LETTERS

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 look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination of pregnancy.

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.1 Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If so, in this case, 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 concerns 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, this is by no means certain for the woman herself. The only other report of people with this mutation also had early onset Alzheimer’s disease,1 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 Val171Ile mutation is 57 years.1 This is a mutation involving the same amino acid (valine at position 171) 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 societal 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.2

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 developing 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.

M B Delatycki
Preimplantation Genetic Diagnosis Team, Genetic Health Services Victoria, Royal Children’s Hospital, Flemington Road, Parkville, Victoria 3052, Australia; delatcm@cryptic.rch.unimelb.edu.au

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 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.3 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 submissions clearly show a broad range of responses will produce a lot of debate, is that the contributions often refer to each other. These responses range from the scholarly and meticulously argued to distressing accounts of suffering. As both an avid reader of rapid responses to the BMJ, and a physician, I consider both sorts of contributions to be valuable, but increasingly feel uncertain about what my written response to them might mean when I wish to enter into dialogue with the author. I feel on sure ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms at drawing up a response to point out its weaknesses. Equally, as a family doctor, I hope that I am able to address distressing accounts of suffering with a degree of empathy. It is sometimes the case, however, that submissions clearly show distress also contain dubious argument that any peer review process would deal with severely. Where accounts of suffering alongside dubious arguments are posted from patients I personally feel squeamish about responding, finding myself caught between the roles of vituperative reviewer and empathic listener. As an editorial in the BMJ on the subject of electronic responses has noted: “We’ve begun to capture the opinions and experience of patients... and publish just about anything that isn’t libellous or doesn’t breach patient confidentiality.”4 Inevitably, such a broad range of responses will produce many that deserve to be challenged. Merely to ignore dubious argument implies that such opinions are correct. Furthermore, it is astonishingly easy to post an electronic response, and the process contains no warning that opinions expressed may be severely challenged. We should consider what the rules of debate on this Journal of Medical Ethics web site should be.

To prevent any misunderstanding, I wish to state that this response does not issue out of intense personal suffering, and that I am prepared for the most stringent peer review of its contents. Say anything in response, but please don’t ignore me.

W Lewis
Carreg Wen Surgery, Church Road, Blaenavon NP4 9AF, Wales, waynel@dlewis.freeserve.co.uk

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Electronic correspondence should serve a significant function in many instances the very bedrock of moral reasoning exposed. The authors seem effortlessly to 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 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 diverse that it is 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 boundaries of the market”; along the way one is referred to books, chapters, and articles for further reading. As might be expected, Fulford’s notion of an explicit analysis of values is helpful in defining diagnostic cases, but in The Rules of Debate, in an interesting chapter Fulford describes the basis for his belief that psychiatry is a useful sample teaching seminar, showing elements of 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 criterion 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 bioethics, “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 book 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 biomedical ethics, explores the difference between truth-telling and honesty, and the philosophy of mind (rationality, reciprocity, and beneficence, with mutual recognition of their duties and obligations. 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. “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 that “truth matters”, so that care is given with integrity, and the 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 skillful communication allows patients to be 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 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...
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 health care. This contribution is a 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 several topics 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.

By the early chapters with 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 principles often thought dry and difficult. newcomers to the study of ethics will be pleasantly surprised.

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 Blane 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 suicide feeding. The Cax case, in chapter 3, elicits a discussion of concepts such as that of a worthless life, the oft-misunderstood 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; by their explanation 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 of Nazi principles. In order to test her principle as outlined, however, Watt needs to examine other situations where the principle of double effect is used.

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 ethical issues and does not attempt to provide a broadly discursive defence of 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 that are not intended. In this case, 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? Or does the man not regard himself as a marked man on the death of the schoolchildren?

The principle suggested by Watt also appears to reconcile the position that even where two patients will die and one is threatening the life of the other unless a doctor intervenes to save one, the doctor is required to do nothing and allow both to die. Such were the circumstances of the recent UK case of the conjoined twins, “Jodie” and “Mary”. It is one thing to say that the doctor may decide not to intervene—for example, on the grounds that he wants to respect the parents’ wishes: it is quite another to say that it is entirely impermissible to perform life-saving treatment on one twin (even where the parents wish it), in the same way as it is impermissible for the Nazi doctor to use a patient as fodder for experimentation. In the conjoined twins’ case, there are relevant moral differences. The immediate aim, not merely the further end, of the doctor in performing the operation is to save the life of one of the children. The Nazi doctor, by contrast, has the saving of lives as, at best, his further end. It is worth remembering too that by Watt’s own account, sometimes omissions to act to save a patient can be justified in cases of mental disordered, for instance whether the requirement that a doctor refrain, on moral grounds, from treating either of the patients destined for certain imminent death is not morally reasoning gone awry.

