

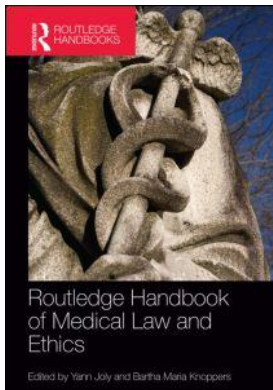
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### Emerging legal and ethical issues in reproductive technologies

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## Part III

# Medical interventions and emerging technologies

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# Emerging legal and ethical issues in reproductive technologies

*Vardit Ravitsky and Raphaëlle Dupras-Leduc*

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## 13. 1 Introduction

Reproductive technology is one of the greatest medical success stories of our time. Since the advent of *in vitro* fertilization (IVF) in 1978, an estimated 5 million babies have been born worldwide as an outcome of this revolutionary technology (Chambers *et al.* 2014), alleviating the burden of infertility and bringing joy to millions of parents and families. The broad social acceptability of reproductive technology has been marked by the 2010 Noble prize in medicine being awarded to Dr Robert Edwards (Nobel prize 2010), developer of IVF and the metaphorical ‘father’ of Louise Brown, the world’s first IVF baby. IVF and some of its associated techniques such as intracytoplasmic sperm injection (ICSI) and preimplantation genetic diagnosis (PGD), have now become commonplace. In the United States, over 1 per cent of all births are of babies conceived through reproductive technology (Centers for Disease Control and Prevention *et al.* 2010). This number is even higher in most European countries, where it is estimated that as many as 6 per cent of births are achieved using assisted reproductive technologies (Nyboe Andersen and Erb 2006). In addition, prenatal screening and testing have now become an integral part of prenatal care in all developed countries (Rapp 2000).

At the same time, reproductive technology has contributed to ‘more radical changes to the understandings of parenthood, kinship, fertility and technology’ (Franklin 2013: 1), bringing about an avalanche of legal and ethical challenges. IVF has changed the way infertility is socially framed and defined, shifting it from a psycho-social condition of ‘involuntary childlessness’ to a medical condition that can be resolved through high-tech interventions (Becker and Nachtigall 1992). These interventions, however, are very costly, raising issues of justice and equal access, and catalyzing debates regarding the appropriateness of public funding.

The emergence of IVF also opened a host of new possibilities for creating families, expanding individuals’ reproductive autonomy while raising novel challenges. For example, gestational surrogacy allows gay couples to have genetically related children. This allows for further emancipation of gay families, but challenges jurisdictions to determine legal mechanisms that recognize new types of kinship, such as the legal parental status of a non-genetic parent in a gay couple (Margalit 2013; Storrow 2012). Moreover, gestational surrogacy created for the first time in human history a distinction between a genetic and a birth mother, opening up a Pandora’s Box

of ethical uncertainties in defining motherhood. It also provoked a diversity of responses regarding the legality of surrogacy agreements, the legal status of the parties involved and the monetary compensation of the surrogate.

Another assisted reproductive option is gamete donation, which allows couples to have a child that is genetically related to the fertile partner, and single and lesbian women to reproduce using donor sperm. Due to the prevalence of anonymous donation, however, it created a ‘donated generation’ (Miller 2008) of individuals deprived of access to the identity of one of their progenitors. These various reproductive avenues have also opened up national and international markets of reproductive labor, producing fertile ground for the possible exploitation of vulnerable surrogates and egg donors.

Prenatal testing empowers parents with an unprecedented degree of control over the health (and even the identity) of their future children, but this new found control is intertwined with the heartache and moral distress surrounding the decision to terminate a pregnancy (Katz Rothman 1993; Rapp 2000). PGD provides a solution by allowing access to genetic information before pregnancy has been initiated (American Society for Reproductive Medicine (ASRM) 2008; Harton *et al.* 2011), but raises social and legal challenges regarding the appropriate threshold of testing (Ravitsky 2009).

Now, a new technology – non-invasive prenatal testing (NIPT) – that allows the testing of fetal DNA found in maternal blood expands old debates regarding appropriate testing and the protection of women’s reproductive autonomy. Innovation has been persistently pushing the technological envelope further in other areas as well. For example, elective egg freezing allows women to possibly expand their reproductive capacity into their 40s and 50s (Brezina *et al.* 2013; European Society of Human Reproduction and Embryology (ESHRE) 2012). Furthermore, mitochondrial transfer might soon allow them to become genetic mothers to healthy babies that would not inherit their mitochondrial disease, creating what is technically a baby with three genetic parents (Human Fertilisation and Embryology Authority (HFEA) 2013).

On the backdrop of this rich and complex terrain, two prevalent elements emerge. First, technological innovation regularly outpaces the ability of legal systems to respond to new challenges, often leaving controversial uses of new technologies unregulated and leading to their resolution by the courts on an *ad hoc* basis. Second, the regulatory responses to these challenges vary greatly between jurisdictions, reflecting the unique sets of cultural values and political contexts of different societies (Donchin 2011; Ouellette *et al.* 2005). For example, different countries offer various mechanisms for publicly funding IVF, ranging from none to full funding with a variety of associated provisos and limitations. Other examples include different prohibitions and limitations on uses of reproductive technologies such as gamete donation, surrogacy, PGD, and now elective egg freezing and mitochondrial transfer.

