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Ethics Can Help Drive Efforts to Address Racial Disparities in Healthcare

As the healthcare industry takes steps to address racial disparities, ethicists have an opportunity to play an important role.

“Hospitals and health systems need to recognize that it’s not enough to simply avoid actions that are affirmatively biased against minority groups. What’s needed is affirmative efforts to overcome a deeply ingrained history of exclusion,” says **Carl Coleman**, JD, professor of law at Seton Hall in Newark, NJ. “Ethicists should identify the lack of attention to these issues as an ethical problem and ensure that it is taken seriously by institutional decision-makers.”

Ethicists need support from hospital leadership to call out racial disparities when they occur, says **Michael Shapiro**, MD, chair of the bioethics consultation committee and associate professor of surgery at Rutgers in Newark, NJ. “Ethics committees need representation from disparate racial/ethnic/gender/social groups so those different perspectives are recognized,” Shapiro says.

Ethics grand rounds should address disparities specifically, according to Shapiro. Issues of capacity, pain management, availability of translators, and informed consent may be handled differently for people of color.

“There is also a long history assuming that African American patients have different values than other patients, without taking the time to explore the question directly. Ethicists can be directly involved in such questions,” Shapiro offers.

Shapiro says any committee considering questions of equity would benefit from ethics input. This might include the credentials committee advocating for a medical staff that looks like the surrounding community. Perhaps the pharmacy and therapeutics (P&T) committee is considering adding an expensive drug to the formulary.

“I have sat on P&T committees where very expensive cancer drugs were only available for outpatient use, and only those patients who could afford to buy them had access,” Shapiro recalls. To address racial disparities at their

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own institutions, ethicists need to educate themselves on implicit and explicit bias, says **Laurie Zephyrin**, MD, MPH, MBA, vice president of delivery system reform at The Commonwealth Fund in New York City. Making use of all the available evidence also is critical.

“If you are able to look at data on outcomes and aggregate that by race and ethnicity, that can be very helpful in understanding if there are disparities and determining structural causes of these disparities,” Zephyrin explains.

During consults, ethicists can explore whether inequitable care could have played a role in poor outcomes. “Quality and safety and equity go together,” Zephyrin observes.

In the research setting, inadequate inclusion of racial minorities is a long-standing concern. “Most clinical studies today still do not come close to reflecting the diversity of the American population,” Coleman laments.

One study of cancer clinical trials revealed that of the trials that reported participants’ race, only 3% of participants were Black, and only 6% were Hispanic.¹ “The underrepresentation of racial minorities in clinical trials is dangerous,” Coleman cautions.

Those from different ethnic and racial backgrounds respond in different ways to medical interventions. Study populations often do not include an adequate number of Black, Asian or Hispanic participants. Thus, says Coleman, “there is no way of knowing whether the treatments that emerge from these studies will be suitable for members of these communities.”

Coleman suggests ethicists can address the problem by helping develop culturally and linguistically

sensitive methods to inform all patients about the availability of clinical trials. Also, help healthcare providers incorporate these tools into their conversations with patients.

A recent policy briefing from the Nuffield Council on Bioethics focuses on equitable access for COVID-19 treatments and vaccines.² “Inequalities will be exacerbated unless treatments and vaccines can be developed, accessed, and distributed in a fair way,” says research officer **Arzoo Ahmed**.

The briefing asserts wealthier nations are morally obligated to share treatments and vaccines with low- and middle-income countries. Otherwise, intellectual property rights, patents, and unaffordable prices could keep life-saving treatments from vulnerable people. “People across the world are still dying from conditions due to a lack of access to treatments and vaccines that already exist,” Ahmed notes.

Counties with larger-than-average concentrations of Black people report more COVID-19 cases and more deaths.³ Even in the United States, Zephyrin notes the pandemic has affected communities of color disproportionately.

Zephyrin says this was not surprising, because communities of color face long-standing disparities that affect both health and access to healthcare services. “These disparities are a result of systemic inequities that affect where people live, the ability to access to healthcare, the social stressors that are experienced, and underlying health conditions,” Zephyrin explains.

For ethicists, clear evidence of racial disparities during the ongoing pandemic “continues to show us where we must do better,” says **Kathleen M. Akgün**, MD, MS, BS, associate professor of medicine

at Yale and director of the medical intensive care unit at VA Connecticut Healthcare System.

