University of Alberta

Women's Experiences of Infertility

by

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Abstract

The goal of the study was to gain a conceptual understanding of the challenges faced by infertile women, as well as they ways in which they deal with their experience. Concept mapping, a methodological approach combining qualitative and quantitative strategies was used to understand the experience of 26 women who were infertile. Five thematic clusters were identified regarding the challenges of infertility: Uncertainty, Medical Stressors, Psychological Impact, Social Reminders of Infertility, and Marital and Interpersonal Strains. The ways in which women deal with infertility were grouped into four thematic clusters: Seeking Information, Coping Strategies, Receiving Support, and Emotional Expression. These results indicate how women prioritized the challenges and methods of dealing with infertility. The uncertainty associated with the infertility experience was perceived as a key challenge, while the importance of seeking information was highlighted as a crucial method for dealing with infertility.

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Chapter 1: Introduction

Since most people assume that they will be able to conceive and bear children if they decide to do so, a diagnosis of infertility is frequently received with reactions of shock, disbelief, and initial denial of the problem (Cooper-Hilbert, 1998; Dunkel-Schetter & Lobel, 1991; Forrest & Gilbert, 1992; Shapiro, 1988; Spector, 2004). Emotional impacts of the infertility experience commonly include feelings of anger and frustration (Dunkel-Schetter & Lobel, 1991), guilt (Applegarth, 1999; Cooper-Hilbert, 1998), shame (Atwood & Dobkin, 1992), anxiety (Gerrity, 2001b; King, 2003), depression (van Balen, 2002; van Balen & Trimbos-Kemper, 1993), and grief (Shapiro, 1988). The difficulty of the infertility experience is compounded because infertility is often not recognized as a loss, leaving infertile individuals to grieve in isolation and without social supports (Applegarth, 1999; Lasker & Borg, 1987; Shapiro, 1988).

Since women experiencing infertility may face stigmatization because of their condition (Atwood & Dobkin, 1992), some individuals conceal their infertility as a method of self-protection (Cook, 1987). Consequently, family and friends may be unaware of their problems conceiving and continue to pressure these women to start a family (Menning, 1988). Infertility may also have detrimental effects on the marital relationship (Boivin, Takefman, Tulandi, & Brender, 1995; Gerrity, 2001b), with particular stress placed on the couple's sexual relationship (Newton, Sherrard, & Glavac, 1999; van Balen & Trimbos-Kemper, 1993). Given the considerable effects of the infertility experience, it is somewhat surprising that infertility has rarely been investigated in social science inquiry (van Balen & Inhorn, 2002).

Prevalence

Current estimates of infertility rates indicate that approximately 80 million people worldwide are infertile (Nachtigall, 2006), and some researchers predict that by 2025 infertility may affect as many as 7.7 million women in the United States alone (Stephen & Chandra, 1998). However, the published estimates of infertility rates vary widely. Conservative estimates suggest that approximately 8% of couples experience infertility (Sciarra, 1994), while other infertility rates in the literature are cited as high as 20% (Butler & Koraleski, 1990). Rates for the Canadian population are proposed at 8.5% of couples (Collins, Feeny, & Gunby, 1997). Part of the apparent variation in these numbers may be due to an inconsistency in the populations for which infertility rates are reported. Some studies only report infertility in women, (Atwood & Dobkin, 1992; Stephen & Chandra, 1998, 2006), which exclude any measure of infertility resulting from male factors. Other studies cite infertility rates in couples (Benyamini, Gozlan, & Kokia, 2004; Butler & Koraleski, 1990). The general consensus among researchers appears to be that infertility affects approximately 10-15% of couples (Benyamini et al., 2004; Spector, 2004).

Infertility rates in women tend to increase with age (Metzger, 1998). Atwood and Dobkin (1992) report information from the National Center for Health Statistics demonstrating a rise in infertility rates from approximately 2% between ages 15-19, to just over 13% between ages 30-34, and increasing to approximately 27% between the ages of 40-44. This age-related decline in fertility, combined with the social trend of women and couples delaying childbearing until later in their reproductive years, translates into higher rates of infertility (Butler & Koraleski, 1990; Metzger, 1998;

Nachtigall, 2006). It is also suggested that sexually transmitted diseases have contributed to a rise in infertility rates (Atwood & Dobkin, 1992; Butler & Koraleski, 1990; Metzger, 1998).

Conversely, some researchers dispute an increase in infertility rates, asserting that infertility in women has actually been decreasing (Stephen & Chandra, 2006). According to Stephen and Chandra, infertility rates for married women aged 15-44 years declined from 8.5% in 1982 to 7.4% in 2002. These researchers suggest that popular opinion about an increase in infertility has been influenced by higher levels of media attention on the subject of infertility, and more women in the older reproductive ages as the baby boom generation progressed into the higher age groups.

Definition

Some variation in the reported prevalence rates for infertility may also be due to the numerous definitions of infertility used in the literature. Infertility is typically defined as the inability to conceive a pregnancy after one year of regular sexual intercourse without contraception (Benyamini et al., 2004; McQuillan, Greil, White, & Jacob, 2003; Stanton, Tennen, Affleck, & Mendola, 1991), although some definitions are more explicit, specifying "heterosexual intercourse at a frequency of one to two times per week" (Paleg & Jongsma, 2000, p. 186). Other references in the literature differ in the time without conception that is necessary to make a diagnosis of infertility. For example, van Balen and Inhorn (2002) state that the time period may be as long as two years, while Hart (2002) limits the specification to six months of unprotected intercourse if the woman is over age 35. Further broadening of the definition of infertility occurs when it is taken

to include the inability to carry a pregnancy to a live birth (Glazer & Cooper, 1988; Menning, 1988).

An additional distinction in defining infertility is the difference between primary infertility and secondary infertility. Individuals experiencing primary infertility have never been able to produce a biological child, whereas secondary infertility is medically defined as a period of infertility that occurs after a documented conception, whether or not the pregnancy results in a live birth (Stanton & Dunkel-Schetter, 1991; van Balen & Inhorn, 2002). However, others recognize that the term secondary infertility is more commonly understood to describe those couples who have one or more children and subsequently are unable to conceive (Peoples & Ferguson, 1998).

Purpose of Research Study

The infertility experience has far-reaching emotional and interpersonal impacts on infertile individuals. Women experiencing infertility must contend with a myriad of emotions as well as strains on their social relationships (Cooper-Hilbert, 1998; Dunkel-Schetter & Lobel, 1991). The ways in which women manage their infertility may further influence the levels of distress they experience (Stanton, 1991; Stanton, Tennen, Affleck, & Mendola, 1992). At the same time, coping strategies employed by both partners have implications for marital satisfaction (Levin, Sher, & Theodos, 1997; Peterson, Newton, Rosen, & Schulman, 2006). Much remains to be learned about how women describe the ways in which they deal with their infertility, and what methods they perceive as being the most important in managing the experience.

As a condition affecting approximately 80 million of the world population, infertility is clearly an issue worthy of research attention (Nachtigall, 2006). While the

psychological impact of infertility is no longer an overlooked area in the literature, the majority of studies have examined this issue from a medical perspective rather than exploring how it is perceived by those experiencing infertility (Greil, 1997). Women's experiences of infertility, as described by infertile women themselves, have been relatively understudied (van Balen & Inhorn, 2002). Some researchers assert that because the ways in which women deal with their experiences of infertility are not yet fully understood, current counselling interventions may not adequately meet the needs of these women (Gibson & Myers, 2002). Accordingly, in order to adequately address the challenges faced by infertile women it is first necessary to comprehend what they perceive those challenges to be, as well as which issues are experienced as the most difficult and therefore deserve the most attention. Furthermore, it is important to be aware of the ways in which women manage the experience of infertility.

The purpose of the present study is to gain a better understanding of the challenges faced by infertile women, and they ways in which they deal with their experience. In addition, the study seeks to examine how women prioritize these challenges and methods of coping. While some qualitative research methods have been used to explore women's experiences of infertility (e.g., Daniluk, 2001; Olshansky, 1987; Williams, 1997), the method of concept mapping has not yet been employed in this area of study. Concept mapping allows participant-generated perspectives to be developed into a conceptual understanding of the phenomenon. It is hoped that a clearer conceptualization of the issues identified by women experiencing infertility will add to the existing knowledge of the infertility experience and provide information for other

infertile women, as well as counsellors and other helping professionals working with these individuals.

Research Questions

The research questions guiding this study were generated to explore the challenges faced by infertile women, as well as the ways in which they deal with their infertility experience. It is anticipated that the difficulties of infertility and the ways of dealing with the experience can be best explored through the biopsychosocial model of infertility. According to this theory, infertility impacts an individual's biological, psychological, and social systems (Williams, Bischoff, & Ludes, 1992). Given that the study gathers information from participants at a specific time in their lives, it is difficult to apply the life crisis theory of infertility, which claims that infertility is initially experienced as an acute crisis and over time may become a chronic crisis (Forrest & Gilbert, 1992). To allow for a wide range of responses, the research questions were phrased in open ended language. The two research questions are "What makes the experience of infertility difficult?" and "How have you managed to deal with the experience of infertility?" To establish the context for the current study, a summary of existing research is presented in the next chapter.

Chapter 2: Literature Review

In order to provide a background for the current study, it is important to have a solid understanding of existing research in the area of infertility. Of particular interest is research literature relating to the challenges faced by infertile women and the ways that these individuals deal with infertility. A summary of the existing literature is presented here, beginning with the etiology and medical treatment of infertility. Subsequently, literature regarding infertility theories and the relationship between infertility and psychological adjustment is explored. Information on how infertile individuals deal with infertility is outlined next, followed by literature on the treatment of psychological aspects of the infertility experience.

Etiology and Medical Treatment of Infertility

Infertile couples are classified as being in one of four categories, depending on whether they are experiencing infertility as a result of: (1) female factors, (2) male factors, (3) combined male and female factors, or (4) undetermined or unexplained factors (Davajan & Israel, 1991). Female infertility is diagnosed in only 35% of cases, with male infertility being diagnosed equally as often (35%), and the remaining cases are either diagnosed as combined infertility (20%) or unexplained infertility (10%) (Menning, 1988). Female factors contributing to infertility are frequently the result of problems with ovulation (Greil, 1991), which may include absent or infrequent menstruation (Davajan & Israel, 1991). Reproductive impairments implicated in male infertility include inadequate semen volume, insufficient sperm concentration or activity, abnormal sperm structure, or difficulties with the sperm transport ducts (Greil, 1991).

Not all couples seek medical treatment to deal with their infertility. Medical help-seeking among infertile couples is generally considered to be less than 50% (Atwood & Dobkin, 1992; Collins et al., 1997). Women engaging in medical treatment for infertility tend to be older and are more likely to be married and to live in urban centers, in comparison to those who do not seek treatment (Nachtigall, 2006). Treatment-seekers are also more likely to be in higher income brackets (Greil & McQuillan, 2004; Nachtigall, 2006). In addition, help-seeking has been associated with actively trying to conceive and having a lower internal locus of control, as well as thinking of oneself as someone with fertility difficulties (Greil & McQuillan, 2004).

Medical treatment for infertility may range from drug therapy or hormone therapy, especially to assist with ovulation difficulties (Davajan & Israel, 1991), to surgical interventions (Greil, 1991), and to more advanced treatment techniques. These advanced techniques, including in vitro fertilization (IVF) and its variants of gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer (SIFT), are most commonly referred to as assisted reproductive technology (Hart, 2002) or advanced reproductive technologies (Metzger, 1998), both abbreviated as ART. Others have referred to these interventions as the new reproductive technologies (NRT) (Robinson & Stewart, 1996; van Balen & Inhorn, 2002), which also include other techniques such as intracytoplasmic sperm injection (ICSI) and intrauterine insemination (IUI) (Metzger, 1998). Methods of insemination may occur by artificial insemination with the husband's sperm (AIH) or artificial insemination by sperm acquired from a donor (AID) (Greil, 1991). Researchers have noted that regardless of the source of the infertility problem, it is

almost always the woman who bears the primary burden of medical investigation and treatment for infertility (Greil, 1997, 2002; van Balen & Inhorn, 2002).

Theories of Infertility

Life-crisis theory of infertility. Menning (1988) describes infertility as a major life crisis. According to this theory, infertility is a stressful event that presents a problem which cannot be solved in the immediate future, and overtaxes one's existing resources. Infertility is perceived as a threat to one's life goals, especially since motivations for parenthood are not able to be realized. Forrest and Gilbert (1992) express that infertility is initially experienced as an acute crisis, although it can become a prolonged or chronic crisis as the situation continues indeterminately without a clear resolution. In reaction to infertility, individuals may go through a number of response phases such as shock and denial, anger, isolation, guilt, depression, grief, and finally resolution. Menning (1988) indicates that infertile individuals cannot remain in crisis indefinitely, and that they will emerge from the situation in one of three ways: (1) with the same level of stability as before the crisis, (2) with more insight and strength, or (3) with a decreased stability of functioning.

Biopsychosocial theory of infertility. In the biopsychosocial model, infertility is perceived as impacting an individual's biological and psychological subsystems, which in turn mutually influence each other and operate within social systems ranging from the marital dyad to larger social systems of political, economic, historical, and cultural realms (Williams et al., 1992). Biopsychosocial theory attempts to address the interaction between existential, physical, emotional, and interpersonal factors, and account for the effect of infertility over time (Gerrity, 2001a). Watkins and Baldo (2004) outline some of

the biopsychosocial effects of infertility, including medical aspects, a lack of social support, being on an emotional rollercoaster, the developmental impact in terms of disrupted life goals, effects on the marital system, sexual effects, and grief. Recognizing that the stressors of infertility may be beyond the average person's usual ability to handle situations, Gerrity (2001a) identifies social support and coping as two important tools suggested by the biopsychosocial model to mediate the effects of infertility.

Infertility and Psychological Adjustment

Three primary perspectives exist concerning the relationship between infertility and psychological adjustment. The first perspective about this association is that infertility can be caused by psychopathology, while a second view suggests psychological difficulties arise from the impact of the infertility experience (Greil, 1997). A third perspective proposes a cyclical relationship between infertility and stress (Greil, 1997; van Balen, 2002).

Infertility caused by psychopathology. In this perspective infertility is considered to result from psychological mechanisms, generally assumed to be caused by existing psychological difficulties in the female partner. Historically, this view likely developed as a result of inadequate knowledge about the process of human reproduction (van Balen, 2002). Instead of considering biological explanations, infertility was believed to be the consequence of a woman's conflicts regarding femininity or an ambivalent relationship with a maternal object (Applegarth, 1999). As a clearer understanding of the physical contributors to infertility evolved fewer cases of infertility were attributed to psychopathology, although cases of unexplained infertility, where no physical cause could be found, were still often assumed to have a psychological basis (van Balen, 2002).

Unexplained infertility continued to be attributed to psychogenic causes, which in essence, blamed women for their own infertility (Spector, 2004).

