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INSIDE

RELIAS MEDIA

Guidance on Grateful Patient Fundraising: No Consensus on Direct Solicitation by MDs

With declining reimbursement and less research funding, donations from grateful patients are an increasing source of support for hospitals.

"Ensuring that hospitals can keep their doors open to provide care to the broader community is a worthy end," says **Reshma Jagsi**, MD, DPhil, director of the University of Michigan's Center for Bioethics and Social Sciences in Medicine.

Asking patients for donations raises multiple ethical concerns: conflicts of interest, patient vulnerability, undue influence, and confidentiality (among others). "Institutions must ensure that their fundraising activities respect all patients and do not disrupt the trust of the doctor-patient relationship," Jagsi advises.

Perception of favoritism toward donors "is certainly a concern," says **Mark A. Rothstein**, JD, director of the Institute for Bioethics, Health Policy, and Law at the University of Louisville School of Medicine. Patients in the hospital's "Smith Wing" might presume members of the Smith family receive better care. More ethically problematic, according to Rothstein, is that at least some people will worry they, or their family members, will receive *substandard* care because they are not donors.

Hospitals and health systems raise billions of dollars from grateful patients each year. "Yet, there was absolutely no published information anywhere, in any medical journal," about how to mitigate ethical concerns, notes **Steven Rum**, MPA, vice president for development and alumni relations fund for Johns Hopkins Medicine.

Lack of Ethics Guidance

Physicians conflicted about their own involvement in patient philanthropy had nowhere to turn for guidance. "I found the biggest obstacle to physician engagement was the ethical piece," Rum says. "Institutions were all over the map

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as to what was acceptable and what wasn't."

In 2017, a group of 29 experts participated in a Summit on the Ethics of Grateful Patient Fundraising and developed a set of recently released recommendations.[1] "Fundraising activities are important but must be structured in ways that provide reassurance that these donations promote the health of all served by the institution," says Jagsi, one of the summit participants.

For physicians, the report authors recommended the following:

- Bring up the topic of donation only if it is apparent the patient wants to contribute and when the physician-patient relationship is well-established while also considering timing and the patient's health status;
- Avoid philanthropic discussions with patients who are clinically vulnerable;
- Receive training in how to broach the topic appropriately.

The group did not reach a consensus on whether it is ethically acceptable for physicians to ask for donations directly. "The goal of the summit was to get feedback from stakeholders across many perspectives," explains **Megan E. Collins**, MD, MPH, lead author of the report. Patients, ethicists, clinicians, hospital leaders, and development professionals all gave input. "We did not endeavor to reach consensus on every point, but rather to map out the ethical issues raised by grateful patient fundraising," says Collins, associate faculty at Johns Hopkins Berman Institute of Bioethics.

Some participants voiced concern about patients losing trust in their doctors. Others maintained that a physician-initiated discussion was appropriate in some cases. The guidelines do not specifically address what constitutes acceptable behavior on the part of physicians, or whether concierge services can be offered to patients who donate. "Each institution should create their own guideline for physicians and for the institution as a whole," Rum says.

This should include education of clinicians and development officers on ethically responsible practices. "All discussions about grateful patient philanthropy should be grounded in beneficence, professionalism, and responsible stewardship," Collins adds.

Physician-Patient Relationship

Contributions from grateful patients or family have been an important source of revenue for hospitals. "They have permitted construction of facilities, recruitment of personnel, funding of research, and providing uncompensated care," Rothstein notes.

EXECUTIVE SUMMARY

There is more attention paid to ethical implications of grateful patient fundraising, particularly when physicians solicit directly from their patients. Recent guidance made three recommendations for physicians:

- Bring up the topic of donation only if it is apparent the patient wants to contribute.
- Avoid philanthropic discussions with patients who are clinically vulnerable.
- Receive training in how to broach the topic appropriately.

However, Rothstein cautions that directly involving treating physicians in fundraising efforts is "ethically troublesome."

"Patients should not be made to feel obligated to make contributions after a positive outcome, nor made to feel guilty if they do not make a contribution," he says.

Direct physician involvement in grateful patient fundraising "has the potential to raise concerns regarding conflicted healthcare decision-making, healthcare resource allocation injustices, financial exploitation, breach of confidentiality, and breach of privacy," says **Stacey Tovino**, JD, PhD, professor of law at the University of Nevada, Las Vegas William S. Boyd School of Law.