Ethicist roles often are voluntary, and some institutions work with limited ethics resources. Ideally, enough ethicists are available to participate in deliberations that seek to promote justice and equality. “Including Black and brown members of the community can enlighten ethicists regarding potential blind spots,” says Akgün, co-chair of the clinical ethics committee at VA Connecticut.

Bias is not always blatant; sometimes, it is more subtle. For example, a lack of adequate personal protective equipment (PPE) to protect healthcare workers has been a major concern throughout the COVID-19 pandemic. “Meeting this need has never been questioned,” Akgün says.

It is just as important to protect individuals who clean rooms and transport patients. “But these demands seem to be much quieter, if existing at all,” Akgün suggests. “These jobs are disproportionately held by Black and brown people, in part due to systemic racism that leads to socioeconomic inequality.”⁴

These workers face unnecessary risk of exposures and illness if they are working without proper PPE. To help ethicists identify these issues, community members can meet with the ethics committee ad hoc. Creating dedicated committees to examine practices that may perpetuate disparity, or directing preventive ethics committees to examine this issue, are two other approaches. “From my experience and perspective, charges of racial disparity are most often arising from institutional practices,” Akgün explains. ■

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Ethical Responses If Patients Ask for Provider of Different Race

What happens when a patient demands a different nurse or physician — one of a different race?

“These situations are difficult for the rejected provider and pose many legal, ethical, and clinical challenges,” says **Kimani Paul-Emile, JD, PhD**, professor of law at Fordham University in New York City.¹

If mishandled, such ethically complex requests can result in problems ranging from bad clinical outcomes

to Emergency Medical Treatment and Labor Act (EMTALA) violations — even litigation.² “Anecdotally, we are seeing an uptick in these cases,” says Paul-Emile, associate director of Fordham’s Center on Race, Law, and Justice and faculty co-director of Fordham’s Louis Stein Center for Law and Ethics.

During the COVID-19 pandemic, some patients rejected providers of Asian descent because of unfounded

fears about virus transmission.³ “Patients do have a right to refuse wanted care from an unwanted physician,” Paul-Emile notes.

This is true both ethically (based on informed consent obligations) and legally (in light of medical battery laws). Patients also have a right to receive a medical screening exam and stabilizing treatment as required by EMTALA. Rejected clinicians have rights, too. “If a healthcare provider

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continually accommodates demands based on race, ethnicity, or religion, it can create the basis for a hostile work environment claim,” Paul-Emile explains.

When patients refused care from Hispanic or Black nurses, some hospitals acquiesced, placing a sign on the patient’s door informing providers of the patient’s wishes. “In those situations, the nurses have sued, and have generally won,” Paul-Emile reports.⁴

All these factors create a highly charged, ethically complex case. “Medical centers need to have clear policies for dealing with patient bias and how to address these situations,” Paul-Emile stresses.

A one-size-fits-all rule will not work. Not all requests for a physician of a different race are the same. “There are some instances where a patient request based on ethnicity could be clinically or ethically appropriate,” Paul-Emile observes.

A sexual assault victim’s request for a gender-concordant physician typically is seen as appropriate. Paul-Emile says the same is true of some requests for race-concordant physicians. A physician could remind a veteran with post-traumatic stress disorder of a former enemy combatant. An older African-American patient in the South might have misgivings about seeing a white physician due to previous personal experiences with bias or an overall profound lack of trust in the healthcare system.

“In the interest of the therapeutic relationship, it might make sense to accommodate the request,” says Paul-Emile, noting the key is to unpack what is behind the request. “Some patients are not so much rejecting a provider as asking for a provider who they feel understands their culture and experience.” Policies can help

providers sort it all out. If providers believe they have reached an impasse, ethicists can elicit what is behind the patient’s request.

“Patients may not be upfront with the physician. A neutral third party can be helpful,” Paul-Emile suggests.

The patient’s mental state has to be evaluated. In some cases, requests for nurses or physicians of a different race are driven by cognitive impairment (e.g., an intoxicated patient). Providers should not try to figure out all this alone.

