

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Newsletter, Spring 2008

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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

Spring 2008

HOW ETHICS COMMITTEES MAY GO WRONG

Inside this issue . . .

How Ethics Committees May Go Wrong	1
Regional News.....	2
Editorial: Disability Rights & Medical Ethics.....	4
Tarzian's Response to Peace's Editorial	5
Case Presentation: Case Study From a Maryland Hospital NICU	6
Comments from a Pediatric Palliative & Critical Care Physician	6
Comments from a Pediatrician & Ethics Consultant.....	8
Considering Baby Doe Rules	9
Retaliation for Requesting Ethics Consultation?	10

There are many ways in which ethics committees (ECs) may function sub-optimally or in a way that does harm. A number of these actions on the part of ECs have been noted in the literature. Recently, for example, Fox, Myers, and Pearlman (2007) surveyed several ECs and reported two remarkable findings. First, many committees take votes. Second, many make single recommendations. Both practices are ethically problematic when competing values are at stake because they may result in the moral biases of a majority of EC members overriding the values of patients or their loved ones. As Fiester has stated, such an EC's recommendation is, at best, "its best guess," and this is not a good enough rationale to dictate the course for a patient (Feister, 2007, p. 32).

The practice of making a single recommendation may reflect a failure to understand the most basic limitations of ethics. That is, ethical analysis often cannot determine which of competing clinical choices is more "right" than another. For example, it cannot determine when, if ever, it is right to have an abortion. The reason for this is that the two values most at stake are mutually exclusive, and ethical analysis simply cannot determine which value, preserving potential human life or protecting a woman's bodily privacy, should prevail.

The implication of this limitation for ECs is far reaching. In the vast majority of ethical dilemmas in which competing, mutually exclusive value conflicts are at

stake, ethical analysis cannot say which single course of action should prevail. What it can say is what kinds of arguments most warrant moral weight, and whether all the arguments that should be "on the table" have been identified.

In most cases, what ECs should offer is acceptable ethical options. What they should not do is offer single recommendations, particularly when these have been decided by a vote. The moral flaw in an EC voting is hopefully self-evident: how this vote turns out may depend on any number of factors, many of which are highly arbitrary. These arbitrary factors may include who happens to be present at a given meeting and what these persons' views on the issues before them happens to be.

Patients, their loved ones, and others personally involved in a case may justifiably experience rage when an EC votes and then tells the patient, family members, or clinicians what they should do. This rage was experienced and expressed by many in a recent case I learned of involving a hospital EC that was faced with the question of what to do in regard to a severely impaired newborn. The committee voted and then indicated that in its "view" the infant's doctors should do all they could to maintain the child's life. Many of the pediatricians at the hospital strongly disagreed.

The source of the rage was that the EC had gone beyond what ethical analysis could determine. Further, since the EC had "declared" this, it was much more

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REGIONAL NEWS

MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

The Maryland Health Care Ethics Committee Network (MHECN) held a one-day conference on April 7, 2008 entitled, "The Ethics of Health Care Reform." Our Summer 2008 Newsletter will feature highlights of the conference. You can learn more about MHECN activities at www.law.umaryland.edu/mhecn, or contact us at MHECN@law.umaryland.edu.

WEST VIRGINIA NETWORK OF ETHICS COMMITTEES (WVNEC)

The West Virginia Network of Ethics Committees (WVNEC) is collaborating with MHECN on a conference on May 14, 2008, entitled, "More is Not Always Better: Seeking Value in End-of-Life Care." MHECN members will receive a 20% discount on registration fees for this conference, which will take place in Morgantown, VA. Visit www.hsc.wvu.edu/chel/wvneec/ for more information, or contact Cindy Jamison at: (877) 209-8086, e-mail cjamison@hsc.wvu.edu.

How Ethics Committees May Go Wrong Cont. from page 1

difficult for the parents and staff to go any other way!

ECs may miss seeing this potential flaw in their ethical reasoning, as well as the negative consequences of their using this reasoning to declare what should be done. This oversight may stem from the false conclusion that if a single EC recommendation is appropriate in one case, it is appropriate for all cases. Providing a single recommendation in some cases is wholly reasonable. For example, in another case in which I was involved, a doctor would not write a Do-Not-Resuscitate (DNR) order requested by his patient. The patient had cancer and chemotherapy had not been successful. His physician believed that the patient still had some chance to be cured by a chemotherapy trial. The physician also believed that when the patient entered the hospital and accepted his care, the patient implicitly was agreeing to the doctor making this decision on his behalf. The EC felt, in this case, that it

had to intervene.

