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INSIDE

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Surrogate Decision-makers Face Ethical Questions If Patient Has Dementia

Challenges mirror those of other surrogates but "on steroids"

Even when the prior wishes of a patient with dementia were known, the process of decision-making was often fraught with complexity, found a recent study.[1] Researchers interviewed 34 family members who had taken on the role of surrogate decision-maker. Most reported there was not an advance care plan in place for the person living with dementia.

"The challenges for surrogate decision-making in patients with dementia are like all such challenges, but on steroids," says **G. Kevin Donovan**, MD, MA, director of the Pellegrino Center for Clinical Bioethics at Georgetown University Medical Center in Washington, DC.

Directives Difficult to Interpret

Many dementia patients don't have advance directives. When they do, they may have a living will, which becomes

EXECUTIVE SUMMARY

Surrogate decision-makers face these unique ethical considerations if the patient has dementia:

- Many dementia patients don't have advance directives.
- Advance directives don't always address dementia.
- Surrogates may lack sufficient information about the patient's wishes.
- It may be unclear whether a patient's wishes prior to their decline should take precedence over the patient's current wishes.

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difficult to interpret. "Or, they may have an appointed surrogate with whom they had insufficient conversation about the values they hold most significant," says Donovan.

Advance directives are often silent on the issue of how an individual wishes to be treated if they develop dementia. **Ben A. Rich**, JD, PhD, emeritus professor and School of Medicine Alumni Association Endowed Chair of Bioethics at the University of California-Davis Health System, explains, "We are still in the early stages of incorporating dementia into advance care planning and advance directives."

Even patients with advanced dementia don't always require medical interventions such as mechanical ventilation, artificial nutrition and hydration, or renal dialysis, which can be prospectively refused by means of a directive. "An individual might execute a very detailed directive indicating they do not wish their life prolonged in a profoundly demented state," says Rich. Such a directive would be ineffective, however, in preventing the provision of nutrition and hydration by mouth. Rich recommends that ethicists educate both healthcare professionals and patients about the importance of including dementia in advance directives.

Even so, it's problematic trying to honor the wishes of a dementia patient who indicated their wish to withhold or withdraw life-sustaining medical treatments in the future as they decline. Donovan explains, "It's often unclear how much of a decline should trigger their advance directive."

If the advance directive includes assisted suicide or voluntary stopping of eating and drinking, the question becomes whether the patient's anticipated low quality of life should take precedence over the patient's current wishes. "Should surrogates hesitate to act when the patient with dementia seems happy, comfortable, and content with their present state?" asks Donovan.

Patients may have made a judgment about their quality of life in advance. However, Donovan says surrogates should not unilaterally impose their own values on patients who, although diminished, seem comfortable and content in the present. "Otherwise we may see more incidents like in the Netherlands recently, where a doctor and family held a woman down to euthanize her over her objections and despite her resistance, because she had indicated that she might prefer that someday if things got bad enough," says Donovan.

No Easy Answers

Evelyne Shuster, PhD, member and former chair of the Ethics Consultation Services at the Philadelphia VA Medical Center, says cases where the patient never had decision-making capacity are most difficult. "Healthcare providers cannot share treatment options with the patient, and they have no idea what the patient would want done," she explains.

Physicians' only option, therefore, is to discuss with the next of kin or surrogate the risks and benefits of possible treatment, including no treatment, and to act in the patient's best interest — including making sure that the patient will not be worse off. Ideally, healthcare providers would listen to the surrogate's concerns about the patient's welfare, and explain possible treatments so that an informed choice can be made that is consistent with good medical practice and good medical

ethics. "There may be a number of obstacles to overcome in the process of achieving this end," Shuster says. Hospital policies on withholding and/or withdrawing of hydration and nutrition are one example. "To avoid conflict, the surrogate should inquire about these and other similar policies before hospitalization of the mentally incapacitated patient," says Shuster.

Less problematic are cases where the patient had decision-making capacity, but is now demented and unable to speak for himself or herself about what he or she would want done. "This patient, now incapacitated, may have a valid advance medical directive document where he or she named a surrogate," says Shuster.

The surrogate's goals are to speak on the patient's behalf and ensure that his or her wishes are respected, and thus, make an informed choice in agreement with the patient's expressed wishes. "If the wishes of the patient cannot be determined, others will make medical decisions for that patient," says Shuster. "I doubt this is what a person would want for oneself."

