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Recommended Citation

Ellen W. Clayton, *What Should the Law Say About Disclosure of Genetic Information to Relatives?*, 1 J. Health Care L. & Pol'y 373 (1998).
Available at: <http://digitalcommons.law.umaryland.edu/jhclp/vol1/iss2/5>

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WHAT SHOULD THE LAW SAY ABOUT DISCLOSURE OF GENETIC INFORMATION TO RELATIVES?

ELLEN WRIGHT CLAYTON, MD, JD*

I. INTRODUCTION

When a person is diagnosed with a genetic disease or characteristic, his or her relatives are more likely than others in the general population to be similarly affected. This fact raises a host of questions. What should these relatives be told about the chance that they, too, inherited a particular mutation? If they should be told, who should tell them? What weight should be given to protecting patient confidentiality? The increasing availability of interventions that can ameliorate or even eliminate the symptoms of genetic disorders makes these questions more pressing. In this paper, I will assume, as an ethical matter, that patients should generally tell their relatives about the chance that they, too, inherited a treatable genetic disorder. I will assume, also, that there may be instances in which clinicians are permitted by ethical norms to warn patients' relatives about the chance that they inherited a treatable disorder even over the patients' express objections. I will argue, however, that using the law of negligence to enforce such proposed obligations would represent an unwarranted expansion of legal duty and would entail great costs to the delivery of health care.

II. RELATIVES' DUTIES OF DISCLOSURE—AM I MY SIBLING'S KEEPER?

Let me begin by looking first at a topic that has received little discussion in the law,¹ namely disclosure within families. The following hypothetical illustrates some of the problems.

Tom, who is in his mid-30s, has colon cancer, as did his father and paternal aunt. Tom's surgeon, Dr. Smart, appropriately recognizes that Tom may have a mutation that predisposed him to develop colon cancer and tells Tom that his siblings and his cousins on his father's side may also have such mutations. He recommends that

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1. But see generally Sonia Suter, *Whose Genes are These Anyway? Familial Conflict over Access to Genetic Information*, 91 MICH. L. REV. 1854 (1993).

Tom talk with these relatives so that they can begin routine colonoscopy to try to detect cancer or premalignant changes at an earlier, and hence more curable, stage. Tom, however, decides not to tell his siblings and cousins. His cousin, Sue, develops rectal bleeding two years later and is found to have colon cancer, which had metastasized by the time it was discovered.

Should Sue be able to obtain damages for negligence from Tom? This bare hypothetical calls out for more detail. Why didn't Tom talk with his relatives? Was he embarrassed because he has cancer? Perhaps he has a colostomy² and is embarrassed about that. Was he simply too distracted by his own concerns? Was he worried that his brother, Joe, who was unemployed at the time of Tom's surgery, would not be able to get health insurance if Tom told him or other family members what was going on?³ Or maybe his sister, Ann, was getting married, and he did not want to cast a pall over her happy event. Maybe Tom believes that the risk of heritable cancer is worth talking about only if he knows for sure that he has a mutation, and he did not know about or did not want to have the test. Had Tom had a falling out with his family and decided not to tell them out of spite? Maybe they had just grown apart. Tom might have had any number of reasons for not talking with his relatives. If his story is typical, more than one reason applies.

But learning more about why Tom held his tongue really does not help us very much in deciding whether Sue should be able to get damages from Tom. For purposes of discussion, let us assume that Sue can show that she and Tom in fact shared a mutation that predisposed them to develop colon cancer, that a judge and jury would find that a reasonable person in Tom's position would have disclosed the information to Sue, that Sue and the mythic reasonable person would have sought health care earlier than she did and would have had the recommended colonoscopy,⁴ that her cancer would have been discov-

2. A colostomy is "an artificial opening created in the large intestine and brought to the surface of the abdomen for the purpose of evacuating the bowels." MILLER-KEANE ENCYCLOPEDIA & DICTIONARY OF MEDICINE, NURSING, & ALLIED HEALTH 333 (5th ed. 1992). A colonoscopy is an "endoscopic examination of the colon, either transabdominally during laparotomy, or transanally by means of a colonoscope." *Id.*

3. Exploring the impact of genetic information on access to health insurance is beyond the scope of this paper except to say that the Health Insurance Portability and Accountability Act, Pub. Law No. 104-191, did not solve all the problems. See, e.g., Karen H. Rothenberg, *Genetic Discrimination and Health Insurance: A Call for Legislative Action*, 52 J. AM. MED. WOMEN'S ASS'N 43 (1997); Robert Pear, *Health Insurers Skirting New Law, Officials Report*, N.Y. TIMES, October 5, 1997, at A6.

4. Although I will argue below that the doctrine of informed consent does not extend easily to the problems addressed in this paper, many courts addressing these problems may

ered before it had spread had she had this procedure, and that surgery in that case would have been curative. This is a formidable chain of causation which must be forged before liability could be imposed. But the question I want to focus on is whether Sue can show that Tom had a legally enforceable duty to warn her about her possible genetic predisposition to develop colon cancer.

