
Bioethics Outlook

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On gentleness

Kevin Hart

Earlier today I read on the web a conversation between the ABC's North American correspondent Jane Cowan and Ed Belanger who lives in Newtown, Connecticut. How are people coping after the horror there?, she asked him. Perhaps the most striking thing that Ed Belanger said is this: "I've got a grandchild who doesn't know gentle. You know everything is hard, everything is fast and I think it's the games they play."

Put aside the comment about video games, and the like; it may be true. Equally, though, it is the TV and the movies we watch that make us hard. We are blunted by so much "suffering at a distance" seen on TV, at the movies, and on the Internet. Ed Belanger is pointing to something more disturbing and more essential about our culture. How appalling it would be if children are growing up today without knowing how to be gentle. How terrible it would be if what deflects us from gentleness is living in a culture, one that we make and reinforce day by day, that prizes only hardness and speed. Are we too calloused, too rushed, to be gentle with one another? Have we lost the ability to be gentle? Do we even value it? Or, more darkly, do we even know what it is?

Years ago, to be gentle was to be noble, of a distinguished rank in society, and we hear a trace of that sense in the word "gentleman." More recently, the word "gentle" has become equivocal. It can mean courteous, generous, or polite; but it can also mean quiet, pliant, or tame. Today it has become easy to think of those who are patient, considerate and welcoming to be wishy-washy, tame or weak. They seem to lack that inch of steel in the soul that enables one to get ahead in life.

Today the positive meaning of being gentle is to be kind and tender. We can all learn from Simone Weil, the Jewish philosopher who experienced Christ but who refused baptism in order to express solidarity with the Jews. She says, "There is, in my view, no grandeur except in gentleness." Only those who are gentle have true dignity and stature. And that is because gentleness is an effect of something far more profound, compassion. Christianity has no monopoly on compassion; it is a high value in all the great world religions and among many agnostics and atheists. Yet as we approach Christmas it is worthwhile to reflect on what the New Testament says about compassion.

In this Issue

Kevin Hart's Christmas reflection on gentleness – prompted by a remark made by a distressed grandfather in Newtown, Connecticut – is moving as well as instructive. Bernadette Tobin sets out her reason for thinking that donor-conceived people should have access to identifying information about their biological parents. She also sketches the arguments for and against the patentability of human genes.

In fact, it says very little about it. In the Gospels only Jesus shows compassion or talks about it. Jesus has compassion for crowds waiting to hear him speak, as well as for the mother of Nain whose son has died. Two of his most moving parables are centered on compassion. In one a despised Samaritan has compassion on a man who has been beaten up on a road to Jerusalem. And in another a deeply hurt father shows compassion for his wayward son and runs out to meet him when he returns indigent from a far country.

Paul tells us that God will have compassion on whomever he wants; and he commends us to be compassionate towards one another, especially those who have fallen into the margins of society. What we learn from the New Testament is the bleak truth that we should not expect compassion from one's fellow humans. We are hard, and we have always been hard. We are in a hurry: to get to Jerusalem, to get to the "far land," or just to get to work or home. Only God is compassionate, and our only chance of becoming compassionate is to become like God. Without compassion, there can be no gentleness, and so no true grandeur.

In his short ministry Jesus stressed one thing above all, the need for us to pass from participating solely in "the world" in all its senses (the world of power, prestige, cleverness, even religion) to living in what he called the Kingdom. The Kingdom is the state of being in which God rules over us: not as an earthly King but as a loving parent. We have no choice but to live in the world, but to live well here we must live before God. We must be continually converted, turned around, from world to Kingdom.

This is formidably difficult: every Christian is a failure, and the saints are more honest about it than the rest of us. No one can truly say, "I am a Christian." The best we may say is "Perhaps I will have been a Christian." That means: perhaps it will be seen, from the perspective of eternity, that with the help of God I have attended to the image of God in myself and in others.

