

PROFESSIONAL DISCLOSURE OF FAMILIAL GENETIC INFORMATION

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Genetic conditions, defined as changes in a gene or genes, are often caused by the inheritance of a familial disease gene. Accordingly, genetic information reveals genetic risk information about the individual and his or her relatives as well. This personal, yet simultaneously, familial information, raises new and profound questions with regard to the health care professional's legal and moral obligations to disclose genetic information to at-risk relatives (Andrews 1997a).

This report focuses on the potential conflict within the health care professional-patient relationship should the patient refuse to warn at-risk relatives about relevant genetic information. It maintains that genetic information should be considered as medical information albeit with special concerns and implications. As such, as a general rule, the legal and ethical norm of patient confidentiality should be respected. Only exceptionally is a health care professional ethically permitted to breach confidentiality and as a legal matter ought to be privileged, that is, given a discretionary right to disclose genetic information to at-risk relatives without incurring liability provided certain conditions are met. Finally, and at a minimum, health care professionals should have an ethical duty to inform patients prior to testing as well as upon receipt of results that the information obtained may have familial implications. Thus, the possible disclosure by a health care professional to at-risk relatives should consider the following points:

I. POINTS TO CONSIDER

A. *The General Rule of Confidentiality*

1. *Genetic information, like all medical information, should be protected by the legal and ethical principle of confidentiality that exists within the patient-physician relationship. As a general rule, confidentiality should be respected. In the context of medical information, privacy rights translate into the protection of personal data, the affirmation of confidentiality, and the freedom of choice. However, the principle of confidentiality is not absolute and ethical, legal, and statutory obligations may exceptionally permit physicians to disclose otherwise confidential information.*

B. *Exceptional Circumstances Permitting Physician Disclosure*

1. *Disclosure should be permissible where: attempts to encourage disclosure on the part of the patient have failed; the harm is highly likely to occur and is serious, imminent, and foreseeable; the at-risk relative(s) is identifiable; and the disease is preventable, treatable, or medically accepted standards indicate that early monitoring will reduce the genetic risk. Where these conditions are met, the physician may warn at-risk*

family members where the information reveals that the relative is at a substantially higher risk of suffering from a serious and otherwise undetected genetic disorder and where prevention or treatment is available. Therefore, disclosure for diseases that are neither treatable nor preventable would not be permissible. At-risk relatives possess genetic relatedness, are identifiable, and would include siblings and their children and may also extend to identifiable parents, cousins, aunts, and uncles whom the health care professional can reasonably contact.

2. *The harm from failing to disclose should outweigh the harm from disclosure.* Failure to warn may lead to irreparable harm where opportunities for avoidance, treatment, or prevention of the genetic condition are limited because of non-disclosure. The harm resulting from non-disclosure should outweigh the potential psychological, social, financial, and discriminatory harm which may arise from disclosure.

C. *Ethical Duty to Inform Patient of Familial Implications*

1. *At a minimum, the health care professional should be obliged to inform the patient of the implications of his/her genetic test results and potential risks to family members.* Prior to genetic testing and again upon refusal to communicate results, this duty to inform the patient of familial implications is paramount. It is presumed that most patients, provided with the proper information, will inform their relatives of potential risks so that early monitoring, detection, and treatment are available to them.

II. BACKGROUND

A. *Ethical Frameworks for Disclosure of Otherwise Confidential Information*

There are four ethical positions regarding a health care professional's duty or privilege to warn at-risk relatives about genetic information. In the first paradigm, confidentiality is absolute and all medical information is strictly private. Although the health care professional may inform the patient of familial implications to at-risk relatives, confidentiality prevents the health care professional from disclosing any genetic information to relatives; the health care professional has a duty *not* to breach confidentiality. From this ethical viewpoint, it would be unethical to do so.

Alternatively, the 1983 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research proposed that health care professional disclosure to at-risk family members should take place only when:

1. Reasonable efforts to elicit voluntary consent to disclosure have failed;
2. There is a high probability that harm will occur if the information is withheld, and the disclosed information will actually be used to avert harm;
3. The harm that would result to identifiable individuals 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.

These ethical guidelines do not imply a legal duty to warn; they simply set out circumstances in which the Commission believes it would be permissible to do so. The American Institute of Medicine Committee, in its 1994 report on assessing genetic risks, adopted similar language.

A third possible approach involves a genetic Miranda warning which would inform the patient before testing of circumstances that would result in disclosure of genetic information to other family members regardless of the patient's intentions to disclose (Macklin 1992). In this way, arguably, the doctor-patient relationship would not be jeopardized so long as the health care professional assures the patient of the presumption of confidentiality and outlines the exceptions to that presumption prior to testing.

