Providing Care Viewed as Futile or Unnecessary Linked to Physician Burnout, Intention to Quit

Ethics can do a lot to support clinical team

About one-third of clinicians considered leaving their jobs due to providing care they saw as futile or potentially inappropriate, found the authors of a recent survey.\(^1\)

Lead author Jason Lambden got the idea for the study after seeing a presentation on the causes of moral distress in resident physicians. Findings from focus group discussions suggested that perceived futile care provision played a significant role.\(^2\) This rang true to Lambden, based on his experience working at Weill Cornell Medicine as a medical student. He discussed the study’s findings with several classmates. “They were similarly uncomfortable with some of the care they were providing, to the point that they were unable to study at night,” says Lambden.

The researchers wanted to explore the relationship between clinician wellness and perceived futile care, with two goals:

- to quantify how often clinicians believe they provide futile care;
- to determine correlations between such care and measures of clinician wellness.

Researchers surveyed 349 clinicians at two New York City hospitals in the fields of internal medicine, surgery, neurology, and intensive care, looking

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at outcomes of burnout, depression, and intention to quit. Some key findings include:

- Ninety-one percent of the clinicians believed that they had personally provided futile or potentially inappropriate care to a patient in the preceding six months. Not surprisingly, most cases stemmed from disagreements over end-of-life care.

- “Similar to what has been reported in other studies, more junior clinicians reported higher rates of futile or potentially inappropriate care provision,” notes Lambden.

- 43.4% screened positive for burnout syndrome;
- 7.8% screened positive for depression;
- the amount of perceived futile care provided was significantly associated with burnout and thoughts of quitting.

This was true regardless of experience, position, department, and the number of dying patients cared for. “This suggests that the greater the amount of futile or potentially inappropriate care you believe you provide, the more likely you are to experience burnout and to think about quitting,” says Lambden.

A large majority of clinicians often are uncomfortable with the care that they provide, the survey’s findings indicate. Given that perceived futile care provision is linked to clinician wellness — an increasing priority in healthcare — Lambden says hospitals should consider taking steps to improve communication among clinicians and families at the end of life. Not all disagreements will be reconciled. “But it is important to recognize the toll that this can take on clinicians,” says Lambden.

**Divergent Views**

When bedside clinicians report concerns over nonbeneficial care, it is a possible sign of communication breakdown. “If nurses and physicians are not talking regularly about goals of care or patient side effects from care, then they may have divergent views,” says Timothy Lahey, MD, MMSc, director of clinical ethics at the University of Vermont Medical Center in Burlington.

Nurses, who often spend more of the day in direct interaction with the patient than physicians, can alert physicians if patients are suffering because of a given treatment. Similarly, physicians can clarify things with nurses. “Aggressive care that might not be what everyone would choose could nonetheless be driven by a good conversation the physician had with the patient when the nurse was out of the room,” says Lahey.

Clinicians’ moral distress over provision of nonbeneficial care may reflect a larger issue. “Our medical system prioritizes individual patient autonomy over wise allocation of

**EXECUTIVE SUMMARY**

About one-third of clinicians reported considering quitting due to provision of futile care, according to a recent survey. Ethicists can:

- educate all involved parties on legal requirements;
- correct inaccurate assumptions about obligations to provide care;
- refer to guidelines and position statements.
Unrealistic Expectations

Clinicians frustrated with what they see as poor choices sometimes call ethics for help. It soon becomes apparent that what they really want is for the ethicist to step in and tell the family to withdraw treatment.

“We explain that sometimes families make decisions that we disagree with, but that doesn’t necessarily make them ethically inappropriate,” says Lauren Jodi Van Scoy, MD, an associate professor of medicine, humanities, and public health sciences at Penn State Milton S. Hershey Medical Center. About 65% of consults involve this scenario, she estimates.