It is just as difficult, though in quite other ways, for Jews, Muslims, Hindus, and Buddhists. Most likely Jesus derived his theology of the Kingdom from Aramaic paraphrases of Isaiah and from the Psalms. The Jews knew, in all the density of their tradition, that God calls them to live in the Kingdom. Shiite Muslims also look for the Kingdom, placing an emphasis on the return of the twelfth *iman* and the establishment of God's Kingdom on Earth. In looking for the Kingdom they place a heavy burden of self-discipline on themselves. Hindus know that the *Ramayana* broods on Rama as the divine king embodied on Earth. And in Pure Land Buddhism the Pure Land, a place of freedom and refuge, is presided over by the Buddha Amitabha: sentient beings strive to enter the Pure Land while Amitabha has power to save them from their troubled lives on Earth. The call of the Kingdom is heard in world religions, whether theistic or not, and to respond to that call requires strength beyond what we usually think we have.

Where is the image of God? In Christianity at least it is not in our reason, or our will, or our imagination. It is not something simply inside us, something we possess, but something directed ever outside ourselves. The image of God is in our compassion for one another, especially for those pushed aside in the brutality and speed of life. Compassion and its consequence, being gentle with one another, are very far from being plaint, tame or weak. It takes strength to be compassionate. It does not always call for a large gesture, but it always calls for being attentive to the unique strangeness of each other person.

To be compassionate does not require us to make someone a friend. It does not presume that we agree with another person's views, or approve of what he or she has done. It means, rather, that we treat the other person with kindness, as we would wish to be treated ourselves. No one can legislate compassion; it is not something that a law or a ritual or even a moral code can successfully promote. It abides at a deeper level, one that gets called on in religion (and that religion sometimes distorts, leaving us with false piety).

We are drawing close to Christmas, and the horror of Newtown reminds us how far we are from the spiritual meaning of that special day. Christians believe that Jesus is the Messiah, but this year I recall a Jewish story about the Messiah. It turns out, so the story goes, that one day the Messiah is recognized: he is sitting among the beggars and lepers at the gates of Rome. The one who sees him asks, "When will you come?" And the Messiah says, "Today!" Then he adds, "If you hear my voice."

The story is instructive. The Messiah can be here among us but still not have come. In order for him to enter the world and so allow it to be changed, to take on the lusters of the Kingdom, we must first listen to what he says and act according to it. I read this story years ago in a little book by an atheist, Maurice Blanchot, and his point is not to reject either Judaism (which he reveres, though without believing in Torah as revelation) or Christianity (which he dislikes). Instead, his point is that a Messiah will come only if he is to be received by a people — perhaps only a handful of men and women — who already look to follow his teachings.

Yet many people today are suspicious of any Messiah: Christian, Jewish, or otherwise. Almost predictably, Barak Obama has lost ground among many of his most febrile admirers in recent years. Secularity involves multiplying possibilities for people, as Charles Taylor argues in his remarkable book *A Secular Age*, and not reducing them by excluding religions. In the West, religions must take their places in society as some possibilities of life among others, not as masters of all possibilities. So it may well be that people no longer learn of compassion or gentleness from the Bible, the New Testament, or any other sacred scriptures.

If so, where are they to learn of it? One major insight of religion has been that compassion runs counter to the world, and that it takes enormous work to embody it in one's life. When today people are content to think that the world is all there is, when they do not even lament the loss of God, it is harder than

ever to find places or persons where the wisdom of compassion and gentleness are taught. Universities are no help; in Australia they have largely been turned into absurd parodies of corporations with education as a saleable commodity.

Of course, there are secular people, many of them teachers, who serve s models of exemplary behavior, for an awareness of the fragility of the world can inspire compassion and gentility for those of us in it. And one might learn just as well, I often think, from animals, many of which look after their own and others better than humans do. But for a people on the highway, early and late, already hardened by the need to survive if not always by the desire to succeed, a people perpetually seeking to turn unhappiness into happiness through spending, sex, and glittering image, there are few opportunities to ask where wisdom shall be found and even fewer places where decent answers might be given. Religion often squints at life, to be sure, but secular culture makes it into a blur so that it cannot be seen properly.

And so I think once again of Ed Belanger's grandchild "who doesn't know gentle." It seems that the secular world leaves it hit and miss as to whether he or she will ever be in a position to learn it. And I fear that religion, including my own faith, Christianity, has allowed itself to be pushed to the side of Australian society so that to children today its vocabulary has become opaque, its spiritual power has been downplayed, and the great biblical narratives and poems have been left to compete, badly, with video games, TV, movies, and the Internet. When we see it, we still recognize compassion, and there are times when we all need it. But we have few trustworthy guides to it.

