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

October 1999 **99-4**

President's Message

Kathleen M. Weldon, RN, MN
Assistant Chief, Nursing Service
VA Brevard Outpatient Clinic

In our last newsletter we outlined many of the legislative changes that arose from the "Panel for the Study of End of Life Care". Several FBN members participated on the committee and the End of Life Legislation has now been prepared into a final format for distribution.

An important philosophy for any Ethics committee is EDUCATION, not only to patients and our committees but to others involved in health care decisions.

In keeping with this philosophy, the FBN Board of Directors unanimously decided to perpetuate the learning process by sending each of you a copy of the End of Life Legislation. These legislative changes took effect October 1st and we felt strongly about disseminating the information to our members regardless of cost.

Please share this information with your committees and organizations. You can refer to the August FBN Newsletter, as it included a summary and key points as identified by an FBN member, Attorney Jane Hendricks of Miami. The information contained in the End of Life Legislation is public knowledge and therefore you are free to copy and share with other members of your committee.

Board members are listed in the Newsletter. Should you have any further questions, please contact a member representing your area.

We are very pleased to have had the opportunity to pass this information along to you and maintain your awareness of the legislative changes for this year.

FBN Member Survey results

Submitted by Cathy Emmett, RN, MSN, CS

We were delighted by the response we received to our member survey. Fifty-seven of you (or about 30%) took the time to complete and mail in your forms. We wanted to share the results with you.

We had a good cross section respond, with 10 of you being members for less than one year, 15-members for 1-3 years, 20-members for 4-6 years and 12 being with FBN since at or near it's beginning!

The top two reasons for joining were the opportunity to network with others across the state interested in ethics (50) and the opportunity to learn more about healthcare ethics (49). A close third was wanting information to stay current in the field of ethics (40).

Regarding FBN's affiliation with FHA, the results were more diverse with responses indicating no clear majority opinion.

The Annual educational conference was felt to be the most useful aspect of FBN (26) with information and resource on healthcare ethics (22) and the opportunity to network (20) not far behind. The newsletter was also identified as being useful (17).

continued on page 2

IN THIS ISSUE

FBN BOARD OF DIRECTORS

President
Kathleen M. Weldon, RN, MN, CNA
407-637-3514

President-Elect
Rev. Jerry J. Griffin, BCC
941-335-7148

Secretary
Catherine P. Emmett, RN, MSN, CS
941-929-2205

Treasurer
Joel Mattison, M.D.
813-253-6552

Immediate Past President
Jim Wagner, Ph.D., BCC
352-395-0224

Bioethics Advisor
Ray Moseley, Ph.D.
352-846-1097

Regional Representatives
North
Kathryn A. Koch, M.D.
904-549-4075

South
Marilyn M. Goldaber
305-751-8626 ext. 331

Central
Jim C. Thomas, DMin
941-297-1877

Members-At-Large
Hana Osman, LCSW, DCSW
813-977-0612

Ben Mulvey, Ph.D.
954-262-8214

NETWORK NEWS
The newsletter of the Florida Bioethics Network

Network News welcomes letters, comments and articles for inclusion. Please send any correspondence to Cathy Emmett, Hospice of Southwest Florida, 5955 Rand Blvd., Sarasota, FL 34238, Fax: 941-921-5813.

FBN Member Survey Results

continued from page 1

Many of you contact an FBN Member (22) or Officer (16) when you have questions about bioethics.

There was a strong consensus that we should continue to hold the annual meeting (52), publish the Network News (55) and perhaps sponsor regional meetings (45). Most of you had not visited our web site through FHA's web page (43).

The dues structure was felt to be appropriate by 33 members; however, 14 felt that the dues were too high for the benefits received. Those individuals felt the dues should be in the $30-70 range.

Finally, the majority of you are serving on Bioethics committees (41), the majority of those being in the hospital setting (37). Also represented were Long Term Care (5), Hospice (7) and Community (2). Twenty-one reported that they paid their own dues, while 33 reported that their institutions paid.

Many of you took the time to write comments. All of these have been shared with the board and will be considered in our future planning. Several individuals commented on the importance of networking and the educational conferences. There were also several that advocated for more networking between FBN and other groups. The board very much appreciates your feedback and will work towards incorporating this feedback into our planning for the upcoming year. Thank you again for all that took the time to respond!

