



# MEDICAL ETHICS ADVISOR®

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## Novel Approaches to Justify Ethics Resources: Value Goes Beyond ROI

*Obtain data, enlist help of hospital leaders*

“**B**ecause of ethics, we saved \$10 million in not having to provide futile care in this hospital, five nurses have not left this hospital in search of other jobs due to moral distress, and medical malpractice insurance expenses were cut by 20%.”

A good ethics consultation service might indeed have accomplished all of this and much more, but solid proof is elusive. “It’s very difficult to prove that because of ethics, something bad did not happen,” says **John D. Banja**, PhD, a medical ethicist at the Center for Ethics at Emory University in Atlanta.

For instance, costly burnout and staff turnover can be prevented if ethicists address clinicians’ moral distress

with consults and education. “But if administrators are truly fixated on ROI [return on investment], you’re up against a wall, because that’s going to be hard to show with conclusive data,” says Banja.

Hospital administrators are used to basing their decisions on certain kinds of metrics, as opposed to anecdotal evidence. “It’s always a challenge for ethics folks to show a return on investment to the kind of leadership that is singularly or narrowly fixated on

the bottom line,” says Banja.

Nonetheless, there often is a need to justify resources for ethics. **David A. Fleming**, MD, MA, MACP, co-director and scholar at University of Missouri’s Center for Health Ethics in Columbia, notes, “As with any clinical

“IT’S VERY DIFFICULT TO PROVE THAT BECAUSE OF ETHICS, SOMETHING BAD DID NOT HAPPEN.”

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service, ethics consultation teams  
and committees typically serve at the  
pleasure of hospital systems.”

Fleming adds that ethics services  
exist, for the most part, in response  
to a 1992 Joint Commission  
requirement that all healthcare  
organizations establish a policy  
and mechanism to address ethical  
concerns. How that is manifested is  
up to each healthcare system, ranging  
from minimal to robust.

“The more value realized from  
clinical ethics consultation, the  
greater resources will be invested  
in sustaining and growing those  
services,” says Fleming.

Data supporting the need for  
clinical ethics consultation services  
tend to be more qualitative than  
quantitative. Data often come from  
surveys of patients, families, and  
clinicians who were involved in  
ethics consults. “Satisfaction data is  
important to know if we, as ethicists,  
are well-received and helpful,” says  
Fleming. “More helpful, but difficult  
to find, would be data reflecting  
actual clinical outcomes.”

It seems obvious that ethicists  
positively affect quality of care,  
costs of end-of-life care, allocation  
of resources in making treatment  
choices, and moral distress. But  
demonstrating it with data is another  
thing entirely. On the other hand,  
other hospital departments may  
already be collecting data that can

be useful to ethics. Risk managers  
and quality improvement are two  
examples. “The sensibilities and  
concerns of all these areas are going  
to come together more and more,  
and ethics is definitely going to be  
right in the mix,” predicts Banja.

In Fleming’s experience, moral  
discomfort of team members,  
where it exists, is helped by ethics  
consultation. “This is based on the  
feedback I get from the teams in the  
hours and days following the ethics  
team’s input,” says Fleming. This  
is especially true in complex cases  
where emotions are running high  
and there is ambivalence as to what  
direction to take.

“In end-of-life cases, where futility  
is determined and withholding and  
withdrawing treatment is being  
considered because it is deemed  
ineffective by the team or unwanted  
by the patient, decreased cost and  
length of stay are clearly reduced,”  
adds Fleming.

Data on cost, quality, satisfaction,  
length of stay, and utilization of  
services can serve to convince  
skeptical hospital leaders of the  
financial effect of ethics. “The value  
of ethics services can be determined  
by measuring these variables in  
relations to the consult itself,” says  
Fleming. The training, skills, and  
attitudes of staff; demographics of  
resource allocation; and personal  
experiences of the patient, family,

## EXECUTIVE SUMMARY

Ethics services often find it challenging to demonstrate financial impact  
on the organization due to lack of data and the preventive nature of many  
interventions. Some approaches include the following:

- invite hospital administrators to round with the ethics team;
- regularly report on successful cases;
- ask influential leaders to advocate for ethics.

and team all can be taken into account.

