The Long and Winding Road

Emotional Reactions during In Vitro Fertilization and Attitudes towards Cryopreserved Embryos and Oocyte Donation

BY

AGNETA SKOOG SVANBERG

ACTA UNIVERSITATIS UPSALIENSIS
UPPSALA 2003
Dissertation presented at Uppsala University to be publicly examined in Rosénsalen, Kvinnokliniken, Akademiska sjukhuset, Uppsala, Friday, December 5, 2003 at 09:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract

The main aims were to investigate emotional reactions during in vitro fertilization (IVF) treatment among women and men, attitudes of IVF couples towards cryopreserved embryos and public attitudes towards various aspects of oocyte donation in Sweden. Assessments of emotional, physical and social reactions were made on a daily reaction scale and attitudes on the basis of study-specific questionnaires. Both women and men experienced the stages of oocyte retrieval and embryo transfer, as well as the luteal phase, as being particularly stressful and there was a similarity in the type of reaction pattern. Presence of supernumerary embryos for cryopreservation increased the women’s optimism, but did not seem to reduce their level of distress on the day of embryo transfer. One-third of IVF couples chose not to use their cryopreserved embryos. The main reasons among the respondents concerned family planning and too short a legally allowed time of embryo storage. There was strong support for oocyte donation among a subset of the Swedish population. Women were more positive than men towards oocyte donation and to disclosure of the origin to offspring. Factors that might increase the likelihood of women becoming oocyte donors were talking to women with experience of donating oocytes, proximity to the clinic, accessibility of counselling and having children of their own. These results indicate that different approaches to psychological care for women and men may not be warranted during IVF treatment. Contact should be maintained during the cryopreservation period in order to address the couple’s questions and concerns about the embryos. To increase the donor pool, IVF clinics could provide information about donation to potential donors through the Internet and through experienced donors. The information to donors and recipient couples about different consequences of donation seems to be of great importance.

Keywords: attitude, cryopreservation, discarding, disclosure, distress, emotion, gender, infertility, in vitro fertilization, oocyte donation, psychology, public

Agneta Skoog Svanberg, Department of Women's and Children's Health, Uppsala University, SE-75183 Uppsala, Sweden

© Agneta Skoog Svanberg 2003

ISSN 0282-7476
ISBN 91-554-5777-0
urn:nbn:se:uu:diva-3733 (http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-3733)
Till Carl-Henric
Jenny, Johan och Jacob
List of Papers

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


Reprints were made with the permission of the publishers.
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BACKGROUND</strong></td>
<td>1</td>
</tr>
<tr>
<td>Involuntary childlessness</td>
<td>1</td>
</tr>
<tr>
<td>IVF treatment</td>
<td>5</td>
</tr>
<tr>
<td>Oocyte donation</td>
<td>9</td>
</tr>
<tr>
<td>Care of infertile couples</td>
<td>15</td>
</tr>
<tr>
<td>Summary</td>
<td>17</td>
</tr>
<tr>
<td><strong>AIMS</strong></td>
<td>18</td>
</tr>
<tr>
<td><strong>PARTICIPANTS AND METHODS</strong></td>
<td>19</td>
</tr>
<tr>
<td>Papers I and II</td>
<td>19</td>
</tr>
<tr>
<td>Paper III</td>
<td>22</td>
</tr>
<tr>
<td>Papers IV and V</td>
<td>23</td>
</tr>
<tr>
<td><strong>RESULTS</strong></td>
<td>27</td>
</tr>
<tr>
<td>Paper I: Psychological reactions during IVF treatment</td>
<td>27</td>
</tr>
<tr>
<td>Paper II: The impact of frozen embryos on emotional reactions</td>
<td>29</td>
</tr>
<tr>
<td>Paper III: Factors influencing the decision to use or discard cryopreserved embryos</td>
<td>30</td>
</tr>
<tr>
<td>Paper IV: Public opinions of oocyte donation</td>
<td>31</td>
</tr>
<tr>
<td>Paper V: Characterization of potential oocyte donors</td>
<td>31</td>
</tr>
<tr>
<td><strong>DISCUSSION</strong></td>
<td>33</td>
</tr>
<tr>
<td>Psychological reactions during IVF treatment</td>
<td>33</td>
</tr>
<tr>
<td>Cryopreserved embryos</td>
<td>35</td>
</tr>
<tr>
<td>Oocyte donation</td>
<td>37</td>
</tr>
<tr>
<td>Methodological considerations</td>
<td>44</td>
</tr>
<tr>
<td>Clinical implications in caregiving</td>
<td>47</td>
</tr>
<tr>
<td>The future</td>
<td>50</td>
</tr>
<tr>
<td><strong>CONCLUSIONS</strong></td>
<td>52</td>
</tr>
<tr>
<td><strong>ACKNOWLEDGEMENTS</strong></td>
<td>54</td>
</tr>
<tr>
<td><strong>REFERENCES</strong></td>
<td>56</td>
</tr>
</tbody>
</table>
## Abbreviations and definitions

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>IVF</td>
<td>In vitro fertilization</td>
</tr>
<tr>
<td>ICSI</td>
<td>Intra cytoplasmic sperm injection</td>
</tr>
<tr>
<td>FER</td>
<td>Frozen embryo replacement</td>
</tr>
<tr>
<td>TPB</td>
<td>Theory of planned behaviour</td>
</tr>
<tr>
<td>DRK</td>
<td>Daily record-keeping sheet</td>
</tr>
<tr>
<td><em>Cryopreserved embryos</em></td>
<td>Frozen embryos</td>
</tr>
</tbody>
</table>
BACKGROUND

The thesis describes emotional reactions during in vitro fertilization (IVF) treatment among women and men, and attitudes towards cryopreserved embryos among couples who have previously undergone IVF treatment and received such embryos. Public attitudes towards various aspects of oocyte donation in Sweden are also described. Oocyte donation was forbidden by Swedish law at the time of this study, but a proposed bill was considered which would legalize oocyte donation.

Involuntary childlessness

Introduction

A large part of human life revolves around reproductive issues. Most women and men take it for granted that they can have children when they wish to. In 15% of couples (1) however, the desire to become pregnant is not fulfilled within the expected time. Infertility is defined as the inability of a couple to achieve conception or to bring a pregnancy to term after one year or more of regular, unprotected intercourse (1). The incidence of primary infertility in the western world is estimated to be about 5%, and that of secondary infertility to up to about 10% (2). Childlessness is attributable to the woman in roughly half of the cases and to the man in just over one-third, while in the remaining one-fifth of cases the infertility is unexplained (1). The most common causes of infertility are ovulation disturbances, fallopian tube injuries, unfavourable conditions in the cervix and uterus, endometriosis, reduced sperm motility and/or a low sperm account, and immunological factors (1-3). Extreme under and overweight can also be of importance for the reproduction ability. Irrespective of the cause of the infertility, IVF is considered today to be the most effective method of treatment for the majority of those persons who wish to have help for their childlessness. It is only in causes of complete absence of oocytes and sperm that other methods need to be considered, and nowadays oocyte and sperm donation is a possible alternative.
Emotional reactions

Many couples exhibit a reaction pattern which is consistent with a traumatic crisis, with a shock phase, a reaction phase, a processing phase and a reorientation phase (4). Repeated failure to conceive protracts the infertility crisis, and in particular its reaction phase, in which symptoms of depression, guilt and isolation are especially prominent (5-10). Childlessness is often associated with a sense of powerlessness (11), which is directed both at one’s own body, and toward the institutions that determine what help is to be available. Solidarity with one's partner, sexual identity and parental function are all threatened when a couple cannot have children (12). The childless couple often feel excluded from many activities, and experience a loss of the life that they had expected for themselves (13). Childlessness has been characterized as a sense of meaninglessness and lack of coherence, prompting questions on the meaning of life (14). Knowledge about childlessness and about the help that is available is often limited, thus reducing the couple’s options in terms of influencing their situation. Once the couple seek medical help, the evaluation process can be psychologically stressful, often involving repeated examinations of the woman and a need for number of sperm specimens from the man (2). Infertility constitutes a crisis of varying intensity, depending on the symbolic value that infertility has to the individual. Individual sensitivity and adaptation patterns play important roles as the person copes with the situation (12). However, research results suggest that couples entering an IVF programme are, in general, well adjusted (10, 15).

Gender differences in emotional reactions

Women’s and men’s experiences of involuntary childlessness have been described in a number of studies (5, 11, 12, 15-19). Infertility is something that may be unexpected and unknown, both to those who are affected by it and to many others in the environment (11). In one study (20), 50% of the women and 15% of the men had found childlessness to be the most disturbing experience of their lives. Women and men often find themselves in different phases, and can have different perceptions and experiences, even though childlessness is a joint problem (11). The couple may have difficulty in talking about their childlessness, and their ability to reach one another is then limited by an inability to talk about their situation. The creation of a family also involves perceptions of sexual identity, of what it means to be a woman or a man. Motherhood is often associated with the biological phenomena of pregnancy, childbirth and nursing. Solidarity with one’s partner, as well as with one’s own gender, and also one’s parental function with the desired child are threatened when a couple cannot have children. A number of studies have shown that women are more affected by
childlessness than men (21-23). This is manifested as higher levels of depression and anxiety, and also as low self-confidence, guilt, isolation and diminished sexual satisfaction (6, 24-26). Childlessness appears to have an impact on the woman’s entire life situation, affecting her life at work and among friends, and her dreams, while men find that childlessness chiefly affects their relationship with their partner (11). The importance of parenthood for one’s identity is associated primarily with women, but parenthood is also important to one’s identity as a man, and is associated with masculinity. According to some studies (11, 19), men experience childlessness as being stressful to the same extent as do women, but it is in the way in which they handle their grief that the sexes differ. One biological difference between women and men is that women are reminded of their infertility every month through menstruation. Studies of infertile couples have shown that both women and men, but mainly women, find themselves in the midst of a life crisis during the ongoing medical evaluation and treatment (12). Another study indicated that women who continually set their hopes on treatment or adoption options showed less self-esteem and had more feelings of guilt than those who refrained from undergoing new treatments (17). Women who feel badly about their childlessness assume an identity as an infertile person, and that identity becomes central (27).

Reasons for wanting to have children
Having a child is generally considered to be fundamental to one’s existence, and to confer a sense of fulfilment and personal growth (28). Children form part of most young people’s future images. In a Swedish study consisting of 23-year-old women and 25-year-old men (29), 95 % reported that they wanted to have children some time in the future. The desire for a child is also associated with a desire to deepen the relationship with one’s partner. Children give parents the opportunity to experience and give, and also validate the couple’s emotional relationship (11, 12). The factors that are cited as reasons for wanting to have children are not unequivocal or static, but may rather depend on the social context in which the individual lives. Both the individual’s own desires and the expectations imposed by others are significant. Results reported (30) concerning aspects of women’s and men’s urges to have children showed that the desire seemed to be dominated by two conflicting forces, namely the view of children as providing existential satisfaction and children as implying lack of freedom. Infertile couples might have more difficulties than other couples in admitting these mixed feelings, as they might believe that such feelings will hinder their participation in medical investigations and treatments (6). The following reasons for wanting to have children were cited in two Swedish studies among couples affected by infertility (31, 32): Having children was described as “an expression of love”, “the greatest experience one can have”, “an opportunity to care about
something”, enabling the parent to “grow as a person” and “have something to live for”. Having children was viewed as “the meaning of life”. Other phrases used to describe the reasons for wanting parenthood were “a guarantee against loneliness” and “complement our marriage” but also “outside influences”.

Laws regarding IVF treatment in Sweden in effect at the time of the study
At the time of this study, the following provisions applied in Sweden, imposed by the Swedish Act regarding fertilization in vitro (33) and the general guidelines and instructions of the Swedish National Board of Health and Welfare (34):
(a) Fertilization outside of the body may be carried out only for couples who are married or cohabitant, and only if the couple’s own gametes are used. The written consent of the man is required.
(b) Freezing and storage of embryos should be performed in such a way that no doubt can exist as to the identity of the embryos. The right to dispose of the frozen embryos shall be held jointly by the intended genetic parents. Such a right of disposal shall terminate upon the decease of one or both of them, and cannot be bequeathed in inheritance. The freezing of embryos requires the written consent of the woman and the man.
(c) Embryos may be stored frozen for 1 year. The option of individual extensions for increments of 1 year is, however, available and, in practice, no couple who have applied for an extension of the freezing period have yet been denied. A total period of 3 years is permitted, after which, any unused embryos must be destroyed.
The law was amended on 1 July 1998 to permit a cryopreservation period of, in practice, 5 years.

Provisions of law regarding the donation of oocyte and sperm in connection with IVF treatment in Sweden
The prohibition of oocyte donation was mainly based on the difficult ethical considerations involved in this procedure. This method of treatment concerns especially one single individual who has no possibility of making her or his voice heard, namely the child, and the extent to which one should be allowed to influence the creation of a child. Sweden ratified the United Nations Convention on the Rights of the Child (35) in 1990 and is consequently obligated under international law to comply with the provisions of the convention. The convention provides that children are entitled to know their origins and that the best interests of the child must be accorded highest priority (36). Another fundamental precept of the convention is the child’s right to live and grow, which can become a
controversial factor if, for example, an excessively low or, alternatively, advanced age of the woman could entail risks to the child (37).
Briefly, the following legislation relevant to the donation of oocytes and sperm in connection with IVF treatment in Sweden came into force in January 2003.
(a) As a rule in the majority of cases, one oocyte may be transferred into the woman following fertilization outside of the body.
(b) Oocyte donation or sperm donation is permitted in connection with IVF treatment. The donor may be anonymous or known to the couple receiving donated gametes.
(c) The child who results from IVF involving donated gametes shall be entitled to know, upon reaching maturity, both how she or he was conceived and the identity of the donor.
(d) In connection with oocyte donation, the woman who gives birth to the child shall be considered the child’s mother.