Welcome New Members

FBN welcomes the following new members:

Alan Gasner
Chairman, Ethics Committee
Winter Haven Hospital
941-297-1720

Denise Tucker
Associate in Nursing
Florida State University
850-878-7981

Autonomy: A Universal Ethical Principle, Or A Culturally Mediated Artifact?

Hana Osman, LCSW, DCSW

continued from last issue..

The Case of Leah — Culture, Religion, and Gender

This case was selected for ethical analysis because it epitomizes the concepts already presented in this paper. The case depicts the ethical conflict that arises for health care providers, when the patient's religion and culture collide with physicians' western-ethics culture. This case suggests that there is a divergence between patients who belong to subcultures, and the medical/legal system of health care in the United States. Some solutions that reflect cultural sensitivity are proposed.

The response to illness is different depending on factors such as the person's race, ethnic background, class and gender. Lorber asserts that gender is "socially constructed" (Lorber, 1997, p. 5). In other words, "girls and boys are taught their society's expectations of appropriate behavior; they grow up to enact their society's gendered social roles" (Lorber, 1997, p. 5). These factors also influence the response of health care professionals to patients, and influence the manner in which members of different groups are treated (Lorber, 1997, p. 3). The following case portrays these ideas. Leah is an 18-year old Israeli female diagnosed with clear cell carcinoma of the vagina. In Israel, after reporting irregular vaginal bleeding, she was discovered to have a very rare malignancy, and she was referred to the world expert on this form of cancer at the University of Chicago.

After flying to Chicago for evaluation, the University of Chicago oncologists recommended radiation, the placing of radioactive sources in proximity to the tumor, followed by a hysterectomy. This combined treatment was thought to provide the best long-term recovery.

A day later the radiation oncologist began to talk to the father (via a translator who spoke Hebrew — neither father nor daughter spoke English) while the patient participated in a simulation of the radiation therapy, necessary for the treatment. The radiation oncologist explained that the treatment would result in sterility not only of the ovaries, but also in that the uterus will not function. The father requested that the daughter not be told that she would not be able to have children.

He explained that his family were Orthodox Jews, and that his daughter was to have been married in one month. Under Orthodoxy, an infertile woman may not marry a fertile man, and the daughter's treatment would thus make her marriage impossible. The father was concerned that if informed of the impending infertility and spinsterhood, the young woman would refuse treatment.

The father further explained that in Orthodox Judaism fathers make all the decisions for the family, and especially for unmarried daughters. Once a daughter marries in Orthodoxy, decision making power is turned over to the husband. The father insisted that, in Israel, his decisions would be respected by the hospital and doctors.

It is illegal to perform surgery in the United States without obtaining "informed consent." Informed consent around sterilization is particularly sensitive, since hundreds of thousands of poor and minority American women underwent "eugenic" sterilization before World War II, without ever being told that they were being sterilized.

The father, in turn, consulted with Orthodox rabbis in New York and in Israel, and with Leah's mother. The mother and rabbis insisted that the daughter should not be told, in order to minimize her suffering. The physicians asked about the removal of eggs for artificial insemination and potential use by a surrogate, but the rabbis rejected this option. Finally, the rabbis reassured the family that the daughter would, no matter what treatment she underwent, be able to have her own children *through a miracle.*

The social worker/translator attested that whenever asked about her opinion as to treatment, or anything else, the patient said "Ask my father."

The Hospital ethics committee deliberated and the obstetricians decided that Leah needs to be told "everything." After hearing the information related to infertility, Leah stated that she does not wish to have the surgery and left the hospital with her family.

Two days later, Leah returned to the hospital. She said she wanted treatment. She signed a detailed informed-consent form. She did not want to talk to the doctors about why she had changed her mind.

Leah received all the recommended treatments and returned to Israel after two months.

(This summary was adapted from John D. Lantos' article entitled: What should Leah be told? [1993]).

continued on page 4

Autonomy: A Universal Ethical Principal, Or a Culturally Mediated Artifact?

continued from page 3

This case presents several ethical, legal, religious and cultural quandaries.

