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Communication, Coping and Social Networking regarding Infertility

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To Mikael and Mikko

POPULAR SCIENCE SUMMARY OF THE THESIS

Involuntary childlessness, infertility, is defined as the inability to conceive after one year of sexual intercourse, or to produce a pregnancy resulting in a living child. It is estimated to affect 8-10 percent of couples in Sweden. Infertility is investigated and treated as a medical problem while couples experience it as psychologically stressful and a social problem, often with existential elements. The Internet enables people with infertility to seek information and support through various social media, such as blogs. The importance of the Internet is increasing and gives individuals the opportunity to be more prepared for various examinations, tests, and treatments than before, but can also be a source of misinformation. The aim of this thesis was to explore and describe communication, coping and social networking regarding infertility from a lifeworld perspective.

Study I aimed to explore infertility-related communication and coping strategies among women affected by primary or secondary fertility problems. The participants consisted of two groups: women who were trying to have their first child (primary infertility) and those who already had a previous child and were trying to have an additional child (secondary infertility). Most of the women, in both groups, were able to discuss infertility-related topics with their spouse. However, inability to have a child, the reasons for childlessness and results of tests and examinations could not be discussed. Coping strategies used were avoiding being in the company of pregnant women or women who had children, or leaving exiting when people discussed pregnancies or children.

In **Study II** the aim was to gain insight into which infertility-related issues are discussed on Swedish infertility blogs. The blogs were written by women and most were anonymous. The bloggers often discussed infertility with reference to emotions, relations, time and waiting, body, care and treatment, food and diet, and exercise. Several women reported that if they were not able to discuss infertility issues with their spouse or friends, blogging provided a place where they could express themselves. Spousal relationships could also be affected negatively by infertility, as the women experienced that their partner could not fully understand the affect fertility treatments have on the female body.

The aim of **Study III** was to explore the roles of social media for persons affected by infertility. The majority of the participants were women. They reported that the key benefits of social media, focused on infertility, were solidarity, information, to get and give support, and understanding infertility. Some of the negative experiences were, becoming emotionally affected by treatment failures of the other forum members, and tips and advice not always being evidence based. The impact of infertility was described as being left fragmented, with feelings of disconnectedness.

S**tudy IV** aimed to describe women's experiences of using social media focusing on infertility. The main reasons for using social media were information seeking and fellowship. For example, information about how others have received help, which treatments have been used, if others have succeeded in getting pregnant and how they have felt during investigations and treatment, were valued. The majority of the participants that used Facebook were members in closed groups. Social media focusing on infertility were described as invaluable.

POPULÄRVETENSKAPLIG SAMMANFATTNING (SUMMARY IN SWEDISH)

Ofrivillig barnlöshet, infertilitet, definieras som oförmågan att bli gravid efter ett års sexuell relation eller oförmåga att frambringa en graviditet till ett levande barn. Infertilitet uppskattas påverka 8–10 procent av par i Sverige och utreds och behandlas som ett medicinskt problem. Däremot upplever individen infertilitet som psykiskt stressande och ett socialt problem. Spridning av Internet gör det möjligt för personer med infertilitet att söka information och stöd via olika sociala medier, såsom bloggar. Internets betydelse ökar och ger individer möjlighet att vara mer förberedda på olika undersökningar, tester och behandlingar än tidigare, men kan också vara en källa till felaktig information. Syftet med denna avhandling var att utforska och beskriva kommunikation, strategier för livshantering och socialt nätverkande bland kvinnor med infertilitet ur ett livsvärldsperspektiv.

Studie I syftade till att utforska infertilitetsrelaterad kommunikation och strategier för livshantering bland kvinnor som drabbats av primära eller sekundära fertilitetsproblem. Deltagarna består av två grupper: kvinnor som försöker få sitt första barn (primär infertilitet) samt kvinnor som redan har ett barn och försöker få ett ytterligare barn (sekundär infertilitet). De flesta kvinnorna, i båda grupperna, kunde diskutera infertilitetsrelaterade ämnen med sin make. Oförmåga att få barn, orsakerna till barnlöshet samt resultat av test och undersökningar kunde dock inte diskuteras. De hanteringsstrategier som användes var att undvika att vara i sällskap med andra gravida kvinnor eller kvinnor som hade barn. Ytterligare strategi vara lämna platsen när det diskuterades graviditeter eller barn.

I **studie II** var syftet att få inblick i vilka infertilitetsrelaterade frågor som diskuteras på svenska infertilitetsbloggar. Bloggarna var skrivna av kvinnor och de flesta av var anonyma. I bloggarna diskuterades det flitigt om infertilitet i relation till känslor, relationer, tid, väntan, kropp, vård, behandling, mat, kost och motion. Flera kvinnor rapporterade att om de inte kunde diskutera frågor relaterade till infertilitet med sin make eller vänner, var bloggning en plats där de kunde bearbeta dessa ämnen. Förhållandet med partners kunde också påverkas negativt av infertilitet, eftersom kvinnorna upplevde att deras partner inte förstod hur fertilitetsbehandlingar påverkar kroppen.

Syftet med **studie III** var att utforska betydelsen av sociala medier för personer som drabbats av infertilitet. Majoriteten av deltagarna var kvinnor. De viktigaste fördelarna med sociala medier som fokuserade på infertilitet var solidaritet, information, att få och ge stöd samt förstå innebörden av infertilitet. Några av de negativa upplevelserna var att kvinnorna blev känslomässigt påverkade av de behandlingar som misslyckades hos övriga medlemmar i detta forum och tips och råd som mottogs var inte alltid evidensbaserade. Effekten av infertilitet beskrevs som att vara fragmenterad och med känslor av utanförskap.

Studie IV syftade till att beskriva kvinnors erfarenheter av att använda sociala medier med fokus på infertilitet. De främsta anledningarna till att använda sociala medier med detta fokus var informationssökning och gemenskap. Till exempel uppskattades information om hur andra har fått hjälp, vilka behandlingar som har använts, om andra har lyckats bli gravida och hur de har haft det under utredning och behandling. Majoriteten av deltagarna som använde Facebook var medlemmar i slutna grupper. Sociala medier med fokus på infertilitet beskrevs som ovärderliga för dem.

YHTEENVETO SUOMEKSI (SUMMARY IN FINNISH)

Tahaton lapsettomuus, määritellään siten että raskaus ei ole alkanut 12 kuukauden suojaamattomien yhdyntöjen jälkeen tai nainen ei kykene kantamaan sikiötä täysiaikaiseksi. Ruotsissa lapsettomuudesta kärsii arviolta 8 – 10 prosenttia pariskunnista. Vaikkakin lapsettomuutta tutkitaan ja käsitellään lääketieteellisellä kentällä, on lapsettomuus sitä kokeville monisäikeinen ongelma, joka koskettaa kaikkia elämänalueita. Se on myös heille sosiaalinen ongelma, joka herättää ihmiselämään kuuluvia eksistentiaalisia peruskysymyksiä. Sosiaaliset mediat, kuten blogit internetissä mahdollistavat tietoa ja tukea kysymyksiin lapsettomuudesta. Sosiaalisen median merkitys on kasvussa, koska se antaa ihmisille mahdollisuuden varautua erilaisiin lapsettomuuteen liittyviin tutkimuksiin, testeihin ja hoitoihin. Erilaiset sosiaaliset mediat, kuten blogit voivat olla myös väärän tiedon lähteenä. Väitöskirjan tutkimuspäämääränä oli tutkia ja kuvata tahattomasti lapsettomien naisten viestintää, selviytymistä (coping) ja sosiaalista verkostoitumista elämismaailman näkökulmasta.

Tutkimus I. Tarkoituksena oli tutkia hedelmättömyyteen liittyviä viestintä- ja selviytymisstrategioita primaari- ja sekundaarilapsettomien naisten keskuudessa. Tutkimukseen osallistui naisia, jotka yrittivät saada ensimmäistä lastaan (primaari lapsettomuus), sekä naisia, jotka yrittivät saada lisää lapsia (sekundaari lapsettomuus). Suurin osa naisista molemmissa ryhmissä pystyi keskustelemaan lapsettomuuteen liittyvistä aiheista puolisonsa kanssa yleisellä tasolla. Puolison kanssa ei kuitenkaan voitu lähemmin keskustella omasta kyvyttömyydestä saada lasta. Naiset kuvasivat tilannettaan niin että keskusteluja lapsettomuuden syistä tai testien ja tutkimusten tuloksista kotona välteltiin. Yksi selviytymisstrategioista oli raskaana olevien naisten tai lasten saaneiden naisten seuran välttäminen.

Tutkimuksessa II tavoitteena oli saada käsitys siitä, mistä hedelmättömyyteen liittyvistä asioista keskustellaan ruotsalaisissa lapsettomuusblogeissa. Blogit olivat naisten kirjoittamia, ja suurin osa anonyymejä. Blogien keskustelut liittyivät lapsettomuuden tunteisiin, ihmissuhteisiin, aikaan ja odottamiseen, kehoon, hoitoihin, ruoan, ruokavalioon sekä liikuntaan. Useat blogien aiheet käsittelivät lapsettomuuteen liittyviä asioita, joista ei ollut kyetty keskustelemaan ystävien tai puolison kanssa. Naisten mukaan kumppaneiden ymmärrys hedelmällisyyshoitojen mukanaan tuomista vaikutuksista on puutteellista.

Tutkimuksen III tavoitteena oli tutkia sosiaalisen median merkitystä tahattomasti lapsettomien naisten keskuudessa. He kertoivat, että näiden sosiaalisten medioiden tärkeimmät edut olivat solidaarisuus ja tiedon ylläpito. Sosiaalisen median avulla saadaan tukea, annetaan tukea sekä ne auttavat lapsettomuuden ymmärtämisessä. Sosiaalisen median emotionaalinen vaikutus voi olla myös kielteistä, esimerkiksi silloin kun toisten foorumin jäsenten hoidot epäonnistuvat. Sosiaalisessa mediassa jaetut vinkit eivät aina myöskään perustu faktatietoon. Naisten mukaan blogeissa voidaan käsitellä niitä hajanaisuuden sekä syrjäytymisen tunteita ja kokemuksia, jotka liittyvät tahattoman lapsettomuuden elämismaailmaan.

Tutkimuksen IV tarkoituksena oli kuvata naisten kokemuksia lapsettomuuteen keskittyvän sosiaalisen median käytöstä. Suurin osa Facebookia käyttäneistä osallistujista oli suljettujen ryhmien jäseniä. Lapsettomuuteen keskittyvän sosiaalisen median käytön pääasiallisina motiiveina olivat tiedonhaku ja yhteenkuuluvuus. Tietoa haetaan siitä, miten muut ovat saaneet apua ja mitä hoitoja on käytetty, sekä kuinka niissä on onnistuttu. Kokemuksia ja tunteita tutkimuksista ja hoidoista sekä raskaaksi tulosta ovat tärkeitä näkökulmia lapsettomuuteen keskittyvän sosiaalisen median käyttäjille. Lapsettomuuteen keskittyvää sosiaalista mediaa kuvattiin korvaamattomaksi.

ABSTRACT

Infertility is a worldwide problem and is experienced as psychologically stressful. Communication about infertility varies depending on clinical aspects, personal relationships, and culture. The aim of this thesis was to explore and describe communication, coping and social networking among infertile women from a lifeworld perspective.

Study I explored infertility-related communication and coping strategies among women affected by primary or secondary fertility problems. Structured self-administered questionnaires, administered between January and May 2012, yielded 199 responses. The questionnaire consisted of Likert scale items which were analysed with descriptive statistics and by using the Chi-square test for independence. Twice as many women with secondary infertility acknowledged that they never talked about the causes or results of tests and examinations with other persons, compared to women with primary infertility.

In **Study II** the aim was to gain insight into which infertility-related issues are discussed on Swedish infertility blogs. A total of 4,508 postings from 25 infertility blogs were retrieved, from May to September 2017. An interactive quantitative-qualitative content analysis was performed using the automated text analysis tool, Gavagai Explorer, developed for analysis of large sets of textual data. A sentiment analysis was performed as the tool provides sentiment scores of the data indicating whether the bloggers were writing positively or negatively about a topic. All blogs were written by women and the analysis crystallized into the following topics: Emotions, Relations, Time and waiting, Body, Care and treatment, Food and diet and Exercise. The Body topic stood out by having more negative than positive sentiment.

Study III explored infertile individuals' experiences regarding the use and role of online social media, experiences from participating in online social media and experiences of infertility. A web-based questionnaire, linked to the bulletin boards of six closed online social media groups, during the fall of 2017, yielded 132 responses. A majority of the participants were female, and the questionnaire was answered mostly through Facebook. Of the participants, 60 percent participated in online social media focussed on infertility once a day or more, and 50 percent devoted from one to three hours weekly to these forums, with 40 percent making no postings.

Study IV was a qualitative study based on seven telephone interviews describing women's experiences of using social media focusing on infertility. The interviews were conducted between June 2020 and November 2020 and were analysed with thematic analysis. Two themes were devolved: Invaluable venue and Opportunity of choice. Different forums were used depending where in the treatment process the women were. Further, decisions about the choices of groups were also based on the targeted age groups and geographical locations of the participants.

LIST OF SCIENTIFIC PAPERS

I.   Sormunen T, Aanesen A, Fossum B, Karlgren K, Westerbotn M. Infertility-related communication and coping strategies among women affected by primary or secondary infertility. Journal of Clinical Nursing. 2017; 27:335-344.

II. Sormunen T, Westerbotn M, Aanesen A, Fossum B, Karlgren K. Social media in the infertile community - using a text analysis tool to identify the topics of discussion on the multitude of infertility blogs. *Manuscript is submitted and under review.*

III. Sormunen T, Karlgren K, Aanesen A, Fossum B, Westerbotn M. The role of social media for persons affected by infertility. BMC Women's Health. 2020:112.

IV. Sormunen T, Karlgren K, Fossum B, Aanesen A, Westerbotn M. Focus on infertility -Women's experiences of using social media: A qualitative study. *Manuscript is submitted and under review.*

CONTENTS

LIST OF ABBREVIATIONS

AoIR	The Association of Internet Researchers
AMH	Anti-Mullerian Hormone
ART	Assisted reproductive technology
ASRM	The American Society for Reproductive Medicine
COMPI	Copenhagen Multi-centre Psychosocial Infertility research programme
ESHRE	European Society of Human Reproduction and Embryology
FSH	Follicle-stimulating hormone
GDPR	The General Data Protection Regulation
ICN	The International Council of Nursing
IUI	Intrauterine insemination
IVF	In Vitro Fertilization
PCOS	Polycystic ovarian syndrome
STI	Sexually transmitted infection
TA	Thematic analysis
UGC	User generated content

1 INTRODUCTION

Infertility is defined as the inability of heterosexual couples of reproductive age to conceive, or to bring a pregnancy to term, after 12 months of unprotected intercourse. Infertility is estimated to affect between 8 and 12 percent of reproductive age couples globally, also in Sweden.

This thesis is delimited to women who are affected by infertility and are living in Sweden. Other subjects unrelated to infertility will not be considered since the focus was to explore and describe communication, coping and social networking among infertile persons from a lifeworld perspective, and not to investigate and describe medical investigations and different treatments options that are used in infertility treatments. There are various family constellations in society, such as one parent households and same sex- couples. However, in this thesis the studies are framed from the perspective of infertile women living in a heterosexual relationship.

This thesis comprises four empirical studies; Infertility-related communication and coping were measured on a Likert-type scale with an instrument designed specifically for **Study I**. By utilizing the text analysis tool Gavagai Explorer, in **Study II**, the topics of discussion on the multitude of infertility blogs were identified. The roles of social media for persons affected by infertility were studied with an instrument specially designed for **Study III**, on matrix, multiple choice and open-ended essays or free-text questions. In **Study IV** the infertile women's experiences of using social media focusing on infertility were studied using semi-structured telephone interviews.

This doctoral thesis contributes to the understanding and knowledge of communication, coping and social networking among infertile women. Understanding experiences of those suffering from infertility is a precondition for providing high quality care. The introductory section is followed by a presentation of central concepts and research connected to the topic under discussion.

