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Reproductive Ethics

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Abstract

The social relations of human reproduction underwent radical change in the latter half of the twentieth century, with the development of in vitro fertilization for the treatment of infertility. The dissociation of sex and reproduction led to a transformation of gender and kinship relations, while embryo and fetus diagnostics led to a shift from planning families to planning a child. Of all those involved, women were most deeply affected, since their bodies are necessary to mediate the technologies. But while advanced reprogenetic technologies have proliferated rapidly and brought benefit to many individuals, globally there are many women who lack access to basic reproductive health services for both fertility and infertility. Moreover, intercountry settings of third-party reproductive collaborations (sperm and egg cell donations and surrogate mother arrangements) have emerged under market conditions that are ripe for exploitation. In addition, the existence of fertilized eggs outside the womb is a new form of human life which can be preserved and manipulated and the embryo in the petri dish has become the object of market eugenics, driven by consumers and their claim to a right to reproductive freedom. All these developments challenge deep-set moral perceptions of human dignity and the relation of human beings to their own nature. The conclusion is that the prospect of a posthuman future calls for an ethic of care and responsibility.

Keywords

Reproductive health; Family planning; Fertility preservation; Infertility; Medical tourism; Human embryo; Mitochondrial replacement; Parenthood; Reproductive freedom; Posthumous use of gametes; Commodification; Reprogenetics; Eugenics; Genetic enhancement; Third-party reproduction; Trafficking in human beings

Introduction

Reproductive ethics cover a broad gamut of issues, including global inequities in the enjoyment of basic reproductive health rights, the complexities of medically assisted reproduction (MAR) and third-party reproductive collaborations (TPRCs), the genetic selection of traits in future offspring, and concerns about the potential effect of individual choices on the very nature of the human species. Reprogenetic medicine has proliferated rapidly since the first in vitro fertilization (IVF) child was born in the 1980s. One might characterize its development as marking a paradigm shift from planning families and parenthood to planning a child. Tampering with human reproduction raises a plethora of ethical and moral questions that challenge long-standing religious and moral sensibilities about the meaning of human nature and the forms of human being. Moreover, proliferation of the technology has been driven in large part by private markets, which are increasingly global, rather than being guided by public policy.

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Many of the topics in this entry are addressed at length in other parts of the encyclopedia. This paper offers a general outline of major issues and trends on global reproductive ethics from the perspective of a feminist ethic of care.

Background, History, and Development

The social relations of human reproduction underwent radical change in the latter half of the twentieth century, as the tie between sex and reproduction was severed due to innovations of contraception and assisted reproduction. Pharmaceutical contraception allowed for sex without reproduction, while MAR technologies for infertility treatment, such as artificial insemination and IVF, allowed for reproduction without sex. The dissociation of sex and reproduction, combined with the emergence of new forms of reproductive collaboration with sperm and egg cell donors and surrogate mothers, led to a revolution in gender and kinship relations. Biological parenthood was dissociated from legal parenthood, and courts of law vested parental responsibility and rights in adults without any necessary genetic connection to the child, based on the prior-to-conception intentions of the reproductive collaborators. This, in essence, acknowledged that the moral agency of individuals determines parental responsibility, rather than biological facts. That, in turn, paved the way for a contractual model of reproductive relations, such as surrogate motherhood agreements.

In the traditional view of reproductive relations, marriage was the foundation of the biological family. The institution of marriage, supported by laws of adultery and illegitimacy, was part of a patriarchal social order that confined women’s role in society to that of motherhood, and applied a gendered double standard of sexual morality which served to control female sexuality in order to overcome the uncertainty of biological fatherhood and ensure that a woman’s children were her husband’s. Artificial insemination with donor sperm (AID), the earliest of MAR technologies, was indeed perceived initially as a moral threat to marriage (Shalev 1989). But changing social norms about women’s equality gave rise to the idea of reproductive choice for women, and the notion that women can exercise moral agency over their reproductive capacity was no less than revolutionary. Reproductive freedom was a central motive in the movement for women’s liberation in the second half of the twentieth century: the choice whether and when to become a mother was viewed as essential to gender equality.

Reproductive choice was facilitated by the invention of the contraceptive pill in the middle of the twentieth century, which made it possible for women to be sexually active without fear of unwanted pregnancy. Contraceptive choice was viewed as a matter of constitutional privacy, and this led to acknowledging that women have a right to access medical care so as to terminate an unwanted pregnancy and to the decriminalization of abortion. The tyranny of biology over women’s lives came to a symbolic end, making way for a new era of self-definition, autonomy, and reproductive freedom. Reproductive choice continued to expand with the emergence of new families (single and gay-lesbian). Technological developments that further enhanced the scope of choice included prenatal tests and imaging for fetal disorders and finally the proliferation of MAR together with the social acceptability of TPRC and the possibility of performing genetic diagnosis of human embryos in the laboratory. Contraception and abortion are means to choose *whether, when, and how often* to become a parent, MAR offers means to choose *how* and *with whom* to become one, and reprogenetics offer means to choose *which child* to bring into the world.

The original rationale for the development of MAR was to treat medical infertility. In many parts of the world, it is now accepted for social uses – to create new forms of family and to select traits of future children. The relations between intending parents (married and unmarried, straight and gay) and third-party collaborators (sperm or egg cell donors and surrogate mothers, and medical professionals and entrepreneurs), raise multiple layers of ethical, legal, and social issues. At the same time, fundamental issues of reproductive health rights and distributive justice remain unresolved. Globally, many women do not enjoy access to basic services for family planning and safe abortion or for prenatal and antenatal care and safe childbirth. As a result, they and their children suffer from avoidable and preventable morbidity and mortality, in violation of their human rights to health and to life itself.