As Stanton and Dunkel-Schetter (1991) discuss, there has not been consistent support for psychological causes of infertility and this perspective is not popular at present. However, even recent research continues to attribute some fertility difficulties to female dispositional and psychological factors. Lancastle and Boivin (2005) have examined the effects of dispositional optimism, trait anxiety, and coping on women's biological response to fertility treatment, reporting that these three measures are indicators of a construct that is a better predictor of reproductive health than any of the three variables predict on their own. The researchers speculate that neuroticism is the core construct underlying these variables.

Psychological difficulties as a consequence of infertility. According to this perspective, any evidence of psychological difficulty arises in reaction to the challenges of the infertility experience. Infertility is viewed as resulting from physical factors such as illness, infection, genetics, or trauma to the body, with infertility leading to psychological stress (Greil, 1997). Infertility, as well as the treatment for infertility, can result in psychological difficulties such as stress, low self-esteem, anxiety and depression, and sexual difficulties (van Balen, 2002). According to Greil, most evidence suggests that there is not a significant difference between infertile women and women in the general population in relation to psychopathology, although differences in terms of self-esteem and stress levels do appear to exist.

Cyclical model of infertility and stress. In between the extremes of the two views presented above is the perspective that a cyclical relationship exists between infertility

and stress. According to this model, the experience of infertility can lead to increased levels of stress, which in turn can negatively influence the chance of achieving a pregnancy (van Balen, 2002). Greil (1997) notes that while beliefs about psychological causes of infertility are now rejected by most researchers, the possibility that stress may be a contributing factor in infertility is worthy of further exploration. While there has been some research to support this connection (Möller & Fällström, 1991), other researchers find that stress is no more prevalent in infertile women than in women in the general population, and question the role of stress as a causal contributor to infertility (Paulson, Haarmann, Salerno, & Asmar, 1988). Some researchers express concern that psychological models of infertility continue to attribute some of the responsibility for failure to infertile couples, in that a failure to adjust or adapt is perceived to interfere with medical treatment and pregnancy outcomes (Sandelowski & de Lacey, 2002). In addition, although any relationship between stress and infertility could implicate the male partner as well as the female partner, "the psychologization of infertility has been focused almost exclusively on the female patient" (van Balen, 2002, p. 89).

Psychological Impact of Infertility

The experience of infertility has an impact far beyond the physical implications of such a diagnosis. Spector (2004) recognizes that a diagnosis of infertility can come as a shock, since most couples expect that they will be able to have children. Experiencing infertility can contribute to psychological impacts including shock and disbelief, denial, anxiety and depression, grief, anger, guilt, isolation and alienation, problems with sexual relationships, and feeling a loss of control (Cooper-Hilbert, 1998). Other research

indicates that a negative identity and lower overall life satisfaction may also result, and infertile women often face a lack of understanding from other people (Williams, 1997).

One of the challenges in reviewing the literature on the psychological impact of infertility is that since individuals dealing with infertility often seek medical treatment for their condition, it is very difficult to separate effects of infertility from effects of infertility treatment. As van Balen (2002) states: "There are many more studies on IVF and the various psychological aspects of that treatment than on the psychological consequences of infertility per se" (p.87). Because treatment is a significant aspect of the infertility experience, much of the research discussed in this section includes issues of infertility as well as infertility treatment. Literature on the psychological impacts of the infertility experience is discussed in this chapter according to five main areas: (1) emotional effects, (2) grief, (3) loss of control, (4) effects on self-esteem and identity, and (5) impact on the marital dyad and interpersonal relationships.

Emotional effects. The emotional effects of infertility and infertility treatment are a substantial part of the overall infertility experience. Common reactions include shock, anger and frustration, guilt, depression, and anxiety (Cooper-Hilbert, 1998; Dunkel-Schetter & Lobel, 1991). The infertility experience has been described as an emotional rollercoaster (Greil, 2002; Watkins & Baldo, 2004; Williams, 1997). Consequently, it is somewhat concerning that a majority of women undergoing investigation and initial management of infertility report that they are not given enough help with the emotional aspects of their infertility experience (Souter, Penney, Hopton, & Templeton, 1998). Researchers examining the well-being of couples experiencing long-term infertility find that infertile women are more anxious, more depressed, display more hostility, and report

more health complaints, compared to women in the general population (van Balen & Trimbos-Kemper, 1993). Furthermore, 30% of the female participants in the van Balen and Trimbos-Kemper study demonstrate extremely low scores on one or more dimensions of well-being, leading the researchers to suggest that these women may require emotional help and counselling in learning to live with their childlessness.

Emotional responses to the treatment of infertility are found to consist of an acute stress reaction to the initial diagnosis and infertility treatment, combined with a more chronic strain response treatment that continues long-term (Berg &Wilson, 1991). According to Berg and Wilson, emotional strain is somewhat elevated during the first year of treatment and returns to essentially normal levels during the second year, but increases markedly after the third year. It should be noted, however, that there is an inherent difficulty in comparing participants primarily by time in treatment since the pace and type of interventions can differ greatly among those seeking treatment for infertility (Gerrity, 2001a).

Anxiety appears to increase throughout the first few years of treatment, when the majority of participants move from the stage of diagnostic workup to seeing a number of specialists and trying various treatments for infertility (Gerrity, 2001b). The connection between anxiety and infertility is supported by other research as well. Results of a study conducted with a nationally representative sample of American women indicate that infertility difficulties are associated with an increased likelihood of fulfilling diagnostic criteria for Generalized Anxiety Disorder (King, 2003).

Other researchers suggest that a diagnosis of infertility may not automatically result in emotional distress. McQuillan, Greil, White, and Jacob (2003) state that

infertility is associated with significant long-term distress, but only in those women who do not have any social children (i.e., through adoption or by a partner's previous relationship) or biological children. They further report that women who do not have children but have not experienced fertility problems are not distressed by the absence of children. As a result, the researchers assert that it is neither the state childlessness nor infertility alone that predicts distress, but rather the combination of the two factors. It is suggested that having a child from a past or present relationship or through adoption can act as a buffer against the impact of infertility and treatment failure (Daniluk & Tench, 2007; Newton et al., 1999).

Grief. Because infertility is often experienced as a death of a hypothetical child, infertile individuals may mourn the loss of a baby who has been "planned for, described, dreamed about, and often even named" (Clark, Henry, & Taylor, 1991, p. 170). It is frequently recognized in the infertility counselling literature that one of the difficulties in grieving infertility is the lack of social recognition for this type of loss, as well as a lack of available rituals to help individuals acknowledge and work through this type of grief (Applegarth, 1999; Lasker & Borg, 1987). As Shapiro (1988, p. 2) acknowledges: "No rituals exist to legitimize the grief of the infertile couple who mourn the baby they never conceived or gave birth to. In a sense, infertility is a silent and unrecognized loss, one that many couples struggle to resolve in lonely isolation." It is also important to note that the grief reaction does not only occur in reaction to the overall infertility diagnosis, but may also be experienced in response to each menstrual cycle that does not result in pregnancy, or in reaction to a failed cycle of infertility treatment (Reading, 1991).

Shapiro (1988) describes how the grieving process may be experienced and resolved by those dealing with infertility, based in part on Kübler-Ross' (1969) stage model of coming to terms with death and dying. In this framework, infertile individuals work through five stages: (1) Denial, (2) Anger, (3) Bargaining, (4) Grief, and (5) Acceptance. Shapiro indicates that these stages are not always experienced chronologically, and they may not be experienced with the same intensity by all individuals experiencing infertility. Kirkman (2003) states that part of the work of mourning in infertility can be viewed as "repairing the disruption to one's autobiographical narrative" (p. 244). However, she indicates that society has created a number of barriers to this narrative revision, describing a cultural dominance of the motherhood narrative and the relative absence of a collective narrative of the non-mother. In addition, infertile individuals often do not have meaningful alternative goals, and they may face a lack of audience support in trying to revise their life story.

Loss of control. After unsuccessful attempts to conceive, infertile individuals often feel a loss of control over their situation (Bergart, 2000). Women experiencing infertility often feel "betrayed by their bodies, victimized by their treatments, and totally at the mercy of their doctors and fate" (Butler & Koraleski, 1990, p. 160). A loss of control may be experienced in relation to present circumstances, such as a lack of control of activities, one's body, or one's emotions, or it may extend into the future, through an inability to predict and plan for the future (Dunkel-Schetter & Lobel, 1991).

Both women and men appraise infertility as relatively uncontrollable, with female participants who feel more threatened by their infertility or feel less control over their infertility having higher levels of distress (Stanton, 1991; Stanton et al., 1991). A loss of

control is one of the themes that Greil (2002) found in qualitative interviews with infertile women, noting that while it is common in our society for women to determine the number of children they want to have and even plan the spacing of children, infertile women lose any such control over the family planning process. Griel reports that a further loss of control is experienced in the medical system.

Some women report at least moderate levels of control over certain aspects of their infertility (Campbell, Dunkel-Schetter, & Peplau, 1991). According to Campbell et al., while achieving a pregnancy is perceived by infertile women as being truly uncontrollable, they may feel that they have at least some control over medical treatment and emotional reactions. Conversely, Daniluk (2001) states that infertile individuals experience a loss of control in their experiences of medical investigations and treatments. Before beginning treatment for infertility, most individuals set limits about the alternatives they will consider as well as the time and finances they will commit to treatment. When initial attempts fail, however, infertile individuals may elect to participate in treatments that they had previously decided against.

Daniluk (2001) reports that feeling out of control can be aggravated if individuals feel they have not received adequate information about the realities of the treatment process, especially in the case of unexplained infertility. Women undergoing investigation and treatment of infertility may not receive sufficient information about their treatment plan or possible side effects from medications (Souter et al., 1998). Women participating in infertility treatment generally expect test results and treatment options to be explained by the medical staff, in addition to receiving written information

about treatment, medical services, and psychosocial aspects of infertility (Schmidt et al., 2003).

Effects on self-esteem and identity. Women dealing with infertility frequently experience feelings of inadequacy, changes in their self-concept, a negative body image, or a perception that one's body is defective (Dunkel-Schetter & Lobel, 1991). A negative identity can result (Williams, 1997), which may not be surprising considering that a failure to assume the mother role has traditionally brought a woman's status as adult and as feminine into question (Greil, 2002; Spector, 2004). For some women, particularly those who endorse a stereotyped feminine attitude, an intense desire for children is strongly correlated with motives of identity-development (van Balen & Trimbos-Kemper, 1994, 1995). Motives in the areas of identity (defined as a desire to have a child as a means of achieving adulthood and identity strengthening) and parenthood (defined as an expectation that parenthood will lead to life fulfillment) are much stronger for women in infertile couples, as compared to their male counterparts (van Balen & Trimbos-Kemper, 1995).

Problems with body image are another common effect of the infertility experience (Spector, 2004). Greil (2002) describes that in interviews with infertile individuals, it is common for women to view infertility as a failure of the body to function properly. Furthermore, these women do not seem to distinguish between the failure of their bodies and failure of the self. According to Greil, many women experience infertility as a "generalized role failure" (p. 105). Research with couples experiencing long-term infertility indicates that approximately one third of female participants report

low self-esteem concerning their womanhood as a consequence of their inability to bear children (van Balen & Trimbos-Kemper, 1993).

Impact on the marital dyad and interpersonal relationships. The experience of infertility may lead to a variety of changes and difficulties in an individual's social system, particularly with regard to the marital relationship. Partners may react differently to the diagnosis and treatment of infertility, leading to marital stress (Spector, 2004). Furthermore, communication difficulties and the financial stress of infertility treatment compound the problem (Spector, 2004). Another factor contributing to marital stress is that the medical environment may not always recognize or honour the importance of the marital relationship. For example, a study of women attending outpatient clinics for the investigation and initial management of infertility indicates that 39% of the women surveyed were never asked to bring their partner to the clinic (Souter et al., 1998).

Sexual difficulties, or at least a decrease in sexual pleasure, may occur as a result of the calculated intentionality of prescribed intercourse (Davajan & Israel, 1991). When the focus of intercourse shifts primarily to the reproductive aspect of sex, the former intimacy and mutual enjoyment can seem to fade away (Goodman & Rothman, 1984). In comparison to their male counterparts, women dealing with infertility experience more negative impact on their sexual relationship (Newton et al., 1999). Abbey, Andrews, and Halman (1991) state that women experience more fertility problem stress than men, with a greater impact on women's sexual dissatisfaction. Research with couples experiencing long-term infertility indicates that approximately 50% of women report negative effects on their sex life attributed to infertility (van Balen & Trimbos-Kemper, 1993).

Newton et al. (1999) have developed an instrument to measure perceived infertility-related stress, and suggest that increases in social, sexual, or relationship difficulties appear central to the infertility-related stress in couples actively seeking treatment. The researchers caution that individuals experiencing these difficulties face a higher risk of depression. In addition, while women overall report higher stress than men in terms of social and sexual concerns, both men and women dealing with male infertility report more social and sexual concerns than participants experiencing female infertility (Newton et al., 1999).

Some research suggests that marital relationships remain stable despite the infertility experience, at least throughout the first seven to nine months after couples' initial visit to an infertility clinic (Connolly, Edelmann, Cooke, & Robson, 1992). However, it may be the case that marital discord develops after that initial period. Results of a cross-sectional study of infertile couples indicate that while marital adjustment and sexual satisfaction are fairly stable during the first two years of investigation and treatment, both measures deteriorate after the third year (Berg & Wilson, 1991). Similarly, Gerrity (2001b) reports that individuals in the beginning stages of treatment are significantly happier in their marital relationship than individuals who persist with infertility treatment for five or more years. Corroborating findings are also cited by Boivin, Takefman, Tulandi, and Brender (1995), although they attribute the pattern of marital distress to the number of treatment failure experiences rather than the number of years in treatment. It is worth noting that standardized measures of marital adjustment seem to lack sensitivity to infertility-related issues, but when items focus on the marital aspects that are likely to be impacted by infertility, an increase in infertility-related stress

is associated with a decreased satisfaction in the marital relationship (Newton et al., 1999).

Social relationships beyond the marriage are also be impacted by the infertility experience. According to Menning (1988), infertile women are frequently questioned and pressured about starting a family, and insensitive remarks may lead them to react in anger or withdraw and decide to keep their infertility a secret. Family and friends may attempt to be supportive but unless they have a true understanding of the needs of individuals with infertility, their efforts may not be perceived as helpful (Abbey et al., 1991). Another complicating factor is that friends and family members may hold opposing views about acceptable medical methods for treating infertility (Forrest & Gilbert, 1992). Women often feel very isolated in their infertility experience and feel that they are different from women who are able to have children, creating an "us and them" mentality (Sandelowski, 1993, p. 74).

Dealing with the rites of passage for friends and family members can be a challenge for individuals experiencing infertility. Since being present at occasions like baby showers and christenings can be distressing, infertile individuals may decide against attending these events (Spector, 2004). Infertile couples find it difficult to watch people around them make a relatively easy transition to parenthood while their own struggles to conceive may lead them to feel like failures (Daniluk, 2001). Goodman and Rothman (1984, p. 83) describe the irony of this isolation and alienation: "At a time when the infertile individual or couple most need support, they feel separate and cut off from those they believe cannot comprehend the extent of their pain." Overall, infertile women tend to have more positive views than men do about their social interactions outside of the

marital relationship, although this may leave them with an extra burden in terms of needing to provide almost all of their husbands' social support (Abbey et al., 1991).

