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RELIAS
MEDIA

Program Directors Want More Ethics Education, Limited Resources Constrain Goals

A recent study revealed 96% of plastic surgery residency program directors think ethics training in residency is important. Further, 73% said they want more resources to provide it.¹

It came as no surprise to investigators that program directors believe ethics training is important and want to dedicate more time to it.

“But resources and expertise for training are more limited, so needs don’t actually match up with goals,” says **Brian C. Drolet**, MD, one of the study’s authors and an assistant professor in the department of plastic surgery at the Vanderbilt Center for Biomedical Ethics and Society. Other key findings:

- Most plastic surgery programs offer some form of ethics curriculum, with

a mean of three hours spent on ethics education annually;

- 80% of the 46 program directors surveyed wanted more ethics in their curricula;

- 70% of those surveyed concurred

that their graduating chief residents were competent to handle ethical dilemmas;

- 86% of respondents said a standardized ethics curriculum would be valuable.

The desire for more ethics training is not unique to plastic surgery. Researchers

also administered

the survey to program directors in anesthesiology, pediatrics, and general surgery, with similar findings.

Ethics expertise “needs to be instilled in the culture of our specialty from day one,” says **Jeffrey E. Janis**, MD, FACS, another of the study’s authors.

“WE DON’T NEED TO WAIT FOR AN EGREGIOUS ETHICAL VIOLATION TO REALIZE WE NEED THIS TYPE OF EDUCATION.”

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The study's findings represent an "opportunity to get out in front of this rather than respond to it," says Janis, a professor of plastic surgery at The Ohio State University Wexner Medical Center in Columbus.

"We don't need to wait for an egregious ethical violation to realize we need this type of education," Janis offers. "It needs to begin early in one's career."

The study established that program directors truly want additional ethics resources. "Up to this point, we guessed that ethics was important. Now, we know it is," Janis notes. "We had to diagnose the problem before we treated it."

The findings support the need for an ethics curriculum at a national level, too. "That's useful for faculty who don't have expertise in ethics," Drolet adds.

Some large institutions well-known for ethics expertise have ample resources to train residents. However, that is not generally true for smaller programs.

"It can be difficult for program directors to teach ethics if they have minimal training in it themselves," Drolet laments.

The researchers are designing a modular curriculum that can be implemented in any training program. No ethics expertise on the part of the faculty is necessary.

"It will be case-based and provide the relevant literature and discussion material to teach ethics to residents," Drolet explains.

This would meet the needs of the surveyed program directors. Many expressed interest in an established curriculum that is specialty-specific (and free).

"You can buy several great clinical ethics textbooks. But my research group is of the mindset that this should be free," Drolet says.

The reasoning is that the subject material is so fundamentally important that it should not come with a cost.

"It just needs to be developed by a credible group of surgeon-ethicists and delivered through a reputable professional society," Drolet suggests.

That ethics currently is part of every resident's training is not a given. "That assumption is probably misguided, not only in our specialty but in every specialty," Janis observes. "We could do better in how we provide formal resources."

Ethics questions are included on both the written and oral exams for the American Board of Plastic Surgery. "If you are going to be tested on ethics, shouldn't you be given the opportunity to be taught about it?" Janis asks.

Time constraints are "a major obstacle" to including ethics education in residency training programs, says **Charity Scott, JD, MSCM**, Catherine C. Henson Professor of Law at Georgia State University. Competing demands pull residents in many directions. "Dedicating time to ethics, especially for theoretical discussions of ethics, can become a low priority," Scott says.

Faculty leaders of residency programs are the key to guarding against this possibility. "Without strong, consistent support from leadership, ethics education can become ad hoc at best, and nonexistent at worst," Scott cautions.

To teach residents the day-to-day relevance of ethics, Scott recommends faculty explore the complexities of real-world ethical dilemmas, using case studies from their own clinical specialties and from their own institutions (when appropriate). Further, classroom discussions could be moderated by

those who are knowledgeable about healthcare ethics, and ethics could be included in regular rounds.

“Residency is a critical time to identify ethical dilemmas in real time, while residents are learning the other dimensions of their professional practice,” Scott underscores.

Of course, time and resources are limited for all surgical specialties. If a program director adds four hours of ethics training, it could mean four fewer hours of training in the surgical specialty.

“There’s so much content to deliver to your residents that you have to be very intentional in adding something else,” Drolet says.

Standardized, shared resources could help in this regard. Ideally, says Janis, “we don’t have to depend just on local resources to teach this subject. We can depend on national resources, which are in a constant state of re-evaluation and improvement.”

Janis and colleagues plan to conduct a follow-up study to reassess the state of ethics education in residency programs.