2 LITERATURE REVIEW

INFERTILITY

Fertility is a significant aspect of reproductive health, and infertility is recognized as a global public health concern by the World Health Organization [WHO] (1). Couples going through infertility treatments are repeatedly exposed to long-term, time-consuming and distressing treatment schedules, living with frustration, fear and hope (2). The clinical definition of infertility, according to WHO, is "the inability of a sexually active, non-contracepting couple to achieve pregnancy in one year". A woman who is never able to bear a child, either due to the inability to become pregnant or the inability to carry a pregnancy to a live birth is classified as suffering from primary infertility. Hence, a woman whose pregnancy spontaneously miscarries, or whose pregnancy results in a still born baby, without ever having had a live birth would present with primarily infertility. Secondary infertility is defined as, infertility in a woman who has had one or more previous pregnancies (3). The American Society for Reproductive Medicine [ASRM] defines infertility as the result of a disease (a cessation, an interruption, or disorder of body functions, organs or systems) of the female or male reproductive tract which hinders the conception of a child or inhibits the capacity to carry a gestation to delivery. The period of unprotected sex with failure to conceive should be approximately 12 months before an infertility assessment is commenced, unless age, medical history or physical findings dictate earlier assessment and treatment (4). Globally, secondary infertility is the most common form of female infertility (5).

In Sweden, infertility affects approximately 8 to10 percent of couples of reproductive age. Two-thirds of those who wish to get pregnant, can have a child after investigation and treatment. About 20,000 in vitro fertilisation [IVF] treatments, with own or donated gametes, are performed annually in Sweden and approximately 5,000 children are born due to the treatments, which accounts for four percent of all children born annually in Sweden (6). Currently, no national register exists on pregnancies or deliveries following treatments like ovarian stimulation or intrauterine insemination within the couple, performed at gynaecology clinics. Surrogates and donations abroad are also not represented in this data (6). Infertility is estimated to affect between 8 and 10 percent of reproductive-aged couples (7), equalling approximately 48.5 million couples worldwide (8). In Sweden, assisted reproduction, with donated eggs and/or sperm from a donor and treatment with a donated fertilized egg, are permitted for heterosexual couples, women in same-sex relationships and single women.

Surrogacy is not allowed (9,10). A maximum of three full IVF cycles leading to the couple's first child is reimbursed by the Swedish General Healthcare system (11). The European Society of Human Reproduction and Embryology [ESHRE] is a main stakeholder for the Council of Europe and the EU in the field of medically assisted reproduction (12).

Risk factors and reasons

Ageing is the predominant factor with the strongest association with infertility. Ageing decreases females' chances to become pregnant, increases the risk of miscarriage and of having a child with genetic deviation (13). It is generally agreed that female fertility declines with age, starting in the mid-thirties, due, for example, to decreasing oocyte numbers (14). Reproductive ageing is a normal process of falling fecundability as the women ages. However, the rate at which women pass through these stages is individual (15). Loss of ovarian function is not pathological but rather an unavoidable consequence of ageing and ultimately inevitable (16). Increasing paternal age over 40 years is also associated with reduced fertility, due to decreasing semen quality, genetic factors and endocrinological changes, such as falling androgen levels (17).

Potential behavioural and environmental risk factors for reduced fertility consist of: tobacco and alcohol use, poor nutrition, sexually transmitted infections (STI) caused by unsafe sex, weight gain or loss and environmental hazards. Sexually transmitted infections, such as chlamydia, impact fertility in both women and men (13). Cancer treatments, such as chemotherapy and radiation may interfere with the reproductive process (18,19). Modifiable factors, for example, smoking and weight have a negative effect on fertility and assisted reproductive technologies (20). Tobacco smoking may contribute to several aspects of menstrual dysfunction, such as menstrual irregularity, dysmenorrhea (painful periods), intermenstrual bleeding and secondary amenorrhea (absence of menstruation) (21). Further, smoking affects ovarian follicle maturation, embryo transport, uterine blood circulation and endometrial receptivity (22). Smoking has harmful effects on male fertility, by causing a lower sperm count and an increase in the number of morphological defects in sperm (23).

Overweight may affect female fertility by a number of aspects, such as weakening of ovarian follicles' development, qualitative and quantitative defects of oocyte development, altered fertilization, disrupted meiosis and mitochondrial dynamics imbalances leading to atypical embryo preimplantation (24). The hormonal changes in obese men, including elevated oestrogen and lower testosterone levels, may cause changes in sperm parameters such as abnormal morphology (20).

There is evidence that certain environmental chemicals, such as, heavy metals including lead, organic solvents, for instance, toluene and endocrine disrupting chemicals such as ethane, can impact fertility adversely (25). Alarming reports have been presented claiming a decrease in sperm concentration, for instance, for European men, of 32,5 percent during the past 50 years (26). High levels of stress in women can lead to decreased fecundability (27), and stress in men may impair testicular function (28). The circadian rhythm is regulated by the endogenous biological environment and melatonin modulates the sleep-wake cycle (29). Melatonin may also be important for both development of sperm cells and maturation of the follicles (30). Use of illicit drugs can negatively impact fertility by acting on the body systems responsible for reproduction (31). Environmental and lifestyle risk factors are illustrated in figure 1.
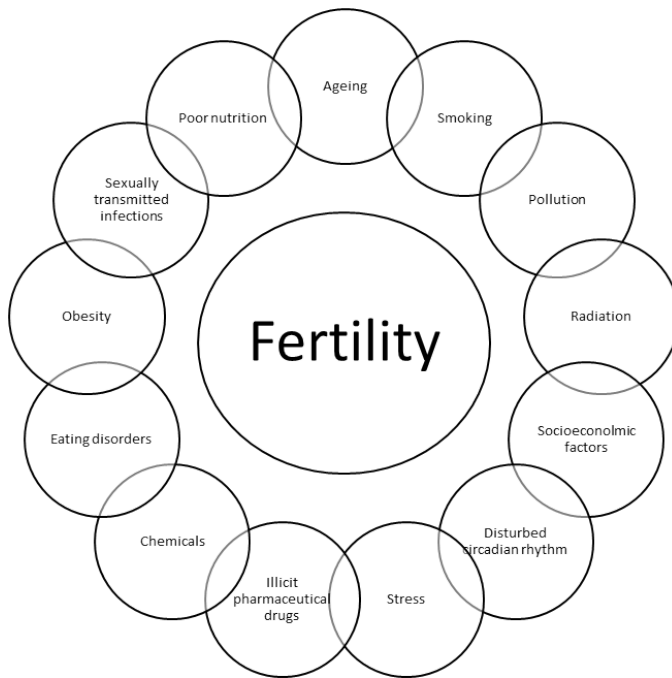
Figure 1. Various environmental and lifestyle aspects that may affect fertility

Female factors

According to WHO, ovulation disorders, such as polycystic ovarian syndrome [PCOS] and amenorrhea, are the cause of infertility in approximately 25 percent of couples who have difficulty conceiving. These disorders are characterized by ovulation disorders and irregular menstrual patterns (32). Endometriosis is a common condition which may cause infertility.

Endometriosis tissue like the uterine endometrium is located outside the uterine cavity. According to the ASRM, 30 to 50 percent of women with endometriosis may experience infertility (18). Both ovulatory dysfunction and endometriosis may have a familial predisposition, and likely a genetic basis (33). Further, congenital abnormalities of the female genital system (34) and acquired defects in the uterine cavity and fallopian tubes may lead to infertility (35). Additionally, cancer therapy may have a negative impact (36).

Male factors

Infertility in men can be caused by low number- and poor functioning of sperm, such as shape and mobility. Hormonal disorders may lead to low production of sperms, which contributes to difficulty in fertilization. Additionally, genetic disorders can be the reason for male infertility (13). Ejaculatory disorders, impotence and immunological disorders, including diabetes mellitus are other contributors to male infertility (37). Use of anabolic steroids is associated with declined fertility in men (38). Loss of genetic material or mutations may be one of the major factors (39).

Unexplained and multiple factors

Infertility in couples, where the infertility work-up is normal, is diagnosed with unexplained infertility (40). To receive a multiple factor infertility diagnosis, one or more female/male reasons for infertility are diagnosed together (41).

TREATMENT OF INFERTILITY

Diagnosis

In Sweden, infertility investigations are provided by both private and public healthcare. Clinics' evaluations of both physiological and psychological conditions are included in the infertility investigation (11). Identifying the cause of infertility can be a long and sensitive process and may be time consuming. Initially, an infertile couple must undergo a diagnostic interview, including both partners' health and medical history (42). Couples will also undergo a physical examination to evaluate physical disorders that may cause infertility (43). Further, diagnostic procedures, both laboratory tests and ultrasound investigations, are normally performed in order to reveal the cause (44).

Treatment options

Treatments for infertility are chosen based on the contributing infertility factor, the duration of infertility and the age of the female partner.

Infertility can be treated with drugs, or in combination with intrauterine insemination [IUI] and assisted reproductive technologies [ART]. Fertility medication can be used, for instance, to stimulate or regulate ovulation (45).

IUI entails placing sperm inside the woman's uterus to enable fertilization. By increasing the number of sperm that reaches the fallopian tubes the chance of fertilisation increases. IUI requires a sperm to reach and fertilise the egg on its own. The most common reasons for IUI are decreased sperm mobility and low sperm count. In the laboratory the semen sample is washed to separate the semen from the seminal fluid and, using a catheter, the sperm is inserted directly into the uterus (46). IVF is a technique where ovarian hyperstimulation leads to the development of several follicles containing oocytes. The oocyte retrieval follows a pretreatment with drugs leading to maturation of the follicles. Oocytes are retrieved by ultrasound-guided aspiration of the follicles, and then fertilized and incubated in specialized laboratories prior to embryo transfer (47).

THE EXPERIENCE OF INFERTILITY

Infertility is a medical condition with psychological consequences (48). The experience of infertility can be unforeseen, traumatic, and regarded as a life changing experience. It can result in feelings of loss and grief (49) that may affect the relationship with the partner (50). The sense of shame and loss can develop into depression (51,52) and even suicidal thoughts (53). Both infertility and infertility treatment cause stress for those affected (48) and make them vulnerable to stress (54).

Infertility is not just a medical condition but also an emotional and social condition, in which a shift in emphasis has occurred from coping with infertility through social means (e.g. participating in bringing up the children of others) to reliance on medical interventions, even if accessing them can be difficult. This process is called "medicalization of infertility", where childless persons become patients, undergoing medical treatments, and undertaking an often passive role as a patient, in physician - patient interactions (55). During fertility treatment, the couple's sexual life can turn into the execution of a reproduction plan, rather than one characterised by intimacy and desire (56). Fertility treatment invades the most private domains of a couple's relationship (57).

Infertility is similar to other major life stressors such as bereavement, chronic disease and divorce (58). Yet, successful treatment can come at high emotional cost.

Compared to infertile men, women affected by infertility experience greater psychological distress (59), score lower on self-esteem, are more depressed (60), and report lower life satisfaction (61). Furthermore, women affected by infertility are more likely to blame themselves for their infertility (62) and to regard childlessness as unacceptable (63). However, results from a Danish study show that women and men undergoing infertility treatment experience equally high distress levels, related to personal and social expectations (64) and social norms (65). An inability to have children may cause not only difficulties in the individuals´ lifeworld, but also affect their ability achieving a potential social role as a parent (48). Infertility can affect how a person communicates in social fields, such as within their family and workplace (66).

COMMUNICATION

Communication is the process by which information or messages are sent from person or place to another (67), for example, by speaking, writing or gesturing (68). The term communication is derived from the Latin word, *communis*, which means common. This definition underlines the fact that unless a common understanding results from the exchange of information, there is no communication (69). Communication is crucial to human life, concerns all human beings and plays an important role in our daily lives (70). Non-verbal communication, such as facial expressions and gestures, is one component in communication that we control directly. A book is a medium of communication and consists of words, drawings, and pictures. Communication is something which makes connections and is experienced as an activity. Communicating is something we learn to do (71). We communicate in order to survive, co-operate and to satisfy our personal needs (72). Communication is intertwined with all human life. Communication is an integral part of everyday actions engaged in while coping with life (73).

In order to communicate with each other in a meaningful way, there must be access to common code. Language is the most important code. When spoken or written language is not enough, body language is needed. This too is a code, albeit a less formal one. Various kinds of media are used to communicate. With the help of media, the conditions for communication have changed throughout history. It has become easier to send messages over large distances. The media have also created an abundance of information that can be difficult to handle. All communication takes place between people and often reflects the individual's position in society. Material and cultural assets and status govern the extent to which the individual can control her/his own communication (74).

A new mode of communication has been created by the internet (75) and has unique characteristics including anonymity, text-based communication and the ability to transcend geographical and temporal barriers (76). Kozinets (77) explains that on-line communication is a part of modern life. Online communication encourages the expressions of emotions and the input of emotional messages, thereupon strengthening and promoting social ties between users, forming a structure of relationships very much alike to ties between friends and family, all happening without participants being physically present (78). Written communication includes any form of interaction that makes use of the written word. Writing enables the person to discover and give voice to existing emotions (79) and generates new meanings and new emotions that are formed through writing itself (80).

COPING

Coping means to manage a challenging situation successfully (81). Cohen and Lazarus define coping as," the special mobilization of effort and the drawing upon unused resources or potentials, and always involves some type of stress" (82). There are two key functions for coping skills. First, they are used to change the demanding circumstances for the better, either by adjusting the threatening environment or by changing one's own inappropriate actions. Secondly, coping skills are used to deal with the physiological and psychological outcome of stress-related emotions themselves, so that individuals are able to function or maintain morale (83). The success of the coping effort depends on the individual, on the type of stress, and the circumstances (84).

Chronic illness takes place in an interpersonal context. The illness affects both the person and their social environment. A partner is a significant member of the person's social world (85) and is also affected by the illness. This, in turn, has the potential to affect the patient's ability to adapt. The coping of the patient and partners is inseparable (86).

In health care, coping and coping strategies are well-known concepts. When a person suffers from severe illness or other life changes, they need to have strategies to cope with the situation. There are several different coping strategies and these change over time (87) i.e. age-related changes (88). Some examples are to: seek the facts, talk, try to forget, help others, outdoor activities, exercise, practice yoga or mindfulness, drink alcohol, or accept the situation (87). Therapies, such as psychological counselling (89), cognitive behavioral therapy (90) can be used to cope with the effects of infertility.

Coping skills in women with infertility

Infertility is experienced as one of the most stressful life events (91) and causes increased distress (92). It is therefore crucial to acknowledge how women manage this experience. Benyamini et al. (93) point out that there are three major strategies regarding the infertility experience. Firstly, in the relationship coping consists of seeking spousal support. Secondly, the avoidance dimension of coping includes, for instance aspects of denial, self-blame, social isolation, and acceptance. Thirdly, practical management, for example, seeking social support, faith, and information-seeking. A Danish study revealed that infertile women who used meaning-based coping, such as finding marriage more valuable and identifying other life goals, predicted low fertility-problem stress in the marital and personal domain (66).

Coping is not only individual process, namely, how one partner copes with the impact of infertility on her or his own level of distress, but also a couple process, that is, how one partner copes affects the other partner's level of distress and also the functioning of the relationship (94). There is evidence that heterosexual women and men may differ in their response to infertility, partly stemming from the fact that most fertility treatments are directed at the woman (91,93). It is the woman who becomes pregnant, and women bear the burden of physical pain, the lifestyle interruption and side effects of drugs (95,96). This places a male partner in a secondary role (97). Gender differences in coping become differentiated in the context of infertility-related stress, as women may feel the need to share emotional reactions, while men try to distance themselves from the problem (98).

Coping and social support

Social support plays an imperative part in the process of managing illness (99). Computer-mediated support contexts, like blogs, are significant in many ways, by providing information and solidarity (100). Blogs can offer an alternative forum when family and friends, generally regarded as critical support sources, are unable to provide satisfactory support (101).

 A blog or Facebook group run by the individual who is ill is an active and problem-focused form of coping. In such a forum, the writer can share their feelings, grief, and joy, worry and anxiety. He or she can help others in the same situation. The writer receives confirmation, support, encouragement, and advice. There are several examples of support blogs and Facebook activity which provide support for persons who are sick; often this support cannot be replaced by anything else. A blog can be regarded as good for both the individual and for the national economy. It can be viewed as one hundred percent self-care (87).

