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Nordic School of Public Health
NHV

Nordic and Infertile.

A study of options and decisions.

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Abstract

Aim: The aim of this thesis was to obtain an overview over the options of Nordic infertile couples regarding assisted reproduction treatment, and to follow couples' arguments and decision-making process to make relevant decisions about these options.

Methods: Quantitative and qualitative methods were used. The study design was inspired by Ecological systems theory, where data was gathered from laws and regulations (macro-level), fertility clinics (meso-level) and the couples using these options (micro-level). Study I consists of results from a review of the legislations in the five Nordic countries and results from a questionnaire that was sent to all fertility clinics to gather information about available options. Papers II and III present the findings of the interviews with 22 Nordic couples, after their first appointment with a specialist at the fertility clinic. The couples came from Denmark (3), Finland (6), Iceland (3), Norway (4) and Sweden (6). Study IV presents the findings of follow-up interviews with the same couples approximately three years later. For the qualitative study the tools of Grounded Theory were used.

Findings: In Study I it was found that Nordic couples generally have good access to assisted reproductive technology treatments (ART), although it is not evenly distributed and there are restrictions related to certain criteria, such as age. There are national differences in the legislations, especially regarding gamete donation. These differences open up for cross-border reproductive care, and more than one third of the fertility clinics offered treatment to people from other countries. Study II describes the decision-making process of the couples when determining the "right time" to try for a child. The couples mention the need to feel prepared for parenthood; such as a stable social situation, and once they felt prepared they became more susceptible to decision-making catalysts, such as influence from friends and family. Fear of infertility made the couple accelerate their decision regardless of preparation. In Study III the decision-making process of seeking medical help is illustrated. The core category was "negotiation and re-negotiation". The process of decision-making is first to accept that they have a problem in common, secondly that they need knowledge and finally to take action and get help. Study IV deals with the decision-making process during treatments. Of 22 couples, 17 had succeeded at becoming parents after approximately three years, three couples were still trying and two had not decided how to continue. The core category was "maintaining control in an uncertain situation". The couples tried to keep focus on the goal and to learn to deal with the new world with various methods.

Conclusions: The structure of and the access to service for infertile couples differ between the Nordic countries. Some of the differences, e.g. regarding subsidy systems and waiting time, affected the decision making process since they could mean a delay in the treatment process or whether a private or public clinic was chosen. Additionally, a couple consists of two individuals with independent decision-making processes, which makes joint decision-making difficult and time-consuming. The couples have to negotiate their way to a consensus and are constantly confronted with new choices they need to re-negotiate on. The decision-making process, when dealing with infertility, is not a straight line, but rather a chain of small decisions affected by feelings, context and situation.

Keywords: Nordic countries, infertility, decision-making process, access, qualitative, ART

Summary in Icelandic

Markmið: Markmið rannsóknarinnar var að ná yfirsýn yfir þeim tæknifrjógungunarmöguleikum sem norrænum pörum sem kljást við ófrjósemi stendur til boða, og að fylgja rökleiðslu þeirra og ákvarðanatökufæri sem tengist þessum möguleikum.

Aðferð: Megindlegum og eigindlegum aðferðum var beitt. Hönnun rannsóknarinnar sótti innblástur til Ecological systems theory, með söfnun gagna frá lögum og reglugerðum (macro-stig), tæknifrjógungunarstofum (meso-stig) og frá pörunum sem nýttu sér þessa möguleika (micro-stig). Grein I inniheldur niðurstöður rýni á reglugerðum Norðurlandanna fimm, ásamt niðurstöðum spurningalista sem sendur var öllum tæknifrjógungunarstofum til að fá upplýsingar um þá möguleika sem stóðu til boða. Greinar II og III kynna niðurstöður úr viðtölum við 22 norræn pör sem fóru fram eftir fyrsta tíma þeirra hjá sérfræðingi á tæknifrjógungunarstofu. Þörin komu frá Danmörku (3), Finnlandi (6), Íslandi (3), Noregi (4) og Svíþjóð (6). Grein IV kynnir niðurstöður framhaldsviðtala við sömu pör sem fóru fram u.þ.b. þremur árum síðar. Fyrir eigindlega hluta rannsóknarinnar var aðferðum úr Grounded theory beitt.

Niðurstöður: Grein I sýndi fram á að aðgengi norrænna para að tæknifrjógungunarméðferðum er alla jafna gott. Þó er aðgengið er ekki jafndreift og það eru hömlur sem tengjast tilteknum skilyrðum, svo sem aldri. Það er munur á reglugerðum landanna, sérstaklega hvað snýr að kynfrumugjöf. Þessi mismunur opnar fyrir tæknifrjógungunarþjónustu yfir landamæri, en meira en þriðjungur tæknifrjógungunarstofa buðu þjónustu sína fólki frá öðrum löndum. Grein II lýsir ákvarðanatökufæri paranna þegar þau ákvarða hvenær sé „réttur tími“ til að reyna að eignast barn. Þörin nefndu þörfina fyrir að finnast þau vera undirbúin fyrir foreldrahlutverkið, svo sem að hafa tryggja félagslega stöðu, en að því búnu urðu þau móttækilegri fyrir ákvarðanatökuhvötum, svo sem áhrifum frá vinum og fjölskyldu. Ótti við ófrjósemi olli því að þörin flýttu ákvörðun sinni, óháð öðrum þáttum. Grein III varpar ljósi á ákvarðanatökufærið sem leiðir til þess að leitað er aðstoðar sérfræðinga. Kjarnaflokkurinn (e. core category) var „að semja og endursemjja“. Færi ákvarðanatökunnar hefst með því að parið þarf að sætta sig við að þau eigi við sameiginlegt vandamál að stríða, því næst þurfa þau að afla sér vitneskju, og loks að bregðast við og leita hjálpar. Grein IV fjallar um ákvarðanatökufærið meðan á meðferð stendur. Af 22 pörum, þá hafði 17 tekist að verða foreldrar eftir þrjú ár, þrjú pör voru enn að reyna og tvö pör höfðu ekki tekið ákvörðun um framhaldið. Kjarnaflokkurinn var „að halda stjórn í ótryggum aðstæðum“. Þörin reyndu að einblína á markmiðið og að nota ýmsar aðferðir til þess að höndla nýjar aðstæður.

Samantekt: Það er munur á uppbyggingu og aðgengi að þjónustu fyrir ófrjó pör milli Norðurlandanna. Sumir þessara mismunandi þátta, t.d. niðurgreiðslur og biðtími, höfðu áhrif á ákvarðanatökufærið þar sem þeir gátu tafið meðferðina eða ráðið því hvort parið leitaði til einkastofu eða opinberrar stofnunar. Þar samanstendur af tveimur einstaklingum hvor um sig með eigið ákvarðanatökufæri, en það gerir sameiginlega ákvarðanatöku erfiða og tímafreka. Parið verður að semja til að komast að sameiginlegri niðurstöðu, en þarf síðan í sífellu að endursemjja um nýja möguleika sem koma fram. Ákvarðanatökufærið eins og það snýr að ófrjósemi er ekki bein lína, heldur er það keðja af litlum ákvörðunum sem mótast af tilfinningum, samhengi og aðstæðum.

List of papers

This thesis is based on the following papers, which in the text will be referred to by their Roman numerals:

- Paper I Sol Olafsdottir, H. Wikland, M. Möller A. (2009). Access to artificial reproduction technology in the Nordic countries in 2004, *ACTA Obstetricia et Gynecologica Scandinavica*. Vol. 88, No.3, pp. 301-307.
- Paper II Sol Olafsdottir, H. Wikland, M. Möller A. (2011). Reasoning about timing of wanting a child: A qualitative study of Nordic couples from fertility clinics, *Journal of Reproductive and Infant Psychology*. Vol. 29, No.5, pp.493-505.
- Paper III Sol Olafsdottir, H. Wikland, M. Möller A. (2012). Nordic couples' decision-making processes in anticipation of contacting a fertility clinic, *Journal of Reproductive and Infant Psychology*. Accepted.
- Paper IV Sol Olafsdottir, H. Wikland, M. Möller A. Nordic couples' decision-making processes during assisted reproduction treatments. Submitted.

Abbreviations

Nordic countries – Denmark, Finland, Iceland, Norway, Sweden

ART – Assisted reproductive technology

IUI – Intra-uterine insemination

IVF – In vitro fertilisation

ICSI – Intracytoplasmic sperm injection

FET – Frozen embryo transfer

AID – Artificial insemination with donor sperm

OD – Oocyte donation

ED – Embryo donation

HIV – Human immunodeficiency virus

STI – Sexually transmitted infection

PCOS - Polycystic ovary syndrome

TFR – Total fertility rate

GDP – Gross domestic product

BMI – Body mass index

WHO – World Health Organization

EU – European Union

EEA – European Economic Area

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Preamble

In my work as a social worker within the Icelandic and Swedish health care systems I have become interested in the process of decision-making of people seeking help, in particular when they are dealing with life-changing events such as illness, death and reproduction. In my counselling work at fertility clinics I meet couples struggling constantly with their decision-making, both individually and as a couple, and I started to wonder how they come to a mutual consensus in a situation over which they have little control.

Introduction

Reproduction

“The act or process of reproducing; *specifically* : the process by which plants and animals give rise to offspring and which fundamentally consists of the segregation of a portion of the parental body by a sexual or an asexual process and its subsequent growth and differentiation into a new individual.” Merriam Webster

Reproduction can be considered as the motor of evolution (1). There is no life if there is no reproduction. This is true for all living organisms, including human beings. Consequently, throughout history people have struggled with reproduction and threats to reproduction; either problems of unwanted reproduction or no reproduction in spite of an intensive desire. Signs appear in ancient art, in fairy tales, folklore and literature of all cultures.

Most aspects of reproduction, such as sexuality, miscarriages, legal abortions, infertility, pregnancies, deliveries, and childrearing are also associated with strong social attitudes, regulations and even laws, although the extent varies among cultures, societies norms and systems of ethics.

The family, with reproduction as one of its functions, is a pillar of society and has existed in one form or other from the beginning of human life. Structures, forms and ways of living differ between cultures and societies. Today there are conflicts between the concept of traditional family roles and new ideas about the role of the family. For example, in the book by Jamrozik and Nocella, The Sociology of Social Problems: Theoretical Perspectives and Intervention, there is a discussion about "*family decline*" and "*threatening condition*" in situations where the family organisation and arrangements are changing (2). In the Nordic countries some of the traditional social security role of the family is no longer necessary. The

responsibility for the young and elderly has, to a certain extent been transferred from the extended family to society, with day care centres and retirement homes. Additionally the role of women and men in the society has changed, with women entering the labour market and men demanding more quality time with their children. This has changed our way of thinking about the family (3,4). People are beginning to question its basic structure and organisation. This means that even recent analyses of family issues and gender roles are being questioned, and people select ideas that appeal to their understanding of themselves and their condition which, in turn, means that the idea of what a family is is being redefined (5). Gender roles have been thoroughly analysed in feminist theories, and demands for gender equality have created a new way of thinking about the roles of women and men. Today, women have many roles apart from being just mothers, e.g. work, studies and career, and women are even starting to question whether they want motherhood at all. The roles of men have also changed from being solely breadwinners to becoming active, caring fathers (6).

As Jamrozik and Nocella argue, these changes could result in that “*certain conditions directly express or infer a threat to dominant social or economic values and interests - that is, to the power structure in society*” (2). This concern can be seen in the family policy of most political parties. There is usually strong support for the traditional nuclear family, that is parents with children, and people are pressured socially and financially to fall into the accepted role. Even with the knowledge that the development of “*reproductive, medical and other technology have made a significant impact on the contemporary family*” there are restraints against acting on these changes (2).

In most dictionaries, a family is usually defined as parents with children, and the public generally defines it the same way. Children seem to be the mandatory variable in the equation for people to qualify as a family. Families with children today are of diverse types, one mother or two, one father or two, step-siblings from both father and mother. A child can be biologically related to its parents or have social parents (adoption or foster home). A child can have a home with two families, staying one week at the time at each home. All these family types are accepted but when a couple live together without children, people tend not to view them as a family, and even they may not consider themselves one (7). Therefore, when people are having an infertility crisis they are stuck in the middle; they are not the classic example of a family, but their longing to become a family controls their lives.

Infertility

“Infertility is defined as the inability to reach a viable pregnancy within a year when having a normal frequency of sexual intercourses and no contraceptives.” WHO

What is infertility?

Infertility as a life experience has existed as long as life has existed. Before the twentieth century, infertility was regarded as an unfortunate but inevitable aspect of life, and people dealt with it by praying or using cures based in folk medicine. During the twentieth century it has increasingly become possible to examine and treat infertility medically, and in the last two to three decades assisted procreation (meaning that the gametes are handled outside the body) has increased tremendously. There are many definitions of infertility. WHO’s definition of a medical condition or a disease is usually accepted, e.g. by ESHRE¹. The concept of subfertility is also commonly used to refer to reduced fertility where no clear cause can be found for not conceiving (8). However none of these concepts cover “social” infertility, where the cause is not medical but rather social, e.g. for same sex couples and single intended parents.

The first IVF (in vitro fertilisation) child was born in England in 1978, and the first IVF child in the Nordic countries was born 1982 in Gothenburg, Sweden. It is estimated that 4.6 million children have now been born after using assisted reproductive treatments (ART) worldwide (9). In the year 2006 approximately 3400 children were born after ART² treatments in Sweden. In Denmark was over 2,600, Finland almost 2,000 and in Norway over 1,600 children born after ART treatment and about 150 children in Iceland (10).

Infertility can also be handled through adoption. In the Nordic countries adoptions are almost exclusively international. In 2008, 449 children born in other countries were adopted in Denmark, 195 in Finland, 13 in Iceland, 298 in Norway, and 784 in Sweden (11-13).

Prevalence

Infertility is found in all societies. The estimated prevalence of infertility in the developed countries ranges from 3.5% to 16.7% and 6.9 % to 9.3% in developing countries (14). In a study from the United States in 2006 only 40% of women had sought medical treatment even though they satisfied the medical definition of infertility, 12 months of regular intercourse

¹ ESHRE – European Society of Human Reproduction & Embryology.

² IVF – In vitro fertilization + ICSI – Intracytoplasmic sperm injection + FET- Frozen embryo transfer

without contraception and no pregnancy, while only 35% identified themselves as having fertility problems (15). It is therefore difficult to estimate the prevalence, when the only information is obtained either from those who seek help or by counting women who are childless at menopause irrespective of whether or not they actually tried to have children.

