

voor Helena

Promotor Prof. dr. Guido Pennings
Vakgroep Wijsbegeerte en Moraalwetenschap
Copromotor Prof. dr. Petra De Sutter
Universitair Ziekenhuis Gent

Decaan Prof. dr. Marc Boone
Rector Prof. dr. Anne De Paepe



Faculteit Letteren & Wijsbegeerte

Wannes Van Hoof

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Preface

Doing a PhD can be hard. When I applied for a job as a PhD student, Guido tried to dissuade me from accepting the offer. He told me that it was going to be lonely and that I was signing up to work on one subject for four years. And indeed, at times it was hard. When you have been transcribing interviews for hours on end, it is very easy to lose your motivation. However, now that I am nearly at the end of the line, I can honestly say that I would do it all over again. It was my job to think about real ethical problems related to cross-border reproductive care. I read interesting books and articles and I had the opportunity to meet intelligent people. I was able to talk to patients, counselors, physicians and ethicists about their take on particular instances of cross-border reproductive care. There were days where I would eat breakfast, lunch and dinner behind my laptop because I had to finish an article. There were also days where I would lie on the couch with an interesting book or where I would go for a run or a bike ride to sort out an argument. There are many different aspects to doing a PhD. It can be a job, a hobby, an education, a teaching experience, lonely, interactive, interesting, boring. In any case, doing a PhD transforms you. You become a researcher.

Four years ago, I did not really know what ‘ethical problems related to cross-border reproductive care’ meant. I still do not have all the answers, but now I can present a dissertation with my arguments and I hope that they will add to the discussion in one way or another. In hindsight, I am very happy with the subject of my PhD. It is a broad subject, which allowed me to work on fundamental ethics about reproduction and ART, on the relationship between culture, ethics and the law, on the relationship between empirical and normative research in bioethics, on medical tourism and on many other interesting topics. Originally, I was mainly interested in the research project because it combined qualitative and normative research. As a philosopher and an anthropologist, this was a perfect match for me. Gradually I became more involved in the issues and I started taking a position. One might discover minor shifts throughout this dissertation, because I also evolved as the research continued.

Table of Contents

Introduction

Infertility.....	1
Ethics of ART	2
Defining cross-border reproductive care.....	5
Doctoral dissertation.....	6
Normative research.....	6
Empirical research.....	8
Overview of the dissertation.....	9
References.....	12
<i>Part 1 Normative research</i>	<i>17</i>
Chapter 1 Cross-border reproductive care around the world: recent controversies.....	19
1.1 Introduction	21
1.2 Cross-border reproductive care around the world	22
1.2.1 Patterns of movement: push and pull	23
1.3 Controversies in cross-border reproductive care.....	24
1.3.1 Legal diversity.....	25
1.3.2 Gamete donation	26
1.3.3 International commercial surrogacy.....	29
1.4 Conclusion	32
1.5 References.....	32
Chapter 2 Extraterritoriality for cross-border reproductive care: should states act against citizens travelling abroad for illegal infertility treatment?	37
2.1 Introduction	39
2.2 Double consistency and analogous situations.....	40
2.2.1 The first consistency demand	40
2.2.2 The second consistency demand.....	40
2.2.3 Abortion tourism	41

2.2.4	Child sex tourism.....	41
2.2.5	Female genital cutting.....	42
2.3	Utilitarianism, deontology and the analogy between donor anonymity and FGC.....	43
2.3.1	Deontological arguments.....	43
2.3.2	Utilitarian arguments.....	44
2.3.3	Concluding the analogy.....	44
2.4	Extraterritorial legislation in areas of contested morality.....	45
2.5	The effect of regulation on the acceptability of a practice.....	48
2.6	Alternative ways to react to extraterritorial ‘criminal’ acts.....	49
2.6.1	Preventing travelling.....	49
2.6.2	Discouragement and forbidding aiding and abetting.....	50
2.7	Conclusion.....	52
2.8	References.....	53
Chapter 3	Limiting access for foreign patients in cross-border reproductive care.....	57
3.1	Introduction.....	59
3.2	The issue of legal diversity.....	60
3.2.1	The practical problems of legal diversity and solutions in the home country.....	60
3.3	Limitations imposed by the destination countries.....	61
3.4	Limitations following from the clinic’s and physician’s duties.....	63
3.4.1	Duty towards the foreign patient: non-maleficence and respect for autonomy.....	63
3.4.2	Duty towards the child: rights and wellbeing.....	64
3.4.3	Duty to local patients: when justice requires different treatment.....	65
3.4.4	Duty to safeguard against exploitation.....	66
3.5	Conclusion.....	67
3.6	References.....	68
Chapter 4	The consequences of S.H. and Others v. Austria for legislation on gamete donation in Europe: an ethical analysis of the European Court of Human Rights judgments.....	71
4.1	Introduction.....	73
4.2	The judgment of the First Section.....	74
4.3	The final judgment of the Grand Chamber.....	76
4.4	After S.H. and Others v. Austria.....	77
4.5	Thoughts for a better future.....	78
4.6	References.....	79
Chapter 5	Risks and challenges for patients crossing borders for infertility treatment.....	81
5.1	Introduction.....	83
5.2	Main risks and challenges in CBRC.....	84
5.2.1	Safety: multiple pregnancies.....	85

5.2.2	Safety: complications	87
5.2.3	Safety: collaboration between providers	88
5.2.4	Safety: reliable information	89
5.2.5	Counselling	91
5.2.6	Legal conflicts	93
5.2.7	Reimbursement and costs	94
5.3	Conclusion	96
5.4	References	96

Part 2 Empirical Research99

Chapter 6 Reflections of Dutch patients on IVF treatment in Belgium: a qualitative analysis of internet forums..... 101

6.1	Introduction	103
6.2	Methodology.....	104
6.3	Results	105
6.3.1	Medical expertise and testing: effectiveness and efficiency	107
6.3.2	Feelings and experiences: patient-centeredness.....	109
6.3.3	Costs.....	111
6.3.4	Trying out different clinics	113
6.3.5	Travel and waiting times: investments.....	114
6.3.6	Treatments in the Netherlands.....	115
6.3.7	Cooperation between clinics/physicians.....	116
6.3.8	Laws and regulations	117
6.4	Discussion	117
6.5	Conclusion	120
6.6	References.....	121

Chapter 7 “Now we feel like we did everything we could”: A qualitative study into the experiences of Dutch patients who travelled to Belgium for infertility treatment. 123

7.1	Introduction	125
7.2	Methodology.....	126
7.3	Results	127
7.3.1	Participants	128
7.3.2	Treatment in the Netherlands.....	129
7.3.3	Information	130
7.3.4	Treatment in Belgium.....	131
7.3.5	Belgium as the next step	132
7.3.6	Donor sperm.....	134
7.4	Discussion	134
7.5	Conclusion	136
7.6	References.....	137

Chapter 8	Cross-border reproductive care for law evasion: a qualitative study into the experiences and moral perspectives of French women who go to Belgium for treatment with donor sperm	139
8.1	Introduction	141
8.2	Methods.....	143
8.3	Results	144
8.3.1	Participants	144
8.3.2	Reasons to travel abroad.....	144
8.3.3	Moral perspectives on society and the rights of homosexual couples ..	145
8.3.4	Moral perspectives on the second mother	147
8.3.5	Moral perspectives on the child.....	149
8.3.6	Challenges: information	149
8.3.7	Challenges: absence from work.....	150
8.3.8	Challenges: medical treatment.....	150
8.4	Discussion	152
8.5	Conclusion	154
8.6	References.....	154
General Discussion	157
	The right to reproduce	159
	The right to reproduce for infertile persons.....	159
	The right to reproduce across borders.....	160
	Cross-border reproductive care	161
	The positive and negative effects of CBRC for patients	161
	The responsibilities of the cross-border patient	162
	CBRC for law evasion and national policy making	163
	Exploitation of women in cross-border reproductive care.....	165
	Safety	165
	Fair compensation	165
	Womb for rent and egg selling	166
	Future research.....	167
	Future research about patients in CBRC	167
	Future research about frozen sperm, eggs and embryos across borders	169
	Conclusion	169
	References	170
Appendix I Interview guide	173

Introduction

Infertility

Reproduction is an important aspect of human life. Some would even argue that to reproduce is the meaning of life (e.g. Stewart-Williams, 2010). In many cultures around the world one must have children to confirm one's masculinity or femininity and to validate a marriage. Even in societies where people tend to postpone reproduction to a later age, creating a family is generally still considered to be an important life goal. Therefore, the inability to reproduce can have a detrimental effect on a person. In different societies, infertility can have deleterious social and psychological consequences on the individual, from overt ostracism or divorce to more subtle forms of social stigma leading to isolation and mental distress (Chachamovich et al., 2010; Cousineau & Domar, 2007).

The clinical definition of 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' (Zegers-Hochschild et al., 2009). Following this definition, infertility is a broad concept. Many couples who fail to achieve a clinical pregnancy after 12 months are actually sub fertile, which means that they still have a chance to become pregnant in the future. There is a distinction between primary infertility, the inability to attain a live birth, and secondary infertility, the inability to have another child. Sometimes a distinction is made between social infertility, the inability to achieve a pregnancy because one is lesbian, gay or single, and infertility because of medical reasons. In this dissertation, infertility is used as a broad concept: everyone who needs assisted reproduction to have a reasonable chance to achieve a pregnancy is described as infertile.

Infertility is very common. The prevalence of infertility lasting for at least 12 months is estimated to be around 9% worldwide for women aged 20-44 (Boivin et al., 2007). The World Health Organization estimated that in 2010, 48.5 million heterosexual couples of reproductive age were clinically infertile worldwide (Mascarenhas et al., 2012). Add to this number every gay or lesbian couple and every single parent by choice and it becomes clear that there is a huge potential market for infertility treatment. Given the near universal importance of reproduction as life goal and the prevalence of infertility, the development of assisted reproductive technology (ART) has changed many lives for the better.

Since the birth of Louise Brown in 1978, it is estimated that more than 5 million IVF babies have been born worldwide (Adamson et al, 2013). The availability of infertility treatment varies enormously per country. For example, the International Committee for

Monitoring Assisted Reproductive Technologies (ICMART) calculated that in 2004, availability of IVF treatment ranged from <100 cycles per million population in several Latin American countries to 3844 cycles per million in pronatalist Israel (Sullivan et al., 2013). The availability of ART largely depends on legislation and guidelines. First, a treatment or technique must be considered morally acceptable by a society or restrictive legislation will prohibit access to particular ARTs. Second, most ARTs are expensive which means that access depends largely on patients' financial means unless infertility treatment is covered by health insurance. Several European countries reimburse a set number of IVF cycles, which explains why most treatments are reported there. In 2009, 537,463 IVF, ICSI or frozen embryo replacement treatment cycles were reported from 34 European countries (Ferraretti et al., 2013). In comparison, 147,260 cycles were reported from the US in 2010 (CDC, 2012). The number of cycles performed in many developed countries has grown significantly over the last few years, but that growth is now showing signs of slowing.

Ethics of ART

There are many different moral positions with regard to ARTs. We will list some of these positions to be able to understand different approaches to particular ARTs around the world.

Unnatural reproduction

ARTs separate procreation from sexual intercourse. Assisted reproduction is artificial and unnatural. This argument is sometimes used to oppose ARTs on moral grounds. However, just because something happens a certain way in nature does not mean that this is the morally preferable state of affairs. To argue that something has moral value because it is a natural process is a naturalistic fallacy. Still, a lot of opposition to ART is grounded in the idea that assisted reproduction is wrong because it is unnatural. For example, some countries (e.g. Germany) justify a prohibition on egg donation and surrogacy on the legal doctrine that the woman who bears a child is always the parent (*mater semper certa est*).

The moral status of the embryo

IVF treatment implies the creation and destruction of human embryos. Those people who attribute a high moral status to the embryo oppose IVF treatment because of this or try to minimize the loss of embryos. In Italy, for example, a strict law was enacted in

2004 which states that no more than three embryos can be created per IVF cycle, that all the embryos must be transferred (even when they are affected by some anomalies) and that cryopreservation of embryos is prohibited. This law is criticized because it affects the quality of services that can be offered to infertile patients (Benagiano & Gianaroli, 2010).

Justice

A worldwide trend is developing towards more access to ART. The European Society for Human Reproduction and Embryology (ESHRE) Task Force on Ethics and Law defends the position that infertility treatment should at least be partially reimbursed based on the impact of not being able to have a child on the quality of life of a person (Pennings et al., 2008). However, reimbursement for infertility treatment is not a simple issue. ARTs are expensive and require technical expertise and specific infrastructure, but other afflictions may cause more health problems. Especially in low resource countries access to ART is a complex issue (Ombelet et al., 2008). Nevertheless, some argue that reproductive rights must encompass the right to facilitate reproduction when fertility is threatened, even in low resource countries (Inhorn, 2009).

Alternative family building

Who should be allowed to create a family? Certain groups (lesbian, gay, transgender and single people) need access to ART to create a family. In some countries (e.g. France, Italy) only heterosexual couples in a stable relationship are allowed access to ART. There are two justifications for this restriction. First, infertility treatment is a medical procedure which aims to alleviate an affliction, but this group of people is not infertile in a medical sense. Second, children should have a mother and a father, which means that alternative family forms are morally inferior. Counterarguments for this position are a universal right to reproduce and the fact that children in alternative families are equally well off (Pennings, 2011).

Welfare of the future child

The welfare of the child argument is used by both supporters and opponents of ARTs, but there is general agreement that it is a very important consideration. The right of the would-be parents to procreate should always be balanced with the well-being of the child. It is argued that the provision of medical assistance in procreation is acceptable when the child born as a result of the treatment will have a reasonably happy life (Pennings, 1999). Some argue that some family forms or some reproductive technologies do not guarantee this. For example, when frozen sperm is stored from a man who died, posthumous reproduction becomes a possibility. In the infamous Diane Blood case, the Human Fertilization and Embryology Authority (HFEA) denied her request to use her

dead husband's sperm for artificial insemination on the ground that posthumous children were bound to suffer psychological trauma (Deech, 2003).

The importance of genetic ties

Moral objections have been made against gamete donation because the genetic link between the parent and the child is cut. For example, until the 1990 UK Human Fertilization and Embryology Act, a child born using donor sperm was officially illegitimate in the UK (Warnock, 2002). Sperm donation is currently banned in several countries (e.g. Middle Eastern countries except Iran and Lebanon) because of the importance of genetic heritage (Inhorn, 2011). From the perspective of the future child, arguments against anonymous sperm donation have been formulated based on the right of the child to know its genetic origins. To protect the rights of the child, identifiable donation policies and a birth certificate which records the donor conception can be imposed (Blyth et al., 2009).

Commodification

Some critics oppose third party assistance in reproduction because of the commodification of the human body when sperm and egg donors or surrogates are paid for their 'donation'. The argument that offers a way around this objection is that these people are compensated for their time and effort rather than paid for their body parts. However, it remains difficult to distinguish reasonable compensation from payment and those who position themselves radically against commodification of the body will not be convinced by this argument.

Eugenics

The use of donor gametes could be a form of eugenics when women can choose a sperm donor of their choice from a catalogue. The critique of eugenics is strengthened by examples of higher donor payments for 'exceptional donors' in the context of egg donation (Levine, 2010). However, it is not clear what the characteristics are that recipients look for. Empirical research indicates that resemblance to the infertile partner is the most important factor in donor choice and the information provided in the donor profile is primarily aimed at providing an impression of the donor as a person (Pennings, 2000). Nevertheless, the argument of eugenics is still used as a justification for a ban on gamete donation in some countries (e.g. Austria).

Exploitation

Egg donation and surrogacy are two techniques that are forbidden in many countries (e.g. Germany, Italy, Switzerland, ...). One of the main concerns regarding these ARTs is

the exploitation of women. The techniques are risky and burdensome for egg donors and surrogates. For both techniques, there are stories of coercion, misconduct and bad clinical practice (Bailey, 2011; Nahman, 2008). On deontological grounds, it can be argued that egg donors and surrogates are merely used as a means to an end. Others argued that the exploitative and harmful factors are the background conditions (like economic inequality and bad clinical practice) and not the techniques themselves (Wilkinson, 2003).

Defining cross-border reproductive care

Cross-border reproductive care (CBRC) is the phenomenon where persons travel from one jurisdiction to another in order to access or provide infertility treatments and where frozen sperm or embryo's (and eggs in the near future) are shipped across borders. There are many different forms of CBRC since there are many different infertility treatments with distinct ethical problems that become even more complex in various cross-border contexts. The main focus in this dissertation will be on the ethical problems related to the movements of patients across borders.

Knoppers and LeBris (1991) were the first to describe what they called 'procreative tourism'. Other terms that are commonly used are reproductive tourism or fertility tourism (Blyth & Farrand, 2005; Deech, 2003), reproductive exile (Matorras, 2005), transnational reproduction (Whittaker, 2009) and cross-border reproductive services (Thorn et al., 2012). We prefer CBRC because it avoids the negative connotations of 'tourism' in a medical context, and it is objective and descriptive since it holds no value judgement regarding the movements (Pennings, 2005).

Some categorize CBRC as a subset of medical tourism (e.g. Whittaker, 2010). However, there are some significant differences that require that CBRC is treated as a separate field. Medical tourism is defined as the intentional pursuit of non-emergency medical treatment outside of a patient's home country that is likely to include a pre or post-operative stay abroad during which some tourist activities may be undertaken (Johnston et al., 2010). Academic research in medical tourism mostly concerns issues of cost and quality of care. CBRC is not generally associated with a positive choice and leisure time, but rather described as burdensome and politically, religiously, socially and ethically controversial (Inhorn & Patrizio, 2009). In medical tourism, travelling to evade the law is the exception rather than the rule (e.g. Cohen, 2012; Hunter & Oultram, 2010). In CBRC, one of the main reasons why patients cross borders is to evade legal restrictions (e.g. Shenfield et al., 2010). Legal and moral pluralism have therefore been at the core of the academic debate on CBRC from the start (Knoppers & LeBris, 1991;

Pennings, 2002; 2004; Storrow, 2005; 2010). Moreover, contrary to most medical interventions that are generally mentioned in the context of medical tourism (e.g. dental care or plastic surgery), infertility treatment is a lengthy process, which implies several visits to a clinic and has a limited chance of success.

There are many different forms of CBRC in the sense that patients travel for different reasons and for different treatments between countries with distinct cultural, religious and ethical contexts for assisted reproduction. So far, scholars have identified at least 10 different reasons why individuals may engage in CBRC (Gürtin & Inhorn, 2011). These are: (i) legal, religious or ethical prohibitions; (ii) denial of treatment to certain categories of persons (based on age, marital status or sexual orientation); (iii) high costs; (iv) absence of assisted reproductive technologies in resource-poor countries due to lack of expertise and equipment; (v) long waiting times due to resource shortages; (vi) safety concerns; (vii) low-quality care and/or success rates; (viii) desires for cultural understanding (e.g. language and religion); (ix) proximity to support networks and family members; and (x) privacy concerns. The motivations for travel, patient experience, provider responsibility, consequences in home and destination countries, policy responses, welfare of the future child, gamete donor and surrogate wellbeing, ... are all intertwined in different forms of CBRC (Hudson et al., 2011). Throughout the dissertation, the ethical problems related to different forms of CBRC will be explored.

Doctoral dissertation

The research project consisted of a normative part and an empirical part. At the start of the PhD project we explored the ethical problems related to CBRC on a theoretical level, which allowed us to prepare the empirical research.

Normative research

‘Ethical problems related to cross-border reproductive care’ is a broad subject for a doctoral dissertation. Writing about a broad subject gives a researcher a lot of freedom to explore different issues and the chance to focus on interesting new developments. For example, we wrote our first article about the inconsistency of prohibiting certain treatments or techniques in assisted reproduction while at the same time allowing patients to go abroad and make use of those treatments or techniques (Chapter 2). That same year, the European Court of Human Rights judged in the case of S.H. and Others that the restrictions on assisted reproduction in Austria were not sufficiently justified, a

decision which was overturned on appeal, partially based on the argument that patients always had the option to go abroad to circumvent the restriction. This inspired us to develop our arguments further through an ethical analysis of the judgments (Chapter 4).

Much of the normative research in this dissertation deals with the issue of legal diversity. There is an enormous diversity in laws on all the different aspects of ART. Treatments or techniques that are prohibited in one country are permitted in others and people who are denied access to ART in one jurisdiction can make use of ART in other jurisdictions. We have written about the effect of legal diversity on patient flows (Chapter 1), on national policy making (Chapter 1, 3 & 4), about potential state reactions for home countries (Chapter 2) and about limiting access in destination countries (Chapter 3).

On a theoretical level, the relationship between ethics, law and common morality is always present in the discussions about legal diversity. On a national level, assisted reproduction is subject to on-going ethical debate. It is very difficult to distil just laws from competing social norms about right and wrong ways to create a family. It is equally hard to balance the rights and wellbeing of infertile people with a child wish, future children and gamete donors and surrogates. Additionally, laws are often the product of political dynamics rather than moral discussion, which means that they can change after every election. In democratic societies, we presuppose that the law expresses the moral position of the majority of citizens, but this may not always be the case in practice due to coalition building dynamics or when people have to choose from many options. One basic problem for all democracies, especially in value laden areas like reproduction, is how to deal with the moral views of the minority (Pennings, 2009).

The moral position of minorities can be protected internally: the majoritarian rule is only one of many principles (e.g. justice and fairness ensured by judicial review) to support the basic principle of democracy, which is political equality (Macedo, 2010). The basic justification to curtail the majority rule is that the majority view is not necessarily the morally preferable position. This is the most important objection against the way the HFEA (partially) organizes its decision making process on morally controversial treatments: public consultations do not provide arguments about the basic morality of a treatment. However, a certain way of life will always be dominant in society and laws will be based on social norms to a certain extent.

It has been argued that allowing people to go abroad for ART can be a way to be tolerant towards different views on family building in a society (Pennings, 2004). However, there are still many areas of tension when people travel abroad to circumvent restrictions in their own countries. This is what many of the normative articles in the dissertation are about: what is the meaning of a restriction if people always have the option to go abroad (Chapter 2); how should legal diversity be dealt with on a supranational level (Chapter 4); how should home countries and destination countries

deal with the effects of legal diversity, for example the children who are born from law evading surrogacy arrangements (Chapter 2 & 3); what are the responsibilities of physicians in CBRC for law evasion (Chapter 3, 5, 7 & 8).

The moral questions surrounding infertility treatment become even more complex in a cross-border context. For example, arguments about payment and compensation for gamete donors or surrogates are transformed when movements between developed and developing countries are at stake (Chapter 1). There are also specific issues related to cross-border reproductive care. For example, patients face specific risks and challenges in CBRC (Chapter 5). Our empirical work (Chapter 6, 7 & 8) offers additional insight in the experiences of cross-border patients and the challenges they face.

Empirical research

Social and psychological studies are adding to the knowledge about the experience of infertility (Greil et al., 2010). By setting up a qualitative interview study about foreign patients who go to Belgium for infertility treatment, we hope to add knowledge about the experience of CBRC. Because there are many different forms of CBRC in different contexts between countries all over the world, a lot of empirical data is needed to inform medical professionals and regulatory bodies (Inhorn & Gürtin, 2011).

The empirical study was prepared in several ways. I visited the fertility clinic at Ghent University hospital many times to sit in on counselling sessions and medical consultations to understand the process infertility patients go through. I even visited the IVF lab to witness first-hand what protocols were in place to ensure quality and safety. I also visited De Montfort University in Leicester for a look behind the curtain of one of the first interview studies about patients' experiences of CBRC (Culley et al., 2011). To prepare the empirical research, I also looked at internet forums to see what kind of information cross-border patients posted there. This proved to be interesting enough to warrant a separate empirical study (Chapter 6). After all these preparations, we developed the interview guide (Appendix I).

In writing about the interview study we conducted (Chapter 7 & 8), it is important to note the difficulties we encountered during recruitment. We did not have access to patients' personal information and medical files. This made the recruitment process significantly more difficult. Someone from the clinic would notify me when foreign patients were scheduled the next day for an embryo transfer or an insemination and then I would go to the clinic to try to recruit them. It was impossible to contact these patients beforehand, which led to the fact that many of them refused to participate because they did not have the time to stay for an interview. Many of these patients expressed an interest in the study and proposed different ways of participating (through email or skype), but in the interest of uniformity all the interviews were done

at the hospital. Especially towards the end of the recruitment process, when we were looking for patients with a specific profile to complete the purposeful sampling, a lot of time and effort was put into recruitment.

It is increasingly fashionable in bioethics to use and even perform empirical research. Some even recognize an empirical turn in bioethics (Borry et al., 2005). Empirical bioethicists should root their enquiries in empirical research, challenge theories using evidence and be reflexive and sceptical about the claims of other bioethicists, scientists and clinicians. The aim of empirical bioethics is to produce a rigorous normative analysis of lived moral experience (Hedgecoe, 2004). However, one should never go directly from an 'is' to an 'ought', meaning that just because something is the case in practice, that does not make it morally right (Braddock & Magnus, 2010). Empirical data can be very informative for normative reasoning, but can never replace it.

In the development of the interview guide, during the interviews and during data analysis one of the main goals was always to try to gather relevant data for bioethical reflection. For example, we have gathered information about cross-border patients' experiences, expectations and moral views, about the way in which cross-border patients gather information and about cross-border cooperation between clinics and physicians. We used our normative research to develop our empirical study and we subsequently used our empirical research to inform our normative reasoning.

Overview of the dissertation

In **chapter 1** we provide a short overview of the data on CBRC, indicating that it is a widespread worldwide phenomenon. We identify push and pull factors that result in patterns of movement in CBRC. We subsequently explore some of the morally controversial cases that are often associated with CBRC. We present the issue of legal diversity, focussing on its influence on patient flows and the effect of these flows on national legislation. We also explore the ethical problems related to gamete donation across borders and international commercial surrogacy. For example, the laws of two countries may assign parenthood to different people when a child is born after surrogacy arrangements. We describe how issues of compensation, donor identifiability and exploitation all pose additional ethical challenges in cross-border situations. We conclude that it is necessary to continue monitoring the ethical problems related to CBRC as the phenomenon develops further.

In **chapter 2** we investigate the consistency and morality of potential home state reactions to CBRC for law evasion, including extraterritorial regulation. Some countries react to their citizens going abroad to evade restrictions by implementing even more restrictive laws. For example, Turkey has become the first state to ban reproductive

travel in pursuit of donor gametes and several states in Australia have enacted laws that prohibit international commercial surrogacy. Such extraterritorial regulation has an intuitive appeal: if an act is considered to be morally wrong, it should not really matter where the act takes place. The only widespread existing extraterritorial regulation of private life concerns female genital cutting (FGC), sex with children and (largely in the past) abortion. We develop an analogy with these cross-border crimes to evaluate the morality of similar legislation in cases of CBRC. The dissimilarity in these analogies shows that extraterritoriality is a radical position that is generally inappropriate in the case of CBRC. Subsequently, we consider several alternative state reactions to CBRC for law evasion like preventing or discouraging travelling and forbidding aiding and abetting. It is concluded that legislation of CBRC should be modest, tolerant and nuanced.

In **chapter 3** we explore the option of closing the door from the other side in the case of CBRC for law evasion. We consider to what extent there are moral arguments to treat foreign patients differently because they come from abroad and discuss possible measures in the destination countries that may prevent problems for cross-border patients or change immoral dynamics in CBRC. It seems counterintuitive to deliberate measures to restrict access to foreigners when they come to do something that is permitted in the destination country. Moreover, good clinical practice should be the same for all patients, regardless of where they come from. However, when patients travel to evade the law of their own country, there are additional challenges with regard to patient autonomy and the wellbeing of the child. The duties towards the foreign patient, the child and the local patients should be balanced to ensure good clinical practice and legislation and guidelines on assisted reproduction should contain safeguards against exploitation. This can be achieved by imposing specific requirements for cross-border patients such as residency requirements, temporary residency requirements, the provision of special counselling and informing, introducing allocation caps for foreign patients and requesting that they bring their own donor.

In **chapter 4** we take a closer look at different national interpretations of the European Convention on Human Rights with regard to gamete donation. In the case of *S.H. and Others v. Austria*, the European Court of Human Rights originally condemned the prohibitions on egg donation and sperm donation for the purpose of IVF. The court judged the Austrian law to be incoherent and disproportionate. This decision was reversed on appeal based on the margin of appreciation doctrine. We critically review the judgments of the European Court of Human Rights and analyse what this case means for the future of legislation on medically assisted reproduction in Europe. It is concluded that legal diversity and cross-border reproductive care will persist and that

the court failed to protect European patients from arbitrary interference with their right to reproduce.

In **chapter 5** we build on data from the 2010 ESHRE Taskforce study and other empirical studies on CBRC to identify the main risks and challenges for cross-border patients. Most of the medical risks associated with CBRC can be managed. Prevention of multiple pregnancy, monitoring complications (like ovarian hyperstimulation and ectopic pregnancy) and provision of counselling are part of good clinical practice for any patient, including cross-border patients. In the case of international commercial surrogacy, the intended parents run the risk of not being able to bring their child home due to visa problems. Patients need to find reliable information, but this is not always easy since information about treatments and success rates may be difficult to interpret and some of the information on the internet is wrong. Many risks and challenges can be managed when clinics cooperate across borders. All risks and challenges associated with CBRC can be prevented by adopting less restrictive laws and providing good quality infertility care at home.

In **chapter 6** the information Dutch patients share on internet forums about IVF treatment in Belgium is analysed. The internet is a very important source of information for cross-border patients and internet forums are a virtual place where patients can help each other with practical, emotional and even medical issues. We analysed all the threads on IVF treatment in Belgium from eight forums that were active in a fifteen month period (October 2010 - December 2011) using inductive thematic analysis. Eight themes emerged after data analysis: medical expertise and testing, costs, feelings and experiences, trying out different clinics, travel and waiting times, treatments in the Netherlands, cooperation between clinics/physicians and laws and regulations. Internet forums offer an easy way for patients to share practical information such as which health insurer offers the best care package for IVF or where drugs are the cheapest. In all eight Dutch forums, the general message about infertility treatment in Belgium was very similar: Belgium offers better quality of care. The most important markers of good quality care were high medical skill (effectiveness), cost-effectiveness (efficiency) and respect for patients' feelings and experiences (patient-centeredness). According to the forum users, the main difference between IVF treatment in Belgium and the Netherlands was the central position of the patient: in Belgium, patients were seen as persons rather than numbers.

In **chapter 7** we present the data from the interview study with Dutch patients who go to Belgium for infertility treatment. 16 heterosexual couples and one single woman

were purposefully sampled based on the available data about Dutch infertility patients travelling to Belgium. The central theme in the data was that going to Belgium was the next step. The Dutch patients believed that the quality of care was very high in Belgium and that in taking this step, they did everything they could to achieve a pregnancy. Several participants encountered difficulties or were denied help when they approached a Dutch clinic to do cycle monitoring for their cross-border treatment. Presumably it is considered 'bad for business' to facilitate going abroad for infertility treatment. However, unwillingness to cooperate is at the cost of patient wellbeing and should be condemned as unethical if it is not properly justified.

In **chapter 8** we present the data from the interview study with French lesbian couples and single women who crossed the border to Belgium because they were denied access to treatments with donor sperm at home. 11 lesbian couples and 2 single women were recruited. The results show that these women faced several additional challenges to the already difficult process of cross-border infertility treatment. Before they could start the treatment, they could only obtain information from the internet or from stories of friends who also went abroad for treatment with donor sperm. During the treatment, they needed to find local clinics or physicians to monitor their cycle. Several women managed to game the French system to ensure reimbursement for the part of the treatment that was performed in France. Most women had difficulties justifying their absence from work. In general these women felt that they were discriminated against and that their rights were not protected. In that regard, the lack of legal recognition of the genetically unrelated partner in their country was particularly hard to cope with for the lesbian couples. These women had to develop many different strategies to deal with the difficulties they faced during cross-border reproductive care. Finding a physician who was willing to support them in their 'baby project' was very important to be able to overcome the challenges of CBRC for law evasion.

