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Survey: Compassionate care could mean life or death

The Schwartz Center surveyed 800 patients, 500 physicians

A majority of patients and physicians polled in a national survey believe not only that health care delivered with compassion can make a difference in how well a patient recovers from illness — it can also make a difference in whether a patient lives or dies.

The survey, commissioned by The Schwartz Center for Compassionate Healthcare at Massachusetts General in Boston, was a national poll of 800 patients and 500 physicians about “the state of compassionate health care in the United States,” according to **Beth A. Lown, MD**, medical director of the center. The center’s programming focuses on facilitating and educating clinicians on the compassionate delivery of care, primarily in the hospital setting, but also in some outpatient settings, nursing homes, and managed care organizations, according to The Schwartz Center’s Executive Director **Julie Rosen**.

The survey, conducted from Sept. 23 to Oct. 29, 2010, asked a series of questions about the importance of compassionate health care to both groups, Lown explains. The patients were those who had been hospitalized for at least three days within the past 18 months. The physicians were those who spend at least some of their time taking care of hospitalized patients.

“I think what was so striking is that moving from . . . treatment is important in recovery, the majority of both doctors and patients said it’s important; and it makes a difference in whether patients live or die — that’s astounding,” she tells *Medical Ethics Advisor*.

And while, as an internal medicine physician, Lown says she thinks the profession believes in the importance of compassionate health care, she “still was surprised that they said it made a difference in life or death.”

The national survey excluded uncomplicated pregnancies, “because we wanted to get at the people who had really had something signifi-

cant wrong in order to be hospitalized in those circumstances.”

According to the center, the poll found that patients and doctors generally agree about the most important elements of compassionate care, which were defined in the poll as:

- showing respect for patients, their families, and those important to them;
- treating patients as people, not a disease;
- conveying information in a way that is understandable;
- listening attentively to patients;

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EDITORIAL QUESTIONS

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- gaining the patient’s trust.

Despite agreeing on the potential impact on the patient of compassionate care, there were specific elements on which physicians and patients did not necessarily agree. For example, 75% of patients rated the objective of apologizing to a patient when a physician has made a mistake as a 10 on a 10-point scale of importance. But only 54% of physicians rated this as a 10.

Likewise, 78% of patients rated communicating test results in a timely and sensitive manner as a 10, compared to 61% of physicians. Also, 63% of patients rated comfortably discussing sensitive, emotional, or psychological issues as 10, compared to 50% of physicians.

The ideal of care vs. reality

While both patients and physicians indicated that compassionate care is important, how that ideal manifests in the hustle and bustle of today’s hospital setting seemed different from the type of care patients indicated they actually received during their most recent hospitalization.

For example, 83% of patients polled indicated they expected that physicians would express sensitivity, caring, and compassion, but fewer, or 67%, indicated that physicians actually demonstrated those behaviors during their hospital stay. Also, 91% of patients said they would expect that physicians would listen attentively, compared to 67% who said this is what they actually experienced in their most recent hospital stay.

As to why the gaps between the ideal and what actually occurs in the hospital care delivered may seem at odds, Lown says, “That is a bit of: Why is our health care system not able to provide as much compassionate care as patients would like to see happen? . . . So, what is it that makes the real different from the ideal? I think it’s just incredibly complicated, and I don’t have data from the poll to support this, but I can tell you my opinion; and I don’t think it’s too far from what others might say.”

For starters, with the institution of DRGs, there have been “shorter and shorter lengths of stays in this country,” she explains.

“That means there’s less and less time for a team to get to know a given individual in a hospital,” she says. “When I was starting, it wouldn’t be unusual to have a patient in the hospital for a week or more. That’s unheard of now, and that actually . . . impairs your ability to really get to

know the patient and his or her concerns. So, it's a very rapid throughput in the hospital these days. That's one issue."

"The second issue is that technology, over time, has superseded presence and touch," Lown says. "So, rather than really having the system encourage people to go and sit at the bedside and actually elicit a robust history — and by that I mean one that has both the clinical clues that you need to really understand and make a diagnosis and fashion therapy — but also the psychosocial, the emotional, the psychological clues that help you understand the context of the patient. The systems don't make it easy to do that at all."

