

Life after Terminated IVF
- experience and quality of life among men and women

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ABSTRACT

The overall aim of this thesis was to study experiences of infertility and quality of life as subjectively experienced health and psychological well-being as well as demographic, socio-economic and health issues in men and women terminating IVF unsuccessfully, i.e. without subsequent childbirth.

The informants in the qualitative studies, in which a descriptive, phenomenological method was used, were eight women (Paper I) and eight men with severe male-factor infertility (Paper II). The informants had, two years earlier, terminated assisted reproductive technology (ART) treatment unsuccessfully. All informants had had fertilized oocytes after in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI) and embryo transfer (ET) had also been performed. Papers III and IV are parts of a large collaborative project in the Västra Götaland region including different perspectives on quality of life 4-5.5 years after terminated IVF treatment provided by the public health system. The informants in Paper III were couples who had undergone unsuccessful IVF treatment. The study in Paper IV was performed on men and women who had successfully or unsuccessfully undergone IVF. Comparisons were made with a control group with spontaneously conceived children. Data were collected with the "Psychological General Well-Being" (PGWB) and "Sense of Coherence" (SOC) instruments, and with two questionnaires focusing on experiences of infertility and socio-economic, demographic and health data.

This thesis shows that the essence of the women's experience of involuntary infertility was *life-grief*, including grief at being childless, unable to reproduce and unable to continue the family, as well as a feeling of being unable to confirm the relationship through parenthood. The essence of the men's experiences was described with a metaphor: climbing a mountain step by step with the aim of reaching the top, i.e. having a child and thus a family with a child.

Quality of life among couples who had terminated IVF unsuccessfully did not differ considerably from that in a control group with children. However, 23% of this unsuccessful IVF group were living without children and 77% were living with children. The 23% living without children had a lower quality of life than the 77% living with children and the control group. Infertility remained a central issue for those living without children.

Quality of life among men in the unsuccessful IVF group living without children was lower than among men in the successful IVF group and men in the control group. Women in the unsuccessful IVF group living without children reported a lower quality of life than women in the successful IVF group and they scored two of the assessed quality of life variables lower than women in the control group. Men in the successful IVF group scored three assessed quality of life variables higher, compared to the women in that group. Men and women in the unsuccessful IVF group living without children did not differ in quality of life.

Keywords: infertility, IVF, ICSI, childlessness, phenomenology, lifeworld, grief, male-factor infertility, obstructive azoospermia, experience, psychology, quality of life, follow-up, gender

PAPERS IN THESIS

This thesis is based on the following papers.

- I Johansson M, Berg M. (2005). Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment.
Scand J Caring Sci 19, 58-63.
- II Johansson M, Hellström AL, Berg M. Severe male infertility after failed ICSI treatment- a phenomenological study on men's experiences.
Submitted.
- III Johansson M, Adolfsson A, Berg M, Frances J, Hogström L, Janson PO, Sogn J, Hellström AL. (2009). Quality of life for couples 4-5.5 years after unsuccessful IVF treatment.
Acta Obstet Gynecol Scand 88 (3): 291-300.
- IV Johansson M, Adolfsson A, Berg M, Frances J, Hogström L, Janson PO, Sogn J, Hellström AL. (2010). Gender perspective on quality of life, comparisons between groups 4-5.5 years after unsuccessful or successful IVF treatment.
Acta Obstet Gynecol Scand 89 (5): 683-691.

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ABBREVIATIONS

ART	Assisted reproductive technology
ET	Embryo transfer
ESHRE	European Society for Human Reproduction and Embryology
FSH	Follicle stimulating hormone
hCG	Human chorionic gonadotropin
HIV	Human immunodeficiency virus
HTLV I, II	Human T-lymphotropic virus I, II
IVF	In vitro fertilization
ICMART	International Committee for the Monitoring of Art
ICSI	Intracytoplasmatic sperm injection
IMAP	International Medical Advisory Panel
MESA	Microsurgical epididymal sperm aspiration
PESA	Percutaneous epididymal sperm aspiration
RAND Europe	Research and Development Europe
SMER	Statens medicinsk-etiska råd (The Swedish National Council on Medical Ethics)
SOC	Sense of Coherence
TESA	Testicular sperm aspiration
TESE	Testicular sperm extraction
PGWB	Psychological General Well- Being
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life

INTRODUCTION

Involuntary childlessness is a global problem which seems to have similar emotional effects regardless of cultural setting. Investigations and treatments are often stressful for the couple. In vitro fertilization (IVF) is a common treatment for involuntary childlessness, but nearly half of the treatments are unsuccessful. Involuntary childlessness can result in deteriorated quality of life and health with consequences for the individual, the family and society. The long-term implications of IVF as it is provided by the Swedish public health system are unknown. Obtaining more knowledge, including from a gender perspective, about experiences of infertility, quality of life and well-being in couples is important; the respective reactions of both men and women to having terminated IVF treatment either successfully or without the birth of a child are one example. Ensuring good care is important in order to prevent ill health among couples who have terminated IVF unsuccessfully. There are few long-term follow-up studies after terminated unsuccessful IVF, particularly concerning men's reactions.

BACKGROUND

Approximately 9% of reproductive-age women are involuntarily childless, ranging from 3.5%-16.7% in the industrialised world and from 6.9%-9.3% in non-industrialised nations (Boivin et al., 2007). In Sweden, involuntary childlessness affects approximately 200 000 couples, who may thus suffer ill health, negatively influencing individual and family quality of life. Infertility is defined as difficulties conceiving or bringing a pregnancy to live birth after one year of regular unprotected intercourse (Healy et al., 1994). The World Health Organization (WHO) considers infertility to be a disease and the prevalence of infertility in women of reproductive age (15-49) is defined as a reproductive health indicator (WHO, 2008). The causes of infertility are different in different parts of the world. Sexually transmitted infections are a common reason for primary infertility and infections after childbirth and unsafe abortions result in secondary infections for many women on the African continent (IMAP, 2006).

Infertility is due to female, male or combined factors, each representing 30% of cases, while approximately 10% of infertility is unexplained. An important consideration related to increased infertility in industrialised countries is the tendency to delay childbearing until after higher education and career start (IMAP, 2006). First-time mothers in Sweden are an average of 28.4 years old and 11% are more than 35 years old (The National Board of Health and Welfare, 2007, Statistics Sweden, 2007). The consequences of an ageing population in Europe are increasing economic, social and healthcare burdens; the older and especially the retired members of the population are gradually outnumbering the younger, working population. The issue of whether assisted reproductive technology (ART) can play a part in preventing countries from falling into the “low fertility trap”, thus offsetting population ageing (Hoorens et al., 2007), has been discussed.

Medical investigation

During the infertility work-up the couple’s reproductive capacity is investigated and their respective and combined reproductive functions are examined. Although infertility has been an important issue in both historical and modern times, it was not until the early 1930s that male partners were included in infertility investigations in Sweden (Essen-Möller and Westman, 1939). The main male factor, i.e. impaired sperm production and sperm quality, is examined early in the work-up. If sperm quality is normal, male fertility is often intact, but the clinical implications of a pathological ejaculate for fertility are often more difficult to evaluate (Gottlieb, 2004).

The most common cause of female infertility is tubal damage, due to previous infections, adhesions or endometriosis, diagnosed via laparoscopy and hysterosalpingography or hydrosalpingosonography. When the damage is limited, the Fallopian tubes can be reconstructed to optimise fertility potential (Strandell et al., 1995). There may also be additional factors, such as hormonal disorders and anovulation, which must be investigated as treatment depends on the cause.

In vitro fertilization

IVF is currently one of the most effective and common treatments for involuntary childlessness. After many years of pre-clinical research, the first child was born after IVF in England in 1978 (Steptoe and Edwards, 1978). In 1982, the first baby was born in Sweden after successful IVF, at Sahlgrenska Hospital in Göteborg (Wikland, 2004, Cohen et al., 2005). Today, more than 40000 children have been born after IVF in Sweden (personal communication/SMER conference Nygren, Stockholm April 2010) and more than four million children have been born after ART treatment in the world (personal communication/ICMART Nygren, Dec 2009). During recent years, there has been a rapidly increasing use of ART, mostly in the industrialised countries.

According to Swedish legislation, the infertility investigation to be undertaken before starting IVF should entail a comprehensive view of the couple and their situation. The National Board of Health and Welfare recommends that the woman be of normal fertile age and that the man's age should enable him to assume parental responsibility during the child's adolescence. The couples must be tested for human immunodeficiency virus (HIV), human T-lymphotropic virus (HTLV) I and II, hepatitis B, hepatitis C and syphilis in order to prevent these contagious diseases from infecting the woman or child throughout treatment and pregnancy. ART may only be performed if pregnancy or contagious or other diseases present no risk to the life and health of the woman or child. Legislation concerning gamete donation, both eggs and sperm, is more detailed than that concerning couples' use of their own fertilized gametes. At the time of the study, Swedish legislation also stipulated that the couple be informed about non medicinal solution to infertility (The National Board of Health and Welfare, 2002).

Women presented in this thesis who have undergone IVF have often started with a shorter or longer "down-regulation" of ovarian hormone activity with GnRH agonists. This medication, given as an injection or by nasal spray, is initiated either in the follicular or luteal phase of the menstrual cycle. The ovaries are usually monitored by vaginal ultrasound and serum levels of oestradiol are measured before starting ovarian stimulation with follicle stimulating hormone (FSH) injections. FSH stimulation proceeds for nine to twelve days and when adequate stimulation is achieved, an injection of human chorionic gonadotrophin (hCG) is given to induce final oocyte maturation and prepare for oocyte retrieval, which it precedes by 36-38 hours. Adequate stimulation is defined as the development of three or more follicles with a diameter of 18 mm or more. During the down-regulation and stimulation period, eight to ten weeks, women usually self-administer medications. Sedatives, opiates and local anaesthesia are administered to minimise pain during egg aspiration, which is performed via ultrasound guided puncture through the vaginal wall. The sperm are allowed to fertilize the collected oocytes in vitro and one or two embryos are transferred into the woman's uterus two days later. Hormone medication is given during the luteal phase, either as a subcutaneous injection of hCG or as vaginal progesterone, to support endometrial maturity until the treatment results are known. Additional embryos of good quality are

cryo-preserved if this is the couple's wish. Cryo-preserved and thawed embryos are later replaced in a natural or stimulated cycle.

Intracytoplasmic sperm injection

The most effective treatment for male-factor infertility is the intracytoplasmic sperm injection (ICSI) technique. The development of this method has provided men with severe infertility with the opportunity to become biological fathers. The method follows the standard routine for IVF except when it comes to fertilization of the oocytes. ICSI entails the injection of one single sperm into the oocyte, whereas standard IVF combines sperm with the oocytes in a Petri dish. The sperm is collected via masturbation or, in cases of obstructive azoospermia, via microsurgical (MESA) or percutaneous epididymal sperm aspiration (PESA), testicular sperm extraction (TESE) or testicular sperm aspiration (TESA). Previously, before IVF era, donor insemination was the only treatment for severe male-factor infertility (Schlegel and Girardi, 1997).