The AMA Code of Ethics encourages physicians to participate in fundraising — but not directly, especially during clinical encounters.[2] "One thing that should be considered is the effect that expectations of fundraising have on the physicians," Rothstein says. Some may leave the hospital staff if they consider soliciting contributions from patients to be unprofessional.

Certain institutions ask physicians to solicit donations; not all physicians are comfortable doing so. Of 405 oncologists, one-third had been asked to directly solicit a donation from their patients, according to one survey.[3] Half of this group declined to do so. While 37% felt comfortable talking to their patients about donation, 74% agreed it could interfere with the physician-patient relationship. Fifty-two percent said they thought a conflict of interest existed.

Notably, two-thirds of the oncologists did not believe that patients who donated could be offered even certain convenience-related services as thanks. "More research is needed to evaluate patient and public perceptions in this context," says Jagsi, the study's senior author. Soliciting donations from patients is only expected to increase. "Going forward, it will be critical to continue thoughtful discussions about how grateful patient fundraising can proceed in an ethically responsible manner," Collins says. ■

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Change in How Donated Livers Are Allocated Sparks Debate

A patient has needed a liver transplant for years, and one finally becomes available in her town. Instead, the organ is shipped by plane to someone hundreds of miles away. Because of a change in how donated livers are allocated, such a scenario could become common.

"There has been a lot of controversy over the proposed changes to liver allocation," says **Jared A. White**, MD, FACS, associate professor and surgical director of liver transplant at Medical University of South Carolina.

The change resulted from a lawsuit against the Department of Health and Human Services. "Waiting times were different in different parts of the country. Some people thought this was inequitable and sued to change this," says **Keren Ladin**, PhD, MSc, director of Tufts University's Research on Ethics, Aging, and Community Health Lab in Boston. In their suit, hospitals and patients argued the new policy will waste viable livers.

The proposed allocation change went into effect for a brief period but then was placed on hold, reverting back to a version of the old system by court mandate. "I suspect it will not be long before another change is made," White predicts. "And then we will have to await the unintended consequences of these policies."

The United Network for Organ Sharing (UNOS) is tasked with devising criteria to allocate organs equitably across the county. "While UNOS sets policies, organ transplantation relies fundamentally on the public's trust and support. It is unclear how they will interpret these changes," says **Leslie M. Whetstine**, PhD, a bioethicist at Aultman Hospital in Canton, OH. Traditionally, UNOS distributed organs within the boundaries of its 11 geographical regions.

"This meant that someone in the Midwest, for example, where donation rates are often many times higher than on the coasts, would have a greater chance of receiving a transplant than someone who may have been sicker in another state," Whetstine explains.

The revised allocation process is based on critical need. This means that an organ procured in Ohio might be sent to a recipient in New Jersey. "Some object to this new process, arguing that it exploits states that have higher donation rates," Whetstine says.

This would negatively affect individuals in rural or underserved communities. "This change could also impact transplant centers if organs are exported outside their locations," Whetstine adds.

This could harm the center's financial viability and, ultimately, the populations served. Compounding the ethical complexities, donation rates vary widely across geographical areas. In Montana, 93% of residents are organ donors, compared to just 32% of New Yorkers.

"In the absence of an opt-out system where citizens are automatically enrolled as organ donors unless they expressly decline, allocation will remain problematic," Whetstine laments.

Little Agreement

The waitlist for liver transplants is large and growing, with a relatively stable number of donor livers and liver transplants performed. States or regions report different prevalence of liver disease, population density, and organ donation rates. Performance of organ procurement organizations (OPOs) also varies.

"Thus, the concept of 'geographic disparity' has been at the forefront of discussion," White says.

There is little agreement on how to best allocate livers equitably from one state or region to the next. Officials in states like New York, California, and Massachusetts suggest that waitlists are so long that patients have to be sicker to receive a liver and die while waiting. Meanwhile, less-sick patients in the Southeast and other regions are receiving transplants. "What they are failing to show is that the rate and risk of death from liver disease is actually much higher in the Southeast," White argues.

However, this is due in part to poor access to transplant centers in the Southeast. "An additional caveat is that some of the OPOs in these states that are speaking out the loudest in favor of allocation changes happen to be among the worst-performing in the country," White notes.

If OPOs improved their performance to even a fraction of the national standard, more organs would be added into the system, according to White. Thus, more transplants would be performed overall, rather than simply rearranging where the current organs go.

