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INSIDE

Rise of concierge medicine raises social justice issues. 100

Ethical challenges of disclosing pathology errors to patients . . . 101

Consult service created specifically to deal with moral distress 102

Ethical considerations if family members want to be egg donors 103

What surgeons really think about device reps in the OR. 103

A new way to assess families' satisfaction with end-of-life care. 104

Good news on accuracy of completed POLST forms. 105

Legislation linked to lengthier hospice care for children. 106

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Case of Terminally Ill Infant Sparks Ethical Debate Over Autonomy

Parental autonomy is a central ethical issue

The highly-publicized case of Charlie Gard, a terminally ill British infant, ignited a recent global ethical controversy. The case involved a court battle between the hospital, who wanted to remove the infant from life support, and the child's parents, who wanted their son transferred to the U.S. for an experimental treatment.

"If the case had occurred in the U.S., the parents would have almost certainly been allowed to proceed with the transfer," says **David Magnus**, PhD, Thomas A. Raffin professor of medicine and biomedical ethics and professor of pediatrics at Stanford (CA) University, and director of the Stanford Center for Biomedical Ethics.

This is because an institution was willing to accept the patient, an experimental treatment was being offered, and the parents had the means to pay for it. The baby finally was moved to a hospice facility to die.

> IN THE U.K., THERE IS MORE EMPHASIS ON A "BEST INTEREST" STANDARD, MAKING IT FAIRLY STRAIGHTFORWARD FOR PROVIDERS TO TURN TO COURTS FOR A DECISION.

"That would never have happened in the U.S., where the best interest of the child is primarily dictated by the parents," says Magnus. "I cannot imagine any hospital in the U.S. would not have transferred the patient."

In the U.K., there is more emphasis on a "best interest" standard, making it fairly straightforward for providers to turn to courts for a decision. In the U.S., this is very uncommon.

"Unless it's abuse or neglect, we

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don't go to court," says Magnus. The only exceptions are generally egregious cases where a child's life is endangered because the parents are refusing a necessary, clearly beneficial surgery or another form of treatment. This reflects the strong emphasis on parental autonomy in the U.S.

"It's been pretty amazing to me how challenging it is to get child protective services to go to court, even when families are making really terrible decisions that could lead to the loss of the child's life," says Magnus.

The Gard case evoked strong public sympathy for the plight of the parents, who wanted to pursue any chance to save their son. **John Lantos**, MD, professor of pediatrics at Children's Mercy Kansas City in Missouri, and director of the Children's Mercy Bioethics Center, says, "Even though the hospital won the legal case, I think the parents won in the court of public opinion."

Doctors and hospitals might be less likely to challenge parents in similar circumstances in the future, fearing a firestorm of bad publicity. "No hospital or health professional would want to be in the news the way that Charlie's doctors were," says Lantos.

The U.K. doctors and nurses reportedly received numerous death threats. "They must be asking themselves whether fighting for their belief that what they were doing was best for Charlie was all worth it," says Lantos.

The doctors and the parents had deeply held convictions about what was right. "This was a case that called for mediation," says Lantos, adding that the judge in the U.K. case recommended mediation for similar cases in the future.

Some hospital policies state that when doctors believe treatment to be futile and harmful, they have no obligation to provide such treatment. "But most also say that, if the parents find another doctor who is willing, the baby should be transferred," notes Lantos.

He says the Gard case raised the following important ethical questions:

• Is the patient actually in pain? "In court testimony, his clinicians acknowledged that they were uncertain whether he was in pain or not," says Lantos.

• Is there any reason to think that the experimental treatment (of nucleoside therapy) had any chance of offering benefit?

"Initially, most doctors said no, and one said yes," says Lantos. "In the end, they all said no."

• Given that the child was not known to be in pain, and that a doctor-stated treatment might be beneficial, then who should decide if it should be offered: doctors, parents, or the courts?

