This issue of the Newsletter is largely devoted to presentations at the Eastern Division session sponsored by the Committee on Philosophy and Medicine. The program addressed the topic of "Sibling Obligations in the Age of Genetics." There were six presentations at the meetings. Together they provide rich insights into sibling responsibilities, genetics, and just how these different sources of moral obligation can converge and inform our understanding of ethics. Five of these presentations are included in this issue.

David Benatar was our first speaker. He presented his remarks on "What's So Special about an Age of Genetics?" He argued that this is not a particularly special age of genetics. Rather, genetic information has been a part of the fabric of moral life throughout recorded history. It is just one of many kinds of information that we can use to help or to harm one another.

Dan Brock took the opportunity to focus on the question of whether medical professionals should breach confidentiality and disclose genetic information to family members when the information might have an impact on the relative's health or reproductive decisions. In his remarks on "Rethinking Confidentiality in the Context of Genetics," Brock reviews the arguments that usually support confidentiality as a special responsibility of health care professionals. He also discusses considerations for breaching confident about genetic information and the framework that would have to be put in place if such breaches were allowed.

Len Fleck continues on this theme of disclosure to siblings by providing a very engaging set of scenarios. In his presentation, "Sharing Genetic Information: What is a Minimally Decent Sibling to Do?" he draws on Judith Thomson's famous abortion paper to show how the concepts of the Good Samaritan and minimal decency can be used as relevant norms for decisions about sharing of genetic information. Fleck also discusses how the standard ideas of ethics, such as relevance, salience, uniqueness, seriousness of consequences, and reciprocity can inform genetic decisions. Fleck's carefully designed and thoroughly entertaining vignettes, and his creative variations illuminate the issues and illustrate the points that he wants us to see.

Karen Kovach and Hilde Lindemann Nelson approach the issue from additional and different perspectives. Kovach draws on Aristotle's discussion of friendship to explain the special moral features of relationships between siblings in her paper, "Extraordinary Knowledge and Ordinary Duties." She then discusses genetic responsibility so as to reflect the source of sibling duties. Nelson takes yet another tack. In her piece, "Unchosen Affinities," she employs narrative description to make sense of the unique and distinctive genetic responsibilities that siblings in different situations can have to one another. She relates an especially engaging story that makes a compelling case for finding the answers among the narrative details.

At the meetings in Washington, D.C., our sixth panelist was Samuel Gorovitz. He spoke more generally about "Sorting Siblings Sensibly" and touched on many of the issues that other presenters chose as their focus. The audience enriched the session with numerous challenging questions and lively repartee. It all added up to an exciting and informative session. We are grateful to those authors who contributed their manuscripts for allowing us to present their thoughts to the larger Newsletter audience. The combination makes a useful unit for those who are interested in the interface of these two challenging topics.

In this issue you will also find another delightful story by Felicia Nimue Ackerman. The one for this issue is "For the Loved Ones in Your Life."

Also, in this issue is a review essay of Stories of Sickness, Second Edition, by Howard Brody. The informative and insightful discussion was provided by Matthew Rottnek.

In his last contribution of "From the Chair," Ken Kipnis outlines his view of what should be covered in an undergraduate medical ethics course. We welcome comments and discussion of his recommendations and approach to such a course.

As always, please continue to send along your announcements, letters, papers, poetry, and stories so that they can be shared, used, and enjoyed by all. Directions for formatting your submission can be found at the end of the Newsletter volume. Feel free to volunteer a book review. Contributions and queries should be sent to Rosamond at the address below. For ease in communication please include your phone and fax numbers and email address if you have one.

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**Teaching Ethics to Future Physicians***

Ken Kipnis

Those of us who teach medical ethics in philosophy departments can find ourselves intellectually positioned between two areas of inquiry. At one end, some of our colleagues are investigating novel problems of philosophical interest that have emerged from health care. Much of the estimable work of Frances Kamm and Jeff McMahon has that character: except for the types of problems they take on, the concepts and methodologies they employ are ones that are familiar to philosophers. John Harris’s anthology Bioethics includes work of this type. These materials are characteristically addressed to philosophers and often support results that are not readily incorporated into the practices of health care professionals who must respond to other imperatives.

At the other end of the spectrum are philosophers like Haavi Morreim and Jeff Spike, who work in medical schools and are very good at conversing with physicians, hospital administrators, researchers, and so on. These “practitioners” publish, consult, and lecture broadly; but despite a foundational philosophical training that is evident in their work, they are not primarily participants in philosophy’s conversations. Their audiences include novices and professionals in health care who need practical advice on the management of immediate and concrete ethical problems.

The spectrum is not unique to medical ethics. Philosophy of law has exponents who look to their philosophical colleagues and others who work with and write for legal professionals. Philosophy of science can also be done in ways that require an understanding of the history and content of science, as well as in ways that do not.

There is, accordingly, a decision that philosophy professors have to make when they take on an undergraduate course in medical ethics. One approach focuses on the conceptual puzzles that fascinate us and can yield to the intellectual tools we have developed to engage them. This is a familiar path. A second approach works through the nettlesome dilemmas that can challenge the ethical judgment and compromise the integrity of health care professionals. It is arguably a preferred route where most students aspire to careers in health care and philosophy majors are a comparative rarity. It demands that instructors know something about clinical practice, how and philosophy majors are a comparative rarity. It demands that instructors know something about clinical practice, how and others who work with and write for legal professionals. Philosophy of science can also be done in ways that require an understanding of the history and content of science, as well as in ways that do not.

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A sixth and final objective takes us to a broader level. For the medical profession exists to serve—centrally—the health needs of its community. The relationship between the two expresses something of a social contract: Benefits and resources flow directly and indirectly to members of the profession as its distinctive services are rendered to its community. A community is in good order when both parties are reasonably satisfied with the balance between the goods they receive and the burdens they are obligated to shoulder. Questions of justice, social values, ethical obligation, and public policy pervade aspects of that transaction and, ironically, physicians will almost inevitably find themselves on both sides of the bargaining table, as providers and, on occasion, as patients.

If, in one context, the ultimate student in a medical ethics course is the medical profession, in another the professor’s ultimate client is the community. For a central collective task of the profession is to reach a stable and just accommodation of its values. The boundary between professional associations and trade associations is often blurred. Accordingly, those who teach professional ethics in health care must...
What’s So Special about an Age of Genetics?*  
David Benatar  
University of Cape Town  

Introduction  

Our topic is “Sibling Obligations in the Age of Genetics.” However, instead of discussing such obligations in the age of genetics, we would be better advised to substitute the indefinite article (and some lower case) and speak about an age of genetics. Although it is tempting to think that the recent and imminently expected advances in genetic knowledge make ours the age of genetics, a more cautious approach is to be preferred. History has a tendency to make fools of us. The grand claims made by those who lack the future’s perspective on their own time, and see their era only against the backdrop of the past, are frequently, and often comically refuted. Our age may seem as though it is the age of genetics. This appearance might even turn out to be true. However, it may also be the case that genetic knowledge in the future far outstrips that available to us. If that happens, then our claim to live in the age of genetics may appear as laughable to future people as Gregor Mendel’s making such a claim about his time appeared to us.  

There are difficulties, though, even with referring to ours as an age of genetics. If we recognize that genetic knowledge is not new and that it could advance far beyond what we currently expect, we are confronted by the following question: What differentiates one age of genetics from another? Although there are important milestones in the history of genetic knowledge, such knowledge, like all knowledge, evolves. Any reference to an age of genetics, must include a recognition that ages of genetics are taxonomic conveniences. I shall understand our age of genetics rather vaguely as one characterized by “new genetic knowledge,” to employ a term in common use. The term suggests that there was an “old” genetic knowledge, and thus our age of genetics is to be distinguished from some earlier age of genetics. I leave open just what that was. Just as the “new genetic knowledge” needs to be distinguished from what came before, it must also be distinguished from that genetic knowledge which might come after it. It would be unhelpful to suggest that the term “new genetic knowledge” excludes everything not known right now. Thus I shall understand it as excluding only that significant future genetic knowledge that cannot now, with some degree of specificity, be reasonably anticipated or expected.  

I shall not discuss whether siblings ever have special obligations to one another. Nor shall I discuss what obligations they might have as result of the new genetic knowledge. Instead, I shall consider what facts about our genetic age might be thought to affect sibling obligations. I shall argue that new genetic knowledge does not generate any new kinds of sibling obligations. In other words, if siblings do have any special obligations to one another, these could as easily arise from old genetic knowledge or from nongenetic knowledge.

How the new genetic knowledge can harm and help  

Those who believe that the new genetic knowledge gives rise to special sibling obligations, point to the ways in which such knowledge enables siblings to harm and help one another. The argument is that since new genetic knowledge empowers siblings in these ways, there must be obligations governing the use of such power.  

In what ways can the new genetic knowledge harm and help siblings? Consider harm first. Given that (full) siblings were produced from the gametes of the same parents, they have close genetic connections. If one sibling seeks and acquires genetic information about himself, this could cause his siblings to acquire information about themselves—information that they might well not want. Of course, it is not true that every bit of genetic information somebody acquires about himself would involuntarily become known to that person’s siblings. If the information is about a sporadic (nonhereditary) mutation, acquiring this information about oneself implies nothing about one’s siblings. Even where the information is about a hereditary condition, one might sometimes be able to conceal it from one’s siblings. However, if the information is of a momentous nature, it is unlikely that siblings (unless estranged or otherwise not in communication with one another) would be able to conceal this effectively from one another. It should be emphasized that, in the case of siblings (unlike other genetic relationships), the nature of the new genetic knowledge about himself that a person could involuntarily acquire from a sibling, would be knowledge of a probabilistic kind. That is to say, knowing that one’s sibling has some genetic condition would not mean that one certainly also had that condition. It would usually indicate, at most, that one had an elevated chance of also having the condition. For instance, if one knew that one’s sibling had the gene for Huntington’s Disease, one would not know for certain that one also had the gene, although one would know that one had a 50% chance of being affected. This (probabilistic) knowledge may be sufficiently devastating to make such involuntary knowledge unwanted. One might prefer to avoid the distress of knowing these odds and rather live with greater uncertainty, as many people do in declining genetic testing.  

An upshot of the relatively close connection of sibling genetic information is that disclosing genetic information about oneself could simultaneously be a disclosure of probabilistic information about one’s siblings—information that those siblings might not want disclosed. If, having established that one has the gene for Huntington’s Disease, one proceeds to disclose this publicly, one will simultaneously be disclosing that each of one’s siblings has a 50/50 chance of having the gene. This is a disclosure that one’s siblings might well prefer one not make. They might fear—often quite reasonably—being ostracized, subject to discrimination or simply being spoken about as an object of pity.

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**Endnotes**  
* Some of the ideas in this article are drawn from my “Professional Ethics and Instructional Success,” in *Professing Medicine*, edited by Audrey Kao, M.D., Ph.D. AMA 2001.  

**Articles**
There are also ways in which the new genetic knowledge can help. Siblings can help one another establish their genetic risks. For instance, siblings may be needed for linkage analysis, which in turn is needed to establish an association between a condition and the genetic marker. For such analysis both affected and unaffected family members are needed. However, it should be noted that these are extremely indirect and relatively unusual ways of helping a sibling. Linkage analysis is a research tool rather than a diagnostic one and is the first part of a long process of discovering a gene or collection of genes that cause a disease. Discovering the genetic cause might then help affected siblings or their children.

The new genetics facilitates more sophisticated and accurate HLA testing for organ transplantation, enabling a more accurate determination of which (if any) siblings would be sufficiently suitable (live) donors for a brother or sister with end-stage renal or liver disease.

**Harming and helping with the old genetic knowledge and nongenetic knowledge**

Tenuous and unusual though some of the above ways of helping and harming one’s siblings with new genetic knowledge may be, I do not deny that new genetic knowledge can enable siblings to harm and help one another. However, the kinds of ways of harming and helping are not new, even if the specific means are. Consider first the two ways of harming.

There is nothing new about somebody’s acquiring unwanted information because a sibling obtained information about himself. If, for example, somebody established that his grandfather had been an SS officer, his father a Klansman, or his mother a prostitute, then, unless he succeeded in hiding this information from his (full) siblings, they too would know about their grandfather, or father or mother. These siblings might much rather not have this knowledge, preferring to think of their parents or grandparents in a more favorable light.

Similarly, if having learnt of grandfather’s, father’s or mother’s activities, one sibling made this information public, he thereby would be publicly disclosing information about the grandfather, father or mother of his siblings. And these siblings might much rather not have this information disclosed. They might fear ostracism or shame. Thus, it is not only the conveying of new genetic knowledge about oneself that conveys information about one’s siblings. Conveying nongenetic knowledge does the same.

There are also special ways in which siblings can help one another without recourse to new genetic knowledge. Siblings can help one another by providing much-wanted non-genetic (or old genetic) information. For instance, where there is an age gap between siblings, and parents are no longer alive, one sibling may well be able to provide helpful familial medical history to benefit another—information not available from another source.