“Hopefully, it will say we are doing a better job, and the trainees who are graduating will be more prepared to tackle not only their boards, but life as a plastic surgeon,” Janis says.

Ideally, faculty simply would incorporate ethics into other subject areas they are teaching already.

“But while topics relevant to ethics are certainly found within ACGME residency milestones, they may not be well-articulated as such,” says **Jean Cadigan**, PhD, core faculty at the University of North Carolina (UNC) Center for Bioethics.

Instead, faculty try (often unsuccessfully) to find time for stand-alone ethics lectures.

“There is a shortage of resources and support for teaching faculty who

wish to feature practical ethics in their teaching,” Cadigan explains.

There are a few ways UNC Hospitals’ clinical ethics service offers ethics education to residents:

- **Ethicists hold informal discussion sessions for pediatric, pediatric critical care, and adult critical care residents.** Residents choose ethically challenging cases from their own practices. Then, the group analyzes the cases.

“Sessions as short as 30 minutes can help residents successfully identify and address important ethical issues,” says **Arlene M. Davis**, JD, director of the clinical ethics service at UNC Hospitals.

Sometimes, senior physicians are surprised at the cases residents view as ethically problematic. “In their view, the situation presented seems a familiar or everyday occurrence,” Davis says, noting that from the residents’ perspective, it is helpful to discuss even “everyday” cases in this manner.

When evaluating the ethics education discussion sessions, ethicists learned something interesting. “We found that residents’ identification of ethical dilemmas is frequently tied, without their apparent awareness, to their performance of emotional labor,” Davis notes.²

Some cases require residents to express emotions different from what they actually feel. For example, this happens when giving bad news to a family member who is hoping for a miracle.

“Identifying and discussing emotions are not common topics in resident education,” Davis says.

Further, ethics education sessions air bad feelings that can lead to burnout. “Bioethicist moderators can make visible the links between ethical dilemmas and emotional labor,” Davis adds.

- **Ethicists attend rounds on critical care units.** “This helps residents to see how ethics methods can help address ethical dilemmas,” Davis explains.

- **Ethicists address residents’ concerns about legality of practice.** Residents worry about the legal implications of informed consent, proxy decision-making, and withdrawal of interventions.

“We invite hospital counsel to participate in some of the sessions to further examine how both law and ethics contribute to practice,” Davis says.

- **The hospital ethics committee (HEC) offers a resident trainee track.** “This is a fairly new track for our HEC, and we’re very excited by it,” Cadigan reports.

Residents attend HEC meetings and participate in clinical ethics consultations. Some teach ethics to medical students or newly hired nurses.

Others conduct a clinical ethics research project or attend (and possibly present at) the Clinical Ethics Network of North Carolina’s annual conference.

- **Ethicists encourage residents to call an ethics consult when they need one.** “Participating in an ethics consult as a requestor can also be an educational experience,” Davis explains. ■

REFERENCES

1. Patrinely JR, Drolet BC, Perdakis G, Janis J. Ethics education in plastic surgery training programs. *Plast Reconstr Surg* 2019; Jun 17. doi: 10.1097/PRS.0000000000005928. [Epub ahead of print].
2. Waltz M, Cadigan, RJ, Joiner B, et al. Perils of the hidden curriculum: Emotional labor and “bad” pediatric proxies. *J Clin Ethics* 2019;30: 154-162.

Ethics Involved as Proposed Hospital ‘Conscience’ Policies Examined Closer

Hospital leaders need ethical input to determine how to address the controversial “conscience” rule issued by the Department of Health and Human Services (HHS) Office for Civil Rights. At press time, its implementation had been delayed to Nov. 22, 2019, amid legal challenges.^{1,2}

“My sense is that there is some uncertainty. Systems haven’t started to make changes based on the new rule, which is still under challenge and won’t be implemented until this fall, if ever,” says **Matthew Wynia**, MD, MPH, FACP, professor of medicine and director of the University of Colorado Center for Bioethics and Humanities.

The protections afforded to clinicians and organizations under the conscience rule “are, in many ways, just a reiteration and reinforcement of existing rules that have been around for many years,” Wynia notes. The rule lists specific services with which healthcare workers can refuse to help. “It broadens the scope to include, for example, a receptionist saying he won’t schedule an appointment,” Wynia observes. “Hospitals should be thinking about how they might work around this to still provide patient care.”

Kenneth W. Goodman, PhD, FACMI, says, “most hospitals already support conscience rules. They seem to honor clinicians’ legitimate moral qualms.”

Policies can be fairly straightforward in this regard. Some policies simply state that physicians will not be required to do something that conflicts with their beliefs, but are required to find another physician who will. “Cases not about abortion

or contraception can be tricky. Ethics committees should be able to address them,” notes Goodman, director of the University of Miami Institute for Bioethics and Health Policy.