And while reimbursement doesn't really exist for time spent conversing with the patient, Lown maintains that it doesn't really take "a tremendous amount of time."

"It takes focused presence; it takes attention; it takes mindful listening; it takes empathic resonance; but I think people fear that [this type of conversation] will open a Pandora's box that they don't know how to manage or they won't have time to manage," she says.

The impact of hospitalists

Another factor in shaping the reality of care vs. the kind of care patients say they want is the impact of the hospitalist movement over the past 10 years, Lown says.

There are both advantages and disadvantages to the rise of hospitalists providing care in the hospital setting, but it has meant that primary care doctors are "less and less present in the patients' hospital experience; some people think that's good, and some people . . . grieve that loss," she notes.

The hospital environment of today has "become an increasingly fast-paced, technical method of taking care of acutely ill patients that doesn't necessarily prioritize or honor the patient's experiences in the way they wish they could have," Lown says.

SOURCES

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Schwartz Center rounds offer emotional outlet

Focus is on compassionate care

The focus of The Schwartz Center for Compassionate Healthcare's programming is something called The Schwartz Center Rounds, which would have a familiar ring to most clinicians.

"The mission of our organization is to strengthen the patient/caregiver relationship and to help educate and support clinicians to provide compassionate health care, to provide support and hope to patients, and sustenance to the healing process," Executive Director **Julie Rosen** tells *Medical Ethics Advisor*. "But 90% of what we focus on is training, educating, supporting clinicians."

Rosen describes the rounds, which are primarily for hospitals, as a "multidisciplinary forum where approximately once a month . . . a multidisciplinary group of clinicians get together to talk about the tough psychosocial issues they face in caring for patients."

Currently, the rounds are in 32 states, in 210 hospitals, reaching about 60,000 clinicians a year. While primarily for hospital staff, The Schwartz Center is also conducting rounds programming in "some outpatient settings, nursing homes, and managed care organizations," Rosen says.

Clinicians who want to launch this program at their individual institutions must first get buy-in from the executive leadership, and a contract is drawn up for the facility. Then, the clinicians who have elected to initiate the program must first travel and observe The Schwartz Center Rounds programming, "usually at a Boston hospital or a New York hospital," Rosen says.

Rounds 'all have a theme'

Once the rounds get under way at an institution, an outside facilitator leads or moderates them. A planning committee at that institution will determine an actual case within that institution to serve as the topic for that particular rounds session, Rosen says.

"[The rounds] all have a theme about . . . the struggles that caregivers face in their daily interactions with patients, and the families' struggles . . .," Rosen explains. "So, the theme could be:

‘How do I take care of my fellow colleague who is dying, and what kinds of issues does that bring up for me? How do I take care of the difficult patient that is from a different culture? How do I show empathy and sympathy towards an incarcerated patient?’”

Following a presentation by a multidisciplinary group about an actual case at that institution, and the session is “professionally facilitated, there’s a discussion where clinicians share their thoughts, feelings, experiences about similar cases,” she says.

Not your typical rounds

Beth A. Lown, MD, who is medical director at The Schwartz Center, suggests that The Schwartz Center Rounds are “not like any other rounds in a hospital.”

“[With] grand rounds, you come in; you sit down; it’s a lecture; and people present technical material and data . . . so these are only rounds in name, but not in spirit,” Lown explains, adding that The Schwartz Center Rounds are a “place for anybody who touches the care of a patient in a hospital or other setting where we have the rounds can come together and talk about some of the psychosocial, the emotional, the psychological aspects of care of patients and their impact on patients, on family members, and particularly on us — the people” who provide that care.

The Schwartz Center Rounds may be the “only place that happens; people don’t get together in this way” ordinarily, Lown says.

“You rush through the day; you try to do your best and take care of all the emergencies that comes your way; and all of these other things that happen to patients have to get stuffed away somewhere, so that you can continue to function and carry on the things you need to do,” she says. “But we need places to come together like this to sort of share what these experiences have been like, so that we can hear what it’s like from the perspectives of our colleagues.”

SOURCES

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- **Julie A. Rosen**, Executive Director, The Schwartz Center for Compassionate Healthcare at Massachusetts General, Boston. E-mail: jarosen@partners.org. ■

Dartmouth Atlas Report: No consistency in care

Care varies markedly across regions, hospitals

Where they live can determine whether Medicare patients with advanced cancer die in a hospital or while receiving hospice care, according to the findings of a Dartmouth Atlas Project report, released in November 2010.

