Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer’s disease

I note with interest the controversy regarding a baby born free of an inherited predisposition to early onset Alzheimer’s disease through the use of preimplantation genetic diagnosis (PGD). As the medical geneticist for the PGD programme for single gene disorders in Melbourne, Australia, I have seen many couples who have considered PGD for a wide range of genetic conditions. My observation is that many women look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination.

An example of this is that in the last 11 years our unit has undertaken 13 prenatal diagnoses for Huntington’s disease from nine couples, whereas in the two years that we have been offering it we have had six requests for PGD for Huntington’s disease and three couples have already had IVF cycles.

I have a number of concerns with the argument that the woman should not have a child utilising PGD because she is predisposed to Alzheimer’s disease. Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If the woman is already pregnant, what lengths should be gone to to prevent the woman becoming pregnant by natural means? If the commentators who make this argument agree that it is not appropriate to prevent couples where one is at risk of a genetic disorder from having children by natural means, then assisting them to have children not predisposed to a genetic disorder is in my view entirely ethically acceptable.

The chances for the child of having a mother suffer from early onset Alzheimer’s disease are that they will not have a mother to bring them up and the impact this will have. While members of the woman’s family have developed disease in their 30s and 40s it is by no means certain for the woman herself. The only other report of people with this mutation also had early onset Alzheimer disease, but the numbers affected are very few, perhaps too few from which to draw a definitive conclusion about the exact age of onset for those with this mutation. For example the average onset of the Val177Ile mutation is 57 years. This is a mutation involving the same amino acid (valine at position 177) and the substitution is for a chemically very similar amino acid (isoleucine compared to leucine). If the destiny of this particular woman is to develop Alzheimer’s disease in her mid 40s or beyond then her child will be an adult by the time she is severely affected. Even if we assume that onset of symptoms will be when the child is about 10 years old, the family are aware of this risk and can take steps to be prepared and put in place plans for this. Are couples with other sociological risk factors that put a child at risk of emotional deprivation prevented from utilising reproductive technology? In Australia at least, those who are from low income brackets or who use illicit drugs are not precluded from assisted reproductive technology, yet both these factors are associated with a number of poorer outcome measures for children.

Finally, PGD is a major undertaking for families. It is a protracted, expensive, and very stressful process and ultimately there is no guarantee that a child will be born through using it. Many couples who consider utilising PGD do not go through with the process for these reasons and choose other reproductive options, including traditional prenatal diagnosis, and natural pregnancy with no intervention, or they decide against having children. Therefore families who undertake this process are generally highly motivated and, one intuitively feels that the resultant child is less likely to suffer social deprivation. This issue will only be resolved by long term follow up studies.

In conclusion, I believe that PGD is ideally suited to situations where families wish to avoid their child’s possession of a genetic disease, but where they feel uncomfortable about terminating pregnancies. This includes late onset conditions such as neurodegenerative diseases and familial cancer syndromes, as well as early onset diseases that are considered relatively mild, such as deafness.

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References


Electronic submissions to the Journal of Medical Ethics

At the time of writing there appear to have been no electronic submissions to the Journal of Medical Ethics. It seems appropriate, therefore, to begin electronic correspondence with a consideration of some of the ethical implications of this new form of ethical dialogue.

I have posted this response to Kenneth Boyd’s editorial on Mrs Pretty and Ms B’ as this article may provoke debate far beyond the medical and ethical establishment. This issue may be of tremendous concern to patients or their carers who are presently suffering in circumstances similar to those described.

The electronic response forum of the BMJ has been in operation for over four years. An editorial in the BMJ on physician assisted suicide has attracted 125 responses at the time of writing. An important feature of electronic responses is that any peer review process would deal with differing opinions while maintaining the scholarly submission that is clearly stated. What lengths should be gone to to prevent the woman becoming pregnant by natural means if the comments agree that it is not appropriate to prevent couples where one is at risk of a genetic disorder. In my view entirely ethically acceptable.

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Editor's response

Dr Lewis raises the important issue of what the rules of debate should be in electronic correspondence.' An editorial I feel as if I am caught in the maelstrom of evolution. The web has radically changed the nature of debate and the presentation of information and knowledge. It is not clear to me how and whether it should be controlled. My general approach has been to let the experiment run in a free way and look at the results. Then it will be clearer what rules are required.