Similarly, even before the new genetics, it was well known that siblings would be more likely to be suitable organ donors for one another than were nonrelatives. The new genetics might facilitate still better matches, but tissue typing is not new and siblings willing to be typed have been especially able, for a long time, to assist one another by donating an organ.

In short, then, siblings have for a very long time—well before the attainment of the new genetic knowledge—been especially well placed (in some ways) to harm and help one another. This is because of the interconnectedness of family information. The new genetic knowledge may be a new kind of knowledge whereby this harm and help can be effected, but the principles remain the same.

Those who think that the new genetic knowledge is exceptional in some way, should consider two facts. First, new genetic knowledge is not necessarily more sensitive than other knowledge. Some of it may be, but other new genetic knowledge is less sensitive than non-genetic (or old genetic) knowledge. Second, some nongenetic knowledge will be more definite than new genetic knowledge. For example, if one’s siblings are full siblings, disclosing that one’s grandparents were Nazis is to convey not mere probabilistic information about one’s siblings’ grandparents, but definite information about them. Thus, new genetic knowledge cannot be said to be exceptional either because it is necessarily more sensitive or more certain.

**What are siblings?**

The claim that an age of genetics does not generate any special kinds of sibling obligations can be further supported by considering what siblings are. Obviously there are different senses in which people can be siblings—most notably genetic and social. People are (full) genetic siblings if they were formed from the gametes of the same parents. (If they have only one genetic parent in common, then they are half genetic siblings.) People are (full) social siblings if they are reared by the same adults, irrespective of whether they were formed from the gametes of those adults. (If they have only one social parent in common, then they are half social siblings.)

For new genetic knowledge to be used to help or harm siblings, the siblings must be genetic siblings. However, it is the social sibling relationship that seems morally more important. That is to say, if there are special familial obligations these would most plausibly be generated by the psychological, emotional and other bonds that often exist between social siblings, rather than the genetic connections. If special duties are owed to family members it is because of what they mean to us, what they have done for us (whether wittingly or unwittingly), and because of how we are especially (socially) interdependent.

Could one, however, have a special obligation to a social stranger just because that person happened to be a genetic sibling? Imagine, for example, a case of genetic siblings who were reared by different parents without knowing one another (or even knowing of one another’s existence), until their genetic connection is discovered much later in adulthood or in old age. Of course, a social sibling relationship could then begin to develop between these people, but we can ask whether they have any special obligations to one another upon discovery of their genetic relationship but prior to any social relationship’s having been developed. It seems that insofar as they do, the special obligation would have to be the kind of obligation that one person is sometimes said to owe a stranger in virtue of being specially placed to be able to help or harm that stranger. It is usually thought, for example, that if one is the only person next to a pool in which a stranger is drowning (and one can save that stranger without too much cost to oneself) that one is obligated to save the stranger’s life. Obviously, there are many different ways in which one can be specially placed to help a social stranger. Being next to the pool in which he is drowning is one such way. Being his genetic sibling—or, put differently, being in a corner of the gene pool with him—is another. Thus we do not have to postulate that it is genetic siblinghood itself that generates any special obligation. A more general principle of helping those whom one is specially placed to help (as long as the cost to oneself is not excessive), would suffice.
Conclusion
We should conclude, then, that our genetic age does not give rise to any special kinds of sibling obligations that could not arise in any other age. We can apply broader principles about obligations in general (and sibling obligations in particular, if one thinks that there are such obligations) to the facts of the new genetics. Although new genetic knowledge may introduce new ways in which siblings are specially placed to harm and help one another, there is nothing new about siblings being specially placed (in other ways) to harm and benefit each other. Thus, the notion of sibling obligations is not challenged by our age of genetics.

Brief remarks made at a session on “Sibling Obligations in the Age of Genetics,” arranged by the American Philosophical Association Committee on Philosophy and Medicine, Monday, December 29 2003.

Rethinking Confidentiality in the Context of Genetics
Dan Brock
National Institutes of Health

The confidentiality of medical information has received new challenges in recent decades. In the Tarasoff case in 1976, the court held that a health care professional has a legal duty to breach confidentiality when necessary to prevent a serious harm being caused by his or her patient to a third party. The court held that the health care professional is obliged to make a judgment about the seriousness of the potential harm, its probability, and what steps are reasonably available to the health care professional to prevent the harm. An important feature of the so-called Tarasoff rule is that it does not only permit the health care professional to breach confidentiality to protect someone who would be otherwise harmed by his patient, but it also places a legal duty on him to do so and holds him civilly liable for damages in the case of failure to do so. Subsequently, the AIDS epidemic focused attention on the risk of infection of others with the HIV virus, unaware that the sexual or drug sharing behavior of infected individuals puts them at that risk. Here too, the law in most states now recognizes that physicians are at the least permitted to breach confidentiality in order to warn others of this risk from their patient, and many physicians now accept that they have a duty to do so when the patient is unwilling to change his behavior and/or warn others at risk.

Now with rapid advances in genetics and genetic testing, information is increasingly available to patients about their likelihood of developing a variety of medical conditions and diseases at some point in their lives, as well as their risk of transmitting those diseases, or the risks of those diseases, to their future children in reproductive contexts. This information can have important consequences for spouses, especially concerning reproductive choices, where both parties may wish to understand their reproductive risks and to make choices about how to deal with them. Because of the way genetic risks and conditions are inherited within families, this kind of genetic information about one individual commonly has implications for other family members of the individual, most obviously siblings but sometimes others as well, whether for their own health or for reproductive choices. Other family members can often take steps to reduce their risks of genetically transmitted harm. For example, women who learn that they are at increased risk of breast cancer because they have inherited the BRCA 1 or 2 genes can increase mammography and other screening measures, or can even undergo more extreme preventive measures like radical mastectomy. Or they may wish to alter their reproductive choices, perhaps by not reproducing at all, or by using pre-conception or pre-natal testing for the particular genetic risks in question.

Now, of course, in most cases individual patients will feel a responsibility to provide this genetic information to other affected family members and will willingly do so. But for a variety of reasons, such as fear of adverse consequences when the information is known by others, fear of embarrassment or stigmatization, estrangement from other family members, or fear of criticism from others about how one is or is not using the information, an individual may be reluctant or unwilling to share the information with affected family members. In the United States at least there is a strong tradition among genetic counselors of so-called nondirective counseling; information is given to patients, but counselors do not pressure or in many cases even urge patients to share that information with other family members who have an interest in it, much less themselves breach the confidentiality of their patients to do so. One issue for public policy is whether individuals should be entitled to have this information treated confidentially by health care professionals when they are unwilling to share it with affected family members. If health care professionals are prepared in some cases to breach confidentiality when necessary to inform family members of their patients about genetic risks, patients should be apprised beforehand of the limits to the confidentiality they will receive. Some psychiatrists, for example, make a point at the outset of therapeutic work with a patient of explicitly informing her of the limits to the confidentiality of information about the patients that the psychiatrist will be able to observe, and the kinds of circumstances in which it may be breached. Failure to warn patients of the limits to the confidentiality that they can expect is to participate in deception of the patient. But should that confidentiality be limited? To answer that question, we need to address what moral reasons underlie the medical practice of confidentiality. Before doing that I want to underline that the argument I shall address below is not based on any special obligation a patient may be said to have to other family members. Others in this session will focus on that issue. But I think it is interesting that even in the absence of any claim about such special obligations, we can make a case for important limits on confidentiality of genetic information in the case of family members.

It is worthwhile noting that in many social circumstances there is no presumption or expectation of confidentiality—if a waiter or a patron at the next table overhears your conversation in a restaurant, they are under no obligation to keep what they hear confidential. So there must be special reasons for the confidentiality of medical information imposed on health care professionals. The most obvious and commonly cited justification for the practice of confidentiality is a consequentialist one—it produces good consequences and avoids bad ones. For example, it is important for optimal diagnosis and treatment of patients that they provide their treating health care professionals with all potentially relevant information without withholding some because of embarrassment or fear that it might be passed on to others. Maintaining confidentiality also avoids potential unjust discriminatory use of that information—for example to deny health insurance or employment. This is obviously a special concern in the case of genetic information because of the predictive power it often has of future health problems which an employer or insurer will often want to avoid if possible. While some states have laws prohibiting the use of genetic
information in insurance or employment, individuals’ fears that those laws will not always be effective are often reasonable. Further, in some cultural contexts some genetic information will be stigmatizing for those it is about. While it is an assumption in many developed country contexts that increased capacity for genetic testing in the reproductive context increases women's reproductive freedom and control, in other contexts it can have the opposite effect. In the context of practices of arranged marriages, the presence of some genetic conditions can make women unmarriageable. In highly patriarchal societies, new genetic information can reduce women's reproductive freedom when it leads to new choices that are coerced by their husbands or other family members.

There is a second moral reason for why confidentiality should usually be maintained: patients have been promised that their medical information will be confidential. Sometimes that promise is explicit, as when health care professionals explicitly reassure patients that their medical information will be confidential. But even in the absence of any explicit discussion or reassurance about confidentiality, the health professions hold out to patients that their medical information will be kept confidential, and there are widely known legal requirements that they do so. These explicit or implicit promises of confidentiality create prima facie moral obligations to respect confidentiality. But these obligations will not be decisive in all cases—obligations to keep promises are in general prima facie. They can be overridden in circumstances in which they conflict with more weighty obligations or when breaking them is necessary to prevent serious harm to others. And of course in the circumstances of concern here, breaching confidentiality to materially affected family members can sometimes be necessary to prevent such harms.

But there are at least two complications to whether any obligation based in a promise of confidentiality does or need apply. First, as I noted at the outset, in recent decades limits to the confidentiality that patients can expect have been established in most state laws. To the extent that the promise of confidentiality is based on these professional and legal practices, then that promise has limits to it. Moreover, since the limits are typically framed not in terms of specific kinds of medical information, such as HIV status, but rather in terms of whether disclosing the information is necessary to prevent serious harms, these limitations arguably cover the cases of genetic information important to the health or reproductive choices of family members. The second complication of a promise as the basis of confidentiality is that even apart from the point just made about whether the promise now applies to the cases of concern here, the policy question for the future is whether any promise should be made that covers the cases of concern here. Just as many psychiatrists now do with their patients at the outset of treatment, health professionals too could explicitly warn their patients that genetic information important for family members’ health or reproductive choices would not be kept confidential from those family members. So any appeal to a promise of confidentiality has little weight with regard to what practice should be for these cases.

There is a third moral reason supporting the practice of confidentiality: it appeals to two ideas—that medical information is typically only obtained with the consent and cooperation of the patient and that because that information is primarily about the patient, the patient should control who has access to it. The first of these two ideas can, I believe, does little work in establishing confidentiality of information in the cases here in question. That is because patients could be told at the outset of any genetic testing that information would not be kept confidential from seriously affected family members. If patients then proceed to give consent and cooperate in the genetic testing, they would have no moral complaint if the information is subsequently shared with those family members. So I believe that what must do the work in this idea is that the information primarily concerns the patient and so the patient should control who has access to it. But of course it is precisely this which is not true in the genetics cases of concern here. The information typically is equally about family members and may be just as vital to those family members’ well being as it is to the patient. So this third moral reason does not support keeping genetic information confidential from seriously affected family members.

I think the upshot of this brief tour of the moral reasons in support of the practice of medical confidentiality is that in the case of genetic information seriously affecting family members, only the first reason which appeals to the good consequences of the practice appears relevant. But in these cases, breaching confidentiality when the patient is unwilling to share the information with affected family members is necessary to prevent serious harms to their family members or their offspring. It is hard to see how the harms to the patient of breaching his or her confidentiality are, except in very unusual cases, plausibly thought to be more serious than those prevented for the family member. Now, of course, in assessing the consequences of a policy for these cases, it is necessary to look beyond the consequences in an individual case to the affects on the practice over time. For example, it might be argued that making clear that confidentiality should not be maintained in these types of cases would discourage people from seeking genetic information and, in turn, from using it to protect their own health or to make wise reproductive choices. A similar argument was made in the early stages of the AIDS epidemic that any limits to the confidentiality of patients HIV status would discourage persons at risk from coming into the health care system. They would lose the benefits of information about protecting their own health and of counseling to protect others; the consequences, all things considered, might be worse from breaching confidentiality to warn persons at risk of infection. Just as in the case of HIV, there is no good data to assess this argument in genetics’ context, but it does pose a speculative harm against an often more direct and probable harm. Any assessment of consequences of practice in this area is obviously fraught with uncertainty. I believe the task for public policy is to carefully frame the circumstances in which genetic information will not be kept confidential from seriously affected family members, and to specify how and by whom it will be shared. Health professionals should in most cases be permitted, but not required, to share the information to enable them to take account of the specific circumstances of a particular case. Moreover, weakening the practice of confidentiality of genetic information in the case of family members provides no basis whatsoever for weakening it for other third parties such as employers and insurers. But in the family context, we must rethink the practice of confidentiality of genetic information.
Sharing Genetic Information: What Is a Minimally Decent Sibling to Do?

