

NETWORK NEWS

The newsletter of the Florida Bioethics Network

a Health Service Group of the Florida Hospital Association - P.O. Box 531107 - Orlando, Florida 32853-1107 - 407-841-6230

April 1, 1996

96-2

CASE PRESENTATION

Case presentation by **Karin K. Murray, RN, CS**, Clinical Nurse Specialist, HealthPark Medical Center, Lee Memorial Health System.

Review of a case presented to the Ethics Consultation Group (ECG) at HealthPark Medical Center, Lee Memorial Health System, February 1995. C.M. was a full-term newborn, white male. Approximately two months prior to birth, a diagnosis of hydrocephalus was made. Upon birth, the diagnosis was confirmed as communicating hydrocephalus associated with calcification in the residual visualized cerebral mantle. There was suspicion of a TORCH infection, although this was later ruled out.

The reason for an ethics review was lodged in the efforts to decide whether a ventriculoperitoneal (VP) shunt should be placed for cosmetic and ease of care purposes. Following the diagnosis during pregnancy, the parents, in consultation with medical specialists, family, peers, and clergy, decided, if upon birth, the hydrocephalus were as profound as had been suspected, to provide whatever comfort means possible for the baby. They preferred no aggressive treatment.

During their deliberations neonatally, the option for an ethics consultation was offered to the parents. They willingly accepted. Present were the parents, and members of the ECG as follows: A pediatrician (Chair of ECG), a neonatologist, a perinatologist, a chaplain, an attorney, a medical social worker, an NICU nurse, and a mental health nurse clinical specialist. A second neonatologist also was present. A pediatric neurologist could not attend, but sent a definitive statement regarding prognosis based upon condition and a recommendation for the placement of a VP shunt.

The parents' wishes "to let C.M. die" were clearly established. The mother's fatigue from delivery was evident. She expressed a sense of being overwhelmed by the repetition of "all this is happening." Her sense was in response to a decision made to transport C.M. to Arnold Palmer Center in Orlando for evaluation for the VP shunt placement. Additionally, the struggle between doing nothing and offering some intervention for comfort and facilitation of care was taxing to the parents' rational thought processes.

The parents stated their concurrence with the decision to transfer C.M. to Orlando. During the review process, the transport team arrived. A member of the team joined the group. When Mr. and Mrs. M. realized that if C. arrested in transport, he would need to be resuscitated, they firmly resisted the decision. Subsequently, they refused to sign the papers for transfer. The team left without C. This action was affirmed with the reality that the shunt placement was not an immediately urgent need.

This session, lasting 3-1/2 hours, was concluded with the parents being affirmed. They requested a follow-up conference the next morning, after they had rested, to verify their decisions. A DNRO was made. C. would be monitored and comfort measures given.

The second forum included those in the first session. In addition, the pediatric neurologist was in attendance.

The neurologist indicated the potential for any independent quality of life for C. to be extremely minimal. Alternatives for caring for C. in their home were addressed. Mr. and Mrs. M. had decided not to bring C. home due in part for the welfare of C.'s eight year old sibling. Issues and methods for comfort care were considered. The M.s were affirmed and their choice to do what they deemed best: taking baby home, or placement for care, or for later VP shunt placement.

Within two to three days, C. was taken by the parents to All Children's Medical Center in St. Petersburg for evaluation. Subsequently, the M.s decided to have the shunt placement for the previously stated reasons: Cosmetic and ease of care purposes. C.M. died several days after the placement of the shunt.

CASE REVIEW/RESPONSE

Submitted by **Rev. Jerry J. Griffin, B.C.C.**,
Director, Chaplaincy Services, Lee Memorial
Health System, Fort Myers, Florida.

This case appeared to be a routine gathering to address a difficult decision for Mr. and Mrs. M. The struggle was between immediate care and the adjoining separation from C.M. through transfer to a distant city for a procedure, which could not be guaranteed to change the course of his life's quality and a level of care that would meet his current needs only with death as a likely outcome. The stated ethical principles of autonomy, beneficence, and nonmaleficence were at play in this case. The makings of a dilemma focused basically on the presented immediacy for the VP shunt placement versus a more deliberated decision-making process. The consideration is more problem-oriented than dilemma-based.

Mr. and Mrs. M. had decided for comfort care prior to C.'s birth. The newborn's presence permitted them to face the stark reality of life and its potentials. The direct possibility for resuscitation in transport or during the VP shunt placement led them to address their previous decision. The ethics group afforded them a forum for addressing wisely the problematic nature of their decisions.

