



# MEDICAL ETHICS ADVISOR®

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JULY 2017

Vol. 33, No. 7; p. 73-84

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## Patients Who Refuse Discharge Are 'Disaster in the Making'

*Hospitals left to 'desperately seek all viable options'*

**S**ome patients are refusing to leave the hospital for weeks or even months, despite being medically cleared for discharge. Regardless of the underlying reasons, it's an ethically challenging situation that can sometimes lead to litigation.<sup>1,2</sup>

"I've been aware and thinking about this problem for at least two decades, and it seems to be worsening," says **John D. Banja**, PhD, a medical ethicist at the Center for Ethics at Emory University in Atlanta.

Some patients no longer require ICU care, but the discharge planner cannot find an appropriate placement site. "So, the facility gets stuck with this individual, and someone has to pay for it — which the facility often does by simply eating the costs," says Banja.

Facilities often are caught off guard by threats of lawsuits if the patient is discharged. "Frequently, such families — sometimes the patient himself — are very clever, threatening, frightening, and manipulative. So, they get their way,"

says Banja.

Banja sees a need for legal immunity for hospitals that discharge patients to reasonable sites over the objections of families. "Such legislation would lay out criteria that if a hospital could show it accommodated them, they would be impervious to a lawsuit,"

says Banja, adding that litigation alleging negligent discharge would still be possible if the family could show that the criteria were not met.

The end result, says Banja: "Hospitals will keep taking losses on these patients,

**"I'VE BEEN AWARE AND THINKING ABOUT THIS PROBLEM FOR AT LEAST TWO DECADES, AND IT SEEMS TO BE WORSENING."**

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**Medical Ethics Advisor®**

ISSN 0886-0653, is published monthly by  
AHC Media, a Relias Learning company  
111 Coming Road, Suite 250  
Cary, NC 27518

Periodicals Postage Paid at Atlanta, GA 30304 and at  
additional mailing offices.  
GST Registration Number: R128870672.

**POSTMASTER:** Send address changes to:  
*Medical Ethics Advisor*  
P.O. Box 74008694  
Chicago, IL 60674-8694

**SUBSCRIBER INFORMATION:**  
Customer Service: (800) 688-2421.  
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8:30 a.m.-4:30 p.m. Friday.

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driving costs up — which they will then pass on to patients, their families, insurance companies, and Medicaid.” Politicians refuse to take on this thorny issue, in large part because it ultimately would mean raising taxes, he says. “Consequently, this is one more piece of the disaster in the making for 21st century healthcare,” says Banja.

## Fairness, Justice Are Issues

Taking up an ICU or acute care rehab bed when a less intense, less costly care setting is appropriate “raises a serious issue of fairness and justice in how we utilize medical resources,” says **Wayne Shelton**, PhD, professor at the Alden March Bioethics Institute at Albany (NY) Medical College.

Keeping someone in the hospital who is ready for discharge prevents other patients in need of hospitalization from being admitted. Thus, physicians and hospital administration have to be firm in cases where patients clearly are ready for discharge, and have a viable discharge plan in place, says Shelton. “It is reasonable to inform the patient they must leave the hospital,” he argues. “To do otherwise is to not fulfill the obligations of a hospital as an institution charged with caring for

the sick who require hospitalization.”

Does a patient have the right to remain in the hospital when that level of care clearly is not required? “From a nonmaleficence point of view, keeping patients in the hospital when they don’t require hospitalization is very concerning,” says Shelton, noting the significant risk of hospital-acquired illnesses.

However, poor reimbursement for nursing home care and limited options available for difficult-to-place patients are a reality. “Hospitals and facilities such as nursing homes are all protecting their own financial interests — and have few, if any, common interests in sharing the burdens of caring for difficult patients,” notes Shelton.

There are limited options available for hard-to-place patients — some of whom the facilities know and refuse to accept. “Hospitals are left in a bind, leaving nurses and social workers to desperately seek all viable options,” says Shelton.

