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RELIAS
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Controversy Persists as States, Courts 'Question, Push Back, and Challenge' Brain Death Criteria

Ethicists must keep close tabs on changing legal landscape

Multiple medical societies recently endorsed guidelines from the American Academy of Neurology (AAN) as a standard for determining brain death.¹ However, a controversial court ruling several years ago cast doubt on the criteria, with lingering effects.²

The case involved a 20-year-old Las Vegas woman, Aden Hailu, whose father sought a restraining order to stop doctors from removing her from life support after she was declared brain dead.

"The Supreme Court of Nevada suggested, though did not rule, that there are two problems with the way

that U.S. clinicians measure brain death," says **Thaddeus Mason Pope**, JD, PhD, who authored a recent paper on this topic.³ Pope is director of the

Health Law Institute and professor of law at Mitchell Hamline School of Law in St. Paul, MN.

First, the court noted that the AAN criteria may not constitute the "accepted medical standards" required by the Uniform Determination of Death Act.

"The Hailu ruling had the potential to be very problematic

for future determinations of death by neurological criteria," says **Ariane Lewis**, MD, associate professor in

THE COURT NOTED THAT THE AAN CRITERIA MAY NOT CONSTITUTE THE "ACCEPTED MEDICAL STANDARDS" REQUIRED BY THE UNIFORM DETERMINATION OF DEATH ACT.

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EDITORIAL QUESTIONS
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the departments of neurology and neurosurgery at NYU Langone Medical Center in New York City. To prevent this, the state of Nevada updated the definition of death to specify that the AAN criteria are the accepted criteria for determination of death by neurological criteria in adults. “It remains to be seen whether other states will also update their definition of death in this manner,” says Lewis, who authored a recent paper on the topic.⁴

The Nevada court also suggested, though did not hold, that the medical criteria for brain death may not measure what the Uniform Determination of Death Act requires: irreversible cessation of all functions of the entire brain. “The legislature did not address this second problem noted by the court,” says Pope. “There may remain a gap between what law requires and what clinicians are measuring.”

More Frequent Objections

The Nevada Supreme Court decision already has been referred to in lawsuits in other states, including the ongoing medical malpractice case filed by the family of Jahi McMath.⁵ “There have been a number of

cases of objections to determination of death by neurologic criteria in the past few years, both in the U.S. and Canada. I expect the frequency of objections will continue to increase,” says Lewis.

Only Hailu, and now McMath, address the question of accepted medical criteria. “Until the AAN and American Academy of Pediatrics [AAP] guidelines are acknowledged to be the accepted medical criteria in the definition of death in all states, objections like the Hailu objection will likely continue,” says Lewis. She recommends ethicists take the following steps:

- ensure that hospitals establish brain death policies that are confluent with the AAN and AAP guidelines to prevent false positive determinations;
 - proactively create guidelines on management of objections to determination of death by neurologic criteria to ensure these cases are treated uniformly;
 - if confronted with objections to determination of death by neurological criteria, they should discuss the appropriate steps to take with their hospital legal team and administration.
- Notably, death by neurological criteria is legal death in every state (although it is not legal death for

EXECUTIVE SUMMARY

Guidelines from the American Academy of Neurology (AAN) were recently endorsed by several organizations as a medical standard for determining brain death, despite a controversial Nevada Supreme Court ruling that casts doubt on this stance. Ethical implications include the following:

- the state legislature specified that the AAN guidelines are accepted criteria for determination of death by neurological criteria in adults;
- the case is only legally relevant as precedent in Nevada, but has been referred to in lawsuits in other states;
- state court rulings on brain death criteria continue to evolve.

someone with a religious objection in New Jersey).

“Family permission is not needed to withdraw organ support after it is declared,” says Lewis. “But withdrawal of organ support over a family’s objections could lead to lawsuits, bad publicity, and controversy.”

Prevention of such conflicts is ideal. “Better communication with decision aids, and even family presence during brain death examination, correlates to higher consensus,” says Pope.

Time for Reassessment

The Nevada case makes it clear “that it is time for a large and public reassessment and reaffirmation of brain death criteria,” says **Kenneth W. Goodman**, PhD, FACMI, director of University of Miami’s Miller School of Medicine Institute for Bioethics and Health Policy in Florida.

