the conditions of inadequate resources continue to perpetuate the harm to patients and clinicians.

In the 2023 session, the Maryland legislature took note of the problem of inadequate behavioral health resources for patients of all ages and passed the Behavioral Health Care – Treatment and Access (Behavioral Health Model for Maryland) Act. The law sets up a Commission to study and make recommendations to address the many elements of the problem. It specifies more than 20 stakeholders who must have representation on the Commission. In turn, a number of subcommittees will be established to break the work down into more manageable parts. Funding for the Commission is provided, and the work is expected to continue over several years.

Groups have also turned to the judicial system to rectify these injustices. On May 30, 2023, attorneys from Disability Rights Maryland and Venable LLP filed a lawsuit against the Maryland Department of Human Services and the Maryland Department of Health for “illegally and unconstitutionally” housing foster children in hospitals and restrictive institutions and failure to provide appropriate placements and medical services to Maryland foster children. The lawsuit is a class action on behalf of Maryland foster children who are currently experiencing, or are likely to experience, medically unnecessary hospitalization. The complaint alleges that many of these children’s guardians sought help from their local Department of Social Services, but DSS would not take custody because beds were not available. Within the complaint, the harrowing stories of several children depict the conditions these youth face; children being confined to hospital beds for weeks and months without education, recreation, or even the basic social interaction necessary for healthy development.

The complaint acknowledges the realities explored above and provides a recommended solution: adoption of the START (Systemic, Therapeutic, Assessment, Resource, and Treatment) system. This research-based program provides comprehensive in-home services and has been adopted by several other states. Maryland implemented a START pilot program in 2017, but officials have declined to fully implement it. The complaint, filed in U.S. District Court for the District of Maryland, seeks declaratory and injunctive relief, as well as monetary damages. The lawsuit covers all jurisdictions in Maryland except Baltimore City, which is covered through separate and ongoing litigation.

The Maryland Healthcare Ethics Committee Network (MHECN) is following this issue closely to both...
better understand it and identify potential solutions. We particularly seek to have input into the deliberations of the Commission and its various subcommittees. To this end, we are interested in hearing from members of the Network regarding their knowledge of or experience with this problem and suggestions for addressing it. We hope to bring stakeholders together to share those experiences and ideas. If you have thoughts you would like to share, please send them to dhoffmann@law.umaryland.edu.

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7 Mitchell Y. Mirviss, Venable and Disability Rights Maryland File Lawsuit Against State Officials Over Long-Term Placement of Foster Children in Hospitals, May 30, 2023,

4 Mid-Atlantic Ethics Committee Newsletter
Limits of Maryland’s Adult Guardianship Process Reduce Quality of Care for Patients

When an adult patient cannot make decisions about their medical care and they have no family or close friends, a guardian may be appointed to make decisions on their behalf. However, because of delays in the appointment process, adult patients in Maryland are left languishing away in hospitals as care teams are stuck waiting for a court-appointed guardian who can approve or deny further treatment.

Guardianship is the legal process by which the court appoints someone to act on behalf of an incapacitated person. A court-appointed guardian will consider the interests of the patient and advice of the medical team before consenting to, or denying, medical treatments and intervention for the patient. The process for appointing a guardian, begins with a petition signed by two approved medical professionals that states that the patient is disabled or incapacitated. Guardians should only be appointed when no other less restrictive alternative is available.

Maryland Rule 10-201(f) outlines that an expedited hearing may occur when the guardianship is for the purpose of providing medical treatment. However, in practice, this expedited process can take several weeks, jeopardizing the quality of life of these patients.

While physicians may provide treatment without consent in emergencies, the line between emergency treatment and treatment requiring consent is not always clear. This ambiguity leaves doctors distressed and can create inadequate care for patients. Because of the legal and professional risks of acting without consent, doctors often conclude that in these situations, the best course of action is to wait. Sometimes the hospital ethics committee becomes involved.

An inappropriate level of treatment can also arise in cases where a patient comes into the hospital unable to breathe on their own, requiring them to be placed on a ventilator. Being on a ventilator too long can damage one’s lungs and increase the risks of complications. These patients are typically housed in the ICU, which comes with its own risks of increased infection. After two weeks on a ventilator, medical teams typically move towards establishing a new care plan for patients; either allowing the patient to breath on
their own or performing a tracheostomy, which they cannot do without the patient’s consent. While on the ventilator, it may take several days for someone to identify that the patient needs a court-appointed guardian, and that the hospital must file the necessary paperwork. By then, the patient’s health is already declining.

Once filed, how quickly the paperwork is processed depends on which jurisdiction it was filed in. According to Dr. Unguru, in Baltimore City, a guardian may be appointed in just a couple of days, while in Baltimore County the process often takes multiple weeks because of backlogs in the courts. Several factors create delays in appointing a guardian. Doctors may not identify the need for a court-appointed guardian when someone is admitted to the hospital because the patient can consent when admitted, but their condition deteriorates such that they then need a guardian later in their stay. There is also significant “hand off” of patients, particularly between residents, which can reduce the sense of agency or “ownership” of any individual doctor over the patient. It may take days or weeks to identify that someone does not have a relative, neighbor, or friend who can serve as their guardian. When families are present in care, they can act as an advocate for their loved one. Dr. Unguru and Dr. Brauer have found that when that advocacy is missing, the quality of care the patient receives declines.