A number of arguments can be made in favor of imposing such a duty on Tom. For much of this century, foreseeability has been a major determinant of the scope of duty in negligence law, and it is certainly foreseeable that people who have mutations that predispose them to develop colon cancer and who do not undergo rather aggressive screening have a high chance of developing invasive disease.⁵ One might also turn to the recent body of cases that have imposed liability on a person who gives a sexually transmitted disease, such as genital herpes, HIV, or condylomata, to another.⁶ Some courts have supported their finding of a duty in this setting by stating, "after all, it is not that much of a burden to have to disclose a risk to a potential sexual partner."⁷

One can, of course, argue that the reasoning of the infectious disease cases does not support imposing liability on patients who fail to warn their relatives of possible shared genetic risks. A closer look reveals that most of the recent infectious disease cases that impose

well import from such cases as *Canterbury v. Spence* the requirement that both objective and subjective causation be shown. 464 F.2d 772 (D.C. Cir. 1972). In *Canterbury* the court found that in the context of a suit claiming inadequate disclosure of risk information by a physician, causation should be determined by looking objectively to whether a reasonably prudent person would have sought treatment if informed of potential risk factors in addition to looking at the plaintiff's subjective testimony after the fact. *See id.* at 791. In some states, however, a patient would need to show only that she would have sought health care and pursued screening. *See infra* note 71 and accompanying text (discussion on informed consent).

5. *See generally* Malcom G. Dunlop et al., *Cancer Risk Associated with Germline DNA Mismatch Repair Gene Mutations*, 6 HUM. MOLECULAR GENETICS 105 (1997) (estimating that 74% of males and 30% of females with mutations in hereditary nonpolyposis colorectal cancer (HNPCC) genes will develop colorectal cancer during their lifetime); Gloria M. Petersen, *Knowledge of the Adenomatosis Polyposis Coli Gene and Its Clinical Application*, 26 ANNALS MED. 205 (1994) (determining that of the more than 90% of mutation carriers who develop polyps, virtually all will develop colon cancer if untreated).

6. *See, e.g.*, *Meany v. Meany*, 639 So.2d 229 (La. 1994); *M.M.D. v. B.L.G.*, 467 N.W.2d 645 (Minn. Ct. App. 1991). Although courts do not always keep them separate, the cases that impose liability on a patient who gives a disease to another raise different concerns than the cases imposing liability on physicians who fail to warn the infectious patient's contacts. *See infra* notes 9-16, 35-39 and accompanying text.

7. *Doe v. Johnson*, 817 F. Supp. 1382, 1392 (W.D. Mich. 1993); *R.A.P. v. B.J.P.*, 428 N.W.2d 103, 108 (Minn. Ct. App. 1988).

liability on patients involve sexually transmitted diseases (STD).⁸ These decisions, while frequently couched in terms of the foreseeable need to protect others⁹ — a rationale that would support far reaching liability — often rely as well on other factors that limit the generalizability of their holdings. In many of these cases, the defendant got the STD as the result of sexual indiscretions (there is a high rate of marital infidelity and/or promiscuity in these cases).¹⁰ The courts seem to feel that after such “bad” deeds, it is particularly wrong to make another person, particularly one’s spouse, run the risk of infection by having sex with them.¹¹ The STD cases begin to look more like cases finding wanton and willful negligence¹² than cases imposing liability on inattentive drivers who run into someone. Other courts hold that one owes a higher duty of care, approaching a fiduciary obligation of full and fair disclosure, to one’s sexual partner.¹³ Still other

8. See, e.g., *Johnson*, 817 F. Supp. at 1389 (alleging that male sex partner wrongfully transmitted HIV to female plaintiff and her infant child); *Meany*, 639 So.2d at 231 (claiming that former husband negligently infected former wife with viruses which caused genital herpes and venereal warts); *M.M.D.*, 467 N.W.2d at 646 (claiming negligent infection of genital warts); *R.A.P.*, 428 N.W.2d at 106 (claiming that wife had negligently infected husband with genital herpes); *G.L. v. M.L.*, 550 A.2d 525, 526 (N.J. App. 1988) (alleging personal injury of wife as a result of husband’s alleged transmission of genital herpes to her); *Maharam v. Maharam*, 510 N.Y.S.2d 104, 105 (N.Y. App. Div. 1986) (claiming husband negligently infected wife with incurable genital herpes); *Mussivand v. David*, 544 N.E.2d 265, 266 (Ohio 1989) (alleging that wife’s paramour was negligent in failing to notify wife that paramour was at risk of passing venereal disease on to wife).

9. See, e.g., *Johnson*, 817 F. Supp. at 1394 (finding “as a matter of law” that it “was not foreseeable that he [defendant] would pass the HIV virus to Ms. Doe [plaintiff] simply because he [defendant] had unprotected sex with multiple partners prior to his encounter with Ms. Doe.”); *R.A.P.*, 428 N.W.2d at 107-08 (indicating that people with genital herpes are in a position to foresee potential injury to others thereby imposing on such persons a duty of reasonable care).

10. See, e.g., *Meany*, 639 So.2d at 231 (alleging that former wife’s infection with herpes occurred after reconciliation with her husband, who had engaged in multiple extramarital affairs for which he could not testify with certainty that protective devices were used).

11. See, e.g., *R.A.P.*, 428 N.W.2d 103; *G.L.*, 550 A.2d 525 (rejecting defense of marital privilege); *Maharam*, 510 N.Y.S.2d 104. One can hypothesize that some of these cases are driven primarily by anger at the infidelity, for which there are fewer and fewer legal remedies given the growing disfavor with “heartbalm” suits. Some courts, in fact, have gone out of their way to say that these are not heartbalm cases. See *Mussivand*, 544 N.E.2d at 274.

12. See W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS, § 34, at 213 (5th ed. 1984). (“The usual meaning assigned to ‘willful,’ ‘wanton,’ or ‘reckless,’ . . . is that the actor has intentionally done an act of an unreasonable character in disregard of a known or obvious risk that was so great as to make it highly probable that harm would follow and which this is usually accompanied by a conscious indifference to the consequences.” (citations omitted)).

