

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Winter 2010

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Winter 2010

DIFFERING MODELS OF ETHICS CONSULTATION AND THEIR LIMITATIONS

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On average, just three ethics consultations are performed per year in U.S. hospitals (Fox, Myers & Pearlman, 2007). Given the likelihood that your hospital will have so few ethics consultation requests each year, how much professional energy should an institution expend maintaining an ethics consultation service? Typically, such consultations are provided, in whole or in part, by members of a health care ethics committee. In Maryland, such committees (i.e., “patient care advisory committees”) are mandated by law. The Joint Commission looks to ethics committees as one mechanism for addressing ethical issues within an institution. But how effective is the ethics committee in “addressing ethical issues” at the institution it serves? And what role should formal ethics case consultation play in this process?

Some institutions have explored alternatives to the types of infrequent, conflict-laden ethics consultations quantified by Fox and colleagues (2007). Columbia St. Mary’s hospital offers one example. The institution’s staff attempted to identify patient care situations that would benefit from ethics consultations closer to a patient’s hospital admission. They

predicted that such consultations would be more advisory in nature—that is, involving interpretations of the Catholic Hospital Association’s Ethical and Religious Directives, or clarification of established hospital ethics policy and procedures. Mark Repenshek, PhD, Health Care Ethicist at Columbia St. Mary’s (CSM’s) Health System, developed a database describing ethics consultations performed between 2003 and 2007. Of 179 consultations performed during this time at CSM’s four acute-care Wisconsin hospitals (totaling about 650 beds), “ethics advisement” accounted for 152 of 179 total requests (84.9%), ethics committee consultation accounted for 24 of 179 requests (13.4%), and retrospective case review accounted for three of 179 requests (1.7%). Repenshek noted that, with increased awareness of ethics services available, retrospective case review is being increasingly requested—that is, “targeted education requested by a unit/department with the goal of organizational process change or development in response to the consultation requested” (p. 12). But more notably, the relatively low number of formal ethics case consultations is dwarfed by the much higher number

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law’s Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

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Differing Models of Ethics Consultation

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of “ethics advisements.” Is this happening elsewhere?

A cousin to ethics advisement might be found in the practice of ethics rounding, which was implemented by DeRenzo and her fellow bioethicists at various MedStar hospitals. The participation of a bioethicist in ICU rounds brings ethical issues to the forefront, and allows the ethics consultant to counsel and educate health care providers at the bedside, demonstrating utility of ethics expertise in everyday patient care decision-making. This increases awareness of the ethics consult service, and achieves a more proactive ethics intervention that may reduce escalation of conflict that so often typifies formal case consultations (Derenzo, Mokwunye, & Lynch, 2006).

The upcoming second edition of ASBH’s *Core Competencies for Health Care Ethics Consultation* considers rounding in an ICU to be something different from ethics consultation, both representing

one of several activities that an ethics consultant may engage in. Other examples include mentoring, lecturing, scholarly writing, policy review, etc. Many ethics consultants also engage in “curbside consultations.” DeRenzo and colleagues report an increase in such consultations in hospital corridors as a result of the increased presence of bioethicists at ICU rounds. The issue of “advisory consults” or “curbside consults,” however, raises questions about due process, procedural standards, and fairness.

Consider an analogy to the field of cardiology. You are a general internist. You ask a cardiologist colleague a question related to treating atrial fibrillation, because you currently have a patient with this condition. Your colleague gives you a general opinion about medications used to treat atrial fibrillation. This is not a cardiology consult, because your colleague has not evaluated the patient’s medical history and conducted a thorough exam. He or

The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network will achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution to act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

she has not entered a note in the patient's medical record. It might meet your needs. It might not.

Similarly, if a physician asks an ethics consultant a question about a patient, she may be seeking general insight or information that is not dependent on the patient's particular circumstances (e.g., "I'm writing a DNR order for a patient based on a medically ineffective-ness certification. Do I have to tell the surrogate?"). This would be an example of what Repenshek would call an "ethics advisement" request, and what Fox and colleagues (2006) at the National Center for Ethics in Health Care would call a "non-case consultation" request. Or, the physician may be seeking input of the ethics expert on a particular patient's plan of care (e.g., "I am thinking of stopping Mr. W's tube feedings based on medical ineffectiveness. Is this OK?"). This would be an example of a "case consultation" request. Each should be handled by a well-informed ethics consultant who is mindful of how particular details of a case may dictate ethically appropriate options. But any recommendation or advice intended to directly influence a particular patient's plan of care should be approached as a "case consultation," in which the consultant follows a standard process (e.g., gathering facts, visiting the patient, convening a meeting of stakeholders, if indicated, entering an ethics note in the patient's medical record, etc.).

Given the range of alternatives to ethics consultation described above, one may ask whether ethics committees should look beyond formal case consultation as the most effective method of addressing ethical issues at their institutions. But this raises questions about whether ethics committees have the skills and staffing

resources necessary to implement these alternative approaches. While the institutions at which Repenshek and DeRenzo are affiliated have trained, paid ethics consultants to staff their services, Fox and colleagues (2007) found that only 16% of hospitals provide salary support specifically for ethics consultation. Many think hospitals would be better off making a financial commitment to support ethics consultation at their institutions. Ethics consultation is best positioned to produce value for a health care organization when it is more readily accessible to health care providers at the bedside, and when it is provided by qualified ethics consultants. Providing services beyond mere case consultation, such as those described above, could improve staff morale and perceptions regarding the ethical climate of the organization, lower perceived moral distress among staff, lower staff turnover, improve palliative care access and outcomes among patients, and reduce resources spent on non-beneficial interventions.¹ Perhaps hospital administrators and ethics committee members are content with the status quo provided by the majority of all-volunteer, low volume ethics consultation services, rather than considering the value added from providing the other types of ethics services described above. Or, perhaps all-volunteer ethics committees are capable of branching out to provide such services with adequate training and leadership support. But it's more likely that the positive impact of health care ethics committees and ethics consult services will be the greatest for those institutions whose budgets support a range of services that address ethical issues throughout the institution.