Clearer guidelines and criteria would help to build trust and give grieving families confidence that their loved ones are indeed dead, says Goodman. Life-sustaining interventions can create doubt and confusion on this point, sowing the

seeds for protracted ethical conflicts. “Improvements in our ability to sustain cardiopulmonary function continue to erode confidence in a 50-year-old consensus,” says Goodman.

At the heart of the issue is the public’s lack of confidence in neurological diagnoses. “It is heartbreaking that family members continue to interpret even spinal reflexes as evidence of cognition and interaction,” says Goodman.

Highly publicized court challenges serve to “upset the cart” for ethics consultants and committees, says Goodman: “If the courts are increasingly willing to question, push back, and challenge, we will need to track the legal environment more carefully.”

Such cases are a reminder that ethicists cannot afford to be complacent about brain death criteria. “We will, perhaps, need to adopt a more nimble and nuanced approach to that which we once took for granted,” says Goodman. ■

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New Data Shed Light on Nurses’ Reasons for Applying to Clinical Ethics Residency

‘It was not just about them, but how to help everyone’

Demand is strong for a clinical ethics residency for nurses (CERN), which is offered selectively to nurses affiliated with two Boston academic medical centers. A team of ethics experts created the program, several of whom had hosted a one-

day nursing ethics conference for several years.

“It was increasingly well-subscribed, and the evaluation feedback was ‘More, please!’” says **Martha Jurchak**, PhD, RN, executive director of the ethics

service at Brigham and Women’s Hospital in Boston. The group had more applicants than it could accommodate.

CERN’s goal was to develop point-of-care and advanced practice nurses to serve as ethics resources.

“Each year for three years, we accepted a cohort of nurses to take part in a multimodel education curriculum,” says **Pamela J. Grace**, RN, PhD, FAAN, associate professor of nursing and ethics at Boston College’s William F. Connell School of Nursing in Chestnut Hill, MA.

Inadequate Ethics Education

About 20 nurses attend a monthly eight-hour program for 10 months. This includes didactic instruction, role-play, and mentored practice. Faculty work with participants to use the skills developed in unit rounds, ethics consultations, educational offerings, and to serve on ethics and patient care committees. Some participants developed unit-based programs, policies, or guidelines, as well.

To learn more about the nurses’ reasons for applying, researchers analyzed 67 successful application essays. These described why nurses wanted to be in the program, and how they would apply the knowledge gained.

The overarching theme identified was “developing abilities to navigate through the gray zones in complex environments.”

“Although nurses may have had some ethics education in practice,

it is inadequate to maintain moral agency in contemporary healthcare environments,” says Grace.

Three subthemes were identified:

- encountering patients who are chronically critically ill, culturally diverse, and presenting with complex circumstances;
- desiring enhanced ethics knowledge and skills to improve quality of care, understand different perspectives, and act as a resource for others;

“ALTHOUGH NURSES MAY HAVE HAD SOME ETHICS EDUCATION IN PRACTICE, IT IS INADEQUATE TO MAINTAIN MORAL AGENCY IN CONTEMPORARY HEALTHCARE ENVIRONMENTS.”

- supporting and facilitating patient-centered ethical decision-making.

“Of the findings that were surprising, the major one was how important learning more about communication skills, and then

getting to practice them, were to the participants,” says Jurchak. For example, lessons learned in the communication module about finding common ground could be readily practiced in the clinical role-play about a mother of a dying patient requesting treatment beyond what the physicians are recommending. “There was very positive feedback about the interwoven modes of learning,” says Jurchak.

Nurses wanted to help their colleagues with tough ethical problems. “It was not just about them, but how to help everyone deal with the clinical ethical problems that were coming up,” says Jurchak.

The researchers are currently analyzing more than 60 post-CERN essays. “Emerging from these analyses is support for the idea that ongoing ethics education is necessary for nurses, and that such multimodal efforts can be personally and professionally transformative,” says Grace. ■

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EXECUTIVE SUMMARY

A clinical ethics residency for nurses met with strong demand at two academic medical centers. Nurses who applied to the program wanted:

- to improve their communication skills;
- to help colleagues with tough ethical problems;
- to learn approaches for management of chronically critically ill and culturally diverse patients.

Report Sheds Light on Inner Workings of Hospital Ethics Committee

A recent report describes the structure and operation of the Boston-based Massachusetts General Hospital (MGH) ethics committee from 2007-2013.¹

“We were fortunate to form a research arm of our ethics consultation committee,” says MGH nurse ethicist **Ellen Robinson**, PhD, RN, one of four ethics committee leaders.