13. See *Kathleen K. v. Robert B.*, 198 Cal. App. 3d 992, 996-98 (Cal. Ct. App. 1984) (extending prior cases that imposed liability when one spouse infected another, saying “a certain amount of trust and confidence exists in any intimate relationship, at least to the extent that one sexual partner represents to the other that he or she is free from venereal

courts rest their finding of a duty, at least in part, on the existence of state statutes that impose criminal penalties on those who transmit sexually transmitted diseases.¹⁴ One question then is whether Tom's failure to warn his relatives is morally culpable enough to be seen as sharing the wages of sin or breaching a fiduciary duty.

Failure to warn about infectious disease differs from failing to disclose genetic risks in other ways as well. In the infectious disease cases, the potential plaintiff was healthy and only became sick as a result of exposure to the infected individual. The courts often say, therefore, that the infected person created a risk for the people who become infected by exposure.¹⁵ In addition, in most of these cases, the infected people were doing something potentially dangerous, such as engaging in unprotected sex, for their own purposes and so exposed others to harm.¹⁶

By contrast, in the genetics cases, the relative who has the predisposing mutation is already at risk to develop the disease. All the affected individual, or the proband, can do is to warn his relatives about the risk so they can engage in prevention or early intervention. When looked at in this way, Sue's case begins to look more like a rescue case — she was at risk, and Tom did not try to save her.

What guidance can be derived from the rescue cases? The general rule in the United States is that one person does not have a duty to rescue another unless the potential rescuer either created the risk¹⁷ (e.g., he pushed someone whom he knew could not swim into a deep lake) or had a special relationship to the potential victim (e.g., he was a lifeguard who was hired to protect people in the lake).¹⁸ If a by-

or other dangerous contagious disease"). *But see Johnson*, 817 F. Supp. at 1393 (holding that no special duties arise from a "single consensual sexual encounter between two adults").

14. *See Berner v. Caldwell*, 543 So.2d 686, 689 (Ala. 1989); *Gabriel v. Tripp*, 576 So.2d 404 (Fla. App. 1991) (discussing an Alabama statute which makes any person found to have knowingly transmitted a sexually transmitted disease to another person guilty of a class C misdemeanor); *Maharam*, 510 N.Y.S.2d at 107 (discussing a New York statute which makes persons who, knowing themselves to be infected with an infectious disease, have sexual intercourse with another, guilty of a misdemeanor). One might argue, for example, that violation of such a statute is negligence per se although most courts to date have hesitated to go this far.

15. *See, e.g., Johnson*, 817 F. Supp. at 1393; *Kathleen K.*, 198 Cal. App. 3d at 996-98.

16. *See, e.g., Johnson*, 817 F. Supp. at 1385.

17. *See Rhodes v. Illinois Central Gulf Railroad*, 665 N.E.2d 1260, 1270 (Ill. 1996) (common law generally imposes no duty to rescue an injured stranger upon one who did not cause the injury in the first place.).

18. *See S & C Company v. Horne*, 235 S.E.2d 456, 459 (Va. 1977) (describing a lifeguard's duty as a twofold process of observing swimmers for signs of distress and attempting rescue at some point of those in distress).

stander who was an Olympic swimmer stood by the lake and knowingly watched the victim drown, we might think him immoral, but he would not be liable to the victim's estate for damages. The law of rescue is one of the few areas of the law of negligence where courts remain more likely to impose liability for acts that cause injury than for omissions.¹⁹

In the case in which Tom fails to tell Sue about her genetic risk, Tom did not push Sue into the lake — she was already there. The question then becomes whether he had a special relationship with her that required him to help her out? Analysis of prior precedent would suggest that being a blood relative is not sufficient by itself to support the imposition of special obligations. Siblings and cousins sue each other all the time, and courts have not been willing to require, for example, one sibling to exercise special care with regard to another unless the one sibling had some special role external to the family that itself required a particular standard of care.²⁰ Thus, the only lawyer in the family who draws up a will for his parents that cuts out all his siblings can be held liable for exerting undue influence.²¹ But for the most part, the law tends to regard relationships between all relatives except parents and children, and husband and wife as being at arm's length.²²

But can one successfully argue that more is required between relatives in this situation because there is something special about risks to health that matters more than fighting about money? Consider the following hypothetical:

Mark becomes ill with cancer, which he discovers is due to toxic fumes seeping into his house from the ground. These fumes can be completely eliminated by applying a special sealant to the walls in his basement, which he does. He does not want to sell his house because he likes it and because he really does not feel up to moving. He also does not want to tell his neighbors about this risk even though their houses may have this same problem. Perhaps he fears they will move which would make him sad. He is particularly concerned that his

19. See generally Francis H. Bohlen, *The Moral Duty to Aid Others as a Basis of Tort Liability*, 56 U. PA. L. REV. 217 (1909).

20. See, e.g., *Holtzman v. Stratman*, 655 S.W.2d 47 (Mo. App. 1983).

21. See *Richland County Bar Ass'n v. Gibson*, 654 N.E.2d 1247 (Ohio 1995) (imposing a two year suspension on an attorney who neglected to disclose a conflict of interest regarding his control of the family business); cf., *Zick v. Krob*, 872 P.2d 1290 (Colo. App. 1993) (refusing to impose liability on brother-in-law attorney because he had made full and fair disclosure of possible conflicts).

22. See, e.g., *Holtzman*, 655 S.W.2d at 49 (holding that a "confidential relationship" comparable to a fiduciary did not exist among siblings).

brother, Jack, who lives just down the street and whom he sees every day might leave. Perhaps he is also worried that the value of his property will go down, possibly precipitously, if news of these toxic fumes gets around. Two years later, Jack also develops the same type of cancer for the same reason. Jack subsequently finds out what Mark knew and wants to sue Mark.

