Swapping Stories: A Matter Of Ethics

By Judith Andre, Ph.D.

"Just promise you'll never write about me," pleaded a friend of mine. There was nothing ethically unusual about his life, and he knew that identities are disguised in case studies—nevertheless, he felt strongly, and I have honored his request. (I feel slightly uneasy even quoting him here.)

Stories are one of the joys of life. In some sense stories are life, for through them we make sense out of what happens. Professionals, like all people, tell stories. We talk about friends, family, colleagues, and clients. Waitresses talk about customers, architects about clients, teachers about students. By telling stories we let off steam, we ask for moral support, we check our judgments against those of others. We entertain: with a good story, the saying goes, one can dine out for weeks.

In some fields stories are also the raw materials with which we work. In ethics and in health care, case studies are crucial. They illustrate, challenge, suggest and anchor all our theory. So we have professional reasons as well as the ubiquitous personal reasons to share what we've been part of.

There are limits, personal and professional, to what can be shared. Most professions hold their members to strict standards of confidentiality, because clients need to talk freely in

(Lottery continued on page 6)
order to get much help from us, and they talk more freely when they believe their secrets will be kept. Something similar could be said of friendship: the good it provides depends on mutual trust.

And here’s the tension: as professionals, as coworkers, and as friends, we need to protect confidences. Revealing what we have been told often violates implicit promises, abuses trust and destroys relationships. Yet as professionals and simply as human beings, we want and need to share our experiences.

Most writing about confidentiality looks at dramatic situations, and looks at conflicts between professional commitments to confidentiality and general obligations to prevent harm. Gunshot wounds, child abuse, and sexually transmitted diseases must by law be reported. Credible threats to harm people must usually be made known. HIV and AIDS create particularly intense conflicts between privacy and the right to know.

I’m interested in more mundane questions: the dangers posed by our human need to talk about one another. I want to evaluate different ways of swapping stories, about clients but also about one another.

The Moral Variables

The following factors make a moral difference. (1) Whether the people who figure in the story want it told. (2) Whether we have committed ourselves to confidentiality. (3) The good and the harm that may result. (4) Our intentions. (5) How easily the people in it can be identified. (6) Whether the audience needs to know.

The worst case would be something like this: a professional passes on to the world at large a story about his client, a story that names her and injures her. He does so against her wishes, and wanting to cause her pain. Could such a thing ever be justified? It might be the only way to prevent still more serious harm. The Tarasoff case comes to mind: a therapist’s patient threatened to kill someone, and eventually did so. The therapist was held liable for not telling the victim of the threats he had heard. Yet even in this case the therapist would not have been justified in telling the world at large. Factor (6) is at work: only a few people needed to know of the threats. At the other extreme, there is no ethical problem with a story in which identities are disguised, the client has agreed, and only good is intended and expected.

Harder cases

As usual, it is the middle ground where hard and interesting questions arise. Some might argue, for instances, that someone’s wishes alone do not count; that factors (2) through (6) above matter, but (1) does not. Such a position would let me write about the friend I mentioned earlier, particularly if I disguised his identity. Yet I do not, and not only because I made the promise he asked of me. My reluctance stems partly from the fact that any story can get back to anyone; if he should someday read a story which he knew was his, he would feel betrayed. What if I disguised his identity so thoroughly that he could not recognize himself? Even here I would hesitate; I suppose what grounds that hesitation is a sense that one’s story is private property. I do not have permission to use his.

Others might argue that factor (3), harm to the figures in the story, does not count, especially where the only harm is knowledge of unflattering facts. Recently, for instance, I heard of a health care professional who refused to care for an AIDS patient. If I added a few more details, knowledgeable readers could track down the provider involved. Does s/he have a right for the story not to be known? Partly that depends on how the story first “got out.” If I learned of it through serving on an ethics committee, then I have probably made an implicit promise not to reveal what I learned. If I learned of it from the patient, however, my telling would violate no commitment, no professional obligation. Refusal of treatment is, in some sense, a public act.

