

## The Revolving Door of Treatment Refusal

ALEXANDRIA P. LESCHER, D.BIOETHICS

Does it surprise you that many people who are hospitalized or in poor health refuse treatment or the medical advice of their doctor?

In the first six months of my Clinical Ethics fellowship, 28 percent of the cases in which I've participated have involved people who refused treatments suggested by their doctors. The first question in my mind when a patient refuses anything is always "Why?" I've found the answer is rarely simple.

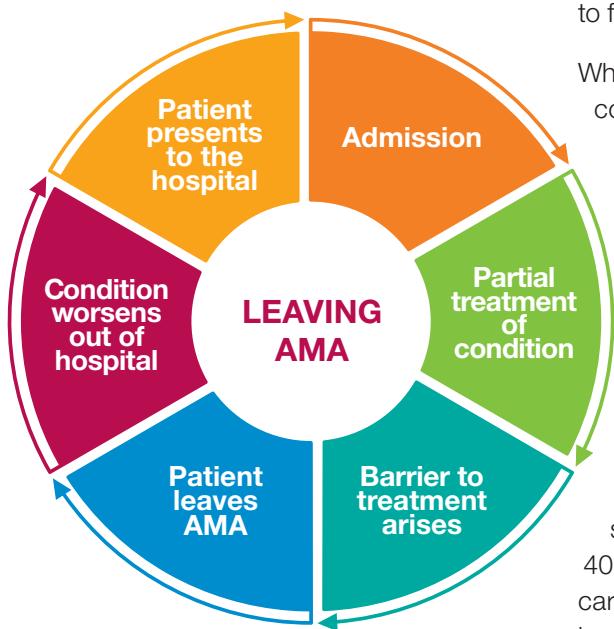
Physicians are accustomed to determining what is best for a patient from a medical perspective. However, patients have different considerations and weigh the information differently. Patients' choices regarding medical treatment are not shaped by life in a hospital alone. They incorporate their outside lives as well. Due to these differences, providers may have difficulty understanding the reasons behind a patient's refusal. From the patient's perspective, the

reasons are often based in rationality that encompasses their history, experiences, and situations. Sometimes these other priorities carry sufficient weight to cause the patients to leave the hospital against the advice or wishes of their physicians. In healthcare, this is known as "leaving against medical advice" (leaving AMA).

While any patient with decision-making capacity can leave AMA, one 20-year study found that the patients who leave AMA are predominantly males, between 35 to 49 years old, with a history of alcohol and drug abuse.<sup>1</sup> Another study found AMA discharges are higher among African-American patients with income levels below the poverty line, who are self-payers or have Medicaid.<sup>2</sup> All of these groups are already at risk for marginalization due to race, socioeconomic status, and social stigma around drug and alcohol abuse, so it is important for providers to take the time to find out their reasons for leaving.

When asked why they leave, patients most commonly cite (in order of frequency) "personal or family matters," "feeling well enough to leave," "dissatisfaction with treatment received," "feeling bored or fed up," and "dislike of hospitals in general" as justification. This further illustrates the importance of life outside the hospital as a priority in patients' decision making.<sup>3</sup>

Regardless of the reason, leaving AMA puts patients in a dangerous situation. Patients who leave AMA are at 40% higher risk of death,<sup>4</sup> require medical care that is more expensive,<sup>5</sup> and have increased rates of readmission,<sup>4</sup> which



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# The Ethicist Is In: A Catheter Dilemma

RYAN F. HOLMES, PH.D.



## The Case:

Allen is a 39-year-old male who presents to the hospital through the emergency department with altered mental status and significant back pain. After a work up, it is evident that he has a history of substance use disorder (SUD; the preferred term over “substance abuse”), questionable decision-making capacity, and end-stage renal disease. Allen tends to go in and out of treatment for his addiction and has lived on the street for the past several years. Allen seeks out dialysis, though it is not clear how regularly. The medical team is concerned about his multiple health issues, including possible endocarditis. The Attending Physician calls the Ethicist: This patient has a history of leaving Against Medical Advice (AMA) after a brief stay at the hospital. His dialysis catheter could very likely be misused for IV drug administration. Given his SUD and non-adherence to medical treatments, would it be ethically appropriate to remove the catheter?