Aetiology

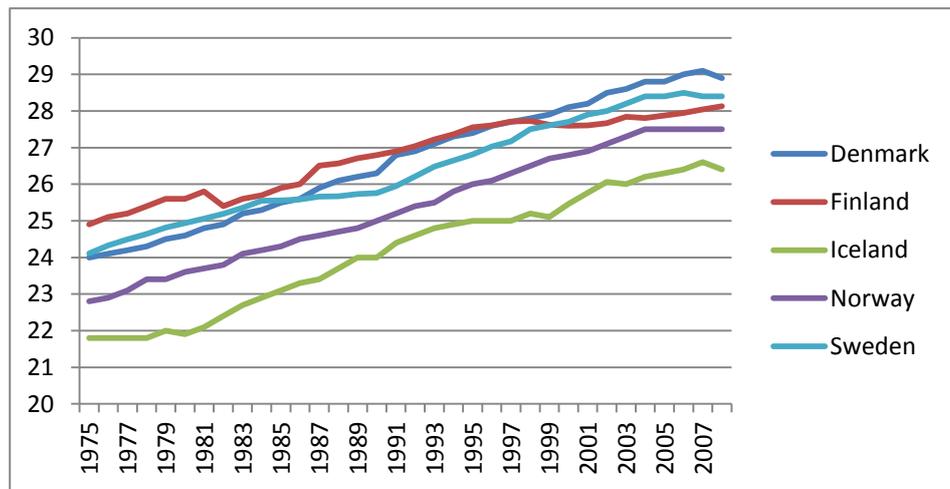
In the ESHRE position paper on Good Clinical Treatments in Assisted Reproduction (16) it is stated that normally 84% of couples will conceive within one year, and another 8% in the second year, with regular intercourse without using contraception. According to a review study from 2007 on 17 studies examining infertile couples' behaviour in seeking infertility medical care, about 56% of the couples sought care (14). Couples usually consult doctors for their problem after 1-3 years of attempting to conceive, or after three or more miscarriages. Medical causes of infertility can be divided into four groups:

- Female factors (approx. 20-35%)
- Male factors (approx. 20-30%)
- A combination of male and female factors (approx. 25-40%)
- Unexplained infertility – no reason can be established (approx.10-20%)

(17)

Lifestyle factors such as smoking, body weight, stress and age have also been associated with infertility (18-20). In the Nordic countries the age of first-time mothers has increased by about 2-4 years from 1975.

Figure 1. Mean age of mother at the birth of her first child 1975 – 2007.



(21)

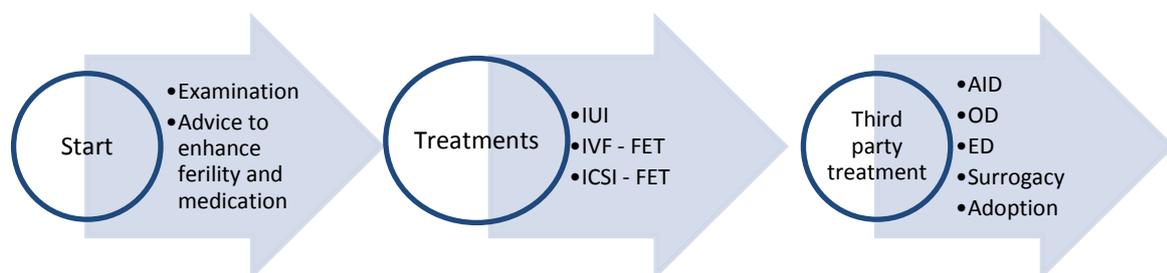
Treatments

Treatment of infertility depends on the aetiology. Hormonal factors can sometimes be treated with hormone therapy (e.g. ovarian hormone stimulation, ovulation induction) and non-severe damage to the fallopian tubes can be treated surgically (e.g. fertility surgery). ART treatments include intra-uterine insemination (IUI), in vitro fertilisation (IVF), intracytoplasmic sperm injection (ICSI) and frozen embryo transfer (FET). IUI is often used as the first line treatment in unexplained infertility or in mild male factor infertility. Couples with tubal factor or unexplained infertility are offered IVF, and during the last decade ICSI has come into clinical use for almost all male factor infertility. IVF/ICSI treatment can be quite an extensive measure that requires several weeks of hormonal treatment with sprays and injections. Today short-term hormonal treatment or a mild hormonal stimulation is tried if it is medically feasible. After hormonal treatment an operation is required, in which ova are picked up from the ovaries of the woman in order to be fertilised outside the body and then transferred back into the uterus after 2-5 days. The possibility of transferring frozen embryos (FET) has diminished the burden for the woman, as it requires much less intervention (22). In addition, the possibility of cryopreservation of embryos has helped decrease the multiple birth rate by making single embryo transfers instead of multi-embryo transfers a viable option, especially in the Nordic countries with Finland and Sweden at the forefront. In 2008, these two countries used single embryo transfers in 70% of IVF/ICSI treatments, as compared to United Kingdom with 13% (9).

However, sometimes a man has no viable sperm. In such cases artificial insemination donation (sperms donated by another man=AID) is the only alternative if the woman wishes to become pregnant. Correspondingly, when no functioning oocytes can be found in the woman, oocyte donation (OD) from another woman via IVF may be possible. For couples with neither oocyte nor sperm, embryo donation (ED) can help and this is allowed in Finland and Iceland (23). In addition, although currently not legal in the Nordic countries, surrogacy makes it possible for women without a womb, men without a partner or same-sex partners to become parents (24).

The results from IVF/ICSI have steadily improved since its beginning in the early 1980s. The probability of becoming pregnant per embryo transfer is now approx. 32-33% per treatment cycle and about 20% for FET, but the probability of delivery per embryo transferred is around 25% owing to the risk of miscarriage (17). IVF is a symptomatic treatment and not a curative one, i.e. the disease that causes the infertility is not cured. A general overview of the process and treatments is shown in figure 2, but it varies between countries, clinics and individual patients (10). This process may take many years from start to finish.

Figure 2. A possible ART treatments process.



Experience of infertility

Studies show that infertility problems can have pervasive negative effects on the mental well-being of both women and men (25-29), although in vitro fertilisation has revolutionised the ability of people to become parents. It is important to note that the majority of studies of experience of infertility are constructed around people who are using or have used ART treatment, that is people who have made the decision to try to reverse their infertility. It is well known that infertility has psychological consequences for the majority of infertile couples (30-32). Depression and anxiety are mentioned in studies, along with lower self-esteem and less satisfaction in the couple's relationship (33-35). Domar et al. showed that the

psychological stress for infertile women was of the same order of magnitude as for cancer, HIV and pain patients (32). In general, infertile women experience more distress than men (36), both mentally and physically, and it is more common among women than men to suffer from severe depression and anxiety disorders while undergoing IVF treatment (37). However, it is likely that the anxiety is associated with the type of treatment techniques used (38). Verhaak et al. showed that women who experienced anxiety before the first treatment also showed increased anxiety about the second treatment (39). A longitudinal study by Verhaak et al. revealed that nearly 20% of women who had not become pregnant showed anxiety and depressive symptoms six months after the latest treatment (25). One can therefore conclude that the infertility and its treatments could cause long term psychological stress in women and men (26) and may manifest itself in crisis and grief reactions for many years, but expressed in different ways between the sexes. In a study by Volgstein et al. it was found that three years after the treatments women with no children showed more grief than men, who saw themselves more in a supportive role to the women (27). Results of another study of couples showed that 20 years after unsuccessful treatments, people experienced repeated crises and grief when their peers had grandchildren (29). One of the problems with these results is that it is difficult to know if the psychological distress was caused by the infertility or the treatments. The feeling of well-being is also highly dependent on successfully becoming a parent (36,40).

After long-term infertility, a long awaited pregnancy may cause emotional stress on the couple. Treatment trials are challenging both mentally and physically, and are often a stress factor on the relationship (28,35). Therefore, for these couples, the need for support continues even pregnancy occurs, and research shows that this group seems to need more education and support during pregnancy than other couples (41,42).

Studies show that anxiety, depression and stress during pregnancy are common in couples who are expecting a baby after IVF (43,44). Furthermore, recent studies suggest that women who show symptoms of depression shortly after IVF treatment are more prone to depression later in life (25).

Consequences

Infertility is a complex problem that affects not only the infertile person or couples, but also the society in terms of health care cost for treatments and sick days and loss of potential tax income. Unresolved infertility has effects on the family systems, such as caring for the elderly or the sadness of not passing the family genes down to future generations. On the personal

level, infertility, like parenthood, is about many core aspects of human life, and as a psychological experience it can be understood in many ways: as a psychological crisis (30), as loss and grief (45,46), as loss of control (47,48), as conflicts regarding gender identity (49), as an existential threat to the identity and the relationship (31), etc.

The Nordic situation

The Nordic countries³ have been in the forefront in both developing and using assisted reproductive technology. Today it is possible to have IUI, IVF, ICSI, FET, and sperm donation treatments in all of the Nordic countries. In all but Norway, oocyte donation is allowed. Each of the countries has specific regulations and laws that deal with ART treatments, and they are all members of the Hague convention from 1993 regarding adoption (50). The Nordic countries are relatively homogeneous in relation to people, their social situations and health care, but are different regarding some aspects of public opinion, legislation, policy, social attitudes and history. Therefore, the Nordic countries are particularly interesting when studying special areas like infertile couples' decision-making.

The welfare system

“[a] concept of government in which the state plays a key role in the protection and promotion of the economic and social well-being of its citizens. It is based on the principles of equality of opportunity, equitable distribution of wealth, and public responsibility for those unable to avail themselves of the minimal provisions for a good life.” Britannica Academic

Welfare systems are meant to fulfil the basic needs of the citizens: social security, education, housing and health care. They are based on three pillars: government, market and family. In the book by Esping-Andersen, The Three Worlds of Welfare Capitalism, he states that all country has a unique way of organising its welfare policy. The welfare system tends to be a mix of many different aspects, such as general country policies, labour market emphasis, and the needs of the society, which make that particular welfare model suitable for that country (51).

³ Denmark, Finland, Iceland, Norway and Sweden.

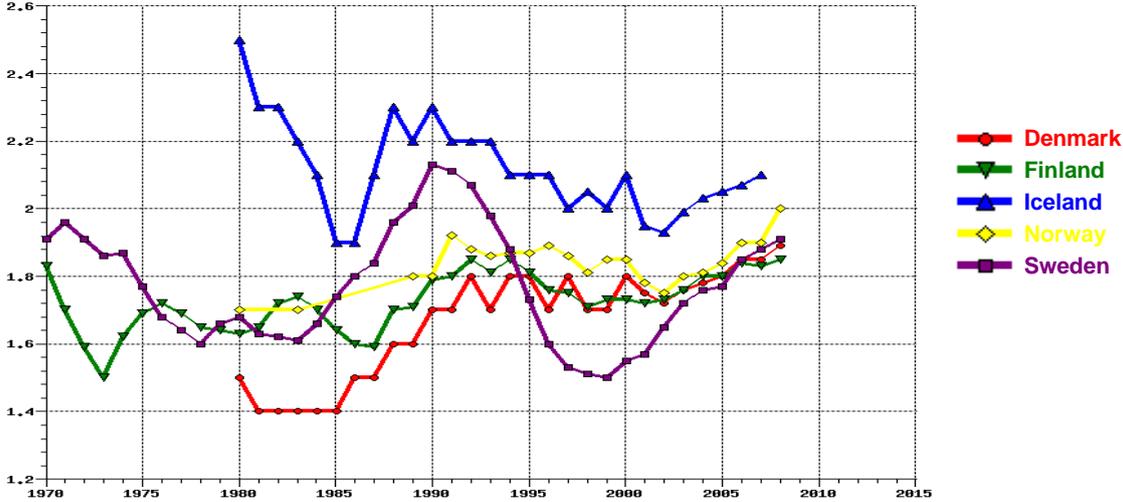
The Nordic welfare system

The development of the welfare systems in the Nordic countries has followed similar paths. Usually all the countries have adopted new social reforms within a few years of each other. This applies, for example, to hospital care after 1850 and social services after 1890 (sickness insurance, pensions, social benefits) (52). The well-known Nordic welfare model has mainly been based on Social Democratic and Liberal ideologies (53). The main characteristics of the Social Democratic model are universalism, modification of social rights, equality of all citizens and solidarity. All citizens receive benefits, so all are dependent on the state and therefore feel obliged to pay their taxes. The Social Democratic ideology strives to increase equality among the citizens through the welfare and tax systems. The close conjunction of the welfare and work is salient in this model. If most of the citizens are working and paying their taxes, then it becomes possible to have a universal and highly modified welfare system (51). According to Esping-Andersen, one characteristic of the Liberal model is less governmental influence, with means-tested assistance and modest universal transfers or social insurance only to meet basic needs. The role of the state is to encourage the market to provide both services and insurance for the majority of the citizens (51).

The Nordic countries have succeeded in having low unemployment rates and women's participation in the labour market is high, while the total fertility rate is not as low as in some other Western countries. The extensive family policy, such as well-developed day care provisioning, child allowances and generous parental leave system for both parents have been important factors (54). But the welfare system is highly complex and one cannot simply focus only on two parts, the family and the state, since the market is equally important. Over the years, the number of children per family has increased and decreased as the labour market situation changes. There are three aspects that influence the number of children born per family; the cost of bringing up a child in a certain society, time lost as people postpone reproduction, and the possibility of reconciling the family life and work (55). Figure 3 shows the fluctuations of total fertility rate (TFR)⁴ average number of children per family in the Nordic countries from 1970 to 2008. Note that the TFR axis starts at 1.2.

⁴ Total fertility rate is defined as the average number of children that would be born per woman if all women lived to the end of their childbearing years and bore children according to a given fertility rate at each age.

Figure 3. Total fertility rate in the Nordic countries from 1970 to 2008.



Source: WHO/Europe, European HFA Database, July 2010(56)

Theoretical considerations

Infertility is a classic example of naturally occurring defects that can be highly dependent on lifestyle and the social situation. As mentioned above, infertility is not only a problem for those affected but also for society, as the number of children per family falls and health care spending rises. This made it easy to choose theoretical standpoints for this study. The framework is Public Health, where both health care systems and health promotion theories are beneficial to understanding how society can assist directly and promote quality of life. Other theoretical frameworks are psychosocial, in the form of Ecological Systems Theory and decision-making theories, where the actions of couples dealing with infertility are explored in relation to the options they have.

