The role of online support communities for people experiencing infertility

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Abstract

People faced with infertility will often experience a strong need for psychosocial support and guidance; a need which is not always adequately met by existing sources of support. The growth in access to the Internet over recent years has opened up new opportunities for people affected by infertility to seek support, advice, and information through the means of an online support community. These online communities can potentially play an important role in addressing the support and information needs of people experiencing infertility; by improving their ability to access peer and professional support. Additionally, online communities may offer a more welcoming and comfortable environment in which these individual's can share their infertility experiences and concerns. This thesis adopted a triangulated approach to research the potential role of online communities in helping people cope with the challenges of infertility. An initial qualitative study was conducted with 95 people accessing online infertility support communities to explore their motives, perceptions, and experiences of online support seeking. Responses revealed that participants especially valued the unique characteristics of computer-mediated communication (e.g. anonymity, asynchrony etc), which appeared to facilitate their ability to access and seek support. In addition, there were a number of psychosocial benefits associated with the online support communities, which appeared to aid the participant's ability to cope with their infertility experiences. Key benefits included reduced feelings of isolation and loneliness, improvements in marital relationships and access to a unique and valuable source of emotional and informational support.

This study was followed by a content analysis of the therapeutic and self-help mechanisms used in 3,500 messages posted to a popular UK online infertility support community. Results from this stage suggested that the key functions of the online support community were to exchange support and empathy and provide a forum for individuals to share their personal experiences related to infertility. Results also revealed that on the whole communication within the online support community was extremely positive and constructive, offering group members the opportunity to utilise many of the therapeutic and self-help mechanisms that are known to be beneficial to people using face-to-face support networks.

The issues and questions raised in these initial studies were further examined in a larger scale survey with 295 users of online infertility support communities. This study quantitatively examined the use and experience of online infertility support communities and how this relates to psychosocial well-being. Results revealed that the majority of participants considered there to be a range of important benefits from accessing online communities. However the study also identified a number of potential disadvantages to accessing online infertility support communities, which appeared to have an impact on the experiences and psychosocial well-being of infertile individuals. The theoretical, methodological and practical implications of these findings are discussed.

List of published papers and conference presentations

Chapter Five

Journal Papers:

Malik, S., & Coulson, N.S. (2008). Computer-mediated infertility support groups: An exploratory study of online experiences. Patient Education and Counseling. 73(1), 105-113.

Conference Presentations:

Malik, S. & Coulson, N.S. (2008). Participation in online infertility support groups: An exploratory qualitative study. Paper presented at: XXIX International Congress of Psychology, Berlin, Germany.

Malik, S. & Coulson, N.S. (2008). Electronic support seeking among individuals affected by infertility. Invited symposium paper presented at: 28th Society for Reproductive and Infant Psychology Annual Conference, London, United Kingdom.

Chapter Six

Journal Papers:

Malik, S., & Coulson, N.S. (In Press). Coping with infertility online: An examination of self-help mechanisms in an online infertility support group. Patient Education and Counseling.

Conference Presentations:

Malik, S. & Coulson, N.S. (2009). An exploration of therapeutic processes in an online self-help community for infertility. Paper presented at: 12th

BPS Division of Health Psychology Annual Conference, as part of the Symposium on Online Communities and Health, Aston, United Kingdom.

Malik, S. & Coulson, N.S. (2009). Self-help processes in online support communities: An analysis of infertility bulletin boards. Paper presented at: 11th European Congress of Psychology, Oslo, Norway.

Chapter Seven

Journal Papers:

Malik, S., & Coulson, N.S. A comparison of lurkers and posters within infertility online support groups. Submitted to Computer, Informatics, Nursing. (under review)

Malik, S., & Coulson, N.S. (In Press). "They all supported me but I felt like I suddenly didn't belong anymore": An exploration of perceived disadvantages to online support seeking. Journal of Psychosomatic Obstetrics and Gynecology.

Malik, S., & Coulson, N.S. (2009). What attracts patients experiencing infertility to an online support community? Journal of Fertility Counselling, 16(3), 23-32.

Conference Presentations:

Malik, S. & Coulson, N.S. (2010). An exploratory study of perceived disadvantages to accessing online support communities. Paper presented at: 1st CyberPsychology and Computer Psychology Conference, University of Bolton, United Kingdom.

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Glossary of terms

Administrator:

A person who manages the technical aspects of running a website or online community. Administrators are usually also responsible for managing the rules and regulations of the site and appointing people as moderators.

Asynchronous online communication:

Online communication that occurs without time constraints; messages and information can be posted, read and replied to at any time and the sender and receiver of information do not have to be online at the same time. Asynchronous online communication is typically facilitated through bulletin boards, e-mails, and mailing lists.

Bulletin board (also known as a discussion forum/message board):

An electronic version of a noticeboard; most bulletin boards serve specific interest groups. They allow users to read and respond to messages left by others and to leave their own messages as well.

Chat room:

A location on the Internet where users can discuss topics of common interest by sending typed messages back and forth. These discussions take place in 'real time' and messages appear to other users as soon as they are typed.

Discussions threads:

A discussion thread is an electronic discussion (via e-mail, bulletin boards, news groups, Internet forums or e-mail lists) in which replies to a message are displayed directly under it, instead of messages being arranged in chronological or alphabetical order.

Listserv:

A brand of email list management software, which is commonly used to run a wide variety of different mailing lists.

Lurkers:

People who access online communities to read messages posted by others, without posting or replying to any message themselves.

Mailing list:

An automatic email system that allows members to carry on a discussion on a particular topic. Participants subscribe to a list and automatically receive copies of messages sent by other members, and can e-mail their own comments.

Moderator:

A person who is granted access to the posts and threads of all members in an online community in order to manage the day-to-day running of the community. Moderators are typically responsible for keeping the community clean from spam, moderating discussions and responding to the questions, comments or concerns of user's.

Online community:

A social network that is created and supported by electronic media.

Peer moderated online support community:

An online support community in which discussions are moderated and managed by one or more members of the online community i.e. people who are experiencing the same problems as the group.

Posters:

People who actively contribute to an online community by posting or responding to messages.

Postings:

Messages submitted to online bulletin boards by users of an online community. They typically contain the user's display name and the date and time the message was submitted. Postings are generally displayed in discussion threads.

Private messaging:

A private message, or PM for short, is an asynchronous message sent in private from one member of an online community to one or more other members.

Professionally led online support community:

An online support community that is moderated and managed by a healthcare professional e.g. a nurse, psychologist, GP or consultant.

Synchronous online communication:

Online communication that takes place in real time. Synchronous online communication is typically facilitated through chat rooms, instant messaging services and audio or visual conferencing software.

1   Chapter One: Introduction

This thesis is a triangulated project exploring the use and experience of online support communities among people affected by infertility. It comes at a time when the Internet is playing an increasingly important role in the personal and work lives of people across the globe. The growth in access to the Internet over recent years has had a profound effect on the ways in which people communicate and exchange knowledge. The ramifications of this Internet revolution are particularly evident in the context of healthcare, which has seen an unprecedented number of people turning to the Internet for information, advice and psychosocial support concerning a range of issues associated with health and well-being. This has also resulted in a new social phenomena, that of health-related online support communities. These online support communities are unique in that they allow people to engage in either synchronous or asynchronous written communication with other patients from all over the world and access a dynamic source of peer and/or professional support, advice and information at virtually anytime of the day.

A review of infertility literature suggests that people faced with infertility will often experience a strong need for psychosocial support and guidance; a need which is not always adequately met by existing sources of support. Anecdotal evidence indicates that online support communities might present a novel and beneficial alternative medium through which these individuals could potentially fulfil their support needs. However, despite the growing popularity of online infertility support communities, the literature base on this novel phenomenon remains scant. Consequently, this thesis was motivated first and foremost by a desire to understand the role of

online support communities in the lives of people affected by infertility and redress some of the gaps in our understanding of this new source of support and communication. To this end an exploratory, triangulated approach was taken to this research thesis. It was anticipated that this would allow for a comprehensive picture of the use and experience of online support communities among individuals coping with infertility issues.

1.1   Structure of this thesis

The main body of the thesis is presented in seven chapters. The following two chapters present a detailed overview of the literature pertaining to the psychosocial aspects of infertility and the phenomenon of online support communities. These chapters together provide the background and context for the thesis. Chapter two begins by defining infertility and describing its prevalence. This is followed by a brief overview of treatment options for infertility. The chapter then moves onto discuss the psychosocial consequences of infertility and explore possible factors that might influence psychosocial distress. This section highlights the important role that social support can play in helping people cope with infertility. It also identifies and discusses current sources of support that are available to people affected by infertility. Chapter three extends this discussion by introducing the reader to the phenomenon of online support communities and exploring their potential advantages and disadvantages as an alternative source of support. The chapter explains current theoretical perspectives of computer-mediated communication and online support seeking. It also provides a review of current research in the area, with a particular focus on examining what is known about who accesses health-related online support communities, how people communicate within online communities and the impact of usage on psychosocial well-being. The chapter concludes by

highlighting the gaps in our understanding of this novel phenomenon and identifying how this thesis aims to redress some of these gaps.

Chapter four focuses on discussing some of the methodological issues associated with the study. Firstly, it highlights the philosophical underpinnings of the research. Secondly, it examines the issues and challenges involved in researching online support communities using online methodologies. Finally, the chapter presents a summary and rationale of the methodological choices made in the empirical studies undertaken.

The next three chapters describe the empirical studies undertaken as part of this doctoral project. Each chapter describes the rationale behind the study, its aims and objectives and the methodology employed. This is followed by a report and discussion of the findings. To sum up, Chapter five presents qualitative data concerning the motives, perceptions and experiences of people accessing online infertility support communities. Chapter six analyses communication in an online infertility support community to examine the self-help mechanisms used by people who participate in these communities. Chapter seven quantifies the main advantages and disadvantages to online support seeking and explores associations between the use and experience of online support communities and psychosocial well-being. The final chapter draws together findings from each stage of the study and discusses these in relation to the research questions and existing literature (Chapter eight). The chapter concludes with a review of the methodological issues encountered and recommendations for future research and practice.

2 Chapter Two: Infertility: Causes, consequences & coping

CHAPTER SUMMARY

This chapter focuses on describing and discussing the impact that infertility can have on the lives of both the individual and the couple. It presents a detailed overview of literature regarding the psychosocial aspects of infertility and identifies the various factors that might influence the extent to which people are negatively affected by infertility. In particular, it highlights the important role that the availability of social support and various coping strategies can play in helping people adjust to different stages of their infertility journey. The review examines current sources of support available to people affected by infertility and provides a basis upon which to consider the possible role of the Internet and online communities in helping meet the support needs of these individuals.

2.1 Infertility: facts and figures

According to the National Institute of Clinical Excellence (NICE) infertility is defined as the inability to conceive after two years of regular unprotected sexual intercourse. Couples can experience either primary or secondary infertility; primary infertility is the term used to describe a couple who have never been able to conceive. While, secondary infertility refers to those couples who are unable to conceive after already having had one or more successful pregnancies. Estimates on the prevalence of infertility suggest that around 72.4 million women worldwide are currently affected by some form of infertility problem, with 40.5 million of these women seeking medical treatment for infertility (Boivin, Bunting, Collins & Nygren, 2007). Within the UK, approximately 3.5 million people experience difficulties achieving a pregnancy, which equates to about one in six or one in seven of all couples (Human Fertilisation & Embryology Authority, 2010). Infertility concerns are also thought to be one of the most common reasons for women between the ages of 20 and 45 to consult a General Practitioner (Human Fertilisation & Embryology Authority, 2007).

Infertility is a complex and sometimes ambiguous condition with numerous potential causes. In the UK, statistics from the Human Fertilisation and Embryology Authority (2007) reveal that infertility affects both men and women equally, with 32% of all cases attributed to problems affecting the male partner's fertility and approximately 32.5% of all cases associated with the female partner's fertility. However, in many cases the cause of infertility may be linked to a combination of male and female factors (17%) or remain unexplained (18.7%). Common factors affecting female infertility include blocked or damaged fallopian tubes, ovulatory problems, problems with the uterus or other underlying conditions such as Endometriosis and

Polycystic Ovary Syndrome (PCOS). There is also evidence to show that women become less fertile as they get older. Research suggests that women experience a sharp decline in fertility in their late thirties, for example figures from the UK reveal that only 77% of women aged 38 years and over will conceive within three years of trying compared to 94% of women aged 35 years (Human Fertilisation and Embryology Authority, 2007). As a growing number of couples delay childbearing until later in life, age is likely to become an increasingly salient issue affecting female infertility (Heffner, 2004). Its affects on male fertility on the other hand are less clearly understood. Factors likely to affect male fertility include damage to the testicles, ejaculation disorders, low sperm count, low sperm motility or abnormal sperm.

There are also a range of additional factors that can affect a couple's chances of conceiving. These can include being under or over weight, having had previous surgery or infections including sexually transmitted infections (STI's) such as Chlamydia, and other health problems like diabetes, epilepsy, kidney problems, high blood pressure and thyroid disorders. In addition, there may be occupational and environmental risk factors for infertility, for example jobs in which an individual is brought into contact with certain chemicals or radiation can increase the chances of fertility problems.

Alongside biological and environmental factors a number of authors have also examined the role of psychosocial factors in the aetiology of infertility. The majority of work in this area has focused on the concept of stress as a potential cause of infertility and a factor influencing success with assisted reproduction (Campagne, 2006; Cooper, Gerber, McGettrick, & Johnson,

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2007; Domar, 1997; Ebbesen et al., 2009; Sanders & Bruce, 1997; Wasser, 1994). Broadly speaking the term stress refers to the psychological, physiological and behavioural responses an individual displays when they perceive an imbalance between the demands placed upon themselves and their ability to cope with these demands (Lazarus & Folkman, 1984). Within the context of reproductive health there are a number of mechanisms through which stress could potentially influence an individual's fertility. For example, high levels of psychological stress and anxiety are thought to lead to hormonal abnormalities, which may affect female ovulation as well as sperm quality and production (Clarke, Klock, Geoghegan, & Travasso, 1999; Domar, 1997; Harrison, Callan, & Hennessey, 1987). Additionally, behavioural responses to stress such as alcohol consumption, drug addiction and sexual problems may indirectly lead to difficulties conceiving (Anderheim, Holter, Bergh, & Moller, 2005). Furthermore, some studies have shown an association between stress reduction interventions like anxiety management or relaxation training programmes and pregnancy rates among patients undergoing assisted reproduction (Domar, Seibel, & Benson, 1990; Domar et al., 2000). However, the evidence in this area is inconclusive with other studies finding no relationship between stress or anxiety levels and treatment outcomes (Anderheim et al., 2005; Harlow, Fahy, Talbot, Wardle, & Hull, 1996; Homan, Davies, & Norman, 2007; Lintsen et al., 2009; Milad, Klock, Moses & Chatterton, 1998). Thus, the role of stress in the aetiology of infertility remains controversial.

2.2 Treatment options available

While the overall incidence of infertility is not thought to have increased significantly, in recent years the developed world has seen a considerable

rise in the number of couples seeking medical help for infertility (National Collaborating Centre for Women's & Children's Health, 2004). One factor accounting for this rise is the development and availability of new and more efficient reproductive technologies and drugs, which allow for better identification and treatment of various fertility problems. Although many couples experiencing difficulties conceiving will become pregnant naturally given time, a significant number may require medical intervention. Estimates suggest that around 56% of infertile couples worldwide are seeking medical care for infertility (Boivin et al., 2007). There are now a range of treatment options available to help these individuals solve their fertility problems. The exact nature of the treatments offered to a couple will depend on the cause of their infertility. This section will provide a brief overview of some of the main reproductive treatments that may be offered to individuals seeking medical help for infertility.

2.2.1 Fertility drugs

Fertility drugs are perhaps one of the cheapest and least invasive forms of infertility treatment available. For many couples, these drugs are prescribed as the first step in treatment. Although couples may become pregnant using fertility drugs alone, they are more often used in conjunction with other treatments like in vitro fertilisation (IVF) or intrauterine insemination (IUI). Commonly prescribed fertility drugs include Ovulation-inducing drugs (e.g. Clomid), Pituitary stimulators, and Ovary-stimulating hormones. These drugs work in the same way as the body's own hormones to trigger egg production. They are therefore particularly effective in treating cases of female infertility resulting from ovulation problems. However, fertility drugs that stimulate ovulation can occasionally be used to treat cases of male infertility or unexplained infertility.

While, fertility drugs are less invasive than some assisted reproductive treatments, they can be associated with a number of unpleasant side effects including hot flushes, mood swings, adverse skin reactions, nausea, heavy periods and headaches. Furthermore some drugs will need to be injected directly into the body, which may be physically and emotionally draining for the woman.

2.2.2 Surgery

In some instances, surgical options could also be considered to help treat fertility problems. For example, keyhole surgery is often used to unblock fallopian tubes that have become blocked as a result of inflammation or scarring. In addition, problems like fibroids, endometrial scarring and ovarian cysts can be removed surgically, which may increase a woman's chances of conception. For men who have had a vasectomy or failed vasectomy reversal, surgical procedures are also an option to retrieve sperm, which can later be used in treatments like In vitro Fertilisation (IVF) or Intrauterine Insemination (IUI).

2.2.3 Intrauterine Insemination (IUI)

Intrauterine Insemination (IUI) is an assisted reproduction technique used to increase the chances of conception. The procedure involves using a catheter (a thin fine tube) to insert sperm directly into the womb at the time of ovulation. It is often used as a first line of treatment for unexplained infertility and can also benefit couples where the male partner has a low sperm count or low sperm motility. The estimated success rate per cycle of treatment is around 15%. Most couples are usually advised to try 3-6 cycles of IUI, after which a doctor might recommend another treatment such as IVF.

When compared with other techniques like IVF or GIFT, IUI is a much simpler and less time consuming procedure. It is also relatively pain free, however some women may experience mild stomach cramping for a period after the catheter is inserted. There may also be some anxiety involved for the male partner, who is required to produce a sperm sample on demand within a hospital setting (Malik & Coulson, 2008).

2.2.4 In vitro fertilisation (IVF)

In vitro fertilisation (IVF) is a technique where eggs are removed from the female partner's ovaries and fertilised in a laboratory dish with sperm from the male partner. Once fertilised the resulting embryos are placed back into the womb using a catheter. IVF can involve a number of complicated and invasive procedures, for instance at the start of treatment women are given drugs to suppress hormones release by the pituary gland and stimulate the ovaries to produce more than one egg. After this regular blood tests and vaginal ultrasounds are carried out to monitor the developing eggs. The eggs are then collected by ultrasound or laparoscopy. At around the same time the male partner will be required to produce a fresh sperm sample for use in fertilisation.

In vitro fertilisation (IVF) has become one of the most popular assisted reproduction techniques available, with approximately 1 in every 80 babies in the UK born as a result of IVF treatment (Human Fertilisation & Embryology Authority, 2007). However the success rate of an IVF treatment cycle is relatively low, for example statistics from the UK show that around 30.4% of all IVF treatment cycles resulted in pregnancy in 2007 (Human Fertilisation & Embryology Authority, 2010). As a result, many couples will endure repeated attempts at treatment. There is also a

financial burden associated with IVF; a single IVF cycle can cost between £4,000 and £8,000. Currently the National Health Service (NHS) will typically offer couples at least one free cycle of IVF. However eligibility for NHS funding can be influenced by a number of factors including age, number of children and cause of infertility. A large number of couples will therefore seek private treatment (Human Fertilisation & Embryology Authority, 2007).

2.2.5 Gamete intrafollopian transfer (GIFT)

Gamete intrafollopian transfer (GIFT) is another potential treatment for infertility, which is particularly beneficial in cases of unexplained infertility or where the male partner has a low sperm count. Initially eggs and sperm are collected from the man and woman using similar procedures to IVF. The healthiest of which are then selected and surgically inserted into the fallopian tubes so that fertilisation can take place naturally inside the body. Estimates suggest that around 25-35% of women will become pregnant with GIFT per treatment cycle (Human Fertilisation & Embryology Authority, 2007). Like IVF, undergoing a cycle of GIFT can involve extremely invasive and uncomfortable procedures. Furthermore, since GIFT also includes minor surgical procedures it is often associated with greater discomfort and a longer recovery time than other assisted reproduction techniques.

2.2.6 Intracytoplasmic sperm injection (ICSI)

Another recent advance in assisted reproduction is the Intracytoplasmic sperm injection (ICSI) procedure. As with other techniques the initial process of ICSI involves taking sperm and eggs from the infertile couple using similar procedures to IVF. Once these samples have been collected a single sperm is injected directly into the centre of an egg, which is then transplanted into the uterus. The technique is mainly used to treat cases of male infertility, where there are problems with sperm count and motility or a high level of anti-sperm antibodies in the semen. However it might also be effective for couples who have previously tried other treatments like ovarian stimulation or IVF but failed to get pregnant because only a few eggs were successfully fertilised.

2.2.7 Surrogacy

Some individuals may consider surrogacy as a means of achieving a birth child of their own. Surrogacy is when another woman is commissioned to carry and give birth to a couple's embryo for them. Couples can have a baby with a surrogate using either their own or donor eggs or sperm. Surrogacy might be the only option for women with a serious medical condition who are unable to give birth to a child themselves or couples that have experienced repeated IVF failure. However, the decision to introduce a surrogate can be a difficult one, raising a number of complex moral, legal and ethical dilemmas. Couples considering a surrogate will therefore require a great deal of support and advice to help them reach a decision.

2.2.8 Donor eggs, sperm or embryos

In some cases couples may require donated eggs, sperm or embryos for fertility treatments. Approximately 1,000 babies in the UK alone are born

using donated eggs or sperm every year (Human Fertilisation & Embryology Authority, 2010). Clinics recommend this option if the chances of success using the couples own eggs or sperm is relatively low. The use of a donor is also an option for single women wishing to become pregnant without a male partner. As with surrogacy, the decision to use a donor is complex and it is recommended that the option is talked through with a counsellor or other individuals who have used a donor before decision making.

2.3 Psychosocial consequences of infertility

Although advances in reproductive technologies offer hope to many individuals facing infertility, estimates suggest that around 4.2% of women wishing to conceive between the ages of 40 and 55 years remain childless (Oakley Doyle, & Maconochie, 2008). In a review of longitudinal studies examining women's emotional adjustment to IVF, Verhaak et al. (2007) conclude that while the majority of women adjust well to unsuccessful treatment, a considerable number may develop clinically significant emotional problems as a result. Furthermore, these fertility treatments are often accompanied by a range of practical, emotional and physical strains for both individuals involved. For example many fertility treatments involve uncomfortable and invasive procedures such as daily injections, blood/sperm samples and daily scans (Eugster & Vingerhoets, 1999; Huisman, Raymakers & Hoomans, 2009). Additionally, couples pursuing assisted reproduction may be faced with a range of difficult decisions, including ethical and moral dilemmas about when to terminate treatment or whether to introduce a third party such as a donor or surrogate (Cousineau & Domar, 2007; Peddie, van Teijlingen, & Bhattacharya, 2005; Robinson & Stewart, 1996).

These activities coupled with uncertainty regarding the outcome of treatment and the large investment of time, energy, hope and money that is required to pursue a course of fertility treatment can have a profound impact on the daily life of a couple. For some individuals the pursuit of fertility treatment may become the sole focus of their life, leading to the postponement of other life goals such as professional or social pursuits (Cousineau & Domar, 2007). Consequently, the diagnosis and treatment of infertility is frequently described as one of the greatest sources of life stress, comparable to other major life stressors such as divorce, bereavement and chronic illness (Leiblum & Greenfield, 1997). In one study, Domar, Zuttermesiter, & Friedman (1993) compared the psychological symptoms of a sample of 149 infertile women with patients suffering from other medical conditions like chronic pain, cancer, hypertension, cardiac rehabilitation and patients with HIV positive status. Results revealed that the anxiety and depression scores of the infertile women were statistically similar to that of the other groups. This suggests that the psychological symptoms associated with infertility are similar to those associated with other chronic medical problems. The emergence of new reproductive technologies has thus transformed the experience of involuntary childlessness, offering both new opportunities and new sources of stress to the infertile couple (Sandelowski, 1999).

Research exploring the psychological impact of infertility has consistently reported that individuals with a diagnosis of infertility typically experience a range of negative psychosocial responses, which may include a sense of loss and bereavement (Lechner, Bolman & van Dalen, 2007) and feelings of anxiety, depression, anger, guilt, helplessness, jealousy and social isolation (Brucker & McKenry, 2005; Dhillon, Cumming & Cumming, 2000;

Greil, 1997; Valentine, 1986). Furthermore, since infertility is a stressor that typically occurs within the context of a couple relationship it can have a considerable impact on the individual well-being of each partner as well as cause significant strains to interpersonal relationships.

However, evidence about the long-term effects of infertility and its treatment on marital relationships is inconclusive. Although some research suggests that infertility can cause serious relationship problems and have long-lasting negative effects on marital satisfaction (Benazon, Wright & Sabourin, 1992; Bengel, Carl, Mild, & Strauss, 2000; Daniluk & Tench, 2007), other studies have shown that in some cases the experience of infertility can in fact bring couples closer together and strengthen their relationship (Baram, Tourtelot, Muechler, & Huang, 1988; Hammarberg, Astbury, & Baker, 2001; Hjelmstedt et al., 1999; Leiblum, 1997; Schmidt, Tjornhpj-Thomse, Boivin, & Nyboe Anderson, 2005). Conversely, several studies report no long-term effects on marital relationships (Holter, Anderheim, Bergh, & Moller, 2006; Sydsjo, Ekholm, Wadsby, Kjellberg, & Sydsjo 2005). Similarly the degree to which individuals experience some of the negative psychological effects of infertility varies considerably in the literature. Consequently, it appears that the psychosocial consequences of infertility for both the individual and couple as a unit are complex.

The remainder of this chapter will therefore focus on examining some of the potential factors that might influence emotional, psychological and marital reactions to infertility. In particular attention will focus on the role of gender differences, causes of infertility, stages of investigation and treatment, coping strategies, social support and stigma.

2.3.1 Factors influencing psychosocial reactions and adjustment

2.3.1.1 Gender

It is frequently reported that marked gender differences may exist in the way that men and women react to the experience of infertility. There is a large body of literature to suggest that infertility evokes considerably more distress in women than men. Men frequently demonstrate lower scores on various indices of emotional disturbance (Beutel et al., 1999; Dhillon et al., 2000; Karlidere et al., 2007; Lund, Sejbaek, Christensen, & Schmidt, 2009) and report being merely 'disappointed' by infertility while women are 'devastated' (Greil, Leitko, & Porter, 1988, p180). Furthermore, it has been observed that women appear to be more committed to the pursuit of medical treatment for infertility (Daniluk, 1997) and experience greater distress following treatment failure compared to men (Glover, McLellan, & Weaver, 2009; Newton & Houle 1993; Verhaak et al., 2005).

In one early study examining psychosocial adjustment to infertility among a cross-sectional sample of 330 couples, Beaurepaire, Jones, Thiering, Saunders, & Tennant (1994) found that female partners generally exhibited greater anxiety and depression than male partners. Similarly, Lee & Sun (2000) observe that husbands in a sample of 59 infertile Chinese couples were less distressed than their wives and expressed higher self-esteem and marital and sexual satisfaction when compared to their wives. Such findings have also been replicated in longitudinal studies of emotional adjustment to infertility, for instance Anderson, Sharpe, Rattray, & Irvine (2003) prospectively followed a cohort of infertile couples referred to a specialist infertility clinic over a 6-month period. Results from the study revealed that women experienced significantly greater infertility-related

concerns particularly regarding self-esteem, avoidance of friends and life-satisfaction. Furthermore women were more likely to report clinically significant levels of anxiety compared to men. These findings suggest that the psychological sequelae of infertility is greatly affected by gender. This is also reflected in the reasons why couples choose to discontinue medical treatment for infertility; with women being more likely to cite problems coping with treatment stress and failure, while men are more likely to cite practical reasons such as a depletion of financial resources (Akyuz & Sever, 2009).

One explanation for these gender differences could lie in the procedures associated with the medical testing and treatment of infertility. As regardless of which partner is biologically responsible for the fertility problem, testing and treatment for infertility typically involves more uncomfortable and invasive procedures for women compared to men (Daniluk, 1997; Slepickova, 2009). Infertility is therefore likely to result in greater disruption to the daily life of the female partner, which may in turn lead to women responding more intensely to the unfulfilled desire for a child than men (Jordon & Revenson, 1999).

Another important factor to consider is the social construction of parenthood. Traditionally, having children is emphasised as the primary social role for a woman and seen as an integral part of her gender role identity (Daniluk, 1997). Conversely, for men fatherhood is often perceived as an important but secondary role to other life achievements such as career success (Daniluk, 1997). When faced with infertility women often find themselves questioning their identity as a woman (Bergart, 2000; Jordan & Revenson, 1999; Lee, Sun, & Chao, 2001). There is also a sense

of isolation from the 'fertile world', particularly friends and family who have children (Allan, 2007; Cousineau & Domar, 2007). Since motherhood is typically viewed as a societal norm, the inability to conceive can carry a hidden stigma for many women (Glover, McLellan, & Weaver, 2009; Slepickova, 2006; Whiteford & Gonzalez, 1995). Consequently, in addition to the stress of infertility treatment women may perceive more explicit social pressures to parent a child than their partner. Indeed a recent study exploring gender role identity and psychological distress among infertile women revealed that those women who perceived more societal pressure for motherhood and endorsed negatively valued gender role traits demonstrated higher levels of infertility-related stress and psychological distress (Miles, Keitel, Jackson, Harris, & Licciardi, 2009). This implies that personal gender-role identities will have a greater impact on psychological distress than gender per se.

Some authors also propose that the observed gender differences may be overstated due to biases associated with infertility research (Greil, 1997; Jordon & Revenson, 1999). For example, past studies in the area have been based on small self-selected samples, in which men are typically underrepresented due to their reluctance to volunteer for research studies in comparison to women (Band, Edelmann, Avery, & Brinsden, 1998; Greil, 1997; Lloyd, 1996; Wright et al., 1991). It has also been argued that researchers have a tendency to frame their questions around women's experiences of infertility, for instance the standardised measures used in many infertility studies are thought to be more sensitive to the ways in which women express distress than men (Dhillon et al., 2000; Jordan & Revenson. 1999). This arises predominantly from the fact that more is known about the experiences of infertile women compared to infertile men. Men are more likely to feel uncomfortable discussing their infertility and

communicating their anxieties to strangers than women (Hjellmstedt et al., 1999; Slade, O'Neil, Simpson, & Lashen, 2007). Furthermore, research suggests that men have a greater tendency to underreport distress and present a favourable image of themselves to researchers (Daniluk, 1997; Greil, 1997; Lalos, Lalos, Jacobsson, & von Schoultz, 1986). Thus, the differences observed in the literature may in fact reflect men's unwillingness to admit to psychological distress in a research context rather than a genuine experience of lower emotional disturbance.

2.3.1.2 Diagnosis

Another factor that could influence the extent to which an individual may experience negative psychosocial consequences as a result of infertility is the nature of their infertility diagnosis. The majority of research in this area has focussed on exploring differences in the experiences of individuals diagnosed with male versus female factor infertility. In general, this body of research suggests that men may experience greater psychological distress in cases where a diagnosis of male factor infertility is received (Band et al., 1998; Connolly, Edelman, Cooke, & Robson, 1992; Kedem, Mikulincer, Nathanson, & Bartoov, 1990; Nachtigall, Beckner, & Wozny, 1992; Smith et al., 2009).

Researchers have often reported that societal norms and values connect male infertility with male virility and sexual competency (Gannon, Glover, & Abel, 2004; Lloyd, 1996). Furthermore, in many cases of male infertility, if couples choose to pursue assisted reproduction techniques as a means of parenting a child they may need to consider the use of 'donor sperm' (Connolly et al., 1992; van Balen, Trimbos-Kemper, & Verdurmen, 1996). Male factor infertility can therefore be viewed as a threat to conventional

constructions of masculinity and associated with high levels of stigma. In a study exploring the views of fertile individuals towards infertile men and women, Miall (1994) found that male infertility was frequently seen as arising from sexual dysfunction and was thus associated with higher levels of stigma than female infertility. In line with these findings Nachtigall et al. (1992) identified that two thirds of a sample of infertile men felt stigmatised as a consequence of a perceived loss of masculinity caused by their infertility. Furthermore, men have been found to be less open about a diagnosis of male infertility compared to female infertility (van Balen et al., 1996). It is therefore likely that men will experience a greater reduction in self-esteem and general psychological well-being when dealing with male infertility compared to female infertility.

Women in comparison do not appear to experience more psychological distress if the cause of the couple's infertility is attributed to a problem with their own fertility (Nachtigall et al., 1992). Interestingly, some studies have implied that male factor infertility may in fact be more stressful for both men and women when compared with a diagnosis of female factor infertility (Connolly et al., 1992; Drosdzol & Skrzypulec, 2009; Lykeridou, Gourounti, Deltsidou, Loutradis, & Vaslamatzis, 2009; Mikulincer, Horesh, Levy-Shiff, Manovic, & Shalev, 1998). These findings are perhaps unsurprising given that previous studies report women experience feelings of guilt for infertility (Lalos et al., 1986; Ulbrich, Coyle, & Llabre, 1990) and are more commonly labelled as responsible, regardless of where the biological causes lie (Miall, 1994). Furthermore as discussed previously, conventionally women tend to experience a stronger need to parent a child than their partners and have to deal with many of the physical strains of fertility treatment (Slepickova, 2009). As a consequence a gender-specific

diagnosis of infertility may be less of a salient issue in women's experiences than men's.

Comparatively, fewer studies have directly compared the effects of other types of infertility diagnoses on psychosocial well-being. However some studies suggest that cases of unexplained fertility problems can be perceived as particularly stressful due to uncertainties surrounding the cause and prognosis of infertility (Greil, 1997). Associations between primary versus secondary fertility problems and psychological distress have also been considered (e.g. Edelmann, Connolly, & Bartlett, 1994; Epstein & Rosenberg, 2005). It has been argued that secondary infertility might pose less threat to an individual's gender role identity; as individuals have already been successful in conceiving a child; and will thus be associated with lower levels of depression (Epstein & Rosenberg, 2005). Despite this most early studies failed to find evidence of a link between primary or secondary infertility and psychological distress (Greil, 1997). More recently, a study by Epstein and Rosenberg (2005) of 308 infertile couples found that couples with primary infertility were significantly more depressed than couples with secondary infertility. This suggests that childlessness may be a greater risk factor for depressive symptoms in infertile couples than the stresses of infertility treatment alone. However, this is only a tentative conclusion that needs to be verified with further empirical studies.

2.3.1.3 Stage of Treatment

The process of medical treatment for infertility typically involves a number of distinct steps or stages, for instance in the case of IVF these include ovarian stimulation, egg retrieval, fertilisation, embryo selection and transfer and pregnancy testing (see section 1.2.4. for further details).

Research has shown that the specific stage of investigation or treatment for infertility can have a particularly strong association with psychological well-being. From the current literature it appears that in general couples entering infertility treatment tend to be psychologically well-adjusted, when compared with normative data or control groups of fertile couples (Eugster & Vingerhoets, 1999; Golomobok, 1992; Verhaak et al., 2007). A study conducted by Edelmann et al. (1994) found that couples entering an IVF programme (n=152), did not differ significantly from normative data on a range of standardised psychological instruments including measures of personality, mood, self-esteem and general health status. It was however noted that female participants demonstrated slightly elevated scores on state and trait anxiety when compared to the norm.

A similar pattern of results have been observed in other studies in the area, for example Visser, Haan, Zalmstra, & Wouters (1994) report that women assessed prior to entering their first IVF cycle demonstrated higher scores of state anxiety when compared to a normal population, but did not suffer from more emotional complaints than the norm group. Bringhenti, Martinelli, Ardenti, & LaSala (1997) compared a cross-sectional sample of women commencing IVF treatment with a control group of mothers attending for a routine gynaecological examination. As with earlier studies, the authors found no evidence of psychological maladjustment in the infertile group compared to the control group, although infertile women were found to display higher levels of state anxiety. Similarly, results from a longitudinal study of couples undergoing IVF reveal that at intake women were significantly more anxious than their partners and a comparative norm (Slade, Emery, & Lieberman, 1997). However, no significant differences were observed for depression scores. Consequently, although

the majority of couples commencing infertility treatment show no signs of psychological maladjustment, it appears that anxiety is a common problem experienced by many individuals at this stage, especially women (Golombok, 1992). It is suggested that this may be due to the fact that only couples who are well-adjusted to begin with will seek medical help and put themselves forward for the stresses of infertility treatment (Golombok, 1992). Less is known about the well-being of individuals who choose not to pursue medical treatment for infertility, in part due to the difficulties of identifying and accessing this population (Greil, 1997).

In comparison, there are certain stages of treatment during which couples are thought to be increasingly vulnerable to psychological distress. A number of studies indicate that the phases of oocyte retrieval, fertilisation, embryo transfer, waiting for a pregnancy result and receiving news of an unsuccessful treatment attempt are the most stressful aspects of treatment and the time at which patients express the greatest emotional disturbance (Ardenti, Campari, Agazzi, & LaSala, 1999; Boivin et al., 1998; Laffont & Edelman, 1994; Mahajan et al., 2010; Newman & Zouves, 1991; Yong, Martin, & Thong, 2000). Furthermore, despite the fact that women consistently report more distress than their partners, similarities have been observed in the pattern of men and women's psychosocial reactions to the different stages of treatment. Laffont and Edelmann (1994) reveal that both men and women undergoing an IVF cycle experienced waiting for the pregnancy result and a negative result as the most stressful phases, although women were significantly more distressed than men throughout the cycle. Another longitudinal study by Boivin et al. (1998) shows that while women undergoing IVF and ICSI cycles report significantly more stress during treatment than men, both partners experienced the stages of

oocyte retrieval, embryo transfer and pregnancy testing as most distressing.

One important determinant of a couple's psychological reaction during treatment is the uncertainty surrounding treatment procedures. As Boivin et al. (1998) point out at each stage of treatment individuals must temper their feelings of hope and anticipation for a pregnancy with the possibility that they will be unsuccessful. It is thus inevitable that patients will express ambivalent feelings of intense anxiety and worry coupled with a sense of hope and optimism at these phases of the cycle (Allard, Sejourne, & Charol, 2007). For this reason infertility treatment is often described as an 'emotional rollercoaster' whereby couples begin each treatment cycle with a sense of hope, which may eventually turn to hopelessness and despair as their dreams of achieving a pregnancy fade away (Jordon & Revenson, 1999).

Perhaps unsurprisingly, the literature indicates that receiving news of an unsuccessful treatment attempt is associated with a range of negative emotions including feelings of anger, frustration, helplessness, grief and sadness (Bergart, 2000; Boden, 2007; de Klerk et al., 2007; Weaver, Clifford, Hay, & Robson, 1997). There is also evidence to suggest that patients who have been unsuccessful in a treatment cycle are at risk for developing depression (Golombok, 1992). For example, Berghuis & Stanton (2002) found that 43 couples assessed one week before and one week after treatment failure, showed a significant increase in depressive symptoms following receipt of the negative result. Likewise, Verhaak et al (2001) report that women who became pregnant following their first treatment cycle for IVF or ICSI were less depressed 3 weeks after the

pregnancy test, than those women who failed to become pregnant. Holter et al. (2006) also report that one month after a pregnancy test, couples who failed to become pregnant rated their emotional well-being as worse than before they started IVF treatment. Whereas those couples who fell pregnant rated their emotional well-being as better than before they started treatment. A similar pattern has also been observed in a longitudinal study with a 6-month follow-up, which found women who became pregnant through IVF to be less depressed and more positive about their relationships than those women who discontinued treatment following 3 failed cycles (Slade et al., 1997). Verhaak et al. (2005) observe that although the majority of women in their study were able to adjust well to unsuccessful treatment, more than 20% of women showed signs of subclinical depression and anxiety six months later. Thus, it appears that women's psychological and emotional well-being following a treatment cycle is determined largely by whether or not they have been successful. How these couples adjust to treatment failure in the long-term is less clear.

A number of authors suggest that the pattern of emotional reactions to a treatment cycle reported in the literature can be explained by the fact that depression results from loss, while anxiety is linked to a future threatening event (Golomobok, 1992; Mahlstedt, 1985). Patients commencing assisted reproduction often have unrealistically high expectations of treatment success, which can temporarily prevent them from facing childlessness and thus lessen the feelings of loss associated with being unable to conceive (Baram et al., 1988; Beaurepaire et al., 1994). These patients will however experience a sense of uncertainty about the outcome of treatment and how it will affect them physically and emotionally, thus leading to higher levels of anxiety at the onset of treatment (Mahlstedt, 1985). On the other hand

those couples whose treatment is unsuccessful or who experience pregnancy loss after conception are once again faced with the prospect of childlessness, which may lead to feelings of loss and depression (Harris & Daniluk, 2010; Verhaak et al., 2002; Verhaak et al., 2005; Verhaak et al., 2007). These couples also need to make the difficult decision of whether or not to continue in their pursuit of a pregnancy. In some cases these decisions may be constrained due to practical and financial considerations or a fear of re-investing in the treatment process, which may intensify the distress experienced following the receipt of a negative pregnancy test (Harris & Daniluk, 2010; Rajkhowa, Mcconnell, & Thomas, 2006; van den Broeck, D'Hooghe, Enzlin, & Demyttenaere, 2009). Indeed, one qualitative study investigating attitudes towards the decision not to pursue further IVF treatment revealed that many women experienced difficulty in accepting that their infertility would remain unresolved and facing the prospect of a childless life (Peddie et al., 2005). For some women, it may take many years after treatment failure for them to come to terms with these feelings of loss and grief and accept childlessness (McCarthy, 2008).

In a similar vein, Eugster and Vingerhoets (1999) propose that couples who experience repeated negative treatment cycles are likely to become increasingly vulnerable to developing clinical depression, as their loss will slowly become more concrete as they confront the possibility that they will be unable to conceive a child. For example, a cross-sectional study of 330 couples undergoing IVF found that a significant minority of women going through repeat-cycles were at risk of developing clinically significant depression (Beaurepaire et al., 1994). There is also some evidence to indicate that couples who have been experiencing infertility for 3-6 years report higher relationship instability and lower sexual satisfaction than

other infertile couples (Drosdzol & Skrzypulec, 2009). Despite this, at present little is known about the psychosocial adjustment of couples following repeated treatment failure (Verhaak et al., 2007). A recent systematic review examining women's emotional adjustment to IVF concluded that while it is clear that unsuccessful treatment heightens negative emotions, which can continue after repeated unsuccessful attempts, there is a need for further longitudinal research to identify risk factors (i.e. the length of infertility, number of treatment cycles etc) for the development of emotional problems and clarify the long-term effect of failed treatment (Verhaak et al., 2007).

Beyond treatment, a number of studies demonstrate that individual's who have achieved a successful pregnancy after IVF, may experience higher levels of anxiety during pregnancy than couples without previous fertility problems (Eugster & Vingerhoets, 1999; Hjelmstedt et al., 2003; McMahon, Ungerer, Tennant, & Saunders, 1997). Often this anxiety is associated with a fear of losing the pregnancy (Sandelowski, Harris, & Holditch-Davis, 1991). However, despite these fears most evidence suggests that the emotional and psychological well-being of infertile women in pregnancy is generally similar to that of fertile women (Hammarberg, Fisher, & Wynter, 2008). In fact some studies reveal that infertile women experience more positive moods during pregnancy and a more idealised perception of parenthood than comparative groups (Fisher, Hammarberg, & Baker, 2007; Hammarberg, Fisher, & Rowe, 2008). Thus when asked about their experiences of infertility and assisted reproduction treatment at this stage, women will often report more positive experiences than those couples who are unsuccessful (Hammarberg et al., 2001).

2.3.1.4 Coping Strategies

Another important factor mediating the psychological effects of infertility is an individual's coping response. Coping refers to the strategies that individuals adopt as a way of controlling and regulating stress (Lazarus & Folkman, 1984). In order to understand the role of coping in psychosocial adjustment to infertility it is first important to consider the Transactional Stress and Coping Model, which provides a framework for evaluating the processes of coping with a stressful life event. According to the Transactional Stress and Coping Model by Lazarus and Folkman (1984) reactions to a stressful life situation are determined largely by cognitive appraisals of the stressor. A distinction is made between primary and secondary appraisals; primary appraisals refer to an individual's initial evaluation of the significance of the threatening event, while secondary appraisals refer to an assessment of the controllability of the situation and a person's ability to cope. The coping strategies that are used to manage the stressful situation will be dependent on the outcome of these appraisals.

Overall, two broad styles of coping can be found in the literature: active problem-focussed coping and passive emotion-focussed coping. Active problem-focussed coping aims to try and manage the stressful situation, through strategies directed at seeking solutions to the problem, seeking support to help manage the problem or attempting to re-appraise the problem in a more positive light. In contrast, emotion-focused coping is concerned with regulating levels of emotional distress associated with the stressful event. Typically, this involves strategies such as escapism, denial, avoidance, wishful thinking, emotional expression or attempting to

understand the emotions surrounding the event (Lechner, Bolman, & van Dalen, 2007). In the context of infertility, examples of an active coping style may involve seeking help or advice to overcome infertility, finding people with similar experiences or developing alternative meanings to life in order to come to terms with permanent childlessness. Emotion-focussed coping on the other hand may involve fixating on the desire to have a child or avoiding children and pregnant women or withdrawing from friends and family with children (Lechner et al., 2007).

Generally, it is believed that active problem-focussed coping efforts are more effective for dealing with stressful life situations than passive emotion-focussed approaches, which may even heighten psychological distress (Weiten & Lloyd, 2006). Indeed several studies of infertile patients indicate that those individuals who adopt more active problem-focussed coping responses to deal with infertility tend to show better psychosocial adjustment, including lower levels of depression and infertility-related stress, than those patients who employ strategies involving avoidance, denial and escapism (Berghuis & Stanton, 2002; Edelmann et al 1994; Lechner et al., 2007; Peterson, Newton, Rosen, & Schulman, 2006; Peterson, Newton, Rose, & Skaggs, 2006; Peterson et al., 2009; Schmidt et al., 2005). For couples with definite involuntary childlessness, Kraaij, Garrnefski, and Vlietstra (2008) demonstrate that strategies involving self-blame, rumination, catastrophising and positive reappraisal may also be associated with depressive symptoms. In particular their study identified that catastrophising appeared to be related to depression two years later.

However, Lazarus and Folkman (1984) argue that while problem-solving strategies are adaptive for dealing with controllable situations, strategies

focussed on managing emotions might be more effective for uncontrollable situations. Since the experience of infertility typically involves both controllable (i.e. the decision to seek treatment) and uncontrollable (i.e. the outcome of treatment) elements, infertile patients may benefit from both an active and passive approach to coping dependent on the stage of their journey. For example, Cina (2007) reported that participants in their study made greater use of problem-focussed coping at the start of an IVF cycle than after embryo transfer, when they reported feeling less in control over the outcome of IVF treatment. Furthermore, individuals who continued to use high-levels of problem-focussed coping at this stage reported feeling more anxious than other participants. Thus, it appears that for those individuals pursuing medical treatment, perceptions of control over a treatment phase are significant in determining the most effective coping response.

Some research evidence implies that certain aspects of both active and passive coping styles might be more or less useful at different stages of the infertility journey. For instance, problem-appraisal and emotion-focussed coping strategies have been found to predict better adjustment to IVF failure than problem-management and escapist strategies (Terry & Hynes, 1998). Women presenting for IVF on the other hand appear to show better adjustment if they adopt a direct action approach, whilst also demonstrating a degree of acceptance of their position (Edelmann et al., 1994).

Most studies examining the effectiveness of coping strategies in infertility fail to take into account the impact of partner coping styles. Although this is an under-researched issue, several studies indicate that similarity in

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coping styles may protect a couple from psychological distress (Levin, Sher, & Theodos, 1997; Pasch, Dunkel-Schetter, & Christenson, 2002; Peterson, Newton, & Rosen, 2003; Peterson et al., 2006). Conversely, Berghuis and Stanton (2002) suggest a compensatory partner interaction model of coping, whereby one partner's use of a particular coping strategy may compensate for the other partners low usage of the same strategy. To date, little work has been carried out to investigate different partner interaction models of coping with infertility. However, since a large number of people seeking medical help for infertility issues do so as a couple, the potential interactions between partner coping styles are important and need to be considered when attempting to understand the efficacy of different coping responses to infertility. The following section will briefly examine differences in partner coping styles in an attempt to illuminate this issue.

2.3.1.5 Differences in partner coping styles

Alongside variations in the intensity with which men and women experience infertility, differences have also been observed in the way men and women cope with infertility. In particular there is evidence to suggest that women are more likely to seek social support as a mechanism for coping with infertility or employ strategies involving escape-avoidance, accepting responsibility and positive reappraisal (Beutel et al., 1999; Greil, 1997; Jordan & Revenson, 1999; Peterson et al., 2006). Men on the other hand have been shown to use greater amounts of planful problem solving, distancing and self-controlling strategies (Peterson et al., 2006). Research suggests that women have a stronger desire to talk to their partner about infertility issues than men do (Mahlstedt, 1985). Furthermore, women often report greater levels of disclosure concerning their fertility problems

than men (Buetal et al., 1999; Hjellmstedt et al., 1999; Slade et al., 2007). Thus it appears that men in general are less open and willing to discuss infertility compared to women.

One explanation for this could be found by examining variations in gender socialisation. Male behavioural norms typically emphasise self-reliance, decisiveness and emotional control. Men are therefore socialised to contain their emotions and are reluctant to discuss sensitive issues outside of the home or disclose personal information that might make them appear weaker (Brucker & McKenry, 2004; Harrison et al., 1995). In comparison, female behavioural norms typically emphasise emotional sensitivity, compassion, nurturing, and supportive activities (Seale, 2006). In the light of this, when a couple experience difficulties conceiving, men are likely to feel especially uncomfortable discussing the emotional and sensitive issues surrounding infertility. Instead, focussing their attention on task-oriented or distancing strategies. In some instances this may also be due to a conscious effort by men to suppress their own emotions in order to focus on supporting their partner who endures much of the physical burdens of fertility treatment (Berg & Wilson, 1991; Beaurepaire et al., 1994; Malik & Coulson, 2008). However, given that women desire communication with their husband concerning the emotional aspects of infertility, such differences in coping styles may lead to marital discord.

A growing number of studies suggest that the extent to which men and women differ in their approach to coping with infertility may be one risk factor for the development of marital problems among infertile couples (Pasch et al., 2002; Peterson, Newton, & Rosen, 2003). For example, Pasch et al. (2002) report that women perceive a more positive impact of infertility on their marriage and less negative quality of life to the extent

that their husbands view having children as important, want to talk about infertility with their wife and actively involve themselves in seeking fertility treatment. Similarly, a study examining coping among couples at different stages of fertility treatment found that similarities in coping styles were related to marital satisfaction (Levin et al., 1997). Results revealed that the use of high levels of task-oriented coping (i.e. coping focussed on managing or altering the stressor) was associated with the highest level of marital satisfaction. Furthermore, for women marital satisfaction was highest in couples where both partners were using low amounts of emotion-focussed coping (i.e. coping directed at managing emotional reactions to the stressor). More recently, Benyamini, Gozlan, and Kokia (2009) examined distress in a cross-sectional sample of couples undergoing infertility treatment. They found that distress was highest for women who perceived low controllability of their fertility problem whereas their partner perceived high controllability, compared to couples who reported similar levels of controllability. These results are reflective of the wider literature on marital relationships, which demonstrates that attitude similarity is an important predictor of marital satisfaction and general psychosocial well-being.

Such differences have also been shown to impact on general psychological well-being. Schmidt et al. (2005) for instance found that difficulties in partner communication concerning fertility problems predicted high fertility-problem stress. Peterson, Pirritano, Christensen, & Schmidt (2008) report that a partner's use of active-avoidance coping (e.g. avoiding pregnant women and children or turning to other activities to avoid thinking about infertility) was predictive of increased marital, personal and social distress for both men and women. An earlier study by Peterson and

colleagues, however found that women's infertility stress and depression increased if a man used a high amount of distancing and his partner did not. Conversely, in situations where the female partner used high levels of emotional self-controlling while the male partner used low amounts, men were shown to display lower levels of marital adjustment and higher levels of infertility stress (Peterson et al., 2006). This again implies that similarities in the way in which partner's deal with infertility can protect couple's from some of the potential negative psychosocial consequences of infertility.

Taken together these findings suggest that a couples approach to coping with infertility and in particular the quality of their communication and openness concerning infertility issues can have a significant impact on each individual's psychosocial well-being. Consequently, when considering the psychological effects of infertility it is important for researchers to take into account the potential role of partner interactions and gender.

2.3.1.6 Social Support

One coping strategy that might be particularly beneficial during infertility is the act of seeking social support. Social support can be defined as a "social networks provision of psychological and material resources intended to benefit an individual's ability to cope with stress" (Cohen, 2004, p676). There is a body of evidence to suggest that social support can provide significant benefits to both mental and physical health (Kettman & Altmaier, 2008; Krokavcova et al., 2008; Luszczynska, Sarkar, & Knoll, 2007; Uchino, 2004). Moreover, social support can act as a buffer to poor psychological adjustment to stressful situations (Bolger & Amarel, 2007).

In the context of infertility a number of studies have shown that perceived social support could protect individuals from the negative psychosocial and interpersonal effects of infertility treatment (Abbey, Andrews, & Halman, 1995; Amir, Horesh, & Lin-Stein 1999; Gibson & Myers, 2002; Hirsch & Hirsch, 1995; Jirka, Scheutt, & Foxhall, 1996; Schmidt et al., 2005; Peterson et al., 2006; Slade et al., 2007; Daniluk & Tench, 2007; Karlidere, 2007) There is also evidence to indicate that social support may be important in helping couples cope with treatment failure (Lund et al., 2009; Verhaak et al., 2005; Verhaak et al., 2005). For example, in a longitudinal study examining emotional responses to IVF, Verhaak et al. (2005) found that social support was associated with better adjustment to an unsuccessful IVF cycle. This suggests that the availability of social support plays an important role in coping with the stresses of infertility and its treatment.

