ASSESSING DECISION-MAKING CAPACITY: CONSIDERATIONS FOR INSTITUTIONAL POLICY

Consider the following scenario:

Mr. Jones, 79 years old, is admitted to your facility with a diagnosis of Parkinson’s disease and is being worked up for altered mental status. His daughter (whom he lives with) has brought him in. Mr. Jones has a living will that restricts certain life-sustaining treatments if he is in a terminal or end-stage condition. His clinicians do not consider his Parkinson’s disease to be in a terminal stage at this time. He has a Maryland MOLST order form completed by his primary care provider with “Attempt CPR” selected. Mr. Jones’ daughter is his appointed health care agent, authorized to make health care decisions for her father when he lacks decision-making capacity. Mr. Jones tells the clinician, when the two are alone together, “When my heart stops, let me go. I don’t want to do this anymore. I’ve lived a good life. I’m ready.”

Whether you are the clinician hearing these words or an ethics consultant called in to assist, providing ethically appropriate care to Mr. Jones requires obtaining an accurate assessment of his decision-making capacity. Does Mr. Jones have the capacity to decide for himself whether to forego cardio-pulmonary resuscitation (CPR) attempts (and possibly other life-sustaining interventions)?

Who actually makes a decision-making capacity (DMC) assessment and how it is done, and who should make a capacity assessment and how it should be done, are addressed in a recent article by Siegel and colleagues (2014). They review data revealing excessive variability in how clinicians—psychiatrists included—evaluate DMC, attributed partly to lack of training and partly to lack of a consistent approach to assessing DMC. The authors review Appelbaum and Grisso’s model (Applebaum, 2007; Applebaum & Grisso, 1988), which evaluates DMC in the following four categories:

1. **Communicating a consistent choice.** This requires that a patient communicate...
The information in this newsletter is not intended to provide legal advice or opinion and should not be acted upon without consulting an attorney.
judgment, or undervalue input from those who know the patient best. Moreover, Appelbaum and Grisso’s four-component model may be overly weighted toward cognitive reasoning to the exclusion of the role of values and emotions in assessing DMC. Some argue that values and emotions can be more informative in determining DMC than cognitive reasoning for some patients. For example, underlying emotions and values might confirm a DMC assessment for a patient who voluntarily stops eating and drinking based on a wish to hasten death from terminal illness, whereas the underlying values and emotions of a patient with anorexia nervosa may call into question her decision to stop eating—something that might not be picked up by the MacCAT-T.

Siegel and colleagues recommend that healthcare ethics committees (HECs) develop or refine policies or guidelines that clarify how DMC assessment is approached in patient care. They identify two extremes to be avoided: (1) Mandating one approach to DMC assessment such as the use of MacCAT-T, and (2) not specifying any consistent approach and deferring completely to individual clinician judgment. Instead, they endorse a “balanced” policy approach that specifies use of both objective DMC assessment criteria (i.e., Applebaum’s model and its application to individual cases) and clinical judgment. For example, a balanced policy for assessing DMC would recognize that clinicians may presume that an adult patient has the capacity to make healthcare decisions unless the attending clinician has reason to believe the patient is not capable of making such decisions. The policy should clarify the distinction between competence (a legal term) and DMC (which is situation-specific). It should recognize that the importance of approaching DMC assessments consistently is an issue of justice, and that the higher the stakes regarding a DMC assessment, the more important it is to employ a reliable, consistent DMC assessment process.

Such a policy should take into account relevant laws and regulations. For example, Maryland’s Health Care Decisions Act (HCDA) stipulates situations in which a patient’s attending physician and a second physician must certify in writing that the patient is incapable of making an informed decision regarding life-sustaining treatment being withdrawn or withheld, based on a personal examination of the patient by one of the two physicians within two hours before making the certification (HCDA, §5–606). The law defines decision-making incapacity in an adult as the inability “to make an informed decision about the provision, withholding, or withdrawal of a specific medical treatment or course of treatment because the patient is unable to understand the nature, extent, or probable consequences of the proposed treatment or course of treatment, is unable to make a rational evaluation of the burdens, risks, and benefits of the treatment or course of treatment, or is unable to communicate a decision.” The law does not stipulate how incapacity should be assessed, and does not preclude having a non-physician perform a DMC assessment to inform the attending or second physician’s assessment. Thus, whether a non-physician may conduct a DMC assessment should be stipulated in the policy. The policy might also address whether a DMC assessment may be performed on a patient’s surrogate decision-maker (for example, in cases where a patient’s appointed health care agent is suspected of meeting the HCDA definition of being “unavailable” by way of being “incapacitated”). Siegel and colleagues underscore the importance of getting support from institutional leadership and buy-in from those affected by such a policy (e.g., patients, health care staff, hospital administrators, and legal counsel). Ethics committee members should be amply informed to help guide this process.