Chapter 3 is followed by brief explorations of the controversial topics of abortion and embryo destruction. The final chapter looks at the question of moral disagreement and conscientious objection. It is a reminder, if any were needed, of the practical nature of moral theory.

It is the book’s simplicity that leads me to believe that it will be read eagerly by students from a range of different disciplines. The layout and typographical style make the book particularly accessible. There is a comprehensive index and bibliography. If I have a criticism, it is that the book could have been longer. However, for those who want a basic text to introduce them to life and death issues in bioethics, this is a most welcome contribution.

J Laing

Medical Ethics, 3rd edition


Medical Ethics, to quote the authors, is intended as a practical introduction to the ethical questions doctors and other health professionals meet. The book is divided into three main sections: Foundations, Clinical ethics and Mediciine and society; each section is further subdivided into topics dealt with in a single chapter.

The first section deals very well with the more contemporary philosophy rather than and does not lay too much stress on the well-established “four principles” (chs 1 and 2). I have rarely read such a seamless introduction to the underlying principles of medical ethics and the discussion is clear and full of “common sense” and if taken to heart would, hopefully, detract from the arguments put forward.

The meat of the book, however, is in the second section (142 pages out of a total of 297). The “standard” topics of genetics, prenatal problems, birth, organ transplantation, AIDS, euthanasia, and brain death are all dealt with well and clearly, especially transplantation. The general format of the chapters is to briefly discuss the medical problems and then to introduce the ethical dimension. This ensures that a reader not familiar with a certain topic is reminded of the problems before entering into the ethical discussion. The chapters on genetics and ending human lives are particularly good in this respect. Two topics not commonly found in introductory texts are dealt with: the section, namely psychiatry and the problems with aging and dementia. Both are discussed sensitively and with compassion and are welcome inclusions in a text of this type.

The final section contains a brief discussion of medical ethics, justice, law and “trying new things”. This rather broad area is dealt with excellently and the rather oddly named chapter on “Trying new and unusual things” is highly recommended reading for anyone wishing to introduce new treatments (medical or surgical).

Overall, the book is well organised and, while it is an introductory text, there are ample references to sustain the authors’ arguments and for further reading. Case studies
T Russell

Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology

This encyclopaedia 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 of the topics 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 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 encyclopaedia that we read were well written and accessible, and 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 encyclopaedia is that they are very well made, attractive, solidly bound books. The format has been reinforced by first use of the encyclopaedia. A great deal of care has gone into making this reference work accessible and a pleasure to use. Two very minor additions that would improve this ease of use would have been 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 two volumes 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 discourse on 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, germ cell gene transfer". The section by Georgia Wiesner, Susan Lewis, and Jennifer Saldich on "subjects research, ethics and pedigree studies" was also excellent and well informed—both from a clinical point of view and also from a bioethics perspective. David Wasserman's heading on "Behavioural genetics" is also a fascinating essay. The discussion of research into the XXY karyotype and the MAO mutation provide an excellent background to the section. Again, this section would be a useful stratification for people wanting to do further work on his topic.

Overall, the editors have assembled an impressive cast, with many of the American names that you would expect to be involved in such a project. This does bring us to our first minor grumble: there are about a hundred contributors to this volume but only three are from the United Kingdom. This absence cannot be due to a lack of UK expertise and it is slightly disappointing that there is no contribution from writers based in the UK such as Ruth Chadwick, John Harris, or Soren Holm. This does raise the question of how attractive this volume is likely to be to the readers who are not in North America. In addition to the majority of authors, being from the USA much of the public policy and legal discussion in the volumes is US centred. It is hard to see how this could have been avoided, given the authors, however, it does mean that the researcher using this text will need to be careful to ensure that the use of everyday language to the rest of the world.

