

## Introduction: recent debates in maternal-fetal medicine – what are the ethical questions?

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This book is arranged by the stages of pregnancy – in part because it is intended for a clinical audience, in part because the stages of pregnancy offer a narrative framework for understanding the recent debates in maternal–fetal medicine. This introduction, however, offers a different kind of descriptive framework – a conceptual one. In the second chapter, Carson Strong complements this introduction by suggesting a *normative* framework for use in debating issues in reproductive ethics generally, and maternal–fetal ethics in particular. (Reproductive ethics would also include other more ‘high-tech’ areas such as reproductive cloning, which are mostly omitted from this book because at present they are not immediately relevant to clinical practice, no matter how many column-inches of newsprint they occupy.)

Judging by the interests of the authors collected here, who come from a wide international and professional range of backgrounds, recent ethical debates in maternal–fetal medicine can be grouped into four principal areas:

- (1) *Power in the obstetrician–patient relationship, and the justifiable limits of paternalism and autonomy.* Another less familiar way of phrasing this tension, as Jean McHale puts it in her chapter (6), is in terms of two dominant but conflicting rhetorics – ‘choice’ versus ‘responsible parenting’.
- (2) *The impact of new technologies and new diseases.* Here IVF (in vitro fertilization) and associated fertility technologies are twinned with HIV and AIDS because in both cases developments from outside ethical theory are driving ethical debate.
- (3) *Disability and enhancement.* Although the concept of disability may appear purely clinical, a growing body of work views it as socially conditioned and value-laden. If there is no such thing as disability per se, in the extreme version of this view, then we must question the basis for interventions aimed at reducing disability in populations or preventing the birth of a ‘handicapped’ child to a particular couple. Similarly, at the other end of the scale, if ‘normality’ is not a clinical but a normative concept, what do we do about the desire to have children who are in some way ‘better’ than ‘normal’? The possibility of genetic therapeutic manipulation accentuates problems about ‘enhancement’ – what is often

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- termed, perhaps with little justification, the ‘designer baby’ syndrome.
- (4) *Difference*. Primarily an issue about culture, but also one about gender. To what extent must the clinician respect the tenets of other faiths in a multicultural society, even when patients or their families request interventions which the doctor believes to be morally wrong? The importance of gender enters in here not only when such interventions disadvantage women, but also because feminist theory, particularly in its psycho-analytical and postmodern versions, offers a way of understanding and foregrounding difference.

These issues are listed in ‘descending order of popularity’, so to speak. As we might expect, the largest number of contributions fall into the first category, the rather traditional but still problematic opposition of paternalism and autonomy in the obstetrical relationship. Into this grouping I have put the articles by Françoise Baylis and Susan Sherwin (18), Susan Bewley (8), Cynthia Daniels (7), Gillian Lockwood (10), Eileen McDonagh (14), Jean McHale (6) and Wendy Savage (17). Feminism informs both this first category and the fourth, although many fewer contributors have concentrated on difference – see Sirkku Hellsten (3) and Françoise Shenfield (9). Into the second category, the impact of new technologies and new diseases, fall the chapters by Donna Dickenson (15), Elina Hemminki (12), Mary Mahowald (16), Rosemarie Tong (5), Heather Widdows (11) and Paquita de Zulueta (4). The third set of issues, concerning disability and enhancement, is the focus of the chapters by Priscilla Alderson (13), Rebecca Bennett and John Harris (20), Neil McIntosh (21) and Christine Overall (19).

