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INSIDE

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Task Force Aims to Grow HEC-C Program

There are more than 27,000 healthcare ethics consultants in the United States.[1] However, only a small percentage have obtained the American Society for Bioethics and Humanities (ASBH) Healthcare Ethics Consultant-Certified (HEC-C) designation. "We are looking to expand the number of people getting certified, and for more people to know about the availability of the credentialing process," says **Chris Feudtner**, MD, PhD, MPH, HEC-C, chair of the HCEC Certification Commission.

The HEC-C program began accepting applications five years ago. As of June 2023, only 779 healthcare ethics consultants have earned the HEC-C. The ASBH recently convened a task force to grow the program. "We are interested in trying to understand why some long-standing consultants are declining the opportunity to become certified," says **Daniel Davis**, PhD, HEC-C, chair of the task force and a founding member of the HCEC Certification Commission. The task force is conducting surveys and interviews to learn more about ethicists' attitudes toward the credential.

Initially, ASBH targeted two groups: ASBH members, and people who expressed interest in certification. "We have broadened our outreach to potential audiences, including hospice and palliative care physicians, nurses, social workers, and chaplains," reports **Mary Beth Benner**, CAE, executive director for ASBH and the HCEC Certification Commission.

Debate is ongoing as to exactly what experience and education demonstrates competency as a clinical ethics consultant. There also is no clear consensus in the field regarding how competency should be assessed. "I'm not suggesting that there's no room for discussion about change. But the rationale for the current eligibility requirements, and the rigor and quality of the exam, are based on data and evidence," Davis asserts.

The HEC-C program always was viewed as a work-in-progress, intended to be adjusted over time based on feedback from the ethics field.

"That's been the case in most other healthcare professions. If we waited to get it just right, we'd never start," Davis says.

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The ASBH task force is actively promoting the HEC-C program among ethicists, organizations that employ ethicists, and through organizations like the American Hospital Association and the Association of American Medical Colleges' Council of Teaching Hospitals and Health Systems.

"We have to find ways to convince them that competent ethics consultants are a worthy investment," Davis reports.

Some hospitals are listing "HEC-C preferred" in job postings for clinical ethicists. Just the fact that there is a credential for ethicists could open the possibility of organizations adding paid positions.

"In some healthcare systems, there is a need to have a credentialed individual in order to post positions," Feudtner explains. "Some healthcare systems are now posting positions for healthcare ethics consultants, where previously they did not."

Hospitals and health systems are becoming more aware of the HEC-C credential. The task force surveyed 134 HEC-Cs in late 2022. About half reported their employer paid part or all of the HEC-C fees. One-fourth received time off to prepare and take the HEC-C exam; 10% received a salary increase, promotion, or both after achieving certification. Additionally, 23 respondents reported supervisors commended the ethicists for obtaining the HEC-C during performance reviews.

"We are hopeful that the credential will have a larger impact, of changing the position from 'It's good to have a healthcare ethics consultant as part of your team,' to 'You really ought to have a certified healthcare ethics consultant — and you need to staff them, the way you would any other service,'" Feudtner shares.

In this way, the HEC-C is advancing the overall professionalization of the field of ethics. "Pick any other area of practice in the hospital. People who are providing services — to patients, to families, even to the institution — are credentialed," Feudtner observes.

Thus, the HEC-C designation puts ethicists on a level playing field with clinical counterparts. It also could advance quality improvement of ethics consultations.

"If ethics is being done as a side job or an afterthought, it's hard to envision how you really get quality improvement done. To improve quality, a necessary step is a system change, where ethics is valued, and supported, and paid for — the way we do anything else in healthcare," Feudtner says.

For individual ethicists, placing the HEC-C after their name signifies professionalism and credibility. "But it's also about contributing a greater good. You are standing up for a movement, not just your own personal career," Feudtner suggests.

Hospitals may perceive a competitive advantage to hiring credentialed ethicists. "If hospital leaders are looking at another healthcare organization that has four credentialed healthcare ethics consultants, and they have none, it

COMING IN FUTURE MONTHS

- Ethical responses if family demands inappropriate care
- Companies are selling patients' data without consent
- Ethical ways to inform patients of genetic testing results
- Ethical controversy over payments made to study participants

puts that organizational role on the map," Feudtner suggests. "The people making staffing decisions say, 'Maybe we need to do this, too.'"

Just a decade ago, the field of palliative care was largely unknown, widely misunderstood, and difficult for patients to access. In recent years, palliative care has grown dramatically in terms of professionalism, training, and demand. The ASBH task force members foresee the same kind of trajectory for the ethics field.

"As a change agent, we do need to recognize that change does not happen overnight," Feudtner admits. "But in 10 years, we will have noticeable change." ■

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Ethicists View HEC-C as One Step Toward Professionalization

A small but growing number of ethicists are obtaining the American Society for Bioethics and Humanities (ASBH) Healthcare Ethics Consultant-Certified (HEC-C) designation. **Joan Henriksen**, PhD, RN, HEC-C, was part of the original cohort of ethicists to take the HEC-C exam, earning the credential in 2018.

"I had already been doing consultation professionally for a long time, and wanted to support efforts to define the work," says Henriksen, a clinical ethicist in the Program for Clinical Ethics and Values at Abbott Northwestern Hospital, part of Allina Health, in Minneapolis.

The HEC-C process ensures a minimal standard of competency for those conducting ethics consultations. The certification alone is not necessarily an indication of excellence in consultation. "Rather, it's a sort of assurance that the person has a basic set of knowledge that should lead to safe practice," Henriksen explains.

With considerable study and practical experience, a person who is not a professional ethicist can earn the certification.