Shuster adds, "The most important thing I have learned in my profession is that there is in each person an incredible will to maintain one's own integrity, control, dignity, and a sense of self."

This is undermined when others make decisions on the patient's behalf without the patient's consent, based on wishes that are not the patient's. "This is what happens when no one knows what the patient's wishes are and there are no advance directives to consult," says Shuster.

Shuster once consulted on a case involving a nursing home patient with mental incapacities, but who had decision-making capacity. The patient wanted solid food, and adamantly refused to eat whenever the food came pureed.

"In talking to him, I began to understand how important food was to him, but the real issue was not the food," says Shuster. The real issue was the patient's desire to maintain a sense of control over his life. "Eating lunch the way he envisioned was his way to tell himself and the world, 'I am here, alive and in control of my life; I am not a child. You must respect my wishes of wanting to eat my lunch the way I can enjoy it,'" says Shuster. The patient understood the risks involved, such as aspiration or pneumonia, and was willing to take those risks.

"But sadly, as I understand it, his request for solid food was denied," says Shuster. "These are difficult cases which have no easy answers." ■

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ED-Initiated Palliative Care Yields Dramatic Cost Savings

ED-initiated palliative care consults have the potential to decrease costs and length of stay, found a recent study.[1]

"We anticipated that creating a culture and redesigning workflows, which made it easier to obtain palliative care consults in the ED, would lead to better outcomes for patients and families, in that care choices would be aligned with patient wishes," says lead author **Robert Femia**, MD, chair of the Ronald O. Perelman Department of Emergency Medicine at NYU Langone Medical Center.

The ED set out to make it "easy, acceptable, and the norm" for ED providers to initiate the palliative care consult in the ED, says Femia. "We went from 66 to 226 palliative care ED consults annually."

A Culture Change

Researchers conducted a retrospective chart review on all ED patients who received a palliative care consult in 2014. The consults were either initiated by the EP, or at

a later time during their inpatient admission. The researchers compared length of stay and costs for 226 patients who received an ED-initiated palliative care consult, with 618 patients who received the consult at a later point in their hospital stay. Their findings include the following:

• For patients who had an ED-initiated palliative care consult, resultant hospice placement, and a length of stay greater than two days, the average length of stay was 5.5 days. The average direct variable cost was $5,856.

• If the palliative care consult was initiated outside of the ED with eventual hospice placement, the average length of stay was 8.6 days. The average direct variable cost was $15,431.

"Our dramatic rise in obtaining ED palliative care consults was the result of a work group that was formed between emergency medicine, palliative care, social work, nursing, and others," says Femia.

The ED's new process allows not only physicians, but also nurses and social workers, to initiate requests for palliative care consults. "One of our obstacles had been a culture where approval of the private medical doctor was needed to obtain a palliative care consultation," Femia explains.

Previously, many ED providers weren't aware of the services offered by the palliative care team. There was also lack of clarity about the depth of conversation expected of the ED provider when discussing end-of-life issues with the patient and family.

"Multiple education initiatives were undertaken," says Femia. "Real-time reference materials were made available in the ED."

ED providers were encouraged to start a gentle conversation with family, inquiring as to whether they had decided on their goals of care. "However, based on comfort level, these conversations could be deferred to the palliative care consultant," says Femia.

For some patients, a shared decision-making process avoided tests, interventions, hospitalizations, and other care that the patients felt were unnecessary and not aligned with their goals.

"By having discussions about goals of care, it is not surprising that some patients avoided options that they presumably felt were unnecessary, futile, painful, and not aligned with their desires," says Femia. The study demonstrated that it also resulted in lower costs to the healthcare system.

Femia expects to see more options made available to dying patients earlier in the course of their visit to the healthcare system. "Better care coordination will become the norm, via new interfaces such as telehealth, care navigators, outpatient, and home-based options," he says.

Robust shared decision-making by informed patients who understand multiple care options available to them, says Femia, "represents a high ethical standard." ■

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ICU Strain Speeds Timing to Withdrawal of Life-sustaining Therapy

End-of-life care can be performed more efficiently

During busy periods in the ICU, decision-making regarding withdrawal of life-sustaining therapy is made more quickly, found a recent study.[1] Researchers analyzed the effect of ICU capacity strain on 9,891 patients dying in the hospital.