Electronic correspondence, for me, is different from scholarly debate. It takes advantage of the web's accessibility to give people the opportunity to express their own views and to see the range of views on a particular issue. At present, the JME operates on the principle that it will publish electronically any response which is not libellous or harmful in other ways. Electronic letters which contribute significantly to the debate (such as Dr Lewis's letter) may be selected for publication in the paper version of the journal.

The core business of a journal such as the JME should be the publication of scholarly articles which contribute to knowledge. But as a medical ethics journal, it should also be engaging and relevant to professionals and non-professionals. We have introduced a current controversy section which reports an issue of contemporary interest and we solicit off the cuff comment from people who may introduce complex philosophical ideas, including sections on the philosophy of science and the philosophy of mind (rationality, meaning, agency, identity etc). The centre-piece of the book is undoubtedly a series of well-chosen cases (thematically progressing from diagnosis to management and prognosis), each followed by an extensive analysis of the ethical issues, including contrasting arguments from different vantage points. There then follows a commentary by a practitioner with relevant experience—in some cases this reflects a practical, no-nonsense approach, while other commentators develop points or themes made by the authors. Each section is rounded off with an extended off with an extensively annotated bibliography. Considerable space is also devoted to legal issues: an appendix provides a four page glossary of key legal cases.

The book is extraordinarily innovative in many respects. Not only is the case history and analysis format interesting and methodologically robust, but the case material is so challenging and the ethical analyses so wide ranging and detailed as to be difficult to put this book down! One discovers how different analytical strategies lead to progressively deeper levels of understanding of the ethical issues, thus exposing "the beauty of the matter" along the way. (Might be referred to books, chapters, and articles for further reading. As might be expected, Fulford's notion that an explicit analysis of values is helpful in defining diagnostic criteria, and is "inevitable" when medicine is a recurring theme. Dickenson's interest in informed consent (also in children), "moral luck", and her feminist reconstruction of rationality, are drawn upon in several sections. Several of the "grey area" cases—cases that do not easily fit into clear diagnostic slots, where clinicians disagree about the precise diagnosis and may start doubting their evidence. For example, the question of the differential diagnosis of a man who appears to have a religious delusion, yet leads a very successful professional life turns "not on the facts about his experiences and behaviour, but on a series of value judgments". The authors point out that the diagnosis of schizophrenia in the DSM-IV (a widely used diagnostic classification system) requires the criterion of "social/occupational dysfunction", below the level achieved prior to the onset". Here a paradox is demonstrated: the evaluation of "social dysfunction" depends on values, yet the authors of the DSM-IV claim that the system was "grounded in empirical evidence". The reader is challenged to come to terms with the value related elements of the diagnosis of schizophrenia and related diagnoses. As with several other cases, the importance of a team approach is emphasised, bringing to bear, as it should, a variety of perspectives that may include elements of cultural formulation and the patient's values.

Other chapters address teamwork and service organisation, and research ethics; a section on wider perspectives gives an international view; in an interesting chapter Fulford describes the basis for his belief that psychiatry can take the lead in biosciences, "providing lessons for medicine as a whole". There is also a useful sample teaching seminar, showing how theory is put into practice.

This book will appeal to any reader who wishes to escape from the well-worn path of "four principles plus". It is likely to be enriching to psychiatrists who feel that the DSM-IV and ICD-10 are constrained not so much by limitations of their science, but of their humanities. It provides thoughtful material for those interested in finding a way of resolving the tensions between physical medicine, psychiatry, and ethics. The book is a treasure trove of annotated bibliographies and very enjoyable to read.

S Louw

Ethical Issues in Palliative Care—Reflections and Considerations


This is a collection of essays by a variety of specialists with a particular interest in palliative care. It contains seven chapters by six different authors.

The first chapter Why is the study of ethics important? is by Patricia Webb, a lecturer in palliative care with a background in medical ethics. She tells us that studying ethics encourages logical reasoning thinking in the face of difficult decisions such as allocation of resources, access to services, best care, clinical research, and rights to life. Webb reminds us that clinical guidelines may not be much help in the face of an ethical dilemma with no clear right or wrong answer.