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Note

¹Repenshek and colleagues were able to show that hospital length of stay was reduced by half for patients who had an ethics consultation (from 36.1 days in 2003 to 18.23 days in 2007). Schneiderman and colleagues had similar findings; Schneiderman, *et al.* (2003), "Effect of ethics consultations on non-beneficial life-sustaining treatments in the intensive care setting: A randomized controlled trial." *JAMA* 290, 1166-1172.

ASBH TO RELEASE 2ND EDITION OF CORE COMPETENCIES

In February, 2006, the American Society for Bioethics and Humanities (ASBH) Board approved a motion to produce an updated version of the *Core Competencies for Health Care Ethics Consultation*. The Core Competencies Update Task Force was formed for this purpose. From November, 2009 through January 31, 2010, a draft of the 2nd edition of the *Core Competencies* was publicly available for open comment at <http://www.asbh.org>. Feedback is now being reviewed and, where necessary, changes are being made to the final draft. The newly formed ASBH Standing Committee on Clinical Ethics Consultation Affairs will review the final draft later this year, and provide a recommendation that the ASBH Board approve it for publication.

Major changes from the first edition, which was published in 1998, include:

1. Boundaries of Health Care Ethics Consultation (HCEC) clarified. HCEC was distinguished from other activities typically performed by health care ethicists, such as developing ethics-related organizational policies, serving on organizational committees, and producing scholarly work. This decision was based on a shared understanding that the competencies required for ethics consultation are different from competencies required for these other activities.

2. Scope of HCEC clarified. The 2nd edition clarifies that HCEC is not necessarily limited to what is often thought of as clinical ethics (e.g., issues relating to end-of-life care), but may encompass a broad range of content domains including, for example, ethical practices in resource allocation, business and management, and research. Clinical ethics, organizational ethics, professional ethics, business ethics, research ethics, medical ethics, and the like, are thus depicted as “sub-specialties” of health care ethics, in recognition of the fact that some health care ethics consultants will limit their practice to one or more of these areas, while other ethics consultants may respond to questions across the full spectrum of health care ethics.

3. Content related to “organizational ethics” integrated into Section 1. The 2nd edition no longer recognizes “clinical ethics” and “organizational ethics” as distinct entities. The decision was made to eliminate this distinction because of both the wide divergence of opinion regarding the meaning of these terms, and recognition of the increasing trend to integrate ethics throughout an organization. Thus, content related to “non-case consultations” was added to Section 1, as well as how the ethics consultation service collaborates with other services within a health care institution.

4. Distinction made between “case” and “non-case” consultations. The 2nd edition divides HCECs into two mutually exclusive categories: ethics consultations that pertain to a specific, active patient case (referred to as “case consultations”) and all other ethics consultations (“non-case consultations”). The Task Force considered a variety of different alternatives for categorizing ethics consultation activities and engaged in lengthy discussions before ultimately deciding to adopt the “case/non-case” terminology.* The rationale for this decision was that the process that should be used by an ethics consultant—and therefore the specific competencies required—hinges on whether the ethics consultation involves a question about a specific, active patient case, or instead involves a more general question such as how to interpret an ethics-related policy, how to understand a particular ethics topic, or how to analyze a hypothetical or a historical (inactive) patient case.

5. Ethics facilitation approach clarified. Content related to the ethics facilitation approach to HCEC was clarified. For example, giving recommendations, sharing expertise, and use of mediation skills are consistent with an ethics facilitation approach. The term “pure facilitation” was replaced with “pure consensus” to more accurately describe the approach involving group agreement regardless of adherence to ethical standards.

6. Emerging ethics consultation service providers recognized. Newer models of ethics consultation services are briefly mentioned, such as regional ethics networks, consortia, and remote access services.

7. Emerging HCEC service and consultation process standards added. The 2nd edition adds a new section on emerging process standards for HCEC—for example, having a policy on ethics consultation that specifies open access and a defined process for approaching a case consultation, such as holding a formal meeting with involved stakeholders (if appropriate), notifying the attending physician (if he/she was not aware that an ethics consultation was requested), and documenting the ethics consultation. This was thought appropriate given the evolution of the field over the years since the first edition of the *Core Competencies* report was published.

8. Skills table expanded. The following competencies were added to the ethics consultation skills table: quality improvement and evaluative skills; the ability to communicate and collaborate effectively with other responsible individuals, departments, or divisions within the institution; and the ability to access relevant ethics literature, policies, and guidelines.

9. Section on evaluating ethics consultations expanded. Section 3 describes approaches to evaluating the quality (i.e., structure, process, and outcomes), access, and efficiency of an ethics consultation service. Where available, examples of empirical data on ethics consultation relating to each component are presented, as well as published tools to evaluate that component. Recommendations for evaluating and improving ethics consultation and priorities for future research are presented.

10. “Character” changed to “attributes.” The content describing character traits that are desirable in ethics consultants was changed to “attributes, attitudes, and behaviors” of ethics consultants, as this is common language that health professions use to describe the behavioral component of practice.

