

ETHICS IN INFERTILITY TREATMENT

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Abstract: The author acknowledges the considerable advancements in the management of the infertile that have taken place in recent years and seeks to explore the fundamental ethical issues that inevitably arise. The rationing of services for financial or organisational reasons is explored, and other questions are raised: Does the donor of sperm or eggs have the right to anonymity or is that an infringement of the child's right to information on their genetic make up? Should there be an upper age limit for women and men for donation and treatment? With genetic diagnosis sex can be determined, and abnormalities detected, what are the links with that information to abortion? A very thought provoking article that concludes with a personal comment on the polarised stances these ethical issues raise, and the place of the Christian healthcare professional somewhere in the middle, alongside the patients.

The Editors

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The last few years have seen astonishing advances in the management of the infertile. Important and fundamental ethical issues are inextricably associated with these developments. The purpose of this brief review is to highlight, within a few key areas of reproductive medicine, some contentious issues, and to elaborate ethical principles, which may help to inform clinical decisions in these difficult areas.

General principles: a framework for ethical practice

As health care workers treating infertile couples, we have obligations to our patients to help them in the management of their infertility. These role-related obligations sometimes conflict with general moral obligations, affecting all in society. Consideration of the three moral principles (non-maleficence, beneficence and respect for autonomy) assist in difficult clinical situations. However, these principles can be complicated in several ways. For example, the assistance of one individual may be at the expense of the welfare of another, to whom one has obligations. Resolution of such conflicts has been the basis of the advancement of two general ethical theories, whereby the rights and wrongs of specific actions can be determined. The first of these is consequentialism, whereby the appropriateness of specific ac-

tions is judged only by the results those actions produce. Since the consequences of an action may not be equally beneficial to all affected by such an action, consequentialists argue about who should derive the maximum benefit therefrom. *Utilitarianism* describes the resolution of such conflict through instructing agents to maximise the good for as many as possible.

The second theory, to which some might subscribe, is termed deontology. In contrast to consequentialism, this denies that the end justifies the means. It is the nature of an action which is of critical importance, and its consequence, while relevant, is not the prime moral measure of acceptability.

Space does not permit further elaboration of these important concepts and the reader is referred to other texts. However, examination of a number of current issues in infertility, with reference to the above framework, may be helpful in an analysis of how ethics impacts on everyday practice in the clinic.

Rationing infertility services

The provision of specialist medical services in society is influenced by an assessment of the health

needs of the population as a whole (demand), the resources allocated for the purpose (supply), and importantly the potential for health gain through medical intervention (clinical effectiveness). Rationing, whereby potentially beneficial healthcare may be withheld for financial or organisational reasons, presents a major ethical problem. This has been at the heart of state financing of medical care since the inception of the NHS. Ethical principles conflict, since rationing of health care resources leads to tension between our utilitarian concern to benefit the maximum number of stakeholders in our society, and our desire to respond to the needs of individuals. The deontological view would be that irrespective of cost, the best possible treatment should be available for all patients.

The proportion of our national gross domestic product which should be invested in the provision of state funded health care is a matter of continued political debate. The consequences for patients of inadequate investment to provide universal funding for care in any branch of medicine, are either to access alternative providers of care in the private sector, or, for those with insufficient personal resources to meet the high costs of such alternatives, denial of access to treatment.

If universal healthcare funding is unattainable we face a problem of establishing justice in determining the relative merits of one form of medical treatment over another. Commissioners of healthcare are required to prioritise amongst diverse medical areas, and thus robust, objective and transparent mechanisms should inform such policy decisions. Utilitarian principles dictate that there should be representation of all stakeholders in bodies making such decisions and that they should be accountable for their actions.

Specifically with respect to infertility services, the policy of central government to devolve decisions on funding treatment to local commissioners has led to inequalities in access to care across the country. Surveys in recent time have highlighted the large variation throughout the country of access to NHS funded IVF. If it is accepted that not all will have access to treatment within a defined population, in the pursuit of equity and justice, agreed UK criteria should be developed and applied in assigning prioritisation amongst couples needing IVF. In Scotland, certain criteria, both medical and social have been

devised and implemented. They may prove to be a model for a national UK policy in this difficult area.