Ethics committees can help by revising hospital policies to “make plain that the mere invocation of a faith-based exemption is likely inadequate to the task and intellectually dishonest,” Goodman offers.

The problem, says Goodman, “is that we are apparently entering the age of religious exemptions for all manner of hard-to-understand positions.” A physician or nurse who invokes scripture in support of a refusal to receive an influenza vaccine “is both faking it — precious few faiths actually say that — and willfully endangering patients,” he argues.

Hospitals have long been reluctant to force any individual to do anything that is contrary to his or her personal religious beliefs. “That makes sense. Most of us, as patients, would want our physicians and other health professionals to be acting with personal integrity,” Wynia says.

But sometimes, there is a direct conflict between what is best for a patient (according to the patient) and what the clinician is willing to do based on personal religious beliefs. In such cases, says Wynia, “the clinician has some additional obligations.”

The patient must be made aware of the limitations on what care the clinician is willing to provide. This communication needs to happen far enough in advance of the clinical need that the patient has a reasonable chance to find someone else to provide the service. “It is clearly

unethical to hide from patients the fact that you are not willing to provide certain services that the patient might want or need,” Wynia says.

In rare cases, the patient needs a service and the clinician has a moral objection to it, but there is no alternative provider available. The clinician needs to set aside his or her personal belief and do what is medically best for the patient, according to Wynia.

“That obligation stems from the core ethical obligation of health professionals to put the needs of the patient over their own needs,” Wynia explains.

Conscience rules are increasingly applied at the level of entire organizations. “This happens a lot because there are lots of religiously affiliated hospitals and health systems,” Wynia explains. “This creates some new ethical dilemmas.”

The central ethical question: What happens when the institution’s “conscience” conflicts with the conscience rights of individual professionals? For instance, a doctor may believe a dilation and curettage is needed to achieve a good medical outcome for a patient. Yet, he or she practices in an organization that forbids performing abortions under any circumstances. “Whose conscience rights should prevail — the hospital’s or the doctor’s?” Wynia asks.

The HHS’ proposed rule seems to suggest that the rights of the organization always should override the rights of the individual health professional in such a case. “But it’s not clear why,” Wynia adds. If it were the other way around (the doctor refused

to participate in an abortion, but the organization allows it), then the provider's rights would take priority, according to the HHS rule.

"In this regard, it seems that the new 'conscience rule' is really just a way to advance a particular moral point of view rather than a serious effort to balance competing rights and responsibilities," Wynia argues.

Ethicists should be particularly attuned to this problematic issue if they work in a healthcare system

that does not provide certain services based on institutional religious beliefs.

For example, some hospitals may not allow doctors to prescribe birth control pills for contraception. In that instance, providers carry a particular ethical responsibility.

"They need to make sure patients are aware of the restrictions with enough advance notice that they can do something about it," Wynia advises. ■

REFERENCES

1. *Federal Register*. Protecting statutory conscience rights in health care; Delegations of authority. Available at: <http://bit.ly/2WKgnpW>. Accessed Sept. 9, 2019.
2. U.S. Department of Health and Human Services. Conscience and Religious Freedom. Conscience rule effective date moved to Nov. 22, 2019. July 3, 2019. Available at: <http://bit.ly/2m0rXwe>. Accessed Sept. 9, 2019.

Overly Aggressive Collection Risks Violating Several Ethical Principles

Hospitals suing low-income patients, garnishing poor people's wages, and asking for money from seriously ill patients have attracted a lot of bad publicity, and even some lawsuits.^{1,2}

"There are so many ethical concerns with aggressive collection practices that it is difficult to narrow them down," says **Thomas D. Harter**, PhD, director of the department of bioethics and humanities at Gundersen Health System in La Crosse, WI. Consider these two problematic issues:

- **Collection practices can fracture trust in the community.** Many hospitals engaged in suing patients are nonprofit hospitals with financial assistance programs in place that presumably could have helped the very people they are suing. "There is also a concern about exploitation and the perpetuation of institutional racism," Harter adds.

Many sued patients have little ability to navigate the complex financial web of healthcare. Some did not even realize they owed money. "Many sought services for mental health problems, such as depression," Harter notes.

Filing lawsuits against vulnerable patients could exacerbate a hospital's already-precarious financial situation. "Members of the community may question the integrity of the health system," Harter cautions. "They may seek other providers to meet their healthcare needs."

- **Aggressive collections clashes with the ethical principle of beneficence and the goals of medicine.**

"We know that socioeconomic factors impact health," Harter says. If a health organization's mission is to care for patients' well-being, this sharply conflicts with lawsuits and garnishing wages. "These activities will negatively financially impact these patients," Harter adds. "It will potentially exacerbate their physical or mental health problems."