Some patients want to go home, but caregivers feel completely overwhelmed by their needs. “We ask patients and their caregivers to do at home, now, many of the things we used to provide in the hospital setting,” says **Cheyne Onarecker**, MD, MA, chair of the Healthcare Ethics Council for The Center for Bioethics & Human Dignity. Onarecker also is an

## EXECUTIVE SUMMARY

Patients refusing to leave the hospital for weeks, or even months — despite being medically cleared for discharge — are a growing problem, according to ethicists interviewed by *Medical Ethics Advisor*. Some ethical considerations include the following:

- Patients may justifiably fear poor outcomes outside the hospital setting.
- Other patients in need of hospitalization are prevented from being admitted.
- Limited options are available for difficult-to-place patients.

adjunct professor of clinical ethics at Deerfield, IL-based Trinity Graduate School.

Good communication is essential to a successful discharge. “But there are many reasons why good communication is difficult in a busy hospital,” says Onarecker. If the attending physician is unavailable at the time the caregivers are in the patient’s room, care instructions are not complete.

“It may be that the primary caregiver cannot be present at just the right time for the medical team to provide careful instructions,” says Onarecker. Contradictory information sometimes is given by different healthcare professionals.

“There may be specific reasons that would make discharge a bad idea,” adds Onarecker. In one case, the patient’s husband — the primary caregiver for his ill wife — had a heart attack just before the patient was discharged. In another case, the patient’s room at home was not big enough for the hospital bed, so the family did not want him discharged until other arrangements could be made.

“The common element in most of these situations is that good communication is not happening,” says Onarecker.

This is sometimes true throughout the hospital stay. Doctors and nurses come and go without explanation, and tests are performed without the results being conveyed. “Folks just don’t feel they are being listened to,” says Onarecker. “When that happens, it is almost predictable that the family is going to be upset when they hear their loved one is being discharged.”

Onarecker finds that in most cases, once the patient and family feel like their concerns are being addressed and they are given adequate information, they relax and begin

making plans for discharge. “Most of the time, there are real issues that need to be addressed,” says Onarecker. “It is rare that a patient or family becomes resistant for no reason.”

## ‘Nuts and Bolts’ of Discharge

**Robert N. Swidler**, Esq, vice president of legal services for St. Peter’s Health Partners in Albany, NY, has authored several papers on difficult discharges.<sup>3,4</sup> He says the following ethical questions should be considered involving the decision to discharge over the objections of the patient or family:

- How much weight should be given to the patient or family member’s preference to stay in the hospital?
- Is there a legitimate benefit to the patient in staying longer, or in leaving sooner?
- Will allowing the patient to stay longer, or discharging the patient sooner, cause more harm?
- Is allowing the patient to stay harming other patients who need the bed, or staff, or the hospital’s mission?

“In my view, the more difficult ethical issues arise after the decision is made to discharge the patient over objection,” says Swidler. These relate to the nuts-and-bolts decisions about exactly how to implement the discharge.

“How can the hospital oust the objecting patient from a hospital room, and from the building?” asks Swidler. “Obviously, the hospital can’t wheel a nonmobile patient into the street.” Hospitals must consider the following:

- under what circumstances it can use security to force a mobile,

seemingly healthy patient to leave;

- whether transportation to the patient’s home or post-acute care will be arranged;
- whether it is ethical to turn off the TV in the patient’s room and stop bringing food.

Answering these questions largely turns on the patient’s status post-discharge. “After discharge papers are signed, is the person in the bed a patient or trespasser?” asks Swidler.

If a patient or family is refusing discharge, ethicists sometimes are called upon to help resolve the situation. “Sometimes, an ethics consultation may provide new perspectives and, at times, open doors,” Shelton says.

Discussions with the patient, family surrogate, or a representative from a nursing home may lead to a resolution. “If nothing else, we can provide support to the care team that they are doing all they can to find an appropriate discharge,” says Shelton. Ethicists can provide a clear rationale for clinicians as to why asking a patient to leave against his or her wishes is justified.

**Julie M. Aultman**, PhD, director of the bioethics program and a professor in the department of family and community medicine at Northeast Ohio Medical University in Rootstown, has been involved in multiple ethics consults where the patient refuses to leave the hospital.