“Objectively determining the value of ethics consults can be done through a QI [quality improvement] project,” adds Fleming. For instance, outcomes could be compared in similar clinical situations that have and have not involved an ethics consult. Some possible variables to analyze include cost, rate of hospice referral, days spent in the ICU, patient/family satisfaction, and provider satisfaction.

Established, data-driven QI and patient safety mechanisms can be of great help. “Clinicians, administrators, and clinical ethicists can work together with a shared goal of improving quality outcomes and decreasing unnecessary cost,” says Fleming.

## Lots of Accessible Data

Ethics consultations favorably affect a hospital financially as a cost-reduction mechanism, says **Gavin Enck**, PhD, director of clinical ethics at Integris Health in Oklahoma City.

“Although ethics committees and a consultation service are not driven by financial considerations, evidence suggests resolving conflicts and patient-provider disagreements, as well as identifying goals of care and values, reduces costs relating to unnecessary care,” says Enck.

Such data incentivize hospitals to invest resources in their clinical ethics programs. Ethicists typically turn to hospital risk managers as a potential source. “While risk management is important, this overlooks a lot of accessible data,” says Enck.

Electronic medical records have generated an immense amount of data, some of which can be put to use by ethics. “The key for the ethicist is

to connect and establish relationships with QI, informatics, IT, and financial services,” suggests Enck.

Working with these other services, ethicists can determine which metrics in a consultation are measurable and can be tracked. “Once measurable metrics are identified, this group can examine the way these consultations affect patient care and quality,” says Enck.

Examples include length of stay, length of stay in ICU, length of stay on mechanical ventilation, readmissions, grievances filed, patient and staff satisfaction scores, and staff turnover.

Data on what occurred after ethics consultations also can be revealing, says Enck. Some areas to look at: patient code status changes, creation of advance care planning documents, stopping or starting of intensive interventions, identification of goals of care or surrogate decision-makers, and patient transfers to other hospitals.

The next step is to compare these measurable metrics against similar patient populations in which ethics consults did not occur. “This comparison should indicate, even if broadly, the financial impact of ethics consults,” says Enck.

## Ethics Team Is Essential

Some services in medicine are central to meeting the core mission of healthcare, and therefore should not be required to demonstrate ROI or cost-effectiveness, argues **Maria Silveira**, MD, MA, MPH, associate director of research at University of Michigan’s palliative care program. Silveira also is a clinician scientist at VA Ann Arbor Health System’s Geriatric Research Education and Clinical Center.

“Those services should be provided without consideration of a price tag,” says Silveira. “No one questions the ROI for the emergency room, the hospitalists, or the general surgeons.”

These services are necessary in order for a hospital to be a place with the capacity necessary to handle most needs related to human illness and suffering. The same is true of ethics services, says Silveira: “I would argue that an ethics service is required in any healthcare setting where you have vulnerable patients, high stakes, and any need for shared decision-making.”

Banja agrees that it’s essential for every hospital to have staff with ethics expertise to help clinicians sort out all kinds of thorny issues. As just one example, physicians and nurses often are unclear on what family members can demand, and what duties the healthcare provider actually has. “It’s remarkable that we don’t spend enough time teaching them what their obligations are, and when they can say no,” say Banja. When inevitable end-of-life conflicts arise, “there can be all kinds of nuances and subtleties that the law has not covered and that perplex doctors and nurses,” says Banja.

For an ethics program to succeed, says Silveira, “you need leadership to buy into the idea based upon principle alone.” She suggests the following approaches:

- inviting hospital leaders to round with the ethics team, to see the work they do firsthand;
- compiling a binder of narratives from cases the ethics service successfully navigated, including quotes from appreciative clinicians and families. Then, use those narratives to report “cases from the field” to relevant leaders in the organization on an annual basis;

- reporting programmatic costs as a percentage of the hospitals' annual operating budget.

This shows administrators how little is actually spent for the service. "In most cases, ethicists are volunteers — though I believe they shouldn't be," notes Silveira.