The actual outcome illustrates an option ECs should keep in mind. An EC member resolved this impasse wholly by meeting with this doctor informally over coffee. In this example, it seemed apparent to all on this EC that the physician had no morally justifiable reason to refuse to write the DNR order for this patient. In this case, it may be that since the physician's action was unjustifiable, the EC had a moral obligation to act on the basis of its moral judgment, and to intervene. In other cases, the EC's moral obligation may be just the opposite; namely, to not make a single recommendation when there is more than one reasonable option.

But what should an EC do when reasonable persons identify more than one ethically appropriate response to a values conflict, whether or not all the committee members around the table happen to share the same view? They may best serve the relevant stakeholders by shifting the question from what

the right answer is to who should decide. Most often, this decision should be left to those most closely involved. Parents should generally make decisions when the patient is their own child. The moral wrong to be avoided here is for ECs to make these decisions themselves, when those who should make these decisions are others more closely involved with the patient and his or her care.

This ethically unwarranted usurping of patients and loved ones' rightful roles also occurs among ethics consultants, sometimes outside their conscious awareness. Watkins and colleagues (2007) describe a case involving a physician who requested an ethics consult for a patient who was gravely ill. The physician favored withdrawing life-sustaining treatment (LST) for this patient, while the family favored continuing LST. The consultant repeatedly offered the family reassurance. However, when the family requested continuing LST for the patient, the consultant responded by asking the physician to review the patient's grim prognosis (what Watkins and colleagues call the "dire scenario").

In this situation, the ethics consultant tried to persuade the family to make a particular choice, not because it was the only ethically justifiable choice, but because the ethics consultant believed it was the right choice. When ethical analysis cannot determine which of reasonable, competing, mutually exclusive values should prevail, it is arbitrary to identify only one choice as being right. So, what does the EC offer in such cases? It should offer the widest range of sound different views and an extensive process of debate and deliberation—much like a jury, although without a single verdict.

On a related topic, ECs go wrong when their members knowingly or unknowingly take on a role as "enforcers" of their hospital's institutional

needs or "hidden agendas." In those cases, ECs' agendas shift from providing a broader and richer analysis of the relevant ethical issues, to influencing patients or their loved ones to comply. In general, ECs should meet patients' and families' needs over the interests of their institution.

An example of such a hidden agenda is a staff member seeking an EC's help in persuading patients or their loved ones to stop using up limited resources such as blood, or an ICU bed. ECs faced with such hidden agendas should, of course, spot them and then consider refusing, since this is not their appropriate role. If they choose to take on these agendas, they should make it clear to patients and/or their loved ones that this is what they are "up to," and what the hospital staff is asking them to do. This transparent approach respects the patient's and family's dignity by ECs not engaging in deceit. Patients and their loved ones, once accurately informed in these instances, may understandably refuse to be involved in further such discussions.

The value of the EC lies in its ability to provide the most relevant facts and the best moral reasoning that can be "on the table." This greatest potential of EC's suggests two practical goals that all ECs should pursue. First, they should strive to be sure that all members present are heard. Second, they should strive to provide time—or some other means—of being able to insure that this occurs.

Commonly, members "higher" on the "medical hierarchy," such as attending physicians and committee chairs, tend to speak most during committee discussions, and others say less, in part, because they may feel intimidated. I can recall, for example, numerous times during which I have remained silent through most of a discussion, only to finally speak. Once I spoke, others who had been silent

until that time echoed my comments, perhaps feeling safer to say what they felt.

All EC members and chairs should take personal responsibility to insure that those with "less power" can speak. If all members do this, unprecedented group upheaval may initially result. However, this upheaval may be unavoidable for the EC to be able to achieve the most desirable end result.

In sum, ECs have the capacity both to help and to harm patients. Their capacity to harm arises, in part, from several pitfalls discussed here. These include making single recommendations when there is more than one ethically reasonable option, voting, adopting a hidden agenda, and responding in ways that overly influence or even determine patient outcomes, when other options may be ethically reasonable. Hopefully, if members are aware of such pitfalls, they can better avoid them.

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EDITORIAL: DISABILITY RIGHTS AND MEDICAL ETHICS

In 2007 hundreds of articles were written about the Ashley Treatment—the subject of Anita J. Tarzian’s article “Disability and Slippery Slopes” (*Mid-Atlantic Ethics Committee Newsletter*, Spring 2007). Over the course of the year thousands of people turned to the internet for more information about Ashley X. Despite the tremendous interest in what was done to Ashley X, no mainstream press outlets have presented or delved into what disability rights activists have to say about the case. Medical ethics committees and medical commentators have been virtually silent as well. I find this alarming, in part because disability rights activists, disability studies scholars, and disability related blogs have been abuzz with activity and are, literally, one click away on the internet (for example, see disstud.blogspot.com/ and <http://notdeadyetnewscommentary.blogspot.com/>). There are, of course, a few exceptions, but to the best of my knowledge, Tarzian is alone in her effort as a medical ethicist to understand the Ashley Case from a disability rights perspective. Tarzian is to be commended for connecting the ethical dimensions of the Ashley Treatment and the civil rights of disabled people in this country and beyond. However, there are elements of her discussion that I strongly disagree with—specifically her position that the rights of those with cognitive and physical disabilities are fundamentally different.