Finally, the duty to warn could be considered an ethical duty. The duty to warn could then eventually become obligatory as opposed to permissive. Indeed, absence of explicit legal regulations does not translate into an absence of duty. An ethical duty can become a professional norm of practice and may become the legal standard so long as there are no other important countervailing policy issues.

B. *The Duty to Warn Under Law*

Statutes and legislation, while protecting the confidentiality of medical/genetic information generally, exceptionally permit health care professionals to disclose otherwise confidential information without incurring liability. Based on public policy interests, physicians are *inter alia* required to report communicable diseases, gunshot and other wounds, and evidence of child abuse and neglect to the appropriate authorities.

US case law dealing with the general duty to warn identifiable third parties of a threat of violence (*Tarasoff v. Regents of the University of California*) found that a duty to warn was likely to exist if: the physician has a *special relationship* with the person who may cause the harm or the potential victim, the potential victim or person at risk is *identifiable*, and the harm to the victim is *foreseeable* and *serious*. Such a duty has been distinguished from a possible duty to warn at-risk relatives about potential genetic risk in so far as it is the patient's actions which are likely to harm others in the former case while in the latter case the patient is not putting relatives at risk by carrying the gene mutation because the relatives already have the mutation or not (Suter 1993; Park and Dickens 1995).

More specifically, a physician's duty to warn in the context of genetic information was recently considered by two US courts who could be considered as indicating an increasing trend toward disclosure in as much as physicians were held to a duty to warn patients of familial implications (*Pate v. Threkel*, Florida, 1995) and more, to a duty to warn relatives known to be at risk (*Safer v. Estate of Pack*, New Jersey, 1996) irrespective of potential conflicts between the duty to warn and the obligation of confidentiality.

C. *International Trends and Positions*

The majority of foreign jurisdictions, while maintaining that confidentiality must be ensured and protected, are however, in favor of limited disclosure of genetic test results (without the consent of the patient) in cases where the harm to at-risk relatives is grave and imminent and the information could result in effective intervention (World Medical Association, World Health Organization, Council of Europe, Nuffield Council on Bioethics, Health Council of the Netherlands, Privacy Commissioner of Australia). Only a few jurisdictions maintain that confidentiality be absolute and that the patient's wishes with regard to non-

disclosure be respected at all times (Norway, The Swiss Academy of Medical Sciences and possibly France's National Ethics Committee).

III. CONCLUSION

Genetic information should be considered as medical information. It is however, both individual and familial in nature. This raises conflicts between the duty of confidentiality and the duty to warn. Yet, ethical, legal, and statutory exceptions limit the principle of confidentiality and only in specific and very limited circumstances permit disclosure. It is clear that a health care professional has a positive duty to inform the patient about the potential genetic risks to his/her relatives. Moreover, where the harm is serious (a concept which defies exact definition and must be determined on an *ad hoc* basis (Knoppers and Wertz 1995), imminent, and likely, and where prevention or treatment is available, the health care professional may have a privilege to warn at-risk relatives irrespective of their patient's wishes. While this is in line with the emerging international trend, the ethical duty of health care professionals to warn at-risk relatives will doubtless be the topic of future debate.

IV. DISCUSSION

Genetic conditions are often caused by the inheritance of a familial disease gene. Accordingly, genetic information reveals genetic risk information about the individual and his or her relatives as well. This personal, yet simultaneously, familial information, raises new and profound questions with regard to the health care professional's legal and moral obligations to disclose genetic information to at-risk relatives (Andrews 1997a; Andrews 1997b).

Given the complex non-individualistic nature of genetic information, some ethicists have maintained that "[i]t's vital to recognize that hereditary information is a family possession rather than simply a personal one."¹ Yet, if genetic information is treated as "family property," traditional boundaries, definitions and obligations of the patient-health care professional relationship would be extended to include family members, leaving the health care professional (family physician, geneticist, genetic counsellor, nurse) in potential conflict between the best interests of his or her traditionally defined patient and newly defined "patients."² Further complicating the medical, legal, and ethical issues surrounding the disclosure of genetic information to at-risk relatives are the inherent limitations of test results to predict the onset, severity, or complexity of a disorder. Like all medical conditions, genetic conditions rarely exhibit homogeneity in terms of how the disease process is manifest. Since some genetic conditions are caused by not one but several genes, the combination of individual variations produces an even more complex set of potential clinical outcomes and often leads to more unknowns than definitive predictions (Abbott 1996; Beardsley 1996).