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Donor-conceived people: Are they entitled to identifying information about their biological parents?

Bernadette Tobin

The New South Wales Parliament is currently conducting an inquiry into the 'management of information relating to donor conception'. This follows an enquiry conducted by the Victorian Law Reform Committee on the same subject last year.¹ It is an important inquiry, for it concerns the community's recognition of what I think is a fundamental moral and social truth: that all children are entitled to know their biological parents.

Almost ten years ago, the Australian Health Ethics Committee (AHEC), a principal committee of the National Health and Medical Research Council, pointed out that people who are conceived by way of assisted reproductive technologies are entitled to know their genetic parents, and thus that fertility clinics must not use donated gametes (sperm or eggs) in reproductive procedures unless the donor has consented to the release of identifying information about himself or herself to the person or persons conceived using those gametes.² The publication of AHEC's 'ethical guidelines on the use of

assisted reproductive technology in clinical practice and research' in June 2004 thus marked the beginning of the end of anonymous sperm donation in Australia.

The ethical standards set out in those guidelines – compliance with which was to be supervised by the Reproductive Technology Advisory Committee of the Fertility Society of Australia – canvas a range of associated issues: clinics must not mix gametes in a way that confuses the genetic parentage of the persons who are born; clinics should help potential gamete donors to understand and accept the significance of the biological connection that they have with the person conceived using their gametes, and help the potential recipients understand this too; clinics should use forums of public information to encourage people who were donors in the past – as well as people who were conceived using donated gametes – to contact them and register their consent to being contacted by their genetic children or genetic siblings and half-siblings.

The background to the publication of these ethical guidelines was the decades-old practice of anonymous donation of sperm. Doctors and clinics had been free to promise that anonymity would be guaranteed. Indeed, in some cases further steps, such as the mixing of sperm from two or more donors, may have been taken so as to make it difficult to identify the actual donor. The publication of AHEC's guidelines marked the beginning of the end of these practices.

What then about people who were conceived with gametes donated anonymously? Should they too have access to information which identifies their biological parents? That is to

¹ The report of the Victorian Law Reform Committee can be found at: <http://www.parliament.vic.gov.au/lawreform/inquiries/inquiry/300> (accessed 11/03/2013)

² As it happens, I chaired the subcommittee of AHEC which drafted these guidelines. They were then extensively considered and adopted unanimously by AHEC itself which then successfully recommended them to the governing council of the National Health and Medical Research Council. The membership of the drafting subcommittee included representatives of fertility clinicians, infertility specialists, counsellor who work with people seeking assisted reproductive technology procedures, etc.

say: should arrangements for access to identifying information by donor-conceived people be retrospective?

Last year the Victorian Law Reform Committee recommended in favour of retrospective arrangements which would grant access to identifying information to all donor-conceived adults. This retrospective access would apply regardless of undertakings previously given to donors regarding anonymity. However, in October 2012, the Victorian Government released an interim response to the Law Reform Committee's report which said that, because the issues were complex, the matter warranted further investigation.

On the matter of 'retrospective access', there are two views: one in favour of granting donor-conceived people – adults who were conceived before the end of fertility clinics facilitating anonymous donation – access to identifying information about their donor, the other against.

Against access

In its 2004 guidelines AHEC took the latter view. It said that clinics must not release identifying information to another person without the consent of the person to be identified. AHEC gave its reason for this position: clinics should respect the privacy of all persons involved in ART procedures.

AHEC did not explain what it meant by 'respect for privacy'. (It seemed to be thinking of this information as information only about the donor.) The idea of privacy has its roots in Greek philosophy, notably in Aristotle's distinction between the public sphere (of political activity) and the private sphere (of family and domestic life). There is no uniform notion of privacy, and plenty of scope for confusion about its meaning, scope and value.