One could say that the 20/20 hindsight view of this case shows the appropriate decision was made.

1) Time was "borrowed" allowing the ultimate decision to be made with clarity of thought and with diminished emotional pressures. 2) Mr. and Mrs. M. were able to decide for the shunt placement based on C.'s potential for "good" rather than to respond to the scientific or medical indications only, as they perceived in the immediate period following C's birth. 3) A total family decision was able to be made in the several days following C's birth. The same day/next day circumstance precluded the opportunity for the M.s to seek extended family consultation and for them to talk with their other child in preparation for their ultimate decision and the outcome of C's life.

Fletcher has noted four goals for ethical consultation. Three of these are clearly appropriate to this case. (1) To increase shared decision-making in the resolution of ethical problems, (2) to prevent poor outcomes of cases involving ethical problems and (3) to increase knowledge of self and others. The other is to increase knowledge of clinical ethics.

The M. family was able to face their problem through a forum which guided them in considering their options, in opening new options, and through affirming their ability to decide regarding C.'s projected quality of life. Affirmation was given to pursue the best outcome for all persons/parties involved. An enhancement of self-awareness was clearly present during the two conferences, as well

as for long range. Mrs. M. has subsequently become a consumer/community member of the ECG.

What might have been done to diminish the pressure for the M.s? The one obvious change would have been for the decision for the initial transport to have been delayed given the non-emergent status. The arrival of the transport team served to accentuate the need for a DNRO, but it led to a "dry run" for the team. Concomitant to this decision-delay is the need for clarity of the parents' desire for non-resuscitative actions. Had their preference been more clearly understood in relationship to the State of Florida codes for resuscitation in transport conditions, the transfer likely would not have been initiated.

The benefits for the consultation have been implied throughout this presentation. One which deserves

highlighting is the opportunity to provide time for the family to adjust to the reality of C.'s life potentials, or lack thereof. When the lack of urgency for a decision was clarified, the M.s were clearly relieved. Mrs. M. had been open with her sense of being overwhelmed. With the release of this pressure provided in the forum setting, the M.'s were able to reach an ultimate decision apropos to the ultimate good of their family. It is obvious that not every situation provides the luxury of time.

This case provided one ethics committee the opportunity to learn again the ever-present value of open communication based on the rights for autonomy and beneficence. It is shared not from the basis of the profound or the unusual, but for the expression of the common.

Recent Articles of Interest

Advance Directives, Mary Ann Burg, PhD, MSW, Christopher McCarty, PhD, William L. Allen, J.D., and Dave Denslow, PhD, J. Florida M.A., December 1995, Vol. 82, No. 12.

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients, The SUPPORT Principal Investigators, JAMA, November 22-29, 1995, Vol. 274, No. 20.

Extreme Risk—The New Corporate Proposition for Physicians, Steffie Woolhandler, MD, MPH, David U. Himmelstein, MD, The New England Journal of Medicine, Dec. 21, 1995.

Nursing Home Residents Preferences for Life-Sustaining Treatments, Linda A. O'Brien, RN, MA, Jeane Ann Grisso, MD, MSC, Greg Maislin, MS, MA, Karin LaPann, Karol P. Krotki, PhD, Peter J. Greco, MD, Elisabeth A. Siegert, MD, Lois K. Evans, DNSC, RN, JAMA, December 13, 1995, Vol. 274, No. 22.

Oregon's Assisted Suicide Vote: The Silver Lining, Melinda A. Lee, MD, Susan W. Tolle, MD, Annals of Internal Medicine, January 15, 1996, Vol. 124, No. 2.

What is Accountability in Health Care, Ezekiel J. Emanuel, MD, PhD, and Linda L. Emanuel, MD, PhD, 1996 American College of Physicians, Ann Intern Med. 1996; 124:229-239.

A Professional Response to Demands for Accountability: Practical Recommendations Regarding Ethical Aspects of Patient Care, Linda L. Emanuel, MD, PhD, 1996 American College of Physicians, Ann Intern Med. 1996; 124:240-249.

PRESIDENT'S MESSAGE

Submitted by **Hana Osman, LCSW, DCSW**, Continuing Education Coordinator, Tampa General Hospital, Tampa.

