Testing Adolescents for the Alzheimer Gene: Tensions in Law and Policy

---

TIMOTHY CAULFIELD*

I. INTRODUCTION

RESEARCH HAS CLEARLY ESTABLISHED that the presence of the gene Apolipoprotein E 4 (APOE4) is a risk factor in the development of Alzheimer disease. Recent evidence indicates that the risk associated with this genetic mutation may increase when an individual has experienced head trauma. A study of 30 boxers suggests that the presence of an APOE4 allele "may be associated with increased severity of chronic neurological deficits."[1] Does this finding, which is consistent with other research,[2] indicate that individuals who participate in high contact sports should be routinely tested for the presence of this gene? Given the large number of Canadian adolescents who are involved in sports such as hockey, this has the potential to be a significant health policy dilemma.[3] In the hope of avoiding a late onset neurological disorder, such as Alzheimer disease, should we be testing, or even screening, children prior to their involvement in activities which may involve a risk of head trauma?

---

[*] LL.M., Research Director, Assistant Professor, Health Law Institute, University of Alberta, and Visiting Fellow, Stanford University's Program in Genomics, Ethics, and Society. I would like to thank Laura McConnell, Jill Frizzley, Hank Greely, Marie Hirtle, Erin Nelson, Gerald Robertson, and all my PGES colleagues for their helpful comments. I would also like to thank the Alberta Heritage Foundation for Medical Research for its continued support.

[1] B. Jordan, N. Relkin & L. Ravdin, "Apolipoprotein E 4 Associated With Chronic Traumatic Brain Injury in Boxing" (1997) 278 J.A.M.A. 136 at 136.

[2] For example see, R. Katzman, D. Galasko, T. Saitoh, *et al.* "Apolipoprotein e4 and Head Trauma: Synergistic or Additive Risks?" (1996) 46 Neurology 889–92; and J. Mortimer, C. Van Duijn, V. Chandra, L. Fratiglioni, *et al.*, "Head Trauma as a Risk Factor for Alzheimer's Disease: A Collaborative Re-Analysis of Case-Control Studies" (1991) 20:2 Int'l J. Epidemiol. 528.

[3] As of the1996–1997 season, there are approximately 507 737 participants under the age of 21 involved in organised hockey (Canadian Hockey Association: 613.748.5613). In addition, there are 3 300 registered/competitive boxers between the ages of 11 and 19 (Canadian Amateur Boxing Association); 462 637 registered soccer participants under the age of 19 (Canadian Soccer Association: 613.237.7678); and 18 225 registered rugby players under the age of 19 (Canadian Federation of Rugby: 613.748.5657).

Of course, this question is inextricably tied to the broad ethical and legal concerns, including confidentiality and genetic discrimination, associated with any genetic test.[4] As such, a comprehensive review of all of the relevant issues is not possible in a short piece of this nature. Rather, this paper seeks to highlight a few of the unique legal and policy issues associated with APOE4 testing and the cognitively mature adolescent, that is, the population most likely to be affected by genetic testing in the context of participation in high contact sports. Although there are certainly one or two straw men present in this paper—the predictive test is not currently available nor recommended—in a field which moves forward as fast as human genetics, a degree of speculation is required for the development of responsive genetic policy. In this regard, APOE4 testing serves as an effective model for the examination of the general issues associated with genetic testing in the context of minors. For example, there is an emerging national and international consensus that minors should not be given predictive tests for late onset disorders for which there are currently no effective therapies or interventions.[5] Due to the potential preventative steps suggested by APOE4 testing in relation to participation in high contact sports, would a divergence from this trend be justified? In particular, I am curious (though unable to answer) how physicians and other genetic professionals will balance this question against their traditional legal and ethical obligations to patients and surrogate decision-makers (e.g., parents).

---

[4] A vast amount has been written on this general topic. See, for example, P. Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (Simon and Schuster: Toronto, 1996); L.B. Andrews, "Compromised Consent: Deficiencies in the Consent Process for Genetic Testing" (1997) 52:1 J.A.M.A. 40–44; R.C. Lewontin, *Biology as Ideology: The Doctrine of DNA* (New York: Harpers Perennial, 1992); G. McGee, *The Perfect Baby: A Pragmatic Approach to Genetics* (Maryland: Rowman and Littlefield, 1997) G. Annas & S. Elias, eds., *Gene Mapping: Use Law and Ethics as Guides* (New York: Oxford, 1992); D. Kevles & L. Hood, eds. *The Code of Codes* (Cambridge: Harvard University Press, 1992); D. Wertz, "Ethical and Legal Implications of the New Genetics: Issues for Discussion" (1992) 35 Soc. Sci. Med. 495; B.M. Knoppers, *Human Dignity and Genetic Heritage* (Ottawa: Law Reform Commission of Canada, 1991); Science Council of Canada, *Genetic in Health Care: Report 42* (Minister of Supply and Services, 1992); L.B. *Andrews et al., Assessing Genetic Risk: Implications for Health and Social Policy* (Washington, D.C.: National Academy Press, 1993).

[5] For example, Clinical Genetics Society, The Genetic Testing of Children: Report of a Working Party of the Clinical Genetics Society (Cardiff, 1994); D. Wertz *et al.*, Guidelines to/of Ethical Issues in Medical Genetics and the Provision of Genetic Services (WHO, Hereditary Disease Program, 1995); and Nuffield Council on Bioethics, Genetic Screening: Ethical Issues (London: Nuffield Council on Bioethics, 1993); Task Force on Genetic Testing of the NIH-DOE Working Groups on Ethical, Legal and Social Implications of Human Genome Research, Promoting Safe and Effective Genetic Testing in the United States: Principles and Recommendations (May 1997).

