

**RECOVERY FROM TRAUMATIC LOSS: A STUDY OF WOMEN LIVING  
WITHOUT CHILDREN AFTER INFERTILITY**

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## **Dedication**

This dissertation is dedicated to all of the women who participated in this study. You not only gave your time, but revisited a painful period of life in a wish to help others. It was an honor to meet all of you, and a privilege to hear your stories. Because of you, this project was far more gratifying than I ever imagined it would be.

*We must be willing to let go of the life we have planned so as to have the life that is waiting for us. -Joseph Campbell.*

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Finally, I would like to thank my husband, Jay, who never stopped believing in me. From him, I learned about love, kindness, and acceptance. He is my rock. Traveling through life with him by my side brings me the greatest happiness.

## **ABSTRACT**

### **RECOVERY FROM TRAUMATIC LOSS: A STUDY OF WOMEN LIVING WITHOUT CHILDREN AFTER INFERTILITY**

Marni Rosner

Ram A. Cnaan, Ph.D., Dissertation Supervisor

Infertility, from a mental health perspective, is known to have a profound effect on the lives and identities of women. Although many women resolve their infertility by incorporating non-biological children into their conception of family, some women are either unable or unwilling to do so, and live without children. This qualitative study focused on the long-term transition to living without children after pursuing treatment for infertility, and the impact living without children after infertility has had on marriages, relationships with family and friends, and identity. In-depth interviews were conducted with 12 women, aged 35-54, who pursued treatment for infertility, are now living without children (either biological, conceived through third-party reproduction, or adopted), and have not pursued treatment for at least three years. Findings include themes of experiencing trauma; actively deciding to end treatment; moving into living without children; a sense of profound loss and grief; processing the grief; acceptance and choice; reestablishing identity and turning toward the future; growth and opportunity; improved spousal relationships, and enduring issues. Like most stage models, progressing through these phases was not systematic. Findings suggest that it took, on average, 3-4 years for the women to fully emerge from feeling like being infertile was their primary identity. Implications for clinical practice and future research are also discussed.

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## Chapter I

### Infertility: Statistics, Culture, and Society

#### Introduction

Infertility, from a mental health perspective, is known to have a profound effect on the lives and identities of women. Most women grow up assuming they will be mothers, and, for many, the urge to have a child is a powerful and complex force. Impacting this desire for children is our society, where biological parenthood and family life are considered normal, desirable and necessary for a successful transition to adulthood (Parry, 2005). When pregnancy does not occur, losses include the devastation that comes with the awareness that there may not be a biological baby; the loss of the expectation of the future that most dream about, consciously and unconsciously, from an early age; and the isolation and stigma that results from infertility. Often, the “death” of the desired future is not understood or seen as valid, making it difficult to receive the public acknowledgement and empathy one would receive if there were a death of an infant or other family member.

For the woman diagnosed as infertile, “the heart of the experience of infertility appears to lie in the inability to proceed with one’s life according to life course norms that are both reinforced by others and accepted as valid by the affected individual” (Greil, 1991, p. 133). Although many women resolve their infertility by incorporating non-biological children into their conception of family through third-party reproduction or adoption, some women are either unable or unwilling to do so, and live without children.

The long-term transition to living without children after treatment for infertility has not been the topic of systematic investigation. At this time, we do not know what

impact living without children after treatment has had on marriages, relationships with family and friends, and identity, and we do not know what is involved in the long-term psychological process of transitioning to living without children. This qualitative study will attempt to address this gap in the literature.

This chapter will begin with an overview of infertility, addressing the scope of the problem and identifying those who seek treatment; review some of the reasons a woman may be infertile; and review current statistics relevant to infertility. Next, pronatalist ideology will be defined and a brief history of pronatalism will be presented. I will then address those women who are living without children voluntarily and perceptions society may have about their childfree status. After that, the transition to biological childlessness will be discussed, followed by a literature review on living without children after infertility treatment. Finally, the importance of social supports systems, and the risk of disruption to these support systems for women experiencing infertility will be addressed, followed by a discussion on disenfranchised grief.