Before I outline my reasons for why I, a disability rights activist and scholar, strenuously object to Tarzian’s attempt to separate the rights of those with cognitive and physical disabilities, let me start by stating that we do share some common ground. American society is inherently biased against those with disabilities—both cognitive and physical. This inherent bias has a direct impact on medical decision-making strategies. The Ashley Treatment is an

extreme example of this. I agree with Tarzian that marginalized people or those who have been ignored should not only be included but also play an active role on medical ethics boards. For example, disabled, transgendered, and conjoined populations to name just three should be given a voice, as they have been and remain well outside contemporary power structures.

Tarzian and I also agree that every effort should be made to maximize the autonomy and opportunities for those with any given disability. Here is where our views begin to diverge in tone and scope. Equality is the starting point for any discussion of disability rights—it is not a choice nor is it something that society should “strive for” as Tarzian puts it. The fact is, it is the law and has been since the Americans with Disabilities Act (ADA) was passed seventeen years ago. Yet, blatant discrimination and outright bigotry remain common place for people with disabilities. It is something I face every time I leave my home for work or go to school to pick up my son. It impacts every facet of my life. In my experience, the civil rights of disabled people are perceived as somehow different in the United States. When this is combined with repressive Supreme Court decisions, particularly the Sutton Trilogy [*Albertson’s Inc. v. Kirkingburg* (1999) 527 US 555, 199 S Ct 2162; *Murphy v. UPS* (1999) 527 US 516, 119 S Ct 2133; *Sutton v. United Airlines* (2002) 527 US 471, 199 S Ct 2139], our country’s record in support of the rights of disabled people is abysmal. This is, in part, why Tarzian’s effort to establish a distinction between the rights of people with a physical and cognitive disability, though well intentioned, has ominous implications in the aftermath of the Ashley X case. It is also reflective of a Supreme Court that can and does deem people either “too disabled” or not “disabled enough” to be eligible for protection under the ADA.

Tarzian acknowledges disabled people have every right to “feel threatened and frustrated by others false assumptions about their rights, worth and abilities.” She also acknowledges and condemns past abuses, most notably the Eugenics movement that resulted in the death and forced sterilizations of thousands of people in this country. This condemnation is nice but does not help Ashley X or me when I interact with others, many of whom pity my existence or assume I am physically and cognitively disabled. There is no “fuzzy logic” here—discrimination hurts Ashley X just as much as it hurts me. At issue are the civil rights of those least able to protect themselves, and in my opinion the most stigmatized and devalued members of our society. Surely, the medical community and American society in general can do better. And while I acknowledge things have gotten better, I also am cognizant that it was just thirty years ago that people like Ashley X and all those with a cognitive disability would have been forced into an institution like the notorious Willowbrook. For decades, it was thought that institutionalization was in the best interests of the parents, family, and child. Doctors, nurses, and social workers all recommended institutionalization. No parent, it was thought, could handle caring for a cognitively disabled child—an argument based on stigma, fear, and public sentiment. The institutionalization of those with cognitive disabilities was the norm. In 1967, at its peak, as many as 100,000 children were institutionalized in 162 state facilities across the country. Conditions at these facilities were horrific, and in retrospect, we know there was no medical reason for institutionalization.

Tarzian acknowledges two models for disability exist—medical and social—but wonders if the term “disabled” used to describe Ashley X and others like her is a misnomer. For me, this is an indica-

tion of how distorted the social perception of disability remains in the medical community. Tarzian is not alone and is in good company. The Supreme Court is equally confused because their decisions have gutted the ADA—literally torn out the heart of the legislation’s intent. Like it or not, disability is first and foremost a social construct. The vast majority of disabled people are oppressed—66% are unemployed and very few have adequate health insurance. Disabled people are keenly aware that medical and ethical decisions are not made in a vacuum. Stigma still figures significantly in the social construction of disability and the treatment of disabled people. Even Hollywood has gotten into the act with what disability rights activists characterize as “dis-

ability snuff films.” Here I refer to films like the highly acclaimed *Million Dollar Baby*. This film delivered a clear message that tapped into the basest elements of humanity in which death was preferable to permanent disability. I recall seeing this movie in the theatre and being shocked that people cheered when the main character was killed. These same cheering people seemed embarrassed by my presence and refused to look me in the eye as they left the theatre.