IVF treatment
Introduction
The first child to be conceived by IVF was born in 1978, and the first child resulting from the transfer of a cryopreserved embryo was born in 1983. In Sweden the first IVF child was born in 1982, and the number of children born following IVF has increased dramatically ever since. Over the years, different treatment methods have been developed, and new options for assisting couples are available, depending on the underlying cause of the infertility. The outcome has improved continuously, and at present an average of one-fourth of couples undergoing IVF treatment have a child, while roughly one-fifth have a child after transfer of cryopreserved embryos. In vitro fertilization is now a routine procedure in cases of involuntary childlessness (38). Some 7 000 transfers of fresh embryos are performed in Sweden annually, resulting in roughly 2 000 children, i.e. about 2% of all children born in Sweden each year (38).

IVF treatment steps at the time of the studies
In vitro fertilization is usually a relatively protracted process, with a treatment cycle extending over 6–8 weeks from the start to the pregnancy test, and comprising the following steps: the first period of just under 2 weeks is a so-called “suppression phase” in which a nasal hormone spray (GnRHa) is administered 2–4 times a day. This is followed by 2 weeks of daily injections for hormone menopausal gonadotrophin (HMG), during which time the growth of ovarian follicles is monitored ultrasonically on one
or two occasions. This period ended by giving a injection of human chorionic gonadotrophine (HCG) 36-40 hours before oocyte retrieval. The puncture to retrieve the oocyte is ultrasonically guided through the vaginal wall, and a paracervical block and sedatives are normally administered to relieve pain. The man’s sperm specimen fertilizes the collected oocytes, and 2–3 days later (usually) two embryos are transferred. At the time of the study it was routine to transfer two embryos, which led to a number of twin pregnancies. Since that time a change has taken place, and most commonly today one embryo is transferred to the woman. This is followed by roughly 2–3 weeks of hormone support and waiting for the couple until the results of the treatment become known, i.e. until menstruation occurs or pregnancy is confirmed.

The most common IVF methods
At in vitro fertilization entails that in the petri dish the sperm fertilize the oocytes of their own accord. If the number of sperm are insufficient and/or the sperm meet the quality requirements, a single sperm is injected into the oocyte; this method is known as intra cytoplasmic sperm injection (ICSI). If there are embryos in addition to the one or two that are transferred, it is sometimes possible to cryopreserve those, which meet specific requirements. Transfer of the thawed embryos in conjunction with spontaneous ovulation is a procedure known as frozen embryo replacement (FER).

Cryopreserved embryos
In Sweden, roughly one-third of the treatments result in extra embryos, which can be cryopreserved. However, not all couples who have cryopreserved embryos use them and only a few studies have addressed the question of what happens to such cryopreserved embryos (39, 40). According to two previous studies (41, 42), difficulties in maintaining contact with the couple have sometimes resulted in failure to make use of the embryos, which meant they were destroyed once their time limits had expired. In 1996, this caused a major uproar in Great Britain, as some 3 000 cryopreserved embryos were destroyed because their time limits had expired and the affected couples had not been heard from (43). This led to a debate regarding IVF clinic routines, and speculation as to why these couples showed no interest in their cryopreserved embryos. In one study from the USA (44), where embryo donation is legal, the following factors were identified as influencing the decision process with regard to embryos: the couple’s success or failure in having a child, the couple’s views with respect to the embryos, their rights and obligations vis-à-vis the future child, financial compensation, and the desire to help others. In a study in Australia (45), 34% of the respondents said that they were willing to give up embryos
for research. The reason why these individuals were positively disposed towards embryo donation was that they did not want to discard the embryos, they wanted to help childless couples, or they wanted to contribute to greater scientific knowledge. Those who were negatively disposed towards embryo donation stated that they viewed the embryo as a potential child, and that they did not feel they had control over the type of research that would be conducted.

*Emotional reactions during and after IVF*

Childlessness per se is a highly stressful condition and IVF treatment is also often associated with stress, anxiety, expectations and disappointments (7, 9, 19). One-third of the participants in one study (9) evaluated IVF as very stressful. In another study (46), women were asked to rate, on a daily reaction scale, their physical and mental symptoms, first during a normal menstrual cycle and then while undergoing IVF treatment. The results were then compared and indicated that women undergoing IVF treatment experienced more pronounced physical and mental symptoms in connection with oocyte retrieval and transfer of embryos as well as during the luteal phase. There is also some evidence to suggest gender differences in social and physical reactions to IVF. As expected, oocyte retrieval has generally been associated with more physical distress in women than in men (9, 46). In one study (9), it was found that women were more likely than men to emphasize contentment and feelings of intimacy with their partners during the IVF treatment, whereas men were more likely to focus on the hope for pregnancy. In another, retrospective study (7) the researchers found that women were more likely than men to seek support from their family and friends, especially during the days prior to the pregnancy test. These findings indicated that a different approach to the care should be taken with wives and husbands in couples. The most stressful aspects for both women and men appeared to be waiting to hear the outcome of IVF, and on unsuccessful IVF (24, 47).

Sadness is described as being the most common feeling experienced after an unsuccessful IVF (7, 47). From the results of one study (8), it was concluded that the sadness could be more lasting after repeated unsuccessful IVF procedures when no pregnancies occurred and in another study (10) women without previous children reported greater anxiety after failure than women with children. It has also been reported (7, 24) that couples were negatively affected up to 18 months after unsuccessful treatment. When the treatment is successful, women and men differ in a number of personality dimensions and emotional responses to the pregnancy (48) compared to couples that conceived naturally. It was found that IVF women and men with high infertility distress were more anxious about loosing the pregnancy and that
the men were more anxious about the baby not being normal. These findings indicate that IVF couples need additional emotional support in early pregnancy. In another study (49), the pregnancy was particularly stressful for women who had undergone more than one IVF cycle. However, there are areas of care within IVF that have not yet been studied, and new treatment methods are rapidly emerging. Psychological research on IVF has mainly focused on the consequences of childlessness (9, 18, 26, 50) and on describing psychological reactions in women at certain stages during IVF treatment (8, 46, 51-53).

**Stress in connection with infertility**
Feelings of stress are often reported in studies on the emotional reactions of infertile couples, with respect both to their life situation and to their feelings during IVF treatment. In some studies (25, 45, 50, 54, 55) stress has been included among a number of negative emotions experienced during IVF, which have been referred to collectively as “distress”. Entering and undergoing an IVF programme include elements of both controllable and uncontrollable events; couples can decide themselves whether they want to undergo the treatment, but they have little control over the outcome. An individual may experience stress in a situation that is viewed by the individual as putting a strain on or exceeding her or his resources, and thus posing a risk to her or his well-being (56). It has been found that the main factors that elicit an experience of negative stress are loss of control, ambiguity and a lack of predictability (57). Three different stress reactions are usually discussed (56) - emotional, social and physical. These different reactions cannot be regarded as being separate from one another, but are all different aspects of the same process. Previous research (58) described how the feeling of control influences the experience of stress, where stress is defined as the interrelationship between a person and her or his surroundings. While the situational aspects were emphasized previous by the impact of personality characteristics on the appraisal, the choice of coping strategy has been approached with renewed interest in recent years (59).

**Children produced through IVF**
Statistically it has been shown that there is some risk attached to being created through IVF. In a follow-up study of IVF children born in Sweden it was found that such children were more likely to be born as part of multiple births; moreover, a high frequency of multiple births and maternal characteristics were the main factors that led to an adverse outcome (60, 61). There is no evidence that IVF techniques (e.g. ICSI) as such entail an increased risk for the child (62). Earlier research has also shown that the levels of psychological well-being among children, and the family function
in IVF families, are as high as they are in families that have had children the “normal way” (63, 64).

Oocyte donation

Introduction

The first IVF treatment with donated oocytes was administered in 1984, and a growing number of children around the world are now being born from donated oocytes. Oocyte donation was originally introduced for women with ovarian dysfunction (roughly 1% of women under the age of 40) (65). Deficient ovarian function can have various causes for example chromosomal defects, removal of ovaries because of cancer, premature lack of function of the ovaries or certain serious hereditary conditions. Oocyte donation is also recommended in many cases involving women who respond weakly to traditional hormone stimulation and whose IVF attempts with their own oocytes have repeatedly proved unsuccessful. The endometrium can be rendered receptive even 10–20 years after the menopause by appropriate oestrogen/progesterone replacement (65). Since the donated oocytes usually come from healthy, fertile women under the age of 36, the odds of having a child by this method are considered to be high, with a 25–50% chance of becoming pregnant per embryo transfer. Oocyte and sperm donation differ from one another insofar as the female oocyte recipient experiences pregnancy and childbirth, and thus forms a biological tie with the child, while the a man in a couple receiving donated sperm forms no biological tie with the child conceived. Oocyte donation is technically more complex, since the woman who is donating the oocytes has to undergo preparatory treatment similar to that associated with IVF treatment. Simultaneous donations of oocytes and sperm cells are, under prevailing circumstances, not permitted in Sweden, as it is considered important that there be a genetic tie to the child. A special donor record must be prepared and kept on file for at least 70 years (66). The Swedish National Board of Health and Welfare has issued instructions and general guidelines covering, among other things, the monitoring of consent from each spouse/cohabitant, and the importance of psychosocial evaluation and counselling for donors as well as recipient couples. In the context of oocyte donation, the woman who gives birth to the child is viewed as the child’s mother in the legal sense. The term “genetic parent” refers to the person who contributes to the creation of the child, “biological parent” refers to the woman who gives birth to the child and “social parent” refers to the person who is the child’s caregiver (e.g. adoption)
The oocyte recipient

The trend in recent years has been towards an increasingly greater demand for oocyte donation from women aged 40 and over. In most European countries oocyte donation is practiced up to the age of 45–55 (65), and in some countries postmenopausal women may also be oocyte recipients. One important ethical issue is that of the upper age limit for the procedure (67). As more and more women are postponing having children (to avoid conflicts with their professional and career goals), many of the women requesting oocyte donations may be near the menopause. There are medical risks to both mother and child in cases involving mothers who are advanced in age when they become pregnant, and these risks may justify setting an age limit (68). However, it is likely that social preconceptions also play a role in the decision to set an age limit on the right to obtain treatment for involuntary childlessness.

In surveys of the literature on long-term consequences of oocyte donation on the psychological well-being of and oocyte donor families (63, 69, 70) as well as donor insemination families (71), there appears to be no indication of a high incidence of problems with respect to the parents’ emotional state, the quality of their marriage, or the child-parent relationship. One qualitative study (72) which described the trauma of accidentally learning, as an adult, that one is the result of such donation was based on a small number of interviews and the conclusions drawn from this are consequently limited, and stand as isolated accounts.

The donor

An oocyte donor should be less than <36 years of age and healthy, and should have no family history of hereditary disease (73, 74). The ideal donor is also considered to be one who has had children of her own, thus confirming her fertility. To prepare for the donation in question, the donor undergoes ovarian stimulation and a puncture procedure similar to the IVF treatment steps.

In the literature views are divided on the type of donation that is preferable, and the role of the donor in the treatment has been investigated and discussed in a number of studies in various countries (75-79). A donor may be anonymous or known to the recipient, and her motives for participating in the oocyte donation process can vary. Anonymous donation usually means that the donor and couple are not known to one another during the donation process, whereas known donation means that the donor and one or both of the recipient couple are friends or relations. The majority of recipient couples prefer the anonymous approach to donation (80), since they consider that the relationship becomes more complicated if the donor and the
recipient know each other personally. In practice, access to anonymous donors has been limited, which has meant that the only means of effecting a donation has been to bring one’s own donor to the clinic. Consistent with this, a number of clinics have advocated a system in which the couple recruit and bring a donor to the treating clinic’s “donation pool”, but themselves receive oocytes from another, anonymous donor (81-84). Other clinics have preferred known donations, since they consider that this better enables the couple to obtain knowledge of their child’s genetic origins (75, 85, 86).

In both anonymous and known donation, altruistic motives are usually cited by the women as the reason for donating their oocytes (87, 88). The term “altruism” is commonly perceived as being positively charged and the word expresses the moral requirement to live for others and not be guided by self-interest. Altruism thus involves putting the interests of others before one’s own. As an ethical principle altruism means that an action is morally good if it is intended to promote the welfare, happiness or well-being of another individual (89, 90). In addition to altruistic motives, monetary considerations have also been mentioned as reasons for donating (91-93). The dominant attitude in European countries has been that donation must occur on altruistic grounds, and that donors should not be compensated financially. This attitude has presumably been based on the desire to avoid donation becoming a financial option for women of limited means, rather than a considered moral decision. Donors in the USA are compensated more generously, and an American report (94) has discussed that financial compensation is a strong motivating factor for many donors.