### Power in the obstetrician–patient relationship

Referring to ‘power in the obstetrician–patient relationship’ will offend some physicians and strike others as inaccurate. In an age of audit and patient consumerism, they may argue, it is misleading to assume that it is doctors who have power over patients; the power dynamic is the other way around. In this section both sorts of power imbalance are explored; for example, Gillian Lockwood, a philosophically trained director of an English fertility services unit, discusses this issue from the point of view of the clinician who sometimes feels powerless to resist the patient’s demands. Her chapter (10) concerns a would-be IVF patient with end-stage renal failure, who has had a kidney transplant, and who has a 10 per cent risk of dying within one to seven years of giving birth. The patient’s initial kidney failure was due to severe recurrent pre-eclampsia in two earlier pregnancies, which both resulted in neonatal death after delivery at 26 weeks. Given that section 13 (5) of the Human Fertilisation and Embryology Act 1990 requires the clinician to consider the welfare of any child who may be born as a result of fertility

treatment, should the clinician resist the woman's request in the name of the future child? In the best interests of the patient herself? It has been argued that this is the first time UK statute law has required doctors to make a value judgement about women's capacity to parent (Rennie, 1999); the test for abortion provision is less stringent and more medical. Does the existence of this legislation put the careful clinician at a power advantage or a disadvantage in dealing with doubtful requests by patients?

Nevertheless, the power of the doctor – the medical mystique is itself a force either to heal or to impede healing (Brody, 1992) – is still too widely ignored in conventional bioethics, which, very broadly speaking, generally conceives of the patient as autonomous and independent. To put it another way, conventional bioethics frequently lacks a political dimension (Dickenson, 2000). Although the principlist approach (Gillon, 1985; Beauchamp and Childress, 1989) includes justice as the fourth principle of medical ethics, the bioethical literature is far fuller on the first principle – that of autonomy. It has taken a feminist analysis to bring power relationships to the fore, and it is particularly appropriate therefore that power in the obstetrician–patient relationship should be the first category in this book, one of the aims of which is to bring together clinicians and feminist theorists.

The clinician who herself most embodies this synthesis is perhaps the English consultant obstetrician Dr Wendy Savage, who was the subject of a lengthy professional investigation in the mid-80s designed, many felt, to discredit her because she was dedicated to giving obstetric patients more power to choose. The investigation failed when it transpired that Dr Savage's record of safe and successful deliveries was actually better than that of her male colleagues, despite her opposition to medical paternalism. It is therefore very fitting that Wendy Savage should have contributed a chapter ('Caesarean section: who chooses – the woman or her doctor?') to this book.

Savage sets out the medical sequelae of Caesarean section in terms which make it clear that judicial interventions to enforce Caesareans on unwilling women put the patient at far greater risk. Emphasizing that the patient is the woman and not the fetus, Savage then details the history of enforced Caesarean judgments between 1992 and 1998. The initial judgment, *Re S* (1992), was based on an erroneous reading by the judge of the US *Carder* case (In *Re AC*, 1990) in which a terminally ill woman was forced to undergo a Caesarean section in an unsuccessful attempt to save the life of a fetus at the borderline of viability. The *Carder* case was overturned on appeal, but the High Court judgment missed that point. From then until 1998, English law, although based on this basic misunderstanding, moved closer and closer to overturning the traditional common law doctrine that the fetus is not a legal person (Scott, 2000). In the process, the Mental Health Act 1983 was also used to enforce Caesarean sections, although section 63 of that statute makes it clear that it must only be used to sanction forcible treatment for a mental

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disorder, never a physical one. The courts pulled back from the brink in 1998 with the *St George's Hospital* judgment (*St. George's Healthcare NHS Trust v S* [1998]), which reiterated that a competent woman has the right to refuse a Caesarean section, as she would any other procedure.

Savage also briefly considers the opposite situation, in which the woman requests a Caesarean section which the doctor opposes on the grounds that it is not clinically indicated and will increase the patient's level of risk. She argues that even a feminist clinician need not accede to any such request: 'So, whilst I as a doctor can support "a woman's right to choose" an abortion, and as a feminist I also support it, I do not think that CS on demand is every woman's right.' Here, as in Lockwood's case, the other aspect of power in the doctor–patient relationship comes to the fore – the case in which the clinician feels at a power disadvantage in resisting requests that are not in the patient's best medical interest.