Summary of psychological impacts. The experience of infertility is associated with a number of detrimental psychological effects. Research in this area indicates that infertile women experience a number of adverse emotional effects, including grief reactions, in addition to problems within the marital dyad and interpersonal relationships. Furthermore, women dealing with infertility may perceive infertility as a threat to their self-esteem and identity, while experiencing an overall loss of control. The psychological impacts of infertility may affect treatment participation, as these factors have been found to contribute significantly to patients dropping out of IVF treatment even before they receive all IVF cycles covered through insurance plans (Domar, 2004).

Not all research supports the belief that infertility results in considerable psychological distress. Bringhenti, Martinelli, Ardenti, and La Sala (1997) investigated the psychological adjustment of infertile women entering IVF treatment compared to mothers who were attending for a routine care visit. The researchers note that in general infertile women do not necessarily show signs of psychological maladjustment, although an increased level of state-anxiety may reflect a situational response to treatment stress. Connolly et al. (1992) also report little evidence of psychopathology in infertile samples, suggesting that marital relationships are stable and depression scores remain low, while scores on tests of anxiety and psychiatric morbidity may actually decline between initial and subsequent assessments (Connolly et al., 1992). Edelmann and Connolly (1998) present similar findings and propose that the considerable psychological effects reported

in the clinical and anecdotal literature are a reflection of only a small subset of the infertile population.

While findings from qualitative studies consistently illustrate poorer psychological functioning among women with infertility, quantitative research has produced conflicting results concerning clinically significant psychological difficulties (Souter, Hopton, Penney, & Templeton, 2002). As Dunkel-Schetter and Lobel (1991) recognize, the discrepancy between the descriptive and empirical literature might be due to an exaggeration or misrepresentation of the infertility experience in the descriptive literature; alternatively it is possible that infertility issues have not been adequately tested in empirical studies.

Dealing with the Infertility Experience

In exploring the infertility literature, it appears that more attention has been paid to the challenges faced by individuals experiencing infertility, as compared to the ways that individuals manage to deal with their experience. Research that has examined the perceived self-efficacy for coping with infertility diagnosis and treatment suggests that women score significantly lower than male participants in this area (Cousineau, Green, Corsini, Barnard, Seibring, & Domar, 2006). With regard to coping strategies and adjustment of infertile couples, female participants are to be more likely than male participants to deal with infertility by using distancing and avoidance, self-control, or through problem solving and mobilizing support (Stanton et al., 1992). Women who use strategies of avoidance or accepting responsibility for their infertility are found to be more distressed, whereas women who mobilize more support are less distressed (Stanton, 1991; Stanton et al., 1992). Gerrity (2001b) reports that women engage in more escape-

avoidance strategies than men do, possibly due to the greater invasiveness of treatment for women.

Cognitions endorsed by infertile women also have an impact on their management of the infertility experience (Benyamini et al., 2004). Women who have perceptions of a longer timeline for the solution of their infertility problem, or perceive infertility as having more severe consequences and less controllability, have greater distress and lower well-being (Benyamini et al., 2004). Greater distress is also related to inward-anger strategies and problem management coping while self-nurturing is associated with greater well-being. However, Benyamini et al. caution that causal relationships cannot be inferred from the associations found in their study.

The different coping strategies that couples use to deal with the infertility experience may affect their marital satisfaction (Levin et al., 1997). According to Levin and colleagues, female participants report the highest level of marital satisfaction when both they and their partners use of high levels of task-oriented coping. Women report the least satisfaction when they use less emotion-oriented coping strategies while their partners use more emotion-oriented coping (Levin et al., 1997). Higher levels of distress are also found in couples where the male partner uses high amounts of distancing but the female partner does not, as well as in couples where the woman uses high amounts of emotional and behavioral self-controlling coping but the man uses low amounts (Peterson et al., 2006). Peterson et al. state that the highest amounts of infertility stress and lowest levels of marital adjustment are found in couples where partners tend to assume a high degree of responsibility for their infertility. Conversely, when neither partner accepts sole

responsibility for the infertility couples report the lowest levels of infertility stress and the highest amounts of marital adjustment (Peterson et al., 2006).

In examining the coping processes of infertile couples in the period prior to and following a negative pregnancy result, Berghuis and Stanton (2002) report that both men and women exhibit a significant increase in depressive symptoms after learning of the failed treatment. Avoidant coping strategies predict increased distress over time, while approach-oriented coping strategies such as problem-focused coping, emotional processing, and expression, predict decreased levels of distress (Berghuis & Stanton, 2002). The researchers state that the coping strategies engaged in by both individuals and partners are predictive of depressive symptoms.

Social support from friends, family, similar others (i.e., other individuals experiencing infertility), and especially support from one's spouse, enhances well-being and can have a beneficial impact on infertile couples' ability to deal with the infertility experience (Abbey et al., 1991). Overall, couples state that discussing their infertility difficulties with family and friends makes them feel somewhat better, although conversations with similar others are viewed as more helpful (Abbey et al., 1991). In their research exploring possible correlations between infertility stress and social coping resources, Gibson and Myers (2002) describe that the majority of women typically turn to a female peer for support. In terms of community support, most women indicate that they receive support through their work, religious group, or school, with only a minority of participants identifying a support group as their primary source of support. Gibson and Myers report that both growth-fostering relationships and social coping resources contribute significantly to the variance in infertility stress, with infertility stress

decreasing in response to increases in these coping resources. In particular, partner support and family support are significant factors.

Using in-depth interviews with infertile couples, Greil (2002) states that a number of women respond to the stresses of infertility treatment by learning as much as possible about the medical system and treatment process, in an effort to increase their knowledge and regain some control in their situation. Shapiro (1988) also identifies information as a useful defense against feelings of helplessness and a loss of control, suggesting that becoming informed about the medical process may help infertile individuals and couples feel like knowledgeable, active participants in their treatment. Some infertile individuals take back control of their lives and their bodies when they decide to abandon treatment; at this point these individuals become free to move on, rather than being controlled by their pursuit of pregnancy (Daniluk, 2001).

Treating the Psychological Impact of Infertility

The litany of stressors and emotional reactions associated with the infertility experience would seem to suggest a significant role for psychological services. There is a call for the treatment of psychological aspects of infertility to be included as part of a more holistic approach to treating infertility (Souter et al., 2002). Interestingly, some research suggests that relatively few patients consider the provision of psychosocial services as important (Schmidt et al., 2003). According to Schmidt et al., approximately 10-21% of women and 5-9% of men feel that this as an important service, and only 9-19% of women and 4-9% of men would use psychosocial services if they were offered. However, the researchers in this study note that since this information was gathered from

participants before they had received infertility treatments, these individuals may not yet realize the challenges of treatment and the importance of psychological services.

Boivin, Scanlan, and Walker (1999) describe some of the reasons that individuals dealing with infertility do not seek counselling. In their study, both men and women expressed significantly more concern about the psychological aspects of infertility than the medical aspects, yet just over 8% of female participants and approximately 6% of male participants sought counselling. The researchers report that participants who are less distressed may feel they do not require counselling services since their present coping resources, including spousal and family support, are sufficient to deal with the strains of infertility. Furthermore, nearly 50% of female participants make use of written information in the fertility clinic, as well as printed information and television documentaries in the media, to assist in coping with infertility and treatment. On the other hand, more distressed participants report not seeking counselling because of practical concerns such as a lack of knowledge about whom to contact or concerns about the financial cost of counselling. Shapiro (1999) recognizes that financial resources for infertile individuals may be depleted as a result of treatment costs, meaning that these people may be put in the position of having to choose between medical and psychological treatment for infertility.

For those individuals who do seek services to deal with the psychological effects of the infertility experience, treatment may take the forms of counselling or self-help support groups. Support groups offer infertile individuals a forum for exchanging information, sharing concerns, and receiving support from others who are undergoing similar circumstances (Reading, 1991). An advantage of group treatment for infertility is

that when individuals realize that their participation in a group can be of benefit to the other members, it may help to "replenish some of the women's loss of self esteem so severely injured by infertility" (Goodman & Rothman, 1984, p. 86).

In terms of individual counselling for the infertility experience, Applegarth (1999) outlines five main treatment approaches that are utilized: psychodynamic psychotherapy, cognitive-behavioural therapy, strategic and solution-focused psychotherapy, crisis intervention, and grief counselling. Psychodynamic approaches focus on examining defense mechanisms, the impact of childhood experiences, and any unresolved conflicts that may relate to fertility difficulties. Cognitive-behavioural therapy looks to alter cognitions and behaviours, assisting in the management of anxiety and depression that is often present in the infertility experience. In terms of strategic and solution-focused therapies, the focus is on exceptions to the current situation, such as times when the presenting problem was not present or had a lesser impact, and solutions are built by identifying and enhancing client strengths. Crisis intervention is a fourth approach, which may be appropriate when clients' normal coping skills are compromised and assistance is required to mobilizing resources. Finally, grief counselling addresses the losses that are experienced as a consequence of infertility, and supports the individual in the mourning process.

In a review of the available literature on psychosocial interventions for infertility, Boivin (2003) reports moderate support for the benefit of psychosocial interventions on the well-being of infertile individuals. With regard to group interventions, Boivin describes that education and skills training contribute significantly more to positive outcomes than interventions that focus on emotional expression, support, or the

discussion of infertility-related thoughts and emotions. Overall, however, Boivin indicates that surprisingly few evaluative studies have been conducted in the area of psychosocial interventions for infertility, and even fewer studies meet minimum requirements for research of good quality since the majority rely on small sample sizes, do not have a control group, and/or do not use random assignment to conditions.

Summary of Existing Literature

In addition to the physical impact of infertility, the infertility experience as a whole can impact women emotionally and socially. Emotionally, infertile women may face feelings like depression (van Balen, 2002; van Balen & Trimbos-Kemper, 1993), anxiety (Gerrity, 2001b; King, 2003), anger and frustration (Dunkel-Schetter & Lobel, 1991), guilt (Cooper-Hilbert, 1998), and grief reactions (Shapiro, 1988). They may also experience low self-esteem (van Balen & Trimbos-Kemper, 1993) and feel as though they have lost control over some aspects of their lives (Greil, 2002). Infertility often has a negative effect on women's social relationships (Dunkel-Schetter & Lobel, 1991), including the marital relationship (Gerrity, 2001b) and more specifically, the couple's sexual relationship (Newton et al., 1999; van Balen & Trimbos-Kemper, 1993). Infertile women may experience stigmatization and they may fear being labeled by others as a failure (Atwood & Dobkin, 1992).

Compared to men, women report lower perceptions of self-efficacy for coping with the diagnosis and treatment of infertility (Cousineau et al., 2006), which may be due in part to the ways that women tend to deal with the infertility experience. More women than men use coping strategies of avoidance or accepting responsibility for their infertility, and these strategies are associated with higher levels of distress (Stanton et al.,

1992). This may be an area where counselling would prove to be of benefit, as counsellors could work with infertile women to minimize coping strategies that increase distress, and focus on learning alternative ways of dealing with the infertility experience. In situations where infertile couples exhibit incompatible coping strategies, which can decrease marital satisfaction (Levin et al., 1997; Peterson et al., 2006), couples counselling may be beneficial.

Many infertile participants indicate that it is important to receive written information about infertility treatment, medical services, and psychosocial aspects of infertility (Schmidt et al., 2003). Knowledge and information can also be useful tools in guarding against feeling a loss of control in the infertility experience (Shapiro, 1988). Social coping resources, especially support from one's partner and family, further protect against the stress of infertility (Gibson & Myers, 2002). These potential resources should not be underestimated by counsellors. Infertile clients may benefit from being encouraged to develop and utilize resources such as information about the infertility experience, as well as supportive relationships within their social network.

Differing views exist with regard to the importance of psychological services in dealing with the experience of infertility. While participants in one study suggest that counselling would have made infertility easier (Williams, 1997), other studies indicate that only a minority view the provision of psychosocial services as important (Schmidt et al., 2003). However, given that infertility is estimated to affect 10-15 percent of the population (Spector, 2004), it is reasonable to assume that counsellors will likely encounter female clients dealing with infertility issues over the course of their practice. It is important that counsellors have a clear knowledge of the challenges affecting infertile

women, as well as an understanding of the ways these individuals already deal with their experience, in order to assess how counselling might further strengthen their abilities and skills to face their situation.

Given that the present study gathers information from participants at a specific point and not over a period of time, it is difficult to apply the life crisis theory of infertility, which claims that infertility is initially experienced as an acute crisis and over time may become a prolonged or chronic crisis (Forrest & Gilbert, 1992). Rather, it is anticipated that the difficulties of infertility and the ways of dealing with the experience might be best explored through the biopsychosocial model of infertility. Biological, psychological, and social realms (Williams, Bischoff, & Ludes, 1992).

Chapter 3: Methodology

Concept mapping is a method used to describe the underlying constructs of a phenomenon as it is experienced by the participants themselves (Kunkel & Newsom, 1996). Using a participant-oriented approach, concept mapping employs a combination of qualitative and quantitative methods to garner an understanding of participants' perceptions (Trochim, 1989). This method consists of a formal process using multidimensional scaling and hierarchical cluster analysis to create a map which represents the aggregate responses of a group of participants (Jackson & Trochim, 2002). Concept mapping has been used to explore the perception of helpful experiences in counselling (Paulson, Truscott, & Stuart, 1999), the problems that prompt clients to seek mental health services (Kunkel & Newsom, 1996), the challenges to rehabilitation faced by federal parolees on release to the community (Brown, 2004), and the experience of depression in college students (Daughtry & Kunkel, 1993).

Concept mapping as described by Jackson and Trochim (2002) consists of five steps: (1) units of analysis are created, (2) the units of analysis are sorted into piles of similar concepts, (3) a multidimensional scaling (MDS) analysis is conducted on the pile-sort data, (4) cluster analyses are run on the MDS coordinates to create a final cluster solution, and (5) clusters on the map are labeled. In order to create the units of analysis, participants are asked open-ended questions about the research topic. Concept mapping is particularly suited for the type of response generated by open-ended questions, since analysis can incorporate shorter list-type answers as well as longer narrative-type replies to research questions (Jackson & Trochim, 2002). Once the participants' self-reports of their experience with the research topic have been gathered, the responses are

qualitatively analyzed by the researchers (Kunkel & Newsom, 1996). The goal of the analysis is to condense the data into a list of representative statements that encapsulate participants' experiences and retain as much of the participants' language as possible (Paulson et al., 1999). The researchers examine the responses, editing them for clarity and eliminating redundant statements.

The second step in the concept mapping process involves sorting the units of analysis into groupings. Participants who have experienced the phenomenon under investigation are asked to sort the statements into piles in a way that makes sense to them, although they cannot place all statements in a single pile or put every single statement into its own pile (Trochim, 1989). Because the sorting task is unstructured in nature, the results of the sorting process are indicative of how the participants organize and categorize the statements (Kunkel & Newsom, 1996).