To this end, this paper will use APOE4 testing as a model to examine four broad issues: *(i)* should children be tested; *(ii)* who prevails in a conflict between the wishes of parents and those of a legally incompetent adolescent; *(iii)* when can an adolescent request and consent to genetic testing; and *(iv)* who should have access to the results of a genetic test of this nature? We will see that the issues which surround APOE4 testing stand as an illustration of the enduring quality of the legal and ethical challenges which are certain to surround almost all of the emerging genetic services.

Each new technology seems to invite new *practice* challenges which strain many of the physician's traditional professional obligations. Furthermore, despite continued efforts to formulate much needed genetic policies and guidelines,[6] these practical "nuts and bolts" issues will inevitably need to be dealt with by Canadian physicians practising in the emerging genetic era. Guidelines, while essential, can only provide broad direction as to what clinicians should do. They cannot, for example, determine if the child in their office is legally competent, or if there is a need to disclose confidential information for the protection of a third party. Guidelines establish the policy options, but the policy judgment remains with the physician or the clinical team.

II. THE ISSUES

A. Should Children be Tested?

Over the past few years a great deal has been written about the genetics of Alzheimer disease (AD).[7] There is little doubt that genetic predisposition can play a significant role in AD. Indeed, possession of the PS1 allele, a relatively rare mutation, is determinative of the disease.[8] However, to date, the consensus in the scientific and medical community is that APOE4 testing is an ineffective and inappropriate predictive tool.[9] As a result, it is now only available as a con-

---

[6] See generally, B.M. Knoppers & R. Chadwick, "The Human Genome Project: Under an International Ethical Microscope" (1994) 265 Science 2033; and S. Le Bris, B.M. Knoppers, & L. Luther, "International Bioethics, Human Genetics, and Normativity" (1997) 33 Health L. Rev. 1363.

[7] A. Roses, "Apolipoprotein E and Alzheimer's Disease" (1996) Ann. N.Y. Acad. Sci. 51–57; D. Blacker, J. Haines, L. Rodes, H. Terwedow, *et al.* "ApoE4 and age at onset of Alzheimer's Disease: The NIMH Genetics Initiative" (1997) 48 Neurology 139–47.

[8] See C. Lendon, F. Ashall & A. Goate, "Exploring the Etiology of Alzheimer Disease Using Molecular Genetics" (1997) 277 J.A.M.A. 825 at 826–29 for a discussion of the PS1 (presenilin-1) allele. Unlike APOE4 allele, which is a "genetic risk factor," presence of the PS1 mutation "can lead to early onset form of AD."

[9] American College of Medical Genetics/ American Society of Human Genetics Working Group on APOE and Alzheimer Disease, Consensus Statement, "Statement on Use of Apolipoprotein E Testing for Alzheimer Disease" (1995) 274:20 J.A.M.A. 1627–29; Na-

firmatory diagnostic aid for those individuals who are already showing signs of dementia.[10]

The recent study of boxers hints at the possible use of the test for a different, more preventative, purpose—that of taking active steps to avoid the onset of a neurological disorder. However, even if used in this limited context, the test would continue to carry the ethical, social, and familial baggage of any test of genetic predisposition. That is, APOE4 testing would provide an adolescent with information—albeit poor information—concerning his, and his family's, predisposition to a largely untreatable late onset disease, thus triggering concerns regarding stigmatisation, psychological implications, genetic discrimination, misinterpretation of results, and so on. The policy question is then: are the potential health benefits associated with APOE4 testing sufficient to outweigh the concerns regarding the use of a poor predisposition test on a minor?[11]

It is, most would agree, far too early to attempt to definitively answer this query. More research is needed. At this time, however, it seems safe to speculate that although the combination of the presence of the APOE4 allele and participation in a contact sport may one day justify an alteration of current conservative policy positions,[12] these "preliminary findings" concerning boxing, on their own, will probably not result in a change. Nevertheless, the reaction already exhibited with respect to these early findings illustrates the potential ramifications of this line of inquiry. For example, Jose Torres, both a former light-heavyweight champion and chairman of the New York State Athletic Commission, stated that if the new study was confirmed he would want all box-

---

tional Institute on Aging / Alzheimer's Association Working Group, Consensus Statement, "Apolipoprotein E genotyping in Alzheimer's Disease" (1996) 347 Lancet 1091–95.

[10] A. Roses, J. Bryan & K. Bryan, "Apolipoprotein E Genotype: Utility in Clinical Practice in Alzheimer's Disease" (1996) 44 J. Am. Geritr. Soc. 1479–1481.

[11] Many of the commentaries that set a cautious tone regarding the genetic testing of children suggest that it may be acceptable if it will benefit the child's health. See, Nuffield, *supra* note 5; Assessing Genetic Risk, *supra* note 5 at 10; and Council of Europe, *Recommendation No. R (92)3 of the Committee of Ministers to Member States on Genetic Testing and Screening for Health Care Purposes* (February 1992), principle 5; and Task Force on Genetic Testing, *supra* note 5: "Genetic testing of children for adult onset diseases should not be undertaken unless direct medical benefit will accrue to the child and this benefit would be lost by waiting until the child has reached adulthood."

