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Mid-Atlantic Ethics Committee Newsletter

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia Published by the Law & Health Care Program, University of Maryland School of Law and the Maryland Health Care Ethics Committee Network

Spring 2002

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AUTONOMY QUESTIONED IN END-OF-LIFE DECISIONMAKING

Years ago, it was customary for physicians to make decisions for ill patients—medical paternalism was considered the vehicle for delivering compassionate, competent care. Then came the post-1960's move toward more open communication, the civil rights movement, the patients' rights movement, the Belmont Report and attention to scientific misconduct, and the popularization of bioethical principles like autonomy. Medical paternalism subsequently became highly suspect and scorned. These days, physicians in the U.S. strive to protect patient autonomy by informing (or at least attempting to inform) patients about treatment options and allowing patients to make decisions about what happens to their bodies.

Yet, some are questioning whether the pendulum has swung too far in this direction. The principle of autonomy is often housed under the broader principle of respect for persons. The latter obligates us not only to protect an individual's self-determination, but also to protect mentally incompetent or decisionally incapacitated individuals

The Mid-Atlantic Ethics Committee Newsletter is a publication of the University of Maryland School of Law's Law & Health Care Program and is distributed in cooperation with the Maryland Health Care Ethics Committee Network. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, "Network News," a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

Diane E. Hoffmann, M.S., J.D. Editor

from harm. Recent evidence suggests that the anti-paternalistic, pro-autonomy culture of U.S. health care favors protecting individual self-determination at the expense of exposing vulnerable individuals to harm. Cassell, Leon, and Kaufman (2001) found signs of cognitive impairment affecting judgment in sicker, hospitalized patients who were otherwise competent adults. Their findings suggest that sick individuals may be as

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The information in this newsletter is not intended to provide legal advice or opinion and should not be acted upon without consulting an attorney.

NETWORK NEWS

Maryland Health Care **Ethics Committee Network (MHECN)**

On January 31st members of MHECN met to approve revisions of the Network's by-laws. The main changes included allowing for mail-in ballots in future elections or referendums and for enlargement of the Board of Advisors from 7 to 11 members. These two provisions will facilitate our ability to hold elections and allow us to have a more diversified board.

Our Journal Club 2002 got underway on April 23rd at Mt. Washington Pediatric Hospital in Baltimore, The movie WIT with Emma Thompson was shown and a lively discussion took place after the movie. Next dates for the Journal Club are June 3rd at Franklin Square Hospital, Baltimore and July 16th at Washington County Hospital, Hagerstown. At the June 3rd Journal Club, we will discuss the article, "Keeping Moral Space Open: New Images of Ethics Consulting" by Margaret Urban Walker, Hastings Center Report, March-April 1993, pp. 33-40.

October 28th 2002 is the date set for our daylong conference, "Spirituality, Healthcare, and the Role of Ethics Committees." The conference is made possible with a grant from the Foundation for Spirituality and Medicine and co-sponsorship from Franklin Square Hospital. Courtney Campbell, a wellknown speaker on philosophy and religion from Oregon State University, will be the keynote speaker. Look for brochures to be arriving by mail in August.

> J. Anne O'Neil, PhD., RN **Executive Director** aoneil@law.umaryland.edu (410) 706-4457

Metropolitan Washington Bioethics Network (MWBN)

The Metropolitan Washington Bioethics Network collaborated on two programs this spring. The Spring Bioethics Colloquium of the Center for Clinical Bioethics of Georgetown University Medical Center was held on March 20. It was entitled "Biblical Traditions of Justice and Healthcare." James Walsh, S.J., Associate Professor of Theology at Georgetown, was the featured speaker, with Drew Christiansen, S.J., a Senior Fellow at Woodstock Theological Center, serving as a respondent. The second program was the annual Sanford L. Leikin Lecture at Children's National Medical Center, which was held on Wednesday, April 10. Jonathan Moreno, Ph.D., spoke on "Human Experiments and National Security." On March 21, a training session was held for individuals interested in becoming a volunteer speaker on advance care planning and advance directives for the D.C. Bar-D.C. Partnership to Improve End-of-Life Care, Naomi Karp, from the American Bar Association Commission on Legal Problems of the Elderly, with a grant from the Fan Fox and Leslie R. Samuels Foundation, is studying and developing recommendations on health care decision-making on behalf of socially isolated, "unbefriended" elderly who lack capacity to make their own decisions. The Network is planning a program for early June (date not yet confirmed) on this topic.