“Their motivations to stay are usually driven by fear of medical decline or a future emergency outside the hospital setting,” says Aultman. Such fears are sometimes justified, as with rural patients who live hours from the hospital. “Some of these patients may not survive the trip back to the hospital if they were to experience an emergency at home,” says Aultman. Extensive patient education — and even resources

including home care — don't necessarily allay these patients' fears.

Some patients are unable to return to their homes due to complex medical conditions or unsafe home environments, but reject the idea of being discharged to a nursing home. "The thought of going to a nursing home, particularly state facilities for our underserved populations, is worse for some patients than staying in the hospital," says Aultman. Ethicists help in the following ways:

- all possible options are evaluated;
- the values and goals of the patient, healthcare team, and others are identified;
- it's determined whether there is a genuine conflict of values;
- support, mediation, and education are offered.

A recent case involved a chronically ill patient and his family, who feared the patient's health would decline at home. "The patient's medical history revealed the reality of his fears," says Aultman. Shortly after each of seven previous discharges, the patient was rehospitalized due to poor home care, lack of adherence to medications, and social stressors in the home environment.

"To make matters more complex,

the patient was told by one of his specialists he could stay in the hospital 'as long as he needed to,' despite the patients' unhealthy dependence on the hospital staff," says Aultman. Ethicists made recommendations for reducing, if not eliminating, the barriers to effective home care.

Regardless of the specifics of each individual case, says Aultman, "The rights and responsibilities of the hospital and medical team, judicial use of hospital resources, risks associated with hospitalizations, and the patient's story — including her values, needs, and goals — are all important ethical considerations." ■

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# New Resuscitation Policy: It's Not Offered Unless Clinically Indicated

*Clinicians frequently reported moral distress*

Over the past several years, ethicists at Charlottesville-based University of Virginia received many requests for consults from clinicians who felt aggressive end-of-life care was causing a patient to suffer.

"Families often ask for treatment at the end of life that's not medically

indicated," says **Mary Faith Marshall**, PhD, FCCM, co-director of the hospital's Center for Biomedical Ethics and Humanities.

The hospital's previous policy stated that patients or their surrogates were the ones who decided whether resuscitation was attempted if the

patient went into cardiac arrest. A group of ethicists set out to update the policy.

"When a family member says, 'I want you to do everything possible for my mom,' when mom has terminal cancer and multisystem organ failure and is dying in the

ICU, the patient is the one who suffers from that, as do the staff,” says Marshall.

The issue of overly aggressive end-of-life care goes beyond psychological distress of clinical team members. “Offering interventions that aren’t clinically indicated is failing to follow recognized professional practice norms,” says Marshall.

## Transparent Process

Development of the new resuscitation policy involved dozens of people with diverse views and took two years. “We were very careful to make sure that the process was totally transparent,” says Marshall. The process involved a great deal of back and forth between stakeholder groups such as the critical care committee, the nursing governance organization, and the patient experience program.

“We wanted them all at the table from the beginning,” explains Marshall. “By the time we rolled the policy out, it was not a big deal. People knew it was coming, and they wanted it.”

The new policy sends a clear message to clinicians: They’re supported in offering only treatments that are clinically indicated. “Clinicians were in an awkward position with the old policy where

the surrogate or family got to decide,” says Marshall. “They didn’t have an institutional policy behind them.”

There always were some physicians who refused to acquiesce to families’ demands for inappropriate care. “We had physicians who would say, ‘I am not resuscitating this person.’ Now, they have a policy to back it up,” says Marshall.

The team discusses a plan based on realistic goals of care. “Just as some patients are told they are not a candidate for liver transplant or for surgery, some patients are told they are not a candidate for resuscitation,” says Marshall. Some families want to transfer elsewhere. “If they say, ‘we want to try and find someone who will provide that,’ we certainly make a good faith effort to make that happen,” says Marshall.

## Shared Decision-making Model

The new policy, which took effect in early 2017, is a shared decision-making model between patients (or authorized surrogates) and the healthcare team, rather than a unilateral decision by either party. “It begins with the team making a collective decision on what is appropriate to offer,” says Marshall. The policy has three levels:

• **Level A: Clinicians do not attempt resuscitation.** The word “attempt” was purposely chosen to stress that the majority of resuscitations aren’t successful. “Of in-house cardiopulmonary arrests, the national data is that they are successful about 24% of the time,” notes Marshall. Clinicians will do everything they can to prevent a cardiopulmonary arrest. This may include intubation, vasopressors, or sending the patient to the ICU — but if the patient stops breathing or has a pulseless cardiac rhythm, clinicians don’t resuscitate.