EXECUTIVE SUMMARY

The case of a terminally ill U.K. infant ignited a global ethical debate on how to resolve conflicts between the hospital and parents. Some ethical implications include the following:

- Doctors and hospitals might be reluctant to challenge parents, fearing bad publicity.
- Ethically sound recommendations about innovative therapies are needed.
- Training can help clinicians and administrations prepare for similar cases.

"Generally, in the U.S., if parents can find a different doctor or hospital, then we allow the patient to be transferred," says Lantos. "The alternative is to have courts deciding which medical opinion is best."

The Gard case reflects the profound responsibility that physicians and researchers have when making recommendations about innovative therapies.

"We need to help parents like Charlie's to make wise choices for themselves and their child, especially in the face of great emotional turmoil and uncertainty," says **Robert D. Truog**, MD, Frances Glessner Lee professor of medical ethics, anaesthesia, and pediatrics, and director of the Center for Bioethics at Harvard Medical School in Boston. Truog authored a recent paper on the Gard case.[1]

"Charlie's parents are like parents everywhere — there are no limits to what they will do for their child," says Truog. "Clinicians should always be willing to think hard and creatively about how we might help them."

However, the fact that parents will grasp at even the faintest of hopes underscores the obligation of making ethically sound recommendations.

"We have an obligation to carefully consider the specifics of the patient's condition, and to make an honest assessment of the likelihood of benefit, before offering experimental treatments as reasonable options," says Truog.

The consensus of those who had access to Charlie's medical record was that he had already sustained severe brain injury that could not have been reversed by the drug, even if it did work.

"It's important to remember that 90% of all drugs never make it past the first round of clinical trials," says Truog. The drug being offered to Charlie had not even progressed to being eligible for a clinical trial. Despite this, many were persuaded that the ability and willingness of Charlie's parents to pay for the treatment out of pocket should have made the decision easy.

"The reality is more complex," says Truog. Even if the treatment did not work at all, Charlie would probably have needed care in a pediatric ICU for weeks or months.

"Even in affluent countries like the United States, pediatric ICUs are operating at full capacity," says Truog. Children who need urgent care are always accommodated. However, this often is accomplished only by delaying essential but nonurgent procedures and operations for other children.

This makes sense when there is good reason to believe that children are benefitting from the care they are receiving. "It is much harder to justify when this is not the case — even when the parents are paying for the treatment," says Truog.

For **Janet L. Dolgin**, PhD, JD, co-director of the Hofstra University Bioethics Center in Hempstead, NY, the Gard case was a reminder of the importance of ethics training in hospitals.

"Clinicians and administrators are better able to respond to the difficult challenges raised by cases such as that of the Gard baby if they have been trained to think about the issues from an interdisciplinary perspective," says Dolgin, director of Hofstra University's Gitenstein Institute for Health Law and Policy. "It's helpful if the team has participated in helping to resolve actual cases or simulated cases constructed for educative purposes."

Unfortunately, cases involving medical decisions for very ill infants and babies are not rare. Yet, each case is unique.

"Every case challenges those involved — parents, guardians, clinicians, and judges — to examine their own assumptions and motives in attempting to mediate among divergent views about the response or responses that will best serve the sick child," says Dolgin.

Significantly different conclusions may be drawn about the appropriate course of action, based on the nuances of a particular case.

"There is often no one correct response to such conundrums," says Dolgin. "They require labor-intensive participation by ethicists, clinicians, family members, and others." ■

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Do Concierge Practices Indicate Medicine 'Needs To Be Fixed?'

Access to care is central ethical concern

The continued growth of concierge medicine is spurred, in part, by a strong desire for longer, more meaningful visits. This is true for both patients and physicians.

"The typical 15-minute, one-size-fits-all, visit is just not enough time to adequately address the myriad patient concerns, provide preventive care and counseling, and establish a trusting relationship," says **William Martinez**, MD, assistant professor of medicine at Vanderbilt University School of Medicine in Nashville, TN.