THEORETICAL FRAMEWORK

This thesis originates in caring science, to which the concept of health is central. Promoting reproductive and sexual health is a main objective for midwives. Midwives in Sweden, who are licensed nurses with post-graduate midwifery education, care for women's sexual and reproductive health during different parts of life: during adolescence; before, during and after childbirth; related to family planning and abortion as well as at the end of reproductive life. They also care for couples, men and women seeking treatment for involuntary infertility (The National Board of Health and Welfare, 2006).

Health is a complex concept which has been defined in a multitude of ways. According to WHO, health is defined as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. This definition, which is also valid for reproductive health, addresses the reproductive process, function and system at all stages of life (WHO, 2008). Reproductive health implies the ability to have a responsible, satisfying and safe sex life as well as the capability to reproduce and the freedom to decide if, when, and how often to do so. Human sexuality is a natural part of human development throughout every phase of life and consists of physical, psychological and social components. Sexual health implies a positive approach to human sexuality and is therefore an essential component of reproductive health. Implicit in this area are the constellation of methods, techniques and services contributing to reproductive health and well-being by preventing and solving reproductive health problems, the purpose of which is the enhancement of life and personal relations (WHO, 2008).

A biostatic approach to the concept of health was developed during the 1970s, describing total health as the normal functions of organ and organ systems; divergence from the norm was defined as disease or disorders. Health is the absence of disease. Disease is an internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation to functional ability caused by environmental agents (Boorse, 1977). The holistic approach, on the other hand, mostly emphasises two characteristics of health: first, a feeling of well-being in the case of health and a feeling of suffering in the case of ill health, and, second, the capacity or incapacity to act (Nordenfelt, 1991). Antonovsky (1987) developed the salutogenetic model which specifies factors contributing to the maintenance and development of health and quality of life. Regarding health as a point on a "health/ease and dis-ease continuum" and striving toward health are fundamental in this model. People's capacity to stay well and even improve their health in stressful situations is based on three essential factors: 1) comprehensibility, i.e. a combination of the ability to assess and understand their situation, 2) meaningfulness, i.e. finding meaning to moving in a health-promoting direction and 3) manageability, i.e. the capability to do so.

Quality of life is an important part of health and can be defined as the degree of well-being felt by individuals or groups correlating to physical and psychological aspects.

The concept is, however, complex and no universally accepted definition exists. The World Health Organization Quality of Life (WHOQOL) Group has defined quality of life in terms of the domains of physical and psychological health, level of independence, social relationships, environment and spirituality (WHOQOL, 2008). Well-being, defined as self-reported intrapersonal affective or emotional states reflecting subjective well-being or distress, for which items such as anxiety, depressed mood, positive well-being, self-control, general health and vitality are central, is a way to describe psychological general well-being (Dupuy, 1984). Quality of life and well-being are the foundations of a person's health.

The ability to reproduce is an inherent part of life for most human beings and impaired fertility may have substantial effects. Watching the next generation grow up has been described as happiness and a driving force in life. Infertility entails an existential problem that becomes apparent in the encounter with a childless couple; it is not only a medical phenomenon, but also a life crisis, as the possibility to have biological children may produce a feeling of eternal life (Möller, 1985b). Everything related to involuntary childlessness, in which an original biological function is threatened, is culturally, socially, psychologically and existentially charged. This issue requires substantial cognitive, emotional and practical space (Möller, 1989) and affects emotional and social well-being (Greil, 1997, Weaver et al., 1997).

When attempting to acquire knowledge of how women and men experience persistent infertility after failed treatment, it is essential to explore the issue from a phenomenological perspective. The philosophy of phenomenology was developed by Husserl and based on the principles "to go to the thing itself" and from which the essence of a phenomenon, i.e. "that which is shown", is derived, yielding a direct description of human beings' experiences as they are. A descriptive phenomenological method provides the possibility to explore human beings' experiences of a studied phenomenon as it takes place in everyday life (Giorgi and Giorgi, 2003). The life world concept is central in this method. A person's life world is constituted by the past, present and future and is the tangible, gathered reality in which we live and that we take for granted (Bengtsson, 1999, Dahlberg et al., 2008).

Men and women with involuntary infertility are a target group for reproductive and sexual health care. Gynaecologists have been responsible for early research and development, including of ART treatments, in this area. Today, skilled multi-professional teamwork is provided at infertility clinics and midwives' knowledge has been increasingly important in the treatment and care of couples with infertility. In Sweden, midwives at reproductive medicine departments and IVF units plan and coordinate ART treatments as well as supporting and empowering individuals and couples during the long procedure from seeking help to undergoing and terminating ART. The support is provided in the form of dialogue concerning infertility and the treatments; preventing and solving problems related to the infertility is central in this context.

In this thesis, health is regarded as both objectively measurable and subjectively experienced and closely connected with quality of life and well-being in daily life.

PREVIOUS RESEARCH

Involuntary infertility influences quality of life negatively (Eugster and Vingerhoets, 1999) and is regarded as psychologically stressful for most couples. The symptoms of this stress are reported to be similar to those associated with medical conditions such as cancer and HIV (Domar et al., 1993) and are also comparable to symptoms related to divorce and death in the family (Baram et al., 1988). Human beings going through repeated losses develop chronic grief (Lindgren et al., 1992) and involuntarily infertile women constantly oscillate between hope and despair, resulting in a infertility crisis which is extended and difficult to solve (Lalos et al., 1986, Lalos, 1993). In a phenomenological study, a cycle of hope and disappointment, powerlessness and social isolation was seen among couples (Imeson and McMurray, 1996). Follow-up studies after terminated unsuccessful IVF report, with a high degree of concurrence, that those women's quality of life is lower than that of women for whom treatment resulted in childbirth. More depression has been reported among women 6 to 32 months after unsuccessful IVF treatment, compared to women having undergone successful treatment, as well as to those with spontaneous pregnancies (Freeman et al., 1987). Hammarberg et al. reported, from a cross-sectional study two to three years after terminated treatment, more life satisfaction among women after successful treatment than in women after unsuccessful treatment. No differences were found between these groups in terms of psychological ill health (Hammarberg et al., 2001). More anxiety and depression were found two years after the last IVF treatment in a group of women with long-term infertility, compared to a control group (van Balen and Trimbos-Kemper, 1993) and psychological problems, impaired self-image and loss of hope were reported three to eight years after unsuccessful treatment among women in a Brazilian study (Filetto and Makuch, 2005). More depression and stress, lower life satisfaction and lower self-esteem were found at follow-up four to nine years after unsuccessful IVF among Irish women, compared to women having undergone successful IVF, as well as compared to a control group (Bryson et al., 2000).

Knowledge of the quality of life among men after terminated unsuccessful IVF is limited, compared to the corresponding knowledge about women. Studies concerning short-term adjustment after unsuccessful treatment show differences between men and women, mainly reporting that women were more affected than men (Newton et al., 1990, Slade et al., 1997, Weaver et al., 1997). Six months after terminated IVF, no differences in anxiety and depression were found when men who had terminated successful and unsuccessful treatment were compared (Verhaak et al., 2005b). Filetto et al. reported that psychological problems were the main experience among men three to eight years after failed IVF (Filetto and Makuch, 2005).

Involuntary infertility may be connected to signs of psychiatric illness; the ill health can manifest as sadness, depression or anger (Eugster and Vingerhoets, 1999). Psychiatric disorders and illness, e.g. depression, anxiety, insomnia and alcohol abuse, are a major public health problem. In different studies, 20-40% of the adult population in Sweden report suffering from psychiatric complaints, which are more common in

women and in lower socio-economic groups (Swedish National Institute of Public Health, 2007, Statistics Sweden, 2007). The consequences for those suffering from psychiatric ill health are often serious as both the family's and the individual's quality of life may be negatively affected.

AIM OF THE THESIS

The overall aim of this thesis was to study the experience of infertility and quality of life, in terms of subjectively experienced health and psychological well-being, as well as demographic, socio-economic and health issues in men and women having terminated IVF unsuccessfully, i.e. without treatment having resulted in the birth of a child.

The overall aim was investigated in four separate studies with specific aims:

1. To describe women's experiences of ongoing childlessness two years after the end of IVF treatment.
2. To describe men's experiences of obstructive azoospermia-related infertility two years after termination of failed ICSI treatment.
3. To describe quality of life in men and women with a history of infertility who had terminated IVF treatment within the public health system 4-5.5 years previously, without treatment having resulted in childbirth.
4.
 - a) To describe and compare quality of life, in relation to gender, in men and women with a history of infertility who had terminated IVF within the public health system, either unsuccessfully, i.e. without treatment having resulted in childbirth and subsequently living without children, or successfully.
 - b) To compare the respective quality of life in men and women in the unsuccessful and successful IVF groups and a control group.
 - c) To describe and compare quality of life among men and women in the unsuccessful IVF subsequently living without children and successful IVF groups, as well as to compare the successful IVF group with the control group.

INFORMANTS AND METHODS

An overview of research design, informants and methods is shown in Table I.

Table I. Research design overview.

Paper		I -II	III	IV
Design		Phenomenological study	Cross-sectional study	Cross-sectional study
Data collection		Interview	Postal questionnaire	Postal questionnaire
Setting		Reproductive Unit, Sahlgrenska University Hospital, Gothenburg Sweden and inhabitants in the region of Västra Götaland		
			Inhabitants in the region of Västra Götaland/Control group	
Inclusion criteria	I	IVF unsuccessful 2 years earlier	Unsuccessful IVF 4-5.5 years earlier	Unsuccessful IVF 4-5.5 years earlier living without children
	II	Obstructive azoospermia ICSI unsuccessful 2 years earlier	Control group with children aged 4-5.5 years	Successful IVF with children aged 4-5.5 years Control group with children aged 4-5.5 years
Participants	I	8 women	270 women and men	26 men/37 women
	II	8 men	211 women and men	135 men/154 women 93 men/118 women
Analysis		Descriptive phenomenological method accordance to Giorgi	Descriptive statistics, parametric and non parametric statistical analysis	

Papers I and II

The informants in Paper I were eight women and the informants in Paper II were eight men. In both cases, the informants had terminated ART at the Reproductive Medicine Unit at the Department of Obstetrics and Gynaecology, Sahlgrenska University Hospital, Gothenburg, two years previously, without treatment resulting in childbirth.

In Paper I there were no inclusion criteria related to the cause of infertility but most of the informants had tubal damage or endometriosis and all informants had undergone embryo transfer (ET).

Inclusion criteria in Paper II were severe male-factor infertility with no detected sperm in the ejaculate and having undergone PESA, MESA, TESA or TESE. All informants in Paper II had undergone ICSI resulting in fertilized oocytes and subsequent ET.