An example from a Baltimore-area hospital earlier this year demonstrates the gravity of these wait times. A patient was admitted to the hospital incapacitated, with no immediately identifiable family. The patient was facing two concurrent medical issues. First, he would have benefited from a blood transfusion, but none of the attending nurses or doctors could get an IV in. The typical subsequent course of action would be for a radiologist to guide an IV in, but the radiologist refused to perform the procedure because it required patient consent. Second, the patient had fluid in his lungs. To properly diagnose and treat the patient, a doctor needed to drain a small amount of that fluid via a minimally invasive, nonsurgical procedure. That procedure required patient consent, so the doctors would not perform it without a guardian’s approval. Nobody in the hospital would perform the procedures because the patient’s condition was still considered non-emergency. The patient’s condition continued to deteriorate, every day, as the hospital waited for the court to review their guardianship petition. A doctor ultimately intervened and performed both procedures, because the doctor was concerned that the patient would only get sicker, and ultimately die.

The patients most affected by guardianship delays are those who are already marginalized, often unhoused and elderly patients with little connection to family or friends. These are patients who should be receiving the best care but are instead languishing away, receiving substandard treatment. This is an ethical issue that needs to be addressed in Maryland.

To improve the quality of care for these patients, both Dr. Unguru and Dr. Brauer advocate for a small, hospital-based committee that is authorized to approve medical intervention when a patient’s health is deteriorating as they wait for a court-appointed guardian. The committee would include experts in guardianship as well as individuals with different backgrounds and knowledge that could convene in 24-48 hours to give best practices recommendations. The hospital ethics committee could serve this function.

Opponents of this approach argue that it would be a conflict of interest for the committee to be comprised of professionals from the same hospital that would be providing treatment. Both Dr. Unguru and Dr. Brauer note, however, that as a practical matter relying on other hospitals to house the committee would create more delays. There are also potential legal issues with this strategy, as it bypasses the legal process for consent and requirements for guardianship. New legislation would be necessary to set up such a committee.

Alternatively, the courts could expedite these cases so that medical treatment decisions can be made in a timely manner that does not harm patients. In either case, both judges and legislators need to be educated about the problem.
and the need for change. Until that change happens, physicians and hospitals need to be educated about how to efficiently navigate the guardianship process and the need to identify patients who may need a court-appointed guardian on admission. Ethics Committees may already do this, but Dr. Unguru noted that more can, and should, be done for unrepresented patients.

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1 The People’s Law Library of Maryland, Adult Guardianship, (May 31, 2023),
3 Md. Code, Estates and Trusts Article §13-705. For further information on alternatives to guardians, see The People’s Law Library of Maryland, Adult Guardianship Process – Alternatives to Guardianship, (May 31, 2023),
4 The current differences in processing time are an improvement from the waits a decade ago, where it could take up to 180 days in some jurisdictions to appoint a guardian. In 2011, expedited hearings for medical guardians were not available statewide, contributing to the vastly different wait times. The average wait time state-wide in 2011 was 45 days. See Report of the Workgroup on Hospitalized Adult Disabled Persons – Appointment of Temporary Limited Guardian, Dep’t Hum. Res., (Nov. 30, 2011),
https://mgaleg.maryland.gov/cmte_testimony/2021/hgo/1ivsqy_g5w197DmAWJ_EV9148rfYA6jch.pdf
5 Doctors can lose their license or face medical malpractice claims for such action.
6 Dr. Unguru is a pediatric hematologist/oncologist with joint faculty appointments at The Herman and Walter Samuelson Children’s Hospital at Sinai and The Johns Hopkins Berman Institute of Bioethics. Dr. Unguru is the Chairman of the Ethics Committee at Sinai Hospital of Baltimore.
7 Dr. Brauer is a pulmonologist in Baltimore, Maryland at Sinai Hospital of Baltimore.
8 In Maryland, the petition may be filed in the jurisdiction where the patient resides, or the jurisdiction that a hospital is located. Because of this, hospitals that are situated on the border of jurisdictions may regularly file in different courts. Md. R. 10-201(c).
Court Determines Maryland Hospital Discriminated in Denial of Gender Affirming Care to Patient

Note: While ethics committees draw on ethical theories and principles for their recommendations, they should also be aware of relevant court opinions that touch on ethical patient care. This article describes one such recent opinion.

In Hammons v. UMMS, the United States District Court for the District of Maryland found that denying a patient a hysterectomy on the grounds that the procedure was part of treatment for gender dysphoria was sex discrimination and violated Section 1557 of the Affordable Care Act. The court found that the University of Maryland Medical System (“UMMS”) was liable for the denial of care by its subsidiary, St. Joseph Medical Center.

UMMS purchased St. Joseph Medical Center (“St. Joseph”) in 2012. Until then, St. Joseph operated as a Catholic hospital by Catholic Health Initiatives. As part of the acquisition, both parties signed an agreement in which UMMS pledged to continue running St. Joseph, “in a manner consistent with Catholic values and principles.” This included adherence to the Ethical and Religious Directives for Catholic Health Services (“ERDs”), as promulgated by the United States Conference of Catholic Bishops. The ERDs prohibit direct sterilization. Guidance on these directives, issued by the National Catholic Bioethics Center, expands on this in the context of gender-affirming care, stating:

Gender transitioning of any kind is intrinsically disordered because it cannot conform to the true good of the human person, who is a body-soul union unalterably created male or female. Gender transitioning should never be performed, encouraged, or positively affirmed as a good in Catholic health care. This includes surgeries, the administration of cross-sex hormones or pubertal blockers, and social or behavioral modifications. The World Professional Association for Transgender Health considers hysterectomies medically necessary surgeries for transgender men diagnosed with gender dysphoria. Gender-affirming hysterectomies are routinely covered by public insurance programs, including Medicare and Maryland Medicaid.