Parsing out legal, ethical, and clinical issues can help. “People will often weaponize the law,” says Van Scoy. When clinicians talk about legal obligations, or families threaten to sue, both sides become defensive. “It’s helpful if the law is explained by an ethics consultant, instead of being it used as a threat,” says Van Scoy.

As a neutral third party, ethics can convey the ethical principles of beneficence and nonmaleficence in the simplest of terms. Ethicists explain the team is obligated to only help patients, not harm them. “We explain that from an ethical standpoint, these things should guide our decision-making,” says Van Scoy.

A 2015 multisociety statement on responding to requests for potentially inappropriate treatments in ICUs provides guidance for clinicians to prevent and manage disputes in patients with advanced critical illness. Ethicists offer the statement to clinicians, who often find they are doing exactly what’s recommended. However, clinicians are not always on the same page. One may believe treatment is futile, while another thinks it is highly unlikely to work but does not quite reach the level of futility.

“That can be really hard. In my experience, clinicians are loath to unilaterally lay down the hammer and say, ‘We are not doing this,’” says Van Scoy. This is not necessarily a bad thing, because unilateral decisions about futility are “especially problematic,” she says. Escalated disputes and even litigation become possibilities.

“Am I within my rights to refuse care?” Physicians expect a yes-or-no answer to this question. “But determining whether care is futile is in the clinical realm, often outside the purview of ethics,” says Van Scoy.

Next, clinicians ask what the definition of “futile” is. “We share it, using Trotter’s definition of futility, which seems easy to tease apart for clinicians,” says Van Scoy. This states that three conditions are needed: A goal, an action aimed at achieving the goal, and virtual certainty that the action will fail. The “virtual certainty” part is where things get complicated. “The challenge is understanding where the line is between something being very, very unlikely to work and being futile,” says Van Scoy.

Multiple meetings build familiarity and trust. Sometimes, all that is needed is for ethics to be present. “You have a level of authority that maybe the clinical team has lost for whatever reason,” says Van Scoy. “It makes the family say, ‘Oh —

No Moral Obligation

Physicians are not morally obligated to provide a treatment or intervention that they do not believe is medically indicated and/or do not believe will be clinically effective, says George L. Anesi, MD, MSCE, MBE, an attending physician in pulmonary and critical care medicine at the Hospital of the University of Pennsylvania and an instructor of medicine at Perelman School of Medicine.

Resuscitation is an intervention, says Anesi. Therefore, if physicians truly believe it will not achieve its purpose, they’re ethically sound in not offering CPR, or ceasing ongoing CPR.

“The ethical crux lies in what the goal is and how certain we are of the outcome,” says Anesi. The physician’s goal may be recovery from critical illness. CPR, even if transiently effective, may be clearly ineffective at reaching it. A family’s goal for their loved one in the same scenario may be very different. “It may sometimes be transient life prolongation at all costs, for which CPR almost always has a nonzero chance of achieving,” says Anesi. “Those are in conflict.”

Any form of life-sustaining treatment should be considered a trial that involves a reasonable prospect of recovery to a meaningful quality of life, according to a 2018 guidance from the Canadian Critical
Care Society. “The reality is that often clinicians aren’t as savvy as they should be, in terms of written statements or legalities,” says Bojan N. Paunovic, MD, FRCPC, co-author of the statement and president of the Canadian Critical Care Society.

Sometimes clinicians operate under assumptions rather than facts, believing they are legally bound to provide futile care. Paunovic advises “getting a good grasp of what the law of the land is.” Some families, and even clinicians, have misinterpreted a recent Canadian Supreme Court decision as a right to life-sustaining interventions. Asking an ethicist to step in to clarify legal requirements can defuse tension. “Often, by that time there is an antagonistic situation built up,” Paunovic explains. “It may help offer an objective view that this is not just a physician doing what they want.”

Regardless of what the law says, there may be pushback from hospital administrators fearing bad publicity. Recent highly publicized cases have fueled this fear. “There may be leadership that say, ‘We don’t want this to get ugly,’” says Paunovic.

