

# MEDICAL HUMANITIES REPORT

MEDICAL HUMANITIES PROGRAM

MICHIGAN STATE UNIVERSITY

WINTER 1983

## DISTINGUISHED STAFF AWARD BESTOWED ON MHP ASSOCIATE FACULTY MEMBER

Maureen Chojnacki, Nurse Manager at the MSU Clinical Center and Associate Faculty Member of the Medical Humanities Program, was one of six MSU non-teaching employees to receive a 1983 Distinguished Staff Award in recognition of her outstanding service to the University. A nurse manager with the University Hematology/Oncology Clinic, Ms. Chojnacki oversees the direct care of cancer patients. According to the MSU News Bulletin, "Those who have worked with her attest to her remarkable dedication, outstanding skills and effective performance. Those who have been touched by her work note that she is a very special person whose care and deep concern for people and her profession are exemplary." The Distinguished Staff Awards, which include checks for \$1,000, were established as a program in 1978 to recognize outstanding employees of the University, and complement an awards program for faculty and graduate teaching assistants begun in 1952. Both programs are funded by alumni and friends of MSU from contributions made through the Development Fund.

## BROWN BAG SEMINARS ON THE HISTORY OF MEDICINE

Winter term saw a return of our brown bag seminars on the history of medicine, conducted by Dr. Peter Vinten-Johansen, Department of History and Associate Faculty Member, Medical Humanities Program. Discussion at the first seminar, held on February 14, was based on the article "Professionalism, Feminism, and Gender Roles: A Comparative Study of Nineteenth-Century Therapeutics" by Regina Markell Morantz and Sue Zschoche (Ref.: The Journal of American History, December 1980). The second seminar, held on March 7, was conducted by Dr. Andrew McClary, Professor of Natural Science, on the topic "What is a Health Fad? The Posture Movement as an Example". Attendance at both seminars was excellent, and discussion was lively. Anyone interested in future seminars in the history of medicine should be sure to contact the Medical Humanities Program (355-7550) to be put on our mailing list.

## CONFERENCE ON THE CRITICALLY ILL AND THE DYING PATIENT

Professor Joy Curtis, Associate Professor of Nursing and MHP Associate Faculty Member, will be commenting on a presentation at an April 15 conference titled "Dilemmas in the Care of the Critically Ill and the Dying Patient: Ethical and Legal Perspectives". Featured conference speakers will include George J. Annas, J.D., State Representative David Hollister, and Robert M. Veatch, Ph.D. The conference, which is intended to address the ethical and legal problems associated with the care and treatment of the hospitalized critically or terminally ill patient, is open to physicians, nurses, ethicists, clergy and attorneys. For further information about the conference, contact the Battle Creek Area Medical Education Corporation (BAMEC), 632 North Avenue, Battle Creek, MI 49017 or call (616) 963-3791.

**CASE CONFERENCE:**

**"BALANCING TREATMENT DECISION AGAINST COST CONTAINMENT"**

Case Presentation by Mark Ensberg, M.D.

Resident in Internal Medicine, GMEI-Lansing

A 15-year-old white male suffers from hemophilia with Factor 8 inhibitor. Over the years he has sustained several fractures and has had several episodes of bleeding into joints, so that he is unable to participate in sports and requires a cane to walk. Nevertheless, he is a reasonably well-adjusted adolescent who is doing fairly well in school. His case, however, is a bit more difficult than a "typical" case of hemophilia because he has developed an inhibitor to Factor 8, an antibody made by his own cells which inactivates the Factor 8 present in cryoprecipitate (the medicine usually given to hemophiliacs to restore normal clotting).

His main medication currently is Autoplex, which contains "activated clotting factors" which can produce normal blood clotting despite the absence of the body's own Factor 8 and the presence of the Factor 8 inhibitor. Autoplex is very difficult to manufacture and costs \$1.00 or more per unit.

Between July and September of this year he was hospitalized three times for the evaluation and treatment of rectal bleeding. The usual X-rays and endoscopic procedures were done, but no definite source for the bleeding could be found. The patient required 6,000, 63,000 and 33,000 units of Autoplex respectively in these three hospitalizations to control bleeding.