The medical, legal and ethical systems, past and present, have consistently failed to protect people with physical and cognitive disabilities. The governmental, medical, and social infrastructure needed to protect the rights of all disabled people remains woefully inadequate. This has led some legisla-

tors to initiate the ADA Restoration Act—an effort that has gone virtually unreported. This is a move in the right direction for the civil rights of disabled people in this country. It is a progressive move, one that acknowledges past abuses and contemporary failures. In contrast, I worry about Tarzian and other medical ethicists who want to separate the civil rights of people with cognitive disabilities from those with a physical disability. I understand the medical needs of those with a cognitive disability and physical disability are different, but their civil rights—their status as human beings—is identical.

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TARZIAN'S RESPONSE TO PEACE'S EDITORIAL

My intent in the article Dr. Peace refers to was not to draw distinctions between persons with physical and cognitive disabilities. Rather, I intended to make the following two points: “Disabled” does not appear to accurately describe the status of individuals who are irreversibly unconscious (like Terri Schiavo) or irreversibly neurologically devastated (like Ashley X). Holding these cases up as paradigmatic of a “disability rights” agenda seems to reinforce the negative stereotypes that “able-bodied” (and minded) persons project onto persons with disabilities (both physical and cognitive).

The “Ashley Treatment” can certainly be judged unethical based on a slippery slope argument (i.e., that while it may not have harmed Ashley, its acceptance will harm others by facilitating misapplication to individuals with less profound neurological impairments). But critics tried to denounce the “Ashley Treatment” using slippery slope arguments disguised as individual benefits-burdens analyses. That

is, rather than argue that the harms to Ashley of the hormones and surgery she received outweighed the benefits to her, opponents argued that harms toward others if the “Ashley Treatment” gained acceptance didn’t outweigh benefits toward Ashley and her family. I accept the slippery slope argument, but have not been convinced that individual harms to Ashley outweigh benefits to her and her family, particularly since the “treatments” (“yuk factor” notwithstanding) were implemented with the intent to keep Ashley out of the institutions Peace refers to. Concerns about surgery risk are no longer relevant. Direct harms to her related to being de-sexualized (by breast bud and uterus removal) and infantilized (by height-stunting hormones) are hard to substantiate for Ashley, whose cognitive capacity will not develop beyond that of a three month old.

Having clarified these points, I am struck by Peace’s call for solidarity to protect the civil rights of people who face discrimination on the basis of a disability. This involves educating

ourselves about our own blind spots and biases. I’m all for that. But I am not convinced that Ashley and Terri Schiavo are victims of discrimination based on a disability.

One definition of discriminate is “to make a distinction in favor of or against a person or thing on the basis of the group, class, or category to which the person or thing belongs rather than according to actual merit” (www.dictionary.com). Peace gives a good example of this in the movie *Million Dollar Baby*, when the main character’s wish for death over permanent disability is actualized, evoking cheers from the theater audience. These moviegoers displayed a common disability-based prejudice in our individualistic society: the belief that anyone would prefer death over a life of paralysis and dependence on others. If the societal shared belief was, instead, that people who become paralyzed should focus on what they *can* do and get the help they need to

Cont. on page 10

CASE PRESENTATION

One of the regular features of the 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, the Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A MARYLAND HOSPITAL NICU*

Baby G is a male infant who was born at 23 weeks gestation, weighing 540 grams. He was transferred to a Level Three neonatal intensive care unit (NICU) at a Maryland hospital on continuous mandatory ventilation. Over the next three weeks, Baby G suffered from multiple maladies including repeated pulmonary hemorrhage, intermittent need for high frequency oscillatory ventilation and multiple blood product transfusions, a Grade Three bilateral intraventricular (brain) hemorrhage, and intestinal perforation requiring placement of a drain and multiple antibiotics. Unable to take formula or fluids by mouth, Baby G receives total parental nutrition through a central IV line. He needs abdominal surgery to correct the intestinal perforation, but in his current condition is a very poor surgical risk. He is receiving opioid medication for pain and sedation.

Relations between Baby G's parents appear strained. They are both unemployed and caring for a two year-old daughter. The baby's father seldom visits the hospital. The gravity of Baby G's condition is explained to them. Based solely on gestational age and weight at birth, survival estimates for Baby G range from 12% to 33%. For infants with his degree of morbidity who survive, the chance of major disability during infancy is 80% or more. The parents are given the option of withdrawing life-sustaining treatments and focusing on comfort care. Baby G's mother insists that he receive full support, including full code status. She states that the baby's survival is up to "God's will."

The neonatologist consults the ethics committee regarding whether any of the life support interventions can be withheld (e.g., CPR attempts, blood products, medications to support blood pressure, abdominal surgery) or withdrawn (e.g., ventilator) based on medical ineffectiveness criteria.