Must the uniqueness of genetic information be established in order to justify a breach of confidentiality in the health care professional-patient relationship and allow disclosure of genetic risk to relatives? Genetic information has been described as unique not only because it is individually identifying and transgenerationally familial, but also because it implies probabilistic risk information. Advocates of such genetic exceptionalism³ have urged that genetic testing warrants additional protections because of the potential for this information to be socially discriminatory and stigmatizing (particularly in the case of insurance and employment). While this genetic exceptionalism argument maintains that genetic information is sufficiently distinct from other health-related information to

warrant special privacy protection, the Committee maintains the more commonly held view that genetic information should be considered part of mainstream medical information albeit with special concerns and implications.⁴ Even those who believe that genetic information cannot be easily distinguished from other medical information note that "genetic information does not have to be completely unique in order to warrant special protection," it simply has to be treated as "distinctive and especially sensitive."⁵ Moreover, genetic exceptionalism only strengthens the notions of genetic determinism and genetic reductionism (Murray 1997).

The contagious disease model, often cited in the context of potential duties to warn at-risk relatives, is not an ideal paradigm for the disclosure of genetic information. First, genetic conditions are inherited, vertically transmitted through succeeding generations, the connections solely dependent on biological relations. Conversely, contagious disease is generally horizontally transmitted (save for transmission from parent to offspring), the impact on others being through some form of contact. Finally, contagious disease is controlled through isolation of affected people, avoidance of whatever contact causes infection, or, by cure. Genetic conditions, on the other hand, are controlled not only through prevention or palliative treatment but also through reproductive decisions and choices (i.e., adoption, reproductive technologies, etc.).

We will now briefly examine the varying ethical (A), legal (B), and international (C) contexts with regard to the issue of disclosure of genetic information by health care professionals to at risk family members. We will not, however, consider the specific particularities of disclosure to minors, to spouses for the purposes of making informed reproductive choices,⁶ or to at-risk relatives who have the same family physician as the patient.⁷

V. CONTEXTS

A. *Ethical Considerations*

The concept of privacy has evolved from a right of privacy to the personal right to be left alone and ultimately to a fundamental right based on human dignity and respect for the individual, the latter notion understood in terms of self-determination (Knoppers 1995; LeBris and Knoppers 1997). Privacy rights, in the context of medical information, translate into the protection of personal data and the affirmation of confidentiality. As such, genetic information is protected by the legal and ethical principle of confidentiality that exists within the patient-physician relationship. There is a commonly held view that without an expectation of confidentiality, patients will be less forthcoming in disclosing sensitive personal information.

Confidentiality, however, is not absolute. Codes of medical ethics exceptionally permit physicians to disclose otherwise confidential information.⁸ Four ethical positions regarding a health care professional's duty or privilege to warn at-risk relatives about genetic information are found in the literature.

In the traditional health care professional-patient relationship, confidentiality is absolute. All medical information is strictly private. The health care professional is obliged to inform the patient of the implications of his/her genetic test results and potential risks to family members. However, confidentiality prevents the health care professional from disclosing any genetic information to relatives; the

health care professional has a duty *not* to breach confidentiality. From this ethical viewpoint, it would be unethical to do so.

Alternatives to this strict view of health care professional-patient confidentiality have been proposed by the 1983 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The President's Commission states that where the patient refuses, health care professional disclosure to at-risk family members would take place only when:

1. Reasonable efforts to elicit voluntary consent to disclosure have failed;
2. There is a high probability that harm will occur if the information is withheld, and the disclosed information will actually be used to avert harm;
3. The harm that would result to identifiable individuals 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.⁹

These ethical guidelines do not imply a legal duty to warn; they simply set out circumstances in which the Commission believes it would be permissible to do so. Accordingly, the health care professional, in addition to informing the patient that the genetic information may affect his/her relatives, may warn at-risk family members if the above criteria are satisfied. Such criteria have been translated into a consideration of the following factors: the seriousness of the defect, the likelihood that the relative has the genetic defect, whether or not the defect is likely to be detected by other means, the availability of treatment and the seriousness of the harm to be suffered by third parties (Macklin 1992). Disclosure without consent is therefore justified where the information reveals that the relative is at a substantially higher risk of suffering from a serious and otherwise undetected genetic disorder and where treatment or prevention is available.

The American Institute of Medicine Committee, in its 1994 report on assessing genetic risks, recommended that genetic information be considered confidential and adopted language similar to that of the President's Commission with regard to possible disclosure.¹⁰ The report indicated that if the genetic disorder is highly likely and treatable or preventable, many health care professionals would overrule a patient's refusal to disclose and would inform a relative.