Blogs are associated with several benefits for the individual, for instance, social support, empowerment, and better health (102).

SOCIAL NETWORKING

According to the Oxford Dictionary (103), *social networking* is defined as," the use of dedicated websites and applications to interact with other users or to find people with similar interest to one's own". Gunawardena et al. define social networking as the practice of expanding knowledge (104). Research indicates that the use of Internet communication can be effective at building high-quality friendships and has a positive effect on health (105). Previous studies have revealed that communication over the Internet supplements other forms of communication (106). Social networking is linked to technological software and services that allow individuals to communicate with each other at any time and from anywhere in the world (104). The Internet, from its initial stages, has been a platform where human beings can communicate with each other (107).

The Internet

During the past two decades, the Internet has developed into the most complete electronic archive of written material and has entirely transformed the way people live their lives, communicate and access information. The daily flow of new information accessible online represents a large spectrum of present opinions, viewpoints, events, and online communities that allow anyone to have an active voice. Social networking sites like Instagram, Twitter, Facebook and illness blogs have developed as popular media for patients (108).

In January 2020, nearly 59 percent (4.574 millions) of the world's population were using the Internet (109), and in 2019 there were a total of 2.5 billion active users of Facebook (110). In 2019, 98 percent of the population in Sweden had access to the Internet and 74 percent had a Facebook account. In Sweden, Internet users are spending an average of 13.8 hours per week online at home (111). In Europe, 70 percent of the Internet users use the Internet for health purposes (112).

SOCIAL MEDIA

Social media are Internet-based tools that allow communities and persons to meet and share personal messages, images, ideas and to collaborate in real time with other users (113).

The evolution of social media from 1969 and onwards reveals that the early social platforms competed. However, at the beginning of 21st century, forums competed more for audience attention and time, and less with each other (114).

Using social media is also referred to as social networking or Web 2.0 (115). There has been a rapid and steep rise in the number of social networks online. Individuals with mutual interests gather digitally to share experiences or to provide self-help and support. Cyber communities are used in health care, where they generally gather around health-related conditions such as coping with disease (116). Social media can help patients become well informed and active, and health outcomes can be improved by Internet support processes (117). In 2018, 71 percent of the population in Sweden (age 9 to 79 years) used various social media daily (118).

Social media can be used by health care and health care professionals to reach patients and the general population as part of patient education, public health programs, patient care or organizational promotion (119). For patients to be able to be involved in decision-making regarding their healthcare they need to acquire knowledge and build up confidence (120). Social media can contribute to such involvement by connecting patients to healthcare through, e.g., enabling access to information quickly and by answering questions of various topics. The emerging utilization of social media in healthcare may affect the relationship between the patient and healthcare professional both positively and negatively – one positive effect is that it may lead to more equal communication between the patient and healthcare professional (121). But patients may also have other motives for using social media and they may use other social network sites than health professionals do (122).

Social media sites offer a mixture of features that serve different purposes for the user (123). These may include social networks (for example Facebook and LinkedIn), blogs (such as Twitter), information/knowledge aggregation (for instance Wikipedia) and virtual reality and gaming environments (such as Second Life) (124). Flashback Forum is the biggest Internet forum in Sweden, with more than one million members (https://www.flashback.org/). The Snapchat forum differs from other networks in that it has a characteristically transient, whereby any message is automatically deleted shortly after the receiver has viewed it, allowing an increased experience of perceived privacy and safety online (125). User generated content [UGC] can be counted as the sum of all ways in which people make use of social media.

UGC must meet the following requirements; first, it must be available on a publicly accessible website or a social networking site; second, it must show a certain amount of creative capability; and third, it must have been established outside of professional practices and routines (126). Electronic mail (e-mail) and text messages are not included under the category of social media because they are private and addressed to one person, and standard websites are not regarded as social as the viewers do not create, or add to, the content (127).

Social media can be further defined as a framework which consists of seven building blocks: conversations, identity, presence, sharing, groups, relationships, and reputation (128). The *conversation* element of the framework features the extent to which users interact with other users in a social media setting. Many of the social media sites are constructed to facilitate conversations among groups and individuals. The goals of these conversations are varied and are used to meet like-minded individuals. In addition to this, others use social media to make their message heard (129).

The *identity* segment outlines the extent to which users reveal their identities. This can consist of revealing information, such as gender, age, location, occupation and even information that describes users in specific ways (128). Uncovering of a user's identity can occur through the unconscious or conscious "self-disclosure" of personal information such as emotions and opinions (130). The *presence* part of the framework represents the extent to which users can know if the other users are accessible. It covers knowing where the other users are in the real or/and in the virtual world and whether they are accessible (128).

Sharing features, the extent to which users exchange, obtain and distribute information. The word "social" implies that exchanges among individuals are necessary. In the majority of cases, sociality is about the objects that mediate the ties between individuals (131). The *groups* aspect of the framework refers to the extent to which users can build communities. The more social a network turns out to be, the larger the group of contacts, followers and friends become. Groups in social media are more than a registering of users. Focus lies on specific permissions for different group membership contents and activities. There is no consensus on how groups accept members and how they share authentic information within the group and possible sub-groups (128).

The *relationships* section of the framework outlines the extent to which users can relate to each other; users have some form of association that motivates them to communicate, meet, share objects of sociality or list each other as fan or friend. Reputation refers to the extent to which users can identify the standing of others and themselves in a social media setting.

In social media, reputation refers both to individuals and content, which is evaluated using content voting systems (128). According to Ritzer and Jurgenson (2012) social media is considered a key characteristic of the cybernetic revolution (132). There are more than 1.6 billion social network users globally (133). According to Quinn (134) there is a gulf between self-reported privacy attitudes and concrete privacy behaviours among social media users, a willingness to trade privacy for social goals.

Blogs

According to the Merriam-Webster online dictionary, *a blog* is defined as a, "website that contains online personal reflections, comments, and often hyperlinks, videos, and photographs provided by the writer", and - "a regular feature appearing as part of an online publication that typically relates to a particular topic and consists of articles and personal commentary by one or more authors" (135). In January 2020, approximately 600 million blogs existed globally (136). Blogs represent the earliest form of social media and are unique types of websites that usually display date-stamped entries in reverse chronological order (126). Blogs have become popular as they are considered easy to start and maintain. Additionally, they facilitate generous, usually long conversations that can be followed retroactively on the blog (128).

Blogs can reach large audiences, if the content is of significant interest (137), and are mostly managed by one individual, but enable interaction with others through the addition of comments. Postings are mainly textual, but some have photos and other multimedia formats and provide hypertext links to other internet webpages (130). Bloggers usually write about a single topic, forming niche communities (138). The two common types of blogs are informative and diary-like blogs. Informative blogs are written by authors who are dedicated to knowledge sharing by providing information. Blogs written by authors who are focused on interaction and towards self-disclosure are called diary-like blogs (139).

The diary-like personal blogs are sites of self-disclosure where persons share observations and thoughts about their offline and online lives (140). Self-disclosure in blogs can be beneficial to users in obtaining support and establishing and maintaining friendships via positive interactions (141). Writing about private experiences can help the individual to understand themselves more deeply and reduce the impact of serious problems (107). Bloggers are, in real time, describing life during illness and treatment for illness, as they live it (142). Blogs can give marginalized groups a place to be heard (143).

Blogs about a chronic illness or health condition, such as infertility, give realistic knowledge about the blogger's illness-related behaviours (144). The illness blogs can be a specific form of self-expression, where feelings, thoughts, creativity and information are shared (142). Illness narratives can help to reduce psychosocial consequences (121). Kim's findings show that persons with cancer increasingly use blogs to support one another, to learn about health and to share information (145).

Use of blogs in Sweden

A public recognition of blogs in Sweden came first after the tsunami in the Indian Ocean December 26, 2004. In 2019, 49 percent of Internet users in Sweden read blogs and seven percent wrote their own. It is more common for women to read blogs than men. In terms of age, blogs are more popular among 26 - 45 years olds. Social networking has become a natural part of our everyday lives. Of Swedish Internet users, 63 percent used social networks daily and 83 percent report occasional use (111).

Infertility blogs

In infertility blogs, women write openly about their experiences of undergoing fertility treatments, trying to conceive, pregnancy and adoption. Blogs offers a space in which private narratives are made public. For this reason, infertility blogs have come to play a powerful role in public and official discussions of fertility issues and a space for private dialogues about changing body image (146). Self-expression through blogging can help the blogger to gain a deeper understanding of themselves while disclosing and describing personal information (147). Intimate thoughts and feelings can be expressed (140) and personal crises can be processed (148). Miller emphasizes that blogs have given infertility, even referred to as, "the silent disorder", a voice (149).

Blog services provide consumers with a range of options in terms of anonymity; identifiable, pseudonymous, or totally anonymous. In a cyber environment, individuals feel unidentified when their private information such as gender, name or location is withheld. The most private blogs are password-protected and anonymous. The public blogs can be recognized and easily found via search engines because they are listed by the blog service. Anonymity plays a significant role for those individuals who are seeking support on the Internet (150) and is likely to be of help for those suffering from a stigmatized condition (151). Kahlor and Mackert's findings showed that women who were infertile used the Internet as a source of: information, social support, access to information and as support groups (152).

Laws and rules for social media

The General Data Protection Regulation [GDPR], which applies to all European Union countries, governs the use of social media in Sweden (153). According to the Act on Copyright in Literary and Artistic works (SFS 1960:729), all material published on social media is ruled by this law. Self-produced material, such as text and photos, can be published. If another person's work is quoted, the original reference must be given (154). The Swedish Penal Code (SFS 1962:700) prescribes that the publisher must ensure that the released material is not racist, sexist, or discriminatory (155).

Guidelines from the Association of Internet Researchers (AoIR) provide support and advice regarding ethical concerns in Internet research (156). Ethical decision-making in Internet research demands adopting a new view on subjects' contributions to research data when the latter are collected without their knowledge. Even if material is published on the Internet, it should be used in accordance with the ethical guidelines provided by AoIR regarding researchers, subjects, and culture.

LIFEWORLD PERSPECTIVE

How we human beings commit to something depends on our experiences and our understanding, as well as our perceptions of what we should attend to or learn. This means that the lifeworld is the basis for acquiring knowledge. Our world is textured, experienced, and embodied through and by us, a world of colours, memories, happiness, sadness, joy, anger, and twinkling stars. It includes family life, culture, and informal social interactions. In brief, it is the sphere within which we lead much of our social and personal life (157). Lifeworld theory is about our living space, how we live, experience and act in a world with other people and it seems obvious and taken for granted. The aim of lifeworld theory is to detect, analyse, clarify, understand, and describe the meaning of everyday life as experienced by individuals (158).

Everyday life, comprises the ways in which people naturally think, act, and feel daily and it is intersubjective in nature, because it is a world shared with others. Various phenomena both influence and are influenced by us. The changes in terms of social interaction has led to the transformation of the ways in which persons construct their lifeworld (75). Daily living consists of two parts; demands of daily life and internal resources such as motivation, and external recourses like friends, available to meet the requirements. Further, day-to-day actions that we perform in the lifeworld are generally communicative in nature.

The lifeworld is based on a tacit fund of shared understandings and meanings that enables us to perform actions that we know others will understand (159). The spread of the Internet, for example, through social media such as blogs, Facebook, and Instagram, has changed the conditions of interpersonal contact and even the scenes of the lifeworld in which we live (75). The Internet is integrated into rhythms of daily life, with life offline linked with life online (160). The use of the Internet transforms people's daily activity patterns and social life with consequences for welfare, society, and the environment (161).

The lifeworld perspective is essential for the caring sciences (162), and care is the core concept of nursing (163). The free dictionary defines caring as "feeling and exhibiting concern and empathy for others, showing care and having compassion" (156, paragraph 1). The definition of nursing according to The International Council of Nursing [ICN] is: "Nursing encompasses autonomous and collaborative care of individuals in all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness and the care of illness, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management and education, are also key nursing roles" (165). A lifeworld perspective emphasizes persons' experiences and expects health-care personnel to acknowledge the world as the person does, especially regarding wellbeing and suffering. It is a matter of getting close to the patient's lifeworld and what it is like to suffer from a disorder and live with illness (162).

EPISTEMOLOGICAL POSITIONING

When approaching this research, I identified with holding a constructivist position. For the constructivist researcher, reality is created by individuals partaking in the research and occurs within a context and several constructions are possible (166). Therefore, when considering the research regarding infertility, I have tried to keep in mind that, how infertility is conceptualised cannot be taken for granted, but instead is part of our existing culture. When trying to understand infertility- related communication, coping and social networking, one must consider that the social discourses in the current culture influences how women feel, think, and describe their experiences.

There are various ways to see the world and diverse perspectives. This thesis tries to give a realistic description of a specific group of women, at a specific point in time, and through the lens of a lifeworld perspective.

The results are a co-creation between myself and the participants of the four studies and the description is unavoidably influenced by my ways of seeing the world and individual points of views. My understanding of the role I have in the construction has underlined the necessity for self-reflection during the research project. Self-reflection has also been a vital element in the research group, with my supervisors, and is further acknowledged through my interpretations when presenting the results.

3 RATIONALE

Throughout history, infertility has always been a preoccupation of human being. The problems which arise in connection with infertility on social-, medical-, ethical-, religious-, and political levels bear witness to this emphasis and even to how difficult infertility is to understand and deal with. In medical practice, infertility has always been a subject in focus. This reflects human beings' thoughts about their origin and future. Today, persons with a history of infertility constitute complex areas of care.

Technological developments are changing human interactions, behaviour and means of gaining knowledge. The Internet has become an increasingly expanding source of information regarding both physical and mental illnesses. People go online to access information about symptoms, prevention, and treatment of diseases and, furthermore, share their private stories about their experiences. This tendency has included blogs for individuals affected by infertility, since they feel secure and are within a context where other persons understand what they are going though. Also, using social media is safe way to communicate during the Covid-19 pandemic. The technology itself has made infertile women's thoughts and experiences available to me as researcher.

Individuals affected by infertility may have difficulties in discussing infertility-related subjects offline, due to the sensitive nature of the matter. For this reason, they may turn to social media to discuss with other persons who have previous experiences of infertility. The literature on blogs focussing on infertility is limited in Sweden. Further empirical studies are required to understand various aspects of infertility blogs.

4 RESEARCH AIMS

The overall aim was to explore and describe communication, coping and social networking regarding infertility from a lifeworld perspective.

THE SPECIFIC AIMS OF THE STUDIES

I.   To explore infertility-related communication and coping strategies among women affected by primary or secondary fertility problems.

II.   To gain insight into which infertility-related issues are discussed on Swedish infertility blogs.

III.   To explore the roles of social media for persons affected by infertility.

IV.   To describe women's experiences of using social media focusing on infertility.

5 MATERIALS AND METHODS

Quantitative research is grounded in the positivist position, which assumes that scientific truths exist and can be studied objectively. Data are collected in a numerical form and analysed statistically. The role of the scientist is restricted to data collection and understanding in an objective way (166).

Qualitative research uses non-quantitative methods to provide new perspectives in health care (167). Phenomena are investigated in a holistic and in-depth manner, through the collection of narrative data using, for instance, interviews. Qualitative analysis is used to organize and interpret narrative data for the purpose of discovering important underlying categories, themes and patterns of relationships (166).

This doctoral thesis uses both quantitative (**Studies I and III**) and qualitative (**Studies II and IV**) research methods. An overview of the four studies included in the thesis is presented in Table 1.

Table 1. Presentation of aims, design, participants, and analysis of the studies.