Gamete donation

Many, if not most, of the most difficult ethical issues relating to assisted reproduction techniques involve donated eggs or sperm. Health care providers have to take in to consideration the needs, not only of the infertile couple seeking treatment but also those of the donor and any potential child that might result as a consequence of treatment. Ethical principles applied in such a triangle may result in conflict of interest between parties. Responsibilities for the well being of patients include adequate information and implications counselling about procedures before, during and after treatment. Support counselling may also be required. Donors require to be informed about their legal rights in relation to donation. They have the ability to withdraw from the process at any point up to the moment of treatment with their gametes, and should be given reassurance regarding anonymity where relevant. An obligation to take account of the welfare of any child which may result from such a donation is enshrined in legislation, and the Code of Practice of the Human Fertilisation and Embryology Authority (HFEA) gives guidance in this area. Clinics offering treatment must obtain a licence to carry out procedures, and failure to comply with HFEA regulations is a criminal offence. While the medical risks of treatment relevant to the welfare of the child may be easily understood, guidance on social hazards is inevitably more nebulous. These include consideration of the need of the potential child for a father. The Code does not preclude the treatment of single women, but exhorts clinics to take care in such situations.

Around 13,000 donor insemination cycles are carried out annually in the UK each year. The treatment is often successful with over 1300 children born in 1997-8. Sperm donations are compensated for financially through the payment of reasonable expenses incurred in the provision of the specimen at the clinic. Questions may arise around the ethics of paying donors, as well as issues surrounding the preservation of anonymity. It is a donor's legal right to expect anonymity to be respected. However, non-identifying information about donors is stored by the clinic, and the HFEA. When a child attains 18 years of age, or alternatively 16 years of age if about to marry, they may apply to the HFEA to find out if

they were born as a result of gamete donation. Where applicable, they may also find out if they are a blood relative of any individual they intend to marry. Preservation of donor anonymity, while protective of the donor, could be perceived as an infringement of the child's rights to knowledge of their genetic origins. There has been considerable debate regarding the possibility of withdrawing donors' rights to anonymity. Clinics, already struggling to provide a service, have major anxieties that such a change in policy would have profound effects on their ability to continue to recruit donors. While perhaps deontologically more attractive, a possible collapse of the service would, from a consequentialist perspective, be undesirable. The same anxieties also exist in relation to arguments about withdrawing payment of expenses for gamete donation, appealing as it does to purely altruistic motives in donors, perhaps desirable, but in practical terms potentially destructive.

Egg donation implies that a woman is prepared to undergo all the hazards of in vitro fertilisation, including ovarian stimulation and egg recovery. It has been argued that, for such an act of sacrifice, financial or other compensation is appropriate. Conversely, others have suggested that women should not be permitted to put themselves at risk for the sake of others, who after all are not "ill" in the true sense of the word. The concept of egg sharing is an interesting ethical conundrum. Women who are unable to afford "private" IVF can be offered treatment if they are prepared to give up some, usually half, of the eggs they might produce after ovarian stimulation, to a couple who require egg donation, and are prepared to pay for the donor's treatment cycle. It is argued that this is a win-win situation, where both the donor and recipient stand to gain. Some however take the view that this mechanism may lead to coercion in recruiting donors, a morally dubious position to advocate. In addition the donor's chance of pregnancy may be reduced if they have to give up some of their own eggs for another individual. Furthermore, were they not to conceive, and the recipient of their eggs to be successful, their distress at their own failure might be greatly magnified.

It is uncertain whether children born through gamete donation would be better off knowing their true genetic origins. The egg donation child's perception of the role of the birth mother in their existence may be clearer than might be the case of the father in sperm

donation offspring where the infertile male has a passive role.

Gamete donation is mostly employed in the treatment of couples where one member has biological infertility. Occasionally clinics receive requests for treatment from individuals, or couples, with a non-conformist lifestyle, e.g. single women, homosexual couples, leading to "social" infertility. Clinics often have to decide on whether such treatment should be made available to such individuals. These difficult scenarios raise the question as to who should judge whether assisted reproductive technology should be applied in these cases. Should one's personal views have any bearing on the acceptability of these requests to generate pregnancies in social situations where biologically conception could not possibly occur, or should one act merely as a morally neutral technician?