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Part 1 Normative research

Chapter 1 Cross-border reproductive care around the world: recent controversies

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1.1 Introduction

Cross-border reproductive care (CBRC) is a growing phenomenon where infertile patients cross borders in order to obtain reproductive treatment abroad. CBRC has many names. Twenty years ago, Knoppers and LeBris (1991) were the first to describe what they called ‘procreative tourism’. In their wake, the phenomenon was also called ‘fertility tourism’ and ‘reproductive tourism’, which seems logical when CBRC is considered a subset of medical tourism. However, medically assisted reproduction is a very specific form of medical treatment with different ethical, legal, social and cultural consequences. Tourism implies travelling for pleasure, and by no means do infertile couples travel for pleasure. Travelling for reproductive care may be challenging, time-consuming, frustrating, impoverishing and frightening (Inhorn & Patrizio, 2009). ‘Reproductive exile’ was suggested as an alternative to the tourism discourse since exile means leaving one’s country, usually for political reasons (Matorras, 2005). The current concept of cross-border reproductive care avoids the connotations of pleasure and leisure time implied in the term ‘tourism’, it is objective and descriptive since it holds no value judgment regarding the movements and it links with the more general term ‘cross-border health care’ that is commonly used when other types of movements for health services are considered (Pennings, 2005).

The different causes of CBRC can be divided into two groups: legal restrictions and/or availability issues in the state of affiliation (Pennings et al., 2008). A very important aspect of CBRC that distinguishes it from medical tourism is the issue of legal diversity (Van Hoof & Pennings, 2012). Many fertility treatments (e.g. egg donation, commercial surrogacy, ...) or techniques (e.g. sex selection) are prohibited in one state and actively advertised in another. Some groups of people (e.g. same sex couples, single parents, women over a certain age, ...) who are denied access to medically assisted reproduction in one country, are treated without any issues in another. The consequence of this diversity is a flow of would be parents from states with restrictive legislation to more permissive countries (Storrow, 2005). This form of cross border care has been categorized as ‘circumvention tourism’ or even ‘rogue medical tourism’ (Cohen, 2012; Hunter & Oultram, 2010). However, it may be more accurate to see it as a form of moral pluralism in motion (Pennings, 2002).

Whether patients travel because of legal prohibitions or because the treatment they need is not available at home (within a reasonable timeframe), most are disappointed in the fertility sector at home. They feel they are being denied the basic right to have children. For example, the UK has a very liberal policy on medically assisted

reproduction, but a shortage of donor gametes. As a consequence, the most important motivation for UK patients to travel abroad is the desire for timely and affordable treatment with donor gametes (Culley et al., 2011). These patients feel that they have been let down by the state, whose legislation on gamete donation should be more attractive for donors. However, the state may have valid moral reasons for regulating gamete donation with limited compensation fees and with identifiability of the donor. The tension between the individual and the state will reappear throughout this chapter.

We will present an overview of CBRC, showing that it is a worldwide phenomenon and specifying some underlying patterns. Subsequently we will turn to some of the ethical controversies in CBRC. We will address the issue of legal diversity, examine the ethics of gamete donation in CBRC and identify some problems with international commercial surrogacy in the context of CBRC.

1.2 Cross-border reproductive care around the world

There is a general lack of data on the prevalence of CBRC. Our focus will mainly be on Europe, because that is where the most reliable data comes from at the moment and because the issue of legal diversity is very apparent there. Much of the data that has been published is based on very gross estimates and the studies are often methodologically lacking (e.g. Nygren et al., 2010). In a recent survey of patients in 44 clinics in six countries it was estimated that at least 12000-15000 patients cross borders for fertility treatment every year within Europe (Shenfield et al., 2010). No reliable data is available for North America, but physicians estimate it to be a widespread phenomenon (Hughes & Dejean, 2010). In Asia, several countries have specialized clinics that are frequented by foreigners for specific treatments (e.g. commercial surrogacy) or applications (e.g. sex selection) (Pande, 2009; Whittaker, 2011a). In South America, the private health care sector has discovered the market for good fertility care in Argentina, Brazil, Chile and Mexico (Smith et al., 2010). In the Middle East, Muslim pronatalist culture is starting to result in a thriving ART industry, but locally there still are many structural and cultural constraints and there is uncertainty about the ethics of gamete donation in Islam. It is forbidden in Sunni Islam but allowed in Shia Islam. The use of donor gametes is considered to be controversial by many Muslims, Sunni or Shia. Therefore, those Muslim couples who want to make use of third party assisted reproduction generally cross borders because of privacy and socio-ethical reasons, often to Iran, where Shia Islam is dominant (Abbasi-Shavazi et al., 2008).

1.2.1 Patterns of movement: push and pull

CBRC is a growing phenomenon. Several factors are responsible for this growth. Worldwide, at least 15% of reproductive-aged couples suffer from infertility (Inhorn, 2009). There are many potential patients who are willing and able to pay and travel for excellent care. This is made possible by globalization, which makes transnational transfer of people, technologies and ideas ever easier, and by commercialization of assisted reproduction (Gürtin & Inhorn, 2011).

Crossing borders for health care has become easier. Within Europe for example, the recent directive on the application of patients' rights in cross-border health care (2011/24/EU) will give patients the right to be reimbursed for care in any EU Member State without prior authorisation up to the limit to which the patient is entitled according to the legislation of the home country. This may prove to be a great instrument to help patients who face long waiting lists.

Traditionally, patterns of movement in CBRC are described only by referring to the push factors. These include: a type of treatment is forbidden by law for moral reasons; a treatment is not available because of lack of expertise or equipment or for safety reasons; certain categories of patients are not eligible for assisted reproduction; waiting lists (e.g. because of a lack of gamete donors); and costs (Pennings, 2002). The focus on push factors stems from the fact that patients generally need to be pushed abroad: they do not want to cross borders for treatment, especially if it is as emotional and personal as fertility treatment.

However, that is only half the story. When patients decide to travel, they still have to decide where to travel to. To that end, patients conduct endless Google searches, read blogs, join support groups and find specialized brokers (Speier, 2011). Because reproduction is such a private matter, patients are pulled towards countries they have some kind of connection with. For example, recent research in an Iranian clinic indicates that Muslim patients want to be treated in a religiously correct fashion (Moghimehfar & Nasr-Esfahani, 2011).

A minority of patients choose to go abroad for fertility treatment even when they could be helped at home. These patients are typically expatriates who return home for medically assisted reproduction because of medical patriotism, a shared language with the medical personnel, co-religion, moral trustworthiness, donor phenotype, the comforts of home and discrimination (Inhorn, 2011). Several traditional emigration regions, like Thailand and the Middle East, are now destination countries for reproductive services to their expatriates (Inhorn, 2011; Whittaker, 2009). In this case, patients are pulled towards a specific country.

Most patients who are planning treatment abroad are looking for a solution to the problem that is pushing them away from home. Several destination countries have an interest in attracting as many of these reproductive travellers as possible. They are

interested in the promise of financial gains by treating rich foreign patients. To accommodate these patients, they are looking to pull them in with lower costs, high quality of care, timely treatment and favourable legislation. For example, North American patients are faced with Canadian donor shortages and high costs in the USA and become “consumers shopping for discount assisted reproduction treatments”: brokers advertise treatments abroad that ensure similar donor phenotypes and high egg donor availability at competitive prices (Speier, 2011). One of the main pull factors in CBRC is the availability of a group of women ready to act as surrogates or as egg donors. The lack of such women is the main reason for waiting lists in Canada and European countries and for the high costs in the USA. In developing economies it is easier to find available women, but this increases the risk of exploitation given the unequal economic position (Whittaker, 2011b). For some controversial treatments, the mere offer of a treatment may be a pull factor. For example, a Thai clinic suggested that the availability of social sex selection was a prime motivator for traveling among its Vietnamese, Indian and Chinese patients (Whittaker, 2011a).

1.3 Controversies in cross-border reproductive care

Medically assisted reproduction is rapidly changing. In 1991, Knoppers and LeBris wrote that there were several areas of consensus: access to fertilization techniques should be limited to heterosexual married couples or to those living in stable unions, commercial surrogacy agencies or intermediaries should be prohibited and reproductive technologies should be free from commercialization. This is definitely no longer the case. There are many controversies surrounding medically assisted reproduction because human reproduction is subject to very strong moral beliefs that differ greatly within and between societies. Is there a right to have children? Does this right extend to everyone (e.g. same-sex couples, single parents, infertile couples, ...)? Should societies support procreation (e.g. public funding)? Moreover, medically assisted reproduction introduces treatments that are controversial themselves. For example, most treatments imply loss of embryos, other treatments depend on third parties who may risk harm or exploitation (e.g. egg donors, surrogates). In general, assisted reproduction challenges traditional (natural) norms of conception and parenthood.

In addition to dynamics at national levels concerning assisted reproduction, ever changing flows of patients add to the complexity of CBRC. In the next sections, we will focus on the ways in which crossing borders causes problems or controversies. First, we will address some of the general issues that arise from the lack of general consensus: what are the consequences of having this legal diversity? Subsequently, we will turn to

gamete donation and international commercial surrogacy to see what legal diversity means for concrete cross-border treatments. Because of the complexity of the situations we address, it is impossible to suggest a straightforward solution for many problems. However, one a priori insight could prevent many problems: when a treatment or technique is allowed in the country, people will no longer be forced to go abroad. Moreover, in that case it would be possible to regulate the technique in a way that is morally acceptable and devise safeguards against abuse.

1.3.1 Legal diversity

Some countries prohibit some forms of medically assisted reproduction (e.g. gamete donation) or deny access to some groups of people (e.g. same sex couples) while other countries permit the same actions. Legal diversity is a necessary condition for cross-border movements for law evasion. Several patterns have developed over the years, directly affected by legal developments. Many European countries in close geographical proximity have very different regulations regarding assisted reproduction. The permissive policies on egg donation in Spain and Czech Republic have made them popular destinations for couples that require donor eggs (Bergmann, 2011). Many Italians go to Spain and many Germans to Czech Republic to evade restrictions on egg donation in their home state (Shenfield et al., 2010). Dutch clinics are reluctant to accept women over 40, so these women turn to Belgian clinics that are open to treatment of older patients (Pennings et al., 2009). In France, only heterosexual couples have access to fertility treatments, so many French lesbians travel to Belgium to be inseminated with donor sperm (Pennings et al., 2009). In Italy, reproductive emigration quadrupled when the restrictive law of 2004 was enacted. This law prohibits gamete donation and surrogacy entirely and restricts access to medically assisted reproduction to heterosexual couples (Boggio, 2005; Ferraretti et al., 2010). Italians who cannot conceive in Italy because of this law feel abandoned by their state (Zanini, 2011).

Legal diversity has been a major point of discussion since CBRC became a prominent subject in academics (Pennings, 2002). One central question is how CBRC for law evasion affects national legislation. It was first argued that CBRC acts as a 'safety valve' for the moral minorities in society, as a way for them to circumvent the majoritarian restrictions on assisted reproduction (Pennings, 2004). Following this view, a country should allow CBRC for law evasion as a form of tolerance. The movements by patients to other countries could change current legislation if the lawmakers would be aware of the extent of the problem. If the lawmakers were to realize that patients who need certain restricted treatments go abroad, they might soften the restrictions. This can only be the case if the movements are visible to the larger public, but this condition is difficult to fulfil as patients generally do not want to go public with their highly personal and

private problems (Pennings et al., 2008). All in all, the effect of a safety valve is primarily that it decreases pressure for law reform internally. The opportunity for patients to go abroad can temper organized resistance to the law and allow governments to pass more restrictive legislation than it otherwise might (Storrow, 2010). This means legal diversity may inherently lead to more restrictions within countries.

Recent developments have shown that legal diversity can have a direct effect on national legislation: in extreme cases the growing phenomenon of CBRC for law evasion has led to a total ban on reproductive travelling. This happens when a radical moral belief, often religiously inspired, is the basis for legislation. In that case, no tolerance in the form of CBRC can be allowed. In Turkey and several states in Australia, respectively gamete donation and commercial surrogacy were made punishable offences, also when performed outside the national territory (Van Hoof & Pennings, 2011). In Turkey, for example, CBRC was very visible: several clinics had sophisticated arrangements with Cypriot clinics to circumvent the restrictive policy (Gürtin, 2011). The effect of this visibility was not that the lawmakers softened the restrictions. On the contrary, they maintained the restrictions and tried to block the escape routes. The movements did not improve the situation for local patients. Moreover, the possibility of CBRC may be used as an excuse to defend the status quo. For example, in a recent case the European Court of Human Rights upheld Austria's restrictions on gamete donation, partly because Austrian patients always have the option of going abroad (Van Hoof & Pennings, 2012). This has recently been called the pluralism problem in CBRC (Storrow, 2010).

While this may be the main problem in the grand scheme of things, for the current traveling patients legal diversity may cause a range of challenging problems as well. If there is a criminal law against a procreation technique, as is the case in Turkey and Australia, patients may face charges when they return. In the next two sections, we will look at what practical problems legal diversity can cause for patients who undergo gamete donation abroad or engage in international commercial surrogacy.

1.3.2 Gamete donation

There are many controversies surrounding gamete donation in general. These moral complexities become even more difficult in a cross border situation. Here, we will focus on how crossing borders complicates the issues of compensation/payment and donor identifiability.

- Compensation/payment: balancing justice and autonomy

In the discussion on gamete donation, it is argued that there is a significant moral difference between compensating someone for their time and inconvenience and

paying someone for their eggs or sperm. In this line of argument, justice requires that a donor is compensated. On the other end of the discussion the argument is made that gamete donors, especially egg donors, are selling their body parts (Almeling, 2007). This is clearly the case when donors are paid per egg they produce at the end of their stimulated cycle. In the same line of argument, some even compare travelling for eggs with transplant tourism (Pfeffer, 2011). It is true that in some instances of abuse, egg donors are treated badly and overstimulated during the donation process and compensated only very little (Nahman, 2011). However, egg selling and overstimulation are malpractices that can and should be prevented: potential harm is not a sufficient reason to ban a practice as a whole. There are guidelines for physicians to ensure ethical practice of CBRC (Shenfield et al., 2011).

The issue is then to decide what counts as fair compensation and what constitutes payment. Those who oppose compensation for gamete donation argue that payment of big sums often leads to coercion and undue inducement. This implies that the autonomy of the donor is not respected. However, minimal compensation for the time spent and inconvenience suffered for egg donation is equally immoral, especially when the infertile woman pays a large sum for her treatment and the clinics and physicians make huge profits using those eggs. In this case, the balance between time and effort on the one hand and compensation on the other is skewed.

In practice, there is a big difference in the compensation that donors receive across the world. In the UK, egg donors are compensated £750 (this used to be £250 plus expenses), in Czech Republic €800 and in Spain €900. One might say that a European consensus is slowly emerging. However, in Romania, egg donors are paid \$200, which arguably constitutes unfair or inadequate compensation. In the USA, there is no cap on payments to donors. There are only guidelines: the American Society for Reproductive Medicine recommends a cap of \$5,000 and called sums over \$10,000 inappropriate (American Society for Reproductive Medicine, 2007). However, offers of \$50,000 have been reported to “an extraordinary egg donor” (Levine, 2010). Clearly, this no longer constitutes mere compensation. If you are looking for an instance of undue inducement, this would be it: that kind of money is a strong incentive for anyone to donate.

The balance between the basic principles of justice and autonomy is complicated by cross-border issues. A reasonably capped compensation is still no guarantee that prospective donors are not unduly induced. Foreign women, for whom the same amount of money can have a totally different meaning, can be attracted by the compensation fee. The availability of donors because of high compensation fees may attract a large population of foreign patients, which may in turn increase the demand for egg donors which may lead to clinics giving them more incentives to donate repeatedly.

The balance between justice and autonomy is even more precarious when frozen eggs cross borders. Freezing technology allows for an invisible current of gametes crossing borders instead of donors. Donor sperm is already being shipped across borders

for years and recent developments in egg freezing will allow the same for donor eggs. The question is whether these overseas donors should be compensated the same amount as local donors, which may constitute a larger sum in their place of origin.

In Ireland, there is already a clinic that transfers frozen sperm from the prospective father to the Ukraine, where the eggs of a donor are fertilized (Walsh, 2010). The resulting embryos are frozen and sent back to Ireland, where they are implanted. Should the Ukrainian donors be compensated the same amount as Irish donors? Should they receive the same amount as other Ukrainian donors? To protect the autonomy of the egg donors, they should be compensated only the same amount as other Ukrainian donors. This would be in accordance with the principle of justice: compensation for time and effort must be related to purchasing power. However, it is unjust to let the clinic absorb the difference in purchasing power as profit. It is equally unjust to allow a two tier system of domestic and foreign eggs at different prices. This would result in a very commercialized form of egg donation. The reproductive labour of egg donors should not be seen as something that can be exported to countries with lower wages. This cross-border problem is a very complex ethical issue that will demand more reflection as the situation progresses.

- Donor identifiability

Both in the academic literature and in legislation across the world, a trend towards more identifiability can be identified (Blyth & Farrand, 2004). Some believe the removal of donor anonymity will deter people from donating their gametes. This is contested by others, who argue that the typical donor will no longer be a student, but someone older, often a parent, and that different recruitment strategies are needed when anonymity is removed (Frith et al., 2007).

Removal of donor anonymity is reported to be a reason to travel abroad for gamete donation. For example, Dutch patients travel to Belgium for anonymous donation (Pennings et al., 2009). 26% of UK women indicated 'a wish for anonymous sperm donation' as their main reason to travel abroad (Shenfield et al., 2010). Some fertility travellers state that donor anonymity is a by-product of their journey because it is obligatory where they were treated, it is not their main reason for travelling (Culley et al., 2011).

When patients who live in a country with identifiable donation make use of anonymous donation abroad, they act against a societal trend. The interest in genetic origins has become a hype in recent years. However, when patients cross borders from a country where gamete donors are identifiable to a country where donation is anonymous (e.g. because of a donor shortage in the home country), their child will grow up in a society where all other donor conceived children can in principle find out about their genetic origins. If the parents are open about the donor conception, the children

face the extra burden of a foreign anonymous donor in the age of donor-sibling registries and TV-shows titled 'Who is my father?'

What identifiability means in fact is 'contactability': whether or not your donor is identifiable may not really matter if he does not speak your language, comes from a very different culture and lives far away in another country. As far as being able to contact your genetic parent is concerned, it may not even matter whether patients make use of an anonymous or an identifiable donor abroad: they are all hardly contactable. Cryobanks are already shipping sperm from 'identifiable' donors across borders to countries that enforce identifiable donation. Due to persisting shortages this practice is likely to increase, but while it is technically within the legal requirements for imported sperm, it is incompatible with the spirit of the law.

1.3.3 International commercial surrogacy

The issue of compensation and payment is also present in discussions on commercial surrogacy, but it runs largely parallel with the discussions on gamete donation. Here, we will focus on the exploitation argument and on issues of comity. Issues of comity are problems commissioning couples face when the legal system of the country where they were treated is not 'compatible' with their domestic laws (Storrow, 2011).

- Exploitation

It is not easy to define exploitation. The exploitation argument has been used against commercial surrogacy in many different ways: sometimes it means commodification of the body, sometimes undue inducement, sometimes taking advantage of vulnerable women, ... In the case of international commercial surrogacy, it is a fact that surrogates often 'work' in abysmal conditions and that there is a huge disparity between the power and wealth of the commissioning parents and that of the surrogate. The first step in making commercial surrogacy less 'exploitative' would be to improve the conditions under which the surrogates work and to change the background inequalities which generate exploitative relationships (Wilkinson, 2003).

Feminist authors have dismissed such arguments as secondary to the real problem. Using a woman as some kind of breeder, a womb for rent, is intrinsically wrong regardless of context or consequences (Ber, 2000). Ultimately, this is based on the Kantian categorical imperative never to use a human being merely as a means to an end, but always as a person. This ethical objection can be overturned if the practice of commercial surrogacy is possible while respecting the surrogate also as a person. Parks (2010) has suggested that the relationship between the commissioning couple and the surrogate should be governed by care and interpersonal relationships rather than by

commercial interests, in which case international commercial surrogacy is not exploitative. Recent ethnographic fieldwork suggests that both the commissioning couple and the surrogate resist the commercial and contractual nature of their relationship by establishing some kind of 'sisterhood' with each other (Pande, 2011).

Even if the nature of the relationship with the surrogate is not personal, she can be respected as a person. If we conceptualize surrogacy as reproductive labour, commercial surrogacy is not exploitative as long as there are fair compensations, good regulations, good working conditions and medical support. In the case of international commercial surrogacy, one might say there that there should be 'fair trade international surrogacy' (Humbyrd, 2009). In that case, a woman can autonomously decide to partake in a valuable surrogacy project.

- Issues of comity

Many surrogacy contracts in frequently visited countries for international commercial surrogacy, such as India, are not legally binding because there is no legislation on the matter (yet). However, this does not deter patients who need surrogacy to engage in the practice. This leads to a lot of uncertainty for both parties in the arrangement: the commissioning couple could be extorted for more money after the child is born, the surrogate mother could decide to keep the child, ... The surrogate mother could be left with the child, especially in case of birth defects, she could be denied necessary medical care after she gave birth, ... However, in practice these problems seem to occur very rarely (Busby & Vun, 2010).

There may be few problems between the couple, the surrogate and the clinic, problems may still arise at state level. Even when the visited country has appropriate legislation on the matter and there is an enforceable contract in place, issues of comity may arise after the birth of the child. For example, when a same sex couple is legally married at home and they move abroad, it is an issue of comity whether or not their marital bond will be recognized. When same sex couples who are denied a right to marry or to adopt a child go abroad to conceive a child, the partner who does not share a genetic link to the child cannot legally recognize it. A similar problem arises in the case of surrogacy contracts across borders: the contract between the commissioning couple and the clinic/surrogate may be considered valid in the country of treatment, but it will not be recognized in the home country of the couple if commercial surrogacy is illegal or unregulated there. When a surrogate has delivered the baby, the surrogacy contract determines who the parents of the child are. Usually, the visited country considers the commissioning couple to be the legal parents. However, when the contract is not recognized by their home country, the woman who gave birth, the surrogate, is considered to be the legal parent. In practice, this leaves these children in a legal limbo, trapped between two legal systems, stateless, legally parentless and without

passports to go home. Such problems have been reported for parents from the UK who went to Ukraine (Theis et al., 2009), Belgian parents who went to the US and to Ukraine (Van Hoof & Pennings, 2012), Japanese parents who went to India (de Alcantara, 2010; Parks, 2010), French parents who went abroad, mostly to the US (Rotman, 2009), German parents who went to India (Mahapatra, 2010) and many others. These cases generally end in court where a judge allows an exception to the law 'in the best interest of the child'. We will address the situation in Ireland to illustrate that it is important to have some kind of regulation and the situation in Germany to show that even with clear prohibitive legislation, problems of legal diversity can persist.

Currently, there is a lot of media attention for 15 Irish children who are stuck in India (O'Brien, 2011a). Their parents are tired and angry with the Irish authorities. First, the lack of regulation in Ireland forced them to travel abroad. Subsequently, the lack of regulation prevents them from returning with their child. One couple is planning to take their case to the European Court of Human Rights because their right to private and family life is being infringed due to the lack of specific legal provisions which allow them to become their child's parents (O'Brien, 2011b). They would have a good case if the right to private and family life entails a right to assisted reproductive technologies. However, previous rulings indicate that the court does not deem this to be the case.

In Germany, commercial surrogacy is explicitly banned. When German couples go abroad for commercial surrogacy, they evade the domestic law and commit an immoral act from the point of view of their restrictive country. When they want to bring their child home, they are actually asking the state to directly contradict its policy by tolerating their law evasion. If the state takes its own moral position seriously, it should be consistent and deny the claim to parental rights. In this case the state cannot be found lacking as long as the laws are morally justified. The judges are caught between the devil and the deep blue sea: if they uphold the law, the child (and family) suffers; if they give in, more couples will go abroad to do the same.

In the current context of legal diversity, the strong wish for a child drives patients to controversial decisions. When they traveled abroad these parents were either uninformed/badly informed or they consciously put themselves and their child through a long and stressful legal battle, during which their child may be 'stuck' abroad in difficult circumstances. Until now, the courts were always persuaded by the arguments that refer to the welfare of the child and allowed exception after exception. We have not seen the last of international commercial surrogacy and the issue of comity.

1.4 Conclusion

There is an urgent need for more reliable data on patterns of CBRC worldwide. This will inform policy makers of the exodus or influx of patients in their country and will allow them to react appropriately. Moreover, the patterns of movement will indicate changing attitudes and increasing needs among the population. More data should also be gathered on the experience of reproductive travellers. This will help ethical reflection on CBRC and will inform clinics and physician of the needs of their international patients.

Many assisted reproductive technologies are ethically controversial. They are subject to rapidly evolving scientific research and changing views in public morality. Cross-border situations introduce new difficulties and complexities to assisted reproduction. In addition, cross-border flows are subject to dynamic conditions like legislation, availability of gamete donors and surrogates, and quality of care. It will be necessary to continue ethical reflection on CBRC as the phenomenon develops further.

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Chapter 2 Extraterritoriality for cross-border reproductive care: should states act against citizens travelling abroad for illegal infertility treatment?

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2.1 Introduction

Reproductive tourism has a bad name, and regarding some important aspects quite rightly so: people would rather stay in their own country, but are often pushed away by unfavourable circumstances at home and subsequently pulled towards a more favourable regime abroad (Inhorn, 2011; Pennings, 2002). This article specifically deals with a very important aspect of cross-border reproductive care (CBRC) that distinguishes it from medical tourism in general: the legality issue. The main reason why patients cross borders for medically assisted reproduction is to evade restrictive legislation (Shenfield *et al.*, 2010). Many infertility treatments that are prohibited in one state are actively advertised in another. This legal and moral diversity has led to ‘the pluralism problem in CBRC’ (Storrow, 2010).

When citizens make use of CBRC for law evasion, they will generally not be prevented from going or punished when they return: states impose rules to regulate conduct on their territory, but the behaviour of citizens while they are abroad is not controlled. This can be a sign of tolerance or the result of the belief that these movements cannot be prevented. In practice, however, the lack of reaction undermines restrictive policy: such a policy is based on the conviction that a certain treatment is morally wrong, so a lack of reaction to overt disobedience seems strange. At the same time, the possibility to go abroad to circumvent the law unpunished means that there is less incentive to fight for a change in the law at home. Moreover, states may enact more restrictive measures than they normally would because they know that citizens always have the option of going abroad (Storrow, 2010). In short: legal diversity may lead to more restrictive policies on a national level.

The starting point of this article is the finding that several states have legislation that expresses a conviction that some reproductive technologies are harmful for some of the people involved or violate a moral rule, while they turn a blind eye to people who make use of them abroad. This finding triggered the first consistency argument: 1) when states issue a law to prohibit a certain act because it causes harm or because it violates a fundamental right, they should try to prevent and/or punish these acts when performed abroad. Some states do have laws that extend beyond the national borders. This finding led to the second consistency argument: 2) when states adopt certain measures to prevent certain cross-border crimes, they should do the same for other acts that share the same morally relevant dimensions. This ultimately relies on the formal principle of justice: equal things ought to be treated equally and unequal things unequally. We only found three instances of such laws in domains that share

characteristics with certain applications of medically assisted reproduction: abortion, sex with children and female genital cutting (FGC). Throughout the article, we develop analogies between crossing borders for these acts and CBRC to illustrate the consistency argument and to determine what the moral grounds are for extraterritorial legislation and whether it would be justified in the case of CBRC for law evasion. In the final section, we will evaluate alternative state reactions to travelling for treatment that is illegal at home.

2.2 Double consistency and analogous situations

2.2.1 The first consistency demand

Despite a political tradition of liberalism in the West, several states do interfere with private life by regulating assisted reproduction. Interference with private life by public authority is justified by arguments based on harm or fundamental rights. If the lawmaker is convinced that harm is caused by a certain action or that an act violates a fundamental rule or right, it is morally irrelevant where the act takes place. Extraterritoriality would be the rule from an ethical point of view, but in practice there is a general lack of state reaction to CBRC for law evasion.

Consider the example of social sexing: the large majority in most western societies believes that this is a discriminating practice. It is even considered a violation of human rights. Most countries specifically ban sex selection for non-medical reasons and it is only available in countries that do not mention it in their laws or where the fertility industry is largely self-regulated (Whittaker, 2011). This results in a current of people travelling for social sexing. If social sexing is a clear human rights violation, the state should not allow its citizens to perform it abroad. Tolerance to travelling for social sexing is only allowed if no clear harm is caused and the basic rights of all people are respected.

2.2.2 The second consistency demand

We investigate the second consistency demand by looking at possible analogies between CBRC and practices that are (or have been) regulated extraterritorially. Regulation of medically assisted reproduction is generally justified by a large number of reasons. The most important reasons include the welfare of future offspring, the commercialisation of bodies or body material, the protection of and respect for the embryo and the moral

view on family formation and reproduction. In three domains we found extraterritorial laws that are justified by similar reasons: 1) abortion laws express respect for the embryo and foetus, 2) sex with children laws intend to protect children from abuse, and 3) legislation on FGC involves respect for women and their rights. By means of analogical reasoning, these paradigmatic cases can be used to decide whether the extraterritoriality should be extended to applications of medically assisted reproduction. If we can establish that an ART application shares relevant characteristics with the paradigm, the rule in the paradigm (i.e., extraterritoriality) should also be applied to the ART case. There will obviously also be differences between the cases but these differences should not be such that they render the analogy invalid. For instance, one difference between the sex with children and FGC paradigms and the ART situations is that the former are concerned with offences committed against an existing person. While this opens up a set of complex philosophical problems, it is not a real impediment for our analogies. CBRC does affect the interests of the specific future persons (and not just abstract possible persons) who will be born because of the treatment and whose rights consequently can be violated by this treatment.

2.2.3 Abortion tourism

We appeal to the analogy with abortion tourism primarily because it is a historical example of moral pluralism in motion, with widely debated issues that are similar to CBRC for law evasion (Dellapenna, 2008; Pennings, 2002). There is still much legal diversity concerning abortion today, ranging from an absolute ban to permission until late in pregnancy. The diversity is most clear when one compares the gestational limits within which abortion is allowed and for what reasons. A recent International Planned Parenthood Federation (IPPF) overview of abortion legislation in Europe shows that while Ireland bans abortion unless the pregnancy endangers the life of the pregnant woman, several countries allow abortions on request before 10 or 12 weeks gestation. Many countries even specify social or medical reasons that justify abortion without gestational limits (IPPF, 2009).

As a historical example, abortion tourism shows that extraterritoriality is not the answer to regulate cross-border behaviour in areas of contested morality. It can, however, serve as a model for alternative state reactions as suggested in the final part of this article.

2.2.4 Child sex tourism

In the case of sex with children, there is general consensus that this is a heinous act. The only discussion may be on the definition of the term 'child.' In countries where there is

a lot of child prostitution, this is believed to be caused by poverty and despair (Steinman, 2002). Because of the lack of law enforcement in many of the destination countries, the home states assert extraterritorial jurisdiction over their citizens (Fralely, 2005). Even though there are practical issues with the enforcement of these laws and only very few people are actually sentenced based on them, the atrocity of the act is believed to necessitate legislation.

Child sex tourism is the textbook example of a cruel practice that justifies extraterritoriality. The similarities and differences with this practice can serve as indicators for the appropriateness of extraterritorial legislation. We develop an analogy between child sex tourism and international commercial surrogacy to illustrate that extraterritoriality is too radical if a practice can be morally sound in case of good territorial regulation.

2.2.5 Female genital cutting

Over the course of the past decades, there was a lot of attention for FGC. International pressure has resulted in an extensive legal consensus. Several European countries reacted to an international lobby by implementing specific legislation (e.g. Austria in 2002, Belgium in 2001, Denmark in 2003, Italy in 2005, Spain in 2003, Sweden in 1982, UK in 2004) or by making general law provisions applicable to FGC (Leye *et al.*, 2007). However, in many countries with legislation on FGC, not a single case has gone to court (Krása, 2010). This could indicate an unwillingness to prosecute or an acceptance of the practice contrary to the law. For moral issues, harm and rights should be more important markers for legislators than views in society. This position is supported by the fact that FGC is legally condemned in more than half of the countries where it is a traditional practice (Ako and Akweongo, 2009).