In November he was readmitted with a new episode of rectal bleeding which initially responded to 12,000 units of Autoplex administered over two days at home but then recurred with greater severity. On admission his hemoglobin was 7.7, PYY 52, Factor 8 assay 15% of normal, and Factor 8 inhibitor assay elevated at 40 Bethesda units. Sulfur colloid abdominal scan showed no source of bleeding. A colonoscopy was successful only to the splenic flexure; a small ulceration was noted at 25 cm but the major source of bleeding appeared to be above the splenic flexure. The patient required 12 units of blood and 58,000 units of Autoplex during this hospitalization before bleeding was controlled and was discharged after 7 days. Future plans call for angiogram or laparotomy if bleeding recurs and the primary bleeding site remains undiagnosed.

Medical Aspects of Therapy for Hemophilic Patients With Inhibitors to Factor 8  
John A. Penner, M.D., Depts. of Medicine & Pathology, MSU

Treatment for the classical form of hemophilia (Hemophilia A) requires the use of a fraction obtained from blood plasma Factor 8. The Factor 8 concentrate is administered to hemophilic patients as they develop bleeding episodes. The concentrate replaces the missing factor and restores the patient's clotting system to normal. Thus bleeding can be rapidly controlled if the product is administered intravenously.

A complication of the disorder is the development of an antibody to the antihemophilic factor. This antibody binds Factor 8, resulting in active bleeding which fails to respond to administration of the Factor 8 concentrate. If the Factor 8 is infused, it induces increased antibody production, thus making it impossible to restore homeostasis, even with vast amounts of Factor 8 concentrate. In the past, many of these patients bled to death from lack of an effective therapeutic agent.

It is possible to bypass the need for Factor 8 in the clotting mechanism by using plasma concentrate containing active forms of clotting factors 7, 9, and 10. A modification in the preparation of this concentrate was undertaken to

provide a product containing these factors. With this product (Autoflex) it was possible to control bleeding in hemophilic patients with inhibitors to Factor 8. The cost of single doses for a bleeding episode, however, ranges from \$2,000 to \$3,000 and may be required weekly.

The hemophilic patient has required substantial funding for management of his disease. Prior to the advent of the blood plasma factor concentrates, the treatment of the hemophilic patient consisted of blood or whole plasma and was not effective. It was not unusual, moreover, to have a patient hospitalized for three months out of a year for treatment of hemorrhages into joints and soft tissues. With the advent of the concentrates, it was possible to initiate treatment on an outpatient basis in the emergency room. However, this proved both costly and inconvenient. Often the patient was forced to wait long periods of time, during which the hemorrhage would become worse. More joint damage would occur, resulting in a chronic arthropathy. A newer approach, allowing patients to administer the product directly themselves at home, was successfully developed. This home care program eliminated hospitalization almost entirely and reduced the need for professional services. With the easy availability of the product, however, usage increased. As a result our average patient on home care now consumes two to three times as much factor. This increased the cost of treatment in one respect, but eliminated hospitalization and time needed for convalescence. As a result, the individual is able to complete his schooling and continue working without being handicapped by his bleeding problem. In addition, it has reduced much of the arthropathy problem, so that need for surgical replacement of knees, hips, etc., has been reduced with a concomitant decrease in the added costs for surgery. Approximately \$6,000 to \$8,000 per year is needed and allows the patient to continue a reasonably normal life and permits him to contribute normally to the community.

The tremendous cost for treatment of the hemophilic patient with inhibitors to Factor 8 depends in large part on the cost of the product. Product cost was based on recovery of investment by the manufacturer plus a profit, the latter being affected by the fact that this was the only available agent for treatment of the condition. From the manufacturer's standpoint, there is reason to expect that the investment cost should be recovered with a profit. When the product was being developed, research monies were requested from the National Institutes of Health for evaluation of the product. They were refused on the grounds that it was a commercial venture and therefore would eventually provide a profit for the company if the venture was successful.