To ensure ethical care, Harter says that transparency and shared decision-making is needed across all aspects of patient care interactions. This includes billing and collections. "I have ethical problems with any form of payment collection from patients when it is evident there is a lack of clear communication about what is charged," Harter explains. This is even the case in the ED, where patients

are asked frequently for high-dollar copays. In this care setting, "people are likely at their most physically and mentally vulnerable," Harter observes.

Some ED patients fear they will not be cared for if they do not pay upfront. "Ethicists should continue to think, research, and write about financial issues that occur at the intersection of business and medicine," Harter offers. Additionally, Harter says ethicists must know what practices are occurring within their organizations and know the personnel who make decisions about billing and collection practices. "Reach out to those persons to get a seat at the table," Harter suggests. ■

REFERENCES

1. Thomas WC. The nonprofit hospital that makes millions, owns a collection agency and relentlessly sues the poor. *ProPublica*, June 27, 2019. Available at: <http://bit.ly/2lKaTKT>. Accessed Sept. 10, 2019.
2. Thomas WC. Memphis hospitals suspend debt collection suits, including suits against employees. National Public Radio, July 3, 2019. Available at: <https://n.pr/2m7DvOl>. Accessed Sept. 10, 2019.

Policies Ensure Ethical Care for Marginalized, At-Risk, Unrepresented Patients

Recently, researchers interviewed 25 healthcare, social service, and legal professionals who worked with unrepresented adults — those who lack capacity to make medical decisions and have no identified surrogate. Participants listed prioritizing autonomy, varying safety thresholds, distributing resources fairly, and the moral toll on stakeholders as ethical challenges.¹

Adults who have lost (or perhaps never had) decision-making capacity and do not have either an advance directive or an identifiable, capable, and willing surrogate “are some of the most marginalized and at-risk members of society,” says **Margaret R. McLean**, PhD. “They are, arguably, our most vulnerable patients.”

The decision-making process assumes that patients can make treatment decisions, relying on their own reasoning, values, and choices, says McLean, associate director and director of bioethics at the Markkula Center for Applied Ethics at Santa Clara (CA) University. Failing this, clinicians assume a loving family member or caring friend will step in to make decisions on the person’s behalf.

“But what happens when there is no identifiable surrogate decision-maker, no loving family, no caring friend, no court-appointed guardian?” McLean asks, adding that medical decision-making then

becomes a problem that is “difficult, if not impossible, to solve.”

Clinicians may have little or no knowledge of the person.

“A large number of people and opinions are involved, including the medical team and administrators — but notably, not the patient,” McLean observes.

The economic burden is large if hospital length of stay is prolonged due to the lack of a decision-maker. “Medical decisions for these patients are often matters of life and death,” McLean says.

What is needed, according to McLean, are “ethically informed policies that structure decision-making in a way that is consistent, transparent, workable, timely, deliberative, and in the best interest of the patient.”

Years ago, the Santa Clara County Medical Association’s bioethics committee developed a policy on healthcare decisions for incapacitated patients without surrogates. A version of this policy has since been adopted by 10 hospitals in the region. The policy’s goals are twofold:

- to make and effect healthcare decisions in accordance with a patient’s best interest, taking into consideration the patient’s personal values and wishes to the extent that these are known;
- to establish uniform procedures for medical decision-making for unrepresented patients.

In cases where there is no valid advance directive, valid POLST, or willing and capable surrogate, the policy empowers the ethics committee to act as the decision-maker.

“Acting as the surrogate in this particular instance importantly changes the role of the ethics committee from advisory-only to that of decision-maker,” McLean says.

The ethics committee provides timely decision-making independent of, but informed by, the attending physician and members of the medical team.

“Ethics committees are, by design, multidisciplinary and able to weigh both medical and nonmedical considerations in determining the best interest of a particular patient,” McLean observes, adding the committee approach means the decision rests on many shoulders, not one individual clinician’s.

“It extends the practice of shared decision-making to unrepresented patients,” McLean says.

The policy also allows time and resources for social workers to search diligently for a surrogate decision-maker. Family members have been located in far-flung locations including Canada, Mexico, and India.

“This often results in more information and, at times, a willing and grateful surrogate decision-maker,” McLean says. ■

COMING IN FUTURE MONTHS

- Ethical concerns if opioids prescribed in ED
- Informed consent practices for stem cell therapies
- Debate over HHS “public charge” rule
- Routine screening for illicit drug use

REFERENCE

1. Verma A, Smith AK, Harrison KL, Chodos AH. Ethical challenges in caring for unrepresented adults: A qualitative study of key stakeholders. *J Am Geriatr Soc* 2019;67:1724-1729.

