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Genetic Privacy, Disease Prevention, and the: PRINCIPLE OF RESCUE

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Abstract

Do patients have a moral duty to share their genetic findings with family members if the information could help their biological relatives avoid disease? Those who have written about this question tend to emphasize the familial nature of genetic information or special obligations to relatives. A better account relies on a general duty to help people in need.

Suppose that you have deeply personal information that you do not want to share. Further suppose that this information could help others, perhaps even saving their lives. What should you do? Reveal the information or keep it secret?

With the increasing prevalence of genetic testing, more and more people are finding themselves in this situation. Predictive genetic testing is used to detect gene mutations—permanent alterations in the nucleotide sequence of an organism’s DNA—that dramatically increase an individual’s risk of developing certain health conditions.¹ If a woman has a pathogenic *BRCA1* mutation, for example, then she is estimated to have a 44 to 78 percent chance of developing breast cancer and an 18 to 54 percent chance of developing ovarian cancer by the age of seventy. *BRCA2* mutation carriers have slightly lower risk estimates—33 to 54 percent for breast cancer and 4 to 18 percent for ovarian cancer by the same age.² By comparison, the general population’s risk for developing these cancers by age seventy is approximately 8.96 and 0.65 percent, respectively.³

While an individual cannot eliminate a harmful mutation from her genetic code, she may be able to significantly reduce her risk of developing and dying from certain hereditary diseases. A pathogenic mutation is considered clinically actionable when there are risk-reducing measures that a carrier can pursue to improve her prognosis. For example, by having a prophylactic bilateral salpingo-oophorectomy (surgical removal of the fallopian tubes and ovaries), *BRCA1* and *BRCA2* mutation carriers can reduce their risk of ovarian cancer by as much as 90 percent.⁴ Since ovarian cancer patients tend to have especially poor prognoses, knowing their genetic risk may be lifesaving.

Although a patient’s genetic results are potentially relevant to all her biological family members, her first-degree relatives—parents, children, and full siblings—are most likely to be affected. This is especially true for genetic mutations—like those in the *BRCA1* and *BRCA2* genes—that are associated with a dramatically increased risk of disease.⁵ Fortunately, people are usually willing to share results with their at-risk relatives.⁶ Occasionally, however, a patient refuses to disclose her findings to anyone outside her clinical team.⁷

To date, scholars have focused almost exclusively on whether it is ever acceptable for health care professionals—particularly physicians and genetic counselors—to breach confidentiality to warn a patient’s relatives of their genetic risk. For the most part, this debate has been framed as a conflict between medical providers’ duty to respect patient confidentiality and their interest in protecting vulnerable third parties from serious yet potentially preventable harm.⁸

Some ethicists have argued that medical providers should never disclose a patient’s genetic findings without obtaining consent first.⁹ And others have maintained that certain situations might merit nonconsensual disclosure.¹⁰ Although the ethical debate is ongoing, the policy debate is largely settled. From a legal standpoint, there is little precedent in the United States for breaching provider-patient confidentiality to warn patients’ at-risk relatives.¹¹

Accordingly, the decision to help those at risk of genetic harm falls almost exclusively to patients. In light of these considerations, it is surprising that ethicists have written so little on patients’ moral duties to their at-risk relatives. Moreover, the few accounts that have been advanced are problematic. Some unnecessarily expose patients’ genetic information to relatives who are unlikely to benefit from it, and others fail to ensure that patients’ most vulnerable relatives are informed of their genetic risks.

Patients’ duty to warn can be defended in a way that avoids these problems. I argue that the duty to share one’s genetic results is grounded in the principle of rescue—the idea that one ought to prevent, reduce, or mitigate the risk of harm to another the person when the expected harm is serious and the cost or risk to oneself is sufficiently moderate.¹² When these two criteria are satisfied, a patient will most likely have a duty to warn.

Patients’ Duty to Warn

The familial nature of genetic information.

Many people share the intuition that the information contained in one’s genome is deeply personal. Daniel Sulmasy writes, for example, “A genome is so integral to what and who one is that one cannot alienate one’s genome from oneself without ceasing to be who one is One cannot ‘extract’ one’s genome from oneself and transfer it to another . . . without self-annihilation.”¹³ Yet genetic information is also profoundly interpersonal, revealing not just of oneself but also of one’s biological relatives.

