

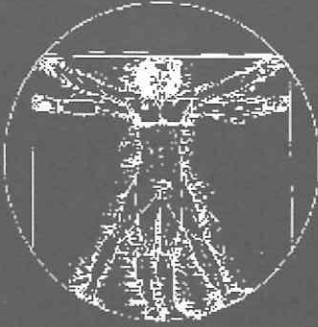
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 1999*

Mid-Atlantic Ethics Committee
Newsletter, Spring 1999

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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MORAL MUSINGS: KNOWING WHEN TOO MUCH OF A GOOD THING IS TOO MUCH

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Aristotle called for moderation—neither too much of a thing, nor too little. But when one looks around, one wonders if we have lost our sense of proportionality. We take our ethical norms to their most illogical extremes, leaving us awash in equivocation and fuzzy thinking. We confuse that which is not illegal with that which is morally justifiable, often on the grounds that it is a patient’s preference. But sometimes we simply have to say that that which someone wants, even when technologically possible and even if financially feasible, is simply beyond the bounds of reasonableness, is morally unacceptable and cannot be ethically justified.

Sometimes, even though what we want is a good thing, e.g., helping others and saving lives, we may have to place limits on achieving it. An inability to identify the boundaries of moral permissibility results in moral paralysis.

Evidence that we have reached this point abounds. The artificial creation of septuplets and octoplets leaves us shaking our heads in dismay. Creating even a single birth from a 65-year-old mother wishing to replace her dead son

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is morally unjustifiable. Just because someone wants something that is achievable technologically does not mean we ought to do it; respect for persons is not defined as supporting every human whim.

The principle of respect for persons calls medical professionals to assist patients to be self-determining agents acting in their own best interests and to protect persons with limited autonomy. The first part of this principle, that of

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NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHECN)

The MHECN is continuing to develop a policy clearinghouse for its members. Numerous hospitals have already submitted their policies. The Network's next steps will be to develop a series of model policies that will be available for members to review. Members of the Network's education subcommittee have been meeting to plan and organize the Network's upcoming conference on "Healthcare Ethics in a Multicultural Society." (See Calendar for details.) The education subcommittee's next meeting is scheduled for April 5, 1999. The topic for discussion will be planning for a general introductory course for new ethics committee members and an advanced course on case consultation skills. The Network's executive committee will also be meeting next month to discuss draft by-laws. All members are invited to attend. Contact Anne O'Neil for information about the time and place of the meeting. Finally, the Network is in the process of developing a listserv for all members. The listserv will be used to keep members informed about Network activities and more generally about issues and events of interest to the bioethics community.

Metropolitan Washington Bioethics Network (MWBN)

The Network's most recent meeting in March was on the topic of "Fairness in Organ Transplantation." Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania spoke on this topic at Children's National Medical Center. The Network's next meeting, on April 20, 1999 from 4:00 to 6:00 p.m. will be held at Walter Reed Army Medical Center. This meeting will be a follow up to the Network's January meeting on organizational ethics and will focus on Walter Reed's organizational ethics program. The May program

of the Network will be on the ethics of pain management and will be conducted by Matt Kestenbaum, M.D., Adell Blankenbaker, M.S.W., and others at the Washington Home & Hospice.

Virginia Healthcare Ethics Network (VHEN)

The Virginia Bioethics Network has changed its name to the Virginia Healthcare Ethics Network (VHEN). This change was made to reflect a broader perspective in the Network's educational offerings and its focus not only on clinical bioethics issues but on organizational ethics issues as well. Newly elected officers of VHEN include President, Jack Turner, M.D., Danville Regional Memorial Hospital; Vice President, Rebecca Bigony, M.D., Mary Washington Hospital; Secretary/Treasurer, Walter Zirkle, M.D., Rockingham Memorial Hospital. The following were also elected to the Board of Directors: Wendy Ault, M.D., Ellison Conrad, M.D., Rebecca Bigoney, M.D., Parker Jones, MBA, Susan Stinson, R.N., Chuck Hite, M.A., Charles Beorn, M.D. and Jack Turner, M.D. The statewide Network hopes to coordinate with regional networks in the state to conduct statewide educational programs. In addition, VHEN has agreed to sponsor, along with the University of Virginia's Center for Biomedical Ethics and the Ollson Center for Applied Ethics at the Darden Graduate School of Business, a conference entitled "Organization Ethics for Healthcare Leaders." The conference will be held in Charlottesville in November and advertised nationally.

