ISSUES OF
OUR TIME

Published in *Issues of Our Time* in 2008 by Future Leaders (www.futureleaders.com.au)

Bioethics

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Consider These Five Cases

1. Assisting a person to die: Terri Schiavo, an American woman aged 41 years, was diagnosed as being in a persistent vegetative state ("brain dead") and was kept alive by a feeding tube. Her husband, Michael Schiavo, was Terri's guardian and, after three doctors had testified that she was in an irreversible vegetative state, he asked that the feeding tube be removed and that she be allowed to die..

Terri's parents, Bob and Mary Schindler, however, refused to believe that their daughter could not recover and mounted a legal action to prevent the feeding tube being removed. They believed that removing the feeding tube was "an unconstitutional deprivation of a constitutional right to life". However, after a lengthy legal process the courts agreed that Terri "would not have wanted to live in her condition" and ordered the tube to be removed. The Schiavo case became of national interest largely because of the opposition of evangelical Christians, supported by President Bush, to any form of euthanasia or assisted death which they saw as a deprivation of a 'right to life' guaranteed by the US Constitution.[1]

The Schiavo case raised a number of questions:

- Can a person who is suffering from a terminal illness and who is in intolerable pain refuse medical treatment that will keep her alive?
- Does a person have a right to determine how and when she dies?

- Given that it is no longer a crime to commit suicide, why should it be a crime if a person asks her doctor for help in taking her life and he agrees?
- Both Holland and Belgium have laws permitting, under certain strict conditions, doctor-assisted suicide where people with a terminal illness are in intolerable pain. Should we have such laws in Australia?
- Most Australian states now recognise "Advance Medical Directives", which people can make about the treatment they want if they are incapable of making decisions for themselves in the future. Is this a good idea?[2]

2. Surrogate motherhood: Maggie Kirkman, who was married, had undergone a hysterectomy and could not bear a child. She was, however, able to produce an ovum which was then, since her husband was infertile, fertilised by the sperm of a known donor. Her sister Linda, who had given birth to two children in her marriage, offered to have Maggie's embryo, produced by IVF, implanted in her. A fortunate circumstance was that Linda's husband had undergone a vasectomy after the birth of his two children so that, so long as Linda remained married to him, she was technically in an "infertile situation". This was important because, under the *Victorian Infertility (Medical Procedures) Act* of 1984, an IVF embryo cannot be transferred into the womb of a fertile woman. At all events, the embryo transfer from Maggie to Linda was successful and the child (a daughter Alice) was duly born to Linda, its gestational mother, and then given into the care of its genetic mother Maggie. Under common law a child is deemed to be the child of the woman who gestates it, so the child in this case had to be formally adopted by the genetic mother Maggie.[3]

The Kirkman sisters' case received wide publicity and was extremely important in shaping people's perceptions about surrogate motherhood. Both were highly intelligent women who knew exactly what they were doing, both had altruistic motives, no-one was being exploited, and, since the child was genetically the mother's offspring, it was not being "sold" or exchanged.

The Kirkman sisters' case raised a number of questions.

- Is surrogate motherhood, where one woman freely consents to bear a child for another woman, morally wrong because it is only married men and women who have a right to have children?
- Are women, who enter into an arrangement with a surrogate mother to have child, being "selfish" in that they want to have child at any cost? Are they brainwashed into thinking that they can only be "real women" if they have children? Shouldn't they just accept the fact that they are infertile and can't have a child?
- Is the child of a surrogacy arrangement likely to feel that she is a "commodity", and to be psychologically harmed by the fact that she has three "parents" (the woman who gestated her in her womb, the woman who contributed the ovum from which she was born, the donor who gave his sperm)?

3. Saviour siblings: In 2004 the UK Human Fertilisation and Embryology Authority (HFEA) ruled that couples could (a) prescreen their IVF embryos and select those embryos that have tissues matching the tissues of an already existing child of the couple, and (b) when the embryo is implanted in the mother and when the child has been born, use the blood from the umbilical cord of the new child to treat its existing sibling who is suffering from the blood disease of beta thallassaemia. A number of children in the United Kingdom have been born in this way in order to save their sibling. They are called "saviour siblings". HFEA has emphasised that this procedure should only be used when all other means of treating the disease of the existing child have failed.