Despite this, the literature also reports that infertile couples often experience difficulties accessing adequate support from within their existing social circles (Domar, 1997; Lechner et al., 2007). Many couples report feeling excluded from interactions with friends and family and a sense of isolation from the 'fertile world' (Cousineau & Domar, 2007). The inability to conceive can also be seen as carrying a hidden stigma (Slepickova, 2006; Whiteford & Gonzalez, 1995). Slade et al. (2007) reveal that perceptions of stigma can lead to less disclosure of fertility difficulties and in turn lower levels of perceived social support. Some individuals may therefore isolate themselves from valuable sources of support due to feelings of jealousy or a fear of stigmatisation (Amir et al., 1999; Lasker & Borg, 1987; Miall, 1994).

Furthermore, a number of studies reveal that individuals experiencing infertility tend to perceive the responses they receive from within their social networks to be unsupportive or inappropriate to their needs (Alesi, 2005; Schmidt. 2009). Dissatisfaction with social support can lead not only to further isolation from social networks but also result in greater psychological distress, lower self-esteem and increased depressive symptoms and anxiety (Mindes et al., 2003; Lechner et al., 2007).

Consequently for many infertile couples the partner becomes the sole confidante and a crucial source of social support for fertility-related concerns. However there is evidence to suggest that partners differ in their approach to seeking social support and coping with infertility (Beutel et al., 1999; Peterson et al., 2006; Slade et al., 2007). As a result some people may experience difficulties communicating with their partner about infertility. For example, many women report feeling insufficiently understood or supported by their partner when it comes to infertility (Leiblum, 1996). Research also shows that high levels of perceived emotional support between spouses can lead to increased psychosocial well-being; conversely difficulties in partner communication may lead to increased stress (Abbey et al., 1995). Thus in the context of infertility relying solely on the partner for social support might be problematic for both men and women.

2.3.1.6.1 Alternative sources of support

2.3.1.6.1.1   Infertility clinics and health care professionals

Infertility clinics and health care professionals are well positioned to provide ongoing support to infertile couples. Perceived support from health care providers can play a significant role in helping some individuals manage the stress and anxiety linked to infertility treatment (Brucker & McKenry, 2004). This is important as there is evidence to suggest that emotional distress is a key reason why couple's discontinue fertility treatment (Brandes et al., 2009). Furthermore, research indicates that satisfaction with infertility treatment appears to be related to the level of patient-centred care available from the fertility clinic (Malin, Hemminki, Raikkonen, Sihvo, & Perala, 2001; Schmidt et al., 2003; Redshaw, Hiocklley, & Davidson, 2007; Wilkes, Hall, Crosland, Murdoch, & Rubin, 2009; van Empel et al., 2010) and in particular, the amount of attention paid to the patient's emotional needs and their understanding of medical procedures (Halman, Abbey, & Andrews, 1993; Wilkes et al., 2009).

However, when evaluating their experiences of infertility treatment many patients report that their emotional needs were not met by health care professionals (Schmidt, 1998; Souter, Hopton, Penney, & Templeton, 1998). Patients also express a wish for more written information on both the psychosocial and technical aspects of infertility treatment and their own medical records (Laffont & Edelmann, 1994; Schmidt, 1998; Souter et al., 1998; van Empel et al., 2010). Moreover, a number of studies indicate dissatisfaction with the level of information and support provided by clinics in relation to the decision to end treatment and alternative options like

adoption (Peddie et al., 2005; Schmidt, 1998; Souter et al., 1998). For example, Peddie et al. (2005) report that women in their study found the information provided at their final consultation to be inadequate and felt a need for ongoing support from the IVF unit. In light of this, it appears that patients may need to seek out additional support resources to help them manage the emotional aspects of infertility and the decision to end treatment.

2.3.1.6.1.2 Counselling

Psychosocial counselling provides individuals or couples with a source of emotional support to help them understand and come to terms with the consequences of infertility and its treatment. The regulatory body for assisted reproduction in the UK, the Human Fertilisation and Embryology Authority (HFEA) requires that all licensed clinics must offer counselling to any patients considering fertility treatment or donor insemination. More specifically the HFEA outlines three types of counselling that should be routinely made available to patients; implications counselling, support counselling and therapeutic counselling. Implications counselling is aimed at couples who are contemplating a course of fertility treatment and is designed to help them understand what the treatment will involve and how it might impact on their life. This is likely to be of particular value to individuals who are considering the implications of introducing a donor or surrogate into the treatment process (Baetens, Devroey, Camus, van Steirteghem, & Ponjaert-Kristoffersen, 2000; Hammarberg, Carmichael, Tinney, & Mulder, 2008). Support counselling on the other hand is designed to provide emotional support during stressful phases of the treatment process, for example following a treatment failure or miscarriage after initial success. Therapeutic counselling goes beyond emotional

support to help individuals cope with the impact that infertility has on their life and relationships, for example by assisting couples to accept their situation or repair any damage to their relationship.

A number of early studies indicate that a large proportion of couples undergoing infertility treatment express a wish for counselling and have stated that they would use such a service if it were made available (Kerr, Brown, & Balen, 1999). In spite of this the number of patients who actually take up counselling when it is offered to them is relatively low (Boivin, Scanlan, & Walker, 1999). Levels of distress are thought to be a key factor in determining which couples seek counselling. Typically it is those couples who are experiencing extremely high levels of distress who feel the need for counselling (Boivin et al., 1999; Pook, Rohrle, Tuschen-Caffier, & Krause, 2001; Wischmann, Scherg, Strowitzki, & Verres, 2009). In comparison couples with lower distress levels may feel that informal sources of support such as documentation or peer support is more appropriate for their needs (Boivin et al., 1999; Laffont & Edelmann, 1995; Souter et al., 1998). Other factors accounting for low uptake may include practical issues such as financial concerns; for example not all clinics offer free counselling services and costs can vary greatly between clinics (Wischmann, 2008). There can also be a stigma attached to seeking professional psychosocial help, which may prevent some individuals from approaching a counselling service (Cousineau & Domar, 2007).

2.3.1.6.1.3 Patient support organisations

There are also a large number of patient support organisations available, which can provide informal support and information on a range of issues related to infertility. For example organisations such as Resolve and

Infertility Network UK offer a range of services to help support people with fertility problems or definite involuntary childlessness including: medical advisors, Internet resources, local support groups, help lines, newsletters and patient representation in the field of infertility. Additionally there are various support organisations dedicated to specific issues surrounding infertility such as donor insemination, Endometriosis, PCOS and adoption. Within the UK, Infertility Network UK represents one of the largest patient support organisations for infertility, covering a broad spectrum of issues ranging from diagnosis and treatment to adoption and permanent involuntary childlessness.

2.3.1.6.1.4 Support groups

To cope with the psychosocial effects of infertility some individuals may seek support from people in similar situations through the means of a patient support group. Wischmann (2008) makes the distinction between self-help and professionally-facilitated infertility support groups; self-help support groups are typically organised and facilitated by members with firsthand experience of infertility, whereas in a professionally-facilitated support group discussions are usually managed and controlled by a professional such as a psychotherapist, psychologist or social worker, who will not necessarily have previous experience of infertility. Despite this distinction, a common and important characteristic of both formats is the provision of support and information for mutual problem-solving and the opportunity for members to share their experiences in a supportive environment.

Although there has been limited research examining the efficacy of these resources, preliminary findings suggest that professionally-facilitated

support group interventions can be beneficial in reducing feelings of depression and anxiety and increasing general psychosocial well-being among both men and women experiencing infertility (Domar et al., 2000; Lemmens et al., 2004; McNaughton-Cassill et al., 2000; McNaughton-Cassill, Bostwick, Arthur, Robinson, & Neal, 2002; Schmidt et al., 2005 Stewart et al., 1992; Thorn & Daniels, 2003). McNaughton-Cassill et al. (2000) report that couples attending brief stress management support groups for IVF found the exchange of social support and opportunity for sharing with fellow patients to be particularly beneficial in helping them cope with infertility. This finding is further supported by the results of a systematic review of psychosocial interventions for infertility, which noted that group interventions emphasizing education and skills training appeared to be most effective in producing positive outcomes, more so than counselling interventions (Boivin, 2003). The author speculates that this may be due to the fact that group formats facilitate the exchange of common experience allowing patients to communicate with other individuals who have first hand understanding of what they are going through. In addition group formats allow individuals to employ social comparison as a coping strategy i.e. compare their own situation with that of other infertile couples (Boivin, 2003).

The efficacy of self-help groups in contrast has not been examined extensively in the infertility literature. However one early study suggests that self-help groups can be equally beneficial; the study reported that both men and women associated a range of benefits with participation, including a sense of belonging, a wealth of information and education and the strength to go on. In addition length of membership and frequency of attendance were both found to positively correlate with the amount of

benefit perceived (Lentner & Glazer, 1991). Black, Delgado and Turek (2001) report that self-help groups might also offer a valuable source of support to infertile men who are often unwilling to share their experiences of infertility within their social network, with 1 out of 3 men in their study expressing an interest in peer support groups. Nevertheless, despite the potential value of peer support, the complexities of infertility treatment can mean that many couples experience difficulties finding the time or energy to attend a regular group meeting (Black et al., 2001 & McNaughton-Cassill et al., 2002).

2.3.1.6.1.5 Internet

More recently the Internet has become an increasingly popular source of support, information and advice for infertility. Survey findings suggest that around half of infertile couples, especially female partners, actively use the Internet to seek fertility-related information and advice (Haagen et al., 2003; Huaang, Al-Fozan, Tan, & Tulandi, 2003; Kahlor & Mackert, 2009; Weismann, Gotlieb, Ward, Greenblatt, & Casper, 2000). Greil and McQuillan (2004) note that a third of Internet users in their sample of 33 infertile women described the infertility information they obtained online as 'very useful'. Similarly, Weissman et al. (2000) observe that 30% of patients in their study found the Internet helpful in their decision-making process. In another study 64% of users reported that the Internet had improved their knowledge about fertility issues (Haagen et al., 2003). However, a number of authors have expressed concerns over the quality of content available in various infertility websites (Epstein & Rosenberg, 2005; Huaang et al., 2005; Marriott et al., 2008; Okamura, Bernstein, & Fidler, 2002). For example, in a review of 107 infertility-related websites retrieved via a Google search, Marriott et al. (2008) found that most of the

websites scored relatively low on predefined criteria assessing credibility, accuracy and ease of navigation.

Alongside web pages containing factual information about infertility and its treatment, the Internet also provides access to a growing number of online self-help communities. These online communities allow individuals to engage in asynchronous written communication with other people experiencing infertility. Some websites also provide question and answer forums, through which patients can put their questions and concerns to infertility specialists. Himmel, Myer, Kochen and Michelmann (2005) conducted an online survey of people visiting an online question and answer forum for involuntary childlessness. They found that the majority of people posted information requests seeking general information concerning involuntary childlessness and treatment options. However a number of posts were also sent with the purpose of seeking emotional support. Interestingly, those users who reported discussing their Internet activity with their doctor were more satisfied with the care provided by their fertility clinic than users who did not discuss it with their doctor. Another research team examined postings to a bulletin board for patients undergoing assisted reproductive treatment (Wingert, Harvey, Duncan, & Berry, 2005). Their study revealed that the majority of users posted messages relating to psychosocial topics such as developing relationships and supportive interactions rather than medical information seeking.

With the exception of these preliminary studies to date there is limited understanding of how infertile couples use online communities and importantly their efficacy as a source of infertility support. In an online survey investigating use of the Internet to talk about infertility, Epstein,

Rosenberg, Grant and Hemenway (2002) found that whilst patients find online communities valuable for sharing information about treatment experiences, those individuals who relied solely on the Internet to talk about infertility experienced higher levels of distress and perceived less real-world support, in comparison to those who had access to more diverse sources of support. This suggests that Internet usage may lead to increased depression and withdrawal from real-world interactions among some individuals. In the light of this it is vital that further in depth research is carried out to examine both the advantages and disadvantages of online support seeking, for people experiencing infertility.

The next chapter will present a comprehensive overview of literature pertaining to online support communities, in order to explore what is already known about this new source of support and to identify gaps in the current research literature.

3 Chapter Three: New opportunities for support: The Internet and online communities

CHAPTER SUMMARY

This chapter presents a comprehensive review of the literature pertaining to online support communities. The review discusses the theoretical advantages and disadvantages of this novel support medium and examines current research findings and theories regarding who accesses online support communities, how they communicate within these online spaces and the possible psychosocial consequences of usage. This review serves to highlight the potential valuable role that online support communities could play in the lives of people experiencing infertility. However, it also allows for a consideration of some of the gaps in our current understanding of this novel phenomenon, particularly in the context of infertility. The chapter concludes by stressing the importance of initiating further empirical research into the area of online support and infertility and identifying the research questions guiding this thesis.

3.1 The rise of the Internet, facts, & figures

Over the last decade, there has been a proliferation in the number of Internet users around the world. Recent statistics indicate that approximately 1,596 million people worldwide have access to the Internet; a 1,235 million increase from 2000 (Internet World Stats, 2009). This rapid growth in Internet access has opened up new opportunities for patients to seek health-related information, advice and psychosocial support. A 2007 survey conducted by the Pew Internet Research Institute revealed that 75% of Internet users in the US had used the Internet to search for health or medical information (Pew, 2008). A similar survey in the UK indicated that around 42% of Internet users had accessed the Internet for health-related information in the past 3 months (Office for National Statistics, 2009).

In addition, to a plethora of web-pages containing factual information about health and illness, many websites now offer communication features that allow individuals to interact with patients and health care providers. This can be through either synchronous (i.e. chat rooms) or asynchronous (i.e. bulletin boards or a mailing list) channels of communication. These interactive functions have proven to be extremely popular among Internet users, leading to the emergence of 'virtual' or 'online' communities surrounding a wide range of psychosocial and health issues[1]. Wellman (1997) describes an online community as a social network that is created and supported by electronic media. In the context of health, online communities are typically facilitated through bulletin boards, which allow users to communicate with one another by posting and replying to

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[1] To give an indication of the prevalence of online support communities, a google search using the term "online support community" was conducted in January 2010; this search returned over 304,000,000 web pages.

messages on a discussion board. Some websites may include additional features such as a chat room or private messaging option. Online support communities for health-related issues can be either peer led or professionally directed by someone with a health or medical background e.g. doctors, nurses, psychologists. A 2005 survey indicated that around 36 million people in the USA alone were members of an online support community (Pew, 2005).

3.2 The unique characteristics of online support communities

Online support communities present several unique communication characteristics, which can include anonymity, asynchronous text-based communication and the ability to transcend geographical and temporal barriers. These unique characteristics also give rise to a number of unique advantages and disadvantages for infertile couples choosing to seek support through the medium of online communities. The following section will briefly outline the key issues that have been identified in the literature.

3.2.1 Advantages

A growing number of studies have documented the potential advantages of online support communities over more traditional face-to-face sources of support (e.g. face-to-face support groups). For example, in contrast to a face-to-face group where members typically meet once a week or less frequently, online communities are available 24 hours a day, 7 days a week. The asynchronous nature of the online environment thus allows members to access the online community to share experiences or seek support at virtually anytime of day. This not only offers a convenience factor but also means participants can potentially offer and/or receive

valuable support and advice at times when traditional sources of help are likely to be unavailable (Ferguson, 1996).

An additional benefit associated with asynchronous communication is the opportunity for members to spend time reflecting on their thoughts and feelings as well as interactions with other members (Finfgeld, 2000). Joinson (2003) argues that asynchronous communication thus reduces the pressure associated with real-time communication allowing participants to carefully construct their messages before contributing to the community. This could potentially reduce the occurrence of impulsive or irrational communication (Finfgeld, 2000). Online communities also offer a degree of anonymity that would not be possible in face-to-face communication. This may encourage certain individuals, particularly those patients who feel stigmatised because of their condition, to openly discuss their experiences without fear of a negative reaction (Coulson & Knibb, 2007; Tanis, 2008; Wright & Bell, 2003).

Additionally, since participation in online support communities is not restricted by geographical, physical or spatial barriers, members can potentially access a larger and more heterogeneous mix of people with ease. This is likely to be of particular benefit to patients suffering from chronic health conditions, as these individuals, may experience difficulties attending a regular face-to-face meeting due to limitations arising from their condition such as problems with mobility or treatment side effects. Patients undergoing infertility treatment may similarly experience problems finding the time or energy to attend a face-to-face group. The Internet thus offers a novel opportunity for these individuals to communicate with

similar others in the comfort of their own home (Braithwaite, Waldron, & Finn, 1999; Finn, 1999).

The ability to reach people from geographically diverse locations also increases the chances of finding others with similar experiences. This is particularly helpful for individuals with rare conditions who may be unable to locate people with the same problem in their geographical area (White & Dorman, 2001). At the same time due to their diversity online communities are advantageous because they can offer participants a wide variety of different perspectives, viewpoints and experiences on issues related to their condition (Walther & Boyd, 2002).

Walther and Boyd (2002) argue that for this reason online communication provides numerous opportunities for people with health concerns to seek support from 'weak tie' relationships. 'Weak ties' refer to relationships between people who might communicate on a regularly basis but are not necessarily close. Prior to the advent of the Internet, weak tie networks typically incorporated neighbours, service providers or individuals known through other associations. However, the recent growth in the popularity of the Internet has led to a larger and more heterogeneous pool of individuals that could potentially develop into weak tie networks for people with health concerns (Wellman, 1997).

Granovetter (1982) proposed that since weak ties provide access to a large pool of individual's with a range of different characteristics they are extremely useful sources of information. In addition, since weak tie relationships tend to exist outside of traditional social networks they

provide a useful alternative for the discussion of taboo topics, which people may feel reluctant or uncomfortable discussing with their close relations (Adelman, Parks, & Albrecht, 1987). Online communities can potentially increase the chances of individuals forming weak tie relationships that offer access to diverse sources of information and advice that would not be available from close tie relationships. Furthermore, the absence of visual cues in the online environment and the opportunity to remain entirely anonymous may further facilitate the discussion of taboo or highly sensitive topics (Tanis, 2008). Additionally, as members of an online community typically share a common problem, they are less likely to stigmatise an individual on the basis of their condition. Indeed, a frequently mentioned advantage of health-related online support communities is the perception that members within these communities attach less stigma to one's illness, thus removing the fear of being judged negatively (Walther & Boyd, 2001; Wright, 2000). Wright (1999, 2000) also found that participants using a computer-mediated support network to discuss care giving issues valued the community because it allowed them to reach individuals with a wide variety of different perspectives and experiences.

3.2.2 Disadvantages

Despite the numerous advantages of online support communities there are also a number of potential disadvantages that require consideration. For example, the anonymity inherent to the Internet could lead to deindividuation (Walther & Parks, 2002). Deindividuation is described by Festinger, Pepitone, and Newcombe (1952) as a state of lowered self-awareness where a person temporarily loses their individual sense of identity and becomes immersed into the identity of a larger group. Some authors argue that due to this deindividuation, Internet behaviour will

inevitably be characterised by increased instances of disinhibited communication such as aggressive and hostile exchanges often referred to as flaming (Short, Williams, & Christine, 1976; Walther 1996). The absence of non-verbal cues may also make it difficult for users to effectively convey emotion and lead to recipients misinterpreting the meaning of messages (Finfgeld, 2000). However, some individuals may attempt to overcome this through employing emoticons to communicate non-verbal cues (Braithwaite et al., 1999; van Uden-Kraan et al., 2008a).

Another disadvantage associated with online support communities is delayed feedback. Although participants can log in and post messages at virtually any time of day, in comparison to face-to-face groups there may be a considerable time lag before the individual receives a response from other participants. Wright (2002) report that many users of online support communities found this disadvantage to be one of the most frustrating aspects of online support seeking.

Concerns have also been raised about the potential exchange of inaccurate or misleading information in online communities (Culver, Gerr, & Frumkin, 1997; Esquivel, Meric-Bernstam, & Bernstam, 2006; Finn & Branch, 2000; Hoch, Norris, Lester, & Marcus, 1999; Winzelberg, 1997). This is a particularly important issue for health-related support communities, as research indicates that participants frequently discuss and exchange advice on a range of medical and treatment-related issues, often without the input of a medical professional (Mascias, Lewis, & Smith, 2005). Some individuals may rely on online communities as an alternative source of information (Hoch et al., 1999; Sharf, 1997).

Given the volume of peer-to-peer based medical advice and information exchanged via the Internet, it is important for researchers and health professionals to examine issues relating to the accuracy and credibility of this information. Although several authors have focused on assessing the quality of infertility websites (Epstein & Rosenberg, 2005; Huaang et al., 2005; Marriott et al., 2008; Okamura et al., 2002), very little research has been conducted to examine the exchange of peer-to-peer informational support in online infertility communities. This issue has however been addressed in the context of other health problems for example, in a study of messages posted to an online disability support community, Braithwaite et al. (1999) reported that there were no obvious examples of false or misleading information. Moreover, it was noted that when one member offered advice, others would often enter into the discussion with their own opinions and experiences thus creating an opportunity for recipients to appraise the accuracy of the initial advice. However, since this study was not specifically concerned with examining the accuracy of information, the authors may have missed some instances of misinformation.

An earlier study by Culver et al. (1996) found that individuals posting information requests on a bulletin board for sufferers of painful hand and arm conditions appeared to accept information uncritically. It was also reported that 55.9% of the messages analysed addressed a medical topic and that 79% of these messages provided medical information. Of particular concern was the fact that 89.3% of these postings were by individuals who did not appear to have any formal medical training and 60% of this information was based on personal experience alone. Furthermore, over one third of the messages recommended unconventional treatments such as acupuncture and homeopathy.

Hoch et al. (1999) found that individuals posting messages to an online epilepsy bulletin board commonly asked questions about treatment and the natural history of the illness. Answers were mostly given by other patients and caregivers, 6% of the information provided was found to be objectively inaccurate. Feenberg, Licht, Kane and Smith (1996) observed that patients and caregivers often posed difficult questions regarding the management of symptoms within a community surrounding an online amyotrophic lateral sclerosis (ALS) journal. Despite some incidences of misleading information, the online community appeared to have the resources to protect members from serious mistakes e.g. other subscribers would post replies to warn people off dangerous treatments.

Similarly, Winzelberg (1997) report that although most medical information provided in an eating disorders online community was accurate, approximately 12% of information could be classified as inaccurate and outside standards of medical and psychological care. Furthermore, a small minority of members appeared to have commercial interests and posted messages recommending ineffective, dangerous and costly treatments. However, although on many occasions other members would post follow-up messages correcting this information, in some instances this could be 1-2 weeks after the original posts. It is thus unclear how many individuals actually viewed the corrected information or acted on the false information.

Esquivel et al. (2006) examined postings to a breast cancer mailing list to determine the prevalence of false or misleading information. It was found that 10 of the 4600 messages examined contained false or misleading information. However, 7 of these were identified as inaccurate by other participants and were corrected in an average of 4.33 hours. However,

again despite the opportunity for individuals to assess the reliability and credibility of the information provided it is unclear how many people critically examined the information they received or acted on the inaccurate information.

The lack of non-verbal cues within the online environment can make it particularly difficult for participants to assess the validity of the information received and the credibility of the information provider (Wright & Bell, 2003). Indeed, Coulson and Knibb (2007) note that members of an online food allergy support community reported mistrust in the reliability of information received to be a key disadvantage of their online experience. The anonymity of the Internet can also make it harder for information and support providers to establish legitimacy and authority in their postings.

To address this issue, Galegher, Sproull and Kiesler (1998) examined how members of three Usenet[2] online support communities and three online hobby communities established legitimacy and authority in their postings. Legitimacy was created in a number of ways for example posters used snappy headings, posted messages appropriate to the function of the community, and referred to their length of membership or how long they had lurked before posting. Within the support communities members would often use self-disclosure (i.e. describe their symptoms or diagnosis before asking a question) to establish legitimacy. The authors observed that questions that received no response typically failed to contain any legitimising information. For information providers establishing authority

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[2] Usenet is a world-wide distributed Internet discussion system, which consists of a collection of electronic bulletin boards (referred to as newsgroups) that cover a wide range of different discussion topics.

within their posts was also important. When providing information based on scientific or factual knowledge members would often use citations or refer to their own expertise in the area. When offering information based on personal experiences members would frequently include caveats such as 'heres my two cents worth.' Furthermore, in instances where postings lacked these features the authority of the message were commonly challenged by other members. This suggests that despite the limitations and challenges associated with assessing and establishing credibility in online communication, Internet users can establish strategies to overcome these issues.

However, despite a growing body of descriptive literature documenting the potential advantages and disadvantages of online support seeking, there is still a lack of understanding concerning how people, and in particular infertile couples, use and communicate within online communities and the psychosocial consequences of usage. The remainder of this chapter will thus review existing research studies, in an attempt to highlight our current knowledge about online support communities and identify directions for future research in the context of infertility.

3.3 Who seeks support online?

3.3.1 Patient characteristics

Empirical data from Internet user surveys suggests that individuals who seek health-related information and support online tend to be white, female, well-educated, of a younger age and in employment (Eysenbach, 2003; Im & Chee, 2005; Im et al., 2007; van Uden-Kraan et al., 2009a Winefield, Coventry, Pradhan, Harvey, & Lambert, 2003; Ybarra & Suman, 2006). There is some evidence to indicate that these factors are also

associated with participation in online support communities (Owen et al., 2010). For example, in a recent survey of cancer sufferers, Im et al. (2007) found that patients accessing online communities were typically middle-aged, well-educated, female and middle class. Similarly, Hoybye et al. (2010) found that cancer patients participating in online support communities belonged to higher socioeconomic groups compared to non-participants. Another recent survey of Internet use among individuals with HIV/AIDS, also revealed that frequent users of online support communities were more likely to be female, younger and single when compared to infrequent or non-users of online support communities (Mo & Coulson, 2010).

The association between patient's demographic characteristics and health-related Internet use may reflect barriers to Internet access among certain groups of people. For instance, individuals who are educated and in employment may be more likely to have easier access to Internet resources compared to those who are unemployed or have a lower educational attainment. Furthermore, some research indicates that ethnic minorities are more likely to be unfamiliar with Internet technologies (Im & Chee, 2005). In relation, to infertility, online support seeking may also be influenced by the nature of the treatment process. For example, since women experience greater physical and psychological stresses during treatment, they may be more motivated to turn to the Internet for support when compared to men (Slepickova, 2009).

Shaw et al. (2006) examined whether demographic variables would predict participation in online support communities when barriers to Internet access were removed. A group of breast cancer patients were therefore provided with free Internet services, computer hardware and IT training.

As hypothesised the study found that demographic differences in participation were diminished. Instead factors that predicted higher levels of participation were found to include having fewer breast cancer-related worries, a positive relationship with doctors and higher levels of social/family well-being. This implies that a range of psychosocial characteristics may influence participation in online communities.

However, there is comparatively little research specifically examining the relationship between patient's psychological characteristics and health-related Internet use, particularly the use of online support communities. Furthermore, results from the few studies that have addressed psychosocial factors are variable. While some studies suggest that individuals turning to online communities report high levels of social support from offline relationships (Bunde, Suls, Martin, & Barnett, 2006; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Kalichman et al., 2003); others have found that individuals seek online support when offline support is perceived as inadequate. For example, in a study comparing women with breast cancer who used the Internet for support and women with breast cancer who did not, Winefield et al. (2003) identified that women using the Internet were significantly less satisfied with support from their family and were more psychologically distressed than non users. Conversely, an Internet use survey conducted by Ybarra & Suman (2006) reveals that those individuals who did not use the Internet for health-related purposes were more likely to report being unhappy or lonely. However, recent surveys by van Uden-Kraan et al. (2009) and Hoybye et al. (2010) found no relationship between psychological well-being and health-related Internet use among arthritis, cancer and fibromyalgia sufferers.

Furthermore, since most studies employ cross-sectional designs it is difficult to determine causality. The exact nature of the relationship between social support, distress and participation in online support communities is therefore unclear. For example, do more isolated and distressed infertile individuals turn to the Internet for support or do high levels of Internet use lead to increased levels of isolation and distress? It is thus clear, that although there is a distinct demographic profile of online support users, further work is required before conclusions can be drawn about the psychological predictors of online support participation.

3.3.2 eHealth Literacy

Another relevant issue when considering who uses online support communities is the concept of eHealth literacy. eHealth literacy refers to an individuals 'ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem' (Norman & Skinner, 2006). eHealth literacy involves a range of skills including basic literacy skills, information seeking skills, critical thinking skills, and the ability to interact with the health care profession and engage in appropriate self-care and IT skills (Norman & Skinner, 2006). Levels of eHealth literacy may influence the likelihood of an individual turning to the Internet to seek health-related information and support. For example, individuals who are unfamiliar with computers and the Internet may lack the skills and confidence to effectively find and utilise support communities found on the Internet. Indeed, as described earlier most health-related online communities are populated by younger patients from higher socioeconomic and educational backgrounds, who are likely to have had greater exposure to Internet technologies. Similarly, individuals with a low level of education may

experience problems understanding and appraising health resources online. At present, however there is little research specifically investigating the perceived eHealth literacy skills of participants in online communities.

3.3.3 Illness characteristics

Aside from demographic and psychological variables, research has also examined the types of conditions for which individuals seek support online. Diseases with fewer treatment options and conditions with an unclear aetiology, which are poorly understood by the medical profession, appear to be particularly common online (Ferguson, 1997). Furthermore, research suggests that conditions described as embarrassing or socially stigmatising, are also associated with higher levels of Internet support behaviour (Berger, Wagner, & Baker, 2005; Davison & Pennebaker, 2001). Indeed, Ferguson (1997) note that while diseases such as cancer and HIV/AIDS are particularly prevalent online, support communities for conditions like heart disease and stroke are less common.

Similar patterns are also visible in face-to-face support communities. Davison, Pennebaker and Dickerson (2000) examined which conditions elicit the highest level of participation in both online and face-to-face support communities. For both mediums the number of available support communities positively correlated with the social burden associated with the disease (i.e. how visible or embarrassing the condition is and the level of stigma associated with the condition). Thus, suggesting that feelings of stigma are an important factor influencing participation in support communities. However, the study found that among the online communities, support for individuals affected by poorly understood

conditions like Multiple Sclerosis, Chronic Fatigue Syndrome and Breast Cancer was particularly prevalent. One explanation for this could lie in the fact that online support communities potentially offer access to diverse sources of information, including a wide variety of perspectives and experiences of the disease. This may help these patients to gain a better understanding of their own condition and treatment options.

The level of perceived stigma associated with a condition may also influence whether patients choose to seek support online or face-to-face. Mickelson (1997) studied the motivations and perceptions of parents of children with a learning difficulty who participated in either a face-to-face support group or an online support community. Interestingly, parents accessing the online support communities reported a greater perceived stigma associated with their child's learning difficulty and lower expectations of support from family and friends than parents using the face-to-face support groups.

Thus it appears that the Internet offers a useful venue for bringing together individuals with rare and poorly understood conditions or those that feel stigmatised as a result of their condition.

3.4   Characteristics of participation in online support communities

3.4.1 Membership life cycle

Individuals accessing peer-to-peer online communities will often adopt different roles within the community. For example, some individuals may provide support and advice, while others will seek out or use this support

and information. There are also different levels to participation; some members will lead discussions, others will contribute to discussions, while some members may simply view discussions without contributing themselves i.e. 'lurk' (Iriberri & Leroy, 2009).

Lave and Wenger (1991) and Kim (2000) propose a five stage model for understanding the cycle of how users become incorporated into different online communities, ranging from bulletin boards and blogs to video sharing websites like youtube. They argue that members will typically begin their life in an online community as guests or 'lurkers'. These members may visit the community from time to time to view messages or search for specific information but will not contribute to any of the discussions. After a period of time some individuals might move to the 'novice' stage and begin active participation in the community. Novices will often post introductions about themselves and their current situation or start to tentatively contribute to a few discussions. After contributing for some time these individuals may become 'regulars' of the online community. Regular members visit the support community frequently to exchange support and information or interact with other participants. If these members continue to participate they become 'leaders'. Leaders are recognised as veteran members of the community. These members may take on a support role within the group and help to sustain and connect members of the community. This could be through regularly responding to new messages, leading discussions or inviting others to contribute on particular topics. The final stage of membership is when an individual becomes an 'elder' of the community. Elders are those members who are in the process of leaving the community due to a change in circumstances, new interests, new positions or new outlooks. For example, in an infertility

support community an elder might be someone who has resolved their infertility either through treatment and adoption or acceptance of a childless life; and no longer feel the need to be part of a support community.

3.4.2 Level of participation

To date little is known about the reasons why some members become active contributors of online communities, while other members are less involved. There are however several ideas which have emerged in the literature; Kollock (1999) propose three motivations for contributing to an online community. Firstly, anticipated reciprocity, where an individual is motivated to offer help and support in the expectation that they will also receive the same support and information when required. Secondly, for a sense of efficacy, where members will contribute useful information or support to the other members in the belief that they are having a valuable impact on the community, which may help to promote their own self-efficacy. Thirdly, to gain increased recognition and build up a reputation in the online community. This is particularly evident in online communities such as Amazon and eBay where a member's status and subsequent success in the community is influenced by the recognition they receive. The extent to which increased recognition is a motivating factor in social support communities is less clear.

Another approach for understanding participation in online communities is through the uses and gratification model. The basic premise of the model is that people are motivated to use mass communication in order to gratify a range of needs or goals (Blumler & Katz, 1974). Thus, when considering level of participation in online communities the theory would suggest that

members are motivated to be passive or active participants depending on which activity offers the best means of meeting their needs. For example, individual's who wish to obtain information whilst also maintaining anonymity, may find gratification in 'lurking' (Nonnecke & Preece, 2000). In comparison, individuals who wish to connect with other participants and develop new friendships will be motivated to take a more active role in the online community. Although the theory offers a useful way for examining participation in online communities, it has not yet been extensively utilised in the literature to understand participation in health-related online support communities.

3.4.3 Lurking behaviour

Individuals who access online communities but do not participate are referred to as 'lurkers'. Lurking describes the act of 'reading messages posted by others on electronic spaces, without also posting ones own messages or in any way signalling ones vicarious observation' (Walther & Boyd, 2002, p168). It is estimated that 'lurkers' make up the largest group of individuals using online communities (Katz, 1998). Nonnecke and Preece (2000) argue that while some communities have no 'lurkers' others have rates as high as 99%. For example, 'lurkers' are thought to make up an average of 45.5% of participants in health-related online support communities (Nonnecke & Preece, 2000).

Despite the prevalence of lurking little is known about the online experiences of 'lurkers' and their motives for visiting online communities, including those relating to infertility. This is in part due to the difficulty of identifying and accessing the views of individuals who choose to remain entirely anonymous. In an attempt to redress this, Preece, Nonnecke and

Andrews (2004) surveyed 219 'lurkers' from 375 MSN bulletin boards to explore their reasons for not posting. The most frequently selected reason for lurking were 'just reading/browsing is enough' followed by 'still learning about the group', 'shy about posting', 'nothing to offer' and 'no requirement to post.' It was observed that many individuals lurked while familiarising themselves with the dynamics and norms of the community. Others commented that by not posting their views they felt they were being helpful e.g. not pretending to be an expert.

Attention has also focussed on investigating differences between the attitudes of 'lurkers' and posters. Research findings indicate that posters perceive a greater sense of community membership in comparison to 'lurkers', who appear to be less positive about the benefits of community participation (Nonnecke, Andrews, & Preece, 2006; Okleshen & Grossbart, 1998; Preece, Nonnecke, & Andrews, 2004). Okleshen and Grossbart (1998) suggest that this might arise from the fact that members who do not actively participate in online discussions will often feel like distant outsiders who are simply observing a separate group of people interacting.

Some authors argue that individuals reading messages within patient support communities on the contrary, are likely to feel empathy with the stories they read due to their shared experiences. As a result these 'lurkers' may perceive a stronger sense of membership and connection to the community (Preece, 1999). Walther and Boyd (2002) propose that patients lurking in online support communities will therefore derive similar benefits to that of active participants. They argue that since patients can obtain information, support and validation of their feelings of stigma through reading other people's messages and without having to contribute

anything themselves, lurking may be as beneficial as active participation. Lurking can also function as a helpful way for patients to find answers to frequently asked questions without overloading the group with a repetition of earlier queries (Soraka, Javoci, & Ur, 2003).

However, there remains a scarcity of empirical work exploring the phenomenon of lurking in the context of health-related support communities. Recently, van Uden-Kraan et al. (2008b) investigated self-reported differences in the benefits associated with participation between 'lurkers' and posters in various online patient support communities. Results indicated that both 'lurkers' and posters gained a range of benefits from the online communities including feeling better informed, enhanced self-esteem, feeling more confident with physicians, and improved acceptance of the disease. Thus, offering support for Walther and Boyd's argument. However, in line with findings from other types of online communities, the study found that 'lurkers' were significantly less satisfied with the online community compared to posters and had poorer social and mental well-being. This suggests that although individuals can benefit from reading messages, individuals who lurk may be less satisfied with their online experiences than active participants and have poorer psychological well-being. It is thus important for future research to examine the efficacy of online support communities for both posters and 'lurkers'.

3.5   The nature of online communication

3.5.1   What do people talk about?

The past decade has seen a considerable increase in the number of published studies investigating the nature of online communication. In the

health domain, many published studies thus far document the topics discussed by patients in various online communities. The main focus of these discussions relate to medical and illness topics such as symptoms, diagnoses, treatments and medication (Finn, 1999; Haker, Laubler & Rossler, 2005; Mursch & Behnke-Mursch, 2003; Perron, 2002; van Uden-Kraan et al., 2008a). However, the discussion of emotions and general everyday conversation is also prevalent in some online communities (Finn, 1999; van Uden-Kraan et al., 2008).

A few researchers have specifically examined discussions in infertility-related online bulletin boards. For instance, Cousineau et al. (2004) conducted a content analysis of an online infertility bulletin board to help inform the development of a psychosocial support CD-ROM for infertile couples. They found that the bulletin board was used predominantly by women to discuss treatment-related topics or emotional issues relating to infertility. A number of messages also contained community updates and 'check-ins'. Another recent study focussed on exploring communication in an online infertility bulletin board for men dealing with infertility (Malik & Coulson, 2008). Results revealed that men utilised the online bulletin board as a venue in which they could talk about their partner's symptoms and disclose their hopes, fears and anxieties about the treatment process.

Recently attention has shifted from exploring topics of communication to investigating the characteristics of communication in online support communities. In particular, there is an emerging body of literature to show the similarities and differences between online communication and face-to-face interactions.

3.5.2 How do they talk?

3.5.2.1 Self-help mechanisms

A small number of research studies have shown that online support communities can provide many of the therapeutic exchanges that occur in face-to-face self-help and support groups (Finn & Lavitt, 1994; Finn, 1999; Haker et al., 2005; Perron, 2002; Salem, Bogar, & Reid, 1997; Schielein, Schmid, Dobmeier, & Spiesl, 2008; van Uden-kraan, 2008a; Weinberg, Uken, Schmale, & Adamek, 1995). For example, Weinberg et al. (1995) investigated the presence of therapeutic factors in an online support community for women with breast cancer. The study was guided by the eleven factors described by Yalom (1995), which are thought to influence the process of change and recovery among patients in group therapy - universality, altruism, instillation of hope, imparting information, catharsis, group cohesiveness, interpersonal learning, imitative behaviour, developing social skills, existential factors and the corrective recapitulation of the primary family experience. Results revealed that women perceived the instillation of hope, group cohesion, and universality to be the most prevalent therapeutic factors. These factors were also moderately correlated with the perceived helpfulness of the community.

Another study developed a coding system of 14 categories to examine the extent to which communication in an online community focusing on issues of disability reflected the helping mechanisms found in traditional self-help groups and the theoretical advantages and disadvantages of online support communities outlined in the literature (Finn, 1999). The study concluded that the online community provided many of the helping techniques used in

face-to-face groups. With mutual support, empathy, problem-solving, information seeking and the expression of feelings playing a central role in community interactions.

Perron (2002) coined the term self-help mechanisms to describe the parts of messages that facilitate the development of supportive or helping relationships among members of a community. Their analysis of communication in an online community for caregivers of people with a mental illness found that similar to face-to-face groups, members of the online community utilised a range of self-help mechanisms. Specifically, self-disclosure and the provision of information or advice were found to be a central focus of many of the messages posted to the online community. Similar findings have been observed in studies examining self-help mechanisms within online schizophrenia and bipolar affective disorder support communities (Haker et al., 2005; Schielein et al., 2008).

While these results are encouraging, the literature base examining the therapeutic potential of online self-help communities is still relatively small. Moreover a large proportion of these studies have focused on examining online communities revolving around mental health issues and cancer. The extent to which online support communities are effective in providing therapeutic processes known to be beneficial, to patients suffering from infertility problems is less clearly understood. A recent study by van Uden-Kraan et al. (2008a) noted subtle differences in the self-help processes occurring in online communities for sufferers of breast cancer, arthritis and fibromyalgia. For instance, breast cancer sufferers engaged in higher levels of empathy and support whereas arthritis sufferers posted more information requests. In comparison, fibromyalgia patients made less use

of self-help mechanisms in general. This suggests that there may be differences between the types of self-help processes occurring in online communities for different health problems. Findings from online communities dedicated to mental health or cancer issues therefore might not be generalisable to online infertility support communities. It is thus important for researchers to explore the therapeutic potential of online support communities across different illnesses and conditions, including infertility.

3.5.2.2 Social support

A larger number of studies have focussed on examining the type and nature of social support exchanged within online communities (e.g. Braithwaite et al., 1999; Bunde et al., 2006; Coulson, 2005; Coulson, Buchanan, & Aubeeluck; Mo & Coulson, 2008; Ravert, Hancock, & Ingersoll, 2004; Tichon & Shapiro, 2003; Wright, 2000). Some of these studies employed content analyses as a means of quantifying the prominence of different categories of social support (Braithwaite et al., 1999; Coulson, 2005; Coulson et al., 2007; Coursaris & Liu, 2009; McCormack, 2010; Mo & Coulson, 2008; Ravert & Crowell, 2008). One study analysed messages posted to an online disability support community for the presence of 5 categories of social support – informational, emotional, network, esteem and tangible aid (Braithwaite et al., 1999). Of the 5 categories it was observed that messages exchanging emotional support, followed by informational support were most prominent, whilst tangible assistance was the least common category. The primary focus of these support messages appeared to relate to life functions affected by disability. For instance informational support typically involved sharing advice and suggestions to help members tend to their self-care and house

keeping needs, while network support aimed to reduce limitations on mobility and access to others. In an analysis of messages posted to an Irritable Bowel Syndrome bulletin board Coulson (2005) also noted that tangible assistance was the least visible category of social support. While the exchange of information concerned with symptom interpretation, illness management and interactions with health-care providers was the most common form of support.

Similar to the findings of Braithwaite et al. (1999) and Coulson (2005) research suggests that informational and emotional support appear to be the most prominent exchanges in online support communities for parenting support (Dunham et al., 1998), sufferers of HIV/AIDS (Coursaris, & Liu, 2009; Mo & Coulson, 2008), Huntington's Disease (Coulson et al., 2007), diabetes (Ravert et al., 2004), breast and prostate cancer (Gooden & Winefield, 2007) hysterectomy patients (Bunde et al., 2006; Bunde, Suls, & Martin, 2007) and an online hospice community (Buis, 2008). Taken together these findings show that online communities can provide a useful venue in which members can seek and give informational and emotional support. The comparatively few examples of tangible assistance on the other hand may reflect a limitation associated with exchanging support via the Internet, as the lack of physical proximity within online communities will inevitably make it harder for individuals to offer and provide this form of support to one another.

Alongside the prevalence of emotional and informational support a number of authors also identify features of online support that appear to be relatively unique to this format. Humour (Hwan et al., 2010; White & Dorman, 2000), personal narratives/journals (Klemm, Hurst, Dearholt, &

Trone, 1999) and poetry (Braithwaite et al., 1999) have all been found to play an important role in supportive exchanges taking place in various online communities. For example, Braithwaite et al. (1999) found that many members of the online disability community joked about their own problems as a method of conveying empathy and in some instances used poetry to express emotional support. In an analysis of postings to an online support community for persons with implantable cardioverter defibrillators, Dickerson, Flaig and Kennedy (2000) observe that alongside information exchange and supportive interactions, storytelling was commonly used as a means of establishing a common grounding with fellow members.

From these studies it is apparent that socially supportive communication appears to play an important role in the interactions that occur in online support communities. To date, however there are no specific studies that examine the exchange of social support in online communities for infertility. Little is therefore known about the type and nature of social support exchanged online by people coping with infertility issues.

3.5.2.3 Empathy

Online support communities provide patients with a unique opportunity to communicate with a large network of individuals affected by similar health problems. Members can thus seek advice, reassurance and companionship from people who have first hand understanding of the challenges and emotions surrounding a particular illness (Wright & Bell, 2003). Perhaps unsurprisingly, therefore empathy appears to be a particularly salient feature of communication in online support communities (Bar-Lev, 2010; Finn, 1999; Perron, 2002; Preece, 1998; van Uden-Kraan, 2008a). Broadly speaking empathy refers to the ability to identify with another individuals

feelings or situation. Levenson and Ruef (1992) define empathy as knowing what another person is feeling, sensing what another person is feeling and responding compassionately to another person. Empathy can thus build a sense of trust and community among a group of people (Yalom, 1995). Potentially, leading to reduced isolation and higher perceptions of social support.

Several authors have commented on the role of empathy in online patient support communities. Preece (1998) described 3 types of empathic communication found in online communities – messages empathising with one's situation and suggesting ways to cope, messages empathizing about lifestyle, and messages indirectly eliciting empathy through self-disclosure. For example, when observing communication patterns in various online support communities, Preece (1998) was struck by the number of similar questions that were repeatedly asked in the same communities. However on closer scrutiny it appeared that in asking these questions participants were not simply searching for factual information but were in fact identifying and seeking communication with people in similar situations.

In a follow-up study, Preece and Ghozati (2001) investigated the presence of empathy in 100 different online communities. Empathy appeared to be a common component of many of these communities. Interestingly, the focus of the online community appeared to influence empathic communication, with support communities showing considerably higher levels of empathy than non-support oriented communities. Notably, only 1 of the 19 communities with no empathic messages was a support community. There was also a suggestion that moderation could influence empathic communication, since moderated communities tended to include

more empathic messages and fewer hostile exchanges when compared to communities without a moderator. This indicates that certain attributes of an online community (e.g. moderation) may serve as a means of encouraging empathic communication and simultaneously reducing hostile communication. With the continuing growth of online support communities this is one area that would benefit from further investigation. Allowing researchers, health care professionals, and site developers to develop and maintain online support communities that promote positive communication.

3.5.2.4 Paralanguage

The presence of socio-emotional communication within online communities contrasts sharply with early theories about computer-mediated communication, which characterise online interactions as impersonal or antisocial (Walther et al., 1994). These theories, often referred to as the 'cues-filtered' out approaches, argue that the lack of non-verbal cues and physical proximity in computer-mediated communication depersonalises online interactions leading to fewer instances of socio-emotional communication compared with face-to-face communication (Kieslar, Siegel, & McGuire, 1984). For instance the Social Presence Theory asserts that the lack of social presence cues in the online medium lead to reduced socio-emotional content and increased uninhibited communication such as the occurrence of flaming or verbal harassment (Short et al., 1972).

More recently, however several alternative theories of computer-mediated communication have been developed to explain the occurrence of supportive and socio-emotional communication observed in the literature. One such theory, the social information processing perspective asserts that

online communicators will adapt their existing linguistic and textual behaviours within the constraints of the computer-mediated environment in order to present effective socio-emotional information through their communications (Walther, 1992). For example, Carey (1980) argues that Internet users have developed an electronic 'paralanguage' to express socio-emotional information. The term paralanguage conventionally refers to non-verbal elements of communication such as body language or the pitch, volume, and tone of speech. These complimentary features of conversation are thought to be invaluable for understanding meaning and expressing emotions. Within the context of online communication some of the linguistic aspects of speech could be conveyed using intentional misspelling (e.g. yeees), repeated use of grammatical markers (e.g. !!!!! or ?????????) or capitalisation to emphasise a particular point. Emoticons (i.e. a textual or graphical portrayal of an Internet user's mood or expressions) are also widely used to convey non-verbal information. The most common emoticons include smiley :-) and sad :-(faces. However, these basic representations have now advanced to incorporate more complex images such as cartoons and moving pictures. Thus, offering Internet users a wide variety of visual options for expressing emotions.

Indeed, several studies examining online support communities report that non-verbal cues such as emoticons are frequently embedded in support messages to convey physical and emotional affection (Braithwaite et al., 1999; van Uden-Kraan et al., 2008a). The extent to which these techniques are effective in expressing care and compassion to participants is less clear. Some individuals entering an online support community may find it difficult to adjust to an electronic paralanguage, particularly if they are unaccustomed to communicating via the medium of the Internet. There

are also cultural differences in the use of emoticons (Kayan, Fussell, & Setlock, 2006), which could lead to problems in the expression of non-verbal information to members from other parts of the world. To overcome this some websites provide guidelines for newcomers in which common terms and abbreviations are outlined (Mendelson, 2003; van Uden-Kraan et al., 2008a).

The social information processing theory also contends that although the exchange of socio-emotional information might be slower in online interactions than face-to-face relationships, it is potentially just as potent over time provided there is opportunity for multiple message exchange. Walther (1994) argues that early computer-mediated communication experiments were typically time limited and did not allow sufficient time for the exchange of both task-related information and socio-emotional communication. Thus, leading theorists to falsely conclude that online interactions will typically be less personal and social than offline communication (Walther, 1994). In their review of the literature Walther, Anderson, and Park (1994) identified that groups with no time restrictions displayed significantly higher levels of socio-emotional communication than time restricted groups. Moreover there appeared to be little difference between the levels of social communication in the online support communities compared to face-to-face groups.

3.5.2.5 Hyperpersonal communication

Walther (1996) coined the term hyperpersonal communication to describe the strong interpersonal exchanges that occur within some online communities. Hyperpersonal communication is a phenomenon in which people feel they can better express themselves in a computer-mediated

environment compared to a face-to-face context. Communicating via the medium of online support communities, thus allows participants to achieve greater intimacy and more socially desirable communication over time than they would in parallel face-to-face discussions. The hyperpersonal model asserts that there are four unique characteristics to online communities, which might facilitate this type of supportive communication. First, members of an online community can develop an idealised perception of the people with whom they are communicating due to the common social categorisation they share. For example, the social identity deindividuation theory (SIDE) contends that in the absence of face-to-face cues and personal knowledge, social context cues in online interactions will take on greater significance and lead to over attribution of participant similarity. This in turn may lead to higher levels of socioemotional and supportive communication, since there will be a heightened sense of connection between participants (Walther, 1996). Second, the lack of social presence in online communities means that members can be highly selective in what they choose to disclose about themselves. Thus, providing the ideal opportunity for optimised self-presentation. Third, the asynchronous mode of communicating in an online community allows participants to spend time carefully crafting their messages and digesting information. This may assist members in creating an idealised representation of themselves to other participants. Finally, Walther (1996) talks about the notion of a feedback loop, whereby each message exchanged reinforces the idealised perception that members have of one another.

From the literature examining online support participation it is apparent that online communities can facilitate the development of strong interpersonal relationships and supportive interactions (Preece, 1999; Robinson, 2003; Weinberg, Schmale, Uken & Wessel, 1996; Wright & Bell,

2003). The extent to which this surpasses normal levels of interpersonal communication that would be found in traditional face-to-face settings has not been examined. However some studies indicate that the unique features of an online support community (e.g. limited physical cues, asynchrony) do in fact influence patterns of hyperpersonal communication (Henderson & Gidling, 2004; Medvene, 1990).

3.5.2.6 Self-disclosure

Alongside the development of strong interpersonal relationships, evidence suggests that Internet behaviour is also characterised by high levels of self-disclosure (Parks & Floyd, 1996). Archer (1980) defines self-disclosure as the act of revealing personal information to others. Computer-mediated discussions are thought to contain higher levels of disclosure compared to face-to-face discussions (Joinson, 2001). Patients discussing their conditions via a computer appear to be more honest and open about their experiences, for instance clients at a STD clinic reported more symptoms when interviewed by a computer than face-to-face by a doctor (Ghanem, Hutton, Zenilman, Zimba, & Erbelding, 2005). In a similar vein psychiatric interviews conducted using a computer were found to yield more candid answers compared to face-to-face interviews (Wallace, 1999).

This phenomenon is also apparent within online support communities (Barak & Gluck-Ofri, 2007). As outlined earlier, content analyses of various online communities reveal that participants frequently disclose extremely personal and intimate details when discussing their conditions and seeking/giving support (e.g. Finn, 1998; Perron, 2002; Winzelberg, 1997). For example, Dickerson et al. (2000) noted that messages posted to an online community for persons with implantable cardioverter defibrillators

would often involve discussions about the emotional issues associated with having the device and the fear of dying. Salem et al. (1997) also note that participants in an online community for depression appeared to engage in considerably more emotional support and self-disclosure than comparable face-to-face interactions. Similarly, a recent study by Rodham, McCabe, & Blake (2009) found that an online bulletin board offered people with complex regional pain syndrome a unique venue in which they could express emotions and experiences linked to their condition. It would thus appear that the Internet can offer a valuable forum in which patients suffering from a range of conditions can share sensitive experiences.

One factor that might explain the high levels of self-disclosure observed in these online communities is the anonymity associated with computer-mediated environments. Online support communities provide individuals with the opportunity to keep their identities entirely anonymous, this may encourage certain individuals to disclose information that they may otherwise feel uncomfortable discussing with others due to the possibility of a negative reaction. As Caplan and Turner (2007) point out the anonymity offered by these communities may help to 'establish a safe and secure environment in which participants are willing to discuss deeply personal and upsetting matters' (page 989). Indeed, research conducted by Henderson and Gilding (2004) reveals that Internet users felt that the anonymity associated with the Internet encouraged self-disclosure and the development of online friendships. Similarly, in a survey of 492 mental health community users, Kummervold et al. (2002) found that that 75% of participants felt more comfortable discussing their problems online than face-to-face. Additionally, many stated that without the ability to adopt a pseudonym they would not have participated. Furthermore, Medvene

(1990) suggest that the lack of non-verbal cues in the online environment may promote perceptions of similarity thus heightening participant's comfort in disclosing personal information.