**Details of this case were modified to protect confidentiality.*

COMMENTS FROM A PEDIATRIC CRITICAL & PALLIATIVE CARE PHYSICIAN

Pediatric cases involving medical futility are often difficult for all involved. Physicians may feel that they are providing medically inappropriate care which violates their professional responsibilities. Families may feel that where there is life, there is hope and wish to continue sustaining a life even though the chances of a good outcome are miniscule. Nursing staff struggle as they witness the suffering of the infant or child hour by hour at the bedside, suffering which they feel will be to no good end.

The greatest difficulties in such cases arise because determining prognosis in pediatrics, particularly in neonatology, can be difficult. The case described mentions a 12-33% chance of survival and an 80% chance of major disability in those who survive. Families, and some physicians, have difficulty interpreting such statistics and applying them to the individual's situation. A family might listen to the above explanation and interpret that their child has a 20% chance of being absolutely normal, whereas the actual number is at best a 2-6% chance of an outcome ranging from minimal to moderate disability.

Yet many parents might decide that a 6% chance is worth taking. The healthcare team's perspective, however, is influenced by the degree of suffering they have seen in similar children who fall into that other 94% who die or have severe disabilities. It is hard to argue with a family who might rationally choose to fight on against very small odds, but the team often gets frustrated with what they see as an irrational hope for a miracle.

In light of such uncertainty, how does one define "futility"? There is a general consensus in law and in ethics that physicians are not obligated to provide "medically ineffective therapy." A patient cannot walk into a neurosurgeon's office and demand surgery for an inoperable brain tumor—the surgeon can rightfully say "I can't fix this." In many cases, however, it becomes difficult to determine what is truly ineffective.

Authors have attempted to determine different types of futility to help clarify the language that clinicians use. "Physiologic futility" means therapies which are simply unable to achieve a certain goal. As an example, continuing resuscitation attempts for more than an hour of asystole will not be able to achieve the goal of restoring a heartbeat. In such a case, there is

no need for the healthcare team to get the family's permission before stopping CPR—there is simply nothing more they can do. Our neonatal case does not entirely meet the definition of physiologic futility, as the ventilator in this case is quite successfully sustaining breathing and circulation; however, it may be possible that pursuing abdominal surgery for the perforation would be obviously more risky than beneficial and there is no requirement to offer it if this is the case.

“Quantitative futility” has been proposed as an alternative, based on a calculation of the odds of a successful outcome. A 1% chance of success is often cited as a reasonable point at which a clinician could claim a therapy is futile. Yet many families might still wish to persevere in the face of such odds.

“Qualitative futility” is the term used when the outcome, from the patient's perspective, will be such a poor quality of life that it is not worth pursuing the treatments. Both quantitative and qualitative futility assessments include value judgments to some degree (what is too poor a quality of life or too low a risk of success?) and patients and families therefore typically share in the decision making about how aggressively to pursue life-sustaining measures when these issues are raised.

Because of the difficulty in determining what is truly futile, many recent policies regarding futile or medically ineffective therapies have taken a procedural approach to these issues rather than attempting to somehow define futile.¹ Such an approach sets up a “due process” for resolving disputes whenever a clinician and patient or patient's surrogate disagree about whether it is worth pursuing aggressive measures. Most such policies contain requirements for two physicians to agree that the therapy is not indicated, for an independent review to take place (usually done by a hospital ethics or medical review committee), for the patient or family to be informed

in writing that the review is taking place, and for the option of transfer to another provider or facility to be offered. Most also impose a waiting period before any therapies can be discontinued. Texas is the first state to have such a statewide procedure for futility disputes,² and there is ongoing debate about whether the process is fair to patients and families. Many argue that a medical review committee associated with the hospital is much more likely to be biased in favor of the clinicians and that “futility” arguments are often used by clinicians as a trump card when they no longer wish to provide expensive, ongoing care.^{3,4}

The Maryland Healthcare Decisions Act states that physicians are not required to provide ineffective therapies that would not, with a reasonable degree of medical certainty, prevent an impending death. This does not mean, however, that therapies can be unilaterally withheld or withdrawn because a prognosis is poor. The attorney general has stated that even if the patient has a fatal illness, a physician cannot write a unilateral “Do not attempt resuscitation” order if resuscitation has a reasonable chance of restoring the patient to his or her current condition (<http://www.oag.state.md.us/Healthpol/dn-rauth.pdf>). In addition, life-sustaining measures cannot be withdrawn while options for transfer are being explored, with no definite limits set on how long a time period this encompasses.