Saviour siblings' cases raise a number of questions:

- When a child comes to know that she was born only because it would help her existing sibling to live, is she likely to feel that she has been used as a means to an end or as a "commodity"?

- In the past, families have been formed by men and women getting together and having children. Now there are a number of ways of forming a family, including the creation of saviour siblings. Does this mean the end of the family as an institution? What limits, if any, should be put on these new ways of family formation?

4. Stem cells: Stem cells are primitive cells which are inherently plastic or malleable in that they can assume the form and function of other bodily cells and so help to repair degenerating or malfunctioning human tissues in the brain, heart, kidneys etc. They are found in human embryos but so-called "adult" stem cells can also be found in tissues of the human body. Embryonic stem cells have proven to be easier to cultivate and use than other stem cells (though this is subject to some controversy) and, as a result, bioscientists have concentrated on embryonic cells. Since research on stem cells involves the destruction of embryos the ethical question is whether this can be justified? This question had, of course, arisen in the 1980s and 1990s apropos of the earlier discussions about IVF and the "surplus" embryos that resulted from its procedures (three embryos may be formed and only one implanted in the mother), and it might have been thought that it had been more or less settled. However, in the context of stem cell research it provoked a huge controversy in Australia as well as in the United States and several European countries. After a Senate committee enquiry and a heated debate in both houses of the Australian Federal Parliament, the *Research Involving Embryos Act, 2002*, was passed.[4] Later a review of this legislation was set up by the Federal Government in 2005 under the chairmanship of John Lockhart, a former judge of the Federal Court. The Lockhart Committee recommended the continuation of the ban on human reproductive cloning, but it also supported an amendment of existing legislation to allow somatic cell nuclear transfer (SCNT). SCNT involves (a) taking the nucleus of a cell donated by a patient, (b) then transferring it into an egg whose nucleus has been removed (this process does not involve sperm so that embryos formed by SCNT are not fertilised, unlike "excess" IVF embryos), (c) growing the cloned embryo that results, for about five days, and (d) extracting the embryonic stem cells. SCNT embryos will not be implanted or allowed to develop. They are not normal embryos that could develop into a human person.

The stem cell debate raises a number of questions:

- Is the early human embryo, before it is implanted in the mother's womb, a human person? Does stem cell therapy involve killing a human person (as an early unimplanted embryo) in order to save other human beings?
- Why do people think that human cloning (producing exact genetic copies of a human, as with identical twins) is immoral? Because only God can create human beings and cloning is an attempt to "play God"? Because cloning involves a loss of individuality? Because we could use cloning to produce, for example, a sub-race of slaves or of aggressive warriors?
- Can we distinguish between a human being and a human person? For example, it might be said that an early pre-implantation embryo is a biological human being but not a human person. No doubt it will eventually grow, if all goes well (though 50% of embryos fail to implant), into a human person who is conscious and can think and be aware of itself and make decisions. But is the early embryo a human person in the full sense? When a woman has a miscarriage early in pregnancy does she think that she has lost a child? Or is an embryo stored in a laboratory before it is implanted in a woman a human person?

How Can We Approach These Ethical Questions Raised By the New Biological Sciences and Technologies?

Some people say that religion provides us with answers to the basic ethical questions. So the Ten Commandments in the *Old Testament* tell us how to live and how not to behave. But the questions raised by the new biotechnologies are totally new and it is difficult to see how the Ten Commandments could have any relevance to them. Again, the Ten Commandments apply only to Jews and Christians, and atheists and agnostics and people from other religious groups, Hindus, Buddhists, Muslims, often think very differently about moral matters. Even within Christianity there are different views between Catholic and Anglicans, for example, about contraception, homosexuality, euthanasia and the status of the human embryo.

Some people say that we should use a "consequentialist" approach. In other words, we estimate the desirable and undesirable consequences of any course of action (for example, sanctioning euthanasia, the use of stem cells and so on). If the desirable consequences are greater than the undesirable consequences then that course of action is morally good. However, it is notoriously difficult to estimate the consequences of any course of action and total them up in an arithmetical kind of way.