Recognizing the familial significance of genetic information, a number of scholars have endorsed a family-centered approach to screening. Roy Gilbar, for example, has suggested that medical providers treat the family, rather than the patient, as the primary unit of care. This approach, he maintains, involves adopting a relational view of patient autonomy that focuses on how decisions about testing affect the entire family.¹⁴ In a similar vein, David Doukas and Jessica Berg have proposed a “family covenant” model, where the provider endeavors to bring the entire family together to discuss testing and the dissemination of results.¹⁵ Bartha Knoppers also thinks that we need to recognize the familial significance of genetic information, writing that, “between the human genome at the collective level being considered the common heritage of humanity and at the personal level as being unique and belonging to the individual, the information it contains is also familial.”¹⁶

These writers do not advocate disclosing patients' genetic findings without their consent, nor do they defend a duty on the part of the patient to share her results. Other ethicists, by contrast, have explicitly argued that sharing genetic information among relatives should be the default. Michael Parker and Anneke Lucassen propose abandoning the current "personal account model," which emphasizes patient privacy and confidentiality, in favor of a "joint account model." As they explain, "Whereas on the personal account model the default position is an assumption of confidentiality, on the joint account model it is assumed that information should be [made] available to all account holders unless there are good reasons to do otherwise."¹⁷

According to the joint account model, an individual ought to make her genetic findings available to her relatives because the information also belongs to them; it is, as Parker and Lucassen write, "essentially and unavoidably familial in nature."¹⁸

Their proposal raises a question: if a patient's genetic information is, by its very nature, fundamentally familial, should it be made available to any interested relative, regardless of the relative's risk of suffering genetic harm? Ethicists who have written about the familial nature of genetic information are concerned primarily with serious genetic conditions like hereditary breast and ovarian cancer syndrome. Yet genetic testing is not limited to rare pathogenic mutations that are associated with a dramatically increased risk of disease. For example, medical providers can now order genetic tests that assess an individual's risk of developing certain common health issues, such as type 2 diabetes.¹⁹ Unlike with single-gene mutations that are known to cause various types of cancer, one's risk of developing a common health condition like type 2 diabetes is determined by a complex interaction of many genes, as well as various nongenetic factors.²⁰ Therefore, many genetic tests have relatively low predictive value or clinical usefulness, for either the patient or her family members.²¹

Given the extent to which the utility of genetic findings can vary, one might propose a more fine-grained approach, where a patient needs to make only certain pieces of genetic information available to her relatives—specifically, those pieces that have significant implications for their health. But if one's genetic information were, as Parker and Lucassen contend, "essentially and unavoidably familial in nature," then it would presumably belong to one's relatives as well as oneself. If this were the case, any biological relative would be entitled to any piece of information, regardless of whether it would be objectively useful. This conclusion is deeply problematic: making patients' genetic findings accessible to all their relatives, including those who are unlikely to benefit from them, needlessly undermines patients' medical privacy.

Besides unnecessarily exposing patients' medical information to others, grounding the duty to warn in the familial nature of genetic information reinforces genetic exceptionalism—the view that genetic information is fundamentally unique and deserves special treatment. Among the most cited reasons for thinking that genetic information is special is the very fact that it has consequences for one's relatives, in addition to oneself. As George Annas explains, one's genetic information is like a "future diary" that is "written in a code that we have not yet cracked . . . [b]ut . . . is being broken piece by piece such that holders of a

sample of an individual's DNA will be able to learn more and more about that individual and his or her family in the future as the code is broken."²²

By appealing to the familial significance of genetic information, ethicists wind up reinforcing the idea that genetic information is qualitatively different from other kinds of medical information. Regardless of whether this view is correct, if patients perceive genetic information as being powerful and deterministic, they will inevitably worry about discrimination and exploitation.²³ Somewhat ironically, the very arguments that are intended to encourage patients to share their genetic findings may actually perpetuate the view that genetic information is unique, which may in turn make patients more reluctant to share important genetic findings with their at-risk relatives.

Special obligations.

A different possibility—but one I will ultimately reject—is that a patient has a duty to disclose her genetic results to her relatives because she has *special obligations* to them. Common sense morality recognizes us as having special obligations to certain individuals, such as our friends and family, in virtue of our relationships with them. Special obligations stand in contrast to natural duties, which are owed to all individuals simply because they are persons with moral standing.²⁴ For instance, as Charles Weijer writes, "Family members are not strangers to one another; rather they share an indissoluble bond. Familial relationships are understood productively as ethical duties that family members owe one another."²⁵

Philosophers continue to debate the grounds of special obligations, that is, why an individual should take himself as being obligated to do more for certain persons just because he happens to stand in a special relationship to them. Regardless of how that debate unfolds, grounding a duty to share genetic findings in special obligations is problematic because it fails to ensure that patients' most vulnerable relatives learn about their genetic risks.