Leonard M. Fleck
Michigan State University

The title of this paper might be a puzzle to many. Is there a problem with sharing genetic information within a family? Empirically, the answer is that such information is generally shared within families, though there may be some practical psychological problems in figuring out how best to do that. But our question is this: What if an individual refuses to share such information with a sibling, and that failure to share might cause irreparable harm to that sibling? Is that sibling with the genetic information then open to moral criticism for failing to share? If so, what are the relevant moral norms that have been violated and that serve as a reasonable basis for that moral criticism? As we shall see, there is a problem here that it is harder to get a handle on than what might first appear.

We need to give our ethically problematic sibling a name. Gene will do very well. Gene asserts that he has a right to privacy. He has the right to control medical information about himself, which means he can deny that information to anyone and everyone. We point out to Gene that his withholding this information might cause serious but preventable harm. Further, we are talking about his brother, not some stranger. But Gene, having been philosophically trained at MIT, points out that the fact that someone has a need, even a very urgent need, does not generate a right against him to meet that need, even if he is well positioned to meet that need.

Someone may be faced with premature death unless they receive a kidney transplant or a bone marrow transplant. Gene may be a perfect match for that person. There might be other matches somewhere in the world, but there is no guarantee that they will be found soon enough. Still, it seems Gene is correct in his philosophic belief that the individual does not have any right to his kidney or to his bone marrow. He concludes that he is not open to any justified moral criticism for his refusal to donate in such a case. However, this is his brother; this is family. Does not this fact by itself have both moral relevance and moral weight, perhaps decisive moral weight? Further, he is not being asked by his brother to give up either a kidney or bone marrow. He is not being asked to undergo major surgery or even endure some significant pain. It is just simple painless medical information that he is being asked to share with his brother in order to prevent serious harm to his brother. Still, Gene might well insist that his brother has no right in this regard, and consequently, he has no duty to provide the needed information. This might well be a correct moral conclusion. For the sake of discussion, I will take it as such. Nevertheless, that leaves us in a morally uncomfortable position. I am inclined to think that Gene’s choice in this matter is open to justified moral criticism. I am reminded of Judith Jarvis Thomson’s “minimally decent Samaritan.” My intuition is that this might be morally helpful in this context in understanding why Gene’s behavior seems morally criticizable.

Thomson provides us with several illustrations of what minimally decent Samaritanism is all about. The one I will call to the reader’s attention is the story of herself and Henry Fonda. Thomson imagines herself in the hospital on the East Coast with a dangerously high fever that will result in her death shortly unless the fever is broken. The only thing which can accomplish that is the “cool touch of Henry Fonda’s hand on her fevered brow.” The only problem is that Fonda is on the West Coast. If he is apprised of her circumstances, she being a complete stranger to him, does he have any moral obligation to fly from the West Coast to save her life. Nothing else can save her life. Still, Thomson is certain that she has no moral right to expect this of him, nor does he have a moral duty to provide this aid. But if Fonda did get on a plane and fly to her side to save her life, then he would be described as the proverbial “Good Samaritan” of the Gospels. By way of contrast, if by some chance he were visiting a friend across the hall in the hospital where Thomson was, and if Thomson’s plight were brought to his attention, and if refused to walk across the hall for a minute or two and just place his cool hand on her fevered brow, then Thomson concludes he would be open to legitimate moral criticism for failing to act as a “minimally decent Samaritan.” He would not have violated her rights, nor would he have failed to carry out a strict moral duty. Nevertheless, his failure to respond would warrant legitimate moral criticism because he fell below a minimal level of human decency. What I want to explore is whether a similar sort of standard might exist within a family among siblings, for example, and whether such a standard can elucidate some of these genetic information issues.

I

Though it may not be obvious at the moment, I believe that the issues raised here are much more contextually complicated and require more contextually sensitive moral judgment than the generic case scenario raised in my Introduction might elicit. So I am going to offer three more concrete scenarios which might elicit those more refined moral judgments.

Scenario 1. Imagine that Al has been given a serious medical diagnosis. He will die in several years as a result of a cancer to which he is genetically susceptible. Nothing can be done to alter his fate in this regard. However, if his younger brother is alerted as to his own risk, and if his brother Bob gets that test and the test is positive, then Bob will have medical options that would likely be able to forestall a terminal outcome for twenty years. (To be clear, it could turn out that Bob does not have the gene that would result in this cancer risk, which would mean he would have a normal life expectancy, all other things being equal.) Al and Bob have never been on very good terms, going all the way back to childhood. Outsiders would just judge that there was a basic personality incompatibility. One complicating factor is that Bob did defraud Al of ten thousand dollars several years ago. Bob did pay back what he had unjustly taken, but this still resulted in increased alienation between the two.

Question: In spite of this family history, is it still the case that Al ought to share with Bob the genetic information he has acquired about himself? And should he do this because this is what a minimally decent sibling ought to do in these circumstances?

Scenario 2. Charles has been given a cancer diagnosis with the same medical consequences as in our first scenario. He has the option of saving his younger brother Dan from this fate by informing him of the genetic risk to which he might be vulnerable. Charles and Dan have always been on good terms and genuinely care about one another. However, they do have very different religious commitments. Charles is a very devout and very conservative Roman Catholic. His brother is a liberal Catholic, the sort who believes that if he cheers vigorously for Notre Dame on a football Saturday he is excused from Sunday Mass. Charles would be happy to share his genetic information with Dan if he were certain that Dan would only use this information for his own personal benefit. But he knows that Dan is planning to start a family soon. If Dan were positive for the same genetic mutation as Charles, then Charles fears that Dan would use this information in making family planning...
decisions as well. Specifically, he is concerned that Dan would either have future fetuses prenatally tested for the mutation or take advantage of pre-implantation genetic diagnosis. In either case Charles sees here the possibility of, to him, the absolutely impermissible destruction of either fetal or embryonic life; and consequently, he is unwilling to share his genetic information with Dan.

**Question:** Is it morally permissible for Charles to invoke both his right to privacy and his deep religious beliefs to justify not revealing this genetic information to his brother? Or must a minimally decent sibling share such information in this situation, no matter what their religious beliefs?

**Scenario 3.** Ed and Frank are brothers. Their father had been a sperm donor several years ago. A child that resulted from one of these donations, Grant, has sought out and now found his father and his two half-brothers. Both brothers have recently had the above referenced genetic test. Ed is the older brother who is now faced with a terminal prognosis. Frank, as it turns out, had a negative genetic test. The question has arisen as to whether or not Grant ought to be apprised of these genetic test results so that he could decide whether or not he wished to pursue testing. Ed is opposed to saying anything to Grant. He has no brotherly sense of attachment to him, as he does with Frank, whom he informed within a week of receiving his test results. Grant is mostly a stranger to him. Ed might have some diffuse negative feelings toward Grant, linked perhaps to the circumstances of his birth and his “intruding” into their lives just now, though he would deny such feelings if asked.

**Question:** Could Ed argue that the “minimally decent sibling” norm is irrelevant as far as Grant is concerned, and consequently, he is not open to any moral criticism? Ed does accept the legitimacy of the norm; it is not a phony philosophic invention. But he emphasizes that he met the requirement of the norm when he informed Frank about the genetic test results.

Another wrinkle can be added to this scenario, Scenario 3b. Frank has warmed up to Grant and sees him as a good and decent person. He is very comfortable with the idea of accepting him as a brother. He personally feels that Grant ought to be told about the genetic test so that he could make his own decisions, but he is also sensitive to Ed’s feelings. Consequently, he has refrained so far from saying anything to Grant.

**Question:** Is Frank open to justified moral criticism for failing to meet the requirements of the minimally decent sibling norm? After all, the relevant genetic information does not just “belong to Ed.” Or is it morally salient that Frank only possesses this information now because Ed motivated him to obtain it by getting the relevant genetic test?

### II

We said at the beginning of this essay that the problem here is more complex than might first appear. It would be helpful to tease out some of that complexity. Part of our initial moral problem clearly is linked to the fact that we are talking about “family.” There is an assumption, often warranted, that we have more in the way of moral obligations to family members than we have to others who are just strangers to us. Before we consider what such obligations might look like, we need to take a closer look at this notion of family.

We tend to think of the defining features of family in biological terms: parents, children, aunts and uncles, cousins, and so on. But if we reflect carefully, those biological connections probably carry very little in the way of moral weight in and of themselves. For example, Osama bin Laden is supposed to have nine wives and fifty children. Do we imagine that all fifty of those children have special moral relationships to one another, just by virtue of the fact that they have Osama as their father? Or should we judge instead that there are really nine families here? What sorts of considerations should push our judgment one way rather than the other? Because of divorce and re-marriage in the United States what are called “blended families” would be a very common phenomenon. Some of these families are “blended” in only the most attenuated sense. That is, there is very little in the way of a shared life or shared affection among the children who have different parents. From a psychological perspective they are mere acquaintances of one another. Other “blended families” may achieve extraordinary degrees of intimacy among themselves. And, of course, there will be lots of degrees in between. What seems to be most morally salient is that individuals have heightened responsibilities for the well being of one another when they have shared in complex and intimate ways long stretches of their lives in the course of which complex relationships and expectations of mutual dependency would naturally emerge.

This is not a very precise description, but my judgment is that the matter may not allow more fine-grained precision. If my brother needs help building a deck for his summer home, then he should feel comfortable asking me for help and expecting that I will respond positively, unless I have some serious conflicting obligation (my employer expects me to work overtime). Morally speaking, this is in the domain of bringing aid. Lots of other people may be building decks, but none of them may legitimately expect that I volunteer to help. If my brother carelessly failed to send me a Christmas card last year, which I found to be very annoying, that would not be sufficient reason for my refusing to assist him in building that deck. He would not have “a right” to my help, nor would I have “a duty” to provide that help. Still, given a background of good sibling relations with the normal ups and downs of such relationships, I “ought” to provide that help, which is to suggest that this is the sort of thing a “minimally decent sibling ought to do.” There are lots of reasonable excusing reasons that would dissipate potential for any moral criticism connected to my not being available to help. However, my annoyance with being overlooked for a Christmas card would not seem to be one of those excusing reasons.

I want to be clear that the comments above do not imply that there are no moral rights or moral obligations within a family. There are. Family members, for example, have privacy rights. They have the right to withhold from other family members information about themselves that they judge to be too personal or too intimate for a very wide range of reasons. Also, there are legitimate expectations of confidentiality within the family. Some analogies exist between the doctor-patient relationship and relationships within the family. Certainly our birth families require our living within close proximity of one another, which means in practice that some very intimate details of our lives will be known to other family members either because there is no practical way to prevent their knowing those details or because we choose to share those details with them in order to elicit emotional support or advice on very sensitive matters. Those matters requiring confidentiality can be pretty sharply delineated in the context of the doctor-patient relationship; the boundaries of those moral expectations are much fuzzier in the context of the family. For the most part (outside strict explicit requests for confidentiality within the family) we must rely upon keen moral sensitivity. With these introductory remarks as background, let us turn to our first scenario.
Al and Bob do not have amicable brotherly relationships with one another. If Bob were going to build a deck on his summer home, he would have no reasonable basis for thinking that Al, as a minimally decent sibling, ought to help him. Does that same logic yield the conclusion that Al does not have to reveal certain genetic facts about himself to Bob as a minimally decent sibling, even though the consequences of his failing to reveal that information would be the loss of many possible years of life for Bob?

Al appeals to his right to privacy as the primary source of moral justification for his decision. But this does not seem to be sufficient for this justificatory task. There are numerous sorts of things related to myself that I might justifiably protect from discovery by others through invoking my right to privacy. I might be ashamed as a philosopher if anyone were to discover that I had received a grade of "C" in a college logic course. This might appear silly and trivial to most people but I would have a strong privacy right in this matter. Recognition of this right is easy because no countervailing moral harms to others can be readily imagined as a result of protecting this right. However, this is precisely what is not the case in our Al and Bob scenario.

Bob is at risk of losing many possible years of life if this information is not divulged to him. If this were the whole story, this might not be sufficient to overcome Al’s presumptive right to privacy. However, it is morally significant in this case that there is no moral substance to Al’s right to privacy. That is, what he is asserting is a "bare right," a right that is essentially content-less in this context. Al cannot tell a story of personal humiliation if he reveals these genetic facts about himself, nor is he at risk for serious financial losses or loss of a job or health insurance or anything else comparable to those theoretically possible losses. Al has nothing at all comparable in the way of emotional fear to what I have with regard to someone discovering I received a "C" in that logic course. To be sure, some emotional feelings attach to that information for Al, but these feelings may be very problematic from a moral point of view. These feelings may have to do with revenge; Al may actively hope that Bob suffers the same fate that he is doomed to endure. In effect, Al is using his moral right to bring about potential harm to Bob.