"This has been a point of contention among all major liver transplant centers," White adds. "Little compromise has been reached."

Continued Debate

Modeling of the new policy suggested an overall decrease in total liver transplant volume. "'Equalizing' the so-called geographic disparity at the expense of millions of dollars of added cost to travel [can lead to] higher discard rates of organs and a number of other challenges yet to be seen," White says.

The potential for fewer transplants is a serious ethical concern. The new system does not address the issue of optimizing organ donation, yield, and allocation at the OPO level.

"Enormous sums of money are predicted to be spent flying livers all over the country," White explains. "In addition, some of the transplant programs in these OPOs aren't optimizing the livers they do have."

For instance, some centers do not accept livers from older donors viewed as "marginal."

"I have personally used several livers from the Northeast that were skipped due to 'poor quality,' and yet those livers worked just fine in the Southeast," White reports.

Most of the focus has been on the differences in waitlist times. "Not enough has focused on outcomes of patients on the waitlist and causes of organ donor-eligible deaths and access to transplant nationwide," Ladin says.

Additionally, there is disagreement on whether equalizing waiting times is actually equitable or whether it will in exacerbate disparities.

"Patients in areas with long wait times often benefit from high market competition," Ladin notes. This is a result of better access to healthcare, including transplantation. Thus, mortality is lower than in other regions with shorter wait times.

"Redistribution of organs across the country may mean worsening the situation of persons who are already worse off with respect to social protections and access to transplantation," Ladin suggests. Higher mortality leading to greater availability of organs may result, in part, from disproportionate risks incurred at the local level, according to the authors of a recent paper.[1]

Although the new system is in the implementation phase, the transplant community remains divided. "As such, we are likely to see these issues continue to be debated," Ladin predicts. ■

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Complex Language Hinders Informed Consent

It is rare for written consent forms used for cancer treatment with radiotherapy to meet recommended readability levels for patient materials, according to the authors of a recent analysis.[1]

"We wanted to better understand how the process of informed consent occurs for cancer patients who undergo radiotherapy and how difficult it may be for patients to understand the information communicated to them," says **Andrew J. Einstein**, MD, PhD, one of the study's senior authors.

Only nine of 113 forms met the recommended eighth grade readability level, and four forms met a sixth grade level.

"Appropriately designed informed consent is critical to ensure patient autonomy and shared decision-making," says Einstein, associate professor of medicine and director of cardiac CT research at Columbia University Medical Center.

Researchers were surprised at the high reading level required to understand consent forms and how many difficult words appear in informed consent documents. "Ethically, it is important to patients to understand the options available to them," says **Nancy E. Kass**, ScD, deputy director for public health at Johns Hopkins Berman Institute of Bioethics. This is particularly important when treatments carry difficult risk/benefit tradeoffs, or when options carry different risks and benefits (e.g., surgery vs. physical therapy for back pain).

Often, patients consider only what their doctors recommend. They do not always understand even the basics of possible side effects or risks, how likely they are to benefit, or how to increase or decrease the chance of the risks or benefits. "This is a missed opportunity to help patients and a missed opportunity to avoid significant problems or disappointments," Kass says.

Written forms should serve as documentation of a conversation that should have happened between a physician and patient. "There is significant data showing that conversation leads to far better understanding than reading a form," Kass notes.

Shorter, simplified forms are ideal but still do not replace a quality discussion. "Looking someone in the eye, getting a sense of whether they're with you, and even asking them to repeat back what they understand is the most likely strategy to achieve a meaningful understanding," Kass offers.

Forms Insufficient

Patients cannot make informed judgments if they do not comprehend the information pertinent to the clinical situation at hand, says **Aaron S. Fink**, MD, FACS, chief medical officer at Taylor Healthcare in Atlanta.[2,3] Informed consent is a much more complex process than just a form read and signed by a patient.

"Indeed, many consent forms offer insufficient or no information about the proposed intervention," Fink explains. Often, there is insufficient time or an appropriate environment to allow a patient to comprehend the necessary information. Even legible and complete informed consent documents are written at a reading level that prevents comprehension.

"Focusing solely on the informed consent document is insufficient to ensure an acceptable informed consent process," Fink says. Still, ensuring appropriate reading levels "is one of the many issues that need to be addressed in seeking improvement of this vital healthcare process," he adds.