Debates on the morality of FGC are a perfect illustration of the implicit discussion on the justification of extraterritorial regulation. In the following section, we will develop an analogy between donor anonymity and FGC to clarify the moral grounds (or lack thereof) for extraterritorial legislation.

2.3 Utilitarianism, deontology and the analogy between donor anonymity and FGC

Two kinds of ethical arguments should be distinguished: utilitarian arguments referring to the effects on the welfare of the persons involved and deontological arguments that refer to moral rules, moral principles and rights and duties. Very frequently, these arguments overlap: interests of people are protected by rights. However, the overlap is not complete: rights can be violated even if the person is better off (or at least not worse off) after the violation. This kind of argument is popular in feminist discourses on surrogacy (Andrews, 1988). From the point of view of the restrictive home country, abortion ('murder'), sex with children (child abuse) and FGC (mutilation/child abuse) are clearly harmful practices. People have a universal right to be protected from such harmful practices, which violate several human rights. One rule in the field of medically assisted reproduction has also been blamed for violating the human rights of the resulting children, i.e., donor anonymity. We will first compare the deontological arguments against donor anonymity to the arguments against FGC and then the utilitarian arguments.

2.3.1 Deontological arguments

Several articles of the United Nations convention on the rights of the child (UNCRC) are relevant for donor conception and access to information about genetic origin. The best interests of the child and the right to know one's parents are often cited in the disclosure debate in donor-assisted conception, sometimes complemented by references to the rights to respect for identity, family and private life; access to information; and protection against discrimination (Blyth and Farrand, 2004). The UNCRC may be ambiguous when it comes to donor anonymity because of a conflict with other rights (like the right to privacy of the parents). However, the UNCRC Committee has demonstrated concern that the existence of donor anonymity may breach several articles of the Convention and has formally endorsed the abolition of donor anonymity (Blyth and Farrand, 2004). Despite this endorsement, the ambiguity of the deontological argument persists.

There are over fourteen international treaties and documents that can be invoked to protect women and children from FGC based on human rights (WHO, 2008). These rights include amongst others the protection of bodily integrity and protection against discrimination. While in the case of donor anonymity the relevance of different rights for all parties involved is disputed, the discussion on FGC has traditionally been characterized by a categorical deontological approach, which resulted in a general

refutation of any practice of FGC. However, there are forms of symbolic cutting in a medicalized setting that would be globally acceptable (Galeotti, 2007). For these minimal invasive forms of cutting, the right to cultural identity and expression can be asserted.

2.3.2 Utilitarian arguments

The utilitarian arguments for donor anonymity involve the welfare of the parents, the donor and the child. In general, it is very difficult and time consuming to get adequate data on the effects of donor anonymity or identity disclosure on donors, parents and children. Donor conceived children are increasingly tracking down their donors and donor siblings and some have even taken up the role of activist for identifiable donation (Clark, 2006; Jadvá *et al.*, 2010). However, the wellbeing of the entire family should be taken into account and many donor children are never told of their donor origin, which makes identifiable donation redundant. It is not clear if there is demonstrable harm done by anonymous donation from a utilitarian perspective.

FGC in its most cruel forms clearly causes a lot of harm, but while the WHO identifies four different types of FGC, they all fall under the general condemnation. This condemnation implies a generalization of a phenomenon that actually takes place in many geographical areas and different cultures, bears distinct meanings and is not a uniform practice (Dustin, 2010). Because of the categorical rejection of any type of FGC, the global ethical approach to this problem does not allow for an application of the most harm-reducing strategy in practice: medicalization (Shell-Duncan, 2001). It is easy to overemphasize the harms of FGC by focussing on the more extensive types, but critical assessment of the available studies shows that in the less extensive cases there are almost no statistically significant health consequences (Obermeyer, 2005). One could even argue that FGC in its mildest forms is less extensive than male circumcision, which is commonly performed in the West. This is concurrent with the recent policy statement of the American Academy of Paediatrics (American Academy of Paediatrics Committee on Bioethics, 2010). Even though it raised a valid point from a utilitarian perspective, this statement was later retracted due to international pressure (American Academy of Paediatrics Board of Directors, 2010). There are no utilitarian grounds for extraterritorial legislation on the least extensive forms of FGC.

2.3.3 Concluding the analogy

A general look at the arguments shows that following the first consistency demand, only the extensive types of FGC require restrictions abroad. The analogy shows that following the second consistency demand, the extraterritorial measures that are in place for FGC because it is considered a violation of the rights of the child, should also be

installed for donor anonymity by states who believe it is a violation of a fundamental right to deny a child access to its genetic origins. If no extraterritorial measures are taken, this is either a sign that donor anonymity is not seen as a violation of a fundamental right of the child, or that another right is deemed more important. From an ethical perspective, there is too much ambiguity about the moral grounds to justify extraterritorial legislation in the case of donor anonymity.

Our analysis of extraterritoriality can illuminate the moral position of a state. Most states that abolished donor anonymity seem to consider the right of a child to know its genetic parents as a basic right. Going abroad to receive treatment with an anonymous donor would then be a violation of the child's right. If it is important enough to make a law about it, then why not do something to prevent people from bypassing the law? One plausible explanation is that even for the lawmakers, it is not such an important right. This is corroborated by the fact that no country forces parents to tell their children of their donor origin. Secrecy is discouraged but not lifted, while it would be relatively easy to do so, for example through the birth certificate (Blyth *et al.*, 2009). As long as this is not the case, it would surely be inconsistent to prosecute parents for using an anonymous donor abroad.

2.4 Extraterritorial legislation in areas of contested morality

The issue at stake here is whether it is justifiable to impose a restrictive law with extraterritoriality in areas of contested morality. Recently, some states have reacted to CBRC for law evasion by installing extraterritorial legislation. For example, Turkish law now condemns CBRC involving gamete donation. Strict prohibitions have been justified with reference to item 231 of the Turkish Penal Code, according to which it is illegal to “change or obscure a child's ancestry,” with a punishment of one to three years imprisonment (Gurtin-Broadbent, 2011). In a recent ruling (*S.H. and Others v. Austria*), the European Court of Human Rights (ECtHR) explicitly mentioned Turkish policy on gamete donation as legitimate because of its consistency and proportionality (European Court of Human Rights, 2010a).

Another rigorous stance is expressed by the recent ‘Surrogacy Bill 2010’ in New South Wales, Australia, which punishes those who enter into commercial arrangements with up to two years in jail or a fine of \$110,000 or both. A last minute amendment extended the application of the original version to all persons “ordinarily resident or domiciled in the State” (Surrogacy Bill, 2010, clause 11, part 2). This was deemed necessary to cement the governments’ position on commercial surrogacy in the best interest of the child, to

close a loophole in the proposed bill and to prevent exploitation of vulnerable women (NSW Parliament, 11/11/2010).

The moral evaluation of these laws very much depends on the purpose one attributes to the law: should it prevent bad things from happening; should it prevent one's citizens from doing bad things; or should it prevent criminal acts on the territory? The central question is whether a state has a moral right or duty to uphold its laws on moral matters abroad, or whether relativism and tolerance demand that they limit themselves to practices taking place on their own territory.

From the point of view of a restrictive state, travelling abroad for abortion is premeditated murder. It is self-evident that consistency requires that an abortion tourist is punished for the act that was performed abroad, even if there are practical problems when one tries to determine who went for an abortion. However, in practice such consistency proves untenable. In the early 90s, Germany enforced gynaecological examinations on women returning from the Netherlands and criminally prosecuted them if it was clear that they had an abortion. However, this practice was condemned by the European Parliament on the grounds that "the internal borders of the [European] Community may not be used to threaten citizens with prosecution for activities that are perfectly legal in some Member States but not in others" (Kreimer, 1992).

Most legislation is limited to the territory of a country. When someone from continental Europe visits the UK, he is expected to drive his car on the left side of the road. We intuitively adhere to this principle. Legal diversity combined with the territoriality principle is the necessary condition for CBRC for legal reasons. In many cases, including CBRC, application of the territoriality principle solves more problems than it raises, providing a safety valve that avoids moral conflict (Pennings, 2004). However, this safety valve may be a threat to the integrity of the legal system. A direct example of the exploitation of the difference in legal systems is the use of international shipping legislation to provide healthcare treatment in states that forbid this treatment. Cryos International once issued the plan to put 'sperm ships' just outside the UK border in international waters (where they would be bound by the laws of the state of which they fly the flag) to provide anonymous sperm donation and sex selection services (Hunter and Oultram, 2008). Such plans illustrate the possible challenge to a state's legal integrity by the application of the territoriality principle. The deliberate offer and facilitation of prohibited treatment to citizens of another country is a moral provocation.

A possible solution to these problems would be the application of the nationality principle. This principle prescribes jurisdiction based on the nationality of the actor. It offers a powerful legal tool to impose a universal duty to obey the law. Restrictive states can use this principle to criminalize extraterritorial acts, including CBRC for law evasion. It directly opposes the territoriality principle and its application leads to controversial claims that are generally renounced. Is a Frenchman smoking weed in

Amsterdam subject to French criminal law? Can a French lesbian receiving infertility treatment in Brussels be legally punished for this act?

To determine the appropriateness of certain legislation, it is important that punishment is proportional to the 'crime.' We raise two points. The first point regards the impact of punishment. We may assume that at least one of the reasons for punishing the wrongdoers is to deter others from doing the same. The aim of prosecution after the fact would then be to prevent future travelling. However, it is very difficult to demonstrate this. Of course, it is possible that lawmakers are just assuming that this is what will happen. Moreover, the threat of big fines or possible jail time is usually enough to deter people.

The second point regards the kind of punishment. The general assumption seems to be that the crime is not so serious that patients have to go to jail. Still, the legislation in several European countries is very harsh for physicians violating the law and stipulates years of imprisonment in case of violation. Remarkably, the Italian law explicitly states that the man and the woman undergoing a gamete donation procedure are not liable and cannot be punished (law 40/04, 2004, art.12, clause 8). Presumably the reasoning behind this is that punishing parents would not do much good and would come down to punishing the child and the family. Still, a considerable number of countries have laws that promise imprisonment of people performing FGC, including the parents. Parents have been put in prison in France for aiding in FGC (Leye *et al.*, 2007). It will be interesting to see what Turkey will do if they prosecute a single mother for using donor sperm.

A central question pertaining to the application of the nationality principle is the question of double criminality. Double criminality means that people can only be punished for actions that are considered a crime in both countries. In most extraterritorial cases, double criminality proves to be an impediment. Still, in the case of FGC some states with recent specific legislation on the matter like Austria, Denmark and Spain require double criminality (Leye *et al.*, 2007). Because of the extensive legal consensus on FGC, this requirement is less limiting. However, in the case of CBRC for law evasion, extraterritorial laws would lose their meaning with double criminality because of the legal pluralism. Without double criminality the nationality principle implies moral radicalism, which is only justified for acts that are universally recognized as harmful or wrong. However, CBRC for law evasion is a complex phenomenon that in almost all cases is not necessarily morally wrong. When the harm or the fundamental right that forms the basis of legislation on a practice is avoidable or disputable, the application of the nationality principle would be too radical. The following analogy shows that the possibility of good regulation limits the justification of extraterritorial legislation.

2.5 The effect of regulation on the acceptability of a practice

It could be argued that recent problems with commercial surrogacy across borders warrant further reflection on the possibility of extraterritorial enforcement of the domestic laws. The children who are stuck abroad because their parents have no legal permission to bring them home are innocent victims of legal diversity (Parks, 2010). Thus, while the ‘Surrogacy Bill 2010’ in New South Wales may cause upheaval in certain circles, a strong argument can be made in its favour. However, we argue that there is no ground for extraterritorial legislation if there is a possibility of good regulation of a practice. To explain this point, we will develop an analogy between international commercial surrogacy and child sex tourism and consider the validity and importance of the exploitation argument for restrictive policy.

Almost all morally relevant arguments for why sex with children is exploitative are applicable to commercial surrogacy and vice versa. The classic exploitation argument against commercial surrogacy focuses on the instrumental nature of the interaction and the unfair conditions that result in a lack of (valid) consent (Wilkinson, 2003). Questions of power, coercion, subordination and undue inducement in an unequal global setting have to be posed with regard to both international commercial surrogacy and child sex tourism. A lack of valid consent is evident in the case of sex with children because it involves children. The little evidence we have suggests that there are also problems concerning valid consent in commercial surrogacy (Palattiyil *et al.*, 2010). A popular feminist argument implies that some practices are exploitative regardless of context or consequences (Widdows, 2009). There can be exploitation even if choice and autonomy are respected when the very nature of a practice is exploitative, i.e. when it violates fundamental rights. This is the case when issues of human dignity and commodification of bodies characterize practices, which may be the case in both instances.

However, it can be argued that the reasons why international commercial surrogacy is said to be exploitative have little to do with the practice itself and are solely grounded in the poor economic situation. Pande (2009a) has suggested that Indian surrogates are ‘sexualized care workers.’ If we conceptualize surrogacy as labour, commercial surrogacy in itself does not have to be exploitative as long as there is fair compensation and good regulation, for example by imposing something like ‘Fair Trade standards’ (Humbyrd, 2009). Imagine a couple who travel to India to stay with the woman who will bear their child and embark on a personal relationship with her instead of a purely contractual and distant arrangement. In a setting that is governed more by care and interpersonal relationships than by commercial interests, there is the potential for a practice of international commercial surrogacy that is not exploitative (Parks, 2010). Recent fieldwork suggests that narratives amongst surrogates are already based on such a conceptualization (Pande, 2009b). It can be argued that “potential abuse, which

undoubtedly has to be combated, is not a sufficient reason for prohibiting a specific procreation technique as a whole, if there exists the possibility to regulate its use and devise safeguards against abuse” (European Court of Human Rights, 2010a).

There is no acceptable form of sex with children below a certain age. One can also argue that certain aspects of the current practice of international commercial surrogacy are unacceptable. This is presumably the reason for the restrictive policies in several countries. However, because there is a potential for an acceptable practice of international commercial surrogacy, we believe that there is no moral ground for the radicalism expressed in an application of the nationality principle.

2.6 Alternative ways to react to extraterritorial ‘criminal’ acts

In this section, we address alternative state reactions to extraterritorial ‘criminal’ acts that do not require the application of the nationality principle.

2.6.1 Preventing travelling

Preventing travelling may seem an evident reaction to CBRC for law evasion at first glance, but there are a myriad of serious legal, political and moral problems with this reaction. In the first place, it is very difficult to identify the people leaving the country for the purpose of CBRC. Moreover, criminal law normally applies to persons who committed a crime, not to those who intend to commit one. However, planning a trip to perform an unlawful act can be seen as part of the offence. Terrorists can be convicted for preparing an attack without ever setting off a bomb. Making appointments with a foreign clinic, transferring money or a patient’s file etc. are all part of the same project. A similar position is adopted in the case of FGC where child protection measures are taken in a number of states when a child is at risk, including withdrawal of travel permission (Leye *et al.*, 2007).

The prohibition of travelling was extensively discussed over the last decades with regard to abortion. The landmark case of Attorney General v. X illustrates this point. In Ireland, abortion was and is illegal unless the pregnancy endangers the life of the woman. In 1992, a 14 year old rape victim was restrained from leaving the country for nine months. This injunction was later overturned by the Irish Supreme Court on the grounds that the girl had suicidal thoughts because of the unwanted pregnancy. The court explicitly rejected the proposition that there is a right to leave the country to

obtain an abortion that would be illegal in Ireland (Kreimer, 1992). However, this right was reasserted by the ECtHR in the case of *Open Door and Dublin Well Women v. Ireland* in 1992 (Wilkins, 2002). Restricting travel is a direct violation of the European Community treaty, which guarantees free movement of persons and services. The UK Department of Health estimated that between January 1980 and December 2009, at least 142,060 women travelled from the Republic of Ireland for abortion services in the UK.

Still, from a moral point of view, it is far from self-evident that the right to travel should always take priority. There exists a *prima facie* right to travel but that does not mean that this right still stands when there is strong evidence that the person is leaving the country to commit a crime. In the case of international commercial surrogacy, for instance, where there are legal problems when the resulting children come home, withdrawing or refusing travel permission might be justified.

2.6.2 Discouragement and forbidding aiding and abetting

The territoriality principle determines which kinds of treatments can be offered in a country. However, it seems logical that this includes all acts that can be considered as part of the treatment. The Human Genetics Commission in the UK, for example, recommended that British physicians or centres should not help those who are planning to go abroad for treatments that are not licensed in the UK (Human Genetics Commission, 2006). There are several different acts that might be considered as contributing to the performance of the 'wrongful' act. The general question behind it is whether the contributing act makes the actor an accomplice to the wrongful act. The accomplices may be relatives of the patient, the doctors, clinics or the state itself.

Medical treatment is composed of several steps that take place over a certain time span. One can distinguish the following parts: information provision, counselling, referral and performing part of the cycle. Each country may have different rules to regulate these issues. Take the provision of information first. The most important aspect of patients' rights is the provision of adequate information in order to allow the patient to make an informed decision. However, in some cases countries have judged that no information can be provided when this may lead to patients availing themselves of options that are legally forbidden. Originally, the Irish courts prohibited publication of information regarding abortion, including information on travelling abroad to obtain abortions that are legal abroad: an effective gag rule policy. That rule was later amended so that information relating to services available in another state can now be provided (Best, 2005). This legislation was passed after Ireland's abortion policy was challenged before the ECtHR, which allowed Ireland a margin of appreciation to ban abortion, but asserted the right to information and the right to travel (Wilkins, 2002). However, the law still does not allow that abortion is promoted or advocated. In the case of A, B and C

v. Ireland, the ECtHR recently reconfirmed that Ireland's ban on abortion is not in violation of the European Convention on Human Rights, but also found that there is a violation because of the lack of an accessible and effective procedure by which a woman can establish whether she qualifies for a legal abortion (European Court of Human Rights, 2010b). In sharp contrast with the Irish policy on the provision of information, the HFEA has decided to provide as much information as possible so that reproductive tourists can make well-informed decisions (Davies, 2010).

Provision of information in the form of counselling warrants special attention. Sufficient counselling is a professional responsibility of physicians, but it may be difficult to provide adequate counselling to foreign patients due to language problems or inadequate standards of the clinic abroad (ESHRE Task Force on Ethics and Law, 2008). While collaboration between clinics across borders could solve this problem, such a system could be seen as an encouragement for patients to circumvent the laws at home. The core issue at stake when evaluating policies of discouragement is whether such an approach is in the best interest of the patient.

Referral raises some peculiar ethical problems. Most countries that provide conscience clauses for medical personnel nevertheless oblige doctors to refer the patient to another doctor who might be willing to perform the procedure. Does it make a difference when the treatment is illegal in the doctor's home country? The contribution of a doctor could be minimised by not forcing him or her to refer to a specific clinic but by asking him or her to distribute a leaflet that contains all the information needed to find a clinic. In a number of countries, such as Germany, Switzerland and Ireland, referral to a doctor or clinic abroad is prohibited (Corveleyn *et al.*, 2008). Although this rule has never been put to the test in court, it seems to be a fairly strong deterrent in practice. Anecdotal evidence suggests that many doctors are afraid to even provide information on the options abroad, let alone to refer to a specific clinic.

In addition to counselling, a part of the treatment may be performed at home. The contribution may include monitoring, performing diagnostics, and prescribing drugs. This usually means that the steps of the treatment that are allowed at home are performed at home. In a European survey, the majority of the patients (59.0%) received some help from their own doctor, for drug prescription (16.7%), cycle monitoring (16.7%) or both (25.6%). This varied across the countries, with a high level of medical support in Germany (81.7%), France (79.0%), Switzerland (86.4%), and a low level in the Netherlands (35.0%), the UK (45.3%) and Sweden (31.4%) (Shenfield *et al.*, 2010). These treatments compose a moral grey area as they are in the best interest of the patient but also facilitate the circumvention of the law.

In some circumstances, the state itself may contribute. This can be indirectly, for instance by governmental organisations contributing to those treatments abroad, or directly, such as by reimbursing treatment abroad. The British Pregnancy Advisory

Service, which is funded by the National Health Service, became the subject of an inquiry when it was discovered that they referred women to Spain for abortion after 22 weeks (Bale, 2004). A much more relevant issue for states is the evolution of European legislation regarding patient mobility. There were some real concerns that the rights given to the patients to obtain treatment abroad would imply that member states would be obliged to pay for illegal treatment (European Parliament, 2009). Therefore, an amendment was introduced to make it clear that the directive does not imply that member states would have to reimburse “ethically controversial medical ‘services’ like euthanasia, DNA-testing or IVF” when the relevant service is not allowed, or at least not financed, in the relevant Member States (European Parliament, 2009). In fact, this abuse would be prevented by the general rule that “the obligation to reimburse costs of cross-border healthcare should be limited to healthcare to which the insured person is entitled according to the legislation of the Member State of affiliation” (Council of the European Union, 2010). These provisions, besides the obvious financial aspects, show that it was a real concern of member states to keep their autonomy to decide which treatments are ethically acceptable and not to have to become accomplices of the faux pas of their citizens.

2.7 Conclusion

Legislation should demonstrate a double consistency because 1) it is morally irrelevant where an act is performed and 2) justice requires that similar things should be treated similarly. Reformulated in the context of extraterritorial laws on private matters, this results in the following statements. Firstly, a state that prohibits a certain act because it causes harm (such as FGC) or because it is morally inappropriate (such as social sexing), should try to prevent and/or punish these same acts when performed abroad. Secondly, when a state adopts legislation to prevent cross-border crimes (such as child abuse), it should do the same for other acts that share the same morally relevant dimensions.

Restrictive legislation should be justified on utilitarian or deontological grounds. Only if these are unambiguous, extraterritoriality can be considered. However, the diversity of legislation and guidelines on applications of medically assisted reproduction demonstrates the lack of consensus on the harmfulness or wrongfulness of these treatments. As a consequence, only in case of double criminality would prosecution of illegal infertility treatment abroad be acceptable.

Other ways to prevent people from going abroad to perform treatments forbidden at home, such as restraining orders and punishment of citizens who help the intended

travellers, are less radical but they too have to be balanced against other rights such as the right to travel or the optimal care of the patient. This article has shown that the moral evaluation of the different ways in which states react to cross-border travelling to circumvent the law depends on the balance between the harm or wrongness of the act and the extent and invasiveness of the restraining measure. This proportionality, combined with the ongoing discussion on the moral value of certain treatments, points in the direction of a modest, tolerant and nuanced legislation on medically assisted reproduction at home and abroad.

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Chapter 3 Limiting access for foreign patients in cross-border reproductive care

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3.1 Introduction

Cross-border reproductive care (CBRC) refers to a widespread phenomenon where infertile patients cross borders in order to obtain reproductive treatment abroad. The main causes of CBRC are generally described as follows: a type of treatment is forbidden by law (e.g. sex selection), certain categories of patients are not eligible for assisted reproduction (e.g. lesbian couples), the waiting lists are too long in one's home country (e.g. oocyte donation), the out-of-pocket costs for the patients are too high (e.g. absence of health insurance), a technique is not available because of lack of expertise or equipment (e.g. preimplantation genetic diagnosis), a treatment or technique is not considered safe enough (e.g. cytoplasm transfer) and personal wishes (e.g. privacy considerations) (Pennings et al., 2008). In short, the different causes of CBRC can be categorized into two groups, both situated in the patients' home country: legal restrictions and/or availability. Hence, most articles about regulating CBRC focus on what measures could improve the situation there (Pennings & Mertes, 2010; Storrow, 2010; Van Hoof & Pennings, 2011). On a global level, the impossibility of legal harmonization and the need for international quality standards dominates the literature (Hudson et al., 2011). For clinics and physicians in the destination countries, the moral message is that the same standards of care should be applied to local and foreign patients (Shenfield et al., 2011).

In this chapter, we will consider to what extent there are moral arguments to treat foreign patients differently because they come from abroad and discuss possible measures in the destination countries that may prevent problems for cross-border patients or change immoral dynamics in CBRC. First, we will explore the issue of legal diversity in CBRC. Then we will raise the question of responsibilities of the treating clinic or physician in the destination country. Finally, we will consider the moral grounds for limitations on CBRC in the destination countries and which measures can be taken in practice based on these grounds. The moral grounds are duties towards the foreign patient, the child, local patients and a duty to safeguard against exploitation. It is concluded that it can be justified for clinics or physicians to treat foreign patients differently because they come from abroad and that there are specific regulations that can be used to support good practice in CBRC.

3.2 The issue of legal diversity

Legal diversity is a necessary condition for CBRC for law evasion. The issue with legal diversity is that some countries permit some forms of assisted reproduction or grant access to some people whereas other countries prohibit the same actions. This has been a major point of discussion since CBRC became a prominent subject in academic literature (Pennings, 2002). There is a debate about the effect of CBRC for law evasion on national legislation. It was first argued that CBRC acts as a 'safety valve' for the minorities in society, as a way for them to circumvent the majoritarian restrictions on assisted reproduction (Pennings, 2004). Following this view, a home state should allow CBRC for law evasion as a minimal form of tolerance. The movements by patients to other countries could then be seen as a form of resistance which could lead to a change in the existing legislation. This can only be the case if the movements are visible to the larger public, but this condition is difficult to fulfil as patients generally do not want to go public with their highly personal and private problems (Pennings et al., 2008). However, the effect of a safety valve can also be that it decreases pressure for law reform internally: the opportunity for patients to go abroad can temper organized resistance to the law and allow governments to pass more restrictive legislation than they otherwise might (Storror, 2010). In extreme cases the growing phenomenon of CBRC for law evasion can be stopped by a total ban on forms of reproductive travelling. This has been the case in Turkey and several states in Australia, where respectively gamete donation and commercial surrogacy abroad were made punishable offences (Van Hoof & Pennings, 2011). The effect of CBRC for law evasion on a restrictive policy can be that it becomes even more restrictive.

If one assumes that CBRC for law evasion will result in more restrictive national policies, pluralism across borders will lead to less pluralism within them. In other words: CBRC then fails to promote moral pluralism and reproductive autonomy in democratic societies. This has recently been called the pluralism problem in CBRC (Storror, 2010).

3.2.1 The practical problems of legal diversity and solutions in the home country

For the patients legal diversity across borders causes a range of challenging problems. In the case of same sex couples who are denied a right to marry or to adopt a child, the partner who does not share a genetic link to the child cannot legally recognize it. When patients cross borders from a country where gamete donors are identifiable to a country where donation is anonymous, their child will grow up in a society where other donor

offspring are entitled to know the identity of their donor. In the case of commercial surrogacy, the surrogacy contract may not be recognized by the home state, which could mean that the child is left officially stateless and parentless. If there is a criminal law against using a procreation technique abroad, as is the case in Turkey and Australia, patients may face charges when they return.

Home countries are caught between two extremes: the moral radicalism of banning CBRC or the moral relativism of accepting these movements. We argued that prohibiting reproductive travel and discouraging or obstructing it will be detrimental for the wellbeing of the patients and the child (Van Hoof & Pennings, 2011). For example, restrictive legislation may inhibit collaboration between the home practitioner and the receiving clinic, while good collaboration offers the best chance of optimal care for the cross-border patient (Van Hoof & Pennings, in press). Moreover, if the effect of restrictive legislation on assisted reproduction is that people go abroad to circumvent it, the restrictions in the home countries may create problems in the destination countries. CBRC for law evasion may lead to immoral practices (exploitation, coercion, commodification of the body, ...) that violate the spirit behind restrictive reproductive laws (Storrow, 2010). The relativism of accepting reproductive travelling does not stop at refraining from prosecution or discouragement of the practice. It also means that one must deal with the practical issues of legal diversity. A country can prohibit certain acts, but still recognize that they happen abroad. While no country will actively support treatment abroad that is prohibited at home, less direct forms of accommodating the cross-border patient can be installed. For example, before 2011 the state of New York did not register same sex marriages itself, but it made public in 2004 that it would recognize same sex marriages that were registered in other states (Nussbaum, 2010). Analogically, in the case of international (commercial) surrogacy and lesbians who evade the law to engage in sperm donation abroad, the partner who has no genetic link to the child could be given parental rights after treatment abroad. In fact, this is indirectly what France has done with the new law (Loi n° 2013-404 du 17 mai 2013) on same-sex marriage: although lesbian couples do not have access to ART, the non-genetic partner can now adopt the child.

3.3 Limitations imposed by the destination countries

Should the destination country itself develop specific legislation for cross-border patients? Perhaps the practical problems of legal diversity would dissolve when clinics or physicians in the destination countries become more sensitive for the moral position of restrictive home countries. However, it seems counterintuitive to request measures

to restrict access to foreigners when they come to do something that is permitted. For example, it seems hard to justify that a country with permissive abortion legislation should deny a perfectly legal abortion to a woman because she comes from abroad. When a certain treatment is considered morally acceptable, it seems odd to refuse treatment to patients based solely on their residence.

There are two reasons why destination countries generally do not impose restrictions on foreign patients or even actively try to attract them. First, the act in question is considered legal and morally acceptable in their country. Second, there are significant financial gains in being a destination for cross-border travellers (Voigt & Laing, 2010). The potential financial gains of the fertility industry may even influence national politics with regard to the regulation of assisted reproduction. Legal restrictions are often cited as the main reason for travelling for assisted reproduction, which means that there is a large group of people who are searching for destination countries with permissive policies (Inhorn & Patrizio, 2009; Shenfield et al., 2010). While financial gain will rarely be accepted as a good reason to introduce a permissive policy, the financial benefits are a powerful incentive to maintain a status quo when a permissive policy is in place.

There are several countries that have tried to limit access for foreigners to something they consider to be legally and morally acceptable. For example, countries that recognize same sex marriages enact residency requirements to prevent 'registration-tourism' (Curry-Sumner, 2005). The American Bar Association suggests residency requirements in a policy guide for states that recognize commercial surrogacy contracts to prevent forum shopping (Kingdregan & Snyder, 2008). In the UK, one or both of the intended parents should be a resident to be able to get a parental order for surrogacy (Great Britain. HFEA, 2008, article 54(4)). Similarly, several countries have residency requirements for abortion to deter people who live in states with more restrictive abortion legislation from crossing borders. Czech Republic, Luxembourg and Sweden only allow abortion for residents, unless the life of the pregnant woman is at stake (IPPF, 2009). In the US, Alaska (30 days), Hawaii (90 days) and Delaware (120 days) impose residency requirements for abortion (US legal, 2013). Presumably it is considered 'bad press' to become a destination for abortion or some states may fear the radicalism of moral convictions surrounding abortion. Beside such 'external' concerns, there is no moral or legal necessity for such a measure.

There are always financial motives to offer expensive infertility treatment to foreigners and it seems only logical to provide treatments that are acceptable for local patients to foreign patients as well. However, several residency requirements show that this logic is not that straightforward in areas of contested morality.

3.4 Limitations following from the clinic's and physician's duties

Every clinic or physician has specific responsibilities for the cross-border patient, the future child, the gamete donors or surrogates and the local patients in CBRC. To balance the interests of these parties, it is necessary to respect a number of ethical principles. In the next sections, we will indicate these principles and suggest possible measures to realize them in practice.

3.4.1 Duty towards the foreign patient: non-maleficence and respect for autonomy

The duties towards the foreign patient are based on respect for patient rights and concern for the wellbeing of the patient. In practice this means that physicians and clinics have a duty of good care and a duty to inform the patient. The state should provide a framework of guidelines or regulations that facilitates the application of these duties. Such a framework may include paternalistic measures. These are necessary because cross-border fertility patients often already have a long journey behind them and may ask for risky treatments. The requirements should also be respected in the case of foreign patients. The same goes for national standards of good practice like the measures to prevent multiple pregnancies (Shenfield et al., 2011). Another example is 'emergency' donor treatment when a couple comes for ICSI but no sperm can be found in the man. A highly emotional decision such as the use of donor gametes should only be taken after a period of reflection. Foreign patients sometimes demand this emergency solution to prevent complete loss of the cycle and the extra cost of a return.