Informants' names were consecutively extracted from the unit's database. Twelve women and 14 men were invited by mail to participate in the study, but four women and six men declined.

A descriptive, phenomenological method was applied (Giorgi and Giorgi, 2003). The informants were encouraged to describe their experiences of infertility and the interviews, lasting 60-70 minutes, were tape-recorded. All interviews were relaxed and open and consisted of one simple open request: "Can you describe your experiences of infertility as extensively as possible?" During the interview, the researcher posed clarifying questions such as: "What do you mean?" or "Can you explain that in greater detail?"

The tape-recorded interviews were transcribed into text by the interviewer shortly after each interview. The analysis of Papers I and II was inspired by Giorgi (Giorgi, 1997, Giorgi, 2000, Giorgi and Giorgi, 2003). The essence of a phenomenon appears through the informants' description of their daily lives, the researcher's scientific perspective and reduction of one's own presuppositions in terms of personal experiences and theoretical knowledge. Although the restraining of presuppositions is necessary, the researcher's closeness to the subject is more of a benefit than a problem (Dahlberg et al., 2001).

Data analysis according to Giorgi consists of four steps. The first step is obtaining a sense of the whole. The entire descriptions from all informants are read and re-read by the researcher to obtain an overall sense of them. This is the basis of the whole analysis and of the second step, i.e. the discrimination of "meaning units"; the entire text is re-read from a phenomenological reduction perspective and divided into smaller units from which changes and transitions in meanings emerge. In the third step, the meaning units are further analysed by the researcher, using reflection, imagination and variation, until the meaning of the phenomenon is touched and the meaningful units appear. In the fourth and last step, the meaningful units are transformed into constituents and the essence of the phenomenon emerges. An understanding of the studied phenomenon develops successively during the analysis. The essence represents the higher abstraction level of the investigated phenomenon (Giorgi, 1997, Giorgi, 2000).

Papers III and IV

Papers III and IV are parts of a large collaboration project in the Västra Götaland region focusing on different quality of life perspectives after terminated IVF treatment provided by the public health system. Infertility was treated in accordance with regional guidelines for involuntary childlessness (Strandell et al., 2003). The collaboration project included Norra Älvsborg Hospital, Södra Älvsborg Hospital, Skaraborg Hospital and Sahlgrenska University Hospital, at which this research project was initiated.

The informants in Paper III, couples who had undergone unsuccessful IVF treatments were recruited from the database of the regional Reproductive Unit at Sahlgrenska University Hospital. Between 4 and 5.5 years were to have elapsed since the couples' last treatment at the department, for inclusion. Two hundred couples, 200 men and 200 women who terminated treatment between March 1, 2001 and August 31, 2002, were consecutively asked to participate, 270 individuals participated in the study (Figure 1).

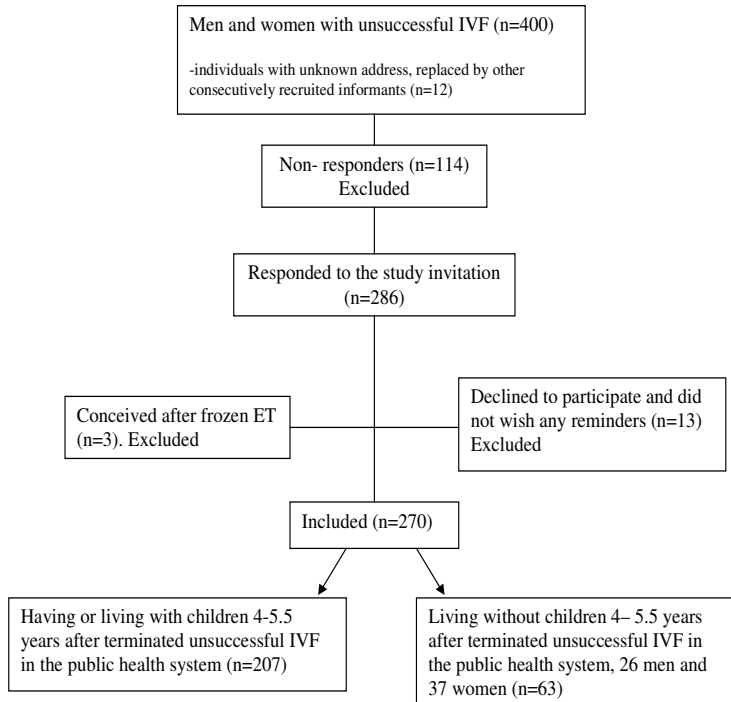


Figure 1. Flowchart of study participants in the total unsuccessful IVF group.

The informants in Paper IV were couples, men and women who had successfully and unsuccessfully undergone IVF, the latter group subsequently living without children. The men and women in the successful IVF group were consecutively recruited from the database of the regional Reproductive Unit at Sahlgrenska University Hospital; two of every three couples were invited to participate. Two hundred couples, 200 men and 200 women treated between May 1, 2000 and October 30, 2001, were asked to participate in the study; 289 individuals were included. The children of the couples were between 4 and 5.5 years old at the time of the study. The group who had undergone IVF unsuccessfully and were still living without children were the 63 individuals presented in Figure 1.

Other inclusion criteria for both papers were that the couples were living in the Västra Götaland region, had undergone treatment provided by the public health system and had undergone complete treatment including ET. The informants' current addresses were obtained from the Swedish Population Register. The couples were asked to participate by mail and, after giving informed consent, answered the questionnaires. Separate letters were sent out to men and women and three reminders were sent to non-responders.

In Paper III, couples who had unsuccessfully undergone IVF treatment were compared to a control group of couples with children aged 4-5.5 years, described at next page. In Paper IV, men and women in the unsuccessful IVF group living without children were compared to men and women for whom IVF had resulted in childbirth, as well as to men and women in the control group. Men's and women's respective reactions in these different studied groups were also compared (Figure 2).

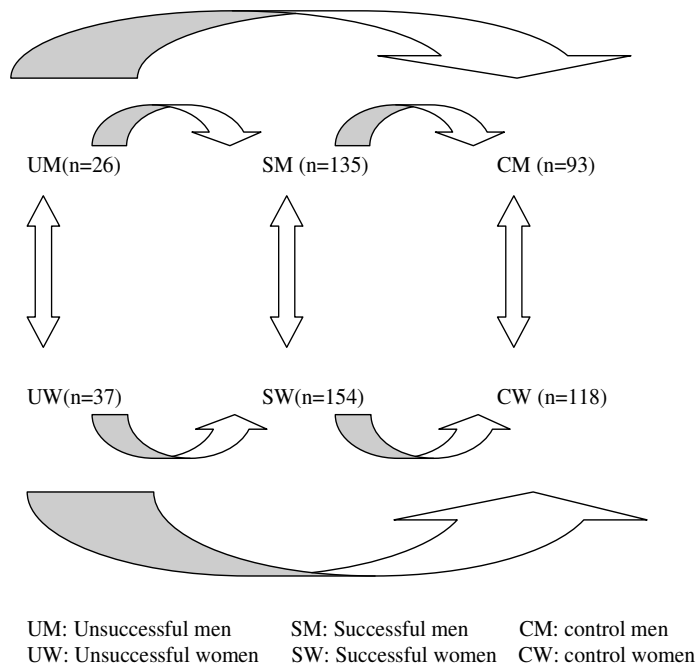


Figure 2. Comparisons with a gender perspective between groups in the study.

Control group in Papers III and IV

Since normal life includes both positive and negative events influencing quality of life and health, a control group was created in order to obtain valid results in the studies. Since conditions in society change over time, the control group was recruited, by Statistics Sweden, during the same period as both IVF groups.

The control group consisted of parents of children born in Västra Götaland. Couples previously treated with IVF were not included. Statistics Sweden created a selective framework that demarcated, identified and enabled connection to individuals in the population. The selection was made from the Population Register in which all children born in the region between March 1, 2001 and August 31, 2002 (n=22 552) were registered. Another criterion was that the children were living in Västra Götaland at the time of selection.

A random sample of 205 children, and thereby 410 parents, was selected. One parent was excluded as the individual could not be identified by Statistics Sweden. The 409 remaining parents of the selected children were asked to participate, gave informed consent and, individually, answered the questionnaires. The questionnaires were sent out by Statistics Sweden to each individual who mailed the completed questionnaires directly to the research group for analysis. Reminders were sent out by Statistics Sweden at the request of the research group. The remaining procedure was similar to that for the IVF groups.

Statistics in Papers III and IV

SPSS version 14.0 was used for statistical analyses in Paper III and SAS version 9.2 was used in Paper IV. Mean, standard deviation (SD), median and range were used for descriptive statistics regarding continuous variables and number and percent were used (n, %) for categorical and dichotomous variables. For comparison between two groups, the Mann-Whitney U-test was used for continuous variables, the Mantel-Haenszel Chi-square test for ordered categorical variables, the Chi-square test for unordered categorical variables and Fisher's exact test for dichotomous variables. All significance tests were two-sided and conducted at the 5% significance level.

Instruments and questionnaires in Papers III and IV

Data was collected with the "Psychological General Well-Being" (PGWB) (Appendix 1) and "Sense of Coherence" (SOC) (Appendix 2) instruments as well as two questionnaires focusing on experiences of infertility and demographic, socio-economic, and health data (Appendix 3 and 4).

The PGWB is a generic instrument that provides a measure of subjective well-being or distress, consisting of 22 items ranked on a six-grade Likert scale (Likert, 1932) and divided into six domains: anxiety, depressed mood, positive well-being, self-control, general health and vitality. The total index identifies general psychological well-being; a higher index indicates increased well-being. Each item has six response options

ranging from 0 to 5 and the total score ranges between 0 and 110. The total index is also distinct from the indices of the respective domains. The instrument is frequently used and has shown satisfactory reliability and validity (Dupuy, 1984, Wiklund et al., 2006).

The SOC is a reliable, valid and cross-culturally applicable instrument (Eriksson and Lindström, 2005) that investigates overall orientation to life: the informant's place on the health/ease and dis-ease continuum. The instrument consists of three components, i.e. comprehensibility, manageability and meaningfulness, and the relationship between the components predicts how the person will manage stressful situations and stay well. The salutogenic "sense of coherence" theory claims that people's view of their lives affects their health (Antonovsky and Elfstadius, 2005, Eriksson and Lindström, 2005, Langius and Björvell, 1996). The SOC questionnaire has been used in many countries in at least 15 different versions. In SOC-13, a short version of the instrument, the ranges of Cronbach's alpha, a statistic used as a measure of reliability for psychometric tests (Gellerstedt, 2004), are comparable with those in the long version (SOC-29). The alpha values in 127 studies using SOC -13 range from 0.70 to 0.92 and the alpha values in 129 studies using SOC -29 range from 0.70 to 0.95. In this study, a short version consisting of 12 items was used (Antonovsky et al., 1991). Cronbach's alpha for this short version indicated satisfactory reliability (0.88).

