Ethical issues in respect of children born after assisted reproduction technologies

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Increasing use of ART brings ethical and social concerns that should be the subject of rational and informed debate and appropriate regulation

"...the only purpose for which power can be rightfully exercised over any member of a civilised community, against their will, is the prevention of harm to others....." John Stuart Mill
On Liberty 1859

In matters concerning the welfare of children there may be tensions between the liberty rights of parents and the protection rights of children.¹ This tension is important in considering the ever-widening application of assisted reproduction technologies (ART) that enable couples to exercise considerable reproductive autonomy. The UK Human Fertilisation and Embryology Act of 1990 requires clinics providing ART to take account of the welfare of children so conceived (the welfare principle).² Since 1990 there have been advances in the scope of ART and possible changes in public perception and attitudes on the complex ethical issues involved. There is continuing debate as to whether the current regulatory framework is sufficient to safeguard the welfare of those concerned, including the increasing numbers of children conceived by ART, or is over intrusive. The UK's regulatory body, the Human Fertilisation and Embryology Authority (HFEA), has revised its guidance on how ART providers should interpret the welfare principle,³ whilst the UK government has published proposals to revise the 1990 Act.⁴ Both have implications for children conceived by ART, which this paper will address.

THE WELFARE PRINCIPLE AND PARENTAL RIGHTS

The UK Human Fertilisation and Embryology Act S13 (5) states: "a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father) and any other child who may be affected by the birth".²

The principle has been criticised by some because it fails to respect parents'

reproductive autonomy by creating barriers that those able to conceive naturally do not face, and fails to take account of changing views on the family.^{5 6} A contrasting view is that it fails to protect the interests of future children to the extent provided by the Children Act 1989 and the Adoption Act 2002.^{7 8}

One element in considering the future child's interests is assessment of couples to determine their capacity to rear a child, as occurs in adoption. But in contrast to adoptive parents, ART couples may be expected to have greater biological affinity with the children they knowingly create and older or single parents, who might be excluded from adoption, do not necessarily make poor biological parents. The adoption analogy may therefore be inappropriate in deciding which couples to help.⁹

Acknowledging the moral importance of respecting adult patients' choices, HFEA recommended that there should be a presumption to provide ART to all who require it unless there is evidence that the child to be born would face a risk of serious medical, physical or psychological harm.³ Providers have to collect information from prospective parents and assess factors in their self-reported medical or social histories or circumstances that would be likely to produce serious harms. Only when such evidence exists would further information be sought (with parental consent) from other appropriate individuals, agencies and authorities. Although this revised guidance is respectful of parental rights, it may not, for some, provide sufficiently rigorous safeguards for the future child's welfare; indeed the consultation process that supported it involved very few with specific and appropriate expertise in childcare.

THE WELFARE PRINCIPLE AND CHILDREN'S BEST INTERESTS

The second element in considering the child's welfare is deciding whether it is in the best interests of a potential child to be born by ART or not to be born at all. Three

formulations of the welfare principle have been used to consider this.¹⁰

The maximum welfare principle places the welfare of the child as the paramount consideration. It would therefore be wrong knowingly and intentionally to conceive a child who does not have a good chance of living a happy and healthy life, as may be the case with some newer applications of ART whose consequences for children are not known. However, preventing application of technology that brings hope of significant benefits may not be logical, feasible and desirable or indeed ethically justified, even if certain safeguards are necessary.¹¹ It is also difficult to argue that parents and society owe the same moral duties to future children as they do to those already living.

The reasonable welfare principle entails that providers of ART need to be sure that the child will have "a decent chance of a reasonable life".¹² Thus it would be wrong to conceive children in whom there is a high risk of transmitting a serious defect of the sort that would deny them the opportunity of a reasonable life or an open future.^{13 14} This may be so even if the future child's welfare is not the paramount consideration.