In a recent survey by the Joint Commission for Accreditation of Healthcare Organizations (JCAHO) much of the patient unit interviews focused on patient rights and organizational ethics. Decision-making, advance directives, conflict resolution, confidentiality, addressing patients' values and spiritual needs, patient restraint policies, pain management, and transfer and discharge planning activities were only a few of the topics the surveyors repeatedly examined.

Although the content of policies and procedures was not necessarily the focus of the survey, the congruence between the policies and practice was scrutinized. Documentation by all members of the health care team was expected to reflect stated documentation standards.

The following is a list of questions that summarizes one survey team's interest in patient rights and organizational ethics:

- ◆ How are decisions reached for incapacitated/incompetent patients?
- ◆ How are patients and their families informed of the existence of your mechanism for addressing ethical conflicts?
- ◆ Who approaches patients and their families about the existence of advance directives?
- ◆ Where are the advance directives documents filed in the patient's medical record?
- ◆ If patients request to complete advance directives, what is your institution's policy on making such documents available?
- ◆ How is ethical conflict addressed?
- ◆ Who serves on the ethics consultation team?
- ◆ What are the goals of your ethics committee?
- ◆ How does your ethics committee reflect community values?
- ◆ How is patient identity protected in your institution?
- ◆ Are community pastors encouraged to participate in patients' care?
- ◆ Is your institution's restraint policy followed?
- ◆ Is the least restrictive environment always pursued?
- ◆ How do you assess patients' level of pain?
- ◆ How is pain management integrated in your institution?
- ◆ How is patient transfer handled from your institution to other hospitals or to community facilities?
- ◆ How is appropriate follow up ensured?
- ◆ How are patients who need assistance with discharge planning identified?
- ◆ How is patient/family education ensured?

It was confirmed by one survey team that patient rights and organizational ethics have become a prominent highlight of the JCAHO, and that staff education is paramount to continued accreditation.

Members in the News

Jim Wagner, Past President of FBN, was recently honored by the College of Chaplains. He received the Professional Service Award recognizing his work in the field of Bioethics. This prestigious award was presented at the Annual Convention for the College of Chaplains held in Boston, MA on February 19, 1996. The College of Chaplains is the National Certifying and Membership Organization for Chaplains.

LETTERS FROM FBN MEMBERS

Dear Dr. Singer,

I read with more than passing interest your contribution to [the January 1996 issue of *Network News*] FHA's newsletter for the Bioethics Network.

The evolution of organ transplant policy is indeed made more difficult in the ventilator scenarios you describe.

As one of many providers greatly concerned with bioethics, we appreciate your taking the time and energy to contribute to our learning.

Sincerely,
Lewis A. Ransdell
Administrator

Summary of Letter from Dr. William Morgan:

Dr. Morgan responded to Dr. Singer's article published in the January 1996 issue of *Network News* with another possible solution to the scarcity of organs. He spoke of his own personal experience with a loved one in a permanent vegetative state. Dr. Morgan stated, "The one experience that would have made withdrawing the feedings and allowing my relative to die a 'good experience' would be to know that some good came out of this tragedy. As indicated in Dr. Singer's article, once the decision is made to do whatever is necessary so that death is the end point, then that patient should become a candidate for transplant donor at that point."

REPLY TO ORGAN DONATION ARTICLE

Submitted by **Glenn Singer, MD, FACP, FCCP**,
Chairman-Bioethics Comm./Pulmonologist,
Broward General Medical Center, Ft. Lauderdale.

Mr. Ransdell is Administrator of Vencor Hospital, a long term facility specializing mostly in long term ventilator dependent patients. As was mentioned in my original article, one of the newer groups of patients being considered for organ donation is the patient with a terminal process maintained on the ventilator. Many of the patients may still have cognitive function and usable organs, but not have any hope of living independently off the ventilator. While some communities have aggressive in home ventilatory care available, this may be a heavy emotional and monetary burden on other patients and families. Indeed, the patient may him/herself decide that he/she does not wish to persevere on the ventilator. Should these patients be allowed to ask for termination of ventilator support for the purpose of donating their organs? Patients with these conditions may not expire promptly on disconnection from the ventilator. Should they then be reintubed, given anesthesia and have cardiectomy, nephrectomy, or whatever other organ removed and die in this manner?