On September 4, 2019, Jesse Hammons met with Dr. Steven Adashek, an attending physician at St. Joseph, who determined that a hysterectomy was the proper treatment for Hammons’ gender dysphoria. Hammons’ surgery was scheduled for January 6, 2020. Hammons underwent several health screenings and took off work in preparation for his procedure. On December 4, 2019, Dr. Adashek spoke with Chief Medical Officer, Dr. Cunningham, about the upcoming procedure, telling her that he was to be performing a hysterectomy for the purpose of gender transition. Dr. Cunningham said that St. Joseph could not perform the surgery because, “it was a gender transition treatment.” Dr. Adashek called Hammons the night before his surgery, informing him that St. Joseph could not perform the surgery because it was for the purpose of treating gender dysphoria, as opposed to another medical condition.

Hammons, represented by the
ACLU, filed suit against UMMS, St. Joseph, and UMSJ Health System, LLC for violation of the Affordable Care Act. Hammons filed a motion for summary judgment (judgment before trial) on the grounds that the undisputed facts demonstrated statutorily prohibited discrimination.

The Court’s Reasoning

At the heart of the lawsuit was whether the ERDs, as implemented by St. Joseph, neutrally applied to all patients, as required by law. The court found that the policy of St. Joseph was not a neutrally applicable ban on performing hysterectomies. Instead, it was a ban specifically on hysterectomies sought by transgender patients for the purpose of treating gender dysphoria. It was undisputed by both parties that Hammons’ surgery was cancelled because it was for the purpose of treating his gender dysphoria. The court stated that the defendants were not able to identify any other medical diagnosis that St. Joseph excludes from treatment eligibility in this way, noting that any cisgender patient seeking, “a doctor-recommended, medically necessary hysterectomy” would not be turned away by UMMS or St. Joseph.8 The court relied on cases that found discrimination against transgender individuals in other contexts constituted sex-based discrimination to find that St. Joseph’s policy discriminated “on the basis of sex,” a violation of the Affordable Care Act. The court also applied recent precedent from the U.S. Supreme Court that established that Title VII of the Civil Rights Act’s prohibition of discrimination “because of sex” includes discrimination against gay and transgender employees.9 After finding that the policy was discriminatory, the court evaluated which entities could be held liable under the Affordable Care Act’s definition of a health program or healthcare provider. Section 1557 of the Affordable Care Act operates like a contract between the federal government and the recipient of federal funds.10 Thus, liability attaches to the recipient of those funds. UMMS argued that because St. Joseph’s surgery department was the recipient, UMMS could not be held liable, only St. Joseph’s. The court was unpersuaded by this argument and reasoned that the actions of all UMMS hospitals fall back on UMMS. The court further explained that all named defendants, including UMMS, receive federal funding and that St. Joseph is a wholly owned subsidiary of UMMS. As a result, the court granted summary judgment in favor of Hammons. At the time of publication, the summary judgment opinion is currently on appeal in the Fourth Circuit. Although Hammons won his statutory claim in summary judgment, the court dismissed two constitutional claims, finding that UMMS was protected by sovereign immunity, which protects governmental actors from suit without their consent. Hammons has appealed his case, arguing that UMMS’s actions also violated the Equal Protection Clause and Establishment Clause of the U.S. Constitution, and thus he should be awarded relief under those constitutional claims as well. If Hammons prevailed on these claims, he would be entitled to further damages. UMMS has filed a motion to dismiss, arguing that because Hammons won in summary judgment, and was fully compensated, he is not entitled to further damages. Appellant’s Response to Appellee’s Motion to Summarily Dismiss for Lack of Jurisdiction, Hammons v. UMMS, No. 23-1394 (4th Cir.).10

Aftermath and Implications for Health Care

This holding has several important takeaways for hospitals and healthcare providers. First, there are potential legal risks that arise when state and federally funded hospitals merge with, or acquire, religious hospitals. Both parties must think carefully about how such a relationship may change the services they can, and must, provide. Although not the case here, religiously based hospitals may defend denial of gender-affirming services under constitutional religious freedom protections and statutes like the Religious Freedom Restoration Act (“RFRA”),11 which prevents the government from infringing on a person or entity’s exercise of its religious beliefs. [See BOX next page]

Second, this case emphasizes that health care systems can be held liable for the actions of their sub-parts in matters implicating federal funding. Health systems must carefully consider the policies and practices of all sub-parts to ensure compliance.

Finally, this case shows a willing-
ness by the courts to recognize discrimination against transgender patients as a form of sex discrimination, which may be significant as states move more broadly towards prohibiting certain forms of gender-affirming care. By June of 2023, at least 19 states had enacted some ban on gender-affirming healthcare. These range from bans on gender affirming surgeries for minors to criminalizing the prescription of hormone blockers. Some states are now moving towards targeting adults as well. In Florida, adults cannot use Medicaid for gender-affirming healthcare. Oklahoma has proposed a bill that would make it a felony for anyone under the age of 26 to receive gender affirming care. In Virginia, a proposed bill bans gender-affirming surgeries for those under 21.

On June 20, 2023, a federal district judge struck down an Arkansas law that banned all forms of gender-affirming care for transgender youth, finding the law unconstitutional under the Equal Protection Clause of the Fourteenth Amendment and the First Amendment. The law also permitted private insurers to refuse coverage for all gender-affirming surgeries, even in adults. The Arkansas case is the first of these severe bans to be assessed by the courts. Similar laws in Alabama, Florida, and Indiana are currently blocked by injunction, and are likely to face the same constitutional and statutory issues. On June 22, 2023, a federal judge struck down a Florida law prohibiting the use of Medicaid funds for gender-affirming care in both adults and minors, finding that the law was unconstitutional and violated the ACA's prohibition on sex-based discrimination. Taken together, these cases all suggest that courts across the nation are taking a similar approach as the Hammons court.