In a cross-border situation, extra facilities can be offered to the patients: collaboration with clinics and physicians in their home country, telemedicine aids, specific counselling, scheduling several appointments closer together, ... The duty towards the foreign patient should however always be balanced with the duty towards the local patient. De Sutter (2011) indicates that preparing a consultation with a foreign patient sometimes takes longer, accommodating them may require extra effort and specific skills and time-consuming tests sometimes need to be done to diagnose difficult cases. Only clinics that are sufficiently equipped to do this (without affecting the right to timely treatment for local patients) should offer treatments to foreign patients with complex reproductive histories.

In the case of cross-border patients the duty to inform also requires extra attention. The morally preferable standard of disclosure, the subjective standard, requires the physician to disclose the information a particular patient needs to know, if it is

reasonable to expect the physician to know that patient's informational needs (Beauchamp & Childress, 2009). The need to know about ethical, social and legal implications of a treatment for the patient and the child clearly falls under this standard. These implications will often be different and more complex for foreign patients. The duty to inform the patient should include reflections on the future wellbeing of the child, who is going to live in a different society where gamete donation, anonymous donation, same sex parenthood, ... may not be accepted. Patients should specifically be informed about potential legal issues by a counsellor, a lawyer or their consulate. At the very least, for treatments that are known to cause problems, like international commercial surrogacy, clinics in destination countries should warn foreign patients. They could even go one step further and refuse treatment to patients coming from restrictive countries that are known to cause problems when couples try to return home with their child. Only when they are fully informed of all aspects and consequences of their cross-border treatment, patients can decide autonomously.

In a local initiative, the consul generals of Belgium, Czech Republic, France, Germany, Italy, the Netherlands, Poland and Spain sent a letter, dated 07/07/2010, to a fertility clinic in Mumbai. In this letter, they stated that surrogacy contracts are “completely null and void and/or illegal in our respective countries.” Referencing cases like baby Manji and the Balaz twins where the child was not recognized by the home country, they continue: “We would like you to ensure that our nationals are informed accordingly in order to avoid cases like the ones that have recently been reported in the Indian media. For this reason, *before initiating surrogacy process in your institution, you are requested to ask our nationals to contact their respective Consulate General*, where they will be given legal information in this regard” (Gabriels, 2010, emphasis in original). In short, they appealed to a sense of responsibility for the children who are unable to follow their parents home and who remain stateless and legally parentless in India.

It is important to add here that the patients themselves also have important responsibilities in CBRC. For example, good preparations like searching a local clinic or physician to help during the treatment process, looking for information online and communicating clearly with the foreign clinic can prevent many practical problems. However, even when physicians have adequately fulfilled their duty to inform, it is still up to the patient to act responsibly. For example, there have been many media reports on the legal problems after international commercial surrogacy, so it is hard to imagine that someone would undertake that endeavour without a clue about potential problems.

3.4.2 Duty towards the child: rights and wellbeing

Ethical grounds for duties towards the child include respect for the rights of the child and concern for its wellbeing. The problems after international commercial surrogacy

are a clear example of a lack of concern for the wellbeing of the child. It is not in the best interest of the child to be left alone in a legal limbo in a country far away from its intended parents. For the wellbeing of the child, the clinic in the destination country must do its best to prevent such problems. India's ART regulation draft bill 2010 attempts to do just that. Article 34, clause 19 of this draft bill states that a local guardian must be appointed who will be legally responsible for taking care of the surrogate and the child. Furthermore, a letter from either the embassy of the country in India or from the foreign ministry of the country is required, stating that the country permits surrogacy, and the child born through surrogacy in India will be permitted entry in the country as a biological child of the commissioning couple/individual.

In general, the clinic should always take into account the different elements that have an effect on the welfare of the child. In practice, this can be a moral ground to treat foreign patients differently from locals. For example, same sex couples and single parents from restrictive countries face additional difficulties when raising a child, which are aggravated if there is no societal support. The genetically unrelated parent often cannot legally recognize the child, there is no framework to deal with a break-up, friends, family or colleagues may not support same sex parenting, ... In several Belgian clinics, decisions to treat or not to treat are made at staff meetings with gatekeeper roles for the psychological counsellors. In these meetings, social or cultural arguments are sometimes formulated to deny treatment in the best interest of the child. Clinics could refuse treatment if homosexuality or same sex parenting is not accepted in the patients' home country, or if the patients did not yet out themselves as homosexuals to their environment.

Donor phenotype can be another ground for different treatment for foreign patients based on the welfare of the child. When foreign patients, for example from a Muslim country, request gamete donation and intend to keep this a secret, they cannot make use of sperm or eggs that will result in a phenotypically different child. Frequently, those are the only gametes available in the clinic. The welfare of the child can be a good reason to impose extra requirements in a cross border situation when the child will grow up in a society that does not accept certain family forms.

3.4.3 Duty to local patients: when justice requires different treatment

Incoming patients can have a detrimental effect on the care for the local population. In the medical tourism literature, the term 'two-tier' medical system is used to describe a situation where good quality care is only available or affordable for foreigners (Chanda, 2002). In the case of CBRC, the influx of foreign patients may not only increase the pressure on the health care system, but may also limit access to egg donors and surrogates for the local population. Although a universal moral community may serve

as an ideal, it does not imply that we have to share everything with everyone (Pennings, 2001).

In 2001, up to 50% of candidates on the waiting lists for donor eggs in Belgium were foreign residents (Baetens et al., 2000). To guard against pressure on egg donation systems from foreign recipients, demanding foreigners to bring their own donor can be a simple solution. They can then choose to proceed with the known donor or exchange her eggs for eggs from an unknown donor. This is already a common policy in several Belgian clinics (Pennings et al., 2009). It is an easy way to prevent shortages and manage pressure in times of shortages. In the case of organ donation it has also been suggested to introduce a system with two waiting lists in which organs are first allocated to residents, then to non-residents. Foreigners should have access only after it has been determined that no suitable allocation can be made to a resident (Bramstedt, 2006). To prevent situations where the local population is 'crowded out' or 'priced out' of the medical system, the government could install an allocation cap. A similar system was tested in the Philippines, where only 10% of the available organs could be allocated to foreigners (Manauis et al., 2008).

3.4.4 Duty to safeguard against exploitation

A country has a general duty to devise safeguards against exploitation of donors and surrogates. We argue that various forms of residency requirements can be imposed in the case of significant payments for gamete donation or surrogacy and that imposing a temporary residency requirement for foreign patients can change the dynamic of international commercial surrogacy. Residency requirements can vary in time (a couple of months to at least three years) and they can be applied to recipients of care (to limit access to infertility treatment for foreigners) or to donors and surrogates (to prevent foreign women from participating in the service). Residency requirements can be a tool to make it possible to monitor morally controversial treatments closely and to prevent an increase in demand by imposing a residency requirement for recipients of care.

Gamete donors (especially egg donors) and surrogates are paid large sums for their reproductive labour in some countries. Some people may argue that this is undue inducement for women from less affluent countries to sell their eggs. Residency requirements for donors or surrogates can be a safeguard when there is a heightened risk of exploitation and coercion. In the case of organ donation it has been suggested that if an incentive model is implemented, only residents should be allowed to donate to limit exploitation of poor vendors from other countries (Israni et al., 2005). In the case of egg donation, where destination countries have installed fixed amounts as 'reasonable compensations', the spending power that these fixed amounts represent, may be much higher for poor women from abroad. Some countries already impose

residency requirements for egg donors and surrogates. Greece requires that gamete donors are residents for three months. The ART regulation draft bill in India suggests a residency requirement for surrogates (article 34, clause 22).

In the case of intercountry adoption, many countries (e.g. Barbados – 18 months, Brazil – 30 days, Cameroon – 3 months cohabitation with the child, Zambia – 12 months, but in practice reduced to three months cohabitation) impose a temporary residency requirement for the duration of the adoption process (US department of state, 2013). This process often entails visits from social workers during a period when the parents build a relationship with the child, prove their commitment and get to know the cultural heritage. The duration of the residency requirement usually varies between six months and two years, although many countries are open to case by case judgements or exceptions to legislation (Breuning & Ishiyama, 2009). These residency requirements are imposed to safeguard against human trafficking and child selling. Similarly, a temporary residency requirement for international commercial surrogacy might change the entire dynamic between the commissioning couple and the surrogate. The morally relevant properties of surrogacy change when a couple establishes a personal relationship with the surrogate and not solely a commercial one (Parks, 2010). It should be noted that the same rules should be applied to locals, but for them the ramifications are different. As for intercountry adoption, a temporary residency requirement for commercial surrogacy can ensure a period of supervision and control to impose the necessary standards for a morally acceptable practice (Humbyrd, 2009). In the ART regulation draft bill, the Indian government similarly seeks to create more supervision and control by requiring the commissioning couple to appoint a local guardian.

3.5 Conclusion

In the literature on CBRC the focus traditionally is on the home country. While the cause of the movement of patients is situated in legal restrictions or availability issues at home, the effect on the destination country and how it should deal with this influx of patients should not be overlooked.

Clinics and physicians who treat foreign patients should be aware of the specific legal and ethical challenges CBRC poses. In general, foreign patients should be treated in the same way as local patients. However, when patients travel to evade the law of their own country, there are additional challenges with regard to patient autonomy and the wellbeing of the child. The duties towards the foreign patient, the child and the local patients should be balanced to ensure good clinical practice and legislation and guidelines on assisted reproduction should contain safeguards against exploitation. This

can be achieved by imposing specific requirements for cross-border patients such as residency requirements, temporary residency requirements, the provision of special counselling and informing, introducing allocation caps for foreign patients and requesting that they bring their own donor.

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Chapter 4 The consequences of S.H. and Others v. Austria for legislation on gamete donation in Europe: an ethical analysis of the European Court of Human Rights judgments

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4.1 Introduction

Two infertile couples have challenged the prohibitions in the Austrian laws. The 1992 Artificial Procreation Act prohibits egg donation entirely and sperm donation for the purpose of IVF. The first and second applicant in *S.H. and Others v. Austria* could only conceive by using donor spermatozoa and IVF, while the third and fourth applicants needed egg donation. They argued that their right to respect for private and family life (European Convention on Human Rights (ECHR) article 8) was violated and that the incoherence in allowing some techniques but not others amounted to unjustified discrimination (ECHR article 14). Austria's justification for the interference with the basic right to private and family life was that the prohibitions were enacted to ensure that only homologous methods, which did not involve a particularly sophisticated technique and closely resembled natural conception, would be allowed. Sperm donation for artificial insemination was allowed because it had already been in use for a long time and because it was such an uncomplicated technique that compliance with a prohibition would have been impossible to monitor.

The case started in May 1998, when the first and third applicants lodged an application with the Austrian Constitutional Court for a review of the Artificial Procreation Act. The Constitutional Court decided that the law was justified. The applicants subsequently lodged an appeal before the European Court of Human Rights (ECtHR). In April 2010, the First Section found that Austria did not have sufficient justification for the law and ruled in favour of the applicants. This decision was appealed by the Austrian government. After a legal battle of over 13 years, the Grand Chamber of the ECtHR ruled against the applicants in November 2011. This judgment is final.

A closer look at the judgments of the ECtHR and the arguments made by the applicants and the Austrian government provides interesting insights into the legal and moral problems with medically assisted reproduction. The judgments touch upon the fundamental morality of gamete donation and the problem of legal harmonization in areas of contested morality. The ECtHR had to determine the meaning of article 8. The question in this case was whether the court would limit the margin of appreciation by indicating the content of the right to respect for private and family life. Recently, the court was heavily criticized when it adjudicated in culturally or ethically sensitive matters because member states regarded this as an infringement on state sovereignty (Timmer, 2011). The question is how far European courts can go in determining which medical treatments should or should not be allowed by law without jeopardizing state

sovereignty on the matter. In this case, the court did not make a substantive decision, which means that many different laws within Europe are considered to be justified, that the right to procreation can easily be limited by national legislation and that patients will continue to go abroad for gamete donation.

4.2 The judgment of the First Section

The First Section court ruled in favour of the applicants. This ruling was hailed by many as a positive step forward: patients' rights were protected from arbitrary interference by national legislators (Gianaroli, 2010). However, a closer look at the judgment revealed problems with the way the court formulated it: as Smet (2010) put it, 'the outcome can be good, but the reasoning sloppy'.

The court started by referring to the doctrine of margin of appreciation. This doctrine is necessary because of the broadly drawn character of the principles of the ECHR. Member states will interpret these principles differently. It is the task of the Court to decide whether the various interpretations are in accordance with the ECHR. In areas of contested morality like medically assisted reproduction, the margin of appreciation afforded to the respondent state is especially wide (Van Hoof and Pennings, 2012). The court found that both a total ban on gamete donation (Lithuania, Italy and Turkey) and very permissive policies can be considered valid appreciations of the ECHR (ECtHR, 2010). Consequently the Artificial Procreation Act of Austria was judged to be within the margin of appreciation.

The court subsequently decided to focus on the concept of proportionality to decide whether the Austrian legislation was justified. Proportionality requires that restrictive policies are rationally related to their final aim. This means that even if a wide range of normative aims is allowed (because of a wide margin of appreciation), not every restriction is automatically justified. A standard of proportionality prevents a legislature from imposing restrictions that have little or nothing to do with the achievement of the normative goals (Storrow, 2010). For example, while the prevention of selective reproduction is a valid normative aim, it cannot be used to justify the exclusion of same-sex couples from assisted reproduction treatment. Because of the private nature of procreative choice and the fundamental rights at stake, 'the least intrusive means of achieving the aim pursued' are preferable (ECtHR, 2010). Thus the court looked at Austria's justification for the law and analysed whether this Act is the least intrusive means to achieve the normative aim.

Before the court, the government expanded the aim to keep reproduction as 'natural' as possible: use of third-party gametes could lead to 'selection' of children, a risk of

exploitation and humiliation of egg donors, allowing gamete donation would lead to unusual (unnatural) relationships and children have a right to be informed about their genetic origins. The German government, which also enacted a law that prohibits egg donation but allows sperm donation, submitted to the court that allowing egg donation would split motherhood in two, which 'would be an absolute novelty in nature and in the history of mankind'. It would interfere with the basic principle *mater semper certa est*: throughout history, one could always be certain that the woman who gave birth was the mother. This principle is used to determine the legal status of mother and child.

The examination of the law by the First Section revealed that Austria did not provide sufficient justification for the restrictions. The arguments of eugenics and the right of the child to know its genetic origins were aimed at gamete donation in general, while sperm donation for artificial insemination was allowed. Thus the court identified an inconsistency in the present law. As far as the risk of exploitation of egg donors is concerned, potential abuse is not a sufficient reason to restrict if there exists the possibility to regulate and devise safeguards against abuse. In this case, the court decided that the law is disproportionate because there are less intrusive means to achieve the valid normative aim. To address the issue of unusual relationships and indirectly the issue of split motherhood, the court stated that a lack of social acceptance is not a sufficient reason for a complete ban of a specific procreation technique. Moreover, unusual family relationships are nothing new in blended and adoption families. In this case, the court held that the argument was incoherent because adoption and divorce are acceptable practices in Austria. However, the court did not really address the issue of split motherhood: the situation arising from donation of ova creates at least a theoretical question at the moment of birth as to who the genetic mother of the child is, while such an issue does not arise in the case of adoption or blended families (Smet, 2010). This complication can be resolved by including a specific rule in family law, accommodating for the particular circumstance. In all states where egg donation is permitted, the egg donor has no parental rights whatsoever. In a sense, this is a confirmation of *mater semper certa est* as the woman who gives birth is recognized as the legal mother. However, this still implies that the doctrine no longer holds in the traditional sense.

The First Section of the court ruled that Austria had stayed within the margin of appreciation, but that the restrictions were disproportionate to the normative aims or were based on incoherent justification. Storrow (2010) suggested that the court narrowed the margin of appreciation using the proportionality principle. However, there is a serious problem with the reasoning of the judgment: it focuses too much on the means-end rationality without interfering with the choice of ends. The court was quick to assert a wide margin of appreciation, which effectively ended the discussion on the meaning of article 8 for gamete donation. The court mentions very restrictive legislations that fall within the margin of appreciation (Lithuania, Italy and Turkey).

This logically means that if natural reproduction is taken as an acceptable end, then a complete prohibition of gamete donation would be proportional. In the case of Austria, this means the court would have judged in its favour if it banned all gamete donation. In this case, the applicants would have been worse off even though the court ruled in their favour. People go to the ECtHR because they want to denounce a certain appreciation of the ECHR, but the court focused on the proportionality of the law with only minor regard for the normative aim.

4.3 The final judgment of the Grand Chamber

The Grand Chamber reversed the judgment of the First Section in favour of Austria. The court did confirm that it considers the right of a couple to conceive a child and to make use of medically assisted reproduction for that purpose as part of the right to private and family life (ECtHR, 2011). However, this right is not absolute. It is up to the individual state to decide whether there are sufficient arguments to prohibit certain treatments or techniques. The court judged that the restrictions in the Artificial Procreation Act fell within the margin of appreciation and that this was sufficient to justify the law. The court attributed special importance to the basic principle of civil law *mater semper certa est*, which was emphasized once more by restrictive states (Germany and Italy) that intervened before the court during the judgment.

In addition to the argument of split motherhood, the Grand Chamber stated that it is not up to the court to decide whether any alternative policy would be better, but to decide whether the current policy falls within the margin of appreciation. This meant that the arguments of exploitation of donors, selection of children and access to information about genetic origins came back into play. As to the incoherence in allowing sperm donation for artificial insemination but not IVF, the court stated that there is a significant difference because sperm donation for IVF is a highly technical medical process that is very different from natural conception. A prohibition on sperm donation for artificial insemination is impossible to monitor, but a restriction on sperm donation for IVF can be enforced. While this may be a difference in practice, it is not a significant difference from an ethical point of view: it is not because something is difficult to monitor, that it is morally right or wrong. To be consistent with its normative aim, the Austrian government would have to ban all gamete donation.

The court criticized Austria because the parliament had not reacted sufficiently to the dynamic developments in science and society with regard to gamete donation since the enactment of the law in 1992. However, the court should merely decide whether the prohibitions were justified at the time they were considered by the Austrian

Constitutional Court (1999). This means that the Grand Chamber has left a door open for different rulings in the future.

The court observed that there is an emerging consensus in Europe that sperm and egg donation for IVF should be allowed. However, ‘that consensus is not based on settled and long-standing principles established in the law of the member States but rather reflects a stage of development within a particularly dynamic field of law and does not decisively narrow the margin of appreciation of the State’ (ECtHR, 2011). As the dissenting judges remarked, this means the court applied a very low threshold to what European consensus entails, potentially extending the margin of appreciation beyond limits.

The separate and dissenting opinions provide an interesting part of the judgment. They raise challenging issues and clarify some of the inherent problems with the majority’s final decision. Judge De Gaetano provided a separate opinion in which he stipulated that the court should not attach so much importance to the lack of a European consensus. This detracts from the actual question of human dignity which is at stake here. Indeed, consensus is not a morally relevant argument: people can agree on immoral things. In their joint dissenting opinion, judges Tulkens, Hirvela”, Lazarova Trajkovska and Tsotsoria expressed their concern over the minimalist approach in this case. They argued that ‘in a case as sensitive as this one, the court should not use the margin of appreciation as a pragmatic substitute for a thought-out approach to the problem of proper scope of review’ (ECtHR, 2011). Indeed, by attributing a wide margin of appreciation to article 8, the court let itself off the hook for not formulating a substantial decision. The decision of the Grand Chamber sends the message that any law in an area of contested morality, like gamete donation, can fall within the margin of appreciation, even if it is irrational or inconsistent.

4.4 After S.H. and Others v. Austria

The decision in S.H. and Others v. Austria has several consequences: legal diversity will persist, there is no recognition of the basic right to procreation for couples who need donor gametes in Europe, and cross-border reproductive care (CBRC) will continue to be the only option for many patients.

The wide margin of appreciation as it is used in this case results in a confirmation of legal diversity. This means the court did not rule according to its task to harmonize the rights guaranteed by the ECHR across Europe (Rozakis, 2005). Italy, Lithuania and Turkey currently prohibit gamete donation completely. In some countries (e.g. Cyprus, Romania), the matter is not regulated, but gamete donation is used in practice. Most

European countries permit gamete donation in one form or another (regulations on compensation and identifiability of the donor vary). The consequence of this legal diversity is that European citizens travel from restrictive states to permissive states to make use of gamete donation (Shenfield et al., 2010).

Gamete donation is an area of contested morality. There is not one morally superior policy, but there are many potentially morally acceptable laws. Legal diversity is not necessarily a bad thing (Pennings, 2002). However, while it is not up to the court to present a unified European position on gamete donation, it is up to the court to decide within which limits legal diversity is acceptable. The current decision has not clarified article 8 with regard to gamete donation and failed to set reasonable limits within which specific laws are acceptable.

While the court confirms that the right to procreate is protected under article 8 of the ECHR, this right is not absolute. For example, when one needs donor gametes to have a child, the court judged that the donor's rights and interests, the rights and interests of the future child and societal values can supersede this right. So the right to procreate is a *prima facie* right. This reasoning is ethically sound. The problem arises when any reason is accepted as sufficient to supersede this *prima facie* right. If one takes the *prima facie* right to procreate seriously, there would have to be very strong arguments to deny the right to a family to couples who need donor gametes with a ban of the technique as a whole. However, in the First Section judgment, it was made clear that Austria's arguments were inconsistent or disproportionate. The Grand Chamber has failed to protect patient interests and rights by accepting weak arguments over the right to procreate.

In the Grand Chamber judgment, the court states that couples always have the option of going abroad (ECtHR, 2011). However, this is not a reason to maintain the status quo: it avoids the real question of interference with private and family life. Whether the applicants have the option of going abroad or not has nothing to do with the recognition of their rights within Austria. Moreover, the possibility to go abroad should not be used to justify more restrictive laws within the country (Storrow, 2010).

4.5 Thoughts for a better future

It is clear that there is a margin of appreciation for every law in areas of contested morality: if one is to depend on a general set of principles like the ECHR, the process of specification will allow for variable outcomes. However, this does not mean that any law is justified. Firstly, the margin of appreciation for the right to procreation should be defined more clearly so that there are also limits of appreciation. In this case, the

doctrine was used to avoid having to make a substantial decision in an area where there is no European consensus. This paper applauds the attempt of the First Section for having tried to develop a standard for legislating in the context of medically assisted reproduction, but it was doomed to fail from the start. The fundamental discussion is on the width of the margin of appreciation (i.e. the normative ends) rather than on the means–end rationality (i.e. proportionality alone).

Secondly, it is clear that some laws that fall within the margin of appreciation are insufficiently justified. Austria was mainly concerned about heterologous methods that do not closely resemble natural conception, but just because something happens a certain way in ‘nature’ does not make it ethically justified. When Austria made their ethical justification explicit, the First Section denounced every argument the government had for the law, but because it fell within the margin of appreciation the law was upheld by the Grand Chamber. Practices in other European countries prove every day that it is possible to organize gamete donation without selection of children, exploitation of donors and with access to information about genetic origins. The principle *mater semper certa est* has not caused any legal or moral problems there. Moreover, the principle has already lost its meaning in contemporary Germany and Austria as many of their citizens already make use of egg donation abroad. The merit of the First Section judgment is that it identifies several inconsistencies in the Austrian law. We believe that a close examination of the justification of a restrictive law, even if it technically falls within the wide margin of appreciation, can show that a law is an inappropriate breach of a basic right. We do not expect the court to act as Europe’s moral compass; however, some moral inconsistencies and fallacies should not be tolerated as justification for restrictive laws.

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Chapter 5 Risks and challenges for patients crossing borders for infertility treatment

Forthcoming as book chapter:

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5.1 Introduction

Cross-border reproductive care (CBRC) is a distinctive form of medical tourism in which infertile patients cross borders to obtain treatment. Infertility treatments present specific legal, ethical, practical, psychological and even medical issues that warrant reflection beyond the scope of general medical tourism. Hence, there are specific risks and challenges for patients who cross borders for infertility treatment.

There is a general lack of empirical data on the prevalence of CBRC (Inhorn & Gürtin, 2011). In the most elaborate study to date data from 46 clinics in six countries (Belgium, Czech Republic, Denmark, Slovenia, Spain and Switzerland) was gathered about 1230 cross-border patients from 49 countries. For one calendar month between October 2008 and March 2009 these clinics conducted a survey on every foreign patients they treated. Based on this study, the European Society for Human Reproduction and Embryology (ESHRE) estimated that at least 12000-15000 patients cross borders for fertility treatment within Europe each year and that this number will continue to rise (Shenfield et al., 2010). No reliable data is available for North America, but physicians estimate it to be a widespread phenomenon (Hughes & DeJean, 2010). Several countries in Asia, most notably India, are often named as popular destination countries for controversial treatments like commercial surrogacy (Humbyrd, 2009). More recently, South American private clinics have discovered the market for fertility care (Smith et al., 2010).

The same conditions that enable patients to travel for medical treatments also facilitate fertility tourism: access to information (internet), cheap flights, hospital networks, patient's rights and attitude change, portability of health insurance, marketing by clinics, commercialization of medical services, etc.... However, the nature of infertility treatment makes it unlikely that, even when there are few limitations on travelling, infertile patients would prefer to travel. Infertility treatment is a physical and emotional burden: an unfulfilled child wish, repeated disappointments and failures, uncertainty, strain on a relationship, ... (Boivin et al., 2012). Given that patients appreciate coordination, accessibility and continuity of care, it follows that they want to continue treatment locally as long as possible (Dancet et al., 2011).

The reasons why some infertile patients do travel can be summed up as legal or access difficulties at home (Pennings et al. 2008). Legal difficulties occur when certain treatments (like egg donation or surrogacy) are forbidden in a country or when specific groups (such as single persons or homosexual couples) are denied treatment. Access difficulties occur when waiting lists are too long, out-of-pocket costs are too high, expertise or equipment is lacking, good quality care is unavailable or when people have

specific desires (e.g. to have an anonymous or identifiable gamete donor). The reasons why patients travel largely depend on the legal situation and the quality of care in the home country. The ESHRE study found that 80.2 per cent of German patients, 70.6 per cent of Italian patients and 64.5 per cent of French patients travelled for legal reasons whereas 53.0 per cent of Dutch patients travelled for better quality of care and 34.0 per cent of UK patients experienced access difficulties at home (Shenfield et al., 2010). The desire for timely and affordable treatment with donor gametes is the most important motivation to travel for UK patients (Culley et al., 2011).

In this chapter, we will address the main risks and challenges for cross-border patients. While this means that we will focus on the (potential) negative aspects of CBRC, we do not consider CBRC as a negative phenomenon in itself. CBRC increases reproductive autonomy. Reproductive autonomy refers to the right of people to decide when, how, with whom and how many children they will have. When infertility treatment is not available at home or when a treatment is forbidden by the law of their home country, it increases the patients' autonomy when they can obtain treatment abroad. The ESHRE Task Force on Ethics and Law argued that the principle of reproductive autonomy justifies transgression of the general obligation to obey the law of one's country in a number of situations as long as safety, efficacy and welfare of the patient and the future child is taken into consideration (Pennings et al., 2008).

5.2 Main risks and challenges in CBRC

CBRC has a bad name. Many organizations warn their members about travelling to another country. Also governmental organizations such as the Human Fertilisation and Embryology Authority in the United Kingdom find it necessary to inform their citizens about the risks involved. We analysed the statements of 5 major organizations (i.e., European Society of Human Reproduction and Embryology (ESHRE); Human Fertilisation and Embryology Authority (HFEA); Donor Conception Network; International Federation of Gynecology and Obstetrics (FIGO); and Infertility Consumer Support for Infertility (iCSi)) on the types of risks and challenges and composed the following list:

- Violation of, or non-compliance with, safety standards (multiple pregnancy, donor screening, Ovarian Hyperstimulation Syndrome (OHSS))
- Violation of, or non-compliance with, quality standards (success rates)

- Confidentiality of patient information (patient medical records)
- Lack or insufficiency of psychosocial and medical counselling (language and culture)
- Financial implications (real cost, reimbursement and so on)
- Differences in gamete donation arrangements and surrogacy (anonymity, legal rights and obligations)
- Legal recourse after treatment (malpractice, indemnification, insurance and so on).

Several strategies have been developed to deal with these issues. The EU has enacted laws and directives to guarantee safety of care and to protect patient rights. ESHRE published a good practice guide for CBRC specifically directed at clinics and practitioners (Shenfield et al., 2011). Outside of the EU, the American Bar Association has issued good policy guidelines to deal with the legal diversity concerning commercial surrogacy in the USA (Kingdregan & Snyder, 2008). Health insurers worldwide are offering portable insurance packages that provide financial and legal support for cross-border patients.

Like all statements in scientific research, the assumed dangers of CBRC should be corroborated by empirical evidence. At the moment, a lot of anecdotal evidence circulates on the internet as well as in academic literature and, given the possible conflict of interest of the sources of the rumours, these should be handled with care. There are, for instance, few reports of cross-border women being overstimulated or gamete donors being improperly screened in countries with many cross-border patients. There have been anecdotal reports of overstimulation of egg donors in clinics in some countries (for example, Romania and Ukraine), where women are paid per egg rather than compensated for their time and inconvenience (Barnett & Smith, 2006). However, before one starts frightening patients with all kinds of horror stories, it would be wise to collect the necessary evidence to support the allegations.

5.2.1 Safety: multiple pregnancies

The most serious harm associated with CBRC is the risk of multiple pregnancies. Multiple pregnancy leads to a strong increase in obstetric complications, perinatal morbidity, maternal and child mortality rate, congenital malformations, pre-term birth,

long-term social, psychological and financial difficulties, etc. ... In a way, the occurrence of this side effect of ART is a test case for the moral quality of the field (Pennings, 2000). The most recent report of pregnancy rates in Europe indicates that there are still huge differences: in 2008, twin pregnancies after IVF or ICSI occurred in 7 per cent of cases in Sweden, 11.5 per cent of cases in Belgium, 23.8 per cent of cases in Spain and 24.5 per cent of cases in the UK (Ferraretti et al., 2012).

It is often claimed that CBRC is responsible for a higher rate of multiple pregnancies. This accusation may be partially caused by the fact that some clinics, mainly outside of Europe, explicitly refer to the fact that they do not have to abide by the same guidelines regarding the number of embryos to transfer (Mulay & Gibson, 2006). The allegation seems to be confirmed by other data. Pennings et al. (2009) provided some evidence for a higher number of embryos transferred in cross-border patients. However, one should take into account that the number of embryos transferred depends on the number of previous unsuccessful cycles and on the age of the patient. On both criteria, cross-border patients as a group differ from the local population. Many cross-border patients have had previous treatments and present difficult cases. In general, infertility patients are looking for the procedure that is most likely to result in a pregnancy and they do not see multiple pregnancy as an unfavourable outcome (Newton et al., 2007). One may expect that cross-border patients, given the price they have to pay for their treatment (in Belgium, one IVF cycle including tests and drugs costs around €5000) and the fact that it is a last chance intervention in many cases, will insist even more than ordinary patients on multiple embryo transfer. However, on this specific point, it is important that good practice guidelines are followed.

The study by McKelvey et al. (2009) is often cited to prove that CBRC causes high order multiple pregnancies which results in additional costs for national health care systems. They stated that a quarter of fertility treated high order pregnancies in their clinic were caused by multiple embryo transfers abroad. However, they showed merely that patients returning to the UK had fewer embryo reductions in case of higher order multiple pregnancies (33% of cross-border patients vs 51.4% of local patients). They did not show that these patients also had more embryos transferred than in the UK. In fact, the multiple pregnancy rate is very high in the UK compared to other European countries (Ferraretti et al., 2012). Whereas CBRC is often cited as leading to more multiple pregnancies, one might also argue that patients from countries with a high multiple pregnancy rate should, for their own safety, seek treatment in countries with a low multiple pregnancy rate. Whether or not CBRC jeopardises patient's health depends on the starting conditions at home.