Questions posed by this case reflect on our willingness to provide effective health care and at what cost. If we treat such patients, the cost to the community will be in the hundreds of thousands of dollars over a short period of time. If we fail to treat, the patients' condition will deteriorate, with the development of arthropathy and, in some cases, with continued bleeding and death. There are, moreover, several thousands of individuals within the United States with this condition, so that treatment costs will be in the millions of dollars. We do not have unlimited resources, but can we allow patients to develop serious medical complications or to die when treatment is at hand?

How an HMO Copes with an Unusually Expensive Medical Bill

D. Bonta Hiscoe, M.D., Medical Director, Health Central, Lansing

The present case brings up the problem of the chronic use of a highly expensive commodity, and it is worth noting that when an HMO copes with a

problem like this, it really is a microcosm of the larger picture.

Health Central is a prepaid medical group. Of our 31,000 members, we have 11,700 subscribers who are the ones who actually pay the bill. We get no subsidy from the government or Blue Cross Blue Shield. HMOs are regulated by law and are required to provide certain minimum benefits. We may add benefits if we wish, but if things get expensive we cannot just stop providing certain services. We also cannot charge extra to the patient if the required services happen to be extra expensive. At the same time, HMOs have to remain competitive as they market to the general public. They have to offer as many services as possible, and still keep the price down. This type of high cost medical problem poses a real challenge to HMOs, and yet is a contingency that must be provided for.

The process followed by us at Health Central, when presented with this kind of situation, begins by establishing our responsibility from an insurance point of view. Our Utilization Review Office checks to see if the patient is a valid member of Health Central; if that membership is current; if the requested service is a benefit provided under our plan; and whether we or another insurance company or agency are primarily responsible for paying this patient's bills. If Health Central is found to have no financial responsibility, efforts are made to direct the patient in the appropriate channels. If, on the other hand, the patient is a member, but the request is medically or financially unusual, it is referred to the Medical Director's Office.

As the Medical Director, I evaluate the medical problem by reading, consultation with our medical staff, and consultation with specialists. We consider the risk to the patient in terms of morbidity and mortality; the advisability of the proposed treatment itself; and whether or not the treatment or drug is considered to be experimental. Experimental drugs and research are not benefits under our plan, and we feel that we have sometimes done our patients a service by being their advocate and not authorizing certain proposed treatments (such as intestinal bypasses for obesity) even when they were not considered experimental.

All of the information collected is then reviewed by the Benefits Committee. This committee is not only concerned about the quality of medicine offered (asking basic questions such as: is the drug cleared by the FDA? Has it been proven to be effective in experimental studies? Is it standard medical treatment in the community?), but also about the competitive position of our organization in the marketplace. Thus part of the overall deliberation would include consideration of the length of treatment required, the expense of the drug over the patient's long term care, potential hospital costs or savings by using the drugs, etc.

Once a decision has been made to proceed with a proposed treatment, as would be the case in the further use of Autoplex, we would then evaluate how we can get the best quality treatment at the best price. We use our own physicians and pharmacy as much as possible. We use consultants who are participating with us in our program, when possible, but sometimes use distant consultants when they are the only ones with a certain expertise. We also use the most cost effective hospitals available to us.

While this is the process we at Health Central follow in coping with an unusually expensive medical bill, we also expect a certain level of cooperation from the patients in question. Thus, for example, in a case of a hemophilia where the patient needs recurrent doses of medication and has a lot to say about their exposure to injury, we feel it is their responsibility to cooperate in their care. We recently had a hemophiliac who was at first reluctant to learn to self-administer his Factor 8. When he finally did learn to self-administer, he began to use much larger amounts of Factor 8. We

discovered that the patient was participating in multiple sports and would give himself a prophylactic injection before going out to play handball or volley ball. We feel that patients such as this do have some responsibility to show some restraint in their activities and not abuse the privilege of being well.

The business community and the public are becoming more exercised about the increasing costs of medical care. They are looking to change incentives through a host of new mechanisms. At different times, and for different reasons, these changes are being resisted by physicians, hospitals, insurance companies, and, not the least of all, patients. We may argue about individual prices or procedures, and there is indeed money to be saved here. But if we are to make fundamental changes in the way medical care is practiced and distributed, these changes will not be made by any single group but rather by society as a whole.