Public health

"Public health is the science and art of preventing disease, prolonging life, and promoting health through the organised efforts of society" (Sir Donald Acheson, 1988, The Public Health in England report)

Ever since people began to live together in communities there has been a need to understand the relationship between individuals and society. Cavemen had separate places for sleeping, cooking and toilet activities, which can be interpreted as some understanding of the relationship between hygiene and health. As towns developed, so did the need for better understanding of the relationship between society and health. There is an ongoing debate as to whether individuals make the society or the society makes the individuals.

Public health research today is based on epidemiology, biostatistics, health promotion/prevention, health policy and health management. Studies are both done on large population levels and on particular groups of the population that share similar situations or conditions. Infertility, with its estimated prevalence of up to 16%, and its consequences for the individuals' quality of life, is a public health concern. In comparison, the world-wide prevalence of diabetes for the age-group 20-79 is estimated to increase to 7.7% in 2030 (57). Infertility is difficult in a society where children is the norm, especially when your right to medical help is questioned and your problem classified as low-priority within the public health care system.

The World Health Organization (WHO) defines infertility as a disease. Although a certain percentage of infertility can be explained in terms of specific diseases, there are other factors that are clearly public health related.

- *Preventing infertility:* According to WHO, sexually transmitted infections (STI) are the main preventable causes of infertility, particularly in women. It is estimated that up to 40% of women with an untreated chlamydia infection develop pelvic inflammatory disease which can cause tubal damage, which, in turn, is responsible for 30% to 40% of female infertility cases (58). There is also increasing attention to environmental factors that may have impact on reproduction (19).
- *Promoting a healthy lifestyle:* Eating disorders, i.e. obesity, anorexia, abuse of nicotine, caffeine and alcohol, and stress are all factors that impact on infertility for both men and women (19).
- *Prolonging life:* This can be understood either on an individual or national level. The latter is more relevant in the present context. The total fertility rate (TFR) for the world in 2010 was 2.5 children per woman: 1.7 in the developed countries and 4.5 in the least developed countries, where the infant mortality rate is 76 per 1,000 births as compared to 5 in the developed countries. In Europe the TFR is 1.6, 1.9 in the northern part, with highest, 2.2, in Iceland (59). An ageing population and a decline in births of new citizens will create new problems for the health care system. According to estimates based on previous developments from the Population Reference Bureau, by 2050 there will be only four working-age people for every person aged 65 years or older (60).

With regard to infertility, the organised efforts of the society and the informed choices, mainly come in the form of medical treatments, adoption and information about these options.

Health care system

The total area of the five Nordic countries is approximately 1,320,000 km², and the total population is 24.5 million (11-13,61,62). Public health care provision is a major item in the Nordic countries' national budgets. In 2007, the total expenditure on health as a percentage of gross domestic product (GDP) ranged from 8.2% in Finland to 9.1% in Iceland and Sweden (63).

The health care systems of the Nordic countries are based on the possibility for both public and private health care to operate in certain fields. Reimbursement systems are widely used.

Table 1. Health expenditure in the Nordic countries, divided by public and private sector 2008

Countries	Total health expenditure €/capita	Public sector %	Private sector %
Denmark	3,712	83.4	16.6
Finland	2,908	74.2	25.8
Iceland	2,539	82.6	17.4
Norway	5,392	84.0	16.0
Sweden	3,477	81.9	18.1

(63)

The national spending on ART treatments in the Nordic countries range from 0.03-0.04% of GDP (crude estimate) in Norway to over 0.06% in Finland and Denmark in 2002 (64).

Health promotion

”Health promotion is the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions.” WHO (65)

Infertility is considered a disease, irrespective of whether it is primary (never conceived a child) or secondary (had a least one child). People dealing with infertility struggle to improve their possibilities of becoming parents by all means, including by improving their health. As mentioned above, the reasons for infertility are a complicated web of biological, cultural, and social structure factors, all of which concern health promotion.

According to the Ottawa Charter, healthy behaviour is maximised when individuals are motivated and educated to make healthy choices with support from policies and the environment (65). With the adoption of the Ottawa Charter in 1986 the focus moved from the larger social structures versus individuals, to trying to mediate between these two interests (66). The strategy for promoting health for all is to advocate for health and to enable people to reach their potential health (67). Since the Ottawa Charter there has been constant development of health promotion internationally, and the more recent Bangkok Charter of

2005 takes a more global view (67). These developments have been criticised by some, as they are thought to steer the discussion of “socio-ecological” justice towards legislation and economics (68). Still, the focus of health promotion is on enabling people to make relevant decisions and changes to improve their situation, by society’s satisfying fundamental prerequisites such as peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity (65).

In the Nordic countries most of these conditions are met, but they are not balanced, since lifestyle diseases are among the main health care problems. The leading causes of death are diseases of the circulatory systems and cancer (69-73). Infertility caused by lifestyle factors has recently attracted more attention in research (18-20). It is now well-documented that smoking and weight (overweight BMI⁵ >25 and underweight BMI <20) impact on fertility for both women and men (74-76). There is growing evidence that stress (77,78), alcohol (79,80) and caffeine (81) are associated with infertility, as all of them, in large quantities, are harmful to the health, but further studies are needed.

There is a reciprocal responsibility between the society and individuals. Society’s role is to make it possible to stay healthy and to help those who are not. The individual has the responsibility to try to live a healthy life. Yet there are people who, regardless of society’s activities and healthy living, still become ill or experience negative health conditions. For society to enable the citizens to achieve their potential well-being there is a need for various methods and interventions adapted to specific situations. For some conditions guidance and information suffice (e.g. dental health of children), for other restrictions are needed (e.g. age limits on alcohol).

The social structure may prevent or promote infertility. The labour market participation of women is high in the Nordic countries, and women have generous parental leave. Since the late 1990s, fathers have also had their own right to parental leave. This social structure may have influenced the higher maternal age for a first child shown in figure 1. This is explained in that young people study longer, and then wait until they have permanent employment, wait to qualify for better income-related parental leave and wait until they have a home. In line with health promotion, infertile couples should be given support to cope, mentally, physically and socially, with their situation in society.

⁵ BMI – Body Mass Index

Health promotion interventions can be on an individual level, where the focus is on changing behaviour using counselling and education, or on a society level, where the focus is on the environment, community and policies (82,83). An emphasis on individual responsibility may result in “blaming the victim” (84), while combined interventions on both levels could be more beneficial. Lifestyle interventions that could have impact on infertility include:

- A) Age-related infertility: “She waited too long”. Focus on individual responsibility could be saying that the woman had a choice of starting earlier to try to have a child. An intervention could be to inform women of a certain age about the connection between infertility and reproductive age when they come in contact with the health care system.
Focus on society’s responsibility relating to the social structure that makes it necessary to have two parents to share the burden, with two incomes and stable work situations to be able to support a child. An intervention based on social responsibility could advocate more support for parents with children, possibility of parental leave while studying and positive attitudes towards families of all types.
- B) The effect of tobacco on infertility: “He smokes”. Focus on the responsibility of the individual is to say that it is his choice to stop smoking. An individual intervention could be giving smoking cessation advice and providing hotlines to guide and support individuals to stop smoking.
Focus on the responsibility of society could be to ask why even with all the evidence that smoking is harmful and costly to the society it is still allowed. Societal interventions could be increasing taxes on tobacco and limiting smoking to specially designated areas.
- C) The effects of obesity on infertility: “They are too fat”. A focus on individual responsibility is to say that it is people’s choice to eat unhealthy food and not to exercise. A classic intervention based on individual responsibility is to give lifestyle advice such as counselling and education. The responsibility of society could be to do something about the fact that the variety of fast food for the same cost or cheaper than healthy food makes it difficult to lose weight. An intervention based on social responsibility could be to make healthy food cheaper and increase taxes on unhealthy food. One

example was the draft bill from the Icelandic Ministry of Health in 2009 proposing to increase the tax on sugar. It was not adopted by the Parliament, since it was feared that it might hurt the food industry.

The goal of health promotion in relation to infertility is preventing infertility by promoting a healthy lifestyle, advocating for better social possibilities to have children early, and enabling people to have good access to relevant medical help for those who need it.

To help understand the behaviour of infertile couples two theories are used in this study; Ecological System Theory with an emphasis on contextual aspects of human life, and decision-making theories which focus on the individual's reaction.

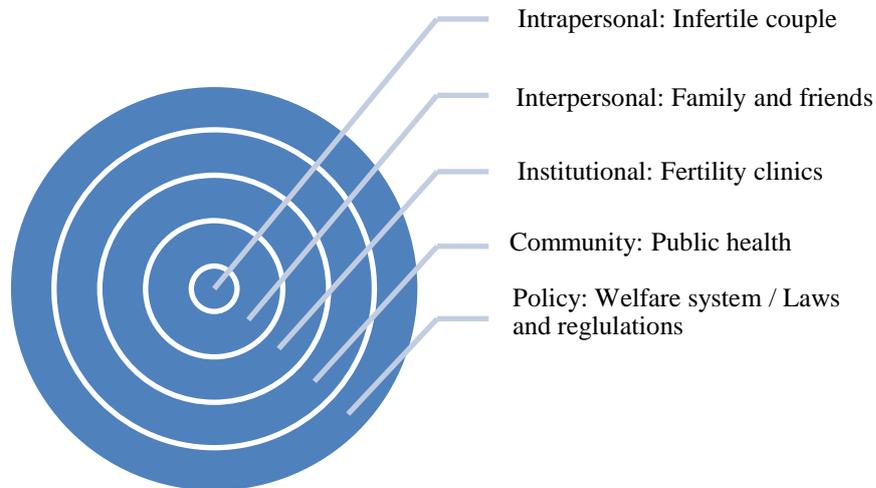
Ecological Systems Theory

Most of the research that has been undertaken in the area of psychological and social aspects of infertility has been performed with a focus on the individual couple. Reactions to and consequences of infertility for the couple have been focused on, as well as psychological factors in the aetiology of infertility.

There is, however, a great need to broaden the focus of reproductive research. Bronfenbrenner has argued that in psychological and social studies, environmental factors are usually given too little attention. These factors can be of different kinds – social, physical, chemical, cultural and so on. He organises these factors with the help of the concepts of micro, meso and exo/macro, and argues that these factors need to be articulated in detail in studies in order to increase the understanding of what is going on and why (85).

In recent years, with more interest in public health and health promotion, researchers in Ecological System Theory have shifted focus from explanatory theories of behaviour to models of behavioural interventions. MacLeroy et al. presented five levels; intrapersonal (biological, psychological), interpersonal (culture, norm and social), institutional, community and policy (86). In 2000, the Structural-Ecological Model was developed where the structural influence is divided into four categories: availability of protective or harmful products, physical structures, social structure and policies and finally media and cultural messages (87). A modified model inspired by ecological system theories could be imagined as below, with the environmental factors closely related both as providers and receivers.

Figure 4. Model of ecological system of infertility.



The welfare system, through public health care, provides health care services both to prevent reproduction and to assist reproduction. Infertility is a threat to the society in that it decreases the total fertility rate, meaning fewer taxpayers contributing to the welfare system in the future, and in that it decreases the quality of life for affected persons and is costly for the health care system. The fertility clinics are bound by laws and regulations of the society, the public health care economy system and furthermore peoples' demand of this specific service. The intrapersonal and interpersonal factors are closely related, since people are usually a part of a social network based on family and friends that have influence and give guidance and support in difficult situations. The norms and attitude of this social network can, like the options for help, have influence on peoples' decision-making processes.

Decision-making theories

One of the first pieces of evidence of a first decision is when the child learns to say no, even though the word does not always match what the child wants. In our daily lives we use decision-making in almost everything we do. There are small day-to-day decisions such as what to have for dinner, and then there are the more serious decisions of planning to achieve personal goals regarding career, marriage and childbearing. There are yet other decisions that are personal and also moral dilemmas, when people have to cope with serious situations such as illness, disability or infertility. Many researchers have shown that the level of stress rises with the seriousness of the decision-making (88,89).

Conflicts and stress are not common when the decision is about everyday things, but are more prevalent with major life decisions (7,88,89). In a situation when infertility threatens people's dreams about a "normal" life, their ability to make rational decisions is constantly challenged. One can argue that it is difficult to distinguish between rational and emotional decision-making, especially for decisions where neither the alternatives nor the possible outcomes are fully known.

There are a few necessary elements in every decision-making process. These are: *goals*, *beliefs*, *desires*, *rationality*, *probability* and *logic* (88,89). *Goals* are designations, for instance the goal of a young woman might be to have children. *Beliefs* are how this woman hopes to accomplish her goal by finding a suitable partner. *Desires* are when the goals and beliefs are made mostly on the hope that they will stay together and have children. *Rationality* is when she uses proper means to make her goal happen and *probability* is what her chances are of succeeding. Finally *logic*: is this goal logical for this woman? If the woman is fertile and has found a fertile male partner then this goal is logical, but if she has no ovaries, for instance, then achieving this goal may not be a logical step.

How does this woman go from her first idea to making a decision to achieve her goals? Initially it is necessary to consider the cognitive processing styles she can use. One is an intuitive style of decision-making when there is a high level of uncertainty, novelty, complexity, and limited information or time pressure that influence her decision-making. Another is an analytical decision-making style which we all hope we use to make difficult decisions.

Analytical decision-making consists of three steps:

Preliminary work – understanding the problem, evaluation of risk or goals, assessment of open options and possibility.

Implementation of choices - becoming comfortable with the decision, modifying the choices into manageable concepts to determine whether it is possible to achieve the goals. Re-run = try a little, win some, lose some, evaluate pros and cons and decide again.

Living with decisions - looking back – post-decision evaluation of experience.

(90)

However it is questionable whether people dealing with infertility are capable of using analytical decision-making effectively because of the emotional effect of outcomes (7,88,89,91). Emotions are not rational, but people may anticipate from previous experience how they will feel and make decisions based on that experience (89). There are two main sets of contrasting emotions of interest to discuss further since they play an important role in all decision-making (89). The first is *regret* and *rejoicing*, where the person will be afraid of having regrets about whether the outcome might have been better if a different decision had been made. The person rejoices if the decision results in a better outcome than anticipated. The other contrasting emotions are *disappointment* and *elation*, where the person sticks with her/his choice no matter what, while regret and rejoicing are about comparing many choices related to one situation (89). These emotions are important factors when decision-making is analysed. They are commonly the picture of personal goals and desires.