The court’s reasoning in Hammons is significant in that it establishes that treatment of Hammons' gender dysphoria was in fact a medical need, differentiating his case from elective surgeries. The Hammons framework may be referenced as other courts assess the legality of laws that restrict these treatments, or whether they can legally be performed at all.

**The Religious Freedom Restoration Act (RFRA)**

The (RFRA) prohibits the government from, “substantially burdening a person’s exercise of religion even if the burden results from a rule of general applicability” unless the government demonstrates, “that application of the burden to the person: (1) furthers a compelling governmental interest; and (2) is the least restrictive means of furthering that compelling governmental interest.” Put plainly, even if a law or policy applies to everyone, if it substantially burdens one’s ability to practice their religion, the government must have an exceedingly strong reason for doing so. “Person” can include private entities like businesses and hospitals. The RFRA only applies to federal actions, but many states have similar measures. The RFRA has been referenced in high-profile cases like Burwell v. Hobby Lobby Stores, Inc., where the Court struck down the contraceptive mandate of the ACA. There, the Court held that private, for-profit corporations can be exempt from a regulation that its owners religiously object to if there is a less restrictive means of furthering the law’s interest.

**In Hammons**, the defendants attempted to argue that such reasoning should apply to St. Joseph and its policies, asserting that performing gender-affirming care would substantially burden the exercise of their Catholic faith and principles. However, the District Court reasoned that because a prior ruling determined that UMMS was a state actor, that as a subsidiary of UMMS St. Joseph was a state actor as well. Because the RFRA only applies to private entities, it did not apply to the defendants in this case. Additionally, the District Court noted that many courts are hesitant to apply the RFRA in claims brought by private parties. Thus, for the courts to evaluate the merit of this defense, it would likely require the government to bring a suit against a private party.

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3 Migdon, supra note 2.
4 Transgender Issues in Catholic Health Care, THE NAT. CATHOLIC BIOETHICS CTR. (2017), https://static1.squarespace.com/static/5e3ada1a6a2e8d6a131d1dcd/t/5ee0f0ae9453fd0090550f0e/1591799983567/2017F AQ_TransgenderIssuesHealthCare_FINAL.pdf.
6 Id.
7 Id. at 10.
8 Id.
10 Id. at 28.
11 The defendants in this case also offered an RFRA defense, but the court found that wholly owned subsidiaries of state actors are also state actors under the RFRA, and thus not covered. Hammons, *47. The RFRA only protects private entities from actions by the State.
13 For up to date tracking on trans-healthcare bans, see the Human Rights Campaign’s “Map: Attacks on Gender Affirming Care by State” at: https://www.hrc.org/resources/attacks-on-gender-affirming-care-by-state-map.
16 ACLU of Arkansas, supra note 15.
18 Hammons, *15.
20 Id.
21 The Supreme Court has reasoned that because a corporation is merely a means of achieving an individual’s goals or group’s goals, that the RFRA can apply to closely held private entities. Burwell v. Hobby Lobby Stores, Inc., 573 U.S. 682 (2014).
22 While the language of the statute includes reference to state governments, in City of Boerne v. Flores, the Supreme Court held that this was not an appropriate exercise of Congressional power, and it must be restricted to federal action. 521 U.S. 507 (1997).
24 Id. at 690-91.
25 This case was complicated because at different points of the litigation, UMMS and St. Joseph claimed they both were, and were not, state actors, depending on what defenses it afforded them. Hammons, *43.
26 Hammons, *44-47.
Mrs. J is a mother of six whose adult children are now living in different states in the U.S. and overseas. Now in her 60s, Mrs. J has widely metastatic cervical cancer that is no longer responsive to oncologic therapy. She was admitted to the hospital with emesis and pain around her G-tube site, which was placed for gastric decompression. She has a malignant bowel obstruction precluding enteral feedings and medication administration. She has HIV but cannot take HIV drugs due to the bowel obstruction. Her CD4 count is currently 7. She is being fed by total parenteral nutrition (TPN). Nephrology placed bilateral nephrostomy tubes for ureteral obstruction. She previously had bacterial and fungal line sepsis. Her code status is Do Not Resuscitate (DNR)/Do Not Intubate (DNI).

On evaluation after her admission, she was found to have a displaced G-tube and evidence of acute cholecystitis. The venting G-tube was replaced and a cholecystostomy tube was inserted for biliary drainage. She was deemed too unstable for cholecystectomy. She was found to have fungi and bacteria in her blood as well as fungi in the biliary drainage, despite administration of antibiotics and antifungals. Mrs. J is encephalopathic. Her middle daughter Grace is her surrogate decisionmaker. Grace has been unable to decide about comfort care or hospice without support from her siblings. However, her siblings and other family members have been unwilling to help with decision-making. Grace feels overwhelmed and frustrated.

A PICC (Peripherally inserted central catheter) line was placed to resume TPN. Mrs. J does not have resources for a skilled nursing facility. The medical team feels they could discharge Mrs. J to die at home with home hospice, but Grace feels unable to care for her at home. A local hospice offered to care for Mrs. J in their inpatient Hospice facility without charge, but not with TPN. Given the impasse in decision-making about how to proceed, Mrs. J’s nurse requests an ethics consultation.
Mrs. J’s daughter is unable to care for her mother at home, even with home health support. The only viable options for care are inpatient hospice or indefinite hospitalization. Inpatient hospice appears to be the most appropriate and supportive setting for this patient, but that option requires discontinuation of TPN and the daughter’s agreement with hospice care.