A family might reject withdrawing life support, but agree to do so after a family member arrives the following day. “But where is that transition point? Is a day OK? What about a week, or a month?” asks Paunovic. This is where jurisdictional policies can be of help. “Leadership wouldn’t feel they are in that position of conceding to inappropriate demands if there is a supported policy they can abide by,” says Paunovic.

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### Ethical Responses if Surrogate Is Unfit for Role

Some decision-makers ‘incapacitated, uncaring, or even nefarious’

Most people have not designated a surrogate decision-maker, but most states specify a priority sequence of default surrogates. Therefore, there is usually sufficient clarity on this issue. “Clinicians should not need ethics consults for this,” says Thaddeus Mason Pope, JD, PhD, director of the Health Law Institute and professor of law at Mitchell Hamline School of Law in St. Paul, MN.

Ethical issues arise when surrogates appear to lack capacity, or act contrary to the patient’s wishes or best interests. “Except in extreme cases, clinicians are too unwilling to challenge surrogates who are not faithfully representing the patient,” says Pope.

Some surrogates are unwilling to perform their duties. “In this case, the ethicist can help to identify ways for that surrogate to step down,” says Margie Atkinson, DMin, BCC, director of pastoral care, ethics, and palliative care at Morton Plant Mease Hospitals/BayCare Health System in Clearwater, FL. This allows the next available person who can abide by the patient’s wishes, by statute or alternate status, to move into the surrogate role.

The Illinois Health Care Surrogate Act provides a hierarchy of next-of-kin candidates for surrogacy. This is followed by healthcare providers in absence of a power of attorney or court-appointed guardian. “This law
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Surrogates may be ill-suited for the role due to lacking capacity themselves or failing to act in the patient’s best interest. Ethical approaches include:
• identify ways for unwilling surrogates to step down;
• as a last resort, seek appointment of a guardian;
• employ mediation skills to identify acceptable solutions.

is reiterated in our policy, and easy to work through,” says Kathy Johnson Neely, MD, MA, medical director of the medical ethics program at Northwestern Memorial Hospital in Chicago.

The clarity of the law makes selection of surrogates very straightforward. There is rarely a reason to involve ethicists to identify a surrogate under the law. “But it may create new problems when an incapacitated, uncaring, or even nefarious surrogate is designated,” says Neely. The following are recent case examples where ethics stepped in:

• A frail woman suffering from dementia was hospitalized, and the husband insisted on making decisions. Yet it became clear he also struggles with cognitive issues. “This happens fairly frequently,” says Neely.

Ethical decision-making strives to ensure that the goals and plan of care are wise, and the discharge plan is safe. At the same time, ethics would urge the clinical team to not summarily dismiss a loving husband.

“The clarity of the law makes selection of surrogates very straightforward. There is rarely a reason to involve ethicists to identify a surrogate under the law. “But it may create new problems when an incapacitated, uncaring, or even nefarious surrogate is designated,” says Neely. The following are recent case examples where ethics stepped in:

• A frail woman suffering from dementia was hospitalized, and the husband insisted on making decisions. Yet it became clear he also struggles with cognitive issues. “This happens fairly frequently,” says Neely.

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“Are there win-win negotiations that could encourage the husband to lean on trusted family or friends, and recuse himself as surrogate?” asks Neely. Only as a last resort would ethics recommend the appointment of a guardian. Even then, ethics would work with the guardian to include the husband as much as possible.

• An older patient with dementia received a surprising diagnosis of HIV/AIDS dementia. His wife was anticipated that the patient, once treated, might regain capacity? Are there other loved ones who can support his wife?