Anita J. Tarzian, PhD, RN
MHECN Program Coordinator

REFERENCES
The Maryland Office of Health Care Quality (OHCQ) has awarded funding to MHECN to evaluate the Maryland Medical Orders for Life-Sustaining Treatment (MOLST) program. The Maryland MOLST evaluation study will determine whether MOLST forms are being used correctly and what impact the MOLST program has had on end-of-life care for Marylanders since the MOLST program went into effect statewide in 2011.

Recognized as a “next generation” advance directive, Physicians (or Medical) Orders for Life-sustaining Treatment (POLST or MOLST) has caught the attention of communities around the country seeking to improve end-of-life care. Currently more than 26 states have implemented POLST-like orders. The POLST/MOLST Program works by transforming life-sustaining treatment preferences into medical orders that can be followed by emergency medical technicians, nursing facility staff, and other health professionals in times of crisis and transition from one setting to the next. However, the program’s success is dependent on appropriate implementation. Evaluating how the MOLST form is being used allows for identifying areas for improvement to achieve the goal of improving end-of-life care.

MHECN is inviting the following Maryland healthcare facilities to take part in a chart audit study to evaluate MOLST form use:

- Adult non-psychiatric hospitals
- Assisted living facilities (50% random selection)
- Dialysis centers
- Home care agencies
- Hospices
- Nursing homes (50% random selection)

This evaluation study will address the following questions:

1. What is the rate of hospital compliance with the MOLST-on-discharge obligation?
2. For MOLST orders written on hospital discharge, what percentage go beyond page 1?
3. Is there evidence of some process underlying completion of the MOLST form?
4. What is the MOLST form completion error rate?
5. How often is each MOLST order section completed and with what orders?
6. Who (RN, SW, MD) is discussing MOLST with whom (patient, surrogate, etc.)?
7. Are methods to track the active MOLST form effective when there are multiple forms?
8. What educational interventions and training materials has the facility employed, and for whom?
9. Is completion of the MOLST form complementing or replacing advance directive completion?
10. What is the rate of compliance with reviewing/revising the MOLST form?

We welcome your support in making this evaluation effort a success! If you would like to volunteer as a MOLST Study Facilitator, please contact Anita Tarzian at atarzian@law.umaryland.edu.
MHECN WEBSITE UPDATES

MHECN has recently updated its website! Visit http://www.law.umaryland.edu/mhecn to see what’s new. Updated content includes:

**Advance Directives**, with links to:
- Maryland MOLST
- Maryland Patient Care Advisory Committee Act
- Respecting Your Choices
- 5 Wishes Document
- Halachic Living Will Forms
- Disability Rights - Jenny Hatch Project

**Effective Communication**, with links to:
- The American Medical Association’s Ethical Force Program: Improving Communication, Improving Care.
- Go Wish end-of-life card game
- Teaching Clinical Ethics and Physician-Patient Communication: The Psych-Ethics OSCE
- Oncotalk. Website sponsored by the University of Washington to improve oncologists’ communication skills.
- Palliative care providers and resources
- ToughTalk. Teaching Module: Talking about Harmful Medical Errors with Patients.

**Healthcare Ethics Committee Best Practices**, including:
- Ethics consultation, education, and policy development
- Functions and Goals of Healthcare Ethics Committees
- Building Effective Ethics Committees

**Healthcare Ethics Consulting**

**Common Topics in Healthcare Ethics**

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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.
On August 13-15, the Johns Hopkins University School of Nursing and Berman Institute of Bioethics convened a National Nursing Ethics Summit in response to the increasingly complex and intense array of ethical issues that nurses confront in their daily practice. The Summit’s 50 attendees are leaders in the fields of nursing ethics, education, and research, and representatives of the major nursing professional organizations, including the American Academy of Nursing, American Association of Critical-Care Nurses, American Nurses Association, American Association of Colleges of Nursing, American Association of Nurse Executives, Association of Women’s Health, Obstetric and Neonatal Nurses, International Care Ethics Observatory, National Institute of Nursing Research, National League for Nursing, National Student Nurses’ Association, Oncology Nursing Society, and Sigma Theta Tau International. The Hastings Center, The Center for Practical Bioethics and the National Council of State Boards of Nursing were also collaborating partners.