Here as well, Mark failed to "rescue" Jack. Let us suppose that the risk of harm from their shared environmental hazard is as large as the risk posed by the mutation that Tom and Sue may share. In this scenario, few would propose that Mark had a legally enforceable duty to warn Jack.²³ The same analysis may well apply to Tom and Sue and their shared genetic predisposition to colon cancer.²⁴ Both factors contribute to the development of disease. Imposing liability only for failure to disclose genetic risks may foster the view that these factors are somehow worse, a result which many commentators who criticize notions of "genetic exceptionalism" seek to avoid.²⁵

The Special Case of Parents

Let us embellish our original hypothetical a little further and suppose that

Tom has a daughter, Jane, who several years after Tom's diagnosis and successful treatment of colon cancer has now grown to adulthood herself. She, too, develops rectal bleeding and is diagnosed with metastatic colon cancer. While she had known that her father was

23. In fact, even sellers of property generally are not required to inform potential buyers about environmental hazards, following the ancient rule of caveat emptor. See, e.g., *NBD Bank v. Krueger Ringer, Inc.*, 686 N.E.2d 704, 707 (Ill. App. 1997); *Hydro-Manufacturing, Inc. v. Kayser-Roth Corp.*, 640 A.2d 950, 955 (R.I. 1994). But see, *Newhall Land & Farming Co. v. Superior Court (Mobil Oil Corp.)*, 23 Cal. Rptr. 2d 377, 385-86 (Cal. Ct. App. 1993) (rejecting the common law rule of caveat emptor).

24. Environmental risks can be shared by nonrelatives as well. Should this change this analysis? Let us suppose that Jack had simply been Mark's neighbor and best friend. One might argue that Mark has even less of an obligation in that setting, reasoning that relatives owe greater care to each other than do friends. Cultural norms in many communities would say that this is true. Adopting a blanket rule that one owes less to one's friends and neighbors than to one's relatives would have bad consequences. For many people, relationships of friendship are more important than those of blood. Moreover, life in our society requires that one build and rely on relationships that extend beyond one's blood kin. It is undesirable to impose a duty to warn relatives but not one's close friends or neighbors of environmental risks, and as a result, neither should be the beneficiaries of a legally enforceable duty to warn.

25. See generally RUTH HUBBARD & ELIJAH WALD, *EXPLODING THE GENE MYTH, HOW GENETIC INFORMATION IS PRODUCED AND MANIPULATED BY SCIENTISTS, PHYSICIANS, EMPLOYERS, INSURANCE COMPANIES, EDUCATORS, AND LAW ENFORCERS* (1993); Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J.L. & MED. 15 (1991).

very sick when she was a child, she did not learn until after her own diagnosis about the nature of her father's disease and about her own substantially increased risk of being similarly affected. Jane is furious with her father and wants to sue him for damages.

Her attorney might attempt to rely on the infectious disease cases,²⁶ arguing that Tom should be liable because he exposed her to the risk by giving her the mutation. The problem with this argument is that the only way that one can "get" this mutation is by being conceived in the first place. The only way that Jane could have avoided having the mutation was by not existing at all. This is not the case of making an otherwise healthy person sick. The more appropriate analogy here is to the wrongful life cases,²⁷ in which the plaintiffs assert that they should never have been born, a cause of action that is widely disfavored, especially when asserted even hypothetically against one's parents.²⁸

Jane's lawyer might also argue that Tom had a duty to rescue Jane by warning her of her risk. This argument is more attractive because the law clearly recognizes that parents owe special obligations to their children, analogous to those of rescue.²⁹ Parents are uniquely required to provide their children with the necessities of life. It may take a village to raise a child, but only parents are legally required to provide food, housing, clothing, and medical care, even if it entails significant cost in time and money to themselves.³⁰ But the law of child neglect³¹ is equally clear that these obligations are enforceable only at the extremes — parents must provide basic nutrition, not caviar; a roof over one's head, not a mansion. Also, parents must ensure that children receive demonstrably effective medical treatment needed to avert serious imminent harm, such as antibiotics for menin-

26. See *supra* note 6.

27. See Lois Shepherd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. ILL. L. REV. 761, 762 (1995).

28. See CAL. CIV. CODE § 43.6(a) (West 1982) (statute rejecting such claims; passed in response to dicta in *Curlander v. Bio-Science Laboratories*, 165 Cal. Rptr. 477, 488 (Cal. App. 1980) that children should be able to sue their parents for such damages); Shepherd, *supra* note 27, at 762. But see Margery W. Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEGAL MED. 63, 107 (1984).

29. See *supra* notes 19-23 and accompanying text.

30. See, e.g., D.C. CODE ANN. § 6-2131 (1981); MICH. COMP. LAWS ANN. § 722.602(d) (West 1983); MO. ANN. STAT. § 210.166 (West 1996); NEV. REV. STAT. ANN. § 432B.140 (Michie 1996); N. D. CENT. CODE § 14-07-15 (1991); OHIO REV. CODE ANN. § 2151.03 (Anderson 1994).

31. See, e.g., D.C. CODE ANN. § 6-2131(1). The D.C. Code defines "child neglect" as "harm to a child's health or welfare that occurs through the failure to provide adequate food, clothing, shelter, education, or medical care." *Id.* (emphasis added).

gitis.³² No state would deem neglectful a parent who failed to talk with her children about genetic risks. One question is whether a court would be willing to impose on parents a more far reaching duty within the law of negligence.