A central aspect of MAR is the ability to fertilize human egg cells outside the womb, and IVF is a platform technology. IVF was developed at first as an infertility treatment for women suffering from blocked fallopian tubes. Soon it came into use for the treatment of ovulation disorders, with egg cells donated by other women. By the mid-1990s, IVF also became the preferred mode of treatment for infertility among men with low sperm count, through a method called ICSI (intracytoplasmic sperm injection), instead of the less intrusive technique of AID. Since the birth of the first "test-tube" baby in 1978, millions of children have been born in these ways.

Reproductive choice expanded even more with developments in genetic medicine. IVF serves as the platform also for preimplantation genetic diagnosis (PGD) and selection of fertilized eggs, which many view as preferable to selective abortion on both moral and emotional grounds, despite the physical burden on women undergoing treatment. Genetic screening of adults and testing of fetuses in pregnancy and of embryos at conception are now generally accepted to avoid the birth of infants with severe genetic disorders. However, a growing demand for social uses of reprogenetics – such as sex selection without medical indication – is ethically controversial. If the right to reproductive choice includes the right to choose the characteristics of future offspring on the basis of personal preference, the door opens to eugenics, genetic enhancement and transhumanism (Buchanan et al. 2000; Habermas 2003; Fukuyama 2002; Sandel 2007).

MAR and reprogenetic interventions have many implications as regards the interests and rights of the children who are the offspring. They also challenge our moral intuitions about the process of bringing a human being into the world. The technology has produced a hitherto unknown human entity – the embryo, a cluster of stem cells, existing in limbo independently of a host mother and freeze-stored in numerous laboratories throughout the world. The ethics of our relation to this new form of human life are uncharted territory, and touch upon the relation of human beings to nature, religious beliefs about the meaning of life, and the hubris of "man playing god."

Meanwhile, the technology and its uses proliferate, driven by a consumerist market that is becoming increasingly global. The growing arena of reproductive tourism for third-party reproductive collaborations (TPRC) is revealing new challenges with regard to the rights of children to parentage and nationality, and to the human rights of the women who collaborate with intending parents, and provide egg cells or carry pregnancies for them to realize their desire for a child. The market is motivated by self-interest and profit making rather than by concern for the future of humanity, respect for the human dignity of the third-party collaborators, or the human rights of the child-to-be. The emerging market of cross-border reproductive care is characterized by geographic and cultural distance, which contributes to conditions that are conducive to objectification of women and their body parts, alienation of the reproductive collaborators, and commodification of the end product – the child-to-be. This is resulting in a global baby business that sometimes borders on trafficking in human beings.

Conceptual Clarification

It is helpful to clarify some basic concepts that recur in the discourse on reproductive ethics.

Reproductive freedom is a key concept. It has both negative and positive aspects. (a) Negative freedom, or reproductive liberty, means that individuals are protected from social intrusion into the "privacy of the bedroom.” Thus reproductive freedom is closely related to the right to privacy, in general, and in family life, in particular. It protects individuals against state interference in reproductive decisions that are essentially personal matters. This is of particular importance in relation to abortion, where political and legal barriers might obstruct realization of women’s right to reproductive health, (b) Positive freedom, or reproductive autonomy, means that individuals are entitled to recognition of their capacity, as human beings, to exercise choice in the shaping of their life, and are empowered to realize their reproductive wishes and to obligate others to assist in achieving such ends by the means of their choice.

The positive aspect of reproductive freedom has given rise to the notion of a “right to parenthood.” This right acknowledges what is perceived to be a fundamental human need for biological continuity. In addition, it encompasses the rights of individuals and couples, both same sex and heterosexual, to use MAR technologies creatively so as to shape novel forms of family and kinship.

It is important to remember that biological parenthood is a gendered phenomenon. Women and men, female and male, differ in their biological capacity to reproduce and fill different biological roles in the process of bringing a child into the world. Women menstruate; men do not. Women have a womb and egg cells; men have testicles and sperm. For men biological parenthood is genetic; for women it is both genetic and gestational. However, increasingly, the proliferation of MAR has been accompanied by a social attitude that attaches primary importance to a genetic relation with one’s child, rather than the nurturing of gestation or social parenting after birth. This geneticization of parenthood might be seen as reflecting a social preference for the male mode of biological parenthood.

Biological parenthood can be distinguished from social parenthood – assuming actual responsibility and care for the child – and from *legal parenthood*. Before the advent of MAR, biological and social parenthood were assumed to go hand in hand, and legal parenthood was attributed to women who gave birth to children, and to their husbands in marriage. Since MAR differentiates genetic, gestational and social functions of reproduction, and allows for extra-marital collaboration among various actors, the result might be a social parent–child relation which lacks any biological connection whatsoever. (For example, a single postmenopausal woman might become a mother by arranging for the birth of a child with the assistance of a sperm donor, an egg cell donor and a surrogate mother).

The law responded to the question of “who is the father and the mother?” in TPRC by defining new forms of parent–child relations that deviate from the traditional model of the marital family. The precedent was set in the earliest technique: AID, where courts of law distinguished biological and legal fatherhood according to the initial intentions of the husband and wife and the sperm donor. They ruled that the donor’s biological relation to the child did not give rise to parental status or responsibility, which was vested in the husband, and the intending father was the legal father for all practical purposes.

At the same time, the early practice of AID adopted standards of secrecy and *anonymity* because of the insinuation of adultery. Donor anonymity was a means to avoid exposure of the sensitive and shameful subject of male infertility. It allowed for the pretense of a pregnancy conceived within the marriage relation, since there was nothing visible to indicate the child was not the husband’s. It served, also, to reinforce the divestment of parental responsibility from the donor and protect him against legal claims by the child to support or inheritance (Shalev 1989).