[12] See for example, The Alzheimer Society of Canada, *Tough Issues: Ethical Guidelines* (undated); and *Predictive Testing and Alzheimer Disease* (information sheet, 1994):

> Although there are commercially available tests to test for the APOE4 allele, the complex nature of the subject of predictive testing makes it imperative that the tests only be done in the controlled setting of research centres which can provide appropriate counselling and guarantee that all the psychological, legal and ethical implications of predictive testing are dealt with.

ers to be tested for APOE4, and further, "would campaign to stop [those with the gene] from fighting."[13]

Despite the tentative conclusion that clinicians should refrain from the use of APOE4 in this context, it must be recognised that research on human genetics is moving at an incredible pace. If these studies are substantiated, parents and other interested third parties, e.g., coaches and, perhaps, school administrators may seek testing for adolescents involved in high contact sports. Indeed, one can envision such inquiries merely as a result of the media attention which has already been generated around this topic.[14] As such, I will proceed on the assumption that APOE4 remains a *potentially* informative test in relation to participation in high contact sports.

B. Who Prevails in a Conflict Between the Wishes of Parents and Those of a Legally Incompetent Adolescent?

Requests for testing will almost certainly create a number of legal and ethical challenges for physicians. In fact, the question of whether APOE4 testing should even be available to those willing to pay, for example, is, in itself, a controversial issue.[15] However, for the purpose of this discussion, let us jump to a specific concern, that of parents requesting APOE4 testing on behalf of an adolescent child.

Given the possible implications respecting participation in a variety of popular sports, an adolescent may not wish to be tested, despite the desires of concerned third parties. In the face of such a refusal, and absent an explicit testing policy, can a physician withhold the genetic test even if the adolescent lacks the legal capacity to consent? Given the current state of knowledge, should the request of parents who wish to protect their children from the speculative future harms associated with APOE4 and high contact sports take precedence over the expressed wishes of an adolescent who does not yet have the legal capacity to consent?

---

[13] G. Kolata, "Study Hints at Gene Link to Boxers' Affliction" *The New York Times* (7 July 1997) A15.

[14] For example, W. Immen, "Slowing Down the March of Alzheimer's" (25 June 1997) *The Globe and Mail.* With respect to requests for the predictive tests, see Lendon *et al.*, *supra* note 8 at 834, note as follows: "Although APOE genetic testing in asymptomatic individuals is not recommended, anecdotal reports indicate that it has been offered by some clinicians to especially demanding consumers who are willing to pay for it. Such testing should be discouraged."

[15] See, for example, D. Wertz, "Professional Perspectives: A Survey of Canadian Providers" (1995) 3 Health L. J. 59 at 82, where is reported that 61 percent of the patients surveyed thought: "Patients are entitled to any service they can pay for out-of-pocket." Similarly, 68 percent thought agreed with the statement: "Withholding any requested service is paternalistic."

There is growing recognition that as a child matures more weight should be given to his opinion concerning health care decisions.[16] In fact, there have been a variety of commentaries specific to genetic testing which have re-affirmed this principle.[17] When dealing with an immutable characteristic such as genetic predispositions, it has been suggested that we should strive to preserve the autonomy of the minor or, more particularly, the child's "genetic innocence."[18] In other words, while the opinion of a minor has relevance to all health care decisions, arguably it has a heightened importance in the realm of genetics. As such, the informed opinion of a "nearly competent" adolescent should be a compelling consideration.[19] The physician who feels torn by the diverging wishes of the child and parents could certainly find emerging ethical and policy commentary supportive of a decision to allow the adolescent's opinion to prevail over the demands of the parents.[20]

Although ethics paradigms may allow for this nuanced approach to the participation of minors in health care decisions, in Canada the law still has an "all

---

[16] C. Harrison, N. Kenny, M. Cedars & M. Rowel, "Bioethics for clinicians: 9. Involving children in medical decisions" (1997) 156:6 C.M.A.J. 825–828; S. Choudhry, "Review of Legal Instruments and Codes on Medical Experimentation with Children" (1994) 3 Camb. Q. Healthc. Ethics 560; and American Society of Human Genetics and American College of Medical Genetics, "Ethical, Legal and Psychological Implications of Genetic Testing in Children and Adolescents: Points to Consider" (1995) Am. J. Hum. Genet. 1233.

[17] Clinical Genetics Society, *The Genetic Testing of Children: Report of a Working Party of the Clinical Genetics Society* (Cardiff, 1994); D. Wertz, J. Fanos, & P. Reilly, "Genetic Testing for Children and Adolescents: Who Decides" (1994) 272:11 J.A.M.A. 875–881.

[18] See Wertz, WHO, *supra* note 5 at 49; and R. Chadwick, *et al.*, *Euroscreen Final Report: Genetic Screening: Ethical and Philosophical Perspectives* (Euroscreen, February 1997) at 11, who note that the "unsolicited disclosure of genetic information to relatives will mean that they irreversibly lose their 'genetic innocence.'" This latter comment relates to the disclosure of information to relatives, however, the rationale is equally relevant in the present context (see also Euroscreen report at 19).

[19] Likewise, the familial implications of such a test suggest that a "family centred" approach to the consent process would be well advised in this context. For example, the impact of the testing on all family members, and on the family dynamic, should be explored. See Harrison, *supra* note 16. In this regard see also, Tri-Council Working Group, *Draft Code of Conduct for Research Involving Humans* (Ottawa: Minister of Supply and Services, 1996) at 15–2. Of course, as with all genetic tests, much of this discussion should be part of an appropriate counselling services.