A third possible ethical position involves a genetic Miranda warning which would inform the patient in advance of circumstances that would result in disclosure of genetic information to other family members. This forewarning would be provided before testing, regardless of the patient's intentions to disclose. In this way the doctor-patient relationship would not be jeopardized so long as the health care professional assures the patient of the presumption of confidentiality and outlines the exceptions to that presumption (Macklin 1992). Such a forewarning suggests that, if the appropriate factors are satisfied, the health care professional, more than just encouraging the patient to disclose, *will* warn at-risk relatives of serious and treatable/preventable genetic information.

Finally, the duty to warn could be considered an ethical imperative. The duty to warn could then eventually become obligatory as opposed to permissive. Indeed,

absence of explicit legal regulations does not translate into an absence of duty. An ethical duty can become a professional norm of practice and may become the legal standard so long as there are no other important countervailing policy issues.

Choosing between these ethical positions also requires further consideration of the notion of harm. It is important to consider the very real possibility that within a family group, knowledge may constitute a greater harm than non-disclosure particularly in the case of family members who do not want to know. Harm from disclosure may include psychological, social, and financial harm as well as the possibility of stigmatization, discrimination, labeling and the potential loss or difficulty in obtaining employment or insurance.

Yet, failure to disclose may also lead to harm. In terms of reproductive choices, children who may have otherwise been spared the effects of a genetic condition will have to endure them, and couples who would otherwise choose not to conceive would be denied such an option.¹¹ Failure to warn may also lead to irreparable harm where opportunities for avoidance, treatment, or prevention of the genetic condition are limited because of non-disclosure. As such, where the genetic condition is serious, and preventable or treatable, that is where the harm from failing to disclose outweighs the harm from disclosure, health care professionals may have an ethical duty to warn family members, depending on the circumstances, irrespective of their patients' wishes. We will now examine the issue of professional disclosure within the legal context.

B. *Legal Considerations*

The duty to maintain confidentiality extends as far back as the Hippocratic oath, and in the absence of statute, is based upon theories of contract and the fiduciary nature of the health care professional-patient relationship. Courts have distinguished between secrets and confidentiality, the former resulting in no liability for disclosure, the latter imposing a duty to protect information obtained through the relationship.¹² Despite its ability to impose liability for breach, confidentiality, as mentioned, is not absolute. As a result, the health care professional may be faced with conflicting ethical, legal, and statutory obligations.

Although specific statutes protect the confidentiality of genetic information, they also set out situations in which such information may be disclosed without liability. For example, in the case of adoption, a genetic history and history of hereditary conditions must be compiled and disclosed, if known, by either the child-placing agency or biological parents to the adoptee/adoptive parents.¹³ Moreover, at least one state provides that where a child-placing agency receives information that a birth parent or subsequent child of a birth parent has or may have a genetically transferable disease, the agency must notify the adoptee of the existence of the disease, if he/she is over 18, or a custodian, guardian or adoptive parent, if the adoptee is under 18 and vice versa.¹⁴

Legislatures have required reporting of other types of medical information as well. There are statutes requiring physicians to report communicable diseases, gunshot and other wounds, and evidence of child abuse and neglect to the proper authorities. Permitting or requiring breach of confidentiality in the case of contagious disease is based on public policy interests of preventing the spread of

disease. However, many contagious disease statutes make breach of confidentiality a last resort measure. Universal precautions against AIDS or hepatitis provide for precaution without having to breach confidentiality (unless the precautions fail, in which case a limited right to disclosure would exist). Finally, notification is only warranted where the disease: (a) is easily transmitted; (b) poses serious harm and (c) treatment can lead to medical benefit.¹⁵

Some proposed legislation¹⁶ would make *no exception* for a health care professional to warn genetic relatives who may be at risk for developing a genetic condition. This "no exception rule" is based on the belief that it is difficult if not impossible to set boundaries on such an exception. Further, such a rule is seen to maximize the privacy between patients who receive private genetic information and their health care providers (Annas et al. 1995b). The responsibility for informing family members of their potential genetic risks is thus on the individual who has such knowledge. Others have also argued that family members should only receive genetic information when the family member, at the behest of the person tested, consents to, or initiates, such an inquiry (Pelias 1991; Pelias 1992).

The leading case on the general duty to warn is *Tarasoff v. Regents of the University of California*.¹⁷ A psychiatrist was held responsible for not warning his patient's intended victim of the patient's murderous intentions. This case held that a duty to warn is likely to exist if: the physician has a *special relationship* with the person who may cause the harm or the potential victim, the potential victim or person at risk is *identifiable*, and the harm to the victim is *foreseeable* and *serious*. Thus, a duty to warn could override the health care provider's duty of confidence where disclosure of genetic information could foreseeably prevent serious harm.