A further debate relates to the gamete donation requests from older (post menopausal) women. What is the upper limit at which couples should be allowed to have babies? Technology can facilitate pregnancies in women in their sixties, and many have called for this to be banned. Yet where is the consistency in a policy which denies women with a potential life expectancy of over 20 years after IVF treatment, yet allows access to some younger individuals with a shorter potential life span, as for example might occur with cancer or multiple sclerosis? Should there be an upper age limit for men to father children?

Clinics often find themselves as the unwilling gatekeepers in issues of access to treatment and, as with NHS funding criteria, perhaps some nationally agreed guidelines in this area would be appropriate.

Surrogacy

A recent survey revealed that around 30% of HFEA licensed clinics, in the UK, provide surrogacy services. These cases, while unusual, present formidable ethical challenges and result in a very large amount of work for the counselling services of clinics involved. Partial surrogacy involves the fertilisation, by insemination, of the eggs of a volunteer woman using the sperm of the male partner of a childless couple, or a donor if no partner exists. Full (IVF) surrogacy involves the use of the sperm and eggs of the childless couple and embryo transfer into

a host female to generate a pregnancy. In both instances the birth mother gives up the infant to the childless (commissioning) couple who then through the issue of a parental order can adopt the child as their own. The interests of a great number of individuals require to be considered. These include the potential child, the surrogate mother, her partner and any children they may have, as well as the commissioning couple and any children they may have. The distress generated where a surrogacy arrangement breaks down is catastrophic and great care should be taken to provide adequate counselling services at all levels before embarking on any treatment.

Consequences of fertility treatment

An assessment of the risks to the prospective mother, and her potential child or children should be made. For the woman, controlled ovarian stimulation may result in an exuberant response leading to ovarian hyperstimulation syndrome. Fatalities, rarely, have been reported, but the morbidity associated with the condition may lead more commonly to prolonged hospitalisation. Trauma and infection occasionally arise, and in addition account should be taken of the psychological consequences of what can be extremely stressful treatment. Should pregnancy occur, ectopic gestations may result which may endanger the life of the woman.

The risk of multiple pregnancy should also be borne in mind. There is irrefutable evidence that twin, triplet and higher order multiple births carry increased risks of congenital abnormality, premature delivery and sequelae of handicap when compared to singleton pregnancies. The psychological and social consequences of caring for a family with multiple births can be catastrophic. A desire to increase the chance of conception through transfer of high numbers of embryos must be balanced by an appreciation that the welfare of any potential offspring may be ill served by such a decision. Clinics generating high numbers of multiple pregnancies should also consider the consequences to the community, not least in blocking neonatal facilities for naturally conceived infants, through too liberal embryo transfer policies. Ethical principles of beneficence, non-maleficence and respect for autonomy may clash in this controversial area. Further complexity arises where consideration is given to fetal reduction, from a standpoint of the sacrifice, entirely arbitrary, of one fetus to increase the chance of safe delivery of

the others. Another concern from the woman's point of view is the current uncertainty about the potential relationship between ovarian stimulation and subsequent ovarian cancer.

For the child, where the cause of infertility is principally due to male factors, there is emerging evidence that low sperm counts may be a consequence of genetic factors linked to the Y chromosome. This will mean that if a male child results from treatment, he will carry the same Y chromosome abnormality, and potential for male infertility, as his father. Consideration of the welfare of the child in this instance raises an important question as to whether it is appropriate to attempt to generate a pregnancy where it is known that an abnormality is likely to affect the potential child. It is also recognised that the incidence of non-lethal sex chromosome abnormalities are increased in ICSI generated pregnancies. Should these concerns lead us to deny couples access to treatment?

