



"Voices": An Experiment at the University/Community Interface

by Howard Brody, MD

Center for Ethics and Humanities in the Life Sciences

"Voices: Health Care Ethics Representing a Diverse Population" was the first in a planned series of conferences designed to highlight the importance of minority and cultural-diversity perspectives in health care ethics. However, it ended up taking on a life of its own and leading all of us in a direction we had only partly anticipated. The results illustrate both the fundamental importance of diverse points of view in academic bioethics, and the challenges academic institutions face in truly responding to the concerns of the community.

Why the Conference Series?

The proposed conference series reflects the Center's commitment to improving the quality of analysis and discourse on issues in health care ethics, and the conviction that doing so requires fully incorporating perspectives from culturally diverse communities into the discussion. Our goal could easily be misunderstood because two jobs need to be done. Both are suggested in the remarks made by anthropologist Rosina Hassoun during "Voices." She explained that if she were to develop a life-threatening medical problem, telling her individually about her medical condition and choices, and seeking her informed consent to treatment would be to treat her disrespectfully as an Arab-American woman. For her, culturally respectful care would involve treating the male head of her family as the decision-maker. (This, of course, might easily not be true for another Arab-American woman who had adopted a relatively more Western value framework.)

Job One is to make health care workers more aware of cultural differences and the need to respect them if we are to provide compassionate, decent care. Job One is very important. Notice, however, that it allows an important level of disengagement. As a Western bioethicist, I do not have to regard the Arab culture as having any claims on wisdom (let alone correctness). I can agree to treat "the other" as that individual wishes to be treated, without learning from "the other" in any deeper way.

Job Two more directly challenges the Center as an academic unit trying to push forward inquiries into health care ethics. It is to engage other cultures to see what bits of wisdom they may offer to help us fill out and correct incomplete or short-sighted views in our framework. In this example, it involves at least a willingness to ask whether the West's love affair with individual freedom and autonomy has systematically blinded us to the ethical importance of our embeddedness in family relationships.

As we thought about a conference series we envisioned holding an annual one-day conference around a question in bioethics that might be illuminated from a cross-cultural perspective. We thought that while we would need input from "real folks" who represented the views of different minority cultures, the main audience would be academics with an interest in health care ethics.

Why "Voices"?

The serendipity that led to choosing "The Challenge of Including Diverse Communities" as the theme for this first conference was Leonard Fleck's involvement in a genome project being carried out by a group from the University of Michigan School of Public Health. That project was grounded in Len's model of "rational democratic deliberation," a special form of community dialogue designed to yield moral values which might form the basis of health care policy. The first phase of the project successfully implemented these dialogues in middle-class communities across Michigan. Phase Two is now being designed to try to extend the dialogue model into marginalized communities, both ethnic minority and lower income. The academic question that arises is: can the model of "rational democratic deliberation," which on its face contains a number of assumptions drawn from middle-class life, actually be applied to minority and marginalized communities? And if so, what specific barriers must be overcome?

Sounds easy; just identify a bunch of academic experts who understand community culture and community dialogue, and hold the usual sort of academic conference for other academics to attend. But right away we ran into the fundamental problem that framed the ongoing challenge of "Voices." At some point, academic discussions become sterile unless they are grounded in the "real" experience of the "real" folks in the "real" communities. Thus, we knew that keeping the conference honest would require involving people capable of representing the community's views (and just what that means is the topic for another conference). This seemed to require that the actual process of community dialogue be a key part of the conference. But is it possible to do a 6-hour conference in which we both engage the actual community in meaningful, informed dialogue about health care issues, and also engage in an academic analysis of how one should ideally approach and implement such a community dialogue?

A wise conference planner would tell us that we were headed for an embarrassing flop if we tried to do these two very different things at the same time. We elected to charge ahead nonetheless and to see what happened. A very dedicated planning committee (among whom I would especially recognize Libby Bogdan-Lovis, Len Fleck, Jim Dearing, Vence Bonham, and Marian Gray Secundy) addressed the problems and came up with novel approaches. When the time came to pay the bills, the Center received generous assistance from the Office of the Provost, the Julian Samora Research Institute, and the David Walker Research Institute.

The "Voices" Conference

More than 100 people of widely diverse backgrounds gathered in the Michigan Library and Historical Center on Saturday, February 20. Vence Bonham kept the entire conference on track as moderator. Len Fleck led off with a demonstration of the computer response system he routinely uses to trigger the process of community dialogue. He posed some difficult cases, very carefully chosen to highlight the issues of the day. For example: If we could save a lot of money by not using an expensive life-sustaining technology in some apparently hopeless cases, but not using the technology would offend the values of a particular minority culture, ought we allow a democratic, society-wide vote to save the money override the views of that minority culture? As usually happens, the exercise stimulated a lively dialogue as to the moral values that lay behind different "votes" on the controversial issues.