Consider a view known as voluntarism, which holds that special obligations arise through a voluntary action on the part of an agent such as making a commitment, agreeing to a contract, or taking on a certain role. On this thesis, a patient's duty to warn a particular relative will depend on whether she undertook some voluntary action with respect to that relative (such as promising to share her genetic results). Absent such a commitment, she may have no obligation to warn. Inasmuch as patients do not always make commitments to share genetic results with their most genetically vulnerable family members, a patient's most at-risk relatives may be denied access to potentially lifesaving genetic information.

Other accounts are not any sounder. Consider Samuel Scheffler's view that a relationship generates special obligations only when one has intrinsic reason to value the relationship.²⁶ The reality is that, while most people value their relationships with their close biological relatives, some do not. In fact, empirical research suggests that social closeness plays a significant role in determining which relatives a patient chooses to warn. Likewise, a lack of social closeness is one of the main reasons patients withhold genetic information from certain relatives.²⁷ Consequently, a patient may keep potentially lifesaving information from a socially distant relative who is at high risk of suffering genetic harm (the biological sibling he has not seen in years, for example) while sharing it with a socially close relative who

most likely did not inherit the patient's problematic gene (such as the second cousin he grew up with and sees every weekend).

Now suppose, for the sake of argument, that one accepts Scheffler's view—that a relationship generates special obligations only when an individual has intrinsic reason to value the relationship—in tandem with the idea that one's duty to warn is grounded in special obligations. The result is that, if our hypothetical patient does not value his relationship with his biological sibling, he would not have a duty to inform his sibling of his genetic risk. In reaching this conclusion, Scheffler's account, much like the voluntarist approach, fails to ensure that patients' most genetically vulnerable relatives learn about their risks.

Alternatively, one might argue that we have special duties to our biological relatives just because they are our biological relatives. To defend this claim, one would need to show that genetic relatedness gives us reason, independent of social or historical associations, to care about genetic relationships. David Velleman, for instance, has argued that genetic ties, particularly to one's parents, give us reason to care about biological connections. The reason, he argues, is that they "provide[] a kind of self-knowledge that is of irreplaceable value in the life-task of identity formation."²⁸ Velleman's claim probably resonates with most people. Still, there are many individuals who, for any number of reasons, have no interest in their ancestry. Unless we are willing to conclude that these people have incomplete identities or that their values are somehow misguided, it is not apparent that we have intrinsic reason to value our genetic relationships.

This is not to suggest that an individual's sense of having a special obligation to her biological relatives may not give her a personal reason to share genetic information. Rather, the point is that an absence of such a sense of obligation should not discharge one from a duty to warn.

The Argument from the Principle of Rescue

Grounding patients' duty to warn in the principle of rescue shifts the focus from familial relationships and social closeness. On my proposal, the basic justification for the presence of a duty to warn is that another person with moral standing, who just happens to be the patient's relative, is at risk of suffering serious harm. While there are many versions of the principle of rescue, the basic idea is that one ought to prevent, reduce, or mitigate the risk of harm to others when the expected harm is serious and one can help at a minimal to moderate cost or risk to oneself.²⁹

Seriousness of the expected harm.

Any attempt to quantify harm will inevitably prove contentious. Nevertheless, two considerations seem central to determining the seriousness of an expected harm: the likelihood that one will experience a particular harm and the severity of that harm.

Before we can calculate someone's risk of suffering some harm, we need to know what the relevant harm is. In the case of genetic mutations, the most salient harm is the manifestation

of a serious hereditary disease. There are several factors that might contribute to the severity of this harm—death, pain, extent and duration of suffering, career setbacks, and financial losses. As a proxy for the severity of a hereditary disease, I use an individual's risk of dying from the disease (or diseases) most strongly associated with a particular mutation. Although other considerations—intensity and duration of one's pain and suffering, for instance—surely influence the severity of a disease, risk of dying is a good proxy for two reasons. First, death is widely regarded as an especially grave harm, and second, risk of dying is a relatively objective and straightforward measure.