Prevention of multiple pregnancy is part of good clinical practice and protection of the patient. On a national level, multiple pregnancy has successfully been managed by linking reimbursement to a SET (single embryo transfer) policy in Sweden, Belgium and

other countries. International accreditation should also be linked to an SET policy in clinics.

5.2.2 Safety: complications

The principle of non-maleficence dictates that all patients should receive safe and effective treatment wherever they go. The harms associated with CBRC are mostly multiple pregnancy and to a lesser extent OHSS. OHSS occurs mostly in mild forms, in which case it is relatively harmless, but in about 1 per cent of hormonally stimulated women severe OHSS occurs, which carries a very small risk of a life-threatening complication (Delvigne, 2009). However, this danger may be referred to the past if research confirms that new stimulation protocols can reduce the risk of OHSS to almost zero (Mertes & Pennings, 2011).

Every patient who needs stimulation is to be considered potentially at risk for OHSS (Delvigne, 2009). In the case of CBRC, the monitoring of OHSS is complicated because its symptoms appear sometime after the treatment. Cross-border patients should be instructed on what to do in case of abnormal fever, pelvic pain, vaginal bleeding or more severe symptoms of OHSS (De Sutter, 2011). When severe OHSS occurs, patients may need to be helped by a local clinic to prevent further harm and complications. One physician with extensive experience in treating foreign patients wrote:

Although collaboration with foreign 'home' clinics is excellent in 99% of cases, once a patient with severe OHSS travelled 200 km back to the centre because their local hospital refused to help them, telling them that if they went abroad for their treatment, they were on their own and should also take full responsibility if something goes wrong. This situation is both unfortunate and potentially dangerous for the patient's health. Although this case is exceptional, the centre always instructs patients to look for 'sympathetic' local clinics before they start treatment (De Sutter, 2011, p. 655).

From an ethical point of view, this home clinic demonstrated a highly dubious attitude. Doctors have a duty to help persons in need even if those persons are (partially) responsible for their own condition. Mancini et al. (2011) reported a case of an Italian woman whose ectopic pregnancy after egg donor treatment in Spain (which is illegal under Italian law) was only diagnosed just in time because the woman had trouble finding a local physician willing to help. Additionally, she did not disclose that she engaged in CBRC for law evasion when she contacted a local physician. It was only when the foreign clinic contacted the local physician that the proper diagnose could be made. It is important that local doctors take an open stance regarding treatment abroad (even when they disapprove) because only then patients will contact and inform them about what they have done.

5.2.3 Safety: collaboration between providers

Good cooperation with a physician at home ensures sufficient follow-up care and continuity of care. Cooperation may include exchange of information and shared treatment. Information exchange is a two-way street: information from the referring centres to the receiving centres can prevent unnecessary testing and inappropriate treatments. Information from the treating centres abroad to the local doctor may improve the follow-up of the patients when complications occur or pregnancy is achieved. For this to be possible, patients should be provided with adequate information about their prior treatment (FIGO, 2010). In order to facilitate such information sharing between health care providers, all kinds of devices or instruments are designed such as an internationally accessible electronic patient file. However, these solutions always hold risks for privacy and data confidentiality and fail-safe solutions still have to be found.

When patients have their infertility treatment abroad, they are to a certain degree socially isolated and have less psychological support from friends and family. Understandably, some patients want to shorten the stay abroad by doing part of the treatment at home. Data from the ESHRE study indicate that not all patients did receive help from their local doctor (Table 1). It is note-worthy that Italian and German patients, whose main reason to travel was to evade the restrictive legislation of their home country, are helped more often than Dutch patients, who travel for better quality care. Collaboration between providers mostly seems to be a question of goodwill. For Dutch physicians, it has been suggested that they do not like to be “errand boys” for their foreign colleagues (Van Hoof & Pennings, 2013). When a restrictive law is in place, the individual opinion of the local physicians on the morality of the law may determine their willingness to collaborate.

Dividing treatment between different clinics also creates new risks and challenges with regard to communication between clinics and adjustment of procedures. Although the available evidence does not indicate major problems in this regard, the discrepancies between what some doctors provide and what other doctors expect in terms of information suggest that there is more work to be done (Hughes & DeJean, 2010).

Table 1 Help received from local doctor (%)

	No help	Drug prescription	Cycle monitoring	Both
France	21.0	37.0	6.0	36.0
Germany	18.3	9.1	31.7	40.9
Italy	44.7	20.5	10.7	24.2
Netherlands	65.0	19.6	4.2	11.2
Norway	27.1	5.1	37.3	30.5
United Kingdom	54.7	15.1	15.1	15.1

Source: Unpublished data from the 2010 ESHRE Taskforce study on CBRC

5.2.4 Safety: reliable information

When patients run out of options at home, they have to select a clinic abroad. The two most important sources of information to select a clinic are the internet (41 per cent) and the local doctor (41 per cent) (Shenfield et al., 2010). Individuals contemplating CBRC who rely on the internet for information find it hard to obtain accessible, accurate and reliable information (Blyth 2010). Patients run the risk of choosing the wrong clinic because there is no reliable information available. Many clinics, for example, offer confusing and exaggerated information on success rates (Spar, 2006). For infertility treatment, success rates largely depend on patient characteristics such as age and indication, and they vary considerably across different treatments. Clinics can easily manipulate data to appear more successful. For the patients, this results in a lack of transparency. However, unreliable website information is not a problem specific for cross-border patients. All patients, regardless of whether they look for a clinic outside their own country, are confronted with this problem.

Patients' organizations should empower patients by providing them with reliable information. However, it is challenging, if not impossible, for any individual or professional organization to always have reliable current knowledge and information

about the entire range of treatment possibilities abroad (Thorn & Dill, 2010). A more comprehensive solution would be to ensure access to 'official' data that allows patients to compare clinics. The Fertility Clinic Success Rate and Certification Act of 1992 in the United States mandates that clinics performing ART annually provide data for all procedures to the Center for Disease Control and Prevention (CDC). These reports are explicitly meant to help patients to find and choose a clinic. It would improve the present situation considerably when clinics would be obliged by law to put a link to the CDC website on their own website. At present, many clinics put all kinds of statements (such as 'better than the national average') but patients do not know how they can verify these statements (Hawkins, 2013). A comparable system exists in the United Kingdom where the Human Fertilisation and Embryology Authority website explains how success rates should be interpreted and also provides a tool on how to choose a clinic. Similar structures in other countries would largely eliminate this issue from the list of potential challenges for all patients, including cross-border patients.

When patients reach a stage where further treatment is no longer available at home (because it is illegal, technologically too advanced and so on), their local physician can help by referring them to a good clinic abroad. A fairly large number of doctors (41 per cent of patients indicate their doctor as a source of information) provide this support to their patients (Shenfield et al., 2010). In a Canadian survey, 52 per cent of doctors always recommend a destination country but only 21 per cent recommend a specific provider (Hughes & DeJean, 2010). However, direct referral assumes that the local physician is aware of the situation in another country and is familiar with at least one clinic there. This is not always the case. One may even question the appropriateness of a direct referral. Two situations should be mentioned. More and more clinics become part of hospital chains with branches abroad. Referral will then evidently be to the affiliated clinics. This is not necessarily a bad thing (assuming that this clinic works according to the same standard of good clinical practice) but it may restrain the patient's freedom of choice. Moreover, this clinic may be suboptimal (more expensive, less successful and so on) compared to other clinics in that country. Still, an unguided choice may be worse. Secondly, there is anecdotal evidence about fee-splitting; that is, the referring doctor receives a fee solely for referring the patient to a specific colleague. This practice, which is condemned as unethical, undoes the benefits of direct referral because it generates a conflict of interest in the doctor that may run counter to the best interest of the patient (Pennings et al., 2008). Besides the problems mentioned above, direct referral may also be either against the law in some countries (like Germany) or against the conscience of the doctor. By referring the patient, and thus helping her to evade the law, the physician may consider him/herself as an accessory of some kind. The Human Genetics Commission in the United Kingdom recommended in 2006 that the HFEA should explore ways to prevent clinics from preparing or otherwise colluding with individuals seeking treatments abroad that are prohibited within the UK (Human Genetics Commission,

2006). Also the ESHRE Task Force on Cross Border Reproductive Care stated that when a home practitioner refers a patient to a specific clinic, he or she shares a responsibility for the general standards used in that clinic (Shenfield et al., 2011). A possible solution to this problem is that professional and patients organizations actively collect and provide information on foreign clinics.

Within the discussion on information, one tends to overlook the possible burden of making arrangements for international travelling. This indirectly leads to a selection of higher educated people who find their way on the internet and speak at least one foreign language. In the field of medical tourism, this problem is solved by host clinics offering package deals to patients including visa, plane tickets, translators, transport from the airport and so on. This seems to be less common in infertility treatment but it surely facilitates things for the patient.

5.2.5 Counselling

Information provision and counselling are important to promote informed consent and thus patient autonomy. Good counselling ensures that all parties are fully informed, aware of the long term consequences of their treatment and prepared for (supported through) the mental strains of infertility treatment. Especially when donor gametes or surrogacy services are used, counselling about long-term social and psychological consequences is indispensable (Thorn et al., 2012). Given the fact that we are talking about highly personal and sensitive topics, this might become very difficult when the counselling has to be done in a language that is not the patient's mother tongue and in a cultural setting that may deviate strongly from the patient's own background. Moreover, a foreign counsellor or physician will have a hard time to fully inform patients due to a lack of knowledge about the patients' personal and medical history, social and cultural differences and so on. There is little data on counselling and CBRC, but the data that has been published so far is mostly reassuring (Hudson et al., 2011; Pennings et al., 2009; Shenfield et al., 2010). Most European patients were able to receive information in their own language when they were treated abroad (Table 2). Given the enormous diversity of patients and languages, it is unrealistic to expect clinics to have a translator for every possible patient. Nevertheless, patients should receive basic counselling in a language they understand reasonably well. If this is impossible, one should refuse treatment.

Table 2 Information received in own language (%)

	No	Unsatisfactory	Satisfactory
Belgium	6.6%	0.9%	92.5%
Czech Republic	2.5%	1.2%	96.3%
Denmark	27.2%	0.0%	72.8%
Slovenia	1.6%	12.7%	85.7%
Spain	5.3%	1.0%	93.7%
Switzerland	1.6%	1.0%	97.4%

Source: Unpublished data from the 2010 ESHRE Taskforce study on CBRC

At the same time, we also know very little about uptake and quality of counselling in normal settings. There are significant differences in counselling practices among countries (who does it? What is the goal? To whom is it offered?) (Blyth, 2012). Moreover, many countries have large minority groups inside their borders that have a different cultural, religious and language background that may render local counselling also very difficult. In addition, many clinics with a considerable population of foreign patients have attracted doctors from countries representing the main countries of origin. It seems again to show prejudice when the point about the difficulty of counselling is advanced specifically against CBRC.

Table 2 shows that the overwhelming majority of foreign patients were satisfied with the counselling they received. However, one should take into account that not all patients take up the offer or want to have counselling. Counselling is a broad term. When it is interpreted as information provision, there are minimum standards with regard to informed consent: a responsibility shared by local and foreign caretakers (Thorn et al., 2012). When it is interpreted as psychosocial counselling, it should be available with a minimal threshold and with regard for the specific profile of a cross-border patient (Blyth et al., 2011).

5.2.6 Legal conflicts

Many patients engage in CBRC to evade a restrictive law of their home country. When these patients return home, they may face practical problems because of the legal diversity (Van Hoof & Pennings, 2012). For example, when gamete donation is prohibited or same sex couples are denied access to assisted reproduction, the partner who is not genetically related to the child will not have parental rights in his/her home country.

When patients from countries with identifiable gamete donation systems travel to countries where anonymous donation is the standard, their future children (if they are informed about their donor conception) will grow up in a society where knowledge of genetic origins is deemed important and where locally conceived donor children do have access to this information. Obviously, patients will have to balance this disadvantage against faster treatment. At the same time, other patients will move to other countries precisely to have either identifiable or anonymous donation that is not available at home.

Other legal conflicts confront patients with more serious problems. In the case of international commercial surrogacy, there are numerous reports of children who are 'stuck' abroad because the surrogacy contract the commissioning couple engaged in abroad is not recognized at home. In that case, the birth mother (the surrogate) is considered to be the legal mother by the home country while the reverse position is adopted in the country of destination (Van Hoof & Pennings, 2012). This has happened to commissioning couples from Belgium, Germany, Ireland, France, Japan the UK and elsewhere. All commissioning couples from countries where commercial surrogacy is not regulated or banned entirely face similar problems after international commercial surrogacy. In the United Kingdom, there is a well-documented case of a couple who went to Ukraine in 2008. They used the husband's sperm to fertilize a donor egg and the Ukrainian surrogate mother gave birth to twins. UK laws allow altruistic surrogacy but condemns commercialization and bans commercial brokering and advertising (Gamble, 2009). The commissioning couple signed a commercial surrogacy contract in the Ukraine, which included payment of £23,000 and gave them parental rights under Ukrainian law. However, under UK law the mother who gives birth is recognized as the legal mother and her husband as the legal father. The effect of the conflict between Ukrainian and UK laws was that the parental status of both couples was abdicated. The only way to recognize the children in the UK was with a parental order, which is used to assign parenthood to commissioning couples in altruistic surrogacy. This was the main point of discussion in the UK courts: the commercial nature of the surrogacy was in direct conflict with the law. The judge ultimately decided to grant the parental order to ensure the welfare of the child (Theis et al., 2009).

Recognition of a child born through commercial surrogacy abroad can be difficult even when it is regulated at home. Most countries recognize two ways to gain citizenship: being born (or spending a certain amount of time) in the country (*ius soli*) or being the genetic offspring of a citizen (*ius sanguini*). In the case of international commercial surrogacy, it is possible that the child is neither born on the territory nor genetically related to a citizen. The US Department of State issued a statement in which they warned US citizens that ‘even if local law recognizes a surrogacy agreement and finds that U.S. parents are the legal parents of a child conceived through ART, if the U.S. citizen parents do not have a biological connection to the child, the child will not be a U.S. citizen at birth’ (US Department of State, 2012). Their advice to patients having ART treatment abroad is to consult with an immigration attorney first. Even more remarkable, and quite worrying, is the fact that the Department of State says that it is aware ‘of cases of foreign fertility clinics that have substituted alternate donor sperm and eggs when the U.S. parents’ genetic material turned out not to be viable’ (US Department of State, 2012). If we read this correctly, the gametes of the would-be parents were switched with other gametes when conception failed; and this without telling the parents. Currently, the long and difficult road of adoption remains the only option to deal with these problems.

5.2.7 Reimbursement and costs

The principle of justice dictates that there should be equitable access to basic health care without excessive burden. The extent to which the principle of justice applies to infertility treatment depends on the status of infertility treatment: is it part of basic health care or not? Since the right to procreate is a human right, it seems evident to classify infertility treatment as basic health care. However, there are several arguments to the contrary: infertility does not lead to physical harm, treatment often does not cure infertility, there are limited resources to be distributed in any health care system and infertility treatment is expensive, there are other parties involved in infertility treatments (future child, medical personnel, gamete donors, surrogates) whose rights may supersede a person’s right to procreate and so on. In a nuanced form the principle of justice dictates that those infertility treatments that are considered to be morally sound and reasonable should be available and affordable for everyone. Financial means should not be a criterion.

The relevant question here is how CBRC affects the principle of justice with regard to infertility treatment. One should distinguish between people who travel because of law evasion and people who travel because the cost of treatment in their home country is too high (Hudson et al. 2011). The colloquial criticism of CBRC is that ‘only rich people can go abroad’. It is obviously correct that one requires money to obtain treatment

abroad but that is also true when no reimbursement is offered at home. Poor people in countries without a reimbursement system may be better off when they travel to another country, even when they have to pay the full price and have to cover the extra costs of travel and stay. The price differences of IVF are considerable, even within Europe (Connolly et al. 2010). So, contrary to the criticism, CBRC increases access for patients from countries without reimbursement through health insurance. Moreover, one should avoid a 'morality of envy': 'if I cannot have it, no one should'. It implies a form of blaming the victim, since patients who cannot access treatment at home first are then denied the option of going abroad as well. Patients who make use of CBRC for law evasion already feel abandoned by their country and the process of CBRC is very difficult for them due to a lack of support (Zanini, 2011).

There is an easy solution that ensures that CBRC increases justice for treatments that are considered legal in the home country: health insurers should reimburse the costs of treatment abroad. Reproductive autonomy and justice are increased through portability of health insurance. The European Union is taking steps in this direction with the recent directive on the application of patients' rights in cross-border health care (2011/24/EU). This directive gives patients the right to be reimbursed without prior authorization for care in any EU Member State up to the limit to which the patient is entitled according to the legislation of home country. This directive means that patients who live in a country with permissive policies, like the UK and the Netherlands, will be reimbursed abroad as well, but patients from countries with restrictive policies like Italy, Germany and France still have to pay themselves. The directive ensures that when infertility treatment is judged to be a part of basic health care, it is reimbursed across borders. However, the decision whether or not the principle of justice applies to infertility treatment is left to the individual state. From the ESHRE study, we learn that before the implementation of the directive, only patients from the Netherlands received partial (44 per cent) or full (17 per cent) reimbursement of their treatment cost (Shenfield et al., 2010). On a practical level, arranging reimbursement may prove to be an administrative burden for patients. A recent review of Dutch internet forums on infertility treatment in Belgium indicated that patients help each other play the system to ensure maximal reimbursement (Van Hoof & Pennings, 2013).

A final challenge for cross-border patients is to obtain a relatively accurate estimation of the costs. This is difficult for two reasons. Firstly, it turns out that many clinics do not mention their prices on their websites (Hawkins, 2013). Secondly, price comparisons between different clinics are very hard to make since clinics frequently bundle treatment into packages differently. Moreover, it is not always clear whether everything is included or whether parts like counselling or medication should be paid for separately. Again, standardization in presentation would be helpful.

5.3 Conclusion

Patients who cross borders for infertility treatment face many risks and challenges, but if all parties involved (patients, physicians, clinics and policy makers) adhere to the general ethical principles (reproductive autonomy, non-maleficence and justice), there are solutions to most problems associated with CBRC. Many risks and challenges can be prevented when patient groups, professional societies and governmental institutes educate patients about what information to seek and how to evaluate this information. All risks and challenges associated with CBRC can be prevented by adopting less restrictive laws and providing good quality infertility care at home.

Many predicted risks did not materialize. It is obviously important that further research is done on the actual experiences of cross-border patients but one should be wary about gratuitous accusations. Many doctors seem to believe that only they offer adequate care. It seems that, at least within Europe, no major problems arise with cross-border infertility treatment. Since cross-border treatment increases justice (in case of restrictive legislation and expensive treatment in one's home country) and autonomy for the patients, it seems that the right way forward is not to emphasize the dangers of going abroad but to adopt measures to empower patients in order to reduce possible dangers.

5.4 References

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Part 2 Empirical Research

Chapter 6 Reflections of Dutch patients on IVF treatment in Belgium: a qualitative analysis of internet forums.

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6.1 Introduction

The internet is an important source of information for IVF and ICSI patients (Haagen et al., 2003). It has also been shown that patients rely heavily on the information they find online (Kahlor & Mackart, 2009). Patients looking for treatment options abroad are especially inclined to search for information online (Speier, 2011). Blyth (2010) found that the internet (64%) and other media (20%) represent the main sources of information accessed by actual and prospective patients regarding cross-border reproductive care (CBRC). In a recent study, 42.3% of Dutch patients who went for treatment abroad reported that they selected their clinic based on online information (Shenfield et al., 2010). The number of patients who search for information on the internet is likely to be much higher.

Infertility patients make use of internet forums for information and support (Kahlor & Mackart, 2009; Kaliarnta et al., 2011). Several studies have found that IVF patients are actively supporting each other on internet forums (Isupova, 2011; Kaliarnta et al., 2011; Toscano & Montgomery, 2009). The forums create a virtual community, a space for shared experience, where these women are less isolated and alone (Toscano & Montgomery, 2009). A content analysis of seven UK infertility support forums identified support and sharing personal experiences as the most frequently used self-help mechanisms (Malik & Coulson, 2010). A qualitative study of 38 forum users showed that internet communication is highly valued by infertile couples (Hinton et al., 2010). However, while internet forums may help people deal with the emotional stresses and isolation they feel during and after treatment, they have the potential to increase isolation as well (Hinton et al., 2010; Malik & Coulson, 2008).

Belgium is a popular destination for Dutch patients who are looking for fertility treatment abroad. It is a relatively short drive, shares the same language and Belgium has some very reputable IVF clinics. Between 2005 and 2007, 1.763 Dutch patients visited a Belgian clinic for fertility treatment and the number continues to grow every year (Pennings et al., 2009). To our knowledge, there are no studies that focus on the experiences of Dutch patients with IVF treatment in Belgium. One quantitative study on CBRC in general found that 53% of Dutch cross-border patients travel for better quality, 32,2% for legal reasons, 25,5% because of previous failure and 7,4 % because of access difficulty (Shenfield et al., 2010). De Sutter et al. (2003) described the evolution in the profile of the typical Dutch patient that goes to Belgium for fertility care. First, most Dutch patients came for ICSI treatment, which, at that time, was unavailable in many Dutch clinics or subject to long waiting lists. Later, patients in need of microsurgical

epididymal sperm aspiration (MESA) or testicular sperm extraction (TESE) came to Belgium because it was unavailable in the Netherlands or (as of 2008) only possible in some clinics. Then, women over 40 with a reduced chance of success started coming to Belgium because they were denied treatment in Dutch clinics. Also, patients who had exhausted their maximum of three reimbursed cycles in the Netherlands and a large group of patients who were 'diagnosed' with unexplained infertility came to Belgium for more answers or continued treatment. Finally, some Dutch patients came to Belgium simply because the Belgian clinic was the closest in the area.

Whereas the previous studies on internet forums in IVF focused on the emotional burden of treatment and the expression thereof on the forums, the study presented in this paper is the first study of patients' opinions on cross-border reproductive care (CBRC) in the context of internet forums. The study aims to provide a better insight in the topics Dutch patients are interested in and the answers they find when they look for information online about IVF treatment in Belgium.

6.2 Methodology

The research unit for this study are the forum posts, rather than the patients posting them. It is impossible to know who actually posted on the forums. Our primary interest is what information circulates online and what information patients consider important enough to share or ask for. It is not our goal to describe patient experience or draw conclusions about IVF treatment in Belgium or the Netherlands. We aim to study the information made available online by patients for patients. Additionally, forum posts are a new way to gain insight into potential opinions, experiences and motivations of patients who went abroad or are considering to go.

We refer to the forum authors as patients although this group consists of actual patients as well as former and potential patients. Most of them exchange messages referring to patient experience but a minority of forum users may never have actually been treated. The term 'patients' is therefore used here to refer to individuals posting on an internet infertility forum.

The study started with a Google search for Dutch websites containing 'IVF' or 'ICSI' and 'Belgium'. This selection process mimics how patients search for information (Speier, 2011). This led to (posts on) forums (or websites about fertility treatment containing forums) that were readily accessible for patients. Only forums that were publicly accessible were included in this study. This means that one does not have to log in to see the information on the forums and that the information on these forums is public. The latter is important from an ethical point of view (Eysenbach & Till, 2001). By

using information that patients posted on public internet forums, we are not invading their privacy because they already chose to make their words publicly accessible (Toscano & Montgomery, 2009).

The selected forums were searched for threads (a set of posts on a newsgroup, composed of an initial post about a topic and all responses to it) containing the terms 'IVF' or 'ICSI' and 'Belgium'. All the threads that were active between the start of October 2010 and the end of December 2011 were retrieved and checked for relevance.

The retrieved threads were read in detail and analysed with Nvivo by the first author using inductive thematic analysis (Braun & Clarke, 2006). This means that the initial codes were gradually combined to form initial themes. The coding process and the emerging themes were checked by the second author and subsequently discussed until consensus was reached and both researchers were satisfied with the thematic map. The contents of the initial themes were analysed in depth and the links between the themes were explored revealing both the meaning of the themes as well as their relationship with one another. Finally, eight themes were identified and defined. Again, definition, content and interrelationships between themes were discussed by the first and second author until consensus was reached.

6.3 Results

Eight different forums were identified, four of which were very active on the subject of CBRC. 77 threads containing 1813 posts written by 397 forum authors were used for further analysis. Eight themes emerged during the data analysis: medical expertise and testing, feelings and experiences, costs, trying out different clinics, travel and waiting times, treatments in the Netherlands, cooperation between clinics/physicians and laws and regulations. All themes not only have a certain degree of independence, but are also intimately connected with the other themes: The first three themes (medical expertise and testing, feelings and experiences and costs) correlate with the common sense distinction between the medical, emotional and financial aspects of infertility treatment. When the last five themes are the subject of a thread, the first three themes are often still part of the discussion because they mostly determine the decision making process. For example, when patients are trying out different clinics, they are mostly looking to get information regarding the medical treatment scheme, to get a general 'feel' of the place and to enquire about the costs. When patients decide whether going to Belgium for their treatment is worth travelling or worth waiting for, they balance the medical, emotional and financial arguments.

It is important to note that internet forums are an important source of information for patients, but that the content of these forums is not necessarily accurate. We are presenting a thematic analysis of information that circulates on the web, not making statements about IVF treatment in Belgium or the Netherlands.

Table 3 Prevalence of themes discussed online by patients from the Netherlands travelling to Belgium for fertility treatment.

THEMES	CODES	THREADS	POSTS
Medical expertise and testing		51	118
	Skill and experience		22
	Individualized treatment		18
	More tests		17
	More treatments		13
	Better techniques		11
	Continuing treatment		10
	Success rates		8
	Reputation		3
Costs		46	160
	Cost of treatment (with or without drugs)		27
	Reimbursement		24
	Questions and problems with reimbursement		19
	Buying drugs		8
	Extra testing		7
	Drug sharing		4
Feelings and experiences		46	141
	Relationship with the staff		22
	Happiness—satisfaction		19
	Skill		17
	Hope		9
	Person, not a number		31 + 9
	Informing and shared decision making	15	22
	Individualized treatment	8	9
	Tried everything		9
	Accessibility		7
	Fear, doubt		4
	Atmosphere buildings		4
	Different physicians		3
	Gratitude		2
	Limits		2
	Frustration		1
Trying out different clinics		30	60
	Testing		14
Travel		29	47
	Travel is a burden		12
	Travel is worth it		10
	Distance influences choice		7
	Loss of time—staying the night		6
	Hospital takes burden of travel into account		4
	Cooperation to avoid travel		3
	You want results when you travel		2
	Hospital does not take burden of travel into account		1
Waiting times		24	54
Treatments in the Netherlands		23	75
	Protocol		15
	They gave up on us		12
	Behind on techniques		7
	Lack of skill		7
	Wait and see next round first		4

	Bad results		1
	Health insurance system		1
Cooperation		20	48
	Success		14
	Problems		8
	Questions		7
	Willingness		6
	Fear of problems		4
	Health insurance		2
Laws and regulations		13	21
	Age		4
	DI		3
	TESE		2
	Reimbursements		2
	Multiple embryos		1
	Surrogacy		1
	Belgium is closed		1

6.3.1 Medical expertise and testing: effectiveness and efficiency

Dutch IVF forum users believe that they receive better medical treatment in Belgium. They are convinced that physicians and other medical personnel are more skilled and experienced, that more tests are done to investigate their particular medical problem and that their treatment is adjusted to their specific situation. In general, Belgian clinics are said to have more experience and better techniques. This explains why Belgian clinics have a better reputation and higher success rates according to the forums. These patients believe that Belgian clinics will continue treatment long after the Dutch system has given up.

Some Belgian physicians are perceived as being more skilled than their Dutch colleagues. According to the forum authors, they show more interest in the patient's individual situation, are more knowledgeable and are open to alternative courses of action using new or even experimental treatments. Physicians are said to be highly specialized, with gynaecologists, immunologists, urologists, ... all highly knowledgeable in ART. However, it is also mentioned that this mainly applies to some reputable specialists in well-known clinics, but not to every Belgian specialist. The skill and experience of the nursing staff and psychological counsellors are also praised repeatedly, even the lab personnel are said to have 'golden hands'.

Belgian clinics are perceived to be more reputable and have higher success rates. However, actual success rates are never mentioned. Mostly people write that they heard many success stories or had good results themselves.

An awful lot of people, even from outside Europe, go there for treatment. They go there for a reason. You'll be amongst Italians, Belgians, Dutch, Arabs, you name it. (noor, 11 October 2011)

It is said that in Belgium new treatments do not remain experimental as long as in the Netherlands. Hence, patients believe that cutting edge research finds its way to mainstream medicine faster and that Belgian clinics are more experienced in these new treatments compared with Dutch clinics. ICSI and more recently TESE operations are given as examples.

Dutch patients appreciate that they are thoroughly tested before treatment starts which in their view charts all factors and will lead to the diagnosis of any potential 'underlying problem'. During the testing process and subsequently the decisions about the optimal treatment scheme, patients report to be actively involved by physicians. They write that they feel informed and empowered as the ultimate decision maker. This convinces them that they are given the treatment that suits them best. In their view, thorough testing ensures that patients are not subjected to unnecessary treatments and stimulations. It guarantees that every possible avenue that is medically justifiable has been explored, which is very important for patients who often have a history of several failed cycles. The extra cost of these tests, which is often not reimbursed by Dutch health insurance companies, does not outweigh the medical and psychological benefits for these patients.

Let me tell you that for us it was not really a miracle. We've searched for years for good physicians abroad and finally found what we were looking for. Because of a personalised treatment we finally managed to become pregnant and stay pregnant for now. (AA, 13 September 2011)

We did all sorts of tests with regard to all the miscarriages I had, tests they wouldn't do in the Netherlands and that are not reimbursed! But I am very happy we did them. (Kim, 27 October 2010)

The overall impression on the forums is that, after the extensive diagnostic process, there are more treatment options in Belgium. In this regard, assisted hatching is mentioned most often. The posts generally mention that there is no scientific evidence that the treatment works, but since it does no harm and might help, patients with several previous failures welcome the opportunity to try assisted hatching. According to the patients, in Belgium different hormonal treatments can be used to achieve better stimulations. There is a close link with the statements about extra tests: immunological diagnoses lead to specific drug prescriptions, issues with egg cell activation lead to Artificial Oocyte Activation, ... The general message about these extra treatments is that they will either do nothing or increase the chance of success of the next IVF treatment.

Several posts contain the very general statement that in Belgium techniques are more advanced: clinics have separate IVF labs and more funding for research, which means clinics offer cutting edge treatments and techniques. Moreover, because of the

skill and experience in Belgium, patients believe that treatments and techniques they were offered at home would be more successful if performed in Belgium.

According to the forum authors, Belgian physicians will go the extra mile with them: they still continue treatments after their Dutch colleagues have given up. Again, these statements are closely linked to the belief that Belgium offers more skill and experience, more tests, more treatments and better techniques.

6.3.2 Feelings and experiences: patient-centeredness

Patients repeatedly mention general feelings of satisfaction about their care in Belgium. They praise their caregivers and sometimes even voice feelings of pride about the way they were treated. When they compare their treatment in Belgium to previous cycles in the Netherlands, forum users mention frustration with the past and a feeling of relief. Some patients even describe themselves as a fan of a certain clinic. Several posts contain expressions of gratitude regarding the care in Belgium, even when treatments were not successful. In general, the importance of a 'good' feeling with your clinic and physician is emphasized repeatedly. They believe that this is important for the success of their treatment, but most importantly for their peace of mind, now and in the future.

There is one statement that is repeated many times across the different forums: "You are treated as a person rather than a number." There is a double meaning behind this statement: patients appreciate that their treatment scheme is adapted to their individual situation and they appreciate that they are actively involved in the decision making process. The patients appreciate that they are given (the feeling that they receive) specially adapted treatment which suits their particular situation best. This is linked with the extra tests and specific treatment category.

They are more sensitive and they treat you as an individual, not just as 'yet another women, so why would you be any different?' (Kiekske, 24 September 2011)

They feel that this acknowledges their personal situation and makes them more than merely part of a protocol. When the treatment scheme is being decided, patients like physicians to inform them fully and to think along with them when different options are considered. This setting of shared decision making gives them the feeling that in the end, they are in charge, but that they are supported as well.

