

consider the proper place of medical care in a just society, to pay attention to the standards that should inform “the deal.” As bioethicists, we have been fairly successful in moving out of the classroom and into the public sphere, making contributions that can potentially reach broad audiences even as they address pressing social concerns. We can show how health care professionals can help craft the social setting within which medicine is practiced even as we equip practitioners to work responsibly within that context.

Endnotes

- * Some of the ideas in this article are drawn from my “Professional Ethics and Instructional Success,” in *Professing Medicine*, edited by Audiey Kao, M.D., Ph.D. AMA 2001.
- 1. John Harris, *Bioethics* (Oxford University Press, 2001).
- 2. Charles Bosk, *Forgive and Remember* (University of Chicago Press, 1981).

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.

ARTICLES

*What’s So Special about an Age of Genetics?**

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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 would have 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

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 this 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

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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