Yet I do not feel free to pass on what I know, without significantly disguising the details. Why? For one thing, “what I know” overstates the case: I heard the story from some-
one who had heard the story from someone else. Every fable, every child's game, about gossip reminds us that stories mutate in being told; in every ethics consultation I've taken part in, it has taken 30 to 45 minutes to arrive at a reasonable grasp of the basic facts, and I've always thought that another 30 or 45 minutes would alter my understanding still further. What is morally relevant here is not any promise I've made, but the chance of harm to someone who does not deserve it. In fact I would make a still stronger claim: even if the provider were without question in the wrong—say, a cardiologist who refused to put her stethoscope to an AIDS patient's chest—I do not think the story should be told without disguise. People do not usually "deserve" to be thought poorly of, even when those thoughts are accurate. More precisely, the advantages of having people understand one another's faults rarely outweigh the harm to the maligned and the danger of exaggeration. We do love to talk.

Finally, there are our intentions (factor (4) above). These are notoriously hard to get hold of. Here I will use "intentions" loosely, to include all that one hopes to accomplish. In cases like Tarasoff one's intentions seem morally irrelevant: the threat has to be made known, even if one secretly takes delight in harming the threatener. Yet even here intentions may matter, not to the rightness of the disclosure, but to the character of the discloser. Morally speaking, it's not great to delight in someone else's suffering.

Intentions also play a deeper and more practical role. We need to be suspicious of our motives. We may think we're telling a story because it's funny—but just under the surface we may be telling it from anger, and a desire to ridicule.

Here we come full circle. Story telling allows us to discharge our anger, check our perceptions, sort out feelings, share our lives. It would be puritanical to deny those needs. Yet stories can easily hurt, and hurt badly; we are likely to underestimate how much they can, and how much we may want them to.

Can we keep our stories and tell them, too? With several cautions, I think we can. Ideally stories are told only with the subjects' permission. Of course groups of friends develop norms, as do cultures, and it becomes understood what is private and what is public. (Watch out, though, for the norms professionals develop about sharing among themselves. Clients may have no idea of the kind of story-swapping their professionals take for granted.)

Without the subjects' permission, implicit or explicit, stories should be so heavily disguised that its characters would not recognize themselves. (In clinical sciences variables should not be changed: age, sex, history all can have clinical significance. What serves as a disguise here is abstraction: a "67-year old female with chronic obstructive pulmonary disease" is too spare a description to pick out anyone. When the combination of physical facts is unique, the client's permission should be gotten.)

Stories that (apparently) can hurt no one need less care.

But sometimes we speak from anger and pain; sometimes we need to. And catharsis demands that names be used. Here the best protection is choosing and limiting one's audience. A single trusted friend, bound to confidence, is the best choice.

**Final Thoughts**

The position for which I argue may seem rigorous, even rigid. But I have seen communities of friends and workers which flourish within its protection, and I have seen others damaged for lack of it. I would be glad to hear what others have to say--your thoughts and your stories.(!)
Fiction as Historical Text: A Country Doctor and the History of Medicine

By Harriet A. Squier, M.D.

Historians in the late twentieth century define the history of medicine as “a subfield of social or cultural history” which necessitates the use of “different sources and approaches” (1). The history of medicine has become a broad field practiced by a variety of writers. As Leavitt says, this is “the history of healers and sick people within the actual context of their interaction (social and intellectual), and one side without the other is only partial history.” (2) Fiction fits well into this broadened definition of the history of medicine.

A frequent misconception about the use of fiction as historical text concerns the perception that fiction by definition is not factual, that it deals with untruths. How can a novel be at all helpful when it describes events that never really happened? But as the writer, Henry Hazlitt, has pointed out, truth can be defined in several ways: “There is a certain ambiguity about the phrase ‘being right.’ For there are several kinds of truth, and the truth of literature is not necessarily the truth of science.” (3)

John Gardner goes further to describe the truth of literature. He divides it into three categories: factually correct truth; emotional truth which requires language and description that accurately reproduce an emotional response to an event; and moral truth, which discovers and affirms the basic essence of human existence, and which is the “highest kind of truth.” (4) We can see, then, that fiction allows the reader to experience the events and emotions that it describes. The reader not only feels and experiences the fictional events, characters, and environments as real, but is also encouraged, if not required, to recognize the shared human experience which defines our moral selves.

A Country Doctor, by Sarah Orne Jewett, published in 1884, is a novel set in rural Maine which describes the lives of Dr. Leslie, a rural physician, and his ward, Nan, who chooses to become a doctor herself. This book gives the student of medical history a very different perspective from texts written by historians. We see a physician in rural practice, the kind of physician whose story is not easily accessible to medical historians, as private practitioners rarely left writings behind. We also learn about a woman in the early 1880’s who chooses to practice medicine in the nineteenth century, we do not often get to see inside a woman’s life as closely as we do in this novel, to see just how many obstacles were in the way of a woman who desired to follow a professional career.