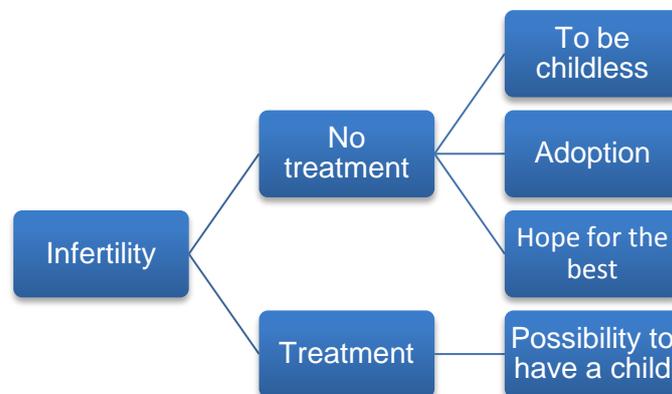
Many researchers have developed models to give more descriptive pictures of the decision-making process. Decision-making in the early process regarding infertility may be based on *Narrative models* (e.g. scenario model Jungermann & Thüring 1987, story model Pennington & Hastie 1986, argument model Lipshitz 1993). In these models a decision-maker will fantasise about the situation, with a lot of arguments and possibilities of how to act in a given situation (92). When people have gained more experience a *Recognition-primed model* as described by Klein (1989) can give a picture of the decision-making process, where people relate to previous experience. They assess the situation based on similar situations rather than making a judgement. Then they try to understand the actions they can use to reach their goal in the given situation. If a new situation arises they use the same strategy again or, if necessary, re-evaluate a previous experience to adapt it to the new situation (92).

Image theory by Beach is another decision-making theory that takes both intrapersonal and interpersonal factors into account. The idea is that every decision-maker has his own values, morals etc that defines for him how things should be and how people ought to behave. The theory claims that the decision-maker has to search his/her mind for the feasible candidate options that will survive after a thorough evaluation. Then the adopted decision has to be tested against the images. The value images or our principles come first, the trajectory image or our goals comes second, and finally the strategic image or our plans. If the adopted decision survives the image test then the decision-maker goes on to the next decision based on the previous decision, and the decision-making progress proceeds (92,93). Image theory has been criticised for its lack of focus on the value of the information-processing capability of

the decision-maker in decisions where a simpler strategy can be used (94). It has also been criticised for not taking into account the coping strategies and context of the situation during difficult decision-making (7).

Even in everyday life there are complicated decisions to be made, and our understanding of the mental process of decision-making is limited. These theories can only give a limited understanding of the decision-making process, since most of the decision-making is very personal and based on the individual's lifelong experience. Can one expect people to make rational decisions when dealing with infertility, and what are the choices?

Figure 5. The choices of infertile couples.

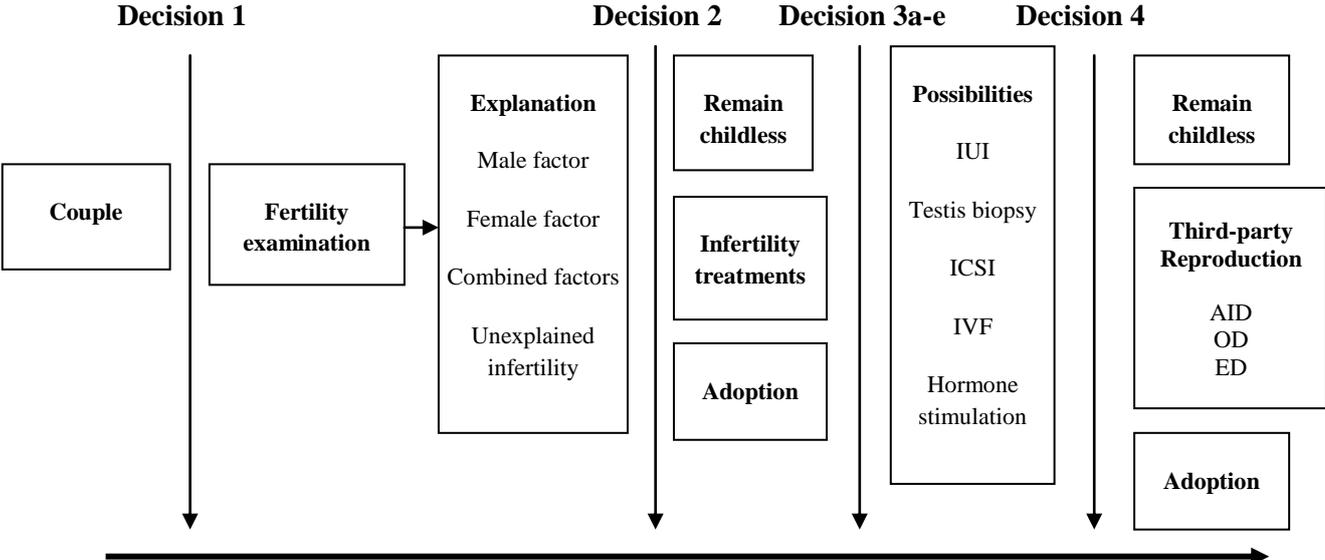


There are only two alternatives if infertile people want a child: ART treatment, with an average pregnancy rate per embryo transfer of 32.7% using IVF or ICSI (17) on the one hand, or adoption on the other. This choice can even be simplified if it is about wanting a biological child or wanting to experience pregnancy, or when people do not qualify as adoptive parents. Then ART treatment is the only option. Similarly, if the treatments are unsuccessful, then adoption is the only option if the couple wants to have a shared child.

There is more to the decision-making process regarding infertility, however. This is often a decision where couples need to reach a consensus, e.g. a wife cannot choose by herself to have ART treatment without her husband's agreement. According to Zeiler a condition for shared autonomous decision-making is that a person can identify and reflect about his or her own and his or her partner's values and beliefs to be able to make decisions about alternatives (95).

There are also decision made by medical experts where the specialist can refuse or allow certain treatments, or the social services deny an application for adoption. The decision-making is primarily individual, secondly a negotiation between partners and finally a joint decision with the health care personnel and the couple, based on present alternatives for help (96). Even after the decision is made to try to have a child with help, this is only the beginning of the process, which includes many decisions, as shown in figure 6.

Figure 6. Decision-making process when dealing with infertility.



Aims

Using the disciplines of public health and psychology together, one can gain a more complete overview, which is important in order to understand the situation of the individual infertile couples. To date, research regarding infertility has mainly focused on only one aspect at a time; aetiology and medical treatments of infertility in medicine and emotional and mental consequences in psychology. A more comprehensive view is needed, where all factors are included; social, psychological and physiological. The Nordic countries are an ideal context with their homogenous populations and cultures, and different legislations and geography.

The main purpose of the study was to obtain an overview over the options of Nordic infertile couples regarding assisted reproduction treatment, and to follow couple's arguments and decision-making processes to make relevant decisions about these options.

The specific aims were:

- To describe and compare the situation in the Nordic countries regarding social, political and legal aspects of the solutions offered to couples with infertility problem.
- To explore the reasoning of Nordic couples in deciding “the right time” to attempt conception.
- To analyse the decision-making process of couples with difficulties conceiving in anticipation of contacting a fertility clinic.
- To examine the process and actors in decision-making during ART treatments.
- To determine whether a country of residence has an impact on reasoning and decision-making.

Research structure and methodology

Research in public health often focuses on the interrelation between the individual and society, and attempts to acquire as extensive as possible a picture of these phenomena, using the available research tools. Research is usually driven by the need for knowledge, rather than mere curiosity. According to Möller and Nyman some important requirements for knowledge to be scientific are “*structure, reliability, the search for truth and objectivity, generality, openness regarding methods, and that underlying assumptions and results are subject to continuous challenges and that they are revised if found to be wrong.*” (97), (p.652)

One public health researcher explains the research drive as a four-step process: first to get a picture of the situation, second, to analyse how it is and why. The third step deals with the possibility of and method for making it better, and finally assessment of whether it works (98). In this study the focus was on steps one and two, with the hope of collecting enough material to be able to put forward a model of possible improvements to be evaluated later.

The thesis consists of four studies carried out between 2003 and 2010 in the Nordic countries: Denmark, Finland, Iceland, Norway and Sweden. The design of the study was inspired by Ecological Systems Theory (85). Information from the macro-level (laws and regulations), the meso-level (access to ART treatments) and the micro-level (the couple’s themselves) was gathered, and one of the focuses of the study was to explore how these levels are connected. Research methods were chosen according to the research questions and both quantitative and qualitative methods were used. To study the development and status of the legal situation in the Nordic countries, an review of legal documents was conducted. To gather information about the access to ART treatments, a questionnaire for the existing clinics was used to gather the most information possible. The main part of the study deals with the experiences of the couples, and therefore a qualitative method was selected, since the focus was on understanding and exploring an area about which there is limited knowledge (99-101).

Review of legal documents

In the seven years of the study period there have been changes to the laws and regulations regarding ART treatments in all of the Nordic countries, the largest change being in 2007 when legislation was adopted in Finland for the first time. The framework for this study was derived from the legislations, and therefore it is important to constantly review how it changed. Laws, regulations and draft bills in all of the Nordic countries during the period

2004 to 2011 was gathered and studied. Information about the similarities and differences in the legislation was continually monitored. Additional literature included information from the respective National statistics agencies about population density, as well as relevant documents regarding the development of legislation that dealt with ART treatments.

Databases that were used included: finlex.fi, althingi.is, lagrummet.se, lovdata.no, retinformation.dk, norden.org, and the websites of the national statistics agencies.

Table 2. Overview of legal documents regulating ART treatments in the Nordic countries.

Laws, regulations and draft bills	
Denmark	Act on Artificial Fertilisation (1997/460), revision, (2003/427, 2004/69, 2004/240, 2006/535)
Finland	Act on Assisted Fertility Treatments (2006/1237), revision, (2009/376, 2009/1415)
Iceland	Act on Artificial Fertilisation (1996/55), revision, (2006/65, 2008/27, 2008/54, 2010/55, 2010/65). Regulation on Artificial Fertilisation (1997/568)
Norway	Act on Artificial Fertilization (1987/68), Act on the Medical Use of Biotechnology (2003/100), revision, (2004/45, 2005/28, 2007/31, 2008/53, 2011/30)
Sweden	Act on Insemination (1984/1140), revision, (2002/253, 2005/443, 2006/351). In Vitro Fertilisation act (1988/711), revision, (2002/252, 2005/445, 2006/351). Act Concerning Measures for Purpose of Research or Treatment Involving Human Ova (1991/115), revision, (1995/82, 1998/282, 2003/462, 2005/39, 2006/351). Act on genetic integrity (2006/351), revision (2009/262, 2010/674, 2010/1297)
Nordic reports	Burrell R.(2005) Assisted Reproduction in the Nordic Countries.(102)

Questionnaire study

The advantage of questionnaire studies is the possibility of gathering specific information from many subjects about the same material at low cost. One of the research questions was about the quantity and the possibility of ART treatments performed in the Nordic countries. A retrospective descriptive survey was conducted at all fertility clinics in the Nordic countries, where the directors of the clinics were asked to answer questions about their practices.

Information about the existing fertility clinics and their geographical locations was gathered from the Nordic Fertility Society and from specialists in the field of infertility. A questionnaire and an information letter were sent to 66 fertility clinics in Denmark, Finland, Iceland, Norway and Sweden in the autumn of 2005.

The questionnaire (appendix 1) consisted of three sections with a total of 48 questions, focusing on the results for the 2004 calendar year. Part one dealt with administrative

information, e.g. whether it was a public or private clinic and number of years of practice. The second part was about medical information, e.g. type of ART procedures offered and cost. The last part dealt with the waiting periods and demographic information about the couples.

Two reminders were sent to clinics that had not responded within 1-3 months. Additionally, non-responding clinics were contacted by telephone in spring 2006. Missing data in the questionnaire was gathered by phone or e-mail or by consulting the clinics' websites. Data analysis was performed as descriptive statistics.

Interview studies

The reason for using qualitative methods in this study is the need to enter the unknown territory of the decision-making process of couples seeking help with infertility. We know very little about these decision processes: the reasons for, factors associated with and ways of coping along this chain have not been studied, with the exception of a few studies of why people stop IVF treatment (103,104). The perspective of the chain of decisions is absent both in research and in clinical practice.

To obtain a comprehensive overview of the decision-making process of infertile couples it was of utmost importance to gather information from the couples themselves. When studying a process from one point in time to another, there are two ways to gather information. One is retrospective, to ask the participant to give information about his/her past. The other way is prospective, to follow the participant from the outset with regular contact over a limited time. In this study both methods were used, because of the complexity of the situation and, more importantly, because of the psychological stress of the couples' experience. One of the known coping strategies in a difficult experience is to just plain forget.

The study was inspired by Grounded Theory as developed by Strauss and Corbin (101) and Charmaz (105,106). This version of Grounded Theory is mainly based on ; constant comparison, theoretical saturation and systematic approach. The constant comparison is when a concept is compared with concept and categories with categories until theoretical saturation is reach (101). It was not possible to make a constant comparison analysis according to Strauss' and Corbin's guidelines after every interview. The interviews were conducted in clusters, because of the researcher having to travel to each country and having a limited amount of time (max two interviews per day), so comparisons were made after each set of interviews. This affected the theoretical saturation, since it was not possible to see whether

saturation was reached after 5-10 or 22 interviews. The theoretical saturation point was found after most of the interviews had been analysed. In the Strauss and Corbin version of Grounded Theory the authors advocate taking “appropriate measures” to minimize the researcher's subjectivity intruding on the research (101). They take a more liberal position concerning the role of literature in the research process, maintaining that “all kinds of literature” can be used before a research study is begun (101). Charmaz (101) proposes a constructivist version of Grounded Theory where she emphasises that the reality discovered is a construction and a mutual creation of knowledge between the informant and the researcher. She does not see reality as an external object to be discovered, but rather as a research area that includes another person's comprehensions that we need to interpret in order to understand them (106). Charmaz's theoretical perspective on the role of the researcher is that researcher constructs their grounded theories, unlike Glaser's and Strauss' perspective (107), where the role of the researcher is to discover a theory that is already within the data (105). In this study Charmaz' approach is adopted, since the researcher and the supervisors had many years of experience working in the field of infertility, had met many couples in all stages in their quest for having a child and therefore had existing knowledge and experience that could give an extra dimension to the study. Nevertheless it is clear that this is the story of the couples, not the story of the researcher, and therefore to quote Charmaz; “the product is more like a painting than a photograph” (108).

Procedure

In contrast with a quantitative study design, the goal of the design of this study was to get a reasonable variation of couples to try to grasp the differences in the decision-making processes. Couples were recruited from the five Nordic countries in order to see whether residence affected the decision-making process. The potential variation in age and social situation was the reason for recruiting at public and private clinics located in both small towns and larger cities. The reason for recruiting only couples was that at the beginning of the study all the countries, except Finland, only allowed heterosexual couples to receive ART treatments.

