

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 1995

95-2

CASE REVIEW

Submitted by **Kathryn Koch, M.D., FCCP**, Associate Professor of Medicine, University of Florida, College of Medicine, Director/Critical Care Services, Chief/Division of Critical Care Medicine, Chair/Hospital Ethics Committee, University Medical Center.

Thirty-eight year old C6-C7 Quadriplegic

This individual had been injured in a diving accident two years previously. He came to my care after his insurance ran out and I admitted him several times over 18 months, primarily for severe atelectasis and sepsis secondary to a sacral decubitus.

When I first met him he was engaged to a woman who was fiercely protective and still kept in contact with his ex-wife and his 8 year old daughter by that marriage. The child had numerous adjustment difficulties and was suicidal; she had been present at the accident which occurred on her 6th birthday. He married his girlfriend who subsequently became angry with him and abandoned him for periods as long as 72 hours. He finally rejected her and at the point where he faced a colostomy and plastic surgery for his decubitus, he asked me to kill him instead. He had no place to live and his friends were bikers who could not provide him a home. He refused nursing home placement (which incidentally was a quite difficult placement anyway due to lack of rehabilitation potential).

Every time he had been hospitalized for his atelectasis during the preceding months, he had insisted on being on the ventilator for no more than 24 hours if he required bronchoscopy; if he wasn't ready to come off the vent within 24 hours post-bronch, he would rather be dead (he had been on the vent for three months after the initial accident.) He had been "DNR" ever since I first met him. The surgeons and anesthesiologists did not want to proceed with the necessary palliative surgery if he was going to insist on a DNR in the OR. For a while

it looked like we weren't going to be able to perform his surgery because of the disagreement between the patient and the other M.D.s. over that issue.

He and I spent hours talking about DNR in the OR and about physician-assisted suicide. I told him that was a felony in the state of Florida. He pointed out that he did not have the physical ability to take matters into his own hands. Then I suggested we stop all supportive therapy and treat him only with pain meds and he might get a pneumonia, which he would not treat, which might lead to his death. He agreed to that idea, but then thrived despite his severe decubitus, staying in the hospital with excellent nursing care because there was no other place for him to go. He then re-initiated the discussion of assisted suicide. I told him he could refuse food and fluids, we could keep his mouth moist, and he would have minimal discomfort after the first 48 hours of his fast. The nurses were horrified that we were having these discussions, incidentally. In any case, he decided that food was his one enjoyment left in life and did not choose that option.

He then chose to have his surgery done by lifting his DNR decision for his trip to the OR and by agreeing to the same deal, he and I had always had whenever there was an indication to place him on mechanical ventilation. He did exceptionally well, was successfully extubated the afternoon of the surgery, and was subsequently discharged six weeks later to home placement arranged by social service. I am still in contact with him four years later and he now has a satisfactory adjustment to his quadriplegia. In retrospect, it would have been a horrible decision to participate in his death.

Many of us are experiencing major institutional reorganization as our health care institutions react to the changing market in the state of Florida. We are having to deal with rapid and fundamental changes as we adjust to the era of managed care. At the same

time we are facing fundamental conflicts of interest in how we deliver care which have surfaced during the necessary excavations required to build a new system. **John Fletcher** notes that health care is not a commodity to be bought or sold, but a moral enterprise. We must however reconcile the reality that health care is both a commodity and a moral enterprise.

The Florida Bioethics Network recently co-sponsored a presentation by the JCAHO and the Bioethics Development Group of Midwest Bioethics on "Patient Rights and Organizational Ethics: Compliance and Beyond." Several of us attended; my own expectations were that a framework for dealing with this new reality would be discussed. My expectations were unrealistic. The focus of the seminar was 90% patient's rights and different mechanisms to meet the JCAHO's requirement that a "mechanism exist"

to handle difficult patient issues and concerns. Only 10% of the seminar was devoted to organizational ethics, i.e., the ethics of the corporation as an entity as compared to the ethics of the individuals who comprise the corporation.

This is territory that deserves further exploration, perhaps at a regional focus seminar in 1996. Ideas and proposals are welcome. Please note that we have discovered through our own efforts to improve general knowledge at our own institution with respect to patient confidentiality, that the Educational Standards Manual (1994, ed.) published by FHA, and the Florida Society for Healthcare Education and Training, contains **NO** information regarding patient standards for your own institution, be aware that it requires supplementation in this specific area. This will be an agenda item for the next board meeting of FBN.

The FBN annual seminar will be held September 20-22, 1995, at Wyndham Harbor Hotel in Tampa. One of the focus issues to be addressed at that seminar is futility. Preceding the annual seminar, the FBN is planning a day long meeting in Orlando at FHA headquarters on June 16, 1995. The regional working groups which have been addressing this futility issue over the past 6 months will be joining together to brainstorm. We hope to develop a statement for presentation at the annual meeting. A basic reading list is included in this newsletter. Any members interested in participating on June 16, please contact John Alfano at 407/841-6230.