Al will argue, of course, that he is not harming Bob. If any harm comes to Bob, the harm will come from Bob’s own genetic constitution. Al had nothing to do with imposing that on him; that is just a natural fact about Bob. Instead, Al will say that he is simply failing to aid Bob, which he has no duty to do. This is where Al will argue the analogy exists with his unwillingness to assist Bob in building that deck. However, the moral dis-analogies seem glaring in that case. Al is not a unique source of free labor when it comes to building the deck. Bob can have other friends help him achieve that goal. Maybe Bob has not been very good at building a network of friends because most people do not trust him. That is regrettable, but nothing of moral consequence attaches to whether or not that deck gets built. The loss of possible life years for Bob is clearly something of moral consequence. Further, no one else is available as a source of this information. Al is uniquely positioned in this regard, even though that unique position came about entirely by chance.

This now looks very much like an "easy rescue" situation. Al is not responsible for Bob’s risk to his future health, but he is uniquely positioned to prevent those risks of harm from being actualized. Further, no additional risks or harms accrue to Al in revealing certain genetic facts about himself. Moreover, this situation is not one that will repeat itself again and again in the future so that there is some aggregate burden that would be generated that might serve as an excuse. (If I give a panhandler a dollar so that he can eat, am I then morally obligated to give the next 10,000 panhandlers in the same situation a dollar each until I am reduced to being a panhandler?) This is just a one-time rescue effort. The fact that Bob defrauded him of $10,000 in the past (and made restitution) does not have any moral salience in the overall situation. The easy rescue is what matters. If Bob were drowning in seven feet of water and Al were the only one around who could rescue him, and Al was an excellent swimmer, then Al would not be excused from making the rescue because Bob had earlier defrauded him of $10,000.

One thing that might not be very clear in this case is whether Al ought to rescue Bob “as a minimally decent sibling.” We return to our Fonda story. Henry Fonda would be less than a minimally decent person if he refused to go across the hospital corridor to rescue Thomson by merely putting his cool hand on her fevered brow. She does not have SARS. She poses no risk to him. But we can imagine this other scenario. If Thomson were his sister, and if Fonda had to drive 100 miles to rescue her from death by putting his cool hand on her fevered brow, then he would be open to moral criticism for failing to be a minimally decent sibling, though my judgment is that he would not be open to moral criticism for failing to be a minimally decent person. So, in our actual scenario with Al and Bob it is not clear that sharing that genetic information is a matter of being a minimally decent sibling. It seems to be mostly a matter of easy rescue, what would be required of any minimally decent person. However we can say this much confidently I believe. If something is required of someone as a minimally decent person, then at least that much will be required of him as a minimally decent sibling.

III

We turn now to our second scenario. Charles and Dan are on very good terms with one another as brothers. But they have very different religious perspectives. What gives this scenario its distinctive character is that Charles has primarily religious reasons for not wanting to share his genetic test results with his brother. These are not the morally tainted reasons that seemed to be motivating Al. Still, the fact is that Dan is at risk for a serious harm that is preventable. Charles is the only one who is uniquely positioned to prevent that harm from occurring. What ought Charles do as a minimally decent sibling?

There are several scenario variations we can consider. We can argue that Charles does not have the option of literally doing nothing, letting nature take its course and hoping for the best. That would not allow him justifiably to think of himself as a minimally decent sibling. He does care about his brother’s future health. He could explain to his brother in very non-specific terms the moral dilemma that he sees himself faced with. He could tell his brother that he would reveal to him the very specific genetic information that he needs to know, but Dan would have to promise him one of two things. He would have to promise that he would have no children (or no more children). Or, alternately, he would have to promise that he would use neither prenatal genetic testing nor pre-implantation genetic diagnosis to avoid having a child who might have the same genetic defect. He would emphasize to his brother how important his religious/moral beliefs are in this matter. He would emphasize that he was seeking from him a sacred and irrevocable promise, since that is the only way in which he could be confident that he had not compromised his fundamental religious commitments.

A case could be made that there is something morally illegitimate about trying to extract a promise of this sort. Prima facie, this looks like an unjust restriction of what would otherwise be Dan’s procreative liberty. Further, such a promise, made under something that looks like duress, might not be a...
“real promise,” one that Dan would be morally obligated to follow through with. Charles could question Dan closely on this matter. He could explain to him that as a brother he would not expect him to use the tricks of casuistry to avoid following through on the promise. Further, the promise would continue to hold even after Charles had died. I need to put aside some of the moral issues that might be raised about this sort of promise since they would distract us from the main line of argument. Dan might think about this very carefully, knowing there might be serious risks to his own health for failing to agree to this promise. But we will assume that he refuses. If Charles has done this much, then I believe Charles would not have failed the norm of being a minimally decent sibling. He made a conscientious effort to compromise in order to prevent this future possible harm to his brother.

But then we return to the “easy rescue” analogy. We might imagine this alternate scenario. Charles and Dan are brothers, Charles being the very conservative Catholic, Dan being very liberal. Dan is very vocal about his liberal ideas. He has insisted that today no one can be morally responsible in reproductive matters unless they have themselves genetically tested and then make appropriate decisions about the genetic endowment of their future possible children. That is, if they knew they were at risk of passing to their children a serious genetic disorder, then they should use pre-implantation genetic diagnosis to make certain that did not happen. Dan now finds himself very close to drowning. The only person available to save him is Charles, for whom the rescue would be easy and risk-free. But Charles will refuse to save Dan unless Dan promises that, if he has children, he will have them with whatever their genetic endowment happens to be. He must promise Charles that he will not destroy any fetal or embryonic lives in order to assure a better genetic endowment for his future possible children. My judgment in this case is that Charles would be open to serious moral criticism if Dan refused to make this promise and Charles simply allowed him to drown. This is an easy rescue. He has no right to extract a promise of that sort under these circumstances, even though it would seem that Charles’ religious commitments are at risk. But if this is so, then why does not this same logic apply in the prior scenario?

The short answer I would suggest is that the “easy rescue” scenario is not as obviously true in both cases. Dan is genuinely at risk in the earlier scenario. There is, we will say, a 50% chance that he has the genetic mutation that would put him at risk for the same cancer. But even if he has the gene, it is, like BRCA1, a susceptibility gene. There must be other factors that would be necessary to achieve that causal result. Dan could be lucky, have the genetic mutation, but those other causal factors might never come together to yield a cancerous process. In other words, in our first scenario Dan is not correctly described as being imminently in need of rescue. Six months from now he could change his mind about making that promise and then be “rescued” by Charles. In the drowning scenario the need for rescue is as imminent as we could possibly imagine, and the promise would be extracted under obvious duress.

Another variation we might briefly mention is this. We could imagine that Dan already has two children, but plans to have on or two more. The premise Charles puts to extract from Dan is that he will not reveal to those children that they might be at risk for these genetic disorders as well, unless they promise to have their children without any effort to alter their genetic endowment (if such alterations required the loss of either fetal or embryonic life). Here it seems to me that our moral intuitions are fairly clear. Dan does not have the right to make such promises on behalf of those whose lives could be affected in such a fundamental way, nor, for the same reason does Charles have the right to request that such a promise be made.

Finally, there is an interesting possible twist we can make to our original second scenario. Pretend as if it is the case that Dan, the liberal Catholic, is the one who has the genetic mutation and is now likely to be faced with a premature death. Further, pretend as if both Dan and Charles are philosophically inclined. They like to argue with one another over matters of health care ethics. They in fact imagined the first version of this scenario. In the course of that discussion Charles asserted with all seriousness exactly what we described above. That is, he would extract this promise from Dan or he would deny him the information that might be necessary to save him from a premature death. This was just a philosophic conversation about a hypothetical scenario.

As Dan reflects on it now, however, he is certain that this is precisely how Charles would react were the situation real. Having thought this, he now concludes that he will not inform Charles of the genetic risks to which he might be vulnerable as well. To justify this conclusion he reasons that morality is fundamentally about reciprocity, and he is morally certain that Charles would do exactly what he said he would do were the situation reversed. Dan sees this as a violation of reciprocity, and therefore he concludes that he is not open to moral criticism for failing to inform Charles of these genetic risks. Is this a correct conclusion? Or does this represent a violation of the minimally decent sibling norm?

My own intuitions are that this would represent a violation of this minimally decent sibling norm. It is not as obvious as Dan believes that the reciprocity condition would be violated in this scenario. After all, Charles would be making an effort based in brotherly concern to save Dan’s life should he prove to be a bearer of this mutation. But he is doing that in a way that would preserve the integrity of his religious commitments. Dan has nothing morally comparable to those religious commitments that would justify his denying this genetic information to Charles. Instead he has as motivating factors for his refusal of something that is morally akin to what motivated Al in our first scenario. Al had suffered actual harm from Bob who had defrauded him of $10,000. Dan has suffered nothing comparable to that. Strictly speaking, Dan has suffered nothing more than hypothetical harm because Charles has explained to him what choices he would make in the course of a philosophic conversation. One could understand why Dan might be annoyed, hearing that from a brother about whom he had always cared. But even in that hypothetical conversation Charles had respectable reasons for his judgment. Dan has nothing more morally worthy than annoyance with his brother for his refusal to share. So that looks like it would fail the minimally decent sibling test. Further, this reversal of circumstances does not look like an actual violation of the reciprocity condition in our moral practices. The situations of Dan and Charles are not just reverse images of one another.

IV

We turn now to our third scenario (after we consider a prefatory scenario). The scenarios I have discussed so far are very simple two-person scenarios. This does not reflect the real world very well wherein there are very often multiple siblings and a significant number of other potentially affected family members. Consider, for example, a family in which there are six siblings. Steve is the affected individual with the genetic mutation, which will result in his premature death. He is the oldest in the family. He has very mixed relations with his other siblings. He has had very good relations with half of them and very unsatisfying relations with the other half. He decides he will inform his favored siblings of the genetic risks to which
they might also be vulnerable, but he will not inform the siblings who, for various reasons, have incurred his disfavor. He has also extracted a promise from his favored siblings that they will not reveal what they have learned from Steve to the siblings that he disfavors. Is Steve open to justified moral criticism for failing as a minimally decent sibling?

My judgment is that he would be open to such criticism. We can imagine many possible reasons for those siblings being in a disfavored position, everything from having annoying personality traits to perpetrating fraud against Steve, as Bob had done in our first scenario. But none of those sorts of considerations seem morally sufficient to excuse Steve from doing what he needs to do as a minimally decent sibling. Essentially the same analysis would apply to Steve that applied to Al in the first scenario. The feature that is added to the Steve scenario is that there are these favored and disfavored siblings. All, however, have grown up together and shared a common family history. Siblings may favor or disfavor one another more or less. This is a common phenomenon. It might be reflected in who gets a birthday present and who does not. There is nothing especially morally problematic about that because there is nothing of significant moral substance at stake in those matters. But this is not true in our scenario with the genetic risks. There is the possibility for the loss of many life years that do not have to be lost. Given this, Steve cannot play favorites with this genetic information without being open to justified moral criticism for failing as a minimally decent sibling.

Our next question is how morally similar or dissimilar the Ed/ Frank/ Grant scenario is to the Steve scenario. Grant is a half-brother who has only entered the family circle within the past year. Ed is the one who has the genetic mutation that will result in his premature death. He has informed Frank of these facts so that Frank can pursue genetic testing and find out what his own health situation is. But he is unwilling to inform Grant because he has no sense of brotherly attachment to him. Frank, however, has connected with Grant and feels a sense of attachment to him. How seriously should we take Ed’s argument that Grant is not a real sibling, and consequently, not entitled to any special moral treatment?

My own intuitions are that we can dodge the issue of sibling status for purposes of determining what is the right thing to do. This looks very much like a matter of easy rescue, something that is rightly expected of any of us as minimally decent persons. Ed might insist on a right to privacy, as Al attempted to do in our first scenario. But this will be, as a practical matter and as a moral matter, a substantively empty right in this context. Ed has nothing to lose in revealing these facts about himself. There are no psychological losses, no financial losses, no morally significant losses whatsoever. But the information could potentially make a very large difference in Grant’s life. That Ed does not have any feelings of brotherly attachment to Grant is insufficient to excuse his failing to make this information available to Grant. This is what a minimally decent person should do.

For the sake of argument, I ask the reader to accept this last conclusion. Where does Frank fit into this picture? He genuinely likes Grant. He does not want any unnecessary harm to befall him. He knows that Ed has indicated he has no intention of revealing this genetic information to Grant. Frank feels intuitively that he himself ought to inform Grant. After all, he rightfully has the information now. Further, it is not as if Ed is the “owner” of the family genome. Still, Frank respects Ed. They have had a long and loving relationship with one another. Ed has even bailed him out of a couple very difficult financial situations that could have had disastrous results. How could a minimally decent sibling go against what he knows to be the clear wishes of his brother in this situation? We might be tempted to think about this from the perspective of legitimate breaches of confidentiality. But my judgment is that this will not take us very far toward a satisfactory resolution. If we think about the Tarasoff case and its lessons, then the first requirement is that there be a risk of harm that is serious, imminent, and irreversible. It is not obvious in this situation that this condition would be met. The harm, if it materializes is serious (we will grant), but we cannot conclude that the harm is imminent. Further, the harm may prove to be reversible. That, of course, will depend upon the relevant facts, as they are revealed.