The Summit agenda moved participants from general concerns about ethical challenges in nursing clinical practice, education, research, and policy to a specific blueprint for fostering and sustaining ethical practices throughout nurses’ professional roles. The invited attendees shared a common vision that nurses must be ethically competent to fulfill their obligations to self and others, even as they advocate for the patients they serve, the profession, and the health of the nation. This social-ecological framework for understanding today’s challenges and opportunities begins with the nurse, then extends to the care team, the health system, and the community.

**Timing of the Summit**

Patients today enter a health care system struggling to cope with unprecedented challenges, including the increasing diversity and acuity of patients, rapid technological change, and pressures to reorganize care delivery and reduce costs. At the same time, the interplay between clinicians’ well-being and resilience, the health of the environments where they practice, and care outcomes is increasingly recognized. Put simply, patients (and organizations) fare better when nurses are supported in their work environment and able to practice high-quality, ethical care.

At this time of rapid evolution, the need for action tempered with thoughtful dialog and analysis is urgent. Effective nursing engagement and leadership is needed, in order to assure that the solutions devised to solve our health care dilemmas sustain the values of the profession and nursing’s place in the inter-professional dialog.

In 2015, the American Nurses Association will release its newly revised Code of Ethics, and the Summit discussions laid critical groundwork for the code’s effective integration into the daily work of the nation’s 2.8 million registered nurses.
"All happy families are alike; each unhappy family is unhappy in its own way."

--Leo Tolstoy

This is how Tolstoy begins *Anna Karenina*, one of the greatest novels of all time. I am not sure whether that statement is universally true; I am sure, however, that it is universally true that nobody should make families unhappier by separating parents from their children unnecessarily. Keeping families together should be a commonplace; yet the opposite takes place far too commonly to be an exception to what should be a golden rule. I will give an example from our pediatric practice.*

Not every parent interacts well with his or her child at our office. (An example: one mother tried to text someone while I was about to give her frightened four-year-old vaccinations.) Most, however, are caring; the parents I will now describe were very caring indeed.

They were obviously different. The man wore the earrings; each had long hair of equal length; none of the socks or shoes matched, etc. I remember asking them, "Whatever you smoke, do you ever smoke it in front of the kids?" You get the idea.

They were, however, model parents. They explained everything I was going to do, and comforted their two little sons admirably. Their jeans might have been torn, their shoes might have been worn, but no matter—their children were very lucky to have such parents.

I was surprised that they didn't keep the next appointment, since they never missed appointments in the past. The following month, however, the children did come to the clinic—this time accompanied by foster parents. Both boys looked miserable. You could see that their world had fallen apart. They were glum and taciturn, the direct opposite of their usual behavior. The foster parents informed me that the boys now attended day care, since both adults worked. They were decent people, but not very affectionate; each one sat silently while I examined two equally silent kids.

What had happened? The foster parents told me that dad and mom had been caught smoking pot and that the children were removed from the home for that reason. Soon after the visit, I received a phone call from the mother; she was so very concerned about how the children were doing. Both parents were in jail.

It is possible that there is more to this story. Perhaps the parents had been caught selling drugs; the biological mother, however, denied that they had done so.

If their sole crime had been possession of a small amount of pot, it certainly wouldn't have been the first time that a family has been split up without good cause. America's incarceration rate is the world's highest; 50% of state inmates and 90% of federal inmates are serving time for non-violent drug-related crimes. In addition, sentences for the same crime often result in years behind bars in America, in contrast with months behind bars in Europe. Punishment for possession of crack—even small amounts of which are equated with much larger amounts of cocaine—is especially unfair and especially hard on the poor and minorities. (African Americans constitute 15% of the general population and 30% of those incarcerated.)

What about the children of those sentenced—sometimes for years—for such "crimes"? The statistics are disheartening. For instance, one in four children of poor African-American parents has had a parent serving time in jail during crucial years of child development. Inmates are able to provide neither emotional nor economic support for their families; it is a real problem, especially for their children. Nor has mass incarceration made neighborhoods safer; there is, in fact, evidence to the contrary. In addition, too many families are the victims of what one reporter calls "poverty capitalism."

This occurs when local communities depend on fines to balance their budgets and thus tend to ticket people—especially poor people—more than necessary. Inability to pay these fines and missed court appearances often result in jail time.