Jack Ende, MD, president of the American College of Physicians (ACP), notes that universal access to care is one of the organization's "fundamental, guiding principles. While it is true that not everyone can afford an expensive car or lavish home, those things are not human rights. But medical care is different. It is a human right; in fact, a very basic human right."

The ethical question is whether this should be an individual clinician's responsibility, or the entire health system's.

"As a nation, we should be able to guarantee access to high-quality care for everyone, regardless of economic status. Moreover, as physicians, we need to advocate for same," says Ende, the Schaeffer professor in medicine at University of Pennsylvania's Perelman School of Medicine in Philadelphia.

The ACP and other organizations provide opportunities for members to press for universal access to care, regardless of the patient's ability to pay.

"But when we examine the responsibility of the individual doctor in his or her own practice, it becomes a more difficult question to answer," says Ende.

There is no consistent definition for concierge medicine, also called "retainer medicine" or "direct primary care." Typically, practices limit patients to the 200 to 1,000 range, compared to the more than 2,000 seen by most primary care doctors, notes Martinez. The exact number of concierge practices is unknown.

"I have seen estimates of 5,000 to 20,000 physicians in the U.S. practicing some version of retainer medicine or cash-only practices, with growth as high as 5% per year," says Martinez. "But without any sort of national registry, it is really hard to know."

Participating patients pay monthly or annual fees, which vary widely depending on the practice. While some practices accept insurance to cover traditional office services like labs and other diagnostics, others are cash-only.

"The negative effects on patients resulting from transitions to retainer medicine don't affect all patients equally," notes Martinez. Patients who are unable to pay the retainer fee are disproportionately affected.

"While concierge medicine is far from the only thing that may impact access to care, the medical profession should be looking for ways to improve access — not lessen it," says Martinez.

Proponents of concierge practices argue that better doctor-patient relationships outweigh the social justice concerns.

"The principal consideration, however, is, can we achieve the purported benefits of retainer practices within a practice model that does not worsen access and particularly disadvantage less affluent patients?" asks Martinez.

Some practices attempt to mitigate social justice concerns by saving some spots for less affluent patients. Others offer reduced or no-fee services to a certain proportion of patients.

"Some retainer practices within academic medical centers use the additional revenue brought in through the retainer fee to subsidize the care of indigent patients," adds Martinez.

Continuing Appeal

The ACP's position paper on concierge practices states that physicians should consider the effect of any changes that could make it more difficult for poorer patients to access their practice.[1]

Ende says, "Whatever happens with the concierge model, the most important consideration is that every member of society has high-quality, affordable care."

Fewer administrative burdens and appropriate reimbursement would lessen the incentive to move to a concierge model. "Absent that, we may see more doctors retiring, cutting back on patient care, or transitioning into models like concierge," says Ende.

The persistent appeal of

concierge medicine is like "the canary in the coal mine," says Ende. "It's a signal that the practice of medicine — which, inherently, should be one of the most rewarding activities anyone can engage in — needs to be fixed." ■

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Study: Pathologists Want More Active Role in Error Disclosure

Many feel ill-prepared for difficult conversations

Pathologists want to play a more active role in conversations about errors with patients, instead of turning to the treating physician to handle it, according to a recent study.[1]

"I was pleasantly surprised that some of these pathologists were willing to play a more active role in conversations about errors with patients, rather than taking the easy way out of hiding behind their microscope and letting the treating physician handle the discussion with the patient," says **Thomas H. Gallagher**, MD, one of the study's authors. Gallagher is a professor in the department of bioethics and humanities at the University of Washington in Seattle.

Researchers held five structured focus groups in Washington and Missouri with 45 pathologists in academic and community practice. Participants discussed the nature of pathology errors, how clinicians respond to pathology errors, and what roles pathologists should play in error disclosure to patients. Some findings include the following:

• Most pathologists lack training in error disclosure.