Another topic of discussion has been the fact that oocyte donation requires medically initiated ovarian stimulation of the donor, which may entail physical risks. It is for this reason that Denmark allows only donation of excess oocytes retrieved during IVF treatment (shared egg donation). This form of donation provides treatment for couples who cannot obtain IVF under the health care system and who otherwise have to fund it privately. In this way the recipient couple can reduce their costs for their own IVF treatment (95). The main objection to egg sharing concerns the quality of consent given by the donor (95). Some see this approach also as a practical means of facilitating donor recruitment. Others may consider it unethical for an infertile woman to part with oocytes, which could ultimately result in the infertile woman’s oocyte producing a child while she herself remains childless. Another interesting issue concerns the extent to which donors have to obtain their own partner’s consent to donate and whether any previous children should be informed. If the donation results in a number of children, then the donor’s own children will acquire half-brothers and half-sisters, which could lead to problems should these children meet at some point in the future and form relationships without knowing that they are siblings.
Follow-up studies have indicated no particular problems with respect to the psychological well-being of donors (87, 96). However, donors have been reported to experience logistic difficulties, e.g. associated with transport problems or social commitments, and concerns about complications have likewise been described (97). It is believed that the level of satisfaction with the donation process could be improved if donors were offered more information about their donation, and improvements of the donation routines might lead to attraction of more potential oocyte donors (98). Former donors have suggested that infertility clinics should organize discussion groups for anonymous donors, in order to provide post-donation support (99). Some authors are in favour of increased flexibility in the way donors are handled (87, 96, 98, 100).

**Disclosure**

The Swedish law concerning the rights of children to know their origins is founded on the premise that children must be given the opportunity to base their lives on the truth about their genetic origins, and that any other approach would entail an infringement of the children’s personal integrity. It has been considered in many countries that children must be informed that they are the result of donation (70, 99, 101-104), but the additional step towards informing the child of the donor’s identity is viewed as a major one. In 1985 Sweden became the first country to establish by legislation a child’s right to find out the identity of the sperm donor upon reaching maturity. Austria, Switzerland, Holland and the province of Victoria in Australia have now enacted similar laws concerning this right. Now that oocyte donation is legal in Sweden, the same law is also applied to this procedure.

Follow-up studies of anonymous oocyte and sperm donation in other countries and in treatment involving donated sperm in Sweden have shown that few of these parental couples inform their child of her or his origins (70, 74, 103). When the donor is known, most parents plan to inform their child of her or his origins (74). When the donor is anonymous, the proportion of parents who intend to inform their child of her or his origins varies considerably, but it is generally greater among couples who have received a donated oocyte than among those who have had sperm donated (70, 74, 105). In cases of children who have learned how they were conceived and wish to know the donor’s identity, the social authorities in Sweden are obliged to assist in providing information about the donor. To gain an idea of the effect of the Swedish Insemination Act on parental behaviour in this respect in Sweden, the Swedish National Board of Health and Welfare commissioned a questionnaire study in 1998 (103) involving couples who had had children by donor insemination since the enactment of the law. The study showed that only 11% had informed their child of his or her origins.
As many as 20% stated that they would not inform their child, 40% reported that they intended to inform their child in the future, and the remainder were either hesitant or declined to respond to the question. The fact that a substantial proportion of parents who have not informed their child of her or his origins have passed that information on to others (63, 70, 103, 105) increases the risk that the children will learn of their origins in an unplanned manner, and from someone other than their parents.

In the aforementioned Swedish questionnaire study (103), the parents were also asked to comment on their decision to inform or not inform their children about their origins, and the responses were then analysed qualitatively (104). Parents who had informed their children argued that children need and are entitled to know about their origins, and that it is important to maintain openness and honesty within the family. Parental reasons for keeping donor insemination a secret included a desire to protect the children against feelings of insecurity or of being singled out, and to protect the social father from becoming distanced from the child. Parents also expressed uncertainty as to how and when such information should be imparted to the child. These results have been confirmed by international research (70, 78, 106). When the donor is anonymous, the absence of information about the donor may reduce the motivation to share information about the donation with the child. Knowledge about the emotional well-being and possible concerns regarding their genetic origins among older children who are the results of gamete cell donation is extremely limited (69, 72).

Public attitudes toward oocyte donation

In vitro fertilization is viewed today as a relatively established and accepted procedure, and many see it simply as a means of giving nature a helping hand. Oocyte donation, which is a new phenomenon, may be perceived as less natural, since genetic material is being transferred from one woman to another. However, previous studies have shown that people are generally positively disposed towards treatment of infertility by means of oocyte donation (77, 107, 108). Individuals who were themselves either recipients or donors have been reported to express a more positive attitude towards oocyte donation than the general population (77, 107). A clear preference for anonymous donors has been expressed among the general population, as well as among recipients and donors of gametes, and health care personnel working in this field (107, 109, 110). In a Danish study (111), health care personnel in gynaecology and obstetrics advocated anonymous oocyte donation despite the fact that the recommendations issued by the Danish Council on Ethics state quite the reverse. In another study (108) it was similarly found that subgroups of Swedish female patients expressed a
preference for donor anonymity, which is in contrast to prevailing legislation concerning the donation of gametes. The interviewed female groups in the study were women undergoing IVF treatment, infertile women during the investigation work-up, recently delivered women, women applying for abortion and women with Turner’s syndrome. Another study (112), investigated how gene technology was presented in the public debate in Sweden (i.e. in daily newspapers, popular science magazines, journals for professionals). The author concluded that the dominant themes in news articles genre were scientific discoveries and technology in use in scientific and clinical work. Debates in this field mainly concerned ethics and regulation, and gene technology was defined as a problem that concerns the whole of society.

At the international level, the number of procedures involving oocyte donation increases each year, which seems to have lead to greater openness regarding these issues (113). Rapid advancements in medical research have imposed a requirement on researchers to release information so as to initiate an open debate. Such debate is viewed as a prerequisite for the ability to take a stand on the implementation of each new technique or piece of knowledge, and to maintain public confidence. Also, it is considered that by debating and rendering practical that which originally is seen as strange and threatening the public, to become mentally habituated to these issues (114). Concepts of what is natural or unnatural form a part of our cultural pattern for creating order and meaning. Such concepts are thus involved in the deliberations that take place when new guidelines are being formulated. One general problem with respect to new medical knowledge is that it often begins to be applied by clinics before society has had the opportunity to take a position regarding its use.

The term “attitude” is usually defined as the stance, which people take towards a particular issue, and the emphasis is on three phenomena. An attitude is a disposition to respond favourably or unfavourably to an object, a person, behaviour, idea or event (56, 115). Like personality traits, attitudes are hypothetical constructs which, being inaccessible to direct observation, must be inferred from measurable responses. “Cognitive responses” are based on an individual’s statements regarding an issue, “behavioural responses” refer to the act, which an individual performs, advocates or facilitates, and “affective responses” refer to the individual’s valuation of an issue. An attitude can either be positive, negative or ambivalent. Factors that can be presumed to affect an individual’s attitudes are age, gender, ethnicity, knowledge, norms and values in the society, and her or his own experiences. The function of an attitude is to express our values, and to tell the world who we are and what we like and dislike.
Researcher has been particularly interested in the importance of a person’s attitude to a phenomenon for that person’s actual behaviour, and several theoretical models of the relation between attitudes and behaviour have been developed. One of the most interesting is the Theory of Planned Behaviour (TPB) (116). According to this theory the likelihood that an individual will perform a certain behavioural action may be predicted by her or his intentions to perform that behaviour. Intentions to perform a certain behaviour (e.g. to donate oocytes) are influenced by attitudes towards the behaviour, as well as by subjective norms and perceived behavioural control. Attitudes towards the behaviour are shaped by the person’s overall evaluation of the behaviour, which may be positive or negative. Subjective norms involve perceptions of how other people think the individual should behave in relation to the particular behaviour. The term “behavioural control” refers to perceptions of personal control over carrying out the behaviour and also to perceptions of the ease or difficulty in performing the behaviour. This theory has been applied in numerous studies in different fields, such as blood donation, nutrition and diet, smoking cessation and contraceptive use (117-119). In the present thesis TPB was used as the theoretical framework upon which the investigation of women’s and men’s willingness to donate oocytes was based.

Care of infertile couples

Care encompasses a broad range of activities, from high-technology initiatives to support in existential crises, which is particularly required in connection with IVF treatment. Quality in contact, security and staff continuity for the patient are basic to all types of quality care. The concept of security for patients includes finding out what types of help are available, and when they are available (120). The law and general guidelines (121, 122) state that “care must be of high quality and must meet the patient’s need for security”. They further state that “each situation is unique, and care must be tailored to the individual”. An empathic approach has been considered to contribute to a better understanding of the actions or dependencies of an individual who is seeking help. Empathy has been said to go deeper than sympathy, and to involve an understanding of how the other person thinks and feels from his or her own individual perspective (123). Most couples seeking IVF treatment do not live geographically near their treatment location. As a result, much of the communication between IVF clinical staff and couples concerned takes place by telephone. Such telephone calls place heavy demands on sensitivity of staff members to patient’s moods, and increase the need for an understanding of the emotional
swings that women and men endure, both together and separately, during the course of the treatment. The problems associated with providing support by telephone are particularly poignant when pregnancy test results are negative. In a previous study it was found that dissatisfaction with infertility treatment was strongly connected with a negative outcome (when a baby was not born) and with care that was given in a poor manner (124, 125). The most positive treatment experience consisted of respectful, empathic and personal care from the staff (125).

As is the case in many other areas of health care, increasing emphasis is being placed on “empowerment”, that is, on authorizing the individual seeking care to take responsibility for certain elements of her or his treatment, and to participate in its design. This occurs in the IVF context in that the couples are given an opportunity to learn about the various steps involved in the process. Examples of such steps include injection of hormones and taking responsibility for seeing that the various steps in the treatment, with their different associated types of medication, are taken. One important task for caregivers is to support and encourage the couple to believe in their ability to cope with these steps independently. Examinations and interviews during the exploratory and treatment processes may be perceived by the couple as infringements upon their integrity. When interviewing the couple and providing them with the information it should be kept in mind that the medical procedure in itself can create additional problems and conflicts for them. For this reason it is deemed important to involve both the woman and the man with the care given throughout the entire treatment process. It is intended that the holistic approach thus taken in providing care will facilitate a positive solution, regardless of whether or not the couple ultimately have a child (6, 12).

Three Swedish doctoral dissertations (6, 11, 12) have addressed in various ways the psychological consequences of childlessness. These theses discuss gender differences and offer advice on how quality care should be provided. In summary, the authors conclude that quality care requires that the couple be engaged and validated both as a couple and as individuals, a woman and a man. Quality care also requires that the couple be given an opportunity to describe their experiences of the situation, and that they receive proper support (12). The importance of participation by both the woman and the man at visits during the evaluation and treatment processes has also been emphasized, since the woman’s experience of childlessness dominates many of such couples’ accounts (11). Along with other research, these studies have influenced the routines and the concepts that have been applied in our current work with couples undergoing IVF treatment in Sweden. In another recent Swedish dissertation (14), an empirical study of outlooks on life, it was concluded that involuntarily childless couples want to maintain a sense
that they do not control everything, that they are not fully in control of life’s transitional phases. The couples in the latter study who had undergone IVF tried to negotiate the interpretations of the assisted conception to make it a natural process, and restore a “normal family pattern”. The sense of being part of a larger context helped couples to interpret what had happened to them, and why. Throughout the thesis it was postulated that historical and cultural contexts, as well as the concrete situation will affect the content and meaning of views of life (14).

Summary

Studies of emotional reactions of infertile couples during IVF-treatment most often concern only one or a few stages of the treatment, and there is a need to investigate a more comprehensive general pattern. In addition, prospective studies have focused almost exclusively on women, and there is little knowledge regarding the experiences of men participating in IVF-treatment. Despite the fact that cryopreservation of embryos is a common procedure in IVF, few studies have addressed what happens to these embryos at the end of their period of cryopreservation, and what reasons couple’s have for discarding embryos.

IVF with donated oocytes has become increasingly common in many countries and there has been much debate regarding different aspects of this procedure. Oocyte donation has been illegal in Sweden, but during the course of the present study, a new law was proposed to allow such donation. In this proposed law, children born from donated oocytes were suggested to have legal right to obtain identifying information of the donor. Overall, very little is known about the attitudes of the Swedish public towards various aspects of oocyte donation. Furthermore, most other countries have so far experienced a lack of oocyte donors and it seems therefore important to investigate women’s willingness to donate oocytes under the circumstances described in the Swedish law proposition.
AIMS

The aims of the studies were:

1. to describe and compare infertile women and men in terms of their experiences of distress, optimism, fatigue, contact with their partner and social behaviour during IVF treatment (Paper I),

2. to compare the experiences of optimism and pessimism of infertile couples who retrieved surplus embryos which could be cryopreserved with those of couples who did not have such embryos (Paper II),

3. to study factors that influence couples’ decisions to use or discard cryopreserved embryos (Paper III),

4. to describe and compare the attitudes of women and men in the general population towards various aspects of oocyte donation (Paper IV), and

5. to characterize potential oocyte donors among the public and investigate what factors would induce women to donate oocytes (Paper V).
PARTICIPANTS AND METHODS

Table I. Design, methods and participants of the included studies

<table>
<thead>
<tr>
<th>Paper</th>
<th>Design</th>
<th>Method</th>
<th>Study groups</th>
<th>Response rate % (n=)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I-II</td>
<td>Prospective</td>
<td>Daily ratings during the IVF treatment, 7-8 weeks</td>
<td>Systematic sample of 89 infertile couples attending the IVF clinic.</td>
<td>Women 45% (40)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Men 45% (40)</td>
</tr>
<tr>
<td>III</td>
<td>Retrospective</td>
<td>Postal questionnaire</td>
<td>124 IVF couples who had previously received cryo-preserved embryos</td>
<td>Women 66% (82)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Men 60% (74)</td>
</tr>
<tr>
<td>IV-V</td>
<td>Descriptive</td>
<td>Postal questionnaire</td>
<td>Random sample of 1000 women and 1000 men living in Uppsala county</td>
<td>Women 73% (729)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Men 56% (556)</td>
</tr>
</tbody>
</table>

Papers I and II

Participants
Eighty-nine couples were invited to participate in the study described in Paper I and II, and 40 (45%) completed it. The reasons for dropping out of the study were: incomplete protocol due to interrupted hormone stimulation (18%), the couple declined to participate in the study after acceptance or did not wish to continue (15%), incomplete protocol for other reasons (10%), the couple never began IVF treatment (6%), and the couple were still involved in ongoing treatments (7%). There were no differences between couples who completed the treatment and those who dropped out in terms of number of years married, number of years of childlessness or attitude towards infertility (54).

