

***** Research on Proxy Consent Begins *****

The Medical Humanities Program has recently received a grant of \$67,294 from the Retirement Research Foundation to study aspects of proxy consent for incompetent elderly persons.

More and more persons are reaching the age of 65, and many live well beyond that into their 80s and 90s. Although many of these persons will remain clear-headed up to the day of their death, others will become comatose, confused, unable to speak or communicate, or otherwise impaired. In such circumstances, the patient is unable to participate directly in the crucial decisions about his or her care which will then necessarily be made by someone else - a proxy decision-maker.

There are at least three ethical principles which a proxy decision-maker could use in reaching a decision about the patient's care. One would be a **utilitarian** principle, which looks to the effects different choices would have on all of the parties involved, including the patient, family, caregivers, and possibly insurers and the wider society. According to this principle the best choice would be the one which on balance maximized benefits (or minimized harms) to all concerned. A different principle, fearful of the conflicts of interests inherent in a utilitarian approach, would focus on the balance of harms and benefits to the patient alone, seeking to make the choice which is in the **patient's best interests**, as these are understood by the decision-maker. This is the principle most closely aligned with the traditional Hippocratic ethic. The well-known difficulty here is that the values which the proxy uses in judging "best interest" may not be identical with those of the patient. Respect for the autonomy of individual values would seem to imply that the relevant values governing the choice should be the patient's. The third principle which emerges is one of **substituted judgment** - to make the same decision that the patient would have made.

Since the aim of substituted judgment is to mimic the decision the patient would have made, it is the principle most consistent with respect for the patient's right to self-determination, which is now among the bedrock values governing the doctor-patient relationship. Because of this connection with the right to autonomy, substituted judgment has become the ideal principle of choice for proxy decisions.

But even if substituted judgment is accepted as an ideal principle, there are serious practical questions which remain concerning its use in real-life clinical settings. For example, family members are usually used as proxy decision-makers, the assumption being that they are more likely than anyone else to know the elderly person's values and preferences, and so are better able to make an accurate substituted judgment. This assumption has never been systematically tested, but it is important to know whether or to what degree it is true. If it is discovered that family members are no better at this task than the patient's physician, then at the very least we will need to develop a different rationale for the use of family members as proxies (a utilitarian one?). On the other hand, if it turns out that family members make much more accurate substituted judgments than physicians, then physicians who respect patient autonomy can be much more comfortable accepting a refusal by a family member of the physician's strong recommendation regarding the patient's care.

Also of practical importance is the issue of how proxy decision-makers should be approached by caregivers. Probably the most common approach is to ask them what they want done for the patient. But this question does not explicitly ask them to consider what the patient would want, and indeed invites the proxies to consider their own values and interests in their deliberations. Does this approach result in decisions which the elderly patient would not have made for herself? That may depend on how much consideration patients give to the interests and values held by the persons who would act as their proxies. An alternative is to **ask the proxy directly what the patient would decide**. Since this question asks explicitly for a substituted judgment, one might conclude that the answer is more likely to agree with the patient's values. But it also **fails to permit the proxy to consider his or her own interests in the matter**. And if those are interests the patient would have considered, then the proxy's answer to the substituted judgment question is **likely not to be an accurate substitute judgment**. Given that there are complex obligations of mutual care and concern that operate among families and friends, it is not obvious that the substituted judgment question would be the more successful approach. The issue is an empirical one, and not only a matter for moral or philosophical analysis.

These are among the empirical and practical problems about proxy consent that the research project will be addressing. In its overall features, the research method is straightforward.

The project staff will develop three scenarios, each of which describes in non-technical language the serious medical condition of a mentally incompetent elderly person, and poses a stark treatment choice. In order to be sensitive to any potential differences between proxies and elderly persons, the scenarios will be controversial enough to significantly divide opinion among elderly persons themselves.

Clearly competent elderly volunteers will be asked what they would like done for them if they were ever in the situations described, and to rate the strength of their conviction. They will also be asked to rate the degree of influence on their choice exerted by various reasons and considerations which arise from each scenario.

Associated with each elderly subject will be up to five other volunteers, representing five different proxy types (spouse, sibling, child, doctor, appointed proxy). They will be presented the same scenarios. Half of them will be asked **what the elderly person's decision would be**, and the reasons for it. The other half will be asked **what they think should be done**, and the reasons for their decisions.