At this point, an additional step may be added to the basic concept mapping process. For the purpose of some studies, it is important to have an understanding of the relative importance of the statements that the participants generated about the research topic. In this case, it is appropriate to have participants complete a rating task, judging each statement on a 5-point Likert-type scale, where 1 = Relatively unimportant (compared with the rest of the statements), 2 = Somewhat important, 3 = Moderately important, 4 = Very important, and 5 = Extremely important (Trochim, Cook, & Setze, 1994). The rating data are analyzed to determine the mean rating of relative importance for each statement.

The third step of the concept mapping process is conducting a multidimensional scaling (MDS) analysis on the data. Multidimensional scaling is a statistical method used

to uncover the hidden structure of the data (Kruskal & Wish, 1978). This technique assists the researcher in exploring the relationships within the data set when the meaningful structure underlying the relationships is not known (Buser, 1989). In MDS, an analogy is made between the psychological concept of dissimilarity and the geometric concept of distance (Davison, Richards, & Rounds, 1986). The data are arranged as points in space located along orthogonal axes, in such a way that the distance between any two points reflects the degree to which they are perceived as similar (Buser, 1989; Kruskal & Wish, 1978). Multidimensional scaling analysis results in a spatial configuration, or map, that graphically displays the relations among the data (Fitzgerald & Hubert, 1987). In the context of concept mapping, MDS arranges data points spatially to reflect how participants tend to categorize and distinguish between items during the sorting task (Kunkel & Newsom, 1996).

Following the multidimensional scaling analysis, data are further analyzed through hierarchical cluster analysis. Cluster analysis is a method of classification used to form homogeneous groups within complex data sets (Borgen & Barnett, 1987). The objective of this analysis is to group the data into clusters so that the units within a cluster have a high degree of natural association among themselves, while the clusters are relatively distinct from each other (Anderberg, 1973). Hierarchical methods, where smaller clusters are arrayed successively within larger superclusters, are the most widely used type of cluster analysis (Borgen & Barnett, 1987). Concept mapping employs hierarchical cluster analysis to group items on the MDS point map into clusters, which reflect similar concepts or aspects of the phenomenon.

During the fifth stage of concept mapping, the clusters on the concept map are labeled. The labeling process can be completed by participants (Trochim, 1989; Trochim et al.,1994) or the researchers (Paulson & Worth, 2002). The items contained in each cluster are examined and descriptive names, which capture the thematic content contained therein, are assigned to the clusters. The final result of the concept mapping process is a visual representation or map of participants' perceptions, illustrating participants' views about the research topic as well as how participants perceive these ideas to be related to each other (Trochim, 1989).

Participants

In advance of participant recruitment, ethical approval for the research was granted by the Faculties of Education, Extension and Augustana Research Ethics Board at the University of Alberta. Participants for the study were recruited through posters displayed in a number of public areas, including local medical centres, counselling centres, and university buildings in Edmonton and the surrounding areas (Appendix A). Further recruitment took place through advertisements placed in local newspapers. In addition, doctors from the Fertility Clinic at the Royal Alexandra Hospital distributed copies of the recruitment poster. The doctors had no access to the research data and had no way of knowing whether or not clients elected to participate in the research.

Potential participants contacted the researcher by phone or email and were screened according to the following inclusion criteria: (1) adult females 18 years of age or older; (2) presently experiencing, or have previously experienced, the inability to achieve a pregnancy after 12 months of unprotected intercourse; and (3) willingness to engage in the research study.

For the statement generation phase (Phase I), 28 people contacted the researcher regarding participation in the study and packages for the first part of the research were mailed out. Twenty-two participants completed and returned the packages. Out of the original 22 participants in the statement generating phase, 16 completed the second research package for the statement sorting and rating phase of the study (Phase II). Eight additional participants were recruited to complete the sorting and rating tasks, and four of these women returned completed packages. In total, 20 women participated in the statement sorting and rating phase of the research.

Demographic information was collected from all participants regarding age, ethnicity, level of education, and marital status. Information specific to the infertility experience was also gathered, including: whether the infertility is a past or present experience, length of the infertility experience, type and cause of infertility, whether participants experienced miscarriages and/or stillbirths, infertility treatments, and involvement in psychological treatments to deal with the infertility experience. The demographic information was compiled separately for the statement generation phase and the statement sorting and rating phase. Demographic information for both phases is presented in Table 1.

Table 1
Participant Demographic Information

Description		Phase 1: Statement Generation $n = 22$	Phase 2: Sorting and Rating $n = 20$
Average Age (years)		$M = 32.9$	$M = 35.9$
Education	High school/GED	2	2
	Post-secondary	14	13
	Graduate/professional education	6	5
Marital Status	Married/common-law	21	17
	Separated/divorced	1	3
Infertility Status	Past infertility	6	8
	Past and present infertility	1	1
	Present infertility	15	11
Length of Infertility	1-5 years	19	15
	6+ years	3	5
Type of Infertility	Primary infertility	16	14
	Secondary infertility	5	5
	Primary and secondary infertility	1	1
Cause of Infertility	Female factors	12	11
	Male factors	1	1
	Combined factors	4	4
	Undetermined	5	4
Previous Miscarriage	Yes	7	7
	No	15	13
Treatment for managing the infertility experience			
	Received	10	9
	None	12	11

Note. Demographic information collected from participants in Phase 1: Statement Generation ($n = 22$) and Phase 2: Sorting and Rating ($n = 20$)

Procedure

Data collection consisted of two separate phases. During the first phase, participants were asked to generate written responses to the research questions. Once these responses were compiled and edited by the researchers, participants completed the

second phase of data collection, which consisted of sorting the statements generated in the first phase of the research. In addition, participants also completed a rating task based on the procedure described by Trochim and his colleagues (1994).

Phase I. Women interested in taking part in the study contacted the researcher via phone or email and were given further information about the research. Participants gave verbal consent to participate in the research and were mailed the first research package. An information letter (Appendix B) in the package outlined the purpose of the research, addressed issues of confidentiality, and described participant rights to discontinue participation in the research. Forms for written informed consent (Appendix C) and demographic information (Appendix D) were also included. Due to the sensitive nature of the research topic, participants were supplied with a list of community resources and information services (Appendix E). For the statement generation data, participants were asked to provide written responses to two questions, "What makes the experience of infertility difficult?" and "How have you managed to deal with the experience of infertility?" (Appendix F). Participants returned the research package to the researcher in postage-paid envelopes.

When all of the research packages had been returned, the participant responses to each of the two questions were compiled. The responses were separated into distinct phrases or statements, while maintaining as much of the original language as possible. For the question "What makes the experience of infertility difficult?", 86 responses were originally identified. Sixty-one statements were selected in response to the question "How have you managed to deal with the experience of infertility?" The researcher and the research supervisor met to examine and edit the statements for clarity and eliminate

redundancy or overlap. The review produced a final list of 52 statements in response to "What makes the experience of infertility difficult?", and 43 statements for the question "How have you managed to deal with the experience of infertility?"

Phase II. Participants were mailed a second research package for the statement sorting and rating phase of the study. The four women who had not participated in Phase I provided written consent and demographic information at this time. In the second research package, participants were given instructions on how to complete the sorting and rating tasks (Appendix G). For each of the two questions, participants were given an envelope containing a number of cards, with each statement generated in Phase I printed on a separate card. Participants were asked to sort the cards into piles in a way that made sense to them, putting statements that seemed to be similar to each other into the same pile. The instructions noted that the cards were not to be placed all in one single pile, nor could each card be sorted alone in its own pile. Following the sorting task, participants rated the relative importance of each of the statements based on a scale ranging from 1, or relatively unimportant, to 5, or extremely important (Appendix H). Again, participants were provided with a community resource list in light of the sensitive nature of the research topic. The completed sorting and rating packages were returned to the researcher in postage-paid envelopes.

Data Analysis

The research data acquired from the sorting task were analyzed using a computer software program, The Concept System (Concept Systems Inc., 1989-2002). The initial analysis applied to the data was MDS, which resulted in a map that represents spatially the interrelations among a set of objects (Fitzgerald & Hubert, 1987). The Concept

System employs a two-dimensional solution for the MDS analysis, which has been found to be an acceptable solution particularly when it is paired with cluster analysis (Kruskal & Wish, 1978; Trochim, 1989). On the concept map, each statement generated by the participants is represented by a single point. The relative position of the points reflects the frequency with which the statements were sorted together by the participants, in that points appearing closer together on the map were more likely to have been sorted together by the participants (Kunkel & Newsom, 1996).

In the MDS analysis, a fit measure was calculated that indicated how well the coordinates on the map account for the proximity data. This measure, referred to as a stress value, equals 0.0 if the coordinates account for the data perfectly, and increases toward 1.0 as the data are less well accounted for (Davison et al., 1986). The MDS analysis also calculated bridging indices, which indicate how frequently the participants sorted statements together in the same pile. Bridging values range from 0 to 1, with lower bridging values indicating that the statement was more likely to have been sorted with statements that are close to it on the map (Trochim, 1993). A high bridging value suggests the statement is a "bridge" between two or more clusters to which it is related (Paulson & Worth, 2002; Trochim, 1993). In addition to the analysis of the sorting task data, the data for the rating task were also analyzed. For each of the statements in each of the two research questions, the mean of all participants' ratings was calculated.

Following the MDS analysis of the data from the sorting task, a hierarchical cluster analysis was conducted on the MDS coordinates. When cluster analysis is used in conjunction with MDS, inferences can be made about participants' categorization of the items, as well as the underlying dimensions of this categorization (Kunkel & Newsom,

1996). The hierarchical cluster analysis used Ward's (1963) algorithm on the MDS coordinates in order to determine how the statements cluster together in terms of similarity (Jackson & Trochim, 2002). This goal of this process is to group the statements into internally consistent clusters.

One of the challenges in cluster analysis is establishing the number of clusters that will be used in the final solution (Anderberg, 1973; Borgen & Barnett, 1987; Everitt, Landau, & Leese, 2001). Cluster solutions ranging from 10 to 3 clusters were considered for each research question, and at each level a decision was made as to whether the merger or split of clusters was reasonable (Trochim et al., 1994). The researcher and the research supervisor jointly determined the final cluster solution for each concept map. In the process of labeling each cluster, primary consideration was given to statements that most contributed to the uniqueness of each cluster, as well as the relative distance of each item to the other items on the map (Paulson & Worth, 2002). Bridging indices were reviewed from the lowest bridging value to the highest bridging value in each cluster. Five additional graduate-level researchers were consulted for suggestions regarding appropriate phrases or words to best describe the set of statements contained in each cluster, and final cluster labels were assigned by the researcher and the research supervisor.

Chapter 4: Results

The results of this research study are discussed according to the two research questions, "What makes the experience of infertility difficult?" and "How have you managed to deal with the experience of infertility?" A concept map is presented for each question, with each of the statements represented by a point on the map and cluster borders demarking the major themes identified through cluster analysis. A summary table of the clusters and items is also included for each question. Finally, an overview of each of the maps is provided, along with detailed descriptions for each of the clusters.

Challenges of the Infertility Experience

In response to the first research question, "What makes the experience of infertility difficult?", 52 statements were sorted by the participants and analyzed according to the MDS procedure. The final stress value was 0.26, which is considered reasonably stable (Kruskal & Wish, 1978; Kunkel & Newsom, 1996; Paulson et al., 1999). Hierarchical cluster analysis was conducted on the MDS configuration and cluster solutions ranging from 3 clusters to 10 clusters were considered. A final solution of 5 clusters was selected, as this solution resulted in most comprehensible view of the concept map. Subsequent merging or splitting of clusters obscured some of the themes that were apparent in the five-cluster solution. In addition, this solution preserved the MDS results in that it did not allow any overlapping of the clusters (Trochim, 1989).

The final concept map is presented in Figure 1. Table 2 contains a statement key, the five clusters and the statements contained in each, as well as the bridging values and rating values for each statement and cluster. Analysis of the concept map reveals five

main themes revolving around issues that make the infertility experience difficult: (1) Uncertainty, (2) Medical Stressors, (3) Social Reminders of Infertility, (4) Psychological Impact, and (5) Marital and Interpersonal Strains.

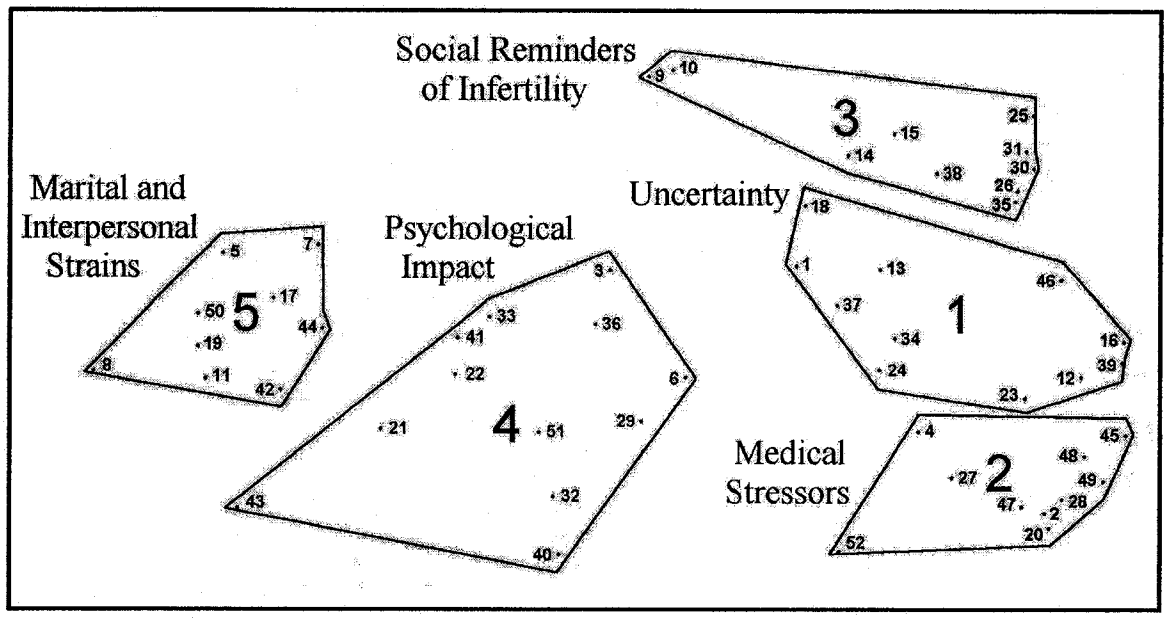

Figure 1. Concept map of 52 elements of what 22 clients identified as challenges of the infertility experience from a qualitative analysis of their response to the probe "What makes the experience of infertility difficult?" (based on multidimensional scaling and hierarchical cluster analysis of 20 participants' open card sorts of these elements).