[20] See, for example, Wertz, WHO, *supra* note 5 at 49: "Decisions that override parental authority may be necessary in order to prevent harm and to preserve a minor's future autonomy, which should be the paramount consideration." See also M. Hirtle, "Children and Genetics: A Comparative Study of International Policy Positions" (1997) [draft book chapter, unpublished], for a review of this and other relevant international commentary.

or nothing" view of legal capacity as it relates to a given procedure.[21] Therefore, the authority to consent on behalf of a legally incompetent minor rests solely with the parent(s) or legal guardian. This does not mean, however, that physicians must acquiesce to the unreasonable demands of parents. The right to consent does not extend to a right of access to all desired services.[22] Two circumstances may arise: if it is clearly not in the best interests of the minor[23] (where the adolescent's opinion would certainly be relevant), or if the test is not offered to this population as a matter of policy,[24] a physician may be legally justified in withholding the test.[25] However, the law continues to place great significance on the right of parents to raise their children pursuant to their particular values and beliefs. As a result, a court will override the wishes of parents only in rare circumstances.[26] While the jurisprudence in this area is largely built on cases involving parents who have refused to consent to a medically necessary procedure, such as blood transfusion[27] or organ transplant,[28] the commentary regard-

---

[21] E. Picard & G. Robertson, *Legal Liability of Doctors and Hospitals in Canada* (Toronto: Carwell, 1996) at 71–75.

[22] See L. Schneiderman & N. Jecker, *Wrong Medicine* (Baltimore: The Johns Hopkins University Press, 1995) at 47; and generally the Canadian Bar Association Task Force on Health Care, *What's Law Got To Do With It?: Health Care Reform in Canada*, (Ottawa: Canadian Bar Association, 1994).

[23] For example see *Re D. (S.)*, [1983] 3 W.W.R. 618 (B.C.S.C.).

[24] For example, the *Draft Report of the Working Group of the Stanford Program in Genomics, Ethics, and Society* (Stanford University Centre for Biomedical Ethics, November 1996) recommends that BRCA testing should only be available to individuals older than 18. In such a circumstance, the testing of a minor could be considered a deviation from an existing standard of *practice*. While not a legally conclusive position, in a technical area such as genetics, the existence of an established medical custom stating that we do not test minors would likely be quite persuasive. See, *ter Nuezen* v. *Korn*, [1995] 10 W.W.R. 1 (S.C.C.).

[25] Because a predisposition test of the child will also, at some level, be a predisposition test of all blood relatives, in assessing the best interests of the child, a physician should be sensitive to the motivation of the requesting parent(s). For example, is this a veiled attempt to obtain information about their own genetic characteristics?

[26] See R. S. Downie & F. Randall, "Parenting and the Best Interest of Minors" (1997) 22 J. Med. Philos. 219 at 230, who argue: "[i]t must be stressed that the courts, guidelines, hospital ethics committees and similar external bodies are relevant to parental decision-making only at the margins of the unreasonable demands or refusals. By and large parents and infants should be left alone in the intimacy of the family relationship." See also E. W. Clayton, "Legal and Ethical Commentary: The Dangers of Reading *Duty* Too Broadly" (1997) 25 J. L. Med. Ethics 19 at 21, who notes that in "most states" in the U.S. "children still cannot obtain damages form their parents for actions or choices the latter make in relation to child rearing."

[27] *Re K (L.D.)* (1985), 48 R.F.L. (2d) 164 (Ont. Prov. Ct.).

ing the importance of parental treatment decisions remains relevant. Recent case law is summarised by Picard and Robertson as follows: "Canadian courts may be willing to give parents greater latitude than before in deciding whether treatment is in the child's best interests, and will override the parents' refusal of consent only where it is patently wrong."[29] If the use of APOE4 could be considered a reasonable treatment request that was not "patently wrong," it would likely be a request outside the realm of court interference.

It is worth emphasising, however, that this is not a situation where a physician is seeking the consent of a patient. Rather, the parents are seeking a genetic service from a physician who may not wish to provide it. The parents' legal options are limited. Though there certainly exists a potential tension between what genetic policies may suggest as a course of action and what the law may (in spirit) permit, the immediate legal ramifications for the health care provider who does not succumb to the demands of a parent would probably be minimal (or non-existent)—particularly if it can be shown that the use of the APOE4 test is not part of the established common *practice*.[30] Indeed, because there would be no immediate "injury" as a result of not performing the test (a neurological deficit such as AD is not likely to present itself for another 40 to 50 years), it is difficult to imagine what the exact cause of action would be in such a case.[31] So, while it is always a mistake to allow "liability exposure" to be a persuasive consideration in the development of health care policy, in this situation the liability concerns appear to be relatively limited.

In general terms, as the clinical and preventive benefits of a test increase these issues will intensify. For instance, if it were found that testing could provide important and clear information that could be used to implement effective preventive measures, should a physician still heed the refusal of the adolescent or allow the wishes of the parent(s) prevail? Ideally, well articulated legal and ethical obligations evolve at the same pace as scientific discovery. Unfortunately, this is rarely, if ever, the case. As a result, physicians inevitably need to weigh, on a case-by-case basis, a number of complex factors including: scientific evidence, existing policy, potential health benefits, parental rights to consent, the autonomy of children, and family dynamics. However, genetic policy, *practice* guidelines, and a clarification of legal duties can, at least, build a framework within which clinicians can begin to resolve these issues, such as emphasising

---

[28] *Saskatchewan (Minister of Social Services)* v. *P.(F.)* (1990), 69 D.L.R. (4th) 134 (Sask. Prov. Ct.).

[29] Picard & Robertson, *supra* note 21 at 77.

[30] [T]*er Nuezen*, *supra* note 24.

[31] Dissatisfied parents can always complain to the relevant professional association.

the need for counselling, outlining the bounds of legal duties, and noting potential liability concerns.

Who should prevail in a conflict between parents and their child? If a physician believes that it is not in the best interest of an adolescent to be subjected to an unwanted test, current policy commentary would suggest that a physician may (or even should) deny a parent's request for the APOE4 test. However, such a decision, although hardly legally "dangerous," may be in conflict with the tenor of current Canadian law.