11. Ethical obligations and components of a code of ethics added. Based on efforts underway at the time of this publication to develop a code of ethics for health care ethics consultants, ethical obligations of such consultants are presented, along with implications for those functioning as professional ethics consultants.

* Resources from the VA’s National Center for Ethics in Health Care are prominently featured in the 2nd edition of the *Core Competencies*. In many instances, no other published resources were located that were as comprehensive as the VA’s. Of note, the staff at VA’s National Center for Ethics conducted a rigorous consensus development process that included systematic reviews and extensive input from multiple ASBH members representing many different organizations.

The American Society for Bioethics and Humanities (ASBH) was founded in January 1998 through the consolidation of three existing associations in the field: the Society for Health and Human Values (SHHV), the Society for Bioethics Consultation (SBC), and the American Association of Bioethics (AAB). ASBH serves to promote the exchange of ideas and foster multidisciplinary, interdisciplinary, and inter-professional scholarship, research, teaching, policy development, and professional development among people engaged in bioethics and the health-related humanities. ASBH’s Clinical Ethics Consultation Affinity Group (CECAG) offers opportunities for individuals involved in clinical ethics to collaborate and share information. For more information about ASBH and CECAG, visit <http://www.asbh.org>.

CASE PRESENTATION

One of the regular features of this Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE FROM A MARYLAND HOSPITAL*

GB is a woman with Stage IV cervical carcinoma that has spread to her lungs. She was so ill from her underlying disease that she was not considered a candidate for further chemotherapy. While she was hospitalized, three of her physicians spoke with her about the futility of further treatment and advised her to enter hospice care. All three physicians documented in her chart the futility of further treatment other than comfort care. She refused all consideration of Do Not Resuscitate/Do Not Intubate status. Upon discharge from the hospital, one of her physicians requested an ethics consultation out of concern that the patient was unrealistic about her medical condition. This physician wished to warn the emergency room (ER) staff about GB's possible return

to the ER in extremis, believing that attempts at full resuscitation would be inappropriate and would actually cause her more pain and suffering.

COMMENTS FROM A GERIATRICIAN

To my knowledge, there are no data available regarding how often physicians in Maryland utilize the provisions of the State's Health Care Decisions Act (HCDA) that allow a medical intervention to be withheld if two physicians certify that it is medically ineffective for a given patient (Sections 5-601 (n) and 5-611 (b)). The Act defines a procedure to be medically ineffective if "to a reasonable degree of medical certainty, it will not prevent or reduce the deterioration of the health of an individual or prevent the impending death of an individual." Orders for cardiac resuscitation procedures, commonly referred to as "Code Status Orders," are typically written after discussion with the patient or surrogate decision maker, or upon review of the patient's advance directives. The order either to attempt or withhold resuscitation efforts is usually entered with the consent of the patient him or her self, the surrogate decision maker or upon the authority of the valid written advance directive. How often physicians and patients disagree on whether cardiac resuscitation should be attempted is unknown. Generally, in today's medical-legal world, physicians will write "Full Code Status" orders at the request or insistence of the patient or surrogate decision maker, even when the physician believes Cardio-

Pulmonary Resuscitation (CPR) to be an ineffective procedure for saving the patient's life. This reflects either the physician's desire to respect the patient's autonomous decision making, or to avoid the risk of potential legal action for writing a Do Not Resuscitate (DNR) order against the patient's wishes, and/or uncertainty about what really constitutes medical ineffectiveness in a legal sense. To my knowledge, no physician in Maryland has ever been sued for using medical ineffectiveness criteria for entering a DNR order against the expressed wishes of a patient or surrogate or written directive. But there is little comfort in this fact since, although there have been no prior lawsuits, there is fear of being the first case. There are anecdotal reports of hospital administrators, acting out of fear of legal action, preventing physicians from using medical ineffectiveness criteria to withhold requested treatment, even when the physician's decision was supported by the deliberations of the hospital ethics committee. Data on the frequency of this sort of occurrence are lacking.

In the case presented above, the ethics committee was not asked to comment on the ethics of using medically ineffective criteria for withholding CPR against the wishes of the patient, but rather on whether the medically ineffective "No CPR" designation should be durable across sites of care. Does the "No CPR" order established during the acute hospital episode have durability if the patient should present to the emergency department at a later date? Does it make a difference if this order were entered upon the

request of the patient, or rather by two physicians certifying that CPR would be medically ineffective? There are concrete logistical issues as well as ethical issues relevant to this case.

If a patient in the community calls for emergency response via 911, the only way that the paramedics in Maryland will withhold CPR efforts is if a valid MEMS (Maryland Emergency Medical System) DNR form is presented. Therefore, a patient or family member who wishes to have CPR performed (even if the physicians believe it is ill advised) will simply not present the MEMS form and CPR will be implemented automatically, if the patient sustains sudden cardiac arrest in the presence of the paramedics. Once transported to the emergency department, the decision to continue or cease resuscitation efforts will most likely depend on the patient's response to the initial efforts. The only way a DNR order would be honored in a community or ER setting would be if the patient presented with a valid MEMS form or personally gave the directive herself for no resuscitation. Logistically, if the patient was brought to the Emergency Department and was able to request full code status, the Emergency Department physician would not likely withhold CPR attempts, even if the anticipated outcome were death.