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Too Much of a Good Thing

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being self-determining in one's own best interests, requires the exercise of good judgement. Although we do allow persons to make seemingly unwise decisions, we abdicate our responsibilities as health professionals if we do not exercise our duty to assist patients in avoiding unwise decisions. For example, it is bad medicine to simply lay out a menu of options to a patient without providing advice on the pros and cons of each of the options. And sometimes technologically available interventions simply ought not be listed in the menu.

In part, this is because of the second half of the definition of the principle of respect for persons. The relationship between patient and physician or nurse or psychologist or social worker is not the same as the relationship between, for example, a homeowner and a lawn mowing service. In the latter, the two are equals, one seeking a service the other selling a service. Both are unconstrained in their dealings with the other. In the health care relationship such is not the case. The patient is ALWAYS at a disadvantage. Patients seek out health care professionals in hopes of having their pain and/or suffering reduced (i.e., treatment and/or cure) or to be reassured that they are not ill (i.e., diagnosis). This can never be a relationship of equality. The power differential limits autonomy.

To guard against misuse or abuse of power, we have created processes and structures to protect persons made vulnerable by pain, disease or differences in knowledge and socio-economic status. But here, too, we seem to have gone overboard. We distort the principle of respect for persons when we allow appropriate ethical and legal mandates for patient consent to get in the way of our ancient and established understandings of good medical practice. For example, a lawyer reported, during a day's ethics training for physicians, that a physician, in the middle of an emergency procedure, stopped and called him to ask if it would be okay to proceed even though he, the

physician, did not know what the patient wanted. The attorney informed the assembled group, noting that he had received more than one such call in the past, that such a call was not necessary and that under emergency conditions physicians should simply proceed using their own best judgement. That one would have to ask such a question demonstrates that we have scant sound judgement left.

Bioethicists are now debating a case that demonstrates just how far beyond the pale we have come. The case, deliberated in a university ethics committee, is about whether or not to permit a father to give his second kidney to his daughter (1).

The case involves an African-American teenager and her jailed father. The father had already given her one kidney. He did so about two years ago. Her body has now rejected it, apparently for reasons of medication non-compliance. She needs a second kidney. The father wants to give his.

Surely, this is a sad case. One feels the grief of a father watching his child die. Perhaps he has made mistakes in his life and is attempting to even out the cosmic balance sheet or assuage his guilt or just show his daughter how much he loves her. One need not consider the morally interesting, but extraneous, facts that he is in jail, that the child is African-American, reducing non-familial matches, or that the first kidney was lost for medication non-compliance. Nor need the possibility that the father may be depressed and/or suicidal be raised for discussion. One may even applaud a parent willing to give his life for his child's.

But this case does not require lengthy deliberation. The decision can only be not to permit such an action. The possibility of using the tools of medicine to so gravely harm a human being, regardless of the impetus or potential outcome, is simply beyond any sustainable ethical justification.

That we are taking so much time and energy debating it, however, is a demonstration that we have gone way

too far in distorting our notions of personal autonomy and our belief that the legitimate end of medicine is cure. In my own non-random poll and in the comments on the Internet (2), the pros and cons tend to cluster. Those indicating that giving his second kidney is morally permissible offered such justifications as, "If he wants to, it's his kidney," or "Of course a parent can give his life for his child's" or "This is a free country, if he wants to, let him. That's what this country is all about, the right to do as you please." Some said, "Sure, there's no law preventing it."

Those opposed said things like, "Since he's in jail, we shouldn't allow it because then the public will have to pay for his dialysis." Or others said, "Since his daughter's non-compliance resulted in rejecting the first one, the second one probably won't work and then we'd be paying for his surgery and dialysis for nothing." Some equivocated with, "It might be okay for him, but you couldn't make a surgeon do it to him."

But all these responses miss the point. Even if this man were free and had so many millions of dollars that he could pay for it all himself, including his own dialysis machine and maintenance personnel, and could somehow surgically remove his own kidney, doing so would still be morally impermissible.

But fuzzy moral thinking sets in when we mix up morally acceptable actions with actions that are technologically achievable and not legally prohibited. Some ideas are just bad ideas. Just because an action is not legally prohibited does not make it ethically acceptable. It is plausible that this man, were he not in jail and were he rich enough, might be able to find physicians and nurses willing to perform the surgery, staff his own dialysis unit and manage his chronic follow-up care. But just because all this could, albeit theoretically, be done, and none of it illegally, does not make it ethically appropriate.