"Prior work had looked at standard outcomes like mortality. We were interested in looking at end-of-life care because it is a time-consuming process," says study author **May Hua**, MD, assistant professor of anesthesiology at Columbia University Medical Center in New York City.

Some of the researchers thought the process would take longer because of the need to discuss the situation with the family. Hua was in this group. "Getting people to the point of realizing that therapy isn't working is time-consuming," she notes.

The rest of the researchers expected

the process to be shorter, and ended up being correct. "They hypothesized that if providers know someone isn't going to do well, they will expedite decision-making in order to free up a needed bed for another patient," says Hua.

If the study had found longer time frames, Hua would have used it as an argument to increase palliative care consultation to facilitate end-of-life discussions. "But the data suggest that we can perform more efficiently at end-of-life care if we are feeling pressured to do so," says Hua. "This suggests that maybe this is a movable target in some way."

Time frames to initiate do-not-resuscitate orders and time to death were shorter during high-capacity times. Some previous research echoes these findings. In Canada, when calling a rapid response team on the floor, the likelihood of having a goals-of-care discussion goes up when there are no available beds on the floor.[2]

"Ethically, you'd think that the process wouldn't be affected by non-patient-centered variables, but they are," says Hua. "We potentially can be more efficient."

Slippery Slope

If the patient is ultimately not going to survive, delaying the dying process in any way is potentially engendering more suffering. "At the same time, you don't want to hasten the dying process," says Hua. "There is a delicate interplay where you need to be sensitive to all of those factors."

In Hua's experience, it's not uncommon for the dying process to be prolonged. One often-cited reason is that families haven't come to terms with things. "That's where we are as a society, and some prolonged suffering exists because of that. At the same time, you see the slippery slope," says Hua. If providers move too far in the other direction, they may be hastening death, or even facilitating death in some patients who would otherwise survive.

The study didn't look at family outcomes. "We know that caregivers of ICU patients go on to suffer psychologically," says Hua. Whether the quality of communication from an ethicist or palliative care specialist would be better than the hospitalist's is unknown. Also unknown is how the quality of communication affects the grieving process. "So while we may be able to do it faster, it's only one metric to look at," says Hua. ■

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Pediatric End-Of-Life Care: An 'Additional Layer Of Complexity'

Education on the unique challenges of providing end-of-life care to children, the importance of self-care, and timely multidisciplinary debriefings are key strategies for improving healthcare staff's experiences and the quality of care they provide, found a recent review of the literature.[1]

"Pediatric palliative care has become a well-established field," notes **Lainie Friedman Ross**, MD, PhD, Carolyn and Matthew Bucksbaum professor of clinical ethics and associate director of University of Chicago's MacLean Center for Clinical Medical Ethics.

One issue raised historically was the ethics of withholding and withdrawing life-sustaining treatment, including fluids and hydration. The American Academy of Pediatrics (AAP) has a long-standing statement outlining its permissibility and some of the criteria for when it is appropriate.[2] A second ethical issue — what role the child should play in end-of-life decision-making — is also addressed in AAP policy statements.[3] Ross feels clinicians would benefit from an ethics consult in the following situations:

• when parents disagree about end-of-life treatment goals;

• when the family is demanding resuscitation when it is clear the child will not benefit and the child is suffering.

"Ethicists can provide support to clinicians to resolve family disagreements," says Ross. "They can work with families who lack trust in

the clinical care team due to family-team disputes."

Disagreement With Decisions

Clinical team members may disagree with a family's decisions or the timing of a decision. "They may be angry because of the amount of suffering they believe a child has suffered, due to family's decisions to push on long after the team believes that aggressive care is more burdensome than beneficial," says Ross.

Ross says such moral distress can be exacerbated when a patient has been in a unit for a long time, or has had a protracted course during which time the care team has become quite emotionally attached to the patient.

Ethicists can provide support with a timely debriefing. "This can be particularly important if the child dies unexpectedly, or if there has been conflict between the many specialties that have been caring for a child," says Ross.

Pediatric end-of-life care is different in that the child isn't usually able to make his or her own decisions independently as some adults can, notes **Becky Benson**, MD, PhD, medical director of the Pediatric Pain and Palliative Care Program at University of Iowa Children's Hospital. A decision may need to be made about whether to forgo treatment, or whether to choose an experimental or high-risk treatment.