## The Ethicists:

Allen's complex situation presents the medical team with a number of concerns. Their primary dilemma is whether they should remove the patient's catheter. The patient has known SUD and has been suspected of utilizing his catheter to administer drugs in the past. Leaving it in the patient with the knowledge that he might use it again leaves them with a strong sense of responsibility that they may be enabling the patient's future substance use, thus contributing to the harms that the patient will suffer. “After all,” they considered, “we have placed the catheter in the patient so we have a level of responsibility to ensure it is not used improperly.”

The concern voiced by the medical team is indeed a dilemma: Do we remove the catheter that has been medically implanted to keep the patient from harm, or do we leave it in, knowing it is the patient's lifeline to much needed dialysis? At the heart of this issue, it seems that there may be a few things going on here, but most important are the questions concerning the medical team's duty to this patient: What is the obligation to the patient and how do we best take care of him? What does the presence of the catheter require of us? These are important considerations, particularly because they tie the team's actions and duties to the patient and his well-being. In this case, it seems the question could be restated as: Which option puts the patient in least jeopardy? Or, more positively, what option might produce the most benefit to the patient?

Let us start by considering the potential harms to Allen. If the catheter is left in the patient, there is a risk of infections

whether it is due to drug use or other reasons. The particular concern, though, is the increased risk of infection engendered if the patient uses it for self-injection. Adding to this concern is the strong sense of duty that the team feels towards the patient to not put him in harm's way due to their actions. If the fear is that the mere presence of the catheter would create a desire to inject drugs, it seems that there might be good reason to remove the temptation.

However, due to Allen's history of SUD, it is unlikely he would stop trying to inject drugs even if the catheter is removed. Since removal of the catheter alone is unlikely to produce the benefit of decreasing his risk for infection, it is unclear what other benefits might come from removal. There might even be more harm to Allen if the catheter is removed. Since he often waits to get medical care until he needs dialysis, he is often very sick by the time he is brought to the hospital. Removing the catheter would mean he would need a new line each time he received dialysis. Each barrier to receiving much needed dialysis could create significant harms for Allen, especially since he frequently presents in such critical condition. Put simply, either the team increases the risk of Allen continuing his injection drug use by making access easier, or they place barriers to his ability to receive dialysis. Given that the consensus is that he will continue using drugs whether he has a catheter in place or not, it seems more harmful to remove his catheter than to limit access to life-prolonging dialysis treatments.

The original issue presented also carries with it a related question of whether medical professionals are obligated

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# The Revolving Door of Treatment Refusal

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means they spend more time in the hospital overall than their so-called ‘compliant’ counterparts. One study found that a patient who leaves AMA is 170 times more likely to have done so in the past, making past behavior the single largest predictor of whether a patient will leave AMA.<sup>1</sup> Essentially, this means patients who leave AMA risk getting caught in a revolving door of repetitive behavior, rotating in and out of the hospital.

As the door rotates, medical treatments are partially completed until treatment is disrupted by a barrier that prevents patients from staying in the hospital. These barriers come in many forms. Common motives include returning to work, a dislike of the physician assigned to their care, the necessity to care for family members, wanting to pick up a paycheck – anything that arises and causes a problem significant enough to make the patient want to stop treatment. Once the barrier arises, the patient decides to leave AMA, which hinders treatment and allows the medical condition to worsen. One of two things will happen next: the barrier will be resolved or the symptoms of the untreated condition will deteriorate to the point that they become more pressing than the barrier. Either way, the patient caught in the revolving door will ultimately return to the hospital for readmission until another barrier presents itself.