The report, “Quality of End-of-Life Cancer Care for Medicare Beneficiaries: Regional and Hospital-Specific Analyses,” states in its introduction that “[t]his Dartmouth Atlas report examines how elderly patients with poor-prognosis cancer are cared for across regions and hospitals and finds remarkable variation depending on where the patients live and receive care.”

“Even among the nation’s leading medical centers, there is no consistent pattern of care or evidence that treatment patterns follow patient preferences,” the report states.

The report’s lead author is **David C. Goodman, MD, MS**, who is co-principal investigator for the Dartmouth Atlas Project and director of the Center for Health Policy Research at the Dartmouth Institute for Health Policy and Clinical Practice in Lebanon, NH.

Good information about the why variability of care exists comes from “a variety of other studies, including two Institute of Medicine reports,” Goodman tells *Medical Ethics Advisor*.

“There are some facts that we know,” as a result of such studies, he explains. “First, we know that generally, on average, patients receive much more aggressive treatment at the end of life and at the end of life with cancer than they prefer. Now, there are, of course, individual preference differences. They are important. They should be respected. But on average, patients are getting more care than they want, and it really degrades their quality of life.

“We also know that palliative care is underutilized in the United States — that many patients near the end of life don’t receive adequate pain control or other adequate comfort measures,” Goodman notes. “They’re not afforded, oftentimes, the full opportunities to be at home and . . . to be communicating and as close as they would like with their families, because they were in the hospital or intensive care units.”

Hospitals, he says, have also leaned toward

underinvesting in palliative care services for patients at the facilities.

“They are sort of the poor relation to oncology and intensive care services,” Goodman explains. “In many places, they are seen as an admission of defeat, which mischaracterizes both cancer, its treatment, as well as patient preferences. So, there are problems with inadequate investment in care that patients want, but there [are] also problems in health care providers’ attitudes and understanding of patients’ wants and needs.”

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, issued a news release following the Dartmouth Atlas Project’s report on cancer care at end of life in this group of Medicare patients.

“The Dartmouth Atlas Project is to be commended for undertaking this thorough examination of end-of-life care for Medicare beneficiaries with advance[d] cancer,” said **J. Donald Schumacher**, president and CEO of the NHPCO, in a news release. “While the findings of variation in care are not necessarily a surprise, one of the key messages that I take away from this report is the critical need for hospitals and all health care professionals to ensure that all patients are informed earlier about the course of an illness and the range of options available — options that include hospice and palliative care.”

Schumacher continued, “It’s important to recognize that this report is not a negative comment on care in our nation’s hospitals or among academic medical centers, rather, it’s a much needed reminder that health care professionals must work to help patients and families understand where the course of their illness may take them. And, when cure is not possible, it is our duty to offer the robust benefits that the hospice team can provide.”

Ethical considerations from the report

There are “fundamental ethical” problems in health care delivery today in the United States, according to Goodman, who is also a practicing physician.

“One of them is that the paradigm that the role of physicians is to gather as much information as they can about their patients and then to provide them with a recommendation which is in the best interest of their patient,” Goodman tells *MEA*. “There certainly are situations when the physician uniquely understands both the

information and what represents best interest, or when decisions have to be made fantastically quickly, and we [place] trust [in] physicians to make the best call.”

“But, in fact, there are many decisions in health care, and certainly at the end of life or when patients are not doing well with treatment, when it is presumptuous to assert that they uniquely understand what’s in the best interest of patients,” he explains. “And yet, this is done every day. It is a failure of ethical communication; it’s a failure of providing adequate information to patients and family; and it leads to patients receiving care that is not the sort of care that they want.”

Variation exists

Variation occurs not only across regions, which Goodman indicates reflects “the care provided by physicians and hospitals,” but also across hospitals.

“It’s interesting,” Goodman says. “I think that every place is unique and special. We found just as much variation in the patterns of care across academic medical centers as we did across community hospitals.”

This is a phenomenon that the Dartmouth Atlas project also has found when it engaged in studies of other aspects of care, he says.