> Joan Lewis, Coordinator Jlewis@dcha.org

Richmond Bioethics Consortium (RBC)

RBC is in the process of developing and launching a website for immediate

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Autonomy Questioned in End-of-Life Decision-Making

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incapable of making important healthcare decisions as pre-adolescent

children. In another study, Christine Puchalski and colleagues (2000) found that 71% of older inpatients and 78% of seriously ill adult inpatients would prefer to have their family and physician make resuscitation decisions for them. Consistent with these findings is evidence discovered by Marie

Nolan (2001), a nurse researcher at Johns Hopkins University. Dr. Nolan and colleagues have been interviewing individuals at different time points who have four different types of terminal diseases with different trajectories to death, ranging from an average of 6 to 9 months (metastatic lung cancer) to 2 to 4 years (amyotropic lateral sclerosis or "Lou Gherig's disease"). These researchers have found that as patients experience increased dependence due to disease progression and symptom exacerbation, they tend to prefer physicians, who have consulted them about their preferences, make decisions for them. If their symptoms abate and they regain independence, they tend to prefer taking a more active role in medical decision-making.

The implications of these findings suggest that the principle of autonomy in medical (particularly end-of-life) decision-making may need to be

reconfigured—very sick individuals may actually prefer having others (e.g., their physician and/or family members) make treatment decisions for them. They may then expect to regain control in decision-making if their physical

> condition improves. How health care providers might incorporate these new findings into their procedures for informed consent for medical treatments and end-oflife decisionmaking has vet to be determined.



Ethics & Research Consultant



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- Puchalski CM, Zhong Z, Jacobs MM, Fox E, Lynn J, Harrold J, Galanos A, Phillips RS, Califf R, Teno JM., "Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project." J Am Geriatr Soc 2000 May; 48(5 Suppl): S84-90.
- Nolan, M. (October 4, 2001), Panelist on session about allocation ethics at "The Ethics of Health Care: An Assessment in Germany and the United States." The Catholic University of America, Washington, D.C.

THE ETHICS **NETWORK OF THE DELAWARE VALLEY REGION** (ENDEVAR)

Overview

The Ethics Network of the Delaware Valley Region (ENDeVaR), an outgrowth of the former Delaware Valley Ethics Committee Network, was established in July 2000 with the following major objectives:

- Foster collaboration among Delaware Valley healthcare facilities
- Promote discussions that relate to biomedical ethics
- Provide educational forums addressing clinically based ethical issues
- Present a collective voice in regional public policy and legislative initiatives
- Establish a web site for resource information, bulletin board, monthly case discussion, network newsletter
- Explore possibilities for clinically based ethics research

The rapidly expanding membership includes representatives from over 50 area health care facilities and individual professionals with a special interest in clinical bioethics. ENDeVaR is committed to enhancing the communication and collaboration among ethics committees and individuals working in the ethics field in the Delaware Valley region. While the earliest focus was on clinical ethics and end-of-life care issues, as our membership base grows, we are expanding our scope to include long-term care issues, research ethics, organizational ethics, pediatric ethics, spirituality and health, and mental health. The diversity of health care institutions and disciplines in the region lend themselves to a vibrant, and everchanging, ethics network. And, as the

ENDEVAR

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nation grapples with biomedical ethics issues, ENDeVaR is poised to contribute a collective voice and vision to the debate.

Mission

ENDeVaR is committed to providing a central forum for discussion among and between regional ethics committee members and others working or interested in the bioethics field. It seeks to foster communication, education, collaboration and networking opportunities, and policy development and research.

History

A longtime interest by former members of the Delaware Valley Ethics Committee Network (DVECN) led to the discussion and establishment of ENDeVaR. Following the demise of DVECN in 1991 there had been neither a catalyst nor financial support to explore that possibility. Through the efforts of Sally Nunn, Clinical Outreach Coordinator and Art Caplan, Director at the University of Pennsylvania Center for Bioethics, start up funding was obtained from donations from the Clinical Nutrition Foundation and the Independence Foundation. This funding has allowed for time limited support for mailing, phone and fax expenses, meeting refreshments. establishment of a web site, coordinator compensation, educational forums and other network related costs.

Contact Information

Please visit our new website at http://www.uphs.upenn.edu/bioethics/
endevar/. It is also accessible through the home page for the University of Pennsylvania's Center for Bioethics (http://www.uphs.upenn.edu/bioethics/center/).

or: Ethics Network of the Delaware Valley Region Sally Nunn & Amy Campbell c/o Center for Bioethics University of Pennsylvania 3401 Market Street Suite 320 Philadelphia, PA 19104-3308

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Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. 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: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 515 W. Lombard St., Baltimore, MD 21201-1786.