Palliative Care Widely Misunderstood by Patients and Professionals

Palliative care misconceptions appear to be both persistent and widespread. In one study, 60% of adults self-reported as knowledgeable about palliative care have at least one misperception. About one-third of participants equated palliative care with hospice care, and 14.5% believe palliative care requires the discontinuation of other treatments.¹

In another survey of 3,504 adults, researchers found that 70% of respondents had never heard of palliative care. Roughly half of the participants were aware that palliative care and hospice are not the same. Fewer than one-third were aware that giving patients more time is not an explicit goal of palliative care.² A third study revealed 55% of caregivers have never heard of palliative care.³

Jeffrey Peppercorn, MD, MPH, MGH, has researched palliative care awareness among patients with metastatic breast cancer. “The most common reaction to questions about palliative care is that patients don’t know what it is, or report that they’ve never heard the term before,” says Peppercorn, cancer center director of supportive care and survivorship at Massachusetts General Hospital in Boston.

Diane E. Meier, MD, says, “Inequity in access to quality palliative care is one of the biggest ethical lapses in the U.S. healthcare system.” There is considerable evidence that palliative care reliably reduces suffering, improves quality of life, and reduces the need for burdensome, risky, and costly interventions, notes Meier, director of the Center to Advance Palliative Care in New York. “Despite all these published data, palliative care remains

available to only a small percentage of people living with serious illness who could benefit from it,” Meier laments. There are some possible reasons for poor access to palliative care:

- **The public misunderstands what palliative care is and who can benefit from it.** “Most people have never heard of it in the first place,” Meier observes. She says ethicists can convey an accurate definition of palliative care and its benefits and ensure patients and families are offered palliative care concurrent with usual disease treatment.

- **Older clinicians who had no exposure to palliative care during their training are unaware of palliative care as a simultaneous care model.** In this model, Meier explains, palliative care is “an added layer of support, delivered at the same time as all other appropriate disease treatment.”

Professional awareness is improving. New generations of physicians and nurses are training in teaching hospitals with well-established and high-quality palliative care teams. “Younger cohorts of clinicians know about it, understand it, and want it for their patients,” Meier reports.

- **There are structural inequities in the U.S. healthcare system.**

“Where you live matters in terms of access to palliative care, as well as other elements of healthcare,” Meier notes. Lack of insurance, underinsurance, income inequality, racism, and geographic variability all play a part. “This is unethical, since equity means that patients with like needs receive like care,” Meier adds.

- **There are no regulatory or accreditation standards.** Currently,

no regulatory or accrediting entities require palliative care teams to meet specific quality standards as a condition of accreditation or of payment. “The public is unprotected from random variation in access to this crucial aspect of medical care when they are most in need and most vulnerable,” Meier says.

It is well-established that many patients misunderstand palliative care. The same is true of healthcare providers.

“Indeed, healthcare providers may feed into these misconceptions if they do not have a robust construct for how to define palliative care,” says **Craig D. Blinderman**, MD, MA, FAAHPM, director of Columbia University Medical Center’s adult palliative care service.

Despite increasing growth of palliative care programs, there remains confusion on when it should be integrated into care. There also is confusion on the difference between generalist-level palliative care and specialist palliative care.

“I have also found that among my colleagues, it is rare that they truly understand the scope of palliative care and the sorts of conditions we can help manage,” Blinderman reports.

Many referring physicians still believe palliative care should be offered only near the end of life.

“In fact, we can be integrated at any point in a patient’s disease or illness trajectory,” Blinderman offers.

Some providers are unaware of the benefits of palliative care in general. “These include increased survival, improved symptom control, less depression and anxiety, and better support for families,” Blinderman adds.

Late referrals due to poor understanding of the role and scope of palliative care can result in needless suffering and worse outcomes. “This, arguably, is in violation of the principle of beneficence,” Blinderman suggests.

Failing to involve palliative care, or doing so late in the patient’s disease course, can lead to unwanted care. “This violates the principle of nonmaleficence — or at least not providing goal-concordant care,” Blinderman says.

Ethicists can help by ensuring hospital policies include screening seriously ill patients for unmet palliative care needs. For

neurologically impaired or critically ill patients without decision-making capacity, hospitals should allow clinicians to treat pain and other symptoms at the end of life if they believe it is appropriate to do so (without requiring informed consent from surrogates or family members).

Ethics consult volume has decreased as palliative care has increased, Blinderman notes: “This suggests that palliative care teams may mitigate conflicts between patients, families, and providers at the end of life.” ■

REFERENCES

1. Cheng BT, Wangmo T, Hauser

JM. Patterns of palliative care beliefs among adults in the United States: Analysis of a national cancer database. *J Pain Symptom Manage* 2019; Aug 10. pii: S0885-3924(19)30447-6. doi: 10.1016/j.jpainsymman.2019.07.030. [Epub ahead of print].