Mrs. J. is at the end of life and beyond medical rescue. Physicians are not obligated to provide interventions that are “medically ineffective” under the Maryland Health Care Decisions Act. (From the Summary of the Act: “A physician or physician assistant need not provide treatment that the physician or physician assistant believes to be ethically inappropriate or that a physician believes to be medically ineffective. Medically ineffective treatment is defined as treatment that, as certified by the attending and a consulting physician to a reasonable degree of medical certainty, will neither prevent or reduce the deterioration of the health of an individual nor prevent the impending death of an individual.”) TPN seems to qualify as medically ineffective under this definition.

Per the HCDA, the care team could obtain certification from the attending physician and one consultant that TPN is medically ineffective and will no longer be provided. However, the daughter’s state of feeling overwhelmed and inability to accept hospice and stopping TPN reveals the need for intensive support from the medical team, and perhaps chaplaincy or social work. One possibility is to reframe this decision as one of “informed assent.” Under this paradigm, the provider would take the lead by informing the daughter that the next step is to move to inpatient hospice while allowing her to ask questions and raise objections. This shifts the moral burden and responsibility to the physician while preserving the autonomy of the patient/surrogate.

In a 2020 JAMA article, Curtis and colleagues (2020) stated: “The advantage of informed assent over a more traditional informed consent approach is that the clinician does not ask the patient or designated family member to take responsibility for the decision but rather asks the patient or family member to allow the clinician to assume responsibility. Some family members may be willing to permit clinicians to make this decision while simultaneously being unable to accept responsibility themselves, even if they agree, because of the psychological burden it places on them. In this setting, informed assent may provide family members a way to agree with the clinician’s determination without assuming responsibility.”

In the article, the authors provide a schematic of the informed assent approach. (See Figure 1. on page 14).

This approach is also reflected in Jack Schwartz’ 1999 opinion on the Maryland Attorney General’s website: “The physician can and should play a key role in the decision-making process: by explaining the situation in a way that is meaningful to the decision maker and by clarifying the choices that are medically reasonable. Indeed, the physician can often help lift a heavy psychological burden from a weary patient or family member by making a recommendation about a plan of care.”

Much of ethics consultation relates to how decisions are communicated and framed. Reframing this decision for Mrs. J’s daughter may relieve her of significant guilt that she would otherwise feel if required to make the decision for hospice care herself as well as be in the best interest of Mrs. J.

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Summary of MD Health Care Decisions Act: (original act 1994)  
https://www.oag.state.md.us/Healthpol/HCDAsummary.pdf


Figure 1. Proposed Components of Informed Assent Framework

From: The Importance of Addressing Advance Care Planning and Decisions About Do-Not-Resuscitate Orders During Novel Coronavirus 2019 (COVID-19)  
Decisions to stop TPN or enter hospice require understanding what these interventions represent symbolically to patients and families, and their “fit” with long held values. The foreseeable, proximate death of the patient does not alter our obligation to attempt to understand what Mrs. J would have wanted and to support Grace.

We are told, in this scenario, that Grace cannot decide whether to stop TPN, thereby allowing transfer of Mrs. J to hospice. Because of this, the patient’s poor prognosis, and concerns about the costs of care in the hospital (and therefore the need to place her elsewhere) a proposed resolution is unilateral withdrawal of care. (Since no direct mention is made of patient suffering, we assume that her pain is adequately controlled.) But by doing this are we inappropriately excluding Grace, relying instead on two physicians’ opinions to decide to withdraw TPN from Mrs. J.?

Could Grace’s current indecision arise from her experiences, not only in the hospital, but throughout her mother’s illness?

Why, for instance, was a woman with untreatable metastatic cancer not already enrolled in palliative care? How has Grace been asked the endless clinical questions? With regard to TPN, was she asked “do you want us to give your mother feeding by her veins?” or, instead,“ do you think your mother would want to have her dying prolonged by artificial nutrition?” So often, we use inappropriate language (“feeding” vs. “artificial nutrition”), misfocus the question (on medical decisions rather than on values), and also misplace the reference frame (what do “you” want, not what would “your mother” want). Furthermore, we know nothing here about Grace’s or her mother’s cultural, religious, or familial values, or the expectations set up by outpatient physicians. Those facts, which can only be learned by listening to Grace and her family, are essential to helping us understand Grace, and to arriving at an ethically defensible process to resolve this case.

Grace seems to lack decisional support from her siblings. Yet, even if they do not feel able to opine on what should be done, they might well have information about Mrs. J’s values throughout her life, and about her and Grace’s relationship. Involvement of patient advocates or chaplains who focus the conversation on listening and learning from the family, rather than on specific resolution of the placement problem and care conundrums, could yield important information and create alliances that support Grace.

What about informed assent, which is indeed a potentially compassionate way to address end-of-life decisions? It requires asking the decision-maker explicitly to cede decision-making authority and relies on trust between clinicians and patients and patients’ families. Intended to alleviate stress on the decision-maker, informed assent, like informed consent, is contingent and revocable at any time. It should never be used in lieu of discussions of values or to subvert the decision-maker’s expressed wishes.

When we invoke the HCDA option of unilateral withdrawal of care, explicitly overriding the family’s and/or patient’s apparent preferences, we should think of that as a “sentinel event” – a prompt to learn. What, in the course of care of the patient and
the patient’s family, could have been done differently to avoid such an impasse? What skills and listening and involvement of other professionals, would have facilitated resolution? End of life decision processes, like all other processes in medicine, require rigorous review and continuous improvement to ensure that we learn from “worst case” scenarios like those involving unilateral withdrawal of care.

