MEDICAL HUMANITIES PROGRAM MICHIGAN STATE UNIVERSITY SPRING 1982

JOHN STONE, M.D., PHYSICIAN-POET, GUEST SEMINAR SPEAKER

Death
I have seen come on
slowly as rust
sand
or suddenly as when
someone leaving
a room
finds the doorknob
come loose in his hand

Spring came late to East Lansing this year, and along with it came the Medical Humanities Program's first and only guest speaker— but everyone agreed he was worth waiting for. John Stone, M.D., cardiologist, director of the emergency medicine residency at Emory University in Atlanta, and author of two volumes of poetry, spoke on "The Physician as Writer" at a Medical Humanities Seminar on Tuesday evening, May 11, as part of a 3-day stay at MSU. After a very brief historical introduction regarding famous physician-authors of the past and present, Stone read many of his own poems, dealing with death, medical practice, the humor of the human condition— but above all else about careful observation of the world around us.

Speaking earlier to a group of emergency medicine residents at Sparrow Hospital at the invitation of Dr. John Wiegenstein, Stone supposedly spent an hour talking about why he, as a physician, writes poetry— but it would be more accurate to say that he spent two hours talking about why it is important to observe carefully and to make sense of all that the world tells us, and why physicians who do not do that are always in danger of turning into machines along with their overused lab devices and CAT scanners.

Also as part of his visit, Stone talked with the elective course on "The Family, Medicine, and Literature" in the Department of Family Practice, visited a course on modern poetry taught by Prof. Doug Peterson in the Department of English, talked for the hematology-oncology division in the Department of Medicine, and was interviewed for WKAR radio.

Stone will be coordinating a required course next year at Emory for second year medical ethics, but also touching on other humanities disciplines including history and literature. He discussed his course outline and described his proposal in consultation with several members of the Medical Humanities Program staff.

Instrumental in inviting Stone to MSU and in arranging for his hospitality here was Maureen Chojnacki, R.N., of the oncology clinic, who first heard Stone read his poetry at the NEH 1981 summer seminar given by Kathryn Hunter at the University of Rochester.

Epitaph: The Auctioneer
Just before the Coffin-Lidder
nails the eternal ceiling on,
tell the next-to-the-highest bidder
I am going, going, gone

ISSUES OF PRIVACY IN MEDICINE

Wade L. Robison
Department of Philosophy
Kalamazoo College

The old child's taunt, "Sticks and stones can break my bones, but words can never hurt me," is false: words can be very hurtful. A properly modified taunt would point up the two ways in which one can be hurt—by deed or by word, to put it too simply.

These general modes of hurting have their parallels in invasions of privacy. For example,

> An intern, sitting in a hospital cafeteria, was talking
> about the details of "A. Smith and her——parents,
> who are so upset and so irritating."[1]

The——parents were sitting at the next table.

This case is a good example of how one harms by words— disclosure, in this case, in a public place. But one can also harm simply by intruding, the analogue in invasion of privacy to hitting a person:

> There was an old woman with probable appendicitis.
> The bed covers were down when we came in, and her gown
> was pulled up to her waist—it wasn't clear why. She
> said, "Please pull my gown down." The physician said,
> "That's all right"—and didn't.[2]

One harms the old woman just by intruding. She was not very forthcoming with her physician: she had been seen in a certain way that she thought made her appear vulgar. And, as she later said, she was nervous about future visits: the same persons who saw her that way would be seeing her again. These are consequences of practical importance: the patient is less likely to get effective medical care if she is nervous about and not open with her physician. But even if there were not these harms, the woman was harmed just by the confrontation, by the seeing of her by others in that way.

These harms occur independently of the physician's disclosing to anyone anything about what was seen. So one can harm just by intruding. One can also harm just by disclosing.

One patient became known throughout a hospital as Miss Conehead: she talked in a high-pitched, penetrating, jerky voice, just like an old-fashioned, long-distance telephone operator. She was harmed just by the telling: any who had heard of her and later met up with her would see her in a certain unflattering way.[3] Disclosure can thus harm even without intrusion.

