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Orders for Genetic Testing: Is the Genie Out of the Bottle?

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Case commented on: *Adacsi v Amin*, 2013 ABCA 315

A recent decision at the Alberta Court of Appeal raises a major issue in personal injury jurisprudence. *Adacsi v Amin*, 2013 ABCA 315, is a precedent setting ruling that allows for the forced collection of a blood test for the purpose of determining the existence of a possible predisposition to disease.

In *Adacsi* the appellant is a woman who was injured in a house fire allegedly caused by the negligence of the respondent (para 3). During an extended stay in hospital several medical professionals suggested that some of her symptoms could be caused by Huntington's disease and not from the fire itself. Huntington's disease was present in the appellant's family, helping to bolster these claims. The disease is caused by the inherited presence of the HD mutant gene which can be easily detected through a straightforward genetic test.

The respondent made an application for an order to collect a blood sample from the appellant pursuant to *Alberta Rules of Court* rule 5.44(2), which provides that "... if the Court so orders, the examining health care professional may (a) take or obtain samples from the person being examined, and make an analysis of the samples, and (b) perform any test recognized by medical science."

In a brief decision delivered from the bench, the Court of Appeal (Justices Hunt, Paperny and O'Ferrall) affirmed the decision of the chambers judge that granted the order:

> [5] She inferred from the evidence that the proposed test was reliable and useful. She noted that the test would not determine whether the appellant's symptoms were a result of Huntington's, but would indicate whether Huntington's could be eliminated as a possible explanation. She considered this relevant to the lawsuit. Although a blood test is intrusive, she stated that it involved no real health risks to the appellant. She took account of the fact that the appellant did not wish to have the test and considered that it would be stressful. Balancing all the factors, the chambers judge concluded that the potential good to be achieved outweighed other considerations, such as the appellant's reluctance.

This decision was contested by the appellant on four grounds that were considered by the Court of Appeal. These grounds of appeal were largely of a definitional nature, challenging the scope of words such as "samples" and "examining health care professional". "Samples" was found to be broad enough to include blood samples, and an "examining health care professional" was found to include third party laboratory technicians and not just the physician herself (paras 8-9).

Additionally, the Court rejected the appellant's submission that taking the test would cause her "severe panic, stress and anxiety, and further her pain and suffering" (para 13). Referring to the appellant's affidavit, the Court of Appeal took notice that she had concerns regarding the test, but rejected them at para 13, noting the following:

> Importantly, her affidavit does not say she is fearful of the knowledge that could result from the test, or discuss any possible psychological impact of such knowledge.

It is crucial to determine whether the above statement was intended to set a threshold that, upon exceeding it, would allow such an order to be granted. Essentially, is a reasonable apprehension of fear stemming from the knowledge of an ordered genetic test enough to dispose of the application? Secondly, why was the fact that the appellant claimed that such a test would increase her panic, anxiety and further her pain and suffering insufficient to block such an order? Does this decision pave the way for further genetic predispositions to be considered as evidence for or against causation arguments made in personal injury disputes? These are questions that will need to be fully examined by the legislature and legal community. This post is intended to be a primer for some of these issues.

Huntington's Disease

While such arguments did not appear to be considered in the judgment, it is likely that the application was granted partially on account of the disease at issue. Huntington's disease is an easily detectable and predictable genetic disease and is therefore a good case study of how the genetic finding of an underlying cause for the malady could impact findings of causation. These features allow a test for HD to accurately determine whether or not there is a genetic predisposition to the disease.

Huntington's disease is contained in the Huntingtin gene (*HTT*), which codes for the protein Huntingtin (Htt). Each individual carries two copies of *HTT*. Within this gene is a trinucleotide repeat that varies in length from individual to individual. The length of this repeating region is heritable and when it is too long, symptoms appear that correspond to Huntington's disease. The longer the trinucleotide repeat, the more severe the symptoms will be.
Huntington's disease behaves as a typical mendelian autosomal dominant gene. Generally, if a carrier mates with a non-carrier wild type, then each child will have a 50% chance of inheriting the mutation (for more information, including some subtleties, see here). There are numerous other conditions that behave in this manner including neurofibromatosis, Marfan's syndrome, and vitamin C deficiency. Theoretically the precedent set in *Adacsi* could be applied to these conditions as well as the likely thousands of traits that exhibit similar heritable behaviour, dramatically altering the way that such cases could be litigated.

Impact of *Adacsi v Amin*

Previous to *Adacsi*, evidence for genetic predisposition was provided by way of expert testimony. For example in *R v Luedecke*, 2005 ONCJ 294, the expert witness, a psychiatrist specializing in sleep disorders, explained that the accused's state of parasomnia included a genetic component. No genetic test was completed, but the expert witness cited a genetic predisposition "as both his mother and brother have had a number of such episodes [sleepwalking]" (at para 18). The Ontario Court of Appeal ordered a new trial after finding that the expert's evidence "establishes that the predisposition for parasomnia … is hereditary" (2008 ONCA 716 at para 106). This predisposition was described as the "epitome [of] an internal cause" (at para 106). Crucially, the accused was never tested for the predisposition through a genetic test.