Comparisons of the decisions made and the reasons given by the elderly person and his or her potential proxies will provide two measures of agreement between them, which will be taken as measures of the accuracy of substituted judgments. Various statistical methods will be used to determine whether the question posed to the proxies influenced the accuracy of their judgments, and also whether the accuracy of judgment was related to other factors, such as the nature of the relationship (including the elderly person's selection of the proxy), age, sex, level of education, level of independent living, and degree of recent contact.

Follow-up interviews will determine whether the administration of the scenarios prompted better family communication on health-care-related values and proxy decision-making.

The research project began January 1, and will continue throughout 1986. The principal investigator is Tom Tomlinson, Ph.D., assisted by coinvestigator Kenneth Howe, Ph. D.

***** ALZHEIMER'S NURSING HOME PLACEMENT AND PROXY CONSENT: A CASE REPORT *****

(Editor's note: Due to space limitations, the case study usually found in this space will not include commentaries from opposing viewpoints. For a more complete discussion of this case I urge the readers to consult the original reference.

Drs. Diane Meier and Christine Cassel discuss a case of a 61-year-old Alzheimer's patient, living alone and with deteriorating function, who refuses to consider nursing home placement as an option. While one son is adamantly seeking nursing home admission and urges that the patient's savings be used to pay for this, other children

insist on continued home care, but then fail to comply with a geriatric staff's recommendations for home services. As the patient's needs are not being adequately met, the question of notifying Adult Protective Services is raised, but the staff fears this would simply further antagonize the family support system.

The authors discuss several related issues and suggest a practical "checklist" for evaluating the ethics of a decision around nursing home placement: (1) What are the patient's wishes? If early enough in the course of dementia, can the patient be asked to name a proxy decision-maker to represent his own wishes later on? (2) Whose needs are being primarily served - patient, family, providers? (3) Have less drastic and less autonomy-limiting options been explored first? (4) Can family and providers unite to push for additional resources in the community?

(1) Reference: **Meier D.E., Cassel C.K.: Nursing home placement and the demented patient.** *Ann Intern Med* 104:98-105, January 1986.

***** MSU's Medical Humanities Thematic Proposal *****
Part I: An Historical Overview

Because current negotiations for a Medical Humanities Thematic at MSU differ substantially in scope and in the anticipated cooperating academic and administrative units from what was envisioned in the past, it seems appropriate to first analyze the major proposal that emerged in the late 1970's. Although it never moved beyond the draft stage, its contents soon became widely known and engendered considerable opposition from various segments of the University. Understandably, some mistrust remains. But by contrasting the original proposal with what we now have in mind, by showing that Medical Humanities seeks constructive, joint efforts rather than imperial expansion, I hope to eliminate any lingering opposition and mistrust for curriculum consolidation that is long overdue if we really want to train broad-minded, problem-solving and humanistically inclined health care professionals.

In the spring of 1977, several individuals peripherally associated with the emerging Medical Humanities Program at MSU circulated a preliminary draft of a "pre-medical degree program in the humanities" for consideration by the Program's Policy and Advisory Board. The draft proposed the creation of a **distinct baccalaureate degree program "to prepare students for admission to medical school who are not only well-grounded in basic science but who will approach the professional study of medicine and their careers as medical practitioners keenly sensitive to the humanistic and value-oriented issues surrounding medicine."**

The curricular requirements of the proposed degree program emphasized repackaging and expansion of existing requirements rather than the formulation of new courses and faculty responsibilities. The Department of English, for example, would replace American Thought and Language and Lyman Briggs College as the primary locus for training pre-medical students in effective writing; the basic science courses would substitute for general education requirements in Natural Science; and the Department of Humanities would expand its offerings in "Medicine and Human Values" so that pre-meds could satisfy that department's general education requirement with courses suitable as an introduction to the degree program. Pre-med students in this degree program would have the traditional penchant for taking heavy loads of elective natural science courses blunted by a requirement to choose 72 credits of course work from two departments in the College of Arts & Letters and one department in the College of Social Science. This represents 40% of the total credits required for graduation. Three proposed senior seminars in "Values of Human Medicine," required of all participating students, still needed formulation and approval via the academic governance system. Faculty for these seminars would be drawn from various participating departments, including some from the Colleges of Human and Osteopathic Medicine. Left unclear, however, was the degree to which the senior seminars were amenable to individual tinkering with the subject matter and how one might garner commitments from various departments to staff the seminars regularly.