The chapter called Care versus cure by David Jeffrey, a consultant in palliative medicine and writer on medical ethics, reminds us that care is concerned as much with the subjective feelings of the patient as with the physical disease, and aims to relieve suffering and improve quality of life. He emphasises that by sharing the reality of uncertainty (with patient, family, and colleagues) we can make more realistic decisions, and that informed consent is a mechanism for sharing the power of doctors and patients.

Giving it straight—the limits of honesty and deception by Heather Draper, a lecturer in biomedical ethics, explores the difference between telling the truth and lying, and introduces the tension between honest and dishonest selective truthfulness. “There is a sense in which we are always selective with the truth”, she writes and reminds me of the saying so useful in palliative care, “truth grace care”: that truth must be skilfully used, respecting its potential to help and to harm.

The chapter on Advocacy by Patricia Webb defines advocacy as “the role of one with expertise who is invited to negotiate on behalf of another”, and is an interesting analysis of the power differences between patients and professionals. She makes the point that “patients have little power to influence the nature of care provision unless a determined effort is made to reduce their actual and perceived vulnerability”. She also emphasises, however, that skilful communication allows most patients to be directly involved in decision making. With good team care few patients need an advocate, except those few who prefer to be very passive, or who are unable to make decisions, such as those with severe learning difficulties.

The next chapter, How informed can consent be?, by Calliope Farsides, a senior lecturer in medical ethics, makes the point that it is often useful to consider consent not primarily as a legal concept but as a moral one, and one that depends on the relationship between patient and carer being a relationship of trust, reciprocity, and beneficence, with mutual recognition of their duties and obligations. She goes on to look at the differences between the...
Life and Death in Healthcare Ethics: A Short Introduction


This is a compact, nicely written book that provides a refreshing alternative to the utilitarian orthodoxy that dominates contemporary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medicine and healthcare. This contribution is short and useful introduction to such an approach.

The book announces itself as being written with “both the general reader and students and professionals in medicine, nursing, law, philosophy and related areas in mind”. Accordingly, it assumes no prior knowledge of ethics. It gives a neat introductory overview of some topics raised by reproduction and death, and dying. The issues considered include euthanasia and withdrawal of treatment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

By beginning with early chapters on a real-life case, Watt captures the interest of the reader. The case is introduced and discussed dispassionately. It is then employed as a springboard for a general discussion of philosophical and legal issues raised by reproduction, death, and dying. The issues considered include euthanasia and withdrawal of treatment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

In the first chapter—for example, the Arthur case is introduced as a context for discussing putative distinctions between killing and letting die, and intending and foreseeing: approaches to homicide suggested by competing ethical theories are also covered. In the second chapter, the Bland case is analysed and philosophical concepts such as that of “personhood” are discussed. Watt considers the notion of life as good in itself and raises questions about the social significance of tube feeding. The Cat case, in chapter 3, elicits a discussion of concepts such as that of a worthless life and the crucial, contested principle of double effect, and questions of autonomy. In this chapter, Watt introduces a concept she calls “lethal bodily invasion”. Even if a Nazi doctor did not care whether his victims survived his experimentation on them, the doctor’s intention to invade their bodies in a way he knew would do them no good, but only lethal harm, would be enough to identify his course of action as grossly immoral. This is plausible enough in the context Watt suggests. In order to test her principle as outlined, however, Watt needs to examine other situations where the principle of double effect may apply.

The principle of double effect is often raised in the context of self defence, defence of a third party, and war. Clearly, the book is an analysis of Watt’s book. A broad discussion of defensive action is well beyond its scope; however, it is profitable to analyse like cases where the principle of double effect is often summoned as a justification for deaths not intended but foreseen. If a mentally disordered man, or child for that matter, runs amok with a shotgun in a school, is a marksman not justified in shooting to maim? If the aggressor dies, is this lethal bodily invasion impermissible? Even if a Nazi doctor did not care whether his victims survived his experimentation on them, the doctor’s intention to invade their bodies in a way he knew would do them no good, but only lethal harm, would be enough to identify his course of action as grossly immoral. This is plausible enough in the context Watt suggests. In order to test her principle as outlined, however, Watt needs to examine other situations where the principle of double effect may apply.

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are used extensively throughout the text to illustrate the discussions. In my opinion, the authors have succeeded in producing a text that is a practical introduction to medical ethics. I would warmly recommend this book to all medical and nursing students and a copy should be in all medical libraries.