Table 2
Clusters and Items from Clients' Concept Map of Challenges of the Infertility Experience

Cluster and Item	Bridging Value	Rating *M*
Cluster 1: Uncertainty	0.21	3.72
24. Life revolving around infertility	0.04	4.15
37. Feeling as though we were the only people unable to have a child	0.04	3.40
23. Getting your period each month	0.09	3.95
34. Constant cycle of hope and loss	0.10	4.25
12. Negative results on pregnancy tests	0.13	4.10
1. People do not understand the experience	0.15	4.00
13. Motherly instincts are not being fulfilled	0.16	3.40
18. Insensitive comments	0.19	4.25
46. Never knowing how to respond when asked about plans for children	0.38	3.55
39. Putting plans on hold	0.50	3.30
16. Financial strain	0.55	2.60
Cluster 2: Medical Stressors	0.15	3.40
28. Going back and forth to the gynecologist	0.02	3.45
2. Procedures are uncomfortable	0.03	2.70
47. Frustration with medical procedures	0.05	3.45
27. Months of judging my ovulation times	0.06	3.65
48. Waiting for test results	0.06	3.80
49. Loss of control over your body	0.09	3.90
20. Side effects from treatment	0.17	3.45
4. Experiencing "unexplained" infertility	0.20	3.40
45. Feeling under the microscope	0.29	3.00
52. Not getting enough information from doctors	0.50	3.20
Cluster 3: Social Reminders of Infertility	0.19	3.18
30. Seeing little children	0.06	3.05
35. Seeing other people conceive quickly	0.07	3.85
26. Holding babies	0.09	3.05
15. Hearing about accidental pregnancies	0.15	3.40
38. Not fitting in with people who have kids	0.15	2.80
31. Being around pregnant women	0.19	3.25
14. Hearing women voice regret about getting pregnant	0.20	3.30
25. Going to baptisms	0.20	2.15
10. Hearing about child abandonment	0.35	3.55
9. Hearing about child abuse	0.41	3.45

Table 2 (continued)

Cluster and Item	Bridging Value	Rating *M*
Cluster 4: Psychological Impact	0.32	3.38
6. Being on an emotional roller-coaster	0.00	4.25
36. Feeling like we are being punished	0.04	2.80
22. Feelings of depression	0.09	3.95
41. The sense of grief is overwhelming	0.09	3.85
29. Feeling like less of a woman	0.15	3.00
33. Feeling pressure because time is running out	0.19	3.80
51. Not remembering who you really were before it all started	0.23	2.70
3. Societal pressure	0.29	2.85
21. Feeling powerless	0.38	4.10
40. Doctors are not able to help with the emotional aspect	0.85	3.45
32. Sex is a job rather than a pleasure	0.57	2.70
43. Not a lot of counselling available that is familiar with infertility treatments	1.00	3.15
Cluster 5: Marital and Interpersonal Strains	0.54	3.16
42. Feeling guilty for being the cause of our infertility	0.24	3.60
11. The stress of knowing how much my husband wants a child	0.34	3.00
19. Husband's anxiety	0.37	2.90
17. Strained relationships	0.48	3.55
44. Trying to keep problems a secret	0.48	2.65
7. Infertility is like a death only others can not see it	0.65	3.55
50. Husband being ready to give up sooner than you	0.72	2.70
5. Battling with feelings of rage	0.76	3.20
8. The longer a couple goes through infertility the more isolated they become	0.79	3.30

Note: Participants rated each item according to its importance to the infertility experience on a 5-point scale ranging from 1 = Relatively unimportant to 5 = Extremely important.

Map overview. Exploring and interpreting the map as a whole entails "informed conjecture" about the structures that may appear on the concept map as a result of the sorting task completed by the participants (Daughtry & Kunkel, 1993, p. 320). This involves conceptualizing various sections of the map as representing discrete areas of participants' experiences (Paulson et al., 1999). An exploration of the concept map

reveals that the themes illustrated do not appear to be located along a continuum, but rather appear to consist of two main regions. The first region, involving Cluster 1 ("Uncertainty"), Cluster 2 ("Medical Stressors"), and Cluster 4 ("Psychological Impact"), includes challenges of infertility that are experienced on an individual and personal level. A common thread across these three clusters is an overall loss of control, including a loss of control regarding life plans as identified in Cluster 1 (e.g., "Life revolving around infertility", "Putting plans on hold"), a loss of control over one's body as described in Cluster 2 (e.g., "Loss of control over your body", "Feeling under the microscope"), and decreased control from a psychological standpoint identified in Cluster 4 (e.g., "Being on an emotional roller-coaster", "Feeling powerless").

The second region of the concept map includes Cluster 3 ("Social Reminders of Infertility") and Cluster 5 (" Marital and Interpersonal Strains"), and is separate from the first region in terms of thematic content. This region of the map illustrates themes concerned with the social and relational challenges of the infertility experience. The social and relational aspects of these two clusters are apparent in themes of isolation or conflict (e.g., "Not fitting in with people who have kids", "Strained relationships", "The longer a couple goes through infertility the more isolated they become"). Other relational aspects include reactions to individuals in the fertile world (e.g., "Seeing other people conceive quickly", "Being around pregnant women"), especially when this special status does not appear to be appreciated (e.g., "Hearing women voice regret about getting pregnant") or is abused (e.g., "Hearing about child abandonment", "Hearing about child abuse").

Cluster 1: Uncertainty. Located in the middle of the right-hand side of the map, Cluster 1 has a relatively low bridging value of 0.21, suggesting that the cluster consists of a relatively cohesive group of statements. The statements in Cluster 1 revolve primarily around the uncertainty that is experienced as a result of infertility. Some of the uncertainty is in regard to the possibility of a pregnancy that exists each month (e.g., "Getting your period each month", "Constant cycle of hope and loss", "Negative results on pregnancy tests"). Uncertainty as a result of infertility is also identified in relation to social relationships (e.g., "People do not understand the experience", "Insensitive comments", "Never knowing how to respond when asked about plans for children"). Other statements point to economical uncertainty (e.g., "Financial strain") and role uncertainty (e.g., "Motherly instincts are not being fulfilled"). Uncertainty is also identified on a larger scale; the uncertainty that evolves with the infertility experience can interfere with making life plans and thinking about the future (e.g., "Life revolving around infertility", "Putting plans on hold").

Cluster 1 has the highest rating of importance of all clusters on the map (3.72), suggesting that uncertainty contributes considerably to the difficulty of the infertility experience. Specifically, two items relating to the uncertainty of pregnancy possibilities ("Constant cycle of hope and loss", "Negative results on pregnancy tests") and two items relating to uncertainty in social relationships ("People do not understand the experience", "Insensitive comments") have average ratings of 4 or higher, indicating that in general, participants rate these items as "Very important".

Cluster 2: Medical stressors. Cluster 2 is located in the bottom right-hand corner of the map, and has an overall bridging value of 0.15. The tightness of this cluster is

indicative of a high level of consistency within the cluster, suggesting that participants frequently sorted the items in this cluster together. Medical issues predominate in this group of statements, ranging from contact with medical professionals (e.g., "Going back and forth to the gynecologist", "Not getting enough information from doctors") to challenges relating to infertility testing and treatment (e.g., "Procedures are uncomfortable", "Waiting for test results", "Side effects from treatment"). The medical issues extend to an acute awareness of one's body (e.g., "Months of judging my ovulation times", "Feeling under the microscope"), contrasted with a loss of control over one's body (e.g., "Loss of control over your body").

This cluster has the second-highest rating of importance (3.40), suggesting that medical stressors contribute to the difficulty of the infertility experience. Interestingly, while the majority of the statements are rated at a 3 or higher, the statement "Procedures are uncomfortable" has a rating of 2.70, indicating that physical discomfort is not considered to be as important to the difficulties of the infertility experience as other medical stressors.

Cluster 3: Social reminders of infertility. Situated in the top right-hand corner of the concept map, Cluster 3 also has a fairly low bridging value (0.19). This cluster involves interactions and cues in the social environment that serve to remind women about their infertility. Some of the statements are fairly immediate and personal (e.g., "Holding babies", "Not fitting in with people who have kids"), while other cues are more general in nature (e.g., "Hearing about accidental pregnancies", "Hearing about child abandonment"). Cluster 3 has the second-lowest rating (3.18), which suggests that the items in this cluster are viewed as relatively less important in comparison to other

clusters. However, the rating still places this cluster within the "Moderately important" range according to the Likert-type scale.

Cluster 4: Psychological impact. Cluster 4 is positioned towards the left-hand side on the bottom of the map. The bridging value is 0.32, indicating that this cluster is not as cohesive as the first three clusters. Participants were less likely to sort the items in this cluster together consistently. In particular, the statement "Not a lot of counselling available that is familiar with infertility treatments" has a bridging value of 1.00. This bridging value indicates that the statement is an outlier and could potentially be sorted in any of the other clusters.

The remaining items in the Cluster 4 relate to the psychological effects (e.g., "Feeling like we are being punished", "Feeling pressure because time is running out", "Feeling powerless") and emotional results (e.g., "Being on an emotional roller-coaster", "The sense of grief is overwhelming", "Feelings of depression") of the infertility experience. Questioning one's identity is another issue identified within this cluster (e.g., "Feeling like less of a woman", "Not remembering who you really were before it all started"). Cluster 4 is rated at 3.38 in terms of relative importance, indicating that emotional and psychological impacts contribute to the difficulty of the infertility experience. Specifically, the statements "Being on an emotional roller-coaster" and "Feeling powerless" have ratings over 4, identifying them as "Very important" in relation to the difficulties of infertility.

Cluster 5: Marital and interpersonal strains. Located on the left-hand side of the concept map, Cluster 5 has the highest bridging value of all the clusters (0.54), suggesting greater diversity among the statements. In particular, there are high bridging

values for the statements "Husband being ready to give up sooner than you" (0.72), "Battling with feelings of rage" (0.76), and "The longer a couple goes through infertility the more isolated they become" (0.79), which increases the average bridging value for this cluster. The high bridging values for these three statements suggests that participants were often unsure of where to sort these items.

Some of the statements in Cluster 5 are connected to relational difficulties on a broad social scale (e.g., "Strained relationships"), including feeling disconnected from others (e.g., "Infertility is like a death only others can not see it", "The longer a couple goes through infertility the more isolated they become"). Other items in the cluster involve strains placed on the marital relationship as a result of the infertility experience (e.g., "The stress of knowing how much my husband wants a child", "Husband's anxiety", "Husband being ready to give up sooner than you"). With a rating value of 3.16 cluster 5 has the lowest rating of the clusters on the map, although this value is still rated within the "Moderately important" range according to the Likert-type scale.

Dealing with the Infertility Experience

Forty-three statements were sorted by participants in response to the second research question, "How have you managed to deal with the experience of infertility?" The data from the sorting task was analyzed according to the MDS procedure. This resulted in a final stress value of 0.26, which again is considered to be stable (Kruskal & Wish, 1978; Kunkel & Newsom, 1996; Paulson et al., 1999). After conducting the hierarchical cluster analysis, cluster solutions ranging from 3 to 10 clusters were considered. A four-cluster solution was selected as the final cluster solution, as it resulted

in a clear distinction between the clusters and presented the most comprehensible view of the concept map.

The final concept map for the second research question is presented in Figure 2. The statement key, the statements within each cluster, and bridging and rating values are presented in Table 3. Analysis of the concept map revealed four main themes in terms of the ways women deal with the infertility experience: (1) Receiving Support, (2) Seeking Information, (3) Coping Strategies, and (4) Emotional Expression.

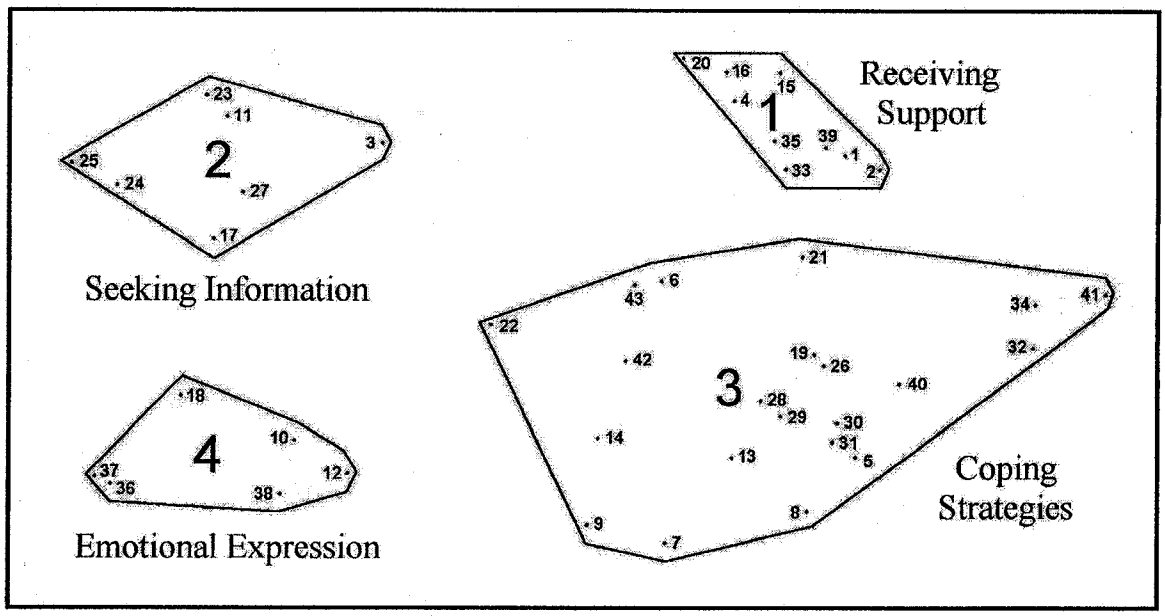

Figure 2. Concept map of 43 elements of how 22 clients described managing the infertility experience, from a qualitative analysis of their response to the probe "How have you managed to deal with the experience of infertility?" (based on multidimensional scaling and hierarchical cluster analysis of 20 participants' open card sorts of these elements).

Table 3
Clusters and Items from Clients' Concept Map of Dealing with the Infertility Experience

Cluster and Item	Bridging Value	Rating *M*
Cluster 1: Receiving Support	0.19	2.90
15. Attending support group meetings validated my feelings	0.14	2.05
16. Receiving information from support group meetings	0.15	2.05
39. Having supportive friends	0.16	4.20
4. Talking to other couples going through infertility	0.16	3.25
20. Receiving support from online community	0.18	2.25
35. Receiving support through adoption agency	0.20	1.80
33. Getting counselling	0.21	2.90
1. Receiving support from husband	0.22	4.20
2. Receiving support from family	0.27	3.40
Cluster 2: Seeking Information	0.61	3.79
11. Continuing to search for answers	0.50	3.80
23. Doing research on the internet	0.54	3.35
3. Reading books on infertility	0.60	3.30
27. Receiving excellent medical care	0.60	4.20
24. Seeing specialists	0.64	4.15
25. Taking steps to find out why I am infertile	0.69	4.25
17. Keeping treatment schedule going as fast as possible	0.70	3.50
Cluster 3: Coping Strategies	0.22	2.91
28. Hoping	0.00	3.85
26. Having faith in God	0.00	2.70
29. Praying	0.02	3.10
19. Trying to stay positive	0.03	3.85
6. Realizing that not having children does not make me any lesser than others	0.05	3.40
43. Accepting infertility	0.06	3.35
42. Believing that I will get pregnant	0.07	3.65
30. Maintaining a good diet	0.09	3.60
31. Getting adequate sleep	0.11	3.50
5. Exercising	0.14	3.45
13. Volunteering	0.17	2.10
21. Fulfilling my role of being a mother through adoption	0.18	2.20
22. Realizing that the things that happen in my life are what make me who I am	0.22	3.55
14. Distracting myself	0.25	3.40
40. Doing relaxation techniques	0.26	2.85
8. Doing yoga	0.33	2.05

Table 3 (continued)

Cluster and Item	Bridging Value	Rating *M*
Cluster 3: Coping Strategies (continued)		
9. Cleaning	0.35	2.05
7. Shopping	0.38	1.70
32. Using visualization techniques	0.50	2.00
34. Journaling	0.53	2.75
41. Receiving acupuncture	0.84	2.00
Cluster 4: Emotional Expression	0.68	2.79
12. Crying	0.46	3.65
38. Getting angry	0.53	3.05
10. Mourning	0.55	3.40
36. Withdrawing	0.70	2.30
37. Refusing to touch babies	0.85	2.05
18. Working extra hours to help with financial strain	1.00	2.30

Note: Participants rated each item according to its importance to the infertility experience on a 5-point scale ranging from 1 = Relatively unimportant to 5 = Extremely important.