So what is the team to do in the case of the unfortunate infant described here? Sometimes the best path is to step away from trying to convince the family that aggressive treatments should be withdrawn and focus instead on working to build an alliance with the parents. The health care providers should do the following:

- Try to understand better what awaiting “God's will” means to the parents.
- Meet with the parents frequently so that they get a good idea of the trajectory of the child's illness.

- Help the parents find support through hospital staff such as social work or chaplaincy, their extended family or their own spiritual providers.

- Insist on treating the infant's suffering with pain or sedative medications if necessary, while waiting to see what the outcome will be.

- Let the parents know that they and their child will be treated with respect, no matter what course of action is taken.

- Bring in a mediator such as the hospital ethics committee. Provide debriefings or other support for staff who are struggling with their own moral distress over the case.

If the family and healthcare team can avoid developing entrenched adversarial positions, and instead work together to negotiate what is in the best interest of the child, the right course of action may become more apparent with time. It is possible that the family will never agree to have aggressive measures discontinued, but if the therapy is truly “futile” then the current status will likely not continue indefinitely.

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Cont. on page 8

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COMMENTS FROM A PEDIATRICIAN AND ETHICS CONSULTANT

The neonatologist raises a good question—does it have to be all or nothing, or can one choose a few treatments and not others for this baby, on the basis of sound ethical reasoning?

Withholding and withdrawing treatments is always associated with a lot of angst and emotional heartbreak, not just for the parents, but also for the health care providers. Ethics consultation can provide an important source of moral support for the staff, and a voice of reason for all who are involved at this pivotal juncture.

Since the parents have been given a choice of comfort care, it shows that the medical team clearly feels that the future is too grim to continue aggressive treatments. Perhaps a better way to resolve this dilemma would be for the medical team to make the “hard decision,” explain to the parents their reasoning for suggesting the shift from life-prolonging treatments to comfort care, and ask for the parents’ agreement. If the parents do not disagree, life-prolonging treatments can be stopped or withheld. In my opinion, asking parents to make the “hard decision” to stop treatments that are prolonging their baby’s life is too great a burden for them to carry alone.

Before deciding on withholding and/or withdrawing other life-sustaining treatments, it would be prudent to have an open, candid meeting with both the

parents to set reasonable, mutually agreed upon goals of therapy that are clearly in the baby’s best interest. If the physician/parent meeting is not productive, an ethics committee consult can help by clarifying short- and long-term goals, helping coordinate care, and mediating conflicts. Although these situations are difficult at best, major conflicts can be avoided by getting everyone concerned on the same page from the beginning.

Physicians are under no obligation to provide treatments that are medically ineffective or ethically wrong. Treatments that are medically ineffective as judged by poor response from a trial of therapy can be withheld on the basis of medical ineffectiveness. As stipulated in the Maryland Health Care Decisions Act, this can be achieved by two physicians, one of them being the attending physician, documenting in the chart the ineffectiveness of those treatments before stopping them, and then informing the parents of this decision.

CPR can be clearly withheld on the basis of futility. If the patient continues to worsen despite the present intensive support and treatment, and then has a cardiopulmonary arrest, clearly a CPR attempt is of no avail and could even be considered unethical.

The more difficult decision is that of discontinuing the ventilator. Years ago, the baby in this case study would have had no chance of survival. Now, it may be possible to keep this baby alive to be discharged from the NICU, albeit severely impaired. The question of whether it is right to keep this baby alive with the technology that we have is an unanswered question. What criteria warrant choosing death over prolonging life with hi-tech medical interventions? Likelihood of death? Likelihood of severe neurological im-

pairment? Degree of pain and suffering endured? Inability to meaningfully interact? When uncertainty remains about a baby’s prognosis, deference is given to the parents to decide whether the primary goal of care should be life prolongation or comfort. If stopping a given therapy is likely to cause this baby’s death, according to Maryland law, it cannot be stopped without parental agreement. So, the ventilator must be continued as long as the parents request this. Again, an ethics consult can be very helpful here. Setting clear goals on a reasonable length of time to continue artificial support therapies, focusing on what is being done to care for the baby, and gently explaining to the parents signs that the baby’s condition is deteriorating can help the parents come to terms with a poor prognosis. The parents should receive adequate time to process information given to them, along with empathic counseling and pastoral care to support them through this process.

In cases like these, there is often frustration and angst among the NICU staff related to inflicting pain and suffering on a baby without a reasonable hope of survival or minimally acceptable quality of life for the baby. The ethics committee should evaluate how the staff coped in response to this case, and explore ways to help them sort through the emotions, questions, and concerns this care-giving experience may have evoked. Of course, such support should also be available to the baby’s parents.