**Alexander A. Kon, MD, FAAP, FCCM**, clinical professor of pediatrics at University of California, San Diego School of Medicine, says most healthcare ethics consultation services would never be able to demonstrate financial viability alone. Ethics consultants don't bill for their time. Kon says that "cost savings to the organization are modest at best," and don't come close to covering consultants' salaries." "So I don't think arguing that the service is self-supporting is a good tack."

A better approach, says Kon, is to view ethics through the same lens as other important, non-financially independent services. For instance, child life specialists on pediatric wards don't generate much income or save significant costs. Yet physician and nursing leadership are advocates for the program.

The same holds true for ethics. "What the ethicist has to do in order to maintain value in the hospital is to get nurses and doctors on their side," says Banja. A grateful physician might tell the hospital CFO, for instance, "The ethicist helped us to navigate this incredibly awful case. There was no question in my mind that we would have had a much harder time without the ethicist."

There are clinicians who are concerned about ethics in every hospital. "More than you think are very concerned about the ethical dimensions of relationships with patients," says Banja. Those are the individuals the ethicist has to keep in close contact with and recruit as champions of ethics.

Kon recommends the following leaders advocate for ethics:

- leaders from medicine, especially in high-revenue areas such as surgery, ICU, and obstetrics;
  - nursing leadership;
  - risk management/legal affairs;
  - representatives on the hospital's family council;
  - major hospital donors.
- "When such leaders come together and tell the hospital

CEO that they need the ethics consultation program in order to appropriately care for patients and run the hospital, the CEO tends to listen," says Kon. ■

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## Many Providers Say Spiritual Needs Should Be Assessed, But Few Do So

*Patients 'often very receptive' to such discussions*

Should health professionals take a screening spiritual history (SSH) of their patients? Most clinicians (45% of 427 physicians, 56% of 86 mid-level practitioners, and 54% of 224 nurses) agreed they should, a recent survey found.<sup>1</sup>

"What was surprising was that many clinicians already take a

spiritual history and address spiritual needs, either themselves or refer patients to chaplains, and that patients are often very receptive to such discussions," says **Harold G. Koenig, MD**, director of Duke University Medical Center's Center for Spirituality, Theology, and Health.

Still, comparatively few (11 to 17%) of the respondents, all providers in outpatient practice in the Adventist Health System, currently performed spiritual assessments in their own practice.

"Given that medical patients often have spiritual needs related to medical illness, in order to provide

holistic healthcare to patients — physically, mentally, socially, and spiritually — such needs should be assessed and addressed as part of routine healthcare,” says Koenig.

Education, training, and support may help health professionals identify and address patients’ values, beliefs, and preferences, the researchers say.

“We believe that this kind of healthcare will improve medical outcomes, improve patient satisfaction, and reduce burnout among healthcare professionals because of the improved results that they see in their patients,” says Koenig.

## Integral to Care

Addressing the spiritual and religious needs of patients and families is integral to quality patient care, says **Margie Atkinson**, DMin, BCC, director of pastoral care, ethics, and palliative care at Morton Plant Mease Hospitals/BayCare Health System in Clearwater, FL.

An interdisciplinary approach to patient care includes professional chaplains and always addresses spiritual and religious aspects of care, says Atkinson.

“Failure to do so can result in a lack of understanding of patients’ wishes and prevent appropriately addressing patient goals of care, which connect to quality of life,” she

adds. Spirituality and/or religious beliefs often influence a patient’s values, preferences for care, and end-of-life decision-making. If such beliefs aren’t addressed, it could mean that patient preferences aren’t honored, she says.

A recent case involved a man who was admitted to the hospital and was found to have a terminal illness. “His illness resulted in his incapacity to make complex medical decisions,” says Atkinson. The patient’s religious preference was Protestant, and he had an advance care plan and living will in place. The patient had named his brother-in-law as the legal surrogate with the patient’s wife as a secondary, both of whom were Muslim. The patient’s subsequent diagnosis by more than two physicians deemed that he was in a terminal condition with no chance of meaningful recovery with or without treatment. This diagnosis statutorily should have activated the patient’s living will. “However, his surrogate refused to give permission for cessation of aggressive care due to his religious beliefs, which were different from the patient’s,” says Atkinson. Since his wife also was of a different faith tradition than her husband, she would not take responsibility for honoring the patient’s wishes, either.