In contrast, the minimal threshold principle would justify withholding ART only when the resulting child's quality of life would be below a minimum standard of acceptability such that it would be better if the child were not to be born at all. For many this seems to set the threshold too low. It may be only severe forms of disability that should be considered worse than no existence, for example permanent vegetative state.¹⁵ If this is so, there may be difficulties in accepting the testing and screening of embryos for conditions that are insufficiently serious to meet these criteria.

SCREENING OF EMBRYOS

Pre-implantation genetic diagnosis (PGD) permits screening and selection of embryos. Its UK use is restricted to individual licensed cases (about 200 per annum)^{2 16} and subject to strict criteria, namely:

- a) significant risk of serious genetic disease in the embryo,
- b) a condition perceived as serious by those seeking treatment and
- c) indications consistent with current practice in prenatal diagnosis (and termination).¹⁶

For some, PGD provides a morally preferable alternative to prenatal diagnosis and termination, and one that requires less justification. Its use to create "saviour siblings" for those with serious illnesses also seems morally acceptable^{17 18} as is sex selection to exclude serious sex-linked

medical conditions. PGD's complexity, cost, and the need for case-by-case approval means that it is unlikely to be used for trivial or ethically doubtful indications, for example hair colour or sex selection for family balancing.

It is possible to select out embryos with conditions insufficiently serious to produce an intolerable life but for which termination is a legal option. Although such conditions may not be intrinsically disabling (though individuals might have strong rational preferences not to have them), their social consequences might produce handicaps.

Others find embryo selection objectionable because of the offence it causes to people currently living with disabilities and the implication that their lives are less valued than others.¹⁹ Nevertheless, the moral obligation not to discriminate against those with disabilities has to be set against that of respecting parental choices, including abortion.¹⁵ Many families affected with genetic disease wish to avoid physical and mental impairments in their children and to have the option of termination.²⁰

Although there is a duty to ensure existing disabled people should receive all the care and social support that they require, there are also obligations to cure, reduce or prevent disability, especially if this involves morally acceptable techniques.¹⁹ The latter might include embryo selection, provided that it is undertaken for valid reasons and subject to regulation. This position appears consistent with the government's proposals to revise the 1990 Act.

THE INTERESTS OF THE STATE AND FUTURE PROPOSALS FOR REGULATION OF ART

Decisions to use ART entail complex value judgements about intensely personal and private matters. But any state funding of ART competes with claims for other things that society may value, for example education and preventative medicine. Even when ART is privately funded, the state may still have interests in outcomes, especially if resulting children require significant medical and educational support. Where ART produces ethical and social concerns, the state has a responsibility to protect and reassure the public as well as providing a transparent and accountable ethical and legislative framework in which professionals can work.

Therefore some form of regulation is morally acceptable and practically important provided that it is comprehensive, well informed and sufficiently free from political influence. It must accommodate complex scientific information, rapid technological change, diverse moral views, lack of clear public consensus, insufficient health and safety data, and intense emotional and intuitive responses.²¹ Importantly, it should have powers to ensure that the interests of those who receive ART and those conceived by it are adequately considered and met.

In the current UK model, parliament sets statutory parameters whilst HFEA licenses and advises on permissible activities. The approach has been widely emulated but also criticised because HFEA's membership and policy-making functions do not permit public control of professional expertise.²² The UK government's proposal to establish a new Regulatory Authority for Tissues and Embryos (RATE) arguably does not address these criticisms and may give the impression that embryos are just another human tissue. The increasing use and success rates of ART means that it will be important to have appropriate paediatric representation on RATE (presumably on the proposed Expert Advisory Panels), to a greater extent than was formerly the case with HFEA, so that welfare of children is adequately and appropriately considered.

CONCLUSION

Increasing use of ART brings ethical and social concerns that should be the subject of rational and informed debate and appropriate regulation. Paediatricians acknowledge the distress that infertility and the presence of serious genetic disorders bring to families. However, the commitment to conceive and rear a child carries with it the implication that parents, in partnership with others, will place the welfare of that child (or children) as a paramount concern. This surely applies as much to ART as it does to natural conception.

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