One of the best and most extensive aspects of A Country Doctor is the description of Dr. Leslie as the ideal physician. This is an ideal most patients would appreciate even today. We see him interact with a variety of patients and friends, and become convinced that he embodies everything good about the practice of medicine. Dr. Leslie is so conscientious, selfless, articulate, thoughtful, and dedicated, and the reader becomes so enamored of him, that he becomes the standard against which all other physicians are measured. Only Nan has the personality and integrity to rival Dr. Leslie.

We see Nan make rounds with Dr. Leslie and, as a child, she is comfortable in all sorts of homes and environments; as an adult, she shares medical anecdotes and opinions with her mentor. She becomes Dr. Leslie’s trusted apprentice and is accepted by the community. We are confident by the end of the book that Nan is like Dr. Leslie in her competence, dedication, selflessness, friendliness, and like him, has obtained and will continue to obtain professional stature. In addition to showing her competence in medicine, however, Nan must grapple with the societal pressures which make it difficult for a woman to pursue medicine (or anything else) as a career. We witness Nan’s struggle with social disapproval and her own insecurities.
about practicing medicine. The novel does best at showing us how different she is from the prevailing norms of female roles in 1880.

Medical history, for the purpose of analysis, tends to isolate the topics under discussion; women in medicine are discussed in separate chapters of volumes from men; hospital medicine is separated from other forms of practice; institutions may be discussed separately from therapeutics; famous practitioners are discussed in relation to their discoveries rather than to their practices, colleagues, or families. A Country Doctor is an example of how these elements are fused in one work. One cannot separate Dr. Leslie from his medical beliefs, from his training, from his practice; Nan, similarly is not separable from her feminist ideals, her profession, her knowledge. While medical history teaches us about the larger developments of trends in therapy, education, and institutions, novels like A Country Doctor show us how this larger picture is or is not important for the individual physician. Without the intimate picture, it is difficult to weight the importance of the larger history on the individual. Without the larger picture, we would not know how representative the individual is. Without both pictures, our knowledge of medical history remains incomplete.

Footnotes


2. Ibid. p. 1473.


Literature Update:


There are two recently published collections of literary treatments of health and medicine which may be of some interest to the readers of the Medical Humanities Report. The first of these, Trials, Tribulations, and Celebrations, is edited by Marian Gray Secundy with the literary collaboration of Lois LaCivita Nixon. Ms. Secundy is a professor of Community Health and Family Practice at Howard University College of Medicine and a King-Chavez-Parks scholar here at Michigan State University for the 91-92 academic year. This collection of short stories, essays, and poetry is subtitled "African-American Perspectives on Health, Illness, Aging, and Loss" and draws from such African American writers as Langston Hughes, Alice Walker, Maya Angelou, Gordon Parks. The book is divided into three sections: Illness and Health Seeking Behavior, Aging, and Loss and Grief, each with an accompanying set of discussion questions.

The second collection is entitled On Doctoring and is edited by Richard Reynolds, M.D. and John Stone, M.D. It too is a collection of short stories, poems, and essays and includes such authors as William Carlos Williams, James Dickey, Richard Seltzer, Flannery O'Connor, David Hilfiger, Tolstoy. Although there are several works which examine the patient's perspective the collection is primarily focused on the experiences, ethical dilemmas, and concerns of physicians. Both books would be an excellent resource for someone interested in further pursuing the general topic of stories and medicine.
stage she gets the black dot. The story concludes with her screaming, "It isn't fair, it isn't right."

My literary friends tell me the story is about cruel and irrational traditions being perpetuated for the sheer sake of tradition. Well, that sounds like what literary folks would say. But I read it as a philosopher. That word "fair" leapt from the pages at me. Maybe this is a parable about life and the unfairness of premature death. We do often speak that way. But this does not seem like a very satisfying interpretation. For what is really bothersome about the story is the fact that everyone participates in stoning to death the unfortunate winner of the lottery. This is not an accident of nature. This is deliberate social policy.

What should we make of Mrs. Hutchinson's cry at the end of the story that her being stoned to death is neither fair nor right? My initial reaction is to say she has been fairly treated. The lottery was not rigged. She stood the same chance of being chosen as every other person in that town. Moreover, in the past she herself had participated in stoning to death other members of the town, some being children no doubt. There is no evidence from the story that anyone took any perverse pleasure from the stoning. As nearly as I can tell, it was done out of a sense of duty. But was it right?