“There should be rules and procedures for when an ethics consult is going to be called, and in what types of situations would accommodation be ethically and clinically appropriate,” Paul-Emile says.

Policies should support clinicians most likely to be rejected by patients and staff who witness the encounters and do not know how to react. “There needs to be a full institutional plan that involves everyone,” Paul-Emile offers.

Most hospitals do not have such policies in place. Those that do vary widely. “They are all over the map,” Paul-Emile says. “Some have zero tolerance. Others read more like difficult patient policies as opposed to addressing bias, which requires more nuance.”

Even if hospitals have created policies for how requests should be handled, it is a good time to revisit them. “It’s hard to talk about race and bias in the workplace. In this moment, people are finding those conversations are easier to have,” Paul-Emile says.

It is not just racism. Healthcare providers occasionally face religious intolerance, sexism, and ageism. “Regrettably, these are fairly common forms of discrimination and prejudice members of the health profession face on a regular basis,” says **Blair Henry**,

D. Bioethics, a senior ethicist at Sunnybrook Health Sciences Centre and North York General Hospital in Toronto, both part of the Health Ethics Alliance.

Staff often deal with the situation without involving ethics. “One of our biggest challenges is to get staff to even report these events. We’ve done a lot of education on this topic,” says Henry, an assistant professor in the department of family and community medicine at the University of Toronto.

Ethics has provided clinicians with an outline on how to fairly and consistently respond to these situations. “Yet the spirit of maximal accommodation, and a misguided understanding of what patient-centered care means, has frequently clouded judgments when it comes to appropriately dealing with any form of discrimination,” Henry says.

Sometimes, racism is overt. Other times, patients or family ask for a change of healthcare provider for valid personal or cultural reasons. For ethics, the first step is to assess the capacity of the person. “Are they able to understand their behavior and to control it, even if we insisted on it?” Henry asks.

In some cases of cognitive impairment and dementia, this may not be realistic. “However, this does not remove the need to protect and support the healthcare professional,” Henry notes.

Assuming patients are not cognitively impaired, says Henry, “then immediate action is called for.” First, the patient or family member is educated about the zero-tolerance policy for any form of racism. Next, ethicists try to determine what is underlying the request for another provider.

“This should happen even in cases where humor was the intended

outcome, where people infer no derogatory or harmful intent. That's what zero tolerance means," Henry explains.

There may be a valid reason for requesting a care provider from another race, culture, or gender. Cases involving individual trauma or religious or cultural values are examples. "We need to listen and acknowledge the concerns being expressed. However, it does not mean we automatically acquiesce," Henry reports. Assuming there is a reasonable basis for the request, and

it is possible for another provider to take over the patient's care, the first provider is given the opportunity to recuse themselves. Patients and families are told that the change in providers is going to mean unnecessary delays to care. "We need to be ready to have more challenging conversations when and where these events occur," Henry adds. "It's the right thing to do." ■

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Black Researchers at Disadvantage for NIH Funding

During the earliest part of the National Institutes of Health (NIH) review process for research grants, reviewers score all submitted applications. A group of researchers were interested in whether differences in the way scores are weighed explain Black/white disparities in research funding.

"This is important because preliminary overall impact scores determine whether an application will make it to the next round of evaluation," says **Elena A. Erosheva**, PhD, associate director of the University of Washington Center for Statistics and the Social Sciences.

Peer reviewers evaluate submissions based on five specific criteria: significance, innovation, approach, investigator(s), and environment. Reviewers also give an overall impact score. "We focused on the earliest part of the review process, where reviewers provide scores for all submitted applications," says Erosheva, lead author of a recent study.¹

Black investigators received worse preliminary scores for all five

criteria and a lower overall impact score.¹ These findings surprised Erosheva and colleagues. "We found that preliminary criteria scores do not explain all of the variability in preliminary overall impact scores," Erosheva says.

This is understandable, since there are additional considerations reviewers use in determining preliminary overall impact scores. More surprising was the finding that scores for these specific criteria completely explain Black-white disparities in the overall scores.

Erosheva and colleagues also reported differences in funding rates. For fiscal years 2014 through 2016, the overall award rate for Black applicants was 10.2% vs. 18.5% for white applicants. "This gap decreases when we consider Black/white applicants who are matched on several key variables," Erosheva explains. These include area of science and application type (new or renewal).