T Russell

Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology

This encyclopedia is an important and comprehensive resource that is likely to be of value to a wide range of academic users for many years to come. It is particularly useful as a starting point for background research by bioethicists writing about topics in genetics and biotechnology. The collection takes a broad view, ranging from core topics such as genetic enhancement and the ethics of genetics research, to a series of sections that take the form of national reports on the political, ethical, and regulatory contexts covering genetics and genetically modified organisms. One potential problem for any reference work of this kind is getting out of date, given the changing nature of biotechnological research. The articles in the encyclopedia that we read were well written and would probably in the main looked likely to be relevant for a while to come.

The first thing that strikes you about the two volumes of this encyclopedia is that they are very well made, attractive, solidly bound books. This attention to detail is reinforced by first use of the encyclopedia. A great deal of care has gone into making this reference work accessible and a pleasure to use. Two very minor additions would have improved this ease of use. We would have been able to add page numbers to the list of headings and a contents page to the second volume. Nevertheless as a whole the collection was extremely easy to navigate.

The sections that we reviewed all start with a summary of the points to be discussed and then proceed to a general overview of the technology or history of the topic. For those topics on very contentious issue there is a discussion of the major arguments for and against. The headings generally have good references to other sources that will be useful for those wanting to know more.

These are very large volumes so we have based this review on a selection of its headings. Some of them are very good indeed. Dan Brock’s heading, “Cloning, ethics” is the ideal introduction to the topic and one that would be useful as a required reading. Similarly positive things can be said about Robert Nelson’s heading “Gene therapy, ethics” or Michael Parker’s heading “Ethics, Social, Economic, and Legal Aspects”. This level of preparation of the topics can be found throughout the encyclopedia.

C Munthe

The Human Embryo Research Debates: Bioethics in the Vortex of Controversy

United States ethicist Ronald M Green approaches the issue of embryo research (ER) in the very accessible form of a “philosophical memoir” (xvi). Reporting in detail from his experience of serving on several high level ethics advisory boards, focusing mostly on his membership of the National Institutes of Health’s (NIH) 1994 human embryo research panel, Green portrays both the true nature of this process and its increasing need for extensive background research. The author also covers extensive ground regarding the subject matter of ER
itself and familiarises the reader with the technical issues and conceptual conundrums (potentially, moral status, harming future persons) involved.

Green states in the title of The Human Embryo Research Debates: Bioethics in the Vortex of Complexity that he is concerned with a plurality of debates. Examining the discourse in the US, he first deals with the different areas in which ER is debated: of the book’s eight chapters, chapters one and four stress the relevance of ER for the fields of in vitro fertilisation (IVF) research, the study of birth defects, and the development of contraceptive methods. Chapter 6 deals with the relation of ER to reproductive cloning, Green formulates a comprehensive criticism of the National Bioethics Advisory Commission’s (NBAC) 1997 report on cloning, claiming that it contributed significantly to the neglect of ER in US public policy. Chapter seven covers NBAC’s 1999 report on stem cell research, stresses the importance of ER on the form of so-called “therapeutic cloning”, and again takes a critical stance towards NBAC’s shapping of the discourse.

As the above issues are of relevance to groups with radically differing interests, throughout the book Green also deals with a second level of ER debates. This concerns the complex interplay of the interests of scientists, patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups. Chapter seven covers the different areas of ER. In light of the fact that the author is chair of Dartmouth College’s department of religion and former president of the Society of Christian Ethics, one might expect that he would advocate arguments by siding with the restrictive conservative party in discourse. This, however, is not the case. Rather, he points out with frustration that a powerful conservative minority has effectively managed to obstruct and stall ER since the mid 90s. Emphasising the negative consequences resulting from ER being forced to take place almost exclusively in the private sector he argues fiercely and outspokenly in favour of a comprehensive federally funded exploration of the potential medical benefits at hand. Given the dramatic clash of interests of the involved parties, the author is centrally interested in isolating an ideal procedure suitable for governing negotiations between the conflicting parties. Here, Green draws strongly on the Rawlsian concept of overlapping consensus and urges discourse participants to be willing to abide by public reason and to set aside their individual special concerns out of respect for other individuals and the common good (page 61, page 155, page 169 and following pages).