The possible impact of such a program was not lost on various colleges already involved in pre-medical training and advising. Although there was general support for the stated goal of augmenting the humanistic component of the pre-medical experience,

some people were concerned (and legitimately so) that the proposed degree program could not establish itself without undermining existing activities; why not adapt these units to new conditions and needs instead of cannibalizing them for something untried and, very possibly, unnecessary? Others noted that the anticipated connections with the two MSU medical schools remained worryingly amorphous, particularly concerning faculty involvement in the senior seminars and the issue of eventual medical school admissions for degree graduates. For example, there was no mention of whether pre-meds from this program should or would be given preferential consideration in comparison to pre-meds applying from "traditional" degree programs. Ironically, the proposed degree program, which was expected to "provide a way to cure the increasing isolation that many humanists seem to feel in respect to scientific education in general and medical education in particular," projected a new form of isolation in that **pre-medical students were the only projected audience**. There was no hint of any desire to include students interested in other health professions and para-professions.

Criticism during the following year, both self-imposed and external, eventuated in several noteworthy changes in the proposed degree program. First, some of the amorphous connections with the two medical schools were clarified. A persuasive case was made that since existing medical school curricula would never be able to incorporate "broad programs in the medical humanities" in a traditional four-year program, as much medical humanities as possible should be worked in at the more flexible, undergraduate level. The revised proposal also recognized that **success of any pre-medical degree program was contingent on revised admissions policies by the medical schools**; no position was taken, however, on whether courses in medical humanities should be required for admission, or whether students presenting such a profile would receive preferential consideration. However, the proposal did ask the MSU D.O. and M.D. medical schools to **guarantee to accept a fixed number of program graduates and to give all program graduates an improved chance of admission vis-a-vis candidates from traditional programs**.

The second major set of alterations in the proposed degree program were curricular. The general education segment assumed substitutions for courses in all four University College departments, with the possible exception of Humanities. Special course-work in three Arts & Letters and Social Science disciplinary departments was reduced by one-fourth. In their place were required courses, totaling 24 credits, from at least one of four multidisciplinary tracks (Biosocial Causes of Illness; Medical Ethics; Communication and the Doctor-Patient Relationship; and Policy Issues in Health). One of the senior seminars was re-situated at the sophomore level as an introduction to the program and an optional field experience of an undisclosed nature was added. Somewhat puzzling was the statement that either Arts & Letters or Social Science would grant the degree at the completion of the senior year, with a notation on the transcript that the student had completed a pre-medical humanities program; this degree program was neither fish nor fowl, neither a major in the traditional sense nor a thematic.

Viewed with hindsight, this proposal was informed by a pragmatic sense of what was possible to implement at MSU in the late 1970s but--ironically for a program concerned with adding more humanities to pre-medical training--unintentionally inhumane in its disregard for faculty and staff in several colleges then primarily responsible for pre-medical training and advising but not incorporated into the proposed program. To be fair to all sides, it was a period of intense re-evaluation of the future roles of both University College in general education and the special residential colleges in undergraduate training as a whole. Imperialistic discourse was, unfortunately, often the rule rather than the exception; it was especially typical at the time for faculty outside the units "targeted" for possible elimination or consolidation to discuss possible disposition of future spoils. Competition for limited student credit hours supplanted prior considerations of prerogative when new programs were considered. The proposed degree program's dependence on the "safe" colleges, however, emerges in striking contrast to its imperialistic attitude toward the "targeted units".

Also striking is the economy of scale in the proposed degree program, particularly the second draft. The size of the initial "class" was set at twenty sophomores, with subsequent classes chosen every two years to permit careful advising by a full-

time director. In other words, the students would be an elite group of pre-meds at MSU, chosen by the director on the basis of an interview, standardized test scores, and academic records in high school and the freshman year at MSU. In addition to selection and advising, it was assumed that the director would teach part-time in the two medical colleges to which the students were expected to apply later and part-time in one or more of the sophomore/senior seminars.