Many of those serving time lose precious time raising their children. You don't have to be a pediatrician to know that a child's perception and interpretation of separation can be very different from that of an adult. What seems like a small amount of time to a judge can seem like an eternity to a child; what might damage an adult for years might damage a child for life.

I later found out that the two boys had been placed permanently with their paternal grandmother in Wyoming. I never heard from them or their parents again.

"Breakin' up is hard to do," is a rock 'n' roll classic that everyone was singing in the 60s. "Breakin' up families must be exceedingly hard to do"—I doubt there will ever be a hit with that title, but I hope that title will someday hit home.

*Details have been changed to protect the privacy of those involved.*

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This article was submitted by Thomas Dorsett, M.D., a pediatrician who has been practicing in Maryland for over 40 years. We encourage submissions of similar narratives, as well as essays or poems by our readers for the Humanities Corner.
CASE PRESENTATION

One of the regular features of this Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. We may also change facts to protect confidentiality. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, Law & Health Care Program, University of Maryland Francis King Carey School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A REHAB FACILITY

A 21-year-old man, Ray, is transferred from one rehab facility to another after a skiing accident one year ago left him with quadriplegia. Ray reportedly had a “difficult personality” before his injury. According to his parents, he always had trouble controlling his anger. At the new rehab facility, he has frequent angry outbursts, yelling loudly at staff and using foul language. One of the facility’s mental health therapists is recruited to address Ray’s emotional response to his quadriplegia. Ray resisted these interventions. The therapist tried to implement a behavioral contract with Ray but the angry outbursts continued. At times he would spit food at staff during feedings. After several months, the director of the rehab facility informed Ray and his parents that Ray would need to transfer out of the facility, as his behavior was creating a hostile work environment for the staff.

Ray’s parents requested an ethics consultation in an attempt to avoid Ray’s discharge from the facility. The facility director informed the members of the ethics consultation service that they will not reconsider their decision to discharge Ray.

COMMENTS FROM HEALTH LAW ATTORNEYS

Although the case does not explicitly say so, presumably Ray objects to the intended discharge. (Unless they are Ray’s guardians his parents have no authority to choose his site of care.) Discharging him involuntarily presents the questions, beyond the ethical issues, whether the facility has a legal basis to do so and whether Ray’s attending physician may sever the physician-patient relationship without risk of liability or disciplinary action.

Although the case does not mention where the rehab facility is located, we have assumed for the purpose of this commentary that the facility is located in Maryland and that Maryland law would apply. One lawful basis for discharging a patient is that the facility cannot meet the patient’s medical needs. The facts don’t indicate how the rehab facility is licensed – rehab facilities are not a category of licensed health care facilities in Maryland. If the facility is licensed as a hospital or specialty hospital, under Joint Commission standards, a hospital “discharges or transfers the patient based on his or her assessed needs and the organization’s ability to meet those needs” (Standard PC.04.01.03, emphasis added). Similarly, Maryland regulations restrict inter-hospital transfers, but the restrictions apply only when “a hospital is able to
provide adequate care to a patient.”

If the facility is a nursing home, one permissible basis for involuntary discharge is that it is “necessary for the resident’s welfare and the resident’s needs cannot be met in the facility.”

The law’s recognition of a possible disjunction between a patient’s medical needs and what a facility is able to provide probably assumes a purely clinical mismatch – a patient whose condition calls for highly technical and specialized surgery, for instance, cannot insist on remaining in a community hospital that simply does not have such a surgical service available. It is possible, however, that Ray’s resistance has rendered the facility unable to provide needed rehabilitation services. Patient cooperation is normally an integral element of rehabilitation, without which the service cannot achieve its clinical objective.

If Ray is experiencing a clinical depression or other psychiatric disorder that is at the root of his behavioral problems, then an intertwined issue is whether the facility has the means available (beyond the efforts of the mental health therapist) for appropriate diagnosis and treatment of that disorder. If it does, then involuntary discharge without attempting an appropriate psychiatric intervention is legally problematic. But if such psychiatric services are not available, or have been tried but failed, the facility may be justified in discharging Ray because it cannot achieve any therapeutic goal. The key, as one Minnesota court wrote, is that a facility may involuntarily discharge a patient for this reason only as “a last resort,” after exhausting the options available to it.