A study published in 2009 from The M.D. Anderson Cancer Hospital in Houston by Hwang et. al., reviewed all cancer patients sustaining cardiac arrest out of hospital treated in their emergency department between 2000 and 2002. Of the 41 patients undergoing CPR in the Emergency Department, 18 (43%) had return of spontaneous circulation and

were admitted to the intensive care unit. Of those 18 patients, 9 did not survive the hospitalization and only two (4.9%) were discharged alive to home, the other 7 being discharged to other institutional care, such as an inpatient hospice or nursing facility. Short or long term survival data on the 9 CPR survivors were not presented. The patient may know the literature and may think that 5% odds are worth the attempt and argue that 5% success rate is medically effective when compared with the 0% success rate of doing nothing. The physicians might argue in response that this particular patient's clinical status is much different from the two survivors in this study and that her likelihood of successful resuscitation is indeed much closer to zero. However, all discussions of ineffectiveness will be based upon probability statistics. Even the language of the HDCA is probabilistic in this regard, stating that "to a reasonable degree of medical certainty.... the procedure will not prevent or reduce deterioration or prevent impending death."

Why do the physicians and patients, such as the one described in the case above, disagree on the issue of Cardiac Resuscitation?

Causes of disagreement between patient and physician on the appropriateness of CPR may be grouped into the following categories:

1. Lack of patient education about the actual processes involved during CPR attempts and about the dismal outcomes of CPR for patients with advanced metastatic cancer;

2. Lack of patient opportunity to participate in advance care planning, to discuss goals of care and preferences for end of life care;

3. Distrust of the medical profession, with the perception that CPR would be withheld due to cost control concerns, rather than its ineffectiveness for the individual;

4. Fear that agreeing to DNR status is agreeing to a lesser level of medical attention prior to cardiac arrest;

5. Belief that a medical breakthrough will occur and a cure will be achievable if only life can be extended until that time, thus giving up CPR is giving up the potential for living long enough for the medical breakthrough to occur;

6. Belief that a Divine Miracle will occur to restore health and wellness and that declining CPR will mean not living long enough for the miracle to become manifest;

7. Use of CPR as a concrete surrogate for hope, so that giving up CPR is equated with giving up hope.

Many physicians do not want to discuss prognosis and "do not resuscitate" orders with cancer patients due to a fear of "taking away the person's hope." The clinical challenge, when caring for patients facing the end of life, is to present factual information on prognosis and what may be expected in the future while maintaining, but transitioning, the meaning of hope for individual patients. Hope at the end of life still deals with the future, despite a limited life expectancy. For some, hope is in the religious belief of a future afterlife, or simply the hope of finding peace in death, or going home in a sense. For others, hope resides in the future success of the children and grandchildren and the

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Case Presentation

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continuation of the family. Hope may be found in reconciliation and forgiveness, and mending broken relationships, prior to death. One patient I cared for described her hope as the transition out of the sadness, knowing that she would no longer hear the ocean surf outside her window, into the joy she found in knowing that the sounds of the ocean surf would survive and continue on despite her absence. For others, hope may be found in the relief of pain and having confidence that care will be present when needed as the end approaches, the promise of non-abandonment.

Several years ago a patient of mine was diagnosed with pancreatic cancer. I performed his preoperative assessment prior to his Whipple procedure. After surgery, he enrolled in various chemotherapy protocols at the university cancer center and was lost to my follow up for one year. Then one day his wife called me in great distress. He had been dismissed from the cancer center because he was no longer responding to any of the protocols. He had been told to enroll in hospice. The patient was in pain and having anorexia, nausea, vomiting and profound weakness. I scheduled an urgent house call and found my patient not only cachectic, but actually cadaveric in appearance. He had lost a tremendous amount of weight, despite having cancer-related fluid retention and swelling in his abdomen and legs. He had low blood

pressure. He was too weak to walk. He was ashen, pale and jaundiced. We discussed whether he would want to return to the hospital or have me call hospice and try to manage his symptoms at home. He opted for hospice care at home. We discussed cardiac resuscitation status. He was a retired physician and agreed that resuscitation would not benefit him at that point. He expressed his hope of being able to return to his native country before he died, though he realized this was unlikely. Comfort meds were ordered for the patient at home and the hospice nurse came on an urgent basis to enroll him that same day. As I left the home, his wife followed me out the door crying. She asked, "Is there no hope?" I responded that we could hope to get his symptoms under control very quickly and that he might have some peaceful time with his family gathered around him for his final hours or days. That night, he fell at home. The hospice nurse came back for an urgent visit. His breathing had become labored and the wife was not satisfied with his response to the comfort meds. She screamed at the hospice nurse, "Do something! Save him!" The wife called 911 and demanded that the hospice nurse start cardio-pulmonary resuscitation. When the paramedics arrived, they called their support physician and did not continue the resuscitation efforts. The patient died at home. When I called the

wife the following day, she said, "It all just happened so quickly." Despite his yearlong illness and slow decline, she was totally unprepared for his death. She had, however, made arrangements for his body to be returned to his native country for burial, as was his wish.

Despite our best attempts to help our patients and their families accept the inevitability of death, some must rage against the dying of the light. Futile CPR attempts are the medical means of raging against the dying of the light. Demanding futile CPR efforts is the last stand of a false hope. Physicians in Maryland have the authority to withhold procedures, including CPR efforts that are deemed medically ineffective. It is the duty of our profession, however, to help prepare our patients and their families for death through honest, ongoing discussion and education. We must help our patients find hope and integrity at the end of life. We must stop offering false hopes of the conquest of our very nature and humanity, of which death is as essential and important as birth.

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COMMENTS FROM THE ETHICS COMMITTEE CHAIR

This case, which came to our ethics consultation service, raises interesting questions about the role of an ethics consultant (individual or team) when responding to consultation requests. The patient's primary physician was out of town. The covering physician was adamant that the patient not receive resuscitative attempts in a future presentation to the hospital. How should the ethics consultant handle such a request? Here is how our ethics consultation service responded.