The norm of anonymity in sperm donation became the benchmark for other practices of third-party reproduction involving women. But it has come to be controversial, because of the assumption that it is in the interests of children to know the circumstances of their birth. The child’s “*right to know*” his or her biological origins is often explained in terms of medical need. (Similarly, concerns about the safety of bio-materials require the traceability of human gamete donations and embryo implantations.) However, the child’s right to know also goes to a deep psychological level of personal identity, not only in relation to genetic parents (gamete donors) but also in relation to the gestational mother, i.e., the woman who carried the pregnancy and gave birth.

The early practice of AID also set a legal standard that permitted payment to sperm donors. This, together with the legal establishment of a father-child relation based on intention rather than biology, laid the grounds for a contractual model of reproductive relations. Since then, however, the principle that the human body and its parts shall not give rise to financial gain has become a rule of international law. And as issues of commercialization and commodification and alienation arise in relation to surrogacy and egg cells, the practice of paying sperm donors has come to be questioned.

Furthermore, reprogenetic technologies raise intrinsic questions about the *moral status of the human embryo* outside the womb. Even the language reflects the conundrum of our moral relation to this new form of human life: some call it a "pre-embryo," to distinguish it from an "early embryo" in the womb, while others prefer the term "fertilized egg cell." The Catholic view is that this entity deserves the full-fledged status of "human being" and recognition as a subject of human rights. The Jewish view is that there is a gradation in the acquisition of moral status that parallels the development of the fertilized egg from a preimplantation embryo, to one that actually implants in the womb, differentiates into placenta and fetus, grows to become viable independent of the womb, and finally is birthed as an infant. In human rights law, the accepted view is that human beings become the subject of rights from the moment of birth onward.

Whatever the moral perspective, whether or not the human embryo is viewed as the subject of rights, research in human embryos and their genetic manipulation for reproductive purposes are ethically sensitive activities, due to concern about the possible impact on future generations. For the time being, there is an international consensus that reproductive cloning and inheritable genetic modification are impermissible. Yet these conventions are challenged of late by advocates of research into mitochondrial replacement (three-parent babies), as well as by consumerist demand to select and enhance embryos based solely on personal preference.

Jurgen Habermas, an opponent of genetic modification of embryos, considered the idea of one human being determining the genetic makeup of the other as a challenge to "the moral self-understanding of the human species" (Habermas 2003). Others justify their objection to the prospect of designer babies in terms of the child's *right to an open future*. On the other hand, proponents emphasize the benefits of scientific progress and the individual's right to reproductive liberty and choice.

Reproductive Health

Reproductive freedom, in its negative sense, means the right of individuals to choose freely whether, when, and how often to have children. This right is recognized in international human rights law as key to women's health, as well as to gender equality, and it includes the right to family planning education, information, and services, including safe abortion. Women are no longer regarded as passive objects of patriarchal oppression or population control, but as autonomous subjects of reproductive capacity. Accordingly, in 1994, the UN International Conference on Population and Development, held in Cairo, acknowledged the need to promote women's sexual and reproductive health and well-being, and their right to make decisions concerning reproduction free of discrimination, coercion, and violence. At the same time, millions of women worldwide do not enjoy their human right to reproductive health. They lack access to safe and effective reproductive health information and services, including emergency obstetric care, and therefore face high rates of maternal mortality and morbidity due to complications of pregnancy and childbirth. Sometimes there are legal barriers to access. Other times the failure to provide maternal health care reflects the low priority attached to women's particular needs in the allocation of resources.

Acknowledgement of women's right to life, health, and personal autonomy led some countries, in the 1970s, to decriminalize abortion under safe medical conditions. At the same time, in others, the issue of safe legal abortion remains contentious. Approximately, one quarter of the millions of women who become pregnant each year choose to terminate their pregnancy, many of them under unsafe clandestine conditions. Legal barriers to abortion and other family planning services reflect the patriarchal attitude that women should not be sexually active outside marriage, that their role should be confined to mothering, and that they should not have control over their bodies. On the other hand, human rights advocates view laws that criminalize medical procedures only needed by women, and punish those who undergo them nonetheless, as a form of gender discrimination and coercion. The most obvious human right violated by avoidable death in pregnancy or childbirth is women's fundamental right to life itself (Cook 1993).

While maternal health care is of major importance, the right to reproductive health also includes the right to treatment of infertility, which is often the cause of social harm to women. Millions of couples in developing countries suffer from infertility, and women carry the brunt of the stigma associated with childlessness. Despite the proliferation of MAR in resource-rich parts of the world, treatment for infertility is not available, affordable, or accessible in resource-poor settings.

Infertility

IVF, pregnancy imaging and testing, and preimplantation genetic diagnosis (PGD) have brought an unprecedented degree of control over the reproductive process, but they have also produced new forms of suffering. For example, prenatal genetic tests create anxiety around tentative pregnancies and termination of pregnancy brings loss and grief. Infertility treatment is likewise associated with anxiety and grief, as well as with stress and disruption of spousal relations, shame and blame, anger and depression, low self-esteem and stigma.

IVF is an invasive medical procedure, involving hormonal treatment and surgery for egg cell retrieval, both of which carry significant health risks for women and children. For example, ovarian hyperstimulation in response to hormonal treatment can be life threatening. IVF also has relatively high rates of birthing and neonatal complications that are connected with high rates of multiple pregnancies and premature babies. Success rates of implantation remain steady, at around 25 % chance of a live birth per treatment cycle. Pregnancy rates are only slightly higher. Statistically, three out of four cycles of treatment fail to result in pregnancy or live birth, and with the rise and fall of hope and despair consecutive failures exact an emotional toll. Third-party women who assist an infertile couple in realizing their desire for a child suffer similar physical and emotional harms because of the inefficacy of the technology (Shalev 2012).