Such distortions are compounded by our excessive focus on cure. Although

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Too Much of a Good Thing

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cure is a central end of medicine, so is the exercise of brinkmanship in the Hippocratic tradition of caring for a patient "overmastered" by disease. Although we want to avoid our own deaths and prevent the death of our children, we need to accept that reduction of pain and suffering is, in and of itself, a legitimate end of medicine. If we don't, we will never let poor Aristotle rest peacefully.

Evan G. DeRenzo, PhD
Center for Ethics
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Notes

1. A short description of the case can be found in the *Health Care Ethics* newsletter of the University of Maryland Medical System, 5(4): 1998.

2. Also, Jeff Kahn, Ph.D., University of Minnesota, has a column about the case, including several reader comments and a way for you to register your own view at <http://cmn.com/HEALTH/bioethics/9901/kidney.donation/template.html>.

IN THE COURTS

WRIGHT V. JOHNS HOPKINS HOSPITAL

Will Maryland Recognize Liability for Failing to Follow a Patient's Advance Directive?—A View from the Plaintiff's Attorney

Currently pending before the Court of Appeals of Maryland is the case of *Wright v. Johns Hopkins Hospital, et al.*, No. 71, September Term, 1998. The central issue before the Court is whether, and to what extent, Maryland will impose liability on health care providers for failing to adhere to a patient's advance directive and/or to clearly ascertain a patient's desire for

the withholding of lifesaving measures such as CPR.

Robert L. Wright, Jr., now deceased, was diagnosed with HIV in 1987. Beginning in 1990 he sought treatment from Johns Hopkins Hospital. In early 1993, Mr. Wright was assessed by Hopkins for HIV Case Management. He filled out various forms including one that affirmatively stated that he did not want to be resuscitated. He was reevaluated in 1994 and made no changes to his previous expressed directives. Also in 1993, Hopkins presented Mr. Wright with a Declaration of Life-Sustaining Procedures and a Durable Power of Attorney for Healthcare. After careful consideration and consultations with his family, Mr. Wright executed both documents. His mother, Jeanette Wright, was granted Power of Attorney in the event Mr. Wright could no longer make his health care decisions. His Declaration indicated that he did not want any life sustaining measures, including CPR, performed.

Over the ensuing year and a half, Mr. Wright had numerous admissions to Johns Hopkins for his various HIV related diseases. At each of the admissions Mr. Wright was asked whether he had made any changes regarding his advance directives and his response was that there had been no changes.

By 1994, Mr. Wright was diagnosed with full blown AIDS and suffered from numerous and debilitating AIDS related diseases. He was bedridden, could no longer walk because of feet ulcers, could not bathe himself, could not get out of his bed and was in extreme pain. He suffered from fatigue, diarrhea, shortness of breath, hypotension, tachycardia, septic arthritis, renal insufficiency and other chronic and painful symptoms. In July of 1994, Mr. Wright was admitted to Hopkins for a palliative blood transfusion to alleviate his fatigue, weakness and pain. He was again asked during this admission whether there had been any changes regarding his advance directive and again he said there had not been. His chart contained a copy of his advance directive and power of attorney.

During the blood transfusion, Mr.

Wright went into cardiac arrest. The nurse in attendance at the time called a code and Mr. Wright was resuscitated. Mr. Wright was initially in a coma and suffered 65% brain damage. He subsequently regained consciousness and suffered in extreme pain until his death approximately 10 days later.

While the code was in progress, Mr. Wright's father had phoned his son's room and whoever answered the phone left the receiver off the hook and Mr. Wright, Sr. could hear the code being performed. He immediately contacted his wife and the family rushed to the hospital. Upon learning of his advance directive, Mr. Wright's health care providers removed him from life support. The nurse who called the code apologized to the family stating that she did not see the advance directive in the chart at the time she called the code.

As a result of the resuscitation, Mr. Wright was kept alive for an additional ten days in a state that he had expressly wished to avoid. His parents were devastated that they had been unable to see that their son's wishes had been honored.

This case presents extremely important issues regarding health care provider liability in the context of providing or withholding life saving measures to a patient who has executed advance directives and has expressed his wishes to health care providers. In this case, the Wrights have contended that the advance directive and durable power of attorney were provided by Hopkins and were thoroughly discussed with Mr. Wright and his family prior to his cardiac arrest. Moreover, the Wrights contend that on numerous occasions, Mr. Wright expressed his desire not to be resuscitated.

Hopkins contends that Mr. Wright never verbally expressed his desire not to be resuscitated. Representatives of the institution further contend that the advance directive never became operative because Mr. Wright had not been certified as being in an end-stage condition (Hopkins also disputes the Wright's claim that he was in an end-stage condition). Moreover, they contend that even if Mr. Wright had expressed his desires and even if the

advance directive was operative, Hopkins is immune from liability pursuant to Md. Code Ann. Health-Gen. Sec. 5-609. Finally, Hopkins contends that even if liability can attach in this case, no damages should be awarded because life in any state is preferable to death.