An ethics consult was called. Ultimately, the ethics team consulted the hospital’s legal department

in order to get a court order to honor the patient’s wishes. Chart documentation from previous visits include chaplain and counselor notations that the patient was “at peace with God” and affirmed his Protestant religious beliefs. After reviewing all of the documentation, the judge agreed that the living will should take effect. The brother-in-law and the wife were relieved because they did not have to make a decision going against their own religious beliefs, and the patient’s wishes were honored.

“Addressing spiritual needs aids in the healing process, both physically and emotionally,” says Atkinson. “It helps patients and families tap into their own sources of strength and resilience.”

## Proactive Approach

Institutions must provide spiritual caregivers who are trained and competent to meet needs based on the patient’s and family’s spiritual preferences — not the healthcare providers’ own preferences, says Rabbi **Jodie Futornick**, MA, BCC, staff chaplain and ethics consultant at Swedish Medical Center in Seattle.

Trained professional chaplains focus on providing spiritual care and addressing spiritual needs of patients, regardless of faith tradition, spiritual paradigm, or no religious preference. They also may serve as a liaison with a patient or family’s own clergy.

“Professional chaplains are able to document and communicate these preferences to the entire healthcare team,” says Futornick. “This frequently becomes a key component in addressing ethical issues.”

This is because spiritual and religious values often impact patients’ and families’ complex

### EXECUTIVE SUMMARY

Most health professionals agreed they should take a screening spiritual history, but few do so currently, found a recent study.

- Inadequate assessment of spiritual values may mean patient preferences aren’t honored.
- Addressing spiritual needs aids in the healing process.
- Patient preferences should be documented and communicated to the entire healthcare team.

medical decision-making. Ethicists should consider advocating for the institution to hire professionally trained, board-certified chaplains, says Futornick: “This ensures a proactive approach to patient rights issues, patient preferences, and provision of care that is in the patient’s best interest.” ■

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# Physicians’ Mental Health ‘Finally Getting the Attention It Deserves’

*Stigma is obstacle to clinicians’ well-being*

A physician feels depressed, overwhelmed, or even suicidal. He or she might not seek help due to worries over future ability to obtain a medical license, or other repercussions.

“Medicine and all of the healthcare professions have always been very high-stress occupations. We’ve known that takes a toll on people,” says **Darrell G. Kirch**, MD, president of the Washington, DC-based Association of American Medical Colleges.

What’s changed is that there finally is evidence showing the true extent of physician distress. “That has raised our consciousness of the problem,” says Kirch. “It has long been an issue,

but is finally getting the attention it deserves.”

Physician well-being is a necessary component of an effective and ethical healthcare delivery system, says **Claire Zilber**, MD, DFAPA, ethics committee chair for the Lakewood-based Colorado Psychiatric Society.

“If a physician is struggling under the weight of anxiety, depression, or burnout, he or she is not at their best,” says Zilber. The quality of patient care can suffer.

“We are held to such high standards in our complex and demanding profession, yet there is little time or encouragement for self-care,” says Zilber.

The principles of clinical ethics

are focused on the patient. Physicians strive to do what is in the patient’s best interest, and avoid harm. Yet there is increasing evidence that physician burnout and distress negatively affect patients.

This is true not just for satisfaction, but also outcomes and even potentially medical errors, says Kirch: “So from an ethical perspective, a duty to our patient really creates a duty to take care of ourselves.”

Ethicists can do these two things to promote physician well-being, says Kirch:

- When consulting on emotionally charged, difficult cases, ethicists can identify clinicians who may be experiencing distress.
- Ethicists can point out that physicians have an ethical obligation for self-care because it affects their ability to practice.