Tichon and Shapiro (2003) argue that self-disclosure plays an important role in the elicitation and provision of support. In their examination of messages posted to a group listserv for siblings of people with special needs and learning difficulties, self-disclosure was used in three distinct ways. Firstly, self-disclosure was used by participants to elicit support and start a relationship with other members, for example members would often share concerns and problems with the community to generate a discussion about ways to cope with their problems. Second, self-disclosure was used by support providers to demonstrate that successful coping is possible through disclosing similar experiences where they had successfully coped. Finally, self-disclosure was used to share social companionship with other members. Some research lends support to these findings; Dickerson et al. (2000) found that sharing personal stories as a method for setting the common ground of the community and establishing credibility was a common theme in an online implantable cardioverter defibrillators support community. Similarly, Campbell-Eichorn (2008) noted that participants accessing eating disorder communities would often share experiences as a method of soliciting informational support and advice. Some authors also report that users frequently share their individual treatment experiences in order to offer advice to individuals seeking treatment information and facilitate social support exchanges (Coursaris & Liu, 2009; Cunningham, van Mierlo, & Fournier, 2008; Mendelson, 2003). From these findings it is evident that the disclosure of personal experiences can play a significant

role in the communication of social support within many online communities.

3.5.2.7 Negative statements

To date there are no published studies examining negative statements in online infertility support communities. However, research carried out in other health-related online communities suggests that contrary to concerns in the literature the occurrence of flaming appears to be relatively rare in online support communities. For example in the work of Finn (1999) there were no hostile or aggressive comments found in their sample of 718 messages posted to an online community. Perron (2002) report only 1 message out of 160 that contained disrespectful comments directed at another participant. This message received no response by other members. Likewise, in an analysis of 1500 messages from 3 different online support communities, van Uden-Kraan et al. (2008a) found only 20 messages that could be categorised as containing negative remarks towards other members. On the whole these remarks did not appear to have a significant impact on the dynamics of the online community.

However, it should be noted that the primary focus of these studies was to quantify the occurrence of a set of predefined categories, thus the researchers might have missed messages which caused offence to members but were not explicitly abusive, humiliating or inflammatory. One such example can be found in the recent work of Rier (2007), who analysed data from HIV/AIDS online support communities. Results showed that members would frequently engage in intense discussions regarding the moral and ethical dilemmas of disclosing HIV+ status. Often these exchanges would include harshly expressed moral judgements and

attempts to enforce ethical views on other members. While these postings were not explicitly abusive, the harsh tone adopted by some members was described as akin to flaming. Consequently, it may be that content analyses of bulletin board postings are limited in the extent to which they can provide insights into flaming within online support communities.

Another limitation of content analysis is the fact that it does not allow the researcher to explore the impact negative exchanges have on how people feel towards the community and their subsequent online behaviour. Hence, a more triangulated research design employing interviews and survey methodologies, alongside bulletin board analysis is needed to both understand the occurrence of negative communication and the impact this has on the dynamics of the group and individual experiences of online support seeking.

3.5.2.8 Gendered Communication

Distinct gender differences in how men and women communicate and seek support for health-related concerns are widely documented in the literature. There is considerable evidence to suggest that men of different ages, ethnicities and social backgrounds are less likely to seek help from health care professionals for physical and mental health issues when compared to women (Addis & Mahalik, 2003; Biddle, Gunnell, Sharp, & Donovan, 2004; Galdas, Cheater, & Marshall, 2005). Men also differ in their likelihood of seeking peer support. Whilst, women typically have a larger network of people in whom they can confide and turn to for social support; in adulthood men tend to rely exclusively on their partner as their sole confidante and source of emotional support (Harrison, Maguire, Pitceathly, 1995). This is particularly evident in the use of face-to-face

support groups, which are more likely to be populated by female participants than male participants. For example, in many cancer support groups women have been found to outnumber men at a rate of four to one (Cella & Yellen, 1993).

Differences have also been observed in how men and women utilise cancer support groups; while females show a stronger preference for emotion-focussed support groups, males appear to prefer information and task oriented support groups (Gray, Fitch, Davis, Phillips, 1996). This mirrors findings from the wider literature on gender differences, which indicates that when faced with a problem men value concrete assistance or activities that distract them from their problems far more than the discussion of their emotions (Wood & Inman, 1993).

The question of whether similar differences exist in the use of online communities has only just begun to be explored. It was originally hypothesised that gender differences might not be as profound in computer-mediated environments due to the absence of gender-related cues. However, recent studies indicate that gender differences appear to be equally apparent in the way men and women use the Internet as a source of communication and support.

In accordance with the offline literature, research findings indicate that men tend to use the Internet primarily for information gathering and entertainment, while women view the Internet as a vehicle for communication (Shaw & Gant, 2002). Furthermore, it has been reported that women are more likely to use the Internet for seeking health and medical information than men. For example, in a recent survey of online health-related information seeking, Von Knoop et al (2003) found that 72%

of women online looked for health-related information compared to only 52% of men online. A similar pattern in also reflected in the use of the Internet for infertility issues (Haagen et al., 2003; Huaang et al., 2003; Weismann et al., 2000).

Gender differences in the use of online communities have also been examined. Herring (1993) analysed male and female participation in two online academic discussion lists. Results indicated marked differences in the style of communication adopted by men and women. While women's postings were characterised by the exchange of advice and supportive comments, men's postings contained higher levels of sarcasm and self-promotion. Wolf (2000) examined emoticon usage in online news communities. They noted that men appeared to incorporate emoticons into their posts primarily to express sarcasm or teasing, whereas women used them for purposes of expressing humour, thanks or solidarity. Other studies have shown that compared to women, men use fewer emoticons in general when posting messages to online communities (Witmer & Katzman, 1997). These findings may arise from gender differences in socialisation. Traditionally, men have been less willing to express their feelings in public, consequently male participants of online communities may avoid using emoticons or supportive communication to express themselves due to the 'public' nature of many online communities.

In the context of health-related online support communities, research suggests that men appear to prefer online communities that offer factual information or practical advice, whereas women prefer to use online communities as an outlet for personal emotions and a source of emotional support. Burri, Baujard and Etter (2006) analysed messages posted to a smoking cessation support community and found that female participants

posted more messages containing expressions of emotional support, while male participants posted more general commentaries and practical advice. It was also found that women were more likely to congratulate fellow members than men were. Preece (1999) identified similar results in a study examining an online bulletin board for individuals with a torn Anterior Cruxiate Ligament (ACL). This study revealed that messages posted by men contained more factual information while women's messages focussed on seeking and providing empathic responses. It was observed that whilst women asked for emotional support directly, men would often elicit empathic responses indirectly, for instance through posting detailed descriptions of their injuries.

A similar pattern has been observed in online cancer support communities; in a comparison of the content of an online Ovarian and Prostate Cancer bulletin board, Sullivan (2003) observed marked gendered styles of communicating. Men in the prostate cancer bulletin board engaged predominantly in the exchange of factual and medical information. In contrast women in the ovarian cancer community used the bulletin board as a venue to seek and provide emotional support. Members of the ovarian cancer bulletin board appeared to be at ease disclosing highly personal and emotional information. Women focussed their discussions on sharing feelings and daily experiences, while men in the prostate cancer community focussed their messages on factual details such as the discussion of research articles and statistics relating to their case.

Sullivan (2003) also reports that the language used by men and women in the two bulletin boards differed greatly. Ovarian cancer patients tended to adopt a style of talk emphasizing co-operative and intimate communication, whereas prostate cancer patients largely engaged in an

instrumental and highly quantitative style of talk. These findings conform to what Tannen (1990) describes as "rapport" and "report" talk. Rapport talk refers to a style of communication preferred by women and report talk refers to a style of communication favoured by men. Similar gendered styles of talk have been identified in other areas of computer-mediated communication, for example according to Kaplan and Farrell (1994) women's online conversations tend to resemble "rapport" talk rather than "report" talk.

This trend is also apparent in studies comparing breast and prostate cancer online communities; Klemm et al. (1999) completed a content analysis of 947 messages posted in three online cancer support communities: a breast, prostate and colorectal cancer community. Messages giving/seeking information were ranked.first in the prostate cancer community and in the breast cancer community messages concerned with personal experiences were given top priority. Furthermore posts by men were twice as likely to contain the exchange of information whereas posts by women were more than twice as likely to feature messages of encouragement and support. These differences were apparent across all three cancer communities.

Other researchers have found that breast cancer patients tend to use a higher number of emotion related words (Davison & Pennebaker 1997; Owen, Klaplow, Roth, & Tucker, 2004) and are more likely to submit multiple messages (Owen et al., 2004) with a supportive orientation in online cancer-related discussions (Blank & Adams-Blodnieks, 2007). Prostate cancer patients on the other hand are more likely to focus on cancer and treatment related concerns (Blank & Adams-Blodnieks, 2007; Owen et al., 2004) and are less likely to seek emotional support or

repeated interaction (Owen et al., 2004). Davison and Pennebaker (1997) also report that prostate cancer patients tend to use a low rate of self-references in their online interactions and were more likely to distance themselves from other users.

Gender differences are also apparent in the use of online cancer communities by relatives of patients. Blank & Adams-Blodnieks (2007) note that partners of prostate cancer patients were more likely to access an online support community, than partners of women with breast cancer. This has also been noted in face-to-face cancer support groups, for example Gray et al. (1996) found that men typically viewed prostate cancer as a family issue and were keen to encourage their partners and grown up children to participate, whilst women generally felt meetings should remain focussed on the needs of women with breast cancer since their husbands had limited tolerance for listening to cancer-related concerns. This reflects gender stereotypic behaviours, as traditionally women are more likely to take an active role in seeking health-related information and support for themselves as well as for their family (Blank & Adam-Blodnieks, 2007).

In contrast some studies reveal more subtle gender differences. For example, Gooden and Winefield (2007) qualitatively analysed postings to breast and prostate cancer communities. The results showed that both men and women predominantly used the communities as information seeking forums and did not differ in the extent to which they engaged in information or emotional support. The authors concluded that users of the breast cancer bulletin boards were informed by similar needs and expectations regardless of gender. Despite this however, subtle differences

were observed in the way men and women conveyed support to one another. Women offered expressions of affection and nurturing, while men tended to provide lengthy accounts of research findings and medical reports. Furthermore, men were found to use jokes and humour to cope with issues and were more likely to provide encouragement through the use of battle like terminology aimed at promoting strength e.g. 'at war with cancer'.

Thus, on the whole current research implies that communication in online communities follows the gendered norms of interaction observed in face-to-face communication. However, the majority of studies assess gender differences through comparing postings to online cancer support communities; predominantly prostate and breast or ovarian cancer communities (Mo, Malik, & Coulson, 2009). While this approach offers a convenient and accessible method for exploring gender differences in health-related online communication, it is important to note that different conditions may be accompanied by differing psychosocial needs that influence the type of social support sought by patients. In comparison to individuals diagnosed with breast cancer, prostate cancer patients have less well-defined treatment options and thus less readily available information concerning what to expect from treatment (Owen et al., 2004). As a result, these individuals may be particularly interested in obtaining information on the medical and treatment-related side of cancer from patients who have been through similar experiences in order to gain a better understanding of what to expect. In contrast, since breast cancer patients already have access to a wealth of information regarding treatment options, these individuals may be likely to prioritise emotional expression and support when interacting with peers. Consequently, the

differences identified between prostate and breast/ovarian cancer patients may in fact reflect the differing needs of the two groups rather than the gender of the participants alone (Mo et al., 2009).

In fact, some studies investigating other single-sex online communities suggest that the Internet might remove some of the gender differences that exist in offline settings. For example, a study of communication patterns within an online support community for fathers of children with Spina Bifida, Nicholas, McNeill, Montgomery, Stapleford and McClure (2003) found that after an initial exchange of information men often switched the content of their messages to emotional expression and the provision of emotional support. There is also some evidence to suggest that the anonymity of the Internet might facilitate self-disclosure among men, for instance in a study exploring communication within a bulletin board dedicated to men coping with infertility, Malik and Coulson (2008) found that the men accessing the online support community were experiencing a range of negative emotions as a result of infertility and thus valued the online community as a useful venue in which they could open up about their emotional experiences and concerns. In a similar vein, a study examining online communication among divorced, non-residential fathers, uncovered an intensity of feelings related to the experience of being a non-residential father, which had not emerged in previous interview and focus group studies with this population (Erera & Baum, 2009). Future research should thus endeavour to compare gender differences by examining online communities for various health-related conditions, in order to explore the extent to which the current findings are replicated.

The composition of the online community may be another important factor to consider when assessing gender differences. In a series of studies by Savicki and Kelley (2000), the variable with the strongest relationship to online communication style was found to be the gender composition of the community in which the communication took place. Same sex communities illustrated gendered patterns of communication, while mixed sex communities varied between the two gender extremes. Through closer examination it was concluded that a community is likely to adopt the communication style of the predominant gender.

Findings from research examining online communities report similar patterns, for example Herring (1993) noted that minority genders in academic bulletin boards appeared to adapt to the dominant gender style of interaction. Baym (1996) found that men in a female dominated discussion adopted less aggressive styles of communication than men in male dominated discussions. Similarly, in a study of online emoticon use, Wolf (2000) found that when moving from same to mixed sex newsgroups, men's use of emoticons increased significantly. Furthermore, in an examination of postings by relatives of breast and prostate cancer patients Seale (2006) found that men participating in the breast cancer community adopted a style of communication very different to their gender stereotype. These men prioritised the emotional welfare of family members and focussed on emotional communication. However, in comparison women in the prostate cancer bulletin board adopted a style similar to women elsewhere i.e. emotion focussed. The authors suggest that this may be due to the fact that there were a larger number of frequently posting women in the online prostate cancer community, whereas in the breast cancer community men were in a minority. As a result, women may have felt

more comfortable adopting their normal style of communication. In addition, men using the breast cancer bulletin board were often responding to the anticipated loss of a partner and therefore had a higher need for emotional expression and support. Taken together these studies suggest that the purpose and composition of online communities may be important factors when exploring gendered communication.

3.5.2.9 Summary

In summary, research exploring communication processes in online support communities indicates that the Internet can offer many features of the socially supportive communication that is seen in face-to-face interactions. Furthermore, the unique characteristics of the Internet appear to facilitate high levels of self-disclosure and hyperpersonal communication. These findings point to the therapeutic potential of online support communities. However, it should be noted that there is a distinct lack of research focusing specifically on communication that occurs in online infertility support communities. The few studies that have examined online support in the context of infertility have focused on determining topics of discussion rather than communication processes as such. Thus, from the current literature base it is difficult to draw conclusions regarding the therapeutic potential of online infertility support communities. Further work is required to illuminate the nature and type of communication taking place in online infertility support communities.

Moreover from an analysis of messages alone it is difficult to determine the extent to which online communities are beneficial to participants. It is thus important to examine both the processes that occur online as well as the

specific therapeutic and psychosocial outcomes associated with accessing an online community.

3.6 Psychosocial benefits of online support communities

To date, there is a distinct lack of outcome research evaluating the efficacy of health-related online support communities. Most quantitative studies in the literature focus on professionally developed online support communities or comprehensive computer support programmes. In addition, to communication features that allow participants to engage in online discussion with other users. Comprehensive support services typically incorporate a wide array of interactive features including question and answer functions, decision-making and problem-solving aids, encyclopedia reference materials and individually tailored behaviour change support (White & Dorman, 2001). Two of the most extensively researched comprehensive computer support systems for chronic health conditions are the Comprehensive Health Enhancement Support System (CHESS) (Bosworth & Gustafson, 1991) and ComputerLink (Brennan, 1996). The basic format of these interventions have been tailored to meet the needs of individuals suffering from various health conditions such as Breast cancer, Prostate cancer, Alzheimer's disease, Asthma and HIV and AIDS, and for patients from different socio-demographic backgrounds. Randomised controlled trials and observational studies assessing the impact of these computer systems indicate that usage may be associated with a variety of positive outcomes including improved emotional well-being and quality of life, more efficient use of health care systems and improved ability to cope (e.g. Bass, McClendon, Brennan, & McCarthy, 1998; Brennan, Ripich, & Moore, 1991; Gustafson et al., 2005; Gustafson et al., 2001; Gustafson et al., 2008). In addition, a number of studies note that the communication

features of the support systems appeared to be the most heavily accessed functions (Boberg et al., 1995; Brennan et al., 2001; Brennan, 1996; Gustafson et al., 1994). This suggests that participants may particularly value and benefit from computer support interventions that offer the opportunity to interact with other patients.

Some researchers have specifically examined the feasibility of computer systems in supporting couples undergoing infertility treatment. One team of researchers developed an online personal health record for patients undergoing IVF treatment at a large University Medical Centre in The Netherlands (Tuil, Hoopen, Braat, De Vries Robbe, & Kremer, 2006). The programme contained a range of functions grouped under three categories. Firstly, a general information section containing generic information about infertility and its treatment and links to other Internet resources and frequently asked questions. Secondly, a personal information section offering patient's access to their individual electronic health record, a personalised day planner and personalised information about their prognosis. Finally, a section providing communication functions for patients to engage in synchronous (chat room) and asynchronous (bulletin boards) discussions with one another.

Evaluation of the online personal health record reveals that patients predominantly used the communication function to talk about the psychological, physical, and social aspects of IVF treatment (Van Selm, Tuil, Verhaak, Woldringh, & Kremer, 2008). Those patients who were more anxious at the start of treatment were more likely to make use of the communication features in the programme (Tuil, Verhaak, De Vries Robbe, & Kremer, 2008). Usage of these functions varied considerably during stages of treatment, with patients making most use of the communication

section at times when there was no contact with the clinic (Tuil, van Selm, Verhaak, De Vries Robbe, & Kremer, 2009). This suggests that online communication might provide a valuable avenue for seeking support at times when alternative sources of help are not easily available. Particularly for those individuals who feel highly anxious about their treatment. However, results from a randomised controlled trial of the programme found that although participants were satisfied with the support system, usage did not have any effect on a range of psychosocial outcome measures including empowerment, social support, anxiety, depression and patient satisfaction (Tuil, Verhaak, Braat, De Vries Robbe, & Kremer, 2007).

Conversely, a recent randomised controlled trial in the US of an online education and support programme for female infertility patients, found that women exposed to the programme for a period of one-month showed significant improvement in infertility distress, social concerns, increased self-efficacy and felt more informed about medical decision-making (Cousineau et al., 2008). Furthermore, Haemmerli, Znoj, & Berger (2010) report that an eight-week German Internet-based cognitive-behavioural treatment for clinically depressed infertile patients was successful in significantly reducing depression levels in the sample and was received positively by the majority of participants.

While these studies show that computer-mediated patient support interventions can have beneficial effects for individuals affected by various conditions including infertility, they tell us very little about the effectiveness of the millions of "natural" online support communities found on the Internet (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Most studies evaluate complex interventions with a range of different

components making it difficult to distinguish the stand alone effect of online communication and peer-to-peer support. Furthermore, these interventions are often only available to members of the study. It may be that there are important differences between individuals who volunteer to participate in a research project and those individuals who access online support via the Internet in their day-to-day life. The presence of a researcher and the reduced anonymity of a research environment may also influence online interaction and subsequent outcomes. Consequently, it would be wrong to generalise findings from comprehensive support systems developed by researchers and health care professionals to other online resources.

However, in a systematic review of the effects of health-related online communities, Eysenbach et al. (2004) found only six studies that evaluated pure peer-to-peer online communication. Most of these studies contained relatively small samples sizes and no comparison group, thus limiting the generalisability of the findings. The review therefore concluded that there was a lack of robust evidence for the psychological and health benefits of peer-to-peer online communities. Despite this, there is a growing body of exploratory and descriptive literature to indicate that use of an online support community can be associated with a range of positive psychosocial benefits for patients.

3.6.1 Empowerment

Research indicates that participation in online support communities can have an empowering effect on patients suffering from physical and mental health problems (e.g. Sharf, 1997; van Uden-Kraan et al., 2008c). The term empowerment describes a process through which people gain 'greater

mastery and control over decisions and actions affecting their lives' (WHO, 1998). In the context of health care, empowerment can reflect an increased confidence in ones ability to manage their condition, the ability to access appropriate health information and greater control over health-related decision-making and interactions with healthcare providers. The exact nature of patient empowerment however is complex; various factors can have an empowering effect including a patient's skills and knowledge, trust, locus of control, and a reduction in feelings of hopelessness, isolation and oppression (van Uden-Kraan et al., 2008c). Different patients may also have different experiences and perspectives regarding empowerment (Broom, 2005). Furthermore, empowerment not only reflects an individual's sense of control and efficacy but can also occur at the group and community level (van Uden-Kraan et al., 2008c). There is also a distinction between empowering processes (i.e. the process through which individuals take control of their life) and empowering outcomes (i.e. the psychosocial consequences of empowerment) (van Uden-Kraan, et al., 2008c). Consequently, according to van Uden-Kraan et al. (2008c) empowerment is best understood as a multifaceted concept.

The majority of research documenting empowerment in online support communities has focussed on exploring the empowering processes that take place in messages exchanged between participants (Finn, 1999; Klemm et al., 2003; Perron, 2002; Sharf, 1997). For instance in a discourse analysis of communication in an online breast cancer mailing list Sharf (1997) report that the online community allowed women to express feelings of grief and depression surrounding their experience of breast cancer whilst simultaneously offering a unique source of information and emotional support. This not only resulted in enhanced decision-making but also helped the women meet new challenges associated with breast cancer

and transform their feelings of negativity into optimism. Similarly, Hoybye, Johansen, & Tjornhoj-Thomsen (2005) found that members of an online breast cancer community were empowered by the exchange of knowledge and experience within the community. The support available through the community helped women find new ways of living with breast cancer, and enabled them to gain a sense of control over their situation.

Relatively little work has been conducted to examine the extent to which the empowering processes that occur online lead to empowering outcomes. Some qualitative studies have addressed this issue through exploring empowerment from the perspective of the patient (Broom, 2005; Buchanan & Coulson, 2007; Coulson & Knibb, 2007; Hoybye et al., 2005; van Uden-Kraan et al., 2008c). Buchanan and Coulson (2007) found that dentally anxious individuals accessing an online support community felt that the guidance, encouragement and shared experience offered by the online community empowered them to try to conquer their own fears. The support available from the community also led to a growth in confidence about disclosing dental anxiety to dental professionals. In another study van Uden-Kraan et al. (2008c) asked participants using online breast cancer, arthritis and fibromyalgia support communities about the full range of both empowering and disempowering processes that occur online. Results revealed that empowering processes included emotional support, information exchange, recognition, sharing experiences and helping others. These processes appeared to bring about a number of empowering outcomes namely feeling better informed, a greater sense of confidence about their treatment and interactions with health care professionals, improved acceptance of the disease, increased optimism and self-esteem and greater social well-being. On the other hand, potentially disempowering processes included concerns about the quality of

information, being confronted with the negative aspects of the illness and the presence of complainers. In a follow-up quantitative study, the authors found that the empowering outcomes experienced most strongly by a cross-sectional sample of 528 users were feeling better informed and improved social well-being (i.e. an increase in the number of social contacts and decreased feelings of isolation). Interestingly, the empowering outcomes identified could only modestly be predicted by the empowering processes that took place (van Uden-Kraan et al., 2008). This suggests that focusing solely on empowering processes in online communities is not sufficient for understanding the empowering effect of participation.

These research findings provide evidence for the value of online support communities in empowering patients. Furthermore, in contrast to reports in the literature that suggest the Internet may have a negative psychological effect on users resulting in higher rates of depression, loneliness and social isolation (Klemm & Hardie, 2002; Kraut, Mukhopadhyay, Szezypula, Kiesler, & Scherlis, 1998), it appears that use of the Internet for communicating health concerns can lead to a reduction in isolation and enhanced social well-being. Given that many individuals suffering from infertility, experience feelings of social isolation, this is an important potential outcome that warrants further investigation in the specific context of participation in infertility support communities.

It is also important to further examine disempowering processes online. While van Uden-Kraan et al. (2008c) report that disempowering processes were mentioned far less by their participants than empowering processes, the majority of participants in these research studies were active users who may have been motivated to take part due to particularly positive

experiences. There is some evidence to suggest that the experience of empowerment may differ between active members of an online community and those individuals who only read messages i.e. 'lurk'. For example, one study reports that while posters and 'lurkers' both felt empowered by their online experiences, 'lurkers' experienced significantly lower improvement in social well-being (van Uden-Kraan et al., 2008). Thus, future research should focus on exploring differences in the positive and negative aspects of participation between different levels of use.

Online support communities can also serve as mechanism for community empowerment, whereby participants take collective action to bring about political or social reform (Radin, 2006). This is one aspect to empowerment that has for the most part been overlooked in the literature, with most researchers limiting their definition of empowerment to the individual level. The potential benefit of collective action for people experiencing physical and mental health problems should not be underestimated. Taking part in such activities may lead to improved quality of life and an enhanced sense of control and self-esteem. It is thus important to explore the role that online communities can play in empowering patients at both the individual and community level.

3.6.2 Social comparison

Online communities provide an ideal venue in which individuals can engage in upward or downward social comparison. The social comparison theory postulates that people have an innate drive to evaluate themselves with others around them (Festinger, 1954). There are two main types of social comparison: upward and downward comparison. Upward comparison occurs when an individual compares their own situation with that of others

who are better off than themselves. For instance, individuals undergoing infertility treatment may look to other couples who have been successful with the same treatment in order to gain a sense of hope and positivity (Stanton, 1992). Downward comparison on the other hand involves comparing oneself with others who have more serious problems (e.g. couples who no longer have any treatment options available). This type of comparison is particularly prevalent in populations with serious medical or behavioural problems (Buunk & Gibbons, 2006). It is hypothesised that downward comparison will help individuals to feel better about their own situation and thus lead to increased self-esteem (Stanton, 1992).

Accessing online support communities can increase an individual's chances of finding people with the exact same experiences as themselves and thus widen their frame of reference for making social comparisons. For example, Hadert & Rodham (2008) report that some users of an online arthritis support bulletin board appeared to benefit from the opportunity to read about other peoples negative experiences, which helped them to realise that there were others worse off compared to them. Similarly, van Uden-Kraan et al. (2008c) found that participants in arthritis, fibromyalgia and breast cancer communities also felt that the opportunities for downward comparison helped them to feel more positive about their situation.

An additional benefit of online support communities is the fact that participants can be highly selective in what they choose to read (van Uden-Kraan et al., 2008c). Most online bulletin boards require members to provide a subject heading when posting messages. This can help to give other members an indication of the content of the postings. Additionally, some online communities may organise messages under different sections e.g. 'Newly diagnosed', 'Failed treatment', 'Secondary infertility',

'Pregnancy loss', 'Treatment success' . Thus, participants can potentially seek out specific social comparisons (e.g. messages suggesting positive information), whilst avoiding exposure to those comparisons, which they feel will heighten distress.

3.6.3 Online helper therapy principle

According to Muncer, Burrows, Pleace, Loader, & Nettleton (2000) members of large self-directed online communities will often become responsible for helping one another. The process of helping others can serve as an important coping strategy for people dealing with stressful life situations like chronic illness (Sullivan, 1997). Reissman (1965) argues that the opportunity to give as well as receive support is an important therapeutic element of support groups. This is known as the helper therapy principle, whereby members gain an increased sense of self-efficacy and self-esteem through the process of helping another individual (Reissman, 1965). This type of altruistic behaviour can also distract patients from ruminating on their own problems (Shaw, Han, Hawkins, McTavish, & Gustafson, 2008). The emerging evidence from descriptive and exploratory studies investigating health-related online communities offers support for this contention (e.g. Shaw et al., 2008; Winefeld, 2006). Online communities appear to have the potential to facilitate the development of strong supportive relationships among members (Henderson & Gilding, 2003; Preece, 1999; Robinson & Turner, 2003; Weinberg et al., 1996; Wright & Bell, 2003). These supportive relationships are further reinforced by the appreciation that individuals receive from others, which can result in a feeling of being valued and the motivation for further support giving (Finn, 1999; Meier, 2007; Perron, 2002; van Uden-Kraan, 2008c). For instance, as Winefield (2006) observes some high frequency posters in an

online breast cancer community appeared to function as volunteer providers of information and support. These women tended to provide rather than seek support and reported gaining considerable personal satisfaction from their support role.

Alongside personal gratification, offering support to others is also an important mechanism for helping sustain an online community (Lampell & Bhalla, 2007). While new members may gain a sense of value from sharing their own experiences to help others, veteran members may be motivated by the desire to connect and maintain the community. Future research should therefore focus on exploring the motives and benefits derived from altruistic behaviour in online communities across different groups of users (e.g. new vs. regularly participating members).

3.6.4 Conditions and factors influencing psychosocial outcomes

3.6.4.1 Activity level

Barak and Dolev-Cohen (2006) argue that one moderating variable influencing the effectiveness of online support communities is the degree of active involvement. In their study of online support communities for distressed adolescents there was a significant correlation between levels of activity and distress. Those individuals who posted a higher number of messages and received more replies reported lower levels of distress than others. This pattern of findings is also reflected in studies of other online communities. For example, posting frequency has been linked to an improvement in mood among women with breast cancer (Rodgers & Chen, 2005), more active community orientation and psychosocial benefits

among people with hearing loss (Cummings, Sproull, & Kiesler, 2002) and a resolution of depression in a prospective cohort of members of an online depression support community (Houston, Cooper, & Ford, 2002). Furthermore, in an evaluation of a computer-mediated social support network intervention for parenting issues, Dunham et al. (1998) report that those women who participated in the community regularly were more likely to experience a decrease in parenting stress after the intervention. Similarly, Mo and Coulson (2010) suggest that frequent use of an online HIV/AIDS support community may facilitate more positive coping behaviours.

Taken together these findings indicate that posting frequency is an important factor influencing psychosocial outcomes. This would suggest that those individuals who never post messages to an online community (i.e. 'lurkers') will experience significantly less benefit than those who regularly post messages. While some studies show that 'lurkers' experience less satisfaction with online communities and lower improvement in social well-being from accessing an online community (Nonnecke et al., 2006; Okleshen & Grossbart, 1998; van Uden-Kraan et al., 2008b), thus far, very little research has been conducted to address differences in health and psychological outcomes between patients who post or lurk. However, given the potentially large number of people accessing online support communities as 'lurkers', this constitutes an important area for future research.

3.6.4.2 Types of communication

The way in which individuals express themselves in online communities might also influence the degree of benefit derived from participation. Research indicates that writing about traumatic experiences, particularly the emotions surrounding a traumatic event can lead to long-term physical and mental health benefits (Lieberman & Goldstein, 2006; Pennebaker & Bealle, 1986; Sheese, Brown, & Graziano, 2004). The act of writing about traumatic experiences may help individuals to organise their thoughts and make sense of distressing experiences.

The Internet offers a unique opportunity for people to engage in written expression about these stressful or traumatic life events, within a large network of similar others, whilst also offering the added benefit of complete anonymity. Individuals who choose to share personal experiences or emotions in online support communities may therefore experience therapeutic benefits from the act of self-disclosure alone.

Recently, several studies have examined links between self-disclosure and psychosocial outcomes in peer online cancer communities. Using a computer-based text analysis and word counting programme (the linguistic inquiry and word count), these studies employed a longitudinal prospective design to explore how different types of communication influenced outcomes for breast cancer patients. Two studies found that women who wrote a higher percentage of insightful disclosure words during the study periods appeared to experience greater improvement in mental health outcomes at follow-up (Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2007; Lieberman, 2007). Other research indicates that the expression of specific emotions may influence the degree of benefit from participation.

For example, one study reports that greater expression of prayer and religious belief was associated with lower levels of negative emotions and higher levels of self-efficacy and functional well-being among women with breast cancer (Shaw et al., 2007). In contrast Leiberman & Winzelberg (2009) found no association between religious expression and positive outcomes amongst cancer patients. Another study demonstrated that the expression of anger appeared to be linked to higher quality of life and lower depression in women. While greater expression of fear and anxiety was linked to lower quality of life and higher depression (Leiberman & Goldstein, 2006). In a follow-up study, Han et al. (2008) focussed specifically on the role of expressing positive emotions in online support communities for breast cancer. They found that the effects of writing positive emotion words on breast cancer-related concerns was highest among those participants who also used a high number of negative emotion words. This suggests that the combined expression of both negative and positive affective reactions may be most beneficial for breast cancer patients. However, at the same time another recent study indicates that communicating too much about oneself within an online support community can increase negative emotions in women with breast cancer (Shaw et al., 2008).

This emerging body of literature is of interest to researchers and health care professionals, as it not only offers support for a relationship between online emotional disclosure and psychological outcomes, but further suggests that the type and amount of emotional expressions may also be important. The extent to which these findings can be generalised to infertility online support communities is however unclear at present. Further research is required to explore whether these findings are also of

relevance for people seeking support for other physical or mental health issues like infertility.

3.6.4.3 Peer versus professional moderation

Another factor that may influence physical and psychosocial outcomes is the type of moderation in online support communities. At present there is a paucity of empirical work addressing the impact of moderation. Some exploratory research indicates that moderation in online communities may play an important role in promoting supportive interactions and minimising negative communication (Preece & Ghozati, 2001). This is perhaps unsurprising given that the role of a moderator typically involves establishing the boundaries of a discussion and encouraging members to participate and respond to one another (Lindsay, Smith, Bellaby, & Baker, 2009). However, the extent to which differences exist between peer moderated and professionally facilitated support communities has received minimal attention in the online literature. While anecdotal and descriptive evidence suggests that both types of groups can be beneficial, most studies evaluating outcomes focus on professionally facilitated communities (Eysenbach et al., 2004). It is thus difficult to compare the extent to which the presence of a health professional influences psychosocial well-being.

3.6.5 Summary

In summary, current research indicates that online support communities can be beneficial to users. There are a growing number of exploratory studies which suggest that usage may be associated with a range of psychosocial benefits including a sense of empowerment, improved self-efficacy, and enhanced quality of life. There is also some indication that factors such as activity level, type of communication and moderation may

influence the degree of benefit derived from participation. In the context of infertility, studies have shown that Internet-based cognitive-behavioural treatment and complex online support interventions, which include interactive information resources, professional support and communication features, can be helpful to individuals coping with infertility. However, there remains a lack of outcome research specifically examining "natural" peer-to-peer online communities for infertility issues. As such, it is difficult at present to draw robust conclusions regarding the effectiveness of online peer-to-peer support and the conditions and factors that induce psychosocial benefits in "natural" online infertility communities. Given the growing volume of "natural" online infertility support communities available on the World Wide Web and the large number of couples turning to the Internet to seek support and information for fertility difficulties, this is an area that clearly warrants further investigation.

While anecdotal evidence suggests that online communities may present a novel and beneficial medium through which people experiencing infertility can fulfil their support needs; further in depth research is needed to achieve a more thorough understanding of this phenomenon, particularly in the context of infertility. A detailed consideration of this topic will allow for an insight into both the positive and negative aspects associated with accessing online infertility support communities. This presents an important and much needed area of research, which may ultimately offer professionals involved in supporting infertile patients a means of determining whether there is any risk of harm associated with using online communities and if "natural" online support communities can in fact be recommended to patients as an alternative or adjunct source of support.

3.7 An introduction to the research aims

This chapter has highlighted the need to initiate empirical research into the role of online support communities in the lives of people experiencing infertility. As discussed in the literature review, there remain a number of gaps in our understanding of the phenomenon of peer-to-peer online support. This raises several important and interesting research questions including: how do people communicate in online infertility support communities? Are online support communities as effective as traditional face-to-face support networks? The remainder of this thesis will focus on redressing some of the gaps in our understanding of online communities by presenting the first in depth exploration of the use and experience of online support communities among individuals coping with infertility issues. It is anticipated that the outcomes of this study will extend our knowledge on the psychosocial impact of online support communities and how infertile couples access and use this medium for support and communication. As well as, allow us to explore any potential limitations of the Internet as a support medium and consider whether online peer-to-peer communities can offer a viable source of psychosocial support.

Due to the scarcity of existing empirical work in the area of online support communities and infertility, an exploratory approach to the research topic was deemed most appropriate. Exploratory research is designed to gain a deeper understanding of a particular issue or problem. Hence, the approach is typically used in under-researched areas where the researchers do not have any pre-determined suppositions about the topic under investigation and therefore wish to develop rather than test hypotheses (Kotler, Adam, Brown, & Armstrong, 2006). To this end the research aims for this study were broadly formulated to allow for a detailed insight into

the phenomenon of online support communities and the emergence of significant issues pertaining to the use of this medium by people experiencing infertility.

3.7.1 Research aims and questions

The specific research questions for this study were developed with a view to address three key aims of the thesis:

Aim One: To explore the motives, perceptions and experiences of people with infertility who access and use online infertility support communities.

- What motivates people affected by infertility to access online support communities?

- How do people affected by infertility experience online communities as a source of support and self-help?

- What are the perceived benefits associated with accessing an online infertility support community?

- Are there any negative aspects to accessing online infertility support communities?

- What impact do online communities have on how individuals and couples cope with infertility?

Aim Two: To examine the efficacy of online communities as an alternative source of self-help and social support for people experiencing infertility.

- What are the self-help processes that occur in online infertility support communities? How do these compare to supportive communication that takes place offline?

- How is accessing an online support community associated with the psychosocial well-being of people experiencing infertility?

- Are online support communities harmful in any way?

Aim Three: To consider some of the issues and challenges associated with researching online support communities.

The study was undertaken in three stages, which employed a combination of qualitative and quantitative methodologies to shed light on the research questions. A detailed discussion of the rationale for this and methodological considerations relating to each stage of the investigation are presented in Chapter four. Initially, an exploratory survey was conducted with people who access online infertility support communities. The survey consisted of a series of open-ended questions that aimed to elicit a breadth of qualitative information concerning the perceptions and motivations of infertile people who access online support communities. This provided a rich insight into how people with infertility experience online support communities and identified the issues that were most salient to members. Additionally, the results of the survey were used to inform the development of a larger scale, more quantitative survey. This second survey was

designed to further examine the perceptions of people accessing online infertility support communities and explore use of online support communities and psychosocial well-being. The final stage of the study involved a content analysis of messages posted to an online infertility support community. This stage was undertaken to understand the types of communication that occur within an online infertility support community and explore the therapeutic and self-help potential of "natural" online communities. In addition, findings from this stage of the study served to verify and substantiate conclusions drawn from the self-report data collected from participants. Results from each stage of the study are presented in Chapters five, six and seven. This is followed by a discussion of the practical and theoretical implications / significance of the findings in Chapter eight.

3.8   Integrating theoretical perspectives in online support communities

As outlined above, the studies undertaken as part of this doctoral project were not undertaken to test a particular hypothesis or theoretical model of behaviour, but rather to extend our knowledge on the role of online support communities in the lives of people experiencing infertility. Nonetheless, as Bryman (2004) argues whether a researcher is engaged in theory testing or not; theoretical perspectives and assumptions play an important role in guiding and influencing the research process. All research is underpinned by underlying assumptions or ideas about the relationships between variables, these implicit theories serve to 'direct the attention of the researcher to focus on some things rather than others, to use certain research approaches rather than others, and to try this rather than that form of analysis' (Breakwell & Rose, 2000, p6). Consequently, it is useful

to focus attention on examining and making explicit some of the theoretical perspectives and models that may have influenced the design and interpretation of this investigation at the onset.

This chapter has highlighted a number of theoretical perspectives that have been used to interpret empirical research into online support communities. For example, from the computer-mediated communication literature the Hyperpersonal interaction and SIDE perspectives (Walther, 1996), suggest that in the absence of non-verbal cues, the issue of commonality (e.g. the diagnosis of a specific condition) between members of an online support community will take on particular significance and lead to the occurrence of higher levels of socio-emotional and supportive communication than in comparative face-to-face exchanges. Others have drawn on the 'weak tie' network theory (Walther & Boyd, 2002; White & Dorman, 2001), to describe how online support communities can facilitate access to diverse sources of information, reduce the sense of stigma associated with a particular illness/condition and promote self-disclosure among people who feel stigmatised because of their problem. Another model proposed by Caplan & Turner (2007) focuses on explaining the process and efficacy of online emotional support. The model based on the appraisal theory of comforting communication (Burleson & Goldsmith, 1998), suggests three conditions necessary for effective comforting communication: 1) a willingness on the part of the participant to discuss a distressing matter 2) the discussion is focussed on the individual's thoughts and feelings about the distressing issue and 3) the discussion facilitates adaptive reappraisals of the situation. Caplan & Turner (2007) argue that due to its unique characteristics computer-mediated communication may be better able to facilitate adaptive comforting communication than face-to-face interaction. For example, online support communities offer greater anonymity, access

to weaker social ties and greater control over self-presentation, which may promote greater willingness to engage in self-disclosure when compared to face-to-face communication.

While, these theories capture certain aspects of the phenomena of online supportive communication, they do not provide an integrated framework that can be used to understand and explore the different elements of online support and the complexities of online support seeking. A more comprehensive theory of online social support comes from LaCousiere (2001), who suggests a relationship between the use of online support communities and health and psychosocial outcomes. The theory offers a multidisciplinary perspective to help conceptualise the phenomenon of online support seeking; through four interrelated components: 1) Initiating events, 2) Mediating factors, 3) Online social support processes, 4) Outcomes.

1) Initiating events

The theory contends that the process of online social support will begin with an initiating event, which will prompt the individual to seek out an online support community. Initiating events typically involve either an alteration to the individual's health status (e.g. the diagnosis of a new illness) or an alteration in perceived health (e.g. fluctuations of a chronic illness). For example, in the context of infertility events such as receiving a diagnosis, starting a new treatment cycle, failed treatment or making a decision about when to terminate treatment are all stages at which people are likely to experience an acute need for peer support, which may prompt them to turn to online support communities. Alternatively, some patients may be introduced to online support communities by researchers or health care providers.

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2) Mediating factors

However not all individuals who experience an increased need for support will turn to an online support community or continue to seek support for the same period of time. It is thus argued that online support seeking behaviour is also influenced by a range of mediating factors that work in conjunction with the initiating event. Mediating factors can be divided into four categories; 1) Demographic factors (i.e. age, gender, race, educational background) 2) Internet Use factors (i.e. IT abilities, comfort and patterns of Internet use, previous online help-seeking behaviour) 3) Health factors (i.e. medical diagnoses, medication use, functional status, quality of life) 4) Individual and Psychosocial factors (i.e. differences in coping ability, perceptions of social support, gender socialisation, stress levels, social isolation etc).

3) Online social support processes

Online social support is defined as the 'process of initiating, participating in and developing electronic interactions or means of electronic interaction to seek beneficial outcomes in health care status, perceived health or psychosocial processing ability' (LaCoursiere, 2001, p66). The process of online social support is thought to occur through three filters: perceptual, cognitive and transactional. The first of these filters; the perceptual level describes the feeling or emotional state of the individual seeking support. The second filter refers to the cognitive or intellectual processing of information presented in online support communities. The final filter; transactional processing; is where an unconscious evaluation of all the information received through online support interchanges is undertaken, to determine the personal relevancy of online social support.

4) Outcomes

It is hypothesised that perceptual and cognitive processes will lead to quantitative and qualitative outcomes of online social support. Quantitative outcomes refer to measurable changes in physical, psychological and social functioning e.g. quality of life, perceived social support. Qualitative outcomes of online social support on the other hand occur as a result of the transactional filter. These outcomes refer to how people perceive their online interactions. This is influenced by a wide range of factors including the number, type and content of communication, relevancy of information, level of expertise and level of engagement in the online community.

The final outcome of online social support is described as linking. Linking refers to a 'conscious and/or unconscious process of relating and weaving emerging awareness to previously learned thoughts or information' (LaCoursiere, 2001, p67). This occurs as a result of both qualitative and quantitative outcomes of online support. Through the process of linking, online support users are able to formulate their own personal meanings associated with the experiences of seeking support online. LaCoursiere (2001) suggests that researchers can determine whether linking has taken place by conducting triangulated research, which allows a synthesis of qualitative and quantitative findings. Inconsistencies between qualitative and quantitative findings would indicate that linking had not taken place. However, if both the qualitative and quantitative outcomes yielded similar results it would be reasonable to conclude that linking has occurred.

In summary, to date the theory of online social support proposed by LaCoursiere (2001) presents the most comprehensive and holistic model for exploring how individuals make sense of their online experiences and the complexity of factors that influence their attitudes towards online

support seeking. In particular, the theory has several implications for research into online support communities; firstly it suggests that in order to achieve a complete picture of experiences associated with online support both qualitative and quantitative outcomes need to be examined. Second, it points to the importance of assessing the role of mediating factors such as Internet usage and demographic or disease characteristics. Finally, it highlights the interrelationship between online support processes and outcomes, thus implying that researchers should examine both the process of online support as well as perceived outcomes. In this way, the framework can serve as a useful starting point to initiate further research and theory development in the area of online support communities. With this in mind the current study adopted a triangulated approach to the research topic, using both qualitative and quantitative methodologies to explore how people with infertility experience online support communities. In addition, attention focuses on exploring some of the factors that might influence the experience of online support communities, including reasons for accessing an online support community, individual mediating factors and the self-help / therapeutic processes that occur online. The discussion chapter will review and integrate findings related to both the qualitative and quantitative outcomes of online infertility support communities and explore whether linking has occurred.

4 Chapter Four: Methodological considerations: Issues and challenges in researching online support communities

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CHAPTER SUMMARY

This chapter has its focus on some of the methodological issues and considerations underpinning the research carried out for this thesis. The first part of the chapter outlines the epistemological and philosophical framework underpinning the research. Additionally, it discusses the benefits of mixed-methods research for exploring the phenomenon of online support communities. It also examines the role of triangulation in this research project. The second part of the chapter describes and discusses the methodological issues and challenges associated with conducting mixed-methods research online. It presents an overview of the different online data collection techniques that could be used in this investigation and considers their possible advantages and disadvantages for researching online infertility support communities. These considerations form the basis for the methodological choices taken at each stage of the investigation, which is presented in the subsequent three chapters.

The previous chapter identified the research questions guiding this study and outlined the research process. A particular emphasis was given to the triangulated mixed-methods approach used to address the research questions. In this chapter, the methodological considerations relevant to the choice of a mixed-methods approach are discussed in more depth. This is followed by a consideration of some of the issues and challenges associated with employing online research methods in the investigation of online infertility support communities.

4.1 Triangulation in the social sciences

In the social sciences, triangulation refers to the combination of two or more methodologies in the study of the same phenomenon (Johnson, Onwuegbuzie, & Turner, 2007). An increasingly common example found in the literature is mixed-methods research where both qualitative and quantitative techniques are employed within a single study. While this is a popular form of data triangulation, triangulation can in fact occur on many different levels. Denzin (1978) describes four distinct types of triangulation; firstly data triangulation which refers to the use of two or more different sources of data in the same study. This could be data collected at different times, from different groups of people or in all together different settings. Secondly, investigator triangulation which involves the use of multiple researchers in the same study for instance two or more interviewers, data analysts or coders. Thirdly, theoretical triangulation which describes the use of multiple theories or hypotheses to study the same phenomenon. For example, a researcher may be interested in examining multiple research questions through the same dataset or testing various opposing theoretical perspectives in order to refute or lend support to a particular theory (Thurmond, 2001). Finally, methodological triangulation which involves using two or more different methods to either

gather data (i.e. interviews, documents, bulletin boards messages, surveys etc) or analyse it (i.e. statistical analysis, qualitative techniques etc), Denzin (1978) further distinguish between two forms of methodological triangulation: within methods triangulation and across methods triangulation. Within methods triangulation is when a researcher employs two or more different qualitative or quantitative methods in their study, for instance the use of different types of statistical analysis techniques to study the same dataset or two types of qualitative data collection methods e.g. bulletin board messages and interviews. Across methods triangulation on the other hand refers to the use of a combination of qualitative and quantitative methods in the same study. Studies, in which more than one type of triangulation is used (e.g. both theoretical and methodological triangulation), are referred to as multiple triangulation studies.

Triangulation in research can be advantageous for a number of reasons. Several authors argue that triangulation allows researchers to draw on the strengths of different research approaches and thus increases the validity and rigour of the study (Johnson & Onwuegbuzie, 2004; Thurmond, 2001; Williamson, 2005). Others purport that triangulated research produces a deeper and wider understanding of the phenomenon under investigation (Johnson & Onwuegbuzie, 2004; Olsen, 2004; Hussein, 2009). This is based on the premise that the use of different approaches will offer diverse perspectives on the same issue and allow the researcher to address a broader range of questions than would be possible with a single method (Williamson, 2005). For example, the use of quantitative data may be helpful in establishing whether or not a particular intervention has been successful, qualitative techniques could then be used to explain the reasons for the success or failure of the intervention. Enabling a more

complete and comprehensive picture of the study topic to emerge (Johnson & Onwuegbuzie, 2004).

As Hussein (2009) points out triangulation essentially aims 'to reveal complimentarity, convergence and dissonance'. While complimentarity can help to produce a more detailed picture of the phenomenon under investigation, convergence of findings across multiple methodologies may instil greater confidence in the conclusions drawn (Risjord, Dunbar, & Moloney, 2002). Dissonance between findings derived from different methodologies on the other hand has the potential to reveal unique outliers or individual cases, which would otherwise have remained unexplored (Jicks 1979). This may generate hypotheses or ideas that can be tested or further explored in future research (Risjord et al., 2001).

However, despite these strengths the use of triangulation in social science research is the subject of much debate. A key criticism levelled at the approach centres on the quantitative versus qualitative paradigm debate. Traditionally, quantitative research in the social sciences has adopted a positivist epistemological perspective to the study of social phenomenon. This perspective holds that social reality exists independently of the observer and as such can be studied objectively using the methods of the natural sciences (Bryman, 2004). Quantitative research is thus concerned with the collection of numerical data for the testing of specific hypotheses. Qualitative research in comparison rejects the positivist paradigm and typically adopts an interpretivist or constructionist viewpoint. Interpretivism emphasises that an understanding of social reality can only be accessed through examining the interpretation and subjective meaning of that world by participants themselves (Bryman, 2004). Constructionism further asserts that social phenomena are continuously being constructed

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through interactions between individuals, thus attention should focus on understanding how individuals and groups create their own perceived social reality (Burr, 1995). For this reason, qualitative research is predominantly concerned with the analysis of words and language, which are used to inductively generate theories and knowledge concerning how individuals construct and interpret their world.

Researchers at either end of this continuum argue that since data generated from qualitative and quantitative methods is based on differing assumptions concerning the nature of reality and how it can be studied, they cannot be effectively combined (Williamson, 2005). However, some authors postulate that mixed-methods research may in fact present an alternative or third research paradigm, which lies somewhere in between the traditional quantitative / qualitative divide (Olsen, 2004). This argument is based on a pragmatic subtle realist philosophy, which acknowledges aspects of both qualitative and quantitative paradigms (Mays & Pope, 2000). This alternative paradigm argues that while there is an external social reality which can be accessed by the researcher, this access is not direct and that all research will involve subjective perception and interpretation (Hammersley, 1992). Taking this stance, qualitative and quantitative methodologies are seen as equally useful instruments through which researchers can interpret and examine different aspects of social phenomena. Mixed-methods research thus offers a practical alternative, which allows the researcher to draw on the strengths of both qualitative and quantitative methods and select the method that they feel will be most effective for addressing their research questions.

4.1.1 Triangulation in this study

In light of the above considerations, this study adopted a pragmatic approach to data collection, which followed a subtle realist philosophy. Both within methods (i.e. qualitative analysis of survey responses and bulletin board messages) and between methods (i.e. qualitative and quantitative data analysis techniques) triangulation were used to address different aspects of the research aims. The review of the literature presented in the previous chapter suggests that the experience of online support communities is a complex phenomenon that is influenced by an interplay of different factors. With this in mind, it was felt that a blending of various qualitative and quantitative methods would allow for a more comprehensive and integrated understanding of online infertility support communities (LaCoursiere, 2001). In particular, triangulation was seen as a useful way of exploring similarities and differences between data collected from different methods. For instance, it may be that an analysis of bulletin board messages reveals that people are extremely supportive towards one another online, whereas survey responses show that participants do not actually perceive this communication as supportive. Exploring such inconsistencies may help to illuminate areas in which researchers and health care professionals need to focus attention.

The remainder of this chapter will explore some of the issues and challenges associated with conducting mixed-methods research via the Internet.

4.2 Quantitative methods

One of the most popular methods for obtaining quantitative data in the social sciences is through the use of a survey. Surveys commonly consist of a series of questions designed to collect quantitative information for the purposes of statistical analysis. For example, a researcher interested in the use of online support communities may wish to use a survey to collect data about the demographics and Internet use patterns of a large sample of online support users. In addition, researchers can incorporate standardised scales into surveys in order to examine relevant outcome variables such as quality of life, depression, or perceived social support. Some surveys may also include open-ended questions about the topic of interest. Open-ended questions allow participants to formulate their own in depth responses to the researcher's questions and can thus be helpful for generating qualitative information from large samples. Surveys are therefore a useful tool for gathering information about both qualitative and quantitative outcomes of online support community participation.

4.2.1 Survey research online

Advances in Internet technology not only offer novel opportunities for patients to seek support and information but also open up new possibilities for the social sciences to conduct research. In studying online support communities, online research presents the most logical and congruent methodological approach for understanding how people use online communities and their online experiences. However, the suitability of the Internet for conducting survey research is only just beginning to receive attention in the literature.