Given that these two volumes cost £370 it's unlikely that any but the most enthusiastic and wealthy individual will be able to buy the encyclopaedia. This is primarily a collection for libraries.

J McMillan
jm439@cam.ac.uk

M Parker
michael.parker@e酌hox.ac.uk

The Use of Human Biobanks. Ethical, Social, Economical, and Legal Aspects

This booklet (freely accessible online at http://www.bioethics.uu.se/biobanks-report.html) documents a conference organised by a Swedish research project on the various social and ethical issues raised by the use of so called biobanks—that is, large collections of human tissue samples. There is considerable interest among researchers, the biotech industry, and society at large in using biobanks for the continued investigation of genetic health factors that is now following the completed mapping of the human genome. Central issues are: the responsibility of biobanks or users of these to protect tissue donors in various ways; how these responsibilities should be balanced against business and research interests, as well as against the interests of people and in general in the case of conflict and, not least, what procedures of informed consent (including the hard question of the scope of the consent) should be deemed as appropriate in the biobank setting.

Although formulating these issues against the background of the actual scientific, legal, and business situation in this area, the booklet provides few answers, but outlines various studies that are to be undertaken. Because the contributions focus almost exclusively on the Swedish context (an addition of “in Sweden” to the title would not have been misplaced), this makes the relevance of this publication to a broader international audience somewhat limited. In some cases, this focus becomes so overwhelming that Swedish research ethical practice and legislation is taken for granted, without any attention being paid to differences that exist in Sweden and other parts of the West. For example, Mats G Hansson states, as a basic feature of the ethical background to biobank issues, that it would be disrespectful of research integrity if their control over collected research materials, data, and results were limited by regulation; and he claims that this can be inferred from the traditional legal right of Swedish individual researchers to have such control. This presupposes, however, that this tradition (which is hardly a given from an international perspective, where universities and funding parties are often granted much more control) should be taken as universal—a presupposition that clearly begs relevant ethical questions. The value of the booklet is further impeded by the lack of a substantial overview chapter (either at the beginning or at the end) which could have served to tie together the rather heterogeneously written pieces on scientific strategies; business interests; ethical point of view deal with the basic conflict between individual integrity and social utility (Mats G Hansson); what model of informed consent is most appropriate in a biobank setting (Stefan Eriksson), and under-
itself and familiarises the reader with the technical issues and conceptual conundrums (potentiality, 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 the 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 shaping 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 complexity of the interests of scientists, patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups with radically differing interests, and different positions on the different issues of the discussion. 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 isolating an ideal procedure suitable for governing negotiations between the conflicting parties, the author is centrally interested in setting the agenda in bioethical policy making, and former president of the Society of Christian Ethics, Philosophy and History of Medicine, University of Nijmegen, the Netherlands (fax: +31 (0)24 321–23 20). Further information: Pat Johnston, Dunedin Conference Management Services, New Zealand. Confirmed invited speakers: Art Frank, Carl Elliott, and Annette Baier. Further information: Professor Dr Henk ten Have, secretariat ESPMHR, Department of Ethics, Philosophy and History of Medicine, University Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@efg.kun.nl).

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The Androgen Insensitivity Syndrome Support Group (AISSG)

The Androgen Insensitivity Syndrome Support Group (AISSG) http://www.medhelp.org/www/ais is a consortium of worldwide support groups, originating in the UK, providing information and support to adults and families 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 AISSG promotes full disclosure of diagnostic information with accompanying psychological support. It also encourages recent moves to evaluate the efficacy of genital reconstruction surgery and supports the notion of autonomy and informed consent. The conditions supported included AIS—an androgen insensitivity syndrome (old name testicular feminization syndrome or testicular feminisation syndrome)—and similar conditions, for example, XY gonadal dysgenesis (Sryver’s syndrome), 5-alpha reductase deficiency, legyd cell hypoplasia, Mayer Rokiten-sky Kuster Hauser (MRKH) syndrome, Mullerian 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 Elliott, and Annette Baier. Further information: Pat Johnston, Dunedin Conference Management Services, New Zealand (tel: +64 3 477 1377; fax: +64 3 477 2720; email: pat@dcrms.co.nz).

European Integration: Philosophy and Ethics of Health Care

The XVIIIth 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 Have, secretariat ESPMHR, Department of Ethics, Philosophy and History of Medicine, University Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@efg.kun.nl).