Frank wants to be a minimally decent sibling to both Ed and Grant. If he were in Ed’s position, then he would be rightly expected to reveal this information to Grant as a minimally decent sibling. Does that all by itself warrant Frank in divulging that information to Grant? I think there is another alternative, which must be tried first. Frank needs to try to make a case with Ed to reveal this information to Grant. This might take several conversations and it might take a prolonged period of time. This seems to be congruent with being a minimally decent sibling. Ed does not have some exclusive right to this information. Hence, Frank would not be violating any of Ed’s rights if he simply revealed this information to Grant. But he should not do that straight out, as a minimally decent sibling. If it becomes clear to Frank that Ed is totally immovable in this matter, then the right thing to do is to reveal this information to Grant since Frank is now the one positioned to effect the easy rescue. In concluding this I am also concluding that Frank does not have the option of silence. That is, he cannot offer as an excuse for not informing Grant that this was contrary to Ed’s wishes since Ed’s wishes are morally flawed.

Let me add one final tweak. If Ed had discussed this matter with Harry, a friend who otherwise does not know Grant, then Harry too should try to persuade Ed to see things differently. But if he failed, and if Frank is out of the picture for whatever reason, then I am less confident that Harry ought to reveal this information to Grant (and would be open to justified moral criticism if he failed to do so). That is (and this is all I mean to say), Harry is not in the position where he is rightly expected to meet the standard of a minimally decent sibling.
Genetic Information and the Special Duties of Siblings

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If one person may be said to have a moral duty to undergo genetic testing for the sake of another, or if she may be said to have a duty to reveal genetic information to another, such a duty would be a positive moral duty. It would also be what we might call an informational duty. A person may have a duty to seek information whether or not she wishes to possess it or she may have a duty to reveal information whether or not she wishes it to be possessed by others.

One important difference between positive and negative duties—between duties to perform and duties to refrain from performing certain acts—is that whether or not a person may be said to have a particular positive moral duty—a duty to aid another in a particular way—depends on how difficult it would be for her to aid in that way. The standard illustration of this difference is a contrast case of two moral agents, one of whom pushes a small child into a river, another who fails to pull the child out. The person who has pushed the child in surely had a negative duty not to endanger the child’s life. What we are to say about the positive duties of passersby is famously less clear. Surely the fit swimmer seeing the child in a calm river has a moral duty to attempt a rescue. Just as surely an individual who is unlikely to succeed at the rescue and likely to lose his own life in the attempt has no duty to try to help in this way. But drawing the line between those who do and those who do not have a duty to jump in cannot be a simple matter. In the context of genetic testing, the “difficulty” would be that involved in possessing or releasing a particular piece of information. How difficult it would be for one individual to possess or to provide the information that would be useful to another will depend on the nature of the information and on the relevant beliefs, desires, and fears of the individual. Some people prefer not to know, for instance, whether they are likely to develop a particular disease; they prefer to live lives in which the state of their future health is epistemically open. Of those who already know significant facts about their own genetic makeup, some prefer to keep this information to themselves.

We typically determine whether or not a moral agent has a particular duty to aid by looking at both the degree of difficulty for the agent and the importance of the aid to the potential recipient. (I will be assuming that the act at issue would indeed benefit the recipient, or, at least, that it would be reasonable for the potential agent to believe it would.) In some circumstances in which we might wonder whether one sibling may be said to have a duty to another based on their shared DNA, the difficulty of providing the needed information would seem to be minimal and the importance of the aid tremendous. Dora and Tina are sisters. Both plan to have children in the near future. Because Dora’s partner knows that he is a carrier for cystic fibrosis, Dora undergoes genetic testing to determine her carrier status. She learns that she too is a carrier. Tina is unaware of the increased risk that she is a CF carrier and will remain in the dark if she is not informed of Dora’s carrier status. Should Dora share this information with Tina? Without further details that would make sense of some extraordinary difficulty Dora would face in doing so, the answer would seem to be, of course. Dora would surely wrong Tina if she did not share information so clearly pertinent to Tina’s decision-making and potentially so significant for the well being of a future person.

In a case such as this, we need not wonder whether siblings have special duties to each other—duties they have to each other by virtue of their relationship. The imbalance of burden and benefit together with the fact that Dora is uniquely placed to help Tina would seem sufficient grounds for us to say that Dora has an obligation to inform Tina. Strangers owe each other more when they are uniquely placed to provide assistance and we might think that they owe each other at least the very little that would meet a pressing need when that need can be met very cheaply. Because biological siblings share genes, they are uniquely placed to share needed information, and so we can account for many of the duties that siblings have to each other strictly in terms of ordinary moral duties.

When, however, the potential benefit to one sibling is less important, or the difficulty for the other is greater, the question arises whether siblings have special moral duties based on their special relationship. I wish to explore the idea that siblings have special duties to each other and to begin with Aristotle’s account of relationships among friends and within families.

While Aristotle surely did not have the expansive ideas that we may have of what constitutes a family, the fact that he locates his remarks on familial duties within his discussion of friendship tells us that he has in mind what is essentially a social and not a biological relationship. Of course, these often go together. We are often raised with those with whom we “share blood.” But what is morally significant, according to Aristotle, is not the blood we share but the social relationship that is formed by people who develop socially and morally together.

The Aristotelian account of friendship—a relationship formed through a lengthy process of shared thought and action, shared appreciations and deliberations that ideally arrives at and continues as a condition of perfect deliberative and evaluative agreement so thoroughgoing that it permits us to consider the friend an “other self”—provides, I wish to suggest, one way of understanding the moral significance of siblinghood. Aristotle thought that siblings were particularly likely to instantiate this kind of relationship. This is a bit surprising perhaps since sibling relationships, unlike most close friendships, are not voluntary. Part of what explains the possibility of close friendships is the fact that friends choose each other. Not just any two people can reach a substantial amount of agreement on practical matters by thinking and acting together. When two people are too dissimilar to reach significant agreement on how to live, they may well see little point in continuing to share their lives. Reaching deliberative concord would seem to presuppose some likeness to begin with, so that the sharing of thought and action might begin in earnest. The relationship between siblings, while not voluntary, is one that develops as the moral personalities of the two individuals develop. Of course, siblings often develop in a very similar context—taught by the same parents, in largely overlapping periods of time, in the same social environment. They also, however, develop within the context of their shared relationship. They are often talking, planning, and acting together as they figure out what is involved in living well and as they begin to take responsibility for their own choices and actions. It is, I think, fair to say that to the extent that a sibling relationship fits this description, the siblings have reason to be grateful to each other. Each may be said to have a special duty to take an interest in the interests of the other and, in particular, a duty to support the other’s ability to make good choices.

Admittedly, not all sibling relationships fit this description to any significant extent. Siblings who are raised together may
not develop close, mutually concerned relationships. Some biological siblings hardly know each other or have never met. When siblings are raised together but do not form an Aristotelian friendship, it is possible all the same that a related debt of gratitude is incurred when children develop socially and morally, at least in part, by acting on each other. Children develop morally by making choices, acting on the choices they make, and witnessing the results of their actions. Since it is typically those nearest who are affected by these actions undertaken by the morally immature, it is frequently siblings who serve as the tools of our moral training. Because our siblings are typically only children themselves at the time of our moral development and because sibling relationships are constant and permanent, the consequences for them of our moral successes and failures can be enormous.

In all cases of biological siblinghood, including those in which the siblings have never met, there is a sharing of at least one parent. This is not the place for an extended discussion of filial obligation, but insofar as we have duties to take into account the interests of our parents and insofar as it is reasonable to suppose that our parents take an interest in the well being of their other children, we have reason to take an interest in the interests of our siblings.

I have suggested three reasons for thinking that siblings may have special moral duties to each other. In one or both of two ways, our siblings often play a significant role in our becoming who we are. Further, they are typically objects of concern for those to whom we are, it is widely thought, less controversially indebted. Of course, these characteristics may not all be found in every sibling relationship. Discord may as well as concord characterize a particular sibling relationship, and some individuals have little reason to be grateful for sibling contributions to their moral personalities. What follows from all of this is that when we ask, in any particular case, whether one sibling has a moral duty to obtain genetic information for the sake of another or a duty to provide genetic information to another, it may be necessary to ask all of the following questions:

- How significant would be the benefit for the recipient of learning this information?
- How difficult would it be for the agent to possess or provide it?
- Is the agent uniquely placed to aid her sibling in this way?

And, finally,

- What is the nature of their relationship and how much more can we therefore expect each to do for the other?

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**Unchosen Affinities**

**Hilde Lindemann Nelson**

*Michigan State University*

Many of the ethical issues surrounding the recent advances in genetic medicine are matters for public policy or involve general duties of physicians to patients. I am not going to talk about those. Instead, my contribution to this panel is to discuss the ethics that govern the interpersonal relationships between brothers and sisters. I am going to offer a strategy for recognizing or assigning responsibilities that attach to sibling relationships, and then suggest ways to assess the credibility of that strategy.

As our connections to our brothers and sisters are paradigmatically connections we haven’t chosen, they fall outside the scope of moral theories, whose purpose is to secure for individuals the greatest amount of liberty that is compatible with the rights or interests of others. Given medical ethicists’ long reliance on those theories to set informed consent at the ethical heart of the doctor-patient relationship, it is perhaps understandable that they have paid relatively little attention to the moral pull exerted by relationships that are indifferent to informed consent. But that attention must now be paid, not only because developments in genetic medicine increasingly give rise to ethical issues involving siblings, but also because of other medical advances, such as living donor organ transplantation, that put pressure on family members to make previously unthinkable sacrifices for one another.

Just what responsibilities siblings have to or for one another depends, as it does in other contexts as well, on the nature of the relationship in which the responsibilities are situated. I do not mean anything very complicated by this: if you are my student I am supposed to teach you, rather than, say, to feed you; if you are my literary agent, you are supposed to find me a publisher rather than sell me a house. As these examples indicate, the responsibilities inhering in many relationships are perfectly straightforward and widely understood, for the roles that constitute the relationship bear socially shared meanings, while the norms that govern those roles are likewise socially shared. Consensus is useful, where it exists, because it shows us what we are expected to do and how we can expect others to treat us—it allows us to make sense of how we live in moral community with others. Responsibilities are perhaps most clearly understood in relationships that can be entered and exited freely, where contracts can be drawn up that spell out who is responsible for what, to whom, and that stipulate the penalties to be incurred for nonperformance.

Matters are not quite so straightforward, however, for nonconsensual relationships, except in the case of parents and their dependent children. There is growing moral agreement in many segments of society that fathers should support their offspring whether or not they consented to the child’s existence, while the norms governing mothers range over everything from what they must or may not ingest during pregnancy to how clean they must keep their houses when their children are half-grown. But when we move from the domain of diapers and hockey practice to that of adult children with elderly parents, there are sharp differences of opinion in the ethics literature as to whether any responsibilities exist, and by the time we arrive at adult sisters and brothers, the philosophical conversation consists mostly of long silences.

There is, to be sure, a shared sense that our siblings have a greater claim on us than strangers do. The fact that the person
in trouble is your brother is a reason for you to help him. But just what that help should consist of is indeterminate—there does not seem to be any settled social understanding about how much help is enough, or how long it should be provided. As the standing moral theories cannot offer much guidance here, I argue that the best way to make sense of our moral responsibilities to our brothers and sisters is via a detailed description of our relationship to them. The description of that relationship is best understood as a narrative description, because it selectively represents morally relevant acts, incidents, and other features of the siblings' shared history, weighting the features according to their relative importance and tracing temporal and causal connections among them. The story's accuracy rests on its following the moral shape that the relationship actually has, and it is the persuasiveness of the story that justifies, or fails to justify, whatever action the sibling now proposes to take.¹

The fact that you and I are children of the same parent might make it reasonable for you to depend on me for something and reasonable for me to believe that you do in fact depend on me for that thing. It is then morally important for me to acknowledge our history, the present state of the relationship, and our possible or probable future together, because the relationship shows me what I owe you, why I owe it, and whether I have any latitude in how or when I discharge my obligation.² The backward-looking stories of my relationship to you can show me not only what I owe you but also how we got into this situation where something is owed. Sideways-looking stories can show me who else has responsibilities here, who will be affected by what I do, and the nature of the context in which I do it. And forward-looking stories display the possibilities for how, or perhaps whether, you, I, and others will go on in the future, and what that going on will mean for all of us.

Let me show you what I mean by telling you a true story. I have a half-sister, whose existence I knew nothing about until I was eighteen years old. At that time, my father told me that he had been married before—to a woman he met, courted, and wed one summer when he was doing philological research in Austria in the late 1930s. The woman spoke no English, so when he brought her home to the United States that autumn he invited his mother, a German-speaking immigrant, to share their household with them and provide companionship for his wife. Soon afterward, he returned home from work to find that his wife had thrown a plate at his mother in the course of a violent quarrel with her. Mother and son talked it over and learned instead that a wrong is compounded when its perpetrator refuses to acknowledge having done anything wrong. And that knowledge made me feel doubly responsible to my sister. I thought then, as I do now, that the fact of my being my father's daughter is a reason for me to do what I can to make amends for what he did to her. It is a reason I have never acted on. Too many other responsibilities, too little information, never enough money to embark on the search. But I had a balanced translocation and that did not think, in the face of what my father had already done to her, that I could sit idly by without warning her of the danger to herself.