These legal limitations set the stage for flourishing and lucrative cross-border international markets for reproductive services (Shenfield *et al.* 2010), a phenomenon dubbed ‘reproductive tourism’ (Bassan and Michaelsen 2013). Individuals in need of certain services travel from countries with strict regulation to those jurisdictions with relatively lax or no regulation, creating ethical and legal complexities that are even harder to address considering the international context in which they arise.

This chapter will present some emerging areas of debate, addressing ethical, social, and legal issues that arise within each and offering some insight into possible future approaches.

## 13.2 Public funding of IVF

For those who are unable to conceive a child, infertility – commonly defined as failure to conceive after 12 months of unprotected sexual intercourse – may be the most painful and

protracted problem they experience in life (Gurunath *et al.* 2011; World Health Organization (WHO) 2013b). For many, IVF may be the only solution to potentially alleviate this devastating condition that affects approximately 8–10 per cent of the population (Hughes and Giacomini 2001). The financial cost of IVF, however, is considerable. On average, IVF can cost \$10,000 US per cycle (or \$34,000 per live birth for women over 38) (Suchartwatnachai *et al.* 2000). As such, the costs can easily become prohibitive, leading to disparities in an area that is fundamental to human well-being (Katz *et al.* 2002).

This leads to the question of whether ‘a responsible and caring society should seek ways to recognize and support the desire of individuals to have children’ (Royal Commission on New Reproductive Technologies 1994). Public funding of IVF has therefore emerged as a highly controversial issue, involving heated public and policy debates (Hughes and Giacomini 2001; Tännsjö 2007). The challenge facing policymakers in this area is to develop policies that are appropriately justified and that reflect the unique cultural and social values of the society in which they are made.

Various Western countries have adopted a spectrum of approaches towards public funding of IVF using various ethical justifications (Agence d’évaluation des technologies et des modes d’intervention en santé (AETMIS) 2009; Mladovsky and Sorenson 2010; Comité directeur de bioéthique 2012). For example, Israel covers 100 per cent of the cost with an age limit of 45 for women using their own eggs, for as many cycles as required to allow for two live births per couple, including single and lesbian women. The UK also fully covers the cost of IVF and priority is given to women between the ages of 23 and 39 who have an identified cause of infertility or who have not been able to conceive for three years, including single and lesbian women. France offers full IVF coverage for women under 43 years of age, but only for heterosexual couples who are married or have lived together for a minimum of two years. In the Netherlands, the first cycle of IVF is not covered, but two subsequent cycles are fully covered with no age limit for women, both single and lesbian, using their own eggs. Germany covers 50 per cent of the cost, and women must be between the ages of 25 and 40. While the law itself does not exclude single and lesbian women, the German Medical Association’s guidelines indicate that only married couples, and in some specific cases unmarried heterosexual couples, should have access to publicly funded IVF (AETMIS 2009). In North America, Quebec is currently the only jurisdiction that fully funds IVF (since 2010) and coverage includes single and lesbian women (*Health Insurance Act* 1970; *Regulation respecting the application of the Health Insurance Act* 1981; Quebec 2013). Funding approaches thus vary greatly in terms of level of coverage and eligibility criteria.

### 13.2.1 The status of infertility

The literature exploring the conceptual and ethical implications of public IVF funding raises numerous considerations such as justice, equitable access, cost-effectiveness, public health, cultural values and norms, and feminist perspectives. In this chapter, we focus on two ways in which the status of (in)fertility is conceptualized: from a medical or *physical* perspective (e.g. is infertility a disease, a condition, a medical need, a handicap?) and from a *conceptual* perspective (e.g. is fertility a human right, a basic human need, an interest, a privilege?).

#### 13.2.1.1 The physical/medical status of infertility

Is infertility a disease? A study that surveyed over 8,000 people in six European countries found that only 38 per cent of them agreed with the statement ‘infertility is a disease’ (Adashi *et al.* 2000), demonstrating the complexity of this issue. The implications of the question are clear: if

perceived as a disease, public funding for its treatment is construed as justified and what remains to be determined is its prioritization in relation to other required treatments competing for limited resources (Hughes and Giacomini 2001; Mladovsky and Sorenson 2010; Tännsjö 2007); if not, its funding may be unjustified from the outset.

The World Health Organization (WHO) suggests that infertility is ‘a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse’ (WHO 2013a). Moreover, the WHO’s definition of health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (2013b) was applied in the following way in the context of reproductive health:

Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have ... the capacity to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the rights of men and women to be informed and to have the right of access to appropriate healthcare services that will ... provide couples with the best chance of having a healthy infant.

(Glazier et al. 2006: 1596)

These definitions, however, are broad and expansive, and they are often seen as portraying an ideal rather than a realistic basis for policy decisions regarding public funding.

Several arguments have been proposed against considering infertility as a disease. First, infertility does not lead to mortality or morbidity, does not entail any physical pain, and does not directly affect the functioning of other physical systems in the body. It has thus been argued that it is not medically necessary to treat it. Similar arguments were used in 1994 by an Ontario judge to justify de-insuring IVF (Hughes and Giacomini 2001) and by the Supreme Court of Nova Scotia in 1999 to argue against public funding (*Cameron v. Nova Scotia (Attorney General)* [1999] NSJ No. 297; Hughes 2008). Second, the diagnosis of infertility is uncertain and variable between countries. In most countries, a couple can be diagnosed as infertile after one year of unprotected sexual intercourse without conception, despite the fact that in many of the cases pregnancy can be achieved given more time. Moreover, a diagnosis of infertility is often given when the medical cause of the inability to conceive is unknown.