The most basic problem with a child's claim against her parent is to convince a court not that the parent had a legal duty to disclose, but rather that the parent should not be immune from liability. Almost all states refuse to impose liability on parents for decisions and actions involved in caring for and rearing children.³³ While the scope of this immunity is not always well defined, parents who argue that they did not discuss genetic risks with their at-risk child because the time was not right or their child was likely to be distressed would almost surely come within its protection. This is precisely the setting in which parental immunity ought to apply.³⁴ Jane is angry at her father right now, but litigation, no matter what its outcome, is likely to set her anger in stone instead of permitting reconciliation. Moreover, Tom's failure to talk with Jane was more likely the result of anguished consideration than simple oversight. His choice, right or wrong, was at its heart what parents do. In hindsight, Tom almost surely should have talked with Jane, but permitting her to obtain damages from him would require a substantial change in the law.

32. See *Walker v. Superior Court*, 763 P.2d 852 (Cal. 1988), *cert. denied*, 491 U.S. 905 (1989) (upholding criminal conviction for failure to seek medical attention for child with meningitis). The courts have been much more reluctant to order onerous treatment that has only a limited chance of success. See, e.g., *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991) (approving decision of Christian Science parents not to give aggressive chemotherapy to child with aggressive Burkitt's Lymphoma). These cases almost always involve parental objection to medical intervention derived from the parents' religious convictions.

33. See, e.g., *Goller v. White*, 122 N.W.2d 193 (Wis. 1963) (finding immunity for "exercise of ordinary parental discretion with respect to provisions of food, clothing, housing, medical and dental services, and other care"). Some states still provide absolute immunity for all claims by children of parental negligence. See *Warren v. Warren*, 650 A.2d 252, 255 (Md. 1994). California is a major exception, rejecting parental immunity and holding that the "proper test of a parent's conduct is this: what would an ordinarily reasonable and prudent parent have done in similar circumstances?" *Gibson v. Gibson*, 479 P.2d 648, 653 (Cal. 1971).

34. The doctrine of parental immunity has come under heavy attack for its origin in the setting of heinous intentional torts; for the notion that by the time litigation is contemplated, harmony no longer exists; for the notion that immunity permits parents to be negligent toward their children; and for the recognition that third party insurance eliminates economic conflict between the parties. See generally *Gibson*, 479 P.2d 648. These critiques do much to explain the erosion that has occurred in parent-child tort immunity, but it is equally important to recognize that most cases that limit immunity still deal with motor vehicle accidents rather than decisions such as the ones at issue here.

III. PHYSICIANS' DUTIES OF DISCLOSURE

The second topic, and the one that has received much more attention over the years, is the question of whether health care providers are either privileged or required to warn their patients' relatives of risks that they might face.

Health care providers are in a difficult position. On the one hand, physicians who care for patients with infectious diseases have been held liable on numerous occasions over many years for failing to warn third parties of their risk of contracting the disease.³⁵ In addition, in the last thirty years, mental health professionals have been required to pay damages when their patients have gone out and assaulted or killed a person whom they had expressed intentions to harm during therapy.³⁶ One court has even said that physicians must warn their patients' spouses of shared epidemiologic risks of disease.³⁷

A major problem with imposing on physicians far reaching obligations to warn third parties is that physicians also have strong ethical requirements to protect patients' confidences, duties that are supported to varying degrees by different legal rules. Protection of confidentiality is thought to be socially desirable because it promotes open communication by patients of their complaints, thereby enhancing the chances of accurate diagnosis, appropriate therapy, and hence the resumption of the patient's health and contribution to society. Some courts have held that the need to protect confidentiality outweighs the rights to third parties to avoid infectious diseases.³⁸ In addition, individuals can sometimes obtain damages from physicians when pri-

35. See *Reisner v. Regents of the Univ. of Cal.*, 37 Cal. Rptr. 2d 518 (Cal. App. 1995) (holding that a physician was liable to a man who became HIV positive after having sex with a girl who had not been told by her physicians that she had received infected blood three years earlier); see also *Hofman v. Blackmon*, 241 So.2d 752 (Fla. Dist. Ct. 1970); *Skillings v. Allen*, 173 N.W. 663 (Minn. 1919).

36. The most famous of these cases is *Tarasoff v. Regents of University of California*. 551 P.2d 334 (Cal. 1976) (holding that a therapist who had knowledge that a patient presented a serious threat of violence against a third party had a duty to warn the the third party of the danger); see also *Estates of Morgan v. Fairfield Family Counseling Center*, 673 N.E.2d 1311 (Ohio 1997) (holding that a psychotherapist whose patient represented a substantial risk of harm to another person had a duty to exercise "best professional judgment" to prevent such harm and citing to extensive list of cases).

37. See *Bradshaw v. Daniel*, 854 S.W.2d 865 (Tenn. 1993).

38. See *Diaz Reyes v. United States*, 770 F. Supp. 58 (D. P.R. 1991) (holding that husband had no duty to tell wife that he was infected with HIV because Puerto Rico's courts had not recognized disclosure of medical information to third parties); *Lemon v. Stewart*, 682 A.2d 1177 (Md. Ct. Spec. App. 1996) (reasoning that since a physician cannot be held liable for good faith failure to meet statutory requirements to warn patient's sexual and needle-sharing partners, he cannot be liable for failing to warn other family members who were at less risk of becoming infected).

vate information is disclosed to third parties without their permission.³⁹

In the last fifteen years, several groups of commentators have opined that physicians may ethically disclose genetic risks over their patients' objections under limited circumstances. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research ("President's Commission") reasoned that such disclosures over the patient's objection were ethically defensible only if:

- (1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.⁴⁰

More recently, the Institute of Medicine's Committee on Assessing Genetic Risks ("IOM Committee") reaffirmed this position, with the additional proviso that "the burden should be on the person who wishes to disclose to justify to the patient, to an ethics committee, and perhaps in court that the disclosure was necessary and met the committee's test."⁴¹

And finally, two cases have already examined questions about whether physicians should be required to disclose genetic risks to the relatives of their patients. In *Pate v. Threlkel*,⁴² Florida's Supreme

39. See *Renzi v. Morrison*, 618 N.E.2d 794 (Ill. App. 1993) (imposing liability on wife's psychiatrist who voluntarily testified on husband's behalf in divorce proceeding); *Hobbs v. Lopez*, 645 N.E.2d 1261 (Ohio App. 1994) (imposing liability when nurse, who had been instructed by physician to call 21 year old patient, instead told patient's mother that patient was pregnant and had sought information about abortion); *Humphers v. First Interstate Bank*, 696 P.2d 527 (Or. 1985). But see *Jones v. Baisch*, 40 F.3d 252 (8th Cir. 1994) (holding that disclosure of patient's genital herpes was not protected by Nebraska's privacy statute because facts were true and that there was no intentional infliction of emotional distress because the behavior was not sufficiently egregious).

40. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: THE ETHICAL, SOCIAL, AND LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING, AND EDUCATION PROGRAMS 44 (1983) [hereinafter PRESIDENT'S COMM'N].

41. COMMITTEE ON ASSESSING GENETIC RISKS, DIVISION OF HEALTH POLICY, INSTITUTE OF MEDICINE, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 23 (1994) [hereinafter COMM. ON GENETIC RISKS]; see also American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure, *Professional Disclosure of Familial Genetic Information*, 62 AM. J. HUM. GENETICS 474 (1998).

42. 661 So.2d 278 (Fla. 1995).

Court held that a physician should have warned his patient who had medullary carcinoma of the thyroid that her relatives might also be at risk of developing the same disease.⁴³ The court went on to say, however, that:

Our holding should not be read to require the physician to warn the patient's children of the disease. In most instances the physician is prohibited from disclosing the patient's medical condition to others except with the patient's permission. Moreover, the patient ordinarily can be expected to pass on the warning. To require the physician to seek out and warn various members of the patient's family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus, we emphasize that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient.⁴⁴

An appellate court in New Jersey reached a markedly different result in *Safer v. Pack*.⁴⁵ In this case, the plaintiff's father was diagnosed with colon cancer in 1956 and ultimately died in 1964.⁴⁶ The plaintiff was diagnosed with colon cancer in 1990 and sued her father's physician's estate, alleging that the physician should have told her that she was at increased risk of developing colon cancer.⁴⁷ There, the court, relying primarily on notions of foreseeability and analogies to the infectious disease and mental illness cases, held that a

duty to warn of avertible risk from genetic causes, by definition a matter of familial concern, is sufficiently narrow to serve the interests of justice. Further, it is appropriate . . . that the duty be seen as owed not only to the patient himself but that it also 'extends beyond the interests of a patient to members of the immediate family of the patient who may be adversely affected by a breach of that duty.' . . . We need not decide, in the present posture of this case, how, precisely, that duty is to be discharged, especially with respect to young children who may be at risk, except to require that reasonable steps be taken to assure that the information reaches

43. *See id.* at 282.

44. *Id.*

45. 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996), *cert denied*, 683 A.2d 1163 (N.J. 1996).

46. *See id.* at 1189-90.

47. *See id.* at 1190.

those likely to be affected or is made available for their benefit.⁴⁸

This court went on to recognize that problems may arise when patients expressly oppose disclosure, saying that:

This case implicates serious and conflicting medical, social and legal policies, . . . Some such policy considerations may need to be addressed in ultimately resolving this case. For example, if evidence is produced that will permit the jury to find that Dr. Pack received instructions from his patient not to disclose details of the illness or the fact of genetic risk, the court will be required to determine whether, as a matter of law, there are or ought to be any limits on physician-patient confidentiality, especially after the patient's death where a risk of harm survives the patient, as in the case of genetic consequences.⁴⁹

While not resolving this issue, this court clearly felt that the patient's wishes may appropriately be overridden in some circumstances.

This contradictory position articulated in scholarly and judicial opinion creates substantial confusion about what legal rules should govern the physician who knows that his patient's relatives may have a mutation that predisposes them to develop a disease that could be ameliorated or cured by early intervention. These questions could arise in a variety of situations.

Going back to the opening hypothetical, suppose Dr. Smart had simply called Sue when he first diagnosed Tom's colon cancer without mentioning anything to Tom first — assuming that Dr. Smart knew that Tom had blood relatives and where they were without asking him. Tom could argue that he had expected that information about him would be kept confidential, perhaps as a matter of express agreement but more likely as a general expectation regarding the practice of medicine in this country. The primary problem, if Dr. Smart were simply to call Tom's relatives, would be his failure to ask Tom whether he agreed with the disclosure. Ethically, Dr. Smart's actions would not be acceptable under the guidelines set forth by the President's Commission⁵⁰ nor the IOM Committee.⁵¹ More generally, spreading information about patients without their consent simply is bad medical practice. From a legal perspective, Tom would have several courses of action available to him. He could report Dr. Smart to the state medi-

48. *Id.* at 1192 (citations omitted).

49. *Id.* at 1193.