Black principal investigators receive lower rates of funding and lower peer review scores than their

white peers, according to the study. "This raises concerns about whether or not NIH grant peer review is upholding the ideal of universalism, and whether NIH grant review is meritocratic or not," says **Carole Lee**, PhD, another of the study's authors and an associate professor in the department of philosophy at the University of Washington. "Scientific ideas should be evaluated on the basis of their merits, not on the social identity — race, gender, religion, or prestige — of the person espousing those ideas."

Black applicants published fewer articles, and these articles appear in less prestigious journals, according to the authors of a another study.² "Although Black investigators publish the same number of papers as white investigators, these papers are cited less often," says lead author **Donna Ginther**, PhD.

Ginther and colleagues discovered some, but not all, reasons for the Black/white funding gap. One explanation is Black investigators may not receive as much advice from mentors regarding tips for successful

publication vs. white colleagues. “These disadvantages appear to accumulate,” says Ginther, director of the University of Kansas Institute for Policy & Social Research.

Regarding gaps in citation and publication, the gulf widens when Black researchers are principal investigators, especially those who did not receive funding. Ginther and colleagues discovered Black investigators trail white colleagues in published papers (two or three fewer, on average). Papers that are published are cited less often.

Further, Ginther and colleagues found Black investigators are listed with fewer co-authors, and there are lower average sums of impact factors for those papers. Topic choice is another cause of the funding gap

in NIH applications submitted by African American/Black scientists vs. white scientists, according to the results of a third analysis.³ African American/Black applicants tended to propose research at the community and population level, which average lower award rates than more fundamental and mechanistic investigations.

Black and African American researchers are more likely to conduct studies to address health disparities, but these studies are less likely to receive funding. “This suggests that, as a society, we are not allocating our research resources to address this pressing need,” Ginther offers.

Ethicists can alert their institutions to disparities. “They can also advocate for increased mentoring

of underrepresented scientists at the PhD student and postdoctoral levels to facilitate improved career outcomes,” Ginther suggests. ■

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Establishing the Right Policies on Decision-Making for Unrepresented ICU Patients

The American Thoracic Society and American Geriatrics Society have issued a new policy statement addressing decision-making for unrepresented patients in the intensive care unit (ICU).¹

“This is an even more prevalent issue in clinical ethics, yet one with even less existing guidance. Guidance on this issue is urgently needed,” says **Thaddeus Mason Pope**, JD, PhD, the policy statement’s lead author.

These individuals are sick enough to be in the ICU, sick enough to be incapacitated, and are without a surrogate who knows and cares about them. “They are vulnerable for all of those reasons. Yet we aren’t doing a very good job of protecting them from the risks of either undertreatment or overtreatment,” says Pope, director of the Health Law Institute and professor of law at

Mitchell Hamline School of Law in Saint Paul, MN.

The policy statement recommends institutions prevent patients from becoming unrepresented in the first place by offering advance care planning. Conduct thorough capacity assessments and search for potential surrogates before assuming patients are unrepresented.

When making medical decisions, seek input from a diverse multidisciplinary committee as opposed to ad hoc decisions made by individual clinicians. Factor in everything that is known on the patient’s preferences and values when making decisions. Finally, use a fair process that comports with procedural due process, even when state requirements are less stringent.

Pope says ethicists should use this policy statement to benchmark their

own institutional policies. These are important questions:

- How carefully does the hospital assess capacity?
- How hard does the hospital search for potential surrogates?
- How diligently does the hospital offer advance care planning?

The fairness of the decision-making process also should be scrutinized. “For example, can the attending authorize her own treatment plan?” Pope asks. “Or must there be vetting through a multiprofessional committee?”

There is a perceived lack of consensus on the best way to make decisions for unrepresented patients, says co-author **Mark D. Siegel**, MD. Clinicians struggled on whether to offer CPR, intubation, or mechanical ventilation. “Many critically ill patients can’t make decisions on

their own behalf for a variety of reasons, including sedation, delirium, and chronic neurocognitive and psychiatric disorders,” says Siegel, director of Yale’s internal medicine traditional residency program.

When patients have a surrogate decision-maker, such as a spouse or other family member, the ICU team can turn to that person to make decisions on the patient’s behalf.