The average age of the women was 32 years (±4.5), and of the men 35 (±5.8) years. The couples had been married for an average of 7 years (±3.4) and
had been involuntarily childless for 5 (±2.9) years. Altogether 45% (n = 18) of the couples became pregnant during the treatment.

Procedure
The study was carried out in two steps:
At their initial visit to the clinic, groups of three to four couples participated in a so-called “information meeting”. On this occasion, the first couple on the list was invited to participate in the study and received a detailed description of the organizational aspects and scope of the study. At this point the couple completed a questionnaire to provide background information, plus a Swedish version of a previously evaluated and published questionnaire concerning their views on their childlessness. This part of the study has been published previously (54). Participating couples were instructed to begin their daily individual assessments of 31 variables on the first treatment day, i.e. the first day of administering the nasal spray, and to continue making these assessments until the day on which their pregnancy test took place.

The instrument
The daily record-keeping sheet (DRK) was designed to assess emotional, physical and social reactions to infertility treatment on a scale of 1 (“none”) to 4 (“severe”) (51) during a period of six to eight weeks. The DRK contains in total 31 items. In paper I and II, 14 of these items were included measuring five variables. The first studied variable included nine negative emotional items that were summed to create the distress subscale (being nervous, irritable, sad, sensitive, pessimistic, angry, quarrelsome, stressed and experiencing mood swings), and the level of reliability has been tested in previous studies, with Crohnbach’s alpha 0.87 (51, 126). Intimacy with spouse comprised two items (affection for spouse, and discussion with spouse). Optimism, fatigue and social contacts were based on single items. Validity has been confirmed by comparison with results from earlier studies (55) and had been shown in a number of ways; the distress level is higher (a) during IVF treatment than during a normal menstrual cycle (46); (b) on days when the treated couples receive negative feedback (127); and (c) when the pregnancy test is negative (51). In one previous study (128) the distress scale was also compared with the Spielberger State-Trait Anxiety Inventory (STAI), and good validity was demonstrated. The Swedish translation proved to be reliable (Cronbach’s alpha 0.91) (126).

Data analysis
Paper I. Emotional, physical and social reactions during IVF were examined using a series of 2 (groups) x 9 (stages) analyses of variance (ANOVA) with
both factors as repeated measures. Significant interactions were followed up with simple main effects tests and simple comparisons. The two groups were: women (n = 40) and men (n = 40). As there were no differences in reactions between the days in HMG and those during the luteal phase, these periods are reported as averages. The nine stages comprised an average of the separate variables, i.e. the 2 weeks of hormone stimulation (HMG), the day of the human chorion gonadotrophin injection (HCG), the day before oocyte retrieval (-1 Retrieval), the day of oocyte retrieval (Retrieval), the day before embryo transfer (Fertilization), the day of embryo transfer (Transfer), the first week of the luteal phase (Days 1-7), the second week of the luteal phase (Days 8+), and the beginning of menstruation or the pregnancy test (Outcome). The days of GnRHa was considered as a pre-treatment period because the only intervention occurring during this period was self-administration of nasal spray.

Various research fields (clinical, psychological, economic) have different operational approaches to analyse the same kind of variables (129). For comparison with the results obtained with the above-mentioned parametric method, analyses with non-parametric methods were performed and will be presented in the following as further information. The stages were examined by Friedman Two-way analysis of variance using the median instead of the mean.

**Paper II.** Data were analysed with a non-parametric method. Only results regarding emotional reactions are included in Paper II (distress, optimism and pessimism). Two days, namely the first day of treatment and the day of embryo transfer, when the couples were informed whether there were enough embryos for cryopreservation, were chosen for comparison in order to determine whether there were any differences in reactions over time. The ratings made on the very first day of treatment were subtracted from those made on the day of embryo transfer. The Mann-Whitney U-test was then used to compare the women (n = 16) and men (n = 16) who received cryopreserved embryos with the women (n = 24) and men (n = 24) who did not; Spearman’s rank correlation coefficient was used to calculate associations between distress, optimism and pessimism. A P-value of <0.05 was considered significant.
Paper III

Participants
During the period January 1994 to April 1995, IVF-treatment was given to 508 couples at a clinic in Sweden. Of these, 124 couples had surplus embryos from the IVF treatment cryopreserved and were invited to participate in the study. After two reminders, a total of 87 women and 79 men responded. Five couples were excluded from the study because they provided information, which was uncertain or discrepant when compared with the information in the records. A total of 82 women (66%) and 74 men (60%) were included in the study. Of these couples, 22 had allowed their cryopreserved embryos to be destroyed. When women and men were compared only the responses from those making up couples were analysed. The average age of female participants were 38.4 (±3.8) years, and that of the male participants 40.6 (±5.0) years. Thirteen of the couples had had children together prior to the IVF treatment.

Procedure
A study-specific questionnaire was constructed and a pilot study was performed on a small group of patients (n = 5). The questionnaire was mailed to the couples together with information about the study and followed by one reminder to non-respondents. The length of time from the IVF treatment to the distribution of the questionnaire in 1999 was considerable, owing to the fact that all the couples were to be given the maximum time allowed to determine whether they wanted to use or discard their embryos that is, 1 year by law but in practice 3 years as a result of extensions granted by the Swedish National Board of Health and Welfare.

The instrument
The purpose of the first section of the questionnaire was to collect background information. This section was followed by 14 structured questions, plus five open-ended questions regarding attitudes toward the cryopreserved embryos. These five questions were aimed to determine why the respondents had allowed their cryopreserved embryos to be destroyed, if such was the case. The structured questions were graded on a Likert-type scale of 1 (“not likely”) to 6 (“highly likely”), or on a scale of 1 (“don’t agree at all”) to 4 (“agree completely”). Space was provided for comments on each question.
A Likert scale or a Likert-type scale is a widely used scaling technique (130). On the scale, the rater expresses an opinion by rating her or his agreement with a series of statements. The unique characteristic of this scale is that responses are framed on an agree-disagree continuum. The given statements should therefore clearly reflect different positions regarding the issue. The aim is to spread out respondents with various attitudes. Both positively and negatively worded statements should be chosen to avoid biasing the responses. The internal drop-out rate for each structured question varied among the women and men in our study from 0% to 5%.

**Data analysis**

Data were analysed with non-parametric methods. The Sign test was used to compare responses from women and men on a couple basis (n = 74). The Mann-Whitney U-test was used to compare differences between couples who used their cryopreserved oocytes (n = 60) and couples who discarded them (n = 22). The responses to the unstructured questions were checked repeatedly to detect patterns and common themes in the material (131, 132). Meaning units with the same content were categorized into sub-themes, which were subsequently organized into four themes. The meaning units were then sorted into the four themes by two independent persons (Kappa = 0.77). Differences in assessments of quotations were then discussed. A \( P \)-value of <0.05 was considered significant.

**Papers IV and V**

**Participants**

The study population comprised 1,000 women aged between 25 and 35 years and 1,000 men aged between 25 and 40 years randomly selected from the national tax register (133). These particular age groups were chosen because they roughly represent the populations of potential oocyte donors and recipients, and their partners. Three reminders were sent. A total of 729 of the 1,000 women (73%) and 556 of the 1,000 men (56%) completed the questionnaire. Fifty-six (3%) envelopes were returned unopened because the persons were either mentally handicapped, had difficulties in understanding Swedish, were living abroad, or had moved without giving a new address. As the third reminder included a shorter version of the questionnaire, 37 women (4%) and 43 men (4%) answered only some of the questions. The great majority of respondents were born in Sweden (90%). There were higher percentages of non-respondents in rural areas (35–47%) than in the largest town, Uppsala (27%). Non-respondents and respondents did not differ with regard to age.
Procedure
This study was a randomized questionnaire study targeting women and men in the county of Uppsala. In February 2002, about 2 months before the decision to allow oocyte donation was made in the Swedish parliament, a questionnaire was mailed to a selected sample of women and men, together with an accompanying letter explaining the purpose of the study and an invitation to participate. In addition, the proposed law, including the stipulation that at a mature age the resultant children should have the right to obtain identifying information about the donor, was briefly described, as also was the procedure of oocyte donation.

The instrument
A study-specific questionnaire concerning attitudes towards oocyte donation was constructed on the basis of previous research and of explorative interviews with eight women and two men. Relevant items were selected in order to get relevant background data. “The Theory of Planned Behaviour” (116) was chosen as the theoretical framework for the investigation of women’s willingness to donate oocytes. A number of statements were formulated for assessment of the TPB components, as well as of attitudes towards various aspects of oocyte donation. The respondents were asked to indicate on a five-point scale to what extent each attitude statement applied to them. For each statement it was possible to respond with “cannot form an opinion”. A pilot study was performed on a group of student nurses (n=25), and on the basis of the results and of comments by these students, the questionnaire was revised. Responses from participants in the pilot study indicated that most sections concerning TPB components were not suitable for women with no or little interest in becoming an oocyte donor. These sections concerned attitudes towards the behaviour (consequences of oocyte donation and evaluation of the act of donating oocytes), subjective norms (support from the partner, family and friends) and behavioural control (perceived control over the behaviour). According to the instructions in the final questionnaire, these sections were to be completed only by women who stated that they would consider donating oocytes in the future. The final version of the questionnaire included items covering the following areas. Some items were reversed so that higher scores consistently indicated a positive attitude.

Questions covering the following items were answered by all participants
Attitudes towards oocyte donation in general (five items). Cronbach’s alpha value 0.67.
Attitudes towards specific components in the procedure of oocyte donation (six items).
Attitudes towards parenthood (six items). Cronbach’s alpha value 0.86.
Attitudes towards the genetic link (four items). Cronbach’s alpha value 0.80.
Attitudes towards disclosure to offspring (six items). Cronbach’s alpha value 0.78.
Response to a recruiting advertisement (four items).
Willingness to donate oocytes in the future/support partner’s decision to donate (one item)
Factors that would induce women to donate (twelve items).
Questions covering the following items were answered only by potential donors
Perceived consequences of oocyte donation (seven items).
Evaluation of the act of donation (four items).
Perceived social support (one item).
Perceived behavioural control (one item).
The importance of having persons to consult (two items)

Data analysis
Comparisons of women’s and men’s background data and comparisons of women’s and men’s choices of assisted reproductive technology (ART) methods were made with chi-squared tests. Median (Md) values were calculated for each attitude sub-scale and person. Some items were reversed so that higher scores consistently indicated a positive attitude towards each aspect of the four sub-scales. The Mann-Whitney U-test was used for comparing median scores of (a) women and men; (b) respondents with and without experience of infertility; (c) respondents with and without children of their own; and (d) respondents who had and did not have previous information regarding oocyte donation. Respondents who could not form an opinion regarding more than one-third of the items in a sub-scale were excluded. For comparisons of single statements, the Mann-Whitney U-test was used on original five-step data. A P-value <0.05 was considered statistically significant. 

Multivariate regression analysis. Much research in the health sciences field is motivated by a desire to understand, describe and make use of the relationship between independent variables and a dependent variable. In this study, several regression analysis was performed to measure the power of independent variables to explain the women’s interest in donating oocytes. When multiple regression is used, in studying the effect of a particular variable, adjustment can be made for the effects of the remaining independent variables. This kind of analysis made on our data did not add further information of importance compared to the non-parametric analysis. The results of multiple regression analyses were therefore excluded from the
published papers concerning oocyte donation and are only presented as additional information in this thesis.

**Analysis I.** Women’s willingness to donate oocytes in the future (one item) was chosen as the dependent variable. The three response alternatives of this item were consolidated into two dichotomous variables, which meant that the response alternatives “yes” and “probably” were consolidated into “yes” ($n = 416$), while “no” simply remained “no” ($n = 271$). A number of independent variables were chosen: age, education, marital status, own children, nationality, religious affiliation, active in a charitable organization, blood donor, previously received information about oocyte donation, and whether the subject knew anyone in her or his circle who had infertility problems. The analysis also included four sub-scales measuring attitudes towards oocyte donation in general (five items), giving information to offspring (six items), parenthood (six items), and the importance of the genetic link (four items).