Both proposals are imbued with a salutary tone, a sense of absolute certainty that various conjunctures assured the degree program's approval and implementation by the early 1980s. But MSU's budgetary crisis, beginning shortly after the proposals were circulated, first pushed the proposed degree program in medical humanities to a back burner, then shoved it off the stove entirely. In the spring issue of *MHR*, I will examine an interim attempt to keep the idea in circulation and the state of current negotiations to formulate an entirely different program for very different circumstances. Peter Vinten-Johansen, Ph.D., History, MHP

*** LITERATURE REVIEW ***

The Silent World of Doctor and Patient by Jay Katz, M.D., New York, Free Press, 1984. \$15.95

To Jay Katz, conversation between doctor and patient means discussion that is specifically aimed at making the patient a participant in decisions about his or her own health care. Katz's thesis is that there is virtually no tradition in the history of medicine of conversation of this sort; silence rather than conversation is the norm. Further, recent court decisions on informed consent which have been interpreted as mandating this sort of conversation really do nothing of the kind since they heavily qualify each recognition of patients' rights with continued reliance on the physicians' clinical judgment.

Katz exhaustively and insightfully reviews all the reasons for this silence through the centuries. To really have conversations with patients, physicians would have to deal with the powerful transference and countertransference feelings engendered by the clinical encounter. They would have to explicitly recognize the ignorance and uncertainty that characterizes much of medical science and practice. And they fear that they would give up much of the positive placebo effect that the healing encounter exercises on the health of the patient. If anything, to make his arguments more compelling, Katz overstates these barriers to conversation.

Still, despite such obstacles Katz believes that **conversation can and must become a moral imperative within medical practice.** Can--because modern scientific medicine has for the first time given us a clear road map of what we know and where we still remain ignorant so we can share both our knowledge and our uncertainty with the patient in a reasonable, objective way. Must--because not to involve patients in decisions affecting their lives is ultimately a form of abandonment, totally destructive of the beneficent motives of the healer.

Katz's book may be an answer to the skeptic's question, "What can a psychoanalyst who teaches in a law school say that is useful about medical ethics?" But more than that, it is a well-reasoned and challenging look at the concept of informed consent, and deserves the careful reading of all thoughtful physicians and medical humanists. Howard Brody, M.D., Ph.D.

Defense of "The Right Kind of Paternalism"

Marzuk (1) advocates an unwillingness to accept a patient's ill-advised refusal of treatment until the physician has explored the underlying psychodynamics of the refusal. Marzuk cites an earlier survey by Jackson and Youngner (2) which revealed that some requests for "death with dignity" were based in fear, depression, or desire to regain control rather than in a true wish to die. Marzuk adds some additional possibilities--refusal might be a part of the newly diagnosed patient's denial of the disease; it may be part of a masochistic view of illness as punishment for past sins; or it may be a testing of the physician and family, in which insistence on treatment will provide a reassuring affirmation of worth for a patient who had wondered whether

the physician still cared about him. Such possibilities should be explored before the physician meekly acquiesces in informed refusal of beneficial therapy.

COMMENT: Philosophers distinguish between "strong" and "weak" paternalism (3). Strong paternalism refuses to honor a person's own wishes despite the fact that that person is fully capable of reasoning and acting on her own. Weak paternalism refuses to honor person's choice because that person displays some defect in ability to reason or choose autonomously. Marzuk makes clear that he advocates only weak paternalism and disapproves of strong paternalism in medical practice.

References: (1) Marzuk P.M., "The Right Kind of Paternalism", New England Journal of Medicine 313: 1474, Dec. 5, 1985. (2) Jackson D.L., Youngner S., "Patient Autonomy and Death With Dignity: Some Clinical Caveats," New England Journal of Medicine 301:404, 1979. (3) Childress J.F.. Who Should Decide? New York, Oxford U. Press, 1982, ch.1.

***** AIDS CONFERENCE DRAWS NATIONAL FIGURES *****
THE PUBLIC, ETHICAL, AND PSYCHOSOCIAL ASPECTS OF AIDS
March 7, 1986

Sheraton Inn, Lansing, Michigan
Sponsored by the Department of Psychiatry and the Medical Humanities Program
at Michigan State University.