"That allows for organizations that are not inclined to invest in an ethicist to still have some attestation of quality and safety for those providing consultation," Henriksen says.

In Henriksen's experience, most clinicians, patients, and hospital leaders are unaware of the HEC-C. Few appreciate its significance. "I have found myself explaining it to organizational leaders and others, drawing parallels to other forms of certification and processes that they are already familiar with," Henriksen says.

For example, most people understand that some chaplains obtain board certification, and that some nurses obtain critical care certification. Although Henriksen is the only full-time ethicist at Allina Health, another ethicist will be added soon. Hospital leaders supported requiring HEC-C. "Broader appreciation of the certification will come with growing understanding of the work that clinical ethicists do," Henriksen predicts.

Across the country, most of the individuals who conduct ethics consults are clinicians who work as volunteers.[1] Henriksen expects the HEC-C might help change that model. "It will demonstrate value to leaders, in terms they understand," she suggests.

Three of Allina Health's ethicists recently obtained the HEC-C. "The preparation required to pass the HEC-C exam has made the clinicians better able to perform consults and participate in quality review processes," Henriksen reports.

Despite debate among ethicists about the value of certification, Henriksen expects the process of professionalization of clinical ethics to continue. More demand for ethics work is the primary reason. "The complexity of healthcare brings more ethical tensions, not fewer," Henriksen says.

Hospitals must identify and address all kinds of ethical issues. That requires people with specific knowledge and skills. "The HEC-C process is part of the scaffolding that can help organizations ensure they have those people among them," Henriksen asserts.

Aimee Milliken, PhD, RN, HEC-C, obtained the certification during postdoctoral fellowship training. Although ethicists were not required to earn the credential, program leaders strongly encouraged it. "This is a trend we are seeing in many large ethics programs," reports Milliken, an associate professor of the practice at the Boston College Connell School of Nursing.

Milliken notes the field of clinical ethics is "professionally diverse." The HEC-C credential sets a baseline standard that can be applied across ethicists of varying backgrounds. "It is important to begin establishing

what criteria are required for someone to call themselves a clinical ethicist," Milliken says. "Credentialing is one step in that direction."

Andrew G. Shuman, MD, FACS, HEC-C, actively encourages clinical ethicists to obtain the credential. "The professionalization of clinical ethics consultation is important to our field, to recognize the importance of rigorous training and experience for the work that we do," says Shuman, co-chief of the clinical ethics service at the University of Michigan Center for Bioethics and Social Sciences in Medicine.

The HEC-C, adds Shuman, also provides external validation of the value of ethics services, and the need to financially support the work of ethics. "As with all professional certifications, I expect the criteria, requirements, and process will evolve to recognize the importance of practical experience, as well as the diversity of professionals doing this critical work," Shuman says. ■

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Ethicists Hold Debriefings After Critical Patient Events

As a new nursing graduate working in a pediatric ICU, **Courtney Nerovich**, BSN, RN, struggled emotionally after experiencing an unsuccessful code for the first time. "I wasn't sure I would be able to handle the stress, anxiety, and trauma this job entailed," Nerovich recalls.

Once Nerovich became the charge nurse in the PICU at Ann & Robert H. Lurie Children's Hospital of Chicago, those feelings only intensified. After another unsuccessful resuscitation, an attending physician noticed Nerovich's emotional distress and pulled her aside to discuss the case. "He gave me the time to ask questions, vent, and decompress. I remembered how much better I felt after talking through the event with a colleague," Nerovich says.

As chair of the hospital's bereavement and wellness committee, Nerovich was determined to find ways to support clinical teams after traumatic events.

"I knew the staff was desperate for support surrounding these types of events," Nerovich says.

Ethicists did offer debriefings to staff after difficult cases. However, the debriefings usually happened days or weeks after the event and were poorly attended. Nerovich, an attending physician, a PICU chaplain, and a nurse manager, developed a Rapid Review of Resuscitation debriefing process with a one-page guide.[1]

The process is simple: Ethicists review the event and the team dynamics, acknowledge the emotional impact of the case, and take a moment of reverence in cases where the patient died. "Many people were willing and open to these debriefings, which gained momentum throughout the hospital," Nerovich shares.

Other clinical areas heard about the debriefings and asked to be included. The committee members

trained those units on how to lead the debriefings and made the tool available hospitalwide. "The culture shifted from 'Suck it up and move on' or 'Just learn how to deal with it or find another department' to finding ways to best support one another," Nerovich says.

Nerovich and colleagues surveyed 222 ICU staff before and after the new debriefing process was implemented. Compassion satisfaction scores were significantly higher one year later. Most (74%) staff found the debriefing "somewhat" or "very" helpful.

In the emotionally charged, fast-paced ICU, clinicians are faced with death and dying daily.

"Staff will regularly face ethical dilemmas and challenges," Nerovich says. "Having open, honest communication about these situations will help build a moral and ethical community." ■

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ICU Staff Report Severe Moral Distress, But Resources Are Underused

There is growing awareness of the prevalence of moral distress in healthcare — and the costs in terms of burnout and staff turnover. However, solutions to this problem remain somewhat elusive. "Moral distress is probably not preventable," acknowledges **Lucia Wocial**, PhD, FAAN, RN, HEC-C, senior clinical ethicist at the John J. Lynch, MD, Center for Ethics at MedStar Washington Hospital Center in Washington, DC.

Healthcare workers continue to face staffing shortages and lack of resources that make their jobs harder. "Doctors and nurses have moral distress when they don't have the resources they need to be at their best," Wocial notes.