**Analysis II.** The correlations between the dependent variable “women’s taking initiative after having read a recruitment advertisement concerning oocyte donation” and a number of independent variables was studied. The dependent variable was divided into two groups: those who responded “very likely” or “quite likely” to any of the sub-questions formed one group, the “active” group ($n = 264$), while the others formed the “inactive” group ($n = 419$). The independent variables included background data (age, education, own children, previously received information about oocyte donation), four attitude sub-scales (attitudes towards oocyte donation, information to offspring, parenthood and the genetic link) and the TPB-scales.

All the studies were approved by the Local Ethics Committee of the Medical Faculty of Uppsala University.
RESULTS

Paper I: Psychological reactions during IVF treatment

Fig 1. Distress and optimism levels in women and men as a function of IVF.

The ANOVA results for the distress subscale showed a significant main effect of sex \((p<0.05)\), showing that overall women reported more distress during the treatment than did their partners (Fig.1). There was also a significant main effect of stage \((p<0.05)\), indicating that the most distressing stages of treatment for both women and men were the active stages of oocyte retrieval and day of embryo transfer.
retrieval, embryo transfer and the pregnancy test. The women and men experienced similar levels of optimism during the treatment, and this was most pronounced during oocyte retrieval and embryo transfer. Spouses reported more intimacy on the day of retrieval and the day of transfer than on other days. “Intimacy” followed a pattern similar to optimism and stage of treatment had a significant main effect on intimacy (p<0.001) except during the final week before the pregnancy test, when the women experienced decreased intimacy with their partners (p<0.01). The women felt more fatigued than the men throughout the entire treatment (p<0.01), and experienced especially pronounced fatigue in connection with oocyte retrieval. Overall there was a tendency for women to report more social contact with family and friends than men.

Table II. Mean (standard deviation) of women’s and men’s distress reactions at the nine different stages of IVF treatment as assessed on a scale of 1 (“none”) to 4 (“severe”).

<table>
<thead>
<tr>
<th>Variable</th>
<th>HMG HCG -1 Retrieval</th>
<th>Retrieval</th>
<th>Fertilization</th>
<th>Embryo-transfer</th>
<th>Day 1-7</th>
<th>Day 8+</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress Women</td>
<td>1.4(0.4) 1.4(0.4) 1.4(0.5)</td>
<td>1.4(0.3) 1.3(0.3) 1.4(0.3)</td>
<td>1.3(0.3) 1.4(0.3) 1.3(0.3)</td>
<td>1.3(0.3) 1.5(0.4) 1.6(0.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distress Men</td>
<td>1.3(0.4) 1.3(0.3) 1.3(0.3)</td>
<td>1.3(0.3) 1.3(0.4) 1.3(0.3)</td>
<td>1.3(0.3) 1.4(0.4) 1.5(0.5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism Women</td>
<td>2.8(0.8) 2.9(1.0) 2.9(0.9)</td>
<td>3.2(0.9) 3.0(1.0) 3.2(0.9)</td>
<td>2.9(0.8) 2.5(0.8) 2.6(1.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism Men</td>
<td>2.6(0.9) 2.9(0.9) 2.9(1.1)</td>
<td>3.1(0.9) 2.8(1.0) 3.2(0.8)</td>
<td>2.8(0.8) 2.6(0.8) 2.6(1.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimacy Women</td>
<td>3.4(0.5) 3.4(0.6) 3.5(0.6)</td>
<td>3.6(0.5) 3.5(0.6) 3.6(0.5)</td>
<td>3.5(0.5) 3.4(0.6) 3.6(0.5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimacy Men</td>
<td>3.5(0.5) 3.5(0.6) 3.5(0.7)</td>
<td>3.7(0.5) 3.6(0.5) 3.7(0.4)</td>
<td>3.6(0.5) 3.6(0.5) 3.6(0.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue Women</td>
<td>2.2(0.8) 2.3(1.1) 2.1(1.0)</td>
<td>3.0(1.0) 2.2(0.9) 2.0(1.0)</td>
<td>1.9(0.8) 2.0(0.7) 2.0(1.0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue Men</td>
<td>1.7(0.7) 2.0(0.9) 1.8(0.9)</td>
<td>1.8(1.0) 1.6(0.8) 1.6(0.8)</td>
<td>1.7(0.7) 1.8(0.7) 1.6(0.9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social contacts</td>
<td>2.4(0.7) 2.2(0.9) 2.0(0.8)</td>
<td>1.6(0.8) 2.1(0.9) 2.1(0.9)</td>
<td>2.3(0.8) 2.2(0.7) 2.2(1.0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social contacts</td>
<td>2.1(0.7) 2.1(0.9) 2.0(0.9)</td>
<td>1.8(0.9) 1.9(1.0) 2.0(0.9)</td>
<td>2.0(0.8) 2.0(0.8) 1.9(1.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The parametric and the non-parametric methods of analysis showed different results in the comparisons between women and men for the variables distress, intimacy and social contacts (Table III). The parametric analyses are based on the mean value and the non-parametric analyses are based on the median.
Table III. Comparison between different statistical methods for calculating differences between women and men over time.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Sex by stage interaction</th>
<th>Sex by stage interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parametric analyses</td>
<td>Non-parametric analyses</td>
</tr>
<tr>
<td></td>
<td>$p&lt;0.05$</td>
<td>$p&lt;0.05$</td>
</tr>
<tr>
<td>Distress</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Optimism</td>
<td>0.05</td>
<td>NS</td>
</tr>
<tr>
<td>Intimacy</td>
<td>0.01</td>
<td>NS</td>
</tr>
<tr>
<td>Fatigue</td>
<td>0.001</td>
<td>0.001</td>
</tr>
<tr>
<td>Social contacts</td>
<td>NS (&lt;0.10)</td>
<td>0.05</td>
</tr>
</tbody>
</table>

NS = non-significant

Paper II: The impact of frozen embryos on emotional reactions

We found that the women in couples who had extra embryos to cryopreserve were more optimistic on the day before the oocyte transfer than were those who did not have extra embryos ($p = 0.024$). Correspondingly, the women who did not have extra embryos to cryopreserve were more pessimistic than those who did have extra embryos to cryopreserve ($p = 0.014$). No such differences were seen among the men. Among the women there were significant correlations between distress and pessimism ($r = 0.644; p<0.01$), pessimism and optimism ($r = −0.535; p<0.01$) and optimism and distress ($r = −0.436; p<0.01$) on the first day of IVF treatment. Similar correlations were found among the men, with the exception of a weak non-significant correlation between optimism and distress ($r = −0.186$). On the day on which the embryos were transferred, there were significant correlations between pessimism and distress and between pessimism and optimism among both women and men, but non-significant correlations between optimism and distress ($r = −0.167$ and $r = −0.135$, respectively).
Among couples with cryopreserved embryos (n=74) the women were more inclined than the men to want to use them on a later occasion (p = 0.014). Before learning the results of the IVF treatment, 18% (n = 13) of the women and 27% (n = 20) of the men were uncertain about whether they would subsequently use the embryos. After they had found out the results, roughly 20% of the participants in both groups were hesitant. Half of the couples had wanted an opportunity to continue to cryopreserve embryos for a longer time, while 34% (n = 8) of those who destroyed their embryos felt that the cryopreservation period had affected their decision. The risk that cryopreservation would have a negative impact on the resulting child was a matter of concern (23% of the women and 28% of the men) (p = 0.01). Couples subsequently described these concerns in their own words; in summary, they were worried that the freezing process as such might cause physical and mental damage.

The responses to the unstructured questions were classified into four themes: *Ethics and morals*, that is, responses associated with ambivalent feelings about discarding life and the ethical dilemma concerning what the embryos represent. Quite a few respondents called the cryopreservation process into question and considered it to be an unnatural step. *Security and hope* responses were associated with additional chances of becoming pregnant and emphasized the embryos as potential future children, and as a source of security in the event of some negative event during or after the IVF treatment. *Anxiety and grief* responses expressed anxiety over the impact of cryopreservation on the foetus or child and also included the question of what would happen to the cryopreserved embryos if they were not used. *Practical consideration:* family planning and an excessively brief cryopreservation period were dominant concerns for a number of couples.
Paper IV: Public opinions of oocyte donation

The majority of both women and men agreed with the statement “Oocyte donation is a good way to help childless people”. With regard to general attitudes towards oocyte donation, women were significantly more positive than men (sub-scale p<0.001). For example, women would be more supportive of friends who wanted to donate or receive oocytes (p<0.001).

The majority of both women (83%) and men (79%) considered that “Parents should be honest with their children with regard to their genetic origin”. Half of the respondents agreed with, and about one-third disagreed with the statement “As an adult the child should be able to find out the identity of the egg donor”. Overall, women had a significantly more positive attitude towards disclosure to the child than did men (sub-scale p<0.001).

Overall, the men placed significantly more importance on the genetic link than did the women (sub-scale p<0.001). In contrast, different aspects of having children were of significantly greater importance to women than to men (sub-scale p<0.001).

Seventeen per cent of the women said they would consider donating oocytes anonymously to another woman in the future, while 56% of the men said they would support their girlfriend/wife’s decision to donate.

Regarding the methods that the subjects said they would consider in the event of difficulties in having a child of their own, a larger proportion of men than of women said that they considered anonymous oocyte donation to be acceptable (p<0.001). Donated oocytes from a friend or relative were favoured less frequently by both women and men.

---

Paper V: Characterization of potential oocyte donors

The sample (n=729) was split into three groups according to women’s willingness to become oocyte donors: “Potential Donors” (n = 120; 17%), who reported that they would be willing in the future to donate oocytes anonymously; “Non-donors” (n = 286; 39%), who were unwilling to donate; and the women in the “Doubtful group” (n = 318; 44%), who were unsure or who could not form an opinion on the subject.

The Non-donors were more likely to have children of their own than were the other groups. The Potential Donors were generally more in favour of oocyte donation than were Non-donors and the Doubtful group (sub-scale p<0.001). In comparison with Non-donors, the Potential Donors and the women in the Doubtful group were more negative towards having an age limit of 43 years for oocyte recipients. In addition, the genetic tie between parents and offspring was less important to Potential Donors than it was to
Almost half of all the respondents (43–48%) were positive towards giving the offspring information about the donor’s identity at a mature age, while one-third were opposed to this (27–32%). Almost half of the Potential Donors answered that they would not want any information regarding the well-being of the child, and one-third stated that they would not appreciate it if their biological child at a mature age tried to contact them. Twenty-two per cent of the Potential Donors stated that they thought they would brood about the donation for the rest of their lives. Almost half of the respondents considered that women would be more likely to become oocyte donors if they were able to speak to women who had already donated oocytes, if they could undergo the procedure at a hospital or clinic in their area, and if they already had children of their own.

Multivariate regression analysis.

Analysis I. Logistic regression analysis indicated that the group of women who might consider donating oocytes (i.e. both the Potential Donors and the Doubtful women) included a significantly higher frequency of women without children of their own (odds ratio (OR) = 1.8; 95% confidence interval (CI) = 1.3–2.5) and with the opinion that the sub-scale concerning the genetic tie between the parents and the child was of less importance (OR = 0.3; 95% CI = 0.2–0.5).

Analysis II. The respondents who took initiative after reading an advertisement were significantly associated with more positive attitudes towards oocyte donation in general (sub-scale n = 632; OR = 0.3; 95% CI = 0.1–0.7), with more positive attitudes towards parenthood (sub-scale n = 662; OR = 0.4; 95% CI = 0.2–0.8) and with brooding less about the oocyte donation (single item n = 102; OR = 2.2; 95% CI = 0.1–0.8).
Psychological reactions during IVF treatment

Psychological studies concerning infertility have generally emphasized differences in emotional reactions between women and men rather than showing similarities. However, using a daily monitoring method we found that whereas women reported more distress than their partners during IVF, there was a remarkable similarity in the pattern of couples’ reactions to the different stages of treatment. Specifically, women and men were consistent in their emotional and social reactions to oocyte retrieval, fertilization, embryo transfer and the pregnancy test. Based on the pattern of ratings across the different stages of IVF, we found that the days surrounding retrieval and transfer of embryos were associated with pronounced changes in reactions in both women and men. During these stages, couples reported mixed feelings, with increased levels of intimacy and optimism regarding pregnancy occurring alongside greater distress, more social withdrawal and (in women) greater fatigue. These reactions cannot be regarded as isolated from one another, but are all different aspects of the same process (56, 58). While the changes in social contact and fatigue may be attributed to the physical demands of treatment, the more ambivalent feelings appear to be due to psychological factors. Closer examination of daily reactions during the four days between the HCG injection and embryo transfer suggests a pattern of anticipatory distress prior to events, with a concomitant increase in more positive reactions as these stages pass. These ambivalent feelings were characterized in a previous retrospective study (9) as “cautious optimism”, and may be attributable to the uncertainty felt by the couple concerning the final outcome. In other infertility studies (134, 135) this cyclic pattern has been expressed in terms of fluctuations between worry and confidence, frustration and relief, and sadness and elation. The similarities in the partners’ reactions to these stages of treatment suggest that women and men are equally affected by the uncertainty of treatment but that women experience the distress components more intensively.
Optimism increased and contact with the partner was more intense in connection with oocyte retrieval and embryo transfer. Our results indicate, however, that this optimism is short-lived, and that it diminishes in both women and men during the luteal phase. One retrospective study (9) has indicated that women stress more strongly the importance of intimacy during this phase, while men experience a renewed hope which arises following the transfer of the embryos. These results are not supported in our study, and the discrepancy may be attributable to differences in study design, since the cited study was retrospective and ours was prospective.