“The notion that academic medical centers practice differently because they are places of teaching and research . . . is not well supported by studies that have been done measuring variation across different types of hospitals,” Goodman says. “There are some slight differences that one might see, but they are really overwhelmed by the amount of variation that’s seen within hospital type.”

The researchers reviewed the records of 235,821 Medicare patients ages 65 or older with aggressive or metastatic cancer who died between 2003 and 2007. According to a news release issued on the project, in at least 50 academic medical centers, “fewer than half of these patients received hospice services. In some hospitals, referral to hospice care occurred so close to the day of death that it was unlikely to have provided much assistance and comfort to patients.”

“The well-documented failure in counseling patients about their prognosis and the full range of care options, including early palliative care, leads many patients to acquiesce to more aggressive

care without fully understanding its impact on the length and quality of life,” Goodman also said in the news release.

Regional variation in care

In the United States, about 29% of patients with advanced cancer died in a hospital between 2003 and 2007, according to the report.

“Cancer patients were most likely to die in a hospital in the Manhattan hospital referral region, where 46.7% experienced death in a hospital,” the report states. “The rates were also high in surrounding regions, including Ridgewood, New Jersey (42.8%), East Long Island, New York (42.5%), and Newark, New Jersey (41.1%).”

According to the report, those rates were about six times higher than the rate in the Mason City, IA. In that area, only 7% of cancer patients died in hospital.

“Cancer patients were also much less likely to experience a hospitalized death in Cincinnati (17.8%) and Fort Lauderdale, Florida (19.6%),” according to the report.

The report also sheds light on hospital admissions during the last month of life among hospital referral regions, indicating that “the percent of cancer patients hospitalized at least once during their last month of life varied by a factor of about 1.6” during the same study period.

“Nationally, 61.3% of cancer patients were hospitalized at least once during their last month of life,” the report indicates.

“Cancer patients were mostly likely to be hospitalized during the last month of life in hospital referral regions in Michigan, including Detroit (70.2%), Royal Oak (69.4%), Pontiac (69.4%), and Dearborn (69.1%),” the report states.

However, “less than half of cancer patients” were hospitalized during their last month in Mason City, IA, at 44.9%, or San Angelo, TX, at 46.3%, Cedar Rapids, IA, and La Crosse, WI, at 49%.

The report also indicates hospital days during the last month of life among hospital referral regions, as well as intensive care admissions during the last month of life among hospital referral regions, among other categories examined.

In the latter category, for example, the report indicates that 40% of cancer patients who died during the study period were admitted to an ICU in the last month of life in Huntsville, AL, compared to 13% in Madison, WI, 14.3% in Portland, ME, and 14.6% in Minneapolis.

Variation across academic medical centers

“There is a remarkable amount of variation in the use of hospitals for elderly patients with poor prognosis cancer who are near the end of life,” according to the report. “Even after controlling for cancer type, age, sex, and race, there were more than twofold differences in the number of days spent in hospitals and intensive care units in the last month of life.”

Such differences should “stimulate teaching hospitals to further examine clinician practice styles and decision-making processes in relation to the evolving national norms of quality end-of-life care,” the authors write. The report states that “the percent of cancer patients dying in a hospital varied threefold among patients receiving most of their care at academic medical centers.”

Also, the authors write that “the likelihood of being admitted to the hospital during the last month of life among cancer patients varied from less than 50% to more than 75% across academic medical centers.”

SOURCE

• **David C. Goodman**, MD, MS, Co-Principal Investigator for the Dartmouth Atlas Project and Director of the Center for Health Policy Research at the Dartmouth Institute for Health Policy and Clinical Practice, NH. E-mail: david.goodman@dartmouth.edu. Information: www.dartmouthatlas.org. ■

NYC begins pilot program for organ preservation

Project initiated with HRSA funds

A pilot program between New York City’s Bellevue Hospital and the city’s police and fire departments is designed to allow the city to test the feasibility of recovering organs from the 400-plus eligible people who die of cardiac arrest outside of Manhattan hospitals each year, according to an announcement from the city.

Mayor Michael R. Bloomberg and the New York Organ Donation Network made the announcement about the pilot program on Dec. 1, when the pilot was initiated. The project is being funded with a \$1.5 million grant from the U.S. Department of Health Resources and Services Administration (HRSA).