"That adds an additional layer of complexity for pediatric healthcare professionals, and for parents as they're trying to navigate what can be a very uncertain situation," says Benson, also medical director for clinical ethics and director of the ethics consult service at University of Iowa Hospitals and Clinics in Iowa City.

IT'S NOT ALWAYS CLEAR THAT THE PATIENT'S BEST INTEREST, WHAT THE FAMILY IS CHOOSING, AND WHAT THE MEDICAL TEAM IS OFFERING, ARE ALL ALIGNED.

It's not always clear that the patient's best interest, what the family is choosing, and what the medical team is offering are all aligned. "In those cases, involving someone with pediatrics ethics expertise can be extremely helpful," says Benson.

If an infant or young child is under consideration for surgery with a fairly low likelihood of success, for instance, families often aren't sure what to do. "They may feel pressure to make one decision or another, based on discussion with the healthcare team," says Benson. Talking with an ethics consultant can help them figure out what's most consistent with their goals and values, and what is best for the patient. The following are other ways ethicists can help:

• Breaking things down into a series of smaller decisions.

"It can be very overwhelming to think about some of the bigger decisions," Benson explains.

• Asking clinicians to think carefully about the language they use.

At times, the healthcare team tells a parent that their child "needs" a treatment, such as a surgery or a tracheostomy. "If later on, we then tell them it's an 'option,' or recommend that they don't choose it, it can be very hard for them to fit that with their previous idea that this is something their child needs," says Benson.

Asking families, instead, to consider a treatment or medication on a "trial basis" can minimize conflict. "This can help people recognize that taking a step in one direction doesn't necessarily mean we need to continue on that path," Benson explains.

• Reminding the healthcare team to ask about families' values and goals.

"When they have to make a challenging decision, we can go back to that basic layer of values," says Benson.

Often, the clinical team presents options in an "a la carte menu style," says Benson. "We are then disappointed by the choice the family makes, when we really haven't given

EXECUTIVE SUMMARY

Ethicists can encourage clinicians to consider language used to communicate with parents and ask about the family's values to ensure ethical pediatric end-of-life care. Ethics consults can help in the following scenarios:

- when parents disagree about end-of-life treatment goals;
- when there is a conflict between parents and the clinical team;
- when the family is demanding resuscitation when it is clear that the child will not benefit.

them enough guidance."

Knowing the family's values and goals, she explains, "helps us make recommendations that are shaped by what the family has told us is important to them." ■

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Big Data in Healthcare: Privacy Is Major Ethical Concern

Big data is an emerging ethical challenge for healthcare privacy — "a tsunami, really," says **Gerard Magill**, PhD, Vernon F. Gallagher chair and professor at Duquesne University's Center for Healthcare Ethics in Pittsburgh.

It allows the targeting of specific interventions — not only for large groups, but also for individual patients, says Magill, "in a sophisticated manner that is not otherwise feasible."

There is no question that individual privacy will be compromised to some degree by computer analytics making use of vast amounts of personal information for medical care, research protocols, and health insurance.

While health data is protected by law, so much data is being collected from so many sources, "that law and custom haven't caught up with protecting information combined into what's called 'big data,'" says **Bonnie Kaplan**, PhD, FACMI, Yale Interdisciplinary Bioethics Center Scholar and faculty in the Yale Center for Medical Informatics at the School of Medicine at Yale University in New Haven, CT.

Medical record and prescription data are being used, and even sold, for a variety of purposes. As long as it's de-identified, patients' permission isn't needed.

"Besides the information people give clinicians as part of their healthcare, they also may freely give out health information via health-related social networking, web postings, and internet searches," notes Kaplan. Their various medical devices, wearables, or smartphone apps also can generate information. Not all of this is covered by HIPAA, says Kaplan — though many people think it is. Information is consolidated and linked with other data.

"Patients may have no idea what is done with that data, and how they may be helped or hurt by it," says Kaplan. Public health, research, entrepreneurship, and marketing uses of these data can help people. "Yet patients can be harmed when data about them are used to violate privacy; to deny employment, credit, housing, or insurance; or for identity theft and other unsavory purposes," says Kaplan. She sees the following as important ethical and legal questions:[1,2]

• As it gets easier to identify someone by combining information from multiple sources, is de-identification of clinical data sufficient for privacy protection?

• How meaningful is consent, authorization, or permission for data release when patients have little choice to get services that require it — such as insurance, participation in research, services that provide very highly priced drugs free or at low cost, or use of health-related social networks, smartphone apps, wearables, and monitors for various health purposes?