Electronic health record administration also is contributing to moral distress and burnout.[1,2] "Anyone who has seen a doctor recently or been in a hospital has probably noticed that the computer is a constant presence. In some ways, it's become a barrier to building therapeutic relationships," Wocial observes.

Missed opportunities for advance care planning before patients face serious illness is another factor. "It is more than talking with patients about their values and goals. It is about setting realistic expectations for what is possible," Wocial explains.

Typically, healthcare providers do not communicate the limits of medicine. This can result in patients or families believing clinicians gave false hope. Simultaneously, the care team is distressed by families demanding inappropriate treatment. "Thus, the whole therapeutic partnership is endangered," says **Matthew Eddleman**, MDiv, BCC, a chaplain at Norton Healthcare in Louisville, KY.

Eddleman and colleagues set out to determine the severity and contributing factors of moral distress in staff in a 36-bed ICU over eight weeks in 2021.[3] Many staff members reported experiencing at least a moderate level of moral distress at any given time.

Researchers also asked ICU staff about resources to help with moral distress. The institution offered an emotional support hotline, virtual well-being seminars, access to chaplains, and employee resource groups. "The data clearly showed that the resources being offered were not being utilized," Wocial says.

Chaplains were an exception, with 17.8% of staff using spiritual care to cope with moral distress. "Chaplains have long been present on the unit; have built relationships with many bedside staff; and were a familiar, readily available resource," Eddleman explains.

Eddleman encourages chaplains to gain expertise in speaking to the ethical principles involved in morally distressing cases. Chaplains can do this by collaborating with ethicists, or by serving on ethics committees. "Doing so enables the chaplain to see the process of working through ethics cases, and hearing different perspectives, as well as adding their unique voice to the deliberations," Eddleman offers.

This allows chaplains to speak empathetically to nursing staff, either one on one or in groups. Chaplains can examine a challenging clinical case from an ethical perspective. "Nurses can then go home at night knowing that although they provided care in a difficult situation, they did so with integrity. In a time when staff shortages abound, this is essential in retaining a healthy workforce," Eddleman says.

Survey respondents indicated communication issues often were root causes of moral distress. Yet, the hospital-provided responses

were designed to help staff cope with moral distress, not address the communication barriers that were causing the moral distress.

"The message from leadership to staff, then, seems to be that moral distress is an unfortunate byproduct of the job, something to cope with but nothing that can be constructively addressed," Eddleman says.

Clinical ethicists can help counter this message by becoming involved in cases earlier. For example, the care providers can alert ethicists if a patient may soon experience a clinical decline and subsequent loss of autonomy. The ethicists can meet with the patient to identify a healthcare surrogate, and facilitate a meeting between the patient and care group. "This ensures that the patient's medical preferences are communicated, and that the plan of care is congruent with their wishes," Eddleman explains.

If ethicists are familiar faces in clinical areas, staff are more likely to ask for help with moral distress, according to **Robin S. Cook**, RN, MBA, former preventive ethics advisor at Veterans Health Administration. For example, an ethicist who spends a lot of time in surgical areas or the ICU can offer support for difficult patient care issues specific to those units.

"Unresolved ethical concerns not only cause individual moral distress, but can also change the staff relationships and clinical cohesiveness," Cook warns. ■

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Ethical Guidance for Research on Dying or Recently Deceased ICU Patients

A group of Canadian healthcare providers, scientists, ethicists, and legal scholars recently produced updated clinical practice guidelines for death determination.[1] "During the process of guideline development, several systematic reviews were conducted to inform recommendation generation," says **Nicholas Murphy**, PhD, one of the authors and a postdoctoral fellow in the departments of philosophy and medicine at Western University in London, Ontario, Canada.

Murphy and colleagues identified important knowledge gaps pertaining to the sensitivity and specificity of testing techniques for neurological determination of death, along with the characteristics of autoresuscitation and prediction of time to death in neonates and children.[2]

"These need to be addressed to buttress the science of death determination," Murphy recommends.

Studies with imminently dying and/or recently deceased study populations in the ICU are needed to answer these questions. Vulnerability of study participants is a central ethical concern. Researchers also are ethically obligated to support the families of dying or recently deceased patients.[3] "Studies of this kind will become more common as science and practice advances," Murphy predicts.

Currently, there are no authoritative international ethical guidelines governing research on dying or recently deceased individuals. Murphy and colleagues sought to start a conversation about challenges and potential solutions. They developed a preliminary framework for the ethical conduct of research with imminently dying patients.[4] "Further work is required to address the ethical challenges of whole-body research with the recently deceased," Murphy notes. Murphy and colleagues examined whether nontherapeutic research with imminently dying patients in the ICU is ethically permissible — and, if so, under what circumstances? The question arose from the Neurological Physiology after Removal of Therapy (NeuPaRT) study, through which investigators are exploring brain activity during planned withdrawal of life support in the ICU.

"Surprisingly, little is known about what happens in the brain when a patient is dying," says **Charles Weijer**, MD, PhD, one of the authors and a bioethicist and professor at Western University.

Advanced neuromonitoring techniques will help researchers observe activity in the patient's brain stem and cortex in the minutes leading up to and following cardiac arrest.[5] "The study would substantially advance our scientific understanding of the dying process," notes Weijer, ethics lead and co-investigator on the NeuPaRT project.

Critical care physicians, ethicists, neurologists, and neuroscientists met to address ethical issues in the NeuPaRT study. Among other suggestions, the group offers these ethical considerations for researchers:

• Although imminently dying patients are vulnerable, they should not be excluded from research (i.e., provided adequate protections are in place). The group concluded an outright prohibition of nontherapeutic research with imminently dying patients would be paternalistic. Patients and their next of kin have the right to consent to donating their organs. "They ought to be offered opportunities to benefit others through participation in valuable scientific studies," Weijer says.