The city announcement said the pilot program will initially cover the borough of Manhattan. Once the 6-month pilot is completed, it will be evaluated to determine the program's potential to be expanded to other areas in New York City.

The pilot, which will run through May 2011, calls for Manhattan's Emergency Medical Services (EMS) calls to be monitored by a trained organ preservation team. This team consists of a family services specialist from the Organ Donation Network, a licensed emergency physician, and two who are trained as organ preservation specialists.

In instances where EMS goes out on a call, if resuscitation efforts fail, the organ preservation team will respond. If there is an organ donor card available — or if the deceased person was registered on the New York State Donor Registry, the Organ Preservation Team will “ask the family to honor those wishes by moving the deceased to the Organ Preservation Ambulance,” according to the news release.

Patients will be taken to Bellevue Hospital, but organ donation “will not occur without written consent, or consent from the family or next-of-kin,” the city's news release states.

Almost 8,000 people in New York City are on a waiting list for organ transplants.

“New York is currently ranked as one of the lowest organ donation rates in the [United States],” said Elaine Berg of the city's organ donation network, in the press release. “This program has the potential to begin to close the tremendous gap between the number of viable organs and the continuously increased need for life-saving transplants. We can prevent needless death on the waiting list by honoring the wishes of New Yorkers who want to be donors, but die outside the hospital.”

The pilot program's genesis

According to Nancy Dubler, consultant for ethics to the New York City Health and Hospitals Corp. as well as a senior associate at Montefiore-Einstein Bioethics Center, the program had its beginnings with a conversation with Bellevue Hospital Center's Director of Emergency Services, Lewis Goldfrank, MD, at an Institute of Medicine committee meeting, where they discussed how to increase organ donation.

“We sat on this committee, and we became con-

vinced that the real source of organs were people who died out of the hospital,” Dubler tells *Medical Ethics Advisor*, adding that “the only other source of organs, except for those who die in the hospital, are live donations, and, in fact, live donation is very complicated.”

“The closer the person donating, the more you worry about coercion, and the more distance the person, the more you worry about commodification,” she says. “So, we were convinced. And Dr. Goldfrank had had many families in the emergency department say to him, ‘Our loved has died; can't we donate organs?’ And he had to say no.”

The next committee meeting of the IOM also was attended by the New York City Fire Department, the Health and Hospitals Corp, the Organ Donor Network, and “all of the players in New York,” she recalls.

That meeting was a vehicle not only for discussing the problem of organ donation, but also they set up a working committee, which then submitted an application to HRSA. HRSA then funded the project three years ago, according to Dubler.

The new team then began to work on several fronts, she says.

“One, in the hospital with the transplant surgeons, and the ER docs, and the perfusion specialists to see what a protocol would look like for when we had a patient who died in the field [and] who had organs perfused, [and] who then came to the hospital and was ready to donate,” she says.

The team also worked with the New York State Department of Health, which oversees organ donation. Originally, the planning team had wanted to design a program similar to ones that have had success in Spain and France, where the program and the EMS teams could “approach people who died in their offices or on the street.”

However, the New York State Department of Health would not agree to that.

“They were only comfortable with someone who died in their home, where that person had filled out a donor card or was on the New York State Registry, which means that there's first-person consent,” Dubler explains.

The program only accepts donations from deceased patients between the ages of 18 and 60. The Dead Donor Rule, i.e., when a patient is determined to be brain dead, is honored, Dubler says.

“In our project, there is no question,” she says.

“The EMTs have been working on this person for half an hour or more, under the supervision of a physician” before death is declared.

“The aim of the project is to respect the family’s position,” she says. “So, we ask the family if the deceased had indicated the desire to donate; we ask the family to honor the deceased’s wishes, but we don’t ignore the family — even though under New York law, we could; but, this is such a radical project that we don’t want to challenge any more than we have to.”

SOURCE

• **Nancy Dubler**, Consultant for Ethics to the New York City Health and Hospitals Corp. and Senior Associate at Montefiore-Einstein Bioethics Center in New York. ■

Report identifies key issues for genomics

Evidence base needed for public health uses

A group of experts in areas ranging from medicine to law and bioethics suggests that a base of quality evidence must exist and associated ethical concerns must be addressed before public health strategies based on genomics are implemented.