The harms associated with a *BRCA1* mutation for a carrier's sister, aunt, and first cousin are depicted in the three tables.³⁰ Table 1 presents each relative's average risks of developing and dying from ovarian cancer. Table 3 provides the equivalent statistics for breast cancer. Finally, table 3 estimates each relative's risks of developing and dying from either ovarian or breast cancer.³¹

Once we know an individual's risks of developing and dying from a hereditary disease, the next step is to determine whether the seriousness criterion of the principle of rescue is satisfied. To assess this, we might stipulate that the seriousness criterion is satisfied when an individual's risks of developing and dying from a hereditary disease exceed some fixed thresholds of likelihood. Alternatively, we might specify that an individual's risks of developing and dying from a hereditary disease satisfy the seriousness criterion when both risks are elevated by some fixed percentage relative to the population norm. Both approaches, however, are problematic. The following hypothetical cases show why.

Absolute risk:

Alice recently learned that she carries a genetic mutation that increases her likelihood of developing a certain kind of cancer. She calculated her relatives' risks and determined that her cousin has a 10.1 percent chance of developing this cancer and a 5.1 percent chance of dying from it. Alice compares these numbers to those for the general population, which are 9.9 and 4.9 percent, respectively.

Suppose we had fixed the absolute threshold of harm for developing and dying from this cancer at 10 and 5 percent, respectively. Because the cousin's risks exceed both thresholds, the seriousness criterion is satisfied. Accordingly, as long as the second criterion of the principle of rescue is also satisfied—namely, that Alice can help her cousin at a minimal to moderate cost or risk to herself—she would have a duty to warn her cousin. This conclusion, however, seems a bit strange. Although her cousin's absolute risks are fairly high, each is only two-tenths of a percentage point higher than the general population risks. Given the negligible difference between her cousin's risks and the population risks, most people would likely conclude that the seriousness criterion is not actually satisfied and that, therefore, Alice does not have a duty to warn her cousin.

But as the next case helps demonstrate, stipulating that the seriousness criterion is satisfied so long as an individual's risk of developing and dying from a hereditary disease is elevated by some fixed percentage relative to the population norm is also problematic.

Relative risk:

Barry recently learned that he carries a genetic mutation that increases his likelihood of developing a certain kind of cancer. He calculates his relatives' risks and determines that his cousin has a 0.1 percent chance of developing the associated cancer and a 0.05 percent chance of dying from it. Barry compares these numbers to those for the general population, which are 0.02 and 0.01 percent, respectively.

Suppose we had fixed the relative threshold of harm at a 100 percent increase. In other words, the seriousness criterion would be satisfied if one's family member's risk of developing and dying from a hereditary disease is more than double the population risk. In this scenario, Barry's cousin's risks are five times higher than the population risks. Barry would, then, presumably have a duty to warn his cousin (once again assuming that the second criterion of the principle of rescue is also satisfied). Yet this result is no less peculiar than with the first case. While the increase in relative risk is high, the increase in absolute risk is miniscule—less than a tenth of a percentage point. For this reason, most people would likely conclude that the seriousness criterion is not actually satisfied and, therefore, that Barry does not have a duty to warn his cousin.

As these examples illustrate, a single metric cannot tell us when the seriousness criterion is satisfied in all cases. Instead, we need a joint measure that accounts for both absolute risk and relative risk. I propose that, to satisfy the seriousness criterion, one's risk must be sufficiently high in absolute terms as well as sufficiently elevated relative to the general population.

Undoubtedly, what counts as "sufficiently high" and "sufficiently elevated" will be vague, and any cut point will be arbitrary. That said, many cases will be relatively straightforward. Because the degree of genetic relatedness, or consanguinity, between a patient and her relative affects the latter's likelihood of developing as well as dying from the relevant disease(s), the seriousness criterion is more likely to be satisfied for one's closer biological relatives. Take, for example, the sister's average combined risks of developing either breast or ovarian cancer, as well as dying from either disease (see table 3). Her average risks are both high in absolute terms as well as significantly elevated relative to the general population. Since the seriousness of a harm is a function of an individual's likelihood of experiencing that harm as well as of the harm's severity, the seriousness criterion is easily met in this case. Now consider the aunt. Like the sister, her average risks are both high in absolute terms and significantly elevated relative to the general population risks. The seriousness criterion is therefore almost certainly satisfied in her case as well.