At the trial court level, the court granted the defendant's motion for summary judgment, determining that there was no dispute as to the material facts of the case. As a result, the factual dispute regarding whether the advance directive was operative and whether Mr. Wright had affirmatively expressed his desire not to be resuscitated were never decided.

As regards the immunity issue, Hopkins essentially argues that blanket immunity should be provided unless a showing of bad faith on the part of the health care providers can be demonstrated. Under that scenario, regardless of what steps a patient takes to ensure that his end of life decisions are respected, a health care provider will incur no liability for failing to adhere to those decisions. This position ignores that portion of the Health Care Decision Act which states "nothing in this subtitle authorizes any action with respect to medical treatment, if the health care provider is aware that the patient for whom the health care is provided has expressed disagreement with the action." Md. Code Ann., Health-Gen, Sec. 5-611(e)(2).

This argument, if successful, would completely negate a patient's right to self-determination. Even a cursory review of the immunity provision in the statute reveals that immunity only attaches when a health care provider acts *pursuant* to an advance directive and not in contravention to either an advance directive or an expressed desire by the patient.

Immunity may also attach if a health care provider has no prior knowledge of the patients' advance directives or expressed instructions and no reason to know of such instructions. In the Wright case, the individual physicians who responded to the code were also sued. Because the case was decided on a motion for summary judgment, the

Wrights were never able to determine whether those individual physicians had prior knowledge of Mr. Wright's advance directives.

However, Hopkins contends that they and any of their employees or agents are immune simply by the fact that this was an "unanticipated emergency." They contend that any failure to have Mr. Wright's medical chart properly documented or to adequately check the chart before calling a code is the responsibility of Mr. Wright. Again, such an interpretation would completely negate the purpose of having advance directives and would leave all those patients who currently have advance directives with a false sense of security that their end of life decisions will be honored.

The Attorney General has issued opinions regarding the providing of life sustaining measures in an emergency situation. As pointed out in those opinions, in a typical emergency situation, health care providers have no time to obtain informed consent or to determine the advance directives of the patient. However, the Attorney General has stated that in a hospital or chronic care setting, discussions with the patient regarding advance directives and life sustaining measures can be accomplished *before* an "emergency" arises. Furthermore, the opinion states that a "facility should not simply assume that it has authority under Md. Code Ann. Health-Gen Sec. 5-607 to perform emergency treatment without consent if consent could feasibly have been solicited before the emergency arises and, given the circumstances of the patient's condition, a decision to decline CPR is a realistic possibility." 79 Op. Atty. Gen. 137 (May 3, 1994).

It is thus the Wrights' contention that if life sustaining measures are instituted by health care providers in contravention to the patient's expressed instructions, they should be held accountable for the damages suffered by the patient which include the added cost of medical care and the emotional pain and suffering experienced by the patient and/or his family.

Contrary to Hopkins' assertions that such potential liability would wreak

havoc in the medical community, it will ensure that the medical community will adequately discuss these issues with patients and further ensure that advance planning decisions will be honored. The obligations of hospitals, physicians and other health care providers will be no greater than what they are already obligated to do, that is, to thoroughly discuss with patients the treatment plans and decisions regarding end of life issues. For example, in a case such as that of Mr. Wright, wherein a patient has a terminal disease and has been seeking health care from the same institution, it simply requires that discussions about advance directives and end of life decisions are made before an "emergency" situation arises. Mechanisms can be put in place which would document these discussions and in the event of a patient's desire not to be resuscitated, properly documenting such preferences in a patient's chart, should ensure that the decisions of the patient are carried out.

It is only in those situations where the medical community fails in its responsibilities to patients that they will be exposed to liability. To hold otherwise would be a grave disservice to patients and their families and would render meaningless the right of patients to determine their own fate.

Matt R. Ballenger, Esq.
Baltimore, MD

Note

This comment reflects the views of the plaintiff's attorney. The defendant's attorneys were unable to submit a comment on the case for this issue but may comment on it in a future issue of the newsletter.

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IN THE LEGISLATURE

The following bills have been introduced this session in the Maryland legislature. They may be of interest to members of ethics committees.

SENATE BILL 589 - Patient Care Advisory Committees - Consultation and Evidentiary Use of Advice.