- How can the health care team proceed with the life-saving surgery while respecting this patient's autonomy? (Ethical)
- How can the legally required informed consent for surgery be obtained? Who is authorized to give this consent, since the family is refusing to include her in the decision making? (Legal)
- How can the health care team adjust to allow this patient to practice her religious and cultural values? (Religious and cultural)
- What should the response be to the reference of the rabbis to *miracles*? (Cultural)

On the surface, this case is uncomplicated and can be easily resolved. As Lantos states, it is a "no-brainer" (1997, p. 107). This can be done by simply informing the family that in the United States we are obligated to obtain informed consent from the competent adult patient. Leah is now in this country and she is eighteen, therefore she is an adult, by our legal definition. The second step would be to obtain the consent from Leah and to proceed with delivering the same standard of care that is delivered to any member of the majority population. Proceeding this way, would be the legal way of dealing with the problem. But is it the ethical way? In this case, the health care team decided to protect the hospital from future litigation (met the legal requirement for obtaining informed consent). But did it meet the ethical responsibility of this health care team?

The physicians have a conflict between two actions:

1. Doing what is legal/ethical, i.e. maximizing Leah's self-determination by fully involving her in the decision making. The physicians are motivated by the principles of autonomy and beneficence (doing the right thing by allowing her to make her own decisions).
2. Doing what is strictly ethical by respecting her expressed wishes: "Ask my father." In this second action, the physicians are still motivated by the principles of autonomy and beneficence, albeit by using a broader interpretation of the principles (doing the right thing by following her directions to defer to her father). Pellegrino asserts that "competent humans are owed the freedom to define beneficence in terms of their own values" (Pellegrino, 1992). Involving Leah in the decision making process by asking her how much she wishes to be involved is showing respect for her autonomy (Macklin, 1998).

Ethical principles:

The ethical concerns in this case arise from the conflict between autonomy, veracity, beneficence and nonmaleficence. All parties involved: parents, rabbis, physicians and the health care team, are motivated by their desire to be beneficent and afford Leah the best available treatment for her rare cancer. They disagree on the amount of information that should be shared with her. The parents and the rabbis insist that Leah should receive all the treatments available to her now and that she ought to be spared the burdens of knowing that she would inevitably become infertile. Although they may be motivated by their desire to do what they think is best for Leah, they are attaining their goal through prevarication and deceit.

The physicians on the other hand are interested in both offering her the most effective treatment available and in upholding her right to autonomy. The physicians are faced with the dilemma of choosing between two options that may cause harm to Leah. They should take into account the harm that they would be inflicting on Leah and her family, which has a different cultural orientation, by imposing their own values and ethical standards. They may also cause Leah harm by violating her right to autonomous decision making. A right that is established in the United States, but is not accepted in Israel. According to Leah's father, typical unmarried young women defer their decision making to their fathers. However, since not all unmarried 18-year old Israeli females choose to defer their decision-making to their fathers, Leah should be asked how much information she wishes to receive, and how she wishes for the consent to be handled. The physicians have a responsibility to find out if Leah is a typical Israeli unmarried young woman (Buckman, p. 206). Violating the principle of veracity compromises the patient/physician fiduciary relationship, therefore the physicians are obligated to gather more information before limiting the information shared with Leah.

The following is the response to the earlier stated quandaries:

> The ethical quandary is resolved by truly respecting the patient's autonomy. Leah has expressly deferred her decision making to her father. Insisting on telling her all the details and the consequences would be violating her right to

continued on page 5

Autonomy: A Universal Ethical Principal, Or a Culturally Mediated Artifact?

continued from page 4

self-determination. As Lorber asserts, "girls and boys are taught their society's expectations of appropriate behavior; they grow up to enact their society's gendered social roles" (Lorber 1997, p. 5). Challenging Leah's decision making process (deferring to her father), would be challenging her social role and her religious commitment, in addition to challenging her medical decision making.

The legally required informed consent could be obtained by ensuring that Leah understands that deferring to her father removes her from the decision-making loop. If she intends for this removal to be her decision, this process needs to be documented in the medical record by the attending physician. The process for obtaining this decision from Leah should be documented and the process of discussing Leah's condition with her parents should be documented. Although the informed consent laws require that consent be obtained directly from the adult competent patient, documenting the above process would provide evidence that every effort was expended to involve Leah to the degree that she wished, and that her right to autonomy was upheld.