• **Level B: “This means we do not escalate,”** says Marshall. For example, clinicians will continue with the current plan of care but won’t add antibiotics or vasopressors.

• **Level C: Comfort care only.** “There are a couple of things we built into the policy that we are particularly proud of,” says Marshall. The policy states: “The patient or the surrogate are entitled to consent to or refuse offered medical treatment. The healthcare team should not offer or provide treatment that is not the standard of practice.”

“We use the word ‘team’ strategically,” says Marshall. The policy defines “team” as the attending physician and the licensed independent professionals — residents, nurse practitioners or physician’s assistants, nursing staff, and respiratory therapists. “The thinking is that those are the people at the bedside taking care of the patient, especially if the patient has a cardiopulmonary arrest,” says Marshall.

Instead of the old model of a physician walking into the patient’s room and asking, “If your heart stops beating, do you want us to try and start it again?” the team comes to a prospective decision about what to

## EXECUTIVE SUMMARY

Ethicists at University of Virginia helped develop a new resuscitation policy stating that patients or surrogates can accept or refuse offered treatment, and that the healthcare team should not offer treatments unless clinically indicated.

- The hospital’s previous policy stated that patients or their surrogates decided whether CPR would be attempted.
- Clinicians were experiencing moral distress due to end-of-life care they believed was harmful to patients.
- Risk managers and general counsel support clinicians in adhering to the standard of care if families threaten litigation.

offer. This means that an individual physician can't make a decision to offer a treatment simply because the family is demanding it. "It also means that a new attending can't come in on Monday morning and do a 180-degree reversal on the plan of care and reverse the DNR order," says Marshall.

Some clinicians fear litigation if they don't offer treatments the family is demanding. "We bring in the general counsel and risk managers right up front," says Marshall. "They

are very good at letting the staff know, 'We've got your back. You should be following the standard of care.'"

Some families do threaten to sue. Marshall tells clinicians, "If you ever do find yourself in court, you want to be able to say, 'I followed the standard of care,' not 'I did this because I thought the family was going to sue me.'"

Fears of being sued for not providing aggressive end-of-life care, for the most part, are unwarranted,

she says. "I think it's kind of amazing there is so much fear there," Marshall adds. "Basically, those lawsuits, for the most part, don't exist. And if they do, they are unsuccessful." ■

## SOURCE

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# 'We Want Everything Possible Done for Mom'

*Families need comprehensive support*

**J**oanne Lynn, MD, a Washington, DC-based geriatrician and director of the Center for Elder Care and Advanced Illness at Altarum Institute, has dedicated her career to finding ways to improve health and healthcare at a sustainable cost. Lynn tells *Medical Ethics Advisor* how hospitals can achieve ethical end-of-life care.

**MEA:** Are hospital "medical futility" policies helpful?

**Lynn:** Sometimes, hospitals have found futility policies helpful, especially with situations where there is no family. But I don't think they have found them to be terribly helpful when there is a lot of anxiety floating around among the people who do care for this person.

We have always had challenges with the boundaries of end of life. When the person is still alive and breathing, it's sometimes hard for families to believe that they are really coming to the end. They think that there must be one more thing that could really pull them out of this situation, especially for younger

people. They may be able to see there really aren't any options for the 97-year-old person. But for the 57-year-old, it's harder to believe there isn't something that can turn this around and make it all go away.

**MEA:** What type of hospital policies would you like to see for end-of-life care?

**Lynn:** The kind of hospital policies that I would love to see would be offering really comprehensive support and care — that we're with you through to the end of life and beyond, and we know how to support you in bereavement.

Like families, we hope that something will show up that makes this difficult situation go away. But on the assumption that this is really what we have to deal with, let's deal with it together. The hospital needs to offer some emotional and spiritual support.