#### Distributive Justice and Scarce Medical Resources Ruth B. Hoppe, M.D., Dept. of Medicine, MSU

The problems posed by expanded alternatives for health care and shrinking financial resources to support these alternatives are large and complex. In the past three decades we have seen the development and dissemination of several new technologies in health care: hemodialysis, coronary artery bypass surgery, neonatal intensive care, computerized axial tomography, and organ replacement, to name but a few. While these technologies have unquestionably benefited many individuals, they have also substantially contributed to rising health care costs. In the United States over the last thirty years, the total expenditure for health care, the per capita health care expenditure, and the health care expenditure as a percentage of the gross national product have all increased significantly. In large part because such services are distributed to individual patients by individual physicians, the financial impact on society of such decision-making often is overlooked, or, worse, is not even apparent. Even the individual cost is usually overlooked because of the ubiquity of insurance coverage. Given these circumstances, the tendency may be to look at health care services as arising from a bottomless pit, and the assumption may be made that "more" is "better". This seems particularly to be the case where a health care service is needed by an identifiable individual, such as in the present Autoplex case. However, we live in a "zero-sum-society". Resources made available for health care are not infinite, but are taken from the total "pie" of social resources at the expense of something else. Beginning in the mid-1800s, our productivity has sharply declined. This means that the "pie" is essentially fixed in total size. Therefore, spending more money on artificial hearts will require spending less money on something else, either in the health care sector or outside it.

Such considerations have given rise to much recent discussion directed toward examining the benefits of health services rendered and exploring cheaper ways of delivering these services. Several such strategies have been well outlined in a recent article by Mechanic<sup>2</sup>. HMO legislation and proposals to alter hospital reimbursement, as well as to change insurance mechanisms, may radically alter the structure of U.S. medicine in the remainder of the 20th century.

Unfortunately, such attention to matters of efficacy and efficiency may not be enough. We may soon reach (indeed, we may have already reached) a point where we cannot afford to fund all health care that is technically feasible to deliver. Other countries, both developing (e.g. China) and developed (e.g. Great Britain), have generated decisions, on a national level, which limit

public access to available health care technology. Should--and can--this happen in the United States?

On the one hand, it may be argued that the dramatic rise in the share of the gross national product spent on medical care reflects not a run-away industry, but consumer satisfaction with the benefits derived from health services. The generally held perception is that both the quality and the quantity of life have been remarkably enhanced as a direct result of advances in personal health care, and that greater expenditures in the name of enhancing health are fully justified. However, a legitimate question then becomes, is the benefit to quality or quantity of life that additional expenditures create worth the cost? It can be demonstrated that each new dollar put into health care produces a smaller benefit than the previous dollar. Is the "cost at the margin" currently something that society is willing to bear? Or, having already achieved a fairly high level of national health, would we like to see resources put into other social needs?

When we begin to consider the concept of limiting the delivery of health care technology, several very interesting and complex questions arise. First, is health care a special type of social good, requiring special distributive mechanisms? Or is it rather that, like automobiles and television sets, health care should be subject to the same distributive schemes as any other commodity (i.e. if you can afford it, you buy it)? Or is health care more like education--a right, something to be guaranteed to all members of society? There are numerous indications that our society does feel differently about health care than about other commodities. The entitlements of Medicare and Medicaid attempt to secure equity of access to all members of society because we feel that ability to pay should not govern distribution of at least some medical care.

The concept of health care as a right gives rise to a second set of questions: what is health care (cosmetic surgery? preventative services?) and how much of it should be distributed to each member of society? Unlike education, which can be socially distributed in equal amounts, health care needs are unpredictable in timing and scope. They also can be heavily dependent on personal values and life styles. Should society pay for Autoplex given the young person wishing to engage in contact sports, or for lung cancer treatment necessitated by a heavy smoking habit? Or should we attempt to define some "decent basic minimum" of health care services to which everyone would be entitled, leaving the rest to be distributed as commodities in the marketplace?