Nonetheless, between 1978 and 2012 the number of babies born as a result of MAR reached an estimated total of five million. Women are the ones who shoulder the primary burden of treatment. ICSI (for the treatment of male infertility) is responsible for more fertilizations than "conventional" IVF (ESHRE 2012). This means that more times than not, otherwise healthy women undergo invasive medical interventions – for the sake of their partners, or in the case of egg cell donation or surrogacy – for strangers who wish to become parents.

ICSI is one example of a tendency to favor hi-tech interventions that subject women's bodies to invasive procedures over less sophisticated and less intrusive alternatives. ICSI treats men with low sperm count or with poor sperm morphology or mortality by selecting a single sperm and injecting it into an egg cell. The advantage of ICSI over AID is that men suffering from subfertility can become genetic fathers, rather than social fathers to children conceived from donor sperm. But it is far more invasive for women, since it involves egg cell retrieval and implantation after fertilization. The readiness of women to undergo these interventions is an indication of the high value placed on genetic parenthood, particularly male. However, it also illustrates of the ways in which technology has a propensity to captivate users.

Hi-tech applications, such as smartphones, exhibit a dynamic of a technological imperative, with each "generation" generating a novel demand for the next. The lure and seduction of technology are particularly difficult to resist in the area of medicine. Once one embarks upon a course of intervention, it is difficult to step down, and one technological fix often leads to the need for another, as in the case of elective cosmetic surgery. In IVF, a similar pattern is evident of compulsive use, almost an addiction to repeated cycles of treatment, especially where public funding is available. To those for whom MAR technology is available, i.e., both accessible and affordable, a choice *not* to use it – not to undergo infertility treatment (or genetic testing) – requires unusual reserves of personal integrity.

The multiplicity of choices, therefore, does not necessarily enhance reproductive freedom. Dependence on technology blinds people to options once considered to be acceptable, such as voluntary childlessness, adoption or simply patience and trust that time will take care of matters. The illusion of control that is offered by the technology produces a sense of urgency. When fortified by an ethos of consumerist individualism, the desire for a child that is "mine" becomes a need and an entitlement for genetic continuity.

Fertility Preservation

The importance of genetic continuity lies also at the heart of new practices of fertility preservation, which originated in cancer patients who undergo treatment that might cause irreversible damage to their gametes as a side effect. The practice began with sperm preservation, but once a technology for preserving egg cells was established it extended also to female patients – even though the physical toll of egg extraction is far more exacting than of sperm, and the preceding hormonal treatment might be counter-indicated medically. In such cases, and for premenstrual girls, the freezing of ovarian tissue is suggested as an alternative option. In any case, fertility preservation is an intervention that delays treatment for the underlying cancer. Moreover, since the efficacy of these techniques over time is as yet unknown they are considered experimental, especially in girl children.

Nonetheless, egg freezing has undergone rapid commercialization and is now marketed to young healthy women for social use, as an option for postponing reproductive decisions and a kind of biological insurance against aging. There are other options, such as AID, egg cell donation, adoption, or childlessness. Each option has disadvantages and none are entirely adequate. Social egg freezing too has its disadvantages: the physical risks of IVF compounded by the uncertainty of the experiment's success. The market claims it answers the needs of career women, but it appears the demand is created by the supply. There is concern that women might be subject to pressure from employers to take "responsibility" and dedicate themselves to their work places. But it seems that most potential consumers are women who would like to start a family but have not found a partner, and the technology gives a false sense of security and control, because of its unknown efficacy, while they are more likely to conceive spontaneously at an earlier age.

Fertility preservation also opens the door to posthumous reproduction. Here, too, sperm preservation set the standard. The first instances involved married women who wanted to use sperm that their husbands had preserved before their death as part of their cancer treatment. Later cases involved women whose husbands died unexpectedly, and who obtained the sperm through a postmortem procedure. There have also been cases in which the parents of deceased young men wished to use their sperm posthumously so as to immortalize them and become grandparents. In at least one case, parents of a young woman who died in a traffic accident and agreed to donate her organs, wanted to make similar use of her egg cells for donation to others. Here a key issue is whether the deceased person wished to bring a child into the world after his or her death, and whether consent to do so can be implied or must be expressed explicitly. But a deeper ethical question is whether an individual has a right to make a “biological will” of this sort, without being able to take responsibility for actually raising the child.

Third-Party Reproduction

One major characteristic of MAR is the fragmentation of genetic, gestational and social parenthood through IVF, which gives rise to practices of “third-party” reproduction. In many countries the anonymity of gamete donation (whether sperm or eggs) precludes personal contact between the individuals who collaborate in the reproductive enterprise. In surrogate mother arrangements, anonymity is less feasible, but the practice is shaped as a quid pro quo contractual transaction and designed measures to protect privacy can preclude an ongoing relationship between the reproductive collaborators and conceal the identity of the birth mother from the child-to-be. In this way, the fragmentation of reproductive functions leads to the objectification and commercialization of sperm, eggs, and wombs as market commodities.

Thus, in addition to the inherent health risks of egg cell procurement, IVF, and pregnancy, women who are involved as egg donors or surrogate mothers in TPRC are vulnerable to social harms of invisibility. In commercial or intercountry settings, they are further vulnerable to forms of exploitation that are rooted in the structural injustice of underlying inequalities. If we do not know the names of the women and do not see their faces, it is easier to objectify their bodily functions and parts and use them as instruments for the fulfillment of another’s desire to become a parent.