Another example, *EB v Order of the Oblates*, 2001 BCSC 1783, involved a plaintiff alleging damages stemming from sexual abuse while attending a residential school. In this case the medical expert witness stated that "looking at what kind of family he came from and genetic and environmental and social [factors]", he believed the plaintiff was at a high risk of becoming an alcoholic but that concurring sexual abuse could exacerbate the risk (at para 198). These factors contributed to a decision that resulted in damages being awarded. Again, the finding of genetic predetermination came from the expert testimony after a review of the plaintiff's family history, not from an ordered genetic test.

Testimony of this nature must be weighed alongside various triggers and environmental factors. In most cases, this is completed by way of qualitative assessment after review of the individual's family tree and familial traits. Essentially, it is the medical expert's 'best guess' as to whether genetic predisposition plays a role in the case at hand and how much of a role it played in the eventual presentation of symptoms.

The application made in *Adacsi* is therefore a crucial divergence in the approach of courts to issues of genetic predisposition. An order for a blood sample and corresponding genetic test eliminates the uncertainty of an expert witness and any doubt of genetic predisposition. In exchange for this accuracy, several new and contentious dilemmas are looming.

Privacy

Because of the intimate nature of personal genetic information, there are additional concerns about its use. An individual's genetic makeup is likely their most personal and private piece of medical information and, unlike other identifiers such as a Social Insurance Number, cannot be changed. Once the information becomes public, there is no taking it back. As a result, genetic information that is used to resolve legal issues in a civil or family dispute could, if entered into evidence, become public knowledge where it would be searchable by future employers or insurance companies. It is currently uncertain how these disciplines would react and interpret this sort of genetic information but the fact that this information is unchangeable and is highly personal necessitates a discussion about the risks of relying on such evidence.

Currently, there is no jurisprudence in Canada regarding the intersection of genetic information and an individual's privacy. While the *Privacy Act*, RSC 1985, c P-21, covers "personal information", it is not been determined whether genetic information would fall into this definition (section 3). Similarly, Alberta's *Personal Information Protection Act*, SA 2003, c P-6.5, would appear to include genetic information as "information about an identifiable individual" (section 1(k)), but the matter has not been judicially tested.

However, the *Privacy Act* is designed to cover the federal government's management of personal information, not necessarily the use of it in private litigation, where the government does not actively collect the information. Likewise, the *Personal Information Protection Act* does not apply to "limit the information available by law to a party to a legal proceeding" (s. 4(5)(b)). These statutes therefore do not provide much assistance in the personal injury litigation context.

Insurance

Further investigation needs to be undertaken by the legislature and legal community in order to assess the potential impact of genetic testing on other disciplines. For example, the *Insurance Act*, RSA 2000, c I-3, would appear to punish anyone who undertakes a personal investigation into the potential future health outcomes of their genetic makeup. Section 4(1) of the Statutory Conditions imposed in section 540 include a clause regarding knowledge of change in risk:

> MATERIAL CHANGE IN RISK 4(1) The insured must promptly give notice in writing to the insurer or its agent of a change that is
> (a) material to the risk; and
> (b) within the control and knowledge of the insured.

It does not appear to have been tested in the jurisprudence how knowledge of one's genetic risk would be interpreted but a general reading of the above section certainly raises a concern that the Statutory Conditions would discriminate against and disadvantage individuals who had undertaken a genetic screening, even one forced upon them by court order.
If this is the case, it would still seem acceptable if an individual understood the possible consequences of getting a test done and voluntarily accepted them. It is another matter entirely if an individual is being forced to undergo such a test by way of a court order. There are numerous unresolved issues in this area that need to be examined before courts should be ordering such tests.

Interpretation of Test

Further complicating matters is the challenge in accurately interpreting such tests. Some diseases, such as Huntington's disease, can be ruled out through a genotypic test that can determine the non-existence of the gene responsible. But the inverse is not always the case. A genetic finding of a gene responsible for Huntington's disease will not necessarily guarantee that symptoms will develop. More immediately, they don't guarantee that the symptoms currently present are caused by that gene. [For further information, see a summary on Wikipedia or in The American Naturalist.]

In *Adacsi*, the medical observation of the expert witness was that some of the symptoms presented by the appellant could have been the result of either a genetic predisposition or through the at-issue accident. If the appellant tests positive for the *HD* gene, this does not provide evidence that the symptoms observed are stemming from the gene. Further tests would need to be conducted to determine what the actual cause of symptoms is. This and other numerous complicating factors surrounding interpreting genotypic evidence raise significant doubts about its usage.

Conclusion

It is important not to overlook the potential value that such tests could provide however. One clear advantage could be the use of an order for genetic testing only when the matter of causation is unresolvable without it. There are obvious advantages to using genotypic evidence and the information could prove vital in some limited situations. However, the introduction of court mandated genetic testing creates new legal and ethical dilemmas that have not been adequately examined judicially or by the legislature.

In *Adacsi*, the Court establishes the relatively low threshold of "not frivolous" in order to mandate a genetic test (para 16). For all of the reasons previously discussed (and many others that were not), the bar to force genetic testing on an individual certainly needs to be set higher than that.

For further information on the use of genetic information in Canadian jurisprudence, please see Mark Pioro et al., "Understanding the Use of 'Genetic Predisposition' in Canadian Legal Decisions", (2013) 7 McGill Journal of Law & Health 1, available here.

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