Surveys are currently one of the most popular data collection techniques for online research. Online surveys can offer considerable savings in cost and result in much quicker responses when compared to postal surveys (Fricker & Schonlau, 2002; Hanna, Weinberg, Dant, & Berger, 2005; Kaye & Johnson, 1999). As a result they have become an increasingly attractive option for researchers across a range of disciplines. Witte (2009) argues that this proliferation in online surveys may lead to 'survey fatigue' among Internet users. It is suggested that the decision to employ online surveys should therefore involve an evaluation of the appropriateness of the method for the specific topic under investigation (Naus, Phillip, & Samsi, 2009). In relation to the study of online communities; as most websites only store minimal contact information for members; the Internet may present the only viable method for contacting and recruiting participants to a study. Respondents can be asked to provide contact details in order to be sent a postal survey. However past research indicates that individuals accessing online support communities value the anonymity afforded by this medium (Coulson & Knibb, 2007; Tanis, 2008; Wright & Bell, 2003), thus a direct request for postal addresses may be viewed as intrusive and discourage some respondents from taking part in the survey. Furthermore, since the potential sampling frame of an online community can consist of hundreds or thousands of people spread across the world, an online survey may offer the more cost effective and efficient way of researching this population.

The administration of a survey online can create a sense anonymity, which may facilitate self-disclosure among participants. Indeed there is evidence to suggest that online surveys contain more candid responses in comparison to postal surveys (Bryman, 2004). For example, Coderre, Mathieu and St-Laurent (2004) note that participants who responded to

questions via e-mail were more likely to complete open-ended questions and write insightful comments compared to individuals responding by mail.

There are however, potential limitations associated with the use of online surveys. Detecting deception for example can be particularly difficult when using an online survey (Mendelson, 2007). Unlike interview methods, surveys do not allow the researcher to probe individual responses in order to detect inconsistencies. Thus, researchers cannot be certain that respondents are who they say they are.

Another potential disadvantage associated with online surveys relates to response rates. There is evidence to indicate that the response rate for online surveys tends to be considerably lower than that of postal surveys (Crawford, Cooper, & Lamias, 2001; Fan & Yan, 2010; McDonald & Adam, 2003; Witmer, Colman, & Katzman, 1999). The reasons behind this discrepancy are not yet clear and as such researchers do not have effective strategies for increasing response rates at present (Crawford, et al., 2001). One possible cause may lie in the fact that Internet users tend to be bombarded with research solicitations on a daily basis and thus have less motivation to complete what is viewed as yet another survey (Kraut et al., 2004).

Several commentators have suggested techniques for increasing motivation to complete an online survey (Cook, Heath, & Thompson, 2000; Harris, 1997; Sheehan, 2001). A number of studies have indicated that response rates may be negatively correlated with the length of the survey (Crawford et al., 2001; Galesic & Bosnjak, 2009; Knapp & Heidingsfelder, 2001; MacElroy, 2000; Sheehan, 2001). Harris (1997) advises that online surveys should contain an average of 10-15 questions in order to maximise

response rates. However, results in this area are mixed with other studies finding no relationship between survey length and response rate (Cook et al., 2000; Sheehan, 2001). Despite this, it is safe to say that in general the longer a survey is the more likely it is to generate fewer responses when compared to shorter surveys (Edwards et al., 2002).

Another important element thought to influence response rates is University affiliation. The anonymity of the Internet means that participants can find it equally difficult to verify the identity of the researcher (Chen & Hinton, 1999). Surveys carrying an institutional logo, departmental contact details or a link to a University website can increase the credibility of research and instil trust in the researcher (Wright, 2005). This combined with detailed information about the project and its importance as well as clear guidelines for completing the survey can encourage individual's to take part in a study (Wright, 2005). Additional factors shown to promote participation include sending follow-up reminders (Solomon, 2001) or personalising research invitations (Heerwegh, Vanhove, Matthijs, & Loosveldt, 2005; Heerwegh, Abts, & Loosveldt, 2007). These strategies while effective for increasing response rates, could lead to individuals feeling pressurised to participate or responding in a socially desirable manner (Heerwegh et al., 2005).

The success of online survey may also vary depending on the mode of administration. Two distinct types of online surveys can be identified from the literature: e-mail and web-based surveys.

4.2.1.1. E-mail surveys

E-mail surveys are sent to potential participants via e-mail either as an attachment or in the body of the e-mail. E-mail surveys offer the respondent greater flexibility when compared to web-based surveys. Participants do not need to complete the entire survey in one sitting; responses can be saved and completed on another occasion. The survey can also be printed and filled out away from the computer, like traditional self-completion surveys.

The method also presents a number of advantages for the researcher. For instance, e-mail surveys are relatively straightforward to produce and do not require a great deal of technical expertise to set-up (Bryman, 2004). In addition, e-mail offers one of the most inexpensive methods for disseminating a survey to a large group of people. E-mail can therefore be an accessible method for conducting online research.

Some studies indicate that surveys, which are embedded into the text of an e-mail are likely to receive a much higher response compared to surveys that are sent as attachments (Dommeyer & Moriarty, 2000). This is thought to be because of the numerous obstacles associated with downloading, saving and returning the attached survey (Dommeyer & Moriarty, 2000). Overall, this process is more time consuming than responding to questions displayed in the body of the e-mail. Furthermore, problems may be encountered if the participant does not have the relevant software or IT skills to download the attachment (Illingworth, 2001). Some authors have also highlighted that researchers should be careful when sending survey attachments to large samples, as there is a risk of

forwarding viruses with the attachment (Hewson, Yule, Laurent, & Vogel, 2003).

Consequently, researchers wishing to increase their response rate may wish to consider restricting questions to the body of the email. However, this method is only appropriate for very short surveys. Since e-mails have limited design and formatting options, longer surveys can appear confusing and difficult to complete when sent in an e-mail (Bryman, 2004). As a result, of these issues some researchers have turned to web-based surveys as an alternative way of surveying Internet user communities.

4.2.1.2. Web-based surveys

This type of survey is designed and hosted as a web-page on a research website. Potential respondents are typically directed to the web-page where the survey can be found and completed, via a hypertext link included in the research invitation. A plethora of web-based survey software tools that allow researchers to create, publish and host such surveys are now easily available on the Internet. These software tools incorporate a range of features and formatting options. For instance, researchers can experiment with colour and graphics, response formats (e.g. open boxes, drop down options, check boxes etc), and include questions filters, which direct participants to different sections of the survey depending on their responses. This can require a slightly higher level of technical ability than producing an e-mail survey, however most websites provide detailed guidelines and extensive support to users. Thus, web surveys often appear more professional, attractive and user-friendly when compared with e-mail based surveys (Bryman, 2004). Whether this impacts on response rates is unclear at present.

The superior interface of a web-based survey can be advantageous to the researcher. Responses can immediately be downloaded into a database for analysis, thus saving time and eliminating data entry errors. Measures can be taken to reduce the occurrence of missing data; some survey tools offer the opportunity for researchers to make it compulsory to answer particular questions or include a prompt if a question is missed. Unlike postal or email surveys, software tools also offer information about the number of people who opened the web survey and either chose not to complete the questions or left without submitting their responses. This type of information can be helpful during the piloting and evaluation stage of a survey, as it can help to determine whether there is a particular stage of the survey at which participants are exiting the page. This allows researchers to edit the length, wording or order of the survey.

However, web-based surveys are not without their disadvantages. The software required to run a web-based survey can be costly. While, some websites allow people to design surveys free of cost others charge a monthly or annual fee to host the survey. Some providers may have additional charges depending on the number of questions or per completed survey (Wright, 2005). Thus, the cost of designing and running an online survey may be equivalent to that of a postal survey for some projects.

Another potential disadvantage to consider when designing web-based surveys is the possibility that a single individual might submit multiple responses to the study. Gosling, Vazire, Srivastava, & John (2004) argue that the greater accessibility and anonymity of the Internet can make web-based surveys easier targets for non-serious responses. This can significantly undermine and challenge the validity of any data collected. For this reason, it is important to ensure that strategies to detect or reduce

multiple responding are built into the design of the study. Wright (2005) suggests that participants could be asked to provide a valid e-mail address before completing the survey in order to discourage non-serious respondents. Gosling et al. (2004) report checking IP addresses to detect repeat responses from the same computer and directly asking visitors to the website whether they had already completed the survey. In cases where repeat IP addresses were detected only the first response was retained for data analysis. This strategy might be problematic in infertility research, as couples may complete the survey from the same location. Other possible strategies include looking for patterns in user names, passwords and demographic details (Bowen, Daniel, Williams, & Baird, 2008).

4.3 Qualitative research

As outlined previously, qualitative research is concerned with gaining an in depth understanding of human behaviour and perceptions. Qualitative data can thus be collected using a variety of methods such as interviews, focus groups and ethnographies. Many of the traditional qualitative methodologies used by social scientists can be adapted to the online medium. In addition interactive features of the Internet like bulletin boards, blogs and chat-rooms provide a wealth of qualitative information, which can serve as a rich source of naturally occurring qualitative data. Since the present study was concerned with examining how people communicate through bulletin board messages and gaining individual perceptions and experiences concerning online communities; this section will explore the potential of the Internet for conducting interviews with people who access online infertility support communities and the use of bulletin board messages in qualitative research.

4.3.1 Analysis of postings to online support communities

Messages posted to online support communities provide a rich source of naturally occurring qualitative data. Most online communities have an extensive archive of messages, which sometimes remain available for a number of years for others to access and peruse (Sixmsith & Murray, 2001). These postings can offer the most comprehensive insight into the purposes and dynamics of various online communities. For researchers interested in studying the phenomenon of online support seeking, the analysis of support messages can help to address a number of research questions. Firstly, bulletin board postings can help to illuminate patterns of usage (i.e. the number of active participants, times of usage etc) (van Uden-Kraan, et al., 2008a). Secondly, the content analysis of bulletin boards offers a unique insight into the processes that occur within online support communities (Finn, 1999; Perron, 2002). Finally, qualitative outcomes (i.e. changes in psychological awareness, communication and interaction etc) can also be examined through discourse within postings to online communities (LaCousiere, 2001).

The use of naturally occurring data to investigate online support communities has various advantages. For example, it offers a practical and instantaneous way of accessing the views and experiences of members of online support communities, including those individuals who may be unwilling to participate in conventional research (Seale, Charteris-Black, Macfarlane, & McPherson, 2010). It can also help to reduce some of the biases associated with participatory research methods like social desirability or selection bias (Malik & Coulson, 2008). Thus, increasing the validity and reliability of findings. However, the approach is not without its disadvantages. The analysis of messages alone does not tell us anything

about the experiences of the large number of individuals who access online communities but do not post messages (van Uden-Kraan et al., 2008b). Furthermore, postings to online support communities are limited in the extent to which they can reveal information about psychological and social outcomes of participation (Eysenbach, 2003). Thus it is suggested that bulletin board messages are best used in triangulation with other methods of data collection such as surveys or interviews (Robinson, 2001).

4.3.1.1. Ethical considerations

Utilising the Internet for research purposes also raises new ethical dilemmas that are not fully covered by existing ethical guidelines. For example, when considering the use of bulletin board messages, gaining informed consent from individual posters can be particularly problematic. Although some online communities allow people to contact other members privately; which could be used to ask posters if their messages can be incorporated in the analysis; this can be time consuming for researchers and may not offer access to all posters (e.g. some contact details may be out of date). Since messages in online support communities typically occur as part of a thread of conversation, analysing messages from conversations in which some people have not given consent may be problematic and have implications for the quality and relevance of the analysis (Flicker et al., 2004). Seeking consent in this way can also be seen as intrusive and have a negative impact on group dynamics (King, 1996; Sixsmith & Murray, 2001). For instance the knowledge that a researcher is present may lead some individuals to withdraw from a community (Eysenbach & Till, 2001) or avoid opening up fully about themselves (King, 1996). In the light of this the issue of whether informed consent should be sought to use

bulletin board postings as research data has been the subject of much debate in the literature.

The British Psychological Society's (BPS) ethical code of conduct postulates that in situations where researchers are unable to obtain informed consent their observations should be restricted to that of public behaviour in situations 'in which persons being studied would reasonably expect to be observed by strangers' (BPS, 2007). In line with this reasoning, some researchers argue that since online support community postings are in the public domain (i.e. accessible to all Internet users) informed consent may not always be necessary for a passive analysis of content (e.g. Coulson, 2005; Coulson et al., 2007; Ess & AoIR, 2002; Finn & Lavitt, 1995; Hewson et al., 2003; Sullivan, 2003). However, this issue remains highly contentious with others believing that informed consent should always be obtained from individuals, as postings were never intended for research purposes (King, 1996; Smith, 2004). Several authors have suggested that although online support postings are publicly available, participants may hold the belief that messages are only public for members of the community but private to outsiders, such as researchers, and thus feel a sense of privacy when contributing to the community (Coulson, Malik, & Mo, 2007; Herring, 1996; Sixsmith & Murray, 2001; Waskul & Douglas, 1996). Eysenbach and Till (2001) further argue that unlike individuals who post a letter in a newspaper or express a view in a public meeting, users of online support communities are not necessarily seeking public visibility. Thus, the need for informed consent can only be established through assessing understandings of privacy and the cultural values of individual support communities.

Several measures could be used to achieve this (Eysenbach & Till, 2001; Robinson, 2001). First, there is a need to consider whether discussions are publicly available without the need for a password or subscription to the community (Bruckman, 2002; Eysenbach & Till, 2001). Robinson (2001) uses the analogy of traditional bulletin boards to describe this. They argue that individuals who post something on a bulletin board in a private office to which only certain people have access do so with the expectation that only a select group of people will view their posting. On the other hand if the same posting were displayed on a bulletin board in a public hallway, the poster has in effect relinquished control over who will and will not view their posting. It can thus be argued that although postings to bulletin boards are in essence public messages, there are important psychological differences between messages posted to boards with limited or open access. Likewise, if an online community requires registration or subscription to access bulletin board postings, it can reasonably be argued that participants are likely to view their communications as public to others with access to the community (i.e. other members) but not to the wider Internet user community, including researchers. Thus, informed consent would almost always be necessary to study the online communication of these individuals.

Second, the size of an online community can function as an important indicator of how public or private a space is perceived to be. Generally, it is believed the larger the membership of an online community, the more 'public' the space is. For instance, individuals contributing to a community with only 10 members are likely to have a greater perception of 'privacy' than individuals contributing to a community with over 100 members (Eysenbach & Till, 2001).

Finally, researchers should take time to examine the regulations and norms of the community under investigation. This can help to establish whether there is an expectation of privacy in the online support community (Eysenbach & Till, 2001; Flicker, Haans, Skinner, 2004; Robinson, 2001; Smith, 2004). For example, some communities may have a clear policy explicitly discouraging researchers or other outsiders from accessing the online environment. In these situations it would be unethical to use the community as a data source, particularly without explicit consent. Conversely, other websites may specifically state (often in frequently asked questions) that privacy cannot be guaranteed and thus personally identifying information should be kept to a minimum. Some online communities also provide information about the number of times a message has been viewed or the number of non-members accessing the board at a given time. In such cases, it is reasonable to argue that members will have an awareness that they are communicating in the public domain and therefore the need for informed consent to observe their communications is removed (Eysenbach & Till, 2001).

Regardless of the need for informed consent, it is widely agreed that Internet researchers have the obligation to ensure that measures are taken to protect the privacy and confidentiality of users of online communities (Allen, 1996; BPS, 2007; Brownlow & O'Dell, 2002; King, 1996; Ohrstrom & Dyhrberg, 2007). Recent guidelines for conducting Internet research issued by the British Psychological Society, state that studies of online communication should avoid the disclosure of names or addresses of websites from which data is collected due to the potential for harm after the publication of results (BPS, 2007). Similarly, researchers should avoid the use of the quotes that may be traced directly to an individual's posting via powerful search engines. An alternative strategy is to revise or

paraphrase quotes (Robinson, 2001). In addition, to further protect the anonymity and confidentiality of online support users it is advised that quotes are carefully reviewed in order to ensure that all personally identifying information including pseudonyms are omitted from the reporting of results (Flicker at al., 2004; Robinson, 2001).

4.3.2 Online interviewing

Interviews typically take place face-to-face between participant and researcher or over the telephone. Both of these approaches are well-established methods of qualitative data collection (Reis & Judd, 2000). In comparison the use of the Internet as an interviewing medium is a relatively novel and ambiguous technique. Despite the lack of formal guidelines for online interviewing, a number of health researchers have successfully utilised the approach to study a variety of sensitive topics (e.g. Dale & Hunt, 2008; Davis et al., 2004; Egan, Chenoweth, & McAuliffe, 2006; Hunt & McHale, 2005; Ison, 2009; Murray, 2005). This implies that the Internet may present a viable method for interviewing infertile men and women about their experiences of online support communities.

Online interviewing has some advantages over the more traditional forms of interviewing. These include savings in terms of both cost and time. For example, since online interviews take place in locations that are convenient for both the participant and researcher, there can be significant savings to the expense and time associated with travelling to interview participants face-to-face. In addition, on completion of the interview, the researcher has an electronic transcript of their entire discussion with the participant, which can be printed for data analysis; thus, eliminating the need for lengthy interview transcription.

Using the Internet as an interviewing medium may also lead to a more diverse research sample (Murray & Sixsmith, 1998). Traditionally geographical and time constraints can limit access to certain participants. The Internet provides a means of reaching individuals who would otherwise be excluded from an interview sample due to their geographical location or communication and mobility problems. This is an important consideration for research concerning online communities, as a key theoretical advantage of online communication is the ability to connect people across geographically dispersed locations. Thus limiting data collection to particular geographical areas may reduce the generalisability of a study.

Meho (2006) argues that the lack of physical proximity between participant and researcher in online interviews can create a sense of anonymity. Some authors hypothesise that this sense of anonymity will encourage individuals to participate in sensitive research (Ayling & Mewse, 2009; Mann & Stewart, 2000). Others suggest that visual anonymity may help participants to express their stories with less inhibition (Poster, 1995). Indeed, several studies show that people appear to be more willing to disclose personal information in computer-mediated interactions than comparable face-to-face interactions (Ghanem et al., 2005; Joinson, 2001). This may also be applicable to research interviews. For example, Murray and Sixsmith (1998) report that interviewees in an online study of prosthesis use were able to discuss sensitive aspects of their personal life more frankly than they perhaps would have done face-to-face. Additionally, since the Internet masks physical cues such as age, race and gender, conducting interviews online may help to reduce interviewer effects.

However, visual anonymity can also present a number of unique challenges to interviewers. Conventional interview guidelines place great emphasis on

the role of body language and tone of voice in contextualising an interview and building rapport between participant and researcher (Bryman, 2004). Subtle visual cues such as smiles and nods can be valuable techniques to help participants feel at ease and encourage them to expand on certain topics. Likewise, observing an interviewee's tone of voice and body language may assist researchers to detect discomfort, confusion or distress. Hence, allowing the researcher to take action to reassure the participant or redirect a particular question. When interviewing online however, these visual and non-verbal cues will be missed.

New techniques and guidelines are thus required to help facilitate rapport online. Some researchers have looked to alternative strategies to engage with participants. O'Connor and Madge (2001) for example showed photos of themselves to potential participants to reduce the sense of anonymity associated with the online medium. In an email interview study, Kivtis (2005) adopted the approach of sharing personal information with participants. Each e-mail exchange would therefore begin or finish with more personal information on topics such as holidays, work and family life. Meho (2006) propose that online interviewers should also encourage participants to use acronyms and electronic paralanguage to help substitute for non-verbal cues. Many members of online support communities will already be accustomed to employing these linguistic methods to convey meaning and express emotions in online communication. Therefore, this may present a useful approach for increasing the depth of online interview data.

Another challenge associated with visual anonymity in interviews is the risk of deception. Although deception can also occur in face-to-face research, Mendelson (2007) argues that the anonymity of the Internet provides

people with an ideal opportunity to experiment with their identity. Thus, making it difficult to determine whether participants are actually who they say they are (Hewson et al., 2003). Since both the experience of infertility and online support seeking are central to this thesis, the potential for data fraud presents a significant threat to the validity of any data collected. While the risk of deception cannot be fully eliminated, Hamilton and Bowers (2006) suggest that interviewers could employ a number of strategies, many of which would also be used in face-to-face interviews, to assess the veracity of a participants account. For instance, similar questions could be asked at different stages of the interview to test for consistency in responses. Knowledge of the areas being addressed and the types of events that might occur during infertility could also be seen as a test of validity (Hamilton & Bowers, 2006).

During an interview the presence of a third party may influence the way in which a participant responds to the researcher's questions. In face-to-face interviews participants will often turn to friends or family for confirmation or additional information to help formulate their responses (Murray & Sixsmith, 1998). The contribution of these individuals thus becomes a part of the data collection process. Conversely, some individuals may feel uncomfortable disclosing certain information in front of others. In online interviews, researchers have no way of assessing third party effects on the interview process. Furthermore, unless the participant chooses to disclose information about their physical environment, the researcher will not be able to determine whether there are external factors influencing the interviewee's responses. For instance, some people may choose to respond to interview questions at work. In this situation external distractions or concerns about privacy may limit the extent to which participants can

provide honest and detailed answers. This presents a potential disadvantage to online interviews, which needs to be taken into account.

Illingworth (2001) suggest that the type of online interviewing technique used and its suitability for the research question is an integral part of designing an Internet based interview study. Broadly speaking there are two types of online interviews; synchronous and asynchronous interviews. A brief overview and discussion of the advantages and disadvantages of each approach is given below.

4.3.2.1. Synchronous interviews

Synchronous interviewing refers to online interviews that take place in 'real-time'. In these types of interviews both the participant and researcher are online simultaneously. This style of interviewing resembles traditional interviews in that the researcher is posting questions and receiving responses at more or less the same time. Synchronous methods therefore attempt to capture some of the spontaneity of a face-to-face conversation. However, to date synchronous methods have largely been reserved for online focus groups, their value for in depth one-to-one interviewing, particularly concerning sensitive health issues is not clearly understood.

While, synchronous communication has the potential to increase the spontaneity of online interviews, it has been suggested that it may lead to a reduction in the depth and quality of interview data (Davis, Bolding, Hart, Sherr, & Elford, 2004). Davis et al. (2004) for example, report that data generated from face-to-face interviews on the issue of HIV transmission risk contained significantly more depth and detail than data generated from online synchronous interviews on the same topic. In some instances, the

online interview transcripts closely resembled conventions of Internet relay chat (i.e. very short replies, which created a sequence of question and answer) (Davis et al., 2004). The authors reflect that this style of interviewing became necessary due to the length of time that some participants took to respond to questions. The use of short closed questions allowed the researcher to probe responses, whilst maintaining a flow of conversation with the participant. Albeit, at the expense of an in-depth exploration of meaning.

There are also a number of technical and practical issues to consider in this type of interviewing. Researchers wishing to conduct synchronous online interviews have several options available. For instance 'chat room' services that are freely available on the Internet allow people to communicate synchronously with one another. While these venues are easy to access and do not require any technical expertise to set up, researchers have little control over who enters the chat. Consequently, chat rooms are not the method of choice for sensitive subjects like infertility, where participant privacy is paramount (Illingworth, 2001). Alternative options include 'instant messenger' services (also freely available on the Internet) and online meeting and collaboration software packages that can be utilised for research purposes (Mann & Stewart, 2000; O'Connor & Madge, 2001). A potential advantage of these services is that they allow individuals to incorporate additional software such as web cams and microphones into the interview process (Matthews & Cramer, 2008). Thus, increasing the wealth of data and in effect facilitating face-to-face interviews across different geographical locations (Chen & Hinton, 1999).

However, these methods require a great deal of commitment on the part of the participant. Participants will need to spend time installing and

familiarising themselves with the software prior to the interview. There may also be technical issues that need to be overcome. Some individuals may lack the time or technical expertise to achieve this and thus be put off from participating in the research. Chen & Hinton (1999) therefore argue that it is important for online researchers to consider both the participants and their own technological skills when selecting software for synchronous interviewing. Another significant factor influencing software selection is cost. Although, free chat room and instant messenger services are available, more advanced software packages can be costly to purchase and install (O'Connor & Madge, 2001)

4.3.2.2. Asynchronous interviews

Asynchronous online interviewing has by far received the most attention in the literature. Unlike synchronous interviews, asynchronous interviewing does not require the participant and researcher to be online at the same time. These types of interviews are typically facilitated by email or a bulletin board; where researchers post or email their questions to individuals and participants reply at their own convenience. The use of e-mail is relatively straightforward and inexpensive when compared to other forms of online interviewing, requiring only basic IT skills and access to an email address, which most regular Internet users will already have. For this reason the e-mail interview is the most widely documented online interviewing method.

E-mail interviews typically involve a sequential exchange of emails between the researcher and participants over a period of time (Kivtis, 2004). This approach has both advantages and disadvantages for the online researcher. One potential disadvantage is the length of time it can take to

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complete an e-mail interview. The literature shows that the completion of a single interview may take several weeks or even months. Kivtis (2004) for example report that their email interviews took an average of 12 weeks to complete, with the longest interview lasting 9 months. Similarly, Murray & Sixsmith (1998) report that the length of interviews in their e-mail study varied from 2-6 months. Some commentators suggest that providing participants with clear guidelines at the start of the interview about the approximate time frame, in which responses should be submitted, may help to impose a time limit on data collection (Bampton & Cowton, 2002; Hunt & McHale, 2007; Meho, 2006). Another strategy is to send all the interview questions in a single e-mail, allowing the participant to respond to all questions at once. However, this can overwhelm participants and reduce the level of interaction between participant and researcher, making the interview similar to an open-ended survey. Thus, to strike a balance most researchers have favoured sending a couple of related questions in each e-mail (Beck, 2005; Dale & Hunt, 2008; Egan, Chenoweth, & McAuliffe, 2006).

A second potential disadvantage of asynchronous methods is the loss of spontaneity in the interview, which may compromise the quality of data. For example, a lack of real time pressure means that participants can draft and redraft their responses in order to convey a particular image of themselves (Bampton & Cowton, 2002). On the other hand an advantage of e-mail interviewing lies in the fact that participants are able to spend time reflecting on their thoughts and experiences before responding. Indeed asynchronous computer-mediated communication is often richer and better thought out than face-to-face conversations; thus suggesting that email interviews may also produce more reflective accounts (Murray & Sixsmith, 1998). In addition, since e-mail interviews are longitudinal in

nature, there is opportunity for repeated contact between the interviewer and interviewee. This may help to facilitate rapport with participants and increase the depth of data (Murray & Sixsmith, 1998). In traditional or synchronous interviewing responses may be influenced by the way participants are feeling on the day of the interview. Asynchronous interviewing however can provide a more balanced account of an individual's experiences, allowing them to clarify or rephrase earlier comments at a later date.

4.3.2.3. Ethical issues in online interviewing

As with conventional interview methods, it is important that online interviewing is conducted in an ethical manner. In accordance with the British Psychological Society's (BPS) ethical code of conduct, researchers are obliged to ensure that measures are taken to obtain informed consent from interviewees, protect their confidentiality and privacy and ensure that they are aware of their right to withdraw from the interview at any point. While the ethical issues facing online interviewers are similar to those that face-to-face interviewers would have to contend with; the unique nature of the Internet can create new ethical challenges for researchers. Written information about the aims of the project and the nature of participation can easily be conveyed to participants in the form of an email or bulletin board message, the process of gaining informed consent however may be more problematic. Typically, once an individual has decided that they wish to take part in the interview the researcher will obtain explicit consent by asking the participant to sign a consent form. In online interviewing this process can be more complex. Participants will need to download, sign and post, fax or scan a copy of the consent form to the researcher, which may be a time consuming and troublesome task. For example, Illingworth

(2001) note that technical competence in opening and returning an email word attachment and incompatible or out of date software were significant barriers to obtaining informed consent in their e-mail study. Such technological barriers may have a negative effect on response rates. Alternative strategies for obtaining informed consent could include mailing copies of the consent form and reply envelopes to participants or adopting a similar approach to online survey research where participants are asked to provide a password or check a box to indicate consent (Bruckman, 2002).

Murray & Sixsmith (1998) suggest that it may be necessary for researchers to confirm consent at different stages of the interview, since the absence of non-verbal communication makes it difficult to detect when a participant has become anxious or hostile. This also raises issues regarding the withdrawal of consent. Participants leaving face-to-face interviews will often make their decision to terminate the interview clear to the researcher. In contrast the reason why an individual fails to respond to an email question or suddenly disconnects from a synchronous meeting is less apparent. It may be that the participant no longer wishes to continue with the interview or that they are experiencing personal or technological problems that prevent them from engaging with the interview. Some authors suggest that it would be helpful for interviewers to inform participants at the start of the interview that in cases of no response one further message will be sent, after which it will be assumed that the participant has withdrawn from the study (Hunt & McHale, 2007). This may help to reduce some of the ambiguity of the situation and allow researchers to move on with the completion of the project.

4.4 Online surveys for gathering qualitative data

An alternative approach to email interviews is the administration of open-ended questions in the form of a web-based survey or questionnaire (Buchanan & Coulson, 2007; Coulson & Knibb, 2007). This approach more closely reflects a structured style of interviewing. Structured interviews typically have a more formalised series of questions and offer less flexibility than would be possible in a semi-structured interview. This means that the researchers are unable to ask follow-up questions or probe interesting aspects of the responses. Nevertheless, online interviews using this format can produce an equally rich source of qualitative data. For example, using an online survey approach Buchanan & Coulson (2007) were able to gain a rich and deep insight into the experiences of people accessing an online dental phobia support community. One reason for this may be that as with asynchronous interviews, online surveys allow participants to spend time reflecting on their experiences and carefully formulating their responses. In addition, online surveys offer a greater degree of anonymity than interactive online interviews, which may encourage people to be more open and candid when responding (Bryman, 2004). This ambiguity might also prompt those people who do not feel comfortable taking part in a one-to-one interview to share their views and experiences. Thus, allowing researchers to potentially access a more diverse sample than they would be able to through semi-structured online interviews.

There are also a number of practical advantages to this type of structured interview. Firstly, it can be completed in a shorter time frame when compared to other types of online interviewing particularly asynchronous interviews. This may be of particular importance for projects, which have tight deadlines for data collection. Secondly, the approach may help to

overcome some of the difficulties of gaining informed consent and determining when someone has withdrawn from the study associated with e-mail interviews. Thirdly, using an online survey, researchers can potentially access the views and responses of a much larger pool of participants than would be possible in an interactive online interview study. For example, Buchanan & Coulson (2007) were able to access the experiences of 143 participants in their study. To interview this number of participants individually would be an extremely time-consuming task for a single researcher, even when taking into account the considerable savings in time associated with not having to travel to interview participants face-to-face.

Open-ended questions in an online survey can thus elicit a breath of qualitative information about the topic under study. This may be ideal for investigating new and under-researched areas such as online support seeking, where the researcher is beginning with very broad and general questions that they wish to address. Data can be compared and contrasted across a wide range of respondents. A key strength of this approach is that it allows for the identification of prevalent themes and issues, which can then be further examined and probed in follow-up research.

4.5 Recruitment and sampling issues in online studies

A key challenge in research concerning online support communities is the identification of recruitment strategies that are both acceptable to the community under investigation and allow the researcher to recruit the desired sample. It can be argued that online researchers interested in specific Internet populations are somewhat restricted in their means of contacting potential participants. Some online communities provide access

to a list of member e-mail addresses, given during the registration process, which could be utilised as a means of contacting individual members. However, the review of research literature on online support communities for this thesis reveals that most researchers access participants by posting research invitations to community bulletin boards, mailing lists or chat rooms (e.g. Buchanan & Coulson, 2007; Bunde et al., 2007; Hewson, 2003; Houston et al., 2002; Leiberman & Goldstein, 2005; van Uden-Kraan et al., 2008a).

Both methods have their strength and limitations. E-mailing members directly helps to ensure that all participants have viewed the research invitation. However, this information is not always available to researchers. Even in cases where e-mail addresses are obtainable, it is likely that some participants will have changed their e-mail address since registering with the community (Im & Chee, 2005; Wright, 2005). Resulting in many research invitations being sent to inactive or out-of-date in boxes. E-mail's can also be deleted without being read or filtered through to a spam box. Posting recruitment messages to bulletin boards on the other hand offers the researcher the chance to recruit from all individuals accessing the online community; including 'lurkers'. However, in very active communities research invitations can quickly become camouflaged by an influx of new postings. This means that the researcher's message will not necessarily be visible to individuals accessing the community after a few days. Although follow-up invitations could be posted at regular intervals, there is a possibility that repeat solicitations may be seen as intrusive by members of the community.

Thus, for both recruitment strategies it is virtually impossible to determine how many potential respondents actually viewed the recruitment message

(Rhodes, Bowie, & Hergenrather, 2003). Consequently, establishing a sampling framework for research with online support communities is difficult (Wright, 2005). This can have implications for the ability for researchers to make generalisations about their findings (Wright, 2005).

Online recruitment also raises new ethical concerns. Yun & Trumbo (2000) highlight that unsolicited research invitations (particularly by e-mail) are perceived as an invasion of private space by some Internet users. Some online communities consider research requests as 'spamming' (Mendelson, 2007). Invitations posted to these communities will often be met with hostile or abusive responses (Andrews, Nonnecke, & Preece, 2003). For example, in an extreme case one individual repeatedly left threatening voice mail messages for the researcher (Wright, 2005).

In order to ensure that the privacy of potential participants is respected, researchers should first take time to familiarise themselves with the culture or 'netiquette' of the community from which they wish to recruit participants. Netiquette is a term used to describe what is considered 'good' or appropriate online behaviour (Mann & Stewart, 2000). Different online communities will have different social conventions influencing what is regarded as appropriate or inappropriate behaviour. For instance, some communities welcome researchers and provide specific notice boards to which recruitment messages can be posted, whereas other communities explicitly discourage the posting of research invitations to their bulletin boards. Cho & Larouse (1999) suggest that it is good practice to treat site administrators or moderators as gatekeepers and seek their permission prior to recruitment. These individuals will be better placed for understanding the culture and netiquette rules of the community and can thus help to negotiate the most appropriate way to access participants.

However, this process is time consuming as not all moderators will respond immediately. Im et al. (2007) for example note that in their work with cancer patients, over 200 online communities were contacted but only 6 agreed to post the research announcement. The majority of the online communities did not respond to the request.

It should also be noted that the support of a moderator is by no means a guarantee that the request will not be considered intrusive by the community (Cho & Larouse, 1999). Hewson (2003) argued that there is an expectation that postings should be relevant to the online community, but research invitations are not always perceived as relevant. It is thus imperative to ensure that both the purpose of the study and its importance for the online community under investigation are explained when initiating contact with gatekeepers and potential participants (Wright, 2005).

4.6 Summary

The study presented in this thesis adopted a mixed-methods approach to data collection, through combining qualitative and quantitative online research methods. This chapter has provided a detailed description of the rationale behind this approach and attempted to highlight some of the practical issues and considerations raised when conducting online research. Based on these considerations the decision was taken to employ online surveys for the collection of both qualitative and quantitative information from participants. In addition an analysis of bulletin board messages was undertaken to understand the self-help processes that occur within an online infertility support community. An in depth description of the methods used in each stage of the investigation follows in chapters five, six and seven.

5 Chapter Five: Study One: A qualitative exploration of online experiences

CHAPTER SUMMARY

Despite the growing number of people turning to online infertility support communities, to date little research has been conducted to understand how people with infertility use and experience online support communities. This chapter describes a qualitative study that was undertaken to explore the motives, perceptions and experiences of people accessing online infertility support communities. Ninety-five participants who were recruited from several online infertility support communities completed an online survey containing a series of open-ended questions. Through the use of an inductive thematic analysis approach, five themes relating to the participant's online experiences were identified from the responses. These included: (i) unique features of online social support, (ii) improved relationship with partner, (iii) reduced sense of isolation, (iv) information and empowerment, and (v) negative aspects of online communities. The emergent themes are discussed in the context of the wider literature pertaining to infertility and online support communities.

5.1   Background

The introductory chapter to this thesis highlighted how the experience of infertility and assisted reproductive treatment can evoke a range of negative psychosocial responses such as feelings of stigma, loneliness, social isolation, depression, anxiety and loss (Brucker & McKenry, 2005; Dhillon et al., 2000; Greil, 1997; Lechner et al., 2007; Valentine, 1986). In recent years, technological advances and a substantial growth in access to the Internet has opened up new opportunities to help people cope with the experience of infertility.

To date the majority of research in this area has focussed on examining the content of infertility-related websites and specially-developed computer-mediated psychosocial support programmes for couples. One area that remains relatively unexplored is that of the numerous 'natural' online infertility support communities found on the World Wide Web. As the discussion of literature in chapter three suggests online support communities can present a number of potential advantages and disadvantages to couples and individuals experiencing infertility.

In this chapter an analysis of qualitative data is presented to shed light on how people with infertility experience online support communities and what they themselves perceive to be the advantages and disadvantages of online support seeking. LaCoursiere (2001) emphasises that eliciting qualitative information from users can play an important role in understanding the phenomena of online support. Qualitative data not only offers rich insights into the experiences of participants but also allows for an exploration of how they perceive and evaluate information / support received through this medium (LaCoursiere, 2001). In the light of this, an

in depth qualitative study was seen as the ideal approach to initiate an investigation of online infertility support communities. The specific aims of the study and methodology used are described below, followed by an analysis and discussion of the findings.

5.1.1 Aims and objectives

This study aimed to provide an insight into the motives, perceptions and experiences of people accessing online infertility support communities. Specifically, the study employed a qualitative methodology to explore the following research questions:

- What motivates people affected by infertility to access online support communities?

- How do people affected by infertility experience online communities as a source of support and self-help?

- What are the perceived benefits associated with accessing an online infertility support community?

- Are there any negative aspects to accessing online infertility support communities?

- What impact do online communities have on how individuals and couples cope with infertility?

5.2 Methods

5.2.1 Choice of data collection method

Following a review of literature pertaining to online research methods (presented in Chapter four) the decision was made to employ an online survey method to elicit qualitative data from people accessing online infertility support communities. This method offered some of the key advantages associated with asynchronous online interviewing such as anonymity and the opportunity for participants to spend time reflecting on their experiences before replying to the researcher. However, it also offered a means of potentially accessing the views and experiences of a much larger and more diverse sample than individual semi-structured interviews.

Although the structured style of questioning inherent to an online survey, does not offer the same flexibility as an in depth semi-structured interview, it was felt that since the research questions for this study were relatively broad, a structured approach would be equally helpful in gaining new insights into the phenomenon of online support communities, whilst also allowing the researcher to understand and explore general patterns in the dataset i.e. similarities and differences in online experiences (Saunders, Lewis & Thornhill, 1997). Thus, offering the *depth* and *breadth* of information that was needed at this initial stage of the investigation.

5.2.2 Sampling procedure

The recruitment criteria for the study were relatively broad and included all individuals who had accessed an online support community for infertility

issues. Participants could be either diagnosed with infertility themselves or in a couple experiencing infertility. Both guest users and registered members were invited to take part in the study. The survey was aimed at adults over the age of 18.

Since the target population for this study was specifically those people who were experiencing infertility and were also Internet users, Internet advertising was seen as the most logical and congruent approach for recruitment to the study. Thus, in the first stage of the research process, an Internet search using the Google search engine was undertaken to identify online support communities for individuals experiencing infertility issues. A combination of the search terms: "infertility", "fertility", "message board", "bulletin board", "online support group", "online community" "discussion board" and "online forum" were used. The message archives and frequently asked questions sections of the search results were examined to determine firstly whether the online communities allowed researchers to recruit members to studies and secondly whether the online communities could be considered 'active' communities. For the purposes of the present research an 'active' community was defined as a community with an average of 5-10 messages posted on a daily basis.

This process resulted in the identification of 16 relevant online communities. Contact was then established with the board moderators of each website in order to obtain permission to recruit people accessing the online community to the study. A single follow-up email was sent to those sites that did not respond to the initial contact after one week. Out of the 16 sites contacted, 6 replied and agreed to participate in the research no response was received from the remaining 10 sites. The sites that

participated in the study were all peer moderated online communities, which varied in size and activity level.

The moderators of the online support communities indicated that their preferred method for recruitment would be through research invitations posted to the community bulletin boards. As discussed in the previous chapter this approach is common when researching online support communities (e.g. Buchanan & Coulson, 2007; Bunde et al., 2007; Hewson, 2003; Houston et al., 2002; Leiberman & Goldstein, 2005; van Uden-Kraan et al., 2008a). Thus it was anticipated that this would yield a good response rate. An additional advantage of this strategy is that it provides a means of recruiting both registered members as well as those individuals who are simply lurking in the online community.

Recruitment messages explaining the aims of the study and inviting members to take part in an online survey were thus crafted and posted to the 6 support communities (see Appendix A). In addition recruitment messages were posted to the infertility newsgroup bulletin boards at alt.infertility and misc.infertility. Individuals wishing to participate in the study were directed to an online survey hosted by SurveyMonkey; where they were provided with further information about the nature of the research project and participation. Recruitment took place between May and July 2007.

5.2.3 The research tool

The online survey was hosted using SurveyMonkey, a web-based survey software tool. SurveyMonkey was favoured over other web-based survey software because it presented a relatively cost effective and easy to use

tool that allowed researchers to independently design and launch a survey. Whilst at the same time offering numerous design and technological features including the ability to download data in various formats, multiple question formats, the ability to upload institutional logos and detect multiple responding. In addition, SurveyMonkey offered extensive customer support and guidance to users, which was considered to be invaluable in case of any technological issues arising during the data collection procedure.

Throughout the designing of the online survey careful consideration was paid to ensuring the survey was clear and easy to follow. A progress bar was displayed at top of each page to show respondents how far they were in completing the survey. In addition, the survey incorporated detailed information regarding the project, contact details of the lead researcher, clear guidelines for completing the survey and details of university affiliation including an institutional logo. These factors are thought to help instil faith and trust in the credibility of the researcher, which may encourage people to complete the survey (Wright, 2005).

To assess the clarity of the survey and help identify poor design features and the length of time required to complete the survey, the research tool was initially shown to colleagues working in the area of online support communities with experience of online research methodology. This process led to some minor amendments in the wording of the survey, which helped to ensure the instructions were as clear as possible. The survey was then piloted on the least active of the 6 communities identified. The first 5 responses from this online community served as pilots, which were used to assess whether further changes should be made to the survey. The responses received at this stage were extremely positive and did not

involve any critical comments or negative feedback. In addition, it was found that the data generated from the initial participants was extremely rich and interesting. As a result no further changes were made.

The survey commenced with an introductory participant information page containing background details about the research, the rights of the participant and contact details of the researcher. This was followed by a page containing details regarding informed consent and a page asking respondents to provide a password and indicate if they were willing to be quoted in dissemination of the work. Participants were then asked to provide some background information about themselves including age, gender, country of residence and diagnosis of infertility. The open-ended questions were displayed on a separate page and were specifically concerned with exploring the following issues: reasons for accessing online support communities, perceived advantages and disadvantages of online support community participation, impact of use on coping with infertility and the impact of use on marital relationships (see Appendix B). The specific questions were derived directly from the broad aims of the research.

5.2.4 Ethical issues

Ethical approval was obtained from the departmental Research Ethics Committee at the Institute of Work, Health & Organisations in the University of Nottingham. In accordance with the ethical code of conduct published by the British Psychological Society, the key ethical considerations reviewed for this study revolved around issues of informed consent, confidentiality, and the right to withdraw.

Prior to consenting to take part in the study all participants were given full information regarding the purpose of the research, the research methodology as well as their right to privacy, confidentiality and withdrawal from the study, in the form of a participant information page at the start of the online survey. Contact details for the lead researcher were also provided in this page and again at the end of survey in case any individual wished to raise queries or concerns regarding the research process. Following the participant information page, participants were reminded that their participation was entirely voluntary and were asked to click the 'NEXT' button to indicate their informed consent to take part in the study. Although SurveyMonkey provided the technological capability to make the completion of each question compulsory, due to the sensitive nature of the research topic it was decided to give participants the option to skip any questions that they did not feel comfortable answering. In addition before completing the survey each participant was asked to provide a password, which would enable their response to be identified should they wish to withdraw from the study after submitting their responses.

A number of measures were taken to protect the privacy and confidentiality of the research participants. Access to the raw data was password protected and only accessible by the lead researcher. Print outs of the data were stored in a locked file. No personally identifying information other than age and gender is reported in the results. Furthermore, in accordance with the British Psychological Society ethical code of conduct for Internet research the name of the online communities from which data were collected is not disclosed. In addition, all participants were given the option to identify whether they would be happy for their responses to be quoted in

any dissemination of the work (only 3 of the 95 participants indicated that they did not wish their quotes to be used in dissemination).

5.2.5 Data analysis

5.2.5.1. Selection of the data analysis technique

Qualitative data can be analysed using a wide array of different analytic methods (such as interpretative phenomenological analysis (IPA), grounded theory, discourse analysis, thematic analysis – to name a few). In the current study thematic analysis was selected to analyse responses to the open-ended questions. Thematic analysis is essentially a 'method of identifying, analysing and reporting patterns within data' (Braun & Clarke, 2006, p79). Similar to other qualitative analysis techniques it aims to provide a rich, detailed and complex account of the dataset. This allows the researcher to identify salient issues whilst also gaining a deeper understanding of the phenomenon under study. It is thus ideal for exploring under-researched issues and identifying similarities and differences across a large dataset.

The method was deemed the most appropriate analytic approach for an investigation into online infertility support communities for both practical and theoretical reasons. For example, due to the volume of responses received and variation in the length and detail of responses across participants, it was the felt that the data was not suited to the more lengthy and intensive qualitative analysis techniques of grounded theory or IPA for instance.

In contrast, to grounded theory and IPA, thematic analysis can also be seen as a theoretically flexible approach. Braun & Clarke (2006) distinguish between qualitative data analysis techniques which are tied to a particular theoretical or epistemological position and qualitative data analysis methods which are independent of theory and epistemology. They argue that techniques such as IPA, grounded theory, and discourse analysis fall into the former category and bring with them different assumptions about the nature of data and what they represent in terms of 'reality'. For instance, IPA originates from a phenomenological tradition, which is concerned solely with the 'lived' experience or reality of humans. While discourse analysis is aligned with a social constructionist paradigm, which seeks to understand the ways in which meaning is constructed through language. Thus, these techniques may be seen as incompatible or inappropriate for use in research conducted from a subtle realist standpoint. Thematic analysis on the other hand is not attached to a specific epistemological position and can thus be used within any theoretical framework (Braun & Clarke, 2006). In the light of this it was felt that thematic analysis was the method that would sit most comfortably with the overall epistemological position and aims of the research.

5.2.5.2. The process

Data analysis was carried out according to the guidelines set out by Braun and Clarke (2006). In line with recommendations from the authors it was considered good practice to make explicit *how* themes would be identified and classified in the analysis. Since the current study was exploratory in nature the decision was taken to adopt an inductive rather than deductive approach to data analysis. Inductive thematic analysis is a data driven approach, which involves identifying themes from within the data rather

than through the lens of a particular theoretical framework. Inductive analysis thus allows a richer and more detailed description of the dataset to emerge. This makes it ideal for under-researched areas in which the researcher does not have any pre-existing assumptions about the issues under investigation.

Due to the theoretical flexibility of thematic analysis a related issue was identifying the epistemological position guiding the analysis. Following on from the subtle realist stance taken in the design of this thesis, the present analysis was broadly conducted within an essentialist / realist framework. This research epistemology aims to report on the experience, meanings and reality of participants and assumes that language allows us to articulate meaning and experiences. Themes were therefore identified at the semantic level i.e. within the explicit or surface meaning of the data.

The actual data analysis was conducted through a series of five interrelated stages: 1) Familiarisation with the dataset, 2) Generating initial codes, 3) Searching for themes, 4) Reviewing themes and 5) Defining and naming themes. Braun & Clarke (2006) argue that before any meaningful patterns can be identified in a dataset it is vital that the researcher is aware of the depth and breadth of their data. This can only be achieved through repeated reading of the data. With this in mind the first stage of the analytic process involved reading the participant's responses to the questions several times in order to become familiar with the dataset. With each reading any interesting features of the responses or emerging patterns were noted. These preliminary notes were revisited in the next stage of the analysis in which codes were generated from the data. This was done manually by writing notes next to each response to highlight any repeated patterns in the dataset or interesting features related to the

research aims. At this stage, coding was undertaken for as many potential themes / patterns as possible. The entire dataset was given equal attention and each individual response was coded in as many different themes as required. This rigorous approach helped to ensure that potentially relevant aspects of the data were not overlooked. This resulted in the generation of a list of different codes from across the dataset. In the third stage of the analysis these initial codes were grouped into potential themes. This involved examining all the relevant coded extracts to identify significant themes and relationships between the various codes. For example, codes relating to the benefits of anonymity and asynchronous communication in online communities were collated into one overarching theme, which related to the unique features of online communication. Once these preliminary themes had been identified the entire dataset including the coded extracts for each theme were re-examined to ascertain the validity of the themes in relation to the original data. The following questions were used to guide this process: Do the themes 'fit' the data? Is there enough data to support each theme? Do data within each theme cohere together meaningfully? Is there a clear distinction between themes? Do any themes need to be collapsed or separated? Following this process of refinement a label was allocated to each of the emergent themes and the scope and content of each theme was clearly defined.

5.3   Results

5.3.1 Participant characteristics

A total of 95 individuals completed the online survey. The majority of respondents were found to be female (93.7%) and residents of the United Kingdom (93.5%). Participants were aged between 25-54 years (Mean age

162

= 35.6 years). Of these, 28.7% indicated that they were suffering from female factor infertility, 23.7% from male factor infertility and 25% male and female factor infertility, while 22.5% stated that the cause of their infertility remained unexplained.

In terms of their use of online support communities 89.5% stated that they were active members of an online support community, while 10.5% identified themselves as 'lurkers' i.e. a guest or members who did not post messages.

5.3.2 Thematic analysis

Thematic analysis of the participant's responses to the open-ended survey questions revealed five recurrent themes, which were labelled:

- **Unique features of online social support**
- **Improved relationship with partner**
- **Reduced sense of isolation**
- **Information and empowerment**
- **Negative aspects of online communities**

A detailed description of the emergent themes is presented in the following sections.

5.3.2.1 Unique features of online social support

In discussing their reasons for accessing online support many participants drew on some of the unique characteristics of computer-mediated communication to describe the benefits conferred by online communities over face-to-face sources of support. In particular frequent references were

made to the convenience and 24 hour availability of online support communities, through which a network of similar others could be accessed with ease:

"It is convenient and I know where to easily find a group of people who know what I'm going through." (Female, 31)

For some individuals the knowledge that they could potentially communicate their feelings and concerns at any time of day or night appeared to provide great comfort and thus aided their ability to cope. For example, when describing the advantages of participation one woman stated:

"It helps very much. Most of the time if you are worried you can ask a question and somebody out there will have an answer for you. People are there 24/7 to offer reassurance". (Female, 40)

While another discussed the therapeutic potential of the online community:

"The ability to offload when you need to talk - if you wake at 2.30am and need to share how you're feeling you don't have to wake up your partner." (Female, 37)

The ease of communicating their emotions with members of the community appears to be further facilitated by the asynchronous and anonymous nature of the online medium. Almost all the respondents expressed the view that the relative anonymity conferred by the Internet removed the complications of face-to-face communication, thus enabling them to express their feelings more fully without fear of embarrassment or stigmatisation. For example, some individuals described how the online

support community encouraged complete honesty when discussing highly personal and sensitive issues:

> *"During our own treatment we discovered we needed to use donor sperm, having access to other people when I was ready to talk was a lifeline. The anonymity meant I could be honest with my emotions and give and receive support form others in similar situations." (Female, 37)*

This appeared to be of particular value when disclosing painful or negative emotions. For example one respondent stated:

> *"I have also felt that the anonymity of a website means I can raise things that I am feeling that I hardly dare admit I am feeling. I can ask questions I wouldn't normally ask or offload my bad/negative emotions." (Female, 33)*

While another wrote:

> *"The online support was also extremely valuable after my miscarriage when I wanted to 'talk' about....It is often easier to talk about difficult or painful issues when you are anonymous." (Female, 28)*

Several participants further noted that the lack of real time pressure within online support communities also offered them a degree of control over their level of participation and involvement, which would not have been possible in traditional face-to-face interactions:

"You can select items which are relevant to your particular situation and participate when you want to or have time." (Female, 41)

"You can also choose when you participate so if you don't feel like talking, then there is no pressure to do so, unlike with friends and family." (Female, 34)

In a number of cases this characteristic of online support communities not only increased the convenience of engaging in online communication but also provided a therapeutic benefit, through offering members the opportunity to reflect on their thoughts and experiences whilst seeking social support. For example when asked to describe the impact of participation on coping one woman stated: *"The ability to "think through" my feelings through the process of posting." (Female, 38).* While another stated: *"It can give breathing space to consider responses, that you don't get in real-time conversation" (Female, 36).*

5.3.2.2 Improved relationship with partner

Many respondents expressed the view that participation in online support communities resulted in positive consequences on their offline relationship with their partner. In numerous instances individuals described experiencing feelings of isolation from friends and family and an inability to open up about their infertility within existing social circles. As a result their partner had become the sole confidante and source of social support when dealing with the emotional strain of infertility:

"At times it has felt like my partner was the only person I could really talk to - after 12 yrs of treatment, I think a lot of my friends

were thinking 'is she still going on about that' and people gradually

stopped asking. Most of my family also found it difficult to talk

about. Having the web forum lessened the burden on my partner so

that he wasn't the only person I was letting off steam to". (Female,

41)

Often it was felt that this support role appeared to cause great anxiety and pressure for the male partner. However, through accessing online support communities many women appeared to discover an alternative venue in which they could discuss negative emotions and vent anxieties or frustrations, thus lessening the strain on their relationship and in particular their partner:

> *"Having an online forum to visit helps me not to bombard my*
> *husband with conversations relating to infertility and IVF etc.*
> *Although we do discuss this together I feel that I have my forum to*
> *give me support as well as he does, which removes extra stress*
> *from our relationship." (Female, 35)*

> *"being able to "discuss" your feelings and get feedback from others*
> *in the same position has stopped me "obsessing" so much and*
> *endlessly going on at my husband......I think by being able to "chat"*
> *in the forum it has stopped me putting so much pressure onto my*
> *husband during an already stressful time, which has helped our*
> *relationship." (Female, 31)*

As these quotes illustrate the online support communities not only functioned as an alternative forum in which to disclose emotions relating to infertility but also provided a valuable source of emotional support and positive encouragement. Many of the participants described how this

helped them feel more 'relaxed' and 'calmer' in their day-to-day life and thus benefited their relationship indirectly by enabling them to be more positive when interacting with their partner. For example one woman wrote:

> *"he is happy I've found people to talk to about our situation. I'm so much more positive and don't have so many bad days about our fertility problems. I'm a lot easier to live with now!" (Female, 29)*

Another wrote: *"My partner never participated in an online support group and asked me not to post personal information about him (such as his sperm count!). But, being able to see our infertility in a positive light (because of being in a support group) made our relationship much stronger." (Female, 34)*

Furthermore in some cases through sharing their experiences with community members who had been in similar situations, several women reported becoming more sympathetic to their partners emotions and coping strategies surrounding infertility. As one participant commented:

> *"It has made me more understanding and, for want of a better word, tolerant of the way my partner deals with his emotions. He is quite typical of how men react I have come to learn, and would not have been able to realise and accept the differences in how we cope if I hadn't shared my experiences/feelings etc with others on the site and heard their stories." (Female, 32)*

5.3.2.3 Reduced sense of isolation

Numerous references were made to the significance of communicating with individuals who have a first hand understanding of the issues surrounding infertility:

"It helped in every way possible. Without these people who understand exactly what I am going through I would be stressed. My friends are wonderful but unable to help me unless they have been through it." (Female, 34)

"These people know what you are feeling, although you have family friends who can emphasise with you nobody really knows what this journey is like unless you go through it. Like other aspects of life I suppose." (Female, 37)

Many of the respondents held the view that friends and family could not fully appreciate the pains of infertility and the strong sense of anxiety accompanying fertility treatment, consequently feelings of loneliness and social isolation were common. In this context the online support communities functioned as an avenue through which individuals could identify people in similar situations to themselves:

"There are times you feel the need to rant, and as much as family and friends will listen, only someone who has actually gone through the same thing as you will understand. This site has been a godsend." (Female, 26)

"When going through the actual treatment it was good to check in with others also going through it, and any fears, get advice and reassurance. I feel people who haven't experienced infertility or the pressures of ivf understand and therefore to have some where you can moan, cry, express fears, anger and grief, and all the other emotions that go side by side with infertility is a great comfort." (Female, 35)

In many cases this led individuals to realise that they were not alone in the distress they were experiencing and there were many who shared similar experiences:

> *"I felt so alone and isolated in how I was feeling and what we were going through but since joining the online support network I have come to realise there are others out there who understand what its like to experience IF and ivf and it makes the world of difference. I have gained so much, support, advice, friends, from the site my only wish is I found it earlier in our journey." (Female, 32)*

Several participants described how this helped to normalise their emotional reactions and thus reduced feelings of guilt and abnormality:

> *"Then women reply, saying they feel the same and suddenly I'm not a bad person for not coping with things such as infertility or a fertile friend's pregnancy. I'm not a bad person for saying why I don't want to use donor eggs; I become someone grieving for her genetic children." (Female, 33)*

> *"When I first joined it was so nice to have someone else to "talk" to who understood the emotions and feelings involved when undergoing fertility treatment.....It certainly made me realise that feeling I had were not uncommon. One particularly common feeling amongst women who experience difficulty conceiving is the intense jealousy when finding out someone close to you be it family, friend or work colleague is pregnant. I have experienced these feelings myself and was enormously relieved to know it wasn't just me who felt like this...." (Female, 40)*

For some simply viewing messages that conveyed common experiences was perceived as highly beneficial. For example one guest user commented:

> *"Looking at the bulletin boards has shown me that I am not the only one who is feeling this way....Other women are having the same feelings as me e.g. why me etc" (Female, 42)*

The empathic understanding available from fellow members was of particular value during periods of uncertainty or failed treatment:

> *"It helps to share and talk to others whom truly understand. I recently got pregnant following our first IVF cycle and was elated, but lost the pregnancy at 7 weeks. The girls on this site have been invaluable support at my darkest times." (Female, 32)*

In this way the online communities not only helped to alleviate the sense of isolation experienced by many participants but also provided a valuable source of emotional support for individuals going through the highs and lows of fertility treatment.