The committee, founded in 1974 as one of the nation’s first hospital ethics committees, has primarily focused on the optimum use of life-sustaining treatments. The report outlines the following:

- specific sociodemographic and clinical characteristics of consult patients during this period;
- demographic differences between the adult inpatient population and patients for whom the ethics committee was consulted;
- salient features of the consults themselves.

“We have long wanted to look objectively at our case themes,” says Robinson. “The stars aligned, and we were able to do so.”

These three consult themes were identified:

- disagreement between the surrogate decision-maker and the healthcare team about goals of care;
- the need for assistance in identifying the appropriate surrogate decision-maker;
- families persisting in requesting life-sustaining treatment that is deemed to be nonbeneficial or harmful.

The ethicists expected to see an even greater percentage of cases that involved disagreements between surrogate decision-makers and the

clinical team about goals of care. “In our everyday practice as ethics consultants, it feels like greater than 41%,” says Robinson.

Forming a research/evaluation/quality improvement group with multiple areas of expertise is the best approach to conducting systemic analyses of ethics consults, says

“ETHICS CONSULTS ARE NOT STRICTLY ‘QUANTITATIVE’ DATA THAT LEND THEMSELVES TO ONLY STATISTICAL ANALYSIS.”

Robinson. Consult notes and the patient’s end-of-life or life going forward trajectories also are rich sources of data. “Ethics consults are not strictly ‘quantitative’ data that lend themselves to only statistical analysis,” she explains.

The report details how the ethics committee developed and utilized policies on end-of-life care, including a “Do No Harm” section that was added to its Life-Sustaining Treatment Policy. The newly added section states that physicians “are not obligated to offer or provide life-sustaining treatments that have no clinical indication or have no reasonable likelihood of providing benefit to the patient in the context of his or her values and prognosis.”

The change was made due to a number of ethics consults involving

dying patients whose families were struggling with do not resuscitate (DNR) decisions. “The policy section basically asks physicians to consider in certain cases of imminent death whether cardiopulmonary resuscitation would be harmful rather than beneficial,” says Robinson.

In cases of clear projected harm, such as for a patient dying with metastatic cancer, physicians are asked to consider a “medical decision” for DNR. Families are compassionately informed of the decision. “Most are relieved that their loved one will be allowed to die peacefully, surrounded by those who care about the patient, and cared for well by nurses and physicians,” says Robinson.

Further detail about the approach to some of these difficult cases is described in a recent paper.² “We were pleased to see objective evidence of fair and appropriate application,” says Robinson. ■

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Patient Left No End-of-Life Wishes? Surrogates Need Ethicists' Help

Good advance care planning means lighter burden for surrogates

Advan­ce care plan­ning in­creases con­fi­dence in surro­gates' ability to make con­sis­tent de­ci­sions, which may lighten the bur­den of sub­sti­tute de­ci­sion-mak­ing, found a re­cent study.¹

“A few ob­ser­va­tional stud­ies had found that con­fi­dence in surro­gates' ability to make de­ci­sions con­sis­tent with the pa­tients' wishes is of­ten high, de­spite a low ability to ac­tu­ally do so,” says **Gina Bravo**, PhD, a pro­fessor of pub­lic health at Cana­da's Uni­ver­sity of Sher­brooke.^{2,3}

The re­searchers de­vel­oped an ad­van­ce care plan­ning in­ter­ven­tion to help surro­gates bet­ter pre­dict an older adult's de­sire to un­dergo, or not un­dergo, vari­ous health­care pro­ce­dures. They then asked 235 older adults and surro­gates how con­fi­dent they were that fu­ture de­ci­sions would match the older adult's wishes. Of the group that par­ti­ci­pated in an ad­van­ce care plan­ning in­ter­ven­tion, con­fi­dence in­creased for both older adults and surro­gates. For older adults, this con­tinued months af­ter the study. “Al­though prior stud­ies sug­gested that con­fi­dence could be high de­spite low pre­dic­tive ability, we did not ex­pect

con­fi­dence to re­main high among older adults six months af­ter the in­ter­ven­tion had ended,” says Bravo.

Higher con­fi­dence in sub­sti­tute de­ci­sion-mak­ing is im­por­tant be­cause it may help surro­gates fo­cus on what the pa­tient would truly want. “Our find­ings in­di­cate that surro­gates need fur­ther help in mak­ing de­ci­sions for an in­capa­ci­tated re­lative,” adds Bravo.