“We would also note the conflict in Illinois law,” notes Neely. The AIDS Confidentiality Act forbids a physician from disclosing HIV status to a spouse, unless the physician has asked the patient to do so, and after a reasonable amount of time — clearly impossible in this case. At the same time, the Illinois Health Care Surrogate Act allows surrogates access to all information that a patient is entitled to. “And common sense would have it that a surrogate has all the clinical information needed to make ethically permissible decisions,” says Neely.

Given these complexities, ethics would assist the team in determining whether and how to disclose the patient’s HIV status.

• A woman suffered a postpartum hemorrhage, necessitating temporary mechanical ventilation support in the ICU. The woman had been with a long-term partner for years, and this was their third child. Her estranged parents arrived at the hospital, and used their status as surrogates to send the woman’s partner away from the bedside.

• Surrogates in the ICU setting often insist on aggressive care. As days turn into weeks, the patient becomes chronically critically ill. The surrogate becomes difficult to contact, and is a reluctant participant in the decision-making process.

The next step, says Neely, is for the ethics consultant to “employ mediation skills to understand the interests of the stakeholders and come up with acceptable solutions.”

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Complex Research Ethics Question?
Consultants Offer Their Expertise

A public health researcher was unclear on the ethical implications of a “secret shopper” concept — in this case, to see how many local stores failed to ask children under 18 for identification before selling them cigarettes. Another researcher wanted to recruit adolescents with chronic illness for a study through social media, but was unclear how to go about ethically obtaining parental consent.

These are two recent issues handled by the research ethics consultation (REC) service at Johns Hopkins. The REC serves as a resource to help answer investigators’ ethical questions. “We have created a place to come talk about research ethics that’s different from the IRB. It is an educational opportunity,” says Holly Taylor, PhD, MPH, PhD program director and core faculty at the Johns Hopkins Berman Institute of Bioethics in Baltimore.

Taylor is lead author of a recent paper on a national REC collaborative. Based on data collected on more than 350 consultations, the authors concluded that REC can assist investigators:
• before and after regulatory review;
• when facing challenging or novel ethical issues;
• navigating informed consent and risk/benefit analysis;
• overcoming study hurdles;
• mediating conflicts within a team;
• directly engaging with research participants.

“What researchers really want is the opportunity to talk to a person about their work,” says Taylor. “That’s really the reason we were created — to meet the investigator where they are.”

The REC works independently from the institution’s IRBs, although the IRBs occasionally reach out for help with challenging cases. Researchers typically seek help early in the process when thinking about recruitment or what populations to include. “The vast majority of consults we get are long before it gets to the IRB,” says Taylor.

Most questions are about study design or informed consent. Sometimes, investigators are recruiting in a region with low literacy levels and need to determine how to obtain informed consent in this population, for instance.

Consultants at Johns Hopkins assess the satisfaction of participants by asking, “Did you get the information you wanted? Would you recommend it?”

“We would like to do a more robust evaluation in the future,” says Taylor. “Perhaps it would be even more powerful if we as a group identified key outcome measures that consultants could collect across institutions.”

The REC service emphasizes education, as opposed to helping investigators gain IRB approval or grant money. “My goal is to help them realize they already know the answer and I’m helping them get there. I’m interested in helping them build their ethics capacity,” says Taylor.

Any and All Areas

Zubin Master, PhD, a consultant at the Mayo Clinic’s biomedical ethics research program, authored a recent paper arguing that the scope of REC services should be expanded. “There is a need for it. It’s a necessary role. It can help solve issues that arise and prevent issues from escalating,” says Master.

At Mayo Clinic, the REC service handles a wide range of issues. These include authorship, mentorship, and conflicts of interests. At Albany (NY) Medical College, where Master was an associate professor at the Alden March Bioethics Institute, a REC was created by the bioethics department. “We did have people coming to us with these sorts of questions,” says Master. “It could be a small chat around an issue, or something that took several days with lots of back and forth.”

Scientists may primarily perform animal research, but are now working with human embryos. They may find that their research integrity office lacks ethics expertise specific to this area. “They can call people like us,” says Master. “We handle any and all areas surrounding research ethics.”