Responding to the logic of *Tarasoff*, many commentaries have distinguished a duty to warn identifiable third parties of a threat of violence from a possible duty to warn at-risk relatives about potential genetic risk.¹⁸ They note that the crucial difference lies in the nature of the harm for which they are at risk. While it is the patient's actions which are likely to harm others in the case of a threat of violence, in the case of genetic conditions, the patient is not putting relatives at risk by carrying the gene mutation because the relatives already have the mutation or not.

Recent case law has specifically dealt with the issue of a physician's duty to warn in the context of genetic information. In a 1995 Florida case, *Pate v. Threkel*,¹⁹ a daughter suffering from medullary thyroid carcinoma sued her mother's treating physician on the grounds that he knew or should have known that the mother's previously diagnosed cancer was hereditary; that this knowledge gave rise to a duty to warn the mother that her children might be at risk and should be tested; and that had she been tested, she would have taken preventative measures, and her condition, in all likelihood, would have been preventable. The court held that based on state law protecting confidentiality and pursuant to the prevailing standard of care, the physician had a duty to warn the mother but not the daughter. The court noted that "[t]o 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."²⁰

The New Jersey court in *Safer v. Estate of Pack* (1996) however, extended the physician's duty to warn to those "known to be at risk of avoidable harm from a genetically transmissible condition" irrespective of potential conflicts between the

duty to warn and the obligation of confidentiality.²¹ In this case, a daughter diagnosed with colon cancer and multiple polyposis sued the estate of her father's treating physician twenty-six years after her father's death, alleging that the disease was hereditary and that the physician breached his duty to inform her, thus depriving her of the chance for monitoring, early detection, and early treatment. The appellate court, even while considering *Pate*, overruled the trial court's need for confidentiality within the doctor-patient relationship and held that there can be a duty to warn relatives.²² The court applied the infectious disease model²³ and noted that genetic risks are as foreseeable as infectious ones and "[t]he individual or group at risk is easily identified, and substantial future harm is easily identified or minimized by a timely and effective warning."

These cases may indicate an increasing trend toward disclosure irrespective of the potential impact of such disclosure. Yet, finally, in the United States, there is no general legal duty to rescue.²⁴ From the perspective of the health care professional, this means that absent other statutory provisions obliging disclosure and new definitions of the patient including the family, he/she is under no legal obligation to warn at-risk relatives particularly since there is no existing relationship with the relative and neither the patient nor health care professional is causing the potential risk to the relative. The health care professional may however have a privilege, that is a discretionary right to act in a manner which would otherwise give rise to legal liability.²⁵ As some commentators have noted, "[t]he courts have recognized that if disclosure is performed to protect a person perceived to be in imminent peril of harm and is the minimum disclosure necessary to serve that purpose, it may be considered legally excusable." (Park and Dickens 1995). A consideration of the international positions on disclosure to at-risk relatives may be helpful in determining the appropriate paradigm.

C. *International Positions*

Many foreign jurisdictions and international organizations have examined questions related to genetic privacy and confidentiality and have formulated recommendations which attempt to balance patients' expectations of privacy with other parties' claims to sensitive genetic information. The majority of foreign jurisdictions are in favor of permitting limited disclosure of genetic test results (without the consent of the patient) in cases where the harm to at-risk relatives is grave and imminent. Only a few jurisdictions maintain that confidentiality and the patient's wishes with regard to non-disclosure be respected at all times.

Limited disclosure has been recognized at the international, regional and national levels. Internationally, the World Medical Association in its Declaration on the Human Genome Project (44th World Medical Assembly, 1992), and experts advising the World Health Organization on their proposed guidelines on medical genetics and genetic services (Wertz et al. 1995) recommend that confidentiality of genetic information be maintained except where there is high risk of serious harm to family members at genetic risk and the information could be used to avert this harm.

At the regional level, in 1992, the Council of Europe, while maintaining that confidentiality of genetic information must be ensured at all times and protected by the rules governing medical data, did make an allowance for disclosure in the case of severe genetic risks affecting the health of family members or their future

children (Council of Europe 1992). However, the genetic data of one member of a couple cannot be communicated without the free and informed consent of the other member (Council of Europe 1990). The 1996 *Convention on Human Rights and Biomedicine* allows for the communication of genetic test results when necessary, *inter alia*, for the interest of public safety, the protection of public health, or the protection of the rights and freedoms of others (Council of Europe 1996).

Nationally, in the United Kingdom, the Nuffield Council on Bioethics recommended in 1993, that accepted standards of the confidentiality of medical information be followed as much as possible and that where a patient refuses to disclose test results to family members and the physician has stressed the importance of sharing such information and has attempted to persuade the individual to allow disclosure, an individual's desire for confidentiality may be overridden in exceptional circumstances only. Such a decision would be made on a case by case basis (Nuffield Council on Bioethics 1993).