Approval for the study was obtained from the Research Ethics Committees in each country or region before contacting the fertility clinics for recruitment of participants. After the first meeting with a specialist at the clinic the couples were given a letter of invitation with information and a prepaid return envelope. They gave their consent and received information that the researcher would contact them to make an appointment for the interview.

The original plan was to have three couples from each clinic, giving a total of 27 couples. Three couples would give variation, yet result in reasonably manageable data. It turned out that two private clinics had problems recruiting couples, so because of time pressure only one couple was recruited from the private clinic in Norway and none from the Danish private clinic. In the first interview the couples agreed to participate again after approximately 3 years for a follow-up interview. The interviewer contacted them again by telephone and made an appointment for the interview. All couples chose to participate (except one husband who was suddenly indisposed).

Participants

Heterosexual couples seeking ART treatment for the first time were invited to participate in the study. Twenty-two couples from Denmark, Finland, Iceland, Norway and Sweden accepted (see table 3). The criteria for participation were: (i) no previous experience of ART treatment, (ii) no biological children together and (iii) being fluent in Danish, Icelandic, Norwegian or Swedish. In Finland we limited the participation to Swedish-speaking couples, since Swedish is an official second language of Finland.

Table 3. Demographic profile of participants at the first interview.

Demographic profile of participants	
n=22	
Median age of women (range years)	30.5 (23 - 40)
Median age of men (range years)	32.5 (25 - 41)
Mean time of relationship (range years)	6 (2 - 11)
Years of trying to have a child (range years)	2.1 (0.4 - 5)
Number of children from previous relationships	11
Woman's children	5 (4 women)
Man's children	6 (4 men)
Couples with children, % of all couples	3.2

Total number of couples 22. Denmark n=3, Finland n=6, Iceland n=3, Norway n=4, Sweden n=6.

Data collection

For the first interview session the data was collected using a semi-structured interview guide (appendix 2). Each interview was audio taped and lasted from one to two hours. Participants selected the interview location: 11 couples came to the fertility clinic and 11 were interviewed

at home. Both partners were interviewed at the same time by the researcher. Qualitative techniques were used, thereby encouraging the participants to elaborate and reflect on their experience and feelings about their situation. The interviewer could potentially gather extensive information from couples during the interview on specific aspects that came up.

Same data collection method was used for the follow-up interview but with another semi-structured interview guide (appendix 3). Twelve interviews were conducted at the participants' home, nine at the clinic and one in another location.

Data analysis

A total of 44 interviews were conducted. Three fourths of the interviews were transcribed verbatim by experienced transcriptionists in each country in the respective language, and the remaining were analysed by listening and taking notes. The primary reason for not transcribing all the interviews was originally financial, since experienced transcriptionists are expensive. Since slightly different analytical methods were used there was a risk of internal bias. Nevertheless, as became clear later, this method had its advantages since there is a difference between the written and the spoken word, so this gave a new dimension of analysis which is in line with Kvale's discussion about the importance of giving sociolinguistics more room in qualitative research (109). The researcher listened to all the interviews several times and made notes to gather both additional information and nuances. Eighteen interviews from the first interview session and 16 interviews from the follow-up interviews were transcribed, a total of 34 interviews, and 10 were analysed by listening. Although the researcher had a good knowledge of the Nordic languages, it became clear that it was important to have native knowledge of each language to get the right words and meaning when writing. Since external transcriptionists were used, with the exception of the Icelandic interviews, the researcher verified the transcripts by simultaneously reading and listening for anomalies, e.g. specialist words like IVF, ICSI, which were sometimes problematic for the transcriptionist.

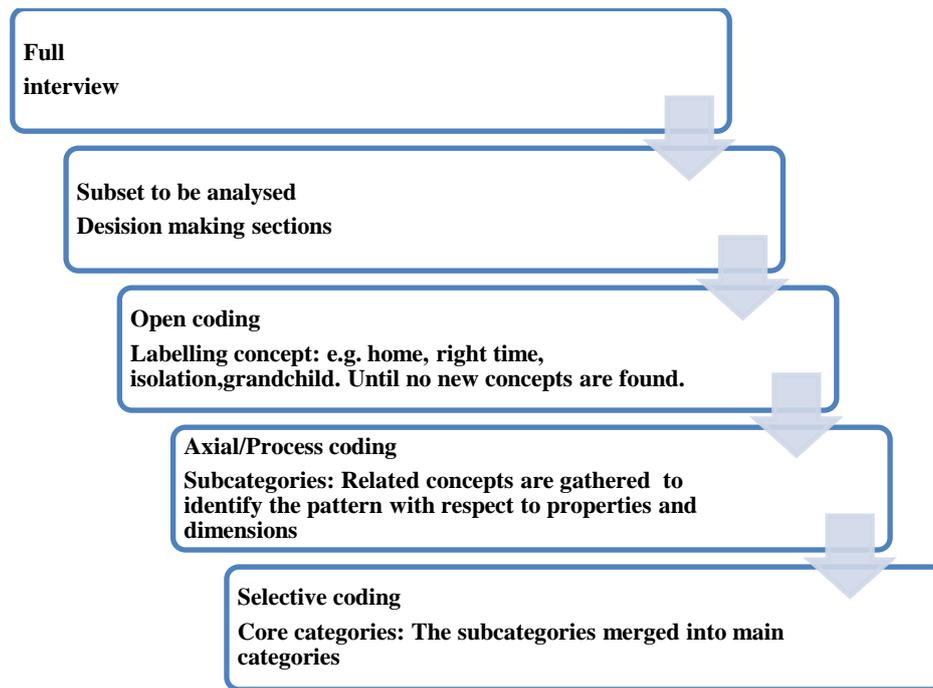
Theoretical saturation for the first interview session was reached after 18 interviews. For the follow-up interview session theoretical saturation was problematic, since new knowledge emerged with every interview and because these were follow-up interviews it was not possible to recruit new couples. The ways of dealing with infertility and the treatments varied greatly among the couples, which had an impact on the decision-making and therefore is difficult to state that theoretical saturation was reached.

When using the tools from Strauss' and Corbin's Grounded Theory (101), one starts by reading the interviews and to perform open coding on them. This is done by labelling the phenomena or the concepts found in the data, giving a name to a relationship or condition of the concept. The use of open coding helps the researcher to question or explore common assumptions about the phenomena and to make new discoveries (101). It is not sufficient to name or label a phenomenon, the idea is to first make subcategories that are later gathered into categories, and then develop a core category for the basis of the theory. The key to open coding is asking questions in terms of properties, such as to find the characteristics or attributes of a category and to discover dimensions of the properties of the concept (101).

In this study open coding was used from the beginning, since the researcher reviewed the interviews and labelled what she thought was the meaning of the participants' thoughts. The goal was to be open to all phenomena that were relevant to the decision-making process. Sometimes the concept or thought was clear, and sometimes it was hidden in a paragraph and surfaced later. The next step of the analysis was axial coding (101), where the researcher linked the subcategories to a category in a set of relationships, conditions, contexts, action/interactional strategies and consequences. The reason was to explore the pattern of the analysis with respect to properties and dimensions. At this stage most of the subcategories were identified.

The last step was selective coding, which according to Strauss and Corbin, is to discover the core categories that can become the basis for a theory (101). One way of working towards this is to make a story line, a process line or a model that shows the relationship between the core categories and the subcategories.

Figure 7. Example of the analysis process.



Methodological considerations

One advantage of qualitative interviews is the possibility of obtaining extensive information by requesting further explanations of specific topics, by reframing the questions and encouraging reflection. The main reason for interviewing the partners together rather than separately, was that process of decision-making was the focus of the study. The decision to seek medical help for infertility is not an individual act on the part of person if living in a relationship, the man and the woman need to negotiate to reach a consensus. Interviewing the man or woman separately would give the individual perspective rather than the couple's perspective on the negotiations. Interviewing the man and the woman together has pros and cons: it was more likely that they could help each other to remember and to elaborate, but on the other hand it was possible that one partner withheld opinions or information to protect the feelings of the other.

Ethical considerations

The first study only used information from official documents, which are referenced to in the normal manner. The second study dealt with fertility clinics. The results are not presented on single-clinic level, with the exception of Iceland, which has only one clinic.

Regarding the interview study, the purpose of a research interview is to gather data for research purposes but not to encourage people to change (99). Kvale defines the research

interview as “*an interview whose purpose is to obtain a description of the life world of the interviewee with respect to interpreting the meaning of the described phenomena*” (109) (pp.5-6). The context or the relation of the interviewees to the research context is the important part. According to Patton research interviews are an intervention in the life of the interviewees (99). Therefore it is important that the purpose of the interview is clear not only for the researcher, but also for the interviewee in order for him or her to be able to make an informed decision on whether to participate. The interviewee should never be left with the feeling of having been used or pressed into revealing too much information.

Kvale also makes it clear that the researcher’s focus is the main driving force. The researcher controls the interview situation, and therefore the balance of power between the interviewee and the researcher is uneven (109). The search for relevant information can make the researcher press the interviewee to go further than is ethically acceptable. In qualitative methods literature, the possible damage done in a research interview has received more attention in recent years (99,110). The national ethics committees are also now more thorough, and in Iceland and Norway it is compulsory to apply for approval for a research interview study. In the Finnish Medical Research Act (488:1999) it is stressed that only researchers with professional know-how are allowed to do research on people (111). This is in line with the Convention on Human Rights and Biomedicine (112).

It is important to bear in mind that without willing interviewees we will not get information to do our research. The researcher should be grateful and handle these opportunities delicately.

For the interview studies in this thesis, approval from the national ethics committees in each country was received before recruitment began. Nevertheless it was important to be sensitive to the couples, since there is a danger that suppressed emotions may emerge when dealing with a sensitive matter such as infertility. On the other hand, the couples were given a chance to discuss the matter with a professional in the field and an experienced counsellor. It can be advantageous to talk to a neutral party and view the matter from a new perspective. Many of the couples expressed their appreciation and asked after the last interview if the researcher would not come again. The couples were offered access to an external therapist if needed, but no couples requested this option.

Summary of findings

The relationship between the papers and theory

Figure 8. The relationship between the papers and theory.

Public health		Psychosocial theories	
Health promotion	Health care systems	Ecological Systems Theory	Decision-making Theories
	Paper I. Access to ART		
Paper II.		The “right time” for a child	
Paper III. Deciding to contact a fertility clinic			
Paper IV. Decision-making during ART treatments.			

The findings are presented as a summary of the four studies, in the same chronological order they were planned and carried out. First the setting, the options available to infertile couples in the Nordic countries are described. Then the couples are introduced, and followed through their decision-making processes, from the initial reasoning about the “right time” for a child and then for a three-year period. One might say that this is the story of 22 couples in five countries who have been dealing with the same problem, each in their own way. There are similarities and differences in both the situations and the decision-making processes. But first an overview of the options available to people requiring ART treatments in the Nordic countries.

Setting

Access to assisted reproduction treatment in the Nordic countries (Paper I)

To understand the decision-making process, it is important to know what the decisions are based on. ART treatments are included in the public health care systems in the Nordic countries, where both public and private clinics are allowed to operate. Denmark has the best access to ART treatments in Europe measured by the number of treatments, and the other Nordic countries follow close behind.

The purpose of the first study was to survey the legal situation for ART treatments, obtain an overview of the possibilities and costs of treatment, and to see the geographical spread of the clinics in relation to the population. This required an analysis of public information, and a questionnaire study to which 52 of the 66 clinics (79%) responded. Twenty-eight were private and 24 public. Of the non-responding clinics, ten were private and three public. The main finding was that couples in the Nordic countries generally have good access to ART treatments, although it is not evenly distributed. Couples living in rural areas have less access to ART treatments, both geographically and financially. Although all countries offer some form of subsidy, they all have restrictions, making only couples that fit certain criteria eligible. The legislation also differs among the Nordic countries, particularly with regard to gamete donation.

At the time of the study, four of the countries had legislation that covered ART treatments. Norway and Sweden were the first to implement such legislation, in the 1980s, and they have revised it regularly since. Denmark and Iceland adopted legislation in 1995 and 1996. Finland had no legislation at the time of the study, but adopted their first law in the autumn of 2007. Since 2004, the legislation in the other countries has been revised, mainly in order to increase the service and treatment possibilities and to prevent cross border reproductive care. For example, in 2004 neither single women nor homosexual couples were eligible to receive ART treatments in any Nordic country that had legislation. Today both groups can receive treatments in Finland, Iceland and Denmark, and homosexual couples in Sweden. Regarding gamete donation, donors are anonymous in Denmark, while anonymity is optional in Iceland, prohibited in Sweden and Norway. Anonymous donations were allowed in Finland before the legislation was adopted in 2007, but now open-identity donations are required. Oocyte and sperm donation is now allowed in all the countries but Norway, where oocyte donation is still prohibited. Embryo donation is allowed today in Finland and Iceland. Surrogacy is not allowed in the Nordic countries.

Table 4. The Nordic countries' ART treatments legislation.

									
	Denmark		Finland		Iceland	Norway		Sweden	
	Pub.	Priv.	Pub.	Priv.	Priv.	Pub.	Priv.	Pub.	Priv.
IUI	X	X	X	X	X	X	X	X	X
IVF	X	X	X	X	X	X	X	X	X
ICSI	X	X	X	X	X	X	X	X	X
FET	X	X	X	X	X	X	X	X	X
AID	X	X	X	X	X	X	X	X	-
OD	X	X	-	X	X	-	-	X	-
ED	-	-	-	X	<i>X</i>	-	-	-	-
<i>Lesbians</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	-
<i>Surrogacy</i>	-	-	X (-)	X (-)	-	-	-	-	-
<i>Single women</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	<i>X</i>	-	-	-	-

Allowed or practiced in 2004 (black). Allowed in 2011 (red italics).

All the countries still have legal restrictions on eligibility for treatment and on who is entitled to subsidies. The clinics are legally obliged to assess the couple in terms of their appropriateness for parenting, by examining their medical, social and psychological situations. In Sweden, equal access to health care is stipulated in the national health care legislation, but some regions offer three fully subsidised treatments while other regions offer one. No such official regional differences are found in the other countries. Restrictions in one country can result in cross-border reproductive care as private clinics in a neighbouring country may offer treatment to couples who are not eligible for a specific treatment in their own country owing to legal limitations. This is further addressed below.

Looking at geographical location, it is clear that not all citizens have equal geographical access since more than one third of the fertility clinics are in large city areas. One explanation for this distribution of clinics may be that some parts of the countries are too sparsely populated to offer this kind of specialised service that probably requires a certain population base to be financially viable. Another explanation may be that the ART treatments are so specialised that the specialists (doctors, nurses and embryologists) performing the treatments

still have, or want to have, the possibility of a relationship with a university hospital. Furthermore, some clinics need to be linked to university hospitals because of the research and training required to perform these treatments. This concentration of clinics to the larger city areas and the absence of clinics in more remote areas may affect couples' decisions about seeking ART treatment.