A questionnaire focusing on self-reported experiences of current childlessness was used, developed from studies of experience of childlessness after terminated IVF (Collins et al., 1992, Hjelmstedt et al., 1999, Johansson and Berg, 2005). The aim of developing a questionnaire concerning infertility-related issues was to increase knowledge of men's and women's experiences many years after having terminated IVF provided the public health system. The instrument includes 15 statements to which subjects respond on a visual analogue scale (VAS). The scale was graded 0-100, where 0 meant agreement and 100 disagreement. The statements concerned children, informants' relationships to childlessness and experiences of infertility after terminated treatment. The statements regarding IVF illuminated the informants' experiences of and the importance they attributed to treatment, albeit unsuccessful. Life and the future from a more existential perspective, as well as the issues of whether the hope of pregnancy still existed and whether menopause was regarded as a normal end of an infertile life, were covered. A pilot study was performed to test this instrument, in which the participants, five women and five men, tested the formulations and scales. Discussions with the respondents were conducted to confirm the comprehensibility of the language used in the instrument (Gellerstedt, 2004).

Additional questions in the questionnaire addressed demographic and socio-economic issues, including age, country of birth, educational level, employment, job-seeking, residential area (current and five years ago), satisfaction with residential area, financial problems, separation from IVF partner/ partner and living with a new partner. Health issues such as seeking primary or specialist medical care, medication, smoking, alcohol consumption (current and twelve months previously), chronic disease and long-term sick-listing were also studied.

ETHICAL CONSIDERATIONS

The regional ethical review board at the University of Gothenburg approved the study (Paper I: Dnr147-93, Papers II, III and IV: Dnr392-04). An additional approval (T 829-08) permitted analysis concerning whether non-responders in the unsuccessful IVF group had children or not. Data was collected from the Swedish Tax Agency and presented at the group level. Contacting couples many years after terminated IVF treatment might be regarded as an integrity intrusion in which questions about infertility could be reactivated. If the couples so requested, they were given the opportunity to obtain professional help to work out an ongoing infertility-related crisis.

MAIN RESULTS

Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment (Paper I)

Women's experiences of childlessness two years after the end of IVF treatment were summarized in five constituents which are presented below, followed by a description of the essence of all constituents.

Childlessness is a central part of life

The women described how fertility is the most central and important part of life, constituting a large part of one's existence. The meaning of life was to reproduce and ensure that the family continued. Pregnancy confirms the relationship one was living in. The women's entire existence was filled by childlessness and their focus was on ovulation and menstruation. At ovulation, there was a chance for pregnancy. Subsequent bleeding was regarded as a failure and confirmed that no pregnancy occurred this time either, reinforcing the experience of childlessness. Females must be able to give birth to a child, which is why they have a uterus and ovaries. A metaphor was presented by one of the women to describe this: "It is almost as if you cannot run with your legs. You have two legs but you cannot run with them".

IVF is a positive and important part of life

The treatment gave the informants a stronger feeling of self-esteem and they are pleased at and proud of having been able to participate in the IVF treatment programme. They perceived the fertilized egg as a child and when bleeding occurred it was experienced as a miscarriage. The body did function, albeit not completely.

Contact with other people is not important

Here the women expressed how they marginalised social life. They described how they withdrew from their surroundings, avoiding making contact with other people as it was considered to be unimportant. They isolated themselves and chose a life where other things were given greater space. Some of the women had never spoken to anyone about their infertility; they regarded it as a private problem and did not expect others to understand the implications of childlessness. The women did not have, and did not feel, anything in common with parents of small children.

Hope of achieving a pregnancy still exists

The women described a persistent hope of becoming pregnant and giving birth to a child. This was experienced as immensely important and was the driving force that enabled life to continue. They hoped for pregnancy, regardless of any known reason for the infertility, especially during ovulation. The opportunity was there but was uncertain. The hope of becoming pregnant decreased with time but it was not until menopause that the women accepted that they could not reproduce; at that point it is definite, it is so for everyone.

Attempts to find other values in life

Childlessness was trivialised and reasons why it might perhaps have been unsuitable to have children were put forward. Other values in life were sought and other things started to take up a larger part of one's life. However, this trivialising of childlessness was contradicted as the women rapidly returned to fertility as the central factor. The women also talked about passing on their genes. A niece or nephew might be regarded as a way to ensure continuation of the family

The essence of the phenomenon: life-grief

The expression "*life-grief*" was abstracted as a common component in all constituents and was found to be an essence of the women's experiences. Life-grief included grief at being childless and unable to reproduce or continue the family. It also included grief at being unable to confirm the relationship through parenthood. The women described feelings of emptiness and depicted the experience of childlessness as a type of pain.

Severe male infertility after failed ICSI treatment - a phenomenological study on men's experiences (Paper II)

The experiences of infertility two years after the end of ICSI treatment in men with a diagnosis of obstructive azoospermia were summarized in four constituents described below, followed by a description of the essence of all constituents.

Inadequacy, followed by a feeling of redress

A feeling of inadequacy was a prominent part of the experience. Being informed about the absence of sperm in the ejaculate was described as the harshest blow in men's lives and the worst news they had ever received. The possibility of biological fatherhood was perceived as non-existent and feelings of powerlessness and of being different emerged. The informants' masculinity was threatened and it felt like their identity was questioned. In all cases, biopsy of the epididymis or testicle led to the detection of sperm which, together with the information that the sperm appeared to be normal, led to a feeling of redress and to partial return of the lost self-esteem. This information also led to the re-emergence of the hope of biological fatherhood, related to the possibility that ART treatment might work. All was not lost, one level had been reached and a partial victory won. A certain feeling of capability began to materialise.

Marginalisation

Marginalisation was another central constituent. A sensation of being an outsider emerged. So much was focused on the woman and the man was more of a companion, an unequal partner. The infertility was not perceived as part of the man's world; it was mainly related to the woman. The wish that the woman and the man be more clearly regarded and treated as a couple with a common problem was expressed. The feeling of marginalisation was aggravated by the fact that the focus of the workup and treatment was not on the man's infertility. The cause of the azoospermia was not investigated. Knowledge about and research concerning azoospermia were perceived

as limited, which reduced the possibilities for treatment. Questions about one's own infertility were central and attempts to find explanations were described by the men. Their frustration at not being given an answer to the question of why their ejaculates lacked sperm was substantial. They were left alone with their questions about the infertility. Knowing what the cause was would have made working out infertility-related issues easier.

Chivalry

The men cared about their loved ones, giving themselves lower priority and thinking about the woman's treatments and how they might affect her. They had thought about stress and hormonal treatment as well as how a large number of treatments might drain the woman's energy. The situation was perceived as harder for the woman and concern about her emotional reactions to the fertility problems was a central theme. Many aspects of infertility were considered to be more difficult for the woman who could not share her experiences with women who had given birth; pregnancy and delivery were associated with the woman's world. Infertility was more concrete for the woman than the man. The psychological pressure was depicted as difficult, but assuming responsibility kept the men going. They described having felt upset, but also having felt that they and their partners had been mutually supportive during the course of the treatments. Supporting other relatives who were disappointed was also portrayed as assuming responsibility. Contact with families with small children was sometimes stressful and informants reported often seeking out families without children. The infertility was considered to have strengthened the relationship between the man and the woman in some respects. It had enabled them to talk about family problems and to give each other support during discussions; they had not felt the need to seek counseling from anyone outside the relationship.

Extension of life and starting a family as driving forces

Starting a family and the perception of belonging to a family were described as central. When the ability to start a family of one's own was threatened, the family of origin-parents and siblings- provided support. Attempts to solve the family-starting problem were described and the need for knowledge of existing alternatives in order to make decisions was brought up. The analogy of a project proceeding according to plan was made. The advantages and disadvantages related to the different alternatives were elucidated. The difficulty and uncertainty entailed in the choice to start a family by sperm donation or adoption occupied a major part of the men's thoughts. It was not an easy decision. The different possibilities were studied from the child's perspective, but also from the point of view of the man-woman relationship.

The decision concerning how to start a family must be well-founded and thoroughly contemplated. The alternative chosen must be a first-hand, rather than a second-hand, choice. The possibility of watching a child, created by the man and his partner, grow up, possibly resembling him, was described as an extension of life. Life continuing through one's children, and the importance of leaving something of oneself for posterity, was described as important.

The essence of the phenomenon

The essence of the infertility experience in men with severe male-factor infertility can be compared to climbing a mountain with the aim of reaching the top, reaching the different levels step by step: having a child and thus a family with children. The detection of sperm in the epididymis or testicle was the first partial victory, since it entailed the possibility of biological fatherhood, and thus a sense of redress after the previous feeling of inadequacy. The feeling of outsidership and marginalisation experienced by the informants was related to the focus on the woman in connection with the infertility. The opportunity to process infertility-related emotions was limited since the cause of the azoospermia was unknown. This was frustrating; the process toward the “mountaintop” halted and there was a feeling of being caught on a “ledge”. Responsibility for loved ones’ wellbeing was assumed at the expense of one’s own emotions. The men felt worried about their partners and protecting the people close to them. A type of chivalry emerged, based on being strengthened by assuming responsibility, which reinforced the man’s sense of self. Different solutions were sought to achieve the goals of children and a family with children, i.e. the “mountaintop”.

The following quotes illustrate the essence of this phenomenon. “The whole process is about climbing a mountain where you never see the top, but it’s like taking it one level at a time. I can’t say that one thing was more important than another; it was a partial victory in its own right, small steps all the time that will possibly result in a baby. It wasn’t the baby we were focused on; our goal was to cope with each step at a time. The mountaintop was having a baby, it wasn’t the sperm, they’re different bits somehow, they’re all connected. Well, of course, they’re all connected but they bring on different kinds of worry and anxiety.”

Quality of life for couples 4-5.5 years after unsuccessful IVF treatment (Paper III)

In this paper we compared PGWB scores in the study group and the control group. We found no differences in total score or when we compared the domains, except vitality, which was scored higher in the study group ($p=0.022$). SOC was scored lower in the study group ($p=0.031$) (Paper III, Table 3). The study group was older ($p<0.001$), more satisfied with their residential area ($p=0.004$), had less economic problems ($p=0.024$) and lived together with their partners more often than the control group. However, the study group used more sleeping pills ($p=0.0024$) (Paper III, Tables 1 and 2).

