

## Infertility in public health: the case of Norway

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### *Abstract*

Infertility is a health issue that demonstrates how unequal access to health care is at a global level. In the poorer segments of the world, and in poor parts of wealthy societies, access is often minimal or non-existent. Public and lay attitudes to modern infertility treatment have been heavily debated alongside development of methods. I have looked at the changes in the public discourse in modern media, legislation, politics, and among professionals. The paper seeks to present and discuss some of these changes as they have evolved in one of the countries that have had one of the more strict laws regulating access to treatment, namely Norway. It is a country that nevertheless offers treatment in the public health system. The paper also tries to connect this discussion to the difficulties faced in every attempt to expand infertility services to the developing world.

*Key words:* Infertility, IVF, human rights, legal issues, reproductive politics, reproductive technology.

### **Background and position.**

Infertility treatments may be both controversial and unevenly accessed. In discussing infertility as a public health problem, and issues of universal access to care, also for the poor, it is important to understand the arguments that shape current opinions on the issue. Norway has always had a restrictive law about reproductive technology, even if it has become somewhat more permissive in recent years (Kahn and Molne, 1998). The debates and their solutions are also recently identified to be influenced by very different reproductive technology cultures. According to a feature article in the New York Times May 30, 2010: *The birds and the bees, via the IVF clinic*, USA has a permissive culture and an unregulated infertility and donation market, while European countries seem to end up with far more restrictive regulations, though with several variations even in the continent. There is also a new challenge coming up because the regulations are so different, and that are the “infertility tourism” issues, where couples travel from one country to another for more permissive or affordable treatment options, for example, almost half of Europe’s egg donations take place

in Spain, where it is permitted, but not in Norway, Germany or Austria. The debates have run in the newspapers, the new social media, in visible public media and also in politics and health priority exercises (Sundby *et al*, 2007; Rostad *et al*, 2006) Unlike many other health issues, the voices of the clients are barely heard as individual stories – but there have been some patient interest organizations that have brought opinions out. In Norway this debate was very strong in two governmental attempts to prioritize issues for health insurance coverage back in the nineties, and infertility was ranked very low, but managed to get public attention after a long debate. The debate has come to forefront again recently because of changes in the law regarding donation of sperm, which no longer can be totally anonymous; and in lack of access to surrogacy, resulting in the recent examples of complications around infertility “tourism” (Kovacks, 2010) .

Also contrary to many other health issues, there is no universal agreement on if and how one should treat infertility. It is certainly not a very visible disease, and in principle, it affects couples, more than individuals (Sundby *et al*, 1990; Sundby, 1989; 1999). Thus, the phenomenon places itself in

between a medical issue, a mental trauma, and a normatively based social dysfunction. This paper is therefore about public opinion and public response to infertility and its treatment as it has evolved during the last three to four decades. As modern technology for fertility treatment has become more known to everyone, access to use is heavily debated. This includes economic access, geographic access, and social access. To explain this in some more detail, I will introduce and discuss some common questions that are often asked about infertility treatment, mainly by the media, the policymakers and also to some extent, the general public. The field is rapidly changing and expanding, and the technology is increasingly sophisticated and experimental. Since most of the debate occurs in the so called developed part of the world, there is still little reference to debates in the South, though there are many parallel issues of cost, access and cultural acceptability.

## Method

First I have to present my field method. The background for this paper is an extensive, multi-level qualitative and participatory field work on issues around infertility in a long time period; from the mid-1970ties until today. I have read and re-read almost every article on the issue in public media since 1975, and participated in the debate, heavily visible and sometimes with my own personal experience. I am also a gynaecologist, a researcher and a patient of infertility. I am therefore duly biased, and use this as my point of departure, because my different positions are the very instruments I have used to understand the complexity of the issue, and the tensions between the different public positions (Sundby, 1999).

Therefore I have to clarify my specific history of experience: I started out as a young married medical student who wanted to become pregnant, but did not manage to. I thus entered contemporary infertility investigations before IVF. Alongside with this, I continued my medical career, and entered gynaecology and obstetrics as a clinician in training. I did not succeed in becoming pregnant, despite several tubal operations (I had had a ruptured appendix at 16 and used a specific first generation IUD around 20-22 years of age), and later four attempts of IVF, two of them in the famous Borne Hall Clinic in the early 1980s. I was young, married, educated in medicine and not poor (Sundby, 1999).