“But this option is not available for unrepresented patients, who are, by definition, vulnerable because they are ill and have no one to represent their wishes,” Siegel cautions.

The policy authors wanted to provide ICU clinicians with guidance on how to handle these difficult cases.

“We clinicians are obliged to respect patient’s preferences when we make clinical decisions,” Siegel notes. “In general, this respect

for autonomy takes precedence over other ethical considerations.” Patients’ preferences supersede clinicians’ assumptions about which treatments are in the patient’s best interest (e.g., whether a patient should be resuscitated if he or she suffers a cardiac arrest).

“Unfortunately, if the patient can’t exercise autonomy and has no surrogate to represent them, the concern would be that respect for the patient’s preferences will not be prioritized as it would when surrogates are available,” Siegel explains.

This means patients might receive treatments they never would have chosen. “This concern could become additionally problematic in populations that are already vulnerable,” Siegel warns.

This includes the homeless, the uninsured, and those belonging

to racial and ethnic groups that have historically suffered from discrimination. The policy statement recommends ensuring a diligent search is made to find potential surrogates, assembling multidisciplinary teams to ensure diverse input, and ensuring due process in decision-making.

“Just by creating a policy, I think we may be able to raise awareness that these patients require extra consideration when making ethically challenging decisions,” Siegel says. ■

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Nurses Create Approach to Ethical Decision-Making

A man admitted to the surgical intensive care unit (ICU) went into cardiac arrest, and was resuscitated. Afterward, he faced a complicated clinical course with intermittent decision-making capacity.

The clinical team responded to every new complication with additional interventions, but soon became concerned that continuing

with this approach was not in the patient’s best interest. The patient’s wife disagreed, and demanded that full treatment, including CPR, be provided.

“This scenario ... is a classic case in the ICU setting,” says **Cynda Hylton Rushton**, PhD, RN, FAAN, professor of clinical ethics at Johns Hopkins Berman Institute of Bioethics. The case is described

in a recent paper as an example of the kind of ethical dilemmas that clinicians face regularly.¹ Rushton and an ICU colleague created a structured mapping process to approach ethical decision-making.

“Our aim was to surface some of the unconscious processes that get us stuck in a hurtful rut, and to identify a potential way forward,” Rushton reports.



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For instance, nurses might view family members negatively because of an inability to accept the family member's conclusions. Many nurses experienced moral distress when visitor restrictions were implemented during the pandemic.

"With hundreds of beds in hundreds of hospitals, all occupied by people enduring illness and injury alone, watched over by wary healthcare providers, considerable trauma is unfolding for all involved," says **Kathleen Turner**, RN, CHPN, CCRN-CMC, the report's co-author and clinical nurse in the medical-surgical ICU at the University of California, San Francisco Medical Center.

Critical care "sets clinicians, patients, and families on a high-stakes path," according to Rushton. For healthcare providers, it is easy to allow habits or assumptions take over.

"For the clinician meeting what may feel like their millionth catastrophe, this individual patient's situation can be superseded by an archetype — 'We've seen this movie before,'" Rushton observes.

Patients and families are facing an unfamiliar, overwhelming situation. Some already expect disrespect from the healthcare system. "In emotionally charged and ethically complex situations, anytime we believe there is one right answer, and it's the one we already know, that is the moment to pause and try this approach," Rushton suggests.

The approach to which Ruston refers is the four "Rs": Recognize what is behind problematic decision-making, Release preconceived attitudes, Reconsider new approaches, and Restart with a fresh focus. Turner says in the context of visitor restrictions, the approach could work something like this:

- Nurses can **recognize** their own anxiety caring for frightened patients who are not allowed visitors. "By becoming aware of my distress, I can take action to stabilize myself," Turner says.

That makes it possible to consider the ethical principles at stake. Nurses vow to foster well-being, not to harm, and to deal with people equitably. The hospital has these same obligations to its staff and to the community. Patients' families have a duty to care for their loved ones.

"From this vantage point, the actions of each participant make sense. It's a shift from seeing myself as a bad nurse, my hospital as cruel, and my patients' families as victims," Turner offers.

- Nurses can **release** themselves from moral responsibility that is not theirs to carry. Nurses do not make the visiting policy, Turner notes. The hospital must adhere to public health guidelines.