There is no shortage of reasons for saying the entire practice was immoral. First, there were no larger social welfare reasons that provided even minimal moral justification for the practice. This was not the draft, where the security of the nation might be at stake and individuals would have to risk their lives in order to protect the nation. In fact, no reasons of any kind are given for the practice. Second, this practice involves the violation of the basic rights of individuals, specifically, the right not to be killed. Third, what seems especially heinous from a moral point of view is that these killings have been given deliberate social approval. These are no gang-on-gang drug killings toward which society might adopt an attitude of indifference. These are the killings of decent ordinary citizens by other decent ordinary citizens. This is morally appalling.

But what is even more appalling is that strict adherence to norms of fairness provides a moral veneer for a morally unconscionable practice.

How might this story be connected to health care? I was reminded by this story of the Harris "survival lottery," one of those clever philosophic thought experiments from the mid-1970's. The survival lottery involved organ transplants. In brief, the idea was that if we were each rational individuals, and if each of us wanted to maximize the likelihood of our survival should a major organ fail (such as heart, lung, liver), then we would not be satisfied with the current policy of waiting for a brain-dead accident victim, who was a good tissue-match with us, to be brought to the local hospital. Instead, we would all be part of a lottery (maybe by tissue-type). When there were 3-5 of us in need of different major organs with the same tissue-type, then a lottery would be held and the "winner" would "donate" their vital organs to these needy individuals. The "winner" might lose thirty years of life, but society, in the person of these other fortunate individuals, would gain 90-150 extra years of life. Should we have a social policy that would create a survival lottery, and perhaps require that all be part of it? Again, the lottery would be perfectly fair. In addition, this seems like a rationally and morally preferable policy to endorse over our current practices since both social utility and individual utility would seem to be maximized by the practice. But would it be right? According to Harris (Violence and Responsibility, 1980) this is a much more difficult question to answer than we might first think.

I suspect that most of my readers do not have much patience with this sort of philosophic thought experiment. So, let us consider another spin-off from this story that is more closely connected to the real world. I have in mind the issue of health care rationing, not at the social level, but at the level of the identifiable individual. Hadorn, for example, has recently observed that what will kill the Oregon health care
rationing experiment is society’s commitment to the “Rule of Rescue.” (See JAMA-- 265 (1991), 2218-25). In essence, this is the rule that is operative when we devote massive resources to saving the life of an identified individual, i.e., the trapped miner or the little girl trapped in a well in Texas.

Insurance companies run up against the Rule of Rescue when they refuse, for example, to pay for an autologous bone marrow transplant (ABMT) for women with breast cancer because the cost is about $150,000 and there is no more than a 5% chance of survival for a year or longer. Note that part of the difficulty is that we are not dealing with something that is absolutely scarce, such as transplantable hearts, where, regrettably, large numbers of individuals will be denied that opportunity for a longer life. Instead, we have a relative scarcity of money, which can be taken from some other social use that does not deny someone extra years of life. That means that we have the capacity to rescue that individual, and what we are lacking is the will to rescue. Further, when we have insurance rules (whether public or private) that announce we will not rescue women with breast cancer through ABMT, then that means their death will be allowed as a matter of deliberate social policy. That is, we cannot use as a moral shield the natural lottery, claiming in effect that their death is merely a result of natural misfortune. This is a social lottery.

David Eddy has suggested an alternative way of viewing this case, which would skirt the Rule of Rescue and give more legitimacy to such a social lottery. (See JAMA-- 265 (1991), 1446-50) He points out that there is an alternative use for the $150,000. Specifically, that will buy ten years of screening mammograms for 150 women, and it will reduce the number of deaths from breast cancer in that group from 36 to 29. He notes that if we have only $150,000 to spend, and if we spend it all to try to save this patient (the identified individual) after she has gotten breast cancer (believing thereby that we are doing everything for her), then “everything will not have been done for that person if you consider that person’s entire lifetime.” For that woman could well be one of those whose salary would have been saved by a screening mammogram if the $150,000 had been available for that purpose. (To avoid a distracting objection, the reader should imagine a male version of this case that would present a similar scenario for testicular or rectal cancer.) Eddy’s point is that this latter scenario is rationally and morally preferable to rescuing identified individuals in these circumstances since each of us and all of us will be better off if we adopt this strategy, that is, if we all become part of this social lottery, this rationing scheme, that we will have imposed upon ourselves.