The ethical principle of beneficence is promoted when physicians are functioning at their best, able to interact with professionalism, and make well-considered treatment decisions, says Zilber.

## EXECUTIVE SUMMARY

Physician well-being is increasingly being recognized as an ethical issue, but mental health stigma remains an obstacle. Ethicists can:

- identify physicians who may be experiencing distress;
- partner with clinical leaders to identify resources;
- participate in wellness committees or task forces.

“Justice — the notion that healthcare resources will be distributed in a fair manner — may be compromised if physicians experience unique obstacles to accessing healthcare for themselves,” adds Zilber.

Increased awareness isn’t enough, says Kirch: “We really need to take action on a number of fronts.” Some examples include the following:

- **Medical schools and residency training programs are emphasizing maintaining personal well-being, fostering resilience, and managing fatigue.**

“I’ve really been impressed that at many schools, the students themselves have created programs to build their sense of community and foster mutual support,” says Kirch.

- **Efforts are underway to make mental health services more accessible and more confidential for physicians.**

A 2017 American Medical Association policy aims to improve physician and medical student access to mental healthcare and reduce stigma associated with mental illness.<sup>1</sup>

“We need to make it clear at the very beginning of their medical training that they themselves need care, and there shouldn’t be any stigma against seeking that care,” says Kirch, co-chair of the National Academy of Medicine’s Action Collaborative on Clinician Well-Being and Resilience.

Physicians seeking mental healthcare have valid concerns about confidentiality. Some are reluctant to use their health insurance to pay for treatment, fearing their employer will find out the physician is accessing psychiatric services, says Zilber. Likewise, physicians are concerned about the confidentiality of the electronic medical record if they seek services within their own healthcare system.

“As long as stigma about psychiatric care exists, there will be

reluctance to receive treatment,” says Zilber.

- **State medical boards are eliminating inappropriate questions regarding past mental health treatment.**

“Those questions aren’t appropriate. The appropriate question is whether the physician has any type of problem that might impact their ability to practice currently,” says Kirch.

“THE  
APPROPRIATE  
QUESTION IS  
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PHYSICIAN HAS  
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CURRENTLY.”

Many state applications for medical licensure inquire about a history of psychiatric or neurological disorders. “An affirmative response requires an explanation, thus revealing to the licensing board one’s diagnosis and treatment history,” says Zilber. This creates an ethical dilemma. “The physician can disclose highly personal information to the organization that controls medical licensure or falsify the answer on the application — which is fraud, and could result in disciplinary action if discovered,” says Zilber.

In a small number of states, including Colorado, the licensing board and physician health program (PHP) have an agreement that if physicians are enrolled with and monitored by the PHP, they’re permitted to answer “no” to the

licensing question about having a psychiatric or neurological condition.

“This removes one obstacle to accessing treatment,” says Zilber. “Unfortunately, most states have not yet adopted this kind of arrangement.” Even in the states where it exists, it isn’t necessarily known or understood by the average physician.

- **Hospitals are creating the position of chief wellness officer.**

Even if the position doesn’t exist at the institution, ethicists can partner with clinical leaders such as the chief medical officer and chief nursing officer to raise awareness of the problem. The group can work together to identify resources that clinicians can be referred to.

“In some places, key leaders have come together and formed a wellness committee or task force,” says Kirch. “Ethicists could certainly be a vital partner in that effort.”

- **Hospitals are reversing stigma by creating a culture that embraces mental healthcare.**

One way of doing this is for hospital leaders to make public statements about the benefits of psychiatric treatment.

“This helps to change the perception that we should be keeping secret our struggles with burnout, depression, anxiety, substance use disorders, or other mental illness,” says Zilber. ■

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# Views on Disclosure of Donor-assisted Conception Are Evolving

*Cultural acceptance, technology are changing*

Should parents inform their children that they were conceived by gamete or embryo donation? A position statement from the American Society for Reproductive Medicine (ASRM) examines the ethics of this issue.<sup>1</sup>

“The ASRM Ethics Committee systematically reviews each of our opinions every three to five years, to keep current with the fast-paced nature of reproductive medicine,” explains **Judith Daar**, JD, chair of ASRM’s ethics committee.