In a sub­se­quent study, the re­searchers found that the con­tent of an ad­van­ce di­rec­tive may pro­vide use­ful in­for­ma­tion re­gard­ing a per­son's wishes for fu­ture health­care that com­ple­ments the guess of a surro­gate.⁴ This sug­gests that ad­van­ce care plan­ning in­ter­ven­tions also should in­clude re­cord­ing wishes in writ­ing. “The more in­for­ma­tion a surro­gate has about a re­lative's wishes, the more he or she will be able to make ap­pro­priate, and of­ten dif­fi­cult, de­ci­sions on their re­lative's be­half,” says Bravo.

More Psychological Stress

There is in­creas­ing evi­dence of the grow­ing bur­den surro­gate de­ci­sion-

mak­ers ex­pe­ri­ence if the pa­tient left no in­for­ma­tion as to his or her end-of-life wishes.^{5,6,7} **Celia B. Fisher**, PhD, co-au­thored a study look­ing at surro­gates who had to give per­mis­sion to with­draw life-sus­tain­ing in­ter­ven­tions with loved ones who had, or did not have, DNRs.⁸

“There was a lot more psy­cholog­i­cal stress in those in which there was no DNR,” says Fisher, Marie Ward Doty Uni­ver­sity chair in ethics and di­rec­tor of the Center for Ethics Edu­ca­tion at Fordham Uni­ver­sity in Bronx, NY.

Surro­gates clearly feel more com­fortable car­ry­ing out some­one's wishes than try­ing to im­ag­ine what those wishes might be. “Relig­ious at­ti­tudes, which phy­sicians of­ten ignore, are also a very im­por­tant part of de­ci­sion-mak­ing,” adds Fisher. This can cause stress for the surro­gate. “As part of stan­dard prac­tice, team mem­bers can let surro­gates know the avail­ability of a chap­lain,” says Fisher.

Some surro­gates dis­agree with pa­tients' wishes for relig­ious re­asons. “A surro­gate might not be com­fortable being the one ap­pointed to that role, and if so, one needs to know that right from the be­gin­ning,” says Fisher. A dif­fer­ent surro­gate may be needed if, for in­stance, the surro­gate be­lieves all de­ci­sions should be left in God's hands, but this con­flicts with the pa­tient's ver­bally ex­pressed wishes.

Even the best ad­van­ce care plan­ning can't cover every de­ci­sion that the surro­gate might need to make. “What's very im­por­tant is that these con­ver­sa­tions are shared,” says Fisher. “It's not just ‘if I de­velop this,

EXECUTIVE SUMMARY

Surro­gates face an in­creased bur­den if they're un­aware of pa­tients' end-of-life wishes, ac­cord­ing to a grow­ing body of re­search. Ethicists can:

- en­courage the clin­ical team to be sen­si­tive to cul­tural and relig­ious val­ues;
- in­volve a chap­lain in dis­cus­sions if the surro­gate's relig­ious val­ues are a fac­tor;
- em­pha­size the im­por­tance of pa­tients con­vey­ing their val­ues to surro­gates and put­ting their wishes in writ­ing.

I want this turned off,’ but that the values are discussed.” ■

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Vast Majority of Patients Want to Be Informed of Overlapping Surgery

Ethicists can expect ‘increasing expectations of transparency’

Overlapping surgery — operations performed by the same surgeon with the start of one surgery overlapping with the end of another — has been common for many years. Yet only 3.9% of the general public had any knowledge of the practice, found a recent study.¹

More than 90% of the 1,454 respondents believed that the attending surgeon should inform patients in advance of overlapping surgery, define what the critical components of the operation are, and document what portion of the surgery he or she was present for.

“Surgeons should not practice in a fashion that they do not feel comfortable explaining to patients,” says **Peter Angelos**, MD, PhD, FACS, Linda Kohler Anderson professor of surgery and surgical ethics, chief of endocrine surgery, and associate director of the MacLean Center for Clinical Medical Ethics at the University of Chicago.