50. See PRESIDENT'S COMM'N, *supra* note 40, at 44.

51. See COMM. ON GENETIC RISKS, *supra* note 41, at 23.

cal licensing board for possible censure.⁵² However, it seems quite unlikely that the medical board would revoke or suspend Dr. Smart's license for this sort of disclosure.⁵³ He could also sue Dr. Smart for damages, alleging that the information disclosed was private. Among the elements that a court might consider in such a claim is whether a reasonable person would be upset by the disclosure of information about genetic risk.⁵⁴ The outcome of such an inquiry is uncertain.⁵⁵

Dr. Smart might argue in defense that he had a duty or at least a privilege to prevent harm. Yet, most of the cases that recognize such duties or privileges can readily be distinguished. The infectious disease cases are premised on the notion that it is important to protect otherwise healthy persons from being made sick by a vector that is entirely external to themselves.⁵⁶ Moreover, states regard the containment of infectious diseases as a uniquely important goal and impose rigorous reporting requirements on physicians and permit a host of interventions by public health officials.⁵⁷ This public policy is often cited to support imposing liability on physicians who fail to warn third parties about the risk of contagion.⁵⁸ By contrast, states do not require providers to report either environmental hazards, such as the one at issue in the case of Mark and Jack,⁵⁹ or genetic risks. Even in the absence of a reporting requirement, one could cite the strong public mandate to try to ameliorate environmental hazards to support imposing liability on those who fail to warn of such risks.⁶⁰ No such

52. See BARRY R. FURROW ET AL., HEALTH LAW § 3-22, 78 (1995).

53. See *id.* at 79 (explaining that disciplinary actions are usually limited for immoral actions and that the grounds for professional discipline must "have a rational connection with applicant's fitness or capacity to practice").

54. See, e.g., *Werner v. Kliwer*, 710 P.2d 1250, 1255-57 (Kan. 1985).

55. The elements needed to establish a legal claim for breach of privacy are quite complex. See *id.* at 1254-57.

56. See *supra* note 6 and accompanying text.

57. See, e.g., NEB. REV. STAT. ANN. § 503 (Michie 1997) (permitting physicians' disclosure of patient's contagious disease without liability unless disclosed with malice); N.Y. PUB. HEALTH LAW §2101 (1) (Consol. 1998) ("[E]very physician shall immediately give notice of every case of communicable disease . . ."); WASH. REV. CODE ANN. §110 (1997) (mandating that physicians and other health officials report specified diseases).

58. See, e.g., *DiMarco v. Lynch Homes-Chester County, Inc.*, 583 A.2d 422, 425 (Pa. 1990) (four to three judge opinion citing state public health laws requiring physicians to report communicable disease cases).

59. To elaborate a little further on the case of Mark and Jack, suppose that Mark had consulted with an environmental engineer who discovered the toxic fumes and advised Mark about how to remedy the problem. No case law supports a duty of the engineer to warn Mark's neighbors.

60. This is yet another area in which there is a rather broad public mandate for governmental intervention as is evidenced by the wide array of laws to protect against environmental hazards. See, e.g., 7 U.S.C. §§ 136-136y (1997); 42 U.S.C. §§ 7401-7671 (1997).

consensus exists regarding the state's role in minimizing the health consequences of genetic risks.⁶¹ We can certainly ask whether the reporting requirements should be broadened beyond infectious diseases to include other sources of ill health, but for purposes of this analysis, the critical difference is that such statutory requirements have not yet been enacted.

*Tarasoff v. Regents of University of California*⁶² and its progeny also can be distinguished because disclosure in those cases is justified in order to prevent assault and murder.⁶³ There may be general agreement that people probably ought to warn their relatives about shared genetic risks, but failure to do so is not a crime. Broad public policies favoring public and private intervention to contain infectious diseases or to prevent mentally ill individuals from assaulting others⁶⁴ underlie imposing liability on physicians who fail to warn those who are put at risk by their patients. Similar public policies do not exist for genetic risks. Indeed, the overwhelming trend in current policy is to try to ensure the privacy of genetic information, not to require its disclosure.⁶⁵

One is left then only with the court's assertion in *Safer v. Pack* that the foreseeability of the risk was sufficient to warrant requiring physicians to warn their patients' relatives about genetic risks.⁶⁶ The difficulty with this position is that foreseeability of harm, while important to the definition of duty, is not the only element in one's duty to warn. The existence of broader, well-recognized public policy bases for *Tarasoff* and the infectious disease cases is an important factor that

61. For one of the most thoughtful recent discussions of this topic, see generally Centers for Disease Control and Prevention, *Translating Advances in Human Genetics Into Public Health Action: A Strategic Plan* (October 1, 1997) (unpublished document, on file with the author).

62. 551 P.2d 334 (Cal. 1976); see *supra* notes 36-37 and accompanying text.

63. See *Rocca v. Southern Hills Counselling Center*, 671 N.E.2d 913, 919 (Ind. App. 1996) (reading exception permitting disclosure of death threats to potential victim into a statute protecting confidentiality of mental health records).

64. See *supra* note 36 and accompanying text.

65. Although most of the bills that seek to protect genetic information are driven by fear that this information will be used to disadvantage patients, primarily in access to insurance or employment, they often contain quite broad language limiting disclosure. See, e.g., The Genetic Information and Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. (1997), and the Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong. (1997). Numerous states are considering or have enacted laws that limit disclosure and use of genetic information. See, e.g., Genetic Information Nondiscrimination in Health Insurance Act of 1997, TENN. CODE ANN. §§ 56-7-2701-8 (1998); Karen Rothenberg, *Genetic Information and Health Insurance: State Legislative Approaches*, 23 J.L. MED. & ETHICS 313-16 (1995).

66. See *Safer v. Pack*, 677 A.2d 1188, 1191-92 (N.J. Super. Ct. App. Div. 1996), *cert denied*, 683 A.2d 1163 (N.J. 1996).

does not apply to the genetics cases. Moreover, the *Safer* court failed to give adequate attention to the importance of protecting confidentiality in the delivery of health care. Confidentiality is not and should not be protected all the time, but neither should it be freely abrogated. The decision in *Safer* is a real departure from previous jurisprudence, and the deficits in that court's analysis make it too weak a reed on which to base a far reaching duty to disclose genetic risks.