One interesting finding in our study was that, compared to men, women reported that they experienced less intimacy with their partner during the week prior to the pregnancy test. One may speculate whether the physical changes a woman undergoes during pregnancy render her more focused on bodily changes, and therefore more withdrawn, or whether the decreased contact is attributable to the fact that women are processing negative experiences, which may have occurred during the IVF treatment. While differences in emotional reactions between women and their partners are not consistently found (20), there does seem to be evidence to support the view that infertility and its treatment have a greater negative impact on women than on men (5). This gender difference has been attributed to general social and biological factors (e.g. identity issues and maternal instinct), as well as to more practical factors since women undergo most of the intrusive medical procedures (25). As gender differences in depression and anxiety are well-established findings in many areas of health and fertility (15, 23), our findings would seem to reflect a general gender discrepancy in emotional profile rather than one specific to IVF.

Research results have suggested that couples entering an IVF programme are, in general, psychologically well adjusted, irrespective of their fertility history and duration of infertility (10, 15). In the beginning this was contrary to expectations, and researchers sought the explanation in a self-selection effect. This would mean that only psychological well-adjusted couples would seek medical help in their efforts to become pregnant and choose to confront the emotional demands of IVF. Another explanation might be that as these couples have experienced years of infertility, they may have developed ways of handling the stress associated with it (20). An explanation often given for the contradictory results obtained in different studies concerning anxiety during IVF has been that measurements have been made on different occasions (18, 52, 134, 136). There seems to be a consensus that the most stressful phase are the period while waiting for the
outcome and the time after an unsuccessful attempt at IVF (5, 136). There is
a need to add further prospective studies so as to allow firm and reliable
conclusions to be drawn regarding this care, so that improvements can be
made. Longitudinal evaluations generally yield more complete assessments
of the phenomena under study.

Cryopreserved embryos

During the course of IVF treatment, women who had extra embryos that
could be cryopreserved became more optimistic and less pessimistic than
those who had no such embryos. While Paper II showed that embryo transfer
of in itself increased the level of optimism among couples during treatment,
the women without cryopreservable embryos did not appear to experience
the same degree of increased optimism. It has been proposed from earlier
research that feelings of over-optimism ameliorate stress at the start of the
treatment, and prepare the individual for the IVF treatment (19); in other
words, that optimism facilitates successful coping (137). Among the women
in our study, greater optimism was correlated with low distress levels at the
start of the treatment, supporting previous findings (19), although there was
no such correlation on the day of the embryo transfer.

Differences in the number of retrieved oocytes and of embryos between the
two groups of women may have affected the results concerning optimism.
The women who did not have cryopreservable embryos responded more
poorly to the treatment and they may have received more negative feedback
from the clinical staff, which may have increased their pessimism and
reduced their optimistic feelings. No such difference was found among the
men. An earlier study showed that women in a couple relationship react
more strongly than do men to their childlessness, while the men react chiefly
to their partners’ reaction (11). When the women became emotional, the men
reacted by becoming “strong, silent types” and assumed a protective role vis-
à-vis the women, which may have dampened their emotional reactions. For
most couples, frozen embryos symbolize their hope of having children and
the anticipation of parenthood. For others, the potential person that a frozen
embryo represents raises moral issues when the question of disposal is
discussed.
The results of the retrospective study indicate that practical circumstances associated with a positive IVF outcome, that is, a child, plus an excessively short allowed period of cryopreservation have dominated couples’ choices to abstain from using their cryopreserved embryos. Of the 22 couples who allowed their cryopreserved embryos to be destroyed, 20 had had children after IVF treatment, and the majority of these children were twins. A number of these couples indicated that they would perhaps have used the cryopreserved embryos at a later juncture if they had had the opportunity to do so at a time of their own choosing. Roughly half of the women who did not use their cryopreserved embryos had wished for a longer preservation period, while one-third indicated that the excessively short preservation period had affected their decision to destroy the embryos. In their comments some women and men expressed a desire to keep the cryopreserved embryos for as long as possible. The reasons given for this were that they wanted to save the embryos in case something should happen in their lives that caused them to change their minds. It may be concluded from this that the couples would perhaps have used the cryopreserved embryos at a later juncture if they had been able to take the decision themselves.

The couples at the clinic that did not personally express a preference concerning their cryopreserved embryos received a letter upon the expiration of the preservation period. The majority of the couples did not answer their letters, and the reasons for this are unknown. It may have implied tacit consent to the destruction on the part of the couple, or a desire of the couple to avoid responsibility for the decision to destroy the cryopreserved embryos. As previously mentioned, there was a lively debate in Great Britain in 1996 concerning the handling of cryopreserved embryos and associated storage routines. The debate was incited by the destruction of 3,000 cryopreserved embryos, which elicited strong emotional reactions (43). It is desirable for couples to be able to decide about their cryopreserved embryos, and for IVF clinics to formulate routines for maintaining contact with the couples (138).

Some couples in our study were concerned about how cryopreservation would affect the embryos and the resulting child. Recent research about attitudes and concerns regarding surplus embryos has shown that the embryos are stored for a mean of 2.25 years (45). The female respondents whose embryos had been stored longer were more worried about their embryos. One reason for this could be the ethical issue about the extent to which the couple view the cryopreserved embryo as a potential child, as has been discussed in one report (139). Previous research (140) has shown gender bias in couples who made decisions regarding disposal of their frozen
embryos. In our study more men than women expressed concern about negative effects of cryopreservation on the embryo. One explanation for this could be that more women talked with friends and relations about their cryopreserved embryos, which could have reduced their doubts regarding the method. Women are also considered to be more focused on becoming pregnant, which can make them more acceptant of risk. The IVF treatment imposes much greater physical stress on the woman than on the man, which may make her more positively disposed towards using the cryopreserved embryos. Those couples who allowed their embryos to be destroyed were not found to be more hesitant about cryopreserved embryos during the actual treatment. Most of the comments indicated that the couples intended to use the cryopreserved embryos in the event that the IVF treatment proved unsuccessful. At this stage the cryopreserved embryos presumably represented security and hope rather than a potential child.

A debate is currently under way about the importance of transferring one fertilized embryo rather than two, in order to reduce the number of twin births. This policy has now taken effect, and the result will be that a larger number of embryos are cryopreserved, and more couples will be involved in cryopreservation procedures in the future. This will increase the need for improved treatment outcomes, and for more knowledge about how couples emotionally experience the various types of treatment. In addition, the disposal of unused embryos is regarded as a pressing problem in in vitro fertilization programs (42, 141). Although cryopreservation of embryos gives couples the chance to make additional attempts at pregnancy, unused frozen embryos seem to require that couples make difficult decisions regarding their disposal.

Oocyte donation

The present results indicate that in general, Swedish women and men of child-bearing age support oocyte donation as an alternative way of starting a family. This finding is in line with previous reports (107, 108, 110, 142-144), as are the present results that the majority of respondents were in favour of anonymous oocyte donation (85, 108). When women and men were asked what methods they would consider acceptable for their own treatment, a surprisingly large proportion chose known donation. This may indicate that the wish to have knowledge of the genetic origin of the oocyte might be stronger from the point of view of recipients (145).
The current Swedish legislation allows the donor to be anonymous during the donation procedure, although she may not remain so when the child becomes older and may wish to know her identity. It has been suggested that the preference for anonymity may reflect a concern that donor identification might pose a threat to family relationships, and may also reflect a wish to protect the donor (145). One of the more frequently debated aspects of oocyte donation pertains to the matter of donor anonymity. On the one hand, there is the donor’s interest in remaining anonymous, while on the other hand, there is the child’s interest in learning her or his genetic origins. Inducing women to donate oocytes presents both a practical and an ethical problem. Here we encounter issues of informed consent and unforced acquiescence from the women who donate gametes. The greatest risk involved in the donation of oocytes under duress presumably arises in cases where the donor and the recipient couple know one another or are related.

The different reactions observed in the contexts of oocyte and sperm donation are of interest from a gender perspective. While 31% of the women and 40% of the men in our study were positive towards receiving oocytes anonymously, only one-fourth among the women and men had positive attitudes towards receiving anonymous donation of sperm. The partial genetic link is preserved in the same way with oocyte donation as it is between parents and child with the donation of sperm cells. In a previous study it was found that assumptions about gender and reproduction lead to a view of oocyte donation in a familiar, clinical and asexual context, while semen donation is seen in an individualistic, unregulated context of dubious sexual connotations (146). In Sweden, the appropriateness of oocyte donation has been called into question more than that of sperm donation. Oocyte donation is regarded as being more complicated, and also as falling further from traditional, unassisted heterosexual reproduction. These differing attitudes may be manifestations of cultural perceptions of motherhood and fatherhood. Presumably the fact that motherhood is an important constitutive factor in femininity throughout the world also plays a major role.

The importance of parenthood and the genetic link

The present results show that the women valued parenthood more than did the men, a finding in conformity with previous observations that women react more strongly than men to their infertility (54). It was discussed in a previous thesis (30) that the decision to become a parent may be more conflicting and greater for men than for women and that men may experience the demands as providers to wives and family more acutely than
they openly admit. The men in our study placed more importance on the genetic link than the women did which also had been shown in earlier reports (147, 148). The men’s only biological relationship with a child is the genetic link and it might be so that from his perspective the defining relationship in starting a family is genetic. The gender differences in these respects observed in previous studies have been attributed to general social and biological factors and also to a general discrepancy in emotional profile between the sexes. The finding that the majority of the men in the study stated that they would support their partner’s decision to donate oocytes was somewhat surprising considering the fact that they placed more importance on the genetic link between the parent and child than did the women. In addition, men were also more positive than women towards receiving oocytes if they and their partner were experiencing infertility. Possible explanations for this include the fact that the men’s physical efforts with regard to donating or receiving oocytes are much smaller than the women’s, and that in oocyte donation it is not the men’s genetic material that is being donated or replaced by someone else’s.

Television and newspapers have more frequently in recent years been giving attention to the consequences of gamete donation and contribute in such way to give more knowledge to the public. The public appear to have more reservations to assisted reproduction than infertility patients (85, 107, 110, 142). Some of the studies have also included groups that have already been involved in assisted reproduction and most studies have been made on smaller groups (149). However, the contemporary attitude towards oocyte donation in our study may reflect that a change has taken place in what people consider to be natural and unnatural, and also in views on how kinship and personal identity may be constituted, as discussed previously (150). Oocyte donation may be said to offer an opportunity for biological although not genetic motherhood, to the woman who undergoes the procedure. With the new reproductive technologies, it is considered that we can now differentiate between genetic, biological and social parenthood (150, 151).

Disclosure or non-disclosure to the children
Disclosure to the offspring has two major components, namely the right to know about the circumstances of the conception and the right to obtain identifying information about the donor. Our results showed that the majority of respondents among the public thought that the offspring should be told about the circumstances of their conception. This findings is in contrast with earlier reports (68, 69, 101, 102, 152), indicating less support for disclosure among parents of donor offspring. In addition, half of the
respondents were positive towards the idea that offspring from oocyte donation should receive identifying information, which is higher than was found in a previous study on infertile patients (153). One possible explanation for these discrepant results is that parents of donor offspring and infertile patients may have more experience of or insight in the difficulties associated with disclosure. Our results confirm an earlier finding that women are more in favour of telling the child about the circumstances of her or his conception than are men (154), although the women and men did not differ in their opinion as to whether the child has the right to receive information on the identity of the oocyte donor.

Infertile patients can probably more easily imagine the difficulties with disclosure of the identity. Whereas most countries continue to support anonymous donation, there are indications that an increasing number of donors are willing to be identified and that public attitudes towards gamete donation are changing over time (113, 155). Interestingly, one-third of our Potential Donors were negatively disposed towards the idea of disclosing the donor’s identity to the offspring and stated they would not want the child to try to contact them once she or he reached a mature age. It should be noted that half of the Potential Donors in our study were in favour of the idea of offspring obtaining identifying information about the donor, and that one-third stated they would be glad if the offspring tried to contact them in the future. Since children conceived by oocyte donation in Sweden have the legal right to obtain information about the donor’s identity, initially interested women who are opposed to disclosing the donor’s identity to the offspring may, after information, be unwilling to donate their oocytes. If this proves to be the case, the proportion of potential oocyte donors will be smaller than is indicated by our results.

Previous studies have shown that the majority of those who become parents by gamete donation do not inform their children about the donation (103, 106, 153). For this reason, the authors of a study on donor insemination in Sweden raised the question of compliance with the Swedish law (103). In practice, a child may only exercise her or his legal right to obtain identifying information about the donor if the parents inform her or him of the circumstances of the conception (79). Most psychologists and therapists familiar with these issues recommend openness with the child to ensure a harmonious relationship between the parents and their child. It may be more difficult, however, to tell the child if information about the donor is not available (156). The dilemma facing the parents is, on the one hand, their interest in maintaining the image of being a “normal” genetic/biological family and, on the other hand, their desire to be honest with the child. The
decision on whether to inform or not inform the child is probably regarded as a private and individual matter by those undergoing treatment. Interests may therefore conflict when the question is considered from the different perspectives of the parents and the unheard children. As a result of the current advances in genetic testing and in the ability to treat hereditary diseases, genetic inheritance will become increasingly important. From a social perspective, an ethical dilemma will then arise if one knowingly withholds information regarding a child’s genetic origins. Arguments in favour of telling the children have been based on experiences from studies of adoptive children who have emphasized the need for and desire to obtain knowledge about their heritage (59). Other arguments favouring disclosure are based on fear that the donation might be exposed by external events or by comments to the children later on in life, since research has shown that many recipient couples do tell others about the donation (103).