If surgeons believe overlapping surgery is ethical, they should feel comfortable disclosing it to patients. “Going forward, there will be increasing expectations of transparency that should improve

the informed consent process,” adds Angelos, co-author of a recent paper on this topic.²

One reason overlapping surgeries aren’t routinely addressed in the informed consent process is that it’s been common practice for decades. “It was done so commonly, particularly in academic centers, that it didn’t rise to the level of something that was necessarily discussed specifically,” says **Michael Kent**, MD, FACS, director of minimally invasive thoracic surgery at Beth Israel Deaconess Medical Center in Boston.

A significant number of

respondents were willing to support overlapping surgeries under certain circumstances. “I was very impressed by the insight that lay respondents had,” says Kent. Written comments acknowledged that portions of an operation were critical while others were not, and that the practice allows experienced surgeons to provide care for more people. “But one consistent message was, ‘I want to know about it. I want to hear you describe it to me, and I want to provide informed consent if I agree, or disagree and not provide informed consent,’” says Kent.

Overlapping surgeries already are becoming part of the informed consent conversation at large medical centers. “If overlapping surgeries are done safely and with the appropriate informed consent, there are advantages not only to the surgeon and hospital, but the patient as well,” notes Kent.

Surgeons can provide care to more patients in a given unit of time. It might be possible for a given patient to undergo surgery in a week instead of a month, for instance.

Another recent study surveyed 200 patients and family members at an academic medical center to quantify patients’ feelings and knowledge of overlapping and concurrent surgery.³

“It was a topic that had gathered a lot of attention in national news. We sought to understand how that impacted patients’ perceptions,”

says **Jonathan Edgington**, MD, the study’s lead author, of the Department of Orthopaedic Surgery and Rehabilitation Medicine at the University of Chicago. On average, respondents were neutral with surgical procedures involving overlap of two noncritical portions, but were not comfortable with overlap involving a critical portion of one or both surgical procedures.

One finding that stood out: strong feelings that hospitals are performing overlapping or concurrent surgery to increase revenue. “This was an important detail to glean, as it helps guide the discussion with patients with regard to the practice,” says Edgington.

Diane Payne, MD, MPT, co-author of a recent paper on overlapping and concurrent surgery,⁴ says nondisclosure of these practices is ethically problematic. “Disclosure is an institutional and provider issue,” says Payne, an assistant professor of orthopaedic surgery at Emory University School of Medicine in Atlanta.

Some institutions include language that covers overlapping surgeries in formal written consent forms. “But whether that language is specifically reviewed is up to the provider obtaining consent,” says Payne. For ethicists, Payne sees “a huge role in educating providers as well as administrators — assuming that the ethicists are aware it happens.” ■

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EXECUTIVE SUMMARY

Only a small minority of patients had knowledge of the common practice of overlapping surgery, but almost all believed it should be part of informed consent. Respondents believed surgeons should:

- inform patients in advance;
- define the critical components of the operation;
- document for what portion of the surgery the surgeon was present.

Blacks and Whites, but Not Hispanics, Increasing Advance Directive Completion

Blacks and whites had longitudinal increased rates of advance directive completion, but the same was not true for Hispanics, a recent study found.¹ Analyzing data from 7,177 decedents, researchers determined that:

- less than half (46%) had completed an advance directive (whites 51.7%, Hispanics 18%, blacks 15%);
- of blacks completing an advance directive, 23.8% elected prolonged care, compared with 13.3% of Hispanics and 3.3% of whites.

“Our hope is that results from this study will encourage communication between healthcare professionals, families, and patients to support end-of-life care that is aligned with the values of patients as individuals,” says **Jaclyn Portanova**, MSG, RN, the study’s lead author and a predoctoral fellow at University of Washington School of Nursing in Seattle.

Ethnic differences in rates of advance directive completion and in care choices have been well-documented over the past decade. “With increased focus on expanding access to palliative care, improving

patient-centeredness in care, and attention to increasing rates of advance directive completion, we wanted to see if there has been any longitudinal change over the past decade,” says **Susan Enguidanos**, PhD, MPH, another of the study’s authors. Enguidanos is an associate professor of gerontology at University of Southern California, Los Angeles.

Hispanics without significant others were more likely to complete advance directives than those with a significant other. “This attests to the reliance on family for care decision-making among Hispanics,” Enguidanos says.

The continued differences in advance directive completion between whites and non-whites point to the need for providers to engage minority patients and their family members in these discussions, says Enguidanos. Once physicians identify patient preferences for care, these preferences can be charted and referred to in the event the patient needs healthcare decision-making in the future.