Since the patient had already left the hospital, it was not possible to meet with her and discuss the situation without making a trip to her home. The question of whether such a contact would violate HIPAA was raised, since HIPAA requires that the use and disclosure of protected health information be limited to what is needed in the course of providing medical care to a patient. HIPAA notwithstanding, the option of calling the patient at home was equally unappealing—imagine the patient, having just returned home from the hospital after this experience, being contacted by a consultant she did not know/had not met, nor even been advised of, wanting to explore these sensitive matters.

We need to be responsive to patients, families and care providers outside of the acute care hospital setting, given that much of health care is provided via short term hospitalization, in outpatient settings, or ultimately, at home. But, as in this particular scenario, the traditional ethics case consultation approach of meeting the patient and reviewing the medical record would have been problematic and insensitive.

Instead of viewing this as an emergent ethical dilemma or conflict between the patient and physician that needed to be quickly resolved, the ethics consultant viewed the situation as non-emergent, and primarily a communication problem between the patient and the covering physician. The patient may have been unrealistic about her prognosis and the treatment options available to her. However, the physician who requested the ethics consultation appeared to harbor unrealistic expectations about how much he could control other medical care providers' actions if the patient presented to the hospital emergency department, perhaps overruling the patient's wishes and/or violating EMTALA guidelines.

Given the limitations imposed by the facts of the case and those raised by Dr. Elon, our ethics committee took the following actions:

- 1) We did not try to make contact with the patient at home.
- 2) We did not request to see the patient's medical record at this time.
- 3) We contacted the hospital administration, via the V.P. for Medical Affairs, to inform them of the request for an ethics consultation by a treating physician and to gain permission to view the patient's medical record when/if it became necessary in the future.
- 4) We explained to the physician who requested the ethics consultation the above considerations, reassuring him that we value his appreciation of this treatment dilemma, and invited him to attend the next monthly meeting of our hospital Ethics Consultation Service, where we would fully discuss this case.
- 5) We thoroughly apprised the patient's primary care physician of the situation at the first opportunity. He thanked us for the call and promised to talk with his patient.

What ultimately happened? The patient entered hospice care and died a short time thereafter. The covering physician did not attend our meeting.

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NEVER AN ORDINARY DAY: STRUGGLES OF A PERINATOLOGIST

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<http://bioethics.northwestern.edu/atrium/>

I prep the room before I call the family: I enlarge images of their fetus onto a 24" screen, I put tissues on the round table, and I put a plasticene model of a brain discreetly to the side so I can describe the pathophysiology of the defect when the time comes. The Smiths sit in the waiting room staring blankly at the TV. Today they've had an ultrasound, fetal MRI, and fetal echocardiogram. I'm one of many strangers this couple has to meet, but our meeting is the day's climax, the time when the pediatric surgeon and perinatologist (a high-risk obstetrician) will synthesize and distill all those test results. They look exhausted and apprehensive, but they smile tentatively as I usher them into the counseling room.

Being a perinatologist is heart-breaking. I love giving my patients information and answers. It may be difficult to hear but it gives families the knowledge, and sometimes even the strength, to take the next step. I hate that too often I'm giving the diagnosis and offering no options. I'm usually the bearer of bad news, and only sometimes the bearer of a tiny life preserver in an otherwise sinking ship. But now these consults represent the hope for a middle option that lies between "doing nothing" and termination, the new option of fetal surgery.

Parents hope invasive fetal therapies will be the "killer app" that can fix their fetuses. It's my job to inform them these technologies and

procedures aren't always the solution. Mrs. Smith starts crying, and tears continue to well up throughout the entire session. She's about 20 weeks and the pregnancy isn't a threat to her health, so if she wants to terminate she needs to decide fast. I ask the Smiths their understanding of the pregnancy and they speak as a team, trading sentences.

Everything was fine until a week ago when we had the ultrasound. We didn't want to have any prenatal testing because we don't believe in termination. The technician got quiet during the ultrasound and seemed uncomfortable; we could tell something wasn't right. Then the doctor came in and told us there was a hole in the baby's spine called spina bifida. It seemed like forever before we could see our OB, and she confirmed it—our baby will have to wear diapers forever, she'll have problems walking, and she might have developmental, behavioral, and mental issues. There's pulling on her spinal cord, so her brain's affected. We felt so overwhelmed.

I review the day's radiologic findings with the family:

"Ventriculomegaly."

"Myelomeningocele."

"L3-L4."

"Open defect."

"Closed defect."

"V-P shunts."

"Wheelchair."

"Leg braces."

"Incontinence."
"

"Intermittent catheterization."

"Bowel regimen."

"IQ points."

"Bell-shaped curves."

Drawings and a model seem to help, but I'm still not sure what they hear. For this family, I sense a lot of indecision and inner turmoil.

Our doctor asked if we'd be interested in a repair. Open the uterus, cover the hole, close the uterus, and continue the pregnancy? Our hearts lifted a little.

The pediatric surgeon steps in. First he focuses on the technical aspects of prenatal surgery, then practical aspects like length of surgery, recovery time, complications for mother and fetus, and the absolute need for cesarean section for delivery. He discusses the research and outcomes for children with and without in utero surgery. He states that this surgery is not a cure. It doesn't reverse what already has happened, the fact that the neural tube didn't

close and the spinal cord has been exposed to amniotic fluid.