On the other hand, several arguments have been proposed in support of the notion that infertility is a disease or a medical condition. First, infertility is a dysfunction of a bodily system that cannot fulfill its natural function. This idea closely aligns with Daniels’ (2008) definition of diseases as deviations from the natural functional organization of a typical member of a species, when those deviations may lead to a negative impact on the individual’s access to equal opportunities. Second, infertility can be treated – or alleviated – through medical intervention. It thus follows a classical medical model that sees a progression from pathology, to symptoms, to medical consultation, to diagnosis and finally to treatment. At the same time, some have noted that IVF does not actually *cure* infertility. It leaves individuals clinically infertile, while alleviating or bypassing infertility to allow conception. However, if an infertility treatment is determined by achieving a live birth, then IVF can indeed successfully treat infertility in many cases.

The debate regarding whether or not infertility qualifies as a disease is thus complex and its resolution does not seem to be in sight. As Shanner noted almost 20 years ago:

Any progress on such a discussion requires a lengthy exploration of the purposes and goals of medicine, the basic concepts of health and disease, the limits of therapeutic as opposed

to cosmetic or elective treatments, and the prioritization among many qualities of life and other values that involve our bodies.

(1995: 856)

Despite these conflicting factors, there is broad agreement regarding the devastating implications of infertility for those who suffer from it. As described by Lord, '[m]any clinicians involved in infertility find that the level of distress and suffering that they see in their patients is far greater than that seen in patients with other benign disorders that are treated free of charge' (Lord *et al.* 2001: 256).

### 13.2.1.2 The conceptual status of infertility

Is reproduction a human right, a basic human need, an interest, a privilege, or a luxury? While this question remains controversial (Warnock 2002), there is broad agreement that reproduction is a basic human drive or interest shared by a vast majority of human beings. Which elements of it are biologically/evolutionarily imprinted and which are culturally or socially constructed remains debatable. However, the human interest in being free and able to found a family and become a parent is widely acknowledged. Certain international documents reflect this view, such as the 1948 *Universal Declaration of Human Rights*: 'Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family' (article 16).

The debate surrounding reproduction as a human right touches on the basic distinction between the negative and the positive aspects of such a right (Quigley 2010). The 'right to found a family' has been traditionally interpreted as expressing a negative right – for example, the right not to be forcibly sterilized or perhaps pay out of pocket for assisted reproduction without state interference or limitations (Robertson 1994). However, public funding of IVF opens up an interpretation of this right to reproduce as a positive right – a right to access services and resources required in order to procreate. Like other positive rights, such as health and education, the implementation of such a right is context-specific – what resources are available and how a given society chooses to prioritize the needs of its citizens based on its shared social values.

The public funding of IVF thus remains a highly controversial area. Much of the difficulty in justifying such funding stems from disagreements on how to frame infertility from a physical or conceptual perspective and whether there is a right to assistance in overcoming it. Moreover, even in societies that acknowledge the interests in reproduction as strong enough to warrant public funding, this decision remains dependent on the availability and prioritization of resources in the face of competing demands on the health budget.

## 13.3 The future of frozen human embryos

The use of *in vitro* fertilization to overcome infertility is increasing. Around 1.5 million IVF cycles are performed each year worldwide, with an estimated 350,000 babies born annually (ESHRE 2013). Many cycles of IVF involve the creation of more embryos than can be implanted in the uterus and therefore 'leftover' embryos remain. The current practice is to freeze – or cryopreserve – these embryos for possible future use. On average, 3.4 embryos are cryopreserved following each cycle of IVF (Gunby *et al.* 2011). The number of leftover frozen embryos is thus increasing constantly.

Many countries put a legal time limit on embryo cryopreservation (for example, two years in Denmark, five years in Belgium and Australia, ten years in the UK) (National Health and



Medical Research Council 2007; Bangsbøll *et al.* 2004; HFEA 2009; Provoost *et al.* 2011; Takahashi *et al.* 2012). However, there is no legal time limit in the USA and Canada (ASRM 2013c; *Assisted Human Reproduction Act* 2004 (Canada)). From a clinical perspective, the time-limit for conceiving a healthy baby from a frozen embryo is not known. The ‘oldest’ frozen embryo to produce a healthy baby was cryopreserved for almost 20 years (Dowling-Lacey *et al.* 2011). The notion that women or couples may reappear after years of not being in touch and demand to use their leftover embryos for reproduction is thus a threatening prospect that underlies clinics’ reluctance to dispose of embryos, even when they are legally entitled to do so.

Recently, researchers have become interested in the ethical, social, legal, psychological, and symbolic aspects of the decision process surrounding cryopreservation of embryos. Studies have explored the factors influencing decision-making regarding the disposition of embryos, such as the conceptualization of the embryo, its perceived moral status, trust in the medical establishment, and absence of appropriate options (Bangsbøll *et al.* 2004; de Lacey 2007; Fuscaldo *et al.* 2007; Hammarberg and Tinney 2006; Lyerly *et al.* 2011). However, most of these studies are based either on speculations regarding the reasons underlying decision-making, or on empirical studies that ask couples hypothetical questions regarding their decision-making. Few studies examine the real-life experiences, emotions, moral reasoning, and general thought process of couples who have lived through decision-making regarding their embryos.