### **Definitions and Statistics**

The definition of “infertility” varies. The Centers for Disease Control and Prevention (CDC) defined infertility as the inability among married women aged 15-44 to conceive after 12 months of regular, unprotected intercourse. According to this definition, in 2002, 7.4% of married childless women in the U.S. were infertile. “Impaired fecundity”, according to the CDC, includes married and unmarried women, and includes problems conceiving as well as problems carrying a fetus to term. In 2002, a total of 11.8% of women met this criteria (CDC, 2010).

The World Health Organization (WHO) considers a couple infertile if the woman has not conceived after 24 months of regular, unprotected intercourse (WHO, 2010a); according to the WHO, in 2002 one in four ever-married women experienced either primary infertility (no biological children) or secondary infertility (failure to conceive after a previous pregnancy) in developing countries (WHO, 2010b). The American Society for Reproductive Medicine (ASRM) defined infertility as the failure to conceive after 12 or more months of regular unprotected intercourse. They distinguish infertility from recurrent pregnancy loss, defined by two or more failed pregnancies, regardless of marital status (ASRM, 2008). Much of the literature on infertility includes recurrent pregnancy loss in defining infertility, and this will also be the definition used for this dissertation.

It is generally accepted that approximately 15% of couples (of child-bearing age) who attempt to conceive in the United States experience infertility (Spector, 2004), although estimates have ranged from 15%-25% (Tierney, McPhee, & Papadakis, 1999). McQuillan, Greil, White, and Jacob (2003), found, in their study of infertility and psychological distress among women, using a random sample of women ages 25-50, that 35% had experienced medically defined infertility at some point in their lives. This is higher than the general estimates found in numerous resources, but similar to other estimates of lifetime prevalence (Greenhill & Vessey, 1990; Page, 1989).

### **Who Seeks Treatment**

In 2002, the latest year statistics are available, 7.3 million American women, or 12% of women of reproductive age (15-44), reported seeking treatment for infertility at some point in their lives. This includes not only Assisted Reproductive Technology

(ART), when both sperm and oocytes (eggs) are handled outside the womb, but consultation and basic services as well (Chandra, Martinez, Mosher, Alma, & Jones, 2005). Of these women, approximately 15% have used fertility drugs and only 1% have tried IVF (Spar, 2005, p. 64).

Data from clinical studies and nationally representative surveys have shown that race and ethnicity are no longer limiting factors to the overall use of infertility services. However, those who use higher-level ART are significantly more likely to be married, older, more highly educated, and more affluent; affluence was found to be the most significant predictor of service use (Chandra & Stephen, 2010; Staniec & Webb, 2007; Vahratian, 2008).

It is estimated that in the United States, only half of couples with infertility seek any treatment (Chandra & Stephen, 1998), and utilization of ART increases when it is economically possible. For example, Feinberg, Larsen, Wah, Alvero, and Armstrong (2007) reviewed the use of ART services in an “equal-access” military health care setting, and found that Black women pursued ART at rates equal to the proportion of the larger U.S. Department of Defense population. In this study, Hispanic women were the exception, accessing higher-level ART far less than what would be expected based on patient demographics, perhaps due to social and cultural influences.

Utilization of ART also increases when there is state-mandated insurance coverage (Jain, Harlow, & Hornstein, 2002). This is apparent in Massachusetts, where demand for fertility services has dramatically increased since state mandated insurance coverage was implemented (Spar, 2005).

As of 2005, nine U.S. states have laws that require insurance companies to cover infertility treatment; five states have laws that require insurance companies to offer infertility treatment (Spar, 2005). However, there are additional barriers to ART other than cost. Utilization of ART requires constant monitoring over many weeks; for some, work schedules will not accommodate this necessity. In addition, facilities tend to be located where populations are dense (CDC, 2009, p. 15); for certain infertile women wishing to seek treatment, physically accessing a facility may not be feasible.