• How can the costs of collecting and curating data for beneficial purposes, such as public health, improving care, adverse event monitoring, and research, be recouped?

• How can we make secondary and subsequent data use more transparent, and allow people to consent (or withdraw consent) for both anticipated and unanticipated future uses?

• How can we advance beneficial data uses without compromising privacy or facilitating nefarious uses?

Kaplan says more discussion is needed about what data uses are acceptable, and what control individuals should have over data about themselves.

More transparency about data collection and uses, and about what the law does and does not protect, adds Kaplan, "can help people make wise choices about what they want to allow, and policy to be made as to harms and benefits."

Blair Henry, a senior ethicist at Sunnybrook Health Sciences Centre and assistant professor at the University of Toronto in Ontario, Canada, says there's a need to move away from a "zero-sum model" with privacy and research. Instead, he argues, "we need to 'design' privacy into our research at the front end — not wait until it's checked at the back end by an IRB."

Currently, there are no established standards for de-identification of health information. "We need to think about consent paradigms of the past, and how we need to adjust things for big data use," says Henry.

Magill says tracking individual consent for all possible uses will become "increasingly complex, and perhaps impossible." Some researchers are adding "open consent" to their informed consent processes, permitting personal data to be used for purposes beyond the immediate cause for giving the consent.

Sharona Hoffman, JD, professor of law and bioethics at Case Western Reserve University School of Law in Cleveland, observes, "Because there is so much good that can be derived from big data in the areas of research and medical advances, we may need to be a little bit less focused on privacy concerns." Hoffman is author of *Electronic Health Records and Medical Big Data: Law and Policy* (Cambridge University Press, 2016).

Education is needed to get public buy-in, however. Many lack understanding about the benefits of big data, fearing invasion of their privacy. "This is not the kind of story that often attracts media attention because it's not an immediate crisis," says Hoffman. "But it's important to get the word out there to counter some of the fear."

People may not realize that big data give researchers the ability to conduct post-market monitoring of drugs and devices to track how well they're working in actual patients, for instance. "And if they are hurting people, interventions can be quickly implemented," says Hoffman.

With the clear potential for widespread abuse by employers, insurers, or the government, ethicists say guidance is needed to protect the privacy of individuals as much as possible. Magill argues, "There is a need for sound regulation to guide and oversee this brave new world of algorithmic-based healthcare."

Going back to the old days is no longer possible, given the widespread use of electronic capacities in healthcare, he adds. "The genie is already out of the bottle." ■

EXECUTIVE SUMMARY

Healthcare privacy is a central ethical concern involving the use of big data in healthcare, with vast amounts of personal information widely accessible electronically.

- There is the potential for abuse by employers, insurers, and the government.
- Ethicists say regulations are needed to protect individual privacy as much as possible.
- "Open consent" permits personal data to be used for purposes beyond the immediate cause for giving the consent.

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Ethical Responses if Clinician Is Asked to Help Law Enforcement

When emergency medicine clinicians are caring for a patient in the custody of law enforcement, multiple ethical issues must be considered, says **Eileen F. Baker**, MD, FACEP, medical director of the ethics curriculum at University of Toledo (OH) College of Medicine and Life Sciences. Baker co-authored a paper analyzing this issue.[1] The following are some ethical issues that can arise:

• Physicians should make every effort to maintain privacy and confidentiality.

"A physician's first duty is to the care of his or her patient," says Baker. "Respect for patient privacy and confidentiality of personal information is paramount."

All patients, regardless of their legal status, should receive appropriate medical care. This includes criminal suspects, prisoners, or illegal immigrants, says Baker.

"Patients in custody have rights to provide informed consent and to refuse medical interventions," notes Baker. Exceptions occur when statute or court order mandates otherwise.

"Medical professionals may override privacy or confidentiality in the reporting of dangerous infectious diseases," notes Baker. The same is true when patients present a risk to themselves or others.

• Physicians may be asked by law enforcement agents to obtain toxicology screens or alcohol levels for patients presenting with intoxication or drug ingestion.

"If doing so is medically appropriate, the physician may perform these tests," says Baker. As a rule, she adds, physicians should not volunteer the results of tests unless permission is granted by the patient, or if there is a subpoena.

• There may be a need for evidence collection in cases involving motor vehicle collisions, assaults, or intoxication.