Map overview. Conceptualizing the map regionally, different approaches to dealing with the experience of infertility are observed. Moving from the top to the bottom of the map illuminates a continuum of external to internal management of the infertility experience. The two clusters at the top of the map, Cluster 1 ("Receiving support") and Cluster 2 ("Seeking information"), both draw on resources outside of oneself in order to deal with infertility. For Cluster 1, this involves receiving support from external parties such as family, friends, or support groups. Cluster 2 revolves around searching externally for information and answers about infertility, looking primarily to the medical community for answers.

Cluster 3 ("Coping Strategies") and Cluster 4 ("Emotional Expression") appear on the bottom of the map and represent internal management of the infertility experience.

Cluster 3 identifies a myriad of strategies individuals use to deal with the experience of infertility on a personal level, including a number of statements relating to personal reflection (e.g., "Realizing that not having children does not make me any lesser than others") and taking individual action (e.g., "Maintaining a good diet", "Getting adequate sleep"). Cluster 4 relates to the expression of emotions experienced at an individual and personal level in response to the infertility experience (e.g., "Crying", "Getting angry") and internal management strategies to control or moderate these expressions behaviorally (e.g., "Withdrawing", "Refusing to touch babies").

Cluster 2 ("Seeking information") has by far the highest rating of importance in dealing with the experience of infertility. While Cluster 1 ("Receiving support") does not have a high overall importance, the importance ratings for personal supports such as spouse, family, and friends are still higher than many of the ratings for statements in Cluster 3 ("Coping Strategies") or Cluster 4 ("Emotional Expression"). This suggests that overall, external methods are viewed as more important than internal management in dealing with the experience of infertility.

Cluster 1: Receiving support. Located in the top right-hand corner of the concept map, Cluster 1 has the lowest bridging value of any of the clusters (0.19). This value suggests that this is a relatively cohesive cluster, consisting of a conceptually similar group of statements. The statements in Cluster 1 are primarily concerned with receiving support and being connected with others. Some of the statements refer to supportive relationships with family and friends (e.g., "Having supportive friends", "Receiving support from husband", "Receiving support from family"), although other items identify more formal supports in the community (e.g., "Attending support group meetings

validated my feelings", Receiving support from online community", "Getting counselling").

Cluster 1 has a rating value of 2.90, suggesting that while other clusters are rated somewhat higher by participants, receiving support is still viewed as "Somewhat important" to "Moderately important" in dealing with infertility. It is important to note, however, that the average importance rating is pulled down by low ratings on statements relating to formalized supports such as support groups or adoption agencies. As such, the high ratings for personal supports like "Having supportive friends" (4.20) and "Receiving support from husband" (4.20) are not immediately visible without closer inspection of importance ratings for individual statements.

Cluster 2: Seeking information. Cluster 2 is located in the top left-hand corner of the map, and has an overall bridging value of 0.61. This value indicates that the statements in this group could potentially be placed in other clusters. Nevertheless, there is a relatively clear theme among the statements, with most items relating to obtaining information and knowledge about infertility. While some of the statements suggest that information is obtained by participants themselves (e.g., "Doing research on the internet", "Reading books on infertility"), some knowledge is derived from medical professionals (e.g., "Seeing specialists"). Cluster 2 has the highest importance rating of all clusters on the map (3.79), suggesting that seeking knowledge and information about one's infertility is a crucial part of how participants manage to deal with the experience of infertility.

Cluster 3: Coping strategies. Situated in the bottom right-hand corner of the concept map, Cluster 3 has a bridging value of 0.22. While this cluster has the largest number of statements, the relatively low bridging value suggests that these items were

frequently sorted together by the participants. A number of positive strategies for dealing with infertility are identified in this cluster, including maintaining a healthy lifestyle (e.g., "Exercising", "Maintaining a good diet", "Getting adequate sleep") and engaging in self-care activities (e.g., "Doing relaxation techniques", "Journaling"). Other aspects of dealing with infertility involve spirituality (e.g., "Having faith in God", "Praying") and positive thinking (e.g., "Trying to stay positive", "Believing that I will get pregnant"). Some of the statements identify diversions to avoid dwelling on the infertility experience (e.g., "Distracting myself", "Volunteering, "Shopping", "Cleaning"), while other statements represent attempts at coming to terms with infertility (e.g., "Realizing that not having children does not make me any lesser than others", "Accepting infertility", "Realizing that the things that happen in my life are what make me who I am").

The relative importance of Cluster 3 is rated at 2.91, the second-highest overall rating. Although clearly not as important as Cluster 2, the coping strategies identified in this cluster do contribute to participants' management of the infertility experience. Statements related to maintaining a positive attitude are rated by participants as particularly important strategies.

Cluster 4: Emotional expression. Cluster 4 is positioned in the bottom-left hand corner of the concept map and has the highest bridging values of all the clusters (0.68). The high bridging value indicates that participants were less likely to consistently sort the statements in this cluster together. More specifically, the bridging value for the statement "Working extra hours to help with financial strain" is 1.00. The high bridging value identifies the statement as an outlier, indicating that participants were unsure of where to sort this statement and it could potentially be grouped with every other cluster.

Aside from the outlier statement identified above, the statements in Cluster 4 are related to experiencing and expressing emotion. The first three statements in the cluster involve the release of emotion ("Crying", "Getting angry", "Mourning"), whereas the next two statements are behaviours employed to forestall emotional expression ("Withdrawing," "Refusing to touch babies").

Cluster 4 has the lowest rating of relative importance (2.79), which is a possible reflection of the ambiguity in this cluster. Overall, however, this cluster is still viewed as "Somewhat important" to "Moderately important" in dealing with infertility. Taking a closer look at the importance ratings of individual statements, it is apparent that the statements most clearly relating to emotional expression ("Crying", "Getting angry", "Mourning") are rated at 3 or above, indicating they are viewed as "Moderately important". The remaining statements in the cluster, including the outlier, have lower ratings and pull down the average important rating of the cluster.

Summary

The results of this study include two concept maps generated by the research participants. These maps provide a visual representation of the difficulties faced as a result of infertility, as well as the ways that infertile women deal with the experience. The first concept map illustrates five main themes that make infertility especially difficult, wherein participants identify the uncertain nature of the infertility experience as the most important challenge. Other difficulties of infertility include medical issues and the psychological impact associated with the infertility experience. Social concerns are also highlighted, in that infertility places a strain on the marriage and other interpersonal

relationships. In addition, cues in the social environment often remind women of their infertility.

The second concept map outlines the ways in which women deal with the infertility experience. While receiving support is an important factor in managing infertility stress, seeking out information about infertility is identified by the participants as being the most important method in dealing with the experience of infertility. Coping strategies and the expression of emotions associated with infertility are additional ways that women deal with the experience of infertility. In the next chapter, these challenges of infertility and methods of dealing with the experience are discussed by comparing findings to the existing infertility literature, while highlighting contributions of the present study.

Chapter 5: Discussion

The purpose of the present study is to gain a conceptual understanding of women's experiences of infertility. Since much of the existing research in this area is conducted from a primarily medical view (Greil, 1997), there is a shortage of research exploring the experience of infertility as perceived by infertile women themselves (van Balen & Inhorn, 2002). By using the method of concept mapping, the women in this study are active participants in the process of developing an awareness of how they experience and deal with infertility. Furthermore, this approach minimizes the possibility that researchers would impose pre-existing categories on the data.

The two concept maps resulting from this study illustrate women's perception of the challenges that make the infertility experience difficult and the ways in which these women manage to deal with their infertility. One of the findings highlighted in this study is that the uncertainty accompanying infertility is perceived as the most important challenge faced by infertile women. They are greatly affected by the constant cycle of hope and loss to the extent that they describe their lives revolving around infertility. The uncertainty of a pregnancy each month, in addition to financial uncertainty, makes it difficult to plan for the future.

The importance of information in dealing with infertility is also emphasized by the women in this research. Seeking out information regarding infertility and relying on the knowledge of medical professionals are identified as crucial strategies for dealing with the infertility experience. Overall, these methods for dealing with infertility are perceived by infertile women as being more important than receiving support, expressing emotions, or other coping strategies.

Additional findings with regard to dealing with infertility highlight the active role women play in the process. Whereas some emotional responses such as crying and mourning are usually described as effects of the infertility experience, these emotional expressions are described in this study as ways that infertile women actively deal with infertility. This suggests that the expression of emotions is an important part of the process in managing the infertility experience.

Challenges of the Infertility Experience

The findings of this research highlight a number of issues that make the infertility experience difficult: uncertainty, medical stressors, psychological impact, social reminders of infertility, and marital and interpersonal strains. These findings indicate that the challenges of infertility are experienced in the psychological, social, and biological realms, consistent with a biopsychosocial model of infertility (see Gerrity, 2001a). The uncertainty associated with infertility is identified by participants as a considerable challenge of the experience, since instability and insecurity may invade a number of life areas. Medical and psychological stresses also contribute to the difficulty of infertility. In addition, women encounter cues in the social environment that remind them of their infertility, while marital and interpersonal strains further add to the challenges of the infertility experience.

Uncertainty. Issues relating to the uncertainty of the infertility experience are documented in existing research, ranging from the uncertain possibility each month that a pregnancy may occur (Daniluk, 2001) to the large-scale uncertainty of the future and life-planning (Dunkel-Schetter & Lobel, 1991). The uncertainty of pregnancy contributes to a constant cycle of hope followed by feelings of loss with a monthly reminder of failure

(Daniluk, 2001; Reading, 1991). Participants in this study identify that their lives revolved around their infertility and plans were put on hold as a result; similar concerns are recognized in the literature (Cooper-Hilbert, 1998; Dunkel-Schetter & Lobel, 1991). This may be due in part to the financial uncertainty that frequently ensues with high costs of infertility treatment (Shapiro, 1999; Spector, 2004).

Individuals dealing with infertility frequently do not know how to respond to questions about children or how to react to insensitive comments and pressure from others to start a family (Menning, 1988). Furthermore, infertile individuals often feel that friends or family do not understand their experience (Dunkel-Schetter, & Lobel, 1991). This can be especially difficult when individuals feel as though they are the only ones affected by infertility (Daniluk, 2001). Compounding this social uncertainty is the invisibility of infertility, as individuals often do not know any other couples in their social network who are infertile (Menning, 1988). Participants in this research express that motherly instincts cannot be fulfilled as a result of infertility since the possibility of becoming a parent is uncertain.

While many issues appearing in the thematic cluster of "Uncertainty" are acknowledged in the literature, the importance of these difficulties is emphasized in the current findings. In terms of the challenges that contribute to the difficulty of the infertility experience, "Uncertainty" was rated by the participants as the cluster with the highest importance, indicating that these issues contribute substantially to the stress of the infertility experience.

Medical stressors. Once infertile individuals or couples decide to seek medical treatment for their condition, they encounter new challenges in a medical system

involving diagnostic and treatment procedures that are frequently invasive and time-consuming (Stanton & Dunkel-Schetter, 1991). Participants in this study report feeling under the microscope, which is not surprising considering that women are the primary focus of medical investigation and treatment for infertility, regardless of which partner is the source of the difficulty (Greil, 2002; van Balen & Inhorn, 2002). Women undergoing infertility treatment are often frustrated by medical procedures and waiting times, with the treatment process generally taking more time than expected (Daniluk, 2001).

The intense medical scrutiny can lead infertile women to feel a loss of control over their bodies (Dunkel-Schetter & Lobel, 1991), which is highlighted in the current findings. Feeling out of control is exacerbated if individuals feel that that they have not received adequate information about the treatment process, especially for those individuals dealing with unexplained infertility (Daniluk, 2001), as are six of the current participants. Unfortunately, it is not unusual for individuals receiving treatment for infertility to receive little or no information about their future treatment plan or possible side effects (Souter et al., 1998).

Psychological impact. Most likely due to the ongoing debate about the relationship between infertility and psychological adjustment, issues in the thematic cluster "Psychological Impact" appear to receive a large amount of attention in the research literature. In the present study, the most highly rated component in this area is the feeling of being on an emotional roller-coaster. This phrase conveys the erratic emotional and psychological experience that frequently accompanies a diagnosis of infertility, and it has been commonly used by participants and researchers in other studies (Greil, 2002; Watkins & Baldo, 2004; Williams, 1997). Feeling powerless is another

important concept in this thematic cluster. Such feelings might be expected in a world where fertile status is the norm and infertile individuals are not always supported emotionally by those in the medical system (Shapiro, 1999). Consistent with the research literature, participants in this study report that doctors are not able to help with the emotional aspects of infertility (Souter et al., 1998).

Researchers in the infertility literature frequently acknowledge reactions such as grief (Cooper-Hilbert, 1998; Forrest & Gilbert, 1992; Reading, 1991; Shapiro, 1988; Watkins & Baldo, 2004; Williams, 1997) and depression (Cooper-Hilbert, 1998; Forrest & Gilbert, 1992; van Balen, 2002; van Balen & Trimbos-Kemper, 1993; Williams, 1997). These experiences are endorsed in the present study as well. The findings suggest that the negative impacts of the infertility experience may even lead some women to feel as though they are being punished, as described by other researchers (Atwood & Dobkin, 1992).

In their quest to become pregnant, participants in this research report experiencing time pressures as well as societal pressure. The social pressures on women to procreate have been acknowledged (Dunkel-Schetter & Lobel, 1991; Greil, 2002; Spector, 2004). Researchers also recognize that self-esteem and identity may be threatened as a result of the infertility experience (Dunkel-Schetter & Lobel, 1991; Williams, 1997), consistent with participants in this study who express feeling like less of a woman. In addition, women sometimes have trouble seeing themselves as attractive when there is a problem with their infertility (Spector, 2004). This can be compounded when sexual activity is perceived as a job with reproductive purposes rather than a pleasurable activity, as

identified by the present findings as well as other literature (Goodman & Rothman, 1984).