We didn't feel like a number: they explain everything to you, even things that may not be useful. The fact that the choice is really yours, is what attracts us the most. (Saskia1984, 19 September 2011)

Many patients share stories on the forums about how vulnerable they felt when they were told they would no longer be treated at their clinic in the Netherlands. In Belgium, they find physicians who are willing to continue to look for solutions. Additionally, Belgian physicians are said to be very supportive when treatments failed: 'they never give up on their patients'. Patients feel like they are in 'skilled hands' who will do their best for them. The impression of skill is an important reassurance. In that regard, patients like to be treated by only one physician, which is not the case in most big clinics. Some patients see this as a disadvantage, while others do not think it is important. Usually the patients say that the first consultation (intake) should be with a specific physician, who is known to be skilled and knowledgeable, because the treatment scheme is decided at that moment.

Everything is done calmly and skillfully. You just feel like you are in perfect hands there. Another place will be better for someone else, but this is a match for me. The nurses are skilled and friendly, everything fits. No surprises. I like reliability when my egg cells are at stake. (noor, 11 October 2011)

In general, Dutch patients write that Belgian physicians and staff are nice and friendly. They especially appreciate that physicians and other clinic staff make time for them. Some physicians and staff members are particularly recommended in because of this. The forum authors write that they appreciate honesty and abundant information. They report that they like physicians who have a positive, yet realistic attitude towards them: no false hope, but support and consideration. In the case of repeated failures, several patients even mention physicians or staff members who comforted them, making the emotional burden of IVF treatment a little easier to bear.

The next step for me was using a donor, even though my physician did not want to give up yet. That's another thing that I like about her: she almost fights alongside you. (AA, 15 December 2012)

Patients write about high hopes about their treatment in Belgium. They seem to firmly believe that the extra tests, specific treatment or better care will give them a higher chance of success. After several failed attempts in the Netherlands, continuing treatment in Belgium is experienced as a new start. However, going to Belgium is also considered to be a last resort, so several patients report feelings of anxiety and doubts.

Several patients write about how every decision was a big step. They pushed their limits whenever it was necessary. They stress how important it is to decide for themselves, as a couple, how far they are willing to go. They believe that that decision should not be up to the physician. Many patients indicate that it is important for them to know that they tried everything.

When you've been to [clinic X], I always told myself, you can really say you did everything you could. (Christel, 24 June 2011)

On the one hand, patients worry because of the success of certain Belgian clinics: they are very busy which might lead to mistakes. On the other hand, Belgian clinics are said to be more punctual and better organized all-round. Patients believe that clinic staff works meticulously. This busyness is also interpreted as a confirmation of the superiority of care in those clinics.

Patients appreciate that clinics or physicians can easily be contacted. They report to each other how short the response time to emails is and what a clinic's policy on phone calls is. Several patients send their 'story' and their medical file in advance by email or by post so their physician can read it in advance.

It is mentioned a couple of times that the buildings of some Belgian clinics are old and cold on the outside, but that the department of reproductive medicine usually is new and up to date on the inside. Moreover:

The building may not look like much, but you forget this once you talk to a physician. (lieff, 29 December 2011)

6.3.3 Costs

Costs are the second most discussed item in the forums. Future patients want to know how expensive their treatment will be and seasoned patients can tell them what extra costs they have to take into account and which extra tests they think are worth the extra cost. Patients share information about reimbursement and help each other with related administrative issues. Patients who are no longer eligible for reimbursement can find out where hormonal drugs are the cheapest.

Discussions about costs are always related to assessments and balancing acts: is it worth it? IVF treatment in Belgium is said to be more expensive than similar treatment in the Netherlands or Germany. However, quality of care is also said to be higher. In that regard, it is noted several times by patients who have already used up their three rounds of reimbursed IVF that if they have to pay for treatment themselves, they want the best possible treatment, so they go to Belgium. Most patients who were already treated, successfully or unsuccessfully, write that even though treatment was more expensive, it was worth it. In general, it seems that extra tests and specific treatment are worth the costs. It is also noted that extra tests are not very expensive compared with the entire treatment, so if they enhance the chance of success, they are cost effective. This is not so for experimental treatments: in this case, patients write that they are only worthwhile if they are cheap ('what's the harm?').

It is difficult to discern what an extra round of IVF treatment will cost the patient: every patient needs different tests, different stimulations, different side treatments, ... which all affect the total cost of the treatment. In general, patients make a distinction between the cost of treatment with or without hormonal drugs. Prices of “around €1500” are mentioned for the lab cost of IVF/ICSI, €3000-€3500 for an entire cycle of IVF or ICSI excluding drugs and around €5000 all included. Additionally, patients have to pay travel costs. If they live far from the border this may include an overnight stay. Humor is one way of dealing with the costs of expensive treatment in Belgium:

Weren't you astonished by the prices in [clinic X]... sigh :\$ We're already calling the future babe million dollar baby :D (Baby09, 08 October 2010)

Patients want to know whether they will be reimbursed for their treatment, how much they will be reimbursed and if there are any pitfalls. Because of the privatization of health insurance in the Netherlands, there are different health insurance companies that handle cross-border reproductive care in different ways. By law, patients have a right to be reimbursed up to the cost of the treatment in the Netherlands during the first three rounds of IVF. However, most health insurance companies reimburse all costs, except for certain tests or additional treatments. The lack of uniformity creates a complicated situation which adds stress to an already stressful process. Moreover, help desks and receptionists at the companies do not always appear to be well informed about their company's cross-border policy, which makes this difficult situation even more uncertain for (future) patients.

By the way, the service desk of my insurer gave me four completely different answers about how ICSI abroad is managed!! One said: just start and declare afterwards. The next one said: ask for permission. After that: start but get a referral from a Dutch gynaecologist, and she also sent me a questionnaire.. pfff. The last one was right by the way: as long as it is your 1st, 2nd or 3rd time and you are under a certain age, you can just start your treatment and declare afterwards, but you need a referral from a Dutch gynaecologist and the IVF physician in Belgium has to fill out the questionnaire. (Yola, 05 January 2011)

On the forums, seasoned patients can offer valuable advice. They inform others about which insurance companies have the most beneficial policy for CBRC. In addition to more beneficial reimbursement schemes, some health insurance companies have cooperation contracts with Belgian clinics, which means that there are no out-of-pocket costs for the patients and considerably less administrative issues. Some forum users changed health insurers for this reason. To get reimbursement, patients need a referral letter from a Dutch gynaecologist, but not every gynaecologist is eager to write one. This is described as yet another difficulty in the reimbursement process.

Forum users also help each other to work the system so they will be partially reimbursed even if they already used up their three reimbursed cycles. Some tests and treatments can be declared in other categories than IVF treatment, like blood tests and ultrasounds. When patients have part of their treatment in a Dutch hospital, these consults and follow-ups are reimbursed as well. Some patients even managed to get reimbursement for expensive hormonal drugs after their third cycle.

When they are still eligible for reimbursement or they successfully worked the system, the patients buy their drugs in the Netherlands. This is reported to be very easy with Belgian prescriptions. When patients have to pay for the drugs, the forums advise to buy them in Belgium, where they are significantly cheaper. Some addresses for well-known pharmacies circulate on the forums. In the past, patients could leave their leftover drugs at the hospital after successful treatment to help patients who were no longer reimbursed. The hospitals stopped doing this because it is illegal. Now, the women appear to share leftovers through the forums, via private messages or password protected threads. This practice is often mentioned or alluded to in the open forums.

6.3.4 Trying out different clinics

During the intake everything is discussed at length. I'm sure you'll never want to leave there...until you have a baby in your tummy :) (Saskia1984, 19 September 2011)

Many Dutch patients who come to Belgium for IVF treatment have already been through the three reimbursed cycles in the Netherlands and therefore present more difficult cases. These people were looking for the reason why their previous attempts failed and when they were confronted with the online information that Belgium offers higher quality of care, they were faced with a choice: to go or not to go. The subsequent question then is: where do I go? The advice to someone struggling with these questions on the forums is universally the same: go for a second opinion or an intake and then decide what to do.

The intake or second opinion serves as a test ride to see which treatment a physician suggests and what kind of feeling the clinic gives you. The costs of an extra round of IVF are high (€5000 all-in), but everyone can pay €80 for a consult. The first consult will then determine whether or not patients will continue their treatment at the clinic. The clinic choice is considered to be very complicated and very personal: different people want different things from their treatment. The general feeling of this first contact is identified as the most important factor to take into consideration: you should follow your gut feeling when you are choosing clinics.

You can always schedule a couple of appointments at different clinics in the Netherlands, Germany and Belgium. Then you can experience for yourself what gives you the best feeling and what suits your finances. (wen72, 23 September 2011)

6.3.5 Travel and waiting times: investments

Patients from the North of the Netherlands drive nearly four hours one way, excluding traffic jams, to their Belgian clinic, but most of the reported travel times are described as minimal. Distance is one factor in clinic choice, along with quality of care, cost, waiting times and laws and regulations, but it is rarely regarded as the most important marker. Travelling has several effects and patients report different attitudes towards them and different ways of dealing with them.

Travelling heightens the burden of repeated treatments and causes practical difficulties. It is reported that travelling long distances affects your mood and physical fitness. Travel time is considered to be lost time. Several patients mention that they lose an entire day every time they have an appointment. Some even have to drive up the day before and stay overnight when they are scheduled early in the morning. Some forum users explore ways to make the journey more pleasant, by visiting restaurants and nice hotels for example, but the general consensus is that even with such measures, travelling is a burden.

It is a burden to have to travel to [clinic X] and back every time, but I think that's all quickly forgotten when you have a positive test in your hands. (Greetje, 03 April 2011)

The general tone of the discussions on travel is that even though it is a burden, it is worth it in the end. If you want the best possible care, you have to be willing to travel. Travelling is also a factor in the patients' feeling that they did everything they could. In the end, what are a couple of hours in the grand scheme of IVF treatment? However, patients do expect something in return: travelling is worth it if the results are worthwhile. They expect a higher standard of care, something 'extra' compared with their previous treatments. Moreover, miscommunication and misunderstandings are greatly frowned upon. For example, one patient wrote that the clinic forgot to tell them that none of the embryo's survived the thawing process, which meant they spent ten hours in the car for nothing.

To avoid unnecessary travelling, patients want to do as much as possible in one visit. Blood tests, counselling, ultrasounds: they want to combine anything they need or might need. Many clinics are reported to accommodate foreign patients for this and even schedule them when it suits them best. Other clinics are said to refuse this kind of

‘service’, meaning that foreign patients may have to get there early in the morning or have to take time off from work. Any accommodation from the clinic in this regard is appreciated by the patients.

Another way to avoid travelling is doing part of the treatment in the Netherlands. Some patients prefer to do this, to save on travelling and costs, but there is an extra burden here as well: the need to make arrangements. Furthermore, things can go wrong (wrong timing, miscommunication, etc.). Moreover, given the firm belief on the forums that expertise is higher in Belgium, it is rational for patients to want all of their treatment done there. There is no clearly favoured option on the forums: patients should decide for themselves what they want.

Waiting times refers to the time patients have to wait before they can start treatment. Opinions about waiting times are straightforward: ‘the shorter, the better’. Patients ask about waiting times abroad and clinic choice is partly determined by it. Again, there is a trade-off: patients appear to be willing to wait for better treatment. Sometimes patients want an appointment with a particular physician, in which case they are also willing to wait longer if necessary.

6.3.6 Treatments in the Netherlands

Because most Dutch patients who are treated in Belgium were previously treated in the Netherlands, the cross-border patients often voice their opinion about treatments in the Netherlands. Posts about treatments in the Netherlands are almost univocally negative: Dutch clinics focus too much on protocols, there is a lack of skill, they are technically behind, the results were bad, etc. In addition, in the Netherlands many patients were told there was nothing the clinic could do for them anymore and they feel the clinic (both the system and the physician) gave up on them.

Many patients talked about the strict protocols in the Netherlands, which they believed not to be suitable for complicated cases. On the forums, patients say that every person should represent a separate case: rather than blindly sticking to procedure, physicians should look at what is best for the patient. They believe not every patient needs the same stimulation and some patients are better off with more tests, especially after several failed cycles. In some posts, patients blame the health insurance system for the extreme emphasis on protocols and procedures.

My experience in the Netherlands is that if you don’t fit the protocol, they don’t really know what to do with you. (Jewel 13 July 2011)

Several patients mention that since they have been to Belgium, they realize what was lacking in the Netherlands before. In addition to the lack of customized treatment, patients write that techniques are old-fashioned, physicians are less skilled and overall

results are worse. There is a logic to these statements: if you believe care to be better in Belgium, you believe it to be worse in the Netherlands. Also, if some extra tests indicate an underlying issue causing infertility, it is normal to feel very frustrated about the waste of effort during previous treatments. Some posts are more nuanced, saying it is more a question of will rather than skill: the same treatments and techniques are possible in the Netherlands, clinics just do not apply them.

It is frustrating to know that we went through 3,5 years of treatments and tests, which would not have been necessary if someone had taken a better a look from the start. (Pien, 05 November 2010)

On the forums, several stories circulate about how women are no longer treated in the Netherlands because they are not (or no longer) eligible (because they are too old, their BMI is too high, ...), or because after several cycles they had no success and are 'diagnosed' with unexplained infertility. Posts of these women show that they are often still treated with success in Belgium. In hindsight, they believe their Dutch physician and the Dutch system gave up on them too soon.

In the Netherlands they are very quick to decide someone is no longer treatable, while abroad they do still see chances and dare to take these chances. (Solvi, 12 September 2011)

On rare occasions someone does write in threads about CBRC that they will do another round in the Netherlands before going abroad. They see a treatment abroad as too much trouble when the next treatment at home or a more specialized Dutch clinic might be successful as well. Generally, reactions to these posts still advise these people to change their mind about travelling to Belgium.

6.3.7 Cooperation between clinics/physicians

Patients share their experiences, both positive and negative, with cross-border clinic cooperation. Many questions arise when people are considering to do part of their treatment at home. On the forums, patients give advice and help each other with practical issues.

Most posts about clinic cooperation describe positive experiences: Belgian clinics treat many Dutch patients and are used to cooperating with local Dutch clinics. Usually, everything seems well organized, even though patients advise each other to keep an eye on things: make sure everything is communicated in a timely fashion and without mistakes. Some clinics are said to be more open to perform part of the treatment than others: patients advise each other where to go to ensure good cooperation. In addition to the obvious advantage of reducing travel burden, some patients report that even

though they were no longer eligible for reimbursement for IVF, they were reimbursed for the blood tests and ultrasounds that were done locally.

Problems with cooperation include communication issues between clinics, finding a clinic at home that will help (also in the weekends and on holidays), making arrangements with the health insurer, ... Several patients write that they do not want to do part of their treatment at home because they fear some things may go wrong. Negative experiences are often attributed to a lack of willingness by Dutch clinics or physicians. The same resistance can be seen towards referrals. Several patients wrote letters to their Dutch clinic after they were treated in Belgium saying what was wrong with their treatment there and that future patients in their situation should be referred to a Belgian clinic.

It's also a question of willingness. My gynecologist also said 'we are not errand boys for Belgium' ;-) And I get that, Belgium eventually gets all the honor... (Baby09, 07 December 2010)

6.3.8 Laws and regulations

The most discussed regulations are clinic regulations. Patients believe that Dutch clinics want to keep up success rates by denying treatment to difficult cases. Some couples went to Belgium for TESE before 2008 because the treatment was not allowed in the Netherlands, and kept going there for subsequent treatments. A small number of posts on the subject of donor insemination handle the question of identifiable versus anonymous donors. Some patients write that they prefer to stay in the Netherlands for identifiable donation while others go to Belgium to make use of a known donor or anonymous donation. There are also general discussions about the number of reimbursed cycles in the Netherlands (three cycles) versus Belgium (six cycles) and about how some Dutch politicians want to reduce this to one cycle.

6.4 Discussion

The unit of analysis of this study is the forum post. The data are not representative of the experience of Dutch IVF patients in Belgium and the Netherlands. These posts are written by a particular group: mostly women, with internet access, who often had several treatments in the past and who show a certain 'extra' interest or motivation by posting on an internet forum. It is impossible to know to what extent the forum users are representative of the overall Dutch population seeking CBRC. Internet forums are

generally not checked for accuracy of information. People can post anonymously, which invites exaggerations and lack of nuance. Some forum users post in almost every thread on cross-border care and set the tone in the discussions. In general, patients are rarely challenged about their views as all forum users consider each other fellow sufferers. Moreover, all forum authors who received care in Belgium invested time, effort and money in their endeavour, which may cloud the critical assessment of their actions. At the same time, these patients can speak freely, without reticence and uncensored on these forums which guarantees a spontaneous and undirected account of their opinion.

It is important to note that some Dutch hospitals also have a good reputation on the forums. Because we only selected threads about Belgium, the image about clinics in the Netherlands may not be generalized to the entire content of the forums. However, the particular focus in this study offers us insight into an important component of CBRC. Apart from the views of (potential) patients on fertility treatment, it presents the information that every Dutch patient looking for information about IVF treatment in Belgium is confronted with. This information rouses certain expectations in patients before their treatment starts.

The data from the forums largely correspond with the findings from earlier quantitative studies about CBRC between Belgium and the Netherlands (Pennings et al., 2009; Shenfield et al., 2010). We already knew that Dutch patients come to Belgium because they believe the quality of care is higher or because of previous failure. However, the 32,2% of Dutch patients who were reported in the ESHRE study to travel for legal reasons seem to be less active on internet forums. The current data allow for more in depth analysis of the meaning of good quality care in the eyes of CBRC patients.

Most Dutch patients who participate in forum discussions describe themselves either as patients looking for information and asking questions, or as patients with a long and complicated history of multiple treatments who share their knowledge. Most stories that circulate on the forums offer descriptions of difficult cases that, according to the patients posting the messages, were not adequately treated in the Netherlands. This is in line with the profile of the typical Dutch patient who visits a Belgian IVF clinic (De Sutter, 2011).

The most discussed item was quality of care. Earlier, six dimensions of quality of care in ART were suggested: safety, effectiveness, patient-centeredness, timeliness, efficiency and equity of access (van Empel et al., 2008). All these dimensions are discussed at length in the forums except for safety, which is to be expected since there are few problems in both Belgium and the Netherlands in this regard. The prevalence of posts on certain themes may be an indication of the importance of the dimensions for patients. Moreover, the meaning of the dimensions and the links between them can be explored further in our results.

The general message on the forums is that quality of care is higher in Belgium for all the relevant dimensions. In terms of medical treatment (effectiveness), feelings and

experiences (patient-centeredness), costs (efficiency), waiting times (timeliness) and laws and regulations (equity of access), patients are said to be better off in Belgium. Our analysis indicates that the fundamental reason why patients write this is because they feel more respected as a person in Belgium. Several forum authors describe themselves as “experts from experience”. They want to be recognized as such. They want to be actively involved in the treatment process and identify openness to their ideas, opinions and questions as essential to good quality care. Regarding their medical treatment, they have the feeling that they are in control: they are fully informed and they are involved in the decision process. Regarding their feelings and experiences, they feel supported and acknowledged in their situation and respected as a patient with a unique and relevant history, and often enjoy special arrangements because they come from abroad. It is possible that physicians treat foreign patients differently because of the extra investment they make and that this partly explains the difference in the experience of quality of care. On the forums, respect for the person behind the patient is identified as the main reason why quality of care is higher in Belgium, both for medical (effectiveness and efficiency) and non-medical (patient-centeredness) aspects of IVF treatment. Whereas patient-centered care is generally seen as a dimension of good quality of care that has nothing to do with effectiveness and efficiency, on the forums the central position of the patient is considered key for every dimension of good quality care.

On the forums, a general distinction is made between the quality of the medical treatment and the care for the person behind the patient. In reality, Belgian clinics do not have significantly higher success rates compared with Dutch clinics for specific treatments (Ferraretti et al., 2012). The belief that patients are better off in Belgium appears to stem from a difference in the approach to medicine in the eyes of the cross-border patient: the Dutch system is portrayed as an assembly line system where clients get a standard treatment package. The Belgian system is presented as a system where the patient rather than the treatment is considered most important. Both aspects of quality of care are intimately linked on the forums: because you are treated as a person in Belgium, the quality of the medical treatment is higher there as well. Because physicians want to treat you the best way possible given your specific case, the outcome will be better for you.

In the academic literature, our finding that respect for the person behind the patient is most important can be categorized under patient-centered care. Patient-centeredness in ART has been a big issue in IVF treatment in recent years (Pennings & Ombelet, 2007; Dancet et al., 2010). The meaning of patient-centeredness was explored in a qualitative study and validated in different European countries (Dancet et al., 2011; Dancet et al., 2012). Infertile patients are known to value patient-centeredness (van Empel et al., 2011). One of the main topics of patient-centeredness is information. Our results also indicate that it is very important for infertility patients to feel informed and to be recognized as equal decision makers in the treatment process. Patient-centeredness is

not only considered to be of central importance for the personal side of infertility treatment, the patient should also be central in the purely medical treatment (consideration of history and uniqueness of every case) and the decision making process.

The belief that Belgium offers better quality of care is the most important reason why so many Dutch patients visit Belgian clinics (Shenfield et al., 2010). The information on the forums regarding care in the Netherlands offers additional explanations. Boivin et al. (2012) identified patient factors, clinic factors and treatment factors that contribute to patients' decisions to end treatment. The clinic factors they identified closely resemble our findings: sub-optimal organizational care (including assembly-line treatment, insufficient information on alternatives, depersonalization, negative doctor attitudes and overly bureaucratic procedures) and negative staff-patient interactions (including insufficient care of the person and insufficient time for questions). It seems that patients who can deal with the personal and physical burden of IVF treatment but face an unfavourable clinic environment may be prepared to look for treatment options abroad rather than discontinue treatment.

6.5 Conclusion

Internet forums are a virtual place where patients can help each other with practical, emotional and even medical issues. Internet forums offer an easy way for patients to share practical information like which health insurer offers the best care package for IVF or where drugs are the cheapest. In all eight Dutch forums, the general message about fertility treatment in Belgium is very similar: Belgium offers better quality of care. The most important markers of good quality are high medical skill (effectiveness), cost-effectiveness (efficiency) and respect for patients' feelings and experiences (patient-centeredness). According to the forums, the main difference between IVF treatment in Belgium and the Netherlands is the central position of the patient: in Belgium, more tests and treatments are possible and patients are seen as persons rather than numbers.

6.6 References

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Chapter 7 “Now we feel like we did everything we could”: A qualitative study into the experiences of Dutch patients who travelled to Belgium for infertility treatment.

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7.1 Introduction

Cross-border reproductive care (CBRC) is a fast-growing phenomenon at the intersection of medicine, law, business and travel (Gurtin & Inhorn, 2011). CBRC is the concept used primarily to describe the travel of infertility patients from one jurisdiction to another in order to access treatments. In Europe, free movement laws and portable health insurance facilitate crossing borders in search for infertility treatment. In 2010, it was estimated that 11000-14000 infertility patients cross borders in Europe annually (Shenfield et al., 2010). This number is likely to be higher now. Patients are crossing borders in Europe in response to a patchwork of local laws and regulations on assisted reproduction and differences in waiting times and quality of care.

Many Dutch infertility patients go to Belgium for treatment every year. For Dutch patients, Belgium is a neighbouring country where some highly reputable IVF centres are located and where they can speak their own language. 1.763 Dutch patients visited a Belgian clinic for fertility treatment between 2005 and 2007, and their number continued to grow every year (Pennings et al., 2009). Most of the Dutch patients in that study travelled to Belgium for ICSI (38% with ejaculated sperm, 15% with non-ejaculated sperm), for sperm donation (16%) or for IVF (14%). There is some anecdotal evidence that some Dutch patients travel to Belgium for egg donation, but Spain is the most popular destination by far for egg donation (van der Meer-Noort, 2011). The largest quantitative study on CBRC in Europe found that 53% of Dutch cross-border patients travelled for better quality, 32,2% for legal reasons, 25,5% because of previous failure and 7,4 % because of access difficulty (Shenfield et al., 2010).

Most Dutch patients travel abroad for better quality or because of previous failure (Pennings et al., 2009; Shenfield et al., 2010). However, there is little difference in quality of care between Belgium and the Netherlands, at least with regard to success rates (Ferraretti et al., 2013). This indicates that further research into the motivations of Dutch cross-border patients is required. CBRC from the Netherlands to Belgium for legal reasons is peculiar in the sense that there are only minor differences in legislation. There is an identifiable gamete donation system in the Netherlands versus an anonymous system in Belgium, but it is not clear to what extent Dutch patients who come to Belgium prefer anonymous gamete donation. Additionally, testicular sperm extraction (TESE) is considered to be an experimental treatment in the Netherlands and is currently only performed in two clinics where waiting lists are long, whereas it is routinely performed in Belgium. This explains the flow of Dutch patients travelling for ICSI with non-ejaculated sperm. The legal age limit for access to IVF in the Netherlands

is 45, but most clinics set the age limit at 43 or lower depending on the ovarian reserve. The women who reach the age limit in the Netherlands can continue treatment in Belgium.

This is the first qualitative interview study looking into the experiences and perspectives of Dutch patients who travel to Belgium for infertility treatment. One qualitative study was conducted recently on the discourses about IVF treatment in Belgium on Dutch internet forums (Van Hoof et al., 2013). The insights from this study were used when the interview guide for the current study was drafted. The general message on the forums was that quality of care is higher in Belgium. According to the information posted on forums, the main difference between IVF treatment in Belgium and the Netherlands was the central position of the patient: in Belgium, more tests and treatments were possible and patients were seen as persons rather than numbers.

In this article, we will build on previous quantitative surveys to explore the motivations of different categories of Dutch patients to go to Belgium for infertility treatment. Based on data from semi-structured interviews, we will present a thematic analysis of the push and pull factors for these cross-border patients and how the conceptualization of Belgium as the next step in the treatment process transforms the experience of cross-border infertility patients.

7.2 Methodology

Between June 2012 and March 2013, 15 Dutch heterosexual couples, one woman whose partner could not accompany her during the visit to the clinic and one single woman were recruited at the department of reproductive medicine at Ghent university hospital. This study was approved by the ethics committee of Ghent University Hospital (EC: 2011/865) and all participants provided informed consent in writing. The couples were interviewed together. In all, 32 Dutch infertility patients were interviewed.

The participants were purposefully sampled based on the available data about Dutch infertility patients travelling to Belgium. Previous research revealed the relevant categories of patients (De Sutter, 2003; 2011; Pennings et al., 2009; Shenfield et al., 2010). We recruited four couples for whom Ghent university hospital was the closest IVF clinic. They had started treatment (intrauterine insemination) in a small Dutch clinic that refers patients to Ghent when they need IVF or ICSI. We recruited two couples in which the woman was 43 years old, which means that they were no longer eligible for treatment in most Dutch IVF clinics due to age limits. We recruited eight couples who had started IVF or ICSI treatment in the Netherlands, but made a decision to go to Belgium hoping to be more successful there. Five of them had exhausted their

maximum of three reimbursed cycles in the Netherlands. Two of them were disappointed with their 'diagnosis' of unexplained infertility and four of them had bad results after ICSI treatment in the Netherlands. They all went to Belgium because they believed that the quality of care was higher there. We also recruited two couples and one single woman who went to Belgium for artificial insemination with donor sperm.

The semi-structured interviews were conducted after the insemination or embryo transfer took place. These are short procedures that could be the endpoint of treatment in the clinic if a pregnancy is achieved. The interviews took place at Ghent university hospital, but it was repeatedly made clear, both in the informed consent form and through oral communication that the interviewer did not work at the hospital.

The interview guide was developed by the first and second author and amended after consulting with the staff of the hospital. The semi-structured interviews started with very open questions about the participants' reasons to go to Belgium. Next, participants were encouraged to adapt a standard timeline (considering going abroad – making the choice – travelling – treatment – after treatment) to their own story using post-its. This timeline remained on the table during the interview to encourage participants to talk about previous experiences as well as more current ones. Subsequently, the interview focussed on the participants' experiences and the practical issues they faced. After this, the participants were confronted with four fictitious declarations of other infertility patients who had gone to Belgium for treatment. This way we questioned their opinions and perspectives. Finally, we asked about the future child and any support from home, and about gamete donation if relevant.

The interviews were transcribed verbatim and analysed with Nvivo by the first author using inductive thematic analysis (Braun & Clarke, 2006). Initial codes were gradually combined to form initial themes inductively to ensure that relevant data that was not a subject of direct questions from the interview guide would get proper attention. The emerging themes were continuously reviewed to see if they worked in relation to the codes and other themes, gradually developing a thematic map of the data. Because the participants had very different medical backgrounds and reasons for going to Belgium, the thematic map was reviewed for differences and similarities between the categories of patients. The thematic analysis was subsequently discussed until consensus was reached between all authors.

7.3 Results

We identified five main themes in the data. 'Treatment in the Netherlands', 'information', 'treatment in Belgium', 'Belgium as the next step' and 'donor sperm'.

Almost all the participants underwent some form of infertility treatment in the Netherlands and all participants talked about why they chose not to start or continue treatment in the Netherlands. Once the participants decided to cross borders for treatment, they needed information to guide their decision making process. We focus on their sources of information and on their own intentions to share their own experiences with others. Next, the participants' experiences during treatment in Belgium are described and specific attention is given to their experiences during cycle monitoring in a local clinic. Finally, the focus was on how the belief that treatment in Belgium was the next or final step in the treatment process transformed the experiences of many Dutch cross-border patients.

The most important theme in the data was that going to Belgium was the next step. The Dutch patients believed that the quality of care was very high in Belgium and that in taking this step, they had done everything they could to achieve a pregnancy. This conviction had an effect on the way they thought about their previous treatments and on how they experienced their current treatment. The experiences and perspectives with regard to treatment in the Netherlands can be seen as push factors and the idea of higher quality of care in Belgium as a pull factor in the cross-border flow from the Netherlands to Belgium.

The experiences of the Dutch patients who travelled to Belgium for treatments with donor sperm partially coincided with the other categories of patients with regard to dealing with practical issues and gathering information, but the need for donor sperm and the choice to use anonymous donor sperm were specific aspects of their stories. After the thematic analysis of the common experiences and perspectives, this specific issue will be addressed.

7.3.1 Participants

Data was gathered about 16 couples and one single woman. The average age of the women was 32 (range 27-43). The average travelling time for the participants to the clinic was 2 hours (range 1-4 hours). Six couples already had a child, in two cases the baby was present during the interview. One woman had conceived a child without assisted reproduction, but since had her fallopian tubes removed. One child was conceived after IVF treatment in the Netherlands and four children were conceived after ICSI treatment in Belgium.

In total, the participants experienced 17 inseminations with donor sperm, 7 IVF cycles and 18 ICSI cycles in Belgium and 24 inseminations with the partner's sperm, 19 IVF cycles and 17 ICSI cycles in the Netherlands. For all treatments, there were participants who went to Belgium for the first time as well as seasoned patients with complicated histories who had undergone several treatments.

7.3.2 Treatment in the Netherlands

The central theme when the participants discussed treatment in the Netherlands was that their treatment was based on rules and protocols that were followed blindly. They compared the care they received to assembly line treatment. Examples included: the physicians had no time for questions or niceties, they did not even recognize you when you came in for your seventh treatment cycle, they always seemed to be in a hurry, ... Several participants used the phrase 'we were treated like a number rather than a person'. Luc explained what happened when they were pregnant for a second time in the Netherlands:

LUC: Let me give you an example. At a certain point during our treatment in the Netherlands she was pregnant and we went to the hospital three times a week for eight weeks straight. Then afterwards there was an evaluation scheduled and we arrive at the gynaecologist's and he asks 'It went wrong, right?' While we practically lived there for eight weeks!

[...]

CYNTHIA: As a patient you recognize this immediately, you know. Did the physician take a minute to read your file or not? That's the difference when you're not a number. You know you're only one of many, but still, it already is an emotional process.