The heart wrenching letter from Dr. Morgan presents a different problem for organ donation. A

tragic auto accident has robbed a family of their son's spirit. The hollow shell of the persistent vegetative state remains. Yet out of this gut churning loss, a chance for magnanimity exists: donation of internal organs. The organs are unlikely to be useful if nutrition and hydration are withdrawn and the patient dies in renal failure. The potential donor may even have indicated on their driver's license that he is an organ donor candidate. It is now well accepted that patients may have food and hydration withdrawn for the purpose of allowing the natural dying process to proceed unimpeded by technologic interference. Dr. Morgan makes an excellent point that these organs may still be useful. How is removal for donation different from withdrawing nutrition and hydration? One obvious difference is the "active" process of removing organs and terminating life in a patient as opposed to the more passive process of halting tube feeding and/or intravenous fluids. Another argument against this change in donation policy would be the possibility that the patient must be truly vegetative and not severely impaired, depressed, or otherwise neurologically diminished.

Improving the donor pool should be a priority for all health care workers. The potential candidates discussed above represent new areas for providing beneficent care to our patients.

ESSENTIAL READINGS #5

Submitted by **Francille MacFarland, MD**, Winter Park.

Managed Care:

Miles, S.H., Koepf, R. End of Life Treatment in Managed Care: The Potential and the Peril. *Western Journal of Medicine* 1995; 163: 302-305.

Ubel, P.A., Arnold, R. M. The Unbearable Rightness of Bedside Rationing: Physician Duties in a Climate of Cost Containment. *Archives of Internal Medicine* 1995; 155: 1837-1842.

Emanuel, E.J. Medical Ethics in the Era of Managed Care. *The Journal of Clinical Ethics* 1995; 6: 335-338.

Sulmasy, D.P. Managed Care and the New Medical Paternalism. *The Journal of Clinical Ethics* 1995; 6: 324-326.

Rimler, G.W., Morrison, R.D. The Ethical Impact of Managed Care. *Journal of Business Ethics* 1993; 12: 493-501.

Morreim, E.H. Balancing Act: The New Medical Ethics of Medicine's Economics. Kluwer; Norwell, Mass. 1991.

Humber, J.M., Almeder, R.F. Allocating Healthcare Resources. Humana Press; Totowa, NJ. 1994.

AMA Council on Judicial Affairs, Ethical Issues in Managed Care. *JAMA* 1995; 273: 331-335.

Pellegrino, E.D. Rationing Health Care: The Ethics of Gatekeeping. *Journal of Contemporary Health Law Policy* 1986; 2: 23-45.

Emanuel, E.J., Dubler, N.N. Preserving the Physician-Patient Relationship in the Era of Managed Care. *JAMA* 1995; 273: 323-329.

CURRENT REFERENCES

1. Callahan, T.C., et al. Ethical Reasoning in Clinical Genetics: A Survey of Cases and Methods. *The Journal of Clinical Ethics*, 1995; 6: 248-253.
2. Fried, T., Gillick, M. The Limits of Proxy Decision-Making: Overtreatment. *Cambridge Quarterly of Healthcare Ethics*, 1995; 4: 524-529.
3. La Puma, J., et al. How Ethics Consultation Can Help Resolve Dilemmas About Dying Patients. *Western Journal of Medicine*, 1995; 163: 263-267.
4. McIntyre, K.M. Medicolegal Implications of Consensus Statements. *Chest* 1995; 4: 502 s.
5. Blackhall, L., et al. Ethnicity and Attitudes Toward Patient Autonomy. *JAMA*, 1995; 274: 820-825.

THE BIOETHICS ADVISOR

Submitted by **Ray Moseley, Ph.D.**, Director, Medical Ethics, Law and the Humanities, University of Florida College of Medicine, Gainesville.

Last week I was asked, "How often should our hospital ethics committee meet?" This is one of the most common questions I receive from those trying to develop a Bioethics Committee. I responded, "40 times." The answer I gave invoked the usual shock response, and a hopeful follow up question, "Do you mean 40 times a decade?" "No," I sympathetically responded, "I mean 40 times per year, and yes, I am serious."

Of course, at least part of the reason for my answer was to draw attention to the reality that a functioning hospital ethics committee takes considerable commitment and effort on the part of its members. In response to this, some might note that JCAHO does not have any magic number of meetings per year it recommends for a hospital ethics committee. This fact has led some hospitals to believe that their ethics committee may meet "whenever needed," which usually translates to "hardly ever" or as few as two or three times a year. However, this approach will lead at the very least to an ineffective ethics committee, and at worst to one that is a potential danger to patients, professional staff, and to the institution! This is certainly unfortunate since an effective hospital ethics committee may be an extremely valuable resource for any hospital.