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CONSIDERING BABY DOE RULES

It is a truism that law and ethics, while usually complementary, are not synonymous. An ethics committee that always says, “Well, that’s it then” after an attorney’s pronouncement is itself ethically impoverished. Yet, law has a claim to respectful attention in the consultation process, for law reflects a distillation of social attitudes about the limits of morally acceptable action. And, of course, an ethics committee will not be taken seriously if, cocooned within its own immunity from suit, it simply ignores concerns about liability.

At some point in the discussion about Baby G, someone might bring up “the Baby Doe rules.” This will stop the conversation, as clinicians worry that, even if a treatment meets state criteria for medical ineffectiveness, withholding or withdrawing it will get them into legal trouble.

The federal law commonly known as the Baby Doe rules originated in controversy over parental decisions, with physician acquiescence, to forgo surgery and other interventions that might have preserved the lives of infants with Down syndrome and other disabilities. First adopted by the Department of Health and Human Services in 1983, restrictive regulations directly applicable to hospitals were struck down by the courts. Then, in 1984, Congress amended the Child Abuse Protection and Treatment Act (CAPTA) to label as “medical neglect” some decisions to forgo treatment. The Department elaborated on the statute through regulations and interpretive guidelines.

The policymakers faced a dilemma. They wanted to stop infants from being left to die solely because of

others’ judgments about future quality of life with a disability. Yet, they also understood that inflexibly mandating treatment could turn out to be a cruel disservice to dying patients. The result, as often happens when the words of the law are brought to bear on a problem with a myriad of variations and gradations, is recourse to ambiguity. The effect of the ambiguous language is to allow the ethically sound process envisioned by the two physician commentators on the case.

The CAPTA amendments condition certain federal financial aid on a state’s having a system for responding to reports of medical neglect, “including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions.” The “withholding of medically indicated treatment” occurs when one or more of the forgone treatments “will be most likely to be effective in ameliorating or correcting all [of an infant’s] life-threatening conditions.” This likelihood is to be judged through “the treating physician’s or physicians’ reasonable medical judgment.” To be considered in this exercise of judgment is whether a treatment would “merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant.” Nutrition, hydration, and medication are to be provided so long as they are deemed “appropriate.”

Under the Department’s guidelines, “reasonable medical judgment will be formed on the basis of knowledge about the condition(s) involved, the degree of inevitability of death, the probable effect of any potential

treatments, the projected time period within which death will probably occur, and other pertinent factors.” In Baby G’s case, as the commentators suggest, these are the very factors that ought to be part of the discussion between the treatment team and Baby G’s mother (and father too, if he returns to play a role in the decision making).

To summarize: If the exercise of reasonable medical judgment is that continued ventilation is futile in terms of Baby G’s survival (if, for example, abdominal surgery is ruled out and the intestinal perforation itself will likely result in death), the Baby Doe rules do not bar withdrawal of the ventilator. The same kind of judgment may be applied to the question of code status. Opioid medication ought to be continued indefinitely, however, as appropriate palliation. Likewise, total parenteral nutrition ought to be continued unless and until it is deemed inappropriate in terms of Baby G’s present well-being. Finally, the physicians ought not to use the high probability of future disability as an argument to try to change the mother’s mind. To do so would be inconsistent with the present-oriented framework for discussion that the Baby Doe rules mandate.

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RETALIATION FOR REQUESTING ETHICS CONSULTATION?

Retaliatory consequences against health care professionals (HCPs) who speak up about ethically worrisome conditions or practices in their institution have reportedly included threats, peer rejection, demotion, and reprimand. Do HCPs who request ethics consults face retaliation? Danis and colleagues (2007) report on a survey of nurses and social workers in Massachusetts, Maryland, Ohio and California undertaken to determine if they experienced or feared retaliation for requesting an ethics consult. They found that among those reporting access to an ethics consultation service, about 11% had experienced or observed other staff experience retaliation for requesting an ethics consult. About a third, while

not experiencing or observing retaliation, considered it to be a realistic fear. However, fear of retaliation was not associated with the likelihood or frequency of requesting an ethics consult. The authors suggest that because the likelihood of requesting an ethics consult was not affected by the fear of retaliation, this may indicate that ethics consultation offers a “sanctioned and safe venue in the healthcare workplace for raising ethical questions,” and that “[p]erhaps ethics committees and consultants have succeeded in creating a forum for discussion of difficult ethical questions that levels the playing field and allows open discussion of moral issues” (p. 33). Findings from this study raise questions about the reputation of the ethics committee

within an institution, and its perceived accessibility. Of note in Danis and colleagues’ study is that about 52% of respondents (licensed registered nurses or social workers with at least 10 hours a week of active patient care) reported not having access to an ethics consultation service. Considering that an ethics consult service may be one method of leveling power hierarchies within an institution, findings from this survey have relevance to those interested in improving their institution’s ethical climate.