In addition to questions of efficacy of drugs and the benefits of diagnostics based on genetic information in individual clinical health, the experts determined that genomic medicine should be a factor in public health, as well, and on a global level.

“By ‘public health,’ we mean ‘the public’s health,’ which can be influenced via a variety of different routes including programmes that operate at both population and individual levels,” according to a report based on the group’s meeting at Ickworth House in Suffolk, UK, on May 10-14 in 2010.

The report, “Public health in an era of genome-based and personalised medicine” was released in November 2010.

“There are a number of ways in which the public’s health can be influenced by public health programs, and one of those programs will likely be genomic-based,” **Eric M. Meslin**, PhD, a member of the steering committee for the international committee and director of the Indiana University Center for Bioethics, and one of the organizers, tells *Medical Ethics Advisor*. “Having said that, there’s an awful lot we still don’t know . . . about genomic medicine and science.”

One of the current concerns emerging in the literature about this is “the worry about overly hyping or inflating expectations . . . the prospect that we’re in a genomic century and pretty soon, we’ll be able to develop all of these wonderful treatments,” Meslin says. “The evidence base right now is that it’s not happening either as quickly as we would have hoped, or it’s harder than we thought, and let’s not run the risk of over-hyping — raising the public’s expectations only to have to dash them later.”

The slow progress or inability to translate genomic research into safe health care treatments or interventions also tends to dampen the confidence of investors, who are needed to fund such research, particularly in the biotech arena, Meslin says.

A global perspective on ethics

One of the premises of the meeting was that genomics and genetic science should play a role in the global public health arena, Meslin says. But from an ethics perspective, “the global public health angle to this is particularly daunting.”

“On the one hand, it would be easy to simply close your eye to genomics and all of the technology and say, ‘They’ve got their hands full in lower- and middle-income countries with just simply feeding and having safe water for people and immunizing them; that’s a tough enough ethical challenge, and that’s where one ought to be spending one’s money.

“On the other hand, the longer that you allow the divide between north and south to persist, where the north is getting access to genomic technologies and genomic science . . . then the gap that exists now will explode and be even wider,” Meslin explains. “So, should [less developed countries] also have equal opportunity to access the benefits of genomic science?”

In the majority of the world’s countries, he points out, access to health care delivery is “principally through public health interventions and not someone going to their [general practitioner] or their gynecologist or their whatever on a daily basis,” he says.

“So, if that’s the case, maybe they have an even greater claim to either the benefits from or the application of genomic science,” says Meslin.

The goal is to see more potential benefits in countries that “could make more use of it.”

Consequently, the group of expert delegates at the Ickworth meeting set forth a model for genomic science to progress to the point of having

evidence-based medicine for public health uses, which it called the Ickworth model. The hope is that stakeholders in public health will at least consider it as a blueprint for going forward.

“I think it is fair to say that the conveners of this [meeting] and all of the delegates did not expect this to be the last word on this topic,” Meslin explains. “This was really the first word on it, so it should be seen as a, ‘You must do this, and now we’re done with our job.’ Many of the recommendations and the conclusions we reached are calling for more research, more integration, more translation — building capacity; and that may take many months, many years to happen, and that’s fine.

“But we wanted to start the conversation with more than just aspirational comments about what the world might look like; we made what we hope were some specific recommendations for action,” says Meslin.

Specific ethical concerns

The ethical concerns for public health are not that different from individual clinical ethics principles, which revolve around consent, privacy, risk, and allocation of resources, he says.

“[These are] . . . the large headlines that we often associate with ethical concerns,” Meslin notes. “On the other hand, the devil is in the details. It really does matter whether you’re thinking about risks to individuals vs. risks to populations. Those ethical issues are often not only profound, but could be seen as . . . diametrically opposed.”

For example, he notes that in the recent pandemic influenza planning, “protecting individuals’ rights against the power of the state are in direct conflict during a pandemic outbreak.”

So, while “the topical names of the ethical issues might not be dramatically different . . . more importantly, the implementation and interpretation of those ethical issues are often profoundly different, principally because in a public health policy space, the state has the authority to do things that in no other environment does anyone have the authority to do, which is restrict liberty in certain ways, deny or withhold certain . . . rights in favor of communities and the broader population.