Regardless, the majority believed that, going forward, pathologists should offer to participate more actively in error disclosure to patients.

• Pathologists believe neither treating physicians nor patients understand the subtleties and limitations of pathologic diagnoses.

"It would be especially surprising to patients, and some clinicians, how pathologic diagnoses are not black and white," says Gallagher. Rather, the diagnoses require considerable judgment and interpretation.

This complexity complicates discussions about pathology errors. "What would seem like a straightforward question — 'Is there cancer present on this specimen?' — can be much harder to answer definitively than patients and other providers think," says Gallagher.

This complexity in diagnosis makes it hard to know what constitutes a pathology error. "It's difficult to determine how to best communicate about these events," says Gallagher.

• Pathologists' lack of confidence in communication skills, and fear of being misrepresented or misunderstood, are major barriers to their participation in disclosure discussions.

"I was surprised at the degree to which some pathologists feel isolated," says Gallagher. "On the one hand, they are critical team members. But they're often working alone, and may have not direct contact with the treating team."

Pathologists face not one, but two challenging conversations when disclosing errors — one with the treating physician, another with the patient. Pathologists in the study felt they were poorly prepared for these discussions, a problem that was identified in previous research on disclosure of radiology errors.[2] "Pathologists don't feel like they are prepared to handle either of these complex conversations," says Gallagher.

Gallagher says the study highlights these two important ethical issues:

• how challenging it can be to implement what seems like a straightforward ethical principle

of truth-telling after errors;

• that much more work is needed to fully understand the nature of "collective accountability" of multidisciplinary teams.

"How do we understand roles, responsibilities, and accountability when something has gone wrong in the patient's care?" asks Gallagher.

In addition to providing much-needed education to pathologists on error disclosure, ethicists can act as coaches or consultants.

"Ethicists can provide real-time support in the process of helping a team understand what happened and prepare to communicate with the patient — and with each other — about what happened," says Gallagher. ■

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Consult Service Created for Moral Distress

When ICU nurses at the University of Virginia Health System were experiencing a serious issue with moral distress, they asked **Ann B. Hamric**, PhD, RN, for help.

"We had tried a number of strategies to help staff with moral distress, most involving a lunchtime discussion," says Hamric. But staff had a hard time getting off their units to attend.

Hamric, former associate dean of academic programs at Virginia Commonwealth School of Nursing and co-chair of the American Academy of Nursing's Bioethics Expert Panel, is part of a research team studying moral distress in ICUs in Vancouver, British Columbia, Canada.

"It was evident that moral distress was continuing in some areas," says Hamric. "I realized that a consultation model might be helpful in targeting our efforts."

There were many challenges in creating the moral distress consultation service. First, interested clinicians had to be identified. "Our early moral distress consultants were not necessarily on the ethics committee," notes Hamric. "I just approached people who I thought would be good for this, and willing to learn."

The service started with about seven consultants, who worked in pairs. "Then, we had to teach ourselves how to do consults for this problem," says Hamric. "The classic ethics consultation process did not really 'fit' moral distress."

Next, it was necessary to publicize the service throughout the organization. "Nurses were the first discipline to raise the issue of moral distress and ask for help. So, we started with them," says Hamric. "But even that was challenging." It required ongoing communication to units.

Another challenge was educating administrators and clinicians about the sensitive nature of the morally distressing issues that were uncovered, and the need for system support. For instance, if the issue was the structure of a medical service, then support from the medical director of the service and the system administrator would be necessary.

"The goal is to address moral distress when it occurs, and intervene effectively," says Hamric.

Part of the process entailed educating staff about how to minimize moral distress on their units and teams. Data is gathered after each consult.

"We think the data show that the moral distress consultation service can be a useful intervention in helping create a more ethical practice environment," says Hamric.

