Petra Thorn

Social Therapist, Family Therapist (DGSF)

Cross border medically assisted reproduction from a psychosocial perspective - legal challenges and the welfare of the child

Introduction

Travelling for medical treatment is not a new phenomenon. For decades, patients have travelled within their country as well as to other countries in the hope to receive medical care unavailable where they live, high quality medical care or more affordable health care. Couples experiencing infertility have also travelled – and very likely for much longer than decades. They have travelled within their home country and to other countries to places conducive to infertility and more recently have been travelling for assisted reproductive technology (ART) in the hope to conceive. This phenomenon was initially described as “reproductive tourism” but has lately been referred to as “cross border reproductive care – CBRC”. As the benevolent character that “care” conveys is not always present, in this chapter, the more neutral term “cross border reproductive services – CBRS” will be used (Thorn, et al., 2012).

The reasons for CBRS are manifold. They include law evasion in countries with restrictive legislation (e.g. Germany, where oocyte donation and surrogacy are prohibited), treatment unavailable or associated with long waiting times (e.g. United Kingdom, where a lack of oocyte donors motivated many to travel abroad; recent changes in financial compensation to donors have contributed to more acceptable or no waiting times), the wish to undergo treatment confidentially (associated with the shame and stigma that infertility still carries) or the hope that treatment is more affordable or of higher quality in another country or jurisdiction (Blyth, 2010, Inhorn and Patrizio, 2009, Thorn, 2008). In recent years, CBRS has gained momentum, esp. as it has become easier to cross borders within Europe, as travelling has become more affordable, as couples have become increasingly mobile and as the use of the internet provides information at a finger-tip, even though this information is not always accurate.
While the reasons for CBRS are fairly well known, there is a lack of data and there are concerns for quality and safety. In 2009, the first international forum on CBRS was held in Canada (see for ex. Blyth, 2010, Collins and Cook, 2010, Davies, 2010, Thorn and Dill, 2010). In 2010, the European Society of Human Reproduction and Embryology (ESHRE) conducted a pilot study and compiled data from 46 clinics in six European countries (Shenfield, et al., 2010). This study suggests that approximately 24,000 to 30,000 treatment cycles are carried out annually on patients that have travelled, mainly for treatment prohibited in their home country, such as oocyte donation, or lack of access, such as lesbian women seeking donor insemination. Apart from this, little data is available, as most other research has conducted qualitative studies (see for ex. the special edition of Reproductive BioMedicine Online (Reprod Biomed Online, 2011).

This chapter will focus on the risks and dilemma situations that intended parents are faced with if they decide to travel for treatment, describe the developments in Germany and argue for necessary changes from a child-welfare perspective. Given the author is a social worker and family therapist who has been working as an infertility counsellor for over two decades, there is a strong focus on the psychosocial aspects.

Crossing many borders – risks and dilemmas

Couples and individuals who travel for infertility treatment do not only cross geographical borders (Knoll, 2008). They often cross moral borders, e.g. in those cases where they are denied access to treatment because of their sexual orientation (homosexual couples) or marital status (single individuals) and they need to justify their decision towards family members and friends. This is similar to couples who carry out treatment prohibited in their home country: For most, it is challenging to say the least, to share with others the type of treatment they are planning. They fear not only negative reactions towards themselves but towards the future child. This often results in couples undergoing treatment confidentially, and thus without any support of family or friends.

If undergoing third party conception (oocyte donation, sperm donation, embryo donation), they cross body borders. For most couples, the medical diagnosis of sub- or infertility, the need for ART and the experience of failed treatment cycles
represent a major psychological burden. The decision to involve a donor often takes time, as couples have to come to terms with these first steps: mourn the child they had wished for and accept an alternative route to parenthood. Conceiving a child with oocyte or sperm donation results in a different family composition and has many short and long term implications (such as sharing the conception with significant others and the child, managing asymmetrical parenthood with one biological and one social parent). In several countries, intended parents are expected to undergo psychosocial counselling prior to third party conception (Thorn and Wischmann, 2009), but for several reasons, this is rarely the case when couples undergo treatment abroad. Often clinics do not offer counselling, counselling may not be available in the language of the intended parents and given the illegal nature of the treatment, they may be reluctant to seek counselling in their home country (Blyth, et al., 2011).

In many cases, treatment abroad crosses time border: Gametes may have been cryopreserved for some time, and gametes from the same “batch” may have been used for other patients, or will be in the future. Thus there may be full or half siblings born (many) years before (or after) the birth of a child. Furthermore, oocyte and embryo donation enable women to conceive beyond their biological phase of reproduction and there have been several cases of mothers in their 50ies and even 60ies (for ex. in Germany: Der Stern, 2007).