Patients "can waive their right to information" (Annas, 1994, p. 224). Leah is allowed to practice her religion and follow her cultural practices by ensuring that deferring her decision making to her father is a conscious decision, and that she is willing to accept the consequences of her father's choices. George Annas affirms this concept by quoting Jay Katz (1987): "..physicians should be guided by the strongest presumption in favor of disclosure and consent which can be modified only by clear and carefully documented evidence that patients do not wish to be fully informed" (Annas, 1994, p. 225).

The rabbis' reference to miracles may have a religious basis that ought not to be challenged by secular health care professionals. Physicians should address this issue by stating that they have a different opinion from the rabbis and make a referral to a local rabbi for further discussion and spiritual comfort.

CONCLUSION

Upholding the ethical principle of autonomy is the ethical and legal medical decision making paradigm in the United States. This standard is based on ancient Greek philosophical theories which have gained popularity especially since the development of the Nuremberg Code of 1949. The Code, and its informed consent doctrine, was developed to protect the rights of research subjects, but rapidly became the standard for medical decision making.

Individual autonomy can be viewed as a universal ethical principle which may be interpreted widely to accommodate culturally diverse groups. The practical application of this philosophical principle lies in obtaining informed consent for medical treatment. In the United States, the informed consent laws are formulated to serve members of the dominant culture. Traditions of members of some culturally diverse groups may not be compatible with the informed consent doctrine.

Family-centered decision making may be viewed as a way to uphold family autonomy. This alternative method of decision making allows patients to defer to their families the onerous task of making health care decisions. Patients need to be informed of this option and given the opportunity to exercise it. Patients would still control the level of information shared with them, hence maximizing their exercise of autonomous decision making. The principle of autonomy is universal, but the approach to implementing it should be flexible to accommodate different cultural groups (Macklin, 1998, p. 13).

Currently, the laws on advance directives and informed consent do not allow for the flexibility required to implement this new decision making paradigm. Informed consent laws allow for a subjective standard of disclosure (tailoring the method and amount of information disclosed to patients according their needs and capabilities to understand). Explicitly extending this subjective standard to deal with limiting the amount of information shared with patients would reflect cultural sensitivity and inclusion of patients' cultural differences.

There is potential for abuse of this subjective standard of disclosure. Physicians may misuse it to justify paternalistic behavior. To avoid this potential abuse, Gostin proposes an ethical review mechanism. This ethical review can be performed by institutional ethics committees and "should include persons with experience and understanding of the patient's culture, customs, and language." Gostin cautions that such deviation from the standard method of decision making should be used sparingly and guided "only by patient-centered values" (Gostin, 1995, p. 845).

The heterogeneity of American society begs for cultural sensitivity and a sincere attempt to accommodate members of culturally diverse groups. An expansion of individual based autonomy to include family-centered autonomy (when the patient expressly requests it) would only serve to maximize the patient's right to self-determination.

continued on page 6

Autonomy: A Universal Ethical Principal, Or a Culturally Mediated Artifact?

REFERENCES

1. Annas, George J., J.D., M.P.H. (1994). Informed Consent, Cancer, and Truth in Prognosis. *The New England Journal of Medicine, 330*, 223-225.

2. Beauchamp, Tom L.; Childress, James F. (1989). *Principles of Biomedical Ethics*. Third Edition. New York: Oxford University Press.

3. Beyene, Y. (1992). Medical disclosure and refugees: telling bad news to Ethiopian patients. *West J Med, 157*, 328-332.

4. Blackhall, Leslie J., M.D., MTS; Murphy, Sheila T., Ph.D; Frank, Gelya, Ph.D; Michel, Vicki, MA, JD; Azen, Stanley, Ph.D. (1995). Ethnicity and Attitudes Toward Patient Autonomy. *Journal of the American Medical Association, 274*, 820-825.

5. Buckman, Robert, M.D.; Kason, Yvonne, M.D. (1992). *How to Break Bad News. A Guide for Health Care Professionals*. Baltimore: The Johns Hopkins University Press.