Social reminders of infertility. Women dealing with infertility are constantly faced with reminders about their condition by cues in their social environment. For these women, their infertility appears to be a stark contrast to the relative ease of the rest of the population making the transition to parenthood (Daniluk, 2001). The participants in this study identify that being around pregnant women, babies, or little children makes the infertility experience difficult. Consequently, important social events such as baptisms or baby showers are distressing (Spector, 2004), as they serve as inescapable cues reminding infertile women of what they cannot have. Women experiencing infertility may feel unaccepted by others or feel as though they do not fit in with people who have children (Dunkel-Schetter & Lobel, 1991). It is common for infertile individuals to feel jealous or resentful of those who can and do bear children (Dunkel-Schetter & Lobel, 1991).

Other challenges that are identified in the current findings include hearing about accidental pregnancies or hearing women voice regret about getting pregnant. It can be particularly distressing to hear about child abuse or abandonment (Williams, 1997). Interestingly, it appears that social reminders of infertility are addressed more frequently in counselling literature and psychoeducational literature for infertile individuals, but aside from some qualitative exploration (e.g., Daniluk, 2001) these issues do not receive much attention in the research literature.

Marital and interpersonal strains. Tension within the marital dyad and conflict in other interpersonal relationships are highlighted in the findings of this study, consistent with other reports in the literature (Dunkel-Schetter & Lobel, 1991; Newton et al., 1999).

Contributing to the strain in the marriage, it is common for one partner to desire a pregnancy more than the other partner (Spector, 2004). In addition, participants in this study report that a challenge of the infertility experience is feeling guilt over being the source of the couple's infertility difficulties. While guilt is a common reaction (Applegarth, 1999; Cooper-Hilbert, 1998; Dunkel-Schetter & Lobel, 1991; Shapiro, 1988), it is concerning that assuming responsibility for the infertility problem is associated with increased levels of distress (Peterson et al., 2006; Stanton, 1991). Marital distress may also increase over prolonged periods of time or persistence in treatment (Boivin et al., 1995; Gerrity, 2001b).

Unfortunately, difficulties within the marriage are often compounded by a deterioration of relationships with family and friends (Butler & Koraleski, 1990). Participants in this study identify that couples become more isolated the longer they have to deal with infertility. In addition, a perceived lack of support from family and friends may persist for infertile individuals after unsuccessful treatment, which is associated with poorer adjustment (Daniluk & Tench, 2007). Interpersonal strains may result from trying to keep infertility problems a secret from others, as noted in the results in this research. This secrecy, often an attempt to avoid embarrassment and unwanted reactions from others, may increase feelings of isolation (Cook, 1987; Menning, 1988). Isolation is also highlighted by present findings as participants express that infertility is experienced as a death by those individuals unable to conceive, although others do not recognize this loss. This is consistent with other literature describing infertility as a death (Clark et al., 1991) and an experience that is not acknowledged by society (Applegarth, 1999; Lasker & Borg, 1987; Shapiro, 1988).

Dealing with the Infertility Experience

A number of approaches for dealing with infertility are identified by the research participants: seeking information, coping strategies, receiving support, and emotional expression. Seeking information about infertility is rated by participants as the most important method for dealing with the experience. It is likely that seeking out information counteracts some of the uncertainty associated with infertility by enabling women to become more informed about their situation, as well as feel some sense of control within their circumstances. Another method for managing infertility is employing coping strategies, which can range from improving physical health to distracting oneself from infertility. Receiving support, especially from informal sources such as one's spouse, friends, and family is also important for managing infertility. Finally, expressing the emotions associated with infertility is identified as a valuable part of dealing with the experience.

Seeking information. The findings of this study indicate that acquiring information about infertility is a crucial part of managing the infertility experience. Participants identify approaches such as searching for answers and investigating infertility in books or on the internet, which are similar to methods described in the literature (Greil & McQuillan, 2004). Individuals undergoing treatment for infertility stress the importance of receiving information presented by the medical staff, as well as receiving information in written form (Schmidt et al., 2003). Infertile women frequently feel a loss of control in their situation, especially if they do not feel adequately informed about treatment (Daniluk, 2001). Seeking out information about their condition can be an opportunity for empowerment. Indeed, information is identified in the literature as a

valuable defense against feelings of helplessness, by helping infertile individuals become active participants and regain some level of mastery over their circumstances (Shapiro, 1988).

Participants in this study also place importance on receiving quality medical care, as these professionals have expert knowledge and information about the medical condition of infertility. This is consistent with research indicating that particularly at the beginning of treatment infertile individuals have "inherent faith" in the medical community to help them fulfill their dreams of conceiving a child (Daniluk, 2001, p. 125). While the thematic cluster of "Seeking Information" is relatively small in terms of the number of strategies it contained, it is by far the most important method for managing the infertility experience, as identified by participant ratings of relative importance. Clearly, the importance of information in being able to deal with the infertility experience should not be overlooked.

Coping strategies. The coping strategies presented in the findings of the current study vary widely, possibly a reflection of the diversity of participants in terms of type and length of infertility as well as differences in treatment experience. Some of these approaches are practical, common-sense strategies such as getting adequate sleep and exercise and maintaining a good diet. It is interesting that such efforts to improve physical health are sometimes identified in the literature as strategies used by individuals in the bargaining stage of mourning infertility, in demonstrating their unwillingness to accept infertility (Shapiro, 1988). Other coping strategies identified by participants in the present research serve primarily as methods of distraction, which is consistent with other research (Fleming & Burry, 1987). The findings of this study also highlight a variety of

strategies for relaxation and reflection, and researchers have found self-nurturing strategies to be associated with greater well-being (Benyamini et al., 2004).

Strategies related to positive thinking, as well as spiritual or faith-related coping strategies, do not appear to receive much attention in the infertility literature. However, a number of these methods are identified by participants in this study and are rated as being relatively important ways to deal with the infertility experience. On the other hand, while adoption is not rated as having high relative importance by these participants, other researchers suggest that having a child through adoption can act as a protective influence against the impact of infertility and treatment failure (Daniluk & Tench, 2007). It is possible that the current participants do not perceive adoption as a desirable route to motherhood. Finally, the participants in this research identify a number of coping strategies related to accepting infertility and accepting oneself as a person with infertility. These findings appear to be consistent with literature describing the process of coming to terms with the infertility experience (Paleg & Jongsma, 2000) and the final stage of grieving infertility (Shapiro, 1988).

Receiving support. Accepting support from a variety of formal and informal sources is identified by the research participants as another method of dealing with infertility. Support from friends and family, particularly one's spouse, is found to enhance well-being for infertile individuals, while discussions with other infertile couples may be especially helpful (Abbey et al., 1991). All of these strategies are endorsed by the participants in the present research.

According to the literature, accessing informal support by talking to friends or family is more common than acquiring formal assistance by joining a support group or

meeting with a mental health professional (Greil & McQuillan, 2004). Similarly, women in this study suggest that receiving support from informal supports such as one's husband, family, or friends is much more important (as indicated by participant ratings) than receiving formal support from support groups, adoption agencies, or counsellors. While both group and individual counselling interventions can be beneficial to the well-being of those individuals experiencing infertility (Boivin, 2003), studies indicate that the number of individuals interested in making use of psychological services is marginal (Boivin et al., 1999; Schmidt et al., 2003). Support groups can also be a valuable source of support (Reading, 1991), although it appears that only a minority of infertile individuals take advantage of this resource (Gibson & Myers, 2002). Regardless of the source of support, women who mobilize more support are found to be less distressed (Stanton et al., 1992). It is important to note that while some women may find that they do not require formal support to deal with their infertility, others do not seek counselling because of practical obstacles such as not knowing who to contact or having concerns about the financial cost of counselling (Boivin et al., 1999; Shapiro, 1999).

Emotional expression. The expression of emotions is perceived by participants in this study to be an important part of dealing with the infertility experience. Reactions such as tearfulness, anger, and grief are identified in the literature as psychological effects resulting from infertility (Dunkel-Schetter & Lobel, 1991; Shapiro, 1999; Williams, 1997). However, actions such as crying, getting angry, and mourning are not identified in this study as reactions or impacts of infertility, but rather as ways in which women manage to deal with the infertility experience. It is interesting that this perspective places infertile women in a much more active role of *doing* these activities, as

opposed to a view that perceives these individuals as passively *experiencing* them as reactions to their condition.

Other strategies described in the current findings involve ways to avoid expressing emotions associated with the infertility experience. Withdrawal and avoidance behaviours have been acknowledged in the literature (Fleming & Burry, 1987), although avoidant strategies have been associated with increased distress (Berghuis & Stanton, 2002; Stanton et al., 1992). On the other hand, strategies such as emotional processing and expression have been shown to predict decreased levels of distress (Berghuis & Stanton, 2002). It appears that the ways in which women deal with their emotions can impact their ability to cope with the infertility experience.

Strengths and Limitations of the Current Study

As mentioned previously, a strength of the concept mapping approach employed in this study is that participants are actively engaged in item generation and data gathering (Trochim, 1989). Furthermore, since concept mapping invites participants to be involved in preliminary qualitative data analysis through the sorting activity, constructs are defined by the participants rather than the researcher (Daughtry & Kunkel, 1993). Infertility, as experienced by the participants, can therefore be more clearly communicated in the research findings than if researcher bias was permitted to influence the sorting data. It is particularly important that infertility be explored in this way, as research on infertility as experienced by infertile women themselves is limited (van Balen & Inhorn, 2002).

A further advantage of the concept mapping design is the illustrative nature of the concept maps, which communicate the concepts identified by the participants and also

demonstrate the relationships between these ideas (Trochim, 1989). It has been observed that since the ways in which women deal with their experiences of infertility are not yet fully understood, current counselling interventions may not adequately meet the needs of these women (Gibson & Myers, 2002). The findings of the present study highlight how women perceive and deal with the infertility experience. Furthermore, information from the ratings questionnaire provides valuable information with regard to the relative importance of the issues identified by the participants. Since the ratings provided by these women suggest which matters are perceived as the most crucial aspects of the infertility experience, this information may be helpful in determining where intervention efforts might be best directed.

In spite of the strengths and contributions of the current research, it is important to acknowledge the limitations that exist. One concern is that the data for this research is obtained through self-reporting by the participants. In addition, some of the participants in this study have experienced a period of infertility in the past but are no longer trying to conceive; these participants provide retrospective reports of their infertility experience. It is possible that these women may not recall the full details of their experience, or that their current interpretations have shifted over time from their initial perception of infertility.

Another limitation of the current study is that the concept mapping method requires researchers to examine the statements generated by research participants, and divide and reconstruct these ideas into simple one-concept phrases to be used in the sorting phase of the research (Jackson & Trochim, 2002). During this process, some contextual information may be lost from these ideas and it is possible that researchers

unintentionally altered the intended meaning of participant responses (Jackson & Trochim, 2002).

In addition, it should be noted that the participant sample in this study may not be representative of the infertile population as a whole. Specifically, this sample is skewed towards a higher education level and primarily includes women who have sought medical treatment for infertility. However, the various types (primary and secondary) and causes (female factors, male factors, combined factors, unexplained) of infertility are all included in this participant sample.

Implications for Future Research

As the findings of this study suggest, the uncertainty and loss of control associated with the infertility experience are considerable challenges for women dealing with infertility. Further research on these issues, as well as how they might be resolved or managed, would be an important contribution to the infertility literature. In addition, the importance of seeking and receiving information is highlighted in this study and this matter would certainly be worthy of further exploration.

While the results of this research provide valuable insight into the challenges of infertile women, as well as the ways in which they deal with their experience, it would advantageous to explore these experiences within specific populations of infertile women. For example, do women experiencing secondary infertility face different challenges and employ different coping strategies than women with primary infertility? Do experiences differ based on the cause of infertility (i.e., male factors, female factors, combined factors, or unexplained infertility)?

In addition, this study is fairly inclusive in terms of the women who were accepted as participants. Women taking part in this research vary in the amount of time they have been dealing with infertility as well as the type and intensity of medical treatment they have received. Future studies could explore how challenges and ways of dealing with the experience might vary at different stages of infertility treatment, or at different points in the process of coming to terms with a diagnosis of infertility. Valuable information may also result from extending the present research to include the experiences of the male partner in infertile couples.

Subsequent research could attempt to provide further information about the findings of this study by creating surveys or questionnaires based on the statements generated by research participants. Questionnaires could be developed to assess how infertility issues of primary importance, as identified in the results of this research, are being addressed by specific clinics or the medical community at large.

Implications for Counselling

The findings of this study have clinical implications for counselling women who are dealing with infertility. As noted by Applegarth (1999), in order for counsellors to best apply their clinical expertise to assist infertile women they must first ensure that they have thorough knowledge of the psychosocial experience of infertility. In addition, since infertility touches on emotionally-charged subjects such as sexuality, morality, and religion, it is essential that counsellors be sensitive to the values and ethics endorsed by infertile clients (Butler & Koraleski, 1990).

While it is not possible to cure infertility through counselling (Butler & Koraleski, 1990), counsellors can assist women in dealing with the psychological impacts of

infertility and the stresses of treatment (Robinson & Stewart, 1996). One of the psychological impacts identified in this study is guilt over being the cause of the couple's infertility. In counselling infertile couples, it is important to recognize infertility as an issue for both partners and avoid assigning blame to either partner (Cook, 1987; Daniluk, 1991). It may also be helpful to externalize the problem of infertility (Atwood & Dobkin, 1992). It has been suggested that psychological treatment should endeavor to reduce coping strategies such as self-blame, and promote the use of task-oriented coping like problem-solving strategies (Levin, Sher, & Theodos, 1997).

Another challenge of the infertility experience acknowledged in the present study is the strain put on the marital relationship. Because both members of a couple may react differently to a diagnosis of infertility as well as the treatment process (Spector, 2004), it may be beneficial for counsellors to assist couples in dealing with their differing reactions, coping strategies, and needs for support (Forrest & Gilbert, 1992). Couples counselling could also be beneficial for dealing with the sexual difficulties that may arise as a consequence of infertility. In these cases, the goal of the therapist is to help the couple find a healthy balance between "sex for procreation" and "sex for recreation" and find ways to make both experiences enjoyable for both partners (Spector, 2004, p. 95).

Difficulties in relationships outside of the marital dyad are also highlighted in these research findings. Gibson and Myers (2000) recognize the importance of women's development within the context of relationships and propose a relational approach to counselling infertile women. This approach may lead to a better understanding of the self and others, which could be helpful in addressing the interpersonal strains that result from the infertility experience.

The findings of this research indicate that infertile women experience a loss of control, in addition to feeling powerless in their situation. Counsellors can assist these women in regaining some element of control by encouraging them to acquire knowledge about their condition, while learning to interact assertively with professionals in the medical community (Butler & Koraleski, 1990). In addition, counselling interventions may help infertile women to surrender control over unchangeable aspects of their situation and assert themselves in other life areas where they do have control (Daniluk, 1991). Women experiencing infertility can also be encouraged to continue moving forward and make plans for the future, rather than putting life on hold while waiting to conceive (Butler & Koraleski, 1990).