Sometimes, the IRB turns to
the REC service for assistance. “It might be over a consent form, unfamiliar research, or a vulnerable population is involved and they just want somebody to double-check something,” says Master.

One issue is that struggling investigators do not always know REC exists at their institutions. Generally speaking, clinical ethics services are “much better embedded institutionally,” says Master. “This is just anecdotal, but people we’ve asked are not necessarily even aware that research ethics consultation services exist.”

Accessible to All

Not every institution offers an in-house REC — but that does not mean REC services aren’t accessible to researchers. The national collaborative hosts a monthly call where a member of the group presents a case and how it was resolved. Any institution can participate in these calls.

“We offer consultations to individuals at institutions that don’t have a consult service,” says Taylor. “Not every institution is going to have the expertise in-house, whether in the IRB or elsewhere.”

However, the service doesn’t need to be resource-intensive. Smaller institutions could conceivably start it up on their own. “If you can find a champion in the institution with research ethics expertise — and there always is — certainly, those people could start a research ethics consultation service,” says Master.

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Law Enforcement Requests Conflict With Nurses’ Ethical Obligations

Nurses around the country are noticing a disturbing trend: Some patients suspected of violent crimes are admitted for medical care but are not arrested.

Danisha Jenkins, MSN, RN, CCRN, manager of the trauma stepdown unit at UC San Diego Health, explains that this might be an unintended consequence of well-intentioned prison reform.

In California, newly passed legislation moved people with selected felonies from state prisons to local county jails, affecting local budgets. To offset the shortfall, it appears that suspected criminals injured during a crime are at times not placed in custody for the duration of hospitalization, with the goal of arrest upon discharge. “In this manner, the city does not pay for the hospital stay or the guard to protect the healthcare workers,” says Jenkins. “But where does that leave the clinicians?”

Law and Ethics Collide

When a man with a gunshot wound presented for medical care, a police officer notified inpatient nurses that the patient was a dangerous felon. He further explained that police intended to arrest the patient upon discharge. The nurses were asked to facilitate this by giving updates on the patient’s condition and time of discharge.

This put nurses in an ethically difficult position. Nurses are duty-bound by a code of ethics, while police are focused on the law. “The two collide in the middle in these situations,” says Judy E. Davidson, DNP, RN, FCCM, FAAN, a nurse scientist at UC San Diego Health.

This was not the first case that nurses had seen. “We struggled trying to figure out how to handle these situations,” says Davidson. Nurses turned to security, privacy, risk management, and legal counsel; however, all of these hospital resources were accustomed to viewing issues from a legal perspective.

“It wasn’t until we refocused the work as an ethical issue and pulled everyone together to evaluate the case through an ethics lens that we...
were able to make real progress,” says Jenkins.

Nurses saw a clear conflict between their ethical obligation to care nonjudgmentally for patients and the request to act as agents of the law by guarding and reporting alleged criminals. The safety of clinicians and other patients was another obvious concern, as were patient privacy regulations. Nurses called ethics for help.

Since there were recurring cases, ethics took a systemwide approach. “The ethics consult team helped mediate how the organization as a whole should handle these situations, instead of consulting on just one case,” says Davidson. After ethics got involved, the nursing division, privacy office, legal counsel, and security department together created the following process:

- the primary nurse is removed from the responsibility of calling for the arrest of patients;
- all law enforcement inquiries will be directed to security, with strict adherence to patient privacy regulations;
- if an in-hospital arrest appears likely, an emergency meeting is held. “Unit leaders, security, and clinicians would determine what interventions are needed to ensure everyone’s safety while maintaining the rights of the patient,” says Davidson.

The hospital now has a solution in place to address the issue with law enforcement. “But there is still more work to do to negotiate the relationship between law enforcement and healthcare during these austere times,” says Jenkins.