Donated gametes are not only associated with body borders, but – in the case of treatment abroad – usually also with crossing ethnic borders. German or British couples participating in an oocyte donation programme in Spain can be relatively certain that the donor has a Spanish background (unless they bring their own donor). This results in a child with a dual ethnic background: German or British (the background of the father) and Spanish (the background of the oocyte donor). Emotional affinity towards or acceptance of, a specific culture, which is often considered at great length by couples facing inter-country adoption, does not seem to be a major concern of couples using gamete donation and is typically not raised prior to medical treatment. Both medical professionals and intended parents may attribute little relevance to this issue. To date, however, nothing is known about the children conceived via treatment abroad and thus we do not know if these children consider their dual ethnic background a benefit or a burden and how they manage this.
Last but not least, they cross various borders of knowledge. In many countries, based on national legislation or common medical practice, gamete donors remain anonymous. This results in not only children who cannot access their biological origin, but also intended parents may lack an anonymous profile with some basic data of the donor. In addition, clinical practice indicates that some treatment centres are reluctant to provide information on the recruitment and screening process of gamete donors, are reluctant to provide contracts prior to treatment thus denying patients adequate time to read and understand them (often these contracts are in English, and non-English speakers may struggle with English medical and legal terminology) or issue contracts with little detail regarding treatment and payment modalities. ART is highly complex and requires compliance, and this is dependent upon patients’ understanding. Third party conception adds to this complexity. A lack of understanding results in patients who are confused, and who may not follow medical advice, esp. if part of the treatment takes place in a country other than the treatment country and communication is restricted to telephone and email.

A lack of knowledge, in combination with the willingness to take higher risks after unsuccessful treatment in their home country can contribute to patients accepting higher numbers of embryos transferred. Patients seeking treatment abroad are shown to have higher rates of multiples (McKelvey, et al., 2009), and de Mouzon et al. (2010) argue that although in general the rate of multiples is decreasing, there are some countries where four or more embryos are transferred regularly. This seems to indicate a sinister link between infertility clinics desiring to improve pregnancy rates and patients’ desire to conceive.

Similar issues are also relevant to donors whose gametes are used for intended parents from abroad. Thorn et al. (2012) noted that they take the risk of hyperstimulation in order to harvest a large number of oocytes, there is no information whether they can access (free) medical or psychosocial follow-up, they undergo psychological screening in order to ensure their emotional stability and eliminate those with major psychiatric disorder, but few receive psychosocial counselling that supports them during and after treatment and helps them explore the short and long term implications of their donation.
Developments in Germany

In Germany, although donor insemination (DI) is permissible and has been practiced for many decades, the Embryo Protection Act (EPA) prohibits oocyte donation and surrogacy (Embryonenschutzgesetz, 1990). Furthermore, lesbian and single women face difficulties when seeking donor insemination. There are no legal restrictions as to who can access DI, but the donor does not enjoy full legal protection if his semen is used in a constellation in which there is only one legal parent. Therefore, many infertility clinics and sperm banks refrain from treating lesbians who are not in a civil partnership and single women. As surrogacy is also prohibited, gay men cannot be treated in Germany.

These legal restrictions have resulted in women and men travelling abroad. Based on the ESHRE pilot study (Shenfield, de Mouzon, Pennings, Ferraretti, Nyboe Andersen, de Wert and Goossens, 2010), approximately 3,300 to 4,200 treatment cycles are carried out on German couples and approximately 1,500 to 1,900 German couples carry out treatment abroad per year. Comparing this to the number of couples who carried out treatment in Germany in the same year as data collection of this study (2008), this equals 8% of all treatment cycles carried out in Germany during that year. It is likely that this is a conservative estimate to begin with and clinical experience of the author suggests that the number of couples seeking CBRS has increased during the last years.

German patients travelling for treatment often have little awareness of the legal ramification. Although in Germany, there is no legislation granting children conceived with donor insemination the right to access the identity of the donor, there is case law suggesting that doctors or clinics must provide this information to offspring (Bundesverfassungsgericht, 1989, Oberlandesgericht Hamm, 2013). There is, however, no stipulation as to the age of offspring (adopted children enjoy this right when they are 16) and according to current legislation, documents pertaining to donor insemination treatment must only be recorded for a minimum of 30 years (Transplantationsgesetz, 2007). Many couples travel to Spain for oocyte donation and in Spain, as in France, Belgium and several other countries, legislation grants donors anonymity. This results in a situation where currently, there are two groups of offspring in Germany growing up: those conceived in Germany (or in any other country that does not permit donor anonymity) who can access the identity of the
donor and those conceived in countries with donor anonymity that do not enjoy this right.