The equivalent legal and political history for the US is set out by Cynthia Daniels (Chapter 7), but in terms which go beyond enforced Caesareans to include other forms of regulation of pregnant women – particularly those who abuse drugs. Women, Daniels argues, are seen as solely to blame for subsequent harm to fetuses, disregarding the documented connection between paternal exposures to toxins and fetal health. Male reproduction is construed in terms of virility, female in terms of vulnerability – with the exception of women of colour, who loom large in the American public debate about 'abusive' crack mothers. Yet sperm are also depicted as 'the littlest ones' at risk from environmental toxins. (We have seen much the same phenomenon in the UK, with publicity concerning the high levels of synthetic oestrogens in water and other sources, which are alleged to reduce male fertility.) Men are not to blame for the toxins to which they are exposed, however: 'Even in newspaper stories that address the connection between paternal exposures and fetal health, certain patterns of reporting emerge that function to reduce male culpability for fetal harm.' In terms of the doctor–patient relationship, then, Daniels's chapter should sensitize clinicians to the ease with which judgements can be made about female culpability for fetal harm – a cautionary note.

This same dilemma is tackled from a more explicitly clinical point of view by Susan Bewley (Chapter 8). Bewley, who is lead clinician in maternal–fetal medicine at St Thomas's Hospital, London, faces similar dilemmas to those which concern Savage – how far should a feminist obstetrician go in imposing treatment on women in the name of their own best interest, and/or that of the fetus? Bewley is willing to recognize the interests of the fetus to a greater, more pragmatic extent – or more correctly, to recognize the uniqueness of the maternal–fetal relationship, without necessarily assuming, in a naturalistic manner, that this uniqueness carries moral weight. Bewley maintains that the regulation of women who have chosen to maintain their pregnancy is also

a different question from the abortion debate. The concepts which have evolved in the abortion literature are not really relevant to the clinician's dilemma in dealing with a drug-using pregnant patient.

In attempting to develop a conceptual framework which fits this particular clinical situation, Bewley draws on Frankfurt's distinction between first- and second-order desires (Frankfurt, 1971). It is a logical error to assume that a pregnant woman who continues to take drugs has a guilty intent to harm her fetus. 'Her first-order desire to take drugs overwhelms another first-order desire to do the best for her fetus, and possibly a second-order desire to be a drug-free woman. This is a double tragedy, as she harms her fetus, against her will, and her will is not free and autonomous.' Here Bewley and Daniels agree – the moral panic over 'crack mothers' is politically motivated but clinically unhelpful. Bewley's article is a model for what this book tries to achieve – the marriage of analytical and clinical arguments, put forward by a philosophically and legally aware clinician.

The British medical lawyer Jean McHale (Chapter 6) likewise considers the manner in which 'pregnancy over the last decade has become policed by those who advocate responsible motherhood'. As more widespread genetic information becomes available, she warns, 'it is likely to render us increasingly critical of those who make what we regard as being the "wrong" decision in relation to reproduction'. Can having a child at all be a 'wrong' decision? – particularly if it is known in advance that the child is likely to be so severely handicapped as to have little or no 'quality of life'. McHale is sceptical of this argument, suggesting that codes of practice stressing parental duties not to reproduce unless the offspring meet certain criteria are really just rationing tools. The argument that it is unfair for society to bear the 'costs' of the couple's penchant for reproduction, if their children are likely to be handicapped, meets with no friendlier reception from her. Pressing on beyond these politically motivated arguments, McHale asks whether there could conceivably be any remedy in law for enforcing a 'right not to be born'.

'Policing' motherhood is also a concern of the American political scientist Eileen McDonagh, who has contributed a groundbreaking chapter on 'Models of motherhood in the abortion debate'. In a previous book, *Breaking the Abortion Deadlock: From Choice to Consent* (1996), McDonagh sought to unite opponents and proponents of abortion behind an argument justifying abortion not in terms of the woman's right to choose, but of her consent to further continuation of the pregnancy. Conceding fetal personhood *in arguendo*, as most pro-choice activists do not, McDonagh argued that even if the fetus were a person, its claims would not necessarily 'trump' the mother's right to withhold consent to continuing the pregnancy and giving birth. (This is perhaps a more coherent argument in the US than in the UK, in that the *Roe* decision already turns on the woman's right to privacy rather than on the fetus's lack of legal personality.) In her chapter for this volume, McDonagh