6. Carrese, Joseph A. M.D., MPH; Rhodes, Lorna A., Ph.D. (1995). Western Bioethics on the Navajo Reservation: Benefit or Harm? *Journal of the American Medical Association, 274*, 826-829.

7. Cross, Alan W., M.D.; Churchill, Larry R., Ph.D. (1982) Ethical and Cultural Dimensions of Informed Consent. *Annals of Internal Medicine, 96,* 110-113.

8. Dalla-Vorgia P.; Katsouyanni, K; Garanis TN, Touloumi, G; Drogari, P; Koutselinis, A. (1992). Attitudes of a Mediterranean population to the truth-telling issue. *Journal of Medical Ethics, 18*, 67-74.

9. Fetters, Michael D. (1998). The Family in Medical Decision Making: Japanese Perspectives. *The Journal of Clinical Ethics*, 132-146.

10. Furrow, Barry R.; Greaney, Thomas L.; Johnson, Sandra H; Jost, Timothy S.; Schwartz, Robert L. (1997). *Bioethics: Health Care Law And Ethics*. Third Edition. St. Paul, Minn.:West Publishing Company.

11. Gostin, Lawrence O., JD. (1995). Informed Consent, Cultural Sensitivity, and Respect for Persons. *Journal of the American Medical Association, 274*, 844-5.

12. Hamadeh, Ghassan N.; Adib, Salim M. (1998). Cancer Truth Disclosure by Lebanese Doctors. *Soc. Sci. Med., 47,*1289-1294.

13. Jonsen, Albert R., Ph.D.; Siegler, Mark, M.D.; Winslade, William J., Ph.D., J.D. (1998). *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. Fourth Edition. New York: McGraw Hill Companies.

14. Katz, Jay. (1987). Physician-patient encounters "On a darkling plain." *W New England Law Review, 9,* 207-26.

15. Lantos, John D. (1993). The Case: What Should Leah Be Told? *Second Opinion, 18,* 81-86.

16. Lantos, John D. (1997). *Do We Still Need Doctors?* New York. Routledge.

17. Lorber, Judith (1997). *Gender and the Social Construction of Illness*. Thousand Oaks: Sage Publications, Inc.

18. Macklin, Ruth (1998). Ethical Relativism in a Multicultural Society. *Kennedy Institute of Ethics Journal, 8,* 1-22.

19. Muller, JH; Desmond, B. (1992). Ethical dilemmas in a cross-cultural context: a Chinese example. *West Journal of Medicine, 157,*323-327.

20. Murphy, Sheila T; Palmer, Joycelynne M.; Azen, Stanley; Frank, Gelya; Michel, Vicki; Blackhall, Leslie J. (1996). Ethnicity and Advance Care Directives. *The Journal of Law, Medicine & Ethics, 24,* 108-117.

21. Osman, Hana (1991). Advance Directives: Development, Opposition, and Criticism. *Discharge Planning Update, 11*, 1, 12-15.

22. Patient Self-Determination Act of 1990, P.L. 101-508, 104 Stat.1388.

23. Pellegrino, Edmund D., M.D. (1992). Is Truth Telling to the Patient a Cultural Artifact? *Journal of the American Medical Association, 268*, 1734-5.

24. Perez-Stable, E.J; Sabogal, F; Otero-Sabogal, R; Hiatt, RA; McPhee, SJ. (1992). Misconceptions about cancer among Latinos and Anglos. *Journal of the American Medical Association, 268,* 3219-3223.

25. Perlin, Terry M. (1992). Clinical Medical Ethics: Cases in Practice. Boston: Little, Brown and Company.

26. Sulmasy, Daniel P.; Terry, Peter B.; Weisman, Carol S.; Miller, Deborah; Stallings, Rebecca; Vettese, Margaret; Haller, Karen B. (1998). The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses. *Annals of Internal Medicine, 128,* 621-629.

27. Surbone, Antonella, M.D. (1992). Truth Telling to the Patient. *Journal of the American Medical Association, 268*, 1661-2.

28. Thomsen, O; Wulff, H; Martin, A; Singer, P. (1993). What Do Gastroenterologists in Europe Tell Cancer Patients? *Lancet, 341*, 473-476.

29. Veatch, R.M. (1981). The Principle of Autonomy, in *A Theory of Medical* Ethics. New York: Basic Books.