Critical Ethics Role

Legal and administrative directives often seek different goals for informed consent. "Medical ethicists can help seek balance between these various competing directives," Fink says.

Ethicists can partner with clinicians to ensure informed consent is understandable to patients, ensuring patient autonomy. "Ethical principles are not theoretical ideals but guidelines for action that should be implemented in practice," Einstein says.

Ethicists can work to make them reality. One way is to engage physician leaders. "Ensure that consent forms and all other aspects

of the informed consent process are comprehensible, meaningful, and educational for patients and ultimately lead to truly informed consent," Einstein says. ■

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When Is It Appropriate to Admit End-of-Life Patients to ICU?

The ICU might not be appropriate for some ED patients with end-of-life care directives limiting aggressive care, but that is not necessarily the case. ICU admission should be based on the alignment of uniquely beneficial treatment offered by the ICU, along with patients' values and stated goals of care, the authors of a recent paper argued.[1]

"If a patient would benefit from this level of care, and they are agreeable, intensive care may be appropriate," says **Catherine A. Marco**, MD, FACEP, professor in the department of emergency medicine at Wright State University in Dayton, OH.

On the other hand, if a patient has declined intensive care, an appropriate disposition might be admission to a medical/surgical bed or discharge to hospice or home. "Individual cases should be assessed based on patient wishes, the current medical condition, and proposed interventions," Marco offers.

Ethical care of patients near the end of life should include "a team-based approach to assessment, diagnosis, communication regarding proposed interventions, prognosis, and patient wishes," she adds.

Some patients arrive with living wills or other advance directives specifying which procedure they want. Often, this cannot be acted on in the ED. "A request for 'Do Not Intubate' documented in an advance directive is predicting a future hypothetical situation," explains **Jean Abbott**, MD, MH, a clinical ethicist at University of Colorado Health.

Standard advance directives give an idea of what might be important to patients. "But these are no substitute for ED conversations about such things as the meaning or goal behind the written directives," Abbott cautions.

Completed Physician Orders for Life-Sustaining Treatment forms give clearer guidance on whether the patient wants CPR, intubation, ICU-level care, or something less aggressive. "The ED provider has an ethical obligation to honor these when they are available and filled out correctly," Abbott says.

But even so, a conversation is needed after initial stabilization. Clinicians need to know if admission, hospice care, or discharge home is desired at this particular point. ICU care remains a possibility even for patients who want "comfort-focused" care only. If the patient experiences a massive gastrointestinal bleed that cannot be managed at home or in a regular hospital bed (or experiences intractable pain), the ICU might be the best place. "Intensive management of symptoms may require intensive nursing and even physician care," Abbott notes.

Ethics Expertise Needed

Engaging in sensitive discussions about preferences at the end of life "are tough for anyone, not just residents," says **Jan Shoenberger**, MD, associate professor of clinical emergency medicine at Keck School of Medicine of USC in Los Angeles.

Emergency medicine residents are trained primarily to perform resuscitation through aggressive, life-prolonging measures. "This mindset is appropriate for the vast majority of patients we see," Shoenberger says. "But for patients who have not much time left, the question of *'How much, and which procedures?'* comes up often."

This is the case when frail, elderly patients found in cardiac arrest are brought to the ED. Three ethical questions that commonly arise are: *Should we keep performing CPR? Should we intubate the patient and put him or her on a mechanical ventilator? What if the family tells you to perform CPR, but you do not think it is the right thing?*

"These kinds of things come up a lot in the ER, and trainees

really struggle with these scenarios," Shoenberger reports, noting that hospice and palliative medicine knowledge is needed in these cases. "This expertise brings a higher level of knowledge about the ethical ramifications of these scenarios."

ED Is Action-Oriented

ED providers are procedure- and action-oriented. "Helping the patient and family with a terminal sepsis event is not something we are as comfortable with," Abbott says.

If a there is a procedure or resuscitation to perform, "particularly as residents, they want to do it, rather than stopping to ask if it is appropriate to the patient's goals and values," Abbott explains.

However, recent lawsuits have alleged that overaggressive treatments were initiated in conflict with patient wishes. "Some have suggested that ignoring advance directives that limit the desired interventions should be treated as a medical error," Abbott adds.

Some ED providers believe their role is strictly to keep patients alive, and patients' end-of-life wishes can be sorted out after admission. "That is no longer acceptable," Abbott stresses. "There is no excuse for not asking a 97-year-old who comes in septic, or their family, what their goals are and where the patient is in the arc of their life."