Such evidence might involve abuse of adults or children, or traumatic injuries. "In the course of law enforcement investigations, official photography and other evidence collection may be legally and ethically permissible," says Baker. A 2013 court ruling determined that intubating and administering medication to a patient to perform a rectal examination to retrieve drug packets was a violation of the patient's constitutional rights.[2]

"Physicians are not law enforcement officers," adds Baker. "Drug and alcohol abuse and immigration status are not reportable." ■

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Overly Strict Criteria For Clinical Trials Is Ethical Problem

Clinical trials routinely use overly strict enrollment criteria, found a recent study.[1] "Real-world patients are often excluded from clinical trials because they do not meet the restrictive eligibility criteria," says lead author **Abby Statler**, MPH, MA, research regulatory quality assurance coordinator for the leukemia program in the Department of Hematology and Medical Oncology at Cleveland (OH) Clinic.

Researchers studied the relationship between eligibility criteria and adverse events in randomized controlled trials of hematologic malignancies. "We wanted to understand if there are specific criteria that may be responsible for inappropriately excluding patients," Statler explains.

The results suggest that excluding patients with hepatic, renal, and/or cardiac abnormalities may not be justified, given the safety profiles of the study interventions. Of the 97 randomized controlled trials analyzed, for instance, 21% had the potential to cause nephrotoxicity. However, nearly 74% of the

trials excluded patients with renal abnormalities.

"The results relevant to neurological function did not follow this same trajectory," says Statler. "Our findings indicate exclusion of patients with peripheral neuropathy may not be conservative enough."

Health Equity Dilemma

Statler concludes, "Our findings suggest clinical research may unintentionally evoke a health equity dilemma."

Clinical trials are designed to contribute to society's general knowledge regarding the diagnosis, cure, mitigation, treatment, or prevention of disease. The study's findings suggest, however, that the studies' results are only applicable to a select cohort of patients. "These select groups of potential beneficiaries are essentially established by the respective clinical trials' eligibility criteria," says Statler.

Many commonly used exclusion criteria may not be appropriate, given the study interventions' safety profiles. Thus, their widespread use might lead to the exclusion of specific groups of patients. "Furthermore, because cancer is a life-threatening disease, access to novel therapies is essential," Statler says.

Additionally, overly restrictive eligibility criteria may limit the therapy options for specific patient populations, such as people with organ function abnormalities, or those with comorbidities. "This presents ethical issues related to justice," says Statler. ■

REFERENCE

1. Statler A, Radivoyevitch T, Siebenaller C, et al. The relationship between eligibility criteria and adverse events in randomized controlled trials of hematologic malignancies. *Leukemia* (7 December 2016) doi:10.1038/leu.2016.374

SOURCE

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Study: Ethics Consults Happen Earlier If Patient Is Female

Clinical ethicists at Springfield, IL-based Memorial Medical Center suspected that ethics consultations about limiting treatment were being requested earlier in patients' hospital stays for African-Americans than for other patients.

"It felt at times like there were 'quality of life' judgments made by hospital staff that made providers uncomfortable with certain care decisions made by minority patients or their families," explains **Christine Gorka**, PhD, director of the Clinical Ethics Center.

Gorka and colleagues decided to find out if the ethicists were right about race playing a role in the timing of ethics consults. The study, which was expanded to include gender, analyzed ethics consults for Medicare patients occurring in 2011 through 2014. All of the consults involved a question about limiting medical treatment. Some key findings include the following:

- Consultation requests for females were made, on average, 6.57 days after the patient was hospitalized, compared to 16.07 days for males.
- For African-American patients, the differences in admission-to-request intervals for female patients (5.93 days) and male patients (18.64 days) were greater than for Caucasian male and female patients.
- Ethicists spent more time on consultations with African-American males (316 minutes, on average), than on any other group studied. Consultations with Caucasian females (195 minutes, on average) turned out to be the shortest.

Bethany Spielman, PhD, JD, the study's lead author and a member of Memorial's Human Values and Ethics Committee, says, "We learned the ethics consultants' hunch was true only for African-American women."

Gorka found this especially surprising in light of the fact that a majority of the African-American female patients did not die or get discharged into hospice. It turned out that consultation requests for African-American men were made significantly later in their hospital stays than for other groups.