The next question then becomes, how do we decide what not to fund and, therefore, what doesn't get distributed? Perhaps we should eliminate health care services for the very old, who have been demonstrated to consume a disproportionate amount, particularly during the last years of their lives? Or perhaps we should eliminate neonatal intensive care treatment for the very young, many of whom have very poor outcomes leading to additional social costs? Or perhaps we should eliminate attempts to treat diseases with very high incurable rates, or extraordinary attempts at life-extension once organs have failed? The complexity of such decision-making has given rise to quantitative efforts, such as cost-benefit analysis, to generate the "best" decision regarding health resource allocations. A full discussion of the limitations of such methods cannot be generated here, but it is important that health planners understand that there are serious ethical limitations to such methods which directly impinge upon the justice of distributions made according to such analyses.

A final set of questions involves the locus of decision-making about health care priorities. If we agree that health is a special type of commodity, and

therefore shouldn't be distributed solely according to market place principles, how can the largely private and entrepreneurially-based U.S. health care industry respond to these larger, social questions? If we are to limit the distribution of health care services, how should the priorities be set and where should the decision making be done? It is sometimes proposed that physicians somehow incorporate issues of cost into their decision making for individual patients. Hopefully, physicians can and do address issues of efficacy and efficiency, but to expect them to set health care priorities is unrealistic. Not only is there no guarantee that such decision making would be equitable, but such behavior would be inimicable to the traditional doctor-patient relationship: The physician cannot simultaneously advocate for society's needs and for his/her patient's needs.

The locus for such priority setting more likely resides in a complex and imperfect interface between politicians, health care institutions, practitioners, and health care recipients. The vulnerability of such a process to the pressures of various interest groups again raises serious questions about the fairness of any distributive decisions that might be made.

Given all this complexity, it may be easier to make no decision at all. It is important to recognize that if ignored, the problem will not disappear: inattention will result in fewer social resources available for non-health related needs, with a largely unknown impact on our society, its values, goals, and accomplishments. It would seem that some limit setting must be accomplished. It is to be hoped that this can occur with regard to some reasonable guidelines for health care priority setting. Such guidelines might include the following: 1) Decision making needs to be an explicit process; 2) Decision making should be guided by some philosophic construct or set of principles which incorporate the concept of equity; 3) Decision making must be able to be reviewed from ethical, financial, and practical perspectives--i.e., it must be visible, public; 4) Health care rendered on the basis of such decision making must be consistently and fairly applied, and be able to be reviewed from this perspective; 5) Decision making should not alter the traditional basis of the doctor-patient relationship, namely, trust and individual advocacy.

It can be argued that very little decision making in our society, even very critical decision making, takes place according to such an idealized process. However, with respect to health care, a process is already at work, responding to demands from health care consumers, health care providers, and health care bill-payers. From what sector will considerations of equity and distributive justice be raised, and who will argue society's case?

#### REFERENCES

1. Thurow, Lester C., The Zero-Sum Society, Basic Books, N.Y., 1980.
2. Mechanic, David, "Approaches to Controlling the Costs of Medical Care", NEJM, 298:249, 1978.
3. Office of Technology Assessment, "Appendix D-Values, Ethics and Cost Benefit Analysis in Health Care", The Hastings Center, OTA, August 1980, pp. 168-182.

FACULTY DIRECTORY: ADDITIONS AND CORRECTIONS

In the "Are Our Faces Red Department": Through an inexplicable oversight, Professor Joy Curtis, College of Nursing, was inadvertently left off our directory of Associate Faculty in the Medical Humanities Program, 1982-1983. Professor Curtis has been an active and enthusiastic participant in the Medical Humanities Program. She has team-taught a course in ethics and nursing with Dr. Martin Benjamin (Department of Philosophy and Associate Faculty Member, MHP), and has co-authored with him a book, Ethics in Nursing (Oxford University Press, 1981).

Other additions to the Directory:

M. Louise Brouillette	Nursing
Louise Knight	Nursing
Tess Tavormina	English
James E. Trosko	Pediatrics & Human Development

COMMENTS?

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