- Nurses can **reconsider** focusing on things beyond their control. Instead, nurses look for ways to provide the most ethical care possible under less-than-ideal circumstances.

"There have always been individual family members who couldn't be present at a patient's bedside. We have found ways for them to tend their loved ones nonetheless," Turner notes.

- Nurses can **restart** by forging new partnerships. Nurse committees, along with patient and family advisory councils, might partner with hospital leadership to determine how to return families to the bedside safely.

"Frontline clinicians, intimately familiar with workflows, hazards, and resources in their areas, can partner with leadership to promote physical and virtual family presence," Turner suggests.

Ethicists should be present on the wards and in the ICUs, listening to the concerns of staff. "We recognize there may be considerable political and cultural resistance in some organizations," Turner admits.

Clinicians or families may be up against hierarchies or other barriers. Ethicists might need to contact these individuals directly instead of waiting for a consult request.

"[Contacting] staff models the stance organizations could be taking with at-risk communities," Turner says. ■

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More Than 300 Clinical Ethicists Have Earned HEC-C Credential

More than 300 ethicists now hold the American Society for Bioethics and Humanities (ASBH) Healthcare Ethics Consultant-Certified (HEC-C) credential. The

authors of a recent analysis studied the program one year after its inception.¹

"Many in the field have been working toward professionalization of

clinical ethics for several years," says lead author **Claire Horner**, JD, MA.

Various methods have been used to assess competence of ethicists. "One of the most notable efforts was

the portfolio/attestation process,” recalls Horner, an assistant professor at the Baylor College of Medicine.

Participants submitted portfolios of their consultation work for evaluation by trained raters.² More recently, ASBH developed a certification exam to evaluate the knowledge and skills of clinical ethics consultants.

“As members of an established clinical ethics program, we wanted to support this effort by taking the exam early on, and offering our honest feedback about the merits and shortcomings of this process,” Horner explains.

Since the certification is so new, it is unclear to what extent hospitals factor it into hiring decisions. “We hypothesize that hiring officers are going to assume this certification signifies a level of competence similar to licensure exam requirements of other healthcare workers, such as nurses or social workers,” Horner offers. Other recent developments:

- **Some job postings now require ethicists to carry the HEC-C credential.**

“This could be dangerous, since this exam seems to establish a minimum threshold of ethics knowledge, which is not sufficient to certify that one is a competent ethics consultant,” Horner cautions.

The concern is hospitals are relying too heavily on the credential. “Hiring officers may assume the credential means the consultant is more highly qualified,” Horner observes.

In fact, there are many expert ethics consultants who have not taken the exam for various reasons. “The exam really establishes a minimum threshold of ethics knowledge,” Horner says. “It is not capable, in its current form, of commenting on the expertise or the clinical skills of the ethicist.”

For instance, communication skills, efficiency, and empathy are not evaluated. “The exam is a good first step,” Horner adds. “But it’s not yet ready to be used by institutions as a measure of a candidate’s ability to perform a high-quality ethics consultation.”

- **The credential could pave the way to justify additional ethics resources.**

“Many clinical ethicists hope that the certification will be helpful to communicate the legitimacy of the field to administrators,” Horner says.

This could result in more financial or personnel support for ethics.

- **The credential has brought attention to the ethics field.**

“It has definitely shined a light on the conversation about professionalizing the field,” Horner offers.

The portfolio process was a pilot project aimed at testing feasibility. In contrast, the HEC-C exam has become an established program. “Regardless of the other ways the field of clinical ethics decides to evaluate and certify ethics consultants, the exam seems like it is here to stay,” Horner predicts. “We now have a solid base to build on.”

Previous approaches included requiring entry into the field through an accredited training program, an entrance exam, or allowing consultants to work in the field and submit evidence of their work for peer review. “All of the ideas put forth are different aspects of the kind of evaluation that is needed to assure that practicing clinical ethics consultants are proficient in their work,” Horner says.