The difference between subsidy models in the countries is also noteworthy. Each Nordic country has its own model. Denmark and Finland seem to be the most generous with regard to the number of subsidised treatments, so it is not surprising that the highest numbers of treatments per capita are performed in those countries. With regard to Denmark, this may have changed since there have been recent changes to the amount of the user charge. The differences become very clear when we examine treatment costs at private clinics. The cost charged for treatment at private clinics differs considerably among the Nordic countries. In addition to these direct costs, there are indirect costs such as medicine, travel and accommodation.

Cross border reproductive care within the Nordic countries

In recent years the Nordic countries have revised their ART treatments legislation, and today the legal situation is more similar than in the past. Norway stands out by moving towards more restrictive legislation that prohibits anonymous sperm donation. So there is some cross-border reproductive care between the Nordic countries, today, although on a small scale.

In our questionnaire study, 32 of 52 fertility clinics offered ART treatment to couples/women from other Nordic countries, while 19 clinics did not (one clinic did not answer the questions). The particular questions asked specifically only about people from the other Nordic countries. All but one of the private clinics and one quarter of the public clinics offered this service. All of the ART treatments, such as IVF, ICSI and FET, are practiced in the Nordic countries and 56% of the clinics offered these treatments to non-residents. Public clinics in Norway and Finland do not offer treatment to non-residents, and in Sweden donor treatments are only offered to Swedish residents. The other countries have no limitations regarding resident, but non-residents have to pay the full non-subsidised cost.

So there was some availability of ART treatments for non-residents in the Nordic countries at the time of the study (2004), but mainly at private fertility clinic and with limited use. The users mostly came from Norway and Sweden where, at the time of the study, there was strict

legislation, and they went to countries with no or more permissive legislation, such as Finland and Denmark (table 5).

Table 5. Clinics with clients from other Nordic countries, by country of origin, in 2004.

	Denmark		Finland		Iceland*	Norway		Sweden	
	9 pub.	9 priv.	5 pub.	9 priv.	1 priv.	6 pub.	3 priv.	4 pub.	6 priv.
Denmark			0	3	1	0	1	0	2
Finland	1	0			0	0	0	0	0
Iceland	0	1	0	1		0	0	2	0
Norway	3	8	0	5	1			3	5
Sweden	2	5	0	7	0	0	1		

* Number for year 2005.

Denmark, Finland and Sweden are members of the EU (European Union), and with the current discussion about the EU Directive on Cross-border Health Care, citizens of these three Nordic countries will be able to participate in a new open market. Iceland and Norway will be part of that agreement through the EEA (European Economic Area) collaboration, and citizens of Nordic countries will therefore be able to seek ART treatments all over Europe, which will lead to better access to good service and short waiting lists at reasonable prices.

The couples' stories

With this background information, we could begin to ask informed questions about why the couples decided to use these services and their experience. We opened with a discussion of the couples' reasoning about wanting a child, and then what they did when they were faced with the possibility of being infertile and finally their experience of going through treatments. The focus was on the decision-making process during their journey.

When is the "right time" for a child? (Paper II)

"The time was right. I'd finished my studies and we had jobs we thought were secure. We were getting our finances in order and we were sort of grown up."

Wanting a child is merely a start, deciding the exact desired time for conception attempts requires a greater commitment. The step of having the first intercourse without

contraceptives, consciously trying to conceive, means that both partners have reached the decisions to have a child together. The aim of this study was to explore the Nordic couples' reasoning in deciding "the right time" to attempt to conceive a child. Additionally, it was of interest to see whether nationality had an impact on the reasoning. Our results showed that there was no one single reason, but a combination of many that made the time right for the couples. Two main categories were identified; "*prepared for parenthood*" and "*decision-making catalysts*". Feeling prepared was associated with couples considering themselves to have a stable social situation, being in a stable relationship, being at appropriate ages and having a mutual desire for a child. When they felt prepared, the couples became more susceptible to catalysts such as maintaining their social balance and duty to the family. The fear of infertility was the only subcategory that made the couple accelerate the decision independently.

Prepared for parenthood

The influence of the Nordic welfare systems was clear in the category of stable social situation, since the couples were clear about the importance of having the main social factors in place: education, work and home. Parental leave remuneration is closely related to income level. Having reached maximum coverage for parental leave and having a permanent work contract were two of the reasons the couples gave for thinking the time was right. Having a stable relationship and being secure with one another also made it easier for the couple to decide. The length of the relationship ranged from two to eleven years. This category was also influenced by the subcategory of appropriate age. The study included couples from 23 to 43 years of age. Older couples, as well as couples where the man and the woman had a wide age span, mentioned age as an important reason. Women were afraid of age-related infertility, men wanted to still be fit to play with the child, and for the older couples it was a race against time. Younger people, on the other hand, focused on the wish to be young parents.

It is not sufficient to have a stable social situation and to be secure with one's partner and of the right age; both partners must want a child at the same time. The findings of this study show that it takes time to come to a mutual agreement, first on the decision to have a child and second on the "right time". In some couples, one partner had no desire for a child until much later than the other. Some needed to argue their case, while for others seeing close friends or family enjoy their children was the turning point. Four men and four women were already parents from a previous relationship. Even when the relationship with these children

was close, the couple described the importance of having a child together and giving their new spouse the enjoyment of becoming a parent.

Decision-making catalysts

When the couples felt prepared to become parents, they were more susceptible to external pressures or catalysts that affected their reasoning about “the right time”. In this study the impact of friends and family on reasoning was commonly mentioned. The social balance of keeping up with the changes in the group of friends, from being singles with no children to becoming couples with children, had an influence on their reasoning. Many mentioned that they wanted to have children of similar ages as those of their friends in order to share social activities, or that they feared isolation or being “the talk of the town”. Friends also triggered discussions, both when they announced their pregnancy and as role models showing that having a child was manageable.

The concept of duty to the family was seen mainly from the perspective of the potential grandparents, since couples expressed their longing to give their parents grandchildren. This had two dimensions: the grandparents’ pleasure at having a grandchild and the couple’s wish for their child to grow up with energetic grandparents. Furthermore, they felt pressured by comments from their parents, which could be classified as the family pressure as seen in other studies.

The concept of fear of infertility was the only category that would accelerate the decision independently of others. This fear could be caused by diagnosed reproductive problems, such as miscarriages, illness or accidents, or just by a feeling based on personal experience or from within the family. A confirmation of reproductive problems increased the couple’s desire for a child and made them almost immediately start to try to conceive or seek medical help. For the couples with unconfirmed infertility, this fear resulted in making them conscious of not waiting too long to start but did not trigger direct action.

In this study no evidence of nationality affecting the categories was found. This could be attributed to the fact that the Nordic countries have similar social structures. We conclude that the reasoning regarding “the right time” depends more on situation than nationality.

Deciding to contact a fertility clinic (Paper III)

“Maybe you are infertile, but I am not yet!”

The journey to the fertility clinic is a conflicting emotional voyage based on a complex relationship of the options and the decisions of two people. The emotional rollercoaster from enjoying sex and hoping to conceive a child to taking an active initiative to contacting a specialist is a complicated ride.

The aim of this study was to analyse the decision-making process of Nordic couples when contacting a fertility clinic after experiencing reproductive difficulties, and also to determine whether nationality had an impact on this process. The mean time from the couples having experienced or suspected infertility until they made the decision to seek medical help was 2.1 years (range 4 months to 5 years). This decision-making process of the couples had three aspects that needed to be negotiated before they could reach a conclusion. The core category that emerged was *negotiation and re-negotiation*. Firstly, both had to accept that there was a *problem in common*, secondly that *they needed knowledge* and finally *to take action and contact a fertility clinic*. The subcategories that emerged were: i) infertile or not, keeping balance in the relationship, ii) information from social networks, information from the health care system, iii) alternative plans, and the fear of a wrong decision. The couple's decision-making process consisted of constant negotiation and re-negotiation, until they achieved a consensus about seeking medical guidance or getting help to have a child. Couples with known reproductive difficulties arrived early at a mutual decision, while the others described a process affected by both coincidence and negotiations. Men and women reacted differently in several respects.

Problem in common

Being infertile was not a description the couple accepted. For them, being infertile meant never having children, while they were only waiting to become parents, which would happen sooner or later. Men were more reluctant than women both to initiate a discussion about and to acknowledge that there might be a problem. This difference could be a source of disagreement, with women arguing age-related reproduction problems, long waiting times for fertility treatments or emotional strain as reasons for contacting a fertility clinic sooner. The

men's arguments for waiting were that they felt they had not tried for long enough or they needed to wait for the right to public reimbursement for the treatments.

The decision to contact a fertility clinic was mutual and without conflict for couples with confirmed reproductive diagnoses. Even if there were moments of sadness, grief and guilt the "healthy" partner was supportive. The men mentioned the unfairness of the physical difficulties the woman in their lives had to experience, with examination and treatments because of their problem, while some women suggested that their men had the option of finding a new fertile partner. But the couples wanted a child together and therefore they agreed that contacting a fertility clinic would be their best chance.

Need for knowledge

To be able to make a decision you need to have at least some knowledge about the options and possibilities. The couples talked about the importance of making an informed decision, and they actively sought knowledge from sources such as family, friends, colleagues, health care personnel and the Internet. They all agreed that the women were more active in gathering knowledge, and then they gave the men information or tips about where to find more information. Women had more discussion partners, while men mainly discussed the matter with their partner, or used the Internet. Women pointed out the benefits of discussing and getting information from friends or family members who had experience of infertility. Furthermore, the women emphasised the support they received from discussing these matter with close friend or family. Men described the opposite, and experienced the same kind of discussions as prying. Knowledge could either push or delay the decision-making process, in particular friends' or family's experience of successful or unsuccessful treatment influenced the decisions of both men and women.

The information about possible help came mainly through the woman and was then relayed to the man, since it was she who had the first contact with the health care system. The semen analysis came as a surprise to the men, and in some cases the man was reluctant to undergo the procedure, which delayed the whole process. Results from the semen analysis were sometimes given to the woman through her doctor, and then she informed the man. Even though they had sought knowledge from several sources, the couples were often unprepared for the number and types of examinations. The gynaecological examination with the man present often came as a surprise to both partners.

The information from the health care personnel was both used to gain knowledge and as a tool to validate the decision the couple had already made. The couples described the information as beneficial but in some cases as irritating. Some of the couples had already made the decision to get specialist help based on their knowledge and situation, and felt that guidance about the necessity of being patient, or not getting stressed out was not beneficial. Furthermore it was sometimes troublesome for the couple in need of a referral to a specialist if they and their general practitioner did not agree on the next step.

Couples with a diagnosis of infertility contacted the health care system mainly for specific guidance or for a referral to a fertility clinic. In some of the other cases the woman had brought up the problem while was having an individual medical consultation, unrelated to reproductive problems. Men were rarely informed in advance about such consultations.

Taking action and getting help.

Regarding having alternative plans, a sex difference was evident. Women mentioned more often alternative plans such as adoption or gamete donation, and wanted to discuss them. Men said that they wanted to focus on one thing only at the time, i.e. the next treatment, and for them alternative planning meant giving up or losing hope. This was in stark contrast to the women, who said that alternative planning eased the stress or maintained hope for them. Contacting a fertility clinic could also be considered an alternative plan as opposed to conceiving by themselves, especially in cases where there was a long waiting time for the first consultation with a doctor. The couples mentioned that they did not want to regret a wrong decision and to miss the opportunity of getting help to have a child.

Nordic comparisons

There were differences found regarding the structure of the ART service in each country that affected the couples' decision-making. There is an obligatory referral system to the public clinics in all of the countries, but not to the private clinics. Referrals from the general practitioner were most common in Denmark and Norway, while in the other countries it was mainly the woman's private gynaecologist or other health care personnel who referred her to a specialist. The waiting time for the first consultation at the fertility clinic was also important for the couple's decision to register early on, or to go to a private clinic while waiting for their turn for the reimbursed treatment at a public clinic. In Sweden and Norway the couples had experienced infertility for a longer time than couples from the other countries (average 3.3

and 2.7 years, respectively) compared, for example, to Danish couples that had experienced infertility for the average of one year.

Decision-making while taking action (Paper IV)

“It is difficult to make decisions about things that you don’t have a clue about. You just want a child, and they say they can help you.”

The lives of infertile couples during assisted reproduction treatments has been described as stepping onto a train and not being able to disembark until the destination is reached, regardless of whether or not the destination is the desired one.

The aim of this study was to follow the decision-making process of the couples, from the first assisted reproduction treatments and approximately three years onwards. A follow-up set of qualitative interviews was carried out about three years later with the same participants. Out of 22 couples 17 had succeeded in having one or more children by various means, including natural conception, ART, third party donations and adoption. A total of 21 children had been born and one on its way. Three couples were still trying to have a child, either through oocyte donation or adoption, while two couples had not decided how to continue. Appendix 4 gives a more detailed picture of the results after 3 years.

The core category was *“Maintaining control in an uncertain situation”*, with the main categories *“Keeping focus on the goal”* and *“Learning to deal with a new world”*. The couples felt they needed to have some control over their situations and had various methods of achieving it. Still, they all acknowledged that it was difficult, since they had to adapt to the situation and had no control over the outcome.

Keeping focus on the goal

The focus of the couples was on having a child, which was the endpoint of all their decisions. In the beginning the primary wish was to be able to conceive unassisted with their own gametes. As time passed and they received more information during their treatments, they adapted to the new situation and modified their longings accordingly to their options. The process of abandoning the longing of making a child of their own, to choosing help from a third party (gamete donation or adoption) took time and effort. The main goal was to become a parent and they followed the paths that were staked out before them.

Three subcategories emerged: “The driving force”, “belonging” and “strategic planning”.

The men and women expressed their longing for a child, but it depended on the sex who was the more active partner in the decisions dealing with treatments. The majority of the couples mentioned it was the woman who pushed the decision forward. The men said that they felt it would not be “right” to pressure the woman into treatment, since it was she who had to go through all the procedures. They mentioned supporting the woman both verbally and with silence while she reached her decision. Furthermore, the men expressed their worries about the wellbeing of the woman. Having experienced the distress the woman showed after negative results, they mentioned having questioned the point of carrying on with the treatments.