Hospitals also need to offer support during the immediate after-death period, when the family is faced with questions on how to deal with funerals and memorials. For example, there needs to be clarity as to whether

they can offer an autopsy if the family is concerned about whether they are hiding something. Families are much easier to convince that the care team has nothing to hide if they are willing to offer that. It's among the things that helps them come on board when they are otherwise very anxious.

The hospital does not need to offer useless or harmful treatments. But we do need to do that with compassion and sincerity. You need to have people that are good at communicating. You may need to buy some time if you possibly can, if the family needs a few hours to pull things together. It may inconvenience the delivery team, but it can be critical for the family to come together.

**MEA:** What do you see as the ethicist's role if the family is demanding care that's not clinically indicated?

**Lynn:** It depends on what the family is demanding. If the family is demanding everything be done to keep the person alive for three hours until the spouse or son can get here, that's a very different situation than

wanting to proceed with surgery for someone who is way too unstable for surgery.

Sometimes, in their anguish, families demand things that really cannot be provided, and they need to be brought down to earth. That can be very hard. Sometimes, you are talking to 30 people who are all queuing in your lobby. The family that shows up demanding all sorts of things, where Mom or Dad is dying, usually implies a substantial deficit in what's been going on with home care, and maybe even hospice.

To have the records and be able to get in touch with people who've been part of this person's care in the past puts the hospital ethicist in a better position to bring in the right sort of supports. It might be useful for the in-hospital care team to know that certain family members have been using mom's Social Security to support drug abuse. Ethicists need to negotiate among the parties to try to craft a way through that is supportive to everybody, but doesn't abuse the

patient in desperately trying to extend life, and doesn't leave the families feeling as though they aren't being heard.

In the way we now live, there shouldn't be very many people who are known to be at the end of life that are not part of a care system that's highly supportive. Every once in a while, you have somebody who had a terrible stroke and dies suddenly. But more than 90% of people who die, die past Medicare age, and of things that existed many weeks ahead of their dying. That gives us an opportunity to build systems that work.

But you still will have unreasonable families, at times. I have sometimes been pushed to the wall, when I've had to say, "Neither you nor I have the clear authority to make decisions for this person who can't make decisions for him- or herself. If we can't make a decision between us, we're going to have to go talk to a judge."

The ethicist has to be willing to

have that card in the deck and have an emergency legal hearing. In my experience, thus far, I've never had to actually do it. Families will say, "Give us a few minutes to talk this over." Just saying there is a possibility of going to court has made all parties willing to try harder to find a decision.

It helps them realize that they don't have clear authority, but neither do I, and if we can't decide what's best for this person between us, we have to get a neutral outside party. They probably thought they had the authority and could bully their way through. I've carried the emergency number for the judge in Washington, DC, for all my clinical life, until the card wore out. But I never actually had to call. ■

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## Study: COPD Symptom Burden Often Goes Unrecognized

*Few achieve wish of dying at home*

Patients with chronic obstructive pulmonary disease (COPD) often experience symptom burden and social isolation that is underappreciated by clinicians.

"Symptom burden can be as high as, or higher than, patients with cancer," says **Crystal E. Brown**, MD, MA, an ICU nocturnist in the Division of Pulmonary, Critical Care, and Sleep Medicine at the University of Washington. Brown also is an ethics consultant at Harborview

Medical Center in Seattle.

COPD patients are much more likely than lung cancer patients to die in hospital than at home, and they often lack palliative care, found a recent study.<sup>1</sup> Researchers examined international death certificate data from 14 countries to determine place of death. They found that while patients with COPD suffer similar symptoms to lung cancer in their final days, few COPD patients receive palliative care or achieve their wish

of dying at home. This may be partly due to the inherent unpredictability of final-stage COPD compared with lung cancer, the researchers theorize.

Recent research by Brown and colleagues demonstrated that patients with COPD were more likely to die in hospital, and had longer lengths of stay, compared to patients with cancer.<sup>2</sup> Brown was lead author of an accompanying piece using the principle of justice to advocate for increased palliative care in patients

with chronic lung disease, including those with COPD.<sup>3</sup> “Patients with cancer benefit from palliative care,” says Brown. “Patients with COPD who have palliative care needs should similarly benefit as well.”