### 13.3.1 What are the options?

Currently, embryos may be frozen (which involves an annual fee to cover the cost of cryopreservation which, in North America, can be approximately \$500 (Rudick *et al.* 2010)); disposed of; donated to other couples; donated for research purposes; used for training embryologists; or used to improve assisted reproduction techniques. While these options are already complex, additional issues should be addressed. For example, what should be the fate of frozen embryos in the event of one partner’s death? Should the surviving partner be allowed to use them for reproduction? What should happen in the event that one partner becomes incompetent to make a decision, or in the event of separation, divorce, or disagreement regarding the future of the embryos? Similar cases have appeared before courts in various countries and have been resolved in very different ways. For example, a US court decided that without the consent of both parties, embryos may not be used (*Davis v. Davis* [1992] 842 SW2d 588, 597 (Tennessee)). However, an Israeli court allowed a woman to use the frozen embryos in recognition of her ‘right to motherhood,’ despite her husband’s objection (*Nakhmani v. Nakhmani* [1995] FH 2401/95 50(4) PD661; Halperin-Kaddari 1999).

### 13.3.2 Consent and abandonment

The complexity of these decisions therefore requires appropriate consent mechanisms. Currently, most clinics do not dedicate enough time to a face-to-face discussion in making this decision. Women and couples are often sent home with a consent form to reflect on their decision alone, with few resources for information or support. The scant literature on counseling and consent regarding cryopreservation demonstrates that patients’ counseling needs are unmet and their consent is not fully informed (Bankowski *et al.* 2005; Machin 2011). To date, many clinics do not include circumstances of death or disagreement in their consent process prior to cryopreservation, and therefore do not have a mechanism in place for addressing such eventualities (ASRM 2013a; Hoffman *et al.* 2003).

In 2013, the ASRM acknowledged that ‘programs should require each individual or couple contemplating embryo storage to give written instructions concerning disposition of embryos

in the case of death, divorce, separation, failure to pay storage charges, inability to agree on disposition in the future, or prolonged lack of contact with the program' (ASRM 2013a: 1). To achieve this laudable goal, novel ways to inform patients should be developed to try and overcome barriers such as time constraints and others.

'Embryo abandonment' (ASRM 2013a; Asemota *et al.* 2013; Walsh *et al.* 2010) creates further challenges for clinics. In such cases, couples do not renew their contact with the clinic and stop paying their annual fees after a few years of cryopreservation. The recent ASRM committee opinion states:

[A]s an ethical matter, a program should be free to dispose of embryos after a passage of time and unavailability of a responsible individual or couple that reasonably indicates that the couple has abandoned the embryos. A program's willingness to store embryos does not imply an ethical obligation to store them indefinitely.

(ASRM 2013a: 2)

However, many clinics are reluctant to dispose of abandoned embryos and continue to keep the frozen embryos indefinitely, incurring the cost of cryopreservation themselves. This creates a financial and logistical burden on clinics, as well as a heavy moral burden on clinic directors and staff.

The complexity of embryo abandonment lies partly in determining the conditions of abandonment. For example, what would be considered diligent effort on the part of the clinic to contact the progenitors of the embryo, and how many years should pass without any contact to consider an embryo 'abandoned'? The ASRM suggests five years as the cutoff, but any proposed number would be arbitrary from an ethical perspective. The future of abandoned embryos thus continues to pose great ethical, legal, and social challenges that policymakers will have to address in the near future.

## 13.4 Elective egg freezing

Elective egg freezing, or 'social' egg freezing, is a relatively new option available to younger women who are not yet ready to conceive, but wish to increase their chances of conceiving at a later time. In 2012, two important professional societies published their clinical recommendations regarding this emerging practice. The American Society for Reproductive Medicine stated that the technique should no longer be considered experimental, although it did not endorse its routine elective use (ASRM 2013b; European Society for Human Reproduction and Embryology (ESHRE) 2012). The ESHRE asserted that it did not find convincing arguments against the elective use of the technique (ESHRE 2012). These recommendations received considerable media attention (Gootman 2012; Inhorn 2013; Knight 2013; Maranto 2013; Mason 2013; Morgan and Taylor 2013; Richards 2013; Rosen 2013), making elective egg freezing a hotly debated social issue. Indeed, this technique raises ethical and regulatory challenges which have been explored in the academic literature in recent years (Donnez 2013; Goold and Savulescu 2009; Lockwood 2011; Petropanagos 2010).

### 13.4.1 Clinical dimensions

Egg freezing is a technique that allows the long-term storage of eggs. Although no reliable data are available, it is believed that to date thousands of babies have been born worldwide from previously frozen eggs. This technique can be used in IVF when more eggs are retrieved than

needed for reproduction, or as a means of fertility preservation in the case of patients suffering from a condition or undergoing a treatment that might compromise their fertility, such as chemotherapy. *Elective* egg freezing, however, is a novel use of the same technique by healthy younger women who freeze their eggs to increase their chance of conceiving a child later in life. Considering that for many women in their forties, an egg donation from a younger donor is required for a successful use of IVF, elective egg freezing may be described as ‘self-donation’ where the young donor and the older recipient are in fact the same woman.