The question that now arises is whether my version of the story is the one that should have guided my actions toward my sister. If my father, for example, were to tend his version of the story, surely it would differ from mine in many crucial respects. When stories conflict, which one should we believe? How can we judge whether a given story has accurately captured the moral dimensions of a particular relationship? Stories are, after all, selective in what they depict. They leave out certain details while emphasizing the importance of others, so there can be serious disagreements about whether they accurately represent an actual state of affairs. I think, though, that narrative descriptions of a moral situation can be assessed for their accuracy in the same way that we assess other descriptions, using the ordinary standards that competent people employ. If, for example, I am an architect and I describe a building to another architect, she can assess my description by looking at the building herself. Then, if we disagree about what we see, she can point out certain features I have overlooked, I can argue that she has missed something important about the overall shape of the building, and so on, until our corrected and augmented joint description satisfies

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Dwight pushed back the hair that had fallen across his forehead: thick, shiny hair, black as a cat’s. “I can tell her to stop phoning here if you want,” he said. His voice, as always, was soft and measured.

“I wish you would,” said Peggy, and cut herself an extra-large slice of chocolate chiffon pie. Magazine articles also said anxiety made you want to overeat, but Peggy always wanted to, anxious or not. Dwight had laughed when she told him about one piece she’d read on the causes of obesity—the author hadn’t even mentioned that fattening foods tasted good.

“You really want her to get the job, don’t you?” she asked, thinking: what a stupid question, before it was halfway out. Dwight was always saying that when it came to philosophical discussion, Natalie was practically the best person he knew.

“Sure,” said Dwight, “for her sake and for ours.”

“Our . . . oh, you mean the department’s.”

“She’s so original, not everyone sees how good her work is,” Dwight continued, “so I’m afraid she’ll end up at a second-rate place that won’t give her much time for research, and we’ll end up compromising and hiring someone safe. Don’t worry; I’ll tell her to stop calling,” he added after a moment. “You come first, of course.”

His eyes were heavy-lidded, remote, almost as if he were avoiding Peggy, but that was just how his eyes naturally looked. He had the longest lashes she’d ever seen on a man, a high-school girl’s dream.

\* * *

The next day, when Peggy awakened, over half the morning was gone and so was Dwight. Ten-thirty, said the blue enamel clock on the night table. That was her compensation for not working or being in school. She could get up when she wanted, do what she felt like, read anything she pleased, and not get graded on her ideas about it. Today she was going to finish Vanity Fair (no time for books like that last year), then drive to the beach at Santa Cruz. Or maybe reverse the order, finish the book on the beach. She looked out the window at the gleaming sun.

An hour later, she was eating a tootsie-roll pop and pulling out of the driveway in her red Stingray, the most unacademic used car she’d been able to find the month after her career ended; let them think she’d chosen not to be one of them. Now the car embarrassed her a little, but it was exciting to drive and she wouldn’t consider trading it in. She switched on the radio, and a thick male voice slithered into the air. “Do it for yourself and for the loved ones in your life.” Just taking it for granted that you and your loved ones wanted the same thing. The song turned out to be a part of a message about blood-pressure pills. As if doing it for yourself wouldn’t be reason enough; you’re nobody till somebody loves you? Unless you were a big success, of course, the way she once thought she might be. The way Natalie was going to be, maybe, if she got the job. She’d started the graduate program five years ago along with Peggy, and now she might be on the faculty soon. Did she ever wonder what Peggy was doing these days? Maybe tonight at the Kramers, Natalie would ask,

—And what have you been up to, Peggy, since you, er, left school?

—Well, let’s see. I drive around in my beat-up old Stingray. I take my cat to cat shows where she never wins any prizes. I lie on the beach and read nineteenth-century novels, not to mention piles of mysteries and magazines. I make chocolate chiffon pies and double the whipped cream; you should like that, Natalie. Want a piece? Impressed? I changed the recipe all by myself.

— Philosophy and Medicine —
And that, of course, was the catch to no school and no job: most people considered you pretty useless, most people including yourself. Sometimes Peggy wished she were back in Salt Lake City, where not being a Mormon had been enough to make her count as accomplished, intellectual, sophisticated, and daring. But Utah had no ocean. And if she hadn’t come to Stanford, she never would have met Dwight. Would he move to Utah now if she wanted, do it for her? He could get a job at the state university, she was sure, and he once told her he’d be willing. But he must have known he was safe, because she didn’t really want to go back. She wanted to stay in California, where she could go to the mountains and the sea on the same day, in the perpetual spring.

...“So what did you decide about tonight?” Dwight asked when he got home in the evening.

“I want to go.” Maybe ‘want’ wasn’t the right word, but she knew she would feel peculiar making no appearance at the first philosophy department party since she’d been dropped from the program. And she knew he’d be counting on going. They always stayed up half the night after the parties, discussing how everyone had acted, and why, and who was really happy. Dwight was almost the only man she had ever known who liked to talk about the same things she did. Maybe that was why he never seemed to care how she looked.

He might not care, but she did, Peggy decided two hours later in front of the bedroom mirror. Her red velvet pants wouldn’t even close, and the green ones she’d bought at the same sale last year were so tight it was like wearing a girdle. And Natalie was thin like a spear. Peggy changed into a flounced denim dress and a long rope of silver beads. Perhaps the extra weight wouldn’t matter tonight. Intelligence and achievements were what counted with those people, even at a party. Peggy didn’t find this reassuring or fair; wasn’t it easier to improve your looks than your brains?

Dwight’s reflection advanced toward hers as he came up from behind, wearing the blue corduroy jacket she had bought him for his birthday. He looks terrific, Peggy thought, and was instantly annoyed with herself. If she wanted Dwight not to care about her appearance, the least she could do was reciprocate.

“I just hope Tony’s wife doesn’t corner me with stories about her kids again, like she did when I ran into her at the mall,” she said. “I hate it when people assume just because I don’t have a career, I’m supposed to be interested in kids.”

Dwight grinned. “Tell her you’re not; give her a surprise.”

He’d like that, Peggy thought. He always seemed pleased when she did something he wouldn’t have the nerve to do. They walked out to the Stingray, and Peggy slid into the driver’s seat. Then she remembered that Dwight hadn’t told her whether he’d spoken to Natalie about not calling at home.

...The Kramers’ house was a mess. It invariably was. Peggy had been there several times, and shelves were always undusted, rugs askew, tables piled with books and papers. To Peggy the sloppiness seemed ostentatious, a way of saying: we’re too busy and important to bother with keeping our house in order. Of course, the Kramers were busy and important. Eleanor Kramer was philosophy department chairman (Peggy was always forgetting to say ‘department chair,’ and remembering struck her as a cheap way of scoring points, like being an atheist in Utah), and Eleanor’s husband was an eminent anthropologist. The Kramers greeted Peggy as pleasantly as if Eleanor hadn’t flunked Peggy on the Plato prelim, but they didn’t linger to talk.
Natalie murmured something Peggy couldn’t make out. Then she said, “Would you believe I can’t call him at home anymore, ever? He asked me not to. I could see it if he couldn’t talk while they’re eating or something, but apparently she can’t entertain herself no matter what. She just has no inner resources.”

“Doing nothing’s such hard work it takes two people,” offered the third student, a very tall man Peggy barely knew.

The conversation moved on to an argument from Natalie’s dissertation before the three of them got up and left.

Peggy wasn’t sure how much time went by before she followed them into the house. She felt unsteady, drunk, although only from what she had overheard. You had to drink in Utah to show how different you were from the Mormons, but there was nothing alcoholic she liked enough to drink in California.

Dwight was in the living room, talking with Natalie and dangling a string in front of the Kramers’ cat.

“I’m ready to leave whenever you are,” Peggy whispered to him, and kept her mind as blank as possible while they said their good-byes.

“Anything interesting happen?” he asked as they got into the car.

“I—can’t stand Eleanor,” Peggy said. “She’s so full of herself, even worse than I remembered.” Her tone was so vehement that Dwight turned to look at her.

“I’m not too crazy about Eleanor myself right now,” he said. “She told me tonight that she doesn’t like Natalie’s thesis. I’ll have to get it fixed, she said. Maybe she’s jealous.”

“Maybe,” said Peggy. She started the car. “Tell me something, Dwight. What do you really think of Natalie as a person? Do you like her?”

Dwight lit a cigarette. “Sure,” he said. “She’s got a good sense of humor sometimes.”

Peggy looked straight ahead. The windshield had a tiny crack she hadn’t noticed before. I’ll have to get it fixed, she thought. Finally she said, “Now I want to ask you something else. You’re going to think it’s pretty awful.”

The following day, Peggy decided to start reading War and Peace, something she’d long vaguely intended to do. By noon she was leaving a bookstore near campus with a glossy new paperback—she didn’t want a used copy full of someone else’s notes.

Over the weeks, the project went as slowly as winter in Utah. Reading the book required a patient, contemplative mood Peggy couldn’t enjoy or even sustain for more than an hour at a stretch. She wondered how the book was supposed to be great literature when all the descriptions and fancy language got in the way of the emotional point of things. Did a bunch of over-educated snobs who liked to make everything hard set the standards? Or was something wrong with her? On this point, Peggy changed her mind every couple of days.

A month after the Kramers’ party, Dwight came home in the afternoon, whistling, “It Never Rains in Southern California.” As soon as she heard him, Peggy ran to the door.

“Well?”

“It worked out fine,” Dwight said. “Natalie won’t be getting a job here.”

“Tell me all about it.”

Dwight wriggled out of his trenchcoat. He put his arm around Peggy. They walked into the living room and sat down on the sofa.

“I didn’t even have to lie,” he was saying. “There was controversy about making her an offer, just as I expected. So when people started raising objections—I simply kept silent.”

“How did you vote?” She was talking almost as fast as Natalie.

“Against her. There was no problem; it was secret ballot. She lost by one vote; so in a way mine was crucial. Of course, everyone who voted against her can say that. But I like to think I did it.”

Peggy smiled. “So she’ll have to go to Wilson College?”

“I suppose so.”

“And she’ll never be a big shot?”

“Probably not.”

“You’re sure you don’t mind?”

“Positive.”

“I mean—I know how much you like her work, and how important the department is to you, and well . . .”

“The only thing that’s more important to me is you.” Peggy let out a delicious long sigh. Then she began to laugh, harder and harder, joined by Dwight, their voices rising, filling the room. Peggy was startled; Dwight never got excited. He was quiet, reserved. Reserved for her.

“You’re wonderful,” she gasped.

“So are you.”

“I really mean it.”

“So do I,” said Dwight. His voice was soft again. “I like most of my colleagues, you know. But they never admit feeling anything human like envy or hate, let alone acting on it. Some of them are so . . . ferociously virtuous, maybe they never do. Then there are the ones who simply invent justifications for whatever they feel like doing anyway. But you came right out and asked me to vote against Natalie because you hated her. You didn’t try to pretend truth and justice were on your side.”

Peggy giggled. “How could I? They weren’t.”

“Eleanor always finds a way, believe me.”

“Anyway,” Peggy said, “I didn’t want you to do it for truth and justice. I wanted you to do it for me.”

“Yes,” said Dwight, “that’s precisely what I mean.” He leaned back and stretched. “I could not love thee, dear, so much, loved I not honor less.”

“Where’s that from?”

“Some seventeenth-century English poet, only he got it backwards. He said, ‘I could not love thee, dear, so much, loved I not honor more.’”

“Jesus,” said Peggy, “I’d hate to be the person he loved.”

“Probably never knew what she was missing,” said Dwight.

“You wouldn’t want everyone to have what we’ve got, would you? Then we wouldn’t be so special.”

The prism in the window made a rainbow on his face. Peggy smiled. “I think we’ve got what psychology types would call a very unhealthy relationship,” she said.

“I certainly hope so,” said Dwight.
Book Review

Stories of Sickness, Second Edition
Howard Brody (Oxford: Oxford University Press, 2003), 295 pp. $XX.XX (Hardback: 0195151399)

Reviewed by Matthew Rottnek
Mount Sinai School of Medicine

It seems like common sense that trying to live a good life involves stories. But formalizing such a stance into a coherent and defensible moral theory—that moral agency, the attribution of moral salience, and moral adjudication inherently involve, rely on, and may very well be reducible to narrative—is a formidable task indeed. Yet this is just the task Howard Brody, Professor of Philosophy and Family Practice at Michigan State University, takes up in Stories of Sickness. Drawing on Alasdair MacIntyre’s assertion that “we can have a comprehensible ethics only when we understand human life as assuming the form of a narrative,” Brody aims “to show how important it is to understand stories of sickness for a philosophical understanding of what it means to be sick, for ethical guidance, and for improving the quality of health care and the education of health professionals.”

First published in 1987, Stories of Sickness was a seminal work in heralding the ‘narrative turn’ in healthcare, a movement which promoted the following tenets: that understanding what patients tell doctors as stories can shed light on medical issues; that medical narrative is key to understanding some aspects of medical knowledge; that certain narrative skills should be taught to health professions students. This second edition is revised and supplemented to include advancements in narrative ethics and new nonfiction writing about illness.