Case Study from a D.C. Hospital

A 79 year old Jamaican-American man, Mr. R., was admitted to a D.C. hospital after being accosted on a street near his apartment, where he lived by himself. He had no identifiable next-of-kin, but a friend was identified. Mr. R. was admitted for treatment of trauma from the assault. Upon admission to the hospital he was also noted to be acutely psychotic, manifested by paranoid behavior. He refused to eat, afraid that others would poison his food. His friend told the staff that he

noticed behavior changes in the patient over the past several months, and a weight loss of about 60 pounds. A psychiatrist who was consulted was unable to adequately evaluate Mr. R. because Mr. R. would not cooperate with the mental exam. Thus, no antipsychotic medications have been prescribed. The attending physician decided it was necessary to place a PEG tube to administer tube feedings to Mr. R.

Meanwhile, Mrs. G., a Jamaican-American nurse, has been able to get Mr. R. to eat by bringing Jamaican food for him and spending time with him. Mrs. G. feels sure that Mr. R. does not want a feeding tube, and that this would worsen his paranoia, making it likely that he might pull out the tube. This might lead to him being restrained (physically or chemically) to keep him from pulling out the tube. which Mrs. G. thinks would do more harm than good for Mr. R. Mrs. G. is concerned that Mr. R.'s right to refuse an invasive medical intervention is not being respected, nor is his best interest being served in placing a PEG tube. She makes her concerns known to the person who petitions the Court on behalf of Mr.R., who then requests that a bioethics visitor be appointed by the Court to address the situation.

See page 9 for more information on D.C.'s Bioethics Visitor program.

Response From a Psychiatrist

Psychiatric evaluation and treatment can occur only with consent or by court mandate. In this particular case, psychiatric services were refused by the patient, never mandated and, therefore, not delivered. Thus, the commentary offered here is limited by viewing the case through non-psychiatric eyes.

Several points in this case are clear. First, Mr. R. had recent changes in his health status, thinking and behavior that were potentially life threatening.

Second, he came to medical attention because of the acute effects of trauma (severe enough to require hospitalization). Third, he refused psychiatric examination and (at least some) medical intervention. Finally, Mr. R.'s behavior and underlying mental state varied according to the persons and circumstances he encountered (e.g. eating for the Jamaican-American nurse).

Less clear are issues regarding Mr. R.'s past history and current circumstances. Has he had previous psychiatric diagnoses or treatments? What was the nature of the bond between Mr. R. and his friend (who appeared to know about his recent history but did not seem involved in efforts to obtain Mr. R.'s cooperation)? Similarly, how extensive was the involvement of his Jamaican-American nurse (who had opinions about what Mr. R. would want but did not appear to have actually asked him)?

One question raised by this scenario is whether refusal to consent to an examination can legitimately be used in the formulation of a psychiatric opinion. D.C. law requires that when two physicians determine a person to be incapable of making a healthcare decision, one must be a psychiatrist. Inferences from Mr. R.'s history (presumably made available to the consultant before he/she attempted an examination), appearance and behavior (including the manner in which he refused), and the life-threatening nature of his condition could legitimately be synthesized into an argument that he suffers from a paranoid condition that impairs his judgment. However, this is not the same as saying that Mr. R. lacked capacity to consent to a specific medical procedure (in other words, a diagnostic classification by itself carries no implication about capacity). Only an actual examination can determine this.

What about involuntary commitment to a psychiatric facility for further evaluation (and possible treatment) of Mr. R.'s condition? As before, two physicians would have had to perform an examination of Mr. R. If Mr. R. had then refused, would the physicians

have been able to meet the minimal criteria needed to compel hospitalization? Here an attempt to examine Mr. R. (with appropriate documentation of relevant history, behavior and the potential consequences of failing to hospitalize) would likely have sufficed. In most jurisdictions, physicians who sign commitment papers are understood to be working with persons who may be less than fully cooperative. From the physician's point of view, a patient with (1) a life-threatening condition and (2) a possible contributing psychiatric condition is enough to justify further evaluation in spite of the patient's (or anyone else's) protestations.

This case highlights the dilemma physicians face in attempting to distinguish between what is "medical" and "psychiatric." For example, the signs and symptoms of psychiatric conditions (such as paranoid disorders) can have medical causes. In Mr. R.'s case, his weight loss and paranoia may have been caused by conditions as varied as pancreatic cancer, dementia and alcohol abuse/dependence. If medical causes are suspected (as they should be in all cases where the patient is unfamiliar to his/her medical providers), further work-up is obligatory. In addition, the trauma that led to Mr. R.'s hospitalization may have resulted in a brain injury affecting his capacity to consent.

A second example of difficulties encountered at the "medical"/"psychiatric" interface is the issue of psychotropic (or any psychiatric medication) administration. Presumably, the medical staff assigned to Mr. R.'s case could have offered him a trial of antipsychotic medication. Had he accepted such an offer, Mr. R. might then have become more amenable to eating non-Jamaican food and/or cooperating with a psychiatric examination. As a footnote, it is a mistake to think of psychiatric medication as interfering with judgment and the capacity to consent. Usually, such treatment improves these abilities in appropriately diagnosed patients. A related point is that many non-psychiatric medications can present with psychiatric "complications" (such as psychosis or cognitive impairment) that may result in impaired judgment.