Some criticize the very notion of a (moral) right to privacy, thinking of as little more than a cloak under which can be hidden domination, degradation, and harm to others. Others treat it as a meaningful and useful concept, one which work draws attention to the desirability of the individual being able to control information about himself or herself, one which identifies an aspect of what is to be respected in 'respect for intrinsic human dignity', or one which identifies something which is necessary for the development of interpersonal relationships.³

Though AHEC took that view, it added that if the records of the clinic are such that they do not include permission from the donor for the release of identifying information, because the donation was made before the introduction of the guidelines and the donor had not come forward in response to a public information campaign designed to encourage them to do so, the clinic should make an appropriate effort 'consistent with the original consent document [of the donor] and the privacy rights of the donor, to contact the gamete donor and obtain his or her consent to release of information'.

So AHEC went only so far as to require that clinics make efforts to encourage people who had donated anonymously to give their permission for identifying information about them to be made available to their biological children.

Other arguments against retrospective access include the ideas that the family situations of donors may have changed since the time they made their donation, and that donors may resent the possible intrusion into their lives of something they considered to be in the past.

³ DeCew, Judith, "Privacy", *The Stanford Encyclopedia of Philosophy (Fall 2012 Edition)*, Edward N. Zalta (ed.), URL = <<http://plato.stanford.edu/archives/fall2012/entries/privacy/>>.

In favour of access

What can be said in favour of the other view, that donor conceived persons should be granted access to identifying information about their biological parents?

Primarily, that it is information to which every human being is entitled. As Article 7 of the *UN Convention on the Rights of the Child* says: a child has 'from birth... as far as possible, the right to know and be cared for by his or her parents'.

Of course, that knowledge may be useful: for understanding one's medical history (particularly in these days of personalized genetic medicine), for reducing the risk that a donor-conceived person will enter into a consanguineous relationship, for enabling opportunities for a donor-conceived person to come to know his or her half siblings and other members of his or her biological family including the donor, to reduce the risk that the donor-conceived person will be burdened by psychological distress, etc. Your own very useful issues papers point all this out. But the primary point is not the usefulness of this information but access to it being a moral right. That is to say, the idea that one is entitled to know one's biological parents⁴ should be understood primarily as a (moral) right to know the truth about one's conception as a (or, perhaps, the) fundamental aspect of knowledge of one's own identity.

Assessing the arguments in favour and against

How are the arguments in favour and against granting access to identifying information to donor conceived people to be evaluated? In the Issues Paper which accompanied the call for submissions to the NSW Parliamentary Enquiry, the arguments for and against are said to be equal.⁵ Are they?

⁴ AHEC uses the term 'genetic' parents.

It is true that there are arguments which can be advanced for maintaining anonymity: promises having been made, donors resenting intrusion into their present lives about matters they consider to be in their past, etc. In fact, and even more seriously, some donors may actually be harmed by their identity being revealed and their being approached by a person or persons conceived as a result of their donation. Fragile donors (the elderly, the cognitively impaired, those whose donation has led to the birth of very many children, etc) could be overwhelmed by such approaches.

But I would argue that the arguments *against* granting access are not as morally important as are the argument *in favour* of access to identifying information, that that donor-conceived person's entitlement to knowledge of his or her biological parents is paramount.

Over human history, the idea that children are entitled to knowledge of, and contact with, their biological parents has been taken for granted. Of course, there have always been exceptions. But they were *exceptions* to a fundamental fact about human social life which was not only assumed but enshrined in law and public policy. Certainly, adoption arrangements have sometimes failed to pay due regard to this entitlement, but in recent years policies have been adopted to rectify this oversight.)

Or, again, as Margaret Somerville has said, the principle of 'anticipated consent' requires that, when a person seriously affected by a decision cannot give consent, we must ask whether we can reasonably anticipate that he or she would consent if able to do so. If not, it is unethical to proceed. It follows that the views of donor-conceived adults are ethically-relevant to an enquiry into managing

⁵ Legislative Assembly's Committee on Law and Safety: Issues Paper: Managing information related to donor conception, November, 2012: <http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/EE71C90F0F8B8713CA257ABC01A28AA>, accessed 11/03/13

information related to donor conception. And they speak of a profound sense of loss, a loss which goes beyond an inability to access medical information about themselves, a loss which goes beyond a fear of consanguinity in their adult relationships, a loss which goes beyond the desire to know their biological relatives. It is the loss of knowledge of something critical to their sense of themselves: their personal identity.⁶

In fact, it is only in recent years that there has been a need to spell out the idea that people are entitled to knowledge of, and contact with, their biological parents. For it is only with the invention of technologies to circumvent infertility that that taken-for-granted assumption has been ignored. The practice of seeking the donation of sperm – with the promise of anonymity to the donor – developed in response to the (understandable) desires of adults to have children, but it developed in a manner which ignored the child's entitlement to knowledge of his or her own biological parents.