Study	Aim	Design	Participants	Analysis
I	To explore infertility-related communication and coping strategies among women affected by primary or secondary fertility problems.	Cross-sectional study. Data were collected by questionnaires.	n =199 women affected by infertility.	Descriptive statistics and Chi-square test for independence.
II	To gain insight into which infertility-related issues are discussed on Swedish infertility blogs.	Qualitative-quantitative study.	A total of 4,508 postings from 25 Swedish infertility blogs.	Content analysis using a text analysis program, Gavagai Explorer.
III	To explore infertile persons' experiences regarding participation in, and the function of, online social media with focus on infertility and to describe experiences of infertility.	Cross-sectional study. Data were collected by online questionnaire.	n=132 persons taking part in social media.	Descriptive statistics and content analysis.
IV	To describe women's experiences of using social media focusing on infertility	Qualitative descriptive study. Interviews were used to collect the data.	Seven women participated.	Thematic analysis.

DESIGN AND DATA COLLECTION

Study I

Study I was designed as a cross-sectional study, using a structured questionnaire. The aim was to explore infertility-related communication and coping strategies among women affected by primary or secondary fertility problems. Cross-sectional studies are carried out over a short period or at fixed point in time (166,168). They can be conducted to estimate the incidence of interest for a given population, and data on various variables can be collected at the same time (168). A questionnaire, based on the Copenhagen Multi-centre Psychosocial Infertility research programme [COMPI] (66), was created for the study by M. Westerbotn. The questionnaire was translated into Swedish and pilot-tested with a group of women affected by infertility. Data were collected between January and May 2012 at a clinic providing infertility investigation and treatment. Female partners in couples going through an infertility investigation were approached. Inclusion criteria for the participants were, women under the age of 44 years, with a history of infertility for a minimum of one year in the current relationship. After obtaining informed consent from the participants, a questionnaire was sent, by post, including information about the study and a prepaid reply envelope. A total of 300 questionnaires was sent and two reminders. One hundred and ninety-nine (66.3%) questionnaires were returned.

Study II

The aim was to gain insight into which infertility-related issues are discussed on Swedish infertility blogs. The practice of using Internet information or Internet-based resources like blogs is classified as Internet research (166). Netnography is the branch of ethnography that studies the behaviour of individuals on the Internet (77). A qualitative-quantitative design was used. The text analysis tool, Gavagai Explorer, enables the analysis of a large amount of text and combines a quantitative and qualitative approach. The results from the quantitative analysis of the text become an inspiration and support for a qualitative analysis, which forms a bases for a new quantitative analysis, and so forth. Swedish infertility blogs were identified through a website for the Swedish infertility interest group *Vill ha barn* (`I want a child`). Inclusion criteria for the blogs were: open access blogs focusing on infertility, written in Swedish by a person affected by infertility, the blog had been maintained for at least for three years and the postings were accessible from the blog archives. Twenty-five blogs that met the criteria were included in the study.

The blog owners' postings were retrieved three years retroactively 2014-2017 by T. Sormunen. The total amount of postings included was 4,508 equalling 33,020 sentences. Data collection took place from May to September 2017.

Study III

A cross-sectional study design was used. A computer-assisted, self-administered online questionnaire, containing both open and closed questions was created using Google Forms to collect data. Ten closed forums were contacted and asked for permission to spread the questionnaire. The latter was linked to the bulletin board of six closed infertility forums. An Internet questionnaire is a favourable approach for accessing groups of people interested in certain topics (166). A total of 132 participants completed the questionnaire containing questions about their use of social media dealing with infertility. The data were collected during the autumn of 2017.

Study IV

Study IV is a qualitative study, based on semi-structured telephone interviews with seven women with history of infertility. The aim was to describe women's experiences of using social media focusing on infertility. The women who agreed to participate in our previous online survey study (Study III) were simultaneously asked whether they were willing to take part. Thirty-eight women indicated their willingness to be interviewed and five participated. Two additional participants were recruited by using snowballing as recommended by Polit and Beck (166). The telephone interviews were carried out in Swedish, audio recorded and transcribed verbatim by T. Sormunen. The data were collected between May 2020 to November 2020. The original project design called for face-to-face interviews. Due to the COVID-19 pandemic it became necessary to conduct interviews by telephone.

DATA ANALYSIS

Study I

In Study I, descriptive statistics were used to summarise the demographics (age, education, profession, marital status and duration and type of residence) of the study sample. Descriptive statistics quantitatively summarises and describes features from a collection of information (166). The association between frequencies in questions regarding infertility-related communication with spouse and other people, and coping strategies, was tested using the Chi-square test for independence.

The Chi-square statistic is a non-parametric tool intended to analyse group differences when the dependent variable is measured at a nominal level (166).

Study II

To analyse the data, interactive quantitative-qualitative content analysis and a sentiment analysis were performed using the Gavagai Explorer analysis program. The latter was developed to analyse large sets of text data (169). Use of this software facilitates the analysis of large texts but requires a high degree of interactivity from the operators. It also makes it possible to group together responses referring to the same subject. The tool analyses texts and helps the analysts by suggesting a list of topics based on meaning. The system uses measures of term specificity in language to assess how specific or general a topic is, and it also ranks the topics according to how frequently they occur in the data, i.e. how often the topics are mentioned by the respondents. Further, the tool lists the related terms found in the data and which build up the topics. Terms or topics be ignored or merged to dig deeper into the data set (170). For example, the tool would suggest the topic *Healthcare personnel* built on associated terms such as *nurse, doctor, midwife, physician, dentist* etc. While all these associated terms could be argued to belong to the topic of healthcare personnel, some of these (e.g. *dentist*) might be considered unconnected with the aim of the study and therefore discarded in the next iteration. Additionally, if a term appeared to be missing in a topic (e.g. *gynaecologist*) it could easily be added to make the topic more precise. A sentiment analysis was performed as the tool provides sentiment scores (an emotional analysis) of the data indicating whether the bloggers were writing about a topic, positively (e.g. being hopeful or confident) or negatively (e.g. being sad, unable to cope) (170) (Figure 2).
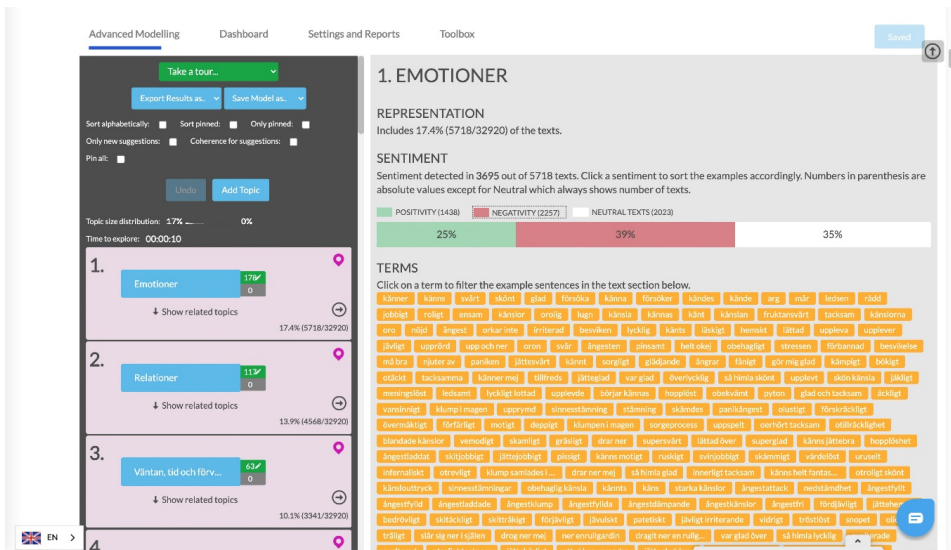
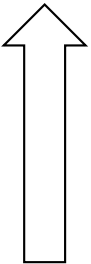**Figure 2.** The Gavagai Explorer analysis program.

The analysis was performed according to the following steps:

1. After collecting the postings, T. Sormunen read and re-read the blog texts several times, to gain an understanding of, and familiarity with, the content.

2. To prepare the analysis for the tool, all blog texts were saved in a comma-separated values [CSV] file, containing a total of 33,020 sentences.

3. The research team analysed the texts using Gavagai Explorer with an iterative approach on multiple occasions. After each iteration, the topics suggested by the tool and their associated terms were scrutinized. The clustering was further refined, and closely related topics were either merged into one or moved into groups containing subtopics. Topics irrelevant to the aim were discarded. Subsequent to the team's decision to keep, or reject or refine topics by adding specifying terms, the tool recalculated frequencies of the topics and suggested new ones.

4. After each iteration, the tool re-calculated the frequencies of the topics and suggested new associated terms for the revised topics. Step 3 and 4 continued until a consensus was reached and until no further new topics related to the aim were discovered.

Study III

Descriptive statistics were used for the analysis of the close-ended responses. Open-ended responses were analysed qualitatively in an iterative process, using conventional inductive content analysis to develop sub-categories, categories, and themes. This was inspired by how Hsieh and Shannon (171) describe conventional content analysis. The open-ended responses were read and re-read to gain a general understanding of what the participants were describing. The text was then broken down into meaning units, containing recognizable pieces of information, and answering the research question. Codes, describing the meaning units were created. Closely related codes were assimilated to sub-categories, and sub-categories related to each other through their content were grouped into categories. A category answers question about what, when, who or where and is an expression of manifest content, what is obvious and visible in the data (171). A theme expressing the underlying meaning, latent level, was formed from the categories (Table 2). A theme answers questions such as how, why, by what means and in what way (171). The text responses were reviewed and the content was discussed and re-sorted until agreement was reached in the research team, as recommended by Sandelowski (172).

Table 2. Example of the content analysis process. (Inspired by Erlingsson and Brysiewicz, 2017), (173)).

Reflects the interpreted, latent meaning of the text. Higher levels of abstraction.	Overarching theme	The experience of being fragmented and feelings of disconnectedness
	Theme	Feelings of disconnectedness
	Category	Alienation from social life
	Subcategory	Social isolation
	Code	Social isolation
Close to the text and manifest content. Lower levels of abstraction.	Meaning unit	I have closed off the outside world and processed feelings of failure and sadness in my home, which has always been my secure place

Study IV

Thematic analysis [TA] with an inductive approach (174,175), was used to analyse the data. TA is a method for identifying, analysing and reporting themes (patterns) within data. It consists of six phases: familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining, and naming themes and producing the report (174). The data were read multiple times by T. Sormunen for familiarisation. They were then systematically coded by using phrases and words to label parts that matched with the study aim and moving codes back and forth. The codes and their relationship with each other were then analysed inductively to generate meaningful subthemes and themes. Themes were mapped, reviewed, and refined to confirm relevance and meaning. T. Sormunen led the analysis process with M. Westerbotn reviewing each stage of the analysis process and both researchers participated in the fifth stage of defining and naming the final themes (Table 3). The content was discussed in the research team and agreement was reached regarding the analysis, as suggested by Sandelowski (172).

Table 3. Example of the thematic analysis process.

Data	Research notes/coding	Subtheme	Theme
I have used Facebook and been in groups, to find others who have been in the same situation as myself. We have been able to discuss feelings and thoughts there. And the advantage of that is that you do not feel so alone. (Interview 1).	Others in same situation To not feel so alone	Fellowship and solidarity	Invaluable venue
I would have gone crazy if I did not have the people online who supported me. It gave hope that if someone else has succeeded so can we. (Interview 5).	Support and hope	Support and hope	

Ethical considerations

The foundation of research ethics in healthcare originates from social, medical, and biological science disciplines, and from the ethical codes directing professional practices. The ethical principles associated with participants' well-being come mainly from biomedical research, whereas concerns related to human rights derive from the social sciences (176).

The studies in this doctoral thesis received ethical approval from the Regional Ethical Review Board [EPN] in Stockholm, Sweden. Study I (EPN 2006/1025-3; EPN 2009/5:9). Study II (EPN 2016/5:1), Studies III and IV (EPN 2016/5:1). The research has been conducted according to ethical principles of research and good research practice concerning humans, in accordance with the Helsinki Declaration (177) and the ICN Code of Ethics (178).

The ethical principles are privacy, autonomy, beneficence, non-maleficence, and justice. The researcher has an obligation to recognize that a person has the right to agree or not to agree to take part in a research study. Respect of this right forms the foundation of attempting to ensure that informed consent is attained. The beneficence principle involves the obligation to help others and that knowledge gained through research will be of wider benefit to society. The principle of non-maleficence obligates the researcher not to cause or expose people to unnecessary risks. The justice principle addresses the right to resources and that people should be treated equally (179).

In **Study I,** participants received oral and written information regarding the study from the healthcare personnel at the clinic. Prior to signing the informed consent form, the participants were given detailed information; the purpose of the study, that participation was voluntary, procedures involved, benefits, risks, compensation, and confidentiality. Only T. Sormunen and the main supervisor M. Westerbotn had access to the whole dataset during the analysis. M. Westerbotn had the code key that was stored locked in a fireproof cabinet separated from other data.

Informed consent is generally expected in ethically sound research. In **Study II** this was methodologically problematic. Informing bloggers that their blogposts would be part of a research project could undermine the research intentions to gain insight into which infertility-related issues are discussed, on Swedish infertility blogs, thus preventing a valid answer to the research question.

Reactivity to researcher presence can be problematical for a study which seeks to observe natural behaviours, as the presence of the researcher is a social stimulus which may change

participants' behaviours (166). The AoIR recommends ethical reflection in the light of the following: respect, harm, and vulnerability (156). The research questions aimed to reveal the variety of infertility-related issues discussed in these blogs. Nothing in the research question and data collection would cause the participants harm psychologically or physically. The intention was to give voice to yet unheard viewpoints and the research was of potential benefit to those whose words were collected. Using blog content for research led to questions about whether blogs are public or private. These blogs used in this study allowed open access and reading the posts was completely unrestricted.

In **Study III,** answering the online questionnaire was considered as giving informed consent to participate. In line with the Helsinki declaration, the participants were provided written research information when using the web-questionnaire link. The questionnaire was anonymous. However, it consisted of questions that concerned a sensitive topic. The participants were asked to enter their name and e-mail address voluntarily for any follow-up questions or if they would consider participating in an upcoming study.

The women who agreed to participate in **Study III** were asked simultaneously to take part in **Study IV.** The participants were provided with both written and oral research information prior to the interviews. Ethical aspects were discussed in the research team at the planning stage of the study. The risk of distressing participants with previous trauma related to an infertility investigation and treatment were cautiously balanced with the benefits, which could be gained through extended knowledge about the participants' experiences about the research topic.

6 RESULTS

Study I aimed to explore infertility-related communication and coping strategies among women affected by primary or secondary fertility problems. One hundred and ninety-nine women participated. The sample was divided into two groups: women with primary infertility (n=156, 78%) and women with secondary infertility (n=43, 22%). The mean age was 36.3 years and nearly 82 percent (n=163) had a postgraduate education. Most of the women were able to discuss infertility-related issues with their partners. However, the inability to have a child (5,3%), the reasons for childlessness (8%), and results of test and examinations (6%) could not be addressed. No significant difference was found between the groups.

Approximately 20 percent of the women did not discuss the results of tests and examinations with persons outside the family, nor did they talk about how examinations and treatments affected them emotionally. There were significant differences between the two groups regarding the subjects of "reasons for infertility" and "results of tests and examinations". Twice the number of women with secondary infertility reported that they never talked about the causes or results of tests and examinations with persons outside the family (30%), compared to women with primary infertility (14%).

Approximately 16 percent (n=31) of the women avoided being in the company of pregnant women or women who had children. Twelve percent (n=23) reported that they made an exit when people were discussing pregnancies or children. Twenty-five percent (n=48) of the women hoped for a miracle. Nearly 15 percent (n=29) indicated that they had grown as a person in a positive way during this period, whilst over half did not think about infertility in a positive light.

Study II aimed to gain insight into which infertility-related issues are discussed on Swedish infertility blogs. The blogs (n=25) were written by women and allowed two-way communication. The total amount of postings included was 4 508 (three-year period), equalling 33 020 sentences, and the length of the postings varied from a few sentences up to four pages. The blogger was anonymous in 80 percent (n=20) of the 25 blogs. However, all the bloggers could be contacted either via email (n=14, 56%) or via the blog (n=11, 44%). The blogs covered a large variety of issues and 49 percent (n=16 807) of sentences were related to infertility. The bloggers frequently discussed infertility with reference to emotions, relations, time and waiting, body, care and treatment, food and diet, and exercise. The most commonly occurring topic was emotions and consisted of both positive (grateful, enjoy) and negative (scared, stressed) ones.