Mr. R.'s cultural heritage certainly adds a level of complexity to this case. However, cultural differences in medicine should not pose an obstacle to appropriate care if they are properly understood. It is well documented that a patient's culturally based assumptions will affect his/her understanding of treatment options. A greater effort to understand and work within Mr. R.'s world-view might have led to a better understanding of his concerns and, possibly, a better outcome. Using culturally specific treatments (such as folk remedies) may be especially appropriate in "treatment-resistant" patients provided the treatments do not interfere with conventional modalities or cause harm to the patient.

In sum, this was a complex case whose problematic outcome might have been avoided with the timely involvement of an ethics consult,

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Chief of Psychiatry
Upper Chesapeake Health

Response From a Health Care Attorney

Discerning what treatment options Mr. R's health care providers are ethically justified in implementing requires consideration of what the law allows. Mr. R's position presents essentially two legal questions – who will make the decision consenting to or refusing the proposed feeding tube (and other future treatment options) and, if not Mr. R, by what standard will his substitute decision-maker be bound?

The fact pattern does not state whether the first candidate for decision-maker—Mr. R.—was ever

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Response From a Health Care Attorney

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consulted. He is apparently capable of choosing to eat in some circumstances and not in others. The only suggested medical reason he would not be qualified to make other decisions is an as yet undiagnosed mental illness, characterized by paranoia. Given that, one reasonable alternative would be to seek his commitment, presumably involuntary, based on his unwillingness to cooperate with the psychiatrist's mental examination, and on certification that continuing refusals to eat would likely injure him.¹

A commitment proceeding would bring Mr. R., within days, before members of the D.C. Commission on Mental Health who would hold an informal hearing to review the evidence regarding his mental illness and dangerousness.2 Counsel would be appointed to represent Mr. R, even if he objected, and that counsel would be able to cross-examine any witnesses presented against him.3 The Commission members would then either release Mr. R. or present findings and a recommendation to the Superior Court regarding further hospitalization or alternative treatment. If continued hospitalization was recommended, Mr. R. would then be entitled to a jury trial,4 and if ultimately committed, to an independent examination of his current mental status at least once every six months by two physicians.⁵ Throughout these proceedings Mr. R. would retain a right to treatment by the least restrictive means possible.6

Commitment alone would not decide the question of Mr. R's feeding tube, however, unless it led to successful treatment of his mental illness and increased voluntary eating. Those who are civilly committed retain the presumption, well established in D.C. law, of capacity to make their own decisions in healthcare as well as other matters.⁷ Non-emergency administration of psychotropic medications may require review by the Court and application of the subjective, "substi-

tuted judgment" doctrine taking into account Mr. R's previously stated views and actions.8

Compare then the path of Mr. R if the institution where he is being treated chooses to pursue the situation not as one of mental illness but simply incapacity to make healthcare decisions, requiring at least the temporary appointment of a guardian. In that case, a petition will be filed seeking a determination from the Superior Court that Mr. R. is an "incapacitated individual." That is, the court must find, by clear and convincing evidence, that Mr. R's ability to receive and evaluate information, or to communicate decisions, is impaired to such an extent that he cannot "meet all or some essential requirements for his ...physical health, safety, habilitation or therapeutic needs" without assistance.9 The petition will be supported by his medical records, including, certifications from a psychiatrist and one other physician that Mr. R. cannot:

"appreciate the nature and implications of a health-care decision, make a choice regarding the alternative presented or communicate that choice in an unambiguous manner."¹⁰

In addition to the ultimate conclusion, the certifying physicians are also expected to opine regarding the cause and nature of the mental incapacity as well as its extent and probable duration. Unfortunately in these proceedings a certificate carefully crafted to conform to each of these information requirements is more the exception than the rule as busy clinicians have limited tolerance for legal niceties.

Counsel will be appointed on Mr. R's behalf, 12 and the court may also appoint an "examiner" (usually a gerontologist or psychiatrist) and/or a "visitor" who may provide the court with further information about Mr. R, his circumstances, and possible guardians. 13 A guardian ad litem may also be appointed to "assist" Mr. R. 14 If a "life threatening emergency" is alleged, the Court may appoint a temporary guardian for up to 15 days

based solely on the contents of the petition. 15 Eventually a hearing on the issue of incapacity will be held at which Mr. R may be present unless "good cause" is shown for his absence.¹⁶ His counsel will be entitled to present evidence and cross-examine witnesses, including the examiner and/ or visitor. Ultimately, however, the determination of incapacity will be made by the judge alone, not a jury, subject only to the deferential review given to factual findings by the appellate court. There is no statutory provision for periodic review of a patient's continued incapacity, although the patient or anyone on his behalf can petition the court for limitation or termination of the guardianship at any time. 17 By statute the court is to use its authority so as "to encourage the development of maximum self-reliance and independence of the incapacitated individual,"18 but there is no requirement that the least restrictive means to that end be chosen.