The Health Council of the Netherlands is of the view that unauthorized disclosure may be permissible under limited circumstances when serious harm can be avoided and has noted that relatives' right to privacy should be a consideration when deciding whether or not a disclosure should be made (Committee of the Health Council of the Netherlands 1989).

A recent report of the Privacy Commissioner of Australia recommends that an individual's right to privacy give way to the imperative to prevent harm where the risk of harm is serious, real, and imminent and "where there is a possibility of effective intervention and the consequences of non-intervention are serious for affected relatives."²⁶

The Japan Society of Human Genetics, in its Guidelines for Genetic Testing also stipulates that where necessary to avoid serious injury, confidentiality can be broken even in the absence of (subject) consent. Such an exception however, must be made by a responsible ethics committee (Japan Society of Human Genetics 1996).

Other jurisdictions explicitly make no allowances for unauthorized disclosure. Norway, for instance, has taken a firm and clear legislative stand on protecting personal privacy with no exceptions being made for disclosure, even under extreme circumstances.²⁷

The Swiss Academy of Medical Sciences and France's National Ethics Committee have established guidelines which do not permit disclosure without the patient's consent.²⁸ In its reiteration of this principle in 1995, the French National Ethics Committee noted however that in the event of a research subject's refusal, the physician will be confronted with an ethical dilemma that must be resolved given the principle of assistance to persons in danger, particularly where children are concerned.²⁹

In 1995, the members of the Science and Technology Committee of the House of Commons disagreed with the Nuffield's Council suggestion that confidentiality should be less than absolute. The Science and Technology Committee is of the opinion that if counselling cannot persuade someone to consent to sharing

information with his or her relatives, then the individual's decision to withhold information should be paramount.³⁰

D. CONCLUSION

It is clear that genetic information is both individual and familial. This raises conflicts between the duty of confidentiality and the duty to warn. Yet, ethical, legal, and statutory exceptions limit the principle of confidentiality and in specific and very limited circumstances may permit disclosure. At the very least, it is clear that a health care professional has a positive duty to inform a patient about the potential genetic risks to his/her relatives. Then, depending on the circumstances, the health care professional may have a privilege to warn at risk relatives where: the harm is serious, imminent and likely; prevention or treatment is available; and where a health care professional in like circumstances would disclose.

Seriousness defies exact definition and must be determined on an *ad hoc* basis.³¹ While overly broad definitions may leave a health care professional confused or in conflict, such ambiguity is often the hallmark of professional judgement. The ethical duty of health care professionals to warn at-risk relatives will doubtless be the topic of future debate.³²

Footnotes

¹ Wertz and Fletcher 1989; Wertz et al. 1995, who suggest that at the level of the person, genetic information while individual, "be shared among family members" - a form of shared familial property.

² Gevers (1988) presents the notion of genetic information as family property as a possible alternative to patient-doctor confidentiality but ultimately rejects this approach arguing that: "[t]he infringements of the principle of confidentiality would be potentially unlimited, partly because it may be impossible to draw the line between medical information that is relevant to genetic counselling and information that is not relevant, and partly because in the future ever more diseases will be found to contain hereditary components". *Contra*: Wertz et al. (1995) who adopt this family property concept; see also Wachbroit (1993) and Wachbroit (1989), where a family health model is suggested which contemplates the physician's patient as the entire family and where family is understood to refer to a genetic network rather than a social institution. The physician's duties are therefore to the genetic family as a whole; see Wachter (1997), who notes that "privacy seen as a family matter should be considered." He further notes UNESCO's attention to varying concepts of privacy amongst various societies and points out that "the duty of the health professional is to secure the appropriate privacy for genetic information that is laid down by the norms of a particular society."

³ See for example Annas et al (1995), who believe that genetic information should be accorded special status and note that "genetic information is uniquely powerful and uniquely personal, and thus merits unique privacy protection."

⁴ This issue has been addressed in the literature specifically with regard to legislation concerning genetic information. See Reilly (1997), who ultimately determines that since genetic information will (in the not too distant future) standardly become part of the general medical record, laws

which protect the privacy of all individual medical records, as opposed to laws which regulate genetic information specifically, are required. He notes that the Medical Records Confidentiality Act of 1995 (s. 1360 104th Cong., 1st sess., § 2(1)) for example, presents a reasonable approach to medical information generally and would be comprehensive if "genetic information" was added to its list of protected entities. See also Gostin (1995) who notes that the enactment of genetic specific privacy legislation could create inconsistencies in the rules governing the dissemination of health information; and since "the flow of medical information is rarely restricted to particular diseases or conditions," "comprehensive legislation on health information privacy, with explicit language applying privacy and security standards to genomic information" would be a better alternative; and B. M. Knoppers, "Privacy, Confidentiality and Genetic Information" UNESCO, IBC (submitted), (hereinafter, Knoppers: UNESCO).