The Moral Distress Consultation Service is now a part of the Ethics Consultation Service. Consultants are trained in both types of consults. "This merger was very important in the sustainability of the service," says Hamric. ■

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Ethics of Using Family Members as Egg Donors or Surrogates

Occasionally, patients request that family members be used as egg donors or gestational surrogates. This issue was addressed in a recently updated position paper from the Ethics Committee of the American Society for Reproductive Medicine (ASRM).[1]

"The ethical considerations surrounding intrafamilial gamete donation and gestational surrogacy focus on the well-being of those who offer to provide reproductive services, those who receive those services, and the offspring born of any such donation," says **Judith Daar**, JD, chair of ASRM's ethics committee. Daar also is clinical professor of medicine at University of California, Irvine School of Medicine.

The position paper states that:

• use of adult intrafamilial gamete donors and gestational surrogates is generally ethically acceptable when all participants are fully informed and counseled, but consanguineous arrangements or ones that simulate incestuous unions should be prohibited;

• adult child-to-parent arrangements require caution in order to avoid coercion;

• parent-to-adult child arrangements are acceptable in limited situations.

"Concerns that inure specifically to familial gamete donors and gestational carriers cluster around the principle of autonomy," says Daar.

It is essential that an individual's participation as a reproductive collaborator be fully informed, unconditionally voluntary, and not the result of coercion or undue influence by the intended parent or other party.

"Our opinion recognizes the potential and unique risk associated with reproductive family dynamics, and strives to help avoid these risks by setting out clear parameters as to the acceptability of various configurations as well as guidance for promoting informed consent," says Daar.

The committee also considered the effect of intrafamilial donation and surrogacy on the resulting child. Several ethical concerns are highlighted.

"First, as in any donor-conceived or surrogacy scenario, the issue of disclosure arises," says Daar.

Family collaborations can involve heightened concerns about disclosure for the donor or surrogate, for that individual's own offspring, or because of the impression of incest or consanguinity that can arise. Additionally, the offspring's relationships within the family can be affected as a result of the intrafamilial ART collaboration.

"To address these concerns, the committee recommends that providers take special care to address these and other potential conflicts before proceeding with the requested treatment protocol," says Daar. ■

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Survey: Device Industry Reps in OR Viewed Positively by Surgeons

Many orthopedic trauma surgeons may see some significant ethical concerns if a drug company representative wanted to be present during all of their procedures. In contrast, most feel they need device sales representatives in the OR, found a recent survey.[1]

"As an orthopedic surgeon, I found it very interesting that orthopedic device sales representatives, who have sales goals similar to pharmaceutical representatives, seem to be viewed in a different way by orthopedic surgeons, as well as our governing bodies," says **Berton R. Moed**, MD, FAOA, FACS, FRCS(I), the study's lead author.

As a Bander fellow in medical business ethics at Saint Louis University's Albert Gnaegi Center for Health Care Ethics, Moed studied the ways in which pharmaceutical

sales representatives gain access to physicians, and how these individuals can influence prescribing habits.

"Over the years, I have noticed a transition from a time when device sales representatives were hardly ever in the operating room, at least in my personal experience, to now, where they are a ubiquitous operating room presence," says Moed. Some key findings of the study, which surveyed 127 orthopaedic trauma surgeons, include the following:

• Overall, respondents viewed device sales representatives favorably.

• Generation X responders felt device sales reps should be in the OR for all cases. In contrast, baby boomers felt there was a place for device reps, but that they should not be in the OR routinely for all cases.

• Most respondents believed that they personally were not at risk for a conflict of interest, but believed their colleagues might be.

"They feel they are not subject to the conflict of interest from the salesman contact that affects their peers," says Moed.

These findings are similar to studies of the pharmaceutical industry, notes Moed: "There are both financial and ethical implications."

The surgeons surveyed clearly believed that orthopedic device sales representatives are needed in the operating room, whether only for new or complicated procedures, or for all procedures. "The sales representatives fill a void in operating room support, most likely created by progressive cutbacks and reorganizations of hospital personnel," says Moed.