To conclude, how should we respond now to Mrs. Hutchinson, dying of breast cancer, who has been denied ABMT therapy by Blue Cross, screaming at us, her neighbors, “It isn’t fair, it isn’t right?”

One characteristic of a story is that it clearly makes sense and hangs together once it has been told, but can seldom be anticipated before it has been told. There is unlikely to emerge any scientific or philosophical truth that will allow the physician to predict accurately what the impact of any given sickness will be on the life plan of any given patient. But it is another characteristic of stories that certain similarities do emerge once one has been told a number of them. We hope that as physicians pay more attention to the stories of the patients, their ethical quest to enhance personal autonomy and self-respect in the wake of sickness will be aided by an increased awareness of the richness of the human response to illness and anguish. ---From Howard Brody’s Stories of Sickness
An Interview With New Center Member Judith Andre

MHR: Could you begin by discussing some of the projects you have been engaged in prior to coming here? For instance, what were you working on when you had your fellowships from 1988-1990?

ANDRE: I began them with one interest and left with two. The project whose description constituted the fellowship application was an examination of the limits of the market. What kinds of things should be for sale, should be commodified? What I developed during that time was an interest in concepts of moral growth and moral maturity.

MHR: What was the transition between these two projects? Could you describe the connection between them?

ANDRE: There's no connection (laughter). The connection is that someone asked me to take part in a symposium honoring the work of Edmund Pincoffs. In preparing my commentary I started playing around with some of the ideas involved.

MHR: Before you came here this fall you were teaching at Old Dominion University. Why did you apply for the position here at the Center?

ANDRE: Well, a couple of things. Primarily, I wanted a job that offered me somewhat more scope. I was in the kind of traditional mid-level state university where I had a very heavy teaching load and a great deal of it was introduction to philosophy, and beginning logic. I liked teaching the introductory courses, but I wanted the chance to teach other things, to work with students who were a little better prepared, a better library, to have more colleagues interested in things I'm interested in.

MHR: And what has it been like these first few months?

ANDRE: It's been exciting. I should say that one of the other things I wanted was that I had been doing practical ethics across the board: engineering, business, municipal clerks, school teachers. I felt stretched too thin. I wanted to concentrate on one area, medical ethics, and know it in depth.

MHR: Could you speak a little bit about your article you wrote for this issue on swapping stories?

ANDRE: Last fall I was invited to speak to the Michigan Midwives Association. The person who invited me was concerned about the way they, but also all health care professionals, including quite mainstream ones, freely share stories about their clients. She wanted a little consciousness raising on that and a chance to talk about it. I'll be giving a similar workshop at the MERN conference.

MHR: What sorts of projects do you plan to pursue now that you are here at the Center?

ANDRE: Partly I was hired because they wanted somebody who was doing something like feminist theory. I can see that already I've introduced topics that weren't there, and have a different perspective on some of the topics that were there. I will be teaching a course next spring on feminism and ethical theory, although that won't be focused on medicine in particular.

Also as I said earlier I am interested in the concept of moral growth, not "development" because that's a term which is tied to invariant stages of growth. That's Kohlberg's kind of thing. I'm interested in growth in a looser sense. This is something I've done a great deal of reading on and some writing. In fact I've got a paper coming out in the Journal of Medical Ethics on medical education. I'm interested particularly in what happens during professional training. If you count as part of moral maturity one's moral perception, what you see, how you value what you see and what you notice, then the concept that's developed of the patient during medical training is a part of the moral growth, or lack of it, or regression, of the medical student.

MHR: Regression?

ANDRE: Yes, there's a sense of distance between you and the patient because of a tendency now to see things in terms of the pathophysiological processes and there's often a sense of frustration and failure. You probably came in with the idea of the patient as someone a lot like you, with some illness that can be fixed, someone who will cooperate with you in the fixing and be really grateful. Instead you're likely to get a lot of patients who are very different from you, often both older and poorer and who can't be "fixed."

Actually, Michigan State has tried to do some very interesting things, especially in the eighties, to help students develop a more sophisticated capacity to deal with these problems. All I can say is that I think that they should continue to try out these ideas and see which ones work. I do have some particular ideas: for instance, that medical students need help dealing with their own pain. You treat other people the way you've been treated. If you don't have an opportunity for dealing with your pain and your mistakes, and you have to suppress this and go on, if you have no time and you're constantly exhausted, for many years constantly exhausted, this does not speak well for psychological growth. And psychological growth is an important element in moral growth.