Nurses should not be expected to guard patients, says Jenkins: “The larger societal issues need to be addressed through collaboration between our professional clinical organizations, law enforcement, and elected officials.”

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Revised Guidelines, New Data Shed Light on Palliative Care

A survey of 347 hospice and palliative care professionals sheds some much-needed light on the current state of palliative care.

There were several important findings, says Lori Bishop, MHA, BSN, RN, CHPN, vice president of palliative and advanced care at National Hospice and Palliative Care Organization (NHPCO). The goal was to understand the following:

- how many of NHPCO’s members are currently providing palliative care services;
- the depth of those services;
- the barriers and challenges members face.

“We also wanted to understand how best to assist them to ensure high-quality care and program sustainability,” says Bishop. The goal is to promote access to the right service at the right time for seriously ill individuals and their families. Some key findings from the survey include:

- 88% of respondents either have created a program or are in the process of developing one;
- of those with existing programs, most have been serving patients for more than three years. “Program sustainability can be a big issue in palliative care due to limited funding and reimbursement,” says Bishop. Notably, respondents identified reimbursement as their biggest challenge.
- Most programs use an interdisciplinary team.

“This is important for person-centered holistic care,” says Bishop.

All seriously ill individuals should have access to palliative and hospice care, says Bishop. While hospice care is a Medicare benefit and is accessible for most Americans, access to palliative care is more limited.

“Vulnerable consumers are confused about how to access palliative care and what services they can expect,” says Bishop.

Bishop says that ethicists in the hospital setting should ask the following:

- Do all seriously ill patients have timely access to palliative care services?
- Are seriously ill patients connected to community-based palliative care services prior to transition/discharge from the hospital?
- Do terminally ill patients have timely access to hospice care?
- Does the palliative care service provide metrics to demonstrate their
value and ensure continuous quality improvement?
• Is the palliative care team interdisciplinary, including access to social workers and chaplains?

Most palliative care services are only available in-hospital. “Seriously ill individuals and their families would benefit from being able to access these services in the community, ideally in their homes,” says Bishop.

The National Consensus Project’s newly revised Clinical Practice Guidelines for Quality Palliative Care emphasize the importance of interdisciplinary care and care coordination as patients move across care settings.1 “Palliative care services in the hospital setting should strive to meet the guidelines,” says Bishop.

Most providers are following the guidelines, which set basic expectations for all palliative care programs. However, 32% of respondents were unsure, not familiar, or not following them at all.

“We revised the guidelines because the field of palliative care is growing so rapidly,” says Betty Ferrell, PhD, CHPN, FAAN, FPCN, co-chair of the guidelines. Ferrell is director and professor of nursing research and education at City of Hope in Duarte, CA.

There is recognition of the need to integrate palliative care into the practice of all clinicians caring for the seriously ill. “This edition of the guidelines continues to build the specialty practice of palliative care,” notes Ferrell. But it also emphasizes the role of all clinicians who care for the seriously ill, and across all settings and all ages. “This edition has added content and practice examples to demonstrate how palliative care can best be integrated into all care,” says Ferrell.

There are critical issues of ethical concern in all areas of the guidelines. These include pain and symptom management and care of patients approaching death. “We want ethicists to be familiar with the guidelines, help us to disseminate them, and to use them to support their practice,” says Ferrell.

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Ethics of Genetic Research on Alcohol Addiction

Genetic testing is not yet ready for use in the prediction of alcohol dependence, according to a recent ethical guidance.1

“The guidelines had a dual focus,” says lead author Audrey R. Chapman, PhD, a Healey professor of medical ethics and humanities at UConn Health in Farmington, CT.

The authors set out to:
• identify the ethical issues and requirements related to carrying out genetic research on addiction;
• specify the ethical, legal, and public policy implications of the interpretation, translation, and application of this research.