So disclosure and intrusion are two different ways of harming a person. We tend, rather naturally I think, to concentrate upon one or the other of these, to take one as paradigmatic of an invasion of privacy and to assimilate the other. This happens at a theoretical level. Charles Fried has written extensively on privacy and takes disclosure to be paradigmatic of invasions of privacy: intrusion is, for him, a kind of disclosure (to just one person, the intruder).[4] And Thomas Gerety takes intrusion—especially into sexual encounters—to be paradigmatic of invasions of privacy: disclosure, and even the Constitutional right to privacy in e.g. Griswold v. Connecticut, becomes a kind of intrusion (the state, for example, intruding by passing laws about what is essentially a private matter).[5]

This tendency to assimilate intrusion to disclosure or disclosure to intrusion happens at a practical level as well, I think. We tend to give as our natural examples either cases of disclosure ("talking too loudly in an elevator") or of intrusion ("walking in on a patient while the patient is bathing"), and we may be led into too simple a conception of the harms—as well as of invasions of privacy—by following our natural temptation. For though, I shall claim, intrusion and disclosure do harm in two common ways, they are different both in the ways they give rise to these common harms and in that they also give rise to different harms.

Let me begin with a brief description of two harms that may result from disclosure:

The practice of disclosure creates a context in which one fears disclosure, and fear of disclosure will constrain one's speech. A patient is less likely to be forthcoming with a therapist if there is fear that the therapist will pass on what has been told.

Disclosure can change our relationships with others. As Charles Fried has claimed, we modulate our relationships in such a way that people are, as it were, placed in rings around us.[6] We are in the center with our most intimate friend or friends, around us our other friends (not so intimate—the ones we, for instance, do not tell our sexual problems to), our acquaintances (whom we might talk to, not about our children, but the children down the street), and those on the outside whom we still know—our nodding acquaintances. One way we modulate these various relations is by controlling what we tell those around us: making information about us available to another may change our relationships with that person. If the information is given to others by another without one's (informed) consent, one has lost the capacity to control the ways in which one presents oneself to others. One may lose a friend, for instance. That is a harm because friends are valuable. There is also, independently of that sort of harm, a loss of liberty. For someone else's giving information precludes your doing so.

Intrusion can also harm:

As with disclosure, there can be a loss of liberty. For intrusion can change the very nature of an act. If someone means to be privately admonishing an employee, for instance, an intrusion by a third party into the scene can turn the admonition into a public humiliation.[7]

There is another loss as well: one becomes an object rather than a person—and so is harmed by being dehumanized. The old woman who asked, "Please pull my gown down," was being viewed as an object by her physician, who ignored her very real and very human request that she not be exposed in that way to strangers.

There are thus clearly differences between intrusion and disclosure: they give rise to different harms, and even where they give rise to the same harm (e.g. loss of liberty), they do so in different ways. But there are also at least similarities:

First, there is loss of control. In intrusion one may lose control over what one does (since the very nature of one's act may change) and over how one is viewed (since one may be treated as an object). And in disclosure one may lose control over how one relates to others and over who has access to information about oneself.

Second, there is a loss of one's sense of humanity. In intrusion one is treated as an object, viewed, looked upon as something to be looked over. In disclosure one's relations with others are manipulated, as though one had no control, no free will.

These sorts of losses occur in institutionalization as a normal consequence of treatment. In a hospital one loses control because one is in a bed, eating at set times, with one's doors open, with a roommate controlling part of one's environment, with physicians, nurses, and other assorted hospital staff entering at will, and so on. And one loses one's humanity as well. In part that is caused by loss of control: one becomes an object to the extent that one loses the capacity to control oneself or one's environment. But one also loses one's humanity because medicine requires a certain way of looking at a person—as a mechanism, with intakes and outgoes, with internal faults and failures that those in health care attempt to manipulate by drugs, operations, or what have you.

There is, in brief, enough loss of the values of liberty and humanity in hospitals to begin with. One should thus mitigate the harms caused by invasions of privacy as best one can, for they simply accentuate the worst features of institutionalization.

Footnotes

[1]This case was reported from a hospital in Michigan. I assume that everyone can generate similar examples.

[2]This case came from my experience at the University of Tennessee Center for the Health Sciences in Memphis when I was a Fellow in their Program on Human Values and Ethics. My thoughts about privacy in medicine began to jell during my tenure there, and I appreciate the opportunities the Program provided.