According to the participants, the consequence of protocol oriented treatment was that patients who differed from standard cases did not get the specific tests and treatment they needed. In some cases, the standard treatment had no chance of success which meant that patients had gone through the disappointment of a failed treatment cycle and lost one of the three cycles that are reimbursed by the Dutch health care system. Several participants voiced frustrations over this.

WILLEM: Exactly. In our case we could have had five more treatment cycles in the Netherlands and there would have never been a pregnancy.

ERIKA: Never.

WILLEM: Because her system blocks it.

ERIKA: Yeah, after our tests here they said 'you had 0% chance of success in the Netherlands'. That hurts, you know.

Many participants complained about how their story in the Netherlands ended. After failed treatment cycles (often the three treatment cycles that are reimbursed in the Netherlands), they were told they had had bad luck, or that 'nature did not want to cooperate'. They felt like they were not informed about what caused their treatment to fail. They felt like they were given up on even though they were ready to continue treatment. Some participants said they had a hard time accepting that someone else had

decided for them that their treatment process would end there. With regard to the age limit, Chloe and Sam were refused another treatment cycle (even though they still had one reimbursed cycle left) because she only produced three eggs after her last stimulation and she was 43.

SAM: You only need one and then you see there is one less than the rule requires, you see, it's just thinking in terms of rules.

CHLOE: Yes, Sam said to me one time 'they are playing God' and I think that's a nice way to put it. That's the way it is. They make this decision even though when David [their first child] was born there were also three eggs.

The participants believed that the reason why care in the Netherlands was often protocol oriented rather than patient-centred was the way the Dutch health care system was structured. Since the privatization of health insurance, medical care was said to be a budget calculation: you have this problem, so you need this treatment at that price. The participants claimed that infertility could be too complex to fit the neat compartments of health insurers. They also felt that cost benefit analyses of extensive testing prior to treatment did not take into account the burden of failed treatment cycles.

BEN: It's simple, no?! Just test us and you can prevent a lot of issues. Even if the results are negative.

VANESSA: At least then you know.

7.3.3 Information

Almost all participants relied on the internet for information about clinics and treatment options abroad. The internet forums of the Dutch patient organization Freya were mentioned explicitly by several patients. Except for the patients who were referred by their Dutch clinic to Ghent because it was the closest IVF clinic, only one couple received useful information from a Dutch physician about treatment options and clinic choice in Belgium. Several patients mentioned talking to their physician about wanting to go abroad, but they all got a similar response: 'ultimately it is up to you, but they cannot do more for you than we can'. Two couples contacted their health insurer for information about success rates and quality of care in different Belgian clinics, but they learned nothing new. Of the eleven couples who did not have a physician as their primary source of information, six reported they had friends or family who also went to Belgium for infertility treatment or came into contact with other cross-border patients through someone in their social life. These first-hand accounts of treatment in Belgium were seen as very important sources of information.

All participants would recommend travelling to Belgium if someone they knew would be in a similar situation. However, for most patients their commitment to information

sharing stopped there because reproduction was a private matter and infertility treatment was a burdensome process they were happy to leave behind. Some participants were already posting their experiences on internet forums or were planning to in order to provide helpful information for future patients. Especially with regard to making practical arrangements with health insurers to secure reimbursement some participants believed they could share valuable insights as many of them had encountered difficulties in that area themselves.

7.3.4 Treatment in Belgium

The core concept describing the experience of the patients during treatment in Belgium was trust. This was largely due to the perception that Belgian clinics were centres of excellence with regard to assisted reproduction. During the first consultation, where previous failures were evaluated and future options were discussed, the feeling of trust was confirmed. The reason why they believed that they were in good hands was the perception that there were more treatment options in Belgium (i.e. assisted hatching, day 5 embryo transfer, different drug treatments, ...), that more tests (extensive blood tests, better ultrasounds) were done, that there was more experience and technical expertise, that physicians took patient input seriously and that physicians made decisions about a specific treatment plan together with the patient.

CHARLES: After our third treatment cycle in the Netherlands they told us 'sorry, that's it for you' and then you arrive here and through thorough testing they find out why exactly it didn't work and if that's something they can treat, then you feel recognized as a patient, like they take you seriously.

All participants explicitly mentioned in some way that they felt good in the clinic. Many patients even referred to this when they were asked if they wanted to add something to the interview at the end. This positive feeling was often not described in more specific terms, but several patients referred to it as patient friendliness or good customer care. Many women explicitly mentioned that the pick-up was less painful in the Belgian clinic. More importantly, physicians were said to be empathic, communicate openly and were willing to make time for questions and niceties. Several participants mentioned that in Belgium midwives were more qualified, which meant that they could answer most questions directly. This was especially appreciated because midwives were more easily accessible than physicians and also available by phone when questions arose after a visit to the hospital. In general, the discourse was that everyone at the clinic was willing to go the extra mile for patients during the burdensome process of cross-border infertility treatment.

VERA: It is a time in your life when you are working intensely towards this goal and well yes, it's just nice here, you feel like everyone at the clinic is here for you.

Most participants opted to do cycle monitoring (ultrasounds and blood tests) in the Netherlands to diminish the need to travel. Because of the conviction that quality of care was higher in Belgium, some patients (one couple and the single woman) preferred to do everything in Ghent, even though this required they drive two to four hours for a five minute ultrasound. For the patients who were referred from the small local clinic to Ghent, clinic cooperation went very smoothly. The other participants had very mixed experiences in that regard. Once they found a clinic or a physician who was willing to cooperate with a foreign clinic, most patients said it all went well. However, some indicated they received spiteful and unfriendly comments about going elsewhere for treatment. Four participants were told in the clinic where they were previously treated that they were not willing to perform tests for a treatment cycle in another hospital and one couple who was never treated in the Netherlands had to contact three clinics to find one willing to help them. Sam and Chloe conceived a child following treatment in a Dutch clinic and had four IVF treatment cycles there.

CHLOE: It's just that in the Netherlands it is hard to find a clinic to do the ultrasounds. I have called different places for hours until I found a place. Hospitals don't want to do that in the Netherlands.

INTERVIEWER: And why?

SAM: Because they are not actually treating you? I don't know why, but it's a little short-sighted.

CHLOE: Not even in the hospital where we've been known for five years, they were not willing.

SAM: It's not the money. We would pay just like that, but still they were unwilling.

[...]

SAM: For me, personally, what really hurt was that they were not willing to do the ultrasound. Five minutes and still refuse, that's just...

CHLOE: Yeah, policy...

7.3.5 Belgium as the next step

Going to Belgium was seen by the participants as the next step in their treatment process. For some it was the logical next step, for example for the patients for whom the Belgian clinic was the closest or the two couples who went to Belgium for TESE and decided to stay in the same clinic for inseminations with donor sperm. Most

participants saw Belgium as the ultimate or final step in the treatment process. In general, the conceptualization of Belgium as the next step transformed the experiences of the cross-border patients.

STEFANIE: 'Go to Belgium, you will succeed there', my mother always said. [...] That's the idea, you know, if you go there it has to work. You definitely get carried away by that.

Cross-border patients potentially face many practical issues, for example making arrangements with health insurers, travelling, having to stay overnight to be on time for an appointment in the morning, taking leave from work and investing time and money. However, because going to Belgium was seen as the next step, these practical issues were seen as part of the deal. It is striking how little talk there was about the financial cost of cross-border treatment during the interviews. Other than what was and was not reimbursed, some people mentioned they were happy they could afford to go to Belgium, but most participants did not talk about costs. The couples who had exhausted their reimbursed treatment cycles talked very little or not at all about the financial burden. The treatment abroad was deemed to be worth all the trouble and the cost.

None of the participants expressed any regrets about their decision, except some regret about not having taken it sooner. Most participants felt like they were taking charge of their own treatment process by going to Belgium. They faced a problem in the Netherlands (a waiting list, perceived incompetence, failed artificial inseminations) and now they were actively working their way around it. Conceptualizing going to Belgium as the next step meant that was a positive choice, which implied that one was partly responsible for all the consequences of this choice.

TIM: Yes, but I also have to say that we actively went looking for a solution to our problem because if you look for a certain recognition of your preferences and well there is a chance of disappointment that it is not available to you nearby, but I think it is an attitude. I think we are very active and keep on looking for solutions.

ELIZE: Of course we would have preferred this kind of hospital to be only half an hour away. Of course this is inconvenient, but it's just the way things are right now. You could ponder over that but it wouldn't change anything.

There was a psychological factor to the idea of Belgium as the ultimate step. It could become easier to stop treatment and to accept that their child wish would go unfulfilled when patients felt they did everything they could. This implied that even if the treatment failed, it was still worth taking this step.

LINDA: Yes, but we had two failed cycles in the Netherlands and then maybe there are more opportunities here and in any case we tried.

KEES: Maybe techniques are a bit further developed here with things they may not yet be allowed to do in the Netherlands.

LINDA: Now we feel like we did everything we could. That's how I feel.

7.3.6 Donor sperm

The participants using donor sperm had all contemplated the difference between identifiable donation and anonymous donation, but the importance they attributed to the fact that Belgium has an anonymous donation policy varied. The two couples in the study wanted to make use of an anonymous donor because they feared third party interference with their family when the child would go looking for the genetic father. The single mother would have preferred an identifiable donor, but she wanted a way around the long waiting list in the Netherlands because she was already 39 years old. None of the participants believed that their choice for anonymous or identifiable donation would have a big effect on the wellbeing of the future child. All participants using donor sperm were telling the same story to their friends and family that they were planning to tell the future child. The single woman and one couple were planning to tell the child about its donor origin and were open about their situation. Fiona and Ronald were not planning to tell the child and told everyone the TESE operation was successful and that they were going to Belgium for ICSI treatments.

7.4 Discussion

The perception of Belgium as the next or ultimate step in the treatment process transformed the experiences of the participants. This idea reinforced bad experiences in the Netherlands and good experiences in Belgium. It served as a justification to invest time and money in cross-border treatment. This means that statements about treatment in the Netherlands and in Belgium should not be seen as necessarily corresponding to reality. For example, throughout the data it was striking how often participants used phrasings (even though they were not used in the questions or the probes in the interview guide) similar to the discourses found on internet forums (Van Hoof et al., 2013). This could indicate that this is the best way to describe the experience. However, it is more probable that most participants formed a certain image of what treatment in

Belgium would be like when they were gathering information on the forums and that this influenced the way they experienced their treatment.

At this point it is interesting to revisit the quantitative data on the motivations of Dutch infertility patients to travel abroad: 53% reported travelling for better quality, 32,2% for legal reasons, 25,5% because of previous failure and 7,4 % because of access difficulty (Shenfield et al., 2010). This data can be combined with the knowledge of the different profiles of Dutch patients in Belgium and the qualitative data from this study (De Sutter, 2003; 2011; Pennings et al., 2009).

Those patients reporting to travel for better quality and previous failure travelled because of the perception that quality of care was higher in Belgium. There is little objective difference between quality of care between Belgium and the Netherlands with regard to success rates and medical expertise. The only difference may be that Dutch clinics discontinue treatment earlier for patients with low chances of success because of age or repeated failure. Some participants suggested that this is the case because of the privatization of health insurance. However, it seems more probable that a difference in quality of care was perceived because of the situation most of these patients were in. When patients travelled a long way and across borders to see a physician, they might get more attention and empathy, especially when they have a long history of failed treatments. Additionally, listening to their history, performing tests and searching for alternative treatment options may provide clarity and answers. The mere fact that a physician is willing to continue treatment when another has given up may also add to a perception of higher quality of care. In that sense, treatment in a Belgian clinic may inherently score higher on all factors of patient-centeredness (e.g. information, communication, competence, attitude, emotional support, ...) in the experience of Dutch patients (Dancet et al., 2011). Previous research has indicated that more patient-centred care alone can be a reason for patients to change clinics (van Empel et al., 2011).

Those patients reporting to travel for legal reasons or because of access difficulty travelled because they felt that they had to go abroad to fulfil their child wish. Because there are few policy differences between Belgium and the Netherlands, it is surprising that almost 40% patients reported this as their reason to cross borders. Presumably these are the patients travelling because of age limits or to avoid waiting lists for a TESE operation or sperm donation. Based on the strong conviction of some of the participants in this study that the Dutch health care system is purely protocol oriented, a possible explanation for this high number may be that patients who travel for assisted hatching or because they suspect immunological or thyroid related problems might report that they travel for legal reasons.

Clinic cooperation is a big help for cross-border infertility patients. The European Society for Human Reproduction and Embryology (ESHRE) confirmed the importance of clinic cooperation in its good practice guide for CBRC (Shenfield et al., 2011). However, several participants reported that it was difficult to find a Dutch clinic or physician who

was willing to help them and were often treated unfriendly during ultrasounds and blood tests. This is in line with the finding from a small qualitative study on the attitude of Dutch gynaecologists towards CBRC: some are not willing to do cycle monitoring for patients who are treated in Belgium (Van 't Hooft et al., 2012). It is hard to understand why certain clinics would refuse to perform a simple blood test or an ultrasound for a treatment that will be paid for by health insurance other than a grudge against a patient who wants to go abroad for treatment. Presumably it is considered bad for business to facilitate cross-border movements for infertility treatment. However, unwillingness to cooperate is at the cost of patient wellbeing and should be condemned as unethical if it is not properly justified. One possible justification for refusing to help a cross-border patient would be that the physician does not want to be complicit in an immoral act. However, most of the Dutch patients who go to Belgium travel for treatments that are very similar to treatment in the Netherlands, so in most cases there seems to be little moral justification for unwillingness to cooperate.

After the change in the Dutch law in favour of identifiable donation, more patients travelled to Belgium to have access to anonymous donor sperm (Ombelet et al., 2007; Pennings et al., 2009). This is true for both couples in this study. Even though identifiable donation is widely supported among people who need donor gametes in the Netherlands, some people still strongly prefer anonymous donation (Brewaeys et al., 2005). Going to Belgium offers these people a way out of the Dutch system. For some patients, however, donor anonymity may be an undesired part of the package in Belgium. The waiting list may be a more important reason to travel abroad than the conviction that using anonymous donor sperm to create a family is better. This was true for the single woman in this study and the same has been suggested in a qualitative study of UK patients (Culley et al., 2011).

7.5 Conclusion

Dutch infertility patients who travel to Belgium for treatment travel primarily because of the perception that quality of care is higher in Belgium. Because of this perception, treatment in Belgium is seen as the ultimate step in the treatment process. This conceptualization in turn transforms the experience of the treatment to confirm the higher quality of care. While success rates and medical expertise are similar in Belgium and the Netherlands, the only objective difference in quality of care may be the fact that Belgian clinics are generally willing to continue treatment after the Dutch system has given up. Additionally, cross-border patients describe care in Belgium as more patient-centred.

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Chapter 8 Cross-border reproductive care for law evasion: a qualitative study into the experiences and moral perspectives of French women who go to Belgium for treatment with donor sperm

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8.1 Introduction

Cross-border reproductive care (CBRC) is a growing worldwide phenomenon where infertile patients travel across borders to obtain treatment abroad (Gurtin & Inhorn, 2011). Pennings et al. (2008) list the main causes of CBRC: a type of treatment is forbidden by law (e.g. sex selection, anonymous gamete donation), certain categories of patients are not eligible for assisted reproduction (e.g. lesbian couples), the waiting lists are too long in one's home country (e.g. oocyte donation), the out-of-pocket costs for the patients are too high (e.g. absence of insurance), a technique is not available because of lack of expertise or equipment (e.g. preimplantation genetic diagnosis), a treatment or technique is not considered safe enough (e.g. cytoplasm transfer) and personal wishes (e.g. privacy considerations). In general, the different causes of CBRC can be divided into two groups: legal restrictions and availability of good quality care. We define CBRC for law evasion as movement across borders to obtain infertility treatment that is forbidden in the home country or that certain categories of patients are denied access to.

CBRC for law evasion is made possible by legal diversity with regard to assisted reproduction. One of the consequences of imposing restrictions within such an international patchwork of radically different policies is that patients always have the option to go abroad to evade them. For example, after the restrictive Italian law was enacted in 2004, 'reproductive emigration' quadrupled (from 1066 in 2003, to 4173 in 2005) (Ferraretti et al., 2010).

CBRC for law evasion is a common phenomenon in Europe. The largest study to date found that 54.8% of patients travelled for legal reasons, resulting in a conservative estimate of 8000 law evading cycles across Europe annually (Shenfield et al., 2010). French patients constitute one of the largest groups in the study, with most of them travelling to Belgium. Belgium is a popular destination country for infertility treatment, because of its central location in Europe, liberal legislation and several highly reputable clinics. Between 2005-2007, 2.288 French women received infertility treatment in Belgium (Pennings et al., 2009). This number is likely to be higher now. The overwhelming majority of French patients who travel to Belgium are lesbian couples and single women who are denied access to treatment with donor sperm at home (Pennings et al., 2009; Gomez & de La Rochebrochard, 2013). Recent changes in the French laws on gay marriage may influence the flow of French women to Belgium in the future because lesbian couples now have the right to adopt a child, giving them the

chance to start a family in France. However, they still have to travel abroad if they want a child that is genetically related to one partner or if they want to experience pregnancy because they do not have access to treatment with donor sperm (Loi n° 2013-404 du 17 mai 2013).

In France, assisted reproduction is intended to respond to the desire for parenthood of a couple, consisting of a man and a woman. Assisted reproduction is considered to be a medical treatment intended to remedy infertility, the pathological nature of which has been medically diagnosed, or to prevent the transmission to the child or to one of the members of the couple of a particularly serious disease. Lesbian couples and single women are not infertile for medical reasons and hence they are denied access to treatment with donor sperm.

This is the first qualitative study looking into the experiences of French women who travel to Belgium for treatment with donor sperm. Culley et al. (2011) described the experiences of UK infertility patients who travelled abroad. The main motivations for travel among these patients were the long waiting lists due to a shortage of gamete donors in the UK. Zanini (2011) gave an ethnographic account of CBRC for law evasion by Italian patients, indicating that these patients feel abandoned and betrayed by their home country and that they see their decision to travel abroad to evade the law as embodied dissent and the affirmation of a different morality. Bergmann (2011) identified the experiences of three German couples who travelled abroad to evade the ban on egg donation as reproductive agency. He described these patients as “some kind of ‘moral pioneers’ in circumventing and overriding national regulations and ethical dilemmas” (Bergmann, 2011). In the present article the focus is on the experiences and moral perspectives of French women who go to Belgium for treatments with donor sperm.

Infertility treatment is a burdensome process (Boivin et al., 2012). Having to deal with the practical issues related to crossing borders for treatment adds even more stress to the process. In practice, treatment with donor sperm is a lengthy process consisting of a general appointment with a physician, counselling by a psychologist, usually mild hormonal stimulation, blood tests and several ultrasound exams to monitor the cycle, the insemination of the donor sperm and ultimately a pregnancy or, in most cases, another insemination or IVF as the next step. For cross-border patients each step in this treatment process involves additional challenges, especially when they are evading the law of their own country. In this article, we aim to identify these challenges and the way in which patients cope with them.

8.2 Methods

We gathered data about 11 French lesbian couples and two single women. Most couples were interviewed together. In two cases only one partner was present, but specific questions were asked about the other partner's experiences and perspectives. The participants were purposefully sampled to ensure that many different profiles of patients were represented. The women were recruited at the department of reproductive medicine at Ghent university hospital. This study was authorized by the ethical committee of Ghent University Hospital (EC: 2011/865) and all participants provided written informed consent. The women were interviewed after their insemination or embryo transfer. This is a relatively short procedure that represents the potential endpoint of treatment in the clinic. After the interview, the women were given pseudonyms to ensure anonymity.

The interviews were conducted by the first author between June 2012 and May 2013. Before the interview, in the informed consent form and through oral communication, as well as during the interview, it was repeatedly made clear that the interviewer did not work at the hospital and that the participants would be anonymous. The semi-structured interviews started with very open questions about the participants' reasons to go to Belgium. After that, a timeline was constructed using post-its which remained in the middle of the table during the interview to remind participants of previous experiences. Next the questions focussed on their experiences and practical issues. Their moral perspectives were subsequently questioned using fictitious declarations from other women who had gone to Belgium for infertility treatment. Finally, we asked about their own experiences in moral areas like gamete donation, legal recognition of the second mother and the wellbeing of the future child.

The interviews were transcribed by the first author, read in detail and analysed with Nvivo using inductive thematic analysis (Braun & Clarke, 2006). Initial codes were gradually combined to form initial themes inductively to ensure that proper attention was given to relevant data not directly asked for in the interviews. The emerging themes were continuously reviewed to see if they worked in relation to the coded extracts and the entire data, gradually developing a thematic map of the data. The links between the themes were explored revealing both the meaning of the themes as well as their relationship with one another. The final thematic map was discussed between the three authors, checking definitions, content and interrelationships until consensus was reached.

8.3 Results

After presenting the participants and their reasons to travel abroad, we will focus on their perspectives on the role their home country played in what some women called their 'baby project'. We will describe how they felt about the French law and society and what their perspective was on their reproductive rights in relation to the French policy. Then we will explore their moral perspectives on the issues of legal recognition of the second mother and the wellbeing of the child. After describing the meaning of CBRC for law evasion for the participants and their feelings and perspectives on the matter of legal and moral diversity with regard to their private life, we will describe their experiences by looking at the main challenges they faced and at the strategies they developed to deal with them.

8.3.1 Participants

Data was gathered from 11 lesbian couples and 2 single women. The average travelling time for the participants from their home to the clinic was 3 hours (range 1-7 hours). The average age of the inseminated woman was 35,5 (range 25-42), the average age of the partners 33,3 (range 23-42). Eight couples were living in a civil solidarity pact (PACS). All but one couple intended to marry when gay marriage became legal in France. Three women already conceived a child. One woman had a child in a previous relationship. One woman already had a child in the current relationship and her partner was being inseminated now. One woman conceived a child in this relationship and was being inseminated again. Her partner had seven failed inseminations trying for their second child and was advised to move on to IVF but did not want to go through that stressful process. The single women were 39 and 42 years old, edging towards the end of child bearing age as becoming a single mother by choice was their 'plan B'. On average, the women had 4 inseminations before this one (range 1-8), two couples were in the process of IVF.

8.3.2 Reasons to travel abroad

The primary reason to travel abroad was straightforward for every woman: because they were denied access to treatment with donor sperm in France. In fact, this was the only answer women gave when asked about their reasons directly. Proximity was only

mentioned as a secondary reason, usually when asked about their reasons to travel to Belgium and not some other country. Most women said they considered Spain and Belgium, but decided on Belgium based on cost and proximity. Interestingly, in that narrative the women thought it was important that the best clinics for reproductive medicine in Belgium were university hospitals, which are not primarily commercially oriented. Several women had read stories online of women who went to Spain and were treated in an unfriendly way, overstimulated and insufficiently informed. They attributed those stories to the commercial nature of the fertility business in Spain. The specific situation of these women may give them a special view on treatment with donor sperm: these women are not technically infertile, they just had no male partner. When asked about their reasons to go to Ghent University hospital specifically, several women indicated that it was very important for them to be able to start treatment with donor sperm without hormonal stimulation, 'as natural as possible'. According to the participants, most other clinics require that the hormonal cycle is mildly stimulated before inseminating a woman with donor sperm. Most women also thought it was important that there was no waiting time in the clinic, indicating that once the decision had been made that they wanted to have a child, they wanted to be able to start treatment as soon as possible.

8.3.3 Moral perspectives on society and the rights of homosexual couples

The women developed a complex narrative about the role of their own country in their 'baby project'. The interviews took place at the time when the policy on gay marriage was being debated in the French media and politics. The question whether gay couples could be parents was part of that debate. As is often the case when legislation on private and family life is at stake, some extreme opinions were voiced and the discussion was highly polarized.

Roxane: Let me tell you a story. This was on the radio a couple of weeks ago. So they were talking about gay marriage and there was this mother from a small town who said 'if we allow gay marriage, we will be allowing incest soon'.

Liliane (shrugs): There's no winning that kind of discussion.

It affects a person when they are in the process of doing exactly that which is vehemently criticized in public by many. However, the general tone of the discussions was that even though they considered France to be a conservative or even retrograde country, things are slowly moving in the direction of more tolerance towards gay marriage. Support for gay family formation was seen as the next step. The women held

that French society is ready for these changes, but religion, politics and the law still lag behind.

The main problem most women had with the current policy on treatment with donor sperm in France is that they are discriminated against. They felt that their basic right to reproduce is not recognized and they indicated several inconsistencies in the French policy to support that claim. They had a problem with what they saw as the foundation of the French policy:

Zoë: In the end I think in France people still think you are homosexual by choice. And if you make this choice, you accept not to have children and all that...

However, they believed being homosexual is not a choice, but an important part of a person's identity. Therefore their rights should be recognized and protected.

Jacqueline: They don't recognize our child wish, not in France at least. Because of our sexual orientation we do not have the right to have children.

So yes, I agree, they fail to recognize our wish. I would even say more

Germaine: The wish is not what is really important, it's the lack of recognition of who I am.

Jacqueline: Yes, of our identity. And maybe even that people see us as bad parents because we are not a couple like everyone else.

They believed these are the inconsistencies in the French policy: we pay our taxes like everyone else, but we are not entitled to the same reimbursed medical treatments; a heterosexual couple on the verge of a separation can get treatment but we cannot; we are allowed to have children as long as we conceive abroad. In general, these women did not describe feeling betrayed or abandoned, it was more fundamental: they felt that they never even entered the equation, that they were left aside. When asked if they were going to take action to change things in France, the narrative was that they would not or could not change anything if they tried. In private, they would all help their friends find their feet in their baby project and some women already shared or were planning to share their story on internet forums. In public, most women merely voted for the presidential candidate who supported gay marriage and signed a petition if it came their way, but they were not inclined to take part in some or another form of public protest about a private matter like family formation.

The only option for these women to conceive in France was to find a sperm donor outside the system, but that meant they would also lose the protection that is guaranteed by the system. They feared the lack of a proper medical screening process for the donor, but most importantly for them was that a third party would be introduced, while for the lesbian couples the baby project was just between them. In

that regard the single women argued: if there had been a man I wanted to have a child with, I would not be here.

These women would rather have had access to treatment at home and they felt marginalized and discriminated because they had to go abroad to fulfil their child wish. They were doing something highly personal and they were fragile and vulnerable having to do this by evading the law of their own country.

Germaine: It's going to be complicated to explain all this to our child. Why did we have to go abroad? Because in France they don't accept that we have children. It's even more difficult for them to understand this. It's true that they are talking and it's slowly changing, but for her [Jacqueline and Germaine already have one child], ... maybe she will say that if we had to go abroad, it's because we should not have children.

Although they had to resort to CBRC for law evasion, all women expressed a sense of happiness or relief about still having options to conceive a child in a clinic using donor sperm. The women were happy that they could travel to a neighbouring country. The different attitudes towards lesbian parenthood in other countries were often used to justify the law evading project and to indicate that the attitudes in France were retrograde and conservative.

When they came to Belgium for treatment with donor sperm, these women were not treated in a special or unusual way. They did not represent difficult cases from a medical point of view and the clinic had no moral objections to lesbians or single women becoming parents. Most women explicitly mentioned that they appreciated that they were treated as a standard case. From their perspective, this validated their baby project.

Liliane: I think we cannot stress enough how appreciative we are about Belgium offering us this option. For all lesbian couples. They make this gesture and all these women get mobilized and the physicians here are very progressive and we're treated like anybody else, not like we're sick. I'm really appreciative and I think the main reason we pulled through all the challenges is because we were treated so good here.

Roxane: We're not treated like aliens when we arrive here (laughs).

8.3.4 Moral perspectives on the second mother

Because lesbian parenthood is not supported in France, there is no framework for a family with two mothers. This means that legally the family is seen as a single mother and her child. The lack of legal recognition of the second mother was an issue all

couples felt very strongly about and they devised different ways to cope with it. On a personal level, the lack of recognition confronted them with the fact that they are not normal, that their family is not automatically entitled to the same treatment as heterosexual families. Zoë and Yvonne already had a child and experienced what the lack of recognition can mean.

Zoë: Well, for the moment she is young, so the problems do not really arise yet. But the lack of legal recognition, it's hard for Yvonne. When she wants to leave the country with our daughter, she needs special permission because she is not recognized as a parent. When she wants to pick her up from school she needs a piece of paper. It's those things. For example, she wanted to pick up our daughter's ID so we could travel to the US but they did not want to give it to her, because she was not the mother. Those things hurt a lot.

Even though both mothers always intended to play an equal role in the education, legal recognition of the second mother is more than just a piece of paper. In the end it was about legitimizing the family and protecting the rights of the second mother.

Nadine: I think it is important to show to the child, like, this is it, two parents, it's written, it's official, that's it. It's just, I think that would help him construct, I don't know, it's important for that also.

Interviewer: So it's not just a piece of paper?

Anne: It's the history of the child.

Nadine: It's the history and it's the legitimacy of the family and that's important. And in daily life Anne should have the same rights I have with regard to the child.

The practical problems that arose from the lack of recognition that concerned these couples the most were situations in which something bad (accident, death) happens to the genetic mother or the child. In that case, the second mother has no right to make medical decisions about the child and does not automatically become the legal guardian. The only way to make sure that does not happen is to start an adoption procedure, but that is a long and expensive road and in the past there was no guarantee it would work. The couples very much hoped the new law will change that.

The couples developed several strategies to cope with the lack of legal recognition. They looked for schools that were open minded about same sex families and would recognize the second mother. They added the name of the second mother to the birth certificate. This had no legal value, but it had symbolic meaning. They made arrangements within the family in the hope that matters like inheritance, medical decision making and guardianship would be taken care of when something bad would

happen. However, in the end they always had to rely on the willingness of others to recognize their family.

8.3.5 Moral perspectives on the child

All the women were very clear about how they would deal with their (future) children. They would always be as open and straightforward as possible. They would start telling the child about its donor conception early on, either when the child starts asking questions or when it is old enough to understand. Many women were planning to bring their children to Ghent someday to show them the city where they were conceived. Some were even keeping a diary with pictures of the city and the clinic. Many women thought it was important that the child would have a fitting life story.

Nicole: I'm not going to tell him he dropped from the sky in a ray of light (laughs). No, of course you have to create a story. I imagine telling him like there was a kind man who gave a present or something like that. [...] Maybe I could write a little story, because I write and I draw a little.

None of the women expected any difficulties with regard to the wellbeing of the child from within the family, but some were afraid of negative reactions from outside the family. This was seen as an additional reason for being open with the child, so that it would be confident and knowledgeable when challenged by other children or when facing a difficult situation.

8.3.6 Challenges: information

When these women made the decision to have a child, they needed to find relevant information about treatment with donor sperm. Because there were no official sources of information due to the legal restrictions, these women relied heavily on the internet. The women in our study usually received their information directly from friends who conceived in Belgium or from internet forums where women in similar situations shared their experiences. When they asked their general practitioner or gynaecologist about advice concerning clinic selection, none of them were willing to help. Some physicians were willing to inform them about the medical side of treatment with donor sperm, but none were willing to refer patients abroad or even inform them about the different practices in countries or clinics. Some women indicated that they provided their French physician with information about their treatment rather than the other way around. Some women scheduled appointments at different clinics in Belgium to

obtain information about treatment cost, waiting time and treatment options like hormonal stimulation and use of anonymous sperm donor.

8.3.7 Challenges: absence from work

The process of treatment with donor sperm requires several visits to the clinic. Before the actual inseminations start, the intake consultation with a physician and the counselling by a psychologist can be planned, but the insemination has to take place at the time of ovulation. If there are no hormonal stimulations, the exact timing of the insemination can vary significantly. In practice, these women only knew when exactly they had to be in the clinic one or two days in advance. They usually had to take a full day off due to traveling time. Several women struggled with this because they did not have flexible working hours and it was hard for them to make arrangements on such short notice. The reason why sometimes the partner could not be present at the insemination was because she could not justify her absence from work. Many women had not told their superior about their project, either because they feared their career would suffer if management knew about their plans to become pregnant or because they did not have a personal relationship with their employer. Because they were going abroad for law evasion, they were not entitled to a medical leave of absence. However, a few women managed to find a highly supportive physician who was willing to justify their absence from work. This was generally seen as a last resort. Most of the time the women tried to arrange for colleagues to cover for them or made up an excuse.