⁵ See Murray (1997). Murray rejects unique distinctions between genetic information and other medical information noting *inter -alia* that cholesterol levels are probabilistic information, that other medical information affects the family (although sensitivity may be amplified with genetic information) and that discrimination occurs with non-genetic information - as is the case in the insurance industry.

⁶ The issue of disclosure to spouses is controversial because while there is no risk to the spouse personally, genetic test results are pertinent for the purposes of making informed reproductive choices. See Institute of Medicine (1994), who recommended that health care professionals not reveal genetic information about a patient's carrier status to the patient's spouse without the patient's permission since a spouse's claim of harm - the possibility of bearing a child with a genetic disorder - could not be considered substantial and imminent.

⁷ This issue raises the question of whether the family physician's obligation to disclose is greater given that he may be already treating relatives of the patient.

⁸ Note that the Code of Ethics of the Canadian Medical Association [(1996) 155(8) Can Med Assoc. J. 1176A] permits a breach of a patient's right to confidentiality, *inter-alia*, "when the maintenance of confidentiality would result in a significant risk of harm to others" (at article 22). In contrast, the Code of Ethics of the American Medical Association [1996, AMA Current Opinions, 624] does not refer to risk of harm but restricts itself to disclosure "need[ed] to protect the welfare of the individual or the public interest." (Fundamental Elements of the Patient-Physician Relationship, article 4).

⁹ Screening and Counseling for Genetic Conditions (1983). Similar positions have been adopted by the Institute of Medicine (1994); the Science Council of Canada (Genetics in Health Care, 1992); Canada (Medical Research Council of Canada et al, 1996); and the United Kingdom (Nuffield Council on Bioethics, 1993).

¹⁰ Institute of Medicine (1994). The committee noted that the strongest case for warning by a health care professional would exist where there is a high likelihood that the relative has the genetic defect, the defect presents a serious risk to the relative and there is reason to believe that the disclosure is necessary to prevent serious harm (at 278).

¹¹ One author argues that warning relatives about the risk of conceiving a child with a deleterious gene does not pose the type of serious, imminent harm which would generally require disclosure (Andrews (1997a)).

¹² See *Humphers v. First Interstate Bank of Oregon*, 696 P.2d 527 (Or. 1985) where a physician revealed the identity of a former patient to the daughter she had given up for adoption, and the

physician was held to a nonconsensual duty of confidentiality imposed upon him by virtue of his profession and "determined by standards outside the tort claim for its breach".

¹³ For an extensive review of genetic disclosure in relation to adoption laws, see Andrews (1997b) and the American Society of Human Genetics (1991) who take the position that genetic history should be included in an adoptee's record and recommend that where appropriate, genetic data should be shared among the adoptive parents, biological parents and adoptees.

¹⁴ Wisconsin Statute § 48.432 (1994).A

¹⁵ Andrews (1997b), citing L. J. Steele "When Universal Precautions Fail: Communicable Disease Notification Laws for Emergency Responders" (1990) 11 J. Leg. Med. 451-480 at 451.

¹⁶ See for example Annas et al. (1995)

¹⁷ 551 P. 2d 334 (Cal. 1976) (en banc). Relevant to the issue of duty to warn and disclosure see also: *Berry v. Moench* 331 P2d 814 (Utah], 1958) where a physician who disclosed a patient's depression and legal and financial problems to a friend of the patient's fiancée was granted a conditional privilege to reveal such information because a sufficiently important interest needed to be protected; *Simonsen v. Swenson*, 104 Neb. 224, 177 N.W. 831, (Neb. 1920) where a physician was granted a privilege to disclose a patient's infectious syphilitic state to the proprietress of a hotel where the patient was staying. He was found immune from liability because he acted in good faith without malice and did not disclose more than was necessary (at 833).

¹⁸ Suter (1993); Park and Dickens (1995); and Miller (1994), who points out that there are number of similarities between the two cases: a special relationship exists between the physician and the patient, the third party is identifiable, there is no special relationship between the physician and the third party, the information to be disclosed is confidential, and there is an opportunity for the prevention of harm.

¹⁹ 661 So.2d 278 (1995). See also *Dimarco v. Lynch Homes-Chester County*, 583 A, 2d 422 (Pa. 1990) where the court held that a physician has a duty of care to tell the patient about the risk of exposing a communicable disease to third parties (hepatitis B). The court considered, in *dicta*, that the physician should recognize that services rendered for the patient are necessary for the protection of third parties likely to be affected by the patient's disease.