The women’s willingness to become oocyte donors
Among the respondents in our investigation, one in six women stated that they would consider donating oocytes in the future to women they did not know. However, hypothetical willingness to donate oocytes expressed by women in a questionnaire is likely to differ from their actual behaviour, as suggested by reported difficulties in recruiting non-related donors (157, 158). Almost half of the respondents in our study stated that already having a child of their own would probably increase the likelihood of their becoming donors. This finding may indicate that women with children of their own are less afraid of ending up as donors with offspring raised by other families but no children of their own. Interestingly, this finding was contrasted by the fact that the group with the largest proportion of mothers was the group of Non-donors. While this finding is not in line with previous reports suggesting that the typical anonymous donor has one or two children (97), it suggests that motherhood may also be associated with a reluctance to donate oocytes. From previous studies (98, 159) it was concluded that the most common motives for donation were the donors’ own love of motherhood and the thought that they would have been devastated if they had been unable to have children. A further motivation may be the gratification of maternal desires. On the other hand, it has been reported that many donors regard their oocytes as a monthly loss, and that they make a distinction between the oocyte donated and the child born afterwards (145). Others regard the oocyte as just another body cell and deny the connection with a potential child. A more unconventional motive among a minority of donors may be that oocyte donation provides them with the opportunity to pass on their own genes (98), which was confirmed in our study. Potential Donors in the present study were generally more positively disposed towards oocyte donation and
considered the genetic link between the parent and child to be of less importance compared with the Non-donors and the Doubtful group, which is to be expected in women who are willing to donate oocytes. Among the Potential Donors, a higher proportion had experience of donating blood, indicating that there may be altruistic motives for donation, as suggested in a number of previous reports (87, 88). Anonymity in this context has a high priority among donors (77), but even when the donation is made anonymously there has been interest among donors to receive information about the outcome of the donation (98, 100).

**Recruitment of potential donors**

Clinics in many countries have difficulties in recruiting altruistically motivated fertile women who would like to become oocyte donors (74), and use different strategies for recruitment (74, 82, 145, 160, 161). A typical oocyte donor is described as a married mother in her late twenties with altruistic values, who acts out of feminine solidarity and feels good about donating a gift to another woman (87, 88). An interesting question is how to recruit such women, and many clinics place advertisements in magazines and newspapers. Our results suggest that the Internet is a good way of reaching women who want to obtain more information about oocyte donation without disclosing their identity. The Internet has already provided a forum for oocyte donors to allow them to interact both with one another and with infertility clinics (100). It has been concluded that improved donor satisfaction is likely to improve donor recruitment (162).

Previous reports have pointed out different donor motivations (76, 96). In the present study, the women reported their own perceptions of what factors of importance would increase their likelihood to become oocyte donors. Almost half of the respondents considered it important to talk to women who had already donated oocytes, supporting previous findings (99). Communicating with other women who have already donated oocytes may give the potential donor a neutral and realistic view of oocyte donation, and such communication could easily be arranged by the infertility clinic. In our study population, proximity to the infertility clinic was regarded as another important factor, a finding in line with results of previous qualitative follow-up studies of donors. The results indicated that several practical improvements, including absence of transportation problems, would attract potential donors (98). Financial compensation and future information about how the child is getting on were generally not among the priorities of respondents on our study. The view in Sweden and in many other European countries is that donation should occur only on altruistic grounds, with no financial compensation beyond reimbursement of actual costs (94, 163).
However, there is a risk that this approach minimizes access to donors. One question of interest is whether compensation must necessarily stand in an adversary relationship to altruistic motives for donating oocytes. The Potential Donors and the Doubtful group gave considerable priority to some additional factors such as accessible counselling, more information about infertility, shorter treatment before donating oocytes and complete anonymity as a donor. More information about the struggle of couples to conceive, and learning more about the great demand for donated oocytes may make some women feel empathy and increase their motivation to donate, as suggested previously (100). Further, information about the outcome of the donation may influence the way in which donors interpret their experience. The most important person that the Potential Donors said they would consult about the donation was the partner/husband, and almost all of the women in our study indicated that they would comply with their partner’s/husband’s wishes. This is in line with the case of donor insemination where support of the semen provider’s partner has previously been found to be important (164). The staff of the infertility clinic were stated to be the second most important group of people to consult about the donation, emphasizing the need for careful professional counseling at these clinics.

Results from a public survey in a number of western countries about perceptions on infertility and its treatment (165) indicated that there was a lack of balanced information about chances of success of assisted treatment and that doctors, midwives and medical personnel in general should be able to provide more complete information. Public perceptions about oocyte donation must be considered to be of major importance, since treatment using donated oocytes is usually dependent on the voluntary initiative of healthy women to become donors. It has been suggested that the use of ART on indications that are not well understood or accepted by the society may lead to situations where there will be a reduction of resources available for treatment of infertility (166). It is also likely that public attitudes play a role in how the individual couple receiving donated oocytes experience their situation and, ultimately, how they view the question of informing their child of his or her origins. Internationally, a few studies have addressed the treatment experiences of women participating as oocyte donors and they are generally revealed as well-adjusted and highly functioning women (85, 96). In a study (167) it was found that basically, recipient women are interested in having healthy educated donors, and similarly, donors may have opinions regarding the use of their oocytes; which both need to be taken into consideration. However, one constant feature of public debate seems to be the conflict between private choice and public regulation. Each of the new
reproductive techniques may be of benefit to some people while possibly offending the moral sensibilities of others.

Methodological considerations

_Papers I and II_

The ratings on the daily assessment scale should not, in our study, be viewed as measurement levels, but rather as revealing a pattern; and furthermore, they should not serve as a comparison between two different groups. As there is no baseline, it is difficult to determine whether the differences between the women and men were attributable to the IVF treatment, or whether dissimilarities existed prior to the treatment. The fact that gender differences occur is apparent in many fields pertaining to health and reproduction, and our results presumably reflect the general differences that exist between the genders to a greater extent that those that are specific to IVF. Pattern differences between the genders were mainly apparent in the degree of social contact and with respect to fatigue, which would indicate that women and men do not influence each other’s perceptions. At the study information meeting, the couples were specifically asked to rate their symptoms separately. Some advantages of using self-evaluation scales are that they are easy to distribute, the material is easy to process, the respondents can be anonymous and a number of measurements can be made over an extended period of time. One of the drawbacks is the risk that the respondents may give the answers they believe the researcher expects, or which accord with their own wishful thinking. There is also a risk, as in this study, that the respondents involved in couple relationships influence one another. The number of treatment days in this study was roughly 50, which is a relatively long period of time, which may entail a risk that the respondents answered routinely, without major deliberation. However, the reaction pattern found in our study contradicts this, since it exhibited differences with respect to fatigue, contact with the partner, and social support.

Altogether 45% of the couples completed the study. Of the drop-outs, 18% were couples who did not complete the treatment for medical reasons (hyper/hypostimulation with hormones), while 15% found the study to be too demanding. Similar response rates have been seen in other studies in which couples gave ratings and responded to questions at only two junctures, before and after IVF (9, 10, 53). While this source of attrition could have a more significant impact on generalizations to other populations, statistical testing showed that the final sample of patients did not differ regarding
medical or demographic variables from the patients who discontinued treatment for either medical or psychological reasons. Given the considerable effort expected of the couples in terms of daily ratings over the course of 7–8 weeks, the number of couples who completed the study may be regarded as representing a reasonable response rate.

Various research fields (clinical, psychological, economic) have different operational approaches for analysing the same kinds of variables. Increasingly strong arguments are being put forward for analysing ordinal data by non-parametric methods (129). In the comparison between parametric and non-parametric analyses only in exceptional cases was any pronounced difference found. One explanation for this is that the non-parametric method is somewhat blunter and does not utilize the data so effectively; also it has lower power, and in our analysis the difference in median value between the women and the men in the couple was often zero, while the difference in mean value more often was different from zero.

**Paper III**

In a retrospective study, interviewees can have problems in remembering what they were thinking and feeling at various points in time and it may consequently be difficult to draw reliable conclusions regarding changes in attitude over time. Also, they may have a tendency to alter their experiences retrospectively (51). In terms of the results, the essential issue is that the answers, which the respondents give in a retrospective study pertain to the feelings/perceptions with which they are living in the present. Based on one analysis of response and drop-out rates in a posted questionnaire study regarding living habits (168), a response rate of 77% may be expected in this type of study. In our study, the response rate for this posted questionnaire was 70% for the women and 63% for the men. The incidence of pregnancy was higher in the group that responded to the questionnaire than in the entire group. Of those who responded, roughly 5% stated that they were no longer living together with their partner. This would indicate that the group that did not respond to the questionnaire would include higher proportions of women and men who had chosen to go their separate ways.

While “internal validity” refers to the degree to which the results of a study reflect reality rather than being an effect of uncontrolled, extraneous factors, “external validity” refers to the degree to which the results can be generalized to settings or samples other than the ones studied. In the present study, internal validity was difficult to check, since the area of questioning was new, and no previous attitude scales were available. In our open questions, we sought not only typical responses, but also possible responses, i.e. various alternative responses. One problem associated with such open
questions is that of describing the results in a lucid and comprehensive manner. In categorizing the responses, the diversity of nuances expressed by the respondent is lost. However, it seems restrictive to have only structured questions when no studies have been published in a particular area of study, as was the case here.

Papers IV and V

The data concerning attitudes towards oocyte donation were compiled from a large, randomized sample of the Swedish population. Considering the topic of the present study, the higher response rate among women (73%) than among men (56%) was not surprising. There were indications of response bias with respect to educational level, place of residence and ethnic background. For instance, there was a large proportion of foreign surnames among the non-respondents. Separate analyses (data not shown) indicated that respondents born outside Sweden were significantly less positive towards both oocyte donation in general and disclosure to the child than were respondents born in Sweden. However, there was no group difference with regard to women’s willingness to donate oocytes. The questionnaire was constructed specifically for this survey in order that the questions formulated would be appropriate under the current legal circumstances. The use of non-standardized questions, however, limits the possibilities of validating the questionnaire and the generalizability of the results. The results regarding women’s willingness to donate oocytes should be regarded with caution, since one can expect a discrepancy between individuals’ reports of what they consider doing in the future and how they will actually behave. In the present study the likelihood of such a discrepancy was increased by the fact that oocyte donation was not yet legalized in Sweden at the time of the survey. For this reason the study results should be regarded as trends among the Swedish public. The multiple logistic regression method did not add to the results of our study beyond what was determined using the more descriptive comparative analyses.

The Theory of Planned Behaviour (TPB)

Responses from participants in the pilot study indicated that most sections concerning TPB components were not suitable for women with no or little interest in becoming an oocyte donor. Therefore, the instructions in the final questionnaire outlined that these sections were to be completed only by women who stated that they would consider donating oocytes in the future. The usefulness of these theoretical variables has been tested in research of many other research areas besides attitudes towards gamete donation (30, 116-118, 169). However, the TPB theory (116) has been repeatedly challenged regarding its assumption that it provides a sufficient description
of the proximal causes of behaviour and that other variables influence behaviour only through their impact on the terms of the model. The investigators who have challenged TPB have shown that intention is determined by a larger set of variables than attitude towards the behaviour and the subjective norm. One suggested addition is that perceived moral obligation and self-identity can determine intentions and behaviours.

Clinical implications in caregiving

Theories regarding care have usually been developed to provide guidance in practical health care, administration and training (170). If care is defined as an activity whose purpose is to assist individuals in meeting their general human needs, a theory as to what those needs comprise is needed. The terms “caring” and “nursing” are used internationally, sometimes in combination (“nursing care”). “Nursing” is usually taken to encompass more than just “caring”. In Swedish, one word, omvårdnad, is used to cover both meanings. This activity, omvårdnad, is intended to promote the patient’s welfare. Four common central concepts may be said to be present in most care theories (171): (a) the human is viewed as an active being who can affect her or his life; (b) the environment, that is, the person’s environment, is taken into consideration; (c) health is more than the absence of illness; and (d) ill/health can be compensated for by an appropriate environment. Health care is provided by a wide range of categories of professionals and the term carer is used for all professionals. At the same time each health professional has something unique to contribute in caring. The national policy programme of the Swedish Midwifery Association states that the midwife should work in a humanitarian and respectful way with regard to the woman (and the baby and the family). The woman’s right to self-determination and self-esteem should be affirmed, and her integrity should be maintained by considering her needs and by demonstrating loyalty to her.

A care theory, which can be used as a framework for working with childless couples

There are various perceptions regarding the meaning of the term “theory”. One definition which is often cited and used in health care theories as well in others, is that: “a theory is a set of concepts, definitions and assertions which presents a systematic view of a phenomenon by specifying the relationships between variables for the purpose of clarifying and predicting the phenomenon” (172). Researchers have formulated theories for care on the basis of different starting-points. These have sometimes been called
structures, sometimes models or theories. In caring science the human being is regarded from a holistic perspective and psychological, social and other factors are considered as well as physiological ones. The so-called “care process” has been created as part of the effort to achieve more individualized care. The care process is often used as a working method, and comprises the following steps: (a) determination of care needs; (b) formulation of the care diagnosis; (c) planning of care measures; (d) execution of care measures; and (e) evaluation of the results. This problem-solving model is very popular, and many care theories have attempted to conform to the care process concept.