Elective egg freezing is controversial because it involves an invasive risky procedure performed on a healthy woman who is not undergoing IVF for fertility treatment nor facing medical risks to her future fertility, except the typical reduced quality of older eggs. Egg retrieval itself carries risks such as ovarian hyperstimulation syndrome, bleeding and infection (ESHRE 2012; Goold and Savulescu 2009) and little is known about its long-term implications for the woman’s health (Carbone and Cahn 2013). These risks must be understood in the context of limited data on how the use of previously frozen eggs impacts conception, perinatal outcomes, and the long-term health of offspring. Some have expressed concerns that the procedure may represent a ‘false promise’ of preserving fertility in the light of current low success rates of IVF in general (ASRM 2013b; Brezina *et al.* 2013; Goold and Savulescu 2009; Lockwood 2011; Shkedi-Rafid and Hashiloni-Dolev 2011; Wyndham *et al.* 2012).

These elements highlight the importance of developing appropriate counseling and consent procedures for elective egg freezing. Since the balance of risks and benefits is distinct from fertility treatment or preservation, the counseling of healthy women considering egg freezing should be tailored to their unique context and provide the most updated evidence regarding the medical risks of the procedure and the actual chances of conception in the future.

### 13.4.2 Social dimensions

In Western societies, delayed motherhood has become prevalent due to women’s greater prominence in the workforce. Current social trends put women’s ‘reproductive age’ out of sync with their ‘developmental age’. While women are in their (physiological) reproductive peak in their early and mid-20s, this is a time during which they can be socially expected to invest in education and career building to secure future financial stability. The biologically ideal window for reproduction has thus become, for many women, a logistically impossible time to start a family. Indeed, the proportion of women giving birth in their early forties in Canada, for example, has doubled between 1988 and 2008 (Daniluk and Koert 2012).

In light of these social forces and trends, elective egg freezing is often perceived as a means of promoting women’s autonomy, allowing them to expand the natural reproductive cycle and to choose motherhood at a time that is appropriate for them (Capps *et al.* 2013; Rybak and Lieman 2009; Shkedi-Rafid and Hashiloni-Dolev 2011; Wyndham *et al.* 2012). It is also perceived as promoting gender equality by ‘leveling the playing field,’ allowing women to have children later in life, a choice that previously belonged only to men (Goold and Savulescu 2009; Rybak and Lieman 2009; Wyndham *et al.* 2012).

Reproductive autonomy is affirmed by international organizations and conventions such as the World Health Organization (2013) and the *Convention on the Elimination of All Forms of Discrimination against Women* 1979. In light of these documents, one can argue that elective egg freezing is a powerful technological tool to promote autonomy and equality and to fight discrimination.

However, this portrayal of the technique overlooks two important elements. First, elective egg freezing is an expensive option, costing approximately \$4,000 to \$15,000 (USD) plus the additional costs of medication ranging between \$2,000 and \$4,000 (USD), and annual storage

fees of around \$440 (Goold and Savulescu 2009; Harwood 2009; Martin 2010). As such, this is an option only available to a rich minority, unless covered by health insurance. The elevated cost of this option therefore means that while it may level the playing field between men and women, it may create a new type of reproductive inequality between rich and poor women and/or couples.

Second, the emphasis on elective egg freezing as promoting reproductive autonomy and individual choice fails to acknowledge the social context of delayed motherhood. Some speak about 'women who have just waited too long to have their children' (Lahl 2012), as if the decision is purely an individual one, which implies lack of appropriate planning or self-centered preferences. If delaying motherhood is simply a 'lifestyle choice' (Sandelowski 1990), then elective egg freezing may be an appropriate solution, perceived as a 'price' women must pay for their life choices despite being medically risky and financially demanding.

However, this portrayal of elective egg freezing 'obscures the social and economic circumstances as to why childbearing may be deferred by many women' (Capps *et al.* 2013: 18), failing to address the tremendous social pressures experienced by younger women to establish themselves before becoming mothers. The strong social message is that to be a responsible mother, a woman should first get an education, establish a career, and attain financial and relationship stability (Cooke *et al.* 2012; Lockwood 2011; Wyndham *et al.* 2012). In light of these pressures, the choice to delay motherhood must be understood not solely in individualistic terms, but rather in the context of the social reality of today's Western societies (Cooke *et al.* 2012). From this perspective, elective egg freezing can be portrayed as an individual solution to a social problem, one that puts 'the onus of the problem' on the woman as an individual (Farrell 2012). This fails, however, to address the social dimensions of the problem in terms of policies that would allow women to choose motherhood earlier in life, such as paid maternity leave, subsidized childcare, and family-friendly work environments.

### 13.5 Donor conception

The use of donor sperm and egg to conceive a child, also known as 'third-party assisted conception,' has become a well-established practice since the advent of IVF. No confirmed data exist, but it is estimated that hundreds of thousands of children have been born to date worldwide using donor conception. This practice raises numerous ethical, psychosocial, and legal issues, such as telling donor offspring the truth about the circumstances of their conception (McGee *et al.* 2001; Patrizio *et al.* 2001), the impact of donor conception on identity formation and family dynamics (Ravitsky 2010, 2012), the legal establishment of parental status of the non-genetic parent, and guaranteeing that donors do not have any legal or financial liability or obligation towards offspring (Blyth and Frith 2009). Donor conception also raises many challenges from a clinical perspective, such as screening procedures for donors and medical follow-up with donors to update medical history that may affect offspring (ASRM 2013c; Ravitsky 2012). This section focuses on an issue that emerged in recent years as extremely contentious and has received ample academic, legal, and media attention: donor anonymity and the access of donor-conceived individuals to information about their origins.