Thus it was that, in 2004, in setting out the ethical basis of its guidelines, AHEC explicitly stated its acknowledgment of this fundamental fact about human social life: *In these guidelines, the Australian Health Ethics Committee has recognized that the welfare of people who may be born as a result of the use of assisted reproductive technology is paramount*⁷(emphasis added). 'Paramount'

⁶ Margaret Somerville. 'Brave new babies: children's human rights with respect to the biological origins and family structure', Published as 'From homo sapiens to Techno sapiens: Children's Human Rights to Natural Human Origins', Proceedings of the 14th World Congress on Reproductive Technologies, Montreal, 17th to 20th September, 2007). Submission No 2 to Senate Inquiry into Donor Conception in Australia.

⁷ National Health and Medical Research Council. *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research*, 2004 (as revised in 2007 to take into account the challenges in legislation) p 9

means that it 'comes first', 'is first in order of importance', etc.

Admittedly, there are several possible objections to the view that the donor conceived person's entitlement to knowledge of his or her biological parents outweighs the right to privacy of the donor. I will outline some of these and indicate how I think they can be answered:

- First it may be said that some donors may be harmed by having their identity revealed. Some may be harmed by being approached by one or more people conceived as a result of their donation of sperm many years ago.

This is true and important. However in reply it can be said that this could be managed by an arrangement which enables a donor who wishes to decline to allow identifying information to be made available to a donor-conceived person or persons to have the substance of his reasons reviewed by a Panel.

The Panel would assess his claim that he would be seriously harmed by the disclosure of identifying information to the donor-conceived person(s) and, if the claim is substantiated, the information could be withheld.

- Secondly, it might be said that people made anonymous donations in good faith and may have been explicitly promised anonymity.

Promises, undertakings, contracts, were (or may have been) made with donors that their privacy would be respected by their donation being anonymous. Release of identifying information would be an infringement

of their privacy, and a breach of this undertaking, contract, etc.

However, in reply it can be said that no such promises, undertakings or 'contracts' should ever have been made. Since such promises or 'contracts' would have a profound effect on the rights of a third party, or indeed multiple third parties, they were not validly made.

Clinicians had no right to make such promises or to enter into such contracts because the profoundly-affected third party (or parties) was not represented when the agreements were entered into. The 'contracts' are void. So there is no such right as a 'donor's right to privacy' which must be respected.

- Thirdly, it might be said that it will not always be possible for donor-conceived persons to access identifying information. Records may have not been kept. Records may have been lost or deliberately destroyed. It may be costly or onerous for clinics to retrieve identifying information.

Again, it is true that there may be difficulties encountered in identifying and securing records. For this reason, registers would need to be established, at the State or Commonwealth level. Public resources would need to be devoted to the gathering of data from clinics and other repositories as best as is possible.

In my view, those Australian parliaments which have not outlawed anonymous

donation should do so. It ought to be illegal to facilitate donor conception unless potential donors agree to having identifying information kept accessible for donor-conceived people. Parliaments should put in place arrangements which ensure that, in the future, donor-conceived people will not have inflicted on them the grave injustice of their not being able to know who the identity of one of their biological parents. Parliaments should then authorize arrangements to address the injustice inflicted on donor-conceived people in the past even though it can be anticipated that this will be resisted by at least some of the 'providers' of assisted reproductive technologies. A useful first step may be a public campaign which encourages donors voluntarily to come forward and register the relevant details about themselves on a public register.

I hope that the tide is turning, that the 'paramountcy' of the donor-conceived person's moral right to knowledge of his or her biological parents will everywhere be acknowledged. For it is unjust, as well as likely harmful, not to tell a child, in an age-appropriate way, the circumstances of his or her birth.⁸



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⁸ Submissions to the parliamentary inquiry will shortly be posted on the following website; <http://www.parliament.nsw.gov.au/lawandsafety>

Should human genes be patentable?