We found that among those in the study group 76.6% had children or lived together with children 4-5.5 years after terminated IVF. Only 23.3% had no children at the time of the study. These two subgroups were analysed further. When we compared the subgroups with children and those without children with the control group, differences were seen in PGWB and SOC as well as in demographic, socio-economic and health characteristics. Compared to the controls, the subgroup without children scored significantly lower in the PGWB domains depression ($p=0.001$), positive well-being ($p=0.009$), self-confidence ($p=0.018$) and general health ($p=0.038$). There were no significant differences in the total PGWB index, compared to the control group ($p=0.066$). SOC was scored lower in the subgroup without children ($p<0.001$) and this

score was the lowest in the whole study (Paper III, Table 3). Furthermore, educational level was lower ($p=0.036$) and there was more chronic disease ($p=0.048$), more use of sleeping-pills ($p<0.001$), more smokers ($p=0.002$) and a higher consumption of alcohol ($p=0.004$) in this subgroup (Paper III, Tables 1 and 2).

Compared to the controls, the subgroup with children had a significantly higher total PGWB index ($p=0.011$) as well as higher scores in the anxiety ($p=0.012$), positive well-being ($p=0.010$) and vitality ($p=0.002$) domains. No differences were found in SOC (Paper III, Table 3). The subgroup with children were more satisfied with their residential area ($p=0.006$) and more often lived in urban areas, both at the time of the study ($p=0.022$) and at the time of IVF ($p=0.035$), than the control group (Paper III, Tables 1 and 2).

Comparison of the subgroups without and with children revealed significant differences in total PGWB index and in all domains. The subgroup without children scored lower PGWB ($p=0.001$) and scored lower in anxiety ($p=0.004$), depression ($p<0.001$), positive well-being ($p<0.001$), self-confidence ($p<0.001$), general health ($p=0.016$) and vitality ($p=0.023$). The SOC score was significantly lower in the group without children (Paper III, Table 3). More of those in the subgroup without children reported a non-Nordic, European country of birth ($p=0.002$) and a lower educational level ($p=0.031$) and this subgroup lived more often in suburban or rural areas at the time of IVF treatment ($p=0.006$). This subgroup also had more economic problems than the group with children ($p<0.001$) and separations from the partner were more common ($p=0.046$). When it came to health, more contacts with psychiatrists/psychologists ($p=0.046$), more use of sleeping pills ($p=0.006$), more smoking ($p<0.001$) and more use of alcohol ($p<0.001$) was found in the subgroup without children (Paper III, Tables 1 and 2).

Responses to statements concerning experiences of infertility differed between the groups. When it came to how children were regarded, those without children scored the statement "To have children is the most important thing in life" lower ($p<0.001$), they avoided families with children more ($p=0.001$) and they felt more uncomfortable when friends had children ($p<0.001$). The statements "My childlessness is central in my life" and "I feel great grief related to my infertility" were more agreed with in the subgroup without children ($p<0.001$). The importance attributed by both groups to IVF and the fertilized eggs was high and did not differ, despite treatment not resulting in childbirth. Concerning life and the future, the group without children agreed less with statements such as "I see many possibilities in life" ($p=0.004$) and "I live a rich life" ($p=0.006$) than the subgroup with children. The hope of pregnancy was expressed more by the group without children ($p=0.009$) than by those with children (Paper III, Table 4).

Gender perspective on quality of life, comparisons between groups 4 - 5.5 years after unsuccessful or successful IVF treatment (Paper IV)

In this paper comparisons between men and women were made as shown in Figure 2. Demographic and socio-economic are present in Table 2 and health characteristics in Table 3.

Table 2. Demographic and socioeconomic characteristics in a gender perspective, there the unsuccessful IVF group living without children is compared with the successful IVF group and the both groups are compared to men and women in the control group. Men versus women are compared in the successful and in the unsuccessful IVF group living without children.

	Unsuccessful IVF living without children						Successful IVF				Control group	
	Men (n=26)	P-value vs successful	P-value vs control	Women (n=37)	P-value vs successful	P-value vs control	Men (n=135)	P-value vs control	Women n=154	P-value vs control	P-value men vs women	Men/Women (n=93/118)
Age												
Mean (SD)	41.5 (6.3)			38.5 (4.2)	0.15	0.001	40.3 (5.5)	0.010	37.5 (3.8)	<0.001	<0.001	38.5 (6.5)/35.4 (5.1)
Median (range)	40.0 (32.0-55.0)	0.45	0.032	39.0 (29.0-46.0)	0.15	0.001	39.0 (28.5-59)	0.010	37.5 (27.0-46.0)	<0.001	<0.001	38.0 (25.0-62.0)/35.0 (23.0-47.0)
Country of birth												
Nordic countries, n (%)	19 (73.1)			29 (78.4)	0.17	0.57	117 (88.0)	0.61	136 (88.3)	0.71	0.62	78 (83.9)/100 (84.7)
Non Nordic-Europe, n (%)	5 (19.2)			4 (10.8)			8 (6.0)		6 (3.9)			9 (9.7)/7 (5.9)
Outside Europe, n (%)	2 (7.7)	0.049	0.44	4 (10.8)			8 (6.0)		12 (7.8)			6 (6.5)/11 (9.3)
Education Level												
Primary school, n (%)	9 (36.0)			2 (5.6)			15 (11.2)		10 (6.5)			7 (7.7)/9 (7.7)
Secondary school, n (%)	12 (48.0)			24 (66.7)			86 (64.2)		98 (63.6)			53 (58.2)/57 (48.7)
Post secondary, n (%)	4 (16.0)	0.014	0.002	10 (27.8)	1.00	0.27	33 (24.6)	0.11	46 (29.9)	0.10	0.15	31 (34.1)/51 (43.6)
Studying, n (%)	1 (3.8)	1.00	1.00	5 (13.5)	0.32	0.54	5 (3.7)	0.52	11 (7.2)	0.50	0.30	5 (5.7)/11 (9.7)
Working, n (%)	23 (88.4)	0.37	0.34	34 (91.9)	0.43	1.00	128 (94.8)	1.00	131 (86.8)	0.33	0.025	89 (95.7)/103 (91.2)
Looking for job, n (%)	2 (7.7)	0.76	0.82	3 (8.1)	0.94	0.40	6 (4.4)	1.00	16 (10.5)	0.31	0.087	4 (4.5)/16 (13.5)
Residential area												
Urban, n (%)	12 (46.2)			17 (45.9)			54 (40.0)		64 (41.6)			43 (46.2)/40 (35.1)
Suburban areas, n (%)	14 (53.8)	0.66	1.00	20 (54.0)	0.71	0.25	81 (60.0)	0.41	90 (58.5)	0.31	0.81	50 (53.8)/74 (64.9)
Residential area <5 years ago												
Urban, n (%)	10 (40.0)			14 (38.9)			63 (47.0)		71 (47.0)			46 (51.1)/49 (43.8)
Suburban areas, n (%)	15 (60.0)	0.66	0.37	22 (61.1)	0.46	0.70	71 (53.0)	0.59	80 (53.0)	0.62	1.00	44 (48.9)/63 (56.3)
Satisfied residential n (%)	25 (96.2)	1.00	0.28	34 (91.9)	0.85	0.88	126 (94.7)	0.044	144 (94.1)	0.19	1.00	80 (86.0)/105 (89.0)
Economical problems n (%)	4 (16.0)	0.85	1.00	11 (31.4)	0.20	0.33	17 (12.6)	0.57	30 (19.6)	0.81	0.15	15 (16.1)/25 (21.6)
Separated/IVF partner/R, n (%)	3 (11.5)	1.00	1.00	5 (13.5)	1.00	0.99	14 (10.4)	0.71	19 (12.4)	1.00	0.74	12 (12.9)/14 (11.9)
Living new partner n (%)	2 (11.1)	1.00	0.58	2 (8.0)	0.86	0.48	5 (3.8)	1.00	8 (5.3)	0.52	0.73	3 (4.5)/2 (2.5)

+Mann-Whitney U-test, Fischer's exact test, Mantel-Haenszel Chi-Square test, Chi-Square test

Table 3. Health characteristics in a gender perspective there the unsuccessful IVF group living without children is compared to the successful IVF group. The successful IVF group is compared to the control group. Men versus women are compared in the unsuccessful IVF group living without children and in the successful IVF group.

	Unsuccessful IVF living without children				Successful IVF				Control group		
	Men (n=26)	P-value vs successful	P-value vs control	Women (n=37)	P-value vs successful	P-value vs control	Men (n=135)	Women n=154	P-value vs control	P-value men vs women	Men/Women (n=93/118)
Medical care last six months, n (%)	12 (46.2)	0.65	1.00	24 (64.9)	0.68	0.61	52 (39.1)	91 (59.5)	0.94	0.001	44 (47.3)/67 (58.3)
General practitioner, n (%)	8 (30.8)	1.00	0.55	14 (37.8)	1.00	1.00	40.0 (29)	60 (39.2)	1.00	0.11	37 (39.8)/46 (39.0)
Gynaecologist, n (%)	0			10 (27.0)	0.38	0.45	0	29 (19.0)	1.00	<0.001	0 (23.1)/19 (5.2)
Psychiatrist/Psychologist, n (%)	2 (7.7)	0.50	0.95	5 (13.5)	0.12	0.77	4 (3.0)	7 (4.6)	1.00	0.69	5 (5.4)/5 (4.2)
Alternative medicine, n (%)	1 (3.8)	0.60	1.00	3 (8.1)	0.18	0.43	1 (0.7)	3 (2.0)	0.73	0.72	2 (2.2)/4 (3.4)
District nurse, n (%)	1 (3.8)	1.00	0.78	2 (5.4)	0.66	1.00	4 (3.0)	4 (2.6)	0.45	1.00	1 (1.1)/6 (5.1)
Physiotherapist, n (%)	1 (3.8)	1.00	0.89	5 (13.5)	0.60	0.76	9 (6.7)	14 (9.2)	0.94	0.58	7 (7.5)/12 (10.2)
Other specialist, n (%)	2 (7.7)	1.00	1.00	3 (8.1)	0.68	1.00	9 (6.7)	19 (12.4)	0.71	0.15	8 (8.6)/12 (10.2)
Using medications/drugs											
Painkillers, n (%)	3 (11.5)	1.00	1.00	12 (32.4)	0.018	0.010	15 (11.2)	21 (13.6)	0.81	0.66	13 (14.0)/14 (11.9)
Antidepressive drugs, n (%)	1 (3.8)	1.00	1.00	2 (5.4)	0.93	1.00	6 (4.4)	12 (7.8)	0.34	0.35	3 (3.2)/5 (4.2)
Sleeping pills, n (%)	2 (7.7)	0.37	0.24	6 (16.2)	0.002	0.002	3 (2.2)	2 (1.3)	1.00	0.88	1 (1.1)/1 (0.8)
Other medications, n (%)	5 (19.2)	0.34	1.00	3 (8.1)	0.62	0.49	14 (10.4)	20 (13.0)	0.87	0.62	19 (20.4)/17 (14.4)
Smokers, n (%)	6 (23.1)	0.34	0.28	14 (37.8)	0.001	0.006	18 (13.5)	19 (12.3)	0.75	0.90	11 (12.1)/17 (14.4)
Alcoholic drinks last month											
Daily/several times a week, n (%)	0 (2 (7.7)			0 (3 (8.1)			2 (1.5) (3.7)	0 (5 (3.2)			1 (1.1) (1.1) (0.9) (0.9) (1.7) (6 (5.1)
1-2 times/w, n (%)	10 (38.5)			7 (18.9)			50 (37.3)	32 (20.8)			34 (36.6)/19 (16.2)
1-3 times/m, n (%)	9 (34.6)			16 (43.2)			56 (41.8)	64 (41.6)			34 (36.6)/53 (45.3)
Non alcoholic, n (%)	5 (19.2)	1.00	0.81	11 (29.7)	0.45	0.76	21 (15.7)	53 (34.4)	0.53	<0.001	16 (17.2)/37 (31.6)
Alcohol drinks last 12 months											
Daily/ Several times/w, n (%)	0 (2 (7.7)			0 (3 (8.1)			2 (1.5) (3.7)	0 (4 (2.6)			1 (1.1) (1.1) (0.9) (0.9) (1.7) (6 (5.1)
1-2 times/w, n (%)	7 (26.9)			7 (18.9)			41 (30.8)	29 (19.0)			24 (25.8)/15 (12.8)
1-3 times/m, n (%)	7 (26.9)			10 (27.0)			40 (30.1)	46 (30.1)			36 (38.7)/38 (32.5)
< Once/m, n (%)	5 (19.2)			9 (24.3)			31 (23.3)	44 (28.8)			14 (15.1)/34 (29.1)
Non alcoholic, n (%)	5 (19.2)	0.58	0.45	8 (21.6)	0.62	0.57	14 (10.5)	30 (19.6)	0.87	0.001	11 (11.8)/24 (20.5)
No of glasses, mean (SD)	4.86 (4.93)	0.30	0.61	3.68 (3.16)	0.001	0.011	3.04 (2.35)	1.99 (1.70)	0.050	<0.001	3.35 (2.45)/2.37 (1.66)
Chronic disease, n (%)	7 (26.9)	0.063	0.16	10 (27.0)	0.24	0.234	14 (10.4)	26 (16.9)	1.00	0.16	12 (12.9)/19 (16.4)
Long time sick listed											
Full time -Part time, n (%)	2 (7.7) (1 (3.8)	0.29	0.11	1 (2.1) (4 (10.8)	0.68	0.34	3 (2.2) (5 (3.7)	6 (3.9) (7 (4.6)	0.46	0.38	1 (1.1) (1.1) (4 (3.6) (4 (3.6) (1 (0.9)