AMERICAN SOCIETY ON AGING CONFERENCE REVIEW . . . submitted by Cathy Emmett, Manager/ Gerontology, Sarasota Memorial Hospital, Sarasota.

I had the pleasure of attending the 41st Annual Meeting of the American Society on Aging (ASA) held in Atlanta, March 10-14, 1995. Many of the sessions focused on "Value and Ethics." I have provided a synopsis of some of the meetings attended:

Ethics & Aging: Preparing for the Millennium: This session focused on current and future issues facing ethics committees. Individuals were present from all parts of the USA representing ethics committees from hospitals, extended care facilities, community school services, and an area agency on aging ethics committee. Much concern was expressed over the changes in the health care system, possibilities of future rationing and its impact on older adults, and the aging of the "Baby Boomers."

Ethics Committees: Case Discussion: This session focused on how ethics committees function and used two case discussions to illustrate the consultative process. One case involved an acute care patient and the other a community client. The cases illustrated the different issues

that may be confronted in acute care — withdrawal/withholding of life support — vs. community care — autonomy vs. safety.

Physician Assisted Dying: Legal & Ethical Challenges: Presented an overview of the main court cases and laws that have occurred and/or been proposed to date.

The issue of inadequate pain control and fear of pain by individuals was perhaps a driving force in the interest nationwide in physician-aided dying. Issues of futility were also discussed.

Overall, the conference, although not focused on ethics, offered many stimulating discussions on this topic. Of particular interest was the emergence of several community based ethics committees and the range of issues facing these groups.

Have you recently attended an interesting conference or workshop? If so, why not submit a brief summary for the next issue of Network News. Please send to **Cathy Emmett**, Gerontology Dept., Sarasota Memorial Hospital, 1700 S. Tamiami Trail, Sarasota, FL 34239 or through E-Mail — **Cathy Emmett** at SMH-COM.

NETWORK NEWS READERSHIP SURVEY

Network News, Florida Bioethics Network's newsletter, is produced and distributed quarterly to Institutional and FBN members.

The FBN board wants to know if we are providing you with the information you need and want. Please take a few minutes to complete the attached short survey and return to **Becky Dunne** of the FHA by April 30. Your response will help us determine if we are meeting your informational needs. Thank you for taking time to help us serve you better.

CALL FOR NOMINATIONS

Anyone interested in serving on the 1996 FBN Board, please contact Jim Wagner at 904/395-0224.

VIDEO EXPLAINS ADVANCE DIRECTIVES TO ELDERLY . . . submitted by **Scotti Strickland, VP/** Marketing, Health Care Productions, Inc., Orlando.

Prospective nursing home residents and their families now have a visual aid to assist their understanding of advance directives in the state of Florida. This 10-minute video uses a sensitive and personal approach to explain four advance directives: Living Will, Health Care Surrogate, Durable Power of Attorney and Do Not Resuscitate Order.

This production entitled "Decisions that make a Difference" was produced by Health Care Productions, Inc. Further information is available from **Scotti Strickland** at 407/672-5128.

ESSENTIAL READINGS FOR ETHICS COMMITTEES . . . submitted by **Francille M. MacFarland, MD,** Winter Park; and **Ray Moseley, Ph.D.,** University of Florida, College of Medicine, Gainesville.

At the November 1994 meeting of the FBN board, different ways of helping FBN members to pursue their self-education were discussed. It was decided to periodically publish a list of eight to fifteen readings that would focus on specific subjects within the medical ethics literature.

The following list is what the board has termed "Essential Readings for Ethics Committees." This first effort addresses the issue of futility. Included articles are considered to set the historical progression of and the debate that followed the subject at hand. The bibliography section of these papers should refer the reader to other excellent articles or books that would have made the list too long if included.