This couple is clearly looking for a miracle, but at what cost? I want to be sure Mrs. Smith doesn't compromise her health unnecessarily, and that she understands the risks of what she might be undertaking. I want to be realistic but hopeful. I emphasize that the bottom line is that fetal surgery is still considered experimental.

I'm uneasy. It's hard to fathom the difficulty and enormity of their decision making. Mrs. Smith's first pregnancy had been uncomplicated, this was going to be a little sister and their second daughter. After almost five months of carrying a pregnancy with many expectations and hopes, Mrs. Smith now faces an uncertain future. I present the options and attempt to be non-directive, but I don't think a physician can be truly objective and non-directive in counseling. We come to the table with our own morals and biases, our own life experiences, and our intimate knowledge of the physiology and how it impacts normal bodily functions. We also know about the worst of the worst scenarios. There are no guarantees until birth, only a range of possibilities, and we can't predict the impact each one will have on any particular family. No matter how many families I counsel, there is no way of conveying this intangible aspect. I can't predict the future, and I can't speak to the social, emotional or financial impact of their decisions.

So far we've been discussing quality of life in terms of the medical model, fixing physical problems to fit into society's understanding of

"normal." I introduce a discussion that this fetus and pregnancy could be another version of functioning and try to juxtapose the concept of disability with the focus on correction and cure. It isn't an easy discussion. The Smiths are quiet as they look at me; I'm not sure if they hear me. Their questions about ambulation, incontinence, mental capacity and school leads me to believe they are trying to fit this possible reality into their current life, and that makes sense—the families I see are generally focused on cure, not handicap. I'm not so different: years of medical training have taught me to think of the human body in terms of function and repair of function to normal too.

The mothers I meet will usually sacrifice their health and body to achieve a chance of a cure. Acceptance of the disability usually isn't made until after all curative options are exhausted and if termination is not an option. Nevertheless, I feel a need to raise the "social model of disability" in this meeting. It may seem odd to the Smiths, they came to us to hear about repair. I feel off-kilter myself since they haven't made a decision yet. But if I don't raise it now, who will? Most medical offices aren't equipped to answer these questions or provide cogent answers. At the very least, we can provide resources and support if the families need information.

It's exhausting. These counseling sessions weigh heavily upon me. My recommendation and description will influence a family decision that will alter their lives. I've never met these people before and this is

probably the last time I'll see them. I usually get one snapshot of their lives and family dynamic, and one chance at a coherent explanation of what's going on. These strangers give me their trust, and in return I must use the power I hold responsibly and balance the mother and family's best interests. But what does that look like, exactly? I feel conflicted because the entire day's focus is on the problem, its diagnosis and solution. I am not sure how to shift the focus beyond the "problem" and focus on the child.

Before the Smiths were able to decide on fetal surgery, that "middle option" was taken away from them—they didn't qualify for the trial based upon the prenatal diagnostic images. Maybe that was devastating, maybe having one less decision to make made it easier—I wish I knew.

Parents come to me in varying degrees of understanding and denial. They come for hope (maybe the initial diagnosis was incorrect), for confirmation, and for the possibility that "something" can be done. I've counseled over a hundred families, and I still can't imagine how my husband and I would react in the same situation. All I can do is continue to grapple with this quandary, and work to help families come to an understanding that encompasses all views, so they can make a truly informed choice.

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THE PHILOSOPHER'S CORNER:

ALLOCATING SCARCE RESOURCES DURING PANDEMICS

During the recent H1N1 pandemic, a variety of shortages – ranging from vaccines and antivirals to ventilators and ECMO machines¹—have challenged our ability to provide prevention and treatment to everyone. Governments, hospitals, and health-care providers have confronted difficult questions about who should receive scarce medical resources when not all can.

In some cases, federal or state agencies have proposed or drafted allocation plans. The Centers for Disease Control and Prevention (CDC), for example, recommended priority access to the H1N1 vaccine for five population groups at high-risk for complications from the illness.² Similarly, Maryland prepared guidelines for the distribution of scarce H1N1 antivirals,³ and New York drafted a scheme for ventilator allocation.⁴ In many cases, however, decisions about how to ethically distribute limited resources during a pandemic have fallen to hospital ethics committees and health-care providers. What criteria should guide their determinations?

Historically, four allocation approaches have shaped decisions about how to ration limited medical resources. Each one can be described by the criteria it uses to select recipients of the scarce good:

- (1) social value criteria,
- (2) socio-medical criteria,
- (3) medical criteria, and
- (4) impartial criteria.

Social value criteria. Of the four criteria, distributing scarce resources on the basis of the potential recipients' comparative value to society is the most controversial. The best-known use of social value criteria dates back to 1962, when the Admissions and Policy Committee of the Seattle Artificial Kidney Center considered factors like prospective patients' net worth, church attendance, and marital status in determining whether they ought to receive access to scarce dialysis machines.⁵ The Committee was criticized for, among other things, “playing God,” reducing people to their social functions, and violating equal respect for persons. Today, ethicists generally eschew social value criteria, except in rare circumstances.⁶

Socio-medical criteria. In contrast to social value criteria, which accord preference to prospective patients based on characteristics that have no bearing on medical outcomes, socio-medical criteria grant priority status to prospective patients based on social and personal characteristics that arguably do impact health outcomes. Among other traits, socio-medical criteria may include a person's age, lifestyle, mental health, history of responsible behavior, and likelihood of complying with medical regimens.