²⁰ *Id.* At 282.

²¹ 677 A 2d 1188 (N.J. Super A.D. 1996).

²² The case was remanded for trial to determine whether the duty to warn was breached in this case. The court noted that the trial court would have to consider the extent of the daughter's risk, the costs of monitoring as compared to the expenses associated with the breach of duty and whether, if the father had instructed the doctor not to disclose to his daughter, that request should have been honored.

²³ For a duty to warn in the contagious disease cases see for example: *Skillings v. Allen*, 143 Minn. .323, 173 N.W. 663 (1919) where a physician was found to have a duty to use due care in advising a patient's parents about the possible transmission of infection; *Gammill v. United States* 727 F. 2d 950, 954 (10th Cir, 1984) where it was held that a physician may be found liable for failing to warn a patient's family, treating attendants, or other persons likely to be exposed to

the patient of the nature of the disease and the danger of exposure. Interestingly, a duty to warn was also recently found in a non-contagious disease case: see *Bradshaw v. Daniel* 845 S.W. 2d 865 (Supreme Court of Tennessee, 1993) where a physician was found to have a legal duty to warn a spouse of the risk of exposure to the source of the patient's non-contagious disease - in this case, Rocky Mountain Spotted Fever (RMSF) - because they had the same epidemiological risk and knowledge of that risk could have saved the spouse's life - notwithstanding that the patient could not give RMSF to his spouse.

²⁴ Generally, in Canada there is no duty to render assistance to individuals in danger in the absence of statute (Linden 1993). However, Quebec (in the civil law tradition) does recognize a general duty to rescue in its Charter of Rights.

²⁵ *Black's Law Dictionary* defines a privilege as, "[t]hat which releases one from the performance of a duty or obligation, or exempts one from a liability..."

²⁶ Privacy Commissioner (1996); see also Medical Research Ethics Committee of NHMRC (1991), who noted that their recommendation to respect the wishes of the individual tested was still contentious at the time of writing the guidelines. They noted that it could well be argued that the right of the person at risk should outweigh privacy when there is a possibility that a life could be saved, or conditions effectively treated, if the information was disclosed to the relative at risk (at 4).

²⁷ Norway Ministry of Health and Social Affairs (1993); (Norway 1994). The Ministry of Health and Social Affairs determined "that information on the genes of people regarded as healthy must remain strictly confidential. Such information must not be stored, not even by health institutions in patient records".

²⁸ Swiss Academy of Medical Sciences, "Medical-Ethical Guidelines for Genetic Investigations in Humans" (1993) Bull. Med. Suisses 74 (No. 38) 1454, Guideline 3.7; Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé, Avis sur l'application des tests génétiques aux études individuelles, études familiales et études de population (Problèmes des "banques de l'ADN, des "banques" de cellules et de l'informatisation des données), 24 juin 1991; Law No. 94-654 of 29 July 1994 on the donation and use of elements and products of the human body, medically assisted procreation and prenatal diagnosis, (1994) 45:4 Int. Digest Health Legis. 473, Title VI, A.L. 145-15.

²⁹ Comité consultatif national d'éthique pour les sciences de la vie et de la santé, Avis No. 46: Génétique et médecine: de la prédiction à la prévention", 7 novembre 1995, rec. 2. The ethics report accompanying this Opinion noted the importance of genetic information for subsequent generations as well as the possible duty on the physician to disclose genetic information to persons at risk when useful. R.3.3.

³⁰ Science and Technology Committee, Human Genetics: The Science and its Consequences, (House of Commons, 6th July 1995) at para. 227-228. The report maintained that the failure to inform relatives places them "at no worse position than if no test has been performed. To fail to respect the privacy of genetic information in this way could discourage couples from participating in research for the common good or from seeking information which could help them safeguard their health."

³¹ The notion of serious harm is highly subjective. See Knoppers et al. (1995), where geneticists certified by ABMG or ABGC, members of the Canadian College of Medical Geneticists, European Society of Human Genetics, and Ibero-American Society of Human Genetics were

surveyed on how they viewed the term "serious". No consensus was found on the definition of "serious". Furthermore, of 947 responses received, 24% in U.S., 18% in Canada, 37% in Europe, and 65% in Latin America thought that professional associations should develop lists of serious disorders. 8% (4% in U.S.) favored a legal definition of "serious". Some thought a national ethics committee (16%), hospital ethics committees (14%) or individual practitioners (28%) should define "serious." 72% in U.S. and Canada, 54% in Europe and 31% in Latin America thought individual patients should define "serious"

³² See *Safer v. Estate of Pack, supra*, note 31 at 1192 where the court noted that "the 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."

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