C. Adolescent Request and Consent to Genetic Testing

Children involved in contact sports may independently request this type of testing.[32] Can a minor request and consent to the use of a genetic test?[33] Capacity to make a treatment decision requires an ability to understand the nature and purpose of the treatment and the consequences of giving or refusing consent.[34] Therefore, if minors, regardless of age, can comprehend the issues surrounding APOE4 testing, they can legally consent to its use without any participation from their parent(s).[35] In fact, one could argue that any restriction on the power of mature minors to make their own health care decisions would be a departure from the emerging trend—recognition of both the legal authority and sufficient cognitive ability of adolescents respecting consent to health care procedures.[36]

Yet, what must a child understand in order to have legal capacity? Must they understand the potential social, ethical, financial, and familial ramifications of the test? While most policy positions seem to advocate the need for a

---

[32] However, see J. Binedell, J. Scourfield & P. Harper, "Huntington's disease predictive testing: the case for an assessment approach to requests form adolescents" (1996) 33 J. Med. Genet. 912 at 917: "[w]e anticipate that clinicians will very rarely encounter the challenge of an adolescent actively requesting predictive testing of his own accord. ... [T]he need or wish to confirm one's genetic status is a concern that generally arises later in adult life."

[33] Physicians should be sensitive to the possible presence of parental (or coach) pressure to get testing as it might affect the voluntariness of consent. See *Re T*, [1992] 4 All E.R. 649 (C.A.).

[34] For example, *Khan* v. *St Thomas Psychiatric Hospital* (1992), 87 D.L.R. (4th) 289 (Ont. C.A.). See also, E. Etchells, *et al.*, "Bioethics for Clinicians: 3 Capacity" (1996) 155 C.M.A.J. 657.

[35] *Ney* v. *Canada (Attorney General)*, [1993] 6 W.W.R. 135 (B.C.C.A.); and *Walker* v. *Region 2 Hospital Corp.* (1994), 116 D.L.R. (4th) 477 (N.B.C.A.). In some provinces, the age when an individual can consent to medical treatment is established by legislation, e.g. in New Brunswick. Nevertheless, even in these jurisdictions a child who is below the age of consent but is determined to be a "mature minor" may consent to medical treatment.

[36] See K. de Ville, "Adolescent Parents and Medical Decision-Making" (1997) J. Med. Philos. 253.

broad understanding,[37] the standard established by Canadian common law may not be so onerous. For example, in an Alberta case dealing with the legal capacity of a sixteen year old to make a decision to have an abortion, the Court of Appeal held as follows:

> It is argued before us today that informed consent means consent after consideration of issues like the ethics of abortion and the ethics of the obligation by children to parents. ... [T]he issue is whether these issues relate to the defence of consent to assault. In our view, they do not.[38]

From a policy perspective this inclusive position makes sense; it affirms the autonomy of minors to make health care decisions and helps to ensure that this right is not limited in an arbitrary manner, for example, arguing that an adolescent is incompetent simply because she does not agree with her parents' position. However, from the perspective of informed consent law a Catch-22 situation may exist. Canadian consent legislation, case law and literature compel physicians to disclose an ever-broadening array of facts.[39] And while an individual may not need to understand the nuances of the information disclosed, a physician nonetheless has a legal obligation to: *(i)* make the disclosure *and* (paradoxically); *(ii)* take reasonable steps to ensure the patient comprehends the relevant facts.[40]

It appears that we have a legal conundrum created by the desire to achieve two laudable policy goals—recognising the autonomy of adolescents in the realm of health care and compelling physicians to disclose all relevant information. When these goals are manifested in legal doctrine they tend to push in opposite directions: forcing the boundary of legal of capacity lower and lower,

---

[37] For what could be considered an extreme position see Wertz, *supra* note 17 at 877.

> Knowledge of facts does not constitute competence to request or consent to testing. A competent person must evidence *(i)* voluntariness; *(ii)* "reasonable outcome" of a choice in terms of the individual's family's social and cultural situation and lifestyle; *(iii)* sound reasons for the choice; and *(iv)* understanding of risks, benefits, and alternatives, including knowledge of both facts and implications.

While intuitively this may seem like a logical approach to the assessment of capacity, it has no basis in Canadian law. In fact, I would suggest that this approach could prove to be quite paternalistic, for example, who decides what is a "reasonable outcome" or a "sound reason for the choice".

[38] *C.(J.S.)* v. *Wren*, [1987] 2 W.W.R. 669 at 671 (Alta. C.A.).

[39] See generally Picard & Robertson, *supra* note 21 at 115–36; T. Caulfield & D. Ginn, "The High Price of Full Disclosure: Informed Consent and Cost Containment in Health Care" (1994) 22 Man. L.J. 328.

[40] See *Ciarariello* v. *Schacter* (1993), 100 D.L.R. (4th) 609 (S.C.C.) at 622: "[i]t is appropriate that the burden should be placed on the doctor to show that the patient comprehended the explanation and instructions given."

and conversely requiring that ever more complex information to be disclosed. In the end, a physician may be faced with a legally competent child who cannot understand the information he is legally required to hear.[41]

Surprisingly, this issue has yet to surface in case law. However, as illustrated by APOE4 testing, the complexity of the information associated with genetic services, coupled with the potential for the frequent involvement of patients on the margins of competency, could move this issue forward. In fact, currently, APOE4 testing may be most relevant to individuals at either end of the competency continuum—those who are just becoming legally competent and those who are just beginning to lose this fundamental right. Given our society's (understandable) reverence for autonomy, Canadian courts and legislators will likely continue to strain to afford these populations as much decision-making authority as possible. And given the implications of genetic testing to notions of "who we are," the arguments for participation from individuals who are going to be tested seem particularly strong.