[3]This case also comes from my stay in Memphis.

[4]Especially, "Privacy," 77 Yale Law Review 475.

[5]Thomas Gerety, "Redefining Privacy," 12 Harvard Civil Rights-Civil Liberties Law Review 233, esp. p. 266, n153, p. 280, n175, and n180.

[6]See Fried, esp. p. 485.

[7]See Fried, p. 483.

Response to Wade L. Robison

Bruce L. Miller
Medical Humanities Program
MSU

In his analysis of privacy in medicine Wade Robison presents the novel suggestion that inappropriate disclosures and intrusions are not fundamentally different ways of violating privacy. Disclosures and intrusion harm in different ways, he observes, yet there are two similarities in the way they harm which Robison regards as the basic harm of violations of privacy, viz. loss of control and loss of humanity. I agree with this approach and disagree with the analysis frequently put forward by legal theorists who regard privacy as a concept which includes several distinct rights which have no further common element.

The basic harm involved in violations of privacy is a violation of the right to autonomy. "Autonomy" is a broadly used moral and legal concept; its full analysis would require a treatise and so only a sketch of part of it can be offered in this note. An autonomous being is a being who is self-determining; what kind and how much self-determination a being has is a primary factor in what moral categories are appropriate to that being, i.e. what that being's rights are, if any, and what obligations are owed it, if any. Rocks and other inanimate objects cannot suffer and have no self-determination and thus there are no obligations to them directly. The same applies to plants. Non-human animals are capable of suffering and so there is an obligation not to cause them suffering. What sort and how much self-determination nonhuman animals have is controversial and hence there is controversy about whether they have rights and what our (humans) obligations to them are. Human beings in the normal range of development clearly have self-determination, though what the bounds of this are is controversial.

Among the protections of the autonomy or self-determination of persons is the right not to be coerced or tricked by fraud into doing something a person wishes not to do. The notion of the legal liberty to do as one chooses rather than do another's bidding is recognition of the right to autonomy. Coercion, trickery and manipulation are only some of the ways autonomy is compromised. The control of information about oneself and control of when and how we are seen by others are important aspects of autonomy. If my bank reveals my assests to someone I'm about to do business with, I may be disadvantaged and less able to determine the deal. If an acquaintance discovers a great deal about my personal life by reading my diary without my permission and knowledge, I can no longer appear to him as I wish to present myself, for the other person has knowledge which exceeds that usual to a mere acquaintance. If I decide to privately warn a good friend that his drunkenness is self destructive, and the conversation is observed and overheard by others without my knowledge, then my warning is more than that; it becomes something other than what I intended and to that extent I have lost the determination of the

character of my interaction with my friend. In sum, disclosure and intrusion both limit and interfere with self determination.

Robison says as much when he claims that both involve loss of control. But he says that both involve loss of one's sense of humanity. Is this a harm separate from loss of control? I believe that the loss of humanity, being treated as an object, is just another way of characterizing loss of autonomy.

To treat something as an object is to treat it as something incapable of self-determination. If it is an object, e.g. a rock or plant, it is silly or preverse to treat it as if it could make choices. When the being can make choices about what will happen to it and how it will relate to others, it is disrespectful of its capacity for autonomy to act towards it as if it did not have that capacity.

If a medical professional ignores a patient's unnecessary nudity or discloses information about a patient to someone not involved in the care of the patient and further takes the position that it doesn't mean much because a medical professional is accustomed to that sort of thing and it is really different in medicine than in other contexts, then the medical professional is treating the patient as an object, for he or she is determining what the nature of the relationship is and not allowing that the patient's view is different; the patient thereby loses the opportunity for self determination.

The right to privacy is one protection of autonomy and the basic harm in violations of privacy, whether by disclosure of intrusion, is a violation of autonomy.

A likely response to the analysis of privacy by Robison and myself is that the practice of medicine, especially in hospitals, requires invasions of privacy—both intrusions and disclosures. A patient cannot be examined and treated unless medical professionals can see and touch the patient's body in ways that others cannot. Disclosure is also necessary; the many medical professionals involved in caring for a patient must keep each other informed about the patient. Of course that's true. But the problem of privacy is its proper bounds.