In many countries surrogate mother agreements are not legally binding; in others commercial surrogacy is not allowed. Legal systems that accommodate the practice focus on regulating two major events: the signing of an agreement prior to conception, and the postbirth delivery of the infant to the intended parents. However, there are other issues of concern, such as the payment of compensation to the surrogate mother for undergoing cycles of treatment that do not result in pregnancy; her right to physical and emotional integrity throughout the period of gestation; and her right to choose whether and how to remain in contact with the child and its family despite there being no formal legal status of parenthood (Hashiloni-Dolev 2013).

Surrogacy practices come to light inevitably when a child is born. Practices of egg cell donation are less visible, but their dimensions are far greater and the size of the global market has outgrown that of surrogacy. Egg cell donation was used at first for the alleviation of ovulation disorders, but the demand grew exponentially as women postponed the age of first-motherhood, together with the social acceptance of one-parent families. The quality of egg cells even in healthy women deteriorates around the age of 40, 10, or 15 years before the capacity to carry a pregnancy diminishes, while egg cell donation from a younger woman enables women to give birth well into their 50s, and this means that the possibility of egg cells donation extends the age of reproduction for women by a decade. Postmenopausal women are now able to carry and birth children conceived from the egg cells of another woman, even though MAR and pregnancy in older women are more dangerous and less likely to succeed.

As opposed to sperm, which is abundant and easily obtainable, mature egg cells are a scarce, delicate and hidden resource. While sperm donation is nonintrusive and voluntary, the extraction of eggs from the follicles is an invasive procedure carried preceded by intensive hormonal treatment, and usually performed under anaesthesia. It can be life threatening in unusual circumstances, and also carries significant health risks, including loss of fertility.

What is more, in the beginning of the twenty-first century, egg cells became an object of demand for embryonic stem cell research for the purpose of personalized regenerative medicine (i.e., the potential production of homologous tissue or organs for transplantation in sick persons, sometimes referred to as "therapeutic cloning"). Scientists' interest shifted to a certain degree from embryonic to adult stem cells following investigation of a scandal surrounding embryonic stem cell research, in Korea in 2005, which found both fraud in the reporting and ethical misconduct in the appropriation of the human egg cells that were used. Nonetheless, egg cells remain an important raw material for research in reproductive and regenerative medicine, and are needed for mitochondrial replacement (Shalev and Werner-Felmayer 2012).

At the same time, egg cells remain in high demand for medical and social uses of MAR, but little is known of the practice and its long-term physical and emotional effects on the women who provide the egg cells. Like surrogacy, there is concern that structural inequalities and intercountry settings increase the vulnerability of women to harm and exploitation. As opposed to surrogacy, it appears that eugenic preferences related to color and so-called race play an important role.

Reprogenetics

Along with all the above developments, prenatal imaging and testing has rendered the fetus visible (in an ultrasound image) and given an unprecedented degree of control over the birth of healthy children. For some, the fetus, no longer hidden inside the womb, has become an entity in its own right. Even for those who adhere to the moral view that it is not a human being and the subject of human rights, pregnancy testing has a profound impact on the experience of pregnancy. Women may be subject to significant social pressure to do all they can so as to give birth to a healthy child, and they often internalize the pressure as an ideal of "responsible motherhood." Future parents make prenatal diagnosis decisions under emotional stress and inherent constraints of time without fully understanding the meaning of genetic probability, or the severity of the diagnosed condition (Hashiloni-Dolev 2013).

Here reproductive autonomy goes beyond the right to make choices that are important for one self, and touch upon the sensitive area of eugenics. Justification for termination of a pregnancy on grounds of fetal abnormality is different from abortion in the case of an unplanned pregnancy. There is a moral difference between saying "I do not wish to have a child" and saying "I do not wish to have this specific child." Furthermore, family planning choices will usually be made at an early point of time, but pregnancy tests often reveal the abnormality at a late stage, where the fetus is already viable and could survive independently outside the womb. Late pregnancy terminations raise thorny dilemmas about the severity of probable disability and the value of prenatal forms of human life, and these are exacerbated by the possibility of intensive neonatal care. In best-case scenarios aggressive intervention results in a healthy child, but more often than not life-saving measures culminate in varying grades of long-term disability.

These and other problems associated with abortion are avoided when IVF is used for the purpose of PGD. Diagnosing the cluster of cells that is the embryo in the laboratory, before implantation in the womb, has clear advantages over interrupting an existing pregnancy – whether the concern is for the well-being of the tentative mother or for the moral status of the embryo or fetus. But for the woman there are risks and discomforts of undergoing IVF treatment, and for the child-to-be of chromosomal abnormality. Moreover, the question remains to what extent reproductive choice includes the right to choose the characteristics of one's offspring. PGD in couples at risk for a certain serious genetic disorder with low quality of life and short life expectancy, such as Tay-Sachs disease, might be acceptable. But ought it be used to eliminate the use of embryos diagnosed with late onset disease, or with mere genetic susceptibility for moderate disorders? And who is to say? What is more, the prospect of whole genome sequencing of embryos, rather than screening for specific conditions based on known risk factors, raises new questions: how will prospective parents make meaning out of the mass of information about statistically probable conditions and traits? What will be the role of genetic counseling? And ultimately, how can decisions be made other than on the basis of simple personal preference?