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again breaks down the barriers between feminist and antifeminist arguments: 'The problem of abortion has been defined by pro-life activists (as we would expect), but also by pro-choice advocates (as we might not expect) on the basis of a very traditional model of motherhood, one invoking cultural and ethical depictions of women as maternal, self-sacrificing nurturers'. That is, by stressing the way in which unwanted pregnancy forces women into the stereotype of sacrificial victims, the model of motherhood used by pro-abortion campaigners is actually deeply conservative, and possibly counter-productive. In terms of the dynamic of autonomy and paternalism, it gives away too much hard-won ground.

McDonagh's chapter, like Daniels's, takes this section of the book out of the confines of the dyadic doctor–patient relationship and into the political arena. By contrast, Françoise Baylis and Susan Sherwin (Chapter 18) extend the political power dimension into a very familiar and 'ordinary' side of the obstetrician–patient encounter – 'non-compliance'. Baylis and Sherwin draw our attention to the way in which this apparently value-free term is used to reinforce the physician's power and to label the patient as an object of concern rather than a partner in the clinical relationship. 'In principle, professional advice is something that patients can choose to follow or not – this is the essence of informed choice... In some instances, however, failure to follow professional recommendations elicits pejorative judgements of non-compliance, and while these judgements are provoked by a failure to comply with specific advice, typically they are applied to the patient as a whole'. By alerting the conscientious practitioner to the ubiquitous presence of ethical issues, Baylis and Sherwin help to counteract the popular media assumption that the *only* serious questions in reproductive ethics are those about new technologies. That certain technology-related questions are also increasingly relevant to everyday practice, however, is the theme of the second section of the book.

### **The impact of new technologies and new diseases**

The questions asked by McHale about limiting the rhetoric of responsible parenting recur in a more technology-driven form in the chapter by the American philosopher and feminist theorist Rosemarie Tong (Chapter 5). Pre-implantation genetic diagnosis (PIGD) extends the boundaries of what 'responsible' parents could and should do for their children, it might be argued. Likewise, the aims of medicine may conceivably be extended from doing no harm to this particular mother and fetus to producing the best babies possible. Perhaps this is a particular temptation in a largely privatized health care delivery system such as the US. As Tong remarks, physicians are unable to resist patient demands for genetic enhancement because there is no

generally agreed set of aims of medicine with which to counter such demands – ‘Medicine, it has been argued, is simply a set of techniques and tools that can be used to attain whatever ends people have; and physicians and other health care practitioners are simply technicians who exist to please their customers or clients, and to take from them whatever they can afford to pay’. Unless doctors are content to play this passive role, it is essential that they should think through the ethical issues surrounding new technologies and the increased demands to which they give rise. Should there be limits to genetic enhancement techniques? Should there even be limits to the obligation to seek to eliminate disease through the use of new technologies such as PIGD?

Advocates of PIGD present it as enhancing parental choice; Tong asks instead whether it might conceivably be a parental duty, either to future generations in general or to their own offspring. Although it seems plausible that there might be a duty to eliminate genetically transmitted diseases, to whom might we owe this duty? It is difficult to see how parents may owe a duty to children they will never have, which is the inevitable corollary of PIGD in that it enables the elimination of ‘defective’ fetuses. (Tong is sensitive to the value implications of ‘defective’, raising issues about disability and ‘normality’ which also recur in the chapters discussed next under ‘Disability and enhancement’.) In her conclusion Tong finishes by arguing that there is a limited right to seek to perfect one’s children genetically, and conceivably also a limited duty, but that society should seek to discourage parents from doing so.