It is not clear that a case for incapacity sufficient to require guardianship over Mr. R's medical decisionmaking can be made out in this case. Mere refusal of life-sustaining treatment alone is not grounds for guardianship. 19 The right of adult patients to make decisions rejecting medical treatment has been upheld even when that decision would have the consequence of eliminating the chance at life of another, such as an unborn fetus.²⁰ In the case of Mr. R., however, the challenge for counsel representing his interests will be to establish that his periodic refusals to eat are sufficiently deliberate and knowing to overcome the presumption of "the known instinct for survival" often brought forward to justify compulsory medical treatment.²¹ Where a patient's actions are not based on adherence to a specific religious doctrine or where there is limited information about the basis for them, courts generally tend to apply a presumption that most individuals wish to survive. Mr. R's apparent absence of family will make his "friend" an important witness, particularly if he

can speak to other choices by Mr. R. consistent with his current behavior.

Notably, if a guardian is appointed. her authority to withhold, but not to consent to, non-emergency, lifesaving medical procedures such as a feeding tube will be limited to cases in which Mr. R's wishes in favor of withholding are known and the authority is explicitly granted by the Court.22 The "known instinct for survival" presumption has, essentially, been incorporated into the guardianship statute to protect those like Mr. R who didn't act ahead of time to empower someone else, for example though a durable power of attorney for healthcare, to make decisions for them in the event of their own incapacity.

> Marty Knutson, JD Chief Compliance Officer Upper Chesapeake Health

2 Id. §21-542 3 §21-543 4 \$21-245 5 §§21-546 & 548 6 In re Richardson, 481 A.2d 473, 479 D.C. 7 In re Boyd, 403 A.2d 744, 747, n.5, D.C 1979; See also D.C. Code Ann. 21-2203. 8 Id. See also In re Bryant, 542 A.2d 1216, 1218-1220 (D.C. 1988). 9 D.C. Code Ann. § 21-2011 10 \$21-2202(5) 11 § 21-2204 12 §21-2041 13 §§21-2033 and 21-2041 14 21-2033

19 In re Osborne, 294 A.2d 372 (DC 1972)

20 In re AC, 573 A.2d 1235, 1244 (D.C.

21 See Osborne at 374-375; AC at 1251

1 D.C. Code Ann. §21-501

15 §21-2046

16 \$21-2041

17 §21-2049

18 §21-2044

22 §21-2047 (c)(3)

FORENSIC PSYCHIATRY: THE ETHICS OF MENTALLY IMPAIRED PATIENT **TERMINATION IN CAPTIVE SITUATIONS**

Comment on the Fall 2001 case study

The fall 2001 newsletter case study, and the thoughtful responses, illustrates on an individual basis the Department of Justice statistic that 16 percent of those incarcerated suffer from a major mental illness. Unfortunately the stigma of major mental illness, which has always curtailed access to adequate mental health care. has now been compounded by the growing impact of managed health care on further marginalizing mental health care via resource restriction such as "behavioral carve outs" and gate keeping. This has led to denial of inpatient mental health care and premature discharge of patients needing inpatient hospitalization and all too often the shifting of long term care from inpatient hospital wards to the streets and then to prisons and jails.

The state has a special responsibility to provide adequate health care for mentally impaired captive patients. Longview Mental Health Center is responsible to plan for patients to be discharged to an appropriate level of care facility. If an error is made, and a patient is discharged inappropriately to a lower level of care than is generally accepted medical practice, the Longview staff has an ethical and professional obligation to take such

steps as are necessary to secure an appropriate level of care post discharge. A failure to do so would constitute an element of failure to appropriately discharge and terminate a patient.

A failure to appropriately discharge is tantamount to patient abandonment. Every relevant medical and mental health professional code of ethics has provisions indicating the importance of appropriate patient termination and avoiding patient abandonment.1 Such codes are especially stringent as to the duties of health care professionals towards individuals who are mentally impaired and captive. Thus the threshold for initiating an inquiry by Longview to the detention center ought to be rather low.

It is a reasonable inference, then, that the next step to avoid patient abandonment needs to be an inquiry from Longview to the detention center for additional information to assess whether its patient is receiving, or can receive, appropriate care at the detention center. This inquiry must be rapidly initiated. If the patient has a guardian, the guardian should also be informed by Longview of any valid concerns. To be valid however, such concerns must be more than simply differences of opinion or judgment among health professionals but indicative of departures from generally accepted levels and standards for mental health aftercare.