Socio-medical criteria have gained some traction in modern medicine, particularly in the context of organ transplantation

policy. People with strong social support systems—and who are young, psychologically stable, and medically responsible—are considered “better” candidates for organ transplantation than those who do not possess these characteristics. Applying socio-medical criteria to determine allocation can, however, deprive some people of fair and equal access opportunities. For that reason, medical or impartial criteria (discussed below) often are viewed as more ethically sound approaches to distributing scarce resources.⁷

Medical criteria. The American Medical Association's (AMA) Code of Ethics recommends medical criteria as the “only ethically appropriate criteria” for allocating limited medical resources.⁸ Accordingly, allocation decisions can consider the prospective patient's “likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and, in some cases, the amount of resources required for successful treatment.”⁹ Medical criteria inform the CDC's H1N1 vaccination scheme, which recommends vaccinating populations at the highest risk for H1N1-related illness first.¹⁰ New York's ventilator allocation plan,¹¹ which provides ventilator access to patients who “have the greatest medical need—and the best chance of survival—if they receive ventilator support,” also employs medical criteria.

Impartial criteria. The AMA Code of Ethics suggests that when there are not significant differences between patients on the basis of medical criteria, resources should be allocated randomly among eligible candidates. There are a variety of equal-opportunity creating mechanisms, including queuing (first-come-first-served) and chance (lottery) systems. During the 2004 flu season, queuing and lotteries were used to distribute the flu vaccine, which was in short supply due to production mishaps. Limited supplies of drugs to treat AIDS have been similarly distributed to patients.¹² Advocates of impartial allocation highlight the fact that it treats all persons fairly and equally.¹³ Detractors “contend that the use of impersonal mechanisms reflects an irresponsible refusal to make a decision,”¹⁴ and that the mechanisms themselves can create unintentional injustices.¹⁵

Hospitals and ethics committees have adopted a variety of approaches to allocating scarce resources during the H1N1 pandemic. It is still too early to determine which criteria are in greatest use, though early evidence suggests a preference for medical criteria.¹⁶ Regardless, it is important to note that these criteria require careful application and transparent execution. Reports suggest that the H1N1 flu season may be ending, but conversations about how to ethically steward our scarce resources must continue.

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NOTES

¹ECMO stands for Extracorporeal Membrane Oxygenation. It is a form of cardiac and respiratory support for a patient whose heart and lungs are not functioning properly.

²CDC, *2009 H1N1 Vaccination Recommendations* (2009), available at <http://www.cdc.gov/h1n1flu/vaccination/acip.htm>.

³Maryland Department of Health and Mental Hygiene, *Pandemic Influenza Response Annex* (Version 7.3, 2009), available at [http://bioterrorism.dhmh.state.md.us/Docs/PandemicInfluenza/PandemicInfluenzaResponseAnnex\(Version7.3\).pdf](http://bioterrorism.dhmh.state.md.us/Docs/PandemicInfluenza/PandemicInfluenzaResponseAnnex(Version7.3).pdf).

⁴New York State Working Group on Ventilator Allocation in an Influenza Pandemic, *Allocation of Ventilators in a Pandemic: Planning Document* (2007), available at http://www.health.state.ny.us/diseases/communicable/influenza/pandemic/ventilators/docs/ventilator_guidance.pdf.

⁵Shana Alexander, “They Decide Who Lives, Who Dies,” 53 *Life* 102-125 (1962).

⁶During World War II, scarce doses of penicillin were administered to soldiers who had contracted venereal diseases rather than soldiers who had infected battle wounds. The rationale was that the former could return to the battlefield more rapidly. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* 270 (5th ed. 2001).

⁷*Id.* at 267.

⁸Code of Medical Ethics §2.03, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion203.shtml>.

⁹*Id.*

¹⁰See *supra* note 2.

¹¹New York State Department of Health and the New York State Task Force on Life & the Law, *New York State Workgroup on Ventilator Allocation in an Influenza Pandemic* (2007), http://www.ama-assn.org/ama1/pub/upload/mm/415/new_york_state.pdf.

¹²Beauchamp and Childress, *supra* note 6, at 268.

¹³*Id.*

¹⁴*Id.*

¹⁵For example, the rule of first-come-first-served can raise questions about whether patients already receiving treatment have priority over prospective patients who arrive later but may have either more urgent medical needs or a better prognosis with treatment.

¹⁶In particular, many hospitals are adopting a clinical algorithm, known as SOFA scoring, for allocating limited resources on the basis of standard medical criteria.

CALENDAR OF EVENTS

MARCH

- 17 (12:15 PM – 1:15 PM) Howard B. Mayes' lecture in ethics. Speaker: Danielle Aubrey, MD. University of Maryland Medical Center, Shock Trauma Auditorium, 22 S. Greene St., Baltimore, MD. For more information, contact Henry Silverman at hsilverm@medicine.umaryland.edu.
- 26 "Health Law and the Elderly: Managing Risk at the End of Life," sponsored by the *Widener Law Review*, in partnership with the Widener University School of Law Health Law Institute, Delaware Hospice, the Delaware End-of-Life Coalition, at the Ruby Vale Courtroom on Widener's Wilmington, Delaware campus. For more information, visit http://widenerlawreview.org/?page_id=329 or contact Thaddeus Pope at tmpope@widener.edu.