A second possible justification for involuntary discharge is that Ray’s

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**Discharging the “Difficult” Patient.** Cases involving difficult and/or abusive patients raise particularly thorny and troublesome issues for health care facilities. Regulatory agencies have dealt with this issue to some extent but perhaps most extensively in the context of renal dialysis patients. In 2008, CMS revised its “Conditions for Coverage for End-Stage Renal Disease Facilities,” expanding the circumstances under which facilities may involuntarily discharge a patient. Added to the prior bases, which included medical reasons, the welfare of the patient, and the patient’s inability to pay, was the facility’s reassessment of the patient and determination that “the patient’s behavior is disruptive and abusive to the extent that the delivery of care to the patient or the ability of the facility to operate effectively has been seriously impaired.” If the facility plans to involuntarily discharge a patient based on this last criterion, it must:

(i) Document the reassessments, ongoing problem(s), and efforts made to resolve the problem(s), and enter this documentation into the patient’s medical record;

(ii) Provide the patient with a 30 day notice of the planned discharge;

(iii) Obtain a written physician’s order that must be signed by both the medical director and the patient’s attending physician concuring with the patient’s discharge or transfer from the facility;

(iv) Contact another facility, attempt to place the patient there, and document that effort; and

(v) Notify the State survey agency of the involuntary transfer or discharge. 42 CFR Sec. 494.180 (f)(4).

CMS in its rulemaking process also encouraged facilities to use materials and a tool kit developed by the “Decreasing Dialysis Patient-Provider Conflict National Task Force” of the End Stage Renal Disease Networks “to proactively prevent conflicts and disruptive situations and to undertake appropriate actions when involuntary discharge is being considered.” The document, which may be helpful for facilities and their ethics committees, is available at: http://www.therenalnetwork.org/services/resources/pdf/DPC_IVDPositionStatement.pdf

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behavior is interfering with the facility’s ability to provide proper care to other patients. The facts don’t indicate whether this is the case but verbal abuse of other patients and staff that has the effect of disrupting care for these patients has been recognized as a justification for involuntary discharge of the abusive patient from an outpatient dialysis center. On similar facts, involuntary discharge from a rehab facility licensed as a hospital would pose little risk of liability. Even in the more heavily regulated domain of long-term care, a pattern of verbal abuse directed by one nursing home resident to others that cannot be forestalled may satisfy the “endangerment” standard, which permits involuntary discharge if a resident “endangers the health or safety of other individuals in the nursing facility.”

The third, and most complicated, justification for involuntary discharge is the one stated in the case summary: the negative impact of Ray’s angry outbursts on the staff. Here there are competing legal risks. On the one hand, rehab facilities often must deal with difficult patients. Channeling Ray’s anger may indeed be part of the rehabilitation goal for him. To use language related to Americans with Disabilities Act compliance, reasonably accommodating the psychological dimensions of Ray’s injury may be a necessary part of providing services to him (unless he poses a “direct threat” to the health and safety of others). And, if the facility is subject to Hill-Burton Act community services requirements, it must serve even difficult patients.

On the other hand, there is judicial recognition that ongoing patient abuse need not be tolerated indefinitely. If Ray’s verbal abuse of staff and his spitting food at them do amount to creating a hostile work environment and the facility does not respond vigorously, it could face liability in a suit by its affected employees. Although Ray poses no risk of physical violence toward staff, words alone are sometimes enough to require an employer to protect its employees. Suppose, for instance, that Ray’s verbal abuse took the form of racial epithets, coupled with a demand that only staff members of his race provide him care. If the facility tolerated this racially discriminatory working environment, it might well be held liable to the adversely affected employees. Again, the key is for the facility to have tried all therapeutic approaches reasonably within its capacity to change how Ray interacts with staff and to use involuntary discharge only as a last resort.

Essentially the same considerations apply to the issue of physician abandonment, which refers to a physician’s severing of the relationship with a patient without sufficient notice and information about alternative sources of care. Theoretically, Ray’s attending physician faces a risk of disciplinary action by the medical licensing board. Maryland law provides that a physician may be disciplined for abandoning a patient, and the Board of Physicians has in several instances issued charges to enforce the provision. None, however, has involved disruptive or abusive patients. The Board’s website includes suggestions for “avoiding patient abandonment” and properly ending the doctor-patient relationship. Among the reasons identified are “non-compliance, rude and unacceptable treatment of [the physician or his staff], disruptive behavior negatively impacting . . . staff or other patients, multiple missed appointments, etc.” The guidance states that “[i]f you are the one that is initiating the separation, adequate time must be given to allow the patient to obtain a new practitioner. The notice should be in the form of a letter sent to the patient.” Additionally, the physician should “. . . be available to the patient for any needs that arise during the notice period.” If the facility has a sufficiently documented basis for Ray’s involuntary discharge, Ray’s attending physician at the facility would perforce have no continuing obligation. The physician should assure that the facility’s notice to Ray, which would apply to the physician as
well, meets the Board of Physicians’ criteria.