Gail J Povar M.D., M.PH.
Clinical Professor Emeritus of Medicine
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School of Medicine and Health Sciences

References:


Response from Dr. Elson

In response to Dr. Povar, rather than framing the issue as one of "unilateral withdrawal of care," framing it as providing medically effective care seems more helpful in this case. TPN is medically ineffective in this scenario. Therefore, it should not be offered, and we should not ask Grace to decide whether or not to administer it. Framing it as "feeding" vs "artificial nutrition" is beside the point.

Also, the "informed assent" framework was only proposed regarding the move to hospice, not regarding the administration of TPN.
**MHECN Crisis Standards of Care Study**

The Maryland Healthcare Ethics Committee Network (MHECN) is beginning its work on a survey of hospitals that developed and adopted crisis standards of care (CSC) during the COVID-19 pandemic to evaluate the impact of, and lessons learned from, the development and deployment of these processes. As health systems became overwhelmed with critically ill patients during the height of the COVID-19 pandemic, some adopted crisis standards of care but others did not. MHECN hopes to understand why, what triggered their adoption, whether they were adequate to address the kinds of shortages hospitals faced and whether improvements to CSCs that were adopted are necessary. We’d also like to learn whether some hospitals could have benefited from adopting CSCs but did not, leaving providers to make triage decisions spontaneously and without comprehensive resources.

A 2020 study conducted by Johns Hopkins Bloomberg School of Public Health Center for Health Security detailed the experiences of many New York City hospitals where physicians had to make triage decisions without system or state guidance and the challenges that arose during CSC implementation. The Hopkins researchers convened a group of 15 individuals including intensive care unit physicians, mental health physicians, CSC authors, and other physician scholars and researchers based in New York City to discuss their experiences around this topic. In their study the researchers asked the participants the following five questions:

1. To what degree was there institutional engagement and support in CSC planning and implementation?
2. To what degree did institutions collaborate?
3. To what degree did bedside clinicians have situational awareness?
4. How well did CSC plans work?
5. What has been the post-CSC impact on healthcare worker resiliency and healthcare worker wellness?

Through feedback solicited from this working group, the Hopkins researchers drafted a report to describe their findings and summarize the areas for potential improvement in New York health systems’ CSC protocols. Although this report provides clear data on the experiences of New York physicians, it is not yet clear how these experiences translate to other states such as Maryland.

Therefore, similar to the Hopkins 2020 report and following IRB approval, MHECN is planning on conducting interviews with Maryland healthcare stakeholders to better understand the use of CSC plans on Maryland health systems and hospitals. Using these findings, MHECN seeks to write a white-paper describing the lessons learned during the pandemic in order to facilitate more informed and robust CSC plans moving forward in the state of Maryland.

With news reports indicating that approximately 15 hospitals in Maryland adopted CSC plans during the COVID-19 pandemic, MHECN believes that these interviews will be critical in understanding Maryland health system’s experiences of CSC adoption (or lack thereof) during the pandemic. MHECN is looking to partner with hospitals on these interviews with a specific interest in understanding which resources had to be triaged and how CSC plans worked on the ground.

If your hospital would like to participate in the study, please contact Matthew Fleisher, matthew.fleisher@umaryland.edu, for more information.

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**Reference**

CALENDAR OF EVENTS

Columbia University

ELSI Friday Forum: The Genomics of PTSD Risk *(Online Seminar)*
November 10
12:00 – 1:00pm
**Panelist:** Murray B. Stein, MD, MPH, University of CA San Diego, VA San Diego Healthcare System
**Panelist:** Eric Juengst, PhD, MA, University of North Carolina at Chapel Hill
**Moderator:** Josephine Johnston, LLB, MBHL, The Hastings Center, University of Otago
More information is available [here](#)

The Greenwall Foundation’s William C. Stubing Memorial Lecture
Can Mental Health Save the World?
November 14
5:00 – 8:00pm
**Speaker:** Gary Belkin, MD, PhD, Director of the Billion Minds Project
_Pulitzer Hall, 2950 Broadway, New York, NY 10027_  
*Room/Area: World Room*
More information is available [here](#)

Johns Hopkins Berman Institute of Bioethics

Seminar Series: Artificial Intelligence and Ethics: Towards a Robust Normative Framework
October 23
12:00 pm – 1:00 pm
**Speaker:** Marc Spindelman, Isadore and Ida Topper Professor of Law at the Ohio State University Moritz College of Law
_Bloomberg School of Public Health Feinstone Hall_  
615 N. Wolfe Street, Baltimore, MD
More information is available [here](#)

Seminar: Value and Cost of Open and Inclusive Decision-Making in Health Financing
October 30
4:00 pm – 5:00 pm
**Speaker:** Alex Voorhoeve, Department of Philosophy, Logic and Scientific Method at the London School of Economics and Political Science (LSE)
_Deering Hall_  
1809 Ashland Avenue, Baltimore, MD 21205
More information is available [here](#)
CALENDAR OF EVENTS (CONT)

Seminar: The Development of Indigenous Bioethical Guidelines in Aotearoa New Zealand *(Zoom)*
November 13
12:00 pm – 1:00 pm
**Speaker:** Maui Hudson, Associate Professor and Director of Te Kotahi Research Institute, University of Waikato
More information is available [here](#)

Seminar: Health Misinformation Online: Can Social Media Influencers be Liable for Physical Harm?
November 27
12:00 pm – 1:00 pm
**Speaker:** Leah R. Fowler, Research Assistant Professor and Research Director in the Health Law & Policy Institute, University of Houston Law Center
*Bloomberg School of Public Health Feinstein Hall*
615 N. Wolfe Street, Baltimore, MD
More information is available [here](#)