This bill is based, in part, on the fact that, under current Maryland law, a guardian is specifically identified as someone who may petition a patient care advisory committee for advice. A guardian might petition the committee for a recommendation when the guardian, acting independently, or at the court's direction, thinks that the committee's recommendation might be helpful in making a health care decision for an incompetent patient. The bill does two things: First, it makes clear that if a guardian has petitioned the committee for a recommendation, the recommendation is admissible in court as evidence. Second, in pediatric end-of-life care cases, it requires an ethics committee to consult an expert if the committee itself lacks expertise in that type of care. The purpose of the bill is to provide a court with the benefit of an expert assessment of the clinical and ethical situation in these very difficult cases. The committee's recommendation would be only one factor that the court might consider and the court would be able to give the committee's recommendation whatever weight it deemed appropriate.

The bill was voted out favorably by the Senate Finance Committee on March 2nd with minor amendments and went to the floor of the Senate. It passed third reader on the floor on March 9th and went to the House Environmental Matters Committee on March 10th. A hearing on the bill before Environmental Matters was held on March 24th.

SENATE BILL 307 - Research on Decisionally Impaired Patients.

This bill, proposed by a Task Force assembled by Jack Schwartz of the state Office of the Attorney General, sets out guidelines for the conduct of medical research on decisionally impaired individuals, including individuals with such conditions as dementia or schizophrenia. The proposed law fills a gap in federal regulations on research on human subjects which do not provide specific safeguards for conducting research with this vulnerable population. The bill allows for a research advance directive in which a competent individual may specify their wishes to participate in medical research should they lack decisionmaking capacity and to appoint an individual to consent to such participation on their behalf. The proposal would also allow an agent appointed under a health care power of attorney or a surrogate (as identified in the Health Care Decisions Act) to consent to a decisionally impaired patient's participation in research based on the patient's known preferences and on the risks and benefits associated with the proposed research. A hearing on this bill was held before the Senate Judicial Proceedings Committee on March 11th.

HOUSE BILL 496, SENATE BILL 319 - Prohibition of Assisted Suicide.

These bills, which would criminalize assisted suicide in Maryland, have passed committees in both the House and the Senate. SB 319, passed the Senate, 28 - 19 on March 3rd. A similar, but not identical, bill (HB 496), was voted favorably out of the House Judiciary Committee on March 16th. Similar bills in prior years had died in the House committee. The bill would not only criminalize physician assisted suicide but also criminalize assisted suicide by non physicians. As introduced, the House Bill carried a penalty of three years imprisonment, but the penalty was amended in Committee to one year.

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and how the committee resolved it. Individuals 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 of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Study From A Maryland Hospital

Note: The facts of the case were modified, including the name of the health care facilities, to preserve the confidentiality of the patient.

Baby Boy, John Doe, was born on September 7, 1998 at Lincoln Memorial Hospital, a 400 bed acute care hospital in suburban Maryland. His mother, Sarah Doe, was 17 years old and unmarried. The baby's father was not present during the delivery. Baby Doe was delivered by C-section at 24 weeks. He weighed 594 grams and was 31.5 cm long. He was admitted to the hospital's 16 bed neonatal intensive care unit (NICU), for prematurity, respiratory distress and to rule out the possibility of a systemic blood infection. Due to breathing difficulties he was placed on a ventilator. He remained on the ventilator for 21 days, and continued to have oxygen administered until day 55. During his time in the NICU he was also treated with antibiotics for a possible infection. The baby's physi-

cians anticipated that he would be eligible for transfer to a less intensive medical setting after he was able to breathe on his own and had gained sufficient weight. Early in November, the NICU case manager made several attempts to prepare the mother for transfer of the infant to a more appropriate care facility, to be able to address developmental care issues, typically of concern with micro premature infants. This is considered standard practice for moving infants along the health care continuum, as they become more stable in the NICU environment.

On November 16, the mother was informed that it was time for her child to be transferred to an alternative setting, in this case, Jefferson Pediatric Hospital. (Lincoln Memorial Hospital has a relationship with Jefferson Pediatric Hospital (a chronic pediatric hospital) whereby Lincoln leases space to the Pediatric Hospital which in turn has a 10 bed inpatient program in Lincoln Memorial adjacent to Lincoln's Pediatric Unit. Referrals are made between programs and services and every effort is made to make the transition seamless for the patient and their families.) The mother refused to sign the necessary transfer forms. The mother had become very comfortable with the NICU staff and did not want her baby to leave their care.