Hélène: With work too, yeah, there are challenges, I mean, you need sick leave and you know

Interviewer: And that works out? You...

Hélène: We have a supportive physician

Rachel: He makes them believe we are sick.

Hélène: We're both teachers, we can't be absent from work just like that. This time we're lucky it's a holiday.

8.3.8 Challenges: medical treatment

One treatment cycle consists of one or several ultrasound exams and blood tests to monitor the cycle, possibly hormonal stimulation and the actual insemination. To reduce the need to travel, cycle monitoring is done in France. This implies that the women need to find a physician who is willing to help them evade the law of their own

country. Some women did not find such a physician and had to go to a local hospital where they would not ask too many questions or where they assumed they were heterosexual women in treatment abroad. All women who found a physician who sympathized with their case said that it was very important to have that kind of support. This physician even gamed the system for them: everything that was done in France could be reimbursed, even expensive hormonal drugs, if the physician filed the paperwork the right way. Additionally, they felt it was comforting to have someone close to home who knew about their situation should complications occur and who would follow up the pregnancy if treatment proved successful.

Liliane: We're not dogs, you know, we pay for our consultations. You need that. To be able to call a gynaecologist and be honest with him and then... but there are those who say no. And I don't know why they don't want to help. I pay for my consultations! Sure, you need to follow the law technically, but then there are still things you can do.

There were three different positions French physicians took when they were asked to assist patients through CBRC for law evasion: they refused, they agreed to follow the pregnancy but not to take an active part in the treatment (sometimes they do accept to do cycle monitoring) or they supported the baby project completely and gamed the system for the patient. Of the thirteen women who were being inseminated with donor sperm, four were being followed up by their general practitioner or had already contacted a gynaecologist to follow the pregnancy. Two of these women reported that they did not feel supported by their physician, who only helped reluctantly and explicitly mentioned not being comfortable doing so. They preferred going to the local hospital for their cycle monitoring. Nine women found a supportive physician who was willing to game the system for them. Several women reported encountering negative reactions from physicians in their search for a supportive one. The women who visited the local hospital also reported mixed reactions from different physicians, ranging from supportive small talk to insinuations about their unethical behaviour. When a physician refused to help them in any way, the women experienced this as betrayal and stopped going there altogether.

Sandrine: The gynaecologists, they don't all agree [with what we're doing]

Marie: But we were lucky. He agreed and even prescribes us, you know, for reimbursement.

Interviewer: So you had no difficulty finding a physician to help you in France?

Marie: We were lucky, the first one we asked.

Sandrine: Gynaecologist, yes, general practitioner, ...

Marie: General practitioner no.

Sandrine: Our general practitioner refused.

Marie: Yes, he refused, so we're looking for another doctor. We're not seeing him anymore (laughs).

8.4 Discussion

There is much diversity in the lesbian participants: there are couples who already have a child, there is a couple who came for their first insemination and a couple who had seven inseminations and two IVF cycles. This means that many different perspectives on CBRC for law evasion are voiced in the study. The main weakness of the study is that there are only two single women who participated, but they represent only a small part of French women who go to Belgium for treatment with donor sperm.

The most important factor that determines the experiences of these women is the help from a supportive physician at home. This confirms the importance of cross-border cooperation between physicians that has been advocated as good practice in the case of CBRC (De Sutter, 2011; Shenfield et al., 2011). In the case of CBRC for law evasion, the patients face several additional challenges like gathering reliable information, justifying absence from work and ineligibility for reimbursement, but when they find a supportive physician these challenges are manageable. However, from an ethical point of view serious questions can be asked about practices that game the system. To preserve the integrity of the system it is only justifiable for a physician to game the system for the benefit of a specific group of patients if the system is flawed (Tavaglione & Hurst, 2012). Additionally, only those women who were able to find a physician who was willing to game the system for them would obtain partial reimbursement, which is unfair.

Most of the participants were convinced that the French policy on treatment with donor sperm for lesbian couples and single women would change in the near future. However, they did not want to wait for that to happen. In the case of the single women their age was the main motivator, but for the lesbian couples it seems that having a child wish also implies a sense of urgency to act upon it. Their reproductive project requires more attention because they need help from a third party and maybe discussing this as a couple triggers a need to act when a decision has been made. These women were willing to cross borders, evade the law of their own country and face various practical difficulties to be able to access reproductive treatment right now.

The actions of French women travelling to Belgium for treatment with donor sperm can be characterized as reproductive agency. The data from the interviews shows that this concept should be broadened. Previous research mainly focussed on the travelling

and the medical treatment (Bergmann, 2011; Gurtin & Inhorn, 2011). However, there is more to reproduction than conception. The participants were actively trying to find ways to create a family. They confirmed the importance of the second mother in many ways. They insisted that their child will be raised in an open, honest and supportive environment. On the one hand, they aspired to be a special kind of normal family. Such strategies have been identified before. The importance of the presence of the second mother at the insemination and the preference for anonymous donor sperm reinforce the idea of the couples as full partners in the baby project (Nordqvist, 2012a; 2012b). Naming the children and getting official parental authority for the second mother can be a symbolic way to create kinship (Cadoret, 2009). The civil solidarity pact can be used to normalise the family (Rault, 2005). On the other hand, several women were reluctant to share their plans to create a homosexual family at work and almost all couples feared negative reactions to their future family. Creating a family increases the visibility of the lesbian couple (Nordqvist, 2012b). Especially in a country where the laws try to restrict homosexual family formation, successful conception abroad brings the disobedience out in the open. In general, however, none of the women reported big problems among their friends and family and their fear of negative reactions stemmed from expectations of a distant future or from hypothetical situations. These potential difficulties could once again be used to enforce the idea of a normal family, as members of any family have to support each other through difficult times.

Whereas Zanini (2011) described feelings of abandonment and betrayal in Italian patients who could not conceive a child at home due to legal restrictions, the women in this study mainly felt discriminated against. The difference may be that in Italy certain treatments are forbidden for moral reasons the Italian patients disagree with, whereas in France the treatment is available for others, but lesbian couples and single women are denied access. The French women feel their basic right to reproduce is not respected because of who they are or because coincidentally they did not find a male partner.

Since the change in the French law, French lesbian couples have been asking the clinic to provide documentation stating that they received treatment with anonymous donor sperm in the clinic as a couple. They hope such documents will help them adopt each other's child. It will be interesting to see how CBRC in France evolves with the new law in place.

8.5 Conclusion

The results from the study confirm that it is very important for cross-border infertility patients to have a supportive physician at home, even more so when they are evading the law of their own country. The treating clinic should recommend that foreign patients look for a supportive physician at home. For the local physician who is helping a patient evade the law of their own country a range of ethical issues arise, especially with regard to gaming the system to get partial reimbursement for the patient.

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General Discussion

The right to reproduce

Other academics working on CBRC have referred to our work as ‘championing the rights of patients’ (Storrow, 2012). Indeed, the infertile person’s right to reproduce has been at the core of our reflections about the ethical problems related to CBRC. In most cases, people do not want to go abroad for infertility treatment. CBRC is an endeavour: it is not easy to make practical arrangements, it can be expensive, it is burdensome, ... On the one hand, it would not be necessary to go abroad for treatment if every country in the world allowed every ART for everyone. On the other hand, reproduction is both personal and social, and because of the social aspect of creating a family, society has a right to interfere. There are some strong moral convictions about family building, the moral status of the embryo, the welfare of the future child, etc. that influence the regulation of ART. The question is to what extent it is justifiable to disagree with these convictions. In the answer to this question, the infertile patients are the most important party: it is their life, their future which is at stake. Therefore, we believe that the starting point for reflection on the ethical problems related to CBRC should be the right to reproduce for infertile persons.

Throughout this dissertation we have defended most forms of CBRC by arguing that the ethical problems associated with them can be managed. We have argued that moral pluralism with regard to ART is defensible (Chapter 2), that good regulation and responsible clinical practices can limit risks and challenges for local and foreign patients (Chapter 3 & 5) and that the right to access ART should be protected from arbitrary interference (Chapter 4). The moral evaluation of CBRC depends partly on the importance of the right to reproduce since CBRC enhances reproductive autonomy when people have the option to go abroad to create a family.

The right to reproduce for infertile persons

Robertson (1994) argued that the principle of procreative liberty (the freedom to decide whether or not to have offspring and to control the use of one’s reproductive capacity) should be the foundation of the ethics of ART because of its central importance to individual meaning, dignity, and identity. There are two interrelated aspects to this claim: to be free (i.e. to be able) to reproduce is fundamental to what it means to be human (individual meaning and dignity) and reproduction is an important life choice for autonomous persons (individual meaning and identity).

Following Robertson’s argument, reproduction should be regarded as a basic human capacity and a human right. For example, Nussbaum (2000) included the ability to reproduce in her list of fundamental human capacities. For infertile persons, the

question is whether they can claim a right to ART. Daniels (2008) argued that persons can claim a right to basic health care because it ensures normal species functioning. The question is to what extent being able to reproduce is part of normal species functioning. Being infertile does not cause physical pain or an inability to act (cf. medical definition of health), but creating a family can be a vital part of a normal life (cf. social definition of health). This opens up the discussion about the right to reproduce to what constitutes a normal or a good life. A consensus appears to be developing in European countries that a number of morally accepted infertility treatments should be reimbursed. This indicates that infertility ranks high as a health care issue (Pennings et al., 2008). A broad conception of the right to reproduce for infertile persons can be justified on the ground that reproduction is an important part of human life.

In a weaker version of the argument, reproductive autonomy is used as an argument to make ARTs available as long as the rights of others are respected (Brock, 1996). What is the harm in allowing infertile persons to become parents if nobody else gets hurt? This balancing act between the right to reproduce of the infertile person and the rights of others may lead to different outcomes in different situations. Hence the legal and moral diversity across the globe.

The right to reproduce across borders

We believe that as long as other people are not significantly harmed, infertile persons should have the right to go abroad to fulfil their child wish. The first question is what constitutes significant harm. Some argue that the welfare of the future child may be compromised when they find out that they are the product of a cross-border arrangement in a moral grey area like international commercial surrogacy (Blyth & Farrand, 2005). Others focus on rights violations of egg donors or surrogates (e.g. Palattiyil et al., 2010; Pfeffer, 2011). The importance one attributes to the right to reproduce of infertile persons will determine whether or not certain treatments are acceptable. When the right to reproduce is recognized as an important right, CBRC enhances reproductive autonomy and most of the negative effects can be managed.

In CBRC for law evasion, there is a clash between those who believe that common morality dictates that certain ARTs should be forbidden and those who argue for moral pluralism with regard to ART. For example, reproductive travellers have been described as 'buying their way out' of ethical or moral choices given legislative force in their own country (Hervey, 1998). CBRC for law evasion has been described as against 'the spirit and essence of the law' (Heng, 2006).

We would argue that there is a certain truth in these statements, but they do not show that CBRC is immoral by definition. Even if the law is morally justified, circumventing it may be justifiable as well. For example, a 39 year old woman who lives

in a country where an identifiable gamete donation system is in place can justifiably choose to go abroad to make use of anonymous sperm when the waiting list for donor sperm is two to three years. The right of the future child to know its genetic origins may not outweigh the right of the woman to timely treatment.

On a more fundamental level, moral pluralism is warranted in the case of most forms of CBRC because there are many morally defensible positions where reasonable welfare and basic rights are guaranteed for all parties involved (Chapter 2). The complexity of different ARTs, different situations and different stakeholders across borders invites the moral pluralism in motion that CBRC can offer as long as minimal standards of safety and quality of care are imposed.

Cross-border reproductive care

Many of the positive and negative effects of CBRC depend on the moral position one takes. For example, more reproductive autonomy may be a good thing in the eye of someone who supports a broad conception of the right to reproduce but a bad thing in the eye of someone who believes that CBRC offers infertile persons the option to circumvent righteous limits on ART. Here, we will focus on the positive and negative effects of CBRC for patients, the extent to which patients should be held responsible for these effects and the effect of CBRC for law evasion on national policies on ART.

The positive and negative effects of CBRC for patients

CBRC has both positive and negative effects on most aspects of infertility treatment. Throughout this dissertation we have argued that the negative effects of CBRC for patients can be managed (Chapter 5 in particular). It is certain that legal diversity and differences in cost, waiting times and quality of care will continue to exist across the world and that infertile patients will continue to cross borders in response to these differences. The development of good practice guides (e.g. Shenfield et al., 2011) and international standards of care will hopefully reduce the scandals and misconduct that CBRC has often been associated with. We consider CBRC to be a positive phenomenon.

One of the earliest critiques of CBRC was based on justice with regard to access to ART: only rich people can afford to go abroad for infertility treatment (e.g. Hervey, 1998). However, CBRC may actually increase justice with regard to access to ART since some patients cross borders for infertility treatment because it is too expensive in their home country. When health insurance is portable across borders, going abroad is an

option for every patient. Within the European Union the directive on the application of patients' rights in cross-border health care (2011/24/EU) enforces reimbursement for treatment abroad up to the amount the patient would have been entitled to for the same treatment in the home country.

Waiting lists are an important motivation for patients to cross borders. Especially older women, whose chances of becoming pregnant are diminishing as time goes by, may be highly motivated to receive timely treatment. The option for patients to go abroad should not be seen as a solution to the problem of waiting lists by regulators and an influx of foreign patients should not lead to additional waiting time for the local population. For patients, however, going abroad is a way to avoid a waiting list.

The commercialization of health care and increased patient mobility have led to a situation where some patients compare quality of care in clinics around the world. For patients, the feeling that they are receiving the best possible care may influence the way they experience the treatment and their infertility (cf. Chapter 7). As long as there are large differences in quality of care between clinics with regard to success rates and patient centeredness, infertility patients will travel long distances to maximize their chances of achieving a pregnancy.

The most important negative effect of CBRC is the added burden and the difficulty to deal with complications. These effects are partly manageable through good clinic cooperation, but mostly this is the trade-off for infertile patients: it is up to them to decide whether the benefits of going abroad for treatment outweigh the difficulties. Judging by the number of patients who make the journey, the positive effects outweigh the negative effects.

The responsibilities of the cross-border patient

We wrote about the effects of CBRC in the destination countries (Chapter 3) and about the responsibilities of physicians (Chapter 3 & 5). One question we have not fully answered is to what extent the cross-border patients are themselves responsible for the effects of CBRC. Snyder et al. (2011) argue that patients have a social responsibility for the functioning of their domestic healthcare system and that medical tourists extend this responsibility to the health system of the country to which they travel. This question is relevant on a group level: what is the responsibility of the cross-border patients for the effects of CBRC on the destination countries? The question is also relevant on an individual level: some of the outcomes of CBRC (for example, stateless children after international commercial surrogacy, multiple pregnancy, exploitation of egg donors and surrogates) can be a consequence of the decision making process of the patients.

With regard to the social responsibility of cross-border patients, it is necessary to make a distinction between interventions that are or should be covered by a decent health care scheme and interventions that are not covered by such scheme. A country has the responsibility to organize health care on its territory to guarantee access to decent health care for all. We have repeatedly emphasized that if every country in the world would provide good quality infertility care as a part of basic health care, there would be much less need for CBRC (Chapter 4 & 5). If the home country does not provide decent infertility care for all, the home country, and not the infertile person going abroad, is responsible for the cross-border movements. Examples of problems that are the responsibility of the home country include long waiting lists, substandard care and unjustified limitations of access to ART. In these cases, an infertile person has no choice but to go abroad. For elective treatment, the responsibilities for potential harms fall on the cross-border patients, but if a particular infertility treatment is considered to be elective treatment, there is also little harm in crowding out the local population and little chance of destabilizing the health care system in the destination country.

On a micro level, cross-border infertility patients are responsible for their own treatment. The ultimate decision about a treatment plan should always be theirs. However, infertile persons crossing borders for treatment may travel long distances, may have a history of previously failed treatment cycles or experience a sense of urgency which could lead to irrational decision making. Physicians (and preferably also specialized counsellors) should inform patients about the risks of certain treatments (like multiple embryo transfer and visa problems for the child after surrogacy). In general, the clinic in the destination country should apply the same standard of care to local and foreign patients (De Sutter, 2011; Shenfield et al., 2011). Cross-border patients have an important responsibility to refrain from participating in immoral practices that could lead to exploitation of egg donors and surrogates. It may be hard for patients to know when there is such malpractice, but oftentimes the reputation of clinics and countries can provide a first indication.

CBRC for law evasion and national policy making

In general, we agree with Storrow's (2010) assessment that there is a pluralism problem in CBRC if the effect of CBRC for law evasion on national regulations is that they become more restrictive because patients always have the option to go abroad. Storrow argued that this option lowers internal pressure and hampers organized resistance against restrictive laws.

For organized resistance to the law to develop, it is necessary that people are willing to go public with their struggle with infertility or with their homosexuality. Because reproduction, infertility and sexuality are all part of private life, it is not self-evident

that people who are affected by restrictive policies on ART resist them, even though they may feel very strongly about it. Cross-border movements to evade the restrictions may be seen as a form of resistance, but they may be invisible because of the private nature of reproduction (Pennings et al., 2008). Moreover, cross-border patients do not generally identify as a group, even though they have shared experiences (Hudson & Culley, 2011). There are many arguments to support the claim that the opportunity for patients to go abroad for treatment hampers organized resistance to the law.

In our interview study, we asked cross-border patients whether they were doing or were planning to do something to change the situation in their home country (Appendix I, question 12). Most participants indicated that they would be happy when they would finally be able to move on and were definitely not planning to partake in any public resistance. All participants said they would be willing to help someone in their environment, but the French women believed that it was just a matter of time before public perception caught up to their view on ART and most participants said that it would not make a difference if they would take action. However, some participants were sharing their story on internet forums and helping other people in their situation about practical matters. One Dutch woman even wrote a letter to her clinic explaining why their rules had cost her three reimbursed IVF cycles with no chance of success and telling them that in the future they should perform more tests before starting IVF treatment. One French woman had started a mailing list to garner support for recognition of the second mother in lesbian families. Several respondents indicated that they participated in the study to help people who will be in the same situation in the future. Our interview data suggest that cross-border patients do care about the situation in their home country and that not all patients are satisfied because they had the option to go abroad. Moreover, some patients who went abroad will advocate the better practices there on the internet (c.f. Chapter 6). In all, however, it is still likely that the option to go abroad decreases internal pressure on restrictive laws.

There is an important difference between justified and unjustified restrictions in legislation about ART. The importance of the right to reproduce implies that restrictions on ART cannot be arbitrary, but should be thoroughly justified. For example, justice considerations about allocation of health care resources, concerns for the welfare of the future child or strong beliefs about the high moral status of the embryo can ground morally defensible and consistent restrictions on ART. When there is less internal pressure on restrictive legislation because those who disagree go abroad, it is also less likely that unjustified restrictions are challenged. This was the main reason why we were disappointed with the decision in *S.H. v. Austria*: the court clearly indicated that the law was unjustified, but the Austrian government was not compelled to change it. Moreover, while the case was an opportunity to remedy the pluralism problem in CBRC through judicial review, the court explicitly referred to the option to go abroad as an argument to keep the restrictions in place. CBRC for law evasion can be a way to be

tolerant towards different positions, a safety valve (Pennings, 2004). However, CBRC for law evasion should never be a drain pipe which allows unjustified restrictions on the right to reproduce of infertile persons.

Exploitation of women in cross-border reproductive care

One of the main arguments against CBRC is that women, mostly in developing countries, are being exploited in international commercial surrogacy arrangement and egg donation schemes. Throughout this dissertation we have argued that surrogacy and egg donation are not exploitative practices by definition, but that there is a potential for abuse (Chapter 1, 2 & 3). Here, we will focus on two important prerequisites for an ethical practice of surrogacy or egg donation: safety and fair compensation. Then we will argue that lending or selling body parts is not intrinsically immoral.

Safety

The first prerequisite for an ethical practice of surrogacy and egg donation is safety. For egg donors, the primary concern is ovarian hyperstimulation, especially since higher hormonal stimulation implies more eggs to be harvested. However, there are treatment protocols that reduce the risk of hyperstimulation to almost zero (Mertes & Pennings, 2011). The risks for the egg donor can be minimized when safe stimulation protocols are followed and when she is monitored during the cycle.

For surrogacy, the risks are potentially more severe. In India, for example, which is a popular destination country for commercial surrogacy, 1/70 women die every year from complications during pregnancy and childbirth (Saha & Saha, 2010). It can be presumed that surrogate mothers receive better medical care than the average Indian woman during childbirth (which is an injustice in itself), but there are always risks (such as secondary infertility) associated with pregnancy. The right to reproduce of infertile persons does not justify submitting a third party to a risky procedure: safety should be the first concern of surrogacy clinics.

Fair compensation

In Europe, a consensus seems to be emerging about what constitutes fair compensation in countries which have specified a fixed sum for egg donors (around €900), but

worldwide compensation/ payment for egg donors varies enormously (cf. Chapter 1). The same is true for surrogacy, where women in developing countries are paid far less than their 'colleagues' in developed countries. This is not an injustice in itself: nominal wages may be less to surrogate mothers in developing countries compared to their counterparts in developed countries, but the real wages should be equivalent, and the surrogate mother should be fairly compensated relative to the total amount paid by the prospective parents to the surrogacy agency or broker (Humbyrd, 2009).

The most important aspect of fair compensation is that the women should be compensated for their time and effort, not paid per egg or after the pregnancy is carried to term. Egg donors should be compensated a pre-set amount, payment per egg is immoral and promotes unsafe practices. Surrogates should be compensated in instalments: they should still receive part of the compensation when the pregnancy is not carried to term and full compensation when there is foetal malformation or when the intended couple no longer wants the child after birth (e.g. because of a divorce).

Womb for rent and egg selling

The core argument about the immorality of commercial surrogacy and egg donation is based on the premise that commodification of the human body is unacceptable. In feminist literature, surrogacy is seen as the ultimate form of medicalization, commodification and technological colonization of the female body (Rothman, 2000). Commercial surrogacy is seen as renting women (Neuhaus, 1988). Egg donation is seen as egg selling (Almeling, 2007). Bioavailability is a concept many of the critics use to describe the willingness of poor women to exchange body parts for cash (Cohen, 2005). CBRC has even been compared to transplant tourism based on the argument that commodification of the human body is unacceptable (Pfeffer, 2011).

There is an important difference between egg donation and kidney selling: the quality of life of kidney sellers may be significantly diminished for the rest of their life, while egg donation only causes temporary discomfort (given that safety protocols are in place). Those who oppose any commodification of the body should consider the case of hair selling: it is hard to identify which rights are violated or what the harm is in selling surplus hair. One could even argue that a hairdresser who donates his customers' hair to a foundation that makes custom wigs for cancer patients is performing a charitable act. On the continuum of commodification of the body, egg donation is somewhere between selling hair and selling kidneys, maybe most similar to selling blood in the sense that there is temporary discomfort, but there are no lasting physical consequences. There is no ground to oppose safe and fairly compensated egg donation practices based on the argument that commodification of the body is always immoral. A justified critique of egg donation may be that high sums can constitute undue inducement for women to

abandon their qualms about becoming a donor, because egg donation can have lasting social and psychological consequences for the donor, especially in the case of identifiable donation. However, in the case of fair compensation for time and effort rather than high payments for eggs, it seems reasonable to assume that women can decide for themselves whether or not to donate eggs to help infertile women.

To counter the commodification argument against commercial surrogacy, we have argued for a conception of surrogacy as labour (Chapter 1 & 2). Every form of work involves the human body in some capacity. For example, Nussbaum (1999) compared her work as a professor of philosophy to that of a prostitute: both provide bodily services in areas that are generally thought to be especially intimate and definitive of selfhood; both perform skilled work involving interaction with others; and neither has complete control over the form the interaction takes. Critiques of current practices of international commercial surrogacy in developing countries are often justified because of the poor working conditions, lack of fair compensation and medical malpractice, but not on the ground that surrogacy is intrinsically immoral because it is commodification of the female body. An ethical practice of international commercial surrogacy is possible.

Future research

CBRC is defined as the phenomenon where persons travel from one jurisdiction to another in order to access or provide infertility treatments and where frozen sperm or embryo's (and eggs in the near future) are shipped across borders. Here, we will focus on future research about cross-border infertility patients and cross-border movements of frozen sperm, eggs and embryos.

Future research about patients in CBRC

Inhorn and Gürtin (2011) wrote an article specifically about a future research agenda for CBRC. Their primary concern is the lack of empirical data, especially outside of Europe. In this research project we add to the empirical data on patient experience in CBRC by focussing on the two main types of cross-border patients: those who travel for quality of care (Chapter 7) and those who travel to evade restrictions in the home country (Chapter 8). However, Inhorn and Gürtin are certainly right that more empirical data is needed. Currently, Belgium is the only country where detailed information about foreign patients who received infertility treatment was gathered at a certain point in

time (Pennings et al., 2009). The questionnaire-based study of Shenfield et al. (2010), encompassing 46 clinics in six CBRC destination countries across Europe (Belgium, Czech Republic, Denmark, Switzerland, Slovenia and Spain) provides the most comprehensive survey on CBRC to date, but many clinics in those countries did not participate in the study. These quantitative studies informed our qualitative work, allowing us to identify relevant issues and different patient profiles. We need more numbers about CBRC to inform studies into the lived experience of patients crossing borders and more studies into the lived experience of patients to identify areas where more numbers should be gathered.

Culley et al. (2013) recently identified a marginalization of men in social scientific research on infertility. They called for more research on perceptions of infertility and infertility treatment seeking; experiences of treatment; information and support needs; decisions to end treatment; fatherhood post assisted conception; and the motivation and experiences of sperm donors and men who seek fatherhood through surrogacy or co-parenting. This call can be extended to include CBRC. More research is needed about the role of men in the decision making process to proceed with infertility treatment abroad and about their role in and experiences with the cross-border treatment process. For example, for many visits to the clinic (during cycle monitoring, embryo transfer, ...) it is not necessary for the man to be present. In our study, most men thought that it was very important that they were actively involved in every step, even when they had to travel a long way to the clinic every time. It is interesting to note a significant difference between the French lesbian partners who were not being inseminated and the Dutch men. The French lesbians approached the cross-border treatment as a unity, sharing the practical burdens like looking for information on the internet about treatment abroad, dealing with health insurance, finding a cooperative local physician, dealing with friends and family, etc. The Dutch men were much less involved in these practical arrangements. A UK study similarly suggested that men are supportive, go along with the process of CBRC and 'do their bit' (Hudson & Culley, 2013). The Dutch men were also supportive and sympathetic, but much less actively involved. Maybe the future social mothers in the lesbian couples want to be a part of the treatment as much as possible to affirm their role in the family building project, while the men feel at some level that they are already making a vital contribution by delivering the sperm. It would be interesting to test this hypothesis by studying the involvement of men during inseminations with donor sperm. Our study was too small to draw general conclusions and was not primarily aimed at gender differences, but some themes in our data confirm that further research into the experiences of men is needed.

Future research about frozen sperm, eggs and embryos across borders

A lot of work remains to be done concerning cross-border shipping of frozen sperm, eggs and embryos. To our knowledge, there are no empirical studies that describe this phenomenon. We tried to start up a study to map the cross-border flow of sperm and we nearly succeeded to garner enough support for it. It would be very interesting to have numbers on cross-border sperm (and in the near future also egg) trafficking. What is the extent of the phenomenon? How many women are self-inseminating using sperm they ordered online and how much sperm is shipped to clinics? How many samples from one donor are being sent to different countries? A preliminary look at the data of one sperm bank indicated that anonymous donor sperm was being shipped to countries with identifiable donation policies. We regret that some sperm banks withdrew their participation in the study and we hope that these questions will be answered in the future.

Conclusion

CBRC increases reproductive autonomy of patients, but the fact that infertile persons always have the option to go abroad may lead to more restrictive national legislation. There is an important role for national and international courts to prevent arbitrary interference with the right to reproduce of infertile persons through judicial review. Cross-border patients can play a role in the battle against unjustified restrictions by sharing their stories, their experiences and their opinions with the world.

CBRC increases the burden of the already burdensome process of infertility treatment. There is an important role for local clinics and physicians to alleviate the additional burden of cross-border treatment for patients. They can reduce the need to travel by doing part of the treatment at home, provide comfort and support, diminish the risks associated with complications and help patients make arrangements at work and with their health insurer. Because of the many benefits for cross-border patients, we believe that it is good and responsible practice for local physicians to provide support during cross-border treatment, even in the case of CBRC for law evasion.

CBRC may lead to exploitation and coercion of egg donors or surrogates in destination countries. However, this is not an argument against cross-border egg donation or surrogacy, it is an argument for ethically justified practices in destination countries. The exploitative factors may be bad clinical practice, unfair compensation and economic inequality rather than the cross-border treatment itself. Safeguards

against abuse may not always be in place in destination countries, but potential abuse is not a valid argument to prohibit a practice outright.

The reproductive autonomy of the infertile person must always be limited by considerations for the welfare of the future child: no one's right to reproduce includes the right to bring a child into the world that will not be reasonably well off. Physicians have a duty to limit multiple pregnancies as much as possible and there should be assurances that children born from international commercial surrogacy arrangements can go home with their intended parents.

CBRC increases reproductive autonomy, which is morally defensible based on the right to reproduce of infertile persons. There are many ethical problems related to CBRC and it will be necessary to monitor them as the phenomenon develops further, but overall there are many parents and children who are better off thanks to cross-border infertility treatment.

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Appendix I Interview guide

Background and start

1. Why did you go abroad for treatment?
 - Reasons to leave
 - Reasons to go to Belgium
 - Did you consider other countries as well?
2. Where did you find information about treatment abroad?
 - Role for physician at home? (NL)
3. Why did you come to this clinic??
 - Point out I don't work at the hospital

Patient experience

4. Timeline considering going abroad – making the choice – travelling – treatment – after treatment. (These post-its start the timeline + empty post-its made available to allow them to add important moments or steps)
5. Were there any practical difficulties during your treatment process?
 - Making practical arrangements
 - Distance
 - Work
 - Language problems
 - Drug prescriptions
 - Would you do some things differently in hindsight?

- What advice would you give future patients who want to go abroad for treatment?
6. (NL) Are there differences between treatment in Belgium and treatment in the Netherlands?
 - Attitude of people they were in contact with (physicians, nurses, ...)
 - Quality of medical care?
 7. Who did you tell about your treatment abroad?
 - Why not others?
 - You told them about going abroad specifically?
 - What was their reaction?
 - Were there things you decided not to share with others?

Moral considerations

8. What would the majority of the Dutch/French think about your decision to continue your search for a child abroad?
 - What would you say to the people in the Netherlands/France who think your treatment is useless or should be forbidden?

Declarations: in previous interviews other people made some declarations and I would like to hear your opinion about them.

9. "I think the fact that I had to go abroad to fulfil my child wish is a lack of recognition of my wishes."
 - Other people even talked about exclusion or exile
10. "I'm happy I could go abroad to fulfil my child wish."
11. "I feel like my society decided for me that I cannot have children."
12. "I'm going to make an effort in our country so that people in my situation will be helped in the future."
 - What would you advise to someone who wants to change the law?

13. Will you tell your child in the future that you did all this to become pregnant?
- IVF, IUI, DI, ...
 - That you went abroad and why.
 - (DI) Will you tell the child about its donor origin? Why/ why not? At what age?
14. (DI-FR) In Belgium there is some legal recognition for the second mother, but not in France. What do you think about that?
- What does that mean for the child?
15. (DI) What do you think about the donor choice here?
- Did you think about the difference between an anonymous, known and identifiable donor?
 - What does that mean for the child?
16. (DI-NL) What do you think about the fact that other donor conceived children in the Netherlands can know their donor when they are older?

Concluding questions

17. Did you receive help or support from the Netherlands/France?
- Physician at home?
 - Part of the treatment at home?
 - Health insurer?
 - Employer?
 - Family/friends?
18. Is there anything you would like to add to the interview?
19. Background information
- Age, medical history + diagnosis, length relationship, length child wish + job + education + PACS/married/single/...