APRIL

- 6 (4:00 PM – 6:00 PM) Seminar Speaker: Stephen Latham, JD, PhD, Deputy Director, Interdisciplinary Center for Bioethics, Yale University. Sponsored by the University of Pennsylvania Center for Bioethics, 3401 Market St, Suite 331, Philadelphia, PA. For more information, visit <http://bioethics.upenn.edu/Colloquium.shtml>. To RSVP, e-mail jpringle@mail.med.upenn.edu or call 215-898-7136.
- 8 (12:00 noon) "Futility: What's a Doctor to Do?" Grand Rounds, Shady Grove Adventist Hospital. Speaker: Paul S. Van Nice, MD, PhD, MA. Complimentary lunch. Birch/Sycamore Conference Rooms, Shady Grove Adventist Hospital, 9901 Medical Center Drive, Rockville, MD 20850. For more information, contact paul@yannice.com.
- 12 (12:15 PM – 1:15 PM) Rives Hutzler Lecture: Speaker, Alan Fleischman, MD, Senior Vice President, New York Academy of Medicine. Sponsored by the Berman Institute of Bioethics, Johns Hopkins University, 615 N. Wolfe Street, W3008. For more information, visit <http://www.bioethicsinstitute.org/>, or contact Michelle Martin-Daniels at atmmartind@jhsph.edu.
- 12 (5:30PM - 7:00PM) "Medical Miracles: Doctors, Saints and Healing in the Modern World," the John K. Lattimer Lecture. Speaker: Jacalyn Duffin, MD, PhD, Queen's University. Sponsored by the New York Academy of Medicine, 1216 Fifth Avenue, New York, NY. For more information, visit <http://www.nyam.org/events/>.
- 19 "Health Care Ethics in the 21st Century," Providence Health Care's 2nd Annual Health Ethics Seminar, Conference Centre, 2nd Floor, 1190 Hornby St, Vancouver, BC. For more information, visit http://www.providencehealthcare.org/ethics_services/, e-mail jmonthatawil@providencehealth.bc.ca, or call 604-806-9952.
- 19-20 "Recognizing and Managing Moral Distress in Rehabilitation Health Care." Sponsored by the Rehabilitation Institute of Chicago, Chicago, IL. For more information, visit <http://www.ric.org/education>.

- 22-24** “Pediatric Ethics 2010: Advancing the Interests of Children,” sponsored by the Northern Ohio Regional Pediatric Ethics Consortium. Cleveland Renaissance, Cleveland, OH. For more information, visit www.ccfme.org/PediatricEthics10, or contact Kathryn Wiese at WEISEK@ccf.org.
- 26** (12:15 PM – 1:15 PM) Berman Institute of Bioethics Lunch Seminar Series Speaker: Karen Rothenberg, JD, MPA, Marjorie Cook Professor of Law, University of Maryland School of Law, Visiting Faculty, Johns Hopkins Berman Institute of Bioethics. Sponsored by the Berman Institute of Bioethics, Johns Hopkins University, 615 N. Wolfe Street, W3008. For more information, visit <http://www.bioethicsinstitute.org/>, or contact Michelle Martin-Daniels at atmmartind@jhsph.edu.
- 10** (12:15 PM – 1:15 PM) Berman Institute of Bioethics Lunch Seminar Series Speaker: Peter Whitehouse, MD, PhD, Professor of Neurology, Case Western Reserve University. Sponsored by the Berman Institute of Bioethics, Johns Hopkins University, 615 N. Wolfe Street, W3008, Baltimore, MD. For more information, visit <http://www.bioethicsinstitute.org/>, or contact Michelle Martin-Daniels at atmmartind@jhsph.edu.
- 28** “Disability, Health Care, and Clinical Ethics—What Really Matters.” Co-sponsored by MHECN and Kennedy Krieger Institute, at Thomas B. Turner Building, Johns Hopkins University School of Medicine, 720 Rutland Avenue, Baltimore, MD. For more information and to register online, visit <http://www.law.umaryland.edu/mhecn> (click on “conferences”). Or e-mail MHECN@law.umaryland.edu.
- 29** (10:30AM – 12:30 PM) “A Deeper Diversity, The Nation’s Health: Renewing Social Justice and Human Well-Being in Our Time.” Sponsored by the Office of Sponsored Projects of the Smithsonian Institution in partnership with the Navy Medicine Institute for the Medical Humanities and Research Leadership. National Museum of American History, Smithsonian Institution, Washington, DC. For more information, visit http://www.thechiefinformationgroup.com/conference/smithsonian/index.php?c_id=12, or contact Julie O'Dell at O'DellJ@si.edu.

MAY

- 6-7** “Intensive Workshop in Healthcare Ethics” Sponsored by the University of Arkansas Medical System, Little Rock, AR. For more information, visit <http://www.uams.edu/humanities/HCE-2010.asp>, or contact Carol VanPelt at vanpeltcarola@uams.edu.
- 11-14** “6th International Conference on Clinical Ethics Consultation” (ICCEC), Portland, OR. For more information, visit <http://www.ethics2010.org>.
- 13** (4:00 PM – 6:00 PM) Seminar Speaker: Rita Charon, MD, PhD, Professor of Clinical Medicine, Director, Program in Narrative Medicine, College of Physicians and Surgeons of Columbia University. Sponsored by the University of Pennsylvania Center for Bioethics, 3401 Market St, Suite 331, Philadelphia, PA. For more information, visit <http://bioethics.upenn.edu/Colloquium.shtml>. To RSVP, e-mail jpringle@mail.med.upenn.edu or call 215-898-7136.
- 21-22** “Disability and Ethics through the Life Cycle: Cases, Controversies, & Finding Common Ground.” Sponsored by Albany Law School, the Rapaport Ethics Across the Curriculum Program of Union College, and the Bioethics Program of Union Graduate College and the Mount Sinai School of Medicine. Union College, Schenectady, NY. For more information, contact blooma@union.edu or noltea@uniongraduatecollege.edu.

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