The bloggers described their feelings, ranging from extreme optimism to petrifying pessimism; "It's hard to explain, but the feelings are like riding a roller coaster and I have no control". The *relations* topic included the relationship with a spouse, family members and friends. Several women reported that, if they were not able to discuss infertility issues with their spouse or friends, blogging provided a place where they could express themselves. A spousal relationship could also be affected negatively by infertility, as the women experienced that their partner could not fully understand the affect fertility treatments have on female body. The topic *time and waiting* consisted of terms such as hope, weeks, anticipation and looking forward to. Trying to conceive was a phase of great worry, anxiety, frustration, and the experience was a strain. The *body* topic was associated with terms like failing body, pain, and uterus. The women reported that infertility had led to negative feelings about their body and they felt betrayed by it; "If you, yourself are the cause of childlessness, it is sometimes hard to accept oneself, one's own body". The *care and treatment* topic included descriptions about how the pursuit of fertility dominated their daily life and that making phone calls regarding the treatment was time-consuming. The topic *food and diet* consisted of terms like eating habits, weight nourishment and unhealthy food. Food was described as reducing anxiety. The *exercise* topic involved descriptions of different physical activities used to take their mind off fertility treatment and to get a break. Results of the sentiment analysis revealed that the distribution of positive (28% to 60%) and negative (40% to 72%) sentiments varied. The body topic was described most negatively (72%) of all topics.

The aim of **Study III** was to explore the roles of social media for persons affected by infertility. In total, 132 participated in this study and 97.7 percent (n=129) were women. The online survey was answered mostly via Facebook (n=115, 87.1%) and over 60 percent (n=60) of the participants had read or participated in discussion forums focussing on infertility, from 1- 3 years. Over 39 percent (n=52) took part in infertility forums more than once a day and half of the participants (n=66) devoted between 1 – 3 hours weekly to the forums. Approximately 40 percent (n=53) did not write any postings and nearly 13 percent (n=17) preferred to use a pseudonym while participating in the forums. The participants stated that the main benefits of social media focused on infertility were solidarity, information, to get and give support, and understanding infertility. Some of the negative experiences were becoming emotionally affected by treatment failures of the other forum members, and tips and advice not always being evidence based. The impact of infertility was described as resulting in feeling fragmented and disconnected (Table 4).

Table 4. The theme with corresponding categories and subcategories.

The experience of being fragmented and feelings of disconnectedness			
Influence on psychological health	Lacking meaning in life	Not completed as a woman	Alienation from social life
Depression and anxiety Life´s sadness	Life is on hold Loss of joy in life	Female identity Partner relationship	Social isolation Envy of others

The aim of **Study IV** was to describe women's experiences of using social media focusing on infertility. In total, seven women participated. Two themes were constructed from the data: *Invaluable venue* and *Opportunity of choice* (Table 5). The key reasons for using social media were information seeking and fellowship. For instance, information about how others have received help, which treatments have been used, if others have succeeded to get pregnant and how they have felt during investigation and treatment, were valued. Most of the participants using Facebook were members of closed groups. To access the group's posts, membership must be granted from the administrator of each group. The participants had been in the Facebook groups from six months up to six years. Most of them joined the Facebook groups in search for information on difficulties conceiving. The theme *Invaluable venue* consists of various features, such as finding respite, being incognito, source of information, conveying hope and providing fellowship and solidarity. The theme *Opportunity of choice* is about the user's possibility to select, for instance, which social media forum they want to get involved in, when to participate and whether to be an active participant or a lurker.

Table 5. Themes and corresponding subthemes.

Theme	Invaluable venue	Opportunity of choice
Subtheme	Breathing space and incognito Source of vital information Support and hope Fellowship and solidarity	Part of everyday life Diversity of practice Awareness of the credibility

7 DISCUSSION

REFLECTIONS ON MAIN FINDINGS

One of the many challenges faced by women affected by infertility is to decide how to deal with the stressful situation it causes, how to process infertility in the lifeworld. The latter is the sphere within which we lead much of our social and personal life (158). Everyday actions that persons perform in the lifeworld are largely communicative in nature. The Internet, for instance, through social media has changed the conditions of interpersonal contact and also the scenes of the lifeworld (75). The Internet is integrated into daily life, with life offline linked with life online (160).

The results from the included articles show that women affected by infertility communicate and process infertility-related issues in different arenas, in the physical world as shown in **Study I** and online as revealed in **Studies II, III** and **VI.** The findings in **Study I** show that the majority of the women were able to discuss issues related to infertility with their spouse and family. Nevertheless, seven percent were unable to discuss these subjects with their spouse. Results in **Study II** indicate that spouses may have difficulties in fully understanding the situation women are going through and therefore the women do not always choose to discuss infertility related issues with them. This self-imposed silence may serve as a coping strategy (180). According to the findings in **Study II** the high demands of fertility treatment could not be fully understood by the partner. Further, it was also difficult to find time and energy for deeper discussions, due to stressful everyday life. Van den Broeck et al. (98) point out that there are gender differences in coping with infertility, as women more often have the need to share emotional reactions while men try to distance themselves from the problem.

In **Study I,** a comparison was made between two groups, i.e. women with primary and women with secondary infertility. Women with primary infertility discussed the reasons for infertility and results of tests and examinations with persons outside the family to a greater extent than women with secondary infertility. Couples with secondary infertility may receive less support than couples with primary infertility because they already have a child. They may therefore be more reluctant to reach out to others. Raque-Bogdan and Hoffman (181) state that the experience of secondary infertility presents its own unique challenges, and therefore the need for support should not be ignored. Women affected by secondary infertility describe a sense of isolation from the fertile world, due to lack of understanding of their desire for an additional child.

Kahlor and Mackert (152) suggest that there may be a large number of women with secondary infertility that do not seek medical treatment. An increasing number of individuals are turning to the Internet to connect with others also experiencing infertility. There are online social media groups targeting those affected by secondary infertility, for example, on Facebook.

Active-confronting coping, such as discussing the emotional effects of tests and treatments with someone, was most frequently used compared to other forms of coping, as revealed in **Study I.** Even though the women were able to discuss emotions with family members, the results of **Studies III** and **IV** show that the they much appreciated being able to process their emotions with other persons with similar experiences on social media. The forums were described as a breathing space. Results from Stenström's study (182) are in line with our findings, indicating that social media may be a lifeline for women affected by infertility. In Sweden, 98 percent of the population have access to the Internet and 85 percent own a smartphone (109). This allows the use of the Internet and social media regardless of time and place. The use of social media focused on infertility, in **Study IV**, was described as part of everyday life and construction of the lifeworld. The women were most active during evenings and weekends, although other times, such as travel time on the bus or during a lunch break gave other opportunities. Over 60 percent of the women in **Study III** took part in social media focusing on infertility once a day or more.

According to the participants in **Study III,** infertility influenced psychological health, led to losing a purpose in life, feelings of incompleteness and social isolation. Symptoms of depression among infertile women and men have been reported previously by Volgsten et al. (52), Hoff et al. (183), and Ting-Hsiu et al. (184). Further, the women reported that they had lost the meaning in their life due to infertility and that their lives were on hold. In **Study I,** regarding finding other life goals, over 40 percent of the women had only one goal, that of having a child. Both in **Studies II** and **III** the results show that the women viewed their body as defective, and infertility had led to negative feelings about the body. Disappointment in the body not working as expected and the feelings of being betrayed by it were evident. Words such as hate, and disgust were used to describe the failing body. This could lead to feelings of incompleteness as a woman. Additionally, women are reminded on a monthly basis of their fertility and bombarded with images of women as mothers (185).

The results in **Study II** revealed that emotions, both positive and negative, were the most frequently occurring topic in the blogs. The women in **Study IV** reported that questions concerning emotions could not be answered satisfactorily by health professionals.

Consequently, the women searched for postings about emotions, which helped them to maintain a hopeful belief in the future. To find answers to questions about infertility, is one way to cope with a stressful situation (87). The results of **Study IV** reveal further that healthcare personnel deliberately delayed delivery of important information. This was experienced negatively by the women. In general, the doctor's appointments are short and therefore it is not always possible to discuss issues at length and receive exhaustive answers or information. Findings of Machin's study show that patients may be uncomfortable asking for support (186). It may be too much to ask of clinical personnel that they give such support as, they have other demands associated with their roles (187).

Findings in **Study IV** show that the women were aware of misinformation occurring online. As for the authenticity of the personal stories, the women believed them to be true. They turned to healthcare for reliable medical information. The forum members gave recommendations regarding various fertility clinics, either positive or negative. In Sweden, a maximum of three full IVF cycles is reimbursed by the Swedish General Healthcare System (11). If these treatments fail, it is a possible to get further treatments, which the person/couple must finance themselves. The strongest predominant factor associated with infertility is ageing, as it decreases female chances to become pregnant (13). The results from **Study IV** revealed that forums were chosen based on which age group it was targeted to. The stress caused by age was not always understood by younger forum members. Therefore, women chose forums where members were the same age. The women, in **Study IV**, reported, further, that the public has insufficient knowledge about infertility and its consequences and wished that the topic would generally be highlighted more often. The WHO Regional Office for Europe state in the action plan for sexual and reproductive health, towards achieving the 2030 Agenda for Sustainable Development in Europe, that one of the objectives is to prevent, diagnose, and treat infertility. This includes informing public about the adverse effect of advancing age on fertility (188).

METHODOLOGICAL REFLECTIONS

The overall aim of this thesis was to explore and describe communication, coping and social networking regarding infertility from a lifeworld perspective. Various research methods were used i.e. quantitative method for **Study I,** quantitative-qualitative method in **Studies II** and **III** and qualitative method in **Study IV,** to answer the specific aims. Blending different research methods offers different perspectives on the topics under scrutiny. Nevertheless, some methodological limits in each study must be addressed.

Bias may produce a misrepresentation or error and can jeopardize a study's validity and trustworthiness. In both quantitative and qualitative studies, biases can impact the quality of evidence (166). Bias can take place at any stage of research, during study design, data collection, data analysis and publication (189).

Sample selection

In research, samples are used rather than whole populations, due to deficient resources to study all members of the population. Results from a sample may provide realistic truthful information, but data from samples can be inaccurate. Sampling bias refers to the methodical over- or underrepresentation of a population section on a characteristic relevant to the research aim (166). In **Study I** the participants were recruited from one fertility clinic and the majority had a higher education. Further, the sample size of women with secondary infertility was small, which is a limitation. It can be assumed that if the questionnaire had also been available in English, more potential informants may have been able to participate. The questionnaire was aimed at both partners in the couple, however, only women responded.

When conducting research on social media, there are ethical problems to consider as well as the fact that the blogs were not written for research purposes. In **Study II,** only open blogs were included, all of which were maintained by women. To access the material on closed blogs, it would have been necessary to contact the blogger and apply for a membership. This could have affected the blogger's content and thereby manipulated the research process (190).

The informants in **Study III** were women (98%). In a perfect online questionnaire, all target informants should have equal chance of receiving an invitation to participate in the study. Conducting an online questionnaire restricts its availability to informants who are more active online. However, six different social media forums were used to distribute the questionnaire to improve its visibility among the target informants. Even if the online questionnaire did not have any gender restrictions it was not completed by men, which may indicate that mostly women were active in these forums.

In **Study IV** the results are based on a small sample size (n=7). However, a qualitative study does not seek to be representative in sampling, but to understand the meaning of every individual's experience, and to discover various realities (166).

Data collection and instruments

In **Study I,** the data were collected using a structured questionnaire. The questionnaire was created based on The COMPI research programme (66), with the permission of the authors. The questionnaire has been tested from a validity and reliability point of view in the COMPI research project. During data collection the researchers had no physical contact with the participants and thus could not influence the responses to the questions. Further, the participants could choose when to respond to the questionnaire.

In **Study II**, the data were collected from 25 blogs focusing on infertility. Regardless of the quality of the blogposts, the length of the post or spelling mistakes, all blogs fulfilling the criteria were retrieved and included in the analysis. Weerkamp et al. (191) state that posts from blogs with a recurring interest in the topic are more credible than posts from blogs mentioning the topic occasionally. The blogs included in this study all had a focus on infertility, infertility treatment and how the bloggers experienced infertility. The blogposts are therefore relevant to the aim of the study. The Gavagai Explorer analysis programme, developed for analysing large sets of data (169), was used to analyse the postings. This instrument is used frequently in various research areas, such as marketing. In the research group, there was previous experience of using Gavagai Explorer, and further multiple iterations were made when analysing the data, which increased the accuracy of the analysis. The tool provided support especially in analysing large amounts of data, as after each iteration it provided new suggestions for topics to be explored. By proposing new topics, the tool thereby ensured that important issues were not overlooked, which would have been an imminent risk if trying to analyse such data amounts manually.

In **Study III**, data were collected using online survey. In standard survey research, information, such as dropouts and response rate should be reported. However, when using online surveys, it is impossible to track how many persons view the survey and choose not to participate and, therefore it is not possible to calculate overall response rate, or to evaluate how participants differ from non-participants (192). To increase the number of participants several social media forums could have been contacted. Further, persons with insufficient data skills, are less likely to participate.

The questionnaire was piloted by ten persons with a known history of infertility, who answered, reviewed, and offered qualitative assessment. This allowed for improvements of the questions, such as addressing issues of Swedish language proficiency as well as item precision and applicability.

In **Study IV** seven semi-structured telephone interviews were conducted. The original project design called for face-to-face interviews. Due to the COVID-19 pandemic, it became necessary to conduct interviews by telephone. Creswell and Poth (193) suggest that using telephone interviews is appropriate when the respondents cannot be accessed otherwise. Some methodological strengths of qualitative telephone interviews are, for example, increased privacy for respondents, perceived anonymity, and reduced distraction (194). However, one of the disadvantages is that body language and behaviour cannot be observed (195). Telephone interviews were suitable to study this vulnerable group and make their voices heard. The interviews were scheduled to meet the participants' wishes; three were conducted in the evening and four daytime. The settings of the participants varied. Three were at work during the interview and four in their own homes. Polit and Beck (166) point out that in different settings informants assume different roles, such as employee, spouse, parent, and their answers to questions may be influenced by these roles. In qualitative research, the term credibility is used as a criterion for evaluating trustworthiness of the findings and the extent to which the results reflect the reality of the phenomenon studied. The participants were from different parts of Sweden. To achieve credibility, the results should signify evidence in accordance with the original views of the participants (166).

The emic and etic perspectives

The terms emic and etic have a variety of meanings, definitions, and applications in ethnographic and anthropological research, and are also used in qualitative research. The emic perspective means the insider's perception (**Studies II, III** and **IV**), and the etic perspective (**Study I**) is the scientific framework of the outsider and the researcher. Emic knowledge resulting from interviews and observations while etic knowledge is rooted in the analysis (196). The emic perspective is the concepts, local language or means of expressions used by members of the group to illustrate their experiences. The etic perspective is the researchers' explanation of the experiences of that culture, the language used by the researchers to refer to similar phenomena (166).

My own understanding in the present thesis, regarding individuals affected by infertility, was from an etic perspective when working with and analysing data.

8 CONCLUSIONS

Infertility is experienced as one of the most stressful life events and causes increased distress. Ageing is the factor with the strongest association with infertility. The findings of this thesis reveal that infertility left the person feeling disconnected from society. There are infertile women who are unable to discuss infertility-related issues with their spouses, and some have difficulties in discussing the topic with persons outside the family. Various coping strategies are used to manage the situation. Several women turn to their close relatives or friends for help. Social support plays an important part in the process of managing distress caused by infertility. Since access to the Internet, and thereby social media, is widespread there are various social media forums aimed at persons with various health problems. Social media may be a vital channel for women with infertility and a valuable source for processing issues related to infertility, such as emotions, relations, care, and treatment.

Participation in social media was mostly experienced as positive. Key benefits were solidarity, to receive and to give support, and to obtain information about fertility treatments. Becoming emotionally affected by the experiences of other forum members was reported as one of the adverse aspects. The forums could be used for finding persons in a similar situation, who could understand what infertility involves, and for instant information seeking. The age of the forum members and for whom the forum was targeted geographically, may be central criteria when selecting a forum focusing on infertility.