Some people say that a rational or philosophical approach, which involves careful reasoning about the issues, being consistent, being imaginative and being commonsensical, is the only valid approach. For example, when we look at humans we find that they are conscious beings who can be aware of themselves and make decisions for themselves. They are free to determine how they live. At the same time they are aware that they must treat other humans in the same ways that they treat themselves, because other humans are also autonomous or self-directed beings .

A Short History of Bioethics

There has always been an association between medicine and ethics. This association in Western European culture, began with the Hippocratic tradition in Greece in the 5th century BC, and was continued in the Middle Ages by moral theologians (so-called "casuists") interested in difficult medico–ethical cases about the status of the human embryo and foetus, death and dying, doctor–patient relationships etc. As medicine became scientifically based in the 19th and 20th centuries, medical ethics also developed and a number of international bodies, for instance the World Health Organisation, promulgated codes of behaviour such as the

Helsinki Declaration of 1964. But the emergence of the new biotechnologies in the latter part of the 20th century, which led to new modes of human reproduction and family formation and to the possibility of genetic engineering, raised radically new ethical questions and issues and precipitated a revolution in ethical thinking, not just in that it involved ethical principles being applied to quite novel situations, but because it has forced us to see the business of "applied" ethical reasoning itself in a new way

Beginnings of Bioethics

Bioethics, as it came to be called, began in the United States with the reports of the National Commission for the Protection of Human Subjects in Research in 1974. It was followed in the United Kingdom with the setting up of the Warnock Committee on Human Fertilisation and Embryology in 1984, and almost immediately in Australia where medical scientists (Professor Carl Wood, Professor Alan Trounson and others) at Monash University in Melbourne were pioneers in developing the new techniques of in vitro fertilisation (IVF). To regulate IVF the Victorian Government enacted the *Infertility (Medical Procedures) Act* in 1984. This was the first legislation of its kind in the world. In fact, it can be said that Australia has remained at the forefront of the bioethics movement.

In vitro fertilisation immediately raised a number of crucial issues about human reproduction, the moral and legal status of the human embryo, the possibility of experimentation on early IVF embryos, the donation of ova and sperm to other couples, the role of the law in regulating the new ways of birth and family formation. Various governmental committees, state and federal, were created throughout Australia to advise how the new "industry" could be regulated, and a large number of non-government organisations — church bodies, women's groups, patients' associations — also came into being. Again, many universities established centres for the study of bioethical issues such as the Monash Centre for Human Bioethics in Melbourne, founded by Professor Peter Singer and Dr Helga Kuhse in 1980.

Looking back on the dramatic development of bioethics in Australia and elsewhere one is struck by the speed of its growth and expansion and also by its complex ramifications. For one thing, it required philosophers to radically revise their ideas about the nature of ethical thinking and the scope of "applied ethics", and, above all, to recognise the need to collaborate with medical scientists and lawyers.

National Bodies

In 1988 a National Bioethics Consultative Committee (NBCC) was set up by the Federal Government of Australia. It was concerned not merely with the regulation of IVF, but with wider issues such as, for example, the ethical principles governing the just distribution of health care resources. The NBCC, was loosely based on the model of the US National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research and the President's Commission for the Study of Ethical Problems in Medicine. These bodies had issued a stream of reports between 1975 and 1983 on a wide array of subjects from research on the human foetus, whistle-blowing in biomedical research, gene splicing and research on prisoners. These reports had become the benchmark for other national bodies worldwide.

Again, the French National Consultative Committee on Ethics in the Life and Health Sciences set up by President Mitterand in 1983, largely followed the American model, though in a very French way. For example, the Mitterand committee included representatives from the four main religious faiths, Catholic, Protestant, Jewish, Muslim, and there were also a number of eminent women representatives. In the United Kingdom a Committee of Inquiry into Human Fertilisation and Embryology, 1984, was set up under the chairmanship of Dame Mary Warnock, and the Human Fertilisation and Embryology Authority (HFEA) was established in 1991. This latter body is not just a regulatory authority but it has also initiated research of its own, for example, on the issue of using in vitro fertilisation to produce "saviour siblings". HEFA approved of the creation of saviour siblings in certain circumstances on the ground that parents have a right to found a family.