Can we have it both ways? Can we ask physicians to disclose a vast amount of complex information while still allowing mature minors to consent? The answer, to the probable dismay of physicians and other genetic professionals, is that we must have it both ways. The principles which underlie the consent and informed consent processes are too fundamental to the rights of patients to allow an erosion in either the direction of a weakened disclosure obligation or a paternalistic policy for the determination of capacity.

The dilemma may be mitigated through effective public education programs, thus raising the population's "genetic knowledge base," comprehensive genetic counselling, and the development of informed genetic policy. For example, a physician does not have to provide a service which is futile, or not part of the accepted *practice* standard. Nevertheless, at present it appears that physicians will have to continue to struggle with this awkward legal situation. With respect to physicians' legal obligation to ensure a patient has understood the information disclosed, Professor Gerald Robertson has noted that in order to satisfy this duty they need only take reasonable steps to ensure comprehension.[42] Certainly a thorough genetic counselling process would be considered "reasonable."

---

[41] However, as was pointed out to me by Professor Gerald Robertson, it is arguable that a physician does not have to disclose information which he or she knows the patient would not understand as a reasonable person in the patient's position may not want to be given information beyond his comprehension. However, Robertson also notes that such an argument opens a dangerous door to paternalistic assessments concerning what information should be disclosed.

[42] Picard & Robertson, *supra* note 21 at 137, where he argues: "[t]he doctor should only be required to take *reasonable steps* to ensure that the patient understands the information ... . Exactly what constitutes "reasonable steps" in this context will, of course, depend on the particular circumstances of each case."

D. Access to Results of Genetic Tests of this Nature

The obligation of confidentiality has numerous legal and ethical sources, including codes of ethics, the common law, and federal and provincial legislation.[43] In general, physicians have a broad duty to ensure that they keep information received from or about their patients completely confidential. And while there are exceptions to this duty—being compelled via legal mechanisms, for example[44]—it should generally be narrowly construed.[45] Due to the highly personal nature of the information and the fear of genetic discrimination, the duty of confidentiality has been considered particularly relevant in the context of genetics.[46] At the same time, however, because the results of a genetic test done on an individual may be relevant to an entire family, genetic testing creates unique confidentiality dilemmas. For example, when should a physician override a patient's wishes in order to "warn" a blood relative of a particular genetic risk?[47]

---

[43] In E. L. Oscapella, "Overview of Canadian Laws Relating to Privacy and Confidentiality in the Medical Context" Research Volume 3, Royal Commission on New Reproductive Technologies, 1993. See Drewry Report, *Report of the Task Force to Review the Mental Health Act* (Government of Alberta, 1983); the 1981 The World Medical Association's International Code of Medical Ethics: "The patient has the right to expect that his physician will respect the confidential nature of his medical and personal details." For recent case law see, *Peter-Brown* v. *Regina District Health Board*, [1995] S.J. No. 609 (Sask. Q.B.); *Mammone* v. *Bakan*, [1989] (B.C.S.C.) [unreported]; *Hay* v. *University of Alberta Hospital*, [1990] 5 W.W.R. 78 at 80. For example legislation see Alberta's, *Hospitals Act*, R.S.A., 1980, c. H-11, ss. 40(3); and *Mental Health Act*, S.A., 1988, c. M–13.1, ss. 17(4).

[44] M. McPhedran, "The Legal Assault on Physician-Patient Privilege" (1995) 153 C.M.A.J. 1502; J. Melanson, "Psychiatrist's release of confidential information causes controversy in Halifax" (1994) 150 C.M.A.J. 960.

[45] See generally, W. Flanagan, "Genetic Data and Confidentiality" (1995) 3 Health L. J. 269. I briefly discuss the application of these exceptions elsewhere, see: T. Caulfield, "Practically Confidential: Legal and Ethical Dilemmas in Practice" (1995) 41 Can. J. Fam. L. 2025.

[46] For example see generally, Andrews, *supra* note 4; Task Force on Genetic Testing, *supra* note 5; M. Kapp, "Medical, Employment, and Insurance Issues in APOE Genotyping and Alzheimer's Disease" (1996) Ann. N.Y. Acad. Sci. 139; and C. Ngwena & R. Chadwick, "Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law" (1993) 1 Med. L. 73.

[47] See, for example, Flanagan, *supra* note 45 at 287 who argues:

> [T]he courts are unlikely to grant a broad discretion to physicians to disclose genetic data to biological relatives or reproductive partners, and the courts are even less likely to impose any liability on physicians for refusing to disclose this information. As a result, physicians enjoy at best only a very limited privilege to disclose genetic data without patient consent under current Canadian law.

However, see also, Knoppers & Chadwick, *supra* note 6 at 2033, who summarise the emerging international position thus:

How would the physician's duty of confidentiality play out in the context of APOE4 testing? What if an adolescent requests the test but refuses to discuss a positive test result with anyone? Should a physician, against the wishes of his patient, disclose a positive test result to the adolescent's parent(s), sibling, coach, school, or other such persons?

If an adolescent has the legal capacity to consent to the test, it seems unlikely that a physician would have the authority to disclose that information to a third party without the informed consent of the adolescent patient—at least in the context of APOE4 testing. An autonomous individual has every right to make what most would consider a "bad" decision. Much of Canadian consent law is built on this notion.[48] Therefore, a physician would have little justification for disclosing this information, including, to a coach, school administrator, or parent, for the purpose of protecting his patient. If an individual wishes to subject himself to the risk of future neurological deficit, the physician can do little to stop him—unless, the patient is incompetent. It is important to note, however, that making a "bad" treatment decision does *not* mean an individual is incompetent: "people must have the right to make choices that accord with their own values regardless of how unwise or foolish those choices may appear to others."[49]

Furthermore, given our current state of knowledge concerning APOE4, this is not a situation where a third party may be faced with a "significant risk of substantial harm"[50]—thereby invoking the physician's "duty to warn" (the legal principle which allows physicians to breach their duty of confidentiality in order to protect a third party).[51] Although the results of an APOE4 test have rele-

---

> Most guidelines, however, advocate the communication of relevant information to family members at high risk for serious harm without the consent of the patient or of the research participant only when all attempts to elicit voluntary communication have failed.