Not only do these patients have inferior health outcomes, they are also an ongoing source of frustration for healthcare team members who want to help, but feel powerless to do so. In an outpatient setting, this frustration can sometimes lead to dismissing or “firing” patients who do not comply with treatments. An example can be seen in pediatric offices, when physicians dismiss parents who refuse vaccination for their children for non-medical reasons, leaving parents to find another physician for their children. However, physicians do not have the same option in an inpatient setting. Firing patients who do not adhere to treatment recommendations while in the hospital may lead to patient abandonment and leave physicians vulnerable to legal action.

So what is there to do? The solution may lie outside the hospital altogether. Guidance may come from the great success patient navigator programs have found in their efforts to reduce disparities in cancer centers across the country, especially when navigators come from similar cultural/linguistic backgrounds as the patients they are

helping.<sup>6</sup> Patient navigators are hired by the hospital to guide patients through and around barriers to diagnosis and treatment. They do things like take patients to appointments, remind them to take medications, or foster communication between the patient and the team.<sup>7</sup>

Patient navigators usually work in the settings of cancer or Alzheimer disease. But why stop there? Navigators who have common ground with patients can act as liaisons between the patient’s world and the hospital’s, not only making medical care more accessible, but also more *approachable* and more *realistic* for such at-risk groups. The patient navigator is beneficial in settings beyond cancer and memory centers. If successful in reducing readmission of patients who leave AMA, navigators could reduce distress for the medical team, encourage patient compliance, empower patients to take control of their health outside of the hospital, and potentially have implications for improved patient outcomes and resource sensitivity across hospital systems, effectively stopping the revolving door.

Although the issue of revolving door patients is a healthcare problem, we are coming to understand that solutions are not medical alone. They are complex and require more extensive communication, as well as a collaborative effort between the patient and the medical team. For the physicians, it means taking time to find out what may be the barriers in a patient’s life that stand in the way of their accepting treatment and what can be done to remedy the situation. For instance, if the patient leaves AMA to go home and care for a sick family member, being aware of this situation may give Case Management the opportunity to follow up on possible community resources for the family. Meeting this type of need will ease the burden for the patient, who may then be able to remain in the hospital for the full duration of treatment. If the problem is that the patient does not trust the care team, taking time to build trust before focusing on treatment compliance can help make the patient feel more comfortable in the hospital environment and minimize the instinct to avoid the medical team.

As we continue to learn more about why patients refuse treatment, we will be better equipped to explore what we can do as health professionals to reduce readmissions and stop the revolving door cycle.

We owe it to our patients.

## Summer Workshop XIII

# The Life Cycle of an Ethics Consultation

Defining and Refining Core Skills

Saturday, June 9, 2018 | 9 a.m. to 4:45 p.m.

Register at [cpmc.org/ethics](http://cpmc.org/ethics). Space is limited. No same-day registration.

This workshop will give you an opportunity to understand the process of an ethics consultation from “start to finish.” We will address each aspect of the consultation, offering participants a comprehensive overview of how each step contributes to the process.

This is a skills-based, practical workshop that utilizes real case examples to demonstrate how to conduct an ethics consultation. We will describe a systematic approach, beginning with the ethics consult request and then specifically identifying the ethical question and how to proceed with next steps. Using a standardized process to assess the facts of a case allows for a consistent and comprehensive ethical analysis. You'll also learn what information you'll need to gather, how to elicit patient preferences, and the skills that build rapport and trust in complex situations.

Attendees will groupthink best strategies to resolve conflicts encountered in clinical cases. What is the ethics committee's role and when should it be utilized? What are practical recommendations that the medical team can implement?

In addition, we will share an effective ethics consult note template. Finally, this workshop will present information on how to build an applicable ethics consultation database in order to identify trends and assess the impact of an ethics service.

This workshop is geared to bioethicists, physicians, nurses, legal counsel, risk managers, chaplains, social workers, administrators, ethics committee members, patient advocates, attorneys, security staff and interested others.