5.3.2.4 Information and empowerment

Through reading messages posted to the online communities, individuals were able to draw on the shared experience of community members as a source of informational support for themselves. Participants particularly appeared to value the wealth of information that could be accessed concerning treatments for infertility, which often resulted in a better understanding of their condition and available treatment options:

> *"I have learned about different protocols relating to IVF from forum members and have asked my clinic about this. I am also a poor*

responder to IVF so have learnt about different drug regimes on the Internet, and have also asked my clinic about this." (Female, 35)

"It has made a tremendous difference. I began on a support group after 1 cycle of treatment. I didn't have any knowledge of the drugs, the treatment, the side effects etc, but since joining a group, I was helped by others telling me what their experiences were." (Female, 34)

Some individuals further commented that they now felt more knowledgeable concerning fertility issues than even their GP: *"it's helped with awareness of treatments and tests that I should have. Sometimes I feel that I am more aware than my doctor" (Female, 42)*

This appeared to empower many respondents to take a more active role in overcoming their infertility:

"We have been advised that some women find aspirin can help with implantation - so we spoke to our Doctor about this. I have also had various tests and wanted to know what the result should be, and when my results came in, I knew what I was talking about, and could speak to the nurses with some knowledge." (Female, 26)

"We have a male factor problem and when we first saw a consultant we were told that they could not do anything to help. After doing some research and spending time on the forum I realised that this was not true and there were avenues that we could pursue (SSRs etc)." (Female, 28)

> *"I have challenged Doctors on their choice of treatment for me and explored with them what I believe to be other options that may be more suited to me." (Female, 44)*

As a result these individuals gradually felt more in control of their situation, one woman commented: *"One of the hardest parts of infertility is the lack of control you feel as unlike many things in life there is no set course of action you can follow to get the end result. By actively seeking information and support you feel like you are doing something to achieve your goal"* (Female, 33).

The informational support available via online support communities also appeared to play a significant role in decision-making: *"The shared information makes it much easier to decide how to proceed when you're faced with tough choices." (Female, 34).* For instance several individuals described how they referred to the experiences of others to guide their next steps. One guest user wrote:

> *"I feel more informed in terms of the options that are available to us and also in terms of understanding what is wrong with both of us. I've also been able to look at people know have been on this journey for longer than us and make decisions as to how we can do things differently. As a result of this we are actively trying to inform ourselves about adoption." (Female, 31)*

Often information would be discussed with a medical professional prior to decision-making:

> *"I often research various treatments, drugs either on the Internet, or by asking those on forums of their experiences. This has led me to talk to my Consultant on numerous occasions about the best way*

to proceed. It works for me - in allowing me to get the best advice.. even if my Consultant advises me to follow another route, I feel I have done all I can to help myself. It also works well for Consultants/Nurses to understand what type of questions we are asking, what kinds of treatments we are interested in to help us through this journey" (Female, 34)

The vast majority of individuals reported positive experiences whereby they were able to work with their GP's or consultants to identify the path that was right for them. However, in some cases people described negative reactions from their consultants:

"Unfortunately, most consultants always feel their way is the right way, very egotistic, and will not budge on their protocols unless it is proven. If they took time out and read these boards they may change their minds somewhat. There is such a vast amount of woman using the threads that something could be learned from their experiences. I asked my last consultant about a protocol they use in USA for 'poor responders' like myself, although their stats are high in USA, he wouldn't really entertain it and pulled the information to pieces." (Female, 37).

As a result some patients developed strategies to indirectly elicit their doctor's views on information they had obtained from the Internet. For example one participant stated:

"I have found that medical professionals tend to roll their eyes or glaze over when you say, "I read on the Internet..."! However, when discussing with my consultant the way forward or next step, I have been able to say, "I know someone who did this and this was the result." or, "I know someone who had worse hormone profile

than me and she tried this, do you think it might work for me?""

(Female, 33)

5.3.2.5 Negative aspects of online communities

Although the majority of respondents appeared to gain important benefits from accessing online social support, some individuals also described negative effects associated with participation that revolved around the unique nature of the online medium and fertility treatment itself. For example several participants described how reading stories about other people's grief, particularly relating to negative treatment outcomes led them to experience feelings of overwhelming sadness and distress. As one respondent wrote: *"With so many members there are from time to time terrible stories that are shared, and tragic stories and it can be very distressing" (Female, 35).*

A number of individuals also discussed emotional reactions to success stories posted within the online forums. Whilst these success stories initially appeared to function as a source of hope and reassurance that treatment could be successful: *"reading success stories gives you the hope to carry on". (Female, 31),* overtime for certain individuals, particularly those couples who had been through repeated failed treatment attempts, messages reporting positive treatment outcomes appeared to compound the psychological distress they were experiencing and in some instances resulted in individuals withdrawing active participation from the community:

> *"Initially it made me quite open about my situation, but as time wore on and others moved on to the pregnancy section I felt worse and worse so stopped participating, even to the point that when I*

eventually had success myself I did not want to join in." (Female, 43)

"At some points these support networks have made things much easier, giving much needed support and helping with infertility issues. But at times it's difficult when you make friends with someone and their journey is so different to yours. You start off conversing with them, from the same perspective, then find that you are monitoring their pregnancy. It can be hard to see how long it's been for you compared to them. Also the visits to the boards can become obsessive, and at times I've just stopped completely because it wasn't helping, it was fuelling the obsession." (Female, 35)

As this quote illustrates women often commented that online support community participation led to them becoming preoccupied with their condition to the extent that they were 'obsessive' in their use of the online community. For instance one women spoke of the negative impact participation had begun to have on aspects of her daily life:

"Sometimes I have had to have a break from the boards - gets too much or I find I'm sending too much time on them and not enough time on other home or work matters" (Female, 38)

Another frequently reported disadvantage of online support communities related to misunderstandings occurring among community members. Several individuals recalled instances where certain posts had been taken the 'wrong way', thus leading to disagreements and subsequent bad feeling among various community members. Some participants expressed the

view that these misunderstandings were exacerbated by the stressful nature of fertility treatment, which made many members highly sensitive to the remarks of others:

"With so many women going through a very stressful and emotional treatment and when trying to conceive is such an anxious time, very occasionally comments can be taken out of context and misunderstood...rarely but sometimes I feel because it can be hormonally charged!!" (Female, 38)

5.4   Discussion

The purpose of the present study was to qualitatively examine the motives, perceptions, and experiences of people accessing online infertility support communities. Analysis of responses to open-ended survey questions by a total of ninety-five participants revealed that individuals across several online support communities considered there to be a range of important benefits from their online experiences, which appeared to aid their ability to cope with some of the psychosocial challenges surrounding the diagnosis and treatment of infertility. In particular, the findings suggest that seeking treatment related information, anonymity, reduced feelings of isolation and relationship strain and gaining a sense of control over one's situation were all important motives and benefits of online support seeking across the dataset. However, the results also suggest that there are a number of negative effects associated with usage, namely misinterpretation of messages, becoming preoccupied with infertility through participation and experiencing difficulties coping with the treatment success of fellow members.

From the survey responses, it was apparent that the online communities primarily functioned as a significant and often unique source of informational and emotional support. This finding is consistent with past literature, which suggests that both information and emotional support are the most prominent categories of social support exchanged within online support communities (e.g. Braithwaite et al., 1999; Coulson, 2005; Finn, 1999). For the individuals in this study information exchange centred predominantly around issues concerning treatment options and gaining an insiders perspective on different treatment protocols. Emotional support on the other hand appeared to be of particular value during periods of uncertainty and grief following a negative treatment outcome or the loss of a pregnancy after initial success. These results are largely in keeping with findings documented in the infertility literature; for example there is evidence to suggest that waiting for a treatment outcome or receiving news of an unsuccessful attempt appear to be the most stressful stages of fertility treatment for couples and the time at which individuals are most prone to depressive symptoms (Baram et al., 1988; Connolly et al., 1993), the need for social support and emotion focussed coping strategies is therefore likely to be particularly salient during this period. In addition, research suggests that many infertile patients show a strong desire for the provision of detailed medical information regarding treatments and the options available to them (Halman et al., 1993; Schmidt, 1998; Schmidt et al., 2003; Stewart et al., 2001) and often report dissatisfaction with the level of informational support provided by fertility clinics (Laffont & Edelman, 1994; Schmidt, 1998; Souter et al., 1998; van Empel et al., 2010).

From a theoretical perspective, the prominence of both informational and emotional support could be explained using the theory of optimal matching (Cutrona & Russell, 1990). The theory of optimal matching suggests that certain types of support will be most beneficial following particular types of stress, with the controllability of the situation playing a central role in determining the required support. According to the theory individuals are more likely to perceive emotional support as helpful when they are experiencing distressing events, which they feel are out of their control. In contrast, it is argued that individuals are more likely to require informational support when they feel they can use this information to control the situation. Since the experience of infertility typically involves both controllable (i.e. the decision to seek treatment) and uncontrollable (i.e. the outcome of treatment) elements, infertile couples are likely to experience a strong need for both informational and emotional support along their journey.

These findings also sit comfortably with Lazarus and Folkman's (1984) stress and coping theory; a model frequently used to guide infertility research. The model suggests both emotion-focussed (i.e. focusing on regulating emotional reactions to infertility) and problem-focussed (i.e. seeking information and devising a plan of action) coping strategies are effective dependant on the controllability of the stressful situation. Online support communities can therefore be used as a source of information to aid problem-focussed coping, as well as a forum for seeking emotional support to facilitate emotion-focussed coping during uncontrollable phases of infertility such as waiting for a treatment outcome.

Through seeking fertility-related information in an online community many individuals were empowered to take a more active role in deciding the course of their fertility treatment. The shared experiences of community members was thus considered an extremely valuable resource at stages when decisions had be made about the couple's next steps i.e. whether to continue treatment or which drugs/treatments to pursue. This suggests information available from online support communities can potentially have a significant impact on treatment-related decision making among infertile couples. Although the majority of participants in this study reported directly or indirectly discussing this information with medical professionals prior to decision-making, this finding nevertheless raises concerns regarding the risk of the exchange of inaccurate or misleading medical information. Particularly since past research has reported that a proportion of postings to various health-related online support communities contain medical information that could be classified as outside standards of medical care.

Similar to indications in the literature, the findings from the present study reveal that feelings of social isolation appear to be common among people dealing with infertility. For the individuals in this study these feelings appeared to stem from the belief that only people with first hand experiences of infertility could fully appreciate and empathise with their emotions. A desire to communicate with people in similar situations and feel 'less alone' were thus frequently cited reasons for seeking online support.

The thematic analysis indicated that most participants benefited from the opportunity to discuss their emotions with a network of similar others. For

instance, through discovering a large group of people with similar experiences, individuals no longer felt that their experiences were unique, which lessened the sense of isolation they were experiencing. These findings suggest that accessing online support communities may significantly reduce loneliness among infertile patients. This is one issue that would benefit from further empirical examination in a larger scale study.

Interestingly it was observed that individuals who 'lurked' on the bulletin boards appeared to experience similar benefits in relation to the feelings of isolation they were experiencing than those who actively participated. This finding offers support to Walther and Boyd's (2002) argument that individuals lurking in health-related online support communities may derive similar benefits to that of active participants due to the shared experiences of community members. However, due to the exploratory nature of this research and the comparatively smaller number of 'lurkers' that participated, the study is limited in the extent to which comparisons can be drawn between the online experiences of 'lurkers' and active participants. This is one area that may also benefit from further investigation, particularly given the potentially high numbers of 'lurkers' accessing online infertility communities and suggestions in the literature that 'lurkers' do not experience as much satisfaction with online communities as active members (van Uden-Kraan et al., 2008b).

In addition, many participants in this study derived a range of important benefits from the unique characteristics of the computer-mediated environment. For example, factors, which appeared to encourage individuals to access online support, included the anonymity, 24-hour

availability and asynchrony of computer-mediated communication. Of these factors anonymity appeared to play a particularly pivotal role in enabling members to openly share their experiences with the community. In particular, the responses to the open-ended questions revealed that the anonymous nature of an online community was thought by many to be a key advantage when discussing painful and negative emotions surrounding infertility. This finding suggests that online support communities may promote self-disclosure among people affected by infertility. However further research examining communication in online infertility support communities is needed to shed light on this issue. Overall these results are consistent with studies examining other health-related online support communities, which demonstrate that the unique characteristics of online communication such as anonymity are particularly beneficial when discussing personal experiences (Buchanan & Coulson, 2007; Henderson & Gilding, 2004; Salem et al., 1997).

A relatively unique finding from the present study is the suggestion that online support communities may be one method through which individuals can reduce the amount of strain on their relationship. This is an important finding as past research suggests that couples affected by infertility typically rely on their partner as a crucial source of support. Some authors have suggested that this may cause serious strains to the couples relationship; for instance Mahlstedt (1985) argues that since both partners in a couple are affected by the unfulfilled desire for a child and the emotional strains of fertility treatment, they become less able to fulfill each others individual needs. As a result men often feel a need to suppress their own emotions in order to remain calm and focussed on their wife's needs. In contrast women express a stronger desire to share their thoughts and

feelings in relation to infertility (Buetal et al., 1998; Hjellmstedt et al., 1999; Slade et al., 2007). In addition, it is frequently reported that women are more involved in the process of researching infertility treatments and express greater distress at failed treatment. These differences in men and women's approach to infertility may lead some women to feel that their husband is not equally committed to the goal of conceiving a child. Indeed there is evidence in the literature to suggest that such differences in a couples approach to infertility can be a risk factor for marital problems resulting from infertility (Pasch et al., 2002; Peterson et al., 2003).

The results for the present research show that many women in the study felt that the online communities provided them with a valuable source of support and an alternative venue for venting anxieties and frustrations, which took the strain off the male partner who had previously been the only person to whom these feelings could be communicated. Furthermore, the results suggest that participation may also ease communication problems caused by infertility, by helping women to accept differences in how men and women perceive and cope with infertility. From the current study it can therefore be hypothesised that online support communities may lead to significant benefits for marital relationships. However, given the exploratory nature of this study it is difficult to predict the extent to which usage does in fact improve marital adjustment to infertility. Furthermore, the views presented in this study are predominantly those of the female partner accessing online support. Previous research suggests that while men have a strong desire to be involved in fertility treatment, they often feel distant from the entire process due to the fact that medical testing and treatment tends to centre around the female body, the central role for the male partner is therefore to be a source of strength and

support for their wife (Malik & Coulson, 2008). In this context, some men may feel increasingly helpless and isolated if they are no longer needed as the sole source of support for their partner. There is also a risk that online support usage may lead to reduced communication between partners, as a number of researchers have raised concerns over the potential for online friendships to replace meaningful relationships among 'strong ties' (Eysenbach, 2003). Indeed, there is evidence to suggest that online communication may encourage some people with infertility to withdraw from real-world interactions (Epstein et al., 2002). Further research is therefore required to examine in more detail the impact of online communities on marital satisfaction and adjustment to infertility.

The results also reveal that for some individuals there were a number of disadvantages associated with accessing online support communities. For instance, several respondents described incidents where messages posted to an online community had been misinterpreted by one or more readers. These incidents appeared to have a significant impact on community spirit, resulting in tensions and misunderstandings among community members. This disadvantage may be related to the lack of visual cues within the online environment, as the absence of additional cues such as body language and tone of voice can make it more difficult to interpret the tone or meaning of a message. Some authors have argued that Internet users frequently adopt an electronic 'paralanguage' consisting of emoticons, capitalisation, and the use of intentional misspelling in order to overcome such disadvantages (Carey, 1980; White & Dorman, 2001). The extent to which members of online infertility support communities successfully adopt this paralanguage remains unclear.

Another significant disadvantage related to difficulties coping with the successful treatment outcomes of other members. Some women expressed feelings of overwhelming jealousy, grief, and depression when faced with stories of other women's recent pregnancies. This was particularly salient among women who had experienced a negative treatment outcome or repeated treatment failures. These findings are largely in keeping with past literature, which shows that women frequently experience feelings of intense jealousy when around other people's children and report difficulties maintaining relationships with friends who have children (Miall, 1985). For example, when examining the efficacy of brief stress management support groups for couples, McNaughton-Cassill et al. (2002) found that members often experienced feelings of envy when others were progressing more rapidly. In addition research suggests that women who persist in their attempts to achieve a pregnancy 3-5 years after the termination of IVF experience greater levels of anxiety and depression compared to those infertile women who are able to find new life goals (Verhaak et al., 2007).

Other disadvantages identified included the feeling that online communities resulted in participants becoming obsessive with infertility and spending too much time online to the exclusion of other daily activities. For many couples faced with fertility problems, infertility often becomes the central focus of their life, in some instances to the exclusion of other aspects of daily life (Cousineau & Domar, 2007). Thus, the extent to which the pre-occupation with infertility reported by participants in this study related to their use of online support communities specifically is unclear. However, the finding that some individuals felt they were spending too much time online warrants further empirical investigation. Since past research suggests that Internet usage could be addictive and cause increased levels

of depression and isolation from family and friends (Klemm & Hardie, 2002; Kraut et al., 1998).

5.4.1 Limitations of this study

There are a number of potential methodological limitations to the present study, which should be considered. Firstly, the research participants in this study were a self-selected purposeful sample of individuals who accessed the online support communities during the study period. The extent to which these participants are representative of other individuals accessing online infertility support communities is not clear. It may be the case that the individuals who chose to take part in the study had particularly positive online experiences and were thus highly motivated to contribute to the research. In contrast those individuals who were negatively affected may have withdrawn from the online support community and would therefore have been unavailable to answer researcher questions. The results from this study may therefore over-estimate the positive aspects of online support communities, while underestimating potential disadvantages.

Second, the current study was cross-sectional and is thus based on the participant's views at a single point in time only. Responses may have been influenced by a range of situational factors such as mood or stage of treatment. Furthermore, as the results indicate attitudes towards online support communities may alter over time. Consequently, research adopting a triangulation of methods or a longitudinal prospective design is crucial to understand the phenomena of online infertility support communities.

Third, since the majority of participants in the present study were female it is difficult to generalise the findings to men accessing online support

communities, particularly since past research indicates that gender differences may exist in the reasons why men and women seek online support (Mo et al., 2009), as well as in their reasons for and experiences of seeking fertility treatment. However, this response pattern may simply reflect a higher prevalence of women within online infertility support communities. Indeed, a number of studies indicate that women may be more committed to the pursuit of fertility treatment than men (Daniluk, 1997; Newton et al. 1992) and typically experience greater levels of distress and discomfort during fertility treatment regardless of which partner is biologically responsible for infertility (Connolly et al., 1992; Dhillon et al., 1997). It may therefore be the case that female partners experience a greater need for infertility-related informational and emotional support and are thus more motivated to seek out an online infertility support community.

Based on past literature it could also be hypothesised that men using online support communities may have experienced a greater reluctance to take part in the research. As researchers frequently report great difficulty in recruiting male respondents to infertility research. For instance studies examining the male experience of infertility have consistently tended to achieve lower overall response rates in comparison to studies involving females (Lloyd, 1996). This suggests that researchers interested in examining gender differences in the use of online support communities among people with infertility, may need to employ alternative strategies such as the analysis of bulletin board messages. Examining bulletin board messages may also help to determine how representative the participants of the study are of people using online communities i.e. are the majority of messages in online infertility support communities also posted by women?

Finally, as discussed in the methodological section of this chapter the use of a survey approach to qualitative data collection meant the researcher was unable to probe interesting features of the responses to gain further information about particular issues. Nevertheless, despite this limitation it was found that the survey tool was successful in eliciting both a breadth and depth of information from respondents. As can be seen through the quotes used in the results section, many of the respondents wrote detailed and insightful responses to the questions. Thus providing an extremely rich source of data on which to base the conclusions from this study.

5.4.2 Conclusions

This study presented the first stage of a triangulated investigation into the phenomena of online infertility support communities. The results offer a unique and rich insight into the motives, perceptions and experiences of people who access online infertility support communities. Importantly, they show that online support communities may help some individuals deal with the psychosocial effects of infertility and provide a valuable forum in which individuals can engage in informational and emotional support with patients in similar situations. Specifically, the findings suggest that online communities can reduce feelings of isolation and loneliness, improve marital relationships, empower people to take a more active role in infertility-related decision-making, and encourage the sharing of personal and sensitive experiences. These findings not only add to the growing body of literature purporting that online health-related support communities can produce psychological benefits for users, but also the infertility literature by showing that online communities present a new and valuable avenue through which people coping with infertility can fulfil their support needs.

However, despite these advantages the results also indicate that there may be several disadvantages associated with accessing online infertility support communities. In particular, it appears that overtime some individuals may become increasingly depressed and isolated, particularly if fellow members have moved onto pregnancy while they are undergoing repeat treatment cycles. These findings are reflective of suggestions made by the Weak Tie Network theory (Adelman, Parks, & Albrecht, 1987), which argues that weak ties formed over the Internet can serve several important functions such as facilitating self-disclosure, stigma management and access to diverse sources of information. However, the theory contends that there are also likely to be several disadvantages to weak ties formed in a virtual environment, which may include hostility among individuals and difficulties interpreting information due to the lack non-verbal cues.

Hence, the results of this preliminary study have implications for future research in the area of online infertility support communities, through raising a number of interesting research questions for further investigation. For example, the results imply that further studies exploring psychosocial outcomes associated with the use of online infertility support communities should pay particular attention to factors such as marital satisfaction and stress, infertility-related strain, social support, and loneliness, as these are all areas in which the participants in this study felt that they had benefited. Furthermore, the results indicate that factors such as an individual's stage of treatment or length of diagnosis may influence how individuals perceive the online community and their psychosocial well-being. This is one area that could be further examined through a quantitative study. The results also highlight the need to focus future research on exploring both positive and negative aspects of online communication among people with

infertility. For example, an analysis of bulletin board messages could add to the current findings by giving an indication of the extent of negative versus positive communication in online infertility support communities. Another interesting finding from the current study was the striking similarities between the response patterns of 'lurkers' and posters. Contrary, to indications in the literature this suggests that both 'lurkers' and posters may gain equal benefits from accessing an online support community. Future research with a larger sample size could seek to explore this issue further by comparing the experiences of 'lurkers' and posters.

The next of stage of this thesis will look at communication in an online infertility support community, in order to further examine the efficacy of online infertility support communities as well as explore some of the emerging issues from this study in more depth. A detailed discussion of the aims and objectives of this study are presented at the start of the next chapter, followed by an analysis of bulletin board messages and discussion of findings.

6 Chapter Six: Study Two: An examination of self-help mechanisms in an online infertility support community

CHAPTER SUMMARY

This chapter corroborates and extends the results of the previous chapter by describing a study that was concerned with analysing self-help processes within an online infertility support community. This study involved a content analysis of therapeutic and self-help mechanisms in 3,500 messages posted to the online community. The analysis revealed that the most frequently used self-help mechanisms were support or empathy (45.5%) and sharing personal experiences (45.4%), followed by the provision of information and advice (15.9%), gratitude (12.5%), friendship (9.9%), chit-chat (9.4%), requests for information or advice (6.8%) and universality (4.8%), with negative statements (0.3%) and creative expressions (0.2%) being the least frequent categories. These findings suggest that online support communities can provide a viable alternative source of support and self-help for people experiencing infertility, through allowing them to utilise many of the self-help techniques and therapeutic processes that are known to be beneficial to people accessing face-to-face support groups. The practical and theoretical implications of the results are discussed.

6.1 Background

The results of the previous chapter suggest that people accessing online infertility support communities can potentially gain a range of important benefits from their online experiences, which may help to alleviate some of the negative psychosocial consequences of infertility and its treatment. These findings suggest that online support communities may provide a valuable alternative source of self-help and support to help people cope with infertility. However, as discussed in the previous chapter participants also identified a number of negative aspects to their online experiences. Nevertheless, due to the self-selected nature of the sample it was felt that the study may have overemphasised some of the positive aspects of online communities whilst underemphasising the negative aspects.

This chapter aims to build on the results from the previous study through examining communication in an online infertility support community. As outlined in chapter three, triangulation of research and data collection methods can be valuable for obtaining a comprehensive understanding of new and under researched phenomena. This particular study was undertaken with two objectives in mind. Firstly, it was anticipated that examining naturally occurring online communication would help to address some of the limitations identified in the previous study. For example, an analysis of communication might provide an insight into the characteristics of people who post messages to online infertility support communities and the extent of positive versus negative communication / remarks. Such insights could help to assess the generalisability of survey findings to the larger population of people using online infertility support communities.

Secondly, it was felt that analysing online communication would allow for a more complete picture of online infertility support communities to emerge. As LaCoursere (2001) points out messages posted to online communities can provide a direct and detailed insight into the self-help and therapeutic processes that occur within support communities. Research from face-to-face self-help and support networks identify a number of processes that commonly occur in groups, which can lead to therapeutic or psychological benefits for members. These include a sense of community and universality, catharsis, mutual support and problem-solving and the sharing of experiential knowledge (Borkman, 1990; Gray et al., 1999; Katz, 1992; Solomon, Pistrang, & Barker, 2001; Yalom, 1995). In recent years, a number of authors have begun to study self-help mechanisms in messages posted to various online support communities in order to explore the extent to which these processes also occur online (e.g. Finn, 1999; Perron, 2002). To date however, little research has focussed on the extent to which online infertility support communities offer the processes that are known to be beneficial in face-to-face groups. Examining therapeutic and self-help processes in messages posted to online infertility communities can thus contribute to strengthening our understanding of the efficacy and viability of the Internet as an alternative source of support for people with infertility (Finn, 1999; van Uden-Kraan et al., 2008a).

6.1.1 Aims and objectives

The overall aim of this study was to examine the efficacy of online communities as an alternative source of self-help and social support for people experiencing infertility through exploring self-help processes in an online infertility support community. Specifically, the study was concerned with addressing the following research questions:

• What are the self-help mechanisms that occur in messages posted to online infertility support communities? How do these compare to supportive communication and self-help processes that take place offline?

• What are the demographic and infertility-related characteristics of people who post messages to online infertility support communities?

• Is there any hostile or disinhibited communication in online infertility support communities?

• To what extent do members express negative aspects to participating in an online infertility support community?

6.2   Methods

6.2.1. Selection of online support community and sampling of messages

Data were obtained from an archive of messages posted to a UK online support community for infertility issues. The support community was a peer moderated online community providing free asynchronous support and advice to individuals experiencing a range of infertility problems through a bulletin board format. As outlined in the previous chapter, in the first instance a number of relevant online communities were identified through Google searches using a combination of the search terms: "infertility", "fertility", "message board", "bulletin board", "online support group", "online community" "discussion board" and "online forum". However, due to time restrictions the decision was made to focus the

analysis on a detailed examination of processes in a single online community. Although some may argue that this could limit the generalisability of the findings, the online community selected for the purpose of the study was found to be by far one of the largest and most active online communities of people with infertility with an average of over 50 postings a day. In addition, at the point of data collection the online community had around 23823 registered users and an archive of 1992196 messages. Hence, it was felt that the online community could potentially offer access to the communication of a large proportion of people using online infertility communities in the UK. Thus, providing an ideal sample for the first in depth examination of online self-mechanisms in the context of infertility.

The online support community consisted of seven sub-boards relating to different stages of the infertility journey: "Starting Out", "Two Week Wait", "Negative Cycle", "Inbetween Treatment", "Trying for Another Miracle", "Pregnancy Loss" and "Moving On" (see Table 1 for a description of each sub board). To allow for the exploration of self-help mechanisms at different stages of the infertility journey as well as access a large cross-section of messages posted to the online community messages were sampled from each of the seven sub-boards.

Table 1: Description of sub boards in the online support community

	Main purpose of the sub-board
1. Starting Out	A support and discussion forum for people new to infertility treatment and individuals wishing to introduce themselves to the online community.
2. Two Week Wait	To provide a discussion and support forum for infertile couples who are on the two week wait between ovulation / IUI / IVF etc and pregnancy testing.
3. Negative Cycle	To provide support to individuals and couples who have experienced a negative treatment cycle.
4. Inbetween Treatment	To provide a discussion forum for those people between fertility cycles.
5. Trying for Another Miracle	To provide support to parents of children conceived by Infertility treatment, hoping for another miracle.
6. Pregnancy Loss	To provide support for individuals and couples experiencing pregnancy loss.
7. Moving On	To provide support to those individuals for whom there are no longer any available options regarding successfully achieving a birth child of their own or for those whom the chance of this happening is very slim.

All discussion threads that contained messages posted during a period of three consecutive months were downloaded from each of the sub boards on 16/04/08. This resulted in a total of 864 discussion threads containing 17,686 messages (Starting Out: 5435, Two Week Wait: 4611, Negative Cycle: 703, Inbetween Treatment: 3473, Hoping for Another Miracle: 1086, Pregnancy Loss: 1791 & Moving On: 587). Due to the volume of messages retrieved a random number generator was used to randomly select a sample of 500 messages from each of the data sets for analysis (van Uden-Kraan et al., 2008a). On the basis, of previous research it was felt that this would allow for an adequate cross-section of messages for data analysis (van Uden-Kraan et al., 2008a). This process resulted in a total of 3,500 messages for analysis, which was a considerably larger sample of messages than found in many published studies of bulletin boards (e.g. Coulson, 2005 n=572; Finn, 1999 n=718; Haaker et al, 2005 n=1200; Perron, 2002 n=417).

6.2.2. Data analysis

Content analysis was chosen as the preferred method of analysis for this study. Unlike thematic analysis which aims to provide a rich and detailed account of a dataset, content analysis is concerned predominantly with the prevalence of particular themes or categories in the data. Content analysis can therefore be described as a systematic and objective means of describing and quantifying phenomena (Elo & Kyngas, 2008). The approach is frequently used to quantify theoretical concepts and qualitative data categories in the manifest content of large volumes of textual information. It has also been successfully employed in previous studies analysing naturally occurring communication within online support communities (Braithwaite et al., 1999; Coulson et al., 2007; Finn, 1999; Perron, 2002).

In the light of this content analysis was deemed a more appropriate research tool for this stage of the investigation, which was concerned primarily with the extent to which self-help mechanisms and negative statements occur within an online infertility support community.

Since the study was interested specifically in exploring whether the online support community offered the therapeutic benefits found in face-to-face support groups, a deductive approach was taken to data analysis. Data were analysed according to a pre-determined theoretical framework based on the helping mechanisms found in the self-help and group work literature, and the categories of social support proposed by Cutrona and Suhr 1992 (Finn, 1999). Ten coding categories were derived from the coding systems developed by Finn (1999) and Perron (2002) to analyse self-help mechanisms in messages posted to online support communities (see Table 2). The coding system developed by Finn (1999) isolated 14 categories of helping mechanisms: expressing feelings or catharsis, providing support or empathy, chit-chat, universality, friendship, extra-group relationships, taboo topics, damaging statements, poetry and art, asking information, providing information, problem-solving, computer talk, and group cohesion. This framework was later adapted into 10 categories by Perron (2002), which were labelled: disclosure, providing information or advice, requesting information or advice, empathy or support, gratitude, friendship, creative expressions, negative statements, computer issues and structure. The coding categories selected for the current study were largely reflective of the latter coding system. However, since the research was mainly concerned with the socio-emotional content of messages rather than technical and structural aspects of the online community, the decision

was made to replace the categories of structure and computer issues with universality and chit-chat.

Each posting was analysed for the presence of the ten coding categories. Messages containing more than one category were allocated multiple codes, however if there were multiple instances of a particular category in a single posting the category was only coded once. In keeping with recommendations from previous authors (e.g. Finn, 1999; van Uden-Kraan et al., 2008a) each individual posting was coded in the context of the discussion thread in which it appeared to allow for more accurate judgements to be made concerning the presence of self-help mechanisms. For example, messages containing personal experiences of infertility may have been posted in response to a specific request for information or advice. If reading this type of message out of its original context it would appear that the poster is simply wishing to share their experiences with the community, however in reality their intention is also to offer support to another member through their personal experience of infertility. In the light of this, it was considered important in this study to read the entire discussion thread before allocating codes to a single message.

Table 2: Coding system for self-help mechanisms

Coding Category	Description
Support or empathy	Messages that provide statements of understanding, acceptance and encouragement or contain comforting words. *Example: What a horrible morning you've had. I can imagine how disappointed you were. However, I would say just trying to remain positive. I'm sure they must see this frequently and I am certain they would stop your cycle if they truly thought there was no chance of success.*
Requesting information or advice	Messages asking if others can provide factual information, guidance or advice for dealing with an issue or solving a particular problem. *Example: I have my scan tomorrow and have been reading the literature the clinic gave me about the numbers of follicles. It says if too few are seen they will abandon the cycle and the same if too many for obvious reasons. Does anyone know what is considered good/bad and ugly in terms of numbers?*

Providing information or advice	Messages providing other participants with factual information, guidance or advice for dealing with an issue or solving a particular problem.
	Example: The difference between puregon and menopur is that menopur is combined LH and FSH where as Puregon is just FSH. I asked at the clinic this time about the difference and there seems to be no difference in success rates between the drugs. It just seems to be preferences of the clinics generally and occasionally some women seem to respond better to one than the other.
Sharing personal experiences	Messages sharing personal experiences and thoughts or messages expressing emotions and feelings.
	Example: I wish I could do the logical thing and move on but it feels like letting my other 'dream of' children die and that's too painful. Also it would mean facing up properly to the losses of the last 10 years and the pain of Infertility, rather than putting all that to one side 'just until I get my longed for next baby', when I like to kid myself it won't matter anymore how much pain we've been through to get to that point.
Creative expression	Messages expressing thoughts and feelings through creative means e.g. the use of poetry, prayer, art or prose.
	Example: I wanted to share this poem that I came across. It is beautifully written and I printed it off and aimed to use it everyday as a healing aid...so far I haven't managed to read it all to the end without crying and I am not sure if it makes me cry because its so beautiful or because I still have some grief...perhaps a bit of both.

Universality	Messages expressing the idea that members are 'not alone' and that people have or are experiencing the same or similar feelings and situations. *Example: Please don't ever feel bad for coming on here and being miserable – we've all been there and that's what is so great about this site, it's somewhere where people understand and you can be as miserable as you like without being judged on it.*
Friendship	Messages containing statements that recognise other members as friends or messages containing discussions of making friends or interacting outside the group environment. Sending greetings e.g. birthday or holiday wishes to other participants. *Example: Hi Ladies I was just wondering if anyone fancied meeting up for a chat and coffee..would love to hear from anyone.*
Chit-chat	Messages containing general everyday conversation between members not necessarily related to Infertility issues. *Example: I am soo jealous about your skiing trip, my husband also has the boarding bug and we are really missing a snow holiday this year, but if treatment doesn't go to plan I will try to escape to the snow for a week and hopefully come back in one peace!!!*
Gratitude	Messages that thank other participants for their help and support. *Example: Thank you so much for your words of support and cyber hugs - I've been reading your posts over the last couple of days, and I can't say how much they've comforted me.*

Negative or damaging statements	Messages containing disrespectful or sarcastic comments directed to other participants in the community. Or any statement in which a person acknowledges being hurt by community members or distressed or angered as a result of participating in the online community. *Example: I found I was becoming really really upset when going though the IVF treatment reading about positive and negative outcomes.*

6.2.3. Procedure

Initially a pilot test of the coding framework was carried out in order to assess the applicability of the coding categories. A random sample of 200 messages from the dataset were selected and coded independently by the lead researcher and a second independent academic rater who was unrelated to the research project. The pilot test revealed acceptable levels of inter-rater agreement with a Cohen's kappa of 0.72. It was observed that patterns of disagreement typically revolved around the categories of 'support or empathy' and 'friendship'. Consequently, following discussions between the two independent raters the coding framework was deemed viable, with some minor revisions to the category definitions for 'support or empathy' and 'friendship'.

All messages selected from the seven sub-boards were then coded for the occurrence of the self-help mechanisms. Upon completion of the data analysis process 10% of the postings were coded by the second independent rater to calculate inter-rater reliability. A Cohen's kappa of

0.76 was established for the self-help mechanisms thus indicating satisfactory levels of reliability. Additionally socio-demographic and background details about the posters such as age, gender and diagnosis were identified through information provided spontaneously by users within their postings and membership profiles. This was undertaken to build up a demographic profile of members of the online community and explore how this compared to the demographic profile of the survey respondents.

6.2.4. Ethical considerations

Ethical approval was obtained from the departmental Research Ethics Committee at the Institute of Work, Health & Organisations in the University of Nottingham, in accordance with the ethical guidelines for Internet research published by the British Psychological Society (BPS, 2007). As discussed in chapter four the study of naturally occurring communication in online support communities raises a number of important ethical issues that need to be considered. For the present study, issues concerning informed consent, privacy and confidentiality were considered particularly relevant. In light of recommendations from previous authors (e.g. Eysenbach & Till, 2001), when selecting an online community for the present study, several factors were considered to determine the extent to which, postings were perceived as public or private by members of the community. Firstly, it was ensured that the community selected for the study did not require any form of registration or subscription in order to access and read messages posted to the support community. Secondly, the size of the online community was assessed to determine how "public" the space could be perceived as. In the present study, the chosen online support community consisted of over 22725 registered members and could therefore be regarded as "public" in this respect. In addition, the website

provided a statement advising all members during the registration process that their messages would be visible to members of the public and therefore personal information such as e-mail addresses should be kept anonymous. In the light of these considerations, it was concluded that the online community selected for the purpose of the study could be viewed as "public" in nature. Consequently, informed consent from individual members was not required.

However, in accordance with the British Psychology Society ethical guidelines, to further protect the privacy and confidentiality of individuals using the online community the name of the support community and address of the website from which data was collected has not been disclosed in any dissemination of the work. In addition, all quotations used in the reporting of the results were entered into a search engine to ensure the quotes could not be traced directly to an individual posting.

6.3 Results

6.3.1 Sample characteristics

A total of 778 unique sender names were identified in the selected messages. The average number of messages posted by each member was found to be 4.5 (range 1-73). However, 63% of the sample only posted one or two messages. This indicates that there may be a smaller circle of members who were posting messages on a more regular basis.

From the bulletin boards it was possible to identify that 96.9% of posters were female and 0.8% male. Most of the sample stated that they were living in the United Kingdom (69%); however there were also members from other European countries (1.5%), Australia (0.5%), the United States (0.5%), Dubai (0.4%) and Hong Kong (0.1%). Participants were aged between 20-52 years (Mean age = 34 years). Of these, 29.7% indicated that they were suffering from female factor infertility, 16.6% from male factor infertility and 9.9% male and female factor infertility, while 11.4% stated that the cause of their infertility remained unexplained. The characteristics of participants in each of the sub boards of the support community are presented in Table 3.

6.3.2 Self-help mechanisms

Table 4 shows a summary of the frequency and percentage of self-help mechanisms found in each sub board of the support community (since each message could receive multiple codes, the total percentages do not add up to 100%). As Table 4 illustrates, the most common types of self-help mechanisms used were support or empathy and sharing personal experiences. A total of 45.5% (n=1591) of the messages were coded as providing support or empathy. Postings in this category frequently included messages of condolence, hope, encouragement, reassurance, and validation:

> *"Sweetheart, I am so sorry to hear of your loss. I wish I could reach out and give you a great big hug right now"*

The sharing of personal experiences accounted for 45.4% (n=1588) of the total messages. New members would often introduce themselves by sharing their current situation and offering a short account of their

infertility history, whereas regular participants frequently wrote updates of their lives particularly in relation to progress with fertility treatment. These updates would often include a discussion of their thoughts and emotions.

The third and fourth most frequent self-help mechanisms were the provision of information and advice and gratitude, which accounted for 15.9% (n=558) and 12.5% (n=436) of the total messages. Messages offering informational support and advice were often posted in response to specific requests for support and guidance from community members. This category included the sharing of resources, recommendations for diets and alternative therapies (e.g. acupuncture, homeopathy etc) and the sharing of personal experiences to help an individual solve a particular problem. Messages expressing gratitude were typically posted in reply to previous messages providing information and support to members:

> "Oh thank you all soo much! Your replies are soo helpful and I am grateful that you have shared your personal experiences."

These self-help mechanisms were followed in frequency by the categories of friendship and chit-chat. Comments that specifically expressed experiencing friendship were found in 9.9% (n=345) of the total messages:

> "You have found a great site for friends and support. I was amazed by the number of people on this site - I always feel this is only happening to me."

Participants frequently wrote about interacting outside of the group environment, most commonly through the medium of email, telephone and

social networking sites such as Facebook and would often exchange personal greetings such as birthday wishes. Also, 9.4% (n=329) of the messages contained chit-chat. This category reflected all messages containing off topic conversation that was not directly related to the individual's fertility problem. These conversations typically revolved around topics such as pets, holidays, work-life, daily activities, and family events.

Requests for information or advice were posted less often with only 6.8% (n=238) of the total messages specifically asking for informational support. These messages mainly asked questions related to technical aspects of the site such as how to add a signature line or send a personal message, questions about what to expect during a forthcoming medical consultation, and requests for guidance concerning early signs of a pregnancy or miscarriage.

Some participants also sought advice on how to deal with the impact of infertility on personal relationships:

> *"I think I have reached crunch point with my closest friend........This week she seems to have decided that if she explains how awful it can be to have kids that maybe I won't be so disappointed about our situation... What should I do? How do you cut someone out of your life without upsetting them or it being really awkward??"*

Remarks of universality occurred in 4.8% (n=169) of the postings. These messages explicitly expressed the idea that participants were not alone and that people in the online community had experienced the same or similar emotions. Often these comments were posted in response to introductions

from new members who were feeling lost, lonely, or confused. For example:

> *"You can always post here – that's what this board is for. Know that you are never alone – you always have us."*

Some members talked about how the opportunity to share their experiences with people with first hand understanding of infertility helped to reduce the sense of isolation they were feeling. The least common self-help mechanism used by participants was creative expressions. Only 0.2% (n=7) of the messages were coded as containing creative expressions. Messages in this category were predominantly found in the pregnancy loss sub board of the community. These messages involved the use of poetry to express emotions surrounding the loss of a child. Some messages also used poetry as a means of offering hope and encouragement to fellow members.

Only 0.3% (n=11) of the messages contained negative statements. The majority of these messages described feelings of pain and sadness when faced with the treatment success of other members. Some messages also contained feelings of hostility towards other members:

> *"I find it painful to come on here due to my numerous failed In vitro fertilisation attempts/seeing former cycle buddies successful with their attempts and moving on with their lives is difficult, don't get me wrong I'm pleased for them but unfortunately it has never happened for me..."*

"I joined the support group quite sometime ago and there has been so many people I chat too that have left me behind and gone on to have babies. It's not that I'm not happy for them all but I just feel so left behind and alone! ☺"

When comparing the sub boards of the online support community, it was apparent that the sharing of personal experiences and the provision of support and empathy were the most common element of messages in all areas of the online community. However, some differences were observed in the frequency of the other eight categories; messages containing chit-chat (n=104) and friendship (n=78) were most prevalent within the sub board "Inbetween Treatment", whereas information giving (n=46) and seeking (n=18) were least common in this board. Requests for information were highest among participants in the "Two Week Wait" (n=63) sub board, followed by participants in the "Starting Out" (n=44) and "Pregnancy Loss" (n=37) sub boards. Comments expressing universality were highest in the "Moving On" (n=53), "Starting Out" (46), and "Negative Cycle" (n=36) sub boards. The participants in the "Pregnancy Loss" board (n=6) used the most creative expressions and participants in the "Moving On" (n=7) board made the most negative statements.

Table 3: Participant Characteristics

	Starting Out (n = 227)		Two Week Wait (n = 193)		Negative Cycle (n = 124)		Pregnancy Loss (n = 143)		Inbetween Treatment (n = 98)		Moving On (n = 90)		Trying for Another Miracle (n = 90)	
Gender														
Male	2	0.9%	0	0%	0	0%	1	0.7%	0	0%	3	3.3%	0	0%
Female	222	97.8%	192	99.5%	120	96.8%	142	99.3%	97	99%	82	91.1%	85	94.4%
Unknown	3	1.3%	1	0.5%	4	3.2%	0	0%	1	1%	5	5.6%	5	5.6%
Age in years														
Mean (SD)	33 (4.8)		34 (4.7)		34.5 (4.8)		35 (5.0)		33 (2.5)		36 (4.8)		33.7 (4.9)	
Minimum	20		23		23		21		24		25		21	
Maximum	45		45		46		52		43		52		46	
Unknown	29		27		17		20		11		25		17	
Nature of fertility problem														
Male factor	47	20.7%	41	21.2%	13	10.5%	16	11.1%	10	10.2%	9	10%	17	18.9%
Female factor	75	33%	47	24.4%	37	29.8%	47	32.9%	50	51%	19	21.1%	17	18.9%
Unexplained	23	10.1%	22	11.4%	20	16.1%	21	14.7%	13	13.2%	6	6.7%	7	7.8%
Male and female factor	28	12.3%	18	9.3%	16	12.9%	11	7.7%	3	3%	7	7.8%	11	12.2%
Unknown	54	23.8%	65	33.7%	38	30.6%	48	33.6%	22	22.4%	49	54.4%	38	42.2%

Table 4: Frequency of Self-help mechanisms in messages posted in the seven bulletin boards

Self-help Mechanisms	Starting Out (n = 500)		Two Week Wait (n = 500)		Negative Cycle (n = 500)		Pregnancy Loss (n = 500)		Inbetween Treatment (n = 500)		Moving On (n = 500)		Trying for Another Miracle (n = 500)		Total (n = 3500)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Support or Empathy	240	48	178	35.6	298	59.6	282	56.4	158	31.6	219	43.8	237	47.4	1591	45.5
Requesting Information or Advice	44	8.8	63	12.6	32	6.4	37	7.4	18	3.6	22	4.4	25	5	238	6.8
Providing Information or Advice	119	23.8	99	19.8	62	12.4	86	17.2	46	9.2	103	20.6	63	12.6	558	15.9
Sharing Personal Experience	177	35.4	242	48.4	250	50	264	52.8	165	33	216	43.2	305	61	1588	45.4
Creative Expressions	0	0	0	0	0	0	6	1.2	0	0	1	0.2	0	0	7	0.2
Universality	46	9.2	8	1.6	36	7.2	7	1.4	7	1.4	53	10.6	13	2.6	169	4.8
Friendship	50	10	53	10.6	64	12.8	46	9.2	78	15.6	26	5.2	35	7	345	9.9
Chit Chat	9	1.8	22	4.4	40	8	25	5	104	20.8	70	14	64	12.8	329	9.4
Gratitude	86	17.8	55	11	69	13.8	59	11.8	40	8	81	16.2	49	9.8	436	12.5
Negative Statements	1	0.2	0	0	2	0.4	0	0	1	0.2	7	1.4	0	0	11	0.3

6.4 Discussion

The main aim of this study was to examine the self-help mechanisms that occur in messages posted to an online infertility support community. Content analysis of 3,500 messages revealed that the online community appeared to provide many of the helping techniques and therapeutic processes found in face-to-face support groups (Finn, 1999). In particular, the study indicates that while members engage in a range of self-help mechanisms, the provision of support or empathy, and the sharing of personal experiences are by far the most prevalent categories within the messages. These findings are largely consistent with the results of previous content analyses of various health-related online support communities, which suggest that self-disclosure, empathy and support are all an important element of online communications (Haker et al., 2005; Perron, 2002; van Uden-Kraan et al., 2008a). An additional aim of the study was to further examine findings from the initial study and explore the extent to which members engage in negative communication with one another or make any negative statements about their online experiences. The results reveal that there were very few instances of negative communication in the sample of analysed messages, however a small number of individuals did make negative statements about their experiences within the online support community. Interestingly, these statements were found predominantly in the 'Moving On' sub-board of the online support community.

In the current study, it was apparent that the sharing of personal experiences played a significant role in communication across the different sub boards of the online community. Almost half of the analysed messages

contained some form of self-disclosure. Often these messages were posted to simply record treatment related progress or 'vent' personal emotions in a supportive environment. In other instances, self-disclosure was used as a means of introducing oneself to the online community or eliciting and providing support and advice. This pattern of findings lends support to research conducted by Tichon and Shapiro (2003) who found that self-disclosure had three distinct functions in online postings; firstly to elicit support and start a relationship with other members. Secondly, for support providers to demonstrate that successful coping is possible through disclosing similar experiences where they have successfully coped and finally to share social companionship with other members. Tichon and Shapiro (2003) therefore contend that self-disclosure plays an important role in the elicitation and provision of support within online communities. They further argue that through self-disclosure members of an online support community can experience a number of psychological benefits, some of which may include the ability to organise their thoughts and make sense of distressing experiences or the opportunity to employ downward and upward comparison as coping strategies (Boivin, 2003; Stanton, 1992).

Within the current study, although several participants stated that simply putting their emotions into words had helped to make them feel better; it is difficult to determine from the messages alone the extent to which participants experienced specific psychosocial benefits. Further quantitative work is therefore needed to assess the specific therapeutic factors associated with disclosing personal experiences in online infertility support communities.

One factor that may account for the high levels of self-disclosure observed in the current study is the anonymity associated with the online environment. Although face-to-face support groups also offer numerous opportunities for participants to offload negative feelings and share personal experiences, past research has suggested that the anonymous nature of an online community may encourage certain individuals to disclose information that they would feel uncomfortable discussing face-to-face (Ghanem et al., 2005; Joinson, 2001; Wallace, 1999). Indeed, results from the first stage of this investigation highlight that some participants appeared to value the anonymity of an online community when discussing sensitive issues surrounding infertility. Thus, it can be hypothesised that the unique features of online support communities (i.e. anonymity) serve to facilitate self-disclosure among people with infertility.

The provision of support and empathy also emerged as a major focus of postings to all seven sub boards of the infertility support community. Expressions of condolence, hope, encouragement, reassurance and validation were commonly exchanged by individuals at all phases of the infertility journey. Perhaps unsurprisingly, however these exchanges were particularly prominent within the "Pregnancy Loss" and "Negative Cycle" sub boards where participants were typically dealing with feelings of loss, bereavement, depression, and disappointment and thus expressed a strong need for emotional support.