The other part of my reason for the answer "40 times per year" is because I, in fact, do believe that this is a reasonable number of meetings, when one adds up the different settings in which a functioning ethics committee (or a sub-committee of the ethics committee) meets. Let me explain how I arrive at this magic number.

First, a hospital should probably be meeting at least once a month in order to fill its mission to educate its members, review hospital policies, and to plan educational activities for hospital staff and for the community. Many ethics committees will form subcommittees in conjunction with these missions to work on specific policies or plan educational activities, which could add to my recommended total number of meetings. The bottom line is that it takes at least 12 meetings a year for committee members to keep up with even carefully selected topics in health care ethics.

Second, a functioning hospital ethics committee should plan and host at least four educational meetings/presentations/activities per year for staff education. Hospital staff at the very least need to have a basic understanding of the ethical issues they face and to have knowledge of the "ethics mechanism" at their hospital. Many hospitals do much more such as offering monthly ethics rounds where a particular issue is addressed.

Third, if a hospital ethics committee or a subcommittee/consult team is going to provide clinical ethics case consultation for hospital staff, I believe that the committee should average at least two formal consults per month, in addition to numerous "curbside" consults. Why, at least, two per month? For several reasons, including two that are significant.

The first and most important reason is that the average hospital will have numerous ethical issues arising monthly which will not be adequately addressed and where an ethics committee consult may be of value. Many examples will probably come to mind, think of how many cases you have at your hospital where intense medical treatment was continued because of family insistence, or situations where an incapacitated patient was allowed to make decisions in agreement or disagreement with the wishes of the health care team, in where patient confidentiality was broken, or a patient's advance directive was ignored.

A second reason why a hospital ethics committee should be averaging at least two consults a month is largely practical. Effective ethics consult programs take expertise and experience. This expertise is developed by education and by regular and consistent practice. As with any other professional activity in your hospital, there is a learning curve to achieve proficiency and then consistent and regular practice to maintain proficiency. A poor ethics consult, where ethics committee members do not know when or when not to accept a consult request, which consult format is appropriate for which type of cases, what types of recommendations may be drawn, how to support the recommendations, or how to document recommendations, may result in disaster for the patient, staff or hospital.

Double checking with my calculator . . . the answer is 40 meetings per year!

MEETING CALENDAR

Regional Meetings

- **April 12-13, 1996:** *Ethical Issues in Managed Care*; Jacksonville, FL; Call 800/622-4989 for further information.
- **April 26, 1996:** *Ethics in Emergency Medicine*; Orlando, FL; Call 407/281-7396 for further information.
- **April 26-28, 1996:** *Ethical Issues in Dialysis, Transplantation, and Long-Term Life - Sustaining Treatment*; Rolling Hills Hotel & Golf Resort, Ft. Lauderdale, FL; Contact: Dr. Jos V.M. Welie, CEREC Center, P.O. Box 292932, Ft. Lauderdale, FL 33329. Tel./Fax: 305/424-9304. E-mail: jewlie@bcfreenet.seflin.lib.fl.us.
- **August 23-25, 1996:** *Ethical Issues in the Care of Incompetent Patients*; Rolling Hills Hotel & Golf Resort, Ft. Lauderdale, FL; Contact: Dr. Jos V.M. Welie, CEREC Center, P.O. Box 292932, Ft. Lauderdale, FL 33329. Tel./Fax: 305/424-9304. E-mail: jewlie@bcfreenet.seflin.lib.fl.us.

National Meetings

- **April 19-20, 1996:** *Medicare, Medicaid, and Managed Care*; College Park, MD; Call 800/727-8622 for further information.
- **June 7-8, 1996:** *The 17th Annual Health Law Teachers Conference*; Wilmington, DE; Call 800/685-9636 for further information.
- **June 21-22, 1996:** *Care Near the End of Life*; Cambridge, MA; Call 617/432-1525 for further information.
- **July 14-19, 1996:** *Midwest Intensive Bioethics Course*; Sponsored by: Center for Bioethical Ethics, University of Minnesota; Center for the Study of Bioethics, Medical College of Wisconsin; and Program in Medical Ethics, University of Wisconsin, Madison; Riverwood Conference Center, Monticello, MN; For information and registration materials, contact: Center for Biomedical Ethics, University of Minnesota, Suite 110, 2221 University Avenue SE, Minneapolis, MN 55414. Telephone: 612/626-9756/Fax 612/626-9786 or E-mail at holmb006@maroon.tc.umn.edu.