It is uncertain if legislation will be changed and if oocyte donation will be possible in Germany. In May 2014, there were two conferences on new legislation but there does not seem to be any indication that legislation will be changed. However, Austria will legalize oocyte donation in 2015 (Parlamentsklub, 2014), and this may exert some pressure on Germany to also reconsider its legislation.

There have been some, more discreet developments in Germany. Since the implementation of the EPA, embryo donation has been considered to be illegal unless there were cryopreserved fertilized oocytes which for medical reasons could not be transferred to the genetic mother. There were, however, considerable uncertainties (Wendehorst, 2003). In 2013, the “Netzwerk Embryonenspende” (Network Embryo Donation) was founded in Bavaria (see: http://www.netzwerk-embryonenspende.de). According to the guidelines of this network, “released fertilized oocytes and embryos are donated to infertile couples who for medical and biological reasons cannot have children spontaneously or with ART”. Several couples have donated embryos and in November 2014, the first baby was born. Currently, there are three more pregnancies (Eder, 2014). Research suggests that only few couples donate embryos (de Lacey, 2007) as the decision process seems to be very complex and challenging (Provoost, et al., 2011). It is therefore unlikely, even if embryo donation was adequately covered by legislation, that the number of couples willing to accept embryo donation is on par with the number of embryos free for donation.

A further issue that has the potential to impact on family building by homosexual men is a decision of the German Federal Court of Justice in 2014 (Bundesgerichtshof, 2014). Two gay men who had used surrogacy and oocyte donation in California were both, after several lower court decisions, granted legal paternity. The Federal Court of Justice argued that the welfare of the child and the need for legal certainty as to his parenthood overrides concerns about the illegal nature of the treatment itself.

**Necessary changes from a child-welfare perspective**
From a child-welfare perspective, in Germany, several areas could benefit from clarification and adaptation. These areas concern reproductive medicine as well as family law.

Although there are no legal restrictions, medical guidelines only grant heterosexual couples access to DI. These guidelines argue that the welfare of the child may be compromised if they grow up in lesbian or single-mother headed families. However, from a scientific viewpoint, there are no indications that children in these new family forms fare worth than those growing up in traditional families. In order to grant all groups of intended parents equal rights, independent from their sexual orientation or marital status, it will be important for them to be able to access treatment without restriction. At the same time donors need legal protection if their semen is used for same-sex or single mother families. There should not be any distinction between various groups of children. Therefore, the rights of children conceived by DI should be similar or identical to adopted children. Adopted children in Germany can access information about their relinquishing parents after the age of 16 and these records must be maintained for a minimum of 60 years (Adoptionsvermittlungsgesetz, 2002). The minimum period of documentation for DI offspring must be extended and – similar to adopted people – they should enjoy the legal right to access this information once they turn 16.

Furthermore, these records should be documented not by single clinics or medical professionals, but by a government institution or an NGO in a centralized manner. A central national registry could provide DI offspring with the possibility to have uniform access, independent from the practice and attitude of individual clinics. It could provide psychosocial support and a mediating service for offspring, donors and their families interested in contact, it could evaluate such services so that they can be developed and adapted to the needs of those involved and last but not least, a central record keeping institution could ensure that donors only donate at one clinic and thus make it possible to limit the number of offspring per donor more effectively (Hammel and Thorn, 2014). Although currently, the number of offspring seeking contact is small, the increasing rate of parents disclosing the nature of their child’s conception will result in more and more children and adult offspring voicing the interest and/or the need to access information about the donor or meeting him in person (Blyth, et al., 2012).
Creating a family with donated gametes is associated with many uncertainties for the intended parents. Therefore, they should be able to access psychosocial counselling prior to embarking on medical treatment. In Germany, medical guidelines recommend such pre-treatment counselling (Bundesärztekammer, 2006), but in reality, only few clinics inform couples about the availability of counselling (Stöbel-Richter, et al., 2011). It is therefore important to mandate the information about counselling: It should be compulsory for clinics to inform about counselling but the uptake should be up to the discretion of the intended parents.