The American medical ethicist Mary Mahowald (Chapter 16) raises similar issues about the duties of mothers faced with another set of ‘choices’ created by new reproductive technologies, particularly IVF. ‘Although medical advances have considerably reduced the mortality and morbidity risks of childbearing for most women and their offspring, that same technology has introduced methods by which people who would not otherwise reproduce can have biologically related children. These methods are mixed blessings when the pregnancies they facilitate exacerbate the risks of gestation for women and their fetuses. They are also mixed blessings when, while providing a means to desired motherhood for some, they occasion pressures on others to undergo risks they would not otherwise encounter’. Higher-order pregnancies, as a form of iatrogenic harm occasioned by misapplication of fertility technologies, are the particular focus of Mahowald’s attention.

The usual terminology for discussing such cases is ‘fetal reduction’, but Mahowald regards this concept as an oxymoron. No particular fetus is being ‘reduced’ – it is either being eliminated or preserved. Thus, Mahowald argues, the term ‘fetal termination with pregnancy preservation’ is preferable. This distinction is not merely semantic finickiness – ‘fetal reduction’ obscures the fact that some fetuses are being aborted, and yet even a ‘pro-lifer’ might

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agree that it is better to preserve some fetuses' lives if the alternative is the loss of all the fetuses. But which fetuses' lives? Can selective termination ever be justified, or is allowing 'targeting' of a particular fetus on grounds of sex, for example, simply wrong whether that sex is male or female? In a series of illuminating case examples, Mahowald teases out the ethical issues around selective termination, concluding that it may sometimes be justified but that practitioners need to be alert to possible abuses in justice which it may raise.

The still somewhat taboo question of what duties semen donors may have to their children is explored by Heather Widdows (Chapter 11). Widdows focuses on two main aspects of secrecy – donor anonymity and secrecy within the family, particularly non-disclosure to the child. Traditional arguments for secrecy are beginning to give way to counter-arguments for openness, but will donors still be forthcoming if their identities can be traced? Evidence from Sweden (the first country to introduce non-anonymous donation) indicates that after an initial dip in the number of donors, earlier levels of donation are regained, but with a different sort of donor, with more altruistic motivations.

In her section on secrecy in the family, Widdows covers issues such as accidental disclosure to the child, and the possible analogy between donor insemination (DI) and adoption. She explores what the best interests of the DI child are and discusses the importance of knowing one's genetic heritage in forming a stable identity. She also reflects on the effects of lying within the family, drawing on Kantian arguments. Finally, the validity of the arguments both for and against anonymity are considered, and the implications of changes in the practice of secrecy for donor insemination are outlined.

Elina Hemminki (Chapter 12), a Finnish epidemiologist and health technology assessment expert, approaches antenatal screening from an evidence-based medicine viewpoint. Her contribution is particularly valuable because, as an 'outsider' to medical ethics, she is able to pick up inconsistencies in how the reproductive ethics literature treats different interventions which actually raise many of the same questions. Whereas Tong and Mahowald primarily consider the individual woman or couple, Hemminki concentrates on populations, and on the ethical questions raised by mass screening. Is it right, for example, to impose on those undergoing screening an unavoidable risk of false positives and false negatives – which will never be altogether eliminated, no matter how precise the screening process? What about the impact of a positive test result on the wider family group – i.e. who also may be revealed to be at risk? How far does the duty to be screened extend, if there is such a duty?

'Fetal screening,' Hemminki writes, 'is based on certain values and beliefs, such as the importance of health, the feeling that a handicapped child is worse than none at all (particularly if there is an option of having a chance to try again) and the perception that handicaps cause suffering to the child itself, its



parents and/or to society. Through the organization of screening programmes and concomitant research, medicine and health care have been given the authority to define which diseases and characteristics qualify for these beliefs'. Directing our attention to the wider societal impact of screening, outside the dyadic doctor–patient relationship, Hemminki argues that medicine has been given something of a poisoned chalice. What appeared at first to be a straightforward part of the goals of medicine, the reduction of disease in populations through genetic screening, is neither straightforward nor necessarily part of the goals of medicine.