Because of the significant impact of religious pressure groups in ER debates in the US, Green dedicates considerable attention to religiously motivated arguments and in particular to the frequently encountered claim that human life (and tacitly implied: full moral status) begins “at the moment of conception”. In chapter two he cites detailed current biological evidence, forcefully showing that even on the biological level this claim is difficult to uphold. Setting forth “a Coper- nian Revolution in our thinking about ethical issues related to the life sciences” (page 26, without mention of the Kantian origin of this metaphor) Green argues (a) that it is difficult to talk of one objective point of conception and that biological occurrences are best understood as processes rather than events. Hence, as nature does not provide us with clear cut boundary markers, he suggests analogously to the current practice of brain death that (b) the determination of threshold points involves deliberate choice and decision on our part in such a way that a reasonable compromise is achieved between the benefits and harms associated with the choice of a specific boundary marker, both for the wider public and health related research as well as for the entity under consideration. Arguing further against any kind of “single criterion approach” to determine the status of the embryo Green champions a “pluralistic and pragmatic approach” characterised by the belief that “a variety of criteria interact and work together to lead to a mounting sense of concern and ultimately to judgments of protectability about entities” (page 63 and pages following).

Therefore, in Green’s view, the issue of the embryo’s moral status is essentially a political question and “translates into the question of just how much protection it is reasonable and fair to give it at each point in its development” (page 39). Less detailed is an argument in chapter six attempting to establish that the concept of harm is, contrary to Parfit’s “non-identity argument”, meaningfully applicable in the context of wrongful life cases (pages 126–128).

In the age of the “globalisation of ethics” (John Harris) in which ethics commissions and advisory boards are more and more setting the agenda in bioethical policy making, the strength of Green’s book is that it presents a transparent and valuable case study of this practice. Questions regarding, for example, the criteria for selecting a competent and representative panel; how much power these institutions should be granted; what kind of standards and methodology for published reports is necessary; what degree of public participation is desirable, and how to deal with minority views, have obviously not been settled once and for all with Green’s book, but it is a stimulating and clear account which shows that these issues are just as important, difficult, and necessary as thorough academic debates on—for example, the relation of facts to values. The book will be of interest to anyone who is interested in the mechanics determining the interaction of bioethics and the political sphere; it requires no previous familiarity with the topic and can thus also be recommended to the general reader.

H Schmidt

The Androgen Insensitivity Syndrome Support Group (AISSSG)

The Androgen Insensitivity Syndrome Support Group (AISSSG) http://www.medhelp.org/ www/ais is a consortium of worldwide sup- port groups, originating in the UK, providing information and support to adults and fami- lies affected by some conditions affecting the development of the reproductive system. These are conditions that have been subject to considerable secrecy and paternalism in the past, and AISSSG promotes full disclosure of diagnostic information with accompanying psychological support. It also encourages recent moves to evaluate the efficacy of geni- tal reconstruction surgery and supports the notion of autonomy and informed consent.

The conditions supported included AIS— androgen insensitivity syndrome (old name testicular feminization syndrome or testicular feminisation syndrome) — and similar condi- tions, for example, XY gonadal dysgenesis (Swyer’s syndrome), 5-alpha reductase defi- ciency, ledig cell hypoplasia, Mayer-Rokitansky-Kuster-Hauser (MRKH) syndrome, Mulle- rian dysgenesis/aplasia, and vaginal atresia.

9th Conference of the ABA: “Virtue and Vice in Bioethics”

You are invited to the 9th Conference of the ABA: “Virtue and Vice in Bioethics” on the 3–6 July 2003. The venue is Queenstown, New Zealand. Confirmed invited speakers: Art Frank, Carl Elliot, and Annette Baier. Further information: Pat Johnston, Dunedin Conference Management Services, New Zea- land (tel: +64 3 477 1377; fax: +64 3 477 2720; email: pat@dcms.co.nz).

European Integration: Philosophy and Ethics of Health Care

The XVIIth international congress of the European Society for Philosophy of Medicine and Healthcare will be held from August 21–23 2003 in Vilnius, Lithuania. Its theme is European Integration—Philosophy and Ethics of Health Care.

Further information: Professor Dr Henk ten Haeve, secretariat ESPMH, Department of Eth- ics, Philosophy and History of Medicine, Uni- versity Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@efg.kun.nl).
Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer's disease

M B Delatycki

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Updated information and services can be found at:
http://jme.bmj.com/content/29/2/120.1

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