Previous research shows that physicians are less likely to have

advance care planning and hospice discussions with minority patients.^{2,3} “Increased attention to bridging this gap is needed,” says Enguidanos. ■

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SOURCES

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Patient-reported Resuscitation Status Doesn't Necessarily Match Clinicians' Orders

Patient-reported and clinician-ordered resuscitation preferences were discordant in 20% of patients hospitalized with acute decompensated heart failure, a recent study reports.¹ “We anticipated some discordance, but the proportion that had discordant preferences was

higher than I would have expected,” says **Shannon Dunlay**, MD, one of the study’s authors.

Assessment of preferences for CPR typically is part of the intake process at the time of hospital admission. “We wondered how often patient-reported and clinician-

documented orders for resuscitation were the same or different,” says Dunlay, a practicing cardiologist and an associate professor of medicine at Mayo Clinic in Rochester, MN. The study’s key findings include the following:

- Of 400 patients, 213 stated their

resuscitation preference as full code, 166 do not resuscitate (DNR), and 21 were unsure.

• In comparison, clinician-ordered resuscitation status was full code in 263 patients, DNR in 133, and not documented in four.

• Patients who indicated a different resuscitation preference than what was ordered by their clinical team were less likely to have an advance directive.

“Patients who have thought about their wishes and documented them in the form of an advance directive may be more likely to have those

wishes easily conveyed to the clinical team,” suggests Dunlay.

• When patient-reported and clinician-ordered resuscitation preferences didn’t match, a longer hospital stay was more likely.

“This suggests that patients with discordant preferences may experience more complicated hospitalizations,” says Dunlay.

Additional research is needed on the reasons for the inconsistencies, says Dunlay: “It would be of interest to understand if it were due to lack of communication, confusion, indecision, or other factors.” ■

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SOURCE

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Ethical Dilemma? Too Often, Chaplains Are Involved Last

Conscientious objection of providers, moral distress, patient adherence, and difficult or noncompliant patients all are situations where chaplains can be of help, says **Steven Squires**, PhD, vice president of mission and ethics at Cincinnati-based Mercy Health.

“Chaplains can be great mediators in intractable clinical conflicts, getting to life and purpose issues with greater ease than many healthcare providers,” he adds.

Yet when healthcare teams are concerned about medical ethics dilemmas, chaplains often are the team members who are involved last, according to **Angelika A. Zollfrank**, BCC, manager of spiritual care at Yale New Haven Hospital (CT). Here, Zollfrank shares some common reasons for this:

• **A hospital may not have adequate staffing to allow for chaplains to be as visible as other healthcare providers.**

Chaplains often cover many units,

effectively taking responsibility for the spiritual care of 70 to 100 patients and families at any given time, notes Zollfrank.

• **Medical teams, with the exception of palliative care, tend not to include the chaplain in their daily team structure.**

“Chaplains might find such integration into the team takes time that they would rather spend in direct patient care,” says Zollfrank.

• **Clinicians sometimes are concerned that chaplains will impose their values on the team.**

“This preconceived notion may be fueled by the clinicians’ spiritual or religious beliefs, or lack of such belief,” says Zollfrank. In reality, chaplains’ training enables them to support others in their beliefs and values — even when those beliefs and values are different from their own. “Chaplains offer crucial support to clinicians and families alike,” says Zollfrank.

• **Chaplains vary widely in their training.**

Some have received formal education in medical ethics, while others learn on the job. Some are members of ethics committees, others are not. “Sometimes interns in spiritual care and chaplain residents cover a clinical area and they are just beginning to learn about medical ethics,” says Zollfrank. In other cases, service lines enjoy the constancy of a professional chaplain who is a known and trusted member of the team.

“All these factors can present challenges for medical teams to think consistently of the chaplain as a resource in cases of moral distress, moral uncertainty, or ethical dilemmas,” says Zollfrank.

As highly skilled communicators, chaplains bring unique competencies to medical ethics issues, says Zollfrank. This allows them to pick up on the underlying motivations, concerns, and coping abilities of families and surrogate decision-makers.

“Chaplains are often an effective bridge between the world of science

and healthcare on the one hand, and the world of faith and nonmedical values on the other,” says Zollfrank. Community clergy are typically unfamiliar with medicine and healthcare. In contrast, professional chaplains are healthcare team members who are supportive of families in crisis.