Reprogenetic technologies make it possible to know and control the characteristics of future children (at least to some extent, since they cannot eliminate all congenital mishaps, such as the disabilities associated with premature births). In some parts of the world, screening and selection of fetuses and embryos is becoming a normal consumer procedure, and a deliberate choice to accept any child as a gift whatever its characteristics, is exceptional. Yet social expectations can result in standards of "normalcy" which are intolerant to natural difference and diversity. Even if the purpose is to avoid the birth of seriously disabled children, there is an implicit eugenic tone: a scientific practice of selection to eliminate unwanted forms of human being.

Critical disability studies point out that the selection of embryos and fetuses is problematic because of the rejection of persons who do not conform to cultural standards of acceptability. According to this view, disability is a social phenomenon rather than a physical condition, and the associated harm and suffering is mostly a result of social attitude, such as stigma and exclusion (Asch 1999). Another view claims it is socially irresponsible to knowingly give birth to an infant with a serious genetic disorder. While still others argue that there is even a moral obligation whenever possible to reduce disability in future children and to positively select those who can be expected to enjoy the most well-being and advantage (Savalescu and Kahane 2009).

Eugenics fell into disrepute in the wake of the Nazi policy of "racial hygiene" because of the cruel and inhumane methods it used to "purify" the Arian race and rid it of supposedly inferior individuals, including mentally retarded persons (Kevles 1999). Contemporary scholars dispute the biological foundations of "race" and claim that it is a social construct, like disability. In any event, in the latter half of the nineteenth century, early eugenics was regarded as a progressive science which could be applied to improve the human species through the encouragement of healthy breeding (positive eugenics) and the elimination of undesirable traits (negative eugenics). At the time, the reproducing adult was the object of eugenics and negative measures included forced sterilization, a practice no longer considered acceptable. Today, the fetus or the embryo is the object of intervention. Proponents argue that helping parents to have healthy children in order to reduce suffering is very different from prohibiting "genetically unfit" persons from having children. They also point out another difference between early and contemporary eugenics: whereas the former were dictated by state policy, current practices are characterized and justified as a matter of reproductive freedom and personal choice (Buchanan et al. 2000).

Genetic Enhancement

Currently PGD is used for therapeutic purposes, but it also provides a platform for the engineering and enhancement of embryos, that is, for the modification or alteration of nonpathological traits. A threshold case is sex selection for nonmedical purposes, which is already being practiced, often on the basis of prejudice about the preference of male children. If we allow such a choice, based solely on personal preference, the moral ground for objecting to nonmedical enhancement of embryos is lost. For if we allow people to select a child's sex, what is to preclude genetic programming of children based on any whim?

Another threshold case is mitochondrial replacement for the elimination of mitochondrial disease. Mitochondria – often referred to as the powerhouses of the cells – are found in the liquid surrounding the nucleus, and mutations are the cause of disease which is passed on from mother to child. Mitochondrial replacement is a new approach currently being researched, and it involves removing the nucleus of the mother's egg cell and transferring it into an enucleated egg cell from a healthy donor. This means that the child will have two genetic mothers, hence the term "three-parent babies."

The technique is ethically controversial. The nucleus transfer is similar to the technique envisaged for human reproductive cloning, which international consensus prohibits. The technique also challenges the wall-to-wall agreement that inheritable genetic modification is morally impermissible. True, it does not involve manipulation of human embryos, but nonetheless it appears to breach the solid bioethics principle that stalls at interfering in reproductive biology in ways that are inheritable.

The justification for mitochondrial replacement is the prevention of disease, the importance of genetic parenthood and freedom of scientific research. However, the danger of mishaps constitutes a crucial moral problem. There are serious safety concerns, including the unknowable risks of translation from the laboratory to the clinic. Moreover, genetic manipulation of egg cells (and embryos) may cause unintended, unwanted, and irreversible side effects that are passed on to future generations. These utilitarian objections to genetic engineering call for the exercise of precaution and restraint.

In addition, there is a deontological argument that genetic manipulation and enhancement should not be allowed, because when existing persons make decisions about the genetic makeup of another, they create a relationship of producer-produced which undermines the very possibility of reciprocal interpersonal relations and hence the foundational premise of equality between human beings (Habermas 2003). Even if genetics are not the sole and exclusive factor that shapes a person's identity and life – that is, even if one rejects genetic determinism – controlling the characteristics of an individual's genome may have a profound effect on his or her capacity of self-determination in relation to others. In other words, there is a risk of psychological harm to the child. Some consider that the desire to control the genetic constitution of another human being not only compromises the child's right to an open future, but also amounts to "intergenerational tyranny." Future individuals should be free to develop their potentialities without being biologically conditioned on the basis of another individual's perceptions of what amounts to preferable or nonpreferable, good or bad personal traits.

There are those who regard practices such as reproductive cloning and inheritable genetic modification as actual "crimes against humanity," since they might alter the essence of humanity itself and lead to the evolution of a new species (Annas et al. 2002). This view is wary about playing god and tampering with nature by taking human evolution into our own hands, but it also has human rights and social justice concerns. For example, the UNESCO Universal Declaration on the Human Genome and Human Rights, 1997 opens with the declaration that the human genome underlies the fundamental unity of all members of the human family and is, in a symbolic sense, the "heritage of humanity." It and other international human rights instruments also make it clear that the applications of genetic science should seek to improve the health of humankind as a whole. But the proliferation of IVF and MAR has been led in great part by markets and by motivation for personal fame and profit rather than by a public interest in health.

Bearing in mind growing global gaps between the wealthy and the poor, there is a concern that if reprogenetics are left to the market place, the integrity of the human species will be at stake. Persons with means would want to enhance their children and themselves; genetically enhanced individuals would marry one another; the gen-rich and gen-poor would not intermarry; the human species would split into humans and posthumans (Fukuyama 2002). Moreover, proponents of *trans*-humanism advocate the prospect of a world of cyborgs and transgenic species. But there is a difference between choices we make for ourselves and those we make for others. One might want a chip brain implant or Mr. Spock ears for oneself, but if one were asked to participate in research that might produce such a child, one might not necessarily consent.