REFERENCE

Danis, M., Farrar, A., Grady, C., Taylor, C., & O’Donnell, P. (2007). Does fear of retaliation deter requests for ethics consultation? *Med Health Care and Philos*, 11(1), 27-34.

Tarzian's Response Cont. from page 5

maximize their abilities, perhaps more would have despaired at the character’s decision to end her life, and she may have come to a different decision about ending her life.

Such an alternative view is poignantly portrayed in the movie, *The Diving Bell and the Butterfly*, which depicts French journalist and author Jean Dominique Bauby’s experiences after suffering a massive stroke and finding himself in a “locked-in” syndrome. His cognition was intact, but his body was completely paralyzed. His only method of communicating was by blinking his left eye. Bauby’s merit is well-recognized by his caregivers, who devise a way for him to dictate the book he eventually writes about his experiences, pushing him beyond his initial thoughts

of death. Discriminating against Mr. Bauby based on his disability would have caused him to suffer, and would have deprived him and the world of his beautiful book and subsequent movie. No evidence has been presented that the “Ashley Treatment” has caused or will cause Ashley to suffer (assuming adequate post-op pain management), or that it limits her potential to flourish. This is because Ashley has a very limited experiential range.

Thus, the distinction I’m making is not between physical and cognitive disability, but in the individual’s level of cognitive potential. Individuals who are neurologically devastated such that they will never attain self-awareness or think for themselves (with Ashley X on one end of this continuum and Terri

Schiavo on the other) seem to warrant a different obligation from society—not to maximize their potential (since they have no further cognitive potential to develop), but to treat them with respect, care, and dignity. That can be achieved without concluding that they have unactualized potential they’re deprived of accessing due to societal prejudice. To get serious about disability prejudice and discrimination in our society, I think we need to get clearer about our use and understanding of the terms *disability* and *disability discrimination*.

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CALENDAR OF EVENTS

APRIL

- 24 Practical Clinical Ethics. Sponsored by Harbor Hospital's Ethics Committee. Harbor Hospital's Baum Auditorium at 3001 South Hanover Street, Baltimore, MD. For more information, contact Sally Lewis at 410-350-8218.
- 29 Ethical Dilemmas in Research Involving Children: Damned whether you do or you don't. SUNY Downstate Medical Center, Brooklyn, NY. For more information, call Alice Herb at (718) 270-2752 or e-mail aherb@downstate.edu.

MAY

- 6-7 The Patient Alone: Making Health Care Choices For Patients Without Surrogates. Sponsored by American Health Decisions. John Hancock Hotel & Conference Center, Boston, Massachusetts. For more information, visit <http://www.ahd.org/conference.html>.
- 8-9 Ethical Challenges in Surgical Innovation. Sponsored by the Cleveland Clinic. InterContinental Hotel, Cleveland, OH. For more information, call (216) 932 3448, or visit <http://www.clevelandclinicmeded.com/live/courses/2008/ethicalsurgery08/faculty.htm>.
- 13-14 Seeing Making Healing: Art, the Arts, and Creativity in Medicine and the Medical Humanities: The Sixth Annual Meeting of the Pennsylvania Medical Humanities Consortium. Carnegie Museum of Art, Pittsburgh, PA. For more information, call (412) 647-5700.
- 14 More is Not Always Better: Seeking Value in End-of-Life Care. Sponsored by the West Virginia Network of Ethics Committees. 2008 Stonewall Resort, Morgantown, VA. MHECN members receive a 20% registration discount. For more information, call (877) 209-8086 or e-mail cjamison@hsc.wvu.edu.

JUNE

- 2-6 The Future of Bioethics—How It Began. Where It's Going. The Kennedy Institute of Ethics Intensive Bioethics Course. For more information, visit <http://kennedyinstitute.georgetown.edu/courses/ibc/ibc2008.htm>.
- 14 How Do I Determine if My Patient has Capacity to Make Medical Decisions? Assessing Decision Making Capacity. Fromm Institute for Lifelong Learning, University of San Francisco. San Francisco, CA. For more information, visit <http://www.cpmc.org/services/ethics/seminar.html>.

JULY

- 17-19 Nursing Ethics Health Care Policy: Bridging Local, National & International Perspectives. Yale University School of Nursing, 100 Church St. South, New Haven, CT. For more information, visit <http://nursing.yale.edu/Centers/International/EthicsConference/>.
- 14-17 Building clinical ethics capacity, bettering patient care. Clinical Ethics Summer Institute, Hamilton Health Sciences. Hamilton, ON (Canada). For more information, visit <http://www.clinicalethics.ca>, or e-mail info_clinicalethics@hhsc.ca.

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