Another surprising finding: "Gender matters more than we originally thought it would," says Spielman. The pattern of early consultation requests for females and later requests for males carried over to Caucasians, though the difference

was not so striking as for African-Americans.

"None of the findings could be correlated with the presence or absence of an advance directive, the specific reason for the consult request, the attending physician's specialty, or whether the patient ultimately died during the hospital stay," notes Spielman.

Consider Possible Inequities

The American Society for Bioethics and Humanities recommends that ethics consultants "reduce disparities, discrimination, and inequities when providing consultations."[2] "Consultants will need to understand the race and gender interactions in their own institutions, and how they affect access to their consultation service," says Spielman.

Gorka says ethicists should:

- consider their own biases;
- be active in addressing disparities that may be linked to unintended or unspoken biases.

"Practically speaking, that can mean building a safe space for patient/family values to be heard — or, sometimes, pushing back when a care plan has become derailed," says Gorka.

REFERENCES

1. Spielman B, Gorka C, Miller K, et al. Gender and race in the timing of requests for ethics consultations: A single-center study. *J Clin Ethics* 2016; 27(2):154-162.
2. American Society for Bioethics and Humanities. (2011). Core competencies for healthcare ethics consultation (2nd ed.). Glenview, IL.

SOURCES

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Health Equity Study Finds 'Fundamental Lack Of Fairness'

The burdens of disease and the benefits of good health are inequitably distributed in the U.S. due to factors that range from poverty and inadequate housing to structural racism and discrimination, according to a new report from the National Academies of Sciences, Engineering, and Medicine.[1]

"Those already burdened with poverty are additionally harmed by worse health, representing a fundamental lack of fairness in our nation," says **Tia Powell**, MD, a member of the committee that conducted the health equity study and wrote the report. Powell is division head of biomedical and bioethics research training in the department of epidemiology and population health at Bronx, NY-based Montefiore Medical Center.

Community-driven interventions targeting these factors hold the greatest promise for promoting health equity, according to the report. "For communities to improve health outcomes, policies and interventions must recognize that differences in health are not primarily the result of individual choice," says Powell.

Rather, they reflect the effect of uneven access to benefits like access to transportation, jobs, education, healthy food, and safe and clean places to live and work. "Honestly addressing the systematic causes and likely solutions to achieve health equity can help provide fair opportunities for success to more Americans," says Powell. ■

REFERENCE

1. National Academies of Sciences, Engineering, and Medicine. 2017. Communities in action: Pathways to health equity. Washington, DC: The National Academies Press.

SOURCE

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CME/CE QUESTIONS

1. **Which is true regarding decision-making for patients with dementia, according to G. Kevin Donovan, MD, MA?**

   a. It is often unclear how much of a decline should trigger the patient's advance directive stating that the patient wishes to withhold or withdraw life-sustaining medical treatments in the future as they decline.
   b. Surrogates should override advance directives when determining the patient's wishes if the patient has advanced dementia.
   c. It is very rare to have an advance directive which doesn't specifically address dementia, as a result of widespread education on this issue.
   d. Advance directives indicating the individual does not want life prolonged in a profoundly demented state effectively prevent the provision of nutrition and hydration by mouth.

2. **Which did a recent study find regarding ICU strain and timing of withdrawal of life-sustaining therapy?**

   a. The process took the same amount of time regardless of volume.
   b. During busy periods in the ICU, decision-making regarding withdrawal of life-sustaining therapy is made more quickly.
   c. Fewer patients and families requested withdrawal of therapy during high-volume periods.
   d. Time frames to initiate do-not-resuscitate orders and time to death were longer during high-capacity times.

3. **Which is true regarding ED-initiated palliative care referrals, according to a recent study?**

   a. Overall cost of care increased due to the need for in-depth discussions.
   b. Hospital length of stay increased, but only for patients who weren't placed in hospice.
   c. Family satisfaction was high, but costs increased due to more utilization of the palliative care team and additional diagnostic tests ordered in the ED.
   d. Average length of stay decreased for patients who were placed in hospice care.

4. **Which is true regarding use of big data in healthcare?**

   a. Regulations to protect individual privacy would do more harm than good by creating negative impressions of big data.
   b. "Open consent" approaches permitting personal data to be used for purposes beyond the immediate cause for giving the consent are illegal and unethical.
   c. Even de-identified data require patients' permission to utilize.
   d. Information generated by medical devices, wearables, or smartphone apps may not be protected by HIPAA.