Even if decisions do not happen in the ED when the patient is admitted, end-of-life decision-making still needs to be addressed. "Sometimes, one of the best roles for an ED physician is to prime the patient and family that the admitting team is going to ask some important questions in the coming hours," Abbott offers.

University of Colorado Denver's emergency medicine residency curriculum covers ethical issues at the end of life. The training emphasizes that patients' priorities are different near the end of their lives. "Our role as physicians is to help people understand the medical situations they are in, their options, and respect their wishes," Abbott says. ■

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Ethical Education on Mechanical Circulatory Support Lacking

Modern life-sustaining therapies, such as total artificial hearts, extracorporeal membrane oxygenation (ECMO), and left ventricular assist devices (LVADs) pose some complex ethical questions. Still, most residency and fellowship programs do not address the ethics of these interventions specifically.

"These devices are becoming more prevalent, and residents of all stripes will see them in their patients," says **James Kirkpatrick**, MD, adjunct assistant professor in the department of bioethics and humanities at the University of Washington Medical Center.

Such devices "represent the future of much of medicine, touching on the interaction of humanity with life-sustaining and life-enhancing devices," Kirkpatrick adds. "We all need to realize the potentials and pitfalls of 'bionic' technologies."

Ongoing Ethics Education

The authors of a recent paper proposed integrating the ethics of mechanical circulatory support into graduate medical education, with a focus on patient best interest, autonomy, informed consent, shared decision-making, surrogate decision-making, and end-of-life care.[1] "The medical community, especially cardiology and cardiac surgery, faces difficult decisions around when to initiate therapy, on which patients, and when and how to withdraw that therapy," says **Elizabeth Sonntag**, MD, the paper's lead author.

To provide excellent care to patients who may require these therapies, clinicians need to be able to expertly navigate the ethical considerations. "It only takes caring for one patient on ECMO to think, 'This is something we must explore further,'" says Sonntag.

Researchers were not surprised to find a lack of robust ethics programs in most residency and fellowship programs. As a pulmonary and critical care fellow at the University of North Carolina, Sonntag sees ethical issues in the ICU regularly. In teaching a medical ethics elective at the UNC School of Medicine, she sees how eager students are for an ethical analysis of complicated cases.

"In both of these arenas, I am continually, pleasantly surprised at how empowered students and trainees feel

when they have the tools, language, and framework to approach challenging ethical dilemmas," Sonntag reports.

Ethics education should not stop at medical school, but should continue in residency and fellowship training, as well as throughout a physician's career, Sonntag offers. Ideally, she says, this should be "a collaborative effort between hospital ethicists and practicing clinicians."

Not Enough Time

Emergency ECMO can significantly augment the circulation of patients who have suffered cardiac arrest. These devices are even available on ambulances in some settings. "There is not always a significant amount of time to consider all of the implications of starting ECMO on individual patients," Kirkpatrick notes, adding that this includes goals of care, values, and preferences. "We are at the point that our different resuscitative measures come with very different implications."

Patients who would be comfortable receiving shocks and chest compressions may be averse to allowing a machine to support their cardiac and pulmonary functions, even briefly. Alternatively, ECMO (and percutaneously placed left and right ventricular support devices) are used sometimes to support patients through surgery and procedures. The intent is to remove the devices afterward. "But things don't always go as planned," Kirkpatrick cautions. Some patients become dependent on the support devices for longer than expected. Then, ethical issues center on withdrawal of life-sustaining therapies.

"While much of this has been worked out in relation to withdrawal of ventilators, there remains significant difficulty" in the case of ECMO discontinuation, Kirkpatrick explains. Family members and clinicians sometimes object to removal. This is ethically problematic for several reasons.

"Maintaining patients on support for long periods of time consumes resources," Kirkpatrick says. This can prevent a hospital with few machines or limited trained staff from using them for other patients.

"The hope in most of these cases is that the patient would recover or be bridged to a long-term support solution or transplant," Kirkpatrick says. Instead, patients may suffer complications that make them poor candidates for these plans. "It is not always clear when the trajectory is toward death instead of the hoped-for outcome," Kirkpatrick adds.

Role-Based Ethics Training

There is growing recognition that ethics should be part of all educational offerings for trainees who care for patients with these devices. What is really needed, says Kirkpatrick, "is ethics training that addresses the resident level, and a different curriculum for the fellow level."