However, since imminently dying patients are vulnerable, additional protections must be in place for research to proceed ethically.

• Researchers and attending staff should not assume the option of study participation would be unwelcome to patients, families, or surrogate decision-makers. Some family members find meaning in loss through contribution to science.[6] "Researchers should create space to facilitate 'meaning-making' — for example, by sharing study results with families when published," Murphy advises.

• Research "bystander" interests should be considered. A research bystander is someone who is not a study participant, but who is nonetheless directly affected by research activities. "In this context, the interests of family members, close friends, and significant others of imminently dying or recently deceased patients need to be taken into account," Murphy explains.

The patient is the subject of the scientific study, but it is the family who will live with the effects of the study on the patient's last moments. Steps should be taken to mitigate any potential negative fallout from study activities. "Study interventions can be made less obtrusive in a few ways," Weijer says.

The family can be allowed to remain in the room with the patient throughout the research process, including during the set up of monitoring equipment. Monitoring can be conducted remotely, with data recorded and analyzed after the fact. This allows researchers to leave the room to give the family privacy. Monitors in the room can be set to "comfort mode," with displays and alarms turned off.

"The family should be allowed to interact with the patient as they wish, even if this may interfere with the collection of certain data," Murphy adds.

Because research offers no prospect of direct benefit to subjects, research participation must pose no more than minimal risk to the patient. In the NeuPaRT study, researchers use four neuromonitoring techniques. "To minimize risk to patients, however, we decided that no patient would undergo more than two of the neuromonitoring procedures," Weijer reports.

• Acknowledge the benefits of research participation to the patient and family. Participation in research gives the patient and family "an opportunity to make the patient's death more meaningful, by contributing to scientific knowledge and the betterment of future patients," Weijer offers. ■

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For Clinicians, Discharge Safety Is a Growing Ethical Concern

More often, clinicians are asking ethicists questions such as, "Is this discharge plan ethical?" It seems clinicians are distressed over what they consider to be unsafe discharges.

"As ethicists, we talk to clinicians about how we need to keep in mind the social realities of where our patients are coming from," reports **Elizabeth Sivertsen**, MBE, CCRN, HEC-C, a medical ethicist at Grady Health System, an Atlanta-based safety net health system.

Clinicians create a treatment plan based on what they believe is in the patient's best interest. For various reasons, sometimes the plan is just not feasible.

"That can be very hard for our medical staff," Sivertsen says.

A recent ethics consult involved a homeless woman with a history of HIV infection and schizophrenia. The woman reported trauma over a previous restraining episode. Clinicians believed strongly that inpatient placement was the only way to keep the patient safe and off the streets, but the patient strongly rejected this plan. "We had to consider the socioeconomic factors, and the social determinants of health, that led her to this point," Sivertsen says.

In cases like this, ethicists help the clinical staff find an ethically acceptable alternative to which the patient will agree. "As ethicists, we coach medical staff to be a little more humble, sometimes, in what we can achieve for our patients," Sivertsen explains.

For instance, some patients with mild dementia insist on returning home, yet the environment is unsafe and there is no family support. Ethicists strive to respect a patient's autonomy while concurrently protecting the patient from harm. "It might take some creative thinking to support the patient's independence as long as possible, in a less-than-ideal setting," Sivertsen notes.

A patient may lack capacity for complex decision-making, but still can express a preference more generally on how they want to live their life. Clinicians worry that discharging the patient home is allowing him or her to assume a risk they do not understand fully. "The ethical answer isn't always to override the patient and put them in the safest place possible. Yes, there are risks of harm, but we have to balance that out with other concerns," Sivertsen explains.

Ethicists must weigh the potential risk for harm against taking away a patient's independence and autonomy. "Sometimes, unfortunately, the families aren't in the picture. We may have to consider taking away patient's control of their lives and looking to appoint a guardian," Sivertsen says.

Ethicists have become familiar with the community resources that can mitigate risks of unsafe discharges. In some cases, clinicians can give the patient a chance to remain independent, but with home health support. In some cases, home health support is not an option because the patient is unhoused, and adamantly refuses placement. Understandably, clinicians are distressed about discharging these patients from the hospital to live on the streets. "Ethicists explain that it could be ethically acceptable, but we need to mitigate the risks as much as possible by providing supportive care," Sivertsen stresses.

Depending on the situation, that could take the form of street medical teams, mobile health providers, or behavioral health support for patients living with long-standing mental health issues requiring psychiatric follow-up. Clinicians are ethically obligated to prevent harm and to promote good.

"But in an acute care setting, we cannot solve society's ills. Try as we might, we can only do so much," Sivertsen laments.

Sometimes, just hearing that reassurance from ethicists helps providers feel less distressed about the situation. "As ethicists, we often deal with uncertainty in end-of-life cases," Sivertsen notes. "Here, it's just a different type of uncertainty." ■

Ethical Discharge Planning for Victims of Violence

For most patients, discharge readiness hinges on objective data — vital signs or test results. For patients who are victims of violence, clinicians also must consider more subjective factors, such as safety.

"We don't always identify this as an ethical question. Instead, we talk about a 'difficult disposition,'" says **Allan Peetz**, MD, MPH, FACS, a practicing trauma surgeon and assistant professor of surgery in the division of acute care surgery at Vanderbilt University Medical Center.

Some patients still want to be discharged, even knowing they are at risk for additional violence. "We have to adapt, and consider that, and do the best we can with the resources we have," says Peetz, faculty in Vanderbilt's Center for Biomedical Ethics and Society.