Predicting disease trajectory is part of the problem. With aggressive medical management, some patients have significant reversal of symptoms and disability. **Kirsten Wentlandt**, MD, PhD, MHSc, a palliative care physician at Toronto General Hospital in Canada explains, “No one knows when to say this is now an irreversible exacerbation of disease.”

Palliative care services and focused home care programs are set up to manage very sick patients. “They often do not know what to do when patients are well and independent,” says Wentlandt. Unlike cancer patients’ predictable deterioration over time, requiring escalation in level of care, COPD is a fluctuating chronic disease. “Variable

deterioration and improvement requires a ‘flip-flop’ between surveillance and periods of high intervention,” says Wentlandt.

When patients are feeling well, they are turned down for home care. When they are sick, services are unsure how to support patients. “They lack practice, and haven’t developed protocols or relationships to keep patients at home and out of the emergency room,” says Wentlandt.

Randomized, controlled trials have validated several current palliative care models to support patients with cancer. However, these high-quality studies have not yet been conducted in most non-cancer disease states. “So, we have yet to see if these current models meet the needs of all of our patients,” says Wentlandt. ■

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# Study Identifies Surprising Priorities of Chronically Critically Ill Patients

*Life prolongation was least important for many*

To explore the expectations and goals of chronically critically ill patients, researchers interviewed 30 patients and 20 surrogates at a long-term acute care hospital.<sup>1</sup>

**Daniela Lamas**, MD, the study’s lead author, expected that the patients would value life prolongation above all other goals.

“However, I found that living as long as possible, no matter what, was, in fact, the least important priority ranked for the majority of people surveyed,” says Lamas, a pulmonary and critical care physician at Brigham

and Women’s Hospital and instructor in medicine at Harvard Medical School in Boston.

Life prolongation fell below cognitive impact and physical function for the majority of people surveyed. This was true for both patients and families.

Chronically critically ill patients are frequently cared for in long-term acute care hospitals, yet little is known about their experience in this setting, notes Lamas. “The results of our work suggest to me that it is our ethical duty to try to understand our

patients’ goals,” she says.

The findings indicate overly optimistic expectations about returning home: Nearly 80% identified this a goal, but only 38% were at home at one year. Additionally, unmet palliative care needs suggest the need to integrate palliative care within the long-term acute hospital, the researchers concluded.

Lamas says clinicians have an ethical obligation to try to give patients the care they want and not to give care that patients do not want,

or care that does not move patients toward their goals.

“Long-term acute care hospitals, even if it is aggressive care for ill patients, can be appropriate if it aligns with a patient’s goals,” she says.

Palliative care continues to be seen by many patients, families, and even healthcare providers as “the last resort,” says **Ruby Rajendra Shanker**, MBBS, MHSc (Bioethics), the bioethicist for Canada’s Toronto General Hospital and Women’s College Hospital. “On the contrary, including appropriate palliative care support much earlier may help alleviate pain and ensure better management of symptoms for patients.”

Therapeutic relationships between chronically critically ill patients and healthcare providers tend to develop over extended periods of time. When the patient begins to decline, it can be very hard for healthcare providers to let go.

“Such attachment may impact their ability to fully support the patient in good end-of-life decision-making,” says Shanker. Another

obstacle: Some patients fear they’ll disappoint family or clinicians by robbing them of their sense of purpose in advocating for active treatment.

While healthcare providers’ attitudes toward palliative care have improved significantly in recent years, some still fear it will be seen as “giving up.”

“These attitudes can impede essential efforts toward advance care planning, and understanding the patient’s capable wishes when it is still possible,” says Shanker.

Even if families know the patient’s wishes very well, some have difficulty stepping into the role of decision-maker when faced with a rapidly declining clinical scenario. “The suggestion of palliative care in one such case created much despair for the family, causing them to impede the clinical team’s efforts to speak with the patient,” recalls Shanker.

The family ardently believed that they were protecting the patient’s ability to hope by preventing end-of-life talk. “In such situations, the bioethicist, having no therapeutic relationship with the patient and

representing neutrality, may have more success communicating with families,” says Shanker.

Shanker centered the discussion around quality of life: “I was able to encourage a dialogue between the family and the patient, and support the family in appreciating the value of palliative care as aligned with the patient’s expressed wishes.” ■

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# Are Patients Prepared for Reality of Life With Implantable Devices?