Perhaps the most notable report of the Australian NBCC was that on surrogate motherhood in 1991. The report discussed the ethical and legal aspects of surrogate motherhood and recommended that altruistic or non-commercial surrogacy arrangements be allowed, but that regulatory procedures should be put in place to ensure that adequate counselling was provided for all the parties involved, and that appropriate procedures for relinquishment of the child were observed. The report put great emphasis on the principle of autonomy, namely the right of individuals in a liberal democratic society to form families in the manner they chose, so long as none of the parties in a surrogacy arrangement — the mother, the surrogate mother and the child — were harmed. With regard to women serving as surrogate mothers (like Linda Kirkman) the NBCC invoked the same right of women to control their own bodies that feminists have used with regard to contraception and abortion. If a woman may choose, for a good reason, to use contraceptives, or to have an abortion, and *not* bring a child into existence, she should be able to choose to bear a child for another person and so bring that child into existence. In other words, we cannot assume that a woman will inevitably be demeaned or exploited by acting as a surrogate mother.

The NBCC was eventually transformed into the Australian Health Ethics Committee and its last act was to a prepare a set of materials on embryo experimentation It also commissioned a poll from an independent polling agency on the attitudes of the Australian community to embryo experimentation. This poll was based upon a similar poll conducted in the United Kingdom and it showed an extraordinarily high community acceptance of medical research involving embryo experimentation. Eighty-one per cent of respondents agreed that IVF should be available for infertile couples; 75% approved of embryo research directed at alleviating problems during pregnancy; 68% approved of embryo research aimed at the detection of genetic malfunctioning in the embryo; 58% agreed that couples should be able to donate "surplus" or untransferred embryos for research purposes.[5] It is clear from these figures that the vast majority of Australians do not see the human embryo as having the same moral status and "rights" as a child. Of course, we cannot decide what is right and wrong by polls, but the fact that a majority of people think that embryo experimentation is acceptable in certain circumstances shows at least that it is not obviously wrong.

Stem Cells

The ethical issues involved in the use of stem cells in the treatment of degenerative conditions such as Parkinson's disease have been the subject of much contemporary debate both in Australia and the United States. This debate began around 2000 and is still simmering. For the moment, the Australian government has allowed research in this area but under very stringent conditions. Thus, research is permitted on "excess" or "surplus" embryos produced for IVF procedures before 5 April, 2002, under strict regulations administered by the National Health and Medical Research Council, and the consent of the husband or sperm donor is also necessary. If a sperm donor is involved, the consent of his spouse (if any) must be given. The United Kingdom, Belgium and Sweden have much more permissive legislation which allows the cultivation of embryonic cell lines, research on "surplus" IVF embryos and embryos created for the purposes of research. But, on the other hand, some European countries — Germany and Italy, for example — have more restrictive controls.

Is the Embryo a Human Person?

The question whether the early human embryo is a human being, and even a person with rights, from the moment of conception, or whether it is simply an organised cluster of human cells that may develop through various stages into a human being or person, is a formidably difficult one. We are dealing here with a continuum, or a developing process, so that it is impossible to select a definitive "moment" when we can say that a "human being" has appeared. Notwithstanding this, some have selected the instant when the sperm penetrates the ovum, others have selected the implantation of the embryo in the woman's womb, others again have chosen the phase when the primitive nervous system of the implanted embryo begins to develop, and still others have opted for a much later time when the embryo/foetus is viable or able to survive apart from its mother. If, however, it is not possible to define exactly when the embryo becomes a human being, it is clear that there are crucial stages in its development, and that the respect we give to the embryo has to be geared or adjusted to its stage of development.