Peetz saw clinicians struggle with these cases. Although the facts of individual cases differed, the common ground was patients did not necessarily meet medical criteria for admission, but everyone involved in the case agreed it was unsafe for the person to go home. Sometimes, clinicians advocated for "social admission" to buy some time to hopefully devise a safer discharge plan. "It's often unclear what the 'right' thing to do is. The social context can sometimes play a part in the decision to admit the patient," Peetz admits. Peetz and colleagues decided to explore this subject from an ethical perspective.[1] "In trauma and acute care surgery, moral decision-making is unique. The way we go about answering ethical questions is different, due to the clinical constraints," Peetz explains.

Researchers surveyed 60 emergency physicians (EPs) and 20 trauma surgeons. Participants were given hypothetical cases of patients who sustained minor injuries from intimate partner violence, gun violence, and elder abuse. The patients in the scenarios did not require medical admission, but did not feel safe leaving the hospital. Trauma surgeons and EPs differed somewhat in their ethical perspectives and practices:

- Trauma surgeons were more likely than EPs to offer patients "social admission" for the sole purpose of buying more time to create a safe discharge plan, and less likely than EPs to view social admission as inappropriate resource use;
- In cases of intimate partner violence, EPs were more likely than trauma surgeons to support patient autonomy with a potentially unsafe discharge plan;
- EPs were more likely than trauma surgeons to believe that in cases of elder abuse, admission could facilitate change in the victim's social situation;
- Trauma surgeons were less likely than EPs to support patient autonomy after gun-related violence with a potentially unsafe discharge plan.

"Emergency medicine providers evaluated the challenges somewhat differently than trauma surgeons," Peetz observes. "But we all feel the obligation to try to use the medical institution to benefit patients who are victims of violence."

Decision-making in such cases always is going to be somewhat subjective. Physicians must rely on clinical judgment, along with available resources and information. "We can't do a blood test to find out if it's safe for someone to go home," Peetz notes. "What's important is that the decision is made using an ethical framework." ■

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Viewing Social Media Posts About Ongoing Care Could Harm Patient-Physician Relationship

Some parents post detailed accounts of their child's medical situation on social media. Clinicians might question whether it is ethical to view those posts as a member of the healthcare team.

"Neither hospital policies nor large pediatric organization policies offer clear recommendations for this scenario," says **Imogen Clover-Brown**, MD, a pediatrics resident at Cincinnati Children's.

Recently, a resident physician was caring for a child whose parent posted about their life at home managing many hospitalizations and complex medical needs. The resident heard about the parent's account from other members of the healthcare team who had known the family for a long time and was considering viewing the parent's posts.

"As a millennial physician, I noticed myself and my other younger

colleagues had different opinions of the topic than colleagues from older generations," Clover-Brown observes.

Clover-Brown and colleagues explored this situation in the hopes of providing guidance.[1] The authors agreed that, ideally, providers should discuss concerns with patients or family directly, instead of viewing social media posts surreptitiously. "Healthcare providers should consider their motivations before seeking out social media content shared by patients or families, even if that content is publicly available," Clover-Brown advises.

Clinicians might be motivated to understand the patient's home life better, to see how the healthcare team is portrayed, or just simple curiosity. Regardless, the clinician's goals in viewing the content likely can be better achieved by speaking directly with the patient or family, according to Clover-Brown. "Consuming this content may damage provider-patient relationships by reinforcing biases or degrading trust," warns Clover-Brown.

For instance, if the provider does not like "influencers" or "mommy bloggers," viewing the content could make the clinician think negatively about the family. Worse, the clinician might believe the content misrepresents the care that was provided or misrepresents conversations with the medical team. "That could damage the therapeutic relationship," Clover-Brown says.

By bringing concerns to the family directly, the clinician gives the family the chance to provide context to the posts.

"Professional organizations and medical institutions should establish new social media guidelines that reflect the current and evolving nature of social media, which is more complex than simple two-way 'friendships,'" Clover-Brown suggests. Providers also must set their own boundaries regarding this situation and how to respond ethically. "Public content can arise unsolicited via algorithms," Clover-Brown notes. "Providers should be proactive and make a plan before they see this content pop up in their feed." ■

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Was Resident Involved in Surgery? Some Patients Are Not Informed

Is a resident going to perform most of a surgical procedure? If so, many patients probably would expect to learn this fact before the procedure. However, many urologists do not disclose it, according to a group of researchers.[1]

Investigators surveyed 49 urology residency program directors in 2021 about informed consent processes. About half reported their hospitals do not explicitly discuss trainee involvement in surgery. Most (87.8%) do not explicitly discuss when a resident is going to perform most of the procedure.

About three-fourths of respondents reported a patient declined to allow the trainee to participate in the surgery after the trainee's role was explained. Confusion over the role of residents is a contributing factor, says **Juliana Kim**, the study's lead author and a medical student at Rutgers Robert Wood Johnson Medical School. For example, some patients assume the terms "resident" or "trainee" mean the individual lacks an MD.

"Further efforts are required to improve communication and education regarding resident involvement in surgery, and address patient concerns and preferences more effectively to protect the physician-patient relationship," Kim says.

Who is ethically obligated to explain the resident's involvement? "The lead surgeon or the resident should explain the resident's role in the procedure," according to **Robert S. Olick**, JD, PhD, associate professor emeritus of bioethics and humanities at SUNY Upstate Medical University in Syracuse, NY.

Medical students often are told they should inform the patient about their role and seek express consent for their participation. "But, ultimately, it is the responsibility of the lead surgeon to have this conversation with the patient and family," Olick asserts.