Due to increased volume and baby acuity issues in the NICU, it was necessary to transfer those infants ready for step down care. When the mother refused transfer to a more appropriate setting, staff transferred Baby Doe to the Hospital's six bed Transitional Nursery (TN) on the Pediatric Unit.

Late into the night, on November 20th, the infant was examined by the attending neonatologist on call and determined to have NEC (necrotizing enterocolitis), a common, treatable infection often associated with prematurity. By early morning, the infant was transferred back to the NICU. This occurred so that the neonatologist, covering both locations, would not have to constantly run up four flights to check on the status of Baby Doe. The infant was treated for the NEC and stabilized.

After the baby was stabilized, the

mother was again encouraged to sign the consent form to transfer the infant to the Jefferson Pediatric Hospital. She refused, stating she had been "hearing negative things about the Pediatric Hospital from parents of the preemie Support Group." On November 25th, she agreed to explore and tour another facility located in the City. When the day came to tour the facility, she backed out and did not attend the tour. The infant was once again sent back to the Transitional Nursery for care.

Again, staff attempted to get the mother to agree to sign the infant's discharge papers. Again, the mother refused. Members of the administrative staff of the hospital also met with the mother without success. The baby had remained in the hospital 12 days longer than the physicians, case manager, and the infant's insurer believed was medically necessary. The administrators were frustrated and felt as though this very young woman had them over a barrel. Despite their best efforts, she could not be persuaded. Moreover, although she had insurance and her insurer would no longer cover the costs of the baby's stay, she said that the baby's father, who was 30 years old, had the resources to pay for the baby's care out of pocket. The baby's father, in fact, signed a letter indicating that he would agree to pay for continued care of the infant in the hospital and backed it up with evidence of financial solvency. In spite of this, the hospital felt that the baby's continued stay was inappropriate. The hospital administrators sought the services of the hospital ethics committee for advice.

Comments from a Bioethicist

The comment by "the administrators" that the mother of the child had them over a barrel is not hard to understand. In reading this case as a rather 'thin' description of the situation most of us would agree that the administration and the nursing staff, in particular, attempted to both accommodate and tend to the mother and her child's medical

and psychological wellbeing beyond the endorsement of the insurance carrier. The staff and the hospital are caught between the horns of a dilemma: their obligation to the sick and needy and to stewardship of limited resources.

It does appear that the staff was generally consistent in doing what was 'right' in order to avoid finding themselves in the quandary that finally overcame them. A premature child was properly placed in the NICU with therapies to prevent greater developmental deficits and illness; the mother of the child seemed to be well informed about the why's and wherefores of the child's medical condition, the reasons for transfer, and the costs of care; attempts were made to equilibrate the power differential between the vulnerable patient and those who have the power of care by giving the mother a major say in the course of the baby's treatment including where treatment would take place. While it seems that the hospital was generally clear about procedures, some ambiguity was introduced into the situation by allowing the baby to stay in one unit when it was not medically necessary. The rationale for the placement in the intensive care unit was described as being for the convenience of a physician (in order not to "run up four flights to check on the status of Baby Doe"). The problem is, of course, that what is perceived as a convenience by the physician could be perceived by the mother as what was required to properly tend to the care of her baby.

It is this difference of perception that I would be most interested in discussing with those involved in this situation. In order to 'get at the heart of the matter' we will have to try to make the 'thin' description 'thick' through the encouraging of dialogue and the creation of narrative that will augment the 'facts' of the case.

What we know is that a young woman, some might say not yet adult, gave birth prematurely to a child with medical problems that required intense 24-hour care for nearly three months.

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Case Comments

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We also learn that the father of the child had been physically absent and, I would assume, not emotionally supportive other than to guarantee the payment of fees beyond which the insurance carrier would cover. Of course, one important issue is how relevant it is that the father of the child could pay the hospital bill. When there is a shortage of space or other resources how shall we distribute what resources are available? Shall we approach this by need or the ability to pay? In a situation such as this most would no doubt say that the ability to pay is beside the point: distributive justice requires a minimal qualification of need regardless of financial status.

While the father's money may not be relevant, something of his other intentions in caring for his child certainly is. I would want to know more about his and the mother's relationship. Here we have a very young mother, single, possibly financially strapped with a very sick child who may need special care for some time to come. Nowhere in the 'thin' description do we hear about family support for this young woman and her child (parents, siblings). Presumably, then, we are confronted with giving advice to the hospital concerning a young and no doubt largely unprepared mother with a very sick child who for three months had 24 hour support of a kind that in fact money can't buy. If she had the opportunity to have her child stay with expert childcare why would she do otherwise? Can we blame her? Indeed, keeping her child in intensive care seems from her perspective an option: even a neonatologist had him stay in the NICU when really a step-down unit was more medically appropriate. Is it too hard to understand that the mother may have a different definition of convenience from that of the medical staff?