The Australian Health Ethics Committee

The NBCC was succeeded by the Australian Health Ethics Committee (AHEC) in 1991, but before it disappeared it published a report on the ethical aspects of the allocation of health care resources. The report, Distributing Health Care Resources: Ethical Assumptions, was published by the National Health and Medical Research Council (NH&MRC) in 1992 and it was concerned with the just or fair distribution of health care. If, for example, the government legislated that only people below 30 years of age should receive full health care we would think that the legislation was unjust or unfair.[6]

One of the main functions of AHEC has been to supervise the work of more than 150 Institutional Ethics Committees (IECs), now called Human Research Ethics Committees (HRECs).[7] The HRECs, in effect, monitor and regulate ethical standards in medical research institutions and they have been a significant feature of Australian bioethics.

Apart from national bioethics bodies, each state in Australia has its own bioethics committee and there are often significant differences between their attitudes to reproductive technology issues, end-of-life decisions, the treatment of premature newborn infants and so on. There are also Law Reform Commissions in most states and these bodies have often been concerned with bioethical issues. The Law Reform Commissions of NSW and Victoria have been especially energetic, with reports being published on informed decision making in medical situations, studies of doctors' and patients' attitudes, and so on. One might mention also the pioneering work of the Federal Law Reform Commission in the 1980s and 1990s under the chairmanship of Mr Justice Michael Kirby who was largely responsible for the creation of the National Bioethics Consultative Committee.

Non-Government Bodies

In addition to these government bioethics commissions there has been a multiplicity of non-government bodies, some of them established by the main Australian churches — Catholic, Anglican, Uniting Church and Lutheran.

A number of bioethics centres have also been established within Australian universities. As noted, the Monash Centre for Human Bioethics was set up by Professor Peter Singer and Dr Helga Kuhse in 1981 to foster research on bioethical issues, provide courses and postgraduate studies, conduct public seminars and summer schools, and publish two journals, *Monash Bioethics Review*, and the international journal *Bioethics.*

Again, an increasing number of law, medicine and ethics courses (usually postgraduate) have been set up in law and medical schools in the main Australian universities. Professor Loane Skene's graduate diploma course on law, medicine and ethics at the Melbourne Law School is an excellent example of this kind. There is also a national Australian Bioethics Association, founded by Christine Martin and Max Charlesworth in 1991, which holds a biennial conference with participants from Australia and New Zealand, and which sponsors a quarterly *Journal of Bioethical Inquiry*.

It is worthwhile noting that while disputes over bioethical issues have been vigorous and sometimes acrimonious, in Australia they pale into insignificance when compared with the situation in Germany. There, discussion has taken place in the shadow of the former Nazi government's brutal treatment of the disabled and its racist eugenic program. In fact, the term "bioethics" has been given such a bad name that it is rarely used in Germany. (The term "medical ethics" is preferred.) In 1989 the Australian philosopher Peter Singer was prevented from speaking in German universities on the medical treatment of gravely disabled newborn children by a powerful coalition of church groups, victims of the Nazis, and the disabled.

Bioethics in Liberal Democratic Societies

Some bioethicists have argued that our approach to bioethical issues should be influenced by the values of the liberal democratic society we are living in, where the freedom to choose one's own style of life for oneself (subject to allowing others to do the same) is paramount, and where the state and the law ought to be limited to preventing harm to others. This is, in effect, the essence of John Stuart Mill's definition of the liberal society in his famous essay *On Liberty* (1859). A liberal society is also, at least potentially, an ethically pluralist society in the sense that different individuals may choose different styles of life with diverse views about family formation, and so on. For example, some may choose to enter same-sex unions and to adopt children, as is now possible under recent legislation in the United Kingdom and some states in the United States.

Again, a liberal society will also be, at least potentially, a multicultural society, where diverse religious views (Jewish, Christian, Muslim, Indigenous) may play an important part in bioethical issues.