H. J. Brodsky Bursztajn, MD Associate Clinical Professor of Psychiatry and Co-Director, Program in Psychiatry, Harvard Medical School

^{1.} Bursztajn HJ. Brodsky, A Managed-Health-Care Primer: Complications, Liability Risks, and Clinical Remedies. Primary Psychiatry, (3/2002) in print.

MARYLAND LEGALUPDATES: ADVANCE DIRECTIVES

New Legislation

For a quarter-century, advance directives have been viewed as a potentially effective means for individuals to plan for future health care. In theory, an advance directive, like its elder cousin informed consent, is a concrete means of giving practical effect to the principle of autonomy. Yet, advance directives remain controversial. They sometimes do not correlate well with messy clinical reality, may have little effect on the actual delivery of care, and occasionally conflict with family preferences.

Nevertheless, the Maryland General Assembly continues to support the concept of advance directives and, in recent legislation, extended it from its origins in end-of-life care to mental health care. In a new section of the Health Care Decisions Act, Health-General Article § 5-602.1, the General Assembly authorized "an individual who is competent [to] make an advance directive to outline the mental health services which may be provided to the individual." The new statute goes on to authorize the designation of a mental health care agent and a statement of preferences about providers and medications. The statute also amends the Mental Hygiene Law (Health-General § 10-809(b)(1)(iii) and (2)) to require residential facilities, as part of their aftercare planning process, to notify patients "of the advisability of making an advance directive for mental health services" and to provide requested assistance. Carrying out a statutory duty, the Department of Health and Mental Hygiene is in the process of developing a sample form.

This legislation reflects a judgment that advance directives, used as a means of promoting effective mental health care for those in the community, represent a preferable alternative to more intrusive measures. The legislation was the outgrowth of a study process primarily charged with evaluating the pros and cons of outpatient civil commitment. The study group concluded that state policy

should instead favor advance directives, which by their nature promote the patient's active engagement in planning and are thought to result in greater patient compliance with treatment regimens.

Enforcement in the Nursing Home Setting

Of course, whether the subject of an advance directive is mental health care or end-of-life treatment, planning is mocked if health care providers do not honor the individual's decisions. From the SUPPORT study on, the field has debated how best to promote provider compliance with advance directives. Many advocate a combination of education and quality improvement initiatives. Others believe that only the sharp spur of liability will lead institutions to take advance directives seriously.

When an individual both writes health care instructions in an advance directive and appoints a health care agent, the health care agent is ethically and legally bound to make health care decisions based on the individual's known wishes, and thus should follow the terms of the individual's written directive. In Maryland, the Office of Health Care Quality (OHCQ) has recently taken strong enforcement action against a nursing home for providing treatment contrary to instructions in a written advance directive. The resident had explicitly rejected tube feeding in the instructional portion of her advance directive. Despite this directive, a feeding tube was inserted during a period of hospitalization, apparently at the behest of the resident's son, who was her health care agent. When the resident returned to the nursing home, the facility recognized that the hospital's insertion of the tube was contrary to the advance directive. Doing what it could to honor the resident's wishes, the nursing home initially used the tube for medication delivery but did not

infuse feedings. However, in the face of a threatened suit by the son, the nursing home changed course and began the feedings. OHCQ issued a deficiency for what it deemed a significant violation of the resident's rights and levied a \$10,000 civil penalty. After a hearing on the facility's challenge to OHCQ's action, both the deficiency and the monetary penalty were upheld by an Administrative Law Judge. Should the facility decide to pursue its challenge, the propriety of OHCQ's action ultimately will be decided by a court.

Jack Schwartz, JD, Director Health Policy Development Maryland Office of the Attorney General

VIRGINIA ETHICS BOWL

The third annual Virginia Foundation for Independent Colleges Ethics Bowl took place at Randolph-Macon College in Ashland, VA on February 18, 2002. Teams of undergraduate students from 15 independent colleges in Virginia participated. At an Ethics Bowl, competing student teams receive a set of ethical dilemmas to study in advance. At the bowl, a moderator selects one of the scenarios. Each team of 3-5 students is allowed to discuss the issues for a few minutes, and then one team member presents the opinion of the group. A panel of judges evaluates the responses for their depth, intelligibility, and judgment. The judging teams consist of business, publishing, legal and academic leaders from Virginia.

Last year's ethics bowl centered on issues related to ethics and technology. This year, in light of the events of September 11, the planned topic of Business Ethics was postponed and replaced by issues such as whether academic freedom and civil liberties can be compromised in wartime, whether journalists have a duty to debrief government officials about information obtained through clandestine interviews with terrorist groups,

and to what length, if any, ethnic profiling should be tolerated in post-9/ 11 America. The debates were spirited. principled and provocative. The student teams from Washington and Lee University and Marymount University tied as co-winners.