Similarly, the development of stem cell technologies may appear at first to be an unmitigated blessing in terms of disease reduction, but the manner in which stem cell lines are being established gives profound cause for fears about abuse and exploitation. Donna Dickenson (Chapter 15) likewise moves beyond the confines of the doctor–patient relationship, into wider issues of justice. Most commentators have concentrated on the moral status of the embryo, and those who have concluded in favour of developing stem cell banks or lines have done so on the basis that the embryo used is not harmed because it will in any case be destroyed (e.g. Nuffield Council on Bioethics, 2000). In contrast, Dickenson concentrates on the risks of exploitation of pregnant women, and conversely on the arguments in favour of their possessing a property right in stem cells derived from their embryos or fetuses, in addition to the procedural right to give or withhold consent to the further use of those tissues.

These rights can be viewed in a Lockean fashion, as derived from the labour which women put into the processes of superovulation and egg extraction (embryonic stem cells) or early pregnancy and abortion (embryonic germ cells). Alternatively, a marxist feminist interpretation would emphasize the added value which women put into the 'raw material' of gametes. Uniting philosophical and jurisprudential argumentation, Dickenson argues that it is legally fallacious and politically dangerous to assume that biotechnology companies should necessarily own the products derived from women's labour in reproduction.

It is not only new technologies which pose ethical dilemmas; 'new' diseases do so as well. The British general medical practitioner and lecturer Paquita de Zulueta (Chapter 4) sets out a wide range of ethical issues that are not always fully recognized in the care of HIV-positive pregnant women. Many of these issues centre around responsibility for bringing infected children into the world, or orphaning children, particularly in the Third World context. But equally, in many cultures the notion of individual responsibility would be alien to the question, as would the notion of conflict between the interests of the HIV-positive individual and the wider community (for example, in civil liberties questions).

De Zulueta concentrates particularly on the ethics of anonymized testing,

which sets utilitarian arguments in favour of reducing the incidence in the general population against the individual woman's 'right to know' – and perhaps to take prophylactic measures. She argues that arguments for anonymized testing are dominated by the 'old ethics' of medical paternalism, but that whereas paternalism is usually justified on the basis of the relationship of trust between the doctor and patient, that fiduciary relationship actually rules out anonymized testing. It is wrong, she argues, to use the newborn as a means to test maternal antibodies. In her conclusion, De Zulueta claims that (asymptomatic) pregnant women who undergo anonymized HIV testing are not patients, but rather healthy people who volunteer for testing in order to benefit the fetus. How can we balance the respect due to the pregnant woman's autonomy – particularly when she is not sick – with concern for the welfare of the woman and the fetus?

## Disability and enhancement

Issues surrounding disability and enhancement are touched on by several of the authors already summarized, but they come to the fore in the chapters by Neil McIntosh, Priscilla Alderson, Christine Overall, and Rebecca Bennett and John Harris.

Neil McIntosh (Chapter 21), a consultant paediatrician in Scotland, offers a practising clinician's slant on disability, in the context of ethical issues in withdrawing life-sustaining treatment. He writes, 'Life-sustaining treatment implies that treatment is being given in order to maintain or create the best possible outcome for the child's future life. This future might be abnormal but it would be assumed to be compatible with the self-respect of the family and later of the infant and child. Such management should be in the best interests of the child concerned.' Yet what appears an unexceptionable position here is actually replete with difficult ethical judgements. It seems that McIntosh accepts a 'disability rights' perspective by acknowledging that 'this future might be abnormal'. However, the very notion of 'normality' is seen by some disabled people as itself a form of discrimination. At the end of his chapter, McIntosh offers a useful typology of uncertainty concerning the *probability* of severe disability and its effect on clinical decision-making, but what about the *utility* question? Is even severe disability necessarily a harm or loss?

This sceptical view emerges strongly among the people with disability interviewed by the English sociologist and children's rights advocate Priscilla Alderson (Chapter 13). Offering a qualitative research slant by interviewing adults who have conditions that are the object of antenatal testing, Alderson reviews contrasting positions on the advantages and disadvantages of prenatal counselling. The consensus among her interview subjects is that