Counselling and psychological support for the infertile women must be designed to suit the social setting and culture. Increased mobility across borders and cultures will be challenging for future healthcare professionals working with infertility. As communication and demographic patterns change, our knowledge must meet new demands. This thesis contributes to the understanding of which infertility-related aspects women affected by infertility have a need to discuss and reflect on beyond their contacts with health care personnel.

9 POINTS OF PERSPECTIVE

This thesis focused on communication, coping and social networking regarding infertility from a lifeworld perspective. The results have raised new questions for future research, which could focus on the following:

• To describe experiences of health care personnel such as physicians, midwives, and nurses, working with this patient group.

• To describe how men, experience social media focused on infertility.

• To investigate the support needs of men with a history of infertility.

• To explore family members and friends' experiences when loved one suffers from infertility.

• To describe infertility issues experienced by lesbian, gay, bisexual, and transgender [LGBT] subgroups.

• To follow the development of new social media in the context of infertility and coping.

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11 REFERENCES

1.   World Health Organization, editor. Reproductive health indicators: guidelines for their generation, interpretation and analysis for global monitoring. Geneva: World Health Organization; 2006. 63 p.

2.   Gameiro S, Boivin J, Peronace L, Verhaak CM. Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. Human Reproduction Update. 2012 Nov 1;18(6):652–69.

3.   WHO | Infertility definitions and terminology [Internet]. WHO. [cited 2020 Feb 5]. Available from: http://www.who.int/reproductivehealth/topics/infertility/definitions/en/

4.   Infertility | ASRM [Internet]. [cited 2020 Feb 7]. Available from: https://www.asrm.org/topics/topics-index/infertility/

5.   Nachtigall RD. International disparities in access to infertility services. Fertility and Sterility. 2006 Apr;85(4):871–5.

6.   Assisterad befruktning (Q-IVF) - Nationella Kvalitetsregister [Internet]. [cited 2019 Jul 12]. Available from: http://www.kvalitetsregister.se/hittaregister/registerarkiv/assisteradbefruktningqivf.2303.html

7.   Ombelet W, Cooke I, Dyer S, Serour G, Devroey P. Infertility and the provision of infertility medical services in developing countries. Hum Reprod Update. 2008 Nov 1;14(6):605–21.

8.   A unique view on male infertility around the globe [Internet]. [cited 2020 Feb 10]. Available from: https://www-ncbi-nlm-nih-gov.proxy.kib.ki.se/pmc/articles/PMC4424520/

9.   Riksdagsförvaltningen. Lag (2006:351) om genetisk integritet m.m. Svensk författningssamling 2006:2006:351 t.o.m. SFS 2019:341 - Riksdagen [Internet]. [cited 2019 Sep 26]. Available from: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2006351-om-genetisk-integritet-mm_sfs-2006-351

10.   Senaste version av 2009:32 Socialstyrelsens föreskrifter och allmänna råd om användning av vävnader och celler i hälso- och sjukvården och vid klinisk forskning m.m. [Internet]. Socialstyrelsen. [cited 2020 Dec 29]. Available from: https://www.socialstyrelsen.se/regler-och-riktlinjer/foreskrifter-och-allmanna-rad/konsoliderade-foreskrifter/200932-om-anvandning-av-vavnader-och-celler-i-halso--och-sjukvarden-och-vid-klinisk-forskning/

11.   Ofrivillig barnlöshet - 1177 Vårdguiden [Internet]. [cited 2019 Sep 24]. Available from: https://www.1177.se/stockholm/barn--gravid/barnloshet/ofrivillig-barnloshet/

12.   European Projects and Joint Actions involving ESHRE [Internet]. [cited 2021 Mar 23]. Available from: https://www.eshre.eu/Europe/European-Projects-and-Joint-Actions-involving-ESHRE

13.   Infertility | Reproductive Health | CDC [Internet]. 2019 [cited 2019 Sep 11]. Available from: https://www.cdc.gov/reproductivehealth/infertility/index.htm

14.   Committee Opinion No.589. Female age-related fertility decline. In: Fertility and Sterility [Internet]. 2014 [cited 2019 Aug 23]. p. 633–4. Available from: https://linkinghub.elsevier.com/retrieve/pii/S001502821303464X

15. Soules MR, Rebar R, Woods N. Executive summary: Stages of Reproductive Aging Workshop (STRAW). 2001;76(5):5.

16. Lobo RA. Potential Options for Preservation of Fertility in Women. N Engl J Med. 2005 Jul 7;353(1):64–73.

17. Sartorius GA, Nieschlag E. Paternal age and reproduction. Human Reproduction Update. 2010;16(1):65–79.

18. Rodriguez-Wallberg KA, Tanbo T, Tinkanen H, Thurin-Kjellberg A, Nedstrand E, Kitlinski ML, et al. Ovarian tissue cryopreservation and transplantation among alternatives for fertility preservation in the Nordic countries – compilation of 20 years of multicenter experience. Acta Obstetricia et Gynecologica Scandinavica. 2016;95(9):1015–26.

19. How Cancer and Cancer Treatment Can Affect Fertility in Females [Internet]. [cited 2021 Feb 25]. Available from: https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/fertility-and-women-with-cancer/how-cancer-treatments-affect-fertility.html

20. Rossi BV, Abusief M, Missmer SA. Modifiable Risk Factors and Infertility: What Are the Connections? American Journal of Lifestyle Medicine. 2016 Jul 1;10(4):220–31.

21. Grandi G, Ferrari S, Xholli A, Cannoletta M, Palma F, Romani C, et al. Prevalence of menstrual pain in young women: what is dysmenorrhea? J Pain Res. 2012 Jun 20;5:169–74.

22. Rooney KL, Domar AD. The impact of lifestyle behaviors on infertility treatment outcome: Current Opinion in Obstetrics and Gynecology. 2014 Jun;26(3):181–5.

23. Bundhun PK, Janoo G, Bhurtu A, Teeluck AR, Soogund MZS, Pursun M, et al. Tobacco smoking and semen quality in infertile males: a systematic review and meta-analysis. BMC Public Health. 2019 Jan 8;19(1):36.

24. Jungheim ES, Travieso JL, Hopeman MM. Weighing the impact of obesity on female reproductive function and fertility. Nutr Rev. 2013 Oct;71:S3–8.

25. Hauser R, Gaskins AJ, Souter I, Smith KW, Dodge LE, Ehrlich S, et al. Urinary Phthalate Metabolite Concentrations and Reproductive Outcomes among Women Undergoing in Vitro Fertilization: Results from the EARTH Study. Environ Health Perspect. 2016 Jun;124(6):831–9.

26. Decline in sperm count in European men during the past 50 years - P Sengupta, E Borges, S Dutta, E Krajewska-Kulak, 2018 [Internet]. [cited 2020 Feb 13]. Available from: https://journals.sagepub.com/doi/full/10.1177/0960327117703690

27. Hjollund NHI, Jensen TK, Bonde JPE, Henriksen TB, Andersson A-M, Kolstad HA, et al. Distress and reduced fertility: a follow-up study of first-pregnancy planners. Fertility and Sterility. 1999 Jul;72(1):47–53.

28. Nordkap L, Jensen TK, Hansen ÅM, Lassen TH, Bang AK, Joensen UN, et al. Psychological stress and testicular function: a cross-sectional study of 1,215 Danish men. Fertility and Sterility. 2016 Jan;105(1):174-187.e2.

29. Levi F, Schibler U. Circadian rhythms: mechanisms and therapeutic implications. Annu Rev Pharmacol Toxicol. 2007;47:593–628.

30. Partonen T. Short Note: Melatonin-dependent infertility. Med Hypotheses. 1999(May:52 (5):487-8):2.

31.   Gore AC, Chappell VA, Fenton SE, Flaws JA, Nadal A, Prins GS, et al. Executive Summary to EDC-2: The Endocrine Society's Second Scientific Statement on Endocrine-Disrupting Chemicals. Endocr Rev. 2015 Dec;36(6):593–602.

32.   Ovulation Disorders: World Health Organization (WHO) Categorization [Internet]. Time of Care. 2017 [cited 2019 Sep 19]. Available from: https://www.timeofcare.com/ovulation-disorders-world-health-organization-who-categorization/

33.   Mallepaly, R., Butler, P.R., Herati, A.S. & Lamb, D.J. Genetic Basis of Male and Female Infertility. Basel, Switerland: Karger AG; 2017.

34.   Uterine Factors [Internet]. RESOLVE: The National Infertility Association. [cited 2019 Sep 19]. Available from: https://resolve.org/infertility-101/medical-conditions/uterine-factors/

35.   Hydrosalpinx [Internet]. [cited 2019 Sep 19]. Available from: https://www.reproductivefacts.org/news-and-publications/patient-fact-sheets-and-booklets/documents/fact-sheets-and-info-booklets/hydrosalpinx/

36.   Rodriguez-Wallberg KA, Oktay K. Fertility preservation during cancer treatment: clinical guidelines. Cancer Manag Res. 2014 Mar 4;6:105–17.

37.   Male Factor [Internet]. RESOLVE: The National Infertility Association. [cited 2019 Sep 20]. Available from: https://resolve.org/infertility-101/medical-conditions/male-factor/

38.   El Osta R, Almont T, Diligent C, Hubert N, Eschwège P, Hubert J. Anabolic steroids abuse and male infertility. Basic and Clinical Andrology. 2016 Feb 6;26(1):2.

39.   Poongothai J, Gopenath TS, Manonayaki S. Genetics of human male infertility. Singapore Med J. 2009 Apr;50(4):336–47.

40.   Zegers-Hochschild F, Adamson GD, Dyer S, Racowsky C, de Mouzon J, Sokol R, et al. The International Glossary on Infertility and Fertility Care, 2017. Hum Reprod. 2017 Sep 1;32(9):1786–801.

41.   Infertility Terms to Know [Internet]. American Pregnancy Association. 2012 [cited 2019 Sep 20]. Available from: https://americanpregnancy.org/infertility/terms-to-know/

42.   Infertility | womenshealth.gov [Internet]. [cited 2019 Sep 23]. Available from: https://www.womenshealth.gov/a-z-topics/infertility

43.   How is Infertility Diagnosed? [Internet]. [cited 2019 Sep 23]. Available from: https://www.reproductivefacts.org/faqs/frequently-asked-questions-about-infertility/q03-how-is-infertility-diagnosed/

44.   Fritz MA. The Modern Infertility Evaluation: Clinical Obstetrics and Gynecology. 2012 Sep;55(3):692–705.

45.   Infertility | Reproductive Health | CDC [Internet]. [cited 2019 Sep 24]. Available from: https://www.cdc.gov/reproductivehealth/infertility/index.htm#ART

46.   Intrauterine insemination (IUI): Uses, Risks and Success Rate [Internet]. [cited 2020 Feb 10]. Available from: https://americanpregnancy.org/getting-pregnant/intrauterine-insemination/

47.   In Vitro Fertilization (IVF) [Internet]. [cited 2020 Mar 31]. Available from: https://www.reproductivefacts.org/topics/topics-index/in-vitro-fertilization-ivf/

48. Greil AL, Slauson-Blevins K, McQuillan J. The experience of infertility: a review of recent literature. Sociology of Health & Illness. 2010;32(1):140–62.

49. Lechner L, Bolman C, van Dalen A. Definite involuntary childlessness: associations between coping, social support and psychological distress. Hum Reprod. 2007 Jan 1;22(1):288–94.

50. Hinton L, Kurinczuk JJ, Ziebland S. Infertility; isolation and the Internet: A qualitative interview study. Patient Education and Counseling. 2010 Dec;81(3):436–41.

51. Chochovski J, Moss SA, Charman DP. Recovery after unsuccessful in vitro fertilization: the complex role of resilience and marital relationships. Journal of Psychosomatic Obstetrics & Gynecology. 2013 Sep 1;34(3):122–8.

52. Volgsten H, Skoog Svanberg A, Ekselius L, Lundkvist Ö, Sundström Poromaa I. Prevalence of psychiatric disorders in infertile women and men undergoing in vitro fertilization treatment. Hum Reprod. 2008 Sep 1;23(9):2056–63.

53. Shani C, Yelena S, Reut BK, Adrian S, Sami H. Suicidal risk among infertile women undergoing in-vitro fertilization: Incidence and risk factors. Psychiatry Research. 2016 Jun;240:53–9.

54. Gourounti K, Anagnostopoulos F, Potamianos G, Lykeridou K, Schmidt L, Vaslamatzis G. Perception of control, coping and psychological stress of infertile women undergoing IVF. Reproductive BioMedicine Online. 2012 Jun;24(6):670–9.

55. Covington SN, Burns LH. Infertility Counseling: A Comprehensive Handbook for Clinicians. Cambridge University Press; 2006. 679 p.

56. Eldridge KF, Giraldi A. Communication About Sexual Matters With Women Attending a Danish Fertility Clinic: A Descriptive Study. Sexual Medicine. 2017 Sep;5(3):e196–202.

57. Cousineau TM, Domar AD. Psychological impact of infertility. Best Practice & Research Clinical Obstetrics & Gynaecology. 2007 Apr 1;21(2):293–308.

58. Benyamini Y, Gozlan M, Kokia E. Women's and men's perceptions of infertility and their associations with psychological adjustment: A dyadic approach. British Journal of Health Psychology. 2009 Feb 1;14(1):1–16.

59. Lord S, Robertson N. The role of patient appraisal and coping in predicting distress in IVF. Journal of Reproductive and Infant Psychology. 2005 Nov 1;23(4):319–32.

60. Beaurepaire J, Jones M, Thiering P, Saunders D, Tennant C. Psychosocial adjustment to infertility and its treatment: Male and female responses at different stages of IVF/ET treatment. Journal of Psychosomatic Research. 1994 Apr;38(3):229–40.

61. Monga M, Alexandrescu B, Katz SE, Stein M, Ganiats T. Impact of infertility on quality of life, marital adjustment, and sexual function. Urology. 2004 Jan;63(1):126–30.

62. Onat G, Beji NK. Marital Relationship and Quality of Life Among Couples with Infertility. Sex Disabil. 2012 Mar 1;30(1):39–52.

63. Boivin J, Takefman JE. Stress level across stages of in vitro fertilization in subsequently pregnant and nonpregnant women * †. Fertility and Sterility. 1995 Oct 1;64(4):802–10.

64. Peronace LA, Boivin J, Schmidt L. Patterns of suffering and social interactions in infertile men: 12 months after unsuccessful treatment. Journal of Psychosomatic Obstetrics & Gynecology. 2007 Jan 1;28(2):105–14.

65. Folkvord S, Odegaard OA, Sundby J. Male infertility in Zimbabwe. Patient Education and Counseling. 2005 Dec 1;59(3):239–43.

66. Schmidt L, Holstein BE, Christensen U, Boivin J. Communication and coping as predictors of fertility problem stress: cohort study of 816 participants who did not achieve a delivery after 12 months of fertility treatment. Human Reproduction. 2005 Nov 1;20(11):3248–56.

67. COMMUNICATION | meaning in the Cambridge English Dictionary [Internet]. [cited 2019 Aug 16]. Available from: https://dictionary.cambridge.org/dictionary/english/communication

68. Communication definition and meaning | Collins English Dictionary [Internet]. [cited 2019 Aug 16]. Available from: https://www.collinsdictionary.com/dictionary/english/communication

69. Cheney G, Christensen LT, Jr TEZ, Ganesh S. Organizational Communication in an Age of Globalization: Issues, Reflections, Practices, Second Edition. Waveland Press; 2010. 536 p.

70. McCabe C, Timmins F. Communication Skills for Nursing Practice. Macmillan International Higher Education; 2013. 279 p.

71. Dimberley, R. & Burton, G. More Than Words: An Introduction to Communication. 4th ed. Vol. 2007. Routledge; 283 p.

72. Fossum, B (Red.). Kommunikation, samtal och bemötande i vården. 3rd ed. Vol. 2019. Lund: Studentlitteratur; 432p.

73. Littlejohn SW, Foss KA. Theories of Human Communication: Tenth Edition. Waveland Press; 2010. 500 p.

74. Jansson André. Kommunikation. 1:2. Malmö: Liber; 109 p.

75. Zhao S. The Internet and the Transformation of the Reality of Everyday Life: Toward a New Analytic Stance in Sociology. Sociological Inquiry. 2006 Nov 1;76(4):458–74.