“There is a need to guard against genetic research being misunderstood and misused,” says Chapman. The goal is to contribute to more ethically sensitive research and more socially responsible policies. For example, the potential for stigmatization carries implications not just for the individual but also family members.

“Yet there has been little literature exploring the ethical requirements of this research and its implications for public policy,” says Chapman.

A better understanding of the genetic contributions to addiction could lead to more effective treatment. This could lead to the development of drugs with fewer adverse side effects. There also is the hope that genotyping could better match patients to existing pharmacological treatments for addiction. “These hopes have fueled medical investments in this field of research,” says Chapman.

The ethical guidelines identify the limitations of this paradigm. “Alcohol dependence is a complex, multifactorial polygenic disorder,” notes Chapman. Evidence suggests it is unlikely that one or even a small number of genes will be identified that explain all the variance in its heritability. “Hopefully, the guidelines will help shape future research on the genetic dimensions of alcohol dependence,” Chapman says.

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Ethical Concerns With Quality Ratings of Nursing Homes

Quality ratings of nursing homes are not necessarily what they seem, according to a recent analysis.¹ Researchers analyzed 264 reviews of 51 nursing homes in California. Yelp reviewers gave significantly less favorable ratings than those found on the Centers for Medicare & Medicaid Services (CMS) Nursing Home Compare website.

“Consumers view the quality of nursing homes as poorer than the CMS is reporting it to be,” said Anna Rahman, PhD, a co-author of the study and an assistant research professor at the USC Leonard Davis School of Gerontology in Los Angeles.

More than half of Yelp reviewers posted comments related to staff attitude and caring. Nearly one-third commented on staff responsiveness. Yelp reviewers often posted about the physical environment. Quality of healthcare provided and concerns about resident safety and security were mentioned infrequently. In contrast, Nursing Home Compare ratings focus solely on staffing levels, clinical processes, and outcomes.

Each ratings system has drawbacks, says Rahman: “We advise consumers to consult both sites and then do their own research by visiting the nursing homes they are most interested in.”

Warning consumers about the limitations of Yelp ratings is probably not necessary, says Rahman. Most people are aware some reviews are inaccurate, biased, or even fake.

“In contrast, CMS, as a federal agency professing a commitment to promoting transparency in healthcare data, has a special obligation to inform consumers about known and suspected limitations of its Nursing Home Compare ratings,” says Rahman.

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Ethics of Genomics Consent: Little Is Known on This Issue

Is a patient willing to give consent to participate in genomics research? What about genetic testing in clinical care? Privacy concerns are a factor in both decisions.

To learn where things stand on individuals’ views on privacy and genetic data, researchers analyzed 53 studies involving the perspectives of 47,974 participants.¹

“The thing that was most surprising to me is how little we know about this issue,” says Ellen Wright Clayton, MD, JD, the study’s lead author and co-founder of Vanderbilt University’s Center for Biomedical Ethics and Society in Nashville, TN.

The researchers concluded that “the picture of genetic privacy that emerges from this systematic literature review is complex and riddled with gaps.” Findings include the following:

- When asked specifically “Are you worried about genetic privacy?” the general public, patients, and professionals frequently said yes.
  “In many cases, however, that question was posed poorly or only in the most general terms,” says Clayton.

- Many participants expressed concern that genomic and medical information would be revealed to others.
  “Respondents frequently seemed to conflate privacy, confidentiality, control, and security,” notes Clayton.

- Views varied widely in how much control participants wanted over the use of data.

In general, they were more concerned about use by employers, insurers, and the government, and less concerned about researchers and commercial entities.

“Privacy is a complex topic, involving, among other things, issues of how people want to be seen, how much control they have and want, and what kinds of harms they are concerned about,” says Clayton.

Privacy often is not an absolute. “People often share information in order to get other goods. But the idea of tradeoffs has only recently been explored,” says Clayton.