Each plays a different role. Residents in surgery and internal medicine will rotate through ICUs where ECMO is employed. "Residents will struggle less with decisions about *when* to implant, but may interface regularly with patients, families, and other clinical team members over issues related to discontinuation," Kirkpatrick offers. *(See sidebar box at bottom left for more.)*

Most of the decision-making and follow-up of LVADs will be the purview of cardiology and cardiothoracic surgery fellowships. "Fellows and other higher-level trainees must be educated about ethical issues related to indications and choices to employ the technologies, as well as decisions about discontinuation," Kirkpatrick notes.

Even "durable" devices can wear out. "Significant ethical consideration and even moral distress may center around replacing them," Kirkpatrick cautions.

Patients on devices may develop other diseases, like cancer or dementia, which lead to questioning whether the device should be discontinued.

"Hospice services for patients with devices are generally not considered to be completely adequate in all locations," Kirkpatrick observes. This is due to lack of training, discomfort with the devices, and insufficient resources to maintain them.

In the minds of patients and clinicians, "the idea of 'turning off' a device that essentially functions as a

RESIDENT ETHICS TRAINING

In an ideal world, there would be separate ethics training for residents and fellows. For residents, the curriculum should cover the following:

- Sensitive goals of care discussions;
- Advance care planning;
- State laws and hospital policies on withdrawal of life-sustaining therapies;
- Laws regarding surrogate decision-making.

part of the heart may take on ethical overlays distinct from other organ-supporting devices," Kirkpatrick adds.

LVADs "can absolutely improve survival and quality of life. But there are definitely tradeoffs associated with that," says **Keith M. Swetz**, MD, MA, medical director of the University of Alabama, Birmingham's Supportive Care & Survivorship Clinic.

Clinicians need to know what the patient is really willing to accept in terms of responsibility and care requirements.

"We don't do a great job helping people understand fully what they are getting into," Swetz admits.

Some patients say that they were so sick they felt as though they did not have much of a choice. Other patients had undergone defibrillator or pacemaker implantation procedures and handled it well, saying they are willing to do what it takes. Regardless, patients do not always have all the information they need to make a truly informed decision.

"It's not just about filling out an advance directive or signing a consent for the procedure," Swetz says.

Certain centers might work with patients with LVADs to provide education on how patients can adapt to living with the device. However, those patients tend to be the ones performing better than anyone else.

"If you see one person who's doing great, the thought is, *'I could do great, too.'* But for that person to be successful, a lot has gone into making it happen," Swetz explains.

Often, the consent process is focused mainly on the implantation itself and less on long-term consequences. What is missing is an understanding of the range of symptoms or complications that can happen over time. Clinicians may not always be forthright with patients on how difficult the prospect of living with an LVAD is going to be and what range of outcomes may occur.

"There is a tendency to minimize it and gloss over it," Swetz notes. "Or, it *is* reviewed, and patients are too sick to take it all in."

Reluctance to Deactivate

Consent discussions do not typically cover what happens if things do not work out as planned.[2] A patient may want to deactivate the LVAD later, but find out it is not that simple.

"Even though there has been analysis that this is a therapy that people can stop if they don't want it any longer, just as they can request to have a pacemaker or defibrillator turned off, clinicians are more reluctant to do so with an LVAD," Swetz explains. Often, this is because it results in death much more quickly for most patients.

A patient may find out later that, in fact, her clinician is not willing to turn it off. "And that was never told to them ... to me, that's a really sticky situation," Swetz says.

Some clinicians take the position that they will not turn the device off unless the person is dying.

"I don't think that's something we should take lightly and not include in the consent process," Swetz suggests. "That is poorly addressed, and is a huge gap in current care." In a recent survey of 440 clinicians, 60% of cardiologists said they believed a patient should be imminently dying to deactivate an LVAD.[3] "Some people have much more comfort and experience with this, and others less," says Swetz, one of the study's authors.

Good shared decision-making, conducted early, can prevent problems later. "There is less likelihood of having ethical quandaries or having people dissatisfied with the outcome because it is worked out upfront," Swetz says.

This can prevent the need for ethics consults to answer the thorny question of whether it is right or wrong to turn off the device.