“Often, the dynamics of grief play a crucial role in medical ethics decision-making,” says Zollfrank. Clinicians have a sense of urgency when medical interventions become more burdensome than beneficial. In contrast, chaplains understand the emotional and spiritual processes that families go through.

Zollfrank has found it helpful

to hold a huddle ahead of provider-family meetings to clarify the roles of everyone involved. “Often, it is useful to have the chaplain process with the family or surrogate decision-maker, outside a caregiver-family team meeting,” she says. Zollfrank sees the following as important roles for chaplains:

- Helping with end-of-life decision-making. “For many people, dying is a spiritual and not a medical process,” she explains.
- Counseling patients and family using knowledge of what is ethically permissible in different religious communities.
- Collaborating with community

clergy to ensure continuity of care beyond the hospital stay.

• Bringing spiritual, religious, and cultural sensitivity to medical ethics issues.

“Chaplains are good at communicating that while medical care can become burdensome, healthcare providers and medical teams never stop caring,” says Zollfrank. ■

SOURCE

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Disability Trajectories Give Insights on End of Life

Derived disability trajectories provide useful information about different facets of the end-of-life experience, found a recent study.¹

“From an ethical perspective, the value of the paper is to defend the idea that we can describe different clinical groups or trajectories at the end of life — even if the trajectories of physical function are not ‘pure,’” says **June R. Lunney**, PhD, RN, the study’s lead author.

Individuals won’t necessarily experience the suggested pattern of physical decline. However, the information still is useful for talking about different plans for personal care or different decision-making approaches depending upon the patient’s clinical course.

“This clinical framework allows us to talk about the end of life in more concrete terms, rather than a general abstract concept,” Lunney explains.

The researchers analyzed a large

sample of elderly adults to assess mobility disability trajectories before death. The lack of fit between them suggests a need for greater attention to heterogeneity in disability in the period before death, concluded the researchers. “Additionally, this research helps to make the point that dying suddenly with no care requirements or clinical decision-making is not a very likely option,” says Lunney.

Another study found that older adults who died were more disabled three years before death, and also had a greater risk of increasing disability over each subsequent six-month assessment.²

“It was no surprise to find that those who would die within a few years are more likely to be limited in physical function than those who will survive,” says lead author Lunney.

A more noteworthy finding: that the well-documented gap in functional ability between African-

Americans and whites was erased in the final one to 1.5 years before death. “One could speculate that being sick enough to die involves diminished physical function, regardless of access to healthcare or lifetime physical fitness, or whatever else contributes to the racial gap,” says Lunney. ■

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SOURCE

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CME/CE QUESTIONS**1. Which is true regarding determining brain death?**

- a. Death by neurological criteria is legal death in every state, though exception is made in New Jersey for religious objections.
- b. The AAN criteria do not constitute the "accepted medical standards" required by the Uniform Determination of Death Act.
- c. Medical criteria for brain death state that measurement of irreversible cessation of all functions of the entire brain is not required.
- d. Family permission is needed to withdraw organ support even after death by neurological criteria is declared.

2. What does Massachusetts General's policy on life-sustaining treatment state?

- a. Physicians are obligated to offer life-sustaining treatments if requested by surrogates, even without clinical indication.
- b. In cases of clear projected harm, physicians are asked to consider a medical decision for DNR, and families are informed of the decision.
- c. Families should be given increased autonomy to make their own DNR decisions for patients with metastatic cancer.
- d. Families must be fully informed on the hospital's legal obligations to provide life-sustaining treatments.

3. Which is true regarding the practice of overlapping surgery?

- a. Some institutions include language that covers overlapping surgeries in their formal written consent forms, but whether that language is specifically reviewed is up to the provider obtaining consent.
- b. Surgeons are legally required to inform patients of the possibility of overlapping surgeries.
- c. The practice is clearly unethical because only the hospital benefits.
- d. There is growing evidence that patients are unwilling to support this practice under any circumstances.

4. Which is true regarding resuscitation status of patients hospitalized with acute decompensated heart failure, according to a recent study?

- a. Patient-reported and clinician-ordered resuscitation preferences differed in 20% of cases.
- b. Clinician-ordered resuscitation status differed from what the patient reported only for patients who were unsure of their status.
- c. Clinicians frequently ordered DNR status for patients whose preference was full code.
- d. Patients who indicated a different resuscitation preference than what was ordered by their clinical team were more likely to have an advance directive.