The newly updated opinion on the ethical implications of disclosure to donor-conceived offspring notes the growing use of donor gametes and embryos. It strongly encourages parents to inform donor-conceived children about their genetic provenance.

“Today, 12% of all [assisted reproductive technology] cycles involve the use of donor eggs or embryos, making donor-conceived offspring a significant part of the community of children born of reproductive medicine,” notes Daar.

Increasing sophistication and access to ancestry tracing and sibling

identification “alter the disclosure dynamic,” adds Daar. Donor-conceived persons now have the ability to investigate their genetic heritage independent of information provided by their parents.

Fertility counselors are obligated to discuss with clients the importance of disclosure in donor-assisted conception, including the risk they are taking if they choose not to disclose it to their offspring, according to **Linda D. Applegarth**, EdD, clinical associate professor of psychology at the Ronald O. Perelman and Claudia Cohen Center for Reproductive Medicine at Weill Cornell Medical College in New York City.

“There’s probably no such thing as anonymity anymore, from a genetic standpoint. Anybody can go to the drugstore and buy a DNA test,” says Applegarth. Children might find out the information in ways that are more harmful than if the parents had told them.

“Technology is changing, and so are cultural views that openness is better and secrecy is potentially harmful,” says Applegarth.

Some research suggests that telling children earlier is better.<sup>2</sup> “The sooner the child knows about this, the better they manage. It’s something that is part of their story and their history,” says Applegarth.

Some providers don’t address the issue of disclosure, believing it’s outside their realm of expertise. “It behooves providers to get very well-informed on the issues of disclosure and the pros and cons,” says Applegarth.

Many recipients struggle with disclosure due to persistent social stigma. Other important factors also contribute to nondisclosure. “A lot of parents are hesitant to disclose because they might not be perceived as the child’s ‘real’ parent,” says Applegarth. For some, the infertility experience brought on feelings of personal shame and inadequacy that parents don’t want to acknowledge or revisit through disclosure.

Donor conception remains stigmatized largely because it’s rarely discussed openly. “It’s secret, just like adoption used to be secret. But things are changing on this front,” says **Lisa Campo-Engelstein**, PhD, associate professor at the Alden March Bioethics Institute at Albany (NY) Medical College.

Increasing numbers of gay and lesbian couples using donor conception is one reason, since children will want to know the identity of their genetic mother or father. “We have diverse groups of parents tapping into this, and that’s going to normalize it more and more,” says Campo-Engelstein. “It will become commonplace.”

## EXECUTIVE SUMMARY

Ethical considerations regarding disclosure of donor-assisted conception must balance the rights of the parents, donors, and children.

- Parents reluctant to disclose due to social stigma risk children learning the information on their own.
- Providers don’t always raise the issue, feeling it’s beyond their expertise.
- Some countries have laws mandating information be disclosed to donor-conceived children.

A number of countries, including Sweden, Austria, and Germany, have prohibited egg and sperm donor anonymity. The laws make it mandatory to disclose at least certain information about donors to children who were donor-conceived. “Before, we were prioritizing the rights of the social parent who wanted to keep it secret. But we are seeing movement toward equaling the playing field,” says Campo-Engelstein.

There is growing recognition that the rights of donor-conceived children are at least as important as the rights of the parents. The mandatory disclosure legislation passed by Australia’s Victoria province was named after a donor-conceived woman who died of a genetic bowel cancer, who was unable to find information on the donor. Another issue that could affect the health of donor-conceived children is the inability to know family medical history. “They may provide incorrect information because they don’t realize that their social parent is not their genetic parent,” says Campo-Engelstein.

The right of the donors who don’t want their information shared also needs to be considered. “One of the reasons we have so many donors in the U.S. is that not only do we pay them, but we also keep the information secret,” says Campo-Engelstein. This is unlikely to change, she adds: “I don’t think we will have laws like that, because we prize individual liberty.”