Ray’s behavior might well make it difficult for him “to obtain a new practitioner.” However, that possibility does not curtail the right of the rehab facility and Ray’s attending physician to discharge him if a proper legal basis for doing so is established.9

Finally, with respect to the ethics consultation process: Because a facility’s ethics committee may play an advisory role only, it must make clear to Ray’s parents, who requested the consultation, that the committee cannot undo the discharge decision. At the same time, the committee should make clear to facility management that the consultation will go forward. The committee may come up with a recommendation that would be helpful to resolving the situation more satisfactorily to all parties but, even if it does not, the facts of this case may be useful to the committee in recommending a future policy stating the circumstances under which a patient can be discharged for disruptive behavior. Such a policy can be given to patients prior to admission, so that all parties are aware of the expectations for behavior prior to entry into the facility. Such prior notice would be helpful to the facility both from an ethical and a legal standpoint.

Diane E. Hoffmann, J.D., M.S. Director, Law and Health Care Program and Professor of Law University of Maryland Carey School of Law

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Patient Preferences.

We understand that Ray’s parents do not want to see him transferred. Importantly, we haven’t heard whether Ray has a preference or any capacity to make a choice. As he is an adult, a first goal would be to ascertain his preference and his goals of care. Ray’s capacity to participate in this decision has to be identified. If he doesn’t suggest that there is an ethics concern and the family appears to want the ethics consultation to support them in avoiding transfer.

The case makes us worry that the rehabilitation facility is putting the interests of the institution ahead of the interests of the seemingly vulnerable patient. Additionally, the wishes of the parents, generally considered to have the patient’s best interests at heart, are being disregarded. These are significant concerns and may reflect an important ethical problem in the care of this patient. However, good ethics has to start with good facts and the case requires exploration of those facts.

The 4-Topic Method of ethics case analysis (Jonsen, Siegler & Winslade, 2010) might be very helpful to identify the sorts of information necessary to clarify the ethical issues and options. Establishing details of each of the four topics: patient preferences, medical indications, quality of life considerations and contextual features might help tease apart presumptions to find the crux of the concerns. There may be points of confusion that are unnecessarily interpreted as points of conflict. Ethics consultation often serves most effectively as a means to create open and direct communication between two parties who have been overwhelmed by anxiety, frustration and mistrust.

COMMENTS FROM A PEDIATRICIAN & CLINICAL ETHICS CONSULTANT

The case presents concerns about transferring a troubled young man out of a rehabilitation facility against the family’s wishes. The facility management wishes to implement the transfer because they feel the patient creates a hostile environment for the staff. The team caring for the patient

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NOTES

1. Md. Code Regs. 10.07.01.23A.
3. See In re Involuntary Discharge or Transfer of J.S. by Hall, 512 N.W.2d 604 (Minn. Ct. App. 1994), regarding a 74 yr. old nursing home resident with a history of mental illness.
5. See Md. Code Regs. 10.07.09.10A(1) & (3). See also 42 C.F.R. § 483.12(a)(ii) & (iii).
7. In Brown v. Bower, for example, the court conditioned its order that a university medical center treat a renal dialysis patient on the patient’s refraining from abusive speech or conduct during the treatment.
8. Ira Gottlieb, Avoiding Patient Abandonment, Md. Dep’t of Health and Mental Hygiene, http://dhmh.maryland.gov/mbmpa/SitePages/patientabandon.aspx (last visited Oct. 2, 2014). In an ethical opinion, Med Chi, the state medical society, recommends giving the patient up to four weeks notice in an urban or suburban location or four to six weeks notice in a rural setting before terminating the relationship. See Medical & Chirurgical Faculty of Maryland, Ethical Opinions § 102, available at http://www.medchi.org/sites/default/files/pdfs/Sec_100.pdf (last visited Oct. 2, 2014).
authority transfers, in a limited way, to the family. We accept the right of a competent adult to make choices that are contrary to his/her medical best interest. We are not so likely to do so for parents who are making decisions for minor or incapacitated children. If Ray’s parents are making choices for him, the team caring for Ray has to ascertain whether those choices are in Ray’s best interest, or at least his good-enough interest. The care team should make certain that they understand the rationale for the family’s wishes. Specifically, it makes sense to work with the family to ascertain their goals for Ray and their sense of the next steps in his rehabilitative care. Their argument to keep Ray in the current institution is strongest if it stems from a conviction that the current facility offers Ray the best hope for effective rehabilitation. In that case, any planned transfer should include a clear plan to find a facility that would support the parents’ goals for Ray. If the parents’ desire to keep Ray in place is related to concerns about money or transportation or some other non-medical context, the current facility should work to help Ray’s parents resolve these issues as much as possible. If the parents’ decision is a selfish one and considered contrary to Ray’s best interest, the facility has less duty to work toward compromise.