On a European level, harmonization of legislation is likely to be a challenge, if not impossible. There is also controversy as to its desirability. Pennings (2004) argues that harmonization forgoes cultural and religious pluralism and suggests that CBRS could be considered a safety valve that helps to avoid conflicts. On the other hand, the current situation lends itself to exploit the vulnerable parties, and these are primarily the children thus conceived as well as the donors and surrogates. There is very limited knowledge about the long-term implications of both offspring conceived as a result of CBRS and donors and surrogates involved. There are also worries that CBRS impacts on the quality of treatment in the treatment country. Storrow (2010) is concerned that it may reduce the capacity of a country to provide for the medical needs of its own citizens as it results in migration of medical professionals from the public into the private sector where they can carry out more lucrative treatment for patients from abroad. These difficulties have led Thorn et al. (2012, p. 3ff) to suggest minimum standards of care for clinics involved in CBRS. These standards include the following 10 points:

1. Voluntary oversight of ART and voluntary commitment. As many countries have not established legislation or legislation does not comprise gamete donation and/or surrogacy, and as national registers have not been mandated Europe-wide, voluntary oversight, documentation of ART and outcome offers the possibility of making treatment and research transparent and accountable to patients and professionals. Transparent information easily accessible for all stakeholders, though it does not prevent dubious practice per se, can provide some criteria for orientation when seeking clinics.

2. Altruistic donation and surrogacy. Commercial donation and surrogacy should be discontinued. This is in compliance with the European Tissue Directive
(European Parliament and the Council of the European Union, 2004) which states that voluntary and unpaid donation should be endeavoured but that donors may receive compensation for expenses and inconveniences.

3. Obligation of care. Donors and surrogates should receive the same quality of care as recipients. This applies to medical care as well as to psychosocial care. They should be provided with full healthcare coverage to enable them to access free medical care required after possible complications. Donors’ and surrogates’ family planning should not be affected by medical interventions, therefore they should have children of their own. The number of pregnancies of surrogates and offspring per donor as well as of medical interventions should be limited to avoid unnecessary risks and donors and surrogates should only undergo treatment least harmful for them.

4. Informed consent. Donors and surrogates undergo health risks for the benefits of others. This requires a high level of informed consent to ensure that these parties are informed about medical procedures and psychosocial implications in an unbiased manner, accurately, comprehensively and intelligibly. This should also include legal information. An independent ombudsman or advocate can be established to represent the interests of these parties and intervene in case of disputes.

5. Psychosocial counselling and assessment. All intended donors and surrogates should have access to counselling prior to, during and after medical treatment. Pre-treatment counselling should be strongly recommended to intended parents so that they can explore the long-term implications of third party reproduction. Surrogates should also undergo psychological assessment to evaluate their emotional stability. There should be adequate time between counseling/screening and treatment for reflection.

6. Involvement of ethics committees. In complex cases such as surrogacy, a multi-disciplinary ethics committee comprising medical, psychosocial, and legal professionals as well as a patient representative should be installed. An ethics committee should also review all new and innovative treatment procedure.

7. Avoiding conflicts of interests. In order to avoid conflicts of interests (i.e. excessive hyperstimulation of oocyte donors to maximize the number of oocytes
for donation), the recruitment of donors and surrogates should be carried out independently from those institutions that provide the informed consent procedure, the psychosocial counselling and the legal advice.

8. Identifiability of donors and surrogates. There has been a lot of controversy regarding the anonymity of donors which will not be repeated here. For a moral perspective to respect values such as autonomy, justice and beneficence (Beauchamp and Childress, 2012), offspring as the only party that cannot take active decisions when embarking on ART should not have limited autonomy, which includes the possibility to access the identity of the donor or surrogate. For this purpose, medical records should be maintained in perpetuity, but at least for a minimum of 80 years.

9. National self-sufficiency. All countries should strive towards national self-sufficiency, so that intended parents do not need to travel for treatment and donors and surrogates do not need to provide their service to recipients from abroad (usually from countries with higher living standards). In accordance to national, cultural and ethical principles, ART should be regulated so that this aim is achieved.

10. Framework based on human rights. There are a number of international and European regulations and conventions on human rights including the Convention of Human Rights and Biomedicine of the Council of Europe (Council of Europe, 1997), Ethical Issues on Obstetrics and Gynecology (International Federation of Gynecology and Obstetrics, 2009), the Charter on Sexual and Reproductive Rights (International Planned Parenthood Federation, 2003), Global Principles for assisted conception and infertility: A Patients’ Rights Charter (International Consumer Support for Infertility, 2008) and the International Alliance of Patients’ Organisations – Declaration on Patient-Centered Healthcare (International Alliance of Patients’ Organisations, 2006). These can contribute to, or serve as a basis for minimum standards of care on the bioethical principals of justice, autonomy and benevolence.

In the coming years, it will be important to gather data on CBRS. But it will be equally important to ensure that the quality of care for all involved is as high as possible. This requires cooperation between professionals, clinics, institutions and
countries. ART is more than medical treatment to achieve pregnancy and the birth of a child. ART helps to create families with children whose short and long-term must be respected – just as there should be respect for any person who has contributed to the formation of these families.

References


International Alliance of Patients' Organisations. 2006. Declaration on patient-centered healthcare. check it! 24.08.2009.