Some ethical issues at stake in recent and forthcoming court decisions.

Bernadette Tobin

Are human genes patentable? If so why? If they can be patented, what effect is this likely to have on the availability of, to those who need them, genetic tests for conditions such as breast cancer? If genes cannot be patented, what effect is this likely to have on the biomedicine industry? A recent article in the *New York Review of Books* sets out the issues - with respect to a forthcoming case in the United States - with admirable clarity.⁹

But first to things closer to home. Australia's Federal Court recently dismissed a challenge – from Cancer Voices Australia - to patents held by Myriad Genetics Inc over isolated DNA or RNA sequences. This was the first time an Australian court had considered the matter. The court held in favour of Myriad Genetic's claim to hold a patent relating to the BRCA1 gene, the presence of which gene predisposes a woman to breast cancer and ovarian cancer.¹⁰ The patent grants Myriad Genetics the right to exclude others from using this gene in medical research or health care.

In the next few months, the US Supreme Court will hear a similar case, this time involving Myriad Genetics Inc's patents over two cancer-predisposing genes: BRCA1 and BRCA2.¹¹ In 2009, a lawsuit was filed in the Federal District Court of New York State to overturn the patents Myriad had on BRCA1 and BRCA2, patents which entitled Myriad to exclude others from using these genes in breast cancer research, diagnostics and treatment for the life of the patent (now twenty years). The plaintiffs were not the usual parties in patent suits: competitors. They included the American Civil Liberties Union and the Public Patent Foundation as well as medical geneticists, pathologists, researchers, genetic counsellors, advocates for women's health and several woman with breast cancer: all were opposed to Myriad's patents allowing it to exercise monopolistic control over a biological substance as essential to medical research and health care as the DNA implicated in cancer.¹² Interestingly, in American law, opponents of a public policy cannot ordinarily pursue their objections in the Federal Courts unless the

⁹ Daniel J. Kevles. 'Can they patent your genes?' *The New York Review of Books*, March 7th 2013:

<http://www.nybooks.com/articles/2013/mar/07/can-they-patent-your-genes/> (accessed 23/2/13)

¹⁰ *Cancer Voices Australia v Myriad Genetics Inc* [2013] FCA 65

¹¹ Daniel Kevles, op cit.

¹² The DNA in these two genes is like that in other human genes: a molecule shaped like a double helix, each side of which is joined by two chemicals in the manner of the rungs of a ladder. DNA sequencing is the process of determining the precise order of the components of the DNA molecule.

policy causes an injury that gives them 'standing' to sue. The plaintiffs argued that they had suffered harms from Myriad's enforcement of its BRCA patents: because of the 'gravity' of the issue for health and for science the judge granted them standing.

The matters in the forthcoming American case were first raised in 1990 when a geneticist at Berkeley announced that her laboratory had discovered that BRCA1 was located somewhere on chromosome number 17. In 1994 (after a race amongst several geneticists) its exact location was found, and in 1995 the exact location of BRCA2 was found (on chromosome 13). Myriad promptly applied for patents on both the isolated RNA that makes up the BRCA1 and BRCA2 genes and also on a set of diagnostic tests to detect their presence.

The social utility of patents

Three kinds of arguments are used to justify patents: natural rights arguments, distributive justice arguments and consequentialist arguments. Natural rights arguments go back to John Locke who held that persons have a right to property insofar as they have mixed their labour with it so long as they have appropriated natural things without exhausting them or taken more than their share. Distributive rights arguments hold that patents reward the initiative of inventors: without that reward, others would be able to compete unfairly. Consequentialist arguments relies on the idea that patents encourage innovation and the disclosure of knowledge.¹³

At the time of the American Revolution these ideas were much debated: Thomas Jefferson opposed the monopolies inherent in copyrights and patents, but James Madison persuaded him of their value as incentives to authors and inventors... so long as they were

¹³ For an account of these arguments, together with a critical analysis of each, see Sigrid Sterckx. 'The moral justifiability of patents', *Ethical Perspectives: Journal of the European Ethics Network*, 13, no 2 (2006): 249-265.

temporary. Thus the US Constitution contains what is now called the 'progress clause' which authorizes Congress to 'promote the progress of science and useful arts, by securing for limited times to authors and inventors the exclusive right to their respective writings and discoveries'.¹⁴ A statute of 1793 said that patents could be obtained for 'any new and useful art', and in 1953 the word 'art' was replaced with 'process'. Jefferson's language thus emphasized the requirement of newness or novelty, the necessity of an inventive step. It also implied that products of nature, which were held to be owned by everyone, were not to be removed from common possession.