The other party in this conflict, the rehabilitation facility, has also expressed a clear desire: to transfer a difficult patient. The facility’s reason as offered in the case is that caring for Ray creates undue stress for the staff. From an ethics perspective, the strongest argument for transferring a patient against the family’s wishes is that the facility is unable to provide appropriate care; that the transfer is in the patient’s best interest for medical reasons. The ethics consultants should help the facility clarify whether theirs is a problem of incapacity to provide effective care, maybe due to staffing limits that render them unable to protect Ray’s safety, or inadequate access to behavioral health services. Secondary but ethically important justifications include unresolvable concerns for the wellbeing of other patients, physical safety of the staff, and moral distress of the staff. Anger and frustration at the behavior of a troubled and unruly but sick patient is a different sort of justification altogether. The specific rationale behind the facility’s desire to transfer Ray is relevant to the ethical analysis of the case and an appropriate topic for the ethics consultation.

Medical Indications.

Medical indications are the second of the four topics to be explored. Ray’s problematic behavior may indicate a need to further understand his medical condition. An important consideration is whether the behavior is treatable or even iatrogenic. Quadriplegia after a skiing accident is documented. Survivors of traumatic brain injury may experience a range of neuropsychological problems. If the current facility feels unable to manage impulsive behavior in brain injured patients, it may be that the indications for transfer are strong, as long as there is a receiving facility with better resources for behavior management. Depression and anxiety are also common in adolescents with severe trauma; it is important to make sure that Ray’s behavior is not a treatable condition. Prognosis is equally relevant. The rehabilitation facility and the family should be able to share understanding of Ray’s prognosis and the most appropriate avenues for medical and behavioral therapy.

Contextual Features.

Contextual features that may affect the ethical issues around this case include financial issues, religious concerns, legal implications and social and family interests. These features may have a very strong impact on the family’s preferences but are often left unstated and unexplored. The care team, perhaps with the help of the ethics consultant(s), should help the family to explore all dimensions of their resistance to transfer. The ethics consultant(s) may also be able to help the facility clarify its own context for transfer, especially legal implications of forced transfer.

Quality of Life

The objective of the rehabilitative care is to improve Ray’s quality of life. The impact of any proposed transfer on his quality of life should be considered. Ray is the best source of information about his quality of life. If he is unable to comment, the care team and Ray’s family should work to identify environmental and care factors that seem to enhance his quality of life. These factors should be protected in a proposed transfer.

Once the relevant details are collected, they can inform an analysis of the ethical duties that apply in this case and the ethical character of the proposed transfer. In general, the team caring for Ray has a duty to promote his wellbeing, avoid harms, respect his autonomy (to the extent that it exists) and to be just. These duties are not limitless and difficulties do arise, but discontinuation of a therapeutic relationship is the exception, not the norm.

Promoting Ray’s wellbeing means seeking the most appropriate care for him. As noted above, the most ethically valid justification for a forced
transfer is that the current facility finds itself unable to meet the needs of the patient and transfer will give him access to better care. If the current facility is the best resource for him, the duty to continue care is strong. If there is another local facility that can provide appropriate care, transfer is likely to be ethically permissible. Respect for the family’s goals and preferences matter, especially to the extent that they are directed toward Ray’s best interest and not only self-interested.

The duty to avoid harm applies not only to Ray but to the staff at the rehabilitation facility. Avoiding harm to Ray is the primary duty, but the duty is limited by the threat of significant physical or emotional harm to the team caring for him and to the other patients in the facility. Analysis of the duty in this case requires more explicit information as to the harms suffered by the team and the extent to which they are avoidable.

The question of justice in this case – beyond the requirements of the law – suggests consideration of fairness. How has the rehabilitation facility managed similar patients and is there any underlying prejudice affecting their approach to this individual patient and family?