76. Malik SH, Coulson NS. Coping with infertility online: An examination of self-help mechanisms in an online infertility support group. Patient Education and Counseling. 2010 Nov 1;81(2):315–8.

77. Kozinets RV. Netnography : redefined. Thousand Oaks, CA: Sage Publications Ltd; 2015.

78. Sade-Beck L. Internet Ethnography: Online and Offline. International Journal of Qualitative Methods. 2004 Jun 1;3(2):45–51.

79. Sloan DM, Marx BP. Taking Pen to Hand: Evaluating Theories Underlying the Written Disclosure Paradigm. Clinical Psychology: Science and Practice. 2004;11(2):121–37.

80. Nicholls S. Beyond Expressive Writing: Evolving Models of Developmental Creative Writing. J Health Psychol. 2009 Mar 1;14(2):171–80.

81. COPING | meaning in the Cambridge English Dictionary [Internet]. [cited 2019 Dec 4]. Available from: https://dictionary.cambridge.org/dictionary/english/coping

82. Cohen F, Lazarus RS. Coping and Adaptation in Health and Illness. In: Mechanic D, editor. Handbook of Health, Health Care and Health Professions. New York, NY, USA: Free Press; 1983. p. 608–35.

83. Lazarus R. Stress and emotion. Vol. 1999. New York, NY, USA: Springer Publishing Company; 551 p.

84. Carver CS, Connor-Smith J. Personality and Coping. Annual Review of Psychology. 2010;61(1):679–704.

85. Gamarel KE, Revenson TA. Dyadic Adaptation to Chronic Illness: The Importance of Considering Context in Understanding Couples' Resilience. In: Skerrett K, Fergus K, editors. Couple Resilience: Emerging Perspectives [Internet]. Dordrecht: Springer Netherlands; 2015 [cited 2019 Dec 4]. p. 83–105. Available from: https://doi.org/10.1007/978-94-017-9909-6_5

86. Fife BL, Weaver MT, Cook WL, Stump TT. Partner interdependence and coping with life-threatening illness: The impact on dyadic adjustment. Journal of Family Psychology. 2013;27(5):702–11.

87. Natt och Dag, S. Den bloggande patienten. Hur påverkas patient, anhörig och vård? Stockholm: Gothia Förlag; 2012.

88. Diehl M, Chui H, Hay EL, Lumley MA, Grühn D, Labouvie-Vief G. Change in coping and defense mechanisms across adulthood: Longitudinal findings in a European American sample. Developmental Psychology. 2014;50(2):634–48.

89. Podolska M, Bidzan M. Infertility as a psychological problem. Ginekologia Polska [Internet]. 2011 [cited 2020 Apr 1];82(1). Available from: https://journals.viamedica.pl/ginekologia_polska/article/view/46385

90. Faramarzi M, Alipor A, Esmaelzadeh S, Kheirkhah F, Poladi K, Pash H. Treatment of depression and anxiety in infertile women: Cognitive behavioral therapy versus fluoxetine. Journal of Affective Disorders. 2008 May;108(1–2):159–64.

91. Bell K. Constructions of "Infertility" and Some Lived Experiences of Involuntary Childlessness. Affilia. 2013 Aug;28(3):284–95.

92. Palomba S, Daolio J, Romeo S, Battaglia FA, Marci R, La Sala GB. Lifestyle and fertility: the influence of stress and quality of life on female fertility. Reprod Biol Endocrinol [Internet]. 2018 Dec 2 [cited 2019 Dec 5];16. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6275085/

93. Benyamini Y, Gefen-Bardarian Y, Gozlan M, Tabiv G, Shiloh S, Kokia E. Coping specificity: The case of women coping with infertility treatments. Psychology & Health. 2008 Feb 1;23(2):221–41.

94. Thompson EH, Woodward JT, Stanton AL. Dyadic Goal Appraisal During Treatment for Infertility: How Do Different Perspectives Relate to Partners' Adjustment? IntJ Behav Med. 2012 Sep;19(3):252–9.

95. Greil AL. Infertility and psychological distress: A critical review of the literature. Social Science & Medicine. 1997 Dec;45(11):1679–704.

96. Fathalla MF. Women and the burden of human reproduction: An evolutionary perspective. Journal of Reproductive Health and Medicine. 2015 Jul 1;1(2):103–5.

97. Herrera F. "Men Always Adopt": Infertility and Reproduction From a Male Perspective. Journal of Family Issues. 2013 Aug 1;34(8):1059–80.

98. Van den Broeck U, Emery M, Wischmann T, Thorn P. Counselling in infertility: Individual, couple and group interventions. Patient Education and Counseling. 2010 Dec 1;81(3):422–8.

99.   Uchino BN. Understanding the Links Between Social Support and Physical Health: A Life-Span Perspective With Emphasis on the Separability of Perceived and Received Support. Perspect Psychol Sci. 2009 May 1;4(3):236–55.

100. Wright KB, Miller CH. A Measure of Weak-Tie/Strong-Tie Support Network Preference. Communication Monographs. 2010 Dec 1;77(4):500–17.

101. Coty M-BC, Wallston KAW. Problematic Social Support, Family Functioning, and Subjective Well-Being in Women with Rheumatoid Arthritis. Women & Health. 2010 Mar 23;50(1):53–70.

102. Malik SH, Coulson NS. A comparison of lurkers and posters within infertility online support groups. Comput Inform Nurs. 2011 Oct;29(10):564–73.

103. Social-networking noun - Definition, pictures, pronunciation and usage notes | Oxford Advanced American Dictionary at OxfordLearnersDictionaries.com [Internet]. [cited 2020 Apr 5]. Available from: https://www.oxfordlearnersdictionaries.com/definition/american_english/social-networking

104. Gunawardena CN, Hermans MB, Sanchez D, Richmond C, Bohley M, Tuttle R. A theoretical framework for building online communities of practice with social networking tools. Educational Media International. 2009 Mar 1;46(1):3–16.

105. Valkenburg PM, Peter J. Online Communication and Adolescent Well-Being: Testing the Stimulation Versus the Displacement Hypothesis. Journal of Computer-Mediated Communication. 2007;12(4):1169–82.

106. Barry Wellman, Haase A, Witte J, Hampton K. Does the Internet Increase, Decrease, or Supplement Social Capital?: Social Networks, Participation, and Community Commitment. American Behavioral Scientist. 2001 Nov 1;45(3):436–55.

107. Miura A, Yamashita K. Psychological and Social Influences on Blog Writing: An Online Survey of Blog Authors in Japan. J Comput Mediat Commun. 2007 Jul 1;12(4):1452–71.

108. Ziebland S, Wyke S. Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? The Milbank Quarterly. 2012;90(2):219–49.

109. Internet Growth Statistics 1995 to 2019 - the Global Village Online [Internet]. [cited 2020 Apr 5]. Available from: https://www.internetworldstats.com/emarketing.htm

110. Facebook users worldwide 2019 [Internet]. Statista. [cited 2020 Apr 5]. Available from: https://www.statista.com/statistics/264810/number-of-monthly-active-facebook-users-worldwide/

111. Svenskarna och internet 2019 [Internet]. Svenskarna och internet. [cited 2020 Apr 5]. Available from: https://svenskarnaochinternet.se/rapporter/svenskarna-och-internet-2019/

112. Higgins O, Europäisches Zentrum für die Prävention und die Kontrolle von Krankheiten, editors. A literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective ; insights into health communication. Stockholm: Ecdc [u.a.]; 2011. 12 p. (ECDC Technical report).

113. Lambert KM, Barry P, Stokes G. Risk management and legal issues with the use of social media in the healthcare setting. J of Healthcare Risk Mgmt. 2012 Jan 1;31(4):41–7.

114. McIntyre KE. The Evolution of Social Media from 1969 to 2013: A Change in Competition and a Trend Toward Complementary, Niche Sites. The Journal of Social Media in Society [Internet]. 2014 Dec 31 [cited 2021 Mar 22];3(2). Available from: https://thejsms.org/index.php/TSMRI/article/view/89

115. von Muhlen M, Ohno-Machado L. Reviewing social media use by clinicians. J Am Med Inform Assoc. 2012 Sep 1;19(5):777–81.

116. Demiris G. The diffusion of virtual communities in health care: Concepts and challenges. Patient Education and Counseling. 2006 Aug 1;62(2):178–88.

117. Dedding C, van Doorn R, Winkler L, Reis R. How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients. Social Science & Medicine. 2011 Jan 1;72(1):49–53.

118. Mediebarometern | Nordicom [Internet]. [cited 2020 Apr 18]. Available from: https://www.nordicom.gu.se/sv/mediebarometern-2019

119. Ventola CL. Social Media and Health Care Professionals: Benefits, Risks, and Best Practices. P T. 2014 Jul;39(7):491–520.

120. Siouta E, Muhli UH, Hedberg B, Broström A, Fossum B, Karlgren K. Patients' experiences of communication and involvement in decision-making about atrial fibrillation treatment in consultations with nurses and physicians. Scandinavian Journal of Caring Sciences. 2016;30(3):535–46.

121. Smailhodzic E, Hooijsma W, Boonstra A, Langley DJ. Social media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionals. BMC Health Services Research. 2016 Aug 26;16(1):442.

122. Antheunis ML, Tates K, Nieboer TE. Patients' and health professionals' use of social media in health care: Motives, barriers and expectations. Patient Education and Counseling. 2013 Sep 1;92(3):426–31.

123. Childs LM, Martin CY. Social media profiles: Striking the right balance. Am J Health Syst Pharm. 2012 Dec 1;69(23):2044–50.

124. George DR, Rovniak LS, Kraschnewski JL. Dangers and opportunities for social media in medicine. Clin Obstet Gynecol [Internet]. 2013 Sep [cited 2020 Apr 6];56(3). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3863578/

125. Facebook, Twitter. What Exactly Is Snapchat, Anyway? [Internet]. Lifewire. [cited 2020 Apr 6]. Available from: https://www.lifewire.com/what-is-snapchat-3485908

126. Participative Web and User-Created Content: Web 2.0, Wikis and Social Networking - OECD [Internet]. [cited 2020 Apr 6]. Available from: https://www.oecd.org/sti/ieconomy/participativewebanduser-createdcontentweb20wikisandsocialnetworking.htm

127. Herbert I, Englund Hjalmarsson H. Språket i sociala medier. Vol. 2012. Stockholm: Prodicta; 104 p.

128. Kietzmann JH, Hermkens K, McCarthy IP, Silvestre BS. Social media? Get serious! Understanding the functional building blocks of social media. Business Horizons. 2011 May 1;54(3):241–51.

129. Why Do People REALLY Tweet? The Psychology Behind Tweeting! [Internet]. [cited 2020 Apr 6]. Available from: http://blog.thoughtpick.com/2009/08/why-do-people-really-tweet-the-psychology-behind-tweeting.html

130. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of Social Media. Business Horizons. 2010 Jan 1;53(1):59–68.

131. Panahi S, Watson J, Partridge H. Social Media and Tacit Knowledge Sharing: Developing a Conceptual Model. World Academy of Science Engineering and Technology. 2012(64):1095–102.

132. Ritzer G, Jurgenson N. Production, Consumption, Prosumption: The nature of capitalism in the age of the digital 'prosumer'. Journal of Consumer Culture. 2010 Mar 1;10(1):13–36.

133. Statista. Number of social media users worldwide 2010-2021 [Internet]. Statista. 2018 [cited 2018 Feb 14]. Available from: https://www.statista.com/statistics/278414/number-of-worldwide-social-network-users/

134. Quinn K. Why We Share: A Uses and Gratifications Approach to Privacy Regulation in Social Media Use. Journal of Broadcasting & Electronic Media. 2016 Jan 2;60(1):61–86.

135. Definition of BLOG [Internet]. [cited 2020 Apr 6]. Available from: https://www.merriam-webster.com/dictionary/blog

136. How Many Blogs Are There? (And 141 Other Blogging Stats) [Internet]. GrowthBadger. 2019 [cited 2020 Apr 6]. Available from: https://growthbadger.com/blog-stats/

137. Fogelson NS, Rubin ZA, Ault KA. Beyond Likes and Tweets: An In-depth Look at the Physician Social Media Landscape. Clinical Obstetrics and Gynecology. 2013 Sep;56(3):495–508.

138. Ratliff C. Policing Miscarriage: Infertility Blogging, Rhetorical Enclaves, and the Case of House Bill 1677. Women's Studies Quarterly. 2009;37(1/2):125–45.

139. Miura A. Can weblogs cause the emergence of social intelligence?: causal model of intention to continue publishing weblog in Japan. AI & Soc. 2007 Nov 1;22(2):237–51.

140. Nardi BA, Schiano DJ, Gumbrecht M. Blogging as social activity, or, would you let 900 million people read your diary? In: Proceedings of the 2004 ACM conference on Computer supported cooperative work [Internet]. Chicago, Illinois, USA: Association for Computing Machinery; 2004 [cited 2020 Apr 14]. p. 222–31. (CSCW '04). Available from: http://doi.org/10.1145/1031607.1031643

141. Christofides E, Muise A, Desmarais S. Information Disclosure and Control on Facebook: Are They Two Sides of the Same Coin or Two Different Processes? CyberPsychology & Behavior. 2009 Mar 1;12(3):341–5.

142. Heilferty CM. Toward a theory of online communication in illness: concept analysis of illness blogs. Journal of Advanced Nursing. 2009 Jul;65(7):1539–47.

143. Mitra A. Marginal Voices in Cyberspace. New Media & Society. 2001 Mar 1;3(1):29–48.

144. Neal DM, McKenzie PJ. Putting the pieces together: endometriosis blogs, cognitive authority, and collaborative information behavior. JMLA, BMLA. 2011 Apr 1;99(2):127–34.

145. Kim S. Content analysis of cancer blog posts. J Med Libr Assoc. 2009 Oct;97(4):260–6.

146. Ratliff C. Policing Miscarriage: Infertility Blogging, Rhetorical Enclaves, and the Case of House Bill 1677. Women's Studies Quarterly. 2009;37(1/2):125–45.

147. Bronstein J. Blogging Motivations for Latin American Bloggers: A Uses and Gratifications Approach [Internet]. Blogging in the Global Society: Cultural, Political and Geographical Aspects. IGI Global; 2012 [cited 2020 Apr 15]. p. 200–15. Available from: www.igi-global.com/chapter/blogging-global-society/58959

148. Krasnova H, Veltri NF, Eling N, Buxmann P. Why men and women continue to use social networking sites: The role of gender differences. The Journal of Strategic Information Systems. 2017 Dec 1;26(4):261–84.

149. Miller C. Blogging Infertility. The New Atlantis. 2008;2008(19):79–90.

150. Knoll M, Bronstein J. An examination of the information disclosure behavior of infertility bloggers. Aslib Journal of Information Management [Internet]. 2014 Jul 31 [cited 2019 Feb 22]; Available from: https://www.emeraldinsight.com/doi/abs/10.1108/AJIM-06-2013-0055

151. Wright KB, Bell SB, Wright KB, Bell SB. Health-related Support Groups on the Internet: Linking Empirical Findings to Social Support and Computer-mediated Communication Theory. J Health Psychol. 2003 Jan 1;8(1):39–54.

152. Kahlor L, Mackert M. Perceptions of infertility information and support sources among female patients who access the Internet. Fertility and Sterility. 2009 Jan 1;91(1):83–90.