Other countries struggle to find enough donors in part because potential donors don’t want their identity disclosed down the road or to be contacted by a genetic child. “It’s a question of whose rights we are going to elevate over others. It’s hard, because they are in competition with each other,” says Campo-Engelstein.

**Louise P. King**, MD, JD, an assistant professor of obstetrics, gynecology, and reproductive biology at Harvard Medical School in Boston, says, “We have slowly come around to the importance and potential benefit of disclosure to children.”

What remains unanswered in the U.S. is whether donors can, and even should, expect anonymity.

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“Our laws are protective of donor anonymity, but there is a trend toward favoring open donation,” says King. “Leaving the door open for contact once a child reaches majority, as is done in the U.K., is likely the best option.”

The ASRM statement includes this language: “Counseling recipient parents about disclosure and sharing of information is important even for prospective parents who do not intend to disclose the donor conception to their offspring, because the parents may change their plans in the future.”

“The primary ethical consideration, especially in our age of burgeoning genetic knowledge, is a child’s fundamental interest in knowing their biological origins,” says King.

The only argument against

disclosure that might overcome the child’s interest is that disclosure could be harmful. “Yet studies have shown disclosure is not harmful,” says King. “A parent’s desire for privacy about the genetic nature of their parentage should not trump the child’s interests here.” ■

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# Study: Effects of Early Palliative Care Differ by Age, Gender

The effects of early palliative care differ depending on patients' age and gender, found a recent study.<sup>1</sup> Researchers analyzed data on 350 patients with advanced lung cancer and non-colorectal gastrointestinal cancer. Patients received an early palliative care intervention integrated with oncology care, or usual oncology care alone, and were evaluated at 24 weeks. Key findings include:

- younger patients with lung cancer in the palliative care group reported increased use of active coping and decreased use of avoidant coping;
- the effects of early palliative care on these outcomes were not significant for older patients;
- male patients with lung cancer in the early palliative care group reported better quality of life and lower depression scores. The effect of palliative care on these outcomes was not significant for female patients.

Several studies have shown that patients with access to palliative care

at the time of diagnosis of a serious illness live longer and have a better quality of life.

"They also tend to be protected from burdensome and avoidable hospital admissions and emergency room visits," says **Dana Lustbader**, MD, FAAHPM, chair of the department of palliative medicine at ProHEALTH in Lake Success, NY. This is due to better treatment of their distressing symptoms and around-the-clock availability of providers.

"As we learn more about how to best deliver palliative care, it will be important to study how individual characteristics, demographics, faith backgrounds, culture, and communities experience these services," says Lustbader.

ProHEALTH's palliative care team always asks patients and loved ones, "What matters most to you?" and "What are you worried about most right now?"

The answers to these two questions allow the team to best address what matters most in the moment.

"All too often, healthcare providers presume to know what patients want, and we're often wrong," says Lustbader. ■

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## Barriers Exist to Family-centered ICU Care

*Better outcomes for patient, family, and community*

New guidelines from the Society of Critical Care Medicine (SCCM) emphasize the benefits of

family-centered care in the ICU.<sup>1</sup> "We now know that providing family-centered care improves

outcomes in families of critically ill patients long-term," says **Judy E. Davidson**, DNP, RN, FCCM, EBP, lead author of the guidelines and nurse scientist at University of California, San Diego Health.

A multidisciplinary group of 29 healthcare experts developed recommendations for family-centered care based on an analysis of more than 450 studies. "ICUs may find some recommendations easier to implement than others,"

### EXECUTIVE SUMMARY

New guidelines from the Society of Critical Care Medicine emphasize the benefits of family-centered care in the ICU. Some recommendations include:

- accommodations for loved ones to sleep;
- educational programs to teach family how to assist with care;
- encouraging family members to be part of the decision-making process.

Davidson acknowledges. Some recommendations include:

- educational programs to teach family how to assist with care;
- encouraging family members to be part of the decision-making process;
- accommodations for loved ones to sleep.

The design of older ICUs doesn't allow a sleep space. "But at the very least, prior to remodeling or rebuilding, a sleep surface should be available for those who want to spend the night," says Davidson.