Many health care institutions allow families to request ethics consultation, even without the consent of the care teams. If the rehabilitation facility does not recognize an ethics consultation request made by a family, the consultant may have only limited access to the information necessary to analyze the important ethical questions. It may be possible for an ethics consultant to approach the management of the facility and explain the nature of ethics consultation as non-directive, non-binding and an excellent opportunity to enhance communication around a difficult situation. Without cooperation of the facility, the consultant may simply be able to allow the family to express concerns and develop strategies for communication moving forward.

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REFERENCES
CALENDAR OF EVENTS

OCTOBER

11
Henrietta Lacks Memorial Lecture. Sponsored by the Johns Hopkins Institute for Clinical and Translational Research. Speaker: Gary Gibbons, MD. Turner Auditorium, Johns Hopkins Medical Campus. Free to public but registration required. For more information and to register, visit http://ictr.johnshopkins.edu/service/lecture/.

11
Ethical and Legal Issues in Dementia – Navigating Difficult Decisions, Sponsored By Holy Cross Hospital, Silver Spring, MD. For more information, visit www.holycrosshealth.org/dementiaconference.

11
True Dignity in Life and Death: End of Life Care and the Catholic Medical Profession, Fifth Annual Symposium for Catholic Medical Professionals. St. Agnes Hospital, Alagia Auditorium, Baltimore, MD. For more information, e-mail Johanna.Coughlin@archbalt.org.

13 (12-1:15 p.m.)
Bioethics Seminar speaker Anne Drapkin Lyerly, M.D., M.A., Sponsored by The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, contact Tracie Ugamato at tugamato@jhu.edu, 410-614-5550, or visit http://www.bioethicsinstitute.org/ (click on Education, Seminar Series).

15-17
Public Health Law Conference, Sponsored by the American Society of Law, Medicine & Ethics, Atlanta, GA. For more information, visit phlc2014.org.

16-19
16th Annual Meeting of the American Society for Bioethics and Humanities, Hilton Bayfront, San Diego, CA. For more information, visit http://www.asbh.org/.

23
Domestic Violence: Ethical and Legal Issues, The 21st Annual Thomas A. Pitts Lectureship in Medical Ethics, Charleston, SC. For more information, visit http://academicdepartments.musc.edu/humanvalues/lectureship.

27 (12-1:15 p.m.)
Bioethics Seminar speaker Arthur Kleinman, M.D., M.A., Sponsored by The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, contact Tracie Ugamato at tugamato@jhu.edu, 410-614-5550, or visit http://www.bioethicsinstitute.org/ (click on Education, Seminar Series).
OCTOBER (cont'd)

28 (5:30-7:30 p.m.)
Elder Abuse, Mandatory Reporting and the Issue of Personal Autonomy: An Ethical Dilemma in the Case of an Elderly Man. The Annual Johns Hopkins Geriatric Education Center Consortium, sponsored by the University of Maryland, Baltimore Geriatrics and Gerontology Education and Research Program. Moderated case discussion with panel presentation. University of Maryland, Baltimore SMC Campus Center, 621 West Lombard Street, Elm Ballroom. For more information or to RSVP, e-mail Reba Cornman, rcornman@umaryland.edu.

NOVEMBER

10
Religious, Medical, Ethical and Legal Perspectives on End of Life Issues. Presented by the Institute for Jewish Continuity in cooperation with The University of Maryland Schools of Medicine, Nursing, Pharmacy, and Social Work, and the Maryland Healthcare Ethics Committee Network. University of Maryland Southern Management Corporation, 621 W. Lombard St., Baltimore, MD. For more information, visit http://www.law.umaryland.edu/mhecn (click on “Conferences”).

14-15
MacLean Conference on Clinical Medical Ethics, The 26th Annual Dorothy J. MacLean Conference, Sponsored by University of Chicago’s MacLean Center for Ethics, Chicago, IL. For more information, visit: http://www.eventbrite.com/e/the-26th-annual-dorothy-j-maclean-conference-tickets-9463645017.

JANUARY 2015

17-20
Clinical Mediation Intensive, sponsored by the University of Pennsylvania Department of Medical Ethics and Health Policy. For more information, visit http://medicaleducation.med.upenn.edu/events.

23 (6:00 - 7:30 pm)
Medical Error: Annual Conversations in Bioethics Series, Sponsored by The Kennedy Institute of Ethics, Georgetown University. For more information, visit https://kennedyinstitute.georgetown.edu/.

FEBRUARY

18-20
The Law and Ethics of Those with Special Needs: Fair Is What Fair Is, Sponsored by the American Society of Law, Medicine & Ethics, University of Arizona College of Medicine, Phoenix, AZ. For more information, visit www.bioethics.com.
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