The functional importance of device representatives in the operating room is well-known, and has even been recognized by the Orthopaedic Institute of Medicine.[2]

"Unfortunately, their service comes at a price," says Moed. "That price is the potential conflict of interest from the salesman contact affecting implant selection." ■

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New Tool Assesses Families' Satisfaction With End-of-life Care

A new tool is available to assess family members' satisfaction with end-of-life care in long-term care (LTC). Researchers recently developed and pilot-tested the Canadian Health Care Evaluation Project (CANHELP) Lite Family Caregiver LTC questionnaire.[1]

This LTC tool is part of a suite of tools in Canada that measure satisfaction with end-of-life care in different settings. "The motivation was to support LTC homes to provide better end-of-life care to residents and their families," says **Mary Lou Kelley**, MSW, PhD, one of the study's authors. Kelley led the research for the Quality Palliative Care in Long-Term Care Alliance. She is former research chair in palliative care and professor emeritus in the School of Social Work at Lakehead University in Ontario, Canada.

Family members were mailed a survey to measure what end-of-life care components were most important to them, and how satisfied they were with 21 aspects of care received by their resident.

"This survey can now be used by LTC homes routinely to evaluate their end-of-life care programs, identify areas for staff training and guide them to develop new policies," says Kelley. The tool also can help generate conversations between staff and families about end-of-life care wishes.

Most surveys on satisfaction with end-of-life care are completed following the death of the resident. "This instrument fills a gap, in that it measures the end-of-life experience during the episode of care," explains Kelley.

Overall, families saw all aspects of care as very or extremely important and were generally satisfied. However, day-to-day care issues — whether staff were compassionate and helped the

resident — were more important to families than specific end-of-life items, such as discussing options about life-sustaining technologies or comfort care measures.

Only a small number of respondents (less than 4%) indicated that end-of-life discussions were not important. "It is a positive finding that most families view having end-of-life conversations as important in a LTC home," says Kelley.

However, there was a surprise in the satisfaction results: Many families responded they did not know if they were satisfied because they had not discussed end-of-life issues with staff, including comfort care measures or their relative's end-of-life care wishes.

This response occurred even in situations where the resident was very ill, and could reasonably be expected to die soon. "These findings identify a real need to increase end-of-life conversations with families," says Kelley.

Staff education and incorporating end-of-life care more explicitly in care conferences, care plans, and organizational policies are possible strategies to increase the number of end-of-life conversations. "Families of LTC home residents would also benefit by education on end-of-life care and advance care planning, so they can initiate end-of-life conversations," adds Kelley.

LTC is a unique setting for end-of-life care, in that it is not a specialized care setting focused on care of the dying. "It is a home where residents live, sometimes for several years. The focus is on day-to-day living, as opposed to dying," says Kelley. When death is inevitable, the focus shifts to providing end-of-life care and supporting the resident to die at home.

"Simultaneously supporting residents' quality of life while preparing them for death creates ethical dilemmas for many LTC staff during their day-to-day work," notes Kelley.

LTC home staff find it very challenging to initiate conversations with families about end-of-life wishes. Thus, discussions may be avoided, especially earlier on in the illness process. "This is an ethical issue," says Kelley. "Research has demonstrated that early palliative care is beneficial for supporting a good death in the setting of choice."[2]

Other research by Kelley and colleagues has demonstrated that staffs' comfort level having end-of-life conversations increased after experiential learning.[3,4]

"However, most LTC homes currently lack the funding, resources, and partnerships with palliative care experts to offer staff this specialized education on an ongoing basis," says Kelley.

LTC homes have increasing become a location of death in Canada. Approximately 20% of residents die each year.

"End-of-life issues are very important to families of residents," says Kelley. "However, the prevalence of discussing end-of-life care issues with staff can be improved." ■

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SOURCE

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More Than 90% of POLST Forms Correct and Complete

Less than 10% of completed Physician Orders for Life-Sustaining Treatment (POLST) forms are incomplete or contain contradictory orders, found a recent study.[1]

The fact that more than 90% of the forms in both study states' registries were complete and consistent was "reassuring," says **Alvin Moss**, MD, the study's lead author. Moss is a professor at West Virginia

University's Center for Health Ethics & Law in Morgantown.