Because my own attempts to become pregnant were not successful, even through two different marriages, I realized that my state of infertility left me vulnerable and sad. I had lost control over a very core element of human life, and I faced opinions on

my journey forward from many different members of the general public. I started to question my own integrity, the medical systems' ability to assist me, and the societal norms that surrounded and restricted my access to essential treatment that I needed. I was simply not a priority. It was deeply felt.

I own a curious mind, so I wanted to deliver an alternative argument to the debate. Medical priority, public financing and the ethics of technology were held up as themes that would, inherently, limit access to treatment that was technically available. The counter-argument was that infertility is painful, that it causes mental and marital unhappiness, and that infertile couples demanded treatment. In this debate, I wanted to enter with scientific, not just emotional, arguments. So I sought, and was rewarded with, a stipend to study infertility, health care and emotions as a scientific study. My findings were published in scientific journals; I earned a PhD, and also entered the scene as a public speaker and policy lobbyist, and as an infertility counsellor for couples. I became a "public face" of infertility. Later, I also looked at access in a broader sense, since I expanded my studies to include magnitude, health care and responses to infertility care in some African countries, and participated in delegations and meetings on population issues and reproductive health in the UN and elsewhere. My point of departure is therefore that even if I am biased, I am also well equipped (Sundby and Schei, 1996; Sundby *et al*, 1998).

## A historic glimpse and the two debates

In the period of time that has passed, several major things have happened. IVF was introduced as a way to treat one common cause of infertility, and later expanded to include other problems as well, here as well as elsewhere. It became one of the wonders of gynaecology, and a thick scientific community formed. It was sensational and controversial, but became available for those who could afford the relatively expensive approach. In the first period, richer families from all over the world, including Norway, travelled to the UK and its pioneer clinics to get this famous treatment. The medical technology expanded rapidly, and national clinics soon adopted the methods and started treatments. Norway had an IVF success already 23 years ago, and recently it was reported to the media that this "baby" now has become a mother the natural way. In Norway, IVF was accompanied with several debates, both the ethics of interfering with the "divine" moment of fertilization, and the economics of access to a sophisticated treatment for a relatively minor, not life-threatening ailment. As a young advocate for access, I stood up in front of a relatively massive panel of

public giants: priests, politicians and feminist scholars unanimously claimed two things: “Infertility is not a disease” and “It is not a human right to have children”. As a counter-argument, my claim – along with my informants – was that we wanted reasonable access to a technology that could assist us in becoming like everyone else: becoming parents, having a baby. The issue of human rights and infertility technology is not at all resolved. One argument that always come to the forefront is “having a child is not a human right”. This is in sharp contrast to the fact that never has population fertility been so universal: almost every woman of fertile age does become a mother (Sundby *et al.*, 1990; Sundby and Schei, 1996).

Things did evolve. Although still very few infertile couples want to go public with their misery, enough people in decision making positions knew someone who had this fate. Despite getting a very low rank in the Norwegian public medical priority exercise, receiving no “health rights” points, IVF treatments were eventually offered for a subsidized price within the public health care system. To begin with, not everyone would get access to it. The legislation was surprisingly normative: only couples in stable marriages were granted entry, and several technology methods could not be combined. The underlying moral assumption would have to be that infertility technology is essentially an evil interference with a god-given ability, but for pragmatic reason we could offer it in a limited way to well behaved families. Single women, lesbian couples, and families where the cause of infertility was more complicated were entirely left out.

### **The normative framework for baby making**

In the Norwegian debate, the role of “the child” has always been held up. It is as if infertile couples are thought to have a lesser concern for the hypothetical child, than ordinary, fertile couples have. Infertility treatment is “baby making”. Politicians use a fairly aggressive tone in claiming that “there are no unlimited rights to treatment” and “that people cannot expect to be allowed to travel to bypass the technology restrictions”. The baby making analogy is in a way true. Accidental encounters between two persons who have unprotected sexual intercourse that lead to an unplanned baby is also baby making. Married couples, who plan for a baby and get it, are making babies too. In all these instances, there is a new human being created. However, for some, these so called “natural” babies do have different moral positions.