Why have patents been granted to genetic tests?

It therefore may seem surprising that, since the 1980s, the US Patent and Trademark Office has issued patents on DNA: not however on DNA in the body but on different versions of DNA isolated from the body ('complementary DNA' or 'cDNA'). These patents have been justified on the basis of two long-standing legal doctrines: the first, that products of nature can become eligible for patents if they have 'markedly different characteristics from any found in nature'¹⁵, the second, that having been extracted, purified and thus made useful, the [product of nature] became for every practical purpose a new thing commercially and therapeutically'.¹⁶ The idea is that, when cDNA is made by scientists outside the body, it differs markedly from DNA inside the body: it becomes a new composition of matter.

Against this it is argued that patents should never have been granted (either for the DNA or the tests on it). All that is involved in these genetic tests, it is said, is the comparison of the DNA taken from the patient with a version of the gene that it is known will dispose the

¹⁴ Article 1, Section 8, Clause 8.

¹⁵ *Diamond v Chakrabarty*, 2004: as cited in Kevles, op cit.

¹⁶ *Parke-Davis & Co. V H.K. Mulford, Co.* 1911: as cited in Kevles, op cit.

person to cancer: this does not require a particular process, only the act of looking to see if one DNA sequence matches another!

Some implications of patents on genetic tests

Critics have criticized Myriad with charging prices for genetic tests that put them beyond the reach of some women, of preventing patients from obtaining a second diagnostic opinion from an independent laboratory, of causing the researchers who scrutinize a woman's DNA to violate the ethical norms of medical practice because they are prohibited from telling the woman what they have found, of hampering research because women at risk of breast cancer are disinclined to participate if the results have to be kept from them. Myriad has rejected these criticisms, declared that the company freely allows academic research on both genes and pointing out that more than eight thousand papers about the genes have been published around the world.¹⁷

In the recent Australian decision, the judge said: 'The real problem lies in knowing, or rather not knowing, what degree of human intervention is necessary before it can be concluded that the requisite artificial state of affairs exists. It is an especially difficult problem in the present case, not so much because the authorities provide no clear solution to it, but because the problem has an almost metaphysical dimension to it.'¹⁸

The Australian decision may well be tested on appeal. It will most certainly be cited in the forthcoming case in the US Supreme Court.

¹⁷ Kevles, op cit.

¹⁸ *Cancer Voices v Myriad Genetics Inc.* As cited in Bill Madden. 'Gene Patenting: Australian court rules BRCA1 patent is legal'. *The Conversation*, 18th February, 2013. <http://theconversation.edu.au/gene-patenting-australian-court-rules-brca1-patent-is-legal-12240> (accessed 18/2/13)

Postscript

As a matter of justice, health care – in particular basic health needed by everyone – ought to be available according to need, and not on the basis of capacity to pay. Christians, and other people of good will, should be able to recognize the truth of that claim: Jesus' attitude to sickness and disability was a world away from a conception of health care which portrays it as a consumer good and conceives of sick people as 'consumers' and doctors as 'providers'. And his healing was available to *all*.

There is much that can be done to mitigate injustices in access to health, by biotech companies, by politicians, and (best) by collaboration between the two. At some cost to their shareholders, a biotech company could set licensing conditions which make the techniques more rather than less accessible to all whose health could benefit. At some cost to the community, politicians could prioritize the subsidizing of these tests in the design of health care budgets. These matters raise complex ethical and social issues. But the ethical starting point is clear: that health care should be available on the basis of sheer need, that access to needed tests and treatments ought not to be limited by the operations of the market.



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Bioethics Outlook

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