Joyce Travelbee’s theory. This theory may be described in brief as a developmental theory (173). Care is an interpersonal process through which the professional caregiver helps an individual or a family to prevent or cope with disease and suffering (in the present case, involuntary childlessness) and to find meaning in the experience (174). Travelbee asserts that it is more important for the caregiver to relate to and gain knowledge about how the individual perceives her or his disease and suffering than to concentrate on the caregiver’s own objective assessment. It is of fundamental importance to find meaning in life’s changing experiences, and people often need help in finding it. It is important to obtain answers to questions such as “Why did this happen to me?” and “How am I going to get through this?” Travelbee has an individualistic outlook on mankind and places the individual person in the center; the principal thesis of her theory is that illness (e.g. infertility) is a personal experience. The interpersonal relationship is achieved after several interaction phases have been undergone: a) the first meeting, b) development of identities, c) empathy, d) sympathy, e) mutual understanding and contact.

Links between the dimensions of Joyce Travelbee theory and the suggested care during IVF treatment.

The suggested content of care for each dimension in this thesis is based on previous published research, from the experience working with infertile couples and from the results in Paper I-V.

“The patient concept (when a person seeks help)”: Early identification of the needs of each infertile woman of and the man. Provision of supplementary psychosocial counselling if necessary. Special needs of immigrant couples.

“Problem areas with respect to care (everything that can have a disruptive effect on the individual’s health and well-being)”: The cause of the couple’s childlessness. The couple’s knowledge about the problems. How are the
women and men affected psychologically. Do they have any financial problems?

“Relevant factors and the patient’s surroundings (the patient’s cultural background and social network)”: Identify the social and cultural backgrounds of the couple. Evaluate the mutual relationship between the couple. What support do they derive from each another and from other people?

“General care goals (subjective dimension)”: Help to reduce the stress. Give adequate information during the procedure and maintain a realistic hope that the woman will become pregnant. Information and results from the investigation should be given to the woman and the man at the same time. Be available to answer the couple’s questions and for support. It is important to be aware of common emotional reactions and personality traits among infertile women and men, such as feelings of distress, optimism, guilt, sadness and so on; also of possible gender differences in reactions. Some couples may feel ambivalence and anxiety about certain reproductive methods.

“Care methods (interaction and communication in order to establish an interpersonal relationship)”: The couples should be given an introduction to IVF, including information about procedures, results and common physical effects during and after treatment. They should be informed about common psychological reactions during IVF treatment. The waiting time should be short and it should be easy to get an appointment at the clinic. It should be easy to get in touch with clinic midwife/nurse for feedback or if support is needed. If possible the couples should see the same personnel each time at the clinic (continuity).

“Context of the care (the interpersonal relationship)”: An individual programme of care should be formulated in consultation with the childless couple. Empower the couple and increase their autonomy. The staff’s knowledge and understanding with respect to the process that the individual couple are going through are essential. If treatment fails or if miscarriage occurs, help the couples to resolve and come to terms with the situation. Maintain contact with the couple during the period of cryopreservation. Identify the couple’s need of further support at repeated times. If pregnancy occurs, facilitate the transitions from an infertile couple to a pregnant couple. Assess the couple’s need of support from the IVF clinic until the first visit to the antenatal care unit. Evaluate the couple’s own experience of subsequent care in order to facilitate care improvements. Meetings between potential donors and former donors should be organized.
The future

The technical options available for assisted fertilization have become increasingly familiar to the public. This has led to a comprehensive debate regarding their moral desirability and justification. In involuntarily childless couples the decision to undergo IVF is not just about finding a place as a family, it also has to do with a cultural and personal action, which raises individual issues and reveals gender-specific roles and patterns. Older women may confirm that the existential crisis of infertility is not a temporary one. The treatment of infertility has contributed to reducing the stigma once associated with infertility and has resulted in the birth of many healthy babies. However, IVF treatment does not always result in a baby and many people experience unsuccessful IVF as a personal failure. Historical and cultural contexts, as well as the concrete situation with its different circumstances and purposes, will affect the content and views of life.

A discussion of IVF and human dignity will also presumably shed light on the value of the family. Against this background, the biomedical treatments probably maintain the traditional ideal of a family, which is rooted in a country’s culture. The dream of a family can certainly be realised by different strategies, such as open legislation, which allows utilization of all the options offered by modern technology, or through more restrictive use of IVF. The challenge, particularly from a feminist perspective, is to consider the social arrangements and cultural values underlying the human urge to take the risks associated with IVF. IVF has now been available for more than 20 years, and is regarded by many as a routine procedure. New technologies have been developed to help more couples. Rapid advances in research impose upon researchers the need to initiate an open debate. Discussion is essential to the ability to take a position with respect to where each new technique and piece of knowledge will lead. Caregivers have an important duty in helping couples who undergo treatment involving IVF, and donated gametes imply a positive approach towards the fundamental problem and future parenthood. To be able to discharge this duty, it has been pointed out previously (30) that caregivers must have given thought to their own values regarding parenthood. For the future, studies of gamete donors’ and recipient couples’ attitudes and experiences, as well as the perception of the offspring must be regarded as important research in Sweden.
The emphasis on biological parenthood appears to have grown even stronger in recent years, and the question has therefore being raised as to what role the advances in medical technology will play in terms of social pressures. Many childless couples can now experience pregnancy and childbirth, and the normal reproductive span can be extended. When technology no longer sets limits on human power over life, ethics and morals will take a central place. What limits should society then impose if we also wish to take into account what is best for the children? What ends are acceptable when humans intervene in the natural order? It is important to study and understand the extent of the questions and concerns which these types of treatment elicit, so that they do not become overshadowed by the obvious goal of the involuntarily childless couple: to have a child.
CONCLUSIONS

The woman and the man should be offered the same support during the IVF treatment, since they have similar reaction patterns during treatment. Both women and men experienced the times of oocyte retrieval and embryo transfer, as well as the luteal phase as being particularly stressful. Spouses appeared to be equally sensitive to the uncertainty of treatment procedure. To help reduce this uncertainty, clinic staff should provide couples with better expectations for medical procedures and by providing results more swiftly.

Women with supernumerary embryos for cryopreservation became more optimistic than women without such embryos. However, this increased optimism did not reduce women’s experience of distress on the day of embryo transfer. Support to women with or without surplus embryos should be offered with these differences in emotional reactions in mind.

One-third of the couples chose not to use their cryopreserved embryos. The main reasons among the respondents concerned family planning and too short a legally allowed time of embryo storage. The IVF clinic should maintain contact with the couples during the period of cryopreservation of embryos in order to respond to questions and concerns, which both the woman and the man may have regarding cryopreserved embryos.

There is strong support for the practice of oocyte donation among a subset of the Swedish population. While a majority of the respondents advocated openness regarding the circumstances of conception between parents and child, there was less support for the offspring’s legal right to receive identifying information about the donor. Recipient couples should be given time and opportunities to discuss all the consequences of donation with the clinic staff.

There was considerable interest in donating oocytes among a subset of women in Sweden. It was found important for potential donors to get opportunity to talk to experienced donors. Information to the donors about
the consequences of donation is of great importance. The results of the present study could have implications for the way in which clinics should develop a programme to attract potential donors.
Acknowledgements

I wish to express my sincere gratitude to all who have supported me during this process and to all the women and men who participated in these studies. I particularly would like to thank the following persons:

Torbjörn Bergh, my supervisor, for sharing your broad knowledge, for very skilful scientific guidance, for always being accessible, for constructive criticism, patience and your never failing support.

Claudia Lampic, my co-supervisor, for sharing your impressing scientific knowledge, for very inspiring discussions and great support, for very skilful advice and friendship.

Örjan Lundkvist, for an encouraging positive and supportive attitude, for very skilful contribution of scientific knowledge to my research and for a genuine interest in discussing my studies.

Jacky Boivin, for an invaluable introduction into psychological reactions in the field of infertility and for an enjoyable co-authorship. A special thank for all good laughs during the working process and for the support during the ESHRE conference in Edinburgh.

Ove Axelsson, for giving me access to doctoral studies and positive support. Torsten Tuvemo, for very important support in the academic world. Tanja Tydén, for invaluable and inspiring advice from the very start, for very friendly accessibility and for interesting and fruitful discussions.

Gunilla, Margareta, Elisabeth, Inga och Kristina for intellectual fellow-ship in doctoral studies, for support and very interesting meetings in a friendly, joyful atmosphere in Vårdforskningsgruppen at the Department of Women’s and Children’s Health.

Annelie Mååg, P-O Karlström and the staff in Reproduktionssentrum, Akademiska sjukhuset, for positive attitudes and support during the last study and for your contribution of experiences from working with infertility.
Lena Andersson Bergh, for sharing the interest for developing good caring at the Carl von Linné Kliniken and for fruitful and enjoyable co-authorship.  
Katarina Wesslén, for constructive feed-back, for important help to recruit IVF-patients and for great friendship.  
Oddvar Bakos, for inspiring support from the very start and invaluable advice in the academic world.  
Jan Holte, for stimulating discussions in the field of infertility.  
Anna, Janet, Ulrika, Birgitta och Ulla, for support, important feed-back and friendly atmosphere at the time of the first studies at Carl von Linné Kliniken.  
Anna Hjelmstedt och Aila Collins, for fruitful co-authorship.

Ulf Hansson, for showing interest in my work.  
Inga Andersson, for an important guidance, friendly attitude and brilliant administrative support.  
Maud Marsden, for professional linguistic guidance and very friendly attitude.  
Marie-Louise Nordström, for statistical guidance in Paper II and III.  
Johan Bring och Anna Nilsson Statisticon AB, for statistical guidance in Paper IV and V.  
Kenneth Björklund, for important introduction in the SPSS world.  
Vera Holmgren, for a friendly attitude and administrative support.  
Proper English AB, for English translation of questionnaire.  
Jörgen Allstedt, for rapid help whenever there were computer problems and for a relaxed and friendly attitude.

My parents and sisters with families, for giving me strength and for your never failing support.  
All my friends, for your encouraging interest in my profession and my doctoral studies.

Our children Jenny, Johan and Jacob, who in an impressive way have shown patience with “Mummy’s research” and inspired me a lot by showing pride in what I achieved.

Finally, my dear husband Carl-Henric, for your love, for all the joy and for always giving me support to carry on.

These studies were financially supported by:  
Foundation of Family Planning, Uppsala, Postgraduate Studies Committee, Uppsala, Serono Nordic AB, Stockholm, Department of Health and Caring Sciences and Department of Women’s and Children’s Health, Uppsala University.
REFERENCES

34. SOSFS. Socialstyrelsens föreskrifter som styr IVF-verksamheten;1989:35.
35. UN. United Nations convention on the rights of the child, part 1 article 8; 1989.
38. Socialdepartementet. Barn födda efter konstgjord befruktning (IVF);1999:147


78. McWhinnie A. Gamete donation and anonymity: should offspring from donated gametes continue to be denied knowledge of their origins and antecedents? Hum. Reprod. 2001;16(5):807-17.

80. Frith L. Gamete donation and anonymity. The ethical and legal debate. Hum.
82. Englert Y, Rodesch C, Van den Bergh M, Bertrand E. Oocyte shortage for
donation may be overcome in a program with anonymous permutation of related
84. Ahuja KK, Simons EG, Mostyn BJ, Bowen-Simpkins P. An assessment of the
motives and morals of egg share donors: policy of 'payments' to egg donors
86. Greenfeld DA, Greenfeld DG, Mazure CM, Keefe DL, Olive DL. Do attitudes
toward disclosure in donor oocyte recipients predict the use of anonymous
87. Söderström-Anttila V. Follow-up study of Finnish volunteer oocyte donors
concerning their attitudes to oocyte donation. Hum. Reprod. 1995;10(11):3073-
3076.
88. Sauer MV, Ary BR, Paulson RJ. The demographic characterization of women
participating in oocyte donation: a review of 300 consecutively performed
89. Kalkas H, Sarvimäki A. Omvårdnadsutسئens grunder. Falköping: Liber AB;
1996.
1998.
92. Lyall H, Gould GW, Cameron IT. Should sperm donors be paid? a survey of the
93. German EK, Mukherjee T, Osborne D, Copperman AB. Does increasing ovum
donor compensation lead to differences in donor characteristics? Fertil. Steril.
94. Sauer MV. Indecent proposal;  $5,000 is not "reasonable compensation" for
95. Ahuja KK, Mostyn BJ, Simons EG. Egg sharing and egg donation: attitudes of
96. Klock SC, Braverman AM, Rausch DT. Predicting Anonymous Egg donor
97. Kan AK, Abdalla HI, Oguyemi BO, Korea L, Latahere E. A survey of
98. Kalfoglou AL, Geller G. A qualitative follow-up study of women's experiences
99. Partrick M, Smith AL, Meyer WR, Bashford RA. Anonymous oocyte donation:
100.Kalfoglou AL, Geller G. A follow-up study with oocyte donors exploring their
experiences, knowledge and attitudes about the use of their oocytes and the
A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to October, 1985, the series was published under the title “Abstracts of Uppsala Dissertations from the Faculty of Medicine”.)