### CME

California Pacific Medical Center (CPMC) is accredited by the Institute for Medical Quality/California Medical Association (IMQ/CMA) to provide continuing medical education for physicians. CPMC takes responsibility for the content, quality and scientific integrity of this live CME activity. CPMC designates this educational activity for a maximum of **6** AMA PRA Category 1 Credits™. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the CMA Certification in Continuing Medical Education.



### CEU

**Nursing:** Provider approved by the California Board of Registered Nursing, California Pacific Medical Center, Provider No. 1956 for **6.0** contact hours. Attendees must attend the course in its entirety.

**Social Work:** CPMC provider #2245. Course meets the qualifications for **6** hours of continuing education credit for MFTs or LCSWs as required by the California Board of Behavioral Science.

# Neuroethics News

## Moving Ahead

We are pleased to announce the receipt of a generous grant from The Hearst Foundations to the Clinical Neuroethics Initiative (CNI) within PMHV. The focus of the grant will assist CPMC neurologists to devise and implement innovative strategies for addressing ethical dilemmas that arise in caring for people with neurological and psychiatric diseases and disorders. This investment from The Hearst Foundations in CNI will enable PMHV to better respond to the growing population of complex neurological patients and expand the program's ability to serve these people. Dr. Guillermo Palchik,

a neuroscientist and clinical neuroethicist, will lead this effort along with PMHV's Dr. Thomasine Kushner.



The range of questions is far-reaching and the answers are urgent: How can neurological patients with communication disabilities be aided in expressing their wishes? How best to determine whether a patient with brain damage has decisional capacity to be able to participate in determining their care? If a neurological patient refuses to eat, should their wishes be respected even if it means their death? These are ubiquitous dilemmas in caring for this vulnerable population.

This Hearst grant aids our program in reaching new frontiers in the field of neuroethics and, as we discover new and unique ways of responding to these increasingly pressing issues, we will circulate and disseminate our findings through publications and international professional conferences.

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## The Ethicist Is In

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to steward resources in patients who will use their medical devices to harm themselves. This is an important consideration and might be a factor for future treatments for patients like Allen. The medical team was considering whether they had obligations beyond the particular patient in front of them and how they ought to consider their role in the medical system. Allen's situation helps us understand that while we can make decisions about his catheter and whether it is used appropriately, we must also consider how we ought to treat his main medical issue, SUD. A patient like Allen would benefit from a broader approach that starts with the patient wanting to get better and connecting him with appropriate resources like a rehabilitation program, access to addiction

specialists, addressing mental health issues, and providing community resources to help with the patient's social issues. While some of this may be beyond the immediate resources of the hospital, they may offer more benefit to Allen in the long run.

Outcome of the case: Allen ultimately left AMA before the team could have a full discussion about his treatments, but his case is not unique. Though there is broader conversation around how to help those who slip through our current safety nets, it is important to consider what benefit we are trying to achieve in patients like Allen and what harms we are trying to prevent.

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## Program in Medicine & Human Values

2324 Sacramento St.  
San Francisco, CA 94115

Tel 415-600-1647  
Fax 415-600-1355  
Hotline 415-600-3991

[www.cpmc.org/ethics](http://www.cpmc.org/ethics)

Email: [ethics@sutterhealth.org](mailto:ethics@sutterhealth.org)

### **William Andereck, M.D., FACP**

Senior Scholar and  
Program Director

### **Albert Jonsen, Ph.D.**

Bioethics Scholar Emeritus

### **Steve Heilig, M.P.H.**

Public Affairs Specialist

### **Ryan Holmes, Ph.D.**

Bio ethicist

### **Linda Hummel, Ph.D.**

Program Supervisor

### **Antonio Kruger**

Administrator

### **Thomasine Kushner, Ph.D.**

Neuro ethicist

### **Alexandria Lescher, D.B.E.**

Clinical Ethics Fellow

### **Ruchika Mishra, Ph.D.**

Senior Bio ethicist

### **Guillermo Palchik, Ph.D.**

Clinical Neuro ethicist

### **Shilpa Shashidhara, Ph.D.**

Bio ethicist