2. Taber JM, Ellis EM, Reblin M, et al. Knowledge of and beliefs about palliative care in a nationally-representative U.S. sample. *PLoS One* 2019;14:e0219074.
3. Dionne-Odom JN, Ornstein KA, Kent EE. What do family caregivers know about palliative care? Results from a national survey. *Palliat Support Care* 2019:1-7.

Survey: More Difficult for Oncologists to Predict Minority Parents’ Decision-Making

Oncologists struggle to predict decisional preferences for minority parents more than they do for white parents, according to the authors of a recent survey of 365 parents of children with cancer and their oncologists.¹

“This study was motivated by a desire to better understand the decision-making experiences of racial and ethnic minority parents in pediatric oncology,” says **Jennifer W. Mack**, MD, MPH, one of the study’s authors.

Previously, researchers had found that minority parents were more likely to regret treatment decisions for their children.²

“We were especially interested in whether the experiences they reported differed from experiences of white parents,” says Mack, co-director of the pediatric hematology/oncology fellowship program and associate professor of pediatrics at Harvard Medical School.

Oncologists accurately predicted parental preferences for 53% of white parents, 23% of black parents, 37% of Hispanic parents, and 43% of Asian/other race parents. Minority parents held more active roles than white parents. One-quarter of white parents reported parent-led decision-making, compared to 37% of black parents, 48% of Hispanic parents, and 56% of Asian/other race parents.

“We were surprised to find that minority parents were at risk for holding more active roles in decision-making than they really wanted,” Mack observes. The researchers interpreted this as minority parents feeling less well-supported by clinicians in their decisions. Previous work regarding adult patients and decision-making suggested that minority patients may be less involved than white patients in making decisions.³

“But our findings identified the opposite pattern,” Mack reports.

Clinicians also were not as adept at recognizing parents’ preferred decisional roles for minority parents as they were for white parents. This could explain the mismatch between minority parents’ preferred and actual roles.

“We, therefore, worry that minority parents have less optimal experiences making decisions for their children,” Mack laments. The study’s findings suggest that clinicians partner with minority parents in these decisions less effectively than for white parents.

According to Mack, both clinicians and ethicists “need to be aware of the importance of developing a supportive partnership with all parents and supporting their desired roles in making decisions for their children.” ■

REFERENCES

1. Sisk BA, Kang TI, Mack JW. Racial and ethnic differences in parental

decision-making roles in pediatric oncology. *J Palliat Med* 2019; Aug 13. doi: 10.1089/jpm.2019.0178. [Epub ahead of print].

2. Sisk BA, Kang TI, Mack JW. The

evolution of regret: Decision-making for parents of children with cancer. *Support Care Cancer* 2019; Jun 20. doi: 10.1007/s00520-019-04933-8. [Epub ahead of print].

3. Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA* 1999;282: 583-589.

Limited Exposure to End-of-Life Care for Pediatric Residents

As a pediatric resident, **Amy Trowbridge**, MD, encountered the death of a patient infrequently. Later in her career, she found the same was true for the residents she teaches.

“Generally, this is a good thing. Chronically or critically ill children are living longer, fuller lives, and that should be celebrated,” says Trowbridge, an assistant professor of pediatrics and palliative care at Seattle Children’s Hospital.

However, Trowbridge worried that pediatric residents do not receive enough exposure to family-centered, end-of-life care. “When children die, they deserve to have a clinical team caring for them that is competent and experienced in providing this type of care,” Trowbridge offers.

Trowbridge and colleagues wanted to quantify how often residents are involved in the care of a child at the end of life, and under what circumstances. Researchers conducted

a retrospective chart review of all deceased patients at a children’s hospital over a three-year period. The study revealed that most pediatric residents had limited exposure to end-of-life care.¹ This was expected; more surprising was the finding that the average pediatric resident is involved in the care of a child at the end of life less than six times over their residency.

“That’s not very many, and this is in a very busy, highly specialized children’s hospital,” Trowbridge observes, adding that the numbers probably are even lower in residency programs at community hospitals or less specialized children’s hospitals. “When we consider this from an educational perspective, it begs the question of how do we best train residents in end-of-life care?”

For ethicists, it is important to bear in mind that end-of-life care is a rare clinical event for trainees. “These trainees may need extra support, as

well as clinical insight and education from all of the involved consultants in the case, including ethicists,” Trowbridge explains.

Most deaths in pediatrics do not involve ethical concerns. However, ethical questions regarding decision-making and discontinuation of life-extending therapies are common.