So, one thing is clear: Baby Boy, John Doe cannot stay in the hospital any longer no matter who is willing to pay. It is not right to provide medical care that is not needed. That Baby John Doe may go home with a mother ill prepared to care for him is of concern to an ethics

committee and to the hospital as fiduciary agent. That the hospital can open conversations with the father of the child and with other relatives of the child and mother to 'thicken' the narrative is compelling. Relying on mid-level principles will not get us to these questions much less to their answers. Without asking the questions in hopes of finding answers this 'case' will remain within the domain of rules and procedures somewhat removed from the motivations and desires and resources of a young woman and her infant son. That is an ethical problem.

Brian H. Childs, Ph.D.
Ethics and Organizational Development
Shore Health System
Easton, MD

Comments from an Attorney/Ethics Committee Chair

Thoughts of patients who refuse to leave disturb the sleep of most hospital administrators.

This patient's parents actually present a less difficult situation than many. They have agreed to pay for the care they are demanding and provided evidence that they may actually be able to live up to that commitment. Some care beyond what could be provided at home is apparently necessary. This relieves, if not eliminates, all too common concerns in similar situations.

Legally, the hospital has few choices. The recent decision of the United States Supreme Court in *Roberts vs. Galen* (U.S. Jan. 14, 1999) has raised the possibility that the federal Emergency Medical Treatment and Labor Act (EMTALA), 42 U.S.C. 1395dd, will be interpreted to cover transfers of patients who are weeks of treatment away from the emergency department. While the care providers in this situation appear to be confident of the patient's ability to survive the risks of transfer to the other facility, there is no way for the hospital to meet the EMTALA requirement of a

request for the transfer, in writing, from the patient's representative.

1395dd(c)(1)(A)(I). The hospital could argue, of course, that the child no longer has an "emergency medical condition," as defined in the statute, and therefore this requirement does not apply.

Even assuming the inapplicability of the EMTALA statute, however, the proposed transfer to the other facility would run into the impediment of the Maryland regulations regarding intra-hospital transfers. These regulations prohibit hospital to hospital transfer, absent a request from the patient or patient's representative, so long as the current facility can provide "adequate care." COMAR 10.07.01.23. This limitation is not contingent, as EMTALA arguably is, on the patient's condition. Since the adequacy of the care Lincoln Memorial can provide is not in question, it cannot meet the requirements of the Maryland regulation, absent a "request" from the child's parents.

Some might look for relief based on the section of the Maryland Health Care Decisions Act which provides that Maryland health care providers are not required to provide medically "ineffective" treatment simply because it is demanded by a patient or surrogate decision maker. Ann. Code MD HG §5-611(b). But it seems unlikely that a court would be persuaded that the care being requested at Lincoln Memorial is "ineffective." More care than the child needs is apparently available there, but the parents are not demanding particular therapies that the medical team feels are inappropriate. Also, the statutory provision provides no shield against liability in the event that the provider actually chooses to withhold "ineffective" care, thus making this an even less attractive avenue to pursue.

If there are services available at Jefferson Pediatric Hospital which are *not* available at the acute care facility and the providers could clearly establish that the child was being harmed by not receiving those services, the final legal option is to report the child as neglected and let Child Protective Services

TWELVE ERRORS TO AVOID WHEN ESTABLISHING AND MAINTAINING AN ETHICS SERVICE

Five Errors in Establishing an Ethics Committee (It's never too late to correct them!)

1. Allowing risk managers, lawyers, administrators, or others to do the ethics committee's job.
2. Appointing ineffective community members.
3. Establishing the ethics committee as a medical staff committee having no reporting relationship to the institution's governing body.
4. Failing to construct an annual work plan or line-item budget.

5. Being content with committee status and failing to offer education, policy studies or consultation services.

Five More Errors

(These occur frequently in ethics consultation)

6. Being morally proactive in consultations, and trying to engineer the "right outcome"
7. Failing to adopt a policy of open access to consultation or a policy against intimidation of anyone who requests ethics consultation (e.g., nurses)
8. Failing to notify patients or surrogates before a consultation occurs
9. Failing to document consultations in patient charts
10. Failing to evaluate consultations or offer a process for complaints

Two Errors that, Combined with Errors 2,7, and 10, Limit an Ethics Program's Freedom and Integrity

11. Failure to initiate policy studies
12. Failure to examine organizational ethics

Sally Webb

Pediatric Intensivist

Palmetto Richland Memorial Hospital

Columbia, SC, and

Clinical Associate Professor of Pediatrics at the University of South Carolina School of Medicine and the Medical University of South Carolina

This article was excerpted from a larger article entitled, "12 Errors To Avoid When Establishing and Maintaining an Ethics Service," by Sally A. Webb, 1999, ASBH Exchange, 2 (1) p. 7. Copyright 1999 by the American Society for Bioethics and Humanities. Reprinted with permission.