Reed Tuckson, vice-president, American Medical Association, gave a keynote address which stressed the ideal of blending diversity into harmony. He emphasized that while this seems to require calm and reflective reasoning, preventable, premature deaths occurring every day demand our immediate attention. Dr. Tuckson reviewed many issues in health care ethics and the new genetics, and argued that the fundamental task is to empower culturally diverse communities to invite the health care system in on their own terms. We must reject the usual model of the health worker knowing what diseases are prevalent in the community and what the residents

need to do to treat and prevent those diseases. Instead, we need a model that allows both the health care system to admit its ignorance of the way of life of the community and the true priority of needs and concerns among the residents, and the community to inform the system of the community's actual needs and priorities. Dr. Tuckson congratulated the attendees for spending a Saturday at this type of event: "You came here to go to a conference," he said, "but you are actually transforming the nature of the American democratic experience."

An "academic reactor panel" followed. Jorge Chapa, director of MSU's Julian Samora Research Institute, emphasized both the value of what was happening in the room, and the need to recognize whose voices were not present in the room. Anthropologist Rosina Hassoun reminded us of the problems in expanding this dialogue to the illiterate and non-English-speaking citizens. She noted that many new immigrants do not understand the word "gene" and never saw as simple a piece of medical technology as a blood pressure cuff before coming to the U.S. All agreed that the process of creating health policy involves a complex interplay among economics, politics, and moral values. They also agreed that of those elements moral values are often the hardest to talk about in a sustained way.

Following a lunch break, during which a refreshing amount of informal discussion and networking seemed to occur, a "community panel" took over. Facilitator Isidore Flores reminded us that this form of searching moral dialogue might be threatening to many communities because it would force them to confront the differences of opinion among themselves. Connie Marin of Ingham Medical Center stressed the need to address spiritual concerns. Doak Bloss of the Ingham County Health Department challenged us to do more than "admire the problem" (in true academic fashion), to find out what works for the community and what they want for themselves. Since bioethics is not "their thing," we are trying to impose a basically foreign agenda upon their already busy lives. The "pay" that the community receives for its involvement in meaningful dialogue, Bloss added, is not really money or food, but respect. The key is genuine listening. If we come to regard listening to others' views as a burden, rather than as something that enhances and enriches our own lives, then we are ill-suited for the task. Bill Memberto, director of Detroit's Office of Urban Indian Affairs, noted that within his culture the norm is consensus and not democracy, and that the Indian community views itself as a group of sovereign nations rather than as a "minority." Michael Murphy of St. Stephen's Community Church noted that so long as "separation of church and state" is stressed, we will lose out on the positive role that churches can play in community organizing and involvement.

Marian Gray Secundy, newly named director of the National Center for Bioethics in Research and Health Care at Tuskegee University, provided a summary at the end of the day. She offered an optimistic view of the future of American democracy and highlighted the challenge, noted by the audience all through the day, of keeping this valuable dialogue going.

Where Next?

In a sense, the predictions of the nay-sayers, that we were hopelessly confused about our conference objectives, were borne out. We were regularly criticized for holding a conference on community dialogue in a place, at a time, and under circumstances which naturally excluded so many members of marginalized communities. In addition, from a purely academic standpoint, little new information emerged. No one at the conference argued that the concept of "rational democratic deliberation" would not work in culturally diverse communities; and as to the barriers that would have to be overcome to make it work, none were mentioned at the conference which had not already been anticipated in the discussions within the planning committee.

But that way of looking at the day's events is inadequate. It is one thing to be told that a process can occur, and quite another thing to participate in the process and to sense the real

energy, enthusiasm, and hunger among a group who feels that this approach needs to be more widely implemented and disseminated. It seemed clear that at the "Voices" conference, people felt listened to, and felt that they themselves could listen, in a way that was all too rare in their work-a-day lives. They wanted more, and they asked the Center to provide them with more.

At one level, they will get more, and that was the design of the conference from the start. Len Fleck and his colleagues will use the advice and insights generated during "Voices" as they proceed with the next phase of the genome project. This phase will involve community dialogues in a number of community sites across the state.

But, I believe, the Center is obligated to go beyond this specific genome-related effort. Somehow, we must find a way to pick up the momentum generated at "Voices," and launch some sort of effort here in the Lansing community which builds upon that foundation. Doing so will involve more than proceeding with the next conference in our planned series on minority and cross-cultural health care ethics. That conference, when it comes, will probably be another "standard" academic conference, though it will have improved input from the local community and, I hope, improved community attendance as a result of our experience with "Voices." I will continue to defend that sort of conference, for the academic world of bioethics needs to have those conferences.