“And, the justification for action may not be defending human dignity or human liberty; it may be enhancing and promoting the population’s health, which may ironically, and on occasion with regret, negatively impact a particular individual’s health,” he explains.

One of the specific ethics concerns relates to informed consent, which typically involves an individual giving his or her consent for a particular treatment or intervention.

“In public health ethics, we’re only now having deeper conversations about things like community consent,” he says, noting that there really isn’t even a word to describe the concept.

“So, we’ve watched how this has been challenged in the area of biobanks, where individuals might be asked to allow biological specimens to be collected, stored, and used for a long [period of time] with or without very specific consent for unspecified future research,” Meslin explains.

Another area of concern in the public health arena is confidentiality. He gives the example exhibiting similar concerns demonstrated last year, when genetic samples collected and used many years ago of the Havasupai in Arizona “revealed things about them that made them very concerned,” he says.

“To have revealed something about their genetic provenance and their ancestry that they had historically not known was damaging in a sense, not only to them as persons but to the kind of private lives that they felt they were living,” he says.

All of the issues like consent, privacy, and confidentiality are “terms that themselves are getting blurred — in the genomics world, anyway,” Meslin says.

Unlike in past years, when “confidentiality used to be just information about you,” and privacy “used to simply be about my ability to look at you, or look at you privately via means of literally accessing your body,” these words mean something different now, when it’s possible to know just about everything about a person from a swab from his or her cheek.

“Then, if that’s not tough enough, is there such a thing as community privacy, or community confidentiality, or group harms of that kind?” he asks.

Compounding those concerns is the global perspective the Ickworth meeting and the resulting report took.

“I think that’s what we were trying to get across — that the ethics is hard; we need to work on it,” Meslin says.

SOURCE

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Aging population will add EOL demands on EDs

Emergency physicians and nurses require more training to manage the complex needs of growing numbers of patients who come to the emergency department for end-of-life care, according to a study published online Dec. 3, 2010, in *Annals of Emergency Medicine*.

The article is titled “Trajectories of End-of-Life Care in the Emergency Department.”

“Patients and their families receive a lot of attention and support in the emergency department when there is an unexpected acute medical illness or a sudden, often traumatic event that results in death,” said lead study author Dr. Cara Bailey of the College of Medical and Dental Services at the University of Birmingham in Birmingham, England, in a news release issued by the American College of Emergency Physicians.

“While the emergency department is not designed for end-of-life care, the reality is that many patients in this category go there for help, sometimes not realizing this is the end. Emergency resources are focused on saving lives, which tends to shortchange the patients who have terminal illnesses.”

The study, conducted at and funded by the Centre for Social Research in Health and Healthcare at the University of Nottingham, England, is based on 1,000 hours of observation, plus interviews with health care professionals, patients with terminal illnesses and their relatives.

“Death, dying, and bereavement are daily occurrences in the emergency department, but it is a sadly neglected area of research, professional development, and practice,” said Dr. Bailey. ■

Medicare finalizes new equal visitation rules

The Centers for Medicare & Medicaid Services (CMS) on Nov. 17 issued new rules for Medicare- and Medicaid-participating hospitals

that are designed to protect patients’ right to choose their own visitors during a hospital stay, including a visitor who is a same-sex domestic partner.

“Basic human rights — such as your ability to choose your own support system in a time of need — must not be checked at the door of America’s hospitals,” said U.S. Department of Health and Human Services (HHS) Secretary Kathleen Sebelius, in an HHS news release. “Today’s rules help give ‘full and equal’ rights to all of us to choose whom we want by our bedside when we are sick, and override any objection by a hospital or staffer who may disagree with us for any non-clinical reason.”

The new rules follow from an April 15, 2010, Presidential Memorandum, in which President Obama tasked HHS with developing standards for Medicare- and Medicaid-participating hospitals — including critical access hospitals — that would require them to respect the right of all patients to choose who may visit them when they are an inpatient of a hospital.

The President’s memorandum instructed HHS to develop rules that would prohibit hospitals from denying visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, or disability. It also directed that the rules take into account the need for a hospital to restrict visitation in medically appropriate circumstances, according to the HHS news release.

The new rules require hospitals to have written policies and procedures detailing patients’ visitation rights, as well as the circumstances under which the hospitals may restrict patient access to visitors based on reasonable clinical needs.