The first of two main sections, narratives in health care, is a multidisciplinary analysis of the role of stories in creating meaning, structure, and relatedness in life, the ways in which a “life narrative” can be disrupted by serious illness, the experience of illness—for the individual, for those affected by another’s illness, and for society—and the social-political value of testimony, or “stories of sickness.” The second section, narrative ethics in health care, is a more straightforward philosophic account of the nature and method of narrative ethics, responses to critics, and an application of this method to the patient-physician relationship.

Drawing on Wittgenstein’s proposition that meaning is located in use in human activity and Rorty’s arguments against privileging transcendental or foundational knowledge, Brody promotes narrative as the only cognitive-experiential structure that both unifies the temporal, historical dimension of our existence and highlights the purposes, plans, and goals that give life direction and significance. For Brody, narrative, or story telling, is the primary human mechanism for maintaining a coherent, stable identity (one’s “life story”), for making sense of the world, for attaching meaning to particular experiences, and for relating to others. Serious illness, though, often disrupts one’s life story, and this loss of narrative coherence can result in alienation from others, devaluation of the self, and compromised personal identity.

Considering the person, in the phenomenologist tradition, as a fundamental unity of mind/body, Brody defines sickness as an “ontological assault” which turns the “lived body” into an “object body.” This disintegration can produce feelings of egocentricity and a constricted worldview (as in Charles Lamb’s “The convalescent”) which may result in a preference for solitude (as in Virginia Woolf’s “On being ill”) or, alternatively, in greater dependency on others (as in John Donne’s “Devotions”). Varied degrees of disorientation—a sense of being “out of time” or a loss of awareness of causal relatedness between events—may render communication about one’s experience difficult or impossible. Previously celebrated qualities of difference or uniqueness may also come to add to the sense of “not feeling oneself” and even produce an impression of abnormality. This experience, when heightened or prolonged, as in serious or chronic illness, can lead to true suffering, which, for Brody, is “a serious split within oneself or between oneself and one’s social group of community…[that calls into question the continued, integrated existence of the personal self].”

Brody’s phenomenologic analysis includes an equally extensive exploration of the potential meaninglessness and alienation experienced by family members and others witnessing illness. But what is perhaps most valuable in this section is Brody’s exposition of the ostracism experienced by those who are ill or disabled. Because illness reminds us of our own vulnerability and mortality—in effect, a kind of psychological contagion—there is a common human impulse (a kind of irrational survival instinct) to regard the sick in a distancing, “other” way. (Kafka’s novella, The Metamorphosis, is an extreme example of this.) So long as we can “see the blessed space” between us and the sick, we are able to go about our lives in the illusion of invulnerability and immortality. Moreover, in American culture, which locates power and agency in the individual and privileges a linear, orderly unfolding of life, the disorder and disruption of sickness have come to symbolize irresponsibility or wrongdoing—hence, a moralizing component. (Recall Sontag’s Illness as Metaphor.) Brody writes, “[M]uch reaction to sickness that superficially appears to be solely outward-directed (that is, toward meeting the needs of the sick person) is, in reality, also inner-directed as an attempt to remove, resolve, or transcend this inner threat to integrity.” [emphasis added] This reaction is even stronger with regard to persons with disabilities, whose “weakness” and “dependency” are the very opposite of the American values of physical strength, independence, order, and control; people with disabilities particularly represent a fearsome possibility—the loss of these seminal American values. What keeps the healthy from viewing the sick and disabled as fully deviant is a coexisting social value that we must express sympathy and compassion toward those suffering from disease and injury, and the interplay of these conflicting values results in varied reactions to illness—impulsive reactions, prejudiced reactions, obscenity reactions (excessive identification with the deformed or disabled), ritual separation, humanitarianism (a broadening of one’s perspective to include the other within the realm of the fully human), spiritual transcendence, normalization (the other is “just like the rest of us”), diversionary tactics (e.g., black humor), and induration (diminished perception of the difference).

But the “blessed space” that provides the well with the illusion of safety, Brody tells us, not only deepens the anguish and suffering of the sick and disabled, but also marginalizes them, leading to social, and possibly political, disenfranchisement.

In a move that recalls the identity politics of the 60s and 70s, Brody promotes testimony as a means of resisting potential or actual insults to selfhood, agency, and citizenship. When one’s experience is at odds with the normalizing ideologies of the culture, testimony—sometimes individual and private;
sometimes within the context of support groups (a type of mini-community of validation and buffering from the potential or actual adversities of the greater community)—can serve to maintain or restore self-respect, reconnect with others and begin a process of reformulating life plans which had been disrupted by illness. Yet, once outside of the protected space of the mini-community, if this testimony contradicts a seminal normalizing ideology of the culture, it may be ignored, resisted, or labeled as deviant by the mainstream.

Drawing on the work of John Rawls, who holds that the attainment and maintenance of self-respect is the foundation of social justice, Brody makes a segue from the value of testimony for the individual to a broader renegotiation of the social-political tension between what is normal and what is different—a tension that the healthy are largely able to ignore. Via political organizing, a coalition can attempt to engage the larger community with its testimony; when resistance is encountered, civil disobedience may be necessary—as has been the case with AIDS and disabilities activists, for example. Brody cites the Americans with Disabilities Act of 1990 and recent advances in the recognition of an intersexed community as successes in this realm.

But—once grievances are addressed—if the testimony of the sick and disabled only reminds us of our own vulnerability and mortality, why should we listen?

Brody gives us at least five reasons:

1. Stories of sickness function as reminders of the human ability to cope with adversity and to find meaning in disorder and chaos.
2. Illness and suffering are contingent (as dramatized in Carus’s The Plague and Poe’s “The Masque of the Red Death”). Those who are well today may be sick tomorrow.
3. Sickness or an awareness of sickness seems necessary for fully appreciating health.
4. Serious illness provides an opportunity to reflect on one’s past life (as in The Death of Ivan Ilich) and ask, Was my life meaningful? The testimony of others invites us to reflect what is meaningful in our own lives.
5. The experience of illness brings into relief the essential interrelatedness of human beings.

II

On Brody’s view, medical ethics over the last three decades has been limited by the hegemony of abstract conceptual analysis; the dominant model of principle-based ethics has lost touch with patients’ stories.

Principle-based ethics, Brody reminds us, involves applying general, universalizable principles to specific cases in order to make moral judgments; the unique features of the cases (the narrative detail) come into play only insofar as they demonstrate that a given case can be subsumed under a general principle. On this model, the moral activity central to ethics is making moral judgments, and the moral knowledge necessary to make such judgments can be codified in a set of abstract—unsituated, impersonal, intellectual, rationalistic, and individualistic—general moral concepts. The use of such knowledge in making moral judgments defines the field of ethics; unique features of particular cases not captured by abstractions fall outside the realm of principlism.

Brody traces the development of modern ethics historically from the Platonic tradition, which privileged “essences” over real life particularities, to the Enlightenment, when Kant focused on logical deduction to make rational ethics a formidable alternative to the “word of god,” to Bentham and Mill, who held fast to universal principles while embracing a mathematical translation of empirical facts about the world and equated ethical decisions to calculations. The bureaucratization of industrial society gave rise to the specialist, and ethics became the turf of philosophical experts who claimed special access to technical knowledge. Throughout this historical trajectory, principlism has been sustained by an overarching imperative that ethics and reason (our higher nature) must keep our lower natures in check. This dualism, Brody suggests, reflects a refusal to accept the inherent disorder and contingency of the world; a kind of existential anxiety sustains the belief that there must be an underlying, logical moral architecture that we can understand and use to deduce moral certainties.

Modernism took hold in medicine in the form of a general split between the patient-body and the experiential self. With rapid scientific progress in the post WWII era, illness and death became technological problems. Then, evidence based medicine replaced anecdotal evidence (read: situated narrative detail) with the pursuit of “real” scientific data from studies reported in the latest medical journals (read: universalizable principles). The result was an algorithmic approach to healthcare—the “essence” of disease is abstracted from the particular context of sickness in order to apply general medical principles to individual patients. This scientific methodology involving categorization (in diagnosis) and algorithms (in treatment) was extended to ethical questions—the birth of modern principle-based medical ethics. As managed care bureaucratized medicine, as the consumerist model of healthcare championed autonomy as noninterference, and as a history of lawsuits shifted the focus from patient care to legally defensible standards of care, principlism became more entrenched. In this ideologic shift, Brody argues, medicine lost not only the anecdotes which capture the individuality of patients—the material necessary to treat effectively and to engage in ethical analysis of complex issues such as compromised autonomy and dependency—but also the primary, immediate experience of illness, insight into which is necessary to address suffering. “Overworked and harried physicians,” Brody writes, “display little tolerance for any information from patients that is not already formulated as, or at least easily translatable into, the standard ‘medical history’—such patients might then be deemed ‘poor historians.’”

More broadly, principle-based ethics as a general method of ethical analysis is, Brody believes, severely limited. It cannot embrace the full range of moral activity, nor can it capture aspects of ethical decision making such as emotional salience, situatedness, moral learning, and moral self-knowledge. In practice, principlist ethics eliminates morally relevant information in order to allow for a decision procedure. Furthermore, Brody argues, principlism as a methodology is deeply flawed. It relies on narrative—moral principles arise out of an aggregate of stories with similar moral content, and judgment and interpretation, both of which require an agent and a narrative to act as a bridge between agent and principles, are essential components of any application of general principles to individual fact. Ultimately, the validity of any principlist analysis is our considered judgments about real world circumstances, i.e., the test is the narrative.

Just as narrative is essential to principlist ethics, “…modern medicine is still a ‘storied’ activity at its core.” Brody gives several examples. Conversations with patients (the story of the patient’s illness) and conversations among physicians are necessary for diagnosis and treatment, and the application of a medical principle to a case at hand also requires a kind of
story telling. Where evidence-based medicine is limited (i.e., studies either not yet completed or not directly applicable to a case at hand), physicians often draw on stories amassed from previous patient experience, or from cases reported in the literature, presented at conferences, or related by colleagues. Physicians must then consider the relationship between the medical stories and the patient's sickness story and negotiate between them in order to provide the patient with the full benefit of the medical work.

III
Contemporary narrative ethics, in contrast to principlist ethics, appeals to stories (narratives of relationship, identity, and value) rather than to principles in order to come to moral conclusions. Grounded in Aristotelian/MacIntyresque virtue ethics and drawing on the Judeo-Christian practice of casuistry, a method which relied on narratives for ethical analysis and dialogue, narrative ethics not only reintroduces the agent as a moral decision maker but also reconstitutes a dialectic approach to moral reasoning. Narrative ethics, then, involves two central claims: (1) The use of general moral principles or norms necessarily involves narrative in some way and ethical knowledge and (2) Ethical justification can follow from narratives without appeal to general principles or moral norms. Removing principles from moral analysis, Brody points out, is not to reject truth or rationality but rather to “modify and extend those canons beyond the limited sense implied by logical argumentation.” In judging a narrative’s adequacy, Brody explains, people appeal to narrative probability and narrative fidelity, and these suggest a coherence, rather than correspondence, theory of truth. Since a sense of narrative probability, fidelity, and coherence is shared by lay persons, ethics—narratively construed—cannot be claimed as the exclusive province of experts, and the stories told by experts do not automatically displace the stories of lay people about their own experiences.

In medicine, attention to the narrative detail of the patient’s life story, the “sickness story,” and the ways in which the life story has been disrupted by illness provides a much richer understanding of the patient, which is useful in many ways. It enables the physician to differentiate among instances of noncompliance, informed decisions to refuse treatment, and “maladaptive” ways of being sick. It helps determine the most appropriate way of presenting information regarding diagnosis and prognosis. And it informs the choice of appropriate and practical treatment plan. Most importantly, this method brings the world of medical reasoning into closer contact with the lived world of the sick person, breaking down barriers in communication and ideology. Brody writes, “The most elegant medical diagnostic and treatment plan is of no use if the patient refuses to accept it as describing her condition or if she does not intend to adhere to the plan in the future.”

Also, by engaging in what Brody calls “co-authorship” with patients, a practice which echoes models of psychoanalysis as a form of story construction, physicians can affect a kind of therapeutic intervention. By giving meaning to the experience of illness and restoring a sense of connectedness with others, co-authorship can alleviate the suffering that would otherwise result from meaninglessness and alienation. For Brody, the ‘storied’ relationship between physician and patient is compassionate, humanistic, and ethical; it is also therapeutically efficacious. Brody writes, “[P]atients are most likely to improve when the meanings of their illness experiences are altered in a positive direction—when things are explained to them, they feel cared for, and they sense an enhanced degree of control over the symptoms.” Brody supports this assertion with references to various studies which demonstrate that writing about stressful life events is therapeutic—hypothetically because the organizational task of writing requires a reflective distance from the event, which allows the individual some control over it and enables her to place it within the overall context of her life. By extension, listening to patients’ stories may be associated with improved physical and mental health outcomes.