"If we adhere to 'do no harm,' we cannot treat the family as if they are an add-on to care, or people you deal with only if you have time," adds Davidson. Engaging families in care can decrease long-term anxiety, depression, and/or symptoms of post-traumatic stress.

"Therefore, we are duty-bound to ascribe to the principles of family-centered care," says Davison. "These are best practices that can prevent harm."

There are more than 11 million ICU patients each year in the United States alone. "One-third of their family members will develop mental health, physical, or social ramifications from their exposure to critical illness. We can make a big dent in that," says Davidson.

By providing family-centered ICU care during times of crisis, says Davidson, "downstream, we can improve the health of our communities."

## Patients Want Family Involved

There is growing focus on the issue of family-centered ICU care, and more evidence-based interventions to improve it.

"However, there is also compelling evidence that we often don't provide high-quality, family-centered care," says **J. Randall Curtis**, MD, MPH, professor of medicine and director of the Cambia Palliative Care Center of Excellence at University of Washington Medicine in Seattle.

The motivation for the SCCM guidelines was threefold: to summarize the existing evidence, make recommendations for best practices, and highlight areas in need of future research. "First and foremost, we know that most patients want their family members to be involved in care and supported through their critical illness," says Curtis. In fact, many patients care as much or more about the care their family is receiving than about their own care.

Curtis cautions that family-centered care must be viewed as an adjunct to patient-centered care, not a replacement: "There are situations where what is in the best interests of the patient and the family are different. These situations need to be negotiated carefully."

One of the recommendations of the SCCM guidelines is to use a palliative care or ethics consult team when challenging situations like this arise, to help sort out appropriate next steps. "Evidence shows that ethicists can improve care when value-laden conflicts arise in the ICU," notes Curtis.<sup>2</sup> Palliative care consultants also can provide similar support.

"The most appropriate consultant will vary from hospital to hospital, depending on the resources available," says Curtis. At UW Medicine, the team often uses palliative care consultants and ethics consultants for the same patient and family.

"We generally start with a palliative care consult to provide additional support for patients and family members, and then add an ethics consult if the conflict or distress remains unresolved," says Curtis. ■

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## COMING IN FUTURE MONTHS

- How certification process will change clinical ethics consultations
- Ethics services are coping with unprecedented surge in demand
- New data on interventions to help surrogate decision-makers
- Ethics of new position statement on life-sustaining treatment

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**CME/CE QUESTIONS**

- 1. Which is true regarding demonstrating the value of ethics, according to Gavin Enck, PhD?**
  - a. Moral discomfort is positively impacted by ethics consultation, with the exception of complex cases.
  - b. Hospital administrators generally place more weight on satisfaction than data on clinical outcomes when determining resources to allocate for ethics.
  - c. Ethics consults have been shown to increase length of stay for end-of-life cases.
  - d. Data on cost, quality, satisfaction, and length of stay are effective in convincing hospital leaders of the financial impact of ethics.
- 2. Which is true regarding spiritual assessment, according to a recent study?**
  - a. Most health professionals agreed patients should take a screening spiritual history.
  - b. Most health professionals currently perform a screening spiritual history.
  - c. The majority of patients believe discussion of spiritual values to be inappropriate.
  - d. Providers felt strongly that such assessments should only be done if patients specifically request it.
- 3. Which is true regarding ethical considerations for disclosure of donor-assisted conception?**
  - a. Parents' rights to privacy supersede donor-conceived children's rights to information.
  - b. As long as stigma exists, non-disclosure is generally the only ethical choice for parents.
  - c. Laws mandating information be disclosed to donor-conceived children violate ethical principles.
  - d. There is growing recognition that the rights of donor-conceived children are at least as important as the rights of the parents.
- 4. Which is true regarding early palliative care, according to a recent study?**
  - a. Patients' age had no bearing on the effects of early palliative care.
  - b. Male patients with lung cancer who received early palliative care reported better quality of life and lower depression scores.
  - c. The effects of early palliative care on depression scores were much more significant for older patients.
  - d. Female patients reported better overall quality of life with early palliative care than male patients.