153. Datainspektionen [The Swedish Data Protection Authority] [Internet]. [cited 2019 Aug 31]. Available from: /lagar--regler/dataskyddsforordningen/dataskyddsforordningens-beaktandesatser/

154. Riksdagsförvaltningen. Lag (1960:729) om upphovsrätt till litterära och konstnärliga verk Svensk författningssamling 1960:1960:729 t.o.m. SFS 2018:1099 - Riksdagen [Internet]. [cited 2020 Apr 15]. Available from: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1960729-om-upphovsratt-till-litterara-och_sfs-1960-729

155. Riksdagsförvaltningen. Brottsbalk (1962:700) Svensk författningssamling 1962:1962:700 t.o.m. SFS 2020:173 - Riksdagen [Internet]. [cited 2020 Apr 15]. Available from: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/brottsbalk-1962700_sfs-1962-700

156. Ethics [Internet]. [cited 2020 Apr 15]. Available from: https://aoir.org/ethics/

157. Husserl, E. The crisis of European science and transcendental phenomenography. Vol. 1970. Evanston: Nothwestern University Press; 405 p.

158. Dahlberg, K. Att undersöka hälsa och vårdande. Vol. 2014. Stockholm: Natur & Kultur; 250 p.

159. Carnevali, D. Handbok i omvårdnadsdiagnostik. Vol. 1996. Stockholm: Liber; 264 p.

160. Wellman B, Boase J, Chen W. The networked nature of community:online and offline. IT & SOCIETY. 2002;2002(Vol1, Issue 1):151–65.

161. Wajcman J. Pressed for Time: The Acceleration of Life in Digital Capitalism. University of Chicago Press; 2015. 228 p.

162. Hörberg U, Ozolins L, Ekebergh M. Intertwining caring science, caring practice and caring education from a lifeworld perspective—two contextual examples. International Journal of Qualitative Studies on Health and Well-being. 2011 Jan;6(4):10363.

163. Sapountzi-Krepia D. Some Thoughts on Nursing. Int J Caring Sci. 2013(6):127–33.

164. Caring - definition of caring by The Free Dictionary [Internet]. [cited 2019 Nov 11]. Available from: https://www.thefreedictionary.com/caring

165. Nursing Definitions [Internet]. ICN - International Council of Nurses. [cited 2020 Apr 17]. Available from: https://www.icn.ch/nursing-policy/nursing-definitions

166. Polit DF, Beck CT. Nursing research : generating and assessing evidence for nursing practice. Philadelphia: Wolters Kluwer; 2016.

167. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007 Dec 1;19(6):349–57.

168. Levin KA. Study design III: Cross-sectional studies. Evidence-Based Dentistry. 2006 Mar;7(1):24–5.

169. Den bästa textanalysen. Någonsin. På vilket språk som helst. [Internet]. Gavagai. [cited 2020 May 14]. Available from: https://www.gavagai.io/sv/

170. Espinoza F, Hamfors O, Karlgren J, Olsson F, Persson P, Hamberg L, et al. Analysis of Open Answers to Survey Questions Through Interactive Clustering and Theme Extraction. In: Proceedings of the 2018 Conference on Human Information Interaction&Retrieval [Internet]. New York, NY, USA: ACM; 2018 [cited 2018 Mar 15]. p. 317–20. (CHIIR '18). Available from: http://doi.acm.org/10.1145/3176349.3176892

171. Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. Qualitative Health Research. 2005 Nov;15(9):1277–88.

172. Sandelowski M. Whatever happened to qualitative description? Research in Nursing & Health. 2000;23(4):334–40.

173. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. African Journal of Emergency Medicine. 2017 Sep 1;7(3):93–9.

174. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006 Jan;3(2):77–101.

175. Thematic analysis - The University of Auckland [Internet]. [cited 2020 Nov 6]. Available from: https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html

176. Aita M, Richer M-C. Essentials of research ethics for healthcare professionals. Nursing & Health Sciences. 2005;7(2):119–25.

177. WMA - The World Medical Association-WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects [Internet]. [cited 2020 May 29]. Available from: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

178. The International Council of Nurses. The ICN code of ethics for nurses [Internet]. Available from: https://www.icn.ch/sites/default/files/inline-files/2012_ICN_Codeofethicsfornurses_%20eng.pdf

179. Burton D. Research Training for Social Scientists [Internet]. 6 Bonhill Street, London England EC2A 4PU United Kingdom: SAGE Publications Ltd; 2000 [cited 2020 May 29]. Available from: http://methods.sagepub.com/book/research-training-for-social-scientists

180. Ceballo R, Graham ET, Hart J. Silent and Infertile: An Intersectional Analysis of the Experiences of Socioeconomically Diverse African American Women With Infertility. Psychology of Women Quarterly. 2015 Dec 1;39(4):497–511.

181. Raque-Bogdan TL, Hoffman MA. The Relationship Among Infertility, Self-Compassion, and Well-Being for Women With Primary or Secondary Infertility. Psychology of Women Quarterly. 2015 Dec 1;39(4):484–96.

182. Stenström K. Involuntary childlessness online: Digital lifelines through blogs and Instagram. New Media & Society. 2020 Oct 26;1461444820968907.

183. Hoff HS, Crawford NM, Mersereau JE. Mental health disorders in infertile women: prevalence, perceived effect on fertility, and willingness for treatment for anxiety and depression. Fertility and Sterility. 2015 Sep 1;104(3):e357.

184. Chen T-H, Chang S-P, Tsai C-F, Juang K-D. Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic. Human Reproduction. 2004 Oct 1;19(10):2313–8.

185. Male Perspective on Male Factor [Internet]. [cited 2021 Feb 10]. Available from: http://familybuilding.resolve.org/site/PageServer?pagename=lrn_jfm_mpomf

186. Machin L. A hierarchy of needs? Embryo donation, in vitro fertilisation and the provision of infertility counselling. Patient Education and Counseling. 2011 Nov 1;85(2):264–8.

187. Schmidt L. High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Human Reproduction. 2003 Dec 1;18(12):2638–46.

188. WHO Regional Office Europe. Action plan for sexual and reproductive health: towards achieving the 2030 Agenda for Sustainable Development in Europe – leaving no one behind. Denmark; 2016 p. 26. Report No.: EUR/RC66/13.

189. Pannucci CJ, Wilkins EG. Identifying and Avoiding Bias in Research. Plast Reconstr Surg. 2010 Aug;126(2):619–25.

190. Prescott J, Gray NJ, Smith FJ, McDonagh JE. Blogging as a Viable Research Methodology for Young People With Arthritis: A Qualitative Study. Journal of Medical Internet Research. 2015 Mar 5;17(3):e61.

191. Weerkamp W, de Rijke M. Credibility-inspired ranking for blog post retrieval. Inf Retrieval. 2012 Jun 1;15(3):243–77.

192. Alessi EJ, Martin JI. Conducting an Internet-based Survey: Benefits, Pitfalls, and Lessons Learned. Social Work Research. 2010 Jun 1;34(2):122–8.

193. Creswell JW, Poth CN. Qualitative Inquiry and Research Design: Choosing Among Five Approaches. SAGE Publications; 2016. 489 p.

194. Lechuga VM. Exploring culture from a distance: the utility of telephone interviews in qualitative research. International Journal of Qualitative Studies in Education. 2012 May;25(3):251–68.

195. Cachia M, Millward L. The telephone medium and semi-structured interviews: a complementary fit. Qualitative Research in Organizations and Management: An International Journal. 2011 Jan 1;6(3):265–77.

196. Holloway I, Holloway Immy B concepts for qualitative research. A-Z of qualitative research in nursing and healthcare [Internet]. 2nd ed. Oxford : Wiley-Blackwell; 2008 [cited 2019 Oct 15]. Available from: https://trove.nla.gov.au/version/46244441

12 APPENDIX

Appendix I Questionnaire Study I

1. Frågor kring bakgrund:

Fråga 1, a-i, berör frågor kring ålder, civilstatus, utbildning m.m. som sammantaget beskriver din sociala bakgrund.

a) Ålder: ………… år

b) Kön:
   Sätt en ring kring siffran framför det alternativ som är korrekt

   1.   man
   2.   kvinna

c) Civilstånd:
   Sätt en ring kring siffran framför det alternativ som är korrekt samt skriv med siffror på den prickade linjen antal år

   1.   gift: antal år ……..
   2.   sammanboende: antal år ……..

d) Hade du barn före besök vid Sophiahemmets fertilitetsmottagning?:
   Sätt en ring kring siffran framför det alternativ som är korrekt samt skriv med siffror på den prickade linjen antal barn

   1.   nej
   2.   ja, i denna relation   antal ……..
   3.   ja, från tidigare relation   antal ……..

e) Vilken typ av bostad bor ni i?:
   Sätt en ring kring siffran framför det alternativ som är korrekt

   1.   lägenhet (borätt)
   2.   lägenhet (hyresrätt)
   3.   villa
   4.   annan boendeform, nämligen ……..

f) Vilken är din högsta utbildningsnivå?:
   Sätt en ring kring siffran framför det alternativ som är korrekt

   1.   nioårig grundskola
   2.   gymnasieutbildning
   3.   högskole-/universitetsutbildning

g) Vilket är ditt yrke eller huvudsakliga sysselsättning?:
   Ange så noga som möjligt, även eventuell yrkestitel

   ………………………………………………………………………………

h) Vilket är din frus/mans/partners yrke eller huvudsakliga sysselsättning?:
Ange så noga som möjligt, även eventuell yrkestitel

………………………………………………………………………………

i) Vad är ditt första språk?
Sätt en ring kring siffran framför det alternativ som är korrekt. Vid svar "annat" skriv vilket ditt första språk är på den prickade linjen

      1. Svenska
      2. annat …………………………

2. Frågor kring kommunikation:

Fråga 2, a-c, berör frågor som sammantaget beskriver vem du vänder dig till då du vill prata om barnlöshet.

a) Finner du det svårt att prata med din fru/man/partner om dina fertilitetsproblem?
Sätt en ring kring siffran framför det alternativ som stämmer bäst

      1. Ja, alltid
      2. Ja, ibland
      3. Nej, aldrig

Egna kommentarer: …………………………………………………………………….
…………………………………………………………………………………………….

b) Kan du prata med din fru/man/partner om…
Skriv med siffror på den prickade linjen det svarsalternativ (1-3) som stämmer bäst överens med följande påståenden:

Svarsalternativ: (1) ofta
                    (2) ibland

                    (3) aldrig

    1. att du inte kan få barn? …….
    2. orsaken till varför du är barnlös? …….
    3. dina provresultat och undersökningsresultat? …….
    4. vilken typ av behandling du prövar? …….
    5. dina känslor kring barnlöshet? …….
    6. hur utredning och behandling påverkar dina känslor? …….
    7. vad du i framtiden vill göra för att få ett barn? …….

Egna kommentarer: …………………………………………………………………………

…………………………………………………………………………………………….

c) Pratar du med andra personer om …

Skriv med siffror på den prickade linjen det svarsalternativ (1-3) som stämmer bäst överens med följande påståenden:

Svarsalternativ: (1) aldrig med utomstående personer
                          (2) bara med närstående personer
                          (3) med alla jag känner

  1. att du inte kan få barn?   ……..
  2. orsaken till varför du är barnlös?   ……..
  3. dina provresultat och undersökningar?   ……..
  4. vilken typ av behandling du prövar?   ……..
  5. dina känslor kring barnlöshet?   ……..
  6. hur utredning och behandling påverkar dina känslor?   ……..

Egna kommentarer: ……………………………………………………………………………

………

3. Frågor kring hantering av problem:

Fråga 3, a-d, berör frågor som sammantaget beskriver hur du hanterar situationen kring barnlöshet.

Människor hanterar problem med fertilitet på olika sätt. Hur hanterar du detta?
Skriv med siffror på den prickade linjen det svarsalternativ (1-4) som stämmer bäst överens med följande påståenden:

a) Jag …

Svarsalternativ: (1) har inte gjort det
                          (2) gör det ibland
                          (3) gör det ofta
                          (4) gör det alltid

  1. undviker att vara med kvinnor som är gravida eller med kvinnor som har barn   …….
  2. går då människor börjar prata om graviditet eller barn   …….
  3. försöker att hålla mina känslor för mig själv   …….
  4. försöker skingra mina tankar genom att arbeta eller utöva någon annan aktivitet mera   …….

Egna kommentarer: ……………………………………………………………………………….

………

b) Jag …
Skriv med siffror på den prickade linjen det svarsalternativ (1-4) som stämmer bäst överens med följande påståenden:

Svarsalternativ: 1) har inte gjort det
                          (2) gör det ibland
                          (3) gör det ofta
                          (4) gör det alltid

  1. låter mina känslor komma ut på något sätt   ……..
  2. accepterar förståelse och sympati från andra   ……..
  3. frågar om råd från någon annan som inte heller har/kan få barn   ……..
  4. frågar en släkting eller en nära vän om råd   ……..
  5. läser eller tittar på tv om barnlöshet   ……..
  6. pratar med någon om mina känslor kring barnlöshet   ……..

7. pratar med någon om hur prover och undersökningar påverkar mig känslomässigt   ……..

c) Jag …
   Skriv med siffror på den prickade linjen det svarsalternativ (1-4) som stämmer bäst
   överens med följande påståenden:

Svarsalternativ: 1) har inte gjort det
                            (2) gör det ibland
                            (3) gör det ofta
                            (4) gör det alltid

1. hoppas på att ett mirakel ska ske   ……..
2. känner att det enda jag kan göra är att sitta och vänta   ……..
3. har drömmar och fantasier   ……..

Egna kommentarer: ……………………………………………………………………
……………………………………………………………………………………………….

d) Jag …

   Skriv med siffror på den prickade linjen det svarsalternativ (1-4) som stämmer bäst
   överens med följande påståenden:

Svarsalternativ: (1) har inte gjort det

                            (2) gör det ibland

                            (3) gör det ofta

                            (4) gör det alltid

1. har vuxit som person på ett positivt sätt   ……..
2. tänker på våra svårigheter i att få barn på ett positivt sätt   ……..
3. upplever mitt äktenskap/partnerskap som mer värdefullt nu   ……..
4. har funnit andra värden i livet   ……..
5. tror att det finns en mening med våra svårigheter i att få barn ……..

Egna kommentarer: ……………………………………………………………………
……………………………………………………………………………………………….

Appendix II   Questionnaire Study III

1. Genom vilken blogg/social media om ofrivillig barnlöshet besvarar du enkäten?
2. Hur många år har du läst och/eller deltagit i bloggar/Facebook grupper/diskussionsforum om ofrivillig barnlöshet?
3. I genomsnitt hur ofta tar du del av bloggar/Facebook-grupper/diskussionsforum om ofrivillig barnlöshet?
4. I genomsnitt, hur mycket tid per vecka lägger du på bloggar/Facebook-grupper/diskussionsforum om ofrivillig barnlöshet? (Uppskatta antal timmar per vecka)
5. I genomsnitt, hur många gånger i veckan gör du inlägg på bloggar/Facebook-grupper/diskussionsforum som handlar om ofrivillig barnlöshet?
6. Vilken funktion fyller bloggar/Facebook-grupper/diskussionsforum om ofrivillig barnlöshet för dig?
7. Vilka i din omgivning vet om att du läser och skriver på bloggar/Facebook-grupper/diskussionsforum om ofrivillig barnlöshet?
8. Skriver du under pseudonym (påhittat namn)?
9. Hur uppfattar du innehållet i den här bloggen/Facebook-gruppen/diskussionsforum?
10. Vilka upplevelser har du av deltagandet i bloggar/Facebook-grupper/diskussionsforum om ofrivillig barnlöshet?
11. Hur många år har du försökt att få barn?
12. Har du, eller du tillsammans med din partner, genomgått fertilitetsbehandling?
13. Har du fått barn genom fertilitetsbehandling?
14. Har ofrivillig barnlöshet påverkat ditt liv?
15. Beskriv på vilket sätt ofrivillig barnlöshet kan ha påverkat ditt liv?
16. Kön
17. Vilken slags relation lever du i?
18. Vilket är ditt födelseland?
19. Vilken är din högsta utbildningsnivå?
20. Vilken är din huvudsakliga sysselsättning?
21. Har du några kommentarer till enkäten får du gärna skriva dem här.
22. Skulle du vara intresserad av att bli intervjuad om ditt användande av Sociala medier vid ofrivillig barnlöshet. I så fall vänligen fyll i din e-post adress på raden här under. Det är enbart Taina Sormunen som kommer att se din kontakt uppgift och som kommer kontakta dig för intervju.