The cousin's case is more difficult to assess. As table 3 shows, the cousin's average risk of developing either cancer is fairly high in absolute terms (18 percent) and elevated relative to the population norm (9.4 percent). But her average risk of dying from either disease (6 percent), while somewhat high, is within a few percentage points of the population norm (1.4 percent). Although the presence of a duty to warn may be less clear in certain situations, given the potential costs of withholding genetic information, when in doubt, it may be best to err on the side of caution by informing one's relatives. To summarize, for genetic conditions that are associated with a dramatically increased risk of disease, the seriousness

criterion will almost always be satisfied for a patient's first-degree relatives, will most likely be satisfied for her second-degree relatives, and will sometimes be satisfied for her third-degree relatives.³²

Cost to oneself.

So far, I have argued that the seriousness criterion of the principle of rescue will typically be satisfied for a patient's close biological relatives, since they are most likely to suffer from the patient's genetic condition. We cannot, however, assume that just because the seriousness criterion has been met in a particular case, the second criterion of the principle of rescue—that the cost or risk to the potential rescuer is sufficiently minimal or moderate—has also been satisfied. An account of when this criterion is likely to be fulfilled is therefore needed.

Possible costs to patients who share their genetic findings might include the loss of one's medical privacy, feelings of vulnerability, anxiety about social stigma, and changes in family dynamics. Although these costs are not trivial and should not be minimized or dismissed, the question is whether they are sufficiently modest to trigger the principle of rescue. To answer this question, we have to weigh the potential costs to the patient from sharing her genetic information against the potential costs to her relatives if she withholds it. In many cases, the potential costs to a patient's relatives may be quite significant. For example, as table 3 illustrates, the sister of a patient with a *BRCA1* mutation has a 40 percent chance of developing either breast or ovarian cancer and an 18 percent chance of dying from either disease. Should the patient refuse to share her genetic results, the potential costs to her sister—health and possibly even life—are very great. Thus, while there may be personal costs to patients who share their results, on balance, these costs tend to be less weighty than the health risks their close biological relatives may face.

To be clear, we should not automatically categorize a cost or risk to a potential rescuer as minimal or moderate just because it is less weighty than the risk faced by the person in need of help. Even if an individual could prevent a more significant harm from befalling another person, some sacrifices are simply too great.

I propose that we establish a fixed level of reasonable sacrifice, beyond which the burden on the rescuer would be considered too great. Until that bar is reached, however, the potential rescuer ought to make increasingly significant sacrifices in accordance with the seriousness of the risk faced by the person in need of help, as long as the potential rescuer would not be making a sacrifice that is equal to or greater than the risk faced by the person in need of aid. For instance, suppose that you see a man drowning in a pool. He is much larger than you, and you do not consider yourself a strong swimmer. You are afraid that if you jump into the pool to rescue him, he may panic and accidentally drown you. In this case, risking drowning exceeds what anyone could reasonably expect you to do. Moreover, jumping into the pool and attempting to save him would constitute a risk to you that is roughly equal to the risk faced by the drowning man. However, because the risk he faces—imminent death by drowning—is quite serious, you ought to make whatever sacrifices you can up to the point where you would seriously jeopardize your own welfare.

A thorough discussion of how to classify specific costs and risks is beyond the scope of this article, but we can assume that sacrifices entailing significant physical harm, devastating financial losses, or major opportunity costs will typically exceed what people can reasonably be expected to give up. Because disclosing genetic information does not normally entail these kinds of risks, barring situations where disclosure would significantly threaten a patient's welfare, the second criterion of the principle of rescue will be satisfied in most cases involving a genetic mutation that dramatically increases a patient's relative's risk of disease.³³

As a caveat to this discussion, I take for granted that, for there to be a moral obligation to rescue, rescue must be feasible. It would, after all, be unreasonable to expect a would-be rescuer to assume a burden if there is no realistic hope of benefitting the person at risk of harm. In the case of sharing a genetic finding, rescue is possible when a patient's relative can act on the information to forestall a bad outcome. For genetic conditions that confer a high risk of disease, including many hereditary cancer syndromes, there are often risk-reducing or preventative measures that one can take. Typically, these measures take the form of surveillance (such as mammography and magnetic resonance imaging of the breasts) or risk-reducing surgical interventions (such as a prophylactic oophorectomy). But not all serious hereditary conditions are actionable in this way.