Interestingly, the findings reveal that there were almost three times as many postings containing emotional support or empathy than there were postings offering information and advice. This contrasts sharply with the results of content analyses of other online support communities, which

show the provision of information to be a major focus of bulletin board postings (Haker et al., 2005; Perron, 2002). In the current study only 15.9% of the total messages could be categorised as providing information or advice and only 6.8% of messages specifically sought advice and information from the community. These requests were particularly frequent among those members who were embarking on fertility treatment (i.e. within the "Starting Out" sub board) or were experiencing anxiety and confusion concerning bodily changes during the two weeks between ovulation and pregnancy testing. Members at these stages of the infertility journey frequently turned to the online community to seek other people's experiences of particular treatments or specific symptoms in order to lessen their anxiety. Beyond this, in some instances the online support community also functioned as a useful venue in which individuals could exchange advice on how to cope with some of the psychosocial consequences of infertility. In particular, the discussion of difficulties maintaining relationships with friends and family who had not experienced infertility was commonplace. Members would therefore use their own experiences to offer guidance to individuals facing similar problems.

The prominence of emotional support and empathy over informational support and advice in the current study could be interpreted using the theory of optimal matching (Cutrona & Russell, 1990). The theory asserts that individuals are more likely to perceive emotional support and emotion-focussed coping strategies as helpful when they are experiencing distressing events, which they feel are out of their control. In contrast, informational support is thought to be most beneficial when the individual feels that they can use this information to control their situation. Since past research has frequently described infertility as a low control stressor with

little certainty over its eventual resolution (Boivin et al., 1998; Schmidt et al., 2005), it is likely that many of the individuals accessing the online community were experiencing a greater need for emotion-focussed support compared to informational support, hence the prominence of supportive and empathic communication. Given the volume of messages that expressed gratitude to individual members and the community as a whole, it appears that many participants reacted positively to the support provided through the online support community and were able to successfully achieve an 'optimal match' between the type of social support offered and the needs presented by their situation.

From a practical perspective, these findings point to the importance of tailoring online support resources/ interventions to the specific needs of patients at different stages of the infertility journey. For example, while patients commencing infertility may benefit from the provision of detailed informational support concerning medical procedures, patients waiting to take a pregnancy test may prefer to hear stories about the symptoms and experiences of other patients.

Some researchers have suggested that the process of providing support may in fact be more beneficial to the provider than it is to the recipient (Salem et al., 1997; Winefield, 2006). Reissman (1965) proposed the "helper-therapy principle" model to describe the therapeutic effects of offering support to others. The model asserts that the process of helping another member can lead to increased self-esteem and a sense of personal satisfaction. The prominence of the support and empathy category within the current dataset suggests that there is ample opportunity for members of an infertility online support network to adopt the role of a "helper".

Future work should therefore seek to address the psychological effects of providing support within an online support community and explore the impact this has on how individual's cope with their own experience of infertility.

The strong presence of socio-emotional communication in this study lends support to the growing body of literature suggesting that online communities can promote hyperpersonal communication (Walther, 1996). However, Walther (1996) propose that four characteristics of online interactions might contribute to creating hyperpersonal communication. Firstly, an idealised perception of the receiver arising from greater perceived similarity due to the assumption that individuals are part of a group sharing a social categorisation. Secondly, the opportunity for optimised self-presentation by the sender. Third, asynchronous channels supporting information management and finally a feedback loop allowing intensification magnified in minimal cue interactions. Despite, the strong socio-emotional content of the messages in this study, the extent to which this pattern of communication is related to the unique characteristics of the Internet (i.e. limited physical cues, asynchrony etc) is unclear. Additional empirical investigation is therefore required to explore how the unique characteristics of online communities facilitate socio-emotional communication among members. For example, researchers may wish to examine differences between interactions in online and face-to-face infertility support networks, in order to determine whether the findings from this study are unique to the online venue.

The content analysis revealed that there were comparatively fewer messages that explicitly expressed a sense of universality. This finding

mirrors results from previous studies examining online support communities, for example, Finn (1999) found that only 8 out of 718 analysed messages from a disability online self-help community contained the coding category universality. As Finn (1999) points out despite the low number of references to universality, it is likely that many members of an online support community do in fact experience a sense of universality through their participation but do not explicitly comment on this in their messages. Indeed, results from the previous chapter reveal that accessing a network of people in similar situations and reducing feelings of isolation were perceived to be key motives and advantages of online support seeking. Consequently, it would be surprising if many of the participants within this sample did not feel a sense of universality with the online community, particularly given the overall empathic and supportive feel of the messages.

Furthermore, within the current study statements of universality predominantly functioned as a means through which members could welcome new participants to the online community or describe their gratitude for the support and friendship offered by other members. This would suggest that members of the online community might only express their feelings of universality when required to do so for other purposes i.e. to offer support or express gratitude. This may also explain why messages containing comments of universality were most prevalent in the "Starting Out", "Negative Cycle" and "Moving On" sub boards of the online community. As people at these stages of the journey were often, feeling particularly isolated and lonely and therefore benefited from the knowledge that others had experienced the same or similar emotions.

Creative expressions were found to be the least common category of self-help mechanisms used by members of the online support community. These results suggest that individuals experiencing infertility may prefer to express their emotions in the form of personal narratives rather than creative means like poetry. However since, all but one of the seven messages containing creative expressions were observed in the pregnancy loss sub board of the online community, it appears that the use of poetry may be a powerful means for people experiencing the loss of a potential child to make sense of their feelings of grief and bereavement and express these emotions to the online community. Online support resources should thus encourage patients experiencing pregnancy loss to express their emotions both in the form of narrative and poetry.

Alongside the occurrence of self-help mechanisms, the content analysis explored the extent to which members expressed / experienced disadvantages to online support communities in their messages. As outlined in the review of literature at the start of this thesis a number of authors have hypothesised that the lack of physical proximity and non-verbal cues in online communication will lead to increased instances of disinhibited communication, such as sarcasm, flaming, and verbal harassment. The findings from this study reveal that although there were no instances of disinhibited communication in the sample of analysed messages, as described by respondents in the first study some messages contained statements that expressed hostility towards opinions expressed by another member. A number of women also described the difficulty of being faced with the successful treatment outcomes of other members. Some women expressed feelings of jealousy, anger, and pain when confronted with the news of another participant's pregnancy. Such

statements were most prominent among participants within the "Moving On" sub board of the online community. One explanation for this could be that most of the women accessing this board no longer had any options available regarding successfully achieving a birth child of their own and were thus facing up to the reality of a life without biological children. In this context, reading stories of other people's success with treatment is likely to be particularly distressing and frustrating for this group of women. This finding suggests a need to develop online support resources, which cater specifically for the emotional and informational needs of patients facing permanent involuntary childlessness. It also highlights the importance of considering the length of time an individual has been experiencing infertility when exploring their online experiences. As it appears that the experience of online support communities may differ between individuals who are starting out and those individuals who have been unsuccessful with treatment.

6.4.1 Who uses online infertility support communities?

An additional aim of this study was to explore the characteristics of people posting messages to an online infertility support community. The sample examined for this study consisted of members posting messages during a three-month study period. From the 3,500 analysed messages a total of 778 unique sender names were identified. Efforts were made to collect demographic and background information for each of these members through reviewing the content of their messages and membership profiles. This was undertaken with the aim of both gaining a comprehensive insight into the characteristics of the sample and to explore how representative participants responding to the surveys were of the people who use online infertility support communities.

Due to the anonymous nature of online support communities background information was not always available for each member in the sample. However, from the available information it would appear that similar to participants in the initial study, the online support community was used mainly by women from the United Kingdom who were experiencing a range of different fertility problems relating to both female and male factor infertility. This would suggest that online infertility support communities are populated predominantly by women. This is perhaps unsurprising given that past research suggests women are more likely to seek Internet support for health-related concerns including infertility compared to men (Eysenbach, 2003; Im & Chee, 2005; Im et al., 2007; van Uden-Kraan et al., 2008a; Von Knoop et al., 2003; Winefield et al., 2003; Ybarra & Suman, 2006). Moreover, the infertility literature indicates that women are more open about their fertility problems than men (Dhillon et al., 2000; Karlidere et al., 2007; Lund et al., 2009) and typically experience greater levels of distress and discomfort during fertility treatment regardless of which partner is biologically responsible for infertility (Drosdzol & Skrzypulec, 2009; Lykeridou et al., 2009). This suggests that women are likely to experience a greater need for informational and emotional support as a consequence of infertility. In addition, since women are often more willing to openly discuss their emotions with others (Sullivan, 2003); the prospect of joining an online community to access this support may be more appealing to the female partner than the male partner. However, an earlier study of online communication among men experiencing infertility found that the Internet also provides a valuable and welcoming forum in which men could potentially open up about their experiences of infertility and share distressing experiences (Malik & Coulson, 2008). Thus, future work may wish to focus on how men can be encouraged to join and communicate within an online infertility support community.

The study also reveals that although the messages were posted by a total of 778 different users, 63% of these senders only contributed 1-2 messages to the total sample. These findings suggest that there are a smaller group of active participants who regularly contribute to the bulletin boards. However, it is important to note that due to the cross-sectional nature of the research the current study only provides a snapshot picture of participation patterns in the online support community. An examination of a larger sample of messages posted over a longer period of time may reveal that the same individuals posted a higher volume of messages at other times.

In addition, it may be that, while only a small number of individuals actively contributed to the discussions a broader segment of the online support community followed the discussions without contributing. Indeed a review of the bulletin boards reveals that although in most cases a single thread only received a handful of replies, the number of viewings for each thread frequently went into the 100's. Furthermore, several new posters introduced themselves to the community by candidly stating that they had 'lurked' in the online community for some time before deciding to make their presence known. This suggests that 'lurking' may play a significant role in online infertility support communities. However, as the aims of the current research were focussed specifically on the examination of communication within the online support community, it is not possible from the findings to make any inferences regarding the extent or role of lurking in online infertility support communities. Consequently, this is one area that would benefit from further investigation.

6.4.2 Strengths of this study

The current research offers a unique insight into the self-help mechanisms that occur in online infertility support communities. Through the use of content analysis, the study was able to successfully quantify the occurrence of qualitative data categories across a sizeable dataset. A number of measures were taken throughout the research process to ensure the validity and reliability of this content analysis. Firstly, an extensive piloting and revision of the coding categories was undertaken to check the applicability of the coding framework. Secondly, each message was coded in the context of the conversation thread in which it appeared to allow for more accurate judgements to be made regarding message content. Thirdly, upon completion of data analysis a sample of messages were re-coded by an independent rater as a final check of inter-rater agreement. Finally, messages were analysed from different bulletin boards in the same online support community, consequently unlike previous analyses of messages in online communities, the researcher was able to explore similarities and differences in the use of self-help mechanisms among people at different stages of the journey to achieving a resolution to infertility.

6.4.3 Limitations of this study

However, despite these strengths there are also a number of potential limitations to the present study that need to be taken into consideration. First, the analysed messages were taken from a single peer-moderated online infertility support community, the extent to which these messages are representative of communications in other online infertility support communities or the same community at other times remains unclear. Differences may exist in the communication of people posting messages to

non-moderated vs. peer-moderated or professionally-led online support communities. For example, a professionally-led online community may contain a higher volume of information seeking posts in comparison to a peer-moderated online support community due to the presence of medical authority. In a similar vein, messages posted to an unmoderated bulletin board may have a greater number of posts containing disinhibited communication or negative statements due to a lack of formal structure or organisation.

Future research should therefore seek to examine messages posted to multiple online infertility support communities over a longer period of time in order to determine the generalisability of the pattern of findings observed in this study. In particular, it is important for researchers to explore the role of organisational factors such as bulletin board structure and moderation in communication patterns and the experiences of people using online support communities.

Second, as Uden-Kraan et al. (2008b) point out many online support communities offer participants the option of sending personal messages to one another so that they can communicate outside of the public domain. From the analysis of messages it is apparent that members of the online support community frequently made use of this function and on some occasions used the public bulletin boards to make a particular user aware that there was a private message waiting for them. However, a content analysis of bulletin board postings does not tell us anything about communication within these private exchanges. The use of questionnaires or interview techniques to elicit information directly from participants may be one method for shedding light on this issue.

Third, from examining messages in the online community it appears that relatively few participants experienced disadvantages or harm as a consequence of participation, as suggested by the low number of negative statements found. However, since the online community was a moderated community messages containing disinhibited communication may have been removed by the moderators and would thus not have been available in the message archive. Furthermore, individuals who experience negative effects from the online community are likely to drop out or stop contributing messages, leaving messages from only the satisfied participants for analysis.

6.4.4 Conclusions

This study examined self-help mechanisms in a relatively large sample of messages obtained from an online infertility support community. The results offer a unique insight into the self-help processes that occur specifically within online communities for infertility issues. In particular, the results show that the key functions of this online community were to exchange support and empathy and provide a forum for people to share their personal experiences and emotions surrounding infertility. Furthermore, from the analysis it appears that for the majority of posters the experience of using the online community was a positive one, with only a very small proportion of the overall messages containing negative statements. This suggests that online support communities provide a viable alternative source of self-help and support for people with infertility.

On the whole this pattern of findings substantiates conclusions drawn from the previous study, which show that online support communities can provide people experiencing infertility with a valuable forum in which they

can open up about their infertility and reduce their feelings of isolation through obtaining empathy and mutual support from people in a similar situation. However, those individuals who have been through numerous failed treatment attempts and have limited options available to conceive a child of their own may perceive more negative aspects to the online community and be most vulnerable to experiencing psychological distress as a result of accessing the online community. This is an important finding that clearly warrants further attention.

While an analysis of bulletin board postings is a valuable method for exploring the processes that occur within an online support community, the study is limited in the extent to which it can comment on whether these processes also result in positive psychosocial outcomes. In addition, as suggested in the qualitative study presented in the previous chapter some individuals may also gain psychosocial benefits from simply reading other peoples postings (i.e. 'lurking'). Consequently, in order to obtain a more complete and comprehensive understanding of the experience of online infertility support communities, follow-up research is needed to examine quantitative outcomes associated with usage.

The next chapter presents results from a larger scale quantitative study of people accessing online infertility support communities. This study forms the final stage of the thesis and was designed to quantitatively explore the use and experience of online infertility support communities and how this relates to psychosocial outcomes. A discussion of the rationale for this study and the specific research questions follows in the next chapter.

7   Chapter Seven: Study Three: A quantitative online survey of the use and experience of online support communities among people with infertility

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CHAPTER SUMMARY

This chapter presents the quantitative element of the thesis that involved a cross-sectional online survey with 295 individuals accessing online infertility support communities. The overall aims of the study were to examine whether use and experience of online support communities is associated with the psychosocial well-being of participants and if factors such as lurking versus posting status are associated with how people use and experience online support communities. The results highlight that negative experiences in online support communities appear to be associated with poorer psychosocial well-being. In addition, the study shows that reading messages posted to online infertility support communities may be as beneficial as interacting with members of the online community. The results also provide a wealth of descriptive information about the use and experience of online infertility support communities. A detailed description and discussion of the results is presented.

7.1 Background

The findings presented in the previous two chapters suggest that on the whole online support communities appear to be beneficial for people with infertility. Chapter five described the motives, perceptions, and experiences of people accessing online infertility support communities; results from this stage highlight that participants appear to especially value the unique characteristics of online communication (e.g. anonymity, asynchrony etc) when seeking support. In addition, there were a number of benefits to online support seeking, which appeared to aid the participant's ability to cope with their infertility experience. Key benefits included reduced feelings of isolation and loneliness, improvements in marital relationships, and a unique source of emotional and informational support. Chapter six examined the efficacy of online infertility support communities as an alternative source of self-help and support, through exploring the use of self-help mechanisms in messages posted to an online infertility support community. Results from this stage reveal that the online community provided many of the therapeutic and self-help processes that are known to be beneficial to people using face-to-face support networks, namely the opportunity for self-disclosure and the exchange of empathy and emotional support.

However, as described in the previous chapter although these studies provide an insight into *how* and *why* online support communities can be beneficial to people with infertility, they do not tell us anything about whether accessing an online support community is in fact associated with measurable psychosocial outcomes. Indeed, the results of both study one and study two indicate that for some individuals accessing an online infertility support community may elicit greater anxiety and infertility-

related distress, if they find that other members have become pregnant while they are still trying to conceive. The extent to which online experiences influence psychosocial well-being among people with infertility is thus an important issue that warrants further investigation. In the light of this, a key focus of the final quantitative stage of the thesis was to examine how the use and experience of online support communities relates to psychosocial outcomes. In particular, the study was interested in exploring whether use of an online infertility support community is associated with factors such as perceptions of loneliness and social isolation, marital satisfaction, perceived social support, and infertility-related stress. Themes from the qualitative stage of the thesis suggest that many users did in fact feel that accessing an online support community had in some way influenced these aspects of their life; establishing whether quantitative measures reveal similar patterns could help to determine whether 'linking' has taken place (LaCoursiere, 2001). For instance, if an individual feels that use of an online support community has reduced their feelings of isolation and also demonstrates lower scores on measures of loneliness, this would suggest that they have successfully been able to 'link' their online experiences with their everyday life and previously learned cognitions.

Research from the online support literature suggests that several factors may influence the degree of benefit derived from accessing an online support community including length of membership and activity level (Barak & Dolev-Cohen, 2006; Cummings et al., 2002; Mo & Coulson, 2010; Rodgers & Chen, 2005). The study presented in this chapter was thus particularly concerned with exploring whether variables such as length of membership, frequency and duration of visits to the online community or

number of messages posted by participants were associated with psychosocial outcomes. The study also examined whether negative online experiences affected psychosocial outcomes in any way. This was considered particularly important since the previous two studies have indicated that some people experience negative aspects to using an online support community, which may influence their attitudes towards online support as well their psychological well-being. Additionally, it was considered important to explore whether any differences exist in the characteristics of people who have experienced disadvantages to online infertility support communities and those individuals who have not experienced disadvantages. As this may illuminate areas in which health care professionals or site moderators could intervene to better support people experiencing infertility or improve their online experiences.

Another key focus of the quantitative study was to examine similarities and differences between 'lurkers' and posters accessing online infertility support communities. Despite some statistics suggesting that the prevalence of lurking in health-related online support communities could be as high as 45.5% (Nonnecke & Preece, 2000), to date there has been a paucity of research specifically examining the experiences of 'lurkers' who access health-related online support communities. Furthermore, as described in the previous chapter the analysis of bulletin board messages revealed that the number of people who viewed discussion threads without posting their own messages appeared to be very high. Consequently, given the potentially high numbers of people lurking in online infertility support communities, understanding the motivations and experiences of 'lurkers' may be equally important when assessing the efficacy of online support communities for this population. Although analysis of the qualitative data

presented in chapter five did not reveal any noticeable differences in the online experiences of 'lurkers' and posters, due to the relatively small sample size of this study it is difficult to draw robust conclusions regarding whether 'lurkers' and posters do in fact benefit to the same degree on the basis of these results alone. The study presented in this chapter thus aimed to build on these findings by quantitatively examining differences in the use and experience of online infertility support communities between 'lurkers' and posters. In addition, the study aimed to explore whether differences exist in the psychosocial characteristics of 'lurkers' and posters. As previous authors have suggested that lurking may be associated with poorer mental and social well-being (van Uden-Kraan et al., 2008b).

Finally, the quantitative stage of the thesis examined whether differences existed in the use and experience of online support communities according to the broad diagnosis type (i.e. male infertility, female infertility etc) of the respondents. As described in the introduction to the thesis one factor that may influence levels of psychological distress associated with infertility is the specific diagnosis of infertility, with some studies suggesting that unexplained infertility or a gender-specific diagnosis of infertility may be more stressful for patients (Greil, 1997). Thus, it could be that the type of infertility people are coping with influences the reasons why they access an online support community or how they interact with the online community and the types of advantages and disadvantages they experience as a result of usage. Exploring any differences between diagnosis groups may help to identify whether any thing could be done to improve the provision of online support resources for different subgroups of people with infertility.

7.1.1 Aims and objectives

The overall aim of this study was to examine the efficacy of online support communities as a source of support and self-help for people experiencing infertility. The broad research questions guiding the study were:

- How is use of an online support community associated with the psychosocial well-being of people experiencing infertility?

- Are online support communities harmful in any way and if so for whom?

- Do factors such as diagnosis of infertility or lurking versus posting influence the use and experience of online support communities?

7.2 Methods

7.2.1 Design

This study was a cross-sectional online survey of people accessing online infertility support communities.

7.2.2 Sampling procedure

Similar to the qualitative study conducted at the start of the thesis, the recruitment criteria for the quantitative survey were relatively broad and included all individuals who had accessed an online support community for infertility issues. Participants could be either diagnosed with infertility

themselves or in a couple experiencing infertility. Both guest users and registered members were invited to take part in the study. The survey was aimed at adults over the age of 18.

In the first instance, contact was established with the board moderators of the 16 online support communities identified in the first study, to invite them to participate in the second phase of the research. Out of the 16 sites contacts, only 5 replied and agreed to participate this time (NB: these 5 online support communities also participated in the qualitative study), 3 replied to say that they did not allow researchers to recruit from their online community and the remaining 8 sites did not reply to the initial email or a follow-up email sent one week later.

Recruitment messages explaining the aims of study and inviting members to take part in an online survey were then posted to the bulletin boards of the 5 online support communities (see Appendix C). In addition, one online community placed the research invitation on the homepage of their website and another online community agreed to email a copy of the research invitation to all registered users. Individuals wishing to participate in the second study were asked to click on a link to the online survey, where they would be given further information about the nature of the research project and their rights as a participant. Recruitment took place between December 2008 and April 2009.

7.2.3 The research tool

As with the earlier survey, a number of measures were taken in this study to ensure that the survey was as clear and easy to follow as possible including displaying a progress bar at the top of each page and providing

clear guidelines for completion. In addition, a key issue for this study was the length of the survey. Previous authors have suggested that the length of an online survey may influence response rates, with longer surveys tending to generate fewer responses (Edwards et al., 2002). Since the current study was concerned with measuring psychosocial factors, the number of questions and overall length of the survey was inevitably considerably longer than the research tool used in the first study. However, to ensure the survey could be completed within a reasonable period of time (20-25 minutes) and was not unnecessarily long, the number of psychosocial measures used were limited to four, which assessed loneliness, perceived social support, marital satisfaction, and perceived infertility-related stress. Based on the literature review presented at the start of the thesis and findings from the first two studies it was felt that these factors were the most relevant and significant to the population under study and their online experiences.

To determine the length of time required to complete the survey and the clarity of the questions and instructions, the survey was again pilot tested by colleagues working in the area of online support communities with experience of online research methodology and by members of the least active of the 5 online support communities participating in the research. As a result of this process a few minor amendments were made to the wording of the survey to improve the clarity of the instructions given to participants. It was also found that on average the survey took around 25 minutes to complete and there was little or no missing data from the first few respondents. It was thus felt that the length of the survey did not deter people from completing all the questions and as a result no further changes were made to the survey length.

7.2.3.1. Survey items

The final survey instrument consisted of 6 sections, which measured the following items (see appendix D for full survey):

1) Background information: Respondents were asked to provide information about their demographic characteristics, which included age, gender, marital status, country of residence, ethnicity, educational background, employment status, diagnosis of infertility and time passed since diagnosis.

2) Use of online support communities: Respondents were asked to indicate how long they had been using an online infertility support community, how frequently they visited the online community, the number of messages they posted and the number of hours they spent in the online community in a typical week. Respondents were also asked to indicate their overall satisfaction with the online support community using a 5-point Likert scale ranging from 1= very dissatisfied to 5= very satisfied and indicate whether they would describe their overall experience of the online support community as positive, negative, or both positive and negative.

A series of open-ended questions were used to identify reasons for accessing the online support community and perceived advantages and disadvantages of usage. An open-ended format was selected for these questions in order to allow for the emergence of new issues and the identification of the issues that were most salient to the respondents.

3) Loneliness: Feelings of loneliness and social isolation were measured using the UCLA Loneliness Scale Version 3 (Russell, 1996). The UCLA Loneliness Scale is a reliable measure that is widely used to describe subjective feelings of loneliness or social isolation. The scale contains 20 items with a four-point Likert-type scale for each item ranging from 1= never to 4= always, with higher scores indicating higher levels of subjective loneliness and social isolation. In the current study, internal consistency for the scale was found to be high, with a Cronbach alpha coefficient of .94.

4) Perceived social support: Perceptions of social support were measured using the Medical Outcomes Social Support Survey, which is a 19-item scale assessing the perceived availability of various dimensions of social support. The scale consists of 4 subscales measuring the following domains of support: emotional/informational support, tangible support, affectionate support and positive social interaction (Sherboune & Stewart, 1991). A five point Likert scale ranging from 1= none of the time to 5= all of the time is provided for each question item, with higher scores indicating greater perceived social support. In the current study, internal consistency for the overall scale was high with a Cronbach alpha coefficient of .96. The Cronbach's alpha of the subscales ranged from .95 (informational/emotional support) to .97 (tangible support).

5) Marital satisfaction: Marital satisfaction was assessed using the Marital Satisfaction Scale from the marital inventory ENRICH (Olsen, Fournier, Druckma, 1987; Fowers & Olsen, 1993). The scale is a measure of global marital satisfaction, which assesses various areas

of the marital relationship such as communication, sexual relationship etc. It comprises 10-items, which are answered on a 5-point Likert scale ranging from 1= strongly disagree to 5= strongly agree, with a higher overall score indicating higher levels of marital satisfaction. In the current study, the Cronbach alpha coefficient for the scale was found to be .75, thus indicating good internal consistency.

6) Perceived infertility-related stress: Perceived infertility-related stress was examined using the Fertility Problem Inventory, which measures 5 parameters of stress specific to infertility: social concerns, sexual concerns, relationship concerns, negative view of a child-free lifestyle, and the need for parenthood (Newton, Sherrard, & Glazer, 1999). The scale consists of 46-items, which are answered on a 6 point Likert scale ranging from 1= strongly disagree to 6= strongly agree. Higher scores indicate higher levels of perceived infertility-stress. In the current study, the Cronbach alpha coefficient for the overall scale was found to be .67. The Cronbach's alpha of the subscales ranged from .37 (relationship concern) to .87 (rejection of a childfree lifestyle).

7.2.4 Ethical issues

Ethical approval for this study was obtained from the departmental Research Ethics Committee at the Institute of Work, Health & Organisations, in accordance with the ethical code of conduct published by the British Psychological Society. As with the qualitative study presented earlier, a number of measures were taken to protect the confidentiality and privacy of the respondents and ensure that all participants were aware of

the nature of the research and their rights as a participant. Firstly, all participants were given full information regarding the purpose of the research, the research methodology as well as their right to privacy, confidentiality and withdrawal from the study in the form of a participant information page at the start of the online survey. Contact details for the lead researcher were also provided in the page and again at the end of the survey in case any individual wished to raise queries or concerns regarding the research process. Following the participant information page, participants were reminded that their participation was entirely voluntary and were asked to click the 'NEXT' button to indicate their informed consent to take part in the study. Due to the sensitive nature of the research topic and some of the questionnaire items participants were given the option to skip any questions that they did not feel comfortable answering. In addition, before completing the survey each participant was asked to provide a password, which would enable their response to be identified should they wish to withdraw from the study after submitting their responses.

Secondly, measures were taken to protect the privacy and confidentiality of the research participants. Access to the raw data was password protected and only accessible by the lead researcher. Print outs of the data were stored in a locked file. No personally identifying information other than age and gender is reported in the results. Furthermore, in accordance with the British Psychological Society ethical code of conduct for Internet research the name of the online communities from which data were collected is not disclosed.

7.2.5 Data analysis

Data analysis was conducted using SPSS version 16.0. Descriptive statistics were used to describe the characteristics of the sample and their use and experience of online infertility support communities. Statistical analysis was carried out around 4 questions:

• Are there any differences in demographic, psychosocial, and use of online support community variables between participants who report experiencing disadvantages and participants who did not report experiencing disadvantages?

• Are there any differences in the use and experience of online support communities according to diagnosis of infertility?

• How does use and experience of online infertility support communities relate to psychosocial factors?

• Are there any differences in the demographic and psychosocial profile or the use of experience of online support communities between posters and lurkers?

Since the variables did not follow a normal distribution relationships between variables were analysed using non-parametric statistics. Differences in categorical variables were assessed using Chi square or Fishers exact tests in 2x2 tables with low expected cell counts and differences in continuous variables between groups were assessed through Kruskal-wallis one analysis of variance and Mann Whitney U tests.

Relationships between continuous variables were investigated using Spearman's Rank Order Correlation (rho).

Inductive content analysis was performed on responses to the open-ended questions to inductively identify the range of reasons for accessing the online support community, and the perceived advantages and disadvantages associated with usage. The first stage of the analytic process involved reading each response several times in order to become familiar with the dataset. The second stage involved coding each respondent's answers for their reasons for accessing an online support community and the main perceived advantages and disadvantages of usage. In the final stage of the content analysis the list of preliminary codes generated from reading the transcripts were collated and labelled. Codes which overlapped with another code were grouped together under higher order categories (Elo & Kyngas, 2008). For instance, for the disadvantages, codes such as "bullying of posters" and "bitchy remarks" were combined under a single higher order category labelled 'hostile behaviour'.

Upon completion of the data analysis process 15% of the responses were coded by a second independent rater to calculate inter-rater agreement. A Cohen's Kappa of 0.8 was established for reasons for accessing an online support community, 0.79 for the main advantages of online support and 0.77 for the main disadvantages of online support; thus indicating satisfactory levels of reliability.

7.3 Results

7.3.1 Participant characteristics

A total of 295 people completed the online survey. Of these the large majority (99.7%) were female (n=294). The age of the respondents ranged from 22 – 48 years with a mean age of 34 years (SD = 4.9). In terms of country of residence, the majority of participants stated that they were from the United Kingdom (88.4%, n=261) or the US (5.1%, n=15). Three participants did not complete the question, three reported that they were from The Netherlands, and another three reported that they were from Ireland. Two respondents were from Italy and the rest came from Australia, Canada, Singapore, Switzerland, India, Croatia, China and Belgium.

The majority of the sample identified themselves as White (95.3%, n=281). Eight participants described their ethnic origin as Asian (2.7%) and three identified themselves as Black (1%). The rest responded as belonging to an ethnic group not specified as an option on the survey (1%, n=3). In terms of their marital status, most of the participants reported that they were in a relationship and were either married (83.4%, n=246) or living with a partner (14.2%, n=42). Only six participants identified themselves as single (2%).

Overall the sample had a high level of educational attainment with over two thirds reporting that they were educated to degree level (67.5%, n=199). The majority of participants were either in full time (62%, n=183) or part time employment (16.9%, n=50). There were also eight students (2.7%) and twenty-five people who described themselves as self-employed

(8.5%). In terms, of infertility diagnosis the respondents indicated that they were suffering from a range of different fertility problems. Broadly speaking, 33.9% could be classified as suffering from female factor infertility (n=100), 29.1% stated that the cause of their infertility was unexplained (n=86), 19% stated that they were suffering from male factor infertility (n=56) and 17.3% reported a combination of male and female factor infertility. Time since diagnosis ranged from 0.25 – 25 years. The average time since diagnosis was found to be 4.8 years (SD=3.6).

In terms, of psychosocial characteristics the results reveal that the mean scores for Perceived Social Support (M=78.5, SD=13.7, range: 19-95), Marital Satisfaction (M=38.5, SD= 6.2, range: 13-50) and Perceived Infertility-Related Stress (M=153.3, SD=18, range: 101-203) were relatively high. The mean score for the UCLA Loneliness scale was 43.2 (SD=10.2, range: 20-69), indicating moderate levels of loneliness in the sample.

7.3.2 Use of online infertility support communities

Analysis revealed that the sample had been accessing online infertility support communities for an average of 1.9 years (SD=1.8). However the length of membership ranged from 2 days to 10 years. Overall satisfaction with the online support community was relatively high with a mean score of 4.3 (SD=1). When asked to describe their experience of seeking online support, the majority of respondents described their experiences as positive (71.5%, n=211), however just over a quarter of respondents (26.1%, n=77) stated that their experiences had been both positive and negative. Only four respondents described their experience as solely negative (1.4%).

Almost two thirds of the sample visited the online support community on a daily basis (60%, n=177) and just under one third visited the online support community weekly (31%, n=92) (see Figure 1).

On average respondents reported spending around 5.9 hours (SD=6.4) accessing online infertility support communities in a typical week (range-0-48 hours). As Figure 2 indicates the majority of respondents reported posting between 1 and 10 messages to the online infertility support community in an average week. Around 15.6% of the sample indicated that they did not post messages to the online support community.

Figure 1. Frequency of visits to the online support community
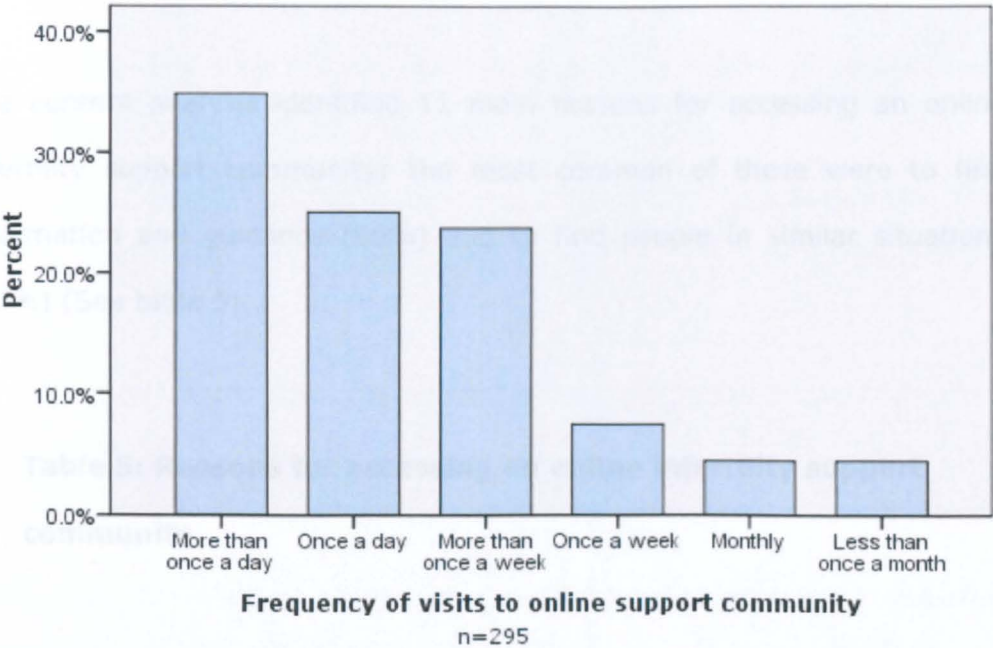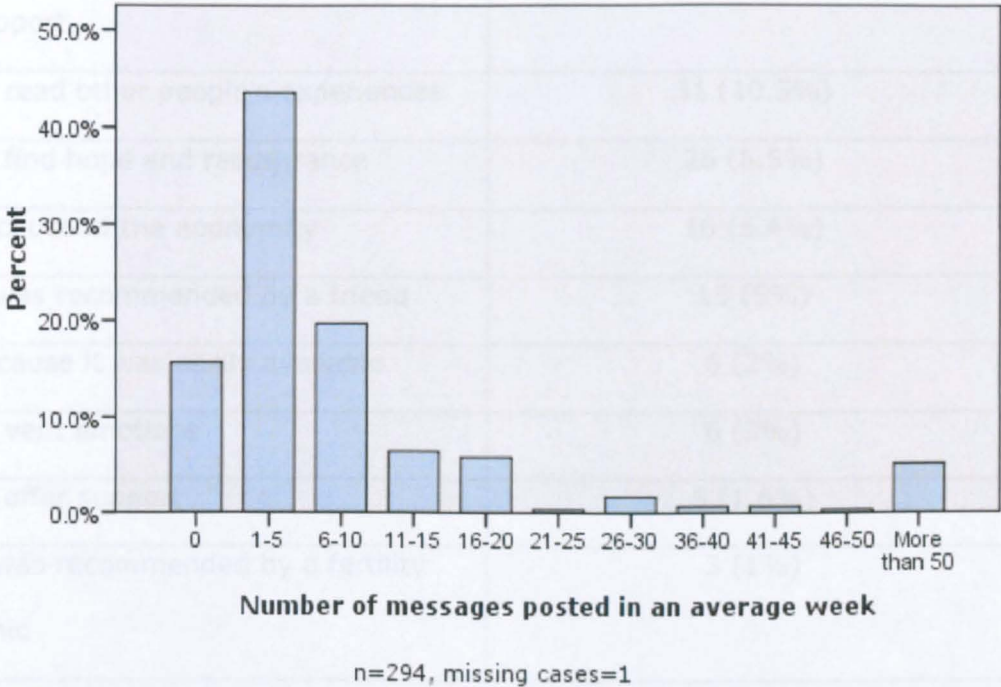

Frequency of visits to online support community

n=295

Figure 2. Number of messages posted to the online support community in an average week

Number of messages posted in an average week

n=294, missing cases=1

7.3.3 What motivates people to access online infertility support communities?

The content analysis identified 11 main reasons for accessing an online infertility support community; the most common of these were to find information and guidance (60%) and to find people in similar situations (53%) (See table 5).

Table 5: Reasons for accessing an online infertility support community

Reason	Total (N,%)
To find information and guidance	178 (60%)
To find people in similar situations	157 (53%)
To find empathy and emotional support	78 (26%)
To read other people's experiences	31 (10.5%)
To find hope and reassurance	25 (8.5%)
Because of the anonymity	16 (5.4%)
It was recommended by a friend	15 (5%)
Because it was easily available	6 (2%)
To vent emotions	6 (2%)
To offer support	5 (1.6%)
It was recommended by a fertility clinic	3 (1%)

To find information and guidance. Informational support was cited as the most common reason for accessing the online support community. Members often reported turning to online communities to seek first hand experiences and information concerning a wide range of issues from treatment options/procedures to pregnancy symptoms:

> *"To access information which is otherwise unavailable through medical specialists locally" (Female, 36)*

> *"To gain information from others with similar problems" (Female, 27)*

There were also instances in which an online community was considered the fastest and most convenient source of information. For example, one participant wrote:

> *"The Internet, or information you receive from consultants, although detailed, is very 'medical' nothing beats talking to people who have experienced it, also the speed of obtaining answers to questions is much quicker than waiting for your consultant, or until working hours when you can call the nurses" (Female, 37)*

To find people in similar situations. Over half of the participants reported accessing the online support community to find people in a similar situation to themselves. Many of the respondents felt unable to discuss their infertility experiences with friends or family, because they believed that only individuals who had experienced infertility themselves could fully understand their emotions. The online support community thus presented these individuals with a unique avenue through which they could access a network of people who had first hand understanding of infertility and its treatment:

"I needed to speak to other women who were experiencing the same pains and worries that I was. All of my friends and family are fertile so no-one could offer any worthwhile advice or support. Unless you have been through this heartache, you can't possibly understand what it feels like." (Female, 34)

"I needed to talk to people who understand my issues of infertility, friends and family try but no one really knows until you go through it, as a female it is a natural instinct to want to be a mum for both." (Female, 30)

To find empathy & emotional support. Others saw online support communities as a venue in which they could gain a unique source emotional support from individuals who understood the highs and lows of fertility treatment and could therefore validate their feelings:

"For support and understanding from people going through the same problems" (Female, 31)

"The support you get from women going through similar experiences is invaluable as they completely understand what you are going through, family and friends don't have that level of understanding. They can answer questions relating to treatment and as you are talking to women from all over the country they can guide you through different treatments that maybe your hospital doesn't provide." (Female, 36)

To read other people's experiences. Several respondents reported initially accessing the online support community to simply read about other peoples experiences of infertility, particularly treatment procedures:

> *"Infertility can be very isolating, when those around you are becoming pregnant very easily, or that's how it seems. I accessed the group to read about other people's experiences to reassure myself I was not alone." (Female, 37)*

> *"To read about the experiences of people going through treatment. To find out about what's likely to be lying ahead so that I can prepare myself for it." (Female, 36)*

To find hope & reassurance. Some participants accessed the online support community in order to find stories about successful treatment outcomes and reassure themselves that their treatment could also lead to a pregnancy:

> *"To hear hopeful stories" (Female, 29)*

> *"To obtain other peoples experiences of treatment and for hope" (Female, 30)*

> *"For some kind of hope - when the odds seem to be against us and to see how we compare to others in the same situation" (Female, 35)*

Because of the anonymity. The anonymity associated with an online support community was also seen was as an important factor influencing the decision to seek support online as opposed to face-to-face. For example, when asked about their reasons for accessing the online community several participants simply wrote:

> *"Anonymous support" (Female, 41)*

> *"You have the option to participate or remain anonymous" (Female, 45)*

It was recommended by a friend. Some women stated that they had decided to join the online support community, upon recommendation from a friend:

> *"Some one who had fertility problems in the past recommended it to me." (Female 33)*

> *"It was recommended by a friend who was also experiencing fertility problems. She said that it had been a great source of support for her and relieves the isolation that you can sometimes feel" (Female, 32)*

Because it was easily available. Some women reported accessing the online community because it was the most convenient and easy to access source of information and support:

> *"The convenience and anonymity. Infertility is a rather taboo topic, and being able to discuss it anonymously was a very inviting reason for choosing online support. Also, I work and attend school, so being able to access support when it was convenient for me also made for a great choice in seeking support." (Female, 33)*

> *"It's relatively anonymous and you can get advice and support from others in the same situation without having to leave your home / desk." (Female, 34)*

To vent emotions. Online communities were also described as a safe environment in which participants could disclose their anxieties and vent frustrations associated with infertility and its treatment:

> *"You can feel very alone dealing with infertility and the online forum provides support, comfort and anonymity to express yourself to people who will understand. It is a way to vent feelings, avoiding overburdening friends and family." (Female, 32)*

To offer support. A small number of participants expressed a desire to help others through sharing their experiences of infertility online and providing other patients with a source peer guidance and emotional support:

> *"To find people in my position who understood how I was feeling and to offer practical advice and support." (Female, 29)*

> *"If it will help others I am happy to assist" (Female, 38)*

> *"Help others with IF problems" (Female, 39)*

It was recommended by a fertility clinic. Only three respondents reported accessing the online support community upon recommendation from a member of staff at their fertility clinic:

> *"I was recommended to use one by gp and clinic" (Female, 28)*

7.3.4 What are the main perceived advantages of accessing an online infertility support community?

The majority of women (97.6%, n=288) reported experiencing at least one advantage to accessing an online infertility support community. The most commonly cited included informational support and guidance (37%),

empathy and support (33%) and realising your not alone (24.7%) (See table 6).

Table 6: Main advantages of accessing an online infertility support community

Advantage	Total (N,%)
Informational support and guidance	109 (36.9%)
Empathy and emotional support	98 (33%)
Realising you're not alone	73 (24.7%)
Sharing personal experiences	37 (12.5%)
Reading other people's experiences	34 (11.5%)
A sense of hope and encouragement	23 (7.8%)
Friendship	18 (5.9%)
24 hour access	6 (2%)
Anonymity	2 (0.7%)

Informational support and guidance. Many women cited the availability of information and advice on a wide range of issues concerning infertility and conception as the most helpful aspect of their online experience:

> *"The availability of information - as usually there have been other women going through exactly the same thing - i.e. drugs, type of treatments etc and it's helpful to read how they have got on."* *(Female, 36)*

Empathy and support. Participants also valued the emotional support and empathy provided by members of the online community:

> *"The outpouring of support when we lost a pregnancy. Only those who have experienced a loss can truly understand. My family was supportive but they weren't able to fully help with the emotional aspects." (Female, 39)*

> *"Support and understanding of the rollercoaster you're on throughout the infertility journey." (Female, 34)*

Some women stated that while their initial reason for accessing the community had been for informational purposes, they eventually found that the support and understanding of fellow members was equally beneficial:

> *"At first it was knowledge on treatment options and testing. However, now I feel very knowledgeable in this area, it is the emotional support has been key. Both emotional support through treatment cycles and 3 miscarriages." (Female, 36)*

Realising you're not alone. When discussing the benefits of online support several women described how using an online support community had made them realise that they were not alone in their struggle to achieve a pregnancy and that there were a large number of women who could relate to their experiences:

> *"Realising you are not the only one with problems, and realising that there are people worse off than you!" (Female, 33)*

> *"Reading other members' posts and realising I'm not alone." (Female, 35)*

This realisation appeared to help reduce the feelings of abnormality and isolation that some women had been experiencing prior to accessing the online community:

> *"You are no longer alone, you know other people are also experiencing the same difficulties as you" (Female, 39)*

> *"Sense of camaraderie - you feel as though you are not alone and that lots of people are going through this too." (Female, 36)*

> *"The feeling that you belong somewhere and that they know what you are going through as they are having similar experiences as yourself." (Female, 34)*

Sharing personal experiences. For some women the online support community was seen as a safe environment in which they could offload their emotions and share experiences, without fear of a negative reaction:

> *"It also helps to be able to vent my feelings about my problems in an environment which is non judgemental and supportive. When things happen on the TTC journey they can be very personal and private and yet it helps to be able to express them" (Female, 32)*

Reading other people's experiences. Some participants felt that they had benefitted from simply reading about the experiences of other women undergoing fertility treatment. For example, one woman described how this helped her decide when to terminate treatment:

> *"The most helpful part was me seeing other couples going through treatment after treatment for yrs and yrs and how stressed people get, although I was also stressed and upset with my whole situation it made me realise early on that, that wasn't what I wanted for me*

and my husband I just wanted a family, and glad it made me come to an early decision to adopt rather than have more treatment." (Female, 26)

A sense of hope and encouragement. Hearing about successful treatment outcomes appeared to instil women at the earlier stages of the infertility journey with a sense of hope and encouragement:

"Seeing so many couples (women) going through similar problems or even worse ones and still being successful gives me hope." (Female, 30)

"It helps to hear you are not the only one with so many problems and its also good to hear people do have success despite the odds... it give me hope" (Female, 34)

"Hope that treatment will work in the future - hearing positive stories of success" (Female, 29)

Friendship. Several women appeared to develop strong bonds with members of the online support community. Thus, when asked about the advantages of online support some respondents stated:

"Support and friendship." (Female, 30)

"I have made at least one lifelong (I hope!) friend through this. The friendships developed" (Female, 39)

When discussing the advantages of online support some women also reported interacting with group members outside of the online community. For example:

> *"Being able to meet up with other women once a month within my area and develop friendships and support from that." (Female, 38)*

24 hour access. The knowledge that the online support community was available 24 hours a day 7 days a week, as a source of information, support or companionship was a great comfort for some respondents:

> *"24 hour support - it is there when you are feeling most desperate and alone." (Female, 32)*

> *"Knowing that 24/7 I could log on and find answers and emotional support." (Female, 29)*

> *"24 hour access a great vent to type feelings that I can't always articulate" (Female, 34)*

Anonymity. Two participants viewed the anonymity of the Internet as a key advantage when sharing their experiences in the online support community:

> *"I liked having the anonymity of the online group as well." (Female, 39)*

7.3.5 What are the main perceived disadvantages of accessing an online infertility support community?

Over half of the sample (57.9%, n=171) reported experiencing disadvantages to online infertility support communities. From these responses the most common disadvantages were found to be reading, about negative experiences (10.8%), reading about other peoples pregnancies (8.8%), inaccurate information (7.8%), it's addictive (5.7%), and unhelpful replies (5.4%) (see table 7).

Table 7: Main disadvantages of accessing an online infertility support community

Disadvantage	Total (N,%)
Reading about negative experiences	32 (10.8%)
Reading about other people's pregnancies	26 (8.8%)
Inaccurate information	23 (7.8%)
It's addictive	17 (5.8%)
Unhelpful replies	16 (5.4%)
Volume of messages	14 (4.7%)
Cliquishness	12 (4%)
Technical issues related to the site	10 (3.4%)
Hostile behaviour	7 (2.4%)
Social comparison	7 (2.4%)
Lack of physical proximity	5 (1.7%)
Judgemental replies	3 (1%)
Lack of privacy	2 (0.7%)
Not receiving a reply	2 (0.7%)

Reading about negative experiences. Through accessing an online support community women were confronted with a range of stories regarding the negative aspects of conception and pregnancy. It was felt that reading about these negative experiences made them more aware of all the potential problems and complications associated with reproductive treatment. As a result, several respondents appeared to experience an increase in feelings of worry and anxiety after visiting the online support community. For example, one participant wrote:

> *"Learning about problems and complications that I did not know about previously – gives me more things to worry about!!" (Female, 31)*

Other participants described how these stories affected their sense of optimism about their own treatment outcome:

> *"Negativity from others can reflect mood, if something bad happens to them it can also make you worry about yourself" (Female, 34)*

> *"Sometimes there are very sad stories and it is difficult not to think that the same thing will happen to you" (Female, 28)*

Reading about other people's pregnancies. A number of women explicitly expressed feelings of jealousy and pain when reading about other women's success with treatment. For example, when citing disadvantages to online support some women wrote:

> *"Negotiating my own difficult feelings of jealousy and grief when other people announce their positive pregnancy results." (Female, 38)*

> *"'Feeling jealousy when other women become pregnant and seeing pictures of pregnant ladies." (Female, 39)*

Others described experiencing a sense of alienation from the online support community when their virtual friends fell pregnant:

> *"It's happy and hard to hear that someone else has gotten pregnant if you haven't. I once took part in a fairly large cycle group. We supported each other from the beginning of our cycles straight through till beta day. They ALL got pregnant expect for me. I felt so*

sad and alone. They all supported me, but I still felt like I suddenly didn't belong anymore." (Female, 37)

This was particularly pronounced for women who had experienced a number of failed treatment cycles and felt that they were no longer able to actively participate in the support community. For example, one woman who had experienced four failed IVF cycles wrote:

"Support groups are success oriented and if you aren't successful there is very little tolerance for talking about that pain. I felt shunned after my 4th IVF failed and I felt this was supported by the owners of the support group. So I stopped using it so much and post very little. The groups seem to propagate the "success" of infertility treatments when the painful truth is that the majority of treatments fail. By being so success orientated they alienate a great many women who normally just stop posting." (Female, 43)

Inaccurate information. Several women reported concerns regarding the accuracy of informational support exchanged within online support communities. The absence of a trained medical professional in the bulletin boards meant that many women felt cautious when interpreting factual information about infertility and its treatment:

"Sometimes everyone gets whipped up about a particular topic and it's a bit 'misinformation' e.g. one of the boards someone said that oral sex means you can't get pregnant because of the pH of the saliva and about 20 people wrote 'wow I didn't know that I'll avoid oral sex from now on.' One woman said that both her kids were conceived after oral sex and I can't help suspecting that this is a bit of group hysteria about a very small possibility. A problem when

there's no medical mediator on a medically themed board" (Female, 35)

"The fact that there are so many protocols and everyone is on a different regimen, so its sometimes scary when you think you're not getting the best meds or you should injecting at this part of your cycle. As most people aren't doctors, sometimes information can be incorrect, so you need to still check everything out with a med" (Female, 36)

It's addictive. When asked to discuss what they felt was the least helpful aspect of online support communities, some women described how their visits to the site were like an 'addiction', which swallowed up time they would usually spend on other tasks:

"The addiction to visiting the site" (Female, 43)

"It's a bit addictive and it's easy to become too wrapped up in it" (Female, 38)

"The time spent in front of your computer. It becomes addictive!" (Female, 35)

"I find it rather addictive which can interfere with my work and speaking to people in person" (Female, 37)

Unhelpful replies. Replies to messages posted within the online support community were not always perceived as supportive. Some participants described instances where they had received replies, which were either unhelpful or inappropriate to their situation:

"Sometimes you get the odd response that isn't helpful but these are very few and far between and I never had one that was meant badly just answers that were no appropriate to my situation" (Female, 32)

"Some people post inappropriately i.e. in areas that they do not have experience and therefore unwittingly cause offence or hurt" (Female, 38)

At times, it was felt that members of the online community were not always able to empathise with their situation. For example, some woman wrote:

"Sometimes people who have gone onto have children seem so utterly disconnected with the emotions of infertility that they knew only too well say 10 months ago" (Female, 32)

"Others not understanding what your going through and making unhelpful comments" (Female, 35)

Volume of messages. Some members viewed the large volume of messages posted to bulletin boards within the online community as a negative aspect to the support community. Highly active discussion threads made it difficult for members to follow one another's infertility journey. For example:

"Very busy threads- hard to keep up with everybody else's journey to support them" (Female, 34)

"Sometimes there are very sad stories and it is difficult not to think that the same thing will happen to you" (Female, 28)

Other respondents reported problems navigating the site, which led to difficulties retrieving information relevant to their situation:

> "*I suppose wading through lots of long conversations that aren't directly relevant – but that's ok as it's part and parcel of the collaborative nature of the bulletin boards*" (Female, 45)

> "*There are too many people and crowded forums*" (Female, 29)

Cliquishness. Some participants felt that the online support community contained a smaller clique of active members who dominated group discussions. Thus making it difficult for newcomers to get involved in conversations:

> "*Some of the discussion threads can be very 'cliquey'*" (Female, 39)

> "*Can be very cliquey. Lots of posters know each other very well and sometimes threads can end up just being a series of good luck messages rather than maintaining the topic*" (Female, 43)

> "*It feels very cliquey, not somewhere I necessarily feel welcome bizarrely*" (Female, 41)

Technical issues related to the site. Several participants discussed problems with registering and accessing the online support communities:

> "*I was unable to login due to unresolved technical issues*" (Female, 39)

> "*Me not being able to always access the site on my mobile phone*" (Female, 25)

Social Comparison. The opportunity for participants to readily compare their treatment process and symptoms to that of other patients was viewed by some as another potential source of anxiety associated with online support communities. For example, one respondent wrote:

"When I was actually having treatment I became obsessed with reading other peoples stories and wondering whether mine had or hadn't worked because I did or didn't feel what they had" (Female, 34)

While another wrote:

"The negative aspect is reading too much into what other people say and needing to be aware that although others may be undergoing the same treatments etc their diagnosis can be very different. It's very easy to assume because something has happened to one person it will be the same for you" (Female, 37)

Hostile behaviour. Some participants reported experiencing hostile behaviour from other members of the online community. This included "bitchy remarks", "bullying of posters" and "patronising responses". Such experiences were especially common among women who were successful with treatment:

"Jealousy and negative emotions expressed by a few when I have been successful leading to a sense of personal guilt" (Female, 36)

"Some tacit exclusion or chilling when I became pregnant from others on my thread who were not pregnant. It is difficult to post on some sites if you have a child already" (Female, 37)

Lack of physical proximity. The lack of face-to-face contact with members of the support community was also cited as a potential disadvantage to online support seeking. One woman wrote:

> *"Not being able to sit down and talk to these amazing women"* (Female, 26)

While another wrote:

> *"Sometimes the lack of physical closeness hinders the ability to really get to know someone" (Female, 33)*

Judgemental replies. There were also some occasions where participants felt that members were judgemental when replying to messages posted in the online support community. For example, one participant described the reaction of the community to her desire to have twins:

> *"Some women who have lost twins seem to be very negative to those who would like twins. I have always wanted twins but some women this desire is a crime I can't help feel there is some bitterness. Even if our twins did not go full term I would always love to have twins" (Female, 31)*

Not receiving a reply. Only two participants cited not receiving a reply to a message as a potential negative of using an online support community:

> *"Not receiving a response to a posting" (Female, 34)*

> *"Lack of responses at times from questions" (Female, 28)*

Lack of privacy. Two participants described the open nature of online communities as the least helpful aspect of seeking support through the Internet:

> *"Anyone can read what you have written" (Female, 25)*

"The forum is accessible to anyone i.e. not password protected, which makes me a little cautious about being open" (Female, 36)

7.3.6 Are there any differences between participants who report experiencing disadvantages and participants who did not report experiencing disadvantages?