#### 13.5.1 Donor anonymity and the right to know one's genetic origins

Donor conception was traditionally based on the assumption that donors should remain anonymous. This was meant to protect donors from liability in a period when legal mechanisms were not yet developed to address the challenges of donor conception (Blyth and Frith 2009). It was also meant to protect the status of non-genetic parents, from a legal as well as from a

psychosocial perspective. Protection of donor anonymity was also based on the notion that donor offspring are better off shielded from the truth about the circumstances of their conception, and that access to donor identity would therefore be irrelevant. The perspectives of donor-conceived individuals themselves have initially been a neglected element in the growing practice of donor conception.

Over the years, however, the interests of donor-conceived individuals in having access to the identity of their donors have come to the forefront. As the first generation of donor-conceived offspring came of age, these young adults started sharing their perspectives. Many tell stories of psychological distress, describing a strong need to know their genetic origins as an essential part of constructing their identities. Their perspectives and interests have now become the center of a lively academic debate (McGee *et al.* 2001; Patrizio *et al.* 2001) as well as a driver for support networks, educational campaigns, and legislative changes (Blyth and Frith 2009).

While most countries still protect donor anonymity, a trend towards openness is gathering momentum and a growing number of countries are adopting laws and regulations banning anonymous donation. To date, these jurisdictions include Sweden (1985), Austria (1992), Victoria (Australia) (1998), Switzerland (2001), The Netherlands (2004), Norway (2005), the UK (2005), Finland (2007), Western Australia (2004), New Zealand (2005), and New South Wales (Australia) (2010) (Blyth and Frith 2009; Thorpe *et al.* 2012).

In North America, donor anonymity is still well established. In the US, legislators have only recently taken a first step in the direction of allowing offspring access to information about donors. Effective 22 July 2011, a new law in the state of Washington requires sperm and egg donors to provide a medical history and identifying information to fertility clinics, allowing donor-conceived individuals to request this information once they reach the age of 18 (*Uniform Parentage Act* 2011). This is a significant legislative milestone in a country that has consistently shied away from any type of regulation of the infertility industry. Although donors may still veto disclosure of their identifying information, offspring in Washington have guaranteed access to at least non-identifying medical history, a tremendous improvement over the current reality in all other US states where fertility clinics can destroy donor medical records on a whim before the child turns 18.

Although the Canadian *Assisted Human Reproduction Act* of 2004 mandated the registration of donors and donor-offspring, this measure was never implemented and clinics could elect to destroy donor records. This was an all-too familiar experience for Olivia Pratten, a journalist conceived through anonymous sperm donation who has been unsuccessfully attempting for years to access medical and identifying information about her donor. Pratten decided to take her case to court in an effort to change this legal reality for future generations (*Pratten v. British Columbia (Attorney General)*, 2012 BCCA 480; Motluk 2011). Interestingly, the High Court in the United Kingdom heard a similar case in 2002 (*Rose v. Secretary of State for Health* [2002] EWHC 1593), which was partially responsible for consequent legislation banning anonymous gamete donation.

Pratten argued that donor-conceived individuals are systematically discriminated against in comparison to adoptees that have legal rights to information about their genetic origins. In May 2011, the Supreme Court of British Columbia rendered a decision in her favour (*Pratten v. British Columbia (Attorney General)*, 2011 BCSC 656), but the Attorney General of British Columbia appealed the decision shortly after and won (*Pratten v. British Columbia (Attorney General)*, 2012 BCCA 480). Pratten's subsequent appeal to the Supreme Court of Canada was ultimately unsuccessful (*Olivia Pratten v. Attorney General of British Columbia et al.* [2013] CanLII 30404). Canada thus missed a unique opportunity to address the issue at the federal level, and in coming years Canadian provinces will have to make legislative decisions on this topic.

The legal and ethical debate surrounding this issue is far from over. In the meantime, jurisdictions that allow donor conception can enhance educational efforts, endorse a culture of

openness and acceptance, fight the stigma of infertility and promote a more nuanced understanding of family relationships, including genetic relatedness and non-relatedness.

### 13.6 Non-invasive prenatal testing

From its early days, prenatal genetic testing (PGT) has been raising sensitive ethical, legal, and social issues. While it allows the detection of numerous hereditary conditions – a valuable source of information for individuals – pregnancy termination remains the only course of action following an undesired genetic diagnosis. At a social level, PGT raises a host of difficult policy choices for medical institutions, healthcare insurers, and society: which tests should be allowed, offered, or funded, based on what criteria, and for whom. These choices reflect a social assessment of when it is justified to ‘screen out’ certain conditions or disabilities. Despite these challenging and sensitive issues, PGT enjoys a high level of social acceptability and has become an integral part of prenatal care in Western countries. This is due in large part to its impact on the promotion of reproductive autonomy and the reduction of the incidence of certain hereditary conditions, an important public health benefit.

Now, non-invasive prenatal testing (NIPT) is being gradually introduced (Agarwal *et al.* 2013; Hill *et al.* 2012b; Hui and Hyett 2013; Yotsumoto *et al.* 2012). It allows genetic testing of cell-free fetal DNA using a maternal blood test (Hill *et al.* 2013; Lewis *et al.* 2013). It thus eliminates the risk of miscarriage associated with current invasive procedures, namely amniocentesis and chorionic villus sampling. It is performed earlier in the pregnancy than either of these current tests, as early as 8–9 weeks gestation. Although NIPT offers early and safe access to predictive genetic information, and thus has the potential to revolutionize prenatal care, it also raises a host of novel concerns.