It always was unclear which aspect of ethics evaluation should be developed first. “Now, we have our starting point,” Horner adds. The authors studied and prepared for

the HEC-C exam as a group. “We had similar reactions throughout the process of studying for and taking the exam,” says **Sophia Fantus**, PhD, an assistant professor at the University of Texas at Arlington School of Social Work. Mostly, the group questioned whether the exam, which consists of 110 multiple-choice questions, really painted an accurate picture of an ethicist’s expertise. It remains unclear how hospital administrators weigh the credential in hiring decisions.

Fantus obtained the certification in the second year of a clinical ethics fellowship, right before entering the job market. “During my interview process, there were some organizations who wanted and expected certification,” Fantus relates.

Others did not seem to place too high a value on it. As for ethicists, some find it valuable as a clear metric they can show to their administration. This is particularly helpful if leaders do not understand how the field of clinical ethics differs in training from other healthcare disciplines.

“Controversy over the credential within the profession is something we will have to consider moving forward, if we want to professionalize the field,” Fantus says.

The credential also does not reflect the amount of hands-on experience with difficult cases and conflict mediation skills. Offering more clinical ethics fellowships and expanding existing programs could fill this gap. “We see programs popping up across universities and hospital systems,” Fantus reports.

Not all have the necessary infrastructure or trained staff to be effective. For that, says Fantus, “you really need a strong interdisciplinary team with well-trained supervisors, and to work at a hospital that deals with a lot of rich and complex ethical dilemmas.” ■

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Data Reveal More About Patients Who Request Medical Assistance in Dying

More people are asking for medical assistance in dying (MAiD), but surprisingly little is known about this population.

“We wanted to better understand the demographics and other characteristics of who was asking for MAiD, as well as what the key reasons for the request were,” says **Debbie Selby**, MD, a palliative care physician at Sunnybrook Health Sciences Centre in Toronto.

Selby and colleagues reviewed the charts of 97 patients making a formal request for MAiD.¹ Of this group, 80 actually received the service. Some key findings:

- **Many patients were concerned about losing decision-making capacity.**

In 39% of cases, the 10-day required reflection period was reduced because of impending loss of decision-making capacity.

“Monitoring each patient closely is critical, given the requirement for capacity and final consent on the day of provision,” Selby explains.

Many requestors placed extremely high value on MAiD as the only end-of-life option that made sense. Those people were distressed about possibly losing capacity — and with it, the option of MAiD.

“We try to mitigate their anxiety by assuring them we will act quickly if there are signs suggesting impending loss of capacity,” Selby notes.

- **Rarely was pain the reason for the request.**

“In contrast to what is often said in the lay literature, our anecdotal experiences had been that ‘pain’ was almost never the reason,” Selby says.

The study’s findings supported this. “Physical symptoms had a much lower importance than personal philosophies and personality styles,” Selby reports. Forty-six percent of the group who received MAiD said the request reflected a long-term belief in the importance of autonomy and independence, which predated their illness. “This was simply the end of life that made sense for those requesting MAiD,” Selby adds.

- **It was not a lack of access to palliative care that prompted a MAiD request.**

In nearly half of cases, MAiD was carried out in the palliative care unit. Virtually all patients had access to palliative care. However, there is a misconception that lack of palliative care is the main reason people request MAiD.

“We hoped to add to the data showing this was not the case for our population,” Selby says.

The study’s findings showed that many people had strong pre-existing beliefs on the ability to access assistance in dying at the end of life. “For a specific subset of the population, the option of MAiD is a very important one to have,” Selby observes. ■

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Ethics of Default Options for Advance Directives

Default options in advance directives strongly influenced patients’ end-of-life care choices, according to the authors of a recent study.¹

“In a prior, smaller trial, we found that the ways in which advance directives are structured strongly influenced the choices made by seriously ill patients,” says **Scott D.**

Halpern, MD, PhD, the study’s lead author. This affected whether patients wanted to maximize comfort or live as long as possible, and their preferences for life support interventions such as ventilators or feeding tubes.²

Some directives included preselected options for forgoing mechanical ventilation or other forms of life support. If so, patients were

much less likely to choose to receive such interventions, even after the use of such defaults was explained to these patients.

In the larger subsequent study, researchers analyzed 492 seriously ill patients. “We sought to determine whether these impacts on patients’ choices in real advance directives would be replicated in a larger and

more diverse cohort of seriously ill patients,” says Halpern, professor of medicine, epidemiology, medical ethics, and health policy at the University of Pennsylvania.