Despite these complexities, many investigators simply asked people if they were worried about privacy. Much more attention was paid to employment and insurance
Discrimination than any other topic. “At a minimum, such explorations should place genetics in the broader data context,” says Clayton.

Specifically, more data are needed on what tradeoffs people are willing to make, and why. “We need a much more nuanced understanding of what people think, if these data are to be helpful in developing policy,” says Clayton.

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Late Referrals to Hospice Continue, Due Largely to ‘Fear and Stigma’

Despite emphasis on the importance of early referral, patients with advanced disease are receiving palliative care very late in their illness trajectory, found a recent study from the United Kingdom. The median time from referral to death for 42,758 decedents was 48 days. Significant differences in referral to death days were found for those with cancer (53 days) and noncancer (27 days).

“Age and diagnosis persist as determinants of duration of hospice specialist palliative care before death,” says Matthew Allsop, PhD, the study’s lead author and a researcher at England’s Leeds Institute of Health Sciences.

Reorientation of Services Necessary

The findings suggest a need for reorientation of services to both older age groups and noncancer conditions, says Allsop. Both groups are associated with limited duration of hospice-based palliative care prior to death.

“As people are living longer with an increased illness burden, many patients will need primary, secondary, and specialist palliative care,” adds Allsop. Efforts to reduce hospitalization in the last months of life, and to support preferences for dying at home instead of the hospital, are resulting in increased out-of-hospital demand for palliative care.

Thus, says Allsop, “it is particularly important that community-based specialist palliative care consider how provision might match demand.”

Late Referrals Are Norm

Camilla Zimmermann, MD, PhD, FRCPC, says results would be similar in the United States and Canada. “Unfortunately, referrals to palliative care continue to occur late in the disease course, across countries and settings,” says Zimmermann, head of the palliative care program at the University Health Network and the Princess Margaret Cancer Centre in Toronto.

For noncancer patients, late referrals are partly due to difficulty prognosticating. It is always hard to predict how long a patient will live, and physicians tend to be optimistic. “For patients with cancer, it is also getting harder to predict survival,” says Zimmermann, adding that newer, targeted treatments and immunotherapies are helping patients live longer.

However, the biggest reason for late referrals is fear and stigma attached to palliative care, says Zimmermann. Patients and even healthcare providers assume that consulting palliative care means death is imminent.

In fact, says Zimmerman, it helps control symptoms and provides much-needed support: “Ethicists can play a role by explaining to patients and clinicians that palliative care can and should begin early.”

REFERENCE

SOURCES
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CME/CE QUESTIONS

1. Which is true regarding clinicians’ providing care viewed as futile or potentially inappropriate, according to a recent study?
   a. Very few considered leaving their jobs as a result of providing such care.
   b. Most clinicians were aware of the issue, but few had personal experience providing such care.
   c. The amount of perceived futile care provided was significantly associated with burnout and thoughts of quitting.
   d. More clinicians screened positive for depression than burnout.

2. Which is true regarding research ethics consultation (REC) services at Johns Hopkins?
   a. REC services primarily have a compliance role at most institutions.
   b. The REC service can override decisions made by IRBs.
   c. Recommendations made by REC are frequently in conflict with IRB decisions.
   d. Most consults involve study design or informed consent.

3. Which do revised palliative care guidelines state?
   a. Reimbursement of providers is no longer viewed as a challenge.
   b. There is a need to integrate palliative care into the practice of all clinicians caring for the seriously ill.
   c. Palliative care services should be available only in-hospital.
   d. An interdisciplinary approach is not feasible with palliative care due to the unique nature of the specialty.

4. Which did a recent study find about timing of hospice referrals?
   a. Patients with cancer are referred later than noncancer patients.
   b. The median time from referral to death declined sharply in recent years due to emphasis on early referrals.
   c. Older age groups are linked to limited duration of hospice-based palliative care prior to death.
   d. Improved ability to prognosticate has resulted in much earlier referrals for noncancer patients.