"Using ethics and palliative care resources to think through some of these problems ahead of time, before we end up facing them, is the ultimate goal," Swetz adds. ■

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COMING IN FUTURE MONTHS

- Meeting ethics demands with limited resources
- Efforts to promote ethical research practices
- Ethics of data linking optimism with better outcomes
- Concerns about aggressive collection practices

Early Documentation of End-of-Life Wishes Linked to Better Outcomes

Careful and early charting of a hospice patient's end-of-life wishes reduces the chance of an unwanted hospitalization, according to the results of a recent investigation.[1] "Patients are making transitions at the end of life, and documentation across care settings is not always consistent," says **Laura Prater**, MPH, MHA, the study's lead author and a postdoctoral researcher in the division of general internal medicine at The Ohio State University College of Medicine.

Researchers analyzed electronic health record (EHR) data for 1,185 cancer patients who were referred to hospice in 2014 and 2015. "We wanted to see if documentation of advance care planning was linked to improved outcomes. The study's findings supported this," Prater reports.

A do-not-resuscitate order placed in the EHR before a patient's last 30 days of life reduced hospitalization rates. Also, notes on end-of-life planning also reduced admission rates, particularly when the notes were created six months before a patient's death.

If the patient's wishes are not documented consistently across care settings, unwanted care may be given. "Just uploading a scanned document didn't have the same improvement in outcome," Prater notes. Ideally, the discussion happens early — even on the outpatient side, at a time when the patient can fully participate. "Earlier vs. later documentation can hopefully [help] avoid some of these crises that we see at the end of life," Prater says.

In their own clinical practice, the researchers had seen "what happens when we pass the buck and defer responsibility for talking to patients about their care preferences," says **Seuli Bose-Brill**, MD, the study's senior author.

Clinical ethicists usually become involved only after there is a serious conflict over how to proceed with care. "The vast majority of clinical ethics consultations result from advance care planning that was suboptimally administered," says Bose-Brill, a clinical ethicist and a primary care physician at Ohio State Wexner Medical Center.

Even when patients present with a life-limiting illness such as advanced heart failure, where any admission could result in critical illness or death, there often is no advance care planning in place. It would come as no surprise to clinicians if the patient ends up in the ICU — and any admission could result in critical illness or death. "In those situations, attention needs to be paid, just like we do with other aspects of care, to the patient's care preferences," Bose-Brill says. At a minimum, the patient should know a surrogate decision-maker with whom he or she is comfortable. Clinicians should talk to patients about their prognosis. For instance, the clinician might ask: *If you are in the ICU and need to be on long-term ventilation support, when would you want to transition to comfort care vs. curative therapy?*

"There needs to be an intentionality on who is documenting the advance care plans, and who's making sure it's correct and scanned in," Bose-Brill says. This requires interdisciplinary collaboration, something on which ethicists are well-versed. "Ethicists can guide challenging conversations about patient preferences," says Bose-Brill, noting that this is true even if it is not the direct question the ethicist is asked to address. "We can remind the team it *should* be addressed, and where it should be documented," Bose-Brill says. ■

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Widespread Boarding of Pediatric Psychiatric Patients Raises Concerns

It is difficult to imagine a child with a medical emergency staying in an ED for several days waiting for an inpatient bed. Yet, it happens routinely to children and adolescents with psychiatric emergencies.

"In terms of parity, which represents justice in healthcare, this is unequal treatment," says **Claire Zilber**, MD, DFAPA, ethics committee chair for the Colorado Psychiatric Society. "Long waits in the ED can exacerbate agitation or psychosis, necessitating the use of restraints, which would otherwise not be needed."

The shortage of psychiatric inpatient beds is well-known. But Zilber argues simply accepting this as the

status quo is ethically unacceptable. "Ethical care means adequately funded care," she says. "Our society undervalues the importance of mental health, and, thus, underfunds mental health services."

Major gaps in resources for child and adolescent mental healthcare "tend to play out in EDs," says **Gail A. Edelsohn**, MD, MSPH, co-chair of the American Academy of Child & Adolescent Psychiatry (AACAP) Ethics Committee. Pediatric psychiatric visits increased by 28% between 2011 and 2015, according to the authors of a recent paper, with the largest increases in adolescents, African American, and Hispanic patients.[1] Researchers also found a large increase in suicide-related visits among adolescents and noted that just 16% of patients were seen by a mental health professional.

"Many youths and their families experiencing a mental health crisis wait hours or days waiting for discharge or transfer to a psychiatric hospital," Edelsohn notes.