People who reported experiencing disadvantages to online infertility support communities were significantly more likely to have a higher level of educational attainment ($\chi^2(3)$ = 12.13, $p<.01$); 74.9% of people who reported disadvantages (n=128) were educated to at least degree level, whereas of those who did not report disadvantages only 57.3% were educated to degree level (n=71). No significant relationships were found between age, marital status, ethnicity, employment status, time since diagnosis or type of infertility diagnosis and the two groups.

People who reported disadvantages were significantly less satisfied with the online support community (M=4.1, SD=1) when compared to people who did not report disadvantages (M=4.5, SD=.96) (Mann–Whitney U = 7308.00, $P<.001$). As shown in Figure 3, people reporting disadvantages were also significantly more likely to describe their online experiences as negative or both positive and negative (40.4%, n=69) than people who did not report disadvantages (9.7%, n=12) ($\chi^2(2)$ = 33.69, $p<.001$). No significant differences were found in psychosocial characteristics or use of online support communities between the two groups.

Figure 3. Overall experience of accessing an online support community

Legend:
- No disadvantages reported
- Disadvantages reported
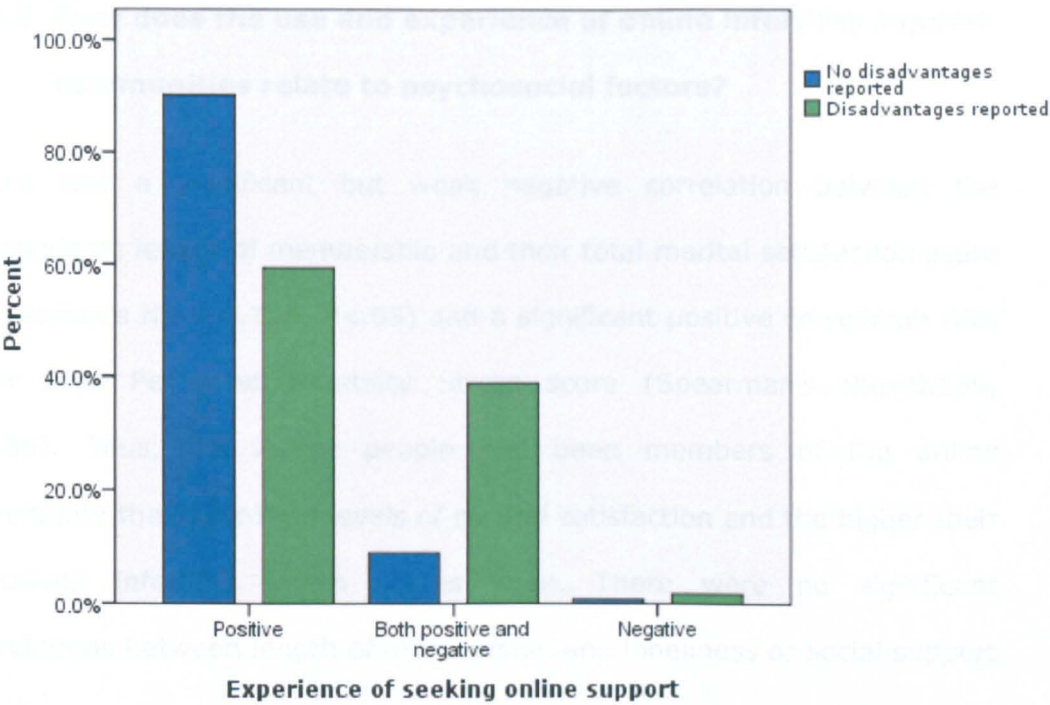
7.3.7 Are there any differences in the use and experience of online support communities according to diagnosis of infertility?

Results from Kruskal-wallis one-way analysis of variance tests reveal that people with a diagnosis of unexplained (M=155.18, SD=18), female factor (M=154, SD=18) and male and female factor infertility (M=153, SD=17) had significantly higher levels of perceived infertility stress than those with male factor infertility (M=147.6, SD=16.8) (H(3)= 7.8, *p*<.05), this was particularly salient on the sexual concern subscale of the Fertility Problem Inventory (H(3)= 9.6, *p*<.05). However, this did not appear to be associated with the participant's use of online infertility support communities, as no significant relationships were found between diagnosis of infertility and the use of online support communities, motives for

accessing online communities or perceived advantages / disadvantages of usage.

7.3.8 How does the use and experience of online infertility support communities relate to psychosocial factors?

There was a significant but weak negative correlation between the respondents length of membership and their total marital satisfaction score (Spearman's rho=-0.136, $P<.05$) and a significant positive correlation with their total Perceived Infertility Stress score (Spearman's rho=0.159, $P<.05$). Thus, the longer people had been members of the online community the lower their levels of marital satisfaction and the higher their perceived infertility stress scores were. There were no significant correlations between length of membership and loneliness or social support scores.

There was also a negative relationship between the number of hours a respondent spent using an online support community in a typical week and their total marital satisfaction scores (Spearman's rho=-0.206, $P<.01$) and a significant but weak positive correlation between hours spent online and scores on the total need for parenthood subscale of the Fertility Problem Inventory (Spearman's rho =0.147; $P<.05$). Thus, the more time people spent in an online support community the higher their need for parenthood and the lower their marital satisfaction was. No significant associations were found between the number of hours spent online and the other four subscales of the Fertility Problem Inventory or social support and loneliness scores.

Results from Kruskal-wallis one way analysis of variances tests reveal that scores on the need for parenthood subscale of the Fertility Problem Inventory were significantly related to frequency of visits to the online support community ($H(5)=13.75$, $p<.05$). Mann Whitney U tests indicated that the significant difference in scores could be found when comparing people who accessed an online support community more than once a day to people who accessed an online support community only once a day (Mann–Whitney $U = 2168.50$, $P<.01$) or once a week (Mann–Whitney $U = 583.50$, $P<.01$). This suggests that people who were accessing an online infertility support community more than once a day had a significantly higher need for parenthood than people who only accessed the online community once a day or once a week.

No significant associations were found between the number of messages posted by the participants and their scores on any of the four outcome measures used.

However, the overall experience of accessing an online support community was found to significantly affect scores on measures of loneliness ($H(2)=10.49$, $p<.01$), marital satisfaction ($H(2)=7.32$, $p<.05$), perceived infertility-related stress ($H(2)=6.29$, $p<.05$), perceived social support ($H(2)=10.25$, $p<.01$) and on the emotional and informational support subscale of the Medical outcomes social support survey ($H(2)=10.55$, $p<.01$). Follow-up Mann Whitney U tests revealed that people who described their online experiences as positive had significantly higher levels of perceived social support (Mann–Whitney $U = 5838.00$, $P<.01$), particularly emotional and informational support (Mann–Whitney $U = 6234.50$, $P<.01$) and had lower levels of perceived infertility-related

stress (Mann–Whitney U = 4028.50, $P<.05$) and loneliness (Mann–Whitney U = 5070.50, $P<.01$) than people who described their online experiences as both positive and negative. No significant differences were found between people with positive or positive and negative online experiences and marital satisfaction scores. However, people with both positive (Mann–Whitney U = 101.50, $P<.05$) and positive and negative (Mann–Whitney U = 56.50, $P<.05$) online experiences had significantly higher marital satisfaction scores when compared to people who described their online experiences as negative.

No association were found between overall satisfaction with the online support community and psychosocial factors.

7.3.9 Are there any difference between 'lurkers' and posters?

A total of 46 people stated that they had never contributed a message to an online infertility support community (15.6%). These respondents were classified as 'lurkers'. This question was missed out by one respondent, thus leaving a total of 248 (84%) 'posters' in the sample. Differences between 'lurkers' and posters were explored through Chi-square (or Fishers Exact tests for 2x2 tables with low expected cell counts) and Mann Whitney U tests.

Posters visited an online infertility support community more often than 'lurkers' ($\chi^2(5)$ = 57.88, $p<.001$), with 67.3% (n=167) stating that they visited the online community daily compared to only 21.7% of 'lurkers' (see Figure 4). Posters also spent a considerably longer period of time in the online support community (M=6.3, SD=6.7) when compared to 'lurkers' (M=3.4, SD=2.9) (Mann–Whitney U = 3738.00, $P<.001$).

Overall 'lurkers' were found to be significantly less satisfied with the online support community (M=4, SD=.84) when compared to posters (M=4.4, SD=1) (Mann–Whitney U = 4312.00, $P<.01$) and were significantly more likely to describe their online experiences as positive and negative ($\chi^2(2)$ = 9.69, $p<.05$) (see Figure 5). There were no significant relationships found between the participant's status as a 'lurker' or poster and their length of membership, time since diagnosis or psychosocial and demographic characteristics.

Figure 4. Frequency of visits to the online support community

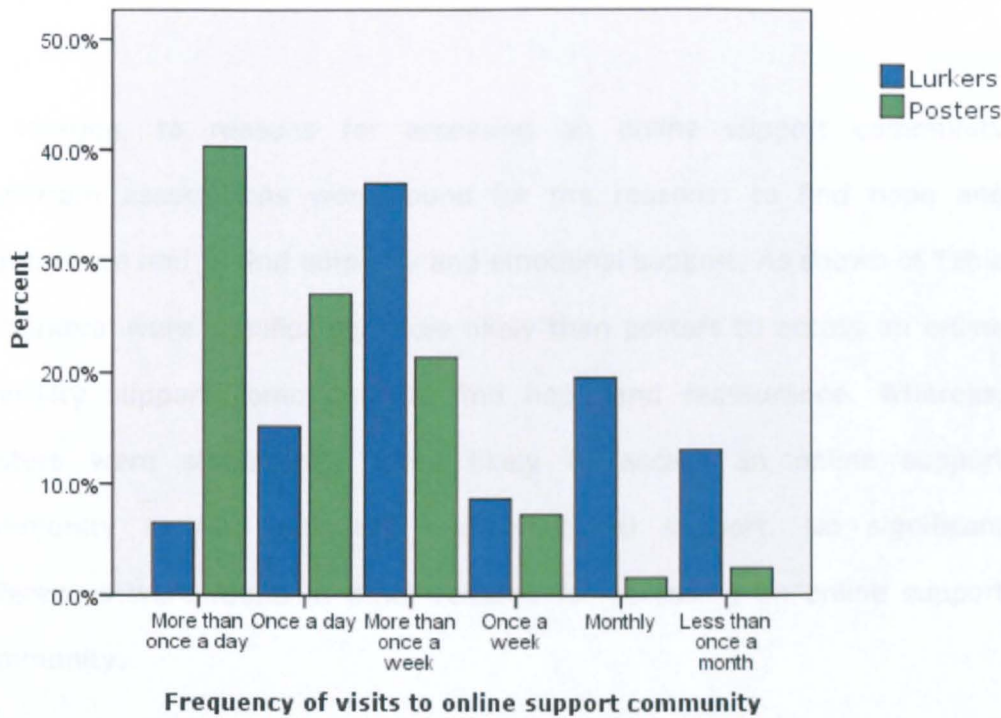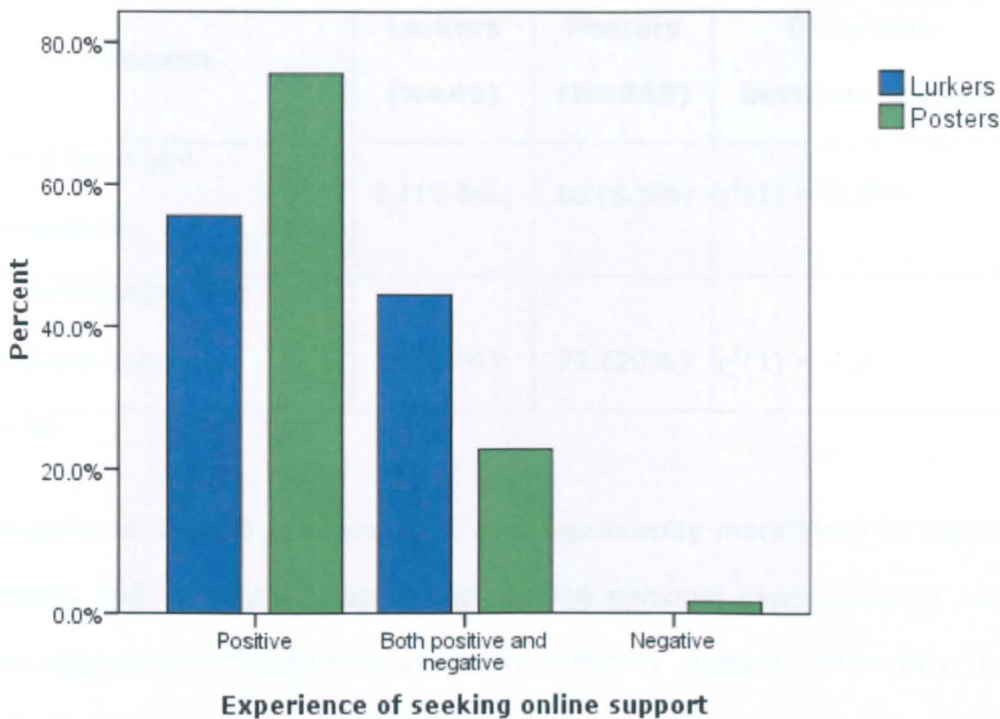Frequency of visits to online support community

Figure 5. Overall experience of accessing an online support community

In relation, to reasons for accessing an online support community significant associations were found for the reasons: to find hope and reassurance and to find empathy and emotional support. As shown in Table 8, 'lurkers' were significantly more likely than posters to access an online infertility support community to find hope and reassurance. Whereas, posters were significantly more likely to access an online support community to find empathy and emotional support. No significant differences were found in other reasons for accessing an online support community.

Table 8: Associations between reasons for accessing an online support community and lurking / posting status

Reason	Lurkers (N=46)	Posters (N=248)	Difference between groups
To find hope and reassurance	9 (19.6%)	16 (6.5%)	$\chi^2(1) = 6.97*$
To find empathy and emotional support	6 (13%)	72 (29%)	$\chi^2(1) = 4.3*$

*$p<.05$

Compared to 'lurkers', posters were also significantly more likely to report empathy and emotional support and sharing personal experiences as the main advantages of accessing an online infertility support community. In contrast, 'lurkers' were significantly more likely to report reading other peoples experiences as the main advantage of an online support community (see Table 9).

Table 9: Associations between perceived advantages of accessing an online support community and lurking / posting status

Advantage	Lurkers (N=46)	Posters (N=248)	Difference between groups
Empathy and emotional support	5 (10.9%)	93 (37.5%)	$\chi^2(1) = 11.3***$
Sharing personal experiences	1 (2.2%)	36 (14.5%)	$\chi^2(1) = 4.3*$
Reading other peoples experiences	13 (28.3%)	21 (8.5%)	$\chi^2(1) = 12.99***$

*$p<.05$, ***$p<.001$

As shown in Table 10, a significantly higher proportion of 'lurkers' cited inaccurate information as the main disadvantage of accessing online support community when compared to posters. There were no significant relationships in the reporting of other disadvantages between the groups.

Table 10: Associations between perceived disadvantages of accessing an online support community and lurking / posting status

Disadvantage	Lurkers (N=46)	Posters (N=248)	Difference between groups
Inaccurate information	8 (17.4%)	15 (6%)	$\chi^2(1) = 5.4$*

*$p<.05$

7.4 Discussion

The study presented in this chapter aimed to quantitatively examine the use and experience of online support communities among people with infertility. Due to the exploratory nature of this thesis the survey responses were used to explore a range of different research questions, which arose both from the review of literature presented at the start of the thesis and the findings of the previous two studies. In this section, the results of the online survey will be discussed in relation to the key objectives of the study and in the context of current research and knowledge concerning the phenomenon under investigation.

7.4.1 Why do people access an online infertility support community and what are the key advantages they can gain from usage?

The results of the present study corroborate findings from the earlier qualitative study by confirming the potential of online support communities to provide people experiencing infertility with a unique source of information and support. Additionally, the findings add valuable information regarding the key motivations and advantages experienced by people accessing online support communities, through quantifying the main reasons and perceived advantages. From the responses it would appear that the key motive for accessing an online infertility support community was to find information and support. Almost two thirds of the sample indicated that informational support was their primary reason for accessing an online support community. Members of the online support community were often viewed as the best source of knowledge on what to expect during the diagnosis and treatment of infertility and the symptoms associated with a pregnancy or miscarriage. Thus, through the online community many individuals felt that they could access information that would not be available from their fertility clinic. In addition, since online infertility support communities were available 24 hours a day 7 days a week they allowed individuals to access information outside of traditional working hours when other sources of support were unavailable.

This finding differs somewhat from the results of the content analysis conducted in chapter six, which found that messages giving or seeking information were fewer in number when compared to messages containing self-disclosure and emotional support. However, it may be that people accessing online support communities are gaining valuable experiential

information and guidance from reading about people's stories and experiences, and therefore do not have a need to ask specific questions of the online community. Indeed, results from the qualitative stage demonstrate how participants felt empowered as a result of the wealth of experiential rather than factual knowledge available in online infertility support communities, which served as a useful way of becoming knowledgeable about treatment protocols and alternative treatment options. This study adds to these findings by highlighting that this is one of the key motives and benefits of online infertility support communities for the large majority of participants.

Over half of the sample reported turning to an online community in order to find people in a similar situation. Online support communities appeared to provide participants with a unique opportunity to communicate with a large network of individuals affected by infertility. Members were thus able to seek empathy, support, reassurance and companionship from people who had first hand understanding of the challenges and emotions surrounding infertility. Indeed, over a quarter of respondents reported turning to an online infertility support community specifically for empathy and emotional support. Furthermore, almost a quarter of participants felt that the online support community helped to reduce their feelings of isolation and over a third felt that it had increased access to emotional support. For individuals at the earlier stages of their infertility journey, accessing an online support community also served as a useful venue in which they could engage in upward social comparison. Upward social comparison occurs when an individual compares their own situation with that of others who are better off than themselves (Stanton, 1992). For instance, in the current study it was found that women undergoing fertility treatment would often look to other members of the online community who

had been successful with the same treatment in order to gain a sense of hope and positivity. These findings confirm the results of the previous two studies and show that online infertility support communities serve as a valuable and important means through which people with infertility can fulfil their support needs. Furthermore, the results reveal that information and emotional support and finding people in similar situations emerged as the top three motives for accessing an online support community as well as the top three perceived advantages of usage. This would suggest that the majority of people in the study were able to gain what they were looking for from accessing the online support community.

7.4.2 What are the main perceived disadvantages of accessing an online infertility support community?

Despite this however, analysis of the survey responses show that a large proportion of participants reported experiencing at least one disadvantage to accessing an online support community. This appeared to be associated with lower overall satisfaction with the online community and an increased likelihood of participants describing their experience of online support communities as both negative and positive. The use of an inductive approach to content analysis of the open-ended survey questions allowed for the identification of the different types of disadvantages experienced as well as highlighting the issues that were of most importance to participants. Specifically, the findings reveal that the disadvantage that was experienced to the greatest degree was 'reading about negative experiences' within the online community. Previous research has shown that reading stories about others who are worse off can help members of health-related online communities feel more positive about their own situations (Hadert & Rodham, 2008; van Uden-Kraan et al., 2008c). Findings from this study in contrast indicate that some individuals may feel

an increased sense of anxiety and worry when confronted with negative experiences associated with infertility and its treatment. Conversely however, exposure to stories regarding the negative aspects of infertility and its treatment could in the long-term help prepare individuals for what treatment will involve and how it might impact on their life. Previous research has suggested that patients commencing infertility treatment often have unrealistically high expectations of treatment success (Beaurepaire et al., 1994), accessing an online support community may serve to temper these expectations, which could mean patients are better prepared and able to adjust quicker to treatment failure. A longitudinal prospective design is required to explore this issue in more detail.

Results of the present study highlight that 'reading about other peoples pregnancies' was seen as another significant disadvantage to online support communities for some women. This finding corroborates suggestions from the previous chapters, which demonstrate that women who had experienced treatment failure found it particularly difficult to hear about treatment success from other members of online support communities. Such findings are perhaps unsurprising given that infertile women often report feelings of intense jealousy and difficulties maintaining relationships with friends who have children (Miall, 1985; Verhaak et al., 2007). The fact that reading about other peoples pregnancies emerged as one of the most frequently cited disadvantages in the current study suggests that this may be an important area for intervention from health care professionals. For example, developing professionally facilitated online support resources that cater specifically for the needs of women who have experienced repeated negative treatment cycles might be beneficial for some women.

Although most participants valued the wealth of experiential knowledge that could be gained from an online community, a number of women expressed concerns about the accuracy of such information. This finding mirrors fears in the literature regarding the lack of control over the quality of medical information found online (Coulson & Knibb, 2007; Culver et al., 1997; Esquivel et al., 2006; Finn & Branch, 2000; Winzelberg, 1997). In the context of infertility, past studies have focussed solely on assessing the quality of informational content in infertility websites (Epstein et al., 2002; Huang et al., 2005; Marriott et al., 2008; Okamura et al., 2002); in contrast little research has been conducted to examine the exchange of information in peer-to-peer online infertility communities. The findings of the present study highlight the need for further research investigating the degree to which postings in online infertility communities contain information that could be considered misleading or potentially dangerous. This will not only allow health professionals to determine the extent of misinformation but might also help to alleviate the uncertainty experienced by those accessing online infertility support communities.

Results from this study further show that participants with a higher educational background were more likely to report experiencing disadvantages to online support communities. One explanation for this could be that individuals with a higher level of education may be more critical about the quality of information found online (Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003) and hence, report more disadvantages and concerns than other participants. As the digital divide continues to narrow, the Internet may become an equally important source of medical information for people from different socioeconomic and educational backgrounds (Kreps, 2005). It is thus increasingly imperative for researchers and health professionals to focus on how people of different

backgrounds assess the credibility and legitimacy of medical information found in online communities.

A notable finding of the study was that several participants felt the online community had in some way interfered with their daily life. For example, some respondents described the online community as 'addictive' and time consuming. Others spoke of how the online community created an 'obsession' to continuously compare their treatment progress and bodily symptoms with that of other members. These findings appear to offer support to the contention that online support communities have the potential to foster Internet addiction among some users (Finfgeld, 2000; White & Dorman, 2000; Young, 1997). Additional research is necessary to determine for whom and under what conditions online communities are addictive.

The results suggest that as with face-to-face social groups and other virtual environments (Cantrell & Conte, 2008; Preece et al., 2003; Rothaermel & Sugiyama, 2001) online infertility support communities can form tight knit friendship cliques. Whilst the development of such bonds can be extremely positive and have a therapeutic effect on community members (Finn & Lavitt, 1994), results of this study highlight that some individuals felt intimidated and unable to get involved in conversations by what was perceived as the 'cliquey' nature of interaction in the online communities. Community moderators are well placed to help newcomers break through membership cliques to begin actively contributing to the group. For instance, moderators could encourage members to interact with one another by introducing newcomers to the online community and inviting them to take part in discussions (Preece et al., 2003). Future research may wish to examine interaction in online support communities to determine

the specific strategies that newcomers use to break into membership cliques.

Interestingly, our results indicate that disadvantages associated with the unique characteristics of the Internet as a support medium were mentioned less often. For instance only five participants mentioned the lack of physical proximity between members as a disadvantage and only two participants cited privacy concerns and not receiving a reply as disadvantages. These results are consistent with the findings of van Uden-Kraan et al. (2008c) who found that most questions posted to online communities for breast cancer, arthritis and fibromyalgia patients received a response within a reasonable period of time. It might therefore be that those participants who regularly access online support communities have developed strategies to manage limitations inherent to the Internet. For example, employing emoticons to compensate for the lack of non-verbal cues online or searching through message archives to find answers to frequently asked questions (Braithwaite et al., 1999; Soroka et al., 2003; van Uden-Kraan et al., 2008a).

Another significant concern mentioned in the literature is the potential for Internet users to engage in 'flaming' i.e. aggressive or hostile interaction. Past studies examining the content of messages posted to online support communities, including the analysis of the online infertility support community presented in chapter six, have found very few instances of flaming (Finn, 1999; Perron, 2002; van Uden-Kraan et al., 2008a). However, it is acknowledged that these studies might have overlooked messages which were not explicitly abusive or humiliating but nonetheless caused offense to members. Results of this study reveal that a number of participants had witnessed hostile behaviour such as bullying and

patronising remarks, within the online support communities. This suggests that research investigating hostile behaviour online should seek to interview participants directly rather than rely solely on message archives.

7.4.3 Are there any differences in the use and experience of online support communities according to diagnosis of infertility?

Past studies have indicated that people with unexplained or a gender-specific diagnosis of infertility may experience greater psychological distress resulting from infertility when compared to other patients (Greil, 1997). It could therefore be hypothesised that people with certain diagnoses may have a greater need for information and psychosocial support and will therefore be more likely to access and benefit from online infertility support communities. The results of the current study however reveal no significant differences in the use and experience of online infertility support communities between people with different types of infertility. The online support communities were used by a combination of people with male infertility, female infertility, unexplained infertility and male and female infertility. The breakdown of participants in each of the diagnostic groups was largely reflective of statistics pertaining to the broad causes of infertility in the UK published by the Human Fertilisation and Embryology Authority (HFEA, 2007). Members in all four groups reported accessing the online communities for similar reasons and gaining similar benefits from participation. Thus it appears that online infertility support communities are able to successfully meet the support needs of people experiencing different types of infertility issues. One explanation for this could lie in the fact that the participants in this study were predominantly female. Several studies have shown that women appear to experience greater stress from a diagnosis of male factor infertility than men do from a diagnosis of female factor infertility (Connolly et al., 1992; Drosdzol &

Skrzypulec, 2009; Lykeridou et al., 2009; Mikulincer et al., 1998). Thus it might be that women coping with infertility experience a greater need for support and are therefore more motivated to access an online support community and derive similar benefits from finding people in similar situations regardless of their infertility diagnosis.

7.4.4 How does use and experience of online infertility support communities relate to psychosocial factors?

The present study found that scores on the Fertility Problem Inventory and Marital Satisfaction scale were significantly correlated with the length of time the respondents had been using the online support communities. Although, this was a weak correlation it nonetheless suggests that people who have used an online infertility support community for longer have higher perceived infertility-related stress and lower levels of marital satisfaction. Results from correlational analysis reveal a perfect positive relationship between length of membership and time since diagnosis (Spearman's Rho = 1.00; p<.05). Thus, it might be that members who have been accessing the community for longer have experienced more negative treatment cycles. As discussed in the introduction to the thesis, several studies show that unsuccessful treatment is associated with more negative emotions in patients (Verhaak et al., 2007). Consequently, it is plausible that people who have been using online infertility support communities for longer are feeling more distressed by their infertility and experiencing more marital problems due to treatment failure.

Analysis of the qualitative data presented in chapter five indicates that women who have been using online infertility support communities for longer appear to experience more negative emotions from accessing online

infertility support communities because they are confronted with the treatment successes of other women, including those individuals who may have commenced treatment at the same time as them. Whether this leads to higher perceived infertility-related stress scores for women who have been using online communities for longer is unclear. As with any cross-sectional design, there remains a question of cause and effect. Consequently, randomised controlled trials and prospective longitudinal studies are needed to further examine this issue.

The results of the analyses also reveal that people who visited the online support community more than once a day and spent longer in the online support community had significantly higher scores on the need for parenthood subscale of the Fertility Problem Inventory. This was not an unexpected finding as people who perceive parenthood as their primary or essential life goal are likely to experience greater distress from infertility and will be more absorbed in seeking information to help them conceive. Hence, these individuals may turn to the online support community more often and for longer durations when compared to people who have other life goals in addition to parenthood.

Interestingly, no associations were found between the frequency / duration of online support usage and scores on measures of loneliness and social support. This pattern of results contradicts suggestions from past authors who argue that higher levels of Internet usage will lead to increased loneliness and social isolation among users (Kraut et al., 1998). However, the results reveal a weak correlation between the number of hours spent in an online infertility support community and levels of marital satisfaction. Thus, it appears that although people who spend longer in online support communities do not have lower levels of perceived social support or

increased loneliness they may be less satisfied with their marital relationships. This differs somewhat from the themes identified in the qualitative study, which imply that some people feel accessing an online support community had resulted in improvements to their relationship with their partner. One possibility could be that people who are spending more time talking about infertility in an online support community are spending less time communicating with their partner and thus have more negative perceptions of their relationship. However, in the absence of baseline measures of marital satisfaction it is difficult to determine causality. Consequently, this is another area that merits further investigation using a randomised controlled trial or longitudinal design. In addition, future research may wish to examine the perceptions and well-being of the male partner to gain a more complete picture of the impact online infertility support communities have on marital relationships.

The current study indicates that the number of messages posted to an online infertility support community was not significantly related to psychosocial outcomes. This is an interesting finding as past research suggests that people who post a higher number of messages have better psychological well-being when compared to people who post fewer messages (Barak & Dolev-Cohen, 2006; Cummings et al., 2002; Rodgers & Chen, 2005). No evidence was found to support this assertion in the current study. In fact the results suggest that participants derived similar benefits from online infertility support communities regardless of posting frequency. This issue is discussed in more detail under the following section (7.4.5.)

An important finding from the current study is that the overall experience of accessing an online support community was found to be a key factor

influencing psychosocial variables. People who stated that their overall experience was positive had significantly higher levels of perceived social support and significantly lower levels of loneliness and perceived infertility-related stress than people who had experienced negative aspects to an online support community. There was also a significant association between levels of marital satisfaction and online experiences, with people who stated that they had negative online experiences scoring significantly lower on marital satisfaction when compared to people with positive or positive and negative experiences. These findings are of significance as they suggest that positive online experiences can also have a positive impact on psychosocial factors. Conversely, experiencing negative aspects to an online support community appear to be related to poorer psychosocial well-being. This suggests that it is important for moderators and other professionals involved in supporting people with infertility to make efforts to reduce the number of disadvantages experienced by people accessing online infertility support communities. As discussed above, the findings of this study point to a number of areas in which this could be done.

In the current study, the majority of participants reported their online experiences as either positive or positive and negative. Comparatively, very few participants described their experiences as completely negative. It is likely that individual's who do not perceive any positive aspects to an online infertility support community will drop-out of the community relatively quickly. Given the findings described above, this study suggests that it may be important for future research to explore why people drop-out of online infertility support communities and whether they have experienced any harm as a result of accessing the online support community.

7.4.5 Are there any differences between 'lurkers' and posters?

Interestingly, when comparing the response patterns of 'lurkers' and posters a number of striking similarities were identified. Most notably, in their motives for accessing online infertility support communities and the perceived advantages and disadvantages of use. Furthermore, in contrast to the results of van Uden-Kraan et al. (2008b) the study found no differences between the demographic and health profiles of 'lurkers' and posters and the time that they had been active in an online infertility support community. These findings are of interest, since past research has suggested that there might be a relationship between lurking behaviour and age and length of membership (Preece et al., 2004; van Uden-Kraan et al., 2008b). For example, Preece et al. (2004) found that lurking was particularly prevalent amongst new members, who wanted to familiarise themselves with the norms and dynamics of the online group before they contributed a posting; a phenomenon described as 'de-lurking' (Rafaeli, Ravid, & Soroka, 2004). This study found little evidence to support the occurrence of 'de-lurking' in online infertility support communities. This suggests that there might be other personality or social factors, which better indicate whether people with infertility choose to post a message to an online support community.

One area, in which 'lurkers' and posters did differ was in the amount of time spent in online infertility support communities. Although both posters and 'lurkers' regularly used an online support community; posters reported accessing the community more regularly compared to 'lurkers' and spent a considerably longer period of time in the online support community than 'lurkers'. These results are not surprising, as individuals who post messages are likely to require longer and more frequent visits to the online

community in order to type their messages and formulate replies. They are also likely to be more engaged in reading and following other member's social exchanges within the online community (Butler, Sproull, Kiesler, & Kraut, 2002).

For both 'lurkers' and posters the two main reasons for accessing an online infertility support community were to find information and guidance and people in similar situations. A key difference between 'lurkers' and posters was found in their attitudes towards empathy and emotional support. Results revealed that significantly fewer 'lurkers' than posters reported accessing an online support community to find empathy and emotional support. One explanation for this could be that 'lurkers' may already have access to a source of emotional support and are therefore able to satisfy their support needs with simply reading messages from people in similar situations (Blumler & Katz, 1974). There may also be some underlying personality and social factors which influence the types of support 'lurkers' prefer. For example, people who value empathic communication and support are likely to be more invested in providing social content to the group and managing social interactions (Butler et al., 2002). Cutrona and Russell (1990) argue that the perceived controllability of a stressful life event can also influence the types of support that individuals prefer. They assert that people are more likely to perceive emotional support as helpful when they are experiencing distressing events, which they feel are out of their control. In contrast, informational support is thought to be most beneficial when the individual feels that they can use this information to control their situation. Further research is needed to examine in more depth the differences in attitudes to stress and coping between 'lurkers' and posters.

The results also indicate that both 'lurkers' and posters gained a range of benefits from accessing an online infertility support community, namely informational support and the realisation that they were not alone in the problems they were experiencing. These results offer support for Walther and Boyd's (2002) argument that individuals lurking in health-related online support communities will derive similar benefits to that of active participants. They contend that since patients can obtain information, support and validation of their feelings of stigma through reading other member's messages and without having to contribute anything themselves, lurking may be as beneficial as active participation. Indeed, a significant number of 'lurkers' in this study reported that simply reading about other people's experiences had benefited them in some way.

One advantage that 'lurkers' did not experience to the same degree as posters was empathy and emotional support. This is perhaps unsurprising given that the 'lurkers' in this study were less concerned with finding emotional support and empathic communication from an online support community when compared to posters. Although, exposure to online discussions appeared to offer an informational benefit to 'lurkers', it is probable that simply reading messages was not sufficient to allow for 'lurkers' to feel emotionally supported (Bane, Haymaker, & Zinchuk, 2005; Butler et al., 2002). Those individuals looking for emotional support should therefore be encouraged to establish contact with other members of online support communities.

This study also provided an insight into the psychosocial characteristics of 'lurkers' in comparison to posters. Results indicate that 'lurkers' do not have a poorer psychosocial profile in the areas of loneliness, perceived social support, infertility-related stress, and marital satisfaction compared

to posters. These results differ from those of van Uden-Kraan et al. (2008b) who found 'lurkers' experienced poorer social and mental well-being, thus suggesting that posting may improve psychosocial well-being. From our results it would appear that individuals lurking in online infertility support communities can derive similar psychosocial benefits to that of active participants. However, due to the cross-sectional nature of these studies it is difficult to draw robust conclusions from these results alone. Further longitudinal research is needed to determine causality.

Interestingly, this study found that 'lurkers' were not any more likely to report disadvantages to online infertility support communities than posters. This suggests that experiencing disadvantages to an online support community is not associated with lurking behaviour. Lurkers did however mention concerns about the accuracy of informational support more often than posters. One explanation for this could be that since 'lurkers' are not personally involved in group interactions they can be more objective when appraising information. Additional research is therefore necessary to determine the strategies that both 'lurkers' and posters use to assess the quality of information exchanged within an online support community.

In line with findings from research examining other types of online communities, the findings reveal that 'lurkers' were significantly less satisfied with online infertility support communities compared to posters (Nonnecke et al., 2006; Preece et al., 2004; van Uden-Kraan et al., 2008b). This suggests that although 'lurkers' can derive similar benefits from simply reading messages; they are likely to gain less satisfaction from their online experiences. Okleshen and Grossbart (1998) suggest that this may be due to the fact that individuals who do not actively take part in online discussions will often feel like distant outsiders who are simply

observing a separate group of people interacting. As a result these individuals will be less positive about the community as a whole. Another explanation could be that online infertility support community simply do not meet the support needs of 'lurkers'. Indeed the previous chapter has shown that much of the communication in the online infertility community was focussed on empathic communication; these results however indicate that 'lurkers' appear to prefer informational support over emotional support. This discrepancy may account for why individuals who lurk spend less time online and are not as satisfied with the online support community. However, further research is required to determine whether dissatisfaction with online communities is in fact a cause or outcome of lurking.

7.4.6 Strengths and limitations of this study

A key strength of this study is the relatively large sample size obtained. However, as with most studies of this nature it is impossible to calculate a response rate due to the difficulties of establishing exactly how many people accessed the online support communities during the period of study. This makes it difficult to assess the risk of sampling bias (De Vaus, 2002). Consequently, the extent to which the people who chose to participate in this study are representative of other people accessing online infertility support communities remains unclear. Nonetheless, the results show that the study was able to recruit participants with both positive and negative experiences and participants with different levels of activity, including a small number of 'lurkers'. Thus, the study does not appear to be biased to a specific subgroup of people accessing online infertility support communities, such as those individuals with more positive online

experiences or who were most active in the online communities. In addition, the demographic and infertility-related characteristics of the sample were similar to those found in the previous two studies and were reflective of the wider literature on online support users (see discussion in chapter six).

Although, this study provided a unique insight into associations between the use and experience of online support communities and psychological and demographic variables; due to its cross-sectional design it is difficult to determine cause-effect relationships. Consequently in order to allow for more robust conclusions regarding the effects of accessing an online infertility support community randomised controlled trials or prospective longitudinal studies are needed. This will also allow researchers a method for determining the characteristics of people who drop out of online infertility support communities and the reasons why people discontinue participation.

7.4.7 Conclusions

The results of this exploratory survey corroborate findings from the previous two studies within a larger sample size. The study also expands on earlier findings by providing a wealth of descriptive information about the use of experience of online support communities and examining associations between certain variables. In particular, this study highlights that negative experiences in online infertility support communities maybe associated with poorer psychosocial well-being. In addition, the study provides a unique insight into the experiences of 'lurkers' within online infertility support communities and suggests that reading messages posted to online infertility support communities may be as beneficial as interacting

with the community. The results also highlight a number of important areas in which health professionals and community moderators could intervene to better support and improve the online experiences of patients experiencing infertility.

However, as this was a cross-sectional study it is important to be cautious when interpreting data as it is difficult to infer causality. Nevertheless, the results of this exploratory survey in combination with the previous two studies provide an important first step in understanding the phenomenon of online infertility support communities, which to date has been a largely unexplored topic. The results also identify significant issues pertaining to online infertility support communities that need to be investigated further in future research. Moreover, the results highlight that use of online infertility support communities can provide an extremely valuable source of support which may help to improve psychosocial well-being among people with infertility. The next chapter will discuss the findings of this thesis in more depth and further consider the practical and theoretical implications of the studies as well as directions for future research.

8 Chapter Eight: Overall Discussion

CHAPTER SUMMARY

The final chapter draws together the results and conclusions from the three empirical studies and examines these findings in the context of wider literature and theory of infertility and online support. It begins by summarising the main findings of the thesis and then discusses the practical implications of these findings for health care professionals and others involved in developing and running online support communities. Future directions in development of research in the area of online support and infertility are also discussed. The chapter concludes with a consideration of some of the methodological issues and challenges encountered in this thesis.

The overall purpose of this thesis was to explore how people with infertility use and experience online support communities. The studies presented in chapters five, six and seven represent the first comprehensive investigation into this novel medium for peer support and communication among people affected by infertility. A key strength of these studies is the emergence of in depth data regarding salient issues surrounding the use of online infertility support communities, from the perspective of those who access and participate in them. Taken together the results from each stage of the investigation offer a detailed and unique insight into the phenomenon of online infertility support communities and importantly how these online communities can meet the support needs of people experiencing infertility. In this chapter, the main findings from the thesis will be discussed in relation to the original research questions and where appropriate in the context of the wider literature on infertility and online support. Attention is then given to the implications of these findings for future research and practice in the area of online support and infertility. This is followed by a consideration of some of the issues and challenges associated with the innovative data collection methods utilised for the thesis.

8.1 Summary of main findings

8.1.1 What do we know about people's motives for accessing online infertility support communities?

The literature reviewed in Chapter two of this thesis highlights the potential negative psychosocial consequences associated with infertility and its treatment and the difficulties people may experience in accessing adequate social support to help them cope with these challenges. Literature discussed in Chapter three suggests that online support communities may present a novel and beneficial medium through which people experiencing

infertility can fulfil their support needs. However, while several authors have discussed the potential advantages of this novel medium for sensitive health issues like infertility; there is limited understanding of the specific motivations that lead people to access an online infertility support community. Findings from the current thesis serve to redress these gaps in the literature by providing valuable insights into the reasons why people choose to access online infertility support communities and what they hope to gain from participation.

In particular, results reveal that the desire to find similar others seemed to be a major motivation for people turning to the Internet. Consistent with findings from the infertility literature, the analysis of qualitative data and communication in bulletin board messages indicated that many of the women appeared to have experienced changes to their interpersonal relationships as a result of infertility (Amir et al., 1999; Cousineau & Domar, 2007; Wilkes et al., 2009). There was also a belief that only people who had firsthand experience of infertility could fully understand and appreciate their situation. The results of the three studies further reveal that many women appeared to express a strong need to communicate and connect with other women affected by infertility. In the absence of similar others within their existing social networks, the Internet was seen as the only means through which people could access a community of infertility sufferers and thereby alleviate the sense of isolation they were experiencing. This was particularly evident in study three which found that for 53% of the participants a significant reason for turning to an online support community had been the desire to find people in similar situations. This suggests that the Internet and in particular online communities can offer a unique and invaluable resource for people who are feeling isolated

or lonely because of their infertility. This issue is discussed further in section 8.1.5.

The desire to find people in similar situations also appeared to be motivated by a need to obtain experiential knowledge concerning infertility. Strikingly, study 3 found that 60% of participants reported turning to an online community in the hope of accessing information and advice to help them cope with infertility issues. While previous authors have raised concerns over the possibility that patients may use health-related online communities as a substitute source of medical information (Hoch et al., 1998; Sharf, 1997), results from the current thesis suggest that for people with infertility, online support communities were primarily seen as a unique source of experiential information, which served to supplement rather than substitute information from health care providers. Indeed, as shown in study 2, messages containing information requests were predominantly concerned with seeking an 'insiders' perspective on treatments for infertility and how these treatments would affect individuals physically and emotionally; rather than factual medical information.

These findings suggest that the weak tie network theory (Granovetter, 1982) might be relevant in contextualizing people's motives for accessing online infertility support communities. Weak ties refer to those relationships which exist outside the dynamics of close relationships with family and friends. Weak ties are considered valuable for providing access to diverse sources of information and advice. Furthermore, since these relationships have a detached connection with the individual's everyday life, they are thought to be more objective when offering support and encourage the disclosure of taboo or sensitive issues (Adelman et al., 1987). Walther and Boyd (2002) argue that due to its diverse coverage

and perceived anonymity and privacy, the Internet has the potential to not only expand but also encourage people to form supportive weak ties. The results of the current thesis provide support for this contention. While, traditionally infertility patients were limited to service providers and support associations for access to weak ties, this research demonstrates how the Internet has opened up new opportunities for individual's to independently form weak ties through the medium of online support communities. As evidenced in this thesis, many people felt that the Internet was the only avenue through which they could obtain the diverse information, support and understanding that they were seeking. Furthermore, as hypothesised by Walther and Boyd (2002) there was evidence to indicate that the unique conditions of the Internet that foster perceptions of anonymity and privacy may also facilitate the discussion of sensitive or taboo topics. Indeed, an important theme that emerged from the initial stage of the thesis concerned how the anonymity conferred by online support communities helped to remove some of the complications associated with face-to-face communication. Thus enabling people to express their feelings more fully and without fear of embarrassment or stigmatisation.

However, although this unique characteristic of the Internet was instrumental in allowing people to openly share personal situations or emotions, anonymity was not mentioned as a specific motivation for seeking out online support over face-to-face support. It appears that for the women who took part in this research, the need to simply connect with other women affected by infertility and learn from their experiences was paramount. This finding is surprising since a previous analysis of an infertility online bulletin board for men revealed that the perception of anonymity appeared to be central to their online experiences (Malik &

Coulson, 2008). One explanation may lie in the gender difference between the studies; as it is established that men are more likely to feel uncomfortable discussing their infertility and communicating anxieties to strangers when compared to women, consequently the potential anonymity of the Internet may be more appealing for men than women (Hjellmstedt et al., 1999; Slade et al., 2007).

8.1.2 What do we know about the experiences of people accessing online infertility support communities?

Alongside the motivations for accessing online support communities, this thesis has sought to explore how people affected by infertility experience online support communities as an alternative source of support and self-help. The evidence obtained from the three studies indicates that for the vast majority of participants the experience of accessing online infertility support communities was an extremely positive one, which offered a range of benefits to the individual. One aspect that came out very strongly was the sense of camaraderie among participants and the strong socio-emotional communication characterising their online interactions. Women in study 1 reported that through online support communities they were able to access valuable emotional support and positive encouragement to help them cope with infertility. This appeared to be of particular value during periods of uncertainty and grief following a negative treatment outcome or the loss of a pregnancy after initial success.

Support for these findings is also shown in study 2 which revealed that the exchange of empathy and emotional support was an important element of communication in a large online infertility support community. An outpouring of emotional support could be seen in response to messages describing distressing events such as treatment failure or pregnancy loss.

Empathy also appeared to play a significant role in interactions and was often used to welcome new members, offer solidarity and convey care and compassion. This sense of connection and supportive interaction appeared to facilitate the development of strong bonds and friendship among members of the community, with many individuals posting messages to simply 'check in' with other community members and see how they were getting on. These findings resonate with an earlier analysis of an online bulletin board for assisted reproduction, which found that the majority of users posted messages relating to psychosocial topics such as developing relationships and supportive interactions rather than medical information seeking (Wingert et al., 2005).

Study 3 suggested that for some women emotional support was perceived as an unexpected benefit of accessing an online infertility support community. Some women stated that while their initial reason for accessing the community had been for informational purposes, they eventually found that the support and understanding of fellow members was equally beneficial. This implies that not all individuals realize the availability and value of the emotional support they can obtain via the Internet. Clinicians can play an instrumental role in making people aware of the availability of this unique source of emotional support.

These findings also have significance for theoretical perspectives of computer-mediated communication. The strong presence of socio-emotional communication identified in this thesis contrasts sharply with the 'cues filtered out' models of computer-mediated communication, which predict that the loss of visual cues in the online environment will have negative repercussions for interpersonal dynamics (Kiesler et al., 1984; Short et al., 1972). Instead the findings mirror the social identity

deindividuation (SIDE) model of computer-mediated communication. According to the SIDE theory in the absence of visual cues and prior knowledge of members, the shared social category between participants will take on greater significance and lead to over attribution of participant similarity. This in turn can heighten the sense of connection that online members feel with one another and may consequently elicit higher levels of socio-emotional and empathic communication (Walther, 1996). The findings also offer some support for the Hyperpersonal model of computer-mediated communication, which predicts that people communicating via the Internet can achieve greater intimacy and more socially desirable communication over time than in parallel face-to-face discussions. The studies presented in this thesis certainly demonstrate that online communities can be an effective medium through which people with infertility can engage in supportive communication and connect with fellow sufferers; however the extent to which this surpasses the types of interactions that occur in face-to-face support networks requires further empirical examination.

Also very evident from this thesis was the important role of self-disclosure in the online experiences of people affected by infertility. Analysis of bulletin board messages indicated that a large of proportion of messages contained some form of self-disclosure relating to the emotions and experiences surrounding infertility. Qualitative data elicited directly from people accessing online infertility support communities further revealed that for many individuals online support communities were perceived as a supportive and non-judgmental environment in which people could offload their personal experiences with a sense of safety. Thus it appears that the supportive culture of online support communities coupled with the

anonymity of the Internet served to encourage people with infertility to open up about their experiences and vent their anxieties or frustrations.

The benefits of engaging in self-disclosure in online infertility support communities can be multi-faceted; for instance sharing personal experiences is instrumental in providing and eliciting support among online members (Galegher et al., 1998). Venting anxieties can also have a cathartic effect allowing members to make sense of their infertility experiences (Pennebaker & Beall, 1986; Sheese, Brown, Graziano, & Butler, 2004; Lieberman & Goldstein, 2006; Yalom, 1995). In addition, the availability of detailed shared experiences through message archives can help to meet the support needs of 'lurkers', many of whom reported that simply reading about the experiences of other people affected by infertility had been beneficial to them. Study 1 also demonstrated how reading about other people's experiences of infertility assisted newcomers in realizing that their feelings and experiences were 'normal', which in some cases served to reduce negative feelings such as guilt and abnormality.

As such, this thesis shows how the process of self-disclosure can benefit both the individual and the online community. The implications of these findings for future research and practice are discussed further in sections 8.2. and 8.3.

Despite the positive experiences described by many individuals, an important finding emerging from the current thesis was the potential for negative consequences from accessing an online infertility support community. Both studies 1 and 2 revealed that a small number of people mentioned negative aspects to their online experiences. This was further substantiated in study 3 which demonstrated that over half of the

respondents had experienced at least one disadvantage to accessing an online support community. These disadvantages appeared to impact negatively on the participants' overall perception of their online experience, with 26% (n=77) of respondents describing their overall experience within an online infertility support community as positive and negative and 1.4% (n=4) describing it as wholly negative. Consequently, this thesis suggests that while accessing online infertility support communities can be beneficial for the vast majority of people, as speculated in the literature, there are a number of potential disadvantages to this medium which may have a negative effect on people's experiences of accessing online support.

These findings are of particular significance, as results from study 3 further indicate that negative online experiences may be associated with poorer psychosocial well-being. Experiencing disadvantages to online support communities may therefore have the potential to exacerbate psychosocial problems among people affected by infertility. It is also likely that the studies presented in this thesis underestimate some of the possible negative consequences of online support communities; since those people who have had wholly negative experiences are likely to have left the community early on. Understanding the types of disadvantages experienced by people who access online infertility communities and the conditions in which these disadvantages occur can thus extend our knowledge about the impact of online communities on patient well-being. It can also provide important insights into the areas in which service providers and site moderators could intervene to better support or improve the online experiences of people affected by infertility. These issues are discussed further in sections 8.1.3. and 8.3.

8.1.3 What do we know about the negative aspects to online infertility support communities?

As outlined above understanding the potential negative aspects to online infertility support communities is a vital area of study, which has important implications for improving the support available to people affected by fertility problems. Several authors have discussed the possible disadvantages associated with online communication and support seeking, however to date there is minimal empirical evidence, particularly in the context of infertility, to support these assertions. The current thesis advances our knowledge on this topic by providing a novel insight into the range of disadvantages experienced by people who access online communities for infertility issues. Evidence from the thesis reveals that while some of these disadvantages reflect fears commonly cited in the literature, there are also disadvantages unique to the experience of infertility (see Chapter seven section 7.4.3. for an in depth discussion).

A key concern expressed by several individuals was related to the abundance of stories about the negative aspects of infertility and its treatment within the online support communities. Being confronted with the potential problems and complications associated with reproductive treatment and the reality of treatment failure, appeared to evoke a range of distressing emotions for some people. These included feelings of sadness, negativity about their own treatment outcome, and a heightened sense of anxiety and worry. This finding suggests that exposure to negative stories in online support communities has the potential to increase psychological distress among people embarking on or undergoing infertility treatment.

Conversely, however the results reveal that positive stories can also be distressing for people at certain stages in their infertility journey. All three studies presented in this thesis show that woman who had experienced treatment failure and were facing permanent involuntary childlessness, found it difficult to hear about treatment success from other members of the online community. Reading about other people's pregnancies resulted in feelings of immense grief, anger, and jealousy and appeared to heighten infertility-related stress. Thus, it appears that while women may initially benefit from accessing a network of similar others, there is a risk that those women who do not fall pregnant will become increasingly depressed and isolated overtime, particularly if fellow members have become pregnant while they are still pursuing treatment or coming to terms with permanent childlessness.

Although people are likely to experience similar emotions in face-to-face peer support networks for infertility, there is some evidence to imply that the unique characteristics of the Internet may exacerbate these emotions for women seeking support through online communities. In a face-to-face support group, members can stop participating when they feel they are no longer benefiting from the group and thus remove themselves from the distressing stimuli. However, the accessibility and anonymity of online support communities means that members can continue to 'lurk' within the community long after they have stopped actively participating (Preece et al., 2004). Indeed, several of the participants in the studies described how they continued to visit the online community despite finding it too distressing to post messages. Some participants also described an 'obsession' with visiting the online support community and the urge to continuously compare their progress with other members.

van Uden-kraan et al. (2008c) speculate that since messages posted to online support communities are often organised under different disease stages/topics and contain subject headings to give an indication of the content of the posting; individual's can be highly selective in what they choose to read. Therefore, avoiding exposure to stories which they might find distressing. Results from this thesis, however reveal that these features of an online support community do not always protect people from exposure to stories which they find distressing. On the contrary some individuals may specifically seek out social comparisons that increase negative emotions. For instance, people commencing infertility treatments often have a desire to understand a particular treatment and its efficacy and will therefore look to other people's experiences. Given that the success rates for many reproductive treatments are relatively low, it is inevitable that these individuals will be confronted with a number of stories concerning negative treatment outcomes. Similarly, women who have been unsuccessful with treatment may have a desire to compare their own progress with that of other members. If they find that fellow members have become pregnant this may elicit feelings of jealousy and isolation from the online community. Future work should thus seek to examine the impact of reading positive or negative experiences in online support communities, across different stages of the infertility journey.