*Informed consent must be device-specific*

**P**atients may view cardiac implantable electronic devices (CIEDs) as a lifesaver — without fully understanding quality of life issues.

“The informed consent conversation must be tailored to the specific device,” says **Cynthiane J. Morgenweck**, MD, MA, a clinical ethicist at the Center for Bioethics

and Medical Humanities at Medical College of Wisconsin in Milwaukee.

The three most common implantable cardiac devices are pacemakers, automatic implantable cardioverter defibrillators (AICD) and ventricular assist devices (VADs). Each comes with a different set of benefits and burdens for the patient.<sup>1</sup>

“Automatic implantable cardiac

devices may or may not be intrusive, depending on the patient’s perceptions of the shocks that are delivered,” says Morgenweck. “The perceptions range from hardly noticed to the proverbial ‘sledgehammer to the chest.’”

Morgenweck says VADs require significant buy-in from the patient after placement: “Intrusiveness of the

device in the patient's life should be described by the provider, as well as strategies to mitigate the burdens of the device."

The utility of the device for the patient at different stages of the patient's life also should be discussed before the implantation.

For example, an AICD prevents sudden cardiac arrest. "But when the patient receives a life-limiting diagnosis such as Alzheimer's, the patient may prefer a sudden cardiac arrest over a long, slow decline with its attendant burdens," says Morgenweck.

After a VAD is placed, patients might conclude that the lifestyle limitations are more burdensome than anticipated. Some ask for the device to be deactivated.

"Providers must decide for themselves whether or not they would be willing to honor such a request," says Morgenweck. "This decision ought to be conveyed to the patient before the implantation." She recommends that providers:

- briefly introduce patients to the possibility of deactivation before any device is implanted;
- remind the patient about deactivation at routine assessment visits, at battery change visits, and at the time of new life-limiting diagnoses;
- encourage patients to fill out a new advance directive outlining under what circumstances, if any, the

device should be deactivated.

**Thomas S. Huddle**, MD, an ethics instructor at UAB's Center for Clinical and Translational Science and professor of medicine at UAB's School of Medicine, says clinicians should clearly state what they'd be willing to do in specific scenarios.

**AFTER A VAD IS PLACED, PATIENTS MIGHT CONCLUDE THAT THE LIFESTYLE LIMITATIONS ARE MORE BURDENSOME THAN ANTICIPATED. SOME ASK FOR THE DEVICE TO BE DEACTIVATED.**

"We, as clinicians, need to be upfront with our patients about all aspects of their future care at the time of CIED implantation," says Huddle. Despite the Heart Rhythm Society's 2010 consensus statement, says Huddle, "the issue of the ethical status of CIED deactivation is not settled either in the ethics literature or in the clinical community."<sup>2</sup>

Some clinicians take the position that deactivating life-sustaining

pacemakers is intentionally hastening death and, hence, not morally permissible.<sup>3</sup> "Those clinicians are not going to deactivate non-burdensome life-sustaining CIEDs, even if patients request it," says Huddle.

Trajectories of the patient's life after deactivation also should be covered during informed consent conversations. Morgenweck would like to see an easily accessible registry of device deactivation protocols and stories: "All providers would be able to more clearly understand the patient's health after deactivation." ■

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## EXECUTIVE SUMMARY

Patients don't always fully understand the lifestyle limitations imposed by cardiac implantable electronic devices. Informed consent conversations should:

- be tailored to the specific device;
- describe strategies to mitigate burdens;
- address different stages of the patient's life.

# Paper Calls for More Transparency of Industry-sponsored Clinical Trials

A recent paper offers consensus recommendations and examples of best practices from the published clinical trial literature to help authors and trial sponsors communicate drug adverse events in a more informative and clinically meaningful manner.<sup>1</sup>

“The intent of the paper is to help improve the reporting of safety outcomes from clinical trials,” says **Jesse Berlin**, senior vice president and global head of epidemiology at Johnson & Johnson in Titusville, NJ. Overall increased transparency is the overarching goal.