Another study found that of 1,746 mental health visits to a pediatric ED in 2016, 386 stayed longer than 24 hours.[2] Presenting with private insurance, physical or chemical restraint use, autism or developmental delay comorbidity, and prior psychiatric hospitalization were associated with pediatric mental health ED boarding.

"EDs do their best to meet the needs of youth and their families," says **Maria E. McGee**, MD, MS, MPH, also co-chair of the AACAP Ethics Committee. However, not all EDs can provide adequate specialized mental health staffing. Not all include calming space to meet the needs of vulnerable, distraught youth who sometimes exhibit dangerous behaviors. "This means youth might be lacking necessary mental healthcare while they are waiting," McGee notes. Prolonged boarding in the ED can result in lower quality care for psychiatric patients. It is not just lack of available inpatient beds that is the problem. "The creation of more pediatric psychiatric beds is a one-dimensional solution to a multidimensional problem," McGee adds.

Various unmet mental healthcare needs, which might precede a mental health crisis, also must be considered. "Prolonged ED boarding is a reflection of deeper gaps in the availability and accessibility of outpatient mental healthcare resources," McGee says. Certain interventions are vital, such as early support of children's developmental needs, early detection and interventions addressing psychiatric illnesses in children and adolescents in school and clinical settings, and addressing adverse childhood experiences.

The average length of stay for mental health visits in pediatric EDs was more than 11 hours, according to the authors of a 2015 study.[3] A prolonged ED stay "translates to ethical concerns revolving around autonomy, beneficence, nonmaleficence, justice, and fidelity," McGee says.

In some cases, patients or family want to leave the ED against medical advice (AMA) because of the long wait for an open bed at a psychiatric facility. In this case, says McGee, "the physician must make a decision that has significant clinical, ethical, and risk management implications." The ED provider either creates a therapeutic alliance so that the patient receives timely and quality psychiatric care, initiates an involuntary commitment proceeding, or faces an AMA discharge. "A hospital ethicist has multiple roles in the case of psychiatric boarding," McGee says. An ethicist can help to assess issues involving distributive justice, including the scarcity or lack of mental health resources and ED crowding. "An ethicist can assist in elevating the constellation of ethical concerns that arise from psychiatric boarding to hospital leadership," McGee offers. These leaders are responsible for institutional policy, practice, and budget allocation that can enhance the training, staffing, expertise, safety, and physical accommodations for the ED. "An ethicist's expertise can also be utilized to advocate for systemic changes to address the mental healthcare needs and psychosocial challenges that culminate into an ED visit," McGee notes.

Ethical challenges arise when the recommended treatment or discharge plan is not acceptable to all the key stakeholders. Child welfare agencies, juvenile justice entities, and parents can disagree on what is in the child's best interest. "These differences can quickly become quite heated," Edelsohn observes.

The physician may recommend community-based services, but the family may want a residential setting. "Ethicists can help address these conflicts by teaching clinicians specific mediation techniques to achieve consensus around treatment decision-making in the ED," Edelsohn says. ■

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CME/CE QUESTIONS

1. **What does a recent paper recommend regarding ICU admissions for ED patients with end-of-life care directives?**
   a. ICU admission is a waste of resources in this circumstance and should not be considered.
   b. ICU admission should be based on the alignment of uniquely beneficial treatment offered by the ICU and patients' values.
   c. Standard advance directives make conversations on the meaning behind them unnecessary in most cases.
   d. ICU care is no longer an appropriate option if patients want comfort-focused care only.

2. **Which is true regarding patient requests to deactivate a left ventricular assist device (LVAD)?**
   a. Addressing this possibility during informed consent is highly inappropriate.
   b. Generally, clinicians are more reluctant to turn off an LVAD than a pacemaker.
   c. Clinicians are barred from turning the device off unless the person is actively dying.
   d. Hospital policies should include language that devices will not be deactivated.

3. **Which is true regarding changes in the way donated livers are allocated?**
   a. The new process is expected to increase the number of viable livers.
   b. The allocation process is based on critical need.
   c. The patient's geographic location will take precedence now.
   d. Livers from marginal donors are no longer accepted.

4. **Which did the authors of a recent study find regarding reading levels in consent forms?**
   a. Few forms met the recommended eighth-grade readability level.
   b. Most forms were written at a sixth-grade reading level or below.
   c. Reading levels have become less important because verbal discussions are happening more often.
   d. Readability of forms is less important if treatments have difficult risk/benefit tradeoffs.