Halpern and colleagues also wanted to measure how the changes affected patient outcomes, such as the number of days survived outside the hospital. “Our two main findings were as expected,” Halpern reports.

Default options in advance directives again strongly influenced the choices patients made in completing these documents. Defaulting patients to receive comfort-oriented care did not reduce their number of hospital-free days. “However, we had anticipated that defaulting patients to more comfort-oriented care may produce certain other benefits,” Halpern explains.

The researchers expected to see improved quality of life, reductions in

healthcare costs, or greater satisfaction with advance care planning. None of these outcomes were altered by the default options in advance directives. “This study confirms that contrary to popular belief, seriously ill patients’ choices about the types of care they wish to receive do not necessarily reflect deep-seated, well-ordered values,” Halpern reports.

Instead, decisions frequently are influenced by the ways in which choices are framed. “As such, clinicians and policymakers must be mindful of the language used in advance care planning conversations and documents,” Halpern stresses. For example, language can be used to encourage families to choose to forgo CPR in cases where the burdens outweigh the benefits.³

Overall, the findings point to the limitations of state-authorized advance directive forms, which focus

narrowly on specific care choices. “We need to develop new approaches to advance care planning that more holistically incorporate patients’ goals and values,” Halpern suggests. ■

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Advance Care Planning Does Not Decrease Hope, Contrary to Common Belief

Regardless of whether patients with advanced cancer had completed advance care planning, hope was equivalent, according to the results of an analysis.¹ Of 672 patients, 20% reported engaging in a discussion about end-of-life planning, 51% reported completing an advance directive, and 85% had chosen a surrogate.

“We conducted this study due to the fact that many oncologists cite fear of giving up hope as a primary reason they defer conversations about end-of-life or advance care planning until late in the course of a patient’s disease,” says **Michael Cohen**, MD, the study’s lead author and a fellow in gynecologic oncology at UPMC Magee-Womens Hospital in Pittsburgh. Researchers found there was

little truth to this. The results revealed no association between hope and advance care planning. “Advance care planning conversations allow patients with terminal diagnoses to guide and manage the end of their lives in a manner consistent with their goals,” Cohen explains.

Cohen and colleagues conducted additional testing to determine whether patients who had completed advance care planning were really as hopeful as those who had not. “We found that level of hope was, indeed,

equivalent,” Cohen reports. This does not support clinician concerns about diminishing hope by engaging in advance planning discussions. Thus, Cohen suggests providers engage in these delicate-but-important conversations with their patients. ■

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CME/CE QUESTIONS

1. Which is true regarding responses if patients ask for a provider of a different race?

- a. Patients have no right to refuse wanted care from an unwanted physician.
- b. If a healthcare provider continually accommodates demands based on race, it can create the basis for a hostile work environment claim.
- c. Patient request based solely on race is ethically appropriate.
- d. Patients give up their right to a medical screening examination as required by the Emergency Medical Treatment and Labor Act once they reject a provider based solely on race.

2. Which does a policy statement from the American Thoracic Society/American Geriatrics Society recommend regarding decision-making for unrepresented intensive care unit patients?

- a. Clinicians should remember there is no evidence that advance care planning can prevent patients from becoming unrepresented.
- b. Ethicists should discourage clinicians from spending unreasonable amounts of time searching for potential surrogates since there is no evidence it changes end-of-life care.
- c. Instead of a committee process, medical decisions should be made

by individual physicians exercising their best clinical judgment.

d. Hospitals should use a fair process that comports with procedural due process, even when state requirements are less stringent.

3. Which did a study reveal regarding requests for medical assistance in dying?

- a. Loss of decision-making capacity was not a concern in the vast majority of cases.
- b. Pain was the most common reason for the request.
- c. Physical symptoms carried much less importance than personal philosophies.
- d. Most people who made the requests had no way to obtain palliative care.

4. Which is true regarding racial disparity in healthcare?

- a. Lack of data is a recognized barrier to changing practices that perpetuate disparities.
- b. Clinical studies adequately represent racial minorities due to updated requirements.
- c. Data show people from various racial and ethnic backgrounds respond the same way to medical interventions.
- d. Communities of color have been disproportionately burdened by COVID-19.