Consider, for example, Huntington's disease, a fatal neurodegenerative disorder caused by a mutated copy of the *huntingtin* gene. While there is currently no way to prevent or delay the onset of symptoms—which can strike as early as one's thirties—knowing that one has the mutation could still be incredibly valuable. If carriers of the gene have not yet had children, then knowledge of their risk may affect their reproductive choices. They might choose not to have biological children, or they may decide to use preimplantation genetic diagnosis to test embryos for the mutation before implantation, ensuring that their future children do not inherit the condition. Besides family planning, genetic knowledge could inform major life decisions such as whether to pursue a particular educational or career path. Going forward, ethicists will need to think more about whether the duty to warn extends to situations where the information is unlikely to provide a direct health benefit to a patient's relatives but could nevertheless be beneficial in other ways.

The Patient's versus the Provider's Duty

People continue to suffer from hereditary diseases that could have been prevented if only they had known about their risks. Ethicists, unfortunately, have done little to address patients' obligations in such situations, instead choosing to focus on providers' duties. But before we think more about whether and under what circumstances providers might have a duty to warn patients' relatives, we should be clear about patients' own duties to their biological family members. After all, if a relative's genetic risk is not sufficiently serious to trigger a duty to warn on the part of the patient, then it is hard to see how it would be permissible, let alone obligatory, for a provider to breach confidentiality to disclose a patient's genetic results to others.

That said, just because a patient has a duty to warn, it does not follow that it would be permissible for her provider to share her genetic results without consent. Unlike their patients, health care professionals are bound by professional obligations—respect for patient confidentiality being among the strongest. Given the primacy accorded to this duty, breaches are typically permissible only when a third party faces an extreme threat of harm. Whether genetic risks meet this standard is an open question. If they do not, situations may arise where it would be impermissible for a provider to breach confidentiality even though his patient has a duty to warn her relatives.

In this article, I have developed a principled way of deciding which relatives a patient ought to warn that is based on their likelihood of suffering genetic harm. On my proposal, the duty to warn arises from the principle of rescue, which holds that one ought to mitigate the risk of harm to another person when the expected harm is serious and the cost to oneself sufficiently moderate. The approach I recommend avoids unnecessarily exposing patients' genetic information, while still protecting their most at-risk relatives.

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Notes

1. Clinical genetic testing includes preimplantation genetic diagnosis, prenatal testing, newborn screening, diagnostic testing, and predictive and presymptomatic genetic testing. Clinical testing differs from research testing in that it is done to discover whether an individual has or is a carrier for a genetic condition for the purpose of facilitating medical or reproductive decision-making.
2. Petrucelli N, Daly MB, and L Feldman G, "Hereditary Breast and Ovarian Cancer Due to Mutations in BRCA1 and BRCA2," *Genetics in Medicine* 12, no. 5 (2010): 245–59. [PubMed: 20216074]
3. National Cancer Institute, Cancer Query System: "Probability of Developing or Dying from Cancer," last updated April 16, 2018, https://canques.seer.cancer.gov/cgi-bin/cq_submit?dir=devcan2015&db=1&rpt=TAB&sel=1,4%5E6%5E1%5E3%5E57,13%5E5%5E14&y=Site%5E57,13&x=StatisticType%5E1,4&dec=2,2&template=null.
4. Domchek SM et al., "Mortality after Bilateral Salpingo-Oophorectomy in BRCA1 and BRCA2 Mutation Carriers: A Prospective Cohort Study," *Lancet Oncology* 7, no. 3 (2006): 223–29. [PubMed: 16510331]
5. In arguing for a duty to warn, I will focus on autosomal dominant, highly penetrant genetic conditions that are actionable.
6. Dheensa S, Fenwick A, and Lucassen A, "'Is This Knowledge Mine and Nobody Else's? I Don't Feel That.' Patient Views about Consent, Confidentiality and Information-Sharing in Genetic Medicine," *Journal of Medical Ethics* 42, no. 3 (2016): 174–79. [PubMed: 26744307]
7. Throughout this paper, I will take for granted that one's genetic relatives, especially one's first-degree relatives, would want to be informed of their genetic risk. If a patient is uncertain about whether her relative would want to be informed, I think it is generally better to risk upsetting someone with unwanted information than to risk someone's health and life. However, if a patient, in consultation with her providers, concludes that informing her relative(s) would be more harmful than beneficial, withholding information may be appropriate.
8. Lucassen A, and Parker M, "Confidentiality and Serious Harm in Genetics—Preserving the Confidentiality of One Patient and Preventing Harm to Relatives," *European Journal of Human Genetics* 12, no. 2 (2003): 93–97.
9. Sankar P, "Genetic Privacy," *Annual Review of Medicine* 54, no. 1 (2003): 393–407.