Trowbridge says ethicists can approach these cases “with the awareness that from a learner perspective, these situations are rare and often one of the most challenging and memorable experiences of pediatric trainees.” ■

REFERENCE

1. Trowbridge A, Bamat T, Griffis H, et al. Pediatric resident experience caring for children at the end of life in a children’s hospital. *Acad Pediatr* 2019; Jul 31. pii: S1876-2859(19)30341-9. doi: 10.1016/j.acap.2019.07.008. [Epub ahead of print].

Fee-for-Service, Value-Based Payment Models Pose Different Ethical Concerns

Physical therapists (PTs) are facing some ethical dilemmas over reimbursements for quantity over quality, according to the authors of a recent study.¹

The issue is that reimbursement in skilled nursing facilities is linked to the number of minutes a patient

receives treatment, which incentivizes over-treatment.

The researchers surveyed 340 PTs in nine workplace settings in Georgia. Of this group, 28 PTs worked at skilled nursing facilities. This group exhibited the lowest perceptions of ethical work environment.

Their primary ethical concerns were overuse issues, productivity standards, and billing and coding problems. The group reported that allowing PTs to make decisions autonomously and easing productivity standards would help ensure ethical care.

Medicare and Medicaid programs are shifting away from fee-for-service reimbursement models and toward value-based payment. “This transition toward value-based payments has the potential for improving healthcare while reducing costs. It also holds potential peril,” says **Katharine Van Tassel**, JD, MPH, a visiting professor of law at Case Western Reserve University in Cleveland.

It is true that fee-for-service reimbursement rewards quantity over quality. However, value-based payment models have the opposite problem since clinicians are financially incentivized to perform fewer services.

“A move from fee-for-service to value-based payment settings reorients the ethical framework for healthcare providers,” Van Tassel argues, adding that business decisions that are made as healthcare providers enter the value-based payment arena are “teeming with ethical consequences impacting patient care.”

Typically, such decisions are made by hospital leaders without ethics input. That is a mistake, according to Van Tassel. “Ethicists should request a seat at the table when decisions are being made on strategies for entering

the value-based arena,” she says. The transition to value-based payments will discourage unnecessary resource use. However, there could be a move toward the underuse of vital tests and procedures. “The quality metrics used in value-based contracts are designed to safeguard against cost as the sole driver of care,” Van Tassel says.

The ethical concern is that financial gain, not quality, could drive clinicians’ healthcare decisions — or insurers might cherry-pick healthier patients. “Adding to this picture is the fact that a typical consumer is ill-equipped to self-protect,” Van Tassel notes.

Consumers are likely to be unaware of the types of underlying incentives that drive the care they receive. For instance, they would not realize that a fee-for-service model might incentivize providers to order additional, unnecessary testing and procedures.

“In an ethical healthcare system, the consumer should have a seat at the table,” says Van Tassel, with reimbursement differences for healthcare choices openly discussed.

As value-based reimbursement plans become as numerous as fee-for-service plans, ethicists can assist

healthcare providers. “Ethical and possible moral angst may arise from providing different treatment to consumers with similar problems based on the consumer’s payment model,” Van Tassel offers.

Ethicists can encourage healthcare providers to explain the reimbursement ramifications of various choices. Some people may choose to spend more out of pocket to pay for a treatment that the health plan does not cover. Others may decide to place more resources in a health savings account to pay for an uncovered treatment or choose the treatment that is covered under the plan.

“This empowers the consumer’s decision-making based on the consumer’s own values,” Van Tassel says. ■

REFERENCE

1. Cantu R. Physical therapists’ ethical dilemmas in treatment, coding, and billing for rehabilitation services in skilled nursing facilities: A mixed-method pilot study. *J Am Med Dir Assoc* 2019; Aug 1. pii: S1525-8610(19)30499-2. doi: 10.1016/j.jamda.2019.06.013. [Epub ahead of print].

Surprisingly Positive Parental Views on Genomic Testing for Seriously Ill Children

Bioethicists have raised many concerns about the possible negative effects of giving genomic information to patients and families. A recent study’s findings were reassuring.¹

“We were surprised to hear parents report overwhelmingly positive perspectives on their experience with genomic sequencing,” says **Janet Malek**, PhD, the study’s lead author

and an associate professor at Baylor College of Medicine’s Center for Medical Ethics and Health Policy in Houston.

Researchers conducted interviews with 64 parents of pediatric cancer patients who underwent exome testing (as part of the larger Baylor Advancing Sequencing in Childhood Cancer Care [BASIC3] study) at baseline, one to eight months after

results disclosure, and one year after disclosure. “The motivation for the BASIC3 study as a whole was to gain a better understanding of the impact of routinely including genomic sequencing in the care of children with cancer,” Malek explains.