Pre-implantation genetic diagnosis

Linked ethical tensions arise in the context of emerging techniques of pre-implantation genetic diagnosis. In this instance it is possible to diagnose certain abnormalities, or determine sex in embryos, before transfer, allowing one to implant only embryos which would not manifest an inherited disorder. These seem laudable aims in the context of serious disease. However, what constitutes a serious medical condition appropriate for this technique may generate debate. Should such techniques be used to select for characteristics unrelated to disease? Who should determine what is appropriate use of this technology? What signal does the use of PGD send to those in society afflicted by the handicap for which one is screening? In some instances of sexing, embryos free of disease may be discarded which for some may present an ethical problem. On rare occasions only affected embryos may be found. If the patient seeks to have these transferred after all, is this ethically acceptable? Whose welfare is being considered?

The link with abortion

Ethical issues in gynaecological practice work are not restricted to those with the misfortune to be infertile. Unwanted pregnancy is a major issue in society, which arouses emotions, often of a virulent

nature, at both extremes of opinion. "Pro-life" and "Pro-choice" lobbies are well publicised but often it is lost sight of that the woman, usually a young frightened girl is desperately seeking help. It is a sad fact that about 50 million abortion procedures are carried out in the world annually, and about half of these are performed in countries where abortion is illegal.

While one can and should argue at length about the ethics of performing such procedures, of equal importance are the needs to examine why women find themselves in the situation of seeking abortion. Wherein lies the problem? Is it lack of knowledge about or failure of access to contraception? What are the pressures from society on the girl, which lead her to believe the only solution to be abortion? Possible solutions to the problem strike at the heart of our social, cultural and ethical principles, and debate is inevitably passionate.

Gynaecologists thus often have somewhat polarised sets of circumstances to deal with. Society exercises itself to afford respect to the embryos created through the assisted reproductive technologies. A government body with the full powers of Parliament behind it to licence practitioners and fertility centres providing such care has been instituted. Society demands that we adhere to high standards of clinical and ethical practice, transgression of such rules leading to the liability of a prison sentence. Yet on the other hand this high regard for the human embryo, a mere cluster of cells, contrasts with the relatively scant regard given to the fetus in the situation of the woman seeking termination of pregnancy. It would appear to be difficult to reconcile the ethic of respect for human life with work involving human embryos and fetal destruction as occurs with abortion.

Underpinning one's approach to medical practice is the knowledge that the patient comes to you as a doctor seeking professional advice. She does not come to you for judgement on her circumstances. She has a medical problem and seeks help. Women seeking termination of pregnancy do not approach the problem lightly. Something akin to a traffic accident has taken place and up until then their attitude was one of "it will never happen to me". When it does, often through no fault of their own, confusion, dismay, embarrassment by the need to seek professional advice and fear of the attitudes of the professionals they will encounter are the pervading

emotions. While no doctor can feel in any way comfortable about performing abortions the alternatives to a safe, legally sanctioned service seem unacceptable.

A personal comment

There are two polarised stances one can take in this field. The first is that it is immoral to interfere with the processes of natural human reproduction. Contraception, fertility treatment and abortion are violations of an ethically acceptable code. The second, entirely permissive allows for no regulation or control of such procedures. Elements within the church have naturally tended to be aligned more to the former stance but my own and most others I suspect lies in the middle ground. As a doctor one feels more like an agent of society conscious of the trust that society imparts upon us to ensure competent delivery of care and willingness to be accountable for one's actions.

Medicine, like the ministry, is in the view of many, one of the vocations, interestingly by definition in the OED "a feeling of being called by God to a certain career". Doctoring is in my view all about service to your patient. This goes beyond mere pill-pushing but in holistic terms requires us to fully inform those who entrust their health to our care, such that the individual herself can participate in decision making. We are required to deal in the best way that we can with emotional as well as the physical pathology in a professional, dispassionate, non-judgemental and unprejudiced fashion.

As a Christian dealing with life at its most fragile and vulnerable decisions are often not easy.

Conclusion

It has been impossible in this review to do other than provide a select sample of the many ethical scenarios confronted in infertility practice. Issues such as cryopreservation of embryos and cloning amongst others have not been elaborated. As advances continue in the exciting field of infertility practice, new ethical challenges will emerge which we shall have to confront. Bearing in mind the general principles outlined above we may be better equipped to resolve these problems with the interests of all those entrusted to our care at the forefront of our thoughts.

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