10. Knoppers BM, "Genetic Information and the Family: Are We Our Brother's Keeper?," Trends in Biotechnology 20, no. 2 (2002): 85–86. [PubMed: 11814599]
11. In *Pate v Threlkel*, the Supreme Court of Florida held that physicians' duties to warn could be discharged by informing the patient of the hereditary nature of her genetic condition (*Pate v Threlkel*, 661 So2d 278 [Fla 1995]). A year later, in *Safer v. Estate of Pack*, the Superior Court of New Jersey held that a physician might have a duty to warn those at risk of a hereditary condition (*Safer v Estate of Pack*, 677 A2d 1188 [NJ Super Ct App Div 1996]).
12. The principle of rescue is a moral concept that addresses what patients ought to do. It is distinct from the duty of rescue, which is a concept in tort law that applies to cases in which a party can be held liable for damages for failing to rescue another party in peril. Some scholars have considered whether patients should be held legally responsible for failing to warn their relatives about genetic risks. Clayton EW, "What Should the Law Say about Disclosure of Genetic Information to Relatives?," Journal of Health Care Law & Policy 1, no. 2 (1998): 373–90. [PubMed: 16281334]
13. Sulmasy DP, "Naked Bodies, Naked Genomes: The Special (but Not Exceptional) Nature of Genomic Information," Genetics in Medicine 17, no. 5 (2014): 331–36, at 332. [PubMed: 25232853]
14. Gilbar R, "Communicating Genetic Information in the Family: The Familial Relationship as the Forgotten Factor," Journal of Medical Ethics 33, no. 7 (2007): 390–93. [PubMed: 17601865]
15. Doukas DJ, and Berg JW, "The Family Covenant and Genetic Testing," American Journal of Bioethics 1, no. 3 (2001): 2–10.
16. Knoppers, "Genetic Information," 86.
17. Parker and Lucassen, "Genetic Information," 166.
18. Ibid.
19. "Cardiac Healthy Weight DNA Insight: Genetic Testing for Weight Loss and Overall Heart Health," Pathway Genomics, <https://www.pathway.com/cardiac-healthy-weight-dna-insight/>.
20. Bao W, "Predicting Risk of Type 2 Diabetes Mellitus with Genetic Risk Models on the Basis of Established Genome-wide Association Markers: A Systematic Review," American Journal of Epidemiology 178, no. 8 (2013): 1197–1207. [PubMed: 24008910]
21. Matthew Liao argues that the extent to which an individual's genetic findings are relevant to her family members is often quite weak. From this, he concludes that the familial nature of genetic information does not justify a system where, by default, genetic information is shared among family members (Liao SM, "Is There a Duty to Share Genetic Information?," Journal of Medical Ethics 35, no. 5 [2009]: 306–9). [PubMed: 19407036]
22. Annas GJ, "Privacy Rules for DNA Databanks," Journal of the American Medical Association 270, no. 19 (1993): 2346–50, at 2348. [PubMed: 8230598]
23. Sankar, "Genetic Privacy," 398–99.
24. Jeske D, "Special Obligations," in Stanford Encyclopedia of Philosophy, Stanford University, article first published October 17, 2002, substantively revised 15, 2014, <https://plato.stanford.edu/entries/special-obligations/>.
25. Weijer C, "Family Duty Is More Important Than Rights," BMJ 321, no. 7274 (2000): 1466.
26. Scheffler S, "Relationships and Responsibilities," Philosophy and Public Affairs 26, no. 3 (1997): 189–209.
27. Gallo AM, Angst DB, and Knafl KA, "Disclosure of Genetic Information within Families," American Journal of Nursing 109, no. 4 (2009): 65–69. See also Dugan RB et al., "Duty to Warn At-Risk Relatives for Genetic Disease: Genetic Counselors' Clinical Experience," American Journal of Medical Genetics 119C, no. 1 (2003): 27–34. [PubMed: 12704635]
28. Velleman D, "Family History," Philosophical Papers, 34, no. 3 (2005): 357–78, at 357.
29. The principle of rescue is sometimes called the "rule of rescue," a phrase originally coined by Albert Jonsen to characterize the moral imperative most people feel to rescue an identifiable individual who is facing imminent and avoidable death (Jonsen AR, "Bentham in a Box: Technology Assessment and Health Care Allocation," Journal of Law, Medicine & Ethics 14, no. 3–4 [1986]: 172–74). Perhaps the most famous articulation of the principle of rescue comes from Peter Singer, who argues that "if it is in our power to prevent something bad from happening, without thereby sacrificing anything of comparable moral importance, we ought, morally, to do it"