Researchers reviewed resuscitation (Section A) and level of medical intervention (Section B) orders in 268,386 forms in the Oregon POLST Registry, and 10,122 forms in the West Virginia e-Directive Registry. Some key findings include the following:

- Of the forms, 99.2% in Oregon, and 96.6% in West Virginia, contained orders in Sections A and B.
- Only 0.11% of forms from Oregon, and 2.53% of forms from West Virginia, contained contradictions. "This should go a long way to ensuring that patients' wishes are known and respected," says Moss.

In contrast, a previous study found that more than half of Medical Orders for Life-Sustaining Treatment (MOLST) forms completed in New York state were either incorrect or contradictory.[2]

"We did not believe the study was representative of POLST completion practices elsewhere, and we studied our databases to see," says Moss. "We learned the results were the exception rather than the rule."

In the New York study, researchers analyzed 100 MOLST forms that accompanied patients transported to an ED. They found that 69% had at least one section left blank. Inconsistencies were found in 14% of forms, such as stated desires for "comfort measures only" when the same form indicated a desire to be sent to the hospital, receive IV fluids, and/or receive antibiotics.

"What this shows is a real variability from state to state in how these forms are completed," says Moss.

West Virginia, Oregon, and California, are the only three states recognized as "mature" programs by the National POLST Paradigm. This means the forms are used in more than 50% of hospitals, nursing homes, and hospices in each region of the state.

"It looks like the education in West Virginia and Oregon has been more successful than in New York," says Moss.

The researchers attribute the results to statewide education efforts through POLST Paradigm Programs.

"We're not doing any magic," says Moss. "It's just really important to make sure that the people completing the forms, in all healthcare settings, know how to do it properly." ■

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SOURCE

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Increased Hospice Length of Stay for Children Receiving Palliative Care

Multiple obstacles hinder access

Children who receive palliative care have increased hospice length of stay, according to a recent study.[1]

"This topic has been a burning issue for me since I started looking at pediatric end-of-life care almost a decade ago," says **Lisa Lindley**, PhD, RN, the study's author. Lindley also is an assistant professor at The University of Tennessee's College of Nursing in Knoxville.

The research looked at the effect of 2010 California legislation that allows children in some counties to receive both curative and supportive care after diagnosis of a life-threatening serious illness.[1]

"When there is an opportunity to empirically look at how state and federal policies have affected the care of kids, you've got to jump at it," says Lindley. Using 2007 and 2010 California Medicaid data, she analyzed hospice use changes for children who resided in that state's pediatric policy counties, compared to those who did not.

Overall, more than 10% of children enrolled in hospice care, with an average of less than three days of hospice care. The policy was positively associated with increasing days in hospice care. "I was happy that the policy did, in fact, impact length of stay for hospice care," says Lindley.

The palliative care policy had no effect on hospice enrollment. In conversations with multiple clinicians practicing in California, Lindley gleaned some insight into a possible reason for this finding. "Many times, palliative care programs in the state are so supportive, that it's enough for families," she explains. "They don't need hospice right away."

Other researchers are looking at the California legislation from a cost perspective. "When we combine all this research, we are able to paint a picture about what's going on here," says Lindley.

The study has important implications as states consider their own approach to palliative care, and also at the federal level. Under the Affordable Care Act (ACA), all state Medicaid programs are required to pay for both curative and hospice services for children under age 21 who qualify.

"It doesn't go as far as the California law. You still need a 'six months to live' diagnosis, but you don't have to give up therapy or treatment," says Lindley. "This can inform regulators who are considering whether to save or scrap the ACA."