[48] For example, *Malette* v. *Shulman* (1990), 67 D.L.R. (4th) 321 (Ont. C.A.); *Fleming* v. *Reid* (1991), 4 O.R. (3d) 74 (C.A.); and *Walker*, *supra* note 35.

[49] Malette, *ibid.* at 328.

[50] CMA, *infra* note 51. Alberta's Bill–30, *Health Information Protection Act*, uses similar language. This Bill has codified the common law duty to warn exception by permitting disclosure without the patient's consent if it is necessary to "avoid or minimise an imminent danger to the health or safety of any person." See G. Robertson, "The Health Information Protection Act" (1997) 6 Health L. Rev. 8 at 10.

[51] See, for example, Canadian Medical Association, *Code of Ethics* (Ottawa, 1996):

> Respect the patient's right to confidentiality except when this right conflicts with your responsibility to the law, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient if the patient is incompetent; in such cases, take all reasonable steps to inform the patient that confidentiality will be breached.

vance to blood relatives—as do the results of all genetic tests—the weak predictive value of the information places this situation outside of the typical "duty to warn" scenario. This is not, for example, a situation where a patient "presents a serious danger of violence to another," as in the famous California decision of *Tarasoff*.[52] Even where a sibling is currently involved in a high contact sport, potentially the most extreme situation in the context of APOE4 testing, disclosure would not be legally justified. It is unlikely that the "duty to warn" includes speculative or theoretical future harms. As noted above, the notion of confidentiality at the present time is a fundamental and strongly held ethical and legal principle. While there is little, if any, Canadian jurisprudence directly on point,[53] it is reasonable to conclude that exceptions to this principle should be applied in only exceptional circumstances.[54] In fact, in the cases where the duty

---

The earlier version reads as follows: "[a]n ethical physician will keep in confidence information derived from a patient, or from a colleague regarding a patient, and divulge it only with the permission of the patient except when otherwise required by law." For relevant case law on the duty to warn see *Tarasoff* v. *Regents of University of California*, 551 P. 2d 334 (Cal. Sup. Ct., 1976); *Wenden* v. *Trikha* (1993), 14 C.C.L.T. (2d) 225 (Alta. C.A.); and *W.* v. *Egdell*, [1990] 2 W.L.R. 471 (Eng. C.A.) where it was held that a psychiatrist was justified in disclosing information about his violent client to the patient's parole board since the interest of protecting the public outweighed the patient's right to confidentiality. In the context of genetics see B. Knoppers & R. Chadwick, "The Human Genome Project: Under an International Ethical Microscope" (1994) 265 Science 2033; and W. Flanagan, "Genetic Data and Confidentiality" (1995) 3 Health L. J. 269; N. Park & B. Dickens, *Legal and Ethical Issues in Genetic Prediction and Genetic Counselling for Breast, Ovarian and Colon Cancer Susceptibility* (Background Paper for the International Research and Policy Symposium, Toronto, 1995).

[52] *Tarasoff*, *ibid.* at 340. In this case a patient told his psychiatrist that he was going to kill a particular women. The psychiatrist was found liable for not taking appropriate steps to warn the individual in danger.

[53] However, see *Wenden* v. *Trikha*, *supra* note 51 on the potential duty of health care providers to third parties.

[54] In fact, Flanagan, *supra* note 45 at 285, concludes as follows in relation to the disclosure of genetic information:

> It is unlikely that a court would excuse a breach of patient confidentiality if the physician were unable to satisfy the court that disclosure was required in order to prevent imminent harm.

See also, Picard & Robertson, *supra* note 21 at 31:

> In determining whether, in any given case, this exception [the duty to warn] applies, the importance of maintaining medical confidentiality must be borne in mind. It is only in truly exceptional situation, where the public interest is clearly compelling and paramount, that it overrides the patient's right to confidentiality.

For an example of a case where a court strictly applied a statutory confidentiality provision see *R* v. *Noonan* (1987), 53 Alta. L.R. (2d) 341 (Q.B.).

to warn has been considered, the potential harm was severe and nearly certain, such as exposure to the AIDS virus.[55] However, if future research demonstrates a definite connection between APOE4 and head trauma induced neurological deficits, the arguments in favour of invoking a duty to warn would be stronger, although probably not conclusive.[56]

On balance, therefore, a physician has a legal obligation to comply with his patient's wishes concerning the disclosure of APOE4 results. This is particularly so given the recent Canadian jurisprudence which emphasises the health care provider's fiduciary obligation in the area of patient records.[57] Unless the patient requests otherwise (in fact, it should be an *informed* request), the APOE4 results should be treated like all medical information and kept strictly confidential.

Genetic tests such as APOE4 may create numerous other, perhaps more difficult, confidentiality dilemmas. For instance, consider the situation of a legally incompetent child where the parents do not want the information disclosed for fear of ruining their aspirations for athletic greatness for their son or daughter—would this be a form of child abuse?[58] Does the above discussion concerning the limited application of the duty to warn apply with equal force to

---

[55] In the case of *Pittman Estate* v. *Bain* (1994), 112 D.L.R. (4th) 257 (Ont. Ct. (Gen. Div.)), for example, a women successfully sued a family physician, among others, for failing to tell her husband that he had AIDS. Although the case does not explicitly address the issue of the duty to warn third parties, it is implied by the finding of liability. See also, Picard & Roberson, *supra* note 21 at 35.