Seminar: One Health, One Ethic? Confronting the Disunity of Ethical Oversight for Human and Nonhuman Animal Research
December 11
12:00 pm – 1:00 pm
**Speaker:** Rebecca Walker, Professor of Social Medicine and of Philosophy, University of North Carolina at Chapel Hill
*Bloomberg School of Public Health Feinstein Hall*
615 N. Wolfe Street, Baltimore, MD
More information is available [here](#)

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**University of Maryland Carey School of Law**

The Rothenberg Health Care Law & Policy Speaker Series

The Battle for Your Brain *(Zoom)*
November 9
4:30 – 5:30pm
**Speaker:** Nita A. Farahany, Robinson O. Everett Distinguished Professor of Law & Philosophy at Duke Law School, the Founding Director of Duke Science & Society, the Faculty Chair of the Duke MA in Bioethics & Science Policy, and principal investigator of SLAP Lab
More information is available [here](#)
SAVE THE DATE:  (Zoom)
January 18, 2024
4:30 – 5:30pm
Speaker:  Vardit Ravitsky, PhD, Senior Lecturer on Global Health and Social Medicine, Part-time at Harvard Medical School, Professor at University of Montréal and Member of HMS Center for Bioethics
More information is available here

Penn Medical Ethics and Health Policy

MBE/MSME Alumni Speaker Series: App Based Mental Health: A View from an MBE Psychiatrist
Accidentally in Industry  (Hybrid)
October 23
5:15 – 7:30pm
Speaker:  Jonathan Kole, Clinical Assistant Professor of Psychiatry and Human Behavior, Brown University
More information is available here

Ethical, Legislative, and Political Responses to Assisted Reproductive Technology and Reproductive Genetic Innovation  (Zoom)
October 24
12:00 – 1:00pm
Speaker:  Myrisha Lewis, JD, Professor of Law, William and Mary Law School
More information is available here

HP/CHIBE and LDI Research Seminar  (Hybrid)
October 26
12:00 – 1:00pm
Speaker:  Kimberly Narain, MD, PhD, Assistant Professor In-Residence of General Internal Medicine and Health Services Research, UCLA David Geffen School of Medicine.
Colonial Penn Center Auditorium, 3641 Locust Walk
More information is available here

Penn Bioethics Seminar Series (PBS) -  (Hybrid)
October 31
12:00 – 1:00pm
Speaker:  Andrew Murray, PhD, Postdoctoral Fellow in Ethical, Legal, and Social Implications of Genetics and Genomics, Department of Medical Ethics and Health Policy, University of Pennsylvania
1402 Blockley Hall, 423 Guardian Drive
More information is available here
CALENDAR OF EVENTS (CONT)

We the Scientists: How the Rise of Patient-Led Research is Changing Medicine *(Hybrid)*
Research Ethics and Policy Series (REPS)
November 8
12:00 – 1:00pm
**Speaker:** Amy Dockser Marcus, Wall Street Journal, Staff Reporter
*RCH B102AB, Richards Bldg., 3700 Hamilton Walk*
More information is available [here](#)

MBE/MSME Alumni Speaker Series: Imperiled Newborns: Converging Ethical Perspectives *(Hybrid)*
November 13
5:15 – 7:30pm
**Speaker:** Matthew Drago, Assistant Professor and Attending Neonatologist - Icahn School of Medicine at Mount Sinai
More information is available [here](#)

Penn Bioethics Seminar Series (PBS) *(Hybrid)*
November 21
12:00 – 1:00pm
Kimberly Arnold, PhD, MPH, Assistant Professor, Department Of Family Medicine And Community Health, Department Of Psychiatry, Perelman School Of Medicine, University Of Pennsylvania
*1402 Blockley Hall, 423 Guardian Drive*
More information is available [here](#)

Penn Bioethics Seminar Series (PBS): Ethical Dilemmas in the Management of Addiction *(Hybrid)*
November 28
12:00 – 1:00pm
Speakers: Samantha Huo, MD, MPH, Assistant Professor, Emergency Medicine, Perelman School of Medicine | University of Pennsylvania
Bridget Durkin, MD, MBE, Assistant Professor of Clinical Medicine
*1402 Blockley Hall, 423 Guardian Drive*
More information is available [here](#)

Penn Bioethics Seminar (PBS) *(Hybrid)*
December 5
12:00 – 1:00pm
**Speaker:** Peter P. Reese, MD, PhD, Attending Physician, Renal-Electrolyte and Hypertension Division, Department of Medicine, Senior Fellow, Leonard Davis Institute Of Health Economics, University Of Pennsylvania, Senior Scholar, Center for Clinical Epidemiology and Biostatistics
*1402 Blockley Hall, 423 Guardian Drive*
More information is available [here](#)
University of Pittsburgh
Center for Bioethics & Health Law

The Remote Body in Medicine: Touch and Telepresence on a Hospital Ward
October 23
12:00pm – 1:00pm
Speaker: Luna Dolezal, PhD, Professor of Philosophy and Medical Humanities, University of Exeter
Room 6012, Forbes Tower
More information is available here

Disability and Technologized Embodiment
October 23
5:00pm – 6:30pm
Speaker: Stuart Murray, DPhil, Professor of Contemporary Literatures and Film, School of English, University of Leeds
Room 501, Cathedral of Learning
More information is available here

Immigration & Health Equity: From Demagoguery to Community (Online)
October 27
1:00pm – 2:00pm
Speakers: Mark G. Kuczewski, PhD, HEC-C
Fr. Michael I English, S.J., Professor of Medical Ethics, Director, Neiswanger Institute for Bioethics, Stritch School of Medicine, Loyola University Chicago
More information is available here