The standard legal analysis of privacy as confidentiality, i.e. limits on disclosure, states that the justifications for not maintaining confidentiality are four: permission of the patient (as in signing a form to permit release of medical records to an insurance company); in the interests of others (as in releasing information about a patient's communicable disease to the proper public health office); in the interest of the patient (in order to get a consult); and when ordered by a court to pursue an adjudication of a criminal or civil dispute. Any disclosure beyond this is legally improper. The complaint about lack of privacy for patients in hospitals is that disclosures go beyond those justified by law (and ethics). When a medical professional discloses information about a patient at a social gathering to persons not involved in the care of the patient, the right to privacy is violated.

One of the aspects of privacy law that is often misunderstood by medical professionals is that the right to privacy is a right of the patient, not a right of the medical professional or hospital. As such it is the patient who has control over the disclosure of information, and not the medical professional. When a patient gives permission for information to be disclosed to some other party for some specific purpose, that's-as far as it goes.

The law has less to say about intrusions of the sort Robison discusses. The reason is that it would be difficult to bring a case involving monetary damages for such a violation of privacy. However, the general approach is the same. An intrusion by touching or observation is justified when the patient gives permission. Again, the permission extends only as far as it is given. Intruding beyond that and intruding when it is not required is not justifiable. The complaint of patients is that hospital employees do not recognize this; they seem to think that once a person is in a hospital he or she has given carte blanche permission, that patients surrender all rights to control how and by whom they will be seen and touched. There is no malice in their acting so, rather it's a lack of awareness of the patient's sensitivities regarding intrusions. Though such things may be ho-hum and entirely innocent to hospital personnel, they are not ho-hum and innocent to patients. Changing an intrusion from one that is inapporpriate to one that is warranted requires a similarity in

perception by the patient and the medical professional. It can't be done by one of the parties to the interaction.

WHATEVER HAPPENED TO DONALD C.?

Lia Gaggino
MSU - College of Human Medicine

"Please Let me Die" is a classic case in the field of medical ethics - a dramatic tale of a man severely burned over 67% of his body who, although he insisted on being allowed to die, was medically treated against his will. A widely used videotape vividly portrays the agony a burn patient suffers, leaving nothing to the imagination. This case and others like it throw a monkey wrench into the medical works. Doctors, trained to treat and to cure, are by profession bent opponents of death, even when death appears to be ordained by nature.

Despite Donald's pleading and suicide attempts, doctors continued to insist that Donald receive full medical care. Donald did not die. He lost sight in both of his eyes (one was removed), he lost all of his fingers due to scarring and amputation, and he is partially deaf. The burned flesh has, however, healed after many years. In April 1982, Donald made his first public appearance at the American Medical Student Association national convention in San Diego to discuss his feelings about his experience.

The moment Donald walked through the door, a hush fell over the room full of students. He walked slowly with some difficulty to the front of the room and sat down, carefully arranging himself. He wore dark sunglasses and a three piece suit - only his face and the stumps of his hands revealed the scars of his tragic accident. He spoke softly in a gentle southern drawl as he recounted the story that so dramatically altered his life. He spoke without anger or malice, but it was obvious that Donald felt that his rights had been violated. Earlier that morning Donald had seen the video tape "Please Let Me Die" for the first time. He said the pain came back at the sounds of the clanking harness and rushing water that filled the treatment tub. He winced at the sound of his own voice begging the nurses to stop the treatment.

Nine years later, Donald is self-sufficient, lives alone and has no desire to die. The doctors who treated Donald would undoubtedly pat themselves on their backs, proud that they had saved Donald's life. Donald, however, feels otherwise. Despite the fact that he survived, Donald still feels that his rights as a human being were trespassed. He said he was initially delirious with pain and not capable of making decisions. Six months, a year, two years later, however, he was still holding fast to his convictions - he did not want to live. The pain was unbearable, excruciating, and his once bright future promised only hardship. Donald tried to kill himself. He once tried to jump out of the window, but he didn't have the strength to drag himself across the room and collapsed on the floor. He begged his family and friends to help him die, and he attempted to get legal aid, but was refused access to a phone. Looking back Donald said, "If I had to go back to those early months following the fire, knowing full well that in nine years I would be where I am today, I would still choose to die. The end does not justify the means."