It was usually the woman who had first mentioned other alternatives. For the couples with the options of oocyte donation or adoption, it was an individual process that took time to reach a joint decision on. After they had reached the decision together, all the couples in this situation expressed relief and excitement about the new possibility. Additionally, they were grateful for the adoption classes, which had helped them realise that adoption could be a positive experience.

The couples described the struggle to be simultaneously trying to be prepared for negative results and a possible change in their life if there were positive results. The preparation for a negative result was equal between men and women, with the exception of the first treatment where the majority of the men said that they had expected it to work. Nevertheless, the couples expressed the difficulty of balancing hope against preparing for a negative result, which also became increasingly difficult with each treatment. For some couples, being prepared for positive results meant having prepared their home for a child, including a room for the child, or buying a larger car. Couples also mentioned planning holidays according to whether they were due to have a treatment or might possibly be pregnant.

The category of belonging had two aspects. The first was the couple’s feeling of being in it together and of their decision belonging to them both. All the couples were still together. Some admitted that there had been difficult periods, but no couple said they had discussed splitting up. Many described it as their “*mutual project*”, and most couples expressed that even though it had been individually difficult they felt that the experience had strengthened their relationship. The second aspect was of belonging to a group of people with reproductive difficulties. In this respect, feelings were mixed. Some couples expressed relief at seeing other

couples in the waiting room of the clinic or at the information meetings. They were glad to see that they were not alone and that there were couples “*just like us*” in the same situation. Other couples described the same situations as difficult, and were not happy to take part in a “*kind of group therapy*” that they felt was an invasion of their privacy.

Being strategic in their planning was necessary to optimise their possibilities. Starting an adoption process was an example of this for some of the couples. After a few treatments they had started to suspect that they might need to make that decision at some time. Their reasoning was based on the long process needed for adoption and therefore “*why not have the rest of the treatment and adoption process simultaneously?*” Another strategic plan the couples mentioned was to optimise each treatment by using their frozen embryos before starting a new treatment. This was both physically easier for the woman and less expensive at the private clinics.

Learning to deal with a new world

Most people know how children are made and have some experience of health care services, and yet assisted reproductive treatments are a new world for most people. To deal with all the new information, roles and structures the couples had to find a way to comprehend and react to the new situation. “Trust”, “cultural competence” and “support” were the subcategories that were found.

The couple said that they were relieved at the beginning to be “*in the hands of professionals*” and some expressed great gratitude over the help they received – irrespective of whether or not they had succeeded in having a child. In the beginning they had full confidence in the personnel at the clinic, since the doctors were specialists and knew what was best for them. Nevertheless, many of the couples said that they frequently requested more information, especially concerning their specific condition, and many couples expressed a feeling of distrust caused by not having one primary doctor who was the specialist in their case. In some cases the couple mentioned that they felt that the personnel did not take their requests seriously, did not have the time, or possibly did not know the answers to their questions. Couples who had undergone several treatments but had not succeeded in conceiving expressed a greater need for information and had more questions regarding the treatment than those who had become pregnant after one treatment. Nevertheless couples that who came back to try for a sibling later on also expressed a need for information. Some of the couples felt that the health care personnel did not trust the couples’ judgement, with mainly the pain

reduction during oocyte pick-up treatment being mentioned as a problem. A few women mentioned that their request for pain medication was met with distrust and they had trouble convincing the nurses that they knew what they wanted, even in a case where the woman had a previous experience of treatment.

The couple expressed that they felt, with more experience of treatment, that they got better at understanding and at asking the “right” questions. They expressed their own sense of responsibility to comprehend the doctor’s direct information and in some cases their unspoken messages. On several occasions in the research interviews, the couples expressed the need to read into what the doctor was saying and then to interpret the meaning. The couples often based their decisions on these assumptions. A common remark was “*he/she said it was our decision, but I knew what his/her opinion was*”. They also expressed that they noticed when the personnel were giving them a pep talk, but in many cases they appreciated it. Another aspect of sensitivity to the culture was when some couples mentioned that they were quick to sense when someone was being unprofessional or did not have enough knowledge. Many couples explained the lack of information as the personnel being pressed for time, and therefore also mentioned being reluctant to ask for information.

The couples expressed mixed feelings towards the support from the clinic. Two different couples described the same clinic as “*welcoming them with open arms*” and “*like being a product on an assembly line*”, and in both cases the couples had a child after one treatment. Some of the couples had changed from a public clinic to a private one or vice versa, and felt that private clinics were less stressful and that the personnel had more time for them. Nevertheless, for both private and public clinics, a common remark was that the couples would have liked to be seen and noticed more. Some couples mentioned that a simple question about how they were coping mentally with the treatment would have made a difference. One couple at the clinics that offered specialist psychosocial support had used it. Some couples had not been aware of the service, while others had thought it was only for emergencies or for couples with severe psychological problems.

Nordic comparisons

Some differences related to the structure of the ART treatments services were noticed between the countries. At the time of the study, Sweden and Norway had long waiting times for an appointment at public clinics. Two of the Swedish couples at the private clinic and the only couple from the private clinic in Norway mentioned the long waiting time at public

clinics as a reason for choosing a private clinic. A similar structural reason accounted for couples in Sweden and Denmark wanting to try for siblings to seek medical treatment at private clinics, since the public clinics prioritise couples without a mutual child. In Sweden, specialist psychosocial support was offered at both the private and public clinic, in Finland at the private clinic, in Iceland it was offered but at a cost, and no specialist psychosocial support was offered at the clinics in Denmark and Norway.

Discussion

The world is changing rapidly, demographically and societally. The challenges to the welfare system have changed dramatically in recent years in the Western world, especially in Europe, with an aging population, a decline in the total fertility rate and unstable family constellations. According to Esping-Andersen: “*Solid investments in children now will diminish welfare problems among future adults.*” (55) (p.51). This thesis focuses on Nordic couples’ options and decisions in dealing with infertility. The aim was to obtain an overview of access to assisted reproduction treatments and then to follow the decision-making process and the reasoning of the infertile couples on their journey towards becoming parents. Information about the available options was gathered by examining the legislation and practises in the five Nordic countries: Denmark, Finland, Iceland, Norway and Sweden. The decision-making process and reasoning were then studied on two occasions by interviewing couples seeking medical help at fertility clinics, at the beginning of their journey and then again after approximately three years.

Access to assisted reproduction treatment in the Nordic countries

The access to health care services can be seen from different perspectives. One of the key concepts in the Nordic countries is equal rights to health care service for all citizens. This is one of cornerstones of the Scandinavian welfare model (113). Oliver and Mossialos present a few principles of equity in health care: equal access, utilisation and equitable health outcomes for those who are in equal need of health care (114). Some components are known to be important to the user of health care: availability to certain health care services, quality, cost and information (115). There are also a few barriers to the use of health care but these are related to specific socio-economic, socio-demographic and health characteristics of individuals (116). In this thesis, access to ART treatment was studied from the points of view of legislation, cost, availability and geographic location.

Historically, the Nordic countries have cooperated in many matters, and their citizens have been able to move between the countries with the same social rights and security regarding health care. The Nordic Council has worked to protect these rights and safeguard Nordic cooperation. Three of the five countries are members of the EU, while Iceland and Norway collaborate with the EU through the EEA. The legal environment is constantly changing,

particularly in a field like ART, where technology developments are so rapid. This development has to be dealt with, both from the point of view of ethics and the social norms in society, as well as the cost of these treatments for the health care system. All the Nordic countries now have legislation regarding ART treatments. The need for legislation in this controversial area is indisputable, since the technology is in constant development, so moral and ethical questions arise frequently. Laws concerning ART treatments are mostly from the late twentieth century, while previously regulations were used. The laws prescribe who is allowed to perform ART treatment, who is allowed to enter ART treatment, what it is allowed to do and what is prohibited.

The ART legislation in the Nordic countries has become more uniform in the recent years. Today it is possible for couples, lesbians and single women to receive all types of ART treatments as well as gamete donation in some of the Nordic countries. Single men and homosexual men have no access to ART treatments combined with gamete donation, since surrogacy is prohibited by law in the Nordic countries.

The health care system and health care financing are closely related. The cost of the health care system accounted for between 8 and 9% of the GDP (gross domestic product) in the Nordic countries in 2007, as compared with 7.5% in Europe as a whole (Turkmenistan was lowest at 2.6% and France highest at 11%) (56). As medical technology improves, there is constant demand for the state to provide and prioritise health care services (69-73). Infertility is not a life-threatening condition. Instead, it can be considered a disability that usually does not affect the citizen's ability to participate in society but has great impact on quality of life of the individuals. In the past infertility has mainly been considered a medical condition. Today it is seen more as a social phenomenon, and it can therefore be regarded as much of a problem for single women and lesbian couples as for traditional nuclear families. Over the years, public funding for ART treatments has been a subject of debate (117,118), in particular regarding cost-effective approaches to availability of treatments (119,120) and requirements the patients receiving the service must fulfil, such as age (121). The ART services provided in the Nordic countries are publicly funded and subsidised fully or up to a certain amount. Our findings show differences between the subsidy models in the Nordic countries, and highlight the diversity in the health care economies of the five Nordic countries (Paper I).

Each Nordic country has its own model that has not changed very much in recent years (122,123), with the exception of Denmark in 2010 and 2011, prior to which Denmark and

Finland had the most generous subsidy systems with regard to the number of subsidised treatments. As discussed in Paper I, the subsidy system in Sweden is based on geographical regions and therefore it is difficult to compare on a national level. Both Norway and Iceland have systems in which a certain percentage of the cost or a certain amount is given, with the Icelandic system being particularly complicated (Paper I). In 2006, the Nordic countries were amongst those that reported the highest number of treatment cycles per capita in Europe (10).

Regarding private clinics in the Nordic countries, access is good, there are short waiting times (Paper I), with no need for referrals (Paper II), but with considerable cost to the clients. Additional reasons for seeking service at private clinics include age, parity and feeling pressed for time (Papers I,II). The differences between the ART subsidy systems in the Nordic countries are mirrored to a certain extent in the cost of treatments at private clinics. The treatments are cheapest in Finland and most expensive in Norway and Iceland (Paper I). Nevertheless a study from the UK showed that it was neither the cost of the treatment nor the distance from home that made people choose private clinics, but the success rate (124). Still it is probable that people who have better financial situations also have better access to the services of private clinics, and therefore there is a need to study the reasons for couples who do not use them.

Availability refers not only to treatments but also to clinics, and our findings showed that more than one third of the clinics were in metropolitan areas, where less than 20% of the population lives. Usually there were one public clinic and several private clinics in the capital city (Paper I). This uneven distribution of clinics influences the availability, since in countries as large as most of the Nordic countries people may need to travel long distances to get to the nearest clinic. In a recent study from the United Kingdom it was found that disadvantaged groups (low income or no car) had lower utilisation of health care services than other groups in terms of geographical access (125).

In some cases in the Nordic countries there is an ART clinic right across the border to the neighbouring country, closer to home than the nearest national clinic (Paper I). Studies have shown that the reasons for cross-border reproductive care include legal issues, cost, availability of certain treatments, waiting lists and personal choice (126,127). Our findings support the existence of a flow of patients for treatment between the Nordic countries, and we suspect it is mainly attributable to restrictive legislations in the home country, long waiting times and expense.

When considering the situation in the Nordic countries, it is clear that the barriers described by Wilson and Rosenberg (116) are also present here, in particular socio-demographic and socio-economic factors. There is very good access to assisted reproductive treatments for those of the right age, who live in a metropolitan area and are financially independent, whereas people living in rural areas, who are older and have lower incomes probably have less access to ART services (Paper I). Earlier studies from Finland similarly showed that highly educated and affluent women living in urban areas had more infertility treatments and were more likely to use private clinics (128,129). Therefore, with regard to treatment for infertility, the assumption of equal access to all health care as the cornerstone of the Nordic welfare system is questionable.

Infertility and decision-making

In the United Nations Declaration on Human Rights (1948) and the European Convention on Human Rights (1950) the rights of all men and all women to settle down and start a family are established. One important aspect of implementing this right is to obtain relevant information about their possibilities to have access to safe, affordable, effective, and acceptable methods of fertility regulation of their choice and appropriate health care.

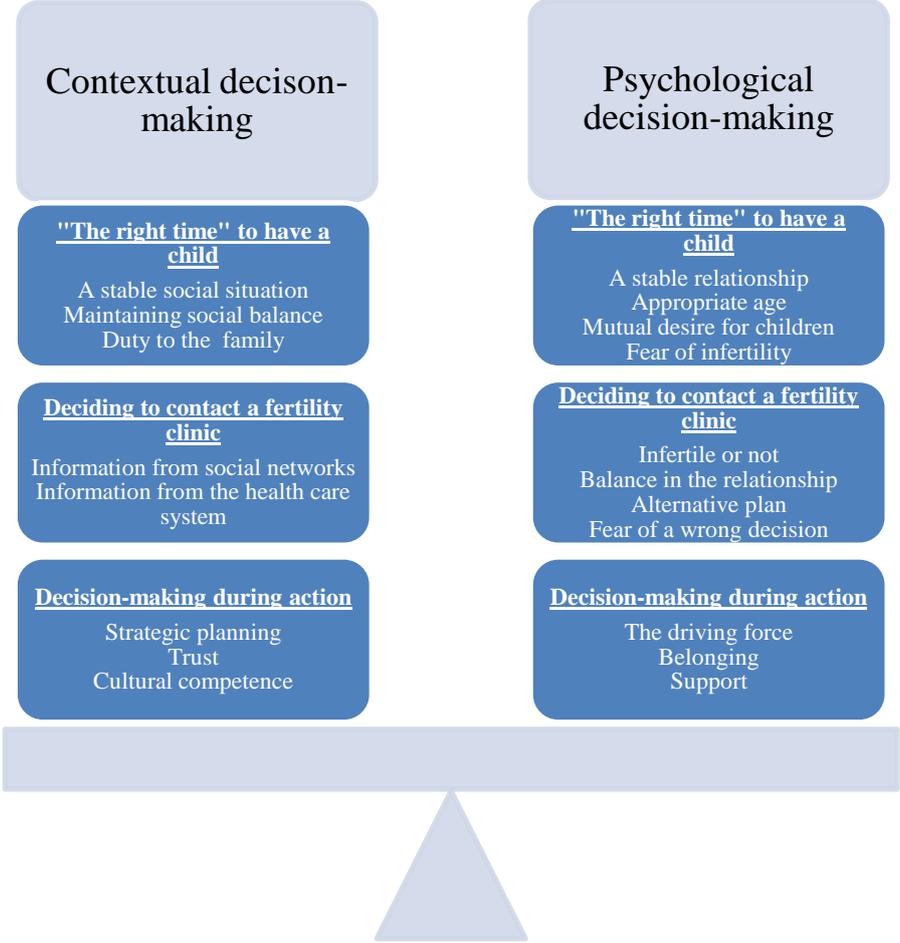
Medical treatments for infertility are almost half a century old, as doctors began to use donor insemination as early as 1950. Advancements in examinations and treatments have been great, with both new medicines, such as synthetic hormones, and microscopic surgery. The first “test-tube baby” (born after IVF) was born in England 1978, and since then millions of children have been born using this technique all over the world. Sweden was the first of the Nordic countries to begin using IVF, with the first child born in 1982 (17). From the very outset there have been conflicts about treatment of infertility, and today there are still people who oppose infertility treatment for ethical, social, religious or medical reasons. Most of the opposition has to do with protests about mankind interfering with nature and “playing God”. Some opposition has also been put forward by people from the medical field, since some professionals are worried about the consequences for the child, of never-ending technology, or are wondering where to stop based on what is ethically correct.