In the market place, self-interest, consumerism, and materialism masquerade as liberty, reproduction transforms from an act of sexual love into a contractual transaction, and the child ceases to be a gift and becomes a technical project. In the process, the mystery and magic of bringing a new life into the world and the human relationships that are essential to procreation lose their soul. Some continue to insist that children are to be cherished and loved for what they are rather than what we want them to be, and that humility and responsibility for one another should be the guiding values rather than control, mastery, and dominion over nature and other individuals (Sandel 2007).

Intercountry Medically Assisted Reproduction

The effect of the market on reprogenetic practices is most notable in intercountry settings. Intercountry medically assisted reproduction (IMAR) is one of a variety of medical tourism practices, including stem cell and organ transplant tourism, which have emerged in recent years and formed new transnational markets in human bodies, body parts, and tissues for biomedical use. In the most general terms, the ethical, legal, and regulatory concerns about such practices address four distinct layers: (1) efficacy: quality and safety of medical procedures; (2) distributive justice: fair allocation of limited resources, service availability, and accessibility; (3) protections against violation of human rights of persons, especially in conditions of vulnerability; and (4) issues of criminal justice related to trafficking in human beings, body parts, and tissue. While organ transplant tourism and trafficking are the subjects of numerous international documents, the complex field of IMAR has been largely neglected so far.

IMAR involves transnational movement, in various permutations, of intending parents, egg cell donors, surrogate mothers, and new-born children, as well as transnational transfers of sperm, egg cells, and human embryos. Like transnational organ transplants, it consists of shifting international collaborations. The chain of medical production starts from sperm donations and egg cell procurement, and continues through fertilization, embryo implantation and gestation, to culminate in birthing. Theoretically, each of these six links could be performed in a different country and the child then transported to the country of the intended parents.

The growth of the IMAR market in recent years is due to complex economic, legal, and cultural conditions. Legal restrictions on local access to reprogenetic technologies, gaps in comparative costs of medical procedures across borders, profit-seeking medical enterprise, and a consumerist culture are all positive contributing factors. With the dramatic growth of international surrogacy in recent years, there are concerns about violations of the human rights and dignity of the women who provide reproductive services, as well as about the rights of the children to legal parentage and nationality, and to identity (Allan 2015). Studies from India of “outsourced pregnancy” describe deprivations of liberty (controlled housing), violations of bodily integrity (nonconsensual abortions, high c-section rates), and exploitation of maternal labor (multiple embryo implantations, parallel pregnancies, wet nursing) (Sharavanan 2013).

As opposed to organ transplant medicine, in IMAR there are neither internationally accepted ethical guidelines nor are there clinical standards for quality and safety. The distribution of human bioresources occurs at a transnational level through an unregulated market system, on the basis of ability to pay rather than criteria of justice or solidarity. Moreover, IMAR is a highly gendered phenomenon of globalization. Women from lower income countries are increasingly providing reproductive services for women and men from higher income countries. Due to structural injustices underlying global inequality, the risks of harm to women undergoing MAR are amplified in the case of intercountry third-party reproduction. The lack of professional governance creates conditions for potential reproductive abuse, including double standards-of-care for invasive medical procedures. Documented harms include *inter alia* collateral infertility, violations of patient autonomy, emotional distress, stigma, and invisibility. Intercountry settings also increase the vulnerability of women and children to violations of human rights and to the risks of exploitation, fraud and coercion which amount to reproductive trafficking. But despite evidence of harmful and degrading practices, as yet there is no international criminal justice redress.

Conclusion

The rapid proliferation of MAR technologies for the treatment of infertility appears to empower women by expanding their individual choice, but it is also creating new forms of suffering for them and their reproductive collaborators, especially in the context of intercountry TPRC. The technology has generated new needs and desires, but if not met, they become the source of new forms of suffering for individuals, particularly women, who wish to become parents. What is more, the satisfaction of those desires comes at substantial cost to other women who assist them in doing so.

The reprogenetics market is driven for the most part by for-profit motivation. Novel reproductive technologies create new markets of consumers; supply generates demand. Once a new market is established, the greed of medical entrepreneurs is complemented by a consumerist discourse of desire. The language of "would like" or "want" translates into "need," which then turns into a sense of entitlement (to have a child that is healthy), the assertion of a "right" (to use the technology), and a demand for instant gratification (Shalev 2012)

The neoliberal view of reprogenetics as a matter of freedom of contract between rational individuals coming together for mutual benefit, fails to capture and address the relational needs and interests of the involved parties – particularly, the children born and the third-party women collaborators. The complexities of reproductive relations seem to call for a reframing of the ethical discourse around reprogenetics from its focus on reproductive choice, preference and desire, to empathy and respect for women who collaborate in the reproductive process and responsibility for the children brought into the world. This would entail moving beyond an ethic of liberty that is based on self-interest and the language of rights, to an alternative ethic of care that is based on self-restraint and the language of responsibilities. An ethic of care (Gilligan 1982) and responsibility would cultivate the empathetic self-reflection of the autonomous actor in relation to the child and those others who are part of the enterprise of bringing him or her into the world.