The study focused on one specific population with a special set of circumstances. Nonetheless, says Malek, “our findings suggest that

assumptions about how people react to genomic information need to be tested empirically.”

Before receiving genomic information, some parents expressed worry that they had passed on a cancer-causing gene or had made parenting decisions that caused the disease. After receiving their child’s exome sequencing results, many parents reported feeling relieved of guilt or worry, and felt they had fulfilled parental duties.

Parents of children with serious illnesses may feel obligated to accept genomic sequencing if it is offered to them.

“Ethicists and clinicians should factor that consideration into decisions about whether to recommend such testing,” Malek advises.

Also noteworthy: The fact that parents found the information valuable regardless of the results returned. “This should reassure

ethicists and clinicians that offering genomic sequencing, under some circumstances, is less ethically fraught than may have been previously thought,” Malek says. ■

REFERENCE

1. Malek J, Pereira S, Robinson JO, et al. Responsibility, culpability, and parental views on genomic testing for seriously ill children. *Genet Med* 2019; Jun 12. doi: 10.1038/s41436-019-0570-6. [Epub ahead of print].

Participants Retained Information Best From Highlighted Informed Consent Form

Study participants retained more relevant information from a consent form based on revised U.S. Common Rule requirements than they did from other designs, according to the authors of a recent study.¹

“People participating in a clinical trial require a lot of information,” notes **Michael Yu**, PhD, the study’s lead author. However, not all of that is important at the point when someone is deciding whether to enroll.

Obviously, contact information and detailed study schedules become important after someone decides to participate.

“But it can distract and obfuscate more critical information during the enrollment decision,” says Yu, a postdoctoral fellow in the biomedical ethics unit at McGill University in Montreal.

To satisfy the needs of people with different values, consent forms usually include information that is irrelevant for individual decision-makers. “To this end, we wanted to explore ways to reformat informed consent documents that improve enrollment

decisions, without removing information that could be important at later stages,” Yu explains.

Participants with an asthma diagnosis were randomized to one of five different informed consent documents: An original full-length document, a concise version, an interactive version, a re-ordered version, and a “highlights” version that followed the suggested Common Rule structure. Participants who saw the “highlights” version, which put important information at the top, were more likely to answer questions correctly.

“Our findings suggest that the Common Rule’s guidelines can improve recall of enrollment-relevant information without hurting recall of other material in the consent document,” Yu reports.

The “interactive” consent form allows participants to navigate to different sections of the consent form as they wished.

“This version performed among the lowest of the formats investigated,” Yu says.

This suggests that people struggle to predict which categories of

information are important to their enrollment decisions. “Efforts to personalize informed consent should recognize that people can benefit from guidance in what may be a complex and unfamiliar process,” Yu suggests.

Different types of information serve different purposes. “Highlighting the information about the clinical trial that is specifically important for the enrollment decision can empower people to make better decisions for themselves,” Yu says.

Those responsible for enrolling people into clinical trials should help potential participants navigate this information. According to Yu, informed consent documents “need to not only provide information, but also help people to use that information to make better enrollment decisions.” ■

REFERENCE

1. Yu M, Fischhoff B, Krishnamurti T. Implementing a new Common Rule requirement for informed consent: A randomized trial on adult asthma patients. *MDM Policy Pract* 2019;4:2381468319839315.

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CME/CE QUESTIONS

- 1. The authors of a recent study on ethics training in surgical residency programs found that:**
 - a. most programs are cutting ethics training due to residents' lack of interest.
 - b. residents demonstrated a high level of competence in managing ethical dilemmas despite little or no training.
 - c. most program directors wanted more resources to teach ethics.
 - d. most programs currently offer no form of ethics curriculum due to resource limitations.
- 2. The goal of a policy for decision-making for incapacitated patients without surrogates developed by Santa Clara Medical Association Bioethics Committee is:**
 - a. decreasing the hospital length of stay.
 - b. establishing uniform procedures for medical decision-making for unrepresented patients.
 - c. ensuring that the decision is made by a designated clinician instead of a committee.
 - d. curtailing the resources expended on searching for a surrogate.
- 3. Which did a study reveal regarding knowledge of palliative care?**
 - a. Patients often misunderstand it, but virtually all providers demonstrated a solid understanding of its role and benefits.
 - b. Most adults surveyed had never heard of palliative care.
 - c. Older clinicians were more likely than younger clinicians to be aware that palliative care can be offered con-current with other treatment.
 - d. Late referrals are not linked to worse outcomes.
- 4. With which type of informed consent document did study participants best retain relevant information?**
 - a. Forms that explained study schedules
 - b. Forms with the most detailed information
 - c. Forms that put important information at the top
 - d. Interactive forms