As time has passed, ordinary IVF with no use of donor gametes appears not to be a major issue. The

law has been changed so that even couples living together informally may have access to treatment. The entry ticket is a union, and a known father and mother, thus a very social normative framework. For more experimental treatment, or less normative social arrangements like same sex unions, countries have different legislation. Thus, for those who do not fit into the specific country criteria, infertility tourism becomes an option. It is indeed happening. Just now, some three or four persons in “non marital” relationships – from Norway – are waiting In India for passport and visa permissions for surrogate babies conceived there. The babies are not straightforwardly allowed into the country, even if they have a Norwegian social and even sometimes biological parent. Most of the Norwegian public opinion is very negative to surrogacy, and call it exploitation of poor women in the third world.

The main uncertainty facing infertility couples have been that even with access to modern technology, there is no guarantee for a child. Thus, while the primary errand; to create an own child, with its genetic and birth position known and “normative” is the main focus, couples may be faced with other dilemmas. The tension then will be between the overall desire for a child – any child – and the type of technology that one may need, or is available for that purpose. Some couples and individuals jump off the carousel altogether and either give up because of social, legal and financial constraints, while others push their own limits. Some – if they are still eligible - enter other types of child making waiting lists, like opting for adoption. Interestingly, in that in order to be accepted on a waiting list for adoption it is an explicit criterion that you are “through” with your attempts to have a biological child this is what our adoption agencies and public social workers demand. This, of course is an emotional impossibility, the main reason why someone wants to adopt, is the experienced inability to produce a child, not an ideal decision that one wants to care for someone in need. The main focus is always “I just want to have a child”.

### **Pushing limits**

The other major concern is whether infertility is a disease that may create a demand for public health coverage and subsidy. Should it be part of a health care plan? If yes, to what limit? These are not only national debates, many countries embark on priority discussions around ART (Makuch *et al.*, 2010).

Many infertile couples do go further than originally intended. Most of the clients that I have counselled on infertility options are not immediately ready for this: they would still want to have their

own child in a normal way. Since after many years of trying there is no success, they are willing to push limits. This doesn't always come easy. Pushing limits may mean several things: It may mean economic priority, like putting their savings into treatment attempts that bear no guarantee. Economic calculations are always part of the discourse in my encounter with these patients. Northern European couples can most often afford a lot, African couples cannot. Other limits are those of technology and biology. People seem to have fewer problems with advanced technology, like pushing a reluctant sperm swimmer into the egg (ICSI) or producing many ova through hormonal stimulation. Main dilemmas occur around failure to produce gametes in one's own body. Donation of genetic material seems to be the threshold where many people – both infertile and fertile – stumble (Rauprich *et al.*, 2010).

In my own country, Norway, genetic donations are still not at all that straightforward. There is a strong emphasis on the potential child's right to know its genetic origin. This right has a much stronger footing than an infertile couple's right to have a child, which is most often not seen as an intrinsic right. Thus, while anonymous and secret sperm donation has been a historic treatment, this has changed dramatically. In order to receive donated sperm now, you have to accept that the child at age 18 has a right to know who the donor is, and the donor cannot deny the child this right. Biological parenthood is – in a way – seen as superior to a lifelong caring social parenthood, in a way that you may be seen as inferior or mentally suffering if you do not know where your genes come from. This is a little different for adoption, where social parenthood is seen as sufficient. There has been a recent heated debate where several prominent scholars have been reluctant to allow their genes to flourish in a human body that they do not have access to. Rather than seeing donation of sperm as an altruistic behaviour to help a suffering couple in need, donation of sperm is seen as an irresponsible act of giving away something precious that you both have an obligation to care for and a restrictive possessive grip on. Your genes are not to enter into “nowhere”. And the idea that there are human beings out there that may resemble you and may want to have contact with you are so overwhelming that it cannot be tolerated. This is in sharp contrast to many men's whimsical readiness for sexual encounters with many different women if the occasion presents itself.

In a way it is understandable. A lot of “talk” around parenthood is about likeness and traits. “Look at him, he is an exact replica of his father at that age”, “In our family, we have always cherished musicality” etc. For me, a mother of an adopted child

with my hair and eye colour, I always laugh a little when ignorant people point to traits that we share, because they most likely are either accidental or a result of a long life together. But is a bare knowledge of a biological person essential for identity formation? The idea is NOT that you get to know this person as a social, human being; it is more an idea about knowledge of how that person looks and what the identity is.