(Singer P, "Famine, Affluence, and Morality," *Philosophy & Public Affairs* 1, no. 3 [1972]: 229–43, at 231).

30. To calculate the patient's relative's risk of developing ovarian cancer or breast cancer, I used the following equation: $(R \times C_{dev}) + ((1-R) \times G_{dev})$, in which R = a relative's risk of having a BRCA1 mutation, C_{dev} = BRCA1 mutation carrier's average risk of developing ovarian cancer or breast cancer (for women ages twenty-five to seventy), and G_{dev} = the general population's risk of developing ovarian cancer or breast cancer (for women ages twenty-five to seventy). To calculate the relative's risk of dying from ovarian cancer or breast cancer, I used the following equation: $(R \times C_{die}) + ((1R) \times G_{die})$, in which R = a relative's risk of having a BRCA1 mutation, C_{die} = BRCA1 mutation carrier's average risk of dying from ovarian cancer or breast cancer (for women ages twenty-five to seventy), G_{die} = the general population's risk of dying from ovarian cancer or breast cancer (for women ages twenty-five to seventy). Statistics for general population risks came from National Cancer Institute, Cancer Query System: "Probability of Developing or Dying from Cancer." Statistics for BRCA1 carrier risks came from Stanford Medicine Cancer Institute, "Decision Tool for Women with BRCA Mutations," last updated December 1, 2011, <http://brcatool.stanford.edu/brca.html>.
31. For the purposes of this article, I assume that, after mutation status is controlled for, there is no correlation between developing ovarian cancer and developing breast cancer. In other words, I treat developing ovarian cancer and developing breast cancer as independent events.
32. With respect to certain genetic conditions (such as those that often arise from de novo mutations or are recessive), Liao is correct that the degree to which an individual's genetic findings are relevant to her family members is frequently weak (Liao SM, "Is There a Duty to Share Genetic Information?," *Journal of Medical Ethics* 35, no. 5 [2009]: 306–9); however, his analysis does not apply to the kinds of autosomal dominant, highly penetrant conditions that I discuss in this article. [PubMed: 19407036]
33. As a general moral principle, the principle of rescue may demand a lot. For example, Singer argues that affluent individuals have a moral obligation to prevent disease and poverty in the developing world by donating significant resources to benefit the global poor if they can do so without having to give up anything of comparable importance. Singer, however, does not specify what counts as being of comparable importance. Many have criticized Singer's proposal, arguing that it is far too demanding. I do not enter into the debate about where the line between the obligatory and the supererogatory should be drawn. I feel confident, however, that warning one's close biological relatives of their genetic risk is not (usually) an overly demanding obligation (Singer, "Famine, Affluence, and Morality").

GROUNDING a duty to share genetic findings in special obligations is problematic because it fails to ensure that patients' most vulnerable relatives learn about their genetic risks.

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IF a patient's genetic information is, by its very nature, fundamentally familial, should it be made available to any interested relative, regardless of the relative's risk of suffering genetic harm?ssss

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WHILE there may be personal costs to patients who share their results, on balance, these costs tend to be less weighty than the health risks their close biological relatives may face.

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Table 1.

Ovarian Cancer Risk

Relationship	Likelihood of developing	Likelihood of dying from
Sister (1st degree)	14%	9%
Aunt (2nd degree)	7%	4%
Cousin (3rd degree)	4%	2%
General population	.65%	.33%

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Table 2.

Breast Cancer Risk

Relationship	Likelihood of developing	Likelihood of dying from
Sister	30%	11%
Aunt	20%	6%
Cousin	14%	3%
General population	8.96%	1.02%

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Table 3.

Ovarian Cancer and Breast Cancer Combined Risk

Relationship	Likelihood of developing either	Likelihood of dying from either
Sister	40%	18%
Aunt	26%	10%
Cousin	18%	6%
General population	9.4%	1.4%