Bioethics and Indigenous Peoples

Perhaps in Australia we could begin by taking seriously the very different views of life and birth and death, and family formation, and illness of our Indigenous peoples. Bioethicists in New Zealand have already begun this task with dialogues between the white "pakeha" and the Maori peoples. Since the Maori renaissance of the 1980s and 1990s the Treaty of Waitangi of 1840 between the British Crown and the Maori chiefs has been interpreted as a charter for a bicultural society with Maori and pakeha seen as two equal groups with cultural parity. Applied to bioethical issues, for example, assisted reproductive technology, surrogacy etc., this has led to the recognition that Maori cultural values — a strong emphasis on the local community and the extended family, and the importance of genetic origins and lineage — may bring about significant differences regarding those issues. Even the basic concept of "informed consent" to medical treatment is affected if it is seen, on the one hand, as an act of the individual patient, or, on the other hand, as something in which one's extended family, and even one's clan, has a say.[8]

There have been similar initiatives with regard to bioethical issues arising in Australian Aboriginal communities. Some interesting work has been done by anthropologists and others on Australian Aboriginal attitudes to health and health care, illness, death and dying, reproduction and birth. One thinks, for example, of Janice Reid's pioneering work *Sorcerers and Healing Spirits; Continuity and Change in an Aboriginal Medical System*,[9] Eric Vanbrux's book *A Death in the Tiwi Islands*[10] and the splendid study by Jeannie Devitt and Anthony McMaster, *Living on Medicine*, that is concerned with the cultural problems surrounding kidney dialysis for Aboriginal diabetics.[11]

Third World Bioethics

So far bioethics has been developed mainly in advanced capitalist countries in Europe, Australia and the United States. But the bioethical problems faced by the third world, economically impoverished but populous, countries are very different. Reproductive technology to aid infertile couples is hardly a pressing problem in India or China or South America, but anti-AIDS pharmaceutical drugs are. In these societies there is at present little hope of providing a just distribution of health care resources for the population as a whole and hard decisions, on a national scale, have to be made about who gets scarce resources and who does not, and about the range of services — hospitals, trained medical staff, expensive pharmaceuticals — available. In South Africa the attempt to control the spread of HIV/AIDS has brought the government into conflict on the one hand with pharmaceutical firms, and on the other hand with a powerful lobby of gay activists and HIV/AIDS patients. The pharmaceutical firms are, of course, driven by the need to make profits for their shareholders, and it may be that shareholder capitalism simply cannot be an efficient basis for coping with the massive medical problems of Third World countries. This in turn will no doubt have a profound effect on medical training and the role of doctors and other health professionals and perhaps bring about the formation of global medical resource groups along the lines of "Médecins sans frontières".

In a recent lecture Nikolas Rose, a professor of sociology and director of a bioscience/biotechnology consortium at the London School of Economics, has castigated Euro-American bioethicists for being almost exclusively concerned with the needs of individuals and has called for "a deeper concern with collective wellbeing and the ethical problems raised by the morbidity of the many rather than the lives of the few". Rose contrasts the hype of Western bioscientists and bioethicists about the transformative effects of the new biotechnologies with the cruel realities of health care in impoverished countries in Africa and Asia. As he shows, a miniscule proportion of biomedical resources is directed at the major health problems (tropical diseases, AIDS, tuberculosis, malaria, malnutrition) of those countries.' There are clearly urgent issues here for bioethicists.

Endnotes

1 Details of the Schiavo case are available through Google.
2 See "Advance Medical Directives" via Google.
3 See M. and L. Kirkman, *My sister's child*, Ringwood, Penguin Books, 1989.
4 See the excellent account by Elizabeth Finkel, *Stem cells: controversy at the frontiers of science,* Sydney, ABC Books, 2005.
5 The Roy Morgan Research Centre, *Survey on Human Embryo Research*, 1991.
6 See Max Charlesworth, *Bioethics in a Liberal Society,* Melbourne, Cambridge University Press, 1993, ch. 5.

7 See National Statement on Ethical Conduct in Research Involving Humans, Canberra, NH&MRC, 1999.

8 Ibid.

9 Canberra, ANU Press, 1983.

10 Cambridge, Cambridge University Press, 1995.

11 Alice Springs, IAD Press, 1998. See also "Euthanasia", in *Aboriginal Health: Social and Cultural Transitions,* ed. G Robinson, Northern Territory University Press, 1996, pp. 262–4.

12 Nikolas Rose, *Will biomedicine transform society?* Clifford Barclay Lecture, 2005, London School of Economics and Political Science, p. 2.

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