The Virginia Foundation for Independent Colleges (VFIC), founded in 1952, is a nonprofit, fundraising and programmatic partnership of colleges and supporting corporations. The Ethics Bowl was made possible by a generous gift from VFIC Honorary Life Trustee Jane Parke Batten and her husband Frank Batten, former Chairman of Landmark Communications in Norfolk. Roger Mudd and Phillip A. Stone, President of Bridgewater College, co-chaired a task force that conceptualized the program. "The Ethics Bowl was created as an outlet for students and faculty to vigorously debate the role of ethics and morality in this non-judgmental era where it is easy to forget there is still right and wrong," said Mudd. "The study and discussion of applied ethics is of utmost importance for students in that it allows them to further develop their system of values on how one responsibly manages the everyday dilemmas and decisions of life."1

About a dozen such bowls are held around the country each year. In addition to regional competitions, the national Intercollegiate Ethics Bowl takes place every year in Cincinnati, The concept for the bowls began in 1993 with Robert Ladenson, a philosophy professor at IIT, which now sponsors the national bowl. "The idea was to develop a capacity for ethical understanding in a world where ethical questions have become more complex, difficult, and ambiguous," he says.2

Laurie Lyckholm, MD Asst. Professor of Internal Medicine and Professor of Bioethics and Humanities, Virginia Commonwealth School of Medicine

THE BIOETHICS VISITOR

About six years ago, a group of individuals in Washington, D.C. recognized a problem related to courtappointed guardians, and crafted a unique solution. A petition to appoint a guardian is made, usually by a hospital or nursing home, on behalf of a mentally incompetent individual who has no functional legal surrogate.

Two problems often encountered were (1) that guardians often had little or no education in ethical decisionmaking, particularly in end-of-life situations; and (2) judges who were instructing the guardians had no background in medical issues and struggled with decisions about end-oflife care.

Andrea Sloan, a D.C. lawyer and nurse who is often involved in petitioning the court for guardianship cases, demonstrated that previous guardianship decisions would have been better informed if the evaluation and insights of a bioethicist were made available to the court. Ms. Sloan, together with Joan Lewis, Coordinator of the Metropolitan Washington Bioethics Network, John J. Lynch, M.D., and Vera Mayer, Esq., Coordinator of the D.C. Long Term Care Coalition, were forerunners of what developed into a D.C. statute that allows the court to appoint a bioethics visitor for guardianship cases. Currently, the Washington Area Bioethics Network recognizes a core group of 25+ volunteers with bioethics expertise who serve as Bioethics Visitors (BV) for the court. When requested, the Court calls on Ms. Sloan, Dr. Lynch or Ms. Mayer to convene a BV panel (the members of which may not visit an individual in an institution where they are affiliated). A member of the panel visits the individual wherever the individual currently resides (e.g., hospital, nursing home, etc.). Other panel members gather information much like in an institutional ethics consult - the panel members speak with the individual (if possible), any available family members or friends, the treating physician and other health care staff, and the

potential guardian (if identified).

A report is then supplied to the court summarizing the evaluation, highlighting ethical issues that should be addressed in light of the individual's diagnosis and prognosis, evidence of advance directives, relevant social, psychological, and spiritual issues, available/recommended medical or surgical treatments, presence of lifethreatening illness or injury, and evidence of any bioethical issues that should be addressed. The report also includes a recommendation, such as directing the guardian to establish a relationship with the treating physician and other key players in order to make decisions that either reflect what the individual would have wanted or promote the individual's best interest.

Dr. Lynch believes that the Bioethics Visitor program is far superior to situations in the past when guardians and judges, with little or no knowledge of medical issues or of bioethics, proceeded to make health care recommendations without understanding the clinical and ethical pros and cons of the different treatment options particularly in end-of-life scenarios. The judges appreciate the bioethics advice because they are making their decisions based on a solid foundation. Some guardians themselves initiate a request for a Bioethics Visitor-one likely measure of the program's success.

¹ Virginia Foundation for Independent Colleges press release, available at www.vfic.org/ programs/ethics/content8c.htm. 2 Sara Steindorf, "Is it ethical to run that light?" From the February 12, 2002 edition of The Christian Science Monitor, http:// www.csmonitor.com/2002/0212/p12s01-legn.html.