Worse, even, is the issue of egg or embryo donation. In Norway, this is not yet allowed. Of course it is technically more complicated, but in a gender perspective the ova carries no more or no less importance for the creation of an individual. In that sense there is “gender equity”.

The rule here is that the “mother” is the one who gives birth, so a baby born by a donated egg will belong to the birth mother. These babies do exist, since infertility tourism exists, but contrary to the case of sperm donation, since it is not legally regulated, the child needs not to know. Maybe the biological bonding that occurs in the uterus is supposed to make up for the lack of genetic link. This uterine bonding between mother and foetus has received a somewhat “mystical” status in this country: one main reason for not favouring adopting a child or not allowing surrogate motherhood is the reference to this biological bonding. Surprisingly less emphasis is put on the social bonding that occurs between two (three) separated human beings: the mother, (father) and child.

So surrogate motherhood is not allowed. Treatment of lesbians and homosexuals has been prohibited (Ethics Committee of ASRM, 2009). The debate is for the time being – heated. As surrogacy is not allowed, even for altruistic purposes between sisters, surrogacy for infertile couples in my country involves both financial transactions and tourism. There are surrogate babies born to Norwegian couples, but they can only become parents of the child through the genetics/sperm of the father. The genetic donor of the eggs cannot become the biological or the social mother other than through adoption. This is of course a complicated phenomenon, but it has practical implications. Surrogate born babies are thus nearly always born outside the country and need citizenship and passports before legal transfer to Norway.

### Concluding discussion

Infertility as a threat to modern couples desire to have offspring is still a heavily debated issue in a moral context. As other population concerns have gained momentum, like population aging, too high fertility in the south, too low fertility in Southern

Europe, and postponement of pregnancy in modern women, more young people who have to seek alternative pathways to parenthood may be blamed as victims of this debate.

Money and failure to provide this care in health insurance schemes may contribute to the remaining discrepancy in access to modern care for infertility. The economic transactions that take place in infertility treatments, both medical treatment schemes and donations/surrogacy, are the bread basket of gynaecologists and serve those who have resources. The Norwegian government subsidizes a few treatment cycles of ordinary IVF in public clinics. Most other governments do not. But treatment regimes that are not available in Norway are neither subsidized nor do they entitle the client to medically certified sick leave. Disparities in access occur here elsewhere (Huddleston *et al.*, 2010). Not everyone gets to be eligible for parenthood, and the decisions are often based on very strict moral values and normativity. A recent example is denial of access to adoption by an immigrant couple who has suffered from mental problems as exiles, and had low income. Their loneliness as immigrants did not count. The cost of treatment in the private sector may be formidable and even more costly for poor couples in the less wealthy part of the world (Folkvord *et al.*, 2005; Austveg and Sundby, 2005). The desire for children in Norway makes it possible to have a career out of poverty for Indian surrogate mothers, but is illegal according to Norwegian policy. In USA, if you want to and can pay, you can get almost any type of child that you may desire. Infertility treatment access is an economic discrimination phenomenon; and in most countries only upper and middle class couples can afford it. It becomes a social good in a favourable normative way or a commodity only for the rich. Access to IVF in African countries is non-existent. Or it is there, but neither successful nor affordable.

This is the global situation because the two important discussions around the framework for infertility have not been solved. First: not everyone thinks that infertility should be treated, and the argument is that “it is not a human right”. This is actually challenging statement, as human rights are supposed to be universal and not used discriminatory, as here. Second: infertility is not accepted as a disease in all contexts either, and thus it falls out of a core health care package for reproductive health. In recent debates, the restrictions are both ethically based and given low financial priority. Sometimes these arguments are even mixed: that people who want ethically controversial treatment do not deserve to

be prioritized. Those of us who have studied and experienced the sufferings of couples unable to conceive have a moral obligation to bring their voices forward, as it is still pretty stigmatizing to stand out as infertile. A few politicians are listening, so there may be some hope – at least – for a continued access to fairly reasonable treatment in the public sector at least in Norway. In an African context one can still hear the echo of concerned voices saying:” But there are already so many babies in Africa”. As if it was a marked. Having children is still a very personal issue. We want treatment, but we have to address “marked” like unethical procedures. That is why these debates continue to be important.

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