When choosing a surgeon, patients often want to know about the surgeon's experience and outcomes. Surgeons are ethically obligated to volunteer this information, or at least ask if patients would like it, according to Olick. "This ethical responsibility extends to residents and medical students who will be involved in the patient's care," he adds.

Surgical training is necessary for residents to become good surgeons; that benefits future patients. "Some may argue that the greater good of having well-trained, competent

surgeons to serve the greater community of patients outweighs the interests of any particular patient," Olick offers.

Often, patients consent to the resident's role. "Willingness to consent varies with the nature of the procedure, its risks, and the resident's role," Olick says.

For example, most patients would be more apprehensive about heart surgery than intubation, and are less concerned about suturing. "Concerns about consent to the resident's role may be exaggerated, especially when the attending surgeon is present and supervising the procedure," Olick suggests.

As a pediatric surgeon, **Catherine Hunter**, MD, FACS, FAAP, has been conflicted between a professional obligation to provide residents with a strong educational experience and an ethical duty to provide the safest, best care to patients. Hunter and colleagues surveyed 51 attending surgeons and 55 residents about ethical principles that guide surgical training.[2]

"It is helpful for residents to understand the ethical considerations that are at play for an attending surgeon," says Hunter, division chief of pediatric surgery at the University of Oklahoma College of Medicine.

Residents were more likely to be involved in less complex cases and cases with perceived lower error margins. Surgeons used intraoperative supervision to mitigate the risk of resident participation and to uphold the principles of beneficence and nonmaleficence. "The attending surgeon must maintain a balance between providing the best, transparent surgical care to patients — while still allowing residents to participate in a broad range of cases on a wide spectrum of patients," Hunter says.

Respondents indicated they used transparent consent practices to uphold the ethical principle of patient autonomy. This gives patients a fuller understanding of the role residents play in their care. "Many cases are quite complex and require an additional set of hands or eyes," Hunter says.

The consent discussion should specify who will be participating in the surgical case, and who will be involved in the postoperative care. "Although a resident may be inexperienced with a procedure, they are still highly educated and skilled individuals who provide real benefits to procedures and patient care when supervised appropriately," Hunter says. ■

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Community Members Help Train Research Staff

Research staff tasked with obtaining informed consent from study participants often are inadequately trained to do so. "Untrained research coordinators will, in essence, read the consent forms. Informed consent is a whole process that involves conversation, not just documents," asserts **Robert Sege**, MD, PhD, director of the Center for Community-Engaged Medicine at Tufts Medical Center in Boston.

This raises some ethical concerns on whether study participants actually are giving true informed consent. Typically, research staff do not receive standardized training on how to engage in informed consent discussions. "The training they do have to go through is about the ethical principles of clinical research, the history of the rules of informed consent, and what the rules are, which is important and foundational," Sege says. "But what they are not trained in is how to have the discussion."

At Tufts Clinical and Translational Science Institute (CTSI), research staff gain this expertise with a novel approach: Community members act as simulated prospective study participants in role-playing exercises.[1] Tufts CTSI's Stakeholder Expert Panel is a group of more than 40 community members, researchers, patients and families, and healthcare providers. The group advises researchers, provides feedback, and helps develop training.

Some panel members had acted as simulated patients to train medical students and residents to take patients' medical histories. "It has become an important way for us to observe some of the soft skills involved in medical care," Sege says.

The panel members suggested study investigators use the same method to train research staff on informed consent. Some panelists enthusiastically volunteered to serve as simulated prospective study participants. "We are not looking for people who are skeptical about research. We are looking for people who think it is important," Sege explains.

The community members expressed strong opinions on how

informed consent is handled, based on their own experiences. Some recalled research staff rushing them through the process. Others could not explain the purpose of the study, or provided inaccurate, incomplete information on risks. "They take their own lived experience of having been a research participant and use that to help train the research coordinators in the skills that they need," Sege explains.

The research staff appreciated the chance to practice informed consent skills. One participant stated, "My simulated patient really challenged me and made me think a lot about how I introduce myself and approach a consent conversation."

Research staff practiced how to determine if a person with limited English language ability needs an interpreter. Many people know enough English to get along in everyday life, but not good enough to make an informed decision on participating in a clinical trial. Research staff also gained practice in using the teach-back method, asking the participant to explain in their own words what they think the study is about.

Both the learners and the simulated study participants had some fun with the process. "We asked the community members to adopt different attitudes, to see how the research staff would handle it," Sege recalls.

Community members were asked to act skeptical about the study, act as though they were in a rush, or to decide against participation. Research staff were observed to see how they responded to these challenges.

The community members also are involved with improving the informed consent process on the IRB side. The IRB includes panel members with diverse backgrounds, including a social worker, a history professor, a pastor in a local church whose first language is not English, and a person who spent most of his life unhoused. "We don't need to simulate people with different backgrounds, because we have people with different backgrounds," Sege says.

One panelist is part of an IRB committee that is reviewing informed consent forms and evaluating what a reasonable person should be expected to understand about a study. The panelists' involvement opens another level of expertise from which IRBs can draw. "These are trained community members who believe in research, but who are also really aware of the flaws in the process," Sege observes.

Researchers are striving to enroll diverse study participants, but face challenges. "One of the main reasons trials fail is lack of enrollment, or lack of diverse enrollment," Sege says.

If people believe staff are not truly engaging, then they are less likely to participate in clinical trials. "That's particularly true for people with less previous experience with research, or who have faced discrimination in their lives," Sege notes.