Network News

Cont. from page 2

access to RBC information and activities. In recognition of its 10 year anniversary, RBC will soon be launching its new logo and publicity materials. Several RBC members have been active in the newly formed Virginia Palliative Care Partnership, an organization committed to improving the quality and accessibility of palliative care in Virginia. RBC has planned a series of workshops for new or interested ethics committee members. The first, which covered content from chapters 1-7 of Fletcher, Lombardo, Marshall, & Miller's Introduction to Clinical Ethics (1977, 2nd ed.) was held on April 19. Two other workshops are scheduled for May 3 and 17

(see Calendar). These workshops are free to individual members and participants from member institutions, and \$50 for non-members. RBC's spring program on May 23 at 7PM features a presentation entitled "Compassion Fatigue... What Is It? Ethical implications for caregivers and organizations" (for more information, see this newsletter's Calendar). Within the next year, an "Advanced Ethics Workshop" is planned for experienced ethics committee members.

Monika Markowitz, President, mmarkowi@hsc.vcu.edu

Errata

Robin Templeton, who responded to the Fall-Winter 2001 case study, was mistakenly referred to as a forensic psychiatrist. Ms. Templeton is a social worker, and her correct title is "Forensic Coordinator" of Crownsville Hospital. Our apologies for this error.

The author of the Fall-Winter 2001 case comment from a "Bioethicist/Nurse" is Anita J. Tarzian.

CALENDAR OF EVENTS

May

- 2002 Shallenberger Lecture, 12:00 noon, sponsored by Johns Hopkins Hospital Ethics Committee. Speaker: Dr. Ashby Sharpe, Former Deputy Director and Associate for Biomedical and Environmental Ethics at the Hastings Center and co-author, *Medical Harm: Historical, Conceptual and Ethical Dimensions of Introgenic Illness.* Hurd Hall.
- Human Suffering: Theological, Philosophical and Pastoral Responses. Sponsored by Georgetown University's Center for Clinical Bioethics. Research Building Auditorium, Georgetown University Medical Center. \$25 registration fee includes lunch. For more information, visit http://clinicalbioethics.georgetown.edu/conferences/faithethics.html.
- "End of Life Decision-Making in End Stage Dementia." 1:00 p.m. Sponsored by the Palliative and End of Life Care Research Interest Group.GIM Conference Room, 1830 Building (JHH, 1830 E. Monument St., Baltimore), 8th Floor. Speaker, Peter Rabins, MD. Professor, Department of Psychiatry, Johns Hopkins.
- 15 "Our Capabilities, Our Conscience—Ethics and Stem Cell Science." 4:00 6:00 p.m. Sponsored by The Phoebe R. Berman Bioethics Institute. Speaker, John Gearhart, PhD, C. Michael Armstrong Professor, Johns Hopkins School of Medicine. East Wing Auditorium, Bloomberg School of Public Health, Johns Hopkins University, Contact (410) 955-3018

- 3rd Ethics Workshop Series, co-sponsored by the Richmond Bioethics Consortium (RBC) and the McGuire Department of Veterans Affairs Medical Center in Richmond, VA, providing basic ethics education for ethics committee members. Free for RBC members, \$50 for non-members. Call RBC voicemail at 804-287-7450 for further information.
- "Compassion Fatigue ... What is it? Ethical implications for caregivers and Organizations." 7:00 p.m. Sponsored by the Richmond Bioethics Consortium (RBC). Speaker is Bonny Dillon, PhD, Director of Bereavement Services, Bon Secours Richmond. Call RBC voicemail at 804-287-7450 for further information.
- 29 "To Err is Human— Using Process Improvement to Eliminate Medical Mistakes." The Till Bergemann, MD Medical Ethics Lecture Series. Speaker is Joseph L. Braun, MD, JD, MPH, MBA, MA. Prince George's Hospital Center Auditorium. 12 noon to 2:00 p.m.

June

- 4-9 Intensive Bioethics Course XXVIII, Kennedy Institute of Ethics, For more information, visit www.georgetown.edu.
- 17-21 Ethics of Research with Humans: Past, Present & Future, University of Washington, Seattle, WA, chaired by Dr. Albert R. Jonsen, directed to current members/managers of IRB committees and other interested research professionals; contact mbarnard@u.washington.edu or (206) 616-1864. Registration deadline is May 31, registration limited to 75 persons.

July

"Ethics and Human Research Subjects: International Issues," One Week Intensive Course.

Sponsored by Johns Hopkins Bloomberg School of Public Health Graduate Summer Institute of Epidemiology and Biostatistics. Contact Nancy Kass at nkass@jhsph.edu or visit http://www.jhsph.edu/summerepi/.

August

5-9 Summer Seminar in Health Care Ethics, University of Washington, Seattle, WA, chaired by Dr. Albert R. Jonsen, directed to health care professionals involved in patient care or provider education; contact mbarnard@u.washington.edu or (206) 616-1864. Registration deadline July 19, registration limited to 125 persons.

If you know of an ethics-related talk or conference taking place at your facility or in the Mid-Atlantic region between September - December, 2001, let us know by August 31 for inclusion in the next newsletter. Contact Anita Tarzian, atarzian@juno.com, (410) 706-1126.

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