The conference is scheduled to begin at 8:00 a.m. and includes lunch. For conference brochures or further information please contact the Medical Humanities Program, C-201 East Fee Hall, MSU, East Lansing, Michigan, 48824. Presenters include the following:

June Osborn, M.D., Dean, School of Public Health, University of Michigan, Professor of Epidemiology, Professor of Pediatrics and Communicable Diseases, University of Michigan.

"An Overview of the AIDS Epidemic"

Myron L. Belfer, M.D., Professor and Chairman, Department of Psychiatry, Cambridge Hospital, Harvard University.

"Psychological Impact of AIDS on Children"

Allan Brandt, Ph.D., Assistant Professor of the History of Medicine, Harvard Medical School, Department of Social Medicine, Harvard University.

"Cultural and Social Issues Related to AIDS"

Jill Joseph, Ph.D., Assistant Professor of Epidemiology, School of Public Health, University of Michigan.

"Behavioral and Psychosocial Responses of an At Risk Population"

Carol Levine, M.A., Editor, Hastings Center Report.

"Ethical Questions Related to AIDS"

Stuart Nichols, M.D., Senior Instructor in Psychiatry, Mount Sinai School of Medicine, City University of New York; Chairperson, American Psychiatric Association Committee on AIDS.

"Psychological and Psychiatric Implications of AIDS"

***** CALENDAR *****

February 18

H. Brody and T. Tomlinson
Dimondale Family Council
Decision Making on Behalf of Elderly Patients

Dimondale Nursing Home

February 26

T. Tomlinson
Ethics Committee Workshop
Problem Solving in Medical Ethics

St. Mary's Hospital
Saginaw, Michigan

March 3	H. Brody and L. Fleck Public Forum Justice, Health Care and the Good Doctor Six followup seminars on alternate Thursday evenings, March 20-June 6	Goshen, Indiana
March 4	T. Tomlinson St. John's Rotary Ethics of DNR Orders	Shangrila Restaurant St. John's, Michigan
March 7	Special Conference Open to all Health Care Professionals Public, Ethical and Psychosocial Aspects of AIDS	Sheraton Inn, Lansing
March 18	M. Benjamin OB-GYN Residents Ethical Issues in OB-GYN	Sinai Hospital Detroit, Michigan
March 26	H. Brody Medical Oncology Group Ethical Issues in Oncology	Flint Community Hospital
March 27	H. Brody Medical Residents Conference on Ethical Issues in Medical Care	Ingham Medical Center, Lansing
March 28	H. Brody Family Practice Conference Family Doctor as Gatekeeper Case Studies in Family Practice Ethics	Towsley Center Ann Arbor
April 2	M. Benjamin Detroit Dietetics Assn. Ethics in Medical and Nutritional Care	Henry Ford Hospital Detroit, Michigan
April 8	Medical Humanities Staff Public Forum Pricing Human Life: Moral and Public Policy Issues Six Consecutive Tuesday evenings April 8 - May 13	Flint Public Library
April 9	H. Brody Obstetrics Residents Ethical Issues in Obstetrics	Providence Hospital, Pontiac
April 11	K. Howe Association of American Medical Colleges Ethical Issues in AIDS	Wayne State University
April 11	T. Tomlinson American Ortho-Psychiatric Assn. Mtg. Psychiatrists' Role in Reproductive Alternatives	Chicago, Illinois
April 21	M. Benjamin Capital Area Nsg. Assn. Commentary on Film: Code Grey	Ingham Medical Center, Lansing
April 22	L. Fleck and H. Brody Workshop for Health Care Professionals Life, Death and the Dollar Sign: Rationing Health Care Resources	Midland Hospital, Midland

April 23-25 H. Brody Western Ontario University
Medicine and Applied Ethics Conference
Medical Ethics as Applied Ethics

May 13 L. Fleck Clinton Memorial Hospital
Medicine Grand Rounds St. Johns, Michigan
Ethical Issues Concerning DRG's and Cost Containment

SPECIAL CONFERENCE
THE PUBLIC, ETHICAL, AND PSYCHOSOCIAL
ASPECTS OF AIDS
See Page 6

Volume 8 No.2

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Published by:
Medical Humanities Program
C-201 East Fee Hall
Michigan State University
East Lansing, MI 48824

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U.S. Postage
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