#### 13.6.1 Counseling and consent

To date, professional societies recommend limiting the use of NIPT to women who are considered to be at a high risk for Down syndrome and some other genetic conditions, based on traditional screening tests (American College of Obstetricians and Gynecologists Committee on Genetics 2012; Devers *et al.* 2013; Gregg *et al.* 2013). However, NIPT has the potential to replace current screening and diagnostic tests in the near future (Benn and Chapman 2009; Henry and Greely 2010) and may eventually be offered to all pregnant women as a routine one-step diagnostic test, without prior screening (Schmitz *et al.* 2009b).

This future scenario may compromise informed decision-making. Currently, prenatal testing requires that women are properly counseled on the risk of miscarriage and give written consent prior to invasive testing. A safe diagnostic test runs the risk of being performed without counseling or consent (Deans and Newson 2011; Hill *et al.* 2012a; King 2011). A pilot study of 231 clinicians shows that this may indeed be the case – in the absence of risk of miscarriage, many perceived consent for NIPT as less important than for invasive testing (van den Heuvel *et al.* 2010). There are thus concerns that rather than enhance the reproductive autonomy of women and couples, NIPT may in fact threaten it (Benn and Chapman 2010; Hall *et al.* 2009; Henry and Greely 2010; Schmitz *et al.* 2009a; Skirton and Patch 2013; van den Heuvel *et al.* 2010).

Since NIPT will be offered to an increasing number of women, it may also significantly increase the need for counseling (Kooij *et al.* 2009; van den Heuvel *et al.* 2010), a need that cannot be met even with regard to current screening tests (Greely 2011; Seavilleklein 2009). NIPT therefore requires the development of appropriate tools for patient and provider

education, counseling, informed decision-making, and consent to protect and promote reproductive autonomy (Bianchi *et al.* 2014; de Jong *et al.* 2010; Lench *et al.* 2013; Ravitsky 2009, 2011). These tools should be creative and innovative, and emphasize the role of obstetricians and primary care physicians rather than rely necessarily on traditional models developed for genetic counselors. They should address the actual concerns of patients and clinicians, as well as concerns related to the social acceptance and impact of NIPT. Furthermore, these tools should also address practical implementation concerns, such as whether the test should be offered and performed on two different days in order to create a 'space' for reflection and consideration (Deans and Newson 2011; King 2011).

In the more distant future NIPT may detect a broad range of genetic conditions, since technological advances such as next-generation sequencing will allow detection of multiple conditions. In this context, counseling patients will become even more challenging (Allyse *et al.* 2012; Chachkin 2007) and additional ethical and legal issues will arise, such as the complexity of counseling regarding multiple conditions at once, each with its own characteristics and prognosis, or regarding genetic results of unclear clinical significance.

### 13.6.2 Social concerns

The expected 'routinization' of NIPT also raises concerns regarding increased social pressure to test and terminate affected pregnancies as an expression of 'responsible motherhood.' Since it is done early in the pregnancy, the results can be available before significant maternal-fetal bonding has occurred. Moreover, early termination is medically safer, emotionally less traumatic and more easily available than second trimester termination (Ravitsky 2009). These elements and the future availability of NIPT may lead to an implicit ethical, and perhaps even legal, obligation to test and consequently to the notion that women are 'responsible for bearing a child with a disability' because they had information about the genetic status of their fetus and still chose to carry their pregnancy to term (Deans and Newson 2011; Newson 2008). Genetic counseling is traditionally non-directive, but pre-test counseling for NIPT will be provided by health professionals without specific training in genetics. One of the challenges will be to ensure that the discussion of Down syndrome and other conditions remains balanced (Hippman *et al.* 2012).

Since NIPT is expected to lead to an increase in diagnoses and in pregnancy terminations, the probable result will be a decreased prevalence of individuals with Down syndrome and other conditions in the population. This raises concerns regarding stigmatization, discrimination, and decrease in support systems and research for individuals and their families with certain genetic conditions (Chachkin 2007; de Jong *et al.* 2010; Greely 2011; Hall *et al.* 2009; Haymon 2011; Schmitz *et al.* 2009b). These concerns may adversely affect the social acceptability of NIPT and will have to be addressed as the technology is introduced and implemented, possibly by proposing appropriate policy and regulatory mechanisms.

### 13.6.3 Legal and policy perspectives

From a legal perspective, NIPT raises challenges related to the obligations of healthcare providers to offer the test (Motluk 2012). It may add further uncertainty to already complex questions such as wrongful life and wrongful birth lawsuits, which have emerged as a morally problematic and legally unsettled area. Wrongful life and wrongful birth claims are claims of negligence brought against healthcare providers for acts or omissions occurring prior to or during pregnancy that result in the birth of a child with a disability or a medical condition. They are based

on the assertion that the mother would have terminated her pregnancy had she been adequately informed or counseled by her healthcare provider regarding the risk or presence of the condition, or regarding available tests that can detect it. In wrongful birth cases the claim is brought by the parents against the provider, while in wrongful life cases the claim is brought by, or on behalf of, the child. Wrongful life cases are therefore more controversial, as the plaintiff child essentially asserts that not having been born would be preferable to living with the effects of the ensuing condition. Both types of claims might potentially be made in the future, in cases where providers fail to offer NIPT once it becomes commonplace. The birth of a child with a condition that could have been detected through NIPT may cause parents to seek compensation for not being offered the test or informed of its existence.