“Improving safety reporting is just one part of the broader emphasis

across the research community on improving transparency with respect to our data,” says Berlin. Recent initiatives have focused on sharing both summary and participant-level data from clinical trials.

“Disclosure of all results — both favorable and unfavorable — is a visible demonstration that industry is reporting the benefits and the risks,” says Berlin.

The complete data set is then made available for those interested in performing further analyses.

“Increased transparency is an ethical obligation we have to the people and care providers who have participated

in studies, and those who use our products,” Berlin says. ■

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- **Jesse Berlin**, Senior Vice President and Global Head of Epidemiology, Johnson & Johnson, Titusville, NJ. Email: JBerlin@its.jnj.com

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# Decisional Conflict Common for Surrogates of ICU Patients

*Families need support from clinicians*

A recent study looked at whether the decision-making process plays a role in the psychological morbidity associated with being a surrogate in the ICU.<sup>1</sup>

“It’s important to note how common surrogate decision-making is in this cohort of patients,” says **Jesse Miller**, MD, the study’s lead author and a physician at United Lung and Sleep Clinic in St. Paul, MN.

Nearly every family member interviewed could recall a decision they made on behalf of his or her loved one. Nearly half of these decisions were classified as “end-of-life” decisions, involving the patient’s “do not resuscitate” status or continuing life support.

The researchers hypothesized that family members facing end-of-life

decisions would have more decisional conflict and regret than those facing non-end-of-life decisions. The small pilot study of 42 surrogates did find more decisional conflict when end-of-life decisions needed to be made. This was especially true where there was uncertainty.

“This has profound implications about how we interact with family members of our sickest ICU patients,” says Miller.

The researchers found that virtually all family members make important, often difficult, decisions, resulting in decision conflict. “It is imperative that clinicians work on improving family engagement and support in the ICU,” Miller concludes.

Ethicists can encourage clinicians to engage with families, and to incorporate family communication strategies. “These strategies include exploring patient values, listening, eliciting questions, and empathy,” says Miller. ■

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1. Miller JJ, Morris P, Files DC, et al. Decision conflict and regret among surrogate decision makers in the medical intensive care unit. *J Crit Care* 2016; 32:79-84.

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- **Jesse Miller**, MD, United Lung and Sleep Clinic, St. Paul, MN. Phone: (651) 726-6200. Fax: 651-726-6201. Email: jesse.miller@allina.com.

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**CME/CE QUESTIONS**

- 1. Which is true regarding patients who refuse discharge?**
  - a. Patients and families cannot allege negligent discharge when discharging patients to reasonable sites over the objections of families unless inadequate notice of the decision was given.
  - b. Since remaining in the hospital usually is beneficial for the individual patient even if not medically indicated, this should be more heavily weighed than concerns over resource allocation.
  - c. There are limited options available for hard-to-place patients — some of whom the facilities know and refuse to accept.
  - d. Use of security to force a mobile patient to leave the hospital against his or her will is illegal in most states.
- 2. Which does University of Virginia's new resuscitation policy state?**
  - a. Patients or their surrogates make the final decision whether resuscitation will be attempted.
  - b. Physicians are fully supported in offering treatments that the family feels strongly should be provided, even if these are not clinically indicated.
  - c. Patients can no longer be told they are not a candidate for resuscitation.
  - d. Patients or surrogates are entitled to consent to, or refuse, offered medical treatment.
- 3. Which is true regarding patients with COPD, according to a recent study?**
  - a. Palliative care often is offered when not appropriate, due to many patients having significant reversal of symptoms between exacerbations.
  - b. Few COPD patients receive palliative care or achieve their wish to die at home.
  - c. Patients with COPD were much less likely to die in hospital compared to patients with cancer.
  - d. Randomized controlled trials have demonstrated that current palliative care models used for cancer patients are just as effective in supporting COPD patients.
- 4. Which did a recent study find about priorities of chronically critically ill patients?**
  - a. Life prolongation was valued above all other goals by respondents.
  - b. Living as long as possible was the least important priority ranked for the majority of people surveyed.
  - c. Life prolongation was valued above cognitive impact and physical function for the majority of people surveyed.
  - d. Families valued life prolongation above all other goals, but this was not true for patients.