But building appropriately on "Voices" will also require that the faculty of the Center find a new venue to engage in some sustained dialogue with interested community groups on their "turf" rather than ours. Given our existing commitments to teaching, research, and outreach, this will be no easy task. But our work will be vastly enriched by opportunities to learn from diverse communities both what they think of the problems we are addressing, and what they would propose as the problems we perhaps ought to be addressing instead. As Doak Bloss suggested during "Voices," if that seems like a distraction from our basic academic mission rather than our mission, then perhaps we are more mixed up than we think.



InkLinks is a regular column in which readers reflect on issues related to the lead article or a previous issue.

Listening to Patients

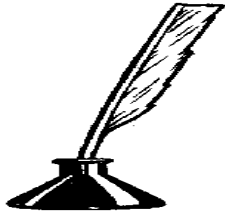
Mark Notman, Ph.D.
College of Osteopathic Medicine

Culture provides a series of implicit assumptions about the "natural order" of things, including the nature of sickness and its alleviation. Patients and caregivers use explanatory models to help explain sickness, offer treatment options, and ascribe meaning to illness and disease. Clinicians need information about patients' explanatory models in order to be of most help.

Kleinman, in *Patients and Healers in the Context of Culture* (1980), itemized questions for obtaining information about patients' explanatory models:

1. What do you call your problem?
2. What caused it?
3. Why do you think it started when it did?
4. What does your sickness do to you?
5. How does it work?
6. How severe is it?
7. Will it have a short course?
8. What do you fear most about your sickness?
9. What are the chief problems it has caused?
10. What kind of treatment is appropriate?
11. What results do you hope to receive?

These questions are relevant for any patient, regardless of cultural background. Each patient is an individual, the bearer of a unique constellation of personality, history, relationships, beliefs, expectations, and pathophysiological processes. These vary across and within patient groups; in fact more diversity is displayed *within* than *across* groups. This means that clinicians, acknowledging that culture does make a difference, must nevertheless be careful not to stereotype patients because of shallow understandings of "culture-bound" beliefs deemed "exotic" by biomedicine.



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Listening to Animals

Sally O. Walshaw, M.A., V.M.D.
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Although animals cannot speak, they certainly do communicate with each other. A person can "listen" to an animal's body language, monitor bodily functions, and assess the animal's well-being. But there is more to this than simple observations. To "listen" well to an animal, the person should indulge in anthropomorphism. One must put oneself in the animal's place and imagine what it would be like to be an animal in various situations, e.g., recovering from surgery, experiencing cancer pain, feeling the discomfort of a fever. Putting oneself in the animal's place (even the cage of a tiny mouse), can help us decide what is the right thing to do for the animal.

Some animals and some species (especially prey animals) tend to conceal their illnesses. One must "listen" very carefully for subtle indications of pain or illness in these animals. Some animals are stoic while others of the same species are very sensitive to pain. We must not discount the pain of one animal because another animal does not react the same way.

"Listening" to animals requires imagination and some guesswork. But if done carefully, it affords the best chance to provide an ethical approach to the complicated questions of animal care and use.



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Listening to the Nurses

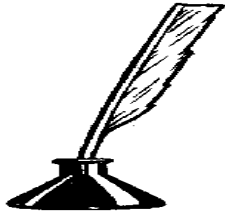
Denise Jacob, R.N., Ph.D.

The headlines are sickeningly familiar. A large health care system announces financial losses leading to job cuts totaling 1,000 or more positions. One by one, every major system in the area adds their announcements to the others. Accompanying each announcement is an official statement that "quality will not be affected."

Nurses, as the front-line for the delivery of care in hospitals will be greatly impacted by these cuts, whether through job losses or increased workload. Yet nurses are rarely interviewed for or mentioned in these media reports.

The invisibility of nursing is effectively portrayed by Suzanne Gordon in her book *Life Support: Three Nurses on the Front Line*. Gordon points out, "hospitals are repositories of thousands of stories about the value of nursing care. Yet these stories are some of the best kept secrets in America. Not only because hospitals refuse to tell them, but because reporters tend to ignore them."

With financial pressures causing dramatic cutbacks in so many health care systems it is time to seek the wisdom and insights of the largest and most affected group of health care professionals, nurses.



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Listening to the One Another: Two Kinds of “Doctor,” Two Casts of Mind

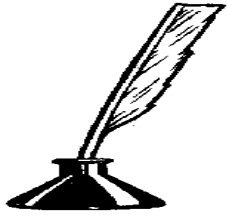
David Rovner, M.D.

College of Human Medicine

Physicians are called "doctor;" so are individuals with the Ph.D. degree. Members of both disciplines sometimes expect the other "doctors" to be like themselves.