Mann-Whitney U-test, Fischer's exact test, Mantel-Haenszel Chi-Square test, Chi-Square test. w=week, m=month.

Comparison of men living without children after unsuccessful IVF and men in the successful IVF group shows that the total PGWB indices, as well as the domains except anxiety ($p=0.056$), were lower among the men without children. A lower total SOC index was also found among the men in the unsuccessful group (Paper IV, Table 1).

Comparison of men living without children after unsuccessful IVF and men in the control group revealed a lower score in the PGWB domains depression ($p=0.019$) and well-being ($p=0.029$) as well as in total SOC ($p=0.001$) in the former group (Paper IV, Table 1).

Comparison of men after successful IVF and men in the control group showed no differences in SOC or in the total PGWB indices. The vitality score was higher among the men in the successful IVF group ($p=0.022$) than in the control group (Paper IV, Table 1).

When women living without children after unsuccessful IVF and women having undergone successful IVF were compared, more signs of anxiety ($p=0.030$) and depression ($p=0.038$) were found in the group without children, while no significant differences were found in total PGWB indices or in the other four domain scores. The total SOC indices were lower in the group living without children ($p=0.008$) (Paper IV, Table 1).

Comparison of women living without children after unsuccessful IVF and women in the control group revealed that the women in the unsuccessful IVF group scored lower in the PGWB domain of depression ($p=0.015$) and had lower total SOC indices ($p=0.004$) (Paper IV, Table 1).

Comparison of women after successful IVF and women in the control group showed no differences in total PGWB indices, PGWB domains or SOC indices (Paper IV, Table 1).

Comparison between men and women living without children after unsuccessful IVF revealed no differences in total PGWB indices, domain scores or SOC indices. No responses to statements concerning children, childlessness, IVF, life, the future or infertility-related issues differed (Paper IV, Table 1 and 2).

Comparison between men and women in the successful IVF group indicated higher total PGWB indices ($p=0.046$), less signs of depression ($p=0.003$) and more self-confidence ($p=0.017$) among men than women (Paper IV, Table 1).

Comparison between men and women in the control group revealed no differences in PGWB indices, domain scores or SOC indices.

Finally, we compared the studied groups (men and women), i.e. those living without children after unsuccessful IVF, with those who had undergone successful IVF and this latter group was also compared to the controls. Demographic and socio-economic data are present in Table 4 and health characteristics in Table 5.

Table 4. Demographic and socio-economic characteristics in the unsuccessful IVF group living without children compared to the successful IVF group. The successful IVF group is compared to the control group.

	Unsuccessful IVF		Successful IVF		Control group All (n=211)
	All (n=63)	P-value vs successful	All (n=289)	P-value vs control	
Age					
Mean (SD)	39.8 (5.4)		38.8 (4.8)		36.7 (5.9)
Median (range)	39.0 (29-55.0)	0.19	39.0 (27-59)	<0.001	37.0 (23.0-62.0)
Country of birth					
Nordic countries, n (%)	48 (76.2)		253 (88.2)		178 (84.4)
Europe n (%)	9 (14.3)		14 (4.9)		16 (7.6)
Outside Europe, n (%)	6 (9.5)	0.015	20 (7.0)	0.39	17 (8.1)
Education Level					
Primary school, n (%)	11 (18.0)		25 (8.7)		16 (7.2)
Secondary school, n (%)	36 (59.0)		184 (63.8)		110 (52.9)
Post secondary, n (%)	14 (23.0)	0.12	79 (27.4)	0.017	82 (39.4)
Studying, n (%)	6 (9.5)	0.25	16 (5.5)	0.35	16 (8.0)
Working, n (%)	57 (90.5)	1.00	259 (90.6)	0.33	192 (93.2)
Looking for job, n (%)	5 (7.9)	1.00	22 (7.6)	0.37	20 (10.4)
Residential area					
Urban, n (%)	29 (46.0)		118 (40.8)		83 (40.1)
Suburban areas, n (%)	34 (54.0)	0.48	171 (59.2)	0.93	124 (59.9)
Residential area <5 years ago					
Urban, n (%)	24 (39.3)		134 (47.0)		95 (47.0)
Suburban areas, n (%)	37 (60.7)	0.32	151 (53.0)	1.00	107 (52.9)
Satisfied residential n (%)	59 (93.7)	1.00	270 (94.4)	0.013	185 (87.7)
Economical problems n (%)	15 (25.0)	0.16	47 (16.3)	0.48	40 (19.1)
Separated IVF partner, n (%)	8 (12.7)	0.93	33 (11.5)	0.88	26 (12.3)
Living new partner n (%)	4 (9.3)	0.35	13 (4.6)	0.77	5 (3.4)

+Mann-Whitney U-test, Fischer's exacta test, Mantel-Haenszel Chi-Square test, Chi-Square test

Table 5. Health characteristics in the unsuccessful IVF group living without children compared to the successful IVF group. The successful IVF group is compared to the control group.

	Unsuccessful IVF		Successful IVF		Control group (n=211)
	All (n=63)	P-value vs successful	All (n=289)	P-value vs control	
Medical care last six months, n (%)	36 (57.1)	0.38	143 (50.0)	0.52	111 (53.4)
General practitioner, n (%)	22 (34.9)	1.00	100 (34.7)	0.34	83 (39.3)
Gynaecologist, n (%)	10 (15.9)	0.27	29 (10.1)	0.87	23 (10.9)
Psychiatrist/Psychologist, n (%)	7 (11.1)	0.053	11 (3.8)	0.77	10 (4.7)
Alternative medicine, n (%)	4 (6.3)	0.075	4 (1.4)	0.41	6 (2.8)
District nurse, n (%)	3 (4.8)	0.63	8 (2.8)	0.92	7 (3.3)
Physiotherapist, n (%)	6 (9.5)	0.85	23 (8.0)	0.80	19 (9.0)
Other specialists, n (%)	5 (7.9)	0.87	28 (9.7)	1.00	20 (9.5)
Using medication/drugs					
Painkillers, n (%)	15 (23.8)	0.042	36 (12.5)	1.00	27 (12.8)
Antidepressive drugs, n (%)	3 (4.8)	0.92	18 (6.2)	0.31	8 (3.8)
Sleeping pills, n (%)	8 (12.7)	0.001	5 (1.7)	0.74	2 (0.9)
Other medications, n (%)	8 (12.7)	0.98	34 (11.8)	0.12	36 (17.1)
Smokers, n (%)	20 (31.7)	0.001	37 (12.9)	0.97	28 (13.4)
Alcoholic drinks last month					
Daily-several times/w, n (%)	0 (0.0)-5 (7.9)		2 (0.7)-10 (3.5)		3 (1.4)-14 (6.7)
1-2 times /w, n (%)	17 (27.0)		82 (28.5)		53 (25.2)
1-3 times/m, n (%)	25 (39.7)		120 (41.7)		87 (41.4)
Non alcohol, n (%)	16 (25.4)	0.69	74 (25.7)	0.48	53 (25.2)
Alcohol drinks last 12 months					
Daily - Several times/w, n (%)	0 (0.0)-5 (7.9)		2 (0.7)-9 (3.1)		2 (1.0)-12 (5.7)
1-2 times/w, n (%)	14 (22.2)		70 (24.5)		39 (18.6)
1-3 times/m, n (%)	17 (27.0)		86 (30.1)		74 (35.2)
<once/m -Non alcoholic, n (%)	14 (22.2)-13 (20.6)	0.95	75 (26.2)-44 (15.4)	0.94	48 (22.9)-35 (16.7)
No of glasses, mean (SD)	4.15 (3.97)	0.003	2.47 (2.09)	0.023	2.83 (2.1)
Chronic disease, n (%)	17 (27.0)	0.023	40 (13.7)	0.86	31 (14.8)
Long time sick listed					
Full time - Part time, n (%)	3 (4.8)-5 (7.9)	0.24	9 (3.1)-12 (4.2)	0.40	5 (2.4)-5 (2.4)

+Mann-Whitney U-test, Fischer's exacta test, Mantel-Haenszel Chi-Square test, w=week, m=month

Comparison between total study groups: living without children after unsuccessful IVF (n=63), compared to successful IVF (n=289)

No differences in demographic or socio-economic characteristics were found except that more individuals in the unsuccessful IVF group were born in non-Nordic Europe ($p=0.015$). Concerning health characteristics, more subjects in the group without children reported chronic diseases ($p=0.023$) as well as use of painkillers ($p=0.042$) and sleeping pills ($p=0.001$). Smoking was more frequent among those in the unsuccessful IVF group ($p=0.001$) and there were also more individuals who smoked more than ten cigarettes per day in that group ($p=0.036$). Alcohol consumption was higher among those living without children ($p=0.003$) (Tables 4 and 5). Consequently, the total PGWB indices, all domain scores except vitality and the total SOC indices were lower in the unsuccessful IVF group living without children (Paper IV, Table 3).