ESSENTIAL READINGS #1

Futility References

1. Amundson, D.W. The Physician's Obligation to Prolong a Life: A Medical Duty Without Classical Roots. *Hasting Cent. Rep.* 1978; 8: 23-30.
2. President's Commission for Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forgo Life-Sustaining Treatment.* Washington, D.C.: US Government Printing Office, 1983.
3. Brett, A.S., McCullough, L.B. When Patients Request Specific Interventions: Defining the Limits of the Physician's Obligation. *N. Engl. J. Med.* 1986; 315: 1347-1351.
4. Ruark, J.E., Raffin, T.A., and the Stanford University Medical Center Committee on Ethics. Initiating and Withdrawing Life Support: Principles and Practice in Adult Medicine. *N. Engl. J. Med.* 1988; 318: 25-30.
5. Scheinerman, L.J., Jecker, N.S., Jonsen, A.R. Medical Futility: Its Meaning and Ethical Implications. *Ann. Inter. Med.* 1990; 112(12): 949-954.
6. Brock, D.W., Wartman, S.A. When Competent Patients Make Irrational Choices. *NEJM* 1990; 332(22): 1595-1599.
7. Callahan, D. Medical Futility, Medical Necessity. *The Problem Without a Name.* *Hastings Cent. Rep.* 1991; 21(4): 30-35.
8. Carter, B.S. Sandling, J. Decision-making in the NICU: The Question of Medical Futility. *J. Clin. Ethics* 1992; 3(2): 142-3; discussion 143-145.
9. Truog, R.D., Brett, A.S., Frader, J. The Problem With Futility. *NEJM* 1992; 326(23): 1560-1564.
10. Schwartz, R.L. Autonomy, Futility, and the Limits of Medicine. *Camb. Q. Healthc. Ethics* 1992; 1(2): 159-164.
11. Snyder, J.W., Swartz, M.S. Deciding to Terminate Treatment: A Practical Guide For Physicians. *J. Crit. Care* 1993; 8(3): 177-185.
12. Cotler, M.P., Gregory, D.R. Futility: Is Definition the Problem? Part 1. *Camb. Q. Healthc. Ethics* 1993; 2(2): 219-224, 225-227.
13. Baker, R. The Ethics of Medical Futility. *Crit. Care Clin.* 1993; 9(3): 575-584.
14. Gregory, D.R. Futility: Are Goals the Problem? Part 2. *Camb. Q. Healthc. Ethics* 1994; 3(1): 125-134.
15. Fins, J.J. Futility in Clinical Practice: Report On a Congress of Clinical Societies. *J. Am. Geriat. Soc.* 1994; 42: 861-865.

BIBLIOGRAPHY

Keay, T.J., Ethics Committees and Family Ghost: Case Studies. The Journal of Clinical Ethics 1994; 5(1):19-22.

Stadler, H.A., et al, HEC Consortium Survey: Current Perspectives of Physicians and Nurses. HEC Forum 1994; 6(4) :269-289.

Morrison, R.S., et al, Physician Reluctance to Discuss Advance Directives: An Empiric Investigation of Potential Barriers. Archives of Internal Medicine 1994; 154: 2311-2318.

Annas, G.J., Death by Prescription: The Oregon Initiative. New England Journal of Medicine 1994; 331 (18) : 1240-1243.

Sulmasy, D.P., Long-Term Effects of Ethics Education on the Quality of Care for Patients Who Have Do-Not Resuscitate Orders. Journal of General Internal Medicine 1994; 9: 622-626.

Maun, A.R., et al, The Passage of Florida's Statute on Assisted Reproductive Technology. Obstetrics and Gynecology 1994; 84: 889-893.

MEETING CALENDAR

REGIONAL MEETINGS

- **April 12, 1995:** Reproductive Ethics, Jacksonville, sponsored by the University of Florida.
- **May 9, 1995:** Over My Dead Body: Understanding Your Options After Death, co-sponsored by Lifelink of Florida, University Community Hospital Auditorium, Tampa.
- **September 20-22, 1995:** FBN Annual Meeting: Focus on Futility, Wyndham Harbour Island Hotel, Tampa, FL, contact Hana Osman at 813/251-7043.

NATIONAL MEETINGS

- **June 1-4, 1995:** Suffering, Dying and Death: The Ethics of Finitude, sponsored by the Center for Clinical Bioethics, Georgetown University Medical Center, Washington, D.C., contact Marti Patchell at the Center for Clinical Bioethics at 202/687-8999.
- **June 2-3, 1995:** The Sixteenth Annual Health Law Teachers Conference, co-hosted by the Health Law Institute of DePaul University and the Institute for Health Law at Loyola University School of Law, Chicago, IL

- **June 4-10, 1995:** Intensive Bioethics Course XXI, Kennedy Institute of Ethics at Georgetown University, Washington, D.C., contact 202/687-6771.
- **June 13, 1995:** Ethical Decision-making: Workshop for Clergy and Pastoral Caregivers, Center for Clinical Bioethics, Pastoral Care Department, Georgetown University Medical Center, Washington, D.C., contact 202/687-8999.
- **September 29-30, 1995:** 1995 ASLME Annual Meeting, Boston, MA

INTERNATIONAL MEETINGS

- **July 16-20, 1995:** The Fourth International Conference, Health Law and Ethics in a Global Community, Amsterdam, the Netherlands, sponsored by the American Society of Law, Medicine & Ethics and the University of Amsterdam.

*Information will be updated as it becomes available.

WELCOME NEW MEMBERS!

The Florida Bioethics Network welcomes **Sandra Pickard-Holley**, Oncology Clinical Nurse Specialist, University of South Florida, College of Medicine, Tampa ~ 813/960-3625; **Brenda Stokes**, Regional Administrator, 1st American Home Care, Ft. Myers ~ 813/365-7222; and **Dr. Jane Trau**, VP/Values Integration & Leadership, Allegany Health System, Tampa ~ 813/281-9098.