Liberal theory rests upon a distinction between self-regarding and other regarding actions. Some individual choices have a profound effect upon others, and once our actions impinge upon others, we are no longer completely free to do as we wish. Reprogenetic choices that individuals make to form and fashion the lives of their offspring are not self-regarding; they are intrinsically other regarding and necessarily affect others. In the first place, the very purpose of the reproductive choice is to create an other (the child-to-be); in the second place, the activity of reproduction is inherently dependent on collaboration with existing others. An ethic of care would require the individual to act as a moral agent, transcend self-interest, acknowledge and appreciate the relational context of his or her reprogenetic choices, care about and for the others whose collaboration is indispensable to realizing the desire to give birth to a child, cultivate acceptance of imperfection and the limits of human control over nature, and assume responsibility for the children who are born, loving them as they are.

Notwithstanding the marvels of reprogenetics, the essential nature of reproduction remains the same – it is relational, and the child-to-be is the connection that forms the relationship and its core. All those collaborating in the reproductive process are in active relationship vis-à-vis the future child, even though it does not yet exist. It is not difficult to imagine the need for a loving, caring, and respectful passage into the world. An ethic of care and responsibility requires a shift in consciousness: from calculation of self-interest and benefit to contemplation of our mutual vulnerability and interdependence; from observation of others as external objects and instruments for our own ends, to inner awareness of the seamless web of relationship in which we are implicated by our very nature as human beings (Shalev 2012).

Encyclopedia of Global Bioethics
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Cross-References

- ▶ Abortion
- ▶ Assisted Reproductive Technology: Artificial Insemination
- ▶ Assisted Reproductive Technology: ICSI (Intracytoplasmatic Sperm Injection
- ▶ Assisted Reproductive Technology: IVF (In Vitro Fertilization)
- ▶ Assisted Reproductive Technology: Surrogate Motherhood
- ▶ Children's Rights
- ▶ Cloning: Human
- ▶ Commodification
- ▶ Designer Babies
- ▶ Donation: Embryos
- ▶ Donation: Gametes
- ▶ Embryo
- ▶ Enhancement
- ▶ Eugenics
- ▶ Fertility Control
- ▶ Fertility Preservation
- ▶ Fetus
- ▶ Future Generations
- ▶ Genetic Determinism
- ▶ Genetic Modification (GMOs): Human Beings
- ▶ Human Body
- ▶ Human Dignity
- ▶ Human Nature
- ▶ Human Rights
- ▶ Identity
- ▶ Infertility
- ▶ Life: Definitions
- ▶ Maternal-Fetal Relationship
- ▶ Medical Tourism
- ▶ Medicalization
- ▶ Moral Status
- ▶ Normalcy
- ▶ Organ Trade
- ▶ Privacy
- ▶ Regenerative Medicine
- ▶ Reproductive Autonomy
- ▶ Research: Embryo
- ▶ Responsibility: Individual
- ▶ Stem Cells: Embryonic
- ▶ Suffering
- ▶ Testing: Genetic
- ▶ Trafficking, Human
- ▶ Transhumanism
- ▶ Vulnerability

References

Allan, S. (2015, forthcoming). The surrogate in commercial surrogacy: Legal and ethical considerations. In *Surrogacy, law and human rights*. Farnham, Surrey: Ashgate Publishing Limited, Ashgate.

Annas, G. J., Andrews, L. B., & Isasi, R. M. (2002). Protecting the endangered human: Toward an international treaty prohibiting cloning and inheritable alterations. *American Journal of Law & Medicine, 28*, 151–178.

Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy. *American Journal of Public Health, 89*(11), 1649–1657.

Buchanan, A., et al. (2000). *From chance to choice: Genetics and justice*. Cambridge, UK: Cambridge University.

Cook, R. J. (1993). International human rights and women's reproductive health. *Studies in Family Planning, 24*(2), 73–86.

European Society of Human Reproduction and Embryology (ESHRE). (2012). The world's number of IVF and ICSI babies. http://www.eshre.eu/Press-Room/Press-releases/Press-releases-ESHRE-2012/5-million-babies.aspx. Accessed 30 Mar 2015.

Fukuyama, F. (2002). *Our posthuman future*. New York: Picador.

Gilligan, C. (1982). *In a Different Voice*. Cambridge, MA: Harvard University Press.

Habermas, J. (2003). *The future of human nature*. Cambridge, UK: Polity.

Hashiloni-Dolev, Y. (2013). *The fertility revolution*. Tel Aviv: Modan [Hebrew].

Kevles, D. J. (1999). Eugenics and human rights. *British Medical Journal, 319*, 435–438.

Sandel, M. J. (2007). *The case against perfection*. Cambridge, MA: Belknap.

Savalescu, J., & Kahane, G. (2009). The moral obligation to create children with the best chance of the best life. *Bioethics, 23*(5), 274–290.

Shalev, C. (1989). *Birth Power*. New Haven & London: Yale University Press

Shalev, C. (2012). An ethic of care and responsibility: Reflections on third-party reproduction. *Medicine Studies, 3*, 147–156.

Shalev, C., & Werner-Felmayer, G. (2012). Patterns of globalized reproduction: Egg cells regulation in Israel and Austria. *Israel Journal of Health Policy Research, 1*(15), e1–e12. doi:10.1186/2045-4015-1-15.

Sharavanan, S. (2013). An ethnomethodological approach to examine exploitation in the context of capacity, trust and experience of commercial surrogacy in India. *Philosophy, Ethics, and Humanities in Medicine, 8*, 10.

Further Readings

Andrews, L. B. (2001). *Future perfect*. New York: Columbia University.

Corea, G. (1979). *The mother machine*. New York: Harper and Row.

Inhorn, M. C., & Patrizio, P. (2012). The global landscape of cross-border reproductive care: Twenty key findings for the new millennium. *Current Opinion in Obstetrics & Gynecology, 24*, 158–163.