Comparison between total study groups: successful IVF (n=289) compared to the control group (n=211)

The successful IVF group were older ($p<0.001$) and more satisfied with their residential area ($p=0.013$) but had higher education to a lesser extent ($p=0.017$) than the control group. No differences in health characteristics were found but the control group reported higher alcohol consumption ($p=0.023$) (Tables 4 and 5). There were no significant differences in the total PGWB indices or in the domain scores except less signs of anxiety in the successful IVF group ($p=0.033$). No differences were found in SOC (Paper IV, Table 3).

DISCUSSION

The overall aim of this thesis was to study experiences of infertility and quality of life among men and women who had terminated IVF unsuccessfully, i.e. without treatment resulting in childbirth. We described the essence of women's experience of involuntary infertility after unsuccessful terminated IVF as *life-grief*. The essential meaning of men's experiences of persisting male-factor infertility after ART treatment was expressed in the metaphor of climbing a mountain with the aim of reaching the top, i.e. having a child and thus a family with children.

Surprisingly, more than 76% of couples who had terminated unsuccessful IVF provided by the public health system were found to be living with children 4-5.5 years later. The men and women who were subsequently living without children reported a lower quality of life than the men and women living with children. No significant differences were found when men and women in the unsuccessful IVF group living without children were compared.

Methodology

Follow-up of failed ART treatments results in a lower response rate and involves more difficulties than follow-up of successful treatments, according to the literature. Individuals whose IVF treatment was unsuccessful may not have resolved their feelings about the infertility or the unsuccessful IVF treatment and may therefore be unwilling to participate in research focusing on IVF (Adler et al., 1991). Indeed, in this thesis there was a slightly higher response rate in the successful IVF group, 73% of whom responded and completed the questionnaires, compared to the 71% of the unsuccessful group who responded and the 68% of that same group who completed the questionnaires. This response rate was, however, acceptable and some informants commented that they had been waiting for some kind of follow-up after terminated IVF treatment.

According to Statistics Sweden, 37.2% of the unsuccessful IVF group who declined to participate in the study were living without children, a higher proportion than the corresponding 23.3% among participants. This discrepancy might have led to the underestimation of negative feelings concerning infertility and of impaired quality of life in the unsuccessful IVF group participating in our study.

Including a control group, recruited during the same period and in the same region as the IVF groups, in order to obtain valid results strengthened the results of our studies (Papers III and IV). Fifty-five percent accepted participation and 53% of the total invited group were included. This can be regarded as a low response rate but when the responders and non-responders were analysed, there were no major differences in age, ethnicity, marital status or residential area between the groups.

The questionnaire concerning infertility-related issues was constructed by the research group and was developed from earlier studies on self-reported experiences of

infertility (Collins et al., 1992, Hjelmstedt et al., 1999, Johansson and Berg, 2005). A pilot study was performed to test and develop the questionnaire; five women and five men, all with a history of infertility answered it. Discussions were conducted with the respondents, of whom two women and two men had children as a result of IVF and one couple had adopted children, to confirm the comprehensibility of the language used in the questionnaire (Gellerstedt, 2004).

Using a qualitative method, i.e. a descriptive phenomenological method in which the life world concept is central, in these studies provided the opportunity to explore men's and women's experiences of infertility more profoundly. This method yielded knowledge of the experiences of men diagnosed with obstructive azoospermia. As far as we know, no such phenomenological study had been published previously (Paper II). The interviews with the women (Paper I) were performed in two sessions, in 1995 and in 2002, respectively, but all the transcribed texts were analysed as one entity and the essential meaning was relevant for all interviewed women. This may be interpreted to indicate that the reported essential meaning of the women's experiences of infertility was solid despite several years having passed between the first and last data collection.

The qualitative research method has occasionally been questioned as a method. In my opinion, the criteria of science as described by Giorgi are met when the knowledge obtained is systematic, methodical, critical and general. "Systematic" entails a connection between various sub-fields within a given discipline. "Methodical" means that certain basic steps are to be followed. "Critical" means that knowledge gained by any method is not to be simply accepted; researchers can challenge the procedure or the results and try to replicate findings. "General" means that knowledge gained is applicable to situations other than the specific one in which it was obtained (Giorgi and Giorgi, 2003).

The combination of qualitative and quantitative research methodologies in the thesis contributed additional dimensions to the total findings. In the qualitative studies, the informants described their experiences without the limitations of standardised questions. The methodology provides the possibility to grasp the subjective experiences of the individual and subsequently to obtain a sense of the whole. Using a quantitative method in which groups are studied results in another type of knowledge. Quantifying data can be a powerful method of comparing groups, describing findings and presenting results. This thesis yielded knowledge of experienced health and well-being related to different outcomes of IVF.

Quality of life in terms of experienced health was assessed with the SOC instrument and psychological well-being was assessed with the PGWB instrument. The results generated important knowledge on how quality of life was experienced by men and women who had terminated IVF treatment with different outcomes. The additional questions related to demographic, socio-economic and health issues and the questions related to experiences of infertility provided us with wider knowledge of men's and women's situations after terminated unsuccessful IVF.

Findings

Involuntary infertility is described in the literature as entailing an existential problem (Möller, 1985a). Life-grief (Paper I) is a part of the woman's life and is due to being childless and unable to reproduce or continue the family but also to being unable to confirm the relationship through parenthood. Grief related to infertility was also described 4- 5.5 years after terminated IVF treatment among couples, both in men and women, who were living without children (Papers III and IV). Other studies confirm these findings (Weaver et al., 1997, Eugster and Vingerhoets, 1999). Lukse and Vacc (1999) reported that neither age, cause and length of infertility nor the number of treatments influenced the experiences of grief. Furthermore, grief was also experienced after spontaneous loss of early pregnancy after IVF treatment (Harris and Daniluk, 2010).

The women in our study (Paper I) experienced that the treatment had given them a stronger feeling of self-esteem and they described the fertilised eggs as children. Furthermore, when bleeding occurred it was perceived as a miscarriage. They did not regret the IVF experience. Despite not having conceived, the women did not relinquish the hope of becoming pregnant, a possibility existing until they reached menopause. This latter finding is new knowledge and was referred to in a recent review by Greil et al (2010). An additional finding was that the women attempted to find other central values in life (Paper I) but then refocused on fertility as a central factor. To "transform hope" was also described in a Chinese study after IVF treatment failure in which themes such as accepting the reality of infertility, acknowledging the limitations of treatment involving high technology and re-identifying one's future were exposed (Su and Chen, 2006).

There are very few qualitative studies concerning men's experiences of infertility due to obstructive azoospermia and this study (Paper II) is the first in its context. A feeling of inadequacy was a prominent part of the experience when the men were informed of the absence of sperm in the ejaculate. They felt that their masculinity was threatened but a form of redress was described when epididymal or testicular sperm was found. The essence of the experiences of infertility was described with a metaphor: climbing a mountain step by step with the aim of reaching the top, i.e. to have children and thus a family with children.

The first factor extracted by Hjelmstedt et al (1999) in a factor analysis of men's experience of female-factor, male-factor, mixed and unexplained infertility was a feeling of inadequacy in the male role and social pressure to have children. The second factor extracted was the desire to have children, described as the major focus of life, as well as regarding infertility as one of the hardest problems in life. The men living without children in our studies (Paper IV) still experienced childlessness as central in life and described grief related to infertility 4-5.5 years after failed IVF. In a Swedish questionnaire study, male-factor infertility was not reported to influence men more negatively than men in couples diagnosed with female-factor, mixed or unexplained infertility (Holter et al., 2007). The same result was also found among Danish men

(Peronace et al., 2007). It would be interesting to study these Swedish and Danish men's experiences of infertility with a descriptive phenomenological method.

Furthermore, we found that having children improves quality of life (Papers III and IV). The couples living without children after terminated IVF reported the lowest measured quality of life and they had also a higher consumption of alcohol, smoked more and used more sleeping pills, compared to the other groups (Papers III and IV). A Norwegian study reported that the a majority of women, 82%, had children 10 years post-treatment (Sundby et al., 2007). In a Swedish study, 73% of the women and 33% of the men reported, 1.5 years after terminated unsuccessful IVF, that they wanted additional ART treatment in order to have a biological child. In the same study, 84% of the women and 77% of the men reported that they had decided to adopt a child/children (Sydsjö et al., 2005). The 77% of couples living with children in our study (Paper III) was a heterogeneous group, with children either born after spontaneous conception, born after additional IVF, adopted, fostered or partners' offspring. We did not study how the quality of life in the respective subgroups was experienced but this issue is of great interest and merits further research.

Several studies have reported that women are more negatively influenced by infertility than men (Leiblum et al., 1987, Eugster and Vingerhoets, 1999, Hjelmstedt et al., 1999, Filetto and Makuch, 2005). Ragni et al. (2005) reported that Italian men's quality of life prior to their first IVF treatment was comparable to that of a control group. Depression was the most common mood disorder in women and men undergoing IVF in Sweden, and was more frequent among women than men (Volgsten et al., 2008). In a recently published short-term follow-up study, more women than men reported severe depressive symptoms one year after unsuccessful fertility treatment (Lund et al., 2009).

A Danish study has shown that childbirth after ART treatment was associated with significantly increased SOC scores in a one- year follow-up study among women. In contrast, there were no significantly increased SOC indices among men (Habroe et al., 2007). Our studies (Papers III and IV) reported lower SOC indices in the unsuccessful IVF group living without children, compared both to the unsuccessful IVF group living with children, to the successful IVF group and to the control group. Both men and women in the unsuccessful IVF group living without children had lower SOC indices than men and women in all studied groups. Regarding health as a point on the health/ease and dis-ease continuum, living with children seems to increase the move towards health for men and women with involuntary infertility.

We found that well-being and quality of life among men who were living without children 4-5.5 years after terminated failed IVF treatment were significantly lower than among men in that same group who were living with children, men who had undergone successful treatment and men in a control group. No significant differences were found between men and women in the unsuccessful group living without children (Paper IV). This was new knowledge. Monga et al. (2004) assert that men in couples with involuntary infertility did not differ from controls in terms of psychological well-

being and no differences were reported in anxiety and depression between men six months after terminated unsuccessful or successful IVF (Verhaak et al., 2005a). There are few long-term studies describing men's well-being after terminated unsuccessful IVF and our results may indicate that men reacted later to involuntary infertility than women did. The qualitative study shows that the men adopted a chivalrous role; they cared for their partners, felt that solving the family-starting problem was a driving force and gave themselves lower priority than their partners (Paper II).