Changing the hypothetical a little, we assume that:

Dr. Smart told Tom that his relatives were at significant risk of developing colon cancer. Dr. Smart recommended that Tom talk with his relatives, but Tom refused even after significant urging.⁶⁷ Although Tom insisted that Dr. Smart not tell his kin, Dr. Smart was so concerned about the risk faced by Tom's relatives that he talked with them anyway.

This hypothetical presents something of an irony. On the one hand, this is exactly the situation in which the President's Commission would say that Dr. Smart's disclosures are ethically privileged.⁶⁸ On the other, there is something particularly troubling about ignoring Tom's explicit request that information about his condition not be shared. Talking with Tom's relatives in this case would be a direct slap in Tom's face. It would be hard to imagine that Tom would ever feel free in the future to talk openly with Dr. Smart or any other physician. News of this sort of blatant disregard of Tom's wishes could undermine the trust of other patients as well. Is imposing a duty to override patients' objections in such cases worth this price, particularly in the absence of other public policy favoring disclosure?

The problems addressed in *Pate* and *Safer* are not unwanted disclosure but rather failure to warn.⁶⁹ In both these cases, the problem probably is failure of a physician to recognize the presence of genetic risk. To begin, it is important to ask just exactly what doctors should know. Medicine is early in its understanding of the genetic contributions to complex diseases, and it seems quite likely that the mythic reasonably prudent practitioner would not have known about the genetic risks in either of these cases.⁷⁰ The evidence is overwhelming

67. Usually, however, patients generally say yes, knowing that that is what their physicians want to hear or perhaps even fully intending to talk, but then patients, for whatever reason, do not tell their relatives.

68. See generally PRESIDENT'S COMM'N, *supra* note 40.

69. See *supra* notes 42-49 and accompanying text.

70. Although familial adenomatosis had been described in 1956, knowing about this disease surely was not part of the standard of care for a general surgeon at that time or for many years thereafter.

that even now, most practitioners are woefully ignorant about genetics, and massive efforts are underway to try to increase their level of knowledge.

Again returning to our basic case, let us assume for purposes of discussion that Tom's physician either knew or should have known about the risk that Tom's relatives shared a mutation that would predispose them to develop cancer. It seems obvious in 1998 that Tom's doctor ought to discuss this with him. But what legal doctrine requires a conversation between doctor and patient about the genetic risks faced by relatives, and that would support the award of damages to the relatives were that information not conveyed?

The most basic law governing physician-patient communication is the doctrine of informed consent which requires that patients be provided with the information needed to enable them to make reasoned decisions about their own health care. That this doctrine is directed to the patient's own health is evidenced by its origin in the ancient law of battery, which imposed liability for unconsented touching of one person by another.⁷¹ Here, by contrast, we are talking about disclosures that might affect the health care of others. Enabling Tom to help his relatives exceeds even the most generous boundaries of informed consent.

The wrongful birth cases⁷² also do not support a requirement that physicians talk with their patients about the genetic risks that might be shared by relatives. The complaints in those cases are that the prospective parents were denied information relevant to their own reproductive decision making.⁷³ For those cases to be helpful to Tom's relatives, they would have to permit damages to be awarded to the siblings of the prospective parents who argue that their reproductive decision making was also impaired by the doctor's failure to talk with his patients. The wrongful birth cases do not reach that far. Ultimately, the law generally does not require physicians to provide their patients with information that would enable their patients to help

71. See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT*, 49-52 (1984).

72. In these cases, parents who have a child with a genetic or congenital disorder seek damages alleging that had they known of their risk of having a child with that disorder, they would have avoided procreation altogether, used donor gametes, or had prenatal diagnosis and terminated the pregnancy. See, e.g., *Siemieniec v. Lutheran General Hospital*, 512 N.E.2d 691 (Ill. 1987); *Schroeder v. Perkel*, 432 A.2d 834 (N.J. 1981).

73. See *Siemieniec*, 512 N.E.2d at 694 (alleging that physician negligently diagnosed and failed to accurately advise parents of the risk of bearing a hemophiliac child); *Schroeder*, 432 A.2d at 835 (alleging that physician negligently failed to diagnose parents' first child with cystic fibrosis and, thus, deprived parents of ability to make informed choice about whether to have a second child).

others. As a result, even the decision in *Pate* is a significant, and perhaps unsupportable, extension of the law.⁷⁴

But let us assume that the law does require physicians to inform patients about the possibility that their relatives might share their genetic risks. Should a negligent failure by Dr. Smart to warn Tom about the possible risks faced by his relatives support a claim by Sue against the doctor? Such a claim would pose formidable problems of causation. Sue would have to show that Tom would have warned her and that she would have sought medical care in time to avert her risk. But beyond that, if it is correct that physicians should not have legally enforceable duties directly to warn individuals who are not their patients about genetic risks, then they should not be subjected to this sort of indirect liability either.⁷⁵

IV. CONCLUSION

In sum, then, while physicians should talk with their patients about genetic risks and patients, in most instances, should discuss these risks with their relatives, neither patients nor their physicians should be legally responsible for warning family members about genetic risks. That result may seem harsh, but imposing liability would represent a major expansion of the law that is unsupported by current public policies and would wreak havoc on the protection of confidentiality and on the physician's focus on the patient before her. These goals are perhaps tattered, but still important in our health care system.

74. See *supra* note 42 and accompanying text (physician should have warned his patient to inform her relatives of risk of developing same disease).

75. Cf., *D'Amico v. Delliquadri*, 683 N.E.2d 814 (Ohio Ct. App. 1996). In *D'Amico*, a woman could not obtain damages from her boyfriend's physician because he allegedly failed to warn her that the boyfriend's genital warts were contagious. *Id.* at 816-17. The court's analysis relied in substantial part on the physician's inability to testify due to the boyfriend's privilege. See *id.*