Case Comments

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investigate. However, unless the harm to the child is immediate, substantial and irreparable (which appears unlikely) it is doubtful that this alternative will lead to a speedy resolution of the situation.

In the end, Maryland law provides little help in this case. Hopefully the intervention of the Ethics Committee would provide a resolution.

COMMENTS WELCOME

Readers are welcome and encouraged to submit articles, topics for inclusion or comments on articles or cases that have appeared in the newsletter. You may submit your comments by mail to Diane Hoffmann, Editor, The Mid-Atlantic Ethics Committee Newsletter, 500 W. Baltimore St., Baltimore, MD 21201, or by Fax 410.706.0407 (Attention: Diane Hoffmann) or by e-mail to dhoffman@law.umaryland.edu.

ADDENDUM

In the last issue of the Newsletter, the names of the individuals who commented on the case were inadvertently omitted.

The commenters were:

Anita J. Tarzian, PhD, RN

Research Associate

University of Maryland, Baltimore

School of Law

Baltimore, MD

and

Brooke Bumpers

Attorney

Hogan and Hartson

Washington, D.C.

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CALENDAR OF EVENTS

April

- 8 Medical Humanities Hour, University of Maryland Medical Systems. Topic: "Medical Harms and Medical Error: New Ways of Understanding Responsibility in Health Care" Speaker: Virginia Ashby Sharpe, PhD, Associate for Biomedical and Environmental Ethics, The Hastings Center. 4:30 - 5:30 p.m. Shock Trauma Auditorium. For information call 410-706-6250.
- 15-16 A conference on "Medicine, Nonviolence and Humanistic Choices," sponsored by the Center for Bioethics, University of Pennsylvania Health Systems, Location: Sheraton Society Hill, Philadelphia, PA. For more information or a conference brochure contact Sally Nunn at sunn2@mail.med.upenn.edu or 215-573-4038.
- 20 Washington Metropolitan Bioethics Network Meeting, "A Case study in Organizational Ethics" Walter Reed Army Hospital, 4:00 - 6:00 p.m. For additional information contact Joan Lewis at 202-682-1581.

May

- 6 Medical Humanities Hour, University of Maryland Medical Systems. Topic: "Unraveling the Ethics of Umbilical Cord Blood Banking: False Promises and Real Hopes." Speaker: Jeremy Sugarman, MD, MPH, MA, Duke University Medical Center, 4:30 - 5:30 p.m. Shock Trauma Auditorium. For information call 410-706-6250.

June

- 3 "Healthcare Ethics in a Multicultural Society," to be held at Harbor Hospital in Baltimore, MD from 8:00 a.m. to 12:30 p.m. Will discuss morality as it is shaped through the cultural values, beliefs and traditions in which one is raised, and the influence of culture on health behavior and ethical decision making as a component of ethics consultation. Sponsored by the Maryland Healthcare Ethics Committee Network, Harbor Hospital and the Transplant Resource Center of Maryland, Inc. For more information contact J. Anne O'Neil, Network Coordinator, 410-706-4457.

- 12-17 "Contemporary Challenges in Health Care Ethics," Kennedy Institute of Ethics' Intensive Bioethics Course, Georgetown University, Washington, D. C. For more information call 202-687-5477.
- 14-18 "Ethics of Research With Humans: Past, Present, and Future," is a one-week course which provides an intensive introduction to ethical issues in research with humans. Sponsored by the University of Washington, Department of Medical History and Ethics. For more information call Marilyn Barnard, Program Coordinator at 206-616-1864.
- 18 Twelfth Annual Symposium of the West Virginia Network of Ethics Committees and statewide summit of the West Virginia Initiative to Improve End-of-Life Care. Days Inn, Flatwoods, WV. For more information call Linda at 304-293-7618.

July

- 19-20 1999 Summer Course - Developing Competencies in Palliative Care, Canaan Valley Resort and Conference Center, Davis, WV. Sponsored by the West Virginia Network of Ethics Committees. For more information contact Linda at 304-293-7618.

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