The community members' involvement with informed consent processes has made research, overall, more ethical. "Research fundamentally depends on a collaboration between investigators and people going into trials," Sege concludes. ■

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Real-Life Experience Allows Researchers to Obtain Ethical Consent

Research staff may have secured a signed consent form from a study participant, but did they obtain that consent ethically? "True informed consent is something so paramount in research decision-making that it should never be taken for granted," emphasizes **Brandon Brown**, MPH, PhD, a health services researcher and professor in the department of social medicine, population, and public health at the University of California, Riverside, School of Medicine.

People considering whether to join a clinical trial may not fully understand the procedures involved, risks and benefits, confidentiality issues, or even that participation is voluntary, depending on how the research is presented. "In short, participants may not know what they are getting into," Brown says.

Research staff likely have completed courses on ethical conduct of research. "That alone may not be enough," Brown warns. "There is a difference between reading about the elements of informed consent and obtaining it in the real world."

Some research staff have worked on the clinical side of informed consent. However, there is a difference between obtaining consent for clinical treatment, and obtaining consent for study participation. "Approaching someone to participate in research the same way as one would address a typical treatment situation can be problematic,"

according to **Currien MacDonald**, MD, CIP, WCG medical chair director.

On the clinical side, patients are requesting to be treated, and healthcare providers are ethically obligated to provide treatment in accordance with the care standard. "Research consent, while similar, is fundamentally different," MacDonald says.

For example, in clinical care, the central question is, "Do you want this treatment, that treatment, or none?" For research, the central question is, "Do you want to forgo an individual, customized care plan to contribute to general knowledge?"

"Especially when the research care will be their clinical care, both healthcare provider and participant need to understand that difference, and how that changes the relationship between healthcare provider and patient," MacDonald stresses.

Physicians might obtain consent from a patient by informing him or her what will (or could) happen during treatment. In contrast, research staff are asking for the patient's choice after giving information about the study. Clinicians might practice shared decision-making and ask for the patient's choice. Even so, says MacDonald, the consent conversation in the clinical context — where the patient gives input on the treatment they want based on the acceptable options outlined by the healthcare provider — is different from the research consent conversation, where the patient is making the decision about whether to participate in the study.

With clinical care, the healthcare provider is focused solely on treating the patient. "For research, the healthcare provider gains a second focus — the research," MacDonald says.

Deviating from a treatment plan based on a person's situation is normal. "In research, needing to follow the plan makes every step a decision of continuing that care plan or abandoning it," MacDonald notes.

Some research staff assume that just reading and signing the form equates to informed consent. "Providing information with the goal of achieving understanding, which is the purpose of informed consent, can easily be lost among the physical processes of reading and signing," MacDonald observes.

Investigators must be confident in each study staff member's ability to assess capacity to consent, says **Meghan K. Mattos**, PhD, RN, CNL, assistant professor at the University of Virginia School of Nursing. Some researchers conduct mock informed consent sessions for staff who assess capacity to consent. Experienced investigators can role-play the potential patient, allowing new staff to practice obtaining informed consent. "We require a minimum of three practice sessions without concerns," Mattos says.

Investigators attend at least one "live" informed consent session with each member of the study staff. "This also allows for observation of potential barriers to challenges related to the study," Mattos says.

For example, investigators might notice issues with location, consent process, or other concerns voiced by participants. Further, these sessions allow staff to identify and correct mistakes they might make while delivering the consent details (e.g., remembering to ask a comprehension question, remembering to put a signature in the right location). "Study investigators should require documentation of the informed

consent process for study records," Mattos asserts.

This provides an opportunity for other researchers to review procedures and to assess adherence to the protocol. "IRBs should require study protocol acknowledgement of study population-specific factors that may limit capacity to consent," Mattos adds. For example, emergency department patients likely are to be in acute distress that requires time-sensitive management or snap treatment decisions. Mattos believes IRBs also should require formal documentation of how investigators determine decision-making capacity for older adults during the consent process. Researchers can do this by asking a few questions that cannot be answered with just "yes" or "no." For instance, researchers might ask, "Can you tell me the overall purpose of this study?" or "Can you tell me the risks and benefits of participating in this study?"

"If, at any time, there are concerns that the questions were not answered correctly or there were other concerns noted by staff, those concerns should be documented and available for study investigator and IRB review," Mattos adds. ■

For Some Ethics Programs, 'Tele-ethics' Is Routine

Telehealth initiatives for clinical areas have been expanded to clinical ethics consultations in some healthcare settings. Investigators recently analyzed two virtual clinical ethics consultation services.[1]

The authors studied the Johns Hopkins Hospital's Ethics Committee and Consultation Service and a Malaysian ethics consultation service. Both platforms improved the ability of local practitioners to obtain ethics consults who otherwise would be unable to. Both allowed ethics consultants to share expertise and collaborate.

"We also found similar challenges to implementation of virtual clinical ethics consultation across these two very different clinical settings," reports **Eman Mubarak**, BS, the study's lead author and a former predoctoral clinical ethics fellow at the University of Michigan Center for Bioethics and Social Sciences in Medicine.

Both programs resulted in less personalized communication between patients and providers. There also were some technical issues, along with logistical and operational concerns.

Mubarak and colleagues would like to see their findings used to expand accessibility to virtual clinical ethics consultation across patient populations and health systems around the globe. "Sustainable development of virtual consultation platforms, funding, training of ethics consultants, and visibility of virtual clinical ethics consultation are priorities," Mubarak says.

Some ethicists gained experience with remote ethics consults before the COVID-19 pandemic. **Barrie J. Huberman**, PhD, HEC-C, tried tele-ethics for the first time in 2016. The facilities at the health system where Huberman was employed were far apart geographically.

This prevented ethicists from timely handling cases. The experience demonstrated remote ethics consults could be effective.