Questions remain about the ethical acceptability of such lawsuits (Hogg 2010; Muriithi 2011; Stein 2009), how courts should respond to such cases (Nelson 2011), whether or how to best compensate parent(s), and the nature and scope of duties owed by doctors to future children (*Paxton v. Ramji* 2008 ONCA 697). Wrongful life claims have not been recognized in Canada, or most other jurisdictions, with the exception of three American states (California, New Jersey, and Washington), Israel (*Zeitsov v. Katz* [1986] 40(2) PD 85), and the Netherlands (*X v. Y (Molenaar)* [2003] 234–5, 236–7, 238, 240 (The Hague Court of Appeals)). In France, the French Court of Cassation found that a healthcare provider's negligence in failing to diagnose a pregnant woman with rubella gave rise to claims on behalf of both the mother and the child, who was born with a disability (*X v. Mutuelle d'Assurance du Corps Sanitaire Français et al. (Perruche)* [2000] JCP 2293). This case raised great controversy, and resulted in the enactment of a law preventing children born with disabilities from bringing claims of this nature to court, and barring parents with wrongful birth claims from collecting damages for the increased cost or 'special burdens' associated with raising a child with a disability (*Loi no. 2002-303 relative aux droits des maladies et à la qualité du système de santé* 2002 (France)). Moreover, when this law came into effect, its application extended to wrongful birth and wrongful life cases. At the time many of these cases were pending before French courts, therefore depriving parents from claiming the 'special burden' damages they otherwise would have been entitled to. As a result, the French government was successfully challenged before the European Court of Human Rights, which found these parents had property interests in their anticipated damages awards for 'special burdens,' and the law therefore violated their right to peaceful enjoyment of property (*Draon v. France* [2005] Application No. 1513/03; *Maurice v. France* [2005] Application No. 11810/03).

In contrast to wrongful life claims, wrongful birth claims are more widely accepted in Canada and abroad, although the method of assessing damages in such claims remains unsettled. While some courts award damages for the full cost of child rearing (e.g. *Cattanach v. Melchior* [2003] HCA 38), others opt not to award any damages on the grounds that the birth of a child should be seen as a blessing regardless of whether it is the result of a provider's negligence. More moderate approaches include awarding damages for the increased cost of raising a child with a disability, costs of raising the child offset against the value that the child's life has brought to the parents and, more commonly, awards for damages incurred in relation to pregnancy, child birth, and the initial cost involved in having a newborn baby (see Nelson 2013; *Roe v. Dabbs*, 2004 BCSC 957, paras 189–94, for a detailed discussion of case law illustrating the different approaches to damages).

Furthermore, NIPT raises intellectual property (IP) challenges related to the use of various testing technologies developed by private companies, as well as the impact of patents on specific genetic tests (Agarwal *et al.* 2013). Substantial debate and calls for effective policy have centered on the potential impact of patents on access to useful genetic technologies (Caulfield 2011;



Hopkins and Hogarth 2012; Huys *et al.* 2012; Van Overwalle *et al.* 2006; Verbeure *et al.* 2006), including relevant case law on the patentability of human genetic material (*Association for Molecular Pathology v. U.S. Patent and Trademark Office* [2011] 653 F.3 d I329; Pollack 2012). The advent of inexpensive whole genome sequencing will shift the nature of the patent debate and introduce new social and clinical issues (Dobson and Evans 2012), for example, the degree to which whole genome sequencing will infringe existing patents (Borrell 2010; Holman 2012). This patent debate is highly relevant to NIPT technologies, which will likely involve testing for a range of conditions that may be associated with one or more patents.

While in some countries NIPT is available on the private market (Morain *et al.* 2013) and individuals can choose whether to pay for it out-of-pocket (Agarwal *et al.* 2013; Allyse *et al.* 2012), it is expected that in some countries, including Canada, NIPT will be integrated into universal healthcare coverage. Policymakers and the public therefore need to address questions regarding what tests to offer, to what populations and for which conditions (Hill *et al.* 2013).

Moreover, the social and ethical implications of public funding may be more far reaching than simply allowing individuals to purchase the test, because public funding sends a stronger message of endorsement for the technology. While this message can validate the safety and utility of the test, it can also be seen as an extension of current social trends that pressure women to test and terminate affected pregnancies. It might also be seen as raising risks of stigmatization and marginalization of individuals who live with those conditions or disabilities that society chooses to 'screen out' (Hill *et al.* 2013; Lewis *et al.* 2013).

### 13.7 Conclusion

The 80th anniversary of Huxley's *Brave New World* gives us pause to consider current advances in the area of reproductive technology and fears of a dystopia. Overall, most of the ominous scenarios described in so lively a manner in this futuristic account have not materialized. Rather, reproductive technologies have brought medical solutions to infertility and allowed a growing degree of control over pregnancy outcomes. Broadly speaking, they have enhanced the reproductive autonomy of women and families, equipping them with better tools to decide when and how to have children. The tremendous benefits introduced by reproductive technologies and prenatal testing are thus widely acknowledged and their social acceptability is high.

At the same time, the ongoing emergence of new technologies constantly raises novel ethical, social, and legal challenges. This chapter has described many of these challenges and attempted to outline possible approaches for optimally addressing them. As we look forward, nuanced ethical analysis, refined legal tools, and an informed public debate remain crucial in developing justified and well-balanced approaches that enhance and protect individual autonomy while promoting public health goals.

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