Pathways to Palliative Care
November 2
5:00pm – 7:00pm
S100 BST (Biomedical Science Tower), 200 Lothrop Street (Accessible entrance: at the western, Darragh Street, side of the building)
More information is available here

A Neurobehavioral Approach to Understanding Implicit Bias in Research and Medicine (Online)
November 3
12:00pm – 1:00pm
Speaker: David Fraser, PhD, Teaching Associate Professor of Neuroscience, University of Pittsburgh
More information is available here
The Role of the Chaplain in a Healthcare Setting *(Online)*
November 7
8:00am – 9:00am
*Speaker:* Tony Conrad, Board Certified Chaplain, Director of Pastoral Care, UPMC Altoona & UPMC Bedford
More information is available [here](#)

*Greg Marshall, author of Leg: The Story of a Limb and the Boy Who Grew from It (Online and in person)*
November 7
7:00pm – 8:30pm
*Speaker:* Theresa Brown, RN, author of The Shift and Healing: When a Nurse Becomes a Patient
More information is available [here](#)

**Decision to Withdraw ECMO from a Patient with Capacity (Online)**
November 13
12:00pm – 1:00pm
*Abstract:* Attendees will discuss the ethical reasons in support of and against unilateral withdrawal of ECMO from a patient with capacity requesting to remain on it. They will examine the lack of uniform policies or recommendations regarding withdrawal of ECMO from a patient with capacity across the US.
More information is available [here](#)

*Systemic Racism and Use of Artificial Intelligence in Medicine (Online)*
December 11
12:00pm – 1:00pm
*Abstract:* Attendees will discuss the ways in which artificial intelligence in medicine may propagate systemic racism. They will examine the lack of standard recommendations for reporting bias of artificial intelligence tools with journal article submissions. Attendees will discuss ways to reduce the risk of artificial intelligence in propagating systemic racism.
More information is available [here](#)

*Substance Use and Drug Testing during Pregnancy: Ethical Issues (Online)*
November 14
7:15am – 8:00am
*Speaker:* Erica Holland, MD, Assistant Professor of Obstetrics & Gynecology, Boston University Chobanian & Avedisian School of Medicine
More information is available [here](#)

**Conscientious Objection: The Pharmacist’s Right to Refuse to Fill Contraceptive Prescriptions**
November 14
1:00pm – 2:00pm
*Speaker:* Tim Stratton, PhD, RPh, Professor of Pharmacy Practice, University of Minnesota College of Pharmacy, Duluth
More information is available [here](#)
Putting Science to Work: Women Healers and the Pursuit of Medical Knowledge in Early Pennsylvania *(Online)*  
November 14  
6:00pm – 7:00pm  
**Speaker:** Susan H. Brandt, PhD, Lecturer in the Department of History, University of Colorado, Colorado Springs  
More information is available [here](#)

Trust Takes Two: Barriers to Trust in the Healthcare System Among Ethnically Diverse Parents *(Online)*  
November 17  
1:00pm – 2:00pm  
**Speakers:** Jennifer Needle, MD, MPH, Associate Professor of Pediatrics, University of Minnesota  
Shannon Pergament, MPH MSW, Founding Member of SoLaHmo and Community-Based Research Facilitator, Community University Health Care Center, University of Minnesota  
More information is available [here](#)

Attending to Disability: Honoring the Religious Lives and Practices of People with Intellectual Disabilities  
December 5  
8:00am – 9:00am  
**Speaker:** Sarah Jean Barton, ThD, MS, Assistant Professor of Occupational Therapy and Theological Ethics, Duke University School of Medicine and Duke Divinity School  
More information is available [here](#)

Yale School of Medicine  
Program for Biomedical Ethics

Moving from the Extraordinary to the Ordinary *(Hybrid)*  
November 1  
5:00 – 6:30pm  
**Speaker:** Alfred Imre Tauber, MD, Professor of Philosophy (tenured, 1998), College of Arts and Sciences, Boston University Zoltan Kohn Professor of Medicine, Boston University School of Medicine; Professor of Philosophy, emeritus, College of Arts and Sciences, Boston University Zoltan Kohn, School of Medicine, Boston University  
More information is available [here](#)
CALENDAR OF EVENTS (CONT)

**Virtue Ethics (Hybrid)**
November 15
5:00 – 6:30pm
**Speaker:** Bryanna Moore, PhD, HEC-C, Assistant Professor, Department of Bioethics and Health Humanities, School of Public and Population Health, University of Texas Medical Branch, Galveston, TX
More information is available here

**The Ethics of Live-Brain Research (Hybrid)**
December 6
5:00 – 6:30pm
**Speaker:** Stephen Latham, JD, PhD, Senior Research Scholar; Affiliated Faculty, Yale Institute for Global Health, Yale Institute for Global Health; Director, Yale Interdisciplinary Center for Bioethics, Interdisciplinary Center for Bioethics
More information is available here

**Personalized Public Health in Africa: Balancing Disease, Privacy and Ancestry (Hybrid)**
December 13
5:00 – 6:30pm
**Speaker:** Stephen Schiff, MD, PhD, FACS, Professor of Neurosurgery; Vice Chair for Global Health, Neurosurgery; Affiliated Faculty, Yale Institute for Global Health, Yale School of Medicine
More information is available here
The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland Francis King Carey School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network attempts to achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

MHECN appreciates the support of its individual and institutional members. MHECN also welcomes support from affiliate members who provide additional financial support.

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