[56] The issue of when a health care provider can warn a blood relative of a genetic risk has been addressed in a variety of genetic policy statements. For example see Assessing Genetic Risk, *supra* note 4; and Science Council of Canada, *supra* note 4. See also the *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, Screening and Counselling for Genetic Conditions* (Washington D.C.: The President's Commission, 1983), which recommends that genetic information can only be disclosed to blood relatives without consent if there is, among other things, a "high probability of serious (e.g., irreversible or fatal) harm to an identifiable relative." See Flanagan, *supra* note 45 at 281–82, for a review of these guidelines. See also, Knoppers & Chadwick, *supra* note 6.

[57] *McInerney* v. *MacDonald* (1992), 93 D.L.R. (4th) 415 (S.C.C.) at 423.

[58] For example, s. 3 of Alberta's *Child Welfare Act*, S.A. 1984, c. C-8.1, ss. 1,3. reads as follows:

> *(1)* Any person who has reasonable and probable grounds to believe and believes that a child is in need of protective services shall forthwith report the matter to a director.
>
> *(2)* Subsection (1) applies notwithstanding that the information on which the belief is founded is confidential and its disclosure is prohibited under any other Act.

Although the "genetic abuse" argument is not entirely novel, for example see R. Green, "Parental Autonomy and the Obligation Not to Harm One's Child Genetically" (1997) 25 J. Leg. Med. 5, its application in this context seems improbable.

the choices of surrogate decision–makers? Once again, the answer to such issues will depend heavily on the state of our knowledge concerning a given genetic test. Intuitively, if parents were, in fact, subjecting a child to a *definite* health risk there would seem to be a stronger argument for judicial intervention. Yet, perhaps the parents simply believe that the benefits their child receives from participation in a given sport outweigh even a real risk of a future neurologic deficit. Is this a parenting decision which should be interfered with?[59] Parents make a host of choices that will ultimately affect their children's future health—decisions about education, lifestyle, and residency, for example. Does the potentially definitive nature of a test such as the APOE4 make judicial intervention more acceptable?

III. CONCLUSION

IN THE END, I OFFER this less than grand point: things are going to be tough for physicians in the era of genetic testing. Physicians will need to respond to and integrate emerging scientific developments, changing social and ethical norms, and a broad array of often conflicting legal forces. Although we should not lose sight of the fact that it is the patient—or, at times, the family—who is the locus of all health care decisions, it is the health care provider, usually a physician, who will inevitably provide the service. And it is the physician who, on those rare occasions, will need to initiate a decision to withhold a genetic service, to breach a patient's confidence, or to override the wishes of parents.[60] Unfortunately, as we have seen, the law can offer only limited guidance. Indeed, the law often seems to intensify the physician's dilemma by creating simplistic or binary frameworks to address infinitely complex issues. For example, from a legal perspective a patient is either competent to make health care decisions or he is not—there is no middle ground. In addition, because the common law is a reactive mechanism, it takes time to reflect changes in science or health policy. Guidelines, position papers, and codes of ethics are relevant to the formulation of legal standards, but they are not determinative. In a field which moves forward as quickly as genetics, this lag between science policy and the evolution of relevant legal duties is particularly apparent.

---

[59] See generally Downie, *supra* note 26; and Green, *supra* 58 at 13 who argues in relation to prenatal diagnosis: "Only in extreme cases are we warranted as a society in denying them [parents] access to the professional services they need to realise their choices or in preventing them exercising those choices."

[60] By emphasising the responsibility of the physician I do not mean to minimise the growing recognition that health care is, in reality, delivered by a broad array of health care professionals working as a team. Also, one would hope that decisions of the nature would also involve consultations, when appropriate, with an institution's clinical ethics committee. Nevertheless, to a large degree Canadian common law still places most of the legal responsibility on the shoulders of the physician.

We have seen the tension between suggested policy and legal reality exemplified by the issues associated with the utilisation of APOE4 testing. For instance, although the law does not provide a mechanism to give lawful force to the opinion of a nearly legally competent adolescent, emerging commentary, particularly in the realm of genetics, encourages physicians to do so. Similarly, the interplay between the legal principles relevant to the determination of capacity and to the scope of the informed consent obligation seems to create an almost "no win" situation for physicians. Though an adolescent may not be able to fully understand many of the social, legal, and ethical ramifications of receiving a genetic test, he may still have the *legal* capacity to consent—and, despite an adolescent's cognitive limitations, a physician must take reasonable steps to ensure he understands the information disclosed. Finally, while at the present time we can be relatively certain that a health care provider has a limited (or non-existent) legal "duty to warn" third parties of the potential presence of the APOE4 allele, changing social norms and emerging scientific data concerning the application of genetics may alter the nature and extent of this duty.

Genetic technologies seem to have a particular tendency to create dilemmas which trigger interaction and competition between numerous strongly held and worthy social values. Notions of patient autonomy; obligations of informed consent and confidentiality; the responsibility to protect vulnerable populations such as children: none of these principles will be easily moulded for the sole purpose of formulating comprehensive genetic policy. Aside from broad statements, such as "this test will not be provided to those under the age of 18," even the most carefully crafted guidelines will need to be actively integrated and interpreted by clinicians. Therefore, genetic professionals will never escape the difficult case-by-case weighing of relevant factors. We can, at least, assist these frontline genetic professionals by providing an ongoing assessment of the legal, ethical, social, and scientific parameters within which they must *practice*.