In the past few years, Donald has become self-sufficient. He applied to law school and was accepted, but decided he did not want to enter the program. He now runs his own business with a friend and is confident that the business will flourish. Donald's best friend, who accompanied him to the convention, commented on Donald's incredible stubborness and indominable will. He stood by Donald throughout his recovery, but had refused to help Donald die. This caused some conflict that was eventually resolved.

Donald has had two girlfriends since his accident, but is currently uninvolved. Relationships were difficult because of the complexity of the situation. Donald says that in time the right person will come along, and he will be ready to settle down.

Donald's parting comments were directed specifically to the room full of doctors-to-be: "Patients in a situation like mine may need a cooling-off period of six months before they can make clear decisions, but after a reasonable length of time, treating a patient who is refusing treatment is a violation of human rights."

MSU James Madison student to do summer internship with MHP

Sue Anne Officer, beginning her senior year in MSU's James Madison College with an interest in pre-medicine and medical ethics, has chosen to fulfill her three-month practical internship requirement by joining the staff of the Medical Humanities Program for the summer of 1982.

Sue's main project will be the survey of existing hospice programs to see what cost-effectiveness models have been used to assess outcomes by economists and policy experts, and then to analyze the ethical and value implications of using those yardsticks of success or failure. One month of this project will be carried out at the Hastings Center in New York, where Sue has been accepted for a summer student internship for July. The project is consistent with the goals of the Medical Humanities Program to explore the interface between economic and policy issues in health care and medical ethics. Sue will also have ready access to the expertise of the Department of Economics at MSU where her husband, Lawrence H. Officer, is a professor.

In any remaining time, Sue will participate in other ongoing activities of the Medical Humanities Program and its staff, including clinical rounds, the curriculum development grant for medical ethics, and perhaps additional research projects.

STAFF NEWS AND ACTIVITIES

The latest issue of the "Notes" of the Society for Health and Human Values contains a lengthy report from SHHV president Andrew D. Hunt, outlining proposed changes in the structure and the future directions of the Society. Dr. Hunt, whose presidency extends through November 1982, is now completing his visiting professorship of adolescent medicine at Stanford and will be resuming his post as Coordinator of the Medical Humanities Program on September 1.

Along with many other organizations, the MHP co-sponsored a seminar on April 28 on "The Consequences of Nuclear War."

Howard Brody's Activities March 16: Talk to Family Practice Department, University of Western Ontario, "Placebo Effect;" talk to Westminster Institute, "Who Should Teach Medical Ethics?"

March 26: Spoke to health care interest group. American Association of University Women, MSU on "Ethics and Medical Technology".

April 15: Moderator for session on legal and ethical issues in genetic counseling, Michigan State Medical Society Maternal and Perinatal Health Conference in Grand Rapids featuring Joseph Fletcher and Margery Shaw.

May 6: Chaired Task Force on Humanities in Family Medicine Education, at Annual Meeting of Society of Teachers of Family Medicine, Chicago.

May 26: Appeared on Ch.23 "Talkabout" show discussing medical consequences of Nuclear War.

April 23/30 issue, JAMA- Brody's review of Robert Veatch, A Theory of Medical Ethics followed by May 7 JAMA, Miller's review of Hiller, Medical Ethics and the Law.

Bruce Miller's Activities Presentations on March 17 and 18 at the University of Western Ontario, London Ontario. To Westminster Institute for Human Values on "The Concept of Person in Medical Treatment" and to College of Nursing on "The Nurses Role in Consent: Respecting Autonomy"

April 2: University of Wisconsin Center System, with Martin Benjamin, on teaching medical ethics to undergraduates.

March 20: Ann Arbor. Committee on Ethics, Humanism and Medicine. Topic: "Ethical Decisions in The Intensive Care Unit."

April 28: Bronson Hospital, Kalamazoo, with Joy Curtis. Cardiology Department Topic: "Decision Making in Critical Care"

COMMENTS?

Send letters in response to the case commentary and other comments to: Medical Humanities Program, A-106 East Fee Hall, Michigan State University, East Lansing, MI 48823. Phone: (517) 355-7550.

VOL 4 NO. 3.

Medical Humanities Program
A-110 East Fee Hall
Michigan State University
East Lansing, Michigan 48824