A key provision of the rules specifies that all visitors chosen by the patient — or his or her representative — must be able to enjoy “full and equal” visitation privileges consistent with the wishes of the patient or his or her surrogate.

The rules update the Conditions of Participation, which are not only applicable to Medicare- and Medicaid-participating hospitals, but are applicable to all patients of those hospitals regardless of payer source. ■

President issues memo on human subjects

President Obama issued a Presidential Memorandum for Dr. Amy Gutmann, chair of the Presidential Commission for the Study of

Bioethical Issues regarding a review of human subjects protections.

The memorandum cited the recent discovery of U.S. Public Health Service research on sexually transmitted diseases that was conducted in Guatemala from 1946 to 1948 involving the intentional infection of vulnerable human populations.

“In light of this revelation, I want to be assured that current rules for research participants protect people from harm or unethical treatment, domestically as well as internationally,” the memorandum states.

The memorandum directs Dr. Gutmann to “convene a panel to conduct, beginning in January 2011, a thorough review of human subjects protection to determine if federal regulations and international standards adequately guard the health and well-being of participants in scientific studies supported by the Federal Government.

“I also request that the Commission oversee a thorough fact-finding investigation into the specifics of the U.S. Public Health Service Sexually Transmitted Diseases Inoculation Study.”

President Obama directed Dr. Gutmann to complete the review and provide a report on the panel’s recommendations and findings within nine months. ■

Health care orgs announce collaboration

Six of the United States’ health care systems announced on Dec. 15 a collaboration among them designed to improve health care quality while reducing costs.

The six health systems include Cleveland Clinic, Dartmouth-Hitchcock, Denver Health, Geisinger Health System, Intermountain Healthcare, and Mayo Clinic, all of which will join The Dartmouth Institute for Health Policy and Clinical Practice to share data on outcomes, quality, and costs across a range of common and costly conditions and treatments.

The group expects to determine best practices for delivering care for these conditions and will quickly disseminate actionable recommendations to providers and health care systems across the country.

The collaborative will initially focus on eight conditions and treatments, for which costs have been increasing rapidly and for which there are wide variations in quality and outcomes across the country.

The conditions and treatments will be: knee replacement; diabetes, heart failure, asthma,

weight loss surgery, labor and delivery, spine surgery, and depression.

“The intractable problems of quality and cost cannot be solved without getting to the fundamental issue of how we deliver health care in this country,” Brent James, MD, chief quality officer at Intermountain Healthcare and executive director of the Intermountain Institute for Health Care Delivery Research, said in a news release. ■

CME INSTRUCTIONS

Physicians participate in this continuing medical education program by reading the issue, using the provided references for further research, and studying the questions at the end of the issue. Participants should select what they believe to be the correct answers, then refer to the list of correct answers to test their knowledge.

To clarify confusion surrounding any questions answered incorrectly, please consult the source material. After completing this activity with the June issue, you must complete the evaluation form provided and return it in the reply envelope provided to receive a credit letter. When your evaluation is received, a credit letter will be mailed to you.

CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

COMING IN FUTURE MONTHS

- The ethics of neuroimaging
- Financial incentives for living organ donors
- Physician responsibilities when the family wants everything
- Rationing of health care

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CME QUESTIONS

1. In a national survey commissioned by The Schwartz Center for Compassionate Healthcare at Massachusetts General in Boston, the survey indicated that a majority of both patients and physicians believe that compassionate health care can make a difference in whether a patient lives or dies.

- A. True
- B. False

2. Where they live can determine whether Medicare patients with advanced cancer die in a hospital or while receiving hospice care, according to the Dartmouth Atlas Projects report, "Quality of End-of-Life Cancer Care for Medicare Beneficiaries: Regional and Hospital-Specific Analyses."

- A. True
- B. False

3. A pilot project in New York City designed to increase the number of donated kidneys was launched first in which borough of the city?

- A. Queens
- B. Bronx
- C. Manhattan
- D. None of the above

4. The Ickworth meeting in Suffolk, UK, in May 2010 focused on which of the following topics:

- A. Organ donation
- B. End-of-life issues in the UK
- C. Abortion
- D. Genomics and global public health

Answers: 1. A; 2. A; 3. C; 4. D

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