"It's possible to use tele-ethics really well, even in highly complex cases," says Huberman, now clinical director of medical ethics at Weill Cornell Medicine in New York City.

Huberman was considering integrating tele-ethics into the consultation process at Weill Cornell when the pandemic accelerated the use of remote consults.

"The objective was — and still is — to preserve the consult process at a very high level, including patient visits [and] team and family conversations," Huberman reports.

Weill Cornell's ethicists learned high-quality ethics consultations and meaningful encounters can be conducted remotely. The ethicists now use a hybrid approach — face-to-face communication combined with remote meetings when it makes sense. Ethicists usually see patients in person, but team meetings and other deliberations are mostly remote.

Multidisciplinary teams and clinical ethicists discuss their encounters with patients and families, and deliberate the issues together in the same thoughtful manner, regardless of whether they are together physically.

"This mixed model is ideal, even in the most complex cases," Huberman offers. "There is no question there's an efficiency to it, but we don't sacrifice process or quality for it."

Remote meetings allow the ethics service to handle more volume and pull in individuals as needed, such as hospital attorneys, interpreters, or family members who live far away. "The culture in our organization is that ethics has a convening power to bring people together for discussions about cases," Huberman explains.

Those meetings usually are remote, cutting down on time demands for overworked clinicians. For example, an ICU nurse might be reluctant to leave the unit to go sit in a room for an hour, but the nurse

could be willing to participate in a remote consult for a short time.

Many meetings of all types in hospitals have remained remote. Thus, remote clinical ethics work reflects the way other clinical areas are operating. Remote meetings enable stakeholders to meet unmasked, to see each other in a way that is not always possible in the hospital.

"We've all learned to respect each other's time, by moving quickly through a meeting together in an electronic space, yet making it very high-touch," Huberman reports.

Ethicists take a cue from stakeholders on whether meetings happen in person or remotely. Many families greatly appreciate the opportunity to participate in remote meetings because they cannot take off from work or struggle to travel to the hospital. If a family member prefers to meet in person, then such a meeting will be arranged.

Sometimes, other factors make it apparent that an in-person meeting is needed. For example, if a patient is cognitively impaired, it might be possible to engage with the patient remotely, but might be ideal to visit the patient at bedside to ensure the person is heard and understood. Generally, Huberman says the remote consults are just as effective as in-person consults.

"At the end of the day, it's about creating instant intimacy, respectful listening, and communication," Huberman says. "That's what it's always been about, whether you are sitting together in a room or not." ■

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CME/CE INSTRUCTIONS

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Upon completion of this educational activity, participants should be able to:

- Discuss new developments in clinical ethics and research regulation and their implications in healthcare systems for patient care, healthcare delivery, and research.
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- Review and apply principles of human subject protection in clinical trial programs, including compliance with mandated regulatory safeguards and educational requirements for human subject research.

CME/CE QUESTIONS

1. **Which did a survey of ethicists reveal regarding the HEC-C credential?**

   a. Hospitals are posting fewer job listings for healthcare ethics consultants.
   b. About half of ethicists' employers paid part or all of the HEC-C fees.
   c. Almost all the ethicists obtained the credential specifically to receive a salary increase.
   d. The Joint Commission requires hospitals to give ethicists time off to take the HEC-C exam.

2. **Which resource did ICU staff use to alleviate moral distress at Ann & Robert H. Lurie Children's Hospital of Chicago?**

   a. An emotional support hotline
   b. Virtual well-being seminars
   c. Access to chaplains
   d. Employee resource groups

3. **Which did researchers find regarding urologists and informed consent discussions?**

   a. About half of program directors said their hospitals do not specifically discuss trainee involvement in surgery.
   b. Program directors are not ethically required to disclose when a resident is going to assist in surgery, since patients should know that.
   c. Program directors believe hospital policies were too stringent on whether surgeons should specifically disclose roles and responsibilities of residents to patients.
   d. About three-quarters of program directors reported no patients declined to allow the

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trainee to participate in the surgery after the trainee's role was explained.

4. **Which is recommended regarding clinicians' concern over unsafe discharges?**

   a. Even with supportive care, it is not ethically acceptable to discharge unhoused patients who refuse placement.
   b. Socioeconomic factors should not play any part in discharge planning.
   c. It is not ethically acceptable to discharge patients with mild dementia to home settings without family support.
   d. Ethicists must weigh the potential risk for harm against taking away a patient's independence and autonomy.

5. **Which approach do ethicists at Weill Cornell use for remote consults?**

   a. In-person consults are conducted if individuals such as interpreters or attorneys are involved.
   b. In-person meetings allow the ethics service to handle more volume so remote consults are limited to cases where the family requests it.
   c. Ethicists usually see patients in person, but team meetings and other deliberations are mostly remote.
   d. Whether meetings are conducted in person depends on the complexity of the case.

6. **Which do experts recommend regarding ethics of research on dying or recently deceased ICU patients?**

   a. Researchers are not ethically obligated to support the families of dying or recently deceased patients.
   b. Imminently dying patients are too vulnerable to participate in nontherapeutic research, even with adequate protections in place.
   c. Researchers should operate under the assumption that study participation would be unwelcome to families, since most strongly object to participation.
   d. Because research offers no prospect of direct benefit to participants, research participation must pose no more than minimal risk to the patient.

7. **Which is recommended for clinical trials involving dying patients in ICUs?**

   a. Ask the family to leave the room during the set-up of monitoring equipment.
   b. Monitor in real time with researchers in the room to improve data analysis.
   c. Set monitors in the room to "comfort mode," with displays and alarms turned off.
   d. Inform families in advance that the collection of data likely will interfere with the family's ability to interact with the patient.