GENERAL SUMMARY AND CONCLUSIONS

Quality of life and well-being are fundamental for health. The WHO defines health as physical, psychological and social well-being and not only the absence of disease. This definition applies to reproductive health as well. Involuntary childlessness occurs in 9% of couples of fertile age and many of them seek health care services for investigation and treatment of the infertility. Today, IVF is an established treatment method and there is rapid progress in the development of ART. This indicates that biological parenthood currently is a possibility for an increasing number of couples.

The general aim of this thesis was to study the experience of infertility and quality of life as experienced health and well-being, as well as to study demographical and socio-economic factors and health in men and women who had terminated IVF treatment unsuccessfully.

In two studies, eight women and eight men who had terminated treatment unsuccessfully two years earlier were interviewed in a life world perspective using a descriptive phenomenological method of analysis. The men had been diagnosed with severe male-factor infertility. All informants had undergone IVF or ICSI resulting in fertilized eggs which were transferred to the uterus of the female partner.

Quality of life, self-experienced health and well-being and the experience of infertility were studied in couples having terminated IVF treatment unsuccessfully 4–5.5 years previously. Comparisons were made with a group of couples for whom treatment had resulted in childbirth, as well as with a control group of couples without infertility problems who had spontaneously conceived children of the same age. The experiences of women and men were also studied separately. Data collection was performed with the established instruments PGWB and SOC and with a questionnaire, created by the research group, on the experience of infertility. Demographic, socio-economic and health data were collected by questionnaires designed by the research group.

The results show that the essence of infertility in women (Paper I) was experienced as life-grief encompassing the grief of being childless, reproductive incapacity and the inability to confirm the relationship through parenthood and to continue the family.

The essence of men's experience (Paper II) can be described in a metaphor: to climb a mountain, step by step, without seeing its peak, which is to have a child. The knowledge that testicular sperm exists, after none being detected in the ejaculate, led to a feeling of redress and the possibility of biological fatherhood and demonstrates that an important step had been reached. Lack of knowledge about the reasons for the infertility was frustrating and caused a feeling of marginalisation and a view that the focus was on the woman. The men felt concern for their relatives and a form of chivalry emerged, related to assuming responsibility. The driving force was the formation of a family and thus the prolongation of life.

Paper III showed that 77% of couples who had terminated IVF provided by the public health care system lived with children 4–5.5 years after treatment; 39.6% had biological children mostly after additional IVF treatment within the private health care sector and 34.8% had adopted children. Furthermore, 3% had foster children and 3.7% lived together with the partners' children. Those who were living without children (23%) had a significantly lower quality of life than couples who had undergone successful IVF, but also compared to the couples in the control group. Those who were living without children still experienced their infertility as a central factor in life.

Paper IV showed that men and women who had undergone unsuccessful IVF treatment and who living without children had a lower quality of life, compared to men and women who had undergone successful IVF treatment, but also in comparison to men and women in the control group. No significant differences were found between the quality of life of women and men for whom IVF treatment had not resulted in childbirth. Quality of life in men without children was more negatively affected than has earlier been reported in studies on involuntary childlessness.

THE FINDINGS' IMPLICATIONS FOR PRACTICE

To have children improves quality of life, as shown in this thesis, essential for couples who have wished and decided to become parents. Offering an additional number of IVF treatments within the public health system is one way to increase quality of life among couples with involuntary infertility. This is, of course, a political issue relating to health economics but might also yield other benefits, such as an increased birth rate and thus more children, in a nation with an ageing population, which leads to increased economic, social and health care burdens (RAND at ESHRE, Prague 2006).

Men and women living without children had a lower quality of life than those living with children a long time after terminated IVF treatment and men seem to be more negatively affected by involuntary infertility than has previously been known. Both men and women experience involuntary childlessness as a central factor in life. This knowledge is important for professionals, midwives and gynaecologists working in reproductive health care and should lead to attempts to optimise care for men and women with involuntary infertility. Medical, psychological and social factors should be taken into consideration in order to maintain health and men's and women's different reactions to infertility must be taken into account when providing care and support during medical investigation and treatment.

Professional support and counselling should be offered when IVF treatment in the public health system. Men's and women's respective reactions to the infertility and thoughts on how to handle the future are valuable subjects for discussion in order to increase the possibility for individuals with involuntary infertility to optimise their life situation. This is important from an individual as well as a societal perspective. The adoption of a gender perspective, focusing on men and women separately, in updated fertility guidelines, such as those presented by the National Institute for Health and Clinical Excellence (NICE) (National Institute for Health and Clinical Excellence, 2004) for investigation, treatment and care, can be one way to increase quality of life in this group.

FURTHER RESEARCH

We found that men seem to be more negatively affected by involuntary infertility than has previously been known. Men with children in the family after unsuccessful IVF reported a higher experienced quality of life than their partners. Further long-term follow-up studies with a gender focus should be performed in order to obtain more knowledge of involuntary infertility's effect on quality of life as well as its health-economic effects.

The couples living with children after unsuccessful IVF treatment were a heterogeneous group with respect to how the children had been included in the family. The children were born after additional IVF treatment, adopted or born after spontaneous conception, were fosterchildren or a partner's children. According to Swedish legislation (National Board of Health and Welfare, 2002) at the time, couples were to be informed about non-medical solutions for infertility, such as adoption, before starting ART treatment, but there are very few studies investigating the interesting issue of whether quality of life is related to these different modes of including children in the family.

Qualitative methodologies contribute additional dimensions and depth and give us knowledge of how a phenomenon is experienced. The strength of our study (Paper II), in which men with a diagnosis of obstructive azoospermia explored their experience of infertility, was that the group was well-defined with respect to the infertility diagnosis. Moreover, research with similar methodology focusing on men with absolute (testicular azoospermia) male-factor infertility, subfertility due to defective sperm or sexual dysfunction may be required in order to increase knowledge of men's experiences of their own infertility.

The men, who had all undergone unsuccessful ICSI, described different solutions to the problem of how to have a family with children. Alternative solutions were acknowledged but the decision to have children through sperm donation via insemination or IVF or by adoption was not an easy one. Future research with phenomenological methodology might be interesting in order to elucidate this decision making process.

SVENSK SAMMANFATTNING

Livet efter avslutad IVF behandling – upplevelse och livskvalitet hos män och kvinnor

Livskvalitet och välbefinnande är grunden för människors hälsa. Världshälsoorganisationen (WHO) definierar hälsa som fysiskt, psykisk och socialt välmående och inte enbart frånvaro av sjukdom. Definitionen gäller även för reproduktiv hälsa. Ofrivillig barnlöshet ses hos 9% av par i barnafödande ålder, många av dessa par söker hjälp från sjukvården för utredning och behandling av infertilitet. In vitro fertilisering (IVF) är idag en etablerad behandlingsform och utvecklingen sker snabbt inom assisterad reproduktionsteknologi. Detta leder till att fler par idag än tidigare har möjlighet att bli biologiska föräldrar.

Övergripande syfte med avhandlingen var att studera upplevelse av infertilitet, livskvalitet som subjektivt upplevd hälsa och välbefinnande samt parametrar avseende demografi, socio-ekonomi och hälsa hos män och kvinnor som avslutat IVF behandling som inte resulterat i födelse av barn.

Intervjuer har genomförts utifrån ett livsvärlds perspektiv med en beskrivande fenomenologisk analysmetod. Intervjupersoner var åtta kvinnor och åtta män i respektive studie där behandlingen avslutats två år tidigare utan att ha resulterat i födelse av barn. Männen hade alla en svår manlig infertilitetsdiagnos. För samtliga informanter hade in vitro fertilisering (IVF) respektive intracytoplasmatisk spermieinjektion (ICSI) resulterat i befruktade ägg som återförts i kvinnans livmoder.

Livskvalitet i form av självskattad upplevd hälsa och välbefinnande men också upplevelse av barnlöshet har studerats hos par som avslutat IVF behandling 4-5,5 år tidigare utan att denna resulterat i barnafödelse. Jämförelser med par där behandlingen resulterade i barnafödelse har gjorts men också med en kontrollgrupp av föräldrar utan infertilitetsproblematik och med barn i samma ålder. Män respektive kvinnors upplevelse är också studerade separat. Datainhämtning har skett med hjälp av instrumenten PGWB (psykologiskt allmänt välbefinnande) och KASAM (känslan av sammanhang) samt ett av forskargruppen utarbetat frågeformulär kring upplevelse av infertilitet. Demografiska och socio-ekonomiska samt hälsokarakteristika har inhämtats via av forskargruppen framtagna frågeformulär.

Resultaten visar att essensen i fenomen barnlöshet bland kvinnor (delstudie I) upplevs som en livssorg vilken innefattar sorgen över att vara barnlös, oförmågan till reproduktion, oförmågan att konfirmera relationen genom föräldraskap samt oförmågan att bära familjen vidare.

Essensen i männens upplevelse (delstudie II) beskrivs i en metafor: att bestiga ett berg, att aldrig se bergets topp och ta en avsats i sänder. Toppen på berget är att få barn. Vetskapen om spermier i testiklarna leder till en upprättelse av en oduglighet, att ett biologiskt faderskap blev möjligt och att en etapp var nådd. Bristande vetskap om orsaken till infertiliteten var frustrerande, en marginalisering upplevdes därför att

fokus låg på kvinnan. Männens värnande om sina närstående och en form av ridderlighet i att bäras upp av ansvar framträdde. Drivkraften var familjbildningen och därmed en förlängning av livet.

Delstudie III visade att 77% av par som avslutat erbjuden IVF behandling inom offentlig sektor efter 4-5,5 år levde med barn, 39,6% hade biologiska barn oftast efter ytterligare IVF behandling inom privat vård och 34,8% hade adopterat barn, 3% hade foster barn och 3,7% levde med partners barn. De 23% som levde utan barn hade en signifikant lägre livskvalitet än dem där IVF behandlingen lyckats men också jämfört med paren i kontrollgruppen. De 23% utan barn upplevde fortfarande infertiliteten som central i livet.

Resultaten i delstudie IV visade att män och kvinnor där IVF behandlingen inte hade lyckats och som fortsättningsvis levde utan barn hade en sämre upplevd livskvalitet jämfört med män respektive kvinnor där IVF behandlingen lyckats, men också jämfört med män respektive kvinnor i kontrollgruppen. Inga signifikanta skillnader sågs i män respektive kvinnors livskvalitet där IVF behandlingen inte resulterat i barn och där man fortsättningsvis levde utan barn. Livskvaliteten hos män utan barn påverkas i högre utsträckning negativt än vad tidigare rapporterats i studier kring ofrivillig barnlöshet.

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