It is important to recognize that the education of physicians and Ph.D.s are, in some ways, very different. Physicians are educated to be broadly based, be acquainted with many areas of medicine, and to make decisions under conditions of uncertainty. Physicians almost never feel that they have time to collect all the information they would like; their basic task is to recognize when enough information is available to allow action. Ph.D.s, in contrast, are educated to have in-depth knowledge about a relatively constricted area. Their basic task is to take time to design an experiment in which the parameters are carefully controlled. (Within each group, naturally, variations occur.)

Both "doctors" are "real," of course, but in some ways they are opposite in their approaches and methodology. Understanding this can help them understand one another.



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Listening by Collecting Data

Linda Beth Tiedje, R.N., Ph.D.

Department of Epidemiology

Three considerations are important in collecting data that's worth listening to. First, what data are collected? While immunization rates, smoking, and obesity are necessary, they are not sufficient. We need to enlarge the focus: what about the number of men in programs for treatment of domestic violence or the number of pregnant women in drug treatment programs? Second, we need data that captures the structure and process of health care delivery, not just indicators/outcomes. Structural variables like RN to patient staffing have been linked to avoidable post-surgical complications. Process variables centered on caregiving relationships have been described by Suzanne Gordon as the unmeasured part of health care. "Illness is a process, not an event," she reminds us. Finally, we need "upstream" thinking and data collection. If congestive heart failure is indeed a problem of the immune system, as a recent study suggested, what caused the immune system to malfunction in the first place? If breast cancer is too common, how could we encourage women to live more nurturing and healthful lives, and collect data on the effects of that prevention?

To collect data worth listening to we must go beyond our current obsession with outcomes.



Center News and Announcements

Congratulations to Dr. **Marian Gray Secundy**. Secundy has been appointed as the first Director of the Center for Bioethics in Research and Health Care at Tuskegee University. Development of the Center is one of the action launched following President Clinton's apology for the U.S. Public Health Syphilis Study. Secundy, who has a Ph.D. in medical humanities/bioethics from Union Graduate Institute in Cincinnati, Ohio, has been a professor in the Howard University College of Medicine for nearly 30 years. She has been an active adjunct faculty member with the Center for Ethics and Humanities for many years. She has spent time as a visiting faculty member, and most recently, was heavily involved in the "Voices" conference as both a planner and presenter.

The MSU "Snowflakes" (**Peter Vinten-Johansen, Howard Brody**, Nigel Paneth, Michael Rip, and Steve Rachman) recently received a major university award and signed a book contract. The group is writing a book about the life of John Snow (1813-1858) and the pioneering work on the transmission of cholera which has earned him a position as a founding father of modern epidemiology. Contract discussions were recently completed with Oxford University Press. The "Snowflakes" received the 1999 "Excellence in Interdisciplinary Scholarship Award" from the honor society of Phi Kappa Phi (funded by a grant from the Kellogg Foundation). This award goes each year to an interdisciplinary team at MSU for outstanding research or public service. The "Snowflakes" attracted the attention of the awards committee, in part, because the committee receives few nominations from the disciplines in the humanities. The group mixes the insights of a historian, a family physician/philosopher, a pediatrician-epidemiologist, a medical geographer, and a professor of English and American Studies to elucidate the historical record of Snow's work and to place it within the social and intellectual context of 19th century England. The Center for Ethics and Humanities and the Department of Epidemiology have helped fund the work of the "Snowflakes" in the past. The group is also the past recipient of an AURIG grant.

Barry DeCoster will take over as editor of the Medical Humanities Report in August. DeCoster, has a B.S. degrees in Biotechnology (concentration in biochemistry) and Humanities and the Arts, (concentration in philosophy) from Worcester Polytechnic Institute. He is currently a graduate student in the Department of Philosophy at MSU. Decoster replaces Scot Yoder who has been the editor since January of 1995. Yoder is completed his Ph.D. in philosophy this semester and has accepted a position in the Department of Philosophy at Seton Hall University.

Len Fleck delivered the second lecture in the Detroit College of Law series "Science and Society's 'Rules of Evidence'" at the Detroit College of Law in mid-March under the title "Intimidating Intersections: Science, Ethics, Medicine, and Social Policy."

Judith Andre convened and chaired a session of the mistreatment of graduate students at the annual meeting of the Association for Practical and Professional Ethics.

Len Fleck did a workshop, "Just Caring: Ethical Challenges in Managed Care Rationing, Cost Control and Priority-Setting," for a group of Kalamazoo physicians in mid-April.

Judith Andre presented a paper called "Humility Reconsidered" at the Pacific Division meetings of the American Philosophical Association in April.

Len Fleck will do a Grand Rounds presentation for the medical staff at Flower Hospital in Toledo in early June. He will present "Ethical Issues in Genetic Testing: What Are the Moral Responsibilities of Physicians?"