Specific interventions may be appropriate at different points in the infertility experience. Problem-focused strategies such as information gathering and problem-solving may be most helpful for individuals recently diagnosed with infertility and those who want to address controllable aspects of infertility, like making treatment decisions or communicating assertively with medical professionals (McQueeney, Stanton, & Sigmon, 1997). However, individuals concerned with grief and loss may benefit more from emotion-focused strategies, including emotional processing and expression (McQueeney et al., 1997). Cognitive-behavioral group interventions are shown to assist in the management of psychological distress resulting from infertility (Domar, Clapp, Slawsby, Kessel, Orav, & Freizinger, 2000), as well as attenuate stress in individuals waiting to receive assisted reproduction treatment (Tarabusi, Volpe, & Facchinetti, 2004).

Conclusion

The goal of this study is to develop a clearer awareness of women's experiences of infertility. Specifically, the objective of this research is to gain a conceptual understanding of the challenges faced by infertile women and they ways in which they deal with their experience. Using concept mapping, information about the phenomenon is gathered and sorted by women who have experienced infertility. This participant-oriented approach helps to ensure that constructs appearing in the final concept maps are determined by the participants, rather than imposed by the researcher. Participants also rate the relative importance of the challenges and methods of dealing with infertility, providing valuable information about how these concepts are prioritized by infertile women. By enhancing our knowledge of this phenomenon, it is hoped that the findings of this study will contribute to the larger resource base for infertile women and counsellors working with these individuals, and perhaps stimulate further research in this area.

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Appendix A

Recruitment Poster

♦♦♦ RESEARCH STUDY ♦♦♦

What is it like to experience infertility?

Hello, my name is Rachel and I am a Masters student in Counselling Psychology at the University of Alberta. I am interested in exploring how women perceive the experience of infertility.

Are you a woman 18 years of age or older?

Have you been unable to conceive for a period of at least 12 months?

If you fit this description and would like to share your experience as part of a brief study designed to achieve a better understanding of how women experience infertility, please contact **Rachel** at **451-9005** or **infertilityresearch@hotmail.com**.

Participation in the study is completely voluntary and your involvement will be kept in strict confidence.

Appendix B

Information Letter

Research Project: **Women's Experience of Infertility**
Department of Educational Psychology
Faculty of Education
University of Alberta

Researcher: Rachel Stege
Supervisor: Dr. Barbara Paulson

The purpose of the present study is to explore the experience of women dealing with infertility. In gathering information from women who are going through this situation first-hand, the study aims to develop a conceptual understanding of how women experience infertility. It is hoped that the findings of this study will raise awareness and sensitivity to the experience of infertility.

This study involves two sections. Section I consists of a questionnaire, including demographic information as well as two questions relating to your experience of infertility. Section II of the study involves the completion of a sorting task, which consists of arranging the responses generated by the questionnaire into groups based on themes. In addition, you will be asked to rate the importance of the statements. You will be contacted to complete Section II after all participants have completed Section I.

Your involvement in this study will be kept confidential and your name will not be attached to the information that you give. You may decline or withdraw your participation in Section I and/or Section II of the study at any time, without penalty. The results of this study may be used for presentation at professional meetings and publication in journals of a professional nature.

Given the sensitive nature of the research matter, it is recognized that this topic may create discomfort for some participants. For that reason, a list of counselling agencies and support resources will be distributed to all participants.

If you have any questions or concerns, please contact the researcher by email at infertilityresearch@hotmail.com, or call Rachel Stege at 451-9005 or Dr. Barb Paulson at 492-5298.

THANK YOU FOR YOUR PARTICIPATION!

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

Appendix C

Informed Consent Letter

Identification #: ____

Research Project: **Women's Experience of Infertility**
Department of Educational Psychology
Faculty of Education
University of Alberta

Researcher: Rachel Stege
Supervisor: Dr. Barbara Paulson (Ph: 492-5298, Email: barb.paulson@ualberta.ca)

The purpose of the present study is to explore the experience of women dealing with infertility. In gathering information from women who are going through this situation first-hand, the study aims to develop a conceptual understanding of how women experience infertility. It is hoped that the findings of this study will raise awareness and sensitivity to the experience of infertility.

This study involves two sections. Section I consists of a questionnaire, including demographic information as well as two questions relating to your experience of infertility. Section II of the study involves the completion of a sorting task, which consists of arranging the responses generated by the questionnaire into groups based on themes. In addition, you will be asked to rate the importance of those statements. You will be contacted to complete Section II after all participants have completed Section I.

Your involvement in this study will be kept confidential and your name will not be attached to the information that you give. You may decline or withdraw your participation in Section I and/or Section II of the study at any time, without penalty. The results of this study may be used for presentation at professional meetings and publication in journals of a professional nature.

Given the sensitive nature of the research matter, it is recognized that this topic may create discomfort for some participants. For that reason, a list of counselling agencies and support resources will be distributed to all participants.

I hereby declare that I have read and understood the above information and give my informed consent to participate in this study. I understand I have the right to withdraw my participation from the study at any time without penalty, and that my anonymity and confidentiality will be maintained.

Name of Participant (print)	**Signature**	**Date**
Name of Researcher (print)	**Signature**	**Date**

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

Appendix D

Demographic Information

Identification #: ____

Please complete the following as fully as possible:

1. Please indicate your highest level of education:

   ☐ Graduate/professional education ☐ College/university degree

   ☐ Partial college/university ☐ Certificate in a trade/technology

   ☐ High school diploma/GED ☐ Partial high school training

2. Please indicate your age: _____

3. What is your ethnic background? _____

4. Please indicate your marital status:

   ☐ Single ☐ Married/Common-law ☐ Separated/Divorced ☐ Widowed

5. Are you presently experiencing infertility or have you experienced infertility in the past?

   ☐ Present ☐ Past

6. How long have you been dealing with (or how long did you deal with) infertility? _____

7. Is/was the infertility primary or secondary infertility?

   ☐ Primary (never had children) ☐ Secondary – please specify # of children: ____

8. Is/was the infertility attributed to:

   ☐ Male factors ☐ Female factors ☐ Combined factors ☐ Undetermined

9. Have you experienced miscarriage or stillbirth?

   ☐ No ☐ Yes – please specify: _____

10. What treatments have you tried to overcome infertility?

    _____

    _____

11. Have you participated in counselling/psychological treatment/support groups to deal with infertility? ☐ No ☐ Yes – please specify: _____

Appendix E

Community Resources

Given the sensitive nature of this topic you have reflected on, we would like to provide you with the following list of counselling agencies and information services.

Community Resources and Information Services

Catholic Social Services	**432-1137**
Clinical Services, University of Alberta	**492-3746**
Cornerstone Counselling	**482-6215**
Distress Line	**482-HELP (4357)**
The Family Centre	**423-2831**
Infertility Awareness Association of Canada Inc. E-mail: info@iaac.ca Internet: www.iaac.ca/index.asp	**(514) 484-2891 or 1-800-263-2929**
Infertility Connection of Edmonton E-mail: edmontoninfertility@shaw.ca Internet: www.members.shaw.ca/edmontoninfertility/	**481-6618**
Infertility Network E-mail: Info@InfertilityNetwork.org Internet: www.infertilitynetwork.org	**(416) 691-3611**

Appendix F

Questionnaire

Identification #: ____

Please reflect on the following questions in as much *detail as possible*. There are *no right or wrong* answers. If you require more writing space, please continue on the back of the sheet.

1. **What makes the experience of infertility difficult?** _____

2. **How have you managed to deal with the experience of infertility?** _____

Appendix G

Instructions for Section II (Sorting and Rating Task)

Research Project: **Women's Experience of Infertility**
Department of Educational Psychology
Faculty of Education
University of Alberta

Researcher: Rachel Stege
Supervisor: Dr. Barbara Paulson

Thank you again for participating in Section I of the study. We are aiming to develop a conceptual understanding of how women experience infertility. It is hoped that the findings of this study will raise awareness and sensitivity to the experience of infertility.

1. Enclosed are two envelopes, each containing statements generated by participants in response to one of the research questions in Section I.
   - Take one envelope at a time and sort the statements into piles in a way that makes sense to you, putting statements that seem to be similar to each other into the same pile.
   - When you are satisfied with your groupings, staple each pile together and seal the piles in the enclosed envelope.
   - Note that you may have as many piles as you feel are appropriate. If you feel that a particular statement is unrelated to all of the other statements, you can place it alone in its own pile. However, you cannot have each statement in its own pile, and you cannot have all the statements in one single pile. Other than those two restrictions, there is no right or wrong way to complete the sorting.

2. You will also find an enclosed list of the statements generated in Section I. Beside each is a scale of 1 to 5, representing a scale of no importance up to very high importance. Please read though the statements and rate the importance of each by circling the appropriate number.

3. When you have completed both tasks, please return the package to the researcher.

You may decline or withdraw your participation in the study at any time, without penalty. Your involvement in this study will be kept confidential and your name will not be attached to the information that you give. If you have any questions or concerns, please contact the researcher by email at infertilityresearch@hotmail.com, or call Rachel Stege at 451-9005 or Dr. Barb Paulson at 492-5298.

THANK YOU FOR YOUR PARTICIPATION!

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

Appendix H

Rating Task for Question 1

Identification #: ____

Below are the statements that were generated in response to the question, *"What makes the experience of infertility difficult?"* Beside each statement is a scale of 1 to 5. Please read though the statements and rate the importance of each by circling the appropriate number, based on the following scale:

1 = Relatively unimportant (compared with the rest of the statements)
2 = Somewhat important
3 = Moderately important
4 = Very important
5 = Extremely important

1 2 3 4 5	1. People do not understand the experience
1 2 3 4 5	2. Procedures are uncomfortable
1 2 3 4 5	3. Societal pressure
1 2 3 4 5	4. Experiencing "unexplained" infertility
1 2 3 4 5	5. Battling with feelings of rage
1 2 3 4 5	6. Being on an emotional roller-coaster
1 2 3 4 5	7. Infertility is like a death only others can not see it
1 2 3 4 5	8. The longer a couple goes through infertility the more isolated they become
1 2 3 4 5	9. Hearing about child abuse
1 2 3 4 5	10. Hearing about child abandonment
1 2 3 4 5	11. The stress of knowing how much my husband wants a child
1 2 3 4 5	12. Negative results on pregnancy tests
1 2 3 4 5	13. Motherly instincts are not being fulfilled
1 2 3 4 5	14. Hearing women voice regret about getting pregnant
1 2 3 4 5	15. Hearing about accidental pregnancies
1 2 3 4 5	16. Financial strain
1 2 3 4 5	17. Strained relationships
1 2 3 4 5	18. Insensitive comments
1 2 3 4 5	19. Husband's anxiety
1 2 3 4 5	20. Side effects from treatment
1 2 3 4 5	21. Feeling powerless
1 2 3 4 5	22. Feelings of depression

Continued on reverse →

1 2 3 4 5	23. Getting your period each month
1 2 3 4 5	24. Life revolving around infertility
1 2 3 4 5	25. Going to baptisms
1 2 3 4 5	26. Holding babies
1 2 3 4 5	27. Months of judging my ovulation times
1 2 3 4 5	28. Going back and forth to the gynecologist
1 2 3 4 5	29. Feeling like less of a woman
1 2 3 4 5	30. Seeing little children
1 2 3 4 5	31. Being around pregnant women
1 2 3 4 5	32. Sex is a job rather than a pleasure
1 2 3 4 5	33. Feeling pressure because time is running out
1 2 3 4 5	34. Constant cycle of hope and loss
1 2 3 4 5	35. Seeing other people conceive quickly
1 2 3 4 5	36. Feeling like we are being punished
1 2 3 4 5	37. Feeling as though we were the only people unable to have a child
1 2 3 4 5	38. Not fitting in with people who have kids
1 2 3 4 5	39. Putting plans on hold
1 2 3 4 5	40. Doctors are not able to help with the emotional aspect
1 2 3 4 5	41. The sense of grief is overwhelming
1 2 3 4 5	42. Feeling guilty for being the cause of our infertility
1 2 3 4 5	43. Not a lot of counselling available that is familiar with infertility treatments
1 2 3 4 5	44. Trying to keep problems a secret
1 2 3 4 5	45. Feeling under the microscope
1 2 3 4 5	46. Never knowing how to respond when asked about plans for children
1 2 3 4 5	47. Frustration with medical procedures
1 2 3 4 5	48. Waiting for test results
1 2 3 4 5	49. Loss of control over your body
1 2 3 4 5	50. Husband being ready to give up sooner than you
1 2 3 4 5	51. Not remembering who you really were before it all started
1 2 3 4 5	52. Not getting enough information from doctors

Rating Task for Question 2

Identification #: ____

Below are the statements that were generated in response to the question, "*How have you managed to deal with the experience of infertility?*" Beside each statement is a scale of 1 to 5. Please read though the statements and rate the importance of each by circling the appropriate number, based on the following scale:

1 = Relatively unimportant (compared with the rest of the statements)
2 = Somewhat important
3 = Moderately important
4 = Very important
5 = Extremely important

1 2 3 4 5	1. Receiving support from husband
1 2 3 4 5	2. Receiving support from family
1 2 3 4 5	3. Reading books on infertility
1 2 3 4 5	4. Talking to other couples going through infertility
1 2 3 4 5	5. Exercising
1 2 3 4 5	6. Realizing that not having children does not make me any lesser than others
1 2 3 4 5	7. Shopping
1 2 3 4 5	8. Doing yoga
1 2 3 4 5	9. Cleaning
1 2 3 4 5	10. Mourning
1 2 3 4 5	11. Continuing to search for answers
1 2 3 4 5	12. Crying
1 2 3 4 5	13. Volunteering
1 2 3 4 5	14. Distracting myself
1 2 3 4 5	15. Attending support group meetings validated my feelings
1 2 3 4 5	16. Receiving information from support group meetings
1 2 3 4 5	17. Keeping treatment schedule going as fast as possible
1 2 3 4 5	18. Working extra hours to help with financial strain

Continued on reverse →

1 2 3 4 5	19. Trying to stay positive
1 2 3 4 5	20. Receiving support from online community
1 2 3 4 5	21. Fulfilling my role of being a mother through adoption
1 2 3 4 5	22. Realizing that the things that happen in my life are what make me who I am
1 2 3 4 5	23. Doing research on the internet
1 2 3 4 5	24. Seeing specialists
1 2 3 4 5	25. Taking steps to find out why I am infertile
1 2 3 4 5	26. Having faith in God
1 2 3 4 5	27. Receiving excellent medical care
1 2 3 4 5	28. Hoping
1 2 3 4 5	29. Praying
1 2 3 4 5	30. Maintaining a good diet
1 2 3 4 5	31. Getting adequate sleep
1 2 3 4 5	32. Using visualization techniques
1 2 3 4 5	33. Getting counselling
1 2 3 4 5	34. Journaling
1 2 3 4 5	35. Receiving support through adoption agency
1 2 3 4 5	36. Withdrawing
1 2 3 4 5	37. Refusing to touch babies
1 2 3 4 5	38. Getting angry
1 2 3 4 5	39. Having supportive friends
1 2 3 4 5	40. Doing relaxation techniques
1 2 3 4 5	41. Receiving acupuncture
1 2 3 4 5	42. Believing that I will get pregnant
1 2 3 4 5	43. Accepting infertility