Important social justice issues were raised by the study's findings. "The policy is geographically defined right now. Only certain counties have access to this policy," notes Lindley. Policymakers selected counties with high mortality and good access to hospice care. "From an ethics standpoint, issues of environmental justice come into play here," says Lindley.

Field Is Catching Up

Policies promoting palliative care are critical to ensuring access to hospice care for children. "Obstacles to children receiving palliative care include a combination of factors," says **Jane Jankowski**, DPS, MSB, LMSW, director of clinical ethics at Alden March Bioethics Institute at the Albany (NY) Medical Center.

A societal reluctance to acknowledge the uncomfortable reality that children do, in fact, suffer from life-limiting diseases is one barrier. Lack of healthcare providers with the necessary expertise is another.

"Though there are more programs emerging for children, it is likely that the field is still catching up," says Jankowski. Historically, the development of programs for palliative care for children has lagged behind those designed for adults. Thus, access may be limited to geographic regions closest to major children's hospitals.

"Funding, training, and institutional support are essential for these programs to take root and grow," says Jankowski.

Community awareness and support also are important. "Many families will continue to care for sick children at home, and need home-based palliative care services," notes Jankowski.

Home care agencies, primary care pediatricians, and hospice programs must work together to deliver high-quality palliative care to children. "All need the support and guidance of expert pediatric palliative medicine practitioners in order to do so," says Jankowski.

Ethicists can support access to pediatric palliative care in the following ways:

• Discussing moral dilemmas with patients, families, and caregivers who are grappling with difficult healthcare decisions.

"This may include education about palliative care programs, particularly where there are concerns about suffering for the patient," says Jankowski.

• Discussing and establishing a plan of care that balances the benefits and burdens to the child.

"This can open the door to discussing palliative care," says Jankowski. ■

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SOURCES

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COMING IN FUTURE MONTHS

- Avoid needless conflicts with early end-of-life conversations
- Ethics of informed consent for research on alcohol use disorders
- Unethical marketing practices for unapproved stem cell treatments
- Effective ways to provide palliative care training to radiologists

MEDICAL ETHICS ADVISOR®

CME/CE QUESTIONS

1. **Which is true regarding cases in which parents are requesting treatment that clinicians believe is inappropriate, according to David Magnus, PhD?**

   a. Child Protective Services universally errs on the side of caution by involving the courts where there is a doubt that a parent's decision isn't in the child's best interest.
   b. Courts typically allow parents wide latitude in cases where a child's life is endangered.
   c. Hospitals are legally obligated to provide requested treatment for minor patients, even if doctors determine it to be without medical benefit.
   d. Patients typically are transferred for care deemed non-beneficial if there is an accepting institution.

2. **Which is true regarding disclosure of pathology errors, according to a recent study?**

   a. Many pathologists want to play a more active role in error disclosure.
   b. Clinicians find disclosure of pathology errors significantly easier than other types of medical errors because there is less complexity in diagnosis errors than in treatment errors.
   c. Pathologists feel confident in having conversations about errors with clinicians.
   d. Pathologists believe that both treating physicians and patients understand the limitations of pathologic diagnoses.

3. **Which is true regarding use of family members as egg donors or gestational surrogates, according to a recent position paper?**

   a. Use of adult intrafamilial gamete donors and gestational surrogates is ethically unacceptable, even if both parties are fully informed.
   b. Consanguineous arrangements or ones that simulate incestuous unions should be prohibited.
   c. Adult child-to-parent arrangements are unacceptable due to the strong possibility of coercion.
   d. Parent-to-adult child arrangements are not acceptable regardless of whether providers take special care to address potential conflicts.

4. **Which did most orthopedic trauma surgeons report regarding device industry representatives in the OR, according to a recent study?**

   a. Strong concern that they were personally at high risk for conflicts of interest.
   b. A belief that their colleagues were not susceptible to conflicts of interest.
   c. That they needed device representatives in the OR.
   d. That overall, device reps had an adverse effect on patient safety.