Another significant disadvantage to online support communities related to the accuracy and reliability of information obtained from this medium. A number of participants echoed concerns expressed in the literature, by describing the difficulties they experienced in assessing the veracity of informational support obtained online (Culver et al., 1997; Esquivel et al., 2006; Finn & Branch, 2000; Hoch et al., 1999; Winzelberg, 1997). These results can be seen as positive as they suggest that people are cautious

when interpreting information obtained from online infertility support communities and are not simply accepting everything they read at face value. However, as discussed in Chapter seven this thesis did not focus specifically on examining the accuracy of information in online infertility support communities or the strategies that people use to assess the credibility of this information. Consequently, without further research it is difficult to draw robust conclusions regarding the extent of misinformation in online infertility support communities or the number of people who accept/ act on this information.

Other concerns commonly expressed in the literature such as the risk of disinhibited communication (Walther, 1996), misinterpretation of messages (Finfgeld, 2000) or delayed feedback (Wright, 2002), were also identified in study 3. However, these disadvantages were mentioned to a lesser degree when compared to the issues described above. Additionally, as outlined previously, the analysis of messages in Chapter six revealed very few instances of negative or hostile communication. Thus, it appears that while such problems do occur in online infertility support communities they are less salient to the individual's online experience.

Wright and Bell (2003) argue that a negative aspect of weak ties in online communities is the difficulty of forming long-term relationships with people within the community. Evidence from this thesis in contrast, reveals that weak ties formed in online infertility support communities can in fact develop into stronger ties. Results from study 2 show that members used several strategies to build and maintain supportive relationships with one another, including finding ways of interacting outside of the online community and posting messages to check in with other members. The development of strong ties in online infertility support communities can

however create problems for new members, some of whom described online infertility support communities as 'cliquey' and reported difficulties getting involved in conversations. The formation of strong ties in online infertility support communities may also be dependent on the outcome of fertility treatment. The vast majority of people who access online infertility support communities are pursuing some form of treatment for infertility and can thus be described as in a 'not yet pregnant' state (Throsby, 2001). While some of these individuals will become pregnant and make the transition to parenthood, others will have to come to terms with permanent childlessness (Daniluk, 1997). Women who fail to become pregnant are at risk for developing depression and long-term emotional problems (Verhaak et al., 2005; Verhaak et al., 2007). These individuals also need to negotiate new life goals and identities for themselves (Lechner et al., 2007; Lee, Hui Choi, Chan, Chan, & NG, 2009). This thesis indicates that women making this transition will often feel alienated from the online community that previously supported them. Consequently, for this group of women the formation of long-term supportive relationships may be problematic.

The implications of these findings are considered further in section 8.3.

8.1.4 What do we know about the impact that accessing an online support community has on how individuals and couples cope with infertility?

Despite the disadvantages experienced by some individuals, for many people the use of an online infertility support community was associated with a number of psychosocial benefits which appeared to facilitate coping. There is a growing body of research to demonstrate that online support interventions can improve coping with various health conditions (Bass et

al., 1998; Brennan et al., 1991; Gustafson et al., 2008; Gustafson et al., 2005). This thesis adds to previous work by providing a unique insight into *how* naturally occurring online support communities can help people to cope with infertility.

As indicated by previous studies of online support seeking and health-related Internet use, this thesis has shown that people affected by infertility were empowered by the exchange of experiential knowledge, information and advice in online support communities (Buchanan & Coulson, 2007; Hoybye et al., 2005; Sharf, 1997). Unlike the information that could be accessed via fertility clinics and health care providers, online support communities opened up new opportunities for patients to understand exactly what it was like to undergo treatment from those who had first hand experience of infertility. In addition, the heterogeneity of experiences within online infertility support communities meant that people were able to access a wealth of information concerning alternative treatment options. Such knowledge appeared to empower people to take a more active role in overcoming their infertility. This approach is reflective of an active problem-focussed style of coping (Lazarus & Folkman, 1984). Active problem-focussed coping has been associated with better psychological adjustment to infertility and lowers levels of infertility-related stress, particularly for people commencing treatment (Berghuis & Stanton, 2002; Schmidt et al., 2005; Peterson, 2006; Peterson et al., 2006; Peterson et al., 2009). Indeed, this thesis shows that actively seeking out information in an online support community appeared to help people feel more in control of their situation. Furthermore, similar to participants in Cousineau et al's (2008) randomised control trial of an online infertility support intervention, participants reported feeling better informed and more confident about medical decision-making as a result of accessing an

online support community. Thus, it appears that online infertility support communities can not only help people to gain a greater sense of control over their situation but can also help them to develop more adaptive coping styles.

Support and advice from online support communities was considered particularly valuable in assisting coping during periods of uncertainty. Findings from study 2 reveal that specific requests for information and advice were considerably higher among those people who had just received a diagnosis or were about to commence fertility treatment. Informational requests were also high amongst people in the two weeks between ovulation and pregnancy testing; a time at which patients have very little contact with their fertility clinic (Tuil et al., 2009). For people at this stage of treatment, there appeared to a great deal of confusion and concern about how to interpret bodily changes and whether these changes were indicative of a pregnancy. Online infertility support communities offered an avenue through which people could vent their fears and anxieties and gain practical advice about whether their symptoms were 'normal'. This patterns of findings mirrors results from Tuil et al's (2009) piloting of an online personal health records system for infertility patients, they found that use of the communication features were highest at times when patients had little contact with the clinic. Thus, it appears that online support communities can serve as a valuable resource for assisting coping at times when support from other sources is less readily available.

Messages posted to online infertility support communities can also provide clinics with a valuable insight into the information needs of people at different stages of the infertility journey. Previous research suggests that many patients are dissatisfied with the amount of support provided by their

fertility clinic, particularly in relation to psychosocial issues and often express a desire for more written information about infertility and its treatment (Dancet et al., 2010; van Empel et al., 2010; Mourad et al., 2009; Souter et al., 1998). Examining communication in online communities can thus help clinicians to understand the types of information and support that patients require and allow them to tailor their information and support resources accordingly.

For people commencing infertility treatment, finding success stories within an online infertility support community was another beneficial aspect of seeking online support. The studies indicate that upward social comparison was a common strategy used by people pursuing treatment in order to make them feel more positive about their situation and gain reassurance that they were on the right track (Stanton, 1992). As such, online infertility support communities offered many people a sense of hope and encouragement and empowered them to continue in their pursuit of a pregnancy. However, as discussed in the previous section, when reading about other peoples experiences of infertility treatment, members were also confronted with a multitude of stories about negative treatment outcomes or the loss of a pregnancy following initial success, which served to temper their feelings of hope and positivity. Nonetheless, being made aware of the potential for treatment failure can help individuals to accept the possibility that they might be unsuccessful, which may improve coping and adjustment to a negative outcome (Edelmann et al., 1994)

Another notable finding that emerged from the thesis was the perceived positive impact that online infertility support communities can have on women's attitudes and approach towards their marital relationship during infertility. As discussed in Chapter five, an important theme identified in

the qualitative study related to how some women felt accessing an online infertility support community had improved their relationship with their partner. For many women, prior to accessing an online support community their partner had been their sole confidante and source of support for infertility; a role which can cause strain to the couples relationship (Mahlstedt, 1985). Through accessing an online support community, these women found an alternative venue in which they could vent their anxieties and frustrations and seek emotional support. This not only helped to lessen the strain on their partner who had previously been the only person with whom they could discuss their infertility concerns, but also appeared to help women feel more positive and calmer in their day-to-day life, particularly when communicating with their partner about infertility.

Literature reviewed in Chapter two highlights that men and women will often differ in their approach to coping with infertility, with women expressing a stronger desire to talk about their infertility compared to men (Buetal et al., 1999; Hjellmstedt et al., 1999; Slade et al., 2007). Differences in coping styles between partners are important as they have been shown to impact negatively on marital satisfaction and individual psychosocial well-being (Pasch et al., 2002; Peterson et al., 2003). Results from this thesis indicate that use of an online infertility support community may help to reduce some of the problems caused by different coping styles in a couple; with several women reporting that online communities helped them to understand and accept gender differences in coping with infertility. Thus it appears that online support communities can play an important role in helping people cope with the impact of infertility on their marital relationship (Edelmann et al., 1994; Peddie et al., 2005).

However, these findings were not fully supported by results from the quantitative stage of the thesis, which found that those people who had been members of an online community for longer and spent more time accessing online communities had significantly lower levels of marital satisfaction. Due to the cross-sectional nature of this study and the consequent difficulties in determining causality, there are a number of potential explanations when interpreting these findings. For instance, it may be that those individual's who have lower levels of marital satisfaction, receive little support from their partner and thus compensate for this by spending longer in an online support community. Conversely, there is also a risk that heavy usage of an online infertility support community may result in lower levels of marital satisfaction. Despite, the fact that many women felt accessing an online infertility support community had improved their relationships by providing them with an alternative source of support; there is evidence to suggest that high levels of Internet usage can lead to withdrawal from offline interactions (Epstein et al., 2002; Eysenbach, 2003). Consequently, spending a longer period of time in an online infertility support community may impact negatively on couple communication. Furthermore, as outlined in Chapter five, there is a possibility that men may feel increasingly isolated and helpless if they are no longer needed as the sole source of support for their partner, which could have repercussions for marital satisfaction. Understanding the exact nature of the impact online infertility support communities have on marital relationships is thus an important issue for future research.

8.1.5 What do we know about use of online support communities and the psychosocial well-being of people experiencing infertility?

LaCousiere (2001) predicts that use of a health-related online support community can influence the health and psychosocial well-being of patients. This assertion is supported by a growing body of anecdotal evidence, which suggests that online support communities are associated with a number of psychosocial benefits (see Chapter three). The current thesis presents the first in depth study exploring the possible effects of online support communities on the psychosocial well-being of people affected infertility. To achieve this the thesis employed a mixed-methods approach, using qualitative techniques to investigate the perceived effects of online support communities on the lives of participants and quantitative techniques to explore whether frequency of usage and experiences of online support seeking were associated with measurable psychosocial outcomes.

Qualitative data from the thesis indicates that online support communities were instrumental in reducing the sense of isolation that many individuals were experiencing as a consequence of infertility and in expanding their support network. The wealth of shared experience, empathy and emotional support that could be found in online infertility support communities played an important role in assisting people to realise that they were not alone in their experiences of infertility and there were others who were in a similar situation. In this way simply reading messages posted to an online infertility support community appeared to have a therapeutic benefit for participants and served to fill the void in their current support network. Additionally, as discussed in the previous section results indicated that

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accessing an online support community appeared to impact on feelings of empowerment and the dynamics of the marital relationship.

The quantitative data obtained from the final study builds on these findings by examining associations between online support usage and scores on measures of social support, loneliness, marital satisfaction, and infertility-related stress. An interesting finding to emerge from this study was the important role that online experiences appeared to play in the psychosocial well-being of participants. People who described their overall experience of online infertility support communities as completely positive scored significantly higher on measures of perceived emotional and informational support and significantly lower on measures of loneliness and infertility-related stress when compared to people who perceived negative aspects to their online experiences. These findings are of significance as they suggest that experiencing negative aspects to online infertility support communities can impact on the psychosocial well-being of participants accessing an online support community, influencing their perceptions of social support and feelings of isolation and infertility-related stress. Taken in conjunction with the qualitative data, it would appear that positive online experiences reduce feelings of loneliness and infertility-related stress, while increasing perceptions of social support, particularly emotional and informational support. In contrast, experiencing negative aspects to online communities such as being confronted with the negative aspects of treatment or seeing other members become pregnant, has the potential to increase feelings of loneliness and infertility-related stress and reduce perceptions of social support. This finding reinforces the importance of examining and understanding the potential negative aspects to online infertility support communities, so that strategies can be developed to improve online

experiences and reduce the potential for harm. It also raises concerns about the well-being of people who drop out of online infertility support communities; as those people who have had wholly negative online experiences are likely to have left the online community and therefore would not have been available to participate in the research. Further study is thus needed to determine why people drop out of online infertility support communities and whether these people experience any serious negative consequences as a result of accessing the online community.

The results from this study provide some support for LaCoursiere (2001)'s concept of linking. LaCoursiere's theory of online social support offers a comprehensive framework for organizing research into online support communities, within this framework linking is described as the final outcome of online social support and the point at which a 'conscious and/or unconscious process of relating and weaving emerging awareness to previously learned thoughts or information' occurs. The occurrence of linking is assessed through a synthesis of qualitative and quantitative outcomes. In this thesis, examination of the quantitative and qualitative data suggests that people who perceive their online experiences in a positive light (qualitative outcomes) also experience measurable changes in their levels of perceived social support, loneliness and infertility-related stress (quantitative outcomes). Thus, suggesting that for these individuals linking has successfully taken place. Conversely, those people who do not view their experiences within an online infertility support community in the same positive light are less likely to experience the same improvements in measurable psychosocial outcomes and may even experience an increased sense of isolation and infertility-related stress.

Previous studies exploring psychosocial well-being among patients accessing health-related online support communities have suggested associations between the frequency of usage / the number of messages posted and psychosocial benefits (Barak & Dolev-Cohen, 2006; Houston et al., 2002; Mo & Coulson, 2010; Rodger & Chen, 2005). Results from this thesis however found little evidence to indicate that activity level influenced psychosocial outcomes. Importantly, the results reveal that people who actively participated in online infertility support communities (i.e. posters) did not significantly differ on any of the psychosocial measures from people who did not post messages (i.e. 'lurkers'). Furthermore, both 'lurkers' and posters reported deriving similar benefits from accessing an online infertility support community. These findings are notable as past authors have speculated that 'lurkers' are likely to gain fewer psychosocial benefits from accessing online support communities when compared to posters (Okleshen & Grossbart, 1998; Nonnecke et al., 2006). In contrast, this thesis shows that people affected by infertility can benefit from online support communities regardless of whether or not they choose to post a message.

The uses and gratification perspective may be relevant for interpreting this finding. According to the theory people are motivated to seek out mass communication in order to fulfil a specific need or goal (Blumler & Katz, 1974). From this perspective, the impact of online support communities on individual well-being will be determined by their effectiveness in gratifying these needs. When considering online infertility support communities, this thesis indicates that the desire to find people in similar situations was a central motive for 'lurkers' to seek out online support. Since simply reading messages posted by other members allowed these individuals to find a

network of similar others and alleviate their feelings of isolation, it appears that online support communities were successful in 'gratifying' their motives for accessing the online community without them having to post messages. In contrast, while posters were motivated by a similar need to find others experiencing infertility, they also expressed a desire to seek emotional support. Consequently, in order to elicit the support they required these individuals may have a stronger need to communicate with the online community by posting messages and sharing their experiences when compared to 'lurkers'.

Having summarised the main findings of this thesis in relation to relevant research and theory in the field, the remainder of this chapter will consider the implications of these findings for future research and practice. This will be followed by a brief discussion of some methodological issues and challenges encountered in this study of online support communities.

8.2 Directions for future research

As outlined in the above sections, findings from the studies provide important and novel insights into the phenomenon of online infertility support communities, whilst also raising several interesting issues for further investigation. Some of these issues have been flagged in the discussion sections within each of the empirical chapters. This section aims to draw on these findings to highlight key directions for future research.

One particularly important finding emerging from the thesis is the suggestion of an association between the use of online infertility support communities and psychosocial outcomes. The cross-sectional design of the studies however makes it difficult to determine the direction of causality.

Follow-up studies are therefore needed to consolidate and extend these findings further. Ideally, such research should involve randomised controlled trials (RCT's) to empirically evaluate the effects of online peer-to-peer support interventions and identify the exact conditions under which online peer support is beneficial to people with infertility. However, while such studies can provide robust evidence regarding the effectiveness of a given intervention, the extent to which an RCT can successfully recreate some of the unique and dynamic features of 'natural' online support communities (i.e. the strong interpersonal dynamics evidenced in this study, perceptions of anonymity and control and the open access format of an online community) may be limited (Barak, Grohol, & Pector, 2004). This has important implications for the external validity of an RCT of online infertility support communities.

An alternative approach is the use of a longitudinal prospective design to examine the impact of accessing 'natural' online infertility support communities. Longitudinal designs allow for stronger conclusions concerning possible causal relationships when compared to cross-sectional studies. They can also provide insights into the impact of accessing online support communities over a longer period of time. This is particularly important in the context of infertility, as the studies demonstrate that people's attitudes towards online support communities can change over time, with some individuals feeling increasingly depressed and isolated if fellow group members have moved onto pregnancy. Further well-designed quantitative studies are thus needed to extend these findings and determine the extent to which online support communities benefit people at different stages of the infertility journey. Conducting longitudinal research of natural online support communities may however present a number of challenges for the researcher. For instance, difficulties may be

incurred in recruiting and retaining a large enough sample of participants with no prior experience of online infertility support communities. Nonetheless, the method has successfully been employed in a previous investigation of 'natural' online breast cancer support communities by Lieberman (2007), who managed to recruit and follow-up (over 6-months) a sample of 77 new members through bulletin board postings and emails. This suggests that longitudinal study of online support communities is feasible, albeit challenging.

When conducting longitudinal studies of online infertility support communities there is a need to consider the possible confounding effects of treatment stage. For example, are changes in psychosocial well-being a result of accessing an online support community or due to the success / failure of the individual's fertility treatment? Comparison with controls of infertility patients who have not used an online infertility support community may help to shed light on this issue. It would also be valuable to compare online support community users with individuals who access face-to-face infertility support groups, in order to assess whether online support is equal to or more beneficial than face-to-face support.

The results of this thesis also point to the importance of examining the reasons why people drop out of online support communities and whether these individuals experience any harm as a consequence of accessing an online support community. Longitudinal and RCT studies offer an ideal design for identifying members who stop participating in online infertility support communities. Efforts should therefore be made to encourage both current and past members to complete follow-up assessments and share their experiences of online support seeking. There may however be occasions when members simply do not respond to follow-up emails. In

these situations it can be difficult for the researcher to determine whether the participant simply does not want to participate in the research any more or is no longer motivated to take part in the study because they have dropped out of the online support community. Strategies such as examining the individual's membership profile for recent activity (i.e. last login date, last message posted etc) may help to shed light on this.

This thesis focused on exploring associations between the psychosocial well-being of people accessing online infertility support communities and variables such as their experience of online support seeking and the frequency and type of usage. Future research should seek to extend these findings by examining additional factors that might influence psychosocial outcomes. For example, recruitment to this study was predominantly from peer-moderated online support communities. Consequently, one possible avenue for future investigation could involve a comparison between the experiences and well-being of people who access peer-moderated online support communities and those who access professionally facilitated online support communities. This is important as it might be that the presence of a qualified health care professional can serve to allay some of concerns (e.g. information accuracy and credibility) identified in this thesis and thus increase the positive effects of online support communities. Another direction for future research could involve examining how different types of self-disclosure influences psychosocial outcomes. It was apparent from the findings of this thesis that the sharing of personal experiences and emotions was an important self-help mechanism utilised by people accessing online infertility support communities and appeared to benefit both the individual as well as other members of the online community. Studies reviewed in Chapter three however, suggest that the specific type and amount of emotional expression by people in online support

communities can determine the extent to which the individual benefits from using the online community (Han et al., 2008; Lieberman, 2007; Shaw et al., 2008). For instance, spending too long ruminating about the negative aspects of a particular illness within an online support community could lead to an increase in negative emotions (Shaw et al., 2008). Longitudinal studies which incorporate text analysis of bulletin board postings and assess associations between specific types of disclosure and psychosocial outcomes will allow researchers to identify whether these findings are also relevant to people communicating in online infertility support communities.

Alongside, well-designed quantitative studies additional qualitative research can also help to extend the findings of this thesis. For example, there is a suggestion in the current thesis that online support communities do not meet the support needs of people who have been unsuccessful with treatment. In depth interviews with members who have experienced negative treatment outcomes will help to advance our understanding about the role of online support communities in supporting people experiencing treatment failure. Such insights can provide valuable advice to service providers concerning how best to create positive online environments in which people can share experiences of treatment failure and gain the support that they need at this stage of their infertility journey. There is also a need for in depth research examining how individuals make sense of and assess the credibility of information obtained through online infertility support communities. Discursive qualitative analysis of bulletin board postings could offer a valuable method through which researchers can assess how people exchange and respond to information in online infertility support communities.

Another important aspect of the findings which warrants further investigation is the impact of online infertility support communities on marital relationships. There is a perception among some women that the use of an online support community can benefit the couple relationship. However, as discussed there is also a risk that online infertility support communities may reduce marital communication and increase relationship strain, particularly since the results show a negative association between the number of hours spent online and marital satisfaction. In order to gain a more complete picture of the impact online support usage has on the psychosocial functioning of a couple, future research should seek to examine the experiences of both the male and female partner. For instance, interviewing a couple jointly about online support communities could help to identify similarities and differences in their attitudes towards the impact online support has on the individual accessing the online community and how this affects the way in which they collectively manage their infertility.

A related issue that could be addressed in future research is the issue of men's participation in online infertility support communities. The results of this thesis highlight that the majority of people who access online infertility support communities are women. This is not a surprising finding as women often feel more comfortable in seeking social support to cope with emotional difficulties and are also more likely to a feel a need to discuss their infertility issues and actively seek out ways to overcome these (Slade et al., 2007). However, given the numerous benefits of online support communities and the sense of anonymity and privacy associated with the Internet, online infertility communities could offer a beneficial and welcoming venue in which men who are feeling distressed by their infertility can also open up and share their concerns (Malik & Coulson,

2008). Future research targeted at understanding men's perceptions towards online infertility support communities could help to identify whether anything can be done to encourage men to make use of this novel source of support. It could also inform the development and promotion of professionally led online support interventions aimed at the infertile couple. Ensuring such support interventions include and address the needs of the male partner is important since past research has shown that women's satisfaction with fertility care can be influenced by the extent to which clinicians make an effort to involve their partner in the treatment process (Dancet et al., 2010).

8.3   Practical implications

This thesis has identified the potential for online support communities to reduce isolation, normalise emotions and empower individuals affected by infertility. The increasing availability and accessibility of the Internet in the developed world has led to a growing reliance on online health-related information and support. Findings from this thesis demonstrate how online support communities in particular, can play a pivotal role in the lives of people experiencing infertility and assist in meeting many of their support needs. Health professionals involved in the care of people diagnosed with infertility can thus recommend such resources to newly diagnosed patients with a degree of confidence. There is however a need to recognise that online infertility support communities are not without their disadvantages and that these disadvantages can impact on the amount of benefit derived from accessing the online community.

Both health care professionals and the moderators of online infertility support communities are well placed to assist in addressing some of the disadvantages commonly experienced by people who access online

infertility support communities. Community moderators for instance can play a role in integrating new members into the online community and helping them to break through membership cliques. Offering moderation staff training that will assist them to identify dangerous or misleading information might also be of benefit. In addition, there is a need for health care professionals to recognise and acknowledge the important role that online support communities play in supporting and empowering people affected by infertility. Patients should therefore be encouraged by both moderators and health professionals to openly discuss their online experiences (particularly informational support) with clinicians, so that any fears, anxieties or concerns can be put into perspective. As research, into the phenomenon of online infertility support communities grows, clinicians and health care organisations should seek to define and identify good quality online infertility support communities / websites that can be recommended to patients.

One particularly important implication of this piece of research is the suggestion that online infertility support communities do not meet the support needs of people facing permanent involuntary childlessness. These individuals while initially benefiting from online support communities expressed an increasing sense of alienation from the online community as their chances of conception reduced. Dissatisfaction with the provision of support for people facing permanent involuntary childlessness has also been identified in studies evaluating care in fertility clinics (Peddie et al., 2005; Schmidt, 1998; Souter et al., 1998). Women at this stage of infertility, often cite a need for emotional support concerning the decision to terminate treatment and information about alternative options such as adoption, which is not always met by the fertility clinic (Peddie et al., 2005). Improving the support available to this group of women is thus an

important area for intervention. The findings of this thesis suggest a need for more online support resources that cater specifically for the emotional and informational needs of patients facing permanent involuntary childlessness. Although, bulletin boards dedicated to people moving on from infertility treatment are already in existence, it appears that these individuals still have many unmet information and support needs that could be addressed by health care professionals. Developing computer-mediated support interventions that provide a password protected environment in which women can communicate with others facing permanent involuntary childlessness may be beneficial to this population. Detailed information resources about alternative options such as adoption could also be provided. In addition, it would be appropriate to consider the possibility of having a qualified psychologist or health care professional to lead online discussions and to assist women in coming to terms with their loss, whilst identifying new life goals for themselves.

More broadly, the results of this study bring to light the wealth of rich and detailed experiential information that can be obtained through bulletin board messages. Online support communities therefore provide a unique avenue through which health care professionals can learn more about the needs and experiences of patients at different stages of the infertility journey. This information can be utilised to improve the provision of both online and offline support for people affected by infertility. For example, this thesis highlights that information which focuses on the experiences of other patients is particularly valued by people with infertility. Furthermore, the results recommend the establishment of information and support resources that are tailored specifically to the needs of different sub groups of patients experiencing infertility. The previous paragraph outlined the importance of improving the support available to people faced with

permanent childlessness. However, bulletin board analysis in this study also revealed subtle differences between the informational and emotional support needs of people at different stages of infertility treatment. For instance, while patients commencing infertility treatment appear to benefit from the provision of detailed informational support concerning medical procedures, patients waiting to take a pregnancy test may prefer to hear stories about the symptoms and experiences of other patients in order to help them assess whether their own bodily changes are a positive sign. Identifying and addressing the specific concerns facing people at different points in their infertility journey may help to improve patient satisfaction with both online infertility support communities and the care provided by fertility clinics.

Consequently, it is important to ensure that health professionals are aware of the important role that online communities can play in helping them to understand and meet the support needs of people experiencing infertility. Academics involved in researching online support communities should therefore endeavour to make their research findings as accessible as possible to professionals working within the infertility field. Disseminating findings through avenues such as professional journals, practitioner conferences or via the media might present a useful and direct way of sharing and emphasizing the importance of these findings to practitioners. This will allow health professionals to gain up-to-date knowledge concerning the benefits and limitations of online support communities, as well as an understanding of the areas in which they could get involved to improve the online experiences of their patients.

8.4 Methodological discussion

Chapter four highlighted the multitude of potential benefits associated with various online research methods, as well as some of the potential challenges that might be faced when utilizing these methodologies. Given the novelty of online research methods and the lack of concrete guidelines in place for people engaging in Internet-based research, it was considered useful to close this discussion with a brief overview of some of the key advantages and challenges encountered in this particular piece of research.

From the perspective of the researcher a key challenge in this investigation was the recruitment of online infertility support communities to the studies. The online communities identified at the onset of the research process either explicitly asked researchers to contact the moderator prior to posting a message or did not provide any specific guidance on this topic. Thus, in both instances moderation staff were treated as gatekeepers to the online support communities (Cho & Larouse, 1999). This process proved difficult as less than half of the online support communities responded to the initial email contact. Since the majority of online support communities only listed email addresses, the researcher was unable to follow-up this initial contact with a telephone call. This was frustrating as it remained unclear whether the moderators that failed to respond did so because they did not wish to participate in the study or because they were simply too busy to reply. It is also important to note here that the online support communities that did respond to the research invitations were all peer-moderated online support communities that were predominantly located on UK based websites. Consequently, it is difficult to determine whether the results of this thesis can also be generalised to online communities moderated by infertility experts or are reflective of the experiences of people outside of the UK.

Challenges recruiting online communities to research studies have also been reported by other health researchers. For example, in work with cancer patients Im et al. (2007) only received replies from 6 of the 200+ online communities they contacted. This suggests that there is a need for researchers to consider ways in which they can promote research studies to moderators of health-related online support communities. Research focused on exploring the attitudes that moderation staff hold towards research solicitations may help to shed some light on this.

Another challenge inherent to the study of open-access online communities is the difficulty of obtaining a response rate. As flagged in chapters five and seven this raises concerns about the extent to which people who choose to participate in research studies are representative of other people accessing the same online support communities. This issue is particularly relevant for online survey studies as there is evidence to indicate that surveys carried out over the Internet typically achieve a much lower response rate when compared to postal surveys (Crawford et al., 2001; McDonald & Adam, 2003; Witmer et al., 1999). To date little is known about the reasons behind this discrepancy and therefore there is minimal guidance available for online researchers wishing to maximise their response rates (Crawford et al., 2001). Interestingly, this thesis obtained a considerably higher number of responses to the second survey (n=295), despite the fact that it was significantly longer than the first survey and was posted to a similar number of online communities for a similar period of time. One factor that might account for the dramatic increase in responses between the studies is the location of the research invitation; in the final study one online support community posted the research invitation to the home page of their Website. Unlike bulletin board messages, which can quickly become

camouflaged by new messages, this research invitation remained visible to everyone who accessed the Website throughout the study period. Consequently, it appears that the location of the research invitation can have a particularly significant influence on response rates.

As discussed in Chapter four, a common concern in online surveys is the risk of multiple responding. In the present research, although the software for the online surveys gave the option to block multiple responses from a single IP address, thus reducing the risk of multiple responding; this function was not activated by the researcher. This decision was based on the premise that in some couples both partners might be accessing an online support community from the same IP address. Consequently blocking multiple responses might prevent some people from participating in the research. The IP addresses of all the respondents were however recorded and reviewed by the researcher upon completion of the data collection. This review suggested that there were no participants who had accessed the survey from the same IP address as another respondent. Nevertheless, there remains a small possibility that a single individual could have submitted multiple responses from different IP addresses.

One particularly valuable aspect of this research was the richness of the qualitative data obtained through the online surveys. Similar to previous studies employing this methodology (e.g. Buchanan & Coulson, 2007), the participants in the studies wrote at length about their experiences of accessing online infertility communities. Although there were some instances in which people provided only very brief answers to the questions e.g. 'anonymity', these answers were substantiated by other respondents who went onto to explain exactly what it was about the anonymity that they found beneficial. This allowed the researcher to obtain both the

breadth and depth of data that was needed for this exploratory investigation.

Another beneficial aspect of the methodology was the fact that it conferred a greater degree of control to the individual participant, allowing them to take part at a time that was convenient to them, write as little or as much as they wanted and remain entirely anonymous. It is likely that this may have encouraged people who would not normally feel comfortable participating in a qualitative interview to share their experiences and views with the researcher.

Also of value in this thesis was the addition of naturally occurring data obtained from infertility bulletin boards. This data not only allowed the researcher to explore the types of self-help mechanisms used by participants but also presented surprisingly rich narratives about the experiences of people affected by infertility and the value of being able to communicate these experiences to other patients. As evidenced by some of the poignant quotes used in this thesis, these narratives have the potential to offer detailed and unique insights into the lived experience of infertility. This piece of research therefore demonstrates how online communication can offer a new medium through which researchers and health professionals are able to obtain vital insights into the experiences and needs of people affected by infertility or indeed many other sensitive health-related conditions. Consequently, despite the challenges associated with recruitment to online studies, it is apparent that the Internet has great potential both as an alternative and supplementary tool for exploring a wide variety of health-related issues.

8.5 Concluding remarks

In summary, this thesis presents the first in depth exploration of how people with infertility use and experience online support communities. Using a triangulation of qualitative and quantitative methodologies the thesis has provided both a detailed and extensive description of this new phenomenon. The results have shown the ways in which online support communities can meet the support needs of people affected by infertility and the abundance of psychosocial benefits associated with this novel support medium; whilst also highlighting its potential limitations.

Specifically, the accounts of the participants reveal that online infertility support communities present a unique avenue through which they can locate people with similar experiences who can empathise with their situation and offer them the experiential knowledge, information and advice that they so require. Contrary, to suggestions in the literature the findings of this thesis further show that online infertility support communities offer many of the therapeutic and self-help processes that occur in face-to-face support networks and can create a strong sense of camaraderie among participants. The benefits of accessing online infertility support communities were experienced by both 'lurkers' and posters and included reduced feelings of isolation, informational and emotional support, a sense of hope and positivity and tips/advice on how to cope with the effects of infertility on interpersonal relationships. As such it appears that peer moderated online support communities offer a viable and beneficial alternative source of support for many people affected by infertility.

However, this thesis has also established that there are a number of disadvantages to online infertility support communities that can influence

the degree of benefit derived from accessing the online community and the psychosocial well-being of the individual. Importantly, the findings show that online infertility support communities may not fulfil the support needs of people facing permanent involuntary childlessness. There is also a suggestion that individual's at this stage of infertility may experience an increase in negative emotions such as jealousy and isolation, as a consequence of accessing an online support community. This highlights the need for moderators of online support communities and other professionals involved in supporting people with infertility to recognise the important role that online support communities can play in the lives of people affected by infertility, whilst also acknowledging both their advantages and limitations as a support resource.

It is anticipated that the findings of this thesis will add significantly to the literature on Internet use among infertility patients and provide important insights into how online support resources can be improved and further developed to address the specific needs of this population. Whilst also providing a basis for further large scale quantitative research to examine the extent to which online support communities benefit or harm people at different stages of the infertility journey.

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Appendices

Appendix A: Message inviting participation in Study One

Appendix B: Online survey for Study One

Appendix C: Message inviting participation in Study Three

Appendix D: Online survey for Study Three

Appendix A

Message inviting participation in Study One

Research invitation –

Dear Members,

My name is Sumaira Malik and I am a PhD student at the Institute of Work Health and Organisations (I-WHO) in the University of Nottingham, UK. As part of my doctoral studies I am conducting a research study to investigate the role of online support communities in the lives of people experiencing infertility. The study is interested in exploring why people choose to access an online support community for infertility issues and how these online communities can help people cope with infertility.

I would therefore like to invite individuals who are experiencing infertility issues to take part in a short online survey about their experiences of accessing online support communities. It is anticipated that the survey will take between 10-20 minutes to complete.

If you are interested in taking part in the research or would like to find out more about the project, please click the link below to access the survey.

[link to online survey]

This study has received ethical approval from the departmental Research Ethics Committee at the Institute of Work, Health & Organisations in the University of Nottingham.

If you have any further questions about the project please do not hesitate to email me at lwxsm5@nottingham.ac.uk.

Thank you for your interest in this project.

Best Wishes,
Sumaira

Appendix B

Online survey for Study One

Experiences of online support seeking

1. Welcome - Particpant Information Sheet

You are invited to take part in a research study exploring the role of online support communities for people experiencing infertility. Before you decide to participate in the study please take the time to read the following information carefully and ask any questions you may have.

PURPOSE OF THE STUDY:

This study is being conducted as part of a PhD in Applied Psychology in the Institute of Work, Health & Organisations at the University of Nottingham, UK. The purpose of the research is to investigate how people use online support communities to cope with infertility. In particular, the aims of the study are to explore reasons for accessing online infertility support communities, experiences of online support seeking and perceived advantages and disadvantages to online infertility support communities.

PROCEDURE:

As a participant you will be asked to fill in some brief background information and respond to a series of open-ended questions about your experiences of accessing and using and online infertility support community. It is estimated that the online survey may take between 10-20 minutes to complete, depending on how much you choose to write. Please be honest and frank; there are no right or wrong answers.

ELIGIBILITY:

You are eligible to take part in the study if:
1) You are over the age of 18 years
2) You have accessed an online support community for infertility issues either as a member or as a guest.

ANONYMITY & CONFIDENTIALITY:

If you decide to take part in the study please be assured that your anonymity will be preserved at all times and any data collected during the course of the research will be kept secure and entirely confidential. Responses to the open-ended questions will be combined and used for qualitative summaries. If any of your responses are used in the write-up of the project or any academic papers, your anonymity will be preserved by removing any information that may identify you.

FREEDOM TO WITHDRAW:

We hope that you will take part in this study, however participation is entirely voluntary. If you do decide to take part in the project you may skip any question that you do not wish to answer or end the survey at any stage by clicking 'End this Survey'. You are also free to withdraw your response from the study at any point during data collection, without giving any reason and without penalty. Each participant will be asked to provide a unique password and if after completing the survey you wish to remove your responses, you can email the principal researcher with this password and your answers will be removed from the study.

ETHICAL REVIEW:

This research has been subject to ethical review and approval by the departmental research ethics committee in the Institute of Work, Health & Organisations at the University of Nottingham.

If you have any further questions about the study, please do not hesitate to contact me at: lwxsm5@nottingham.ac.uk

Thank you for your interest in this research.

Sumaira Malik
Principal Researcher

2. Consent Form

Please read the following statements carefully:

- I have read and understood the participant information sheet.

- I understand that my participation is entirely voluntary, and that I have the right to skip any question or stop participating at any time without penalty.

- I understand that the project has received ethical approval from the research ethics committee at the Institute of Work, Health & Organisations, University of Nottingham.

- I understand that the data will be kept confidential and secure and that only the principal researcher will have access to my responses.

DECLARATION

Experiences of online support seeking

I have read the consent form and participant information sheet and I give my voluntary consent to take part in the following study by selecting the 'NEXT' button.

3. Participant Information

Please remember that you are free to withdraw your participation at any time during the survey without giving any reason and without penalty; by clicking "Exit this survey."

* 1. Please provide a password in the space below so that we can identify your response should you wish to withdraw your response after completing the survey.

[   ]

* 2. In disseminating our work we may wish to use quotes to illustrate the points we are making. Please can you indicate whether you are willing for us to use quotes from your responses. [In using quotes we will not disclose any personal identifying information other than age and gender]

◯ Yes

◯ No

4. Background

Before we begin – we'd like to ask you some background information

1. Gender

◯ Male

◯ Female

2. Age

[   ]

3. Country of Residence

[   ]

4. Occupation

[   ]

5. Highest level of education

[   ]

6. If you are willing to take part in follow-up studies please provide us with your contact e-mail address (optional)

[   ]

5. Infertility and Online Support

Experiences of online support seeking

1. How would you describe your diagnosis of Infertility?

○ Male factor

○ Female factor

○ Male and Female factor

○ Unexplained

○ Unsure

Other (please specify)

[   ]

2. How would you describe your use of online communities?

○ Guest (read only)

○ Mainly non-participating member

○ Moderator

○ Occasionally participating member (i.e. twice a month or less)

○ Regularly participating member (i.e. minimum once a week)

○ Frequently participating member (i.e. several times a week or more)

3. In your own words, could you tell us why you chose to access an online infertility support community?

[   ]

4. If you never post messages to an infertility-related online support community, what are your reasons?

[   ]

5. In your view, has accessing an online support community made any difference to how you cope with your experience of infertility? If so, could you provide some examples of this?

[   ]

6. In your view, has accessing an online support community had any impact on your relationship with your partner? If so, could you tell us more about this?

[   ]

7. What do you consider to be the main advantages of accessing an online infertility support community?

8. What do you consider to be the main disadvantages of accessing an online infertility support community?

9. Have you ever discussed information, which you have obtained from the Internet with a health care professional [i.e. GP's, consultants, nurses etc]? If so, what were yourexperiences of discussing this information with your health care professional?

6. Thank You!

Thank you for taking the time to participate in this research study, your participation is much appreciated.

If you have any further questions or would like to withdraw your response, please do not hesitate to contact me at: lwxsm5@nottingham.ac.uk.

Appendix C

Message inviting participation in Study Three

Research invitation –

Dear Members,

My name is Sumaira Malik and I am a PhD student at the Institute of Work Health and Organisations (I-WHO) in the University of Nottingham, UK. As part of my doctoral studies I am conducting a research study to investigate the role of online support communities in the lives of people experiencing infertility. The purpose of the study is to explore how people access and use online support communities for infertility issues. In particular, the research is interested in examining reasons for accessing online infertility support communities, experiences of seeking online support and the possible impact of online communities on psychosocial well-being and coping.

I would therefore like to invite individuals who are experiencing infertility issues to take part in an online survey about their use of online support communities. It is anticipated that the survey will take between 15-20 minutes to complete.

If you are interested in taking part in the research or would like to find out more about the project, please click the link below to access the survey.

[link to online survey]

This study has received ethical approval from the departmental Research Ethics Committee at the Institute of Work, Health & Organisations in the University of Nottingham.

If you have any further questions about the project please do not hesitate to email me at lwxsm5@nottingham.ac.uk.

Thank you for your interest in this project.

Best Wishes,
Sumaira

Appendix D

Online survey for Study Three

Online infertility support communities

1. Welcome - Participant Information Sheet

You are invited to take part in a research study exploring the role of online support communities for people experiencing infertility. Before you decide to participate in the study please take the time to read the following information carefully and ask any questions you may have.

PURPOSE OF THE STUDY:

This study is being conducted as part of a PhD in Applied Psychology in the Institute of Work, Health & Organisations at the University of Nottingham, UK. The purpose of the research is to investigate how people with infertility access and use online support communities. In particular, the research is interested in examining reasons for accessing online infertility support communities, experiences of seeking online support and the possible impact of online communities on psychosocial well-being and coping. It is anticipated that the study will help us to gain a better understanding of how online support communities can help people experiencing infertility. The information gained from this study may also help us to further develop services aimed at supporting people experiencing fertility problems.

PROCEDURE:

If you choose to participate in the study you will be asked to fill out some brief background information and complete an online questionnaire about your use of online infertility support communities. It is estimated that the online questionnaire may take approximately 15-20 minutes to complete.

ELIGIBILITY:

You are eligible to take part in the study if:

1) You are over the age of 18 years

2) You have accessed an online support community for infertility issues either as a member or as a guest.

ANONYMITY & CONFIDENTIALITY:

If you decide to take part in the study please be assured that your anonymity will be preserved at all times and any data collected during the course of the research will be kept secure and entirely confidential. If any of your responses are used in the write-up of the project or any academic papers, your anonymity will be preserved by removing any information that may identify you.

FREEDOM TO WITHDRAW:

We hope that you will take part in this study, however participation is entirely voluntary. If you do decide to take part in the project you may skip any question that you do not wish to answer or end the survey at any stage by clicking 'End this Survey'. You are also free to withdraw your response from the study at any point during data collection, without giving any reason and without penalty. Each participant will be asked to provide a unique password and if after completing the survey you wish to remove your responses, you can email the principal researcher with this password and your answers will be removed from the study.

ETHICAL REVIEW:

This research has been subject to ethical review and approval by the departmental research ethics committee in the Institute of Work, Health & Organisations at the University of Nottingham.

If you have any further questions about the study, please do not hesitate to contact me at: lwxsm5@nottingham.ac.uk

Thank you for your interest in this research.

Sumaira Malik
Principal Researcher

2. Consent Form

Please read the following statements carefully:

- I have read and understood the participant information sheet.

- I understand that my participation is entirely voluntary, and that I have the right to skip any question or stop participating at any time without penalty.

- I understand that the project has received ethical approval from the research ethics committee at the Institute of Work, Health & Organisations, University of Nottingham.

- I understand that the data will be kept confidential and secure and that only the principal researcher will have access to my responses.

Online infertility support communities

3. Participant Information

Please remember that you are free to withdraw your participation at any time during the survey without giving any reason and without penalty; by clicking "Exit this survey."

* 1. Please provide a password in the space below so that we can identify your response should you wish to withdraw your responses after completing the survey.

* 2. In disseminating our work we may wish to use quotes to illustrate the points we are making. Please can you indicate whether you are willing for us to use quotes from your responses. [In using quotes we will not disclose any personal identifying information other than age and gender]

○ Yes

○ No

4. Background

Before we begin – we'd like to ask you some background information.

1. What is your gender?

○ Male

○ Female

2. What is your age?

3. What is your country of residence?

4. What is your relationship status?

○ Married / Civil Partnership

○ Living with your partner

○ Separated

○ Divorced

○ Single

○ Widowed

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5. What is your ethnic origin?

○ White

○ Black African

○ Black Caribbean

○ Black Other

○ Pakistani

○ Indian

○ Chinese

○ Bangladeshi

○ Asian Other

If other, please specify

[   ]

6. What is your highest level of education?

[   ]

7. What is your employment status?

○ Student

○ Employed part time

○ Employed full time

○ Unemployed

○ Self-employed

Other (please specify)

[   ]

8. Approximately, how long have you been diagnosed with infertility?

[   ]

9. How would you describe your diagnosis of infertility

○ Male factor

○ Female factor

○ Unexplained

○ Male and Female factor

○ Unsure

Other (please specify)

[   ]

5. Use of online support communities

Online infertility support communities

1. How long having you been using an infertility-related online support community?

2. Which infertility-related online support communities have you used? (please list names)

3. On average, how often do you visit an infertility-related online support community?

- ( ) More than once a day
- ( ) Once a day
- ( ) More than once a week
- ( ) Once a week
- ( ) Monthly
- ( ) Less than once a month

4. On average, since joining how many hours in a week have you spent in the online support community?

5. On average, since joining how many times in a week have you posted a message to the online support community?

- ( ) 0 – I never post any messages
- ( ) 1-5
- ( ) 6-10
- ( ) 11-15
- ( ) 16-20
- ( ) 21-25
- ( ) 26-30
- ( ) 31-35
- ( ) 36-40
- ( ) 41-45
- ( ) 46-50
- ( ) More than 50

6. To date, how would you best describe your experience of accessing an online support community?

○ Positive

○ Negative

○ Both positive and negative

7. Overall, how satisfied are you with the online support community?

○ Very dissatisfied   ○ Dissatisfied   ○ Neither disatisfied nor satisfied   ○ Satisfied   ○ Very satisfied

6. Use of online support communities

1. Could you tell us why you decided to access an online infertility support community?

2. What do you consider to be the most helpful aspect of online infertility support communities?

3. What do you consider to be the least helpful aspect of online infertility support communities?

7. How you feel

The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described.

1. How often do you feel that you are 'in tune' with the people around you?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

2. How often do you feel that you lack companionship?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

3. How often do you feel that there is no one you can turn to?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

4. How often do you feel alone?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

5. How often do you feel part of a group of friends?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

6. How often do you feel that you have a lot in common with the people around you?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

7. How often do you feel that you are no longer close to anyone?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

8. How often do you feel that your interests and ideas are not shared by those around you?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

9. How often do you feel outgoing and friendly?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

10. How often do you feel close to people?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

11. How often do you feel left out?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

12. How often do you feel that your relationships with others are not meaningful?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

13. How often do you feel that no one really knows you well?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

14. How often do you feel isolated from others?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

15. How often do you feel you can find companionship when you want it?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

16. How often do you feel that there are people who really understand you?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

17. How often do you feel shy?

◯ Never   ◯ Rarely   ◯ Sometimes   ◯ Always

Online infertility support communities

18. How often do you feel that people are around you but not with you?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

19. How often do you feel that there are people you can talk to?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

20. How often do you feel that there are people you can turn to?

○ Never   ○ Rarely   ○ Sometimes   ○ Always

8. Availability of social support

Next are some questions about the support that is available to you.

1. Approximately, how many close friends and close relatives do you have that you feel at ease with and can talk to about what is on your mind?

2. People sometimes look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it (in both your online and offline worlds)?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone you can count on to listen to you when you need to talk	○	○	○	○	○
Someone to give you information to help you understand a situation	○	○	○	○	○
Someone to give you good advice about a crisis	○	○	○	○	○
Someone to confide in or talk to about yourself or your problems	○	○	○	○	○
Someone whose advice you really want	○	○	○	○	○
Someone to share your most private worries and fears with	○	○	○	○	○
Someone to turn to for suggestions about how to deal with a personal problem	○	○	○	○	○
Someone who understands your problems	○	○	○	○	○
Someone to help you if you were confined to bed	○	○	○	○	○
Someone to take you to to the doctor if you needed it	○	○	○	○	○
Someone to prepare your meals if you were unable to do it yourself	○	○	○	○	○
Someone to help with daily chores if you were sick	○	○	○	○	○
Someone who shows you love and affection	○	○	○	○	○
Someone to love and make you feel wanted	○	○	○	○	○
Someone who hugs you	○	○	○	○	○
Someone to have a good time with	○	○	○	○	○
Someone to get together with for relaxation	○	○	○	○	○
Someone to do something enjoyable with	○	○	○	○	○
Someone to do things with to help you get your mind off things	○	○	○	○	○

9. Relationships

The questions in this section ask you about your thoughts and feelings regarding your relationship with your spouse/partner. For each statement please indicate the extent to which you agree or disagree.

Online infertility support communities

✱ 1. Before proceeding please confirm your relationship status

◯ I am currently in a relationship

◯ I am currently single

2. I am not pleased with the personality characteristics and personal habits of my partner

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

3. I am very happy with how we handle role responsibilities in our marriage

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

4. I am not happy about our communication and feel my partner does not understand me

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

5. I am very happy about how we make decisions and resolve conflicts

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

6. I am unhappy about our financial position and how we make financial decisions

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

7. I am very happy with how we manage our leisure activities and the time we spend together

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

8. I am very pleased about how we express affection and relate sexually

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

9. I am not satisfied with the way we each handle our responsibilities as parents

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree ◯ Not Applicable

10. I am dissatisfied about our relationship with my parents, in-laws, and/ or friends

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

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Online infertility support communities

11. I feel very good about how we each practice our religious beliefs and values

◯ Strongly Disagree ◯ Moderately Disagree ◯ Neither Agree nor Disagree ◯ Moderately Agree ◯ Strongly Agree

10. Infertility and parenting

The following section asks for your views and experiences about infertility and parenting.

1. For each item please choose one box to indicate the extent to which you agree or disagree with the statement

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
It doesn't bother me when I'm asked questions about children	☐	☐	☐	☐	☐	☐
Family members don't seem to treat us any differently	☐	☐	☐	☐	☐	☐
The holidays are especially difficult for me	☐	☐	☐	☐	☐	☐
Family get-togethers are especially difficult for me	☐	☐	☐	☐	☐	☐
I can't help comparing myself with friends who have children	☐	☐	☐	☐	☐	☐
I still have lots in common with friends who have children	☐	☐	☐	☐	☐	☐
I find it hard to spend time with friends who have young children	☐	☐	☐	☐	☐	☐
When I see families with children I feel left out	☐	☐	☐	☐	☐	☐
I feel like friends or family are leaving us behind	☐	☐	☐	☐	☐	☐
It doesn't bother me when others talk about their children	☐	☐	☐	☐	☐	☐
I find I've lost my enjoyment of sex because of the fertility problem	☐	☐	☐	☐	☐	☐
I feel just as attractive to my partner as before	☐	☐	☐	☐	☐	☐
I don't feel any different from other members of my sex	☐	☐	☐	☐	☐	☐
I feel like I've failed at sex	☐	☐	☐	☐	☐	☐
During sex, all I can think about is wanting a child (or another child)	☐	☐	☐	☐	☐	☐
Having sex is difficult because I don't want another disappointment	☐	☐	☐	☐	☐	☐
If we miss a critical day to have sex, I can feel quite angry	☐	☐	☐	☐	☐	☐
Sometimes I feel so much pressure, that having sex	☐	☐	☐	☐	☐	☐

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becomes difficult

I can't show my partner how I feel because it will make him/her feel upset	☐	☐	☐	☐	☐	☐
My partner doesn't understand the way the fertility problem affects me	☐	☐	☐	☐	☐	☐
My partner and I work well together handing questions about our infertility	☐	☐	☐	☐	☐	☐
It bothers me that my partner reacts differently to the problem	☐	☐	☐	☐	☐	☐
My partner is quite disappointed with me	☐	☐	☐	☐	☐	☐
My partner and I could talk more openly with each other about our fertility problem	☐	☐	☐	☐	☐	☐
I couldn't imagine us ever separating because of this	☐	☐	☐	☐	☐	☐
When we try to talk about our fertility problem, it seems to lead to an argument	☐	☐	☐	☐	☐	☐
Because of infertility, I worry that my partner and I are drifting apart	☐	☐	☐	☐	☐	☐
When we talk about our fertility problem, my partner seems comforted by my comments	☐	☐	☐	☐	☐	☐
Couples without a child are just as happy as those with children	☐	☐	☐	☐	☐	☐
I could see a number of advantages if we didn't have a child (or another child)	☐	☐	☐	☐	☐	☐
I could visualize a happy life together, without a child (or another child)	☐	☐	☐	☐	☐	☐
At times, I seriously wonder if I want a child (or another child)	☐	☐	☐	☐	☐	☐
Not having a child (or another child) would allow me time to do other satisfying things	☐	☐	☐	☐	☐	☐
Having a child (or another child) is not necessary for my happiness	☐	☐	☐	☐	☐	☐
We could have a long, happy relationship without a child (or another child)	☐	☐	☐	☐	☐	☐
There is a certain freedom without children that appeals to me	☐	☐	☐	☐	☐	☐
Pregnancy and childbirth are the two most important events in a couple's relationship	☐	☐	☐	☐	☐	☐

Online infertility support communities

For me, being a parent is a more important goal than having a satisfying career	☐	☐	☐	☐	☐	☐
My marriage needs a child (or another child)	☐	☐	☐	☐	☐	☐
It's hard to feel like a true adult until you have a child	☐	☐	☐	☐	☐	☐
A future without a child (or another child) would frighten me	☐	☐	☐	☐	☐	☐
I feel empty because of our fertility problem	☐	☐	☐	☐	☐	☐
Having a child (or another child) is not the major focus of my life	☐	☐	☐	☐	☐	☐
I have often felt that I was born to be a parent	☐	☐	☐	☐	☐	☐
As long as I can remember I've wanted to be a parent	☐	☐	☐	☐	☐	☐
I will do just about anything to have a child (or another child)	☐	☐	☐	☐	☐	☐

11. Thank you!

Thank you for taking the time to participate in this research study, your participation is much appreciated.

If you have any further questions or would like to withdraw your response, please do not hesitate to contact me at: lwxsm5@nottingham.ac.uk. Alternatively, if you are experiencing any stress or problems related to you infertility please contact your GP or health care provider for assistance.