In addition to the benefits to patients and to the overall quality of health care, a narrative orientation also benefits physicians, who, for Brody, have suffered a loss of meaning—corresponding to a loss of their own stories—within the current institutional climate of medicine. Brody writes: “If we assume that story telling does indeed play an important role in the day-to-day subconscious world of the physician, it is small wonder that such physicians should end their days’ activities feeling vaguely frustrated and unfulfilled . . . [P]hysician burnout seems to be associated with having no one to whom to tell one’s stories of practice, and little opportunity of coming to understand for oneself the meaning of those stories.”

IV
Stories of Sickness is an important book for several reasons.

First, in the spirit of diverse works such as Georges Canguilhem’s The Normal and the Pathological, Richard Rorty’s Contingency, Irony, and Solidarity, and Michael Warner’s The Trouble with Normal, Brody’s analysis of the experience of illness highlights the constructed nature of the category of “the normal” and demonstrates the ways in which the normalizing ideologies of the culture have the potential to constrain human lives or exclude individuals from recognition. Such an analysis is crucial to any responsible sociopolitical discussion of agency, self-respect, and individuality.

Second, Brody succeeds in bringing to the page one of the most valuable and hard-won lessons of medical training—heightened awareness of the inherent contingencies of human life which (hopefully) follows from bearing witness again and again to the suffering and struggles of those who are ill. Listening to stories of sickness offers a similar opportunity to reflect on our commonalities with others and realize the universality of human struggle, suffering, and vulnerability.

With or without the solace of religion or other supportive ideology, how many of us turn to the drink or a joint at the end of a long day, or to diversionary sex, acquisitiveness, or to the self-hypnotic effects of television to alleviate our own (perhaps unrecognized) suffering? Alternatively, how many people have a copy of Scott Peck’s The Road Less Traveled or other popular “self-help” book tucked away shamefully in the corner of the bookshelf? How many rely on psychotherapy, 12 step programs, yoga, or alternative methods to develop or sustain the kind of groundedness that arises, in large part, from a sense of connection with others? And, given our “survival instinct” of invulnerability and immortality, how easily do we forget our struggle—or the struggles of others—when times are good?

By humanizing the experience of illness and disability, Brody’s account both challenges our defensive, distancing impulse toward those who are ill or disabled and reminds us that, in making an effort to understand those who seem different, we might also come to greater understanding of ourselves.

Third, in parallel to Jodi Halpern’s From Detached Concern to Empathy: Humanizing Medical Practice, Brody’s exposition of the impoverishment of the current institutional atmosphere of medicine dominated by market forces, managed care, and legalization, demonstrates what has been lost—or at least threatened with extinction—in healthcare. In fact, in response to “unprecedented challenges . . . [which] center on increasing
disparities among the legitimate needs of patients, the available resources to meet those needs, the increasing dependence on market forces to transform health care systems, and the temptation for physicians to forsake their traditional commitment to the primacy of patients’ interests,” a 1999 joint commission of the European Federation of Internal Medicine, the American College of Physicians—American Society of Internal Medicine, and the American Board of Internal Medicine launched The Medical Professionalism Project to develop a charter of fundamental principles and professional responsibilities with the aim of reaffirming physicians’ commitment to the welfare of patients and society. Brody, too, offers such a “reaffirmation.” His stories of medical practice direct us to collect all the bits of doctoring taught piecemeal on the wards by those distinguished teachers who have been able to sustain their humanism under these adverse circumstances. Stories, in their ability to capture the distinctively human details of patients’ experiences not taught by the “nuts and bolts” of medical education or included in the standard patient presentation (e.g., “65 y.o. male Hx HTN X 20 yrs, s/p MI 1997, s/p CABG X3 1998 now w/ . . .”), refocus our attention to the people behind the illnesses—a point Abraham Verghese makes constantly to his residents in My Own Country—and reaffirm our “professionalism.”

Fourth, Brody’s work identifies, and offers a corrective for, a central flaw in medical ethics and ethics education in medicine. The underlying allegiance to principlism has promoted a high level of abstraction, so that the discourse and teaching of medical ethics is removed from the immediate experience of the patient and physician interacting in the context of the clinic, bedside, or operating room. As a result, medical ethics education is denuded of emotional, psychological, and interpersonal saliences and sanitized of the hierarchical, competitive, and, at times, abusive interpersonal dynamics of medical institutions. Indeed, numerous articles in medical education journals in the last decade have noted a lack of focus on the ethical dilemmas students, under pressures of being evaluated and appearing as a “team player,” actually face, e.g., conflicts between the priorities of medical education and those of patient care, disparities between a student’s capacity tasks or procedures asked to perform, and students’ involvement in patient care they perceive to be substandard. Furthermore, such studies have questioned the value of formal medical ethics curricula in influencing behavior once students arrive on the wards, where a “hidden curriculum”—of clinical teaching and faculty behavior modeling values at odds with what is being taught in the classroom—predominates. It has been suggested that this atmosphere of moral enculturation transmits normative attitudes and behaviors to medical trainees, resulting ultimately in the failure of medical students to develop morally, or even in a gradual loss of moral sensitivity over the course of medical training, a phenomenon reflected in the catch phrase “the ethical erosion” of medical students.

What better way to address this failing than by appeal to physicians’ stories, e.g., Atul Gawande, Richard Seltzer, Abraham Verghese, Jerome Groopman, et al., who, in presenting their moral struggles in situated, narrative detail enhance both our moral understanding and our capacity to act morally.

V

Stories of Sickness is a complex book. In order to lay the groundwork for Brody’s view, for example, early chapters treat, aside from topics already mentioned in this review, the ontology of stories, theories of knowledge, an inquiry into the nature and uses of irony, cross-cultural conceptualizations of disease, necessary and sufficient conditions for the state of illness, the differentiation of medical science from general science, the philosophical problem of personal identity . . . as well as an extensive review of schools of thought in medical ethics. Throughout, Brody makes serial appeals to authority, even nested appeals to authority, to theorists in various fields—philosophy, psychology, psychoanalysis, literary criticism, linguistics, feminist theory, communications theory, and others—to present or substantiate a point in the development of his position. Insofar as this is a multidisciplinary work, some degree of annotation is necessary. But, while these passages consistently contain valuable and interesting information, they often feel tangential—particularly when comprising endnotes sometimes two-three paragraphs in length. Ultimately, so many references and annotations have the unfortunate effect of diluting rather than enhancing the writing. They also necessitate Brody’s frequent reminders to the reader about how these tangents relate to the point at hand. To add to this complexity, Brody has an Aristotelian penchant for taxonomies, lists of necessary and sufficient criteria, and differentiating characteristics. While never gratuitous, the extent of this material can feel excessive, distracting, and obscuring.

One read of this book might be for the literary references alone. Brody has compiled a rich selection of literary works about the experience of illness—short stories, novels, and essays from Chekhov to Donne to Hemingway to Lamb to Mann to Maugham to Solzhenitsyn to Sontag to Tolstoy to Twain to Woolf. And yet, although these references are noteworthy and consistently make valuable points in the exposition, Brody’s often lengthy synopses and analyses will frustrate those readers who prefer primary sources over summaries and interpretations. One wonders why Brody, a family practitioner, would choose to rely on fictional accounts or other writers’ accounts of patient stories (e.g., Seltzer, Groopman,) rather than presenting his own.

From the perspective of philosophy, this is an unusual book. On the face of it, so much of the material presented seems to be not within the realm of ethics—at least ethics traditionally construed; rather, it is a book about the nature of illness, the phenomenology of being sick, and the repercussions of sickness. Ultimately, this is Brody’s point—insight into that which would not be considered within the realm of ethics on a principlist account is fundamental to patient care and to the practice of medical ethics. Yet, when he presents the topic of narrative ethics as a philosophic method, the text often reads as a review of the literature rather than an exposition of Brody’s own thinking. Furthermore, while Brody notes at one point that the claims of narrative ethics can be supported only by demonstration, not by discursive analysis, he still seems burdened, in his justifications, by the sort of analytic, logical method against which he argues. He also seems burdened by scientific method—at times appealing to empirical data to support a point; at other times simply admitting that a point in his argument is without evidence. Brody is well aware that the scientific physician as well as the analytic philosopher are likely to resist an analysis of medical practice that puts story telling at center stage, and this tension may be behind his apparent need to offer justification, albeit inconsistently.

While Brody is highly successful in motivating the importance and pervasiveness of narrative in life, it is not clear that he presents a defense of narrative ethics that would persuade its critics. Many analytically-inclined readers will take issue, for example, with propositions such as the reducibility of principles to narrative, a theory of truth based in narrative probability and coherence, and the reliance of principle-based ethics on narrative. It’s also not clear that Brody presents
coherent defense of narrative ethics as a practical means of conflict resolution.

VI

Then too, one might question the clinical practicability of narrative ethics. As a method, it necessitates what today feel like extraordinary amounts of information, analysis, and time. One might question as well the practicability of Brody’s model of co-authorship, which requires not only a kind of emotional participation in the patient-physician dynamic, but also a good deal of self-knowledge. In the end, Brody shows himself to be very much the virtue ethicist. But does medical education prepare us for this? Does medical education instill, or make an effort to teach, virtue? And does the current atmosphere of medicine allow for a virtue-based ethics?

Ultimately—short of an overhaul of medical education and drastic changes in the institutional environment of medicine—the applicability of narrative ethics seems much more circumscribed, due to time limitations, economic pressures, the constraints of managed care, and the shortcomings of medical education, to more longstanding patient-physician relationships and to those physicians who, for whatever reason, have managed to resist the current institutional pressures within medicine. It makes sense that Brody focuses on the family practitioner in his conclusion.

And here we come full circle. To the extent that we have lost sight of patients’ narratives and to the extent that the institution of medicine, under its current conditions, does not allow for sufficient attention to patients’ stories, we have lost sense of our purpose—a purpose back to which Brody leads us.

For Lucy Grealy, in memoriam.

ANNOUNCEMENTS

August 2-6, 2004
“Summer Seminar in Clinical Ethics” will take place at the University of Washington. The seminar provides an intensive interactive introduction to the four-box method of analysis of ethical problems in clinical care, developed by Jonsen, et al. in their book Clinical Ethics. For information, please contact: Maryilyn J. Barnard, Manager Continuing Education Program University of Washington Department of Medical History & Ethics Campus Box 357120 Seattle, WA 98195-7120 Phone: 206-616-1864 Fax: 206-685-7515 Email: mbarnard@u.washington.edu

August 8-14, 2004
The “Fifth Annual Taos Writing Retreat for Health Professionals,” sponsored by the University of New Mexico Health Sciences Center Institute for Ethics and the University of New Mexico School of Medicine Office of Continuing Medical Education, will take place at the historic Mabel Dodge Luhan House in Taos, New Mexico. The retreat encourages individuals to pursue their writing in a communal environment that provides maximum space for personal exploration and growth. Participants are invited to bring along work-in-progress (both scholarly and creative), ideas for writing they want to begin, or simply a desire to write. No prior experience necessary! For further information:
University of New Mexico School of Medicine Office of Continuing Medical Education MSC09 5370 1 UNM Albuquerque, NM 87131-0001 Phone: 505-272-3942 Email: CMEweb@salud.unm.edu Website: http://hsc.unm.edu/ethics/retreat.shtml, and http://hsc.unm.edu/cme

The Center for the Study of Bioethics at the Medical College of Wisconsin welcomes applications to its Master of Arts Program in Bioethics or Certificate Program in Clinical Bioethics. The MA Program can be completed through either a traditional, campus-based curriculum or through an executive-style curriculum that combines online learning with a two-week intensive session on the MCW campus. The Certificate Program includes four courses offered through an innovative, web-based format. For more information and an application, contact Kristen Tym at 414-456-4299 or ktym@mcw.edu.

October 28-31, 2004
American Society for Bioethics and Humanities 6th Annual Meeting Marriott Philadelphia, Philadelphia, PA Website: http://www.asbh.org/annual_meeting/
November 9-12, 2004  
7th World Congress of Bioethics  
Sydney, New South Wales AUS  
The Congress theme deep listening: bridging divides in local and global ethics will be given further expression through the sub-themes: indigenous health ethics, public health ethics from local and global perspectives, and refiguring the body. In addition there is a broad category for presentations on any topic within bioethics not covered by the theme or sub-themes. There is a stimulating and varied program that will include plenaries on the major themes of the Congress, special symposia on major issues in bioethics, and papers on topics within each of the Sub-themes along with interesting and fun cultural and social events. The Congress will deal with issues of critical importance in the world at this time and will provide attendees with an opportunity to participate in discussion sessions with leading speakers on a variety of topics. Congress attendees will hear from leading speakers in bioethics and meet people from all around the world.

August 24-27, 2005  
“Ethics and Philosophy of Emerging Medical Technologies” is the theme for the XIXth International Conference of the European Society for Philosophy of Medicine and Healthcare (together with the European Association of Centres of Medical Ethics). The conference will be held at the Barcelona, Spain. Abstracts should be submitted before December 1, 2004. For more information please contact:  
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