There is often a long process from the point where the couples realise that they are not achieving a pregnancy (or are having repeated miscarriages), until the end point when they may have a child. Coming to terms with infertility is an ongoing crisis until a conclusion is reached. The first shock comes when the couple realises after some time that they may be

having problems conceiving. Having their fears confirmed is another shock that may lead to seeking help. Deciding to undergo treatments, putting your future in other people’s hands, and relinquishing control over it, is mentally, physically and financially a strain for both women and men, as mentioned in the beginning of the thesis. Behind a decision to undergo ART treatment, there must be a strong drive.

Researchers agree that although a decision is an individual act, it is always made in a social context. Influence from others is always a factor. In decision-making there are three actors: a person, an event or a problem, and a social context, that influence each other and the process of making a decision (92,94,130). The finding in this thesis can therefore be divided into contextual decision-making and personal/internal decision-making aspects concerning infertility.

Figure 9. Model of decision-making in relation to the findings.



Contextual decision-making is in line with Ecological systems theory, according to which decisions are affected by the culture of the society, policies, structure of the services, friends

and family. Personal decision-making is based on psychological theories where regret, fear, longing and interaction between the partners influence the decision-making process.

The categories that were found in this thesis show that there is a relation between contextual and personal decision-making throughout the study period. This is in line with MacLeroy et al. (86) Ecological health promotion model, which advocates the importance of focusing on both individual and social environmental factors to understand changes in people.

The decision-making process during the journey to becoming parents

The journey from planning the “right time” to starting trying to conceive a child, to adoption or gamete donation comprises a decision-making process between the two individuals who undertake the journey together. Decisions are made in a close connection to the context in which the couple lives in and their personal desire for a certain kind of life, preferably with children. This process is affected by contextual factors such as their social situation, support or pressure from family or friends, possibilities for treatment and guidance from health care personnel (Papers II,III,IV). The factors linked to the desire for a certain way of life include having confidence in the relationship, and having the same desires and a mutual strategy (Papers II,III,IV).

Using the previous Ecological system model it is possible to see that these different contextual factors have effect at different times. In the beginning external factors such as interpersonal, community and policy influence the decision-making. Deciding to contact a fertility clinic is an intrapersonal negotiation by the couple. At last, when the couples are making decisions while taking action, external factors such as institutional and interpersonal dominate.

Some psychological models have tried to explain the decision-making process, including Narrative models (e.g. the scenario model) of Jungermann and Thüring (1987), the story model of Pennington and Hastie (1986) and the argument model of Lipshitz (1993). A decision-maker will fantasise about the situation, with lots of arguments and consideration of all the possibilities regarding how to act in a given situation (92,93). This is difficult when dealing with a new situation such as infertility, in which case people tend to rely instead on information from a trusted source, such as friends and family, regarding having children (Paper II), health care personnel and people with relevant experience regarding seeking help at fertility clinics (Paper III), and specialists within reproductive medicine during fertility

treatments (Paper IV). The intrapersonal and interpersonal aspect correlates with the Image theory, as it is not only the values and norms of the individual that affect the decision-making process but the mutual values and norms of the couple and their surroundings.

When the couple has gained experience, the recognition models of Klein (1989) can help us understand the continued decision-making process. According to this model, a decision is based on previous experience, but in a new situation more information is gathered. A decision-maker recognises the moment of the decision and thinks back to similar situations, and uses the same strategy again or, if necessary, re-evaluates previous experience to adapt it to the new situation (92). This ability to use previous experience and adapt is powerful in couples dealing with infertility. They adapt their decisions to what is manageable for them, based on their experience, e.g. time schedules or which treatment is available, and they also adapt their desire to what it is possible to get after examining their options (a child from their own gametes, oocyte donation or adoption) (Paper IV).

Sex differences in decision-making

Several studies have shown that women react more strongly to their infertility than men (36,43,131), but these results have also been questioned on the basis of a potential methodological and gender stereotyping bias, since women are generally expected to be more distressed than men (132). In a study from 1990 concerning sex differences in decision-making about infertility treatments (133), it was found that women have greater emphasis on treatment outcome and expected that the treatments would work. Men, on the other hand, have more focus on potential side effects and on taking each step of the treatment as it comes (133). Findings from our studies show different results: women are more concerned about each treatment and the men are more focused on the endpoint (paper IV). The technology and the public debate about ART treatments have changed since 1990, which may explain our different results today. However, there is a study that shows that women are more treatment-oriented and invest more in having a child (134). Our findings show a similar trend, as the women in the study were the active parties in seeking information (Paper III), contacting the health care system (Paper III) and pushing the decisions-making during treatments or opening up to other alternatives (Paper IV), while the men's main role in the decision-making process was supportive. In a few cases the men played the active role in the decision-making, but in that case with the aim of slowing down the decision-process, mainly for financial reasons (Papers II, III,IV).

The reason for this sex difference in the decision-making process may be related to the traditional view that most aspects of reproduction, i.e. pregnancy, abortion and childbearing, are in the women's domain, since they have to do with her body. Reproductive help also tends to come via the woman's gynaecologist and the main treatment load is on the woman, so therefore the focus is on the woman even though the longing for a child is equal (Paper IV). This is in line with other research that has found that men often feel that they are out of place when it comes to decisions related to pregnancy, and experience that the health care personnel do not view them as active participants in the decision-making (135). Another example of sex differences is related to seeking support and using the support system around the couples, where the women were more active and appreciated the support from others, while the men relied on support from their partners and did not seek other support. White et al. presented social cues, such as approval of infertility treatments, perceived pressure and experience and support from friends and family, as having an impact on the decision to seek help (15).

When asked whether they would recommend ART treatment to a friend or family, all couples said they would. This can be interpreted like they were content with their experience of ART treatments or that they feel it is better to act than wait and risk never becoming parents.

When examining the results and other research, it is difficult to adopt the view that a decision about infertility is always totally controlled and rational. There are too many contextual and psychological factors that affect the decision-making throughout the process to be able to say that a person on her/his own can have the capacity to fully understand and validate all the influences is experiencing when dealing with infertility.

Study validity and limitations

The aim of this study was to study the options and decision-making process of infertile couples in the Nordic countries. The researcher and the supervisors are all professionals in the field of infertility (a counsellor, psychologist and medical specialist). The interest and experience of the researchers guided the choice of research topics and questions, and the research questions in turn guided the choice of methods. Various research methods were used and different types of data was collected in order to obtain an overview of the situation. As time passed during the study, legal documents were continually reviewed. In the thesis both the original and revised legislations are accounted for. For the questionnaire study a simple descriptive analysis was performed, and a drop-out analysis is presented in paper I.

Data gathering in qualitative methods is usually based on interviews or observations, which may be a problem with respect to the objectivity of the researcher. The idea of a totally objective researcher is not a reality, and yet there are unrealistic demands for objective findings from interviews. Kvale and Gilbert have discussed objectivity in qualitative research. They argue that because of the human interaction inherent in the interview situation, the researcher's possibility of remaining totally objective in the study is questionable (109,136). This is not only due to the situation, e.g. interviewing, but also to what other characteristics are involved, including gender, age etc. In this study the researcher made all the interviews herself; she is an Icelandic woman in her forties with long experience of doing interview. This experience was mainly advantageous, but the researcher was also aware of the danger of the interview situation becoming a therapy situation. Language comprehension was also a source of concern, since the interviews were carried out in four languages and misunderstandings could easily arise. Repeating and rephrasing was constantly used during the interviews.

To improve construct validity it is helpful to use multiple sources of evidence, known as data triangulation (137), and in this study the data originated from different countries, private and public clinics and towns or large cities. Validity in its purest positivist form is not a possibility in qualitative methodology, since validity is closely linked to hypotheses. From the outset, the process in the study is viewed from different angles. The researcher in a qualitative study does not know what phenomena he will uncover, while in a quantitative study the researcher knows the phenomena he is dealing with. In this study this became especially clear in the follow-up interviews where the only common factor between these 22 couples was that they had taken part in the first set of interviews. As Silverman explains validity, a study is valid if it actually measures what it is supposed to measure (138). Another way of describing validity in qualitative studies is to argue that almost by definition the validity is good in well-performed qualitative studies, since the qualitative study is about what people say or reflect on or write or is expressed in their behaviour, etc. in their own lives (109,139). Kvale describes the validity as the craftsman's skills of the researcher (109). The researcher's skills and integrity are the basis for judging the validity of the research, rather than just the research methods that are being used. But even an experienced researcher can use research methods incorrectly, and therefore it is good to have a set of guidelines to lead the way, for instance by controlling the findings against other findings, or comparing the data from the inside, between subjects, as is done with Grounded theory methods (100,109). To be able to use this in an internal validation control system, it is necessary for the researcher to be critical of his or her analysis and

purpose. If the researcher is critical of his or her own findings and purpose and transparent in her analysis, and describes the process of the research, the criterion for control is achieved.

Like many researchers within the qualitative methodology circles, Yin is critical of the narrow use of the concept of generalisation. He argues that analytical generalisation, where one case can be used as a guide to what may happen in similar situations, is the preferred choice for qualitative research, rather than statistical generalisation (137). In this study Yin's understanding of generalisation has been used. Statistical generalisation is not possible based on 22 couples but analytical generalisation, based on a comparison of the findings and other researchers' findings and relevant theories, could give an indicator of an infertile couple's decision-making process. A Nordic comparison was only made based on the interviewed couples and in relation to different structures of social and health care service, but it should not be seen as a generalisation about infertile persons within the Nordic countries.

One of the limitations of this study is the homogeneous sample. No immigrants participated, probably because of the language requirements (with one exception of a Nordic person moving to another Nordic country). Furthermore, same sex couples and single women/men might have a different decision-making process than heterosexual couples, but at the time of recruitment only a few countries allowed treatments for same sex couples and single persons. Also, there are no couples from private clinics in Denmark and only one couple from a private clinic in Norway, and therefore it is difficult to compare in detail findings related to private clinics. The Finnish sample of Swedish-speaking Finns could have negative impact, as they are considered a minority group, but fortunately some of the individuals belonged to the Finnish-speaking majority.

Another limitation was the classification of infertility due to male, female, combined and unexplained infertility based solely on information from the couples. At the first interview session 6 of 22 couples had confirmed reproductive difficulties due to special medical conditions, e.g. PCOS (Polycystic ovary syndrome) and endometriosis, that all were female factors. At the follow-up interview this information had in some cases changed, e.g. from having PCOS to not having PCOS, or male factor but no endometriosis. So even if this information might have had impact on the decision-making process, it was not analysed since it seemed unstable.

We had expected to find more differences between the countries, but the main difference was related to legislation and the structure of service. The couples' decision-making process was

affected by the service and benefits they could receive in their home country. Residence was however not found to affect psychological aspects such as e.g. the longing for a child, sex differences in dealing with infertility or influences from friends or family. Nevertheless, since the structure of the service is an important part of the decision-making process, a larger quantitative study would probably give greater variance.

Conclusions

This thesis presents the stories of 22 Nordic couples trying to make relevant decisions about how to deal with their infertility, from the time they started to try to conceive until three years later when they either have a child or are still trying. The finding showed that all the couples had an individual decision-making process, and then had to negotiate to come to a mutual decision. No couple had abandoned their quest, which is in line with earlier findings of the researcher who studied Icelandic couples who had not become parents after more than two years had passed since their last treatment. In that study had they had not made the decision to stop, they were only taking a break, planning for adoption or waiting for time to force them to make a decision (104).

A decision is made by a person in a certain situation based on her or his interpretation of the context and feelings. The situation here is the longing to become parents and the context is reproductive difficulties that affect two people who need to come to a consensus. Infertile couples invest greatly emotionally, physically and economically in their quest to become parents. Even with good support from society, the health care system, friends and family the couples struggle with decision-making throughout the whole process.

The role of the society in the decision-making process is large and complex. The legislation and the support the society provides is only one part of the puzzle, norms and values are equally important. If both legislation and norms prioritise certain types of families, then the citizens will try to decide accordingly. Being prepared for parenthood is a social construct based on working situation, partner (although there are a growing number of single women using ART treatments) and housing. The Nordic countries, with their subsidy systems and reimbursements, have both encouraging and deterring aspects with regards to childbearing. If the Nordic countries want to stop the decline in the total fertility rate, there is a need to either make it economically possible for younger people and students to become parents or to increase the possibility of ART treatments for all. More knowledge is needed about decision-making processes among couples before they contact the medical health system in order to ask for help. This knowledge needs to be based on population-based studies.

Knowledge of the complicated decision-making process could help the health care personnel to understand the difficulties the couples experience. The responsibility of the health care personnel is to give the couple time and space to make their own decision. This can be

difficult, since one of the partners may be more active and putting pressure on the other one. The health care personnel's wish to help can escalate relationship problems. The imbalance in the decision-making process is often the first sign that a couple needs time, and sometimes it could be necessary to refer the couple to a psychosocial specialist. Like mentioned earlier, a larger quantitative study in the Nordic countries where the findings of the qualitative study would be measured could give national variation and guide the way forward.

Cross-border reproductive care was only touched on in this study, but needs more attention. The findings showed that within the Nordic countries people travel across the borders to get the treatment they want. Heterosexual couples, single women and same sex couples already travel to other continents for surrogacy or embryo donation. There will be a growing need to study how this affects these families and their surroundings.

This study has only focused upon the topic of infertility and decision-making, but research in this field is only just beginning and there is always another hill to climb. With the rapid development of technology, people with reproductive difficulties will face new options and choices in the near future. It is important to follow the psychosocial process concerning how infertile people will react faced with these new options, which will give them more hope but also make it difficult to know when to stop in their quest for a child.

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