### **Environmental and Economic Influences on Fertility**

There have been fluctuations in fertility rates over the past century. There are conflicts of opinion over why this is. Researchers have generally attributed this to changing economic conditions, with a correlation between increased wealth and declining birthrates (Hill & Reeve, 2005; Lawson & Mace, 2010; May, 1995; Meisenberg, 2009). Surveys show that the general public suspect environmental factors, such as synthetic chemicals, influence hormonal activity and fecundity in humans (Sharpe, 2004). Researchers and authorities in reproductive toxicology have presented evidence linking environmental chemical exposure to specific examples of declining reproductive functioning; some of the linkages were firmly established while others remained conjectural (Hughes & Acerini, 2008; Rubes, Selevan, Sram, Evenson, & Perreault, 2007; Woodruff, Janssen, Guillette, & Giudice, 2010). Much of the research has focused on the impact of endocrine disruptors on human sperm, while studies on the female reproductive system have been less comprehensive. Although much progress has been made, establishing a firm relationship between disease and environmental exposure remains difficult. Many clinicians remain skeptical regarding the impact of the

environment on human health (Caserta et al., 2008; Jurewicz, Hanke, Radwan, & Bonde, 2009; Safe, 2004).

### **Age and Fertility**

Others have attributed variations in fertility to characteristics of various generations. For example, in 1998, Chandra & Stephen recognized the dramatic increase in infertility among U.S. women (from 8% in 1988 to 10% in 1995) as due to the large baby boom cohort, many of whom had delayed childbearing and had reached a less fertile age. This increase occurred across almost all age, marital status, education, income, race, and ethnicity subgroups. There is reason to believe this will continue due to the increasing age at first marriage and first child in the U.S. According to the CDC (2009), “a women’s age is the most important factor affecting the chances of a live birth when her own eggs are used” (p. 28).

In 2009, the median age at first marriage for women was 25.9. This is an increase of over five years since 1970, when it was 20.8 (U.S. Census, 2010). The median age for first marriage for women was highest in D.C., at 30, and 28 in CT, MA, NY, and RI (Cohn, 2009). The mean age at first birth for women has also increased, from 22.7 in 1980 to 25.1 in 2008 (Martin et al., 2010). In addition, first births for women over 30 increased from 4% in 1970 to 24% in 2000 (Mathews & Hamilton, 2002); first births for women over 35 increased from 1% in 1970 to 8.3% in 2006 (Mathews & Hamilton, 2009). From 1990 to 2008, overall birthrates among women aged 35-39 increased 47%, and increased 80% among women aged 40-44 (Livingston & Cohn, 2010a).

Today, many young people do not expect to marry until their late 20s and do not expect to start a family until their 30s; young women report feeling less urgency to



conceive because of their belief in the efficacy of reproductive technology if pregnancy is delayed (Henig, 2010). This widely held belief is apparent in the ever-increasing amount of resources invested in reproductive endocrinology. According to Spar (2005), in 2004 almost \$3 billion was spent on treatment for infertility, and the use of ART nearly doubled from 81,438 cycles in 1998 to 142,435 cycles in 2007 (CDC, 2009, p. 63). However, despite great innovation in the past 25 years and modest improvement statistically in live births through medical assistance, age remains a tremendous determining factor.

According to the CDC (2009), fertility begins decreasing at age 30 and declines significantly after age 35 (p. 59); the percent of pregnancies and live births are particularly low for women over 40 (p. 29). Put differently, female fertility drops 20% after age thirty, 50% after age 35, and 95% after age 40 (Spar, 2005). These numbers combined with late marriage age may account for a growing cause of childlessness.

Reporting of infertility increased from 8% in 1988 to 11.8% in 2002 (Chandra et al., 2005). In addition, the CDC, in its most recent report on ART, added an age category for women, changing the category “greater than 42” to “43-44” and “greater than 44” (CDC, 2009, p. 9). The average age for women seeking ART is 36; 39% are under 35, 41% are 35-40; 16% are 41-44; and 5% are over 44 years of age (CDC, 2009, p. 17). The chances of success (including all age categories) using a fresh non-donor egg or embryo was 36%; of these, 17 % did not result in a live birth, the net success rate being 29% (CDC, 2009, p. 22-23).

In 2006, 20% of women aged 40-44 in the U.S. were childless, an increase from 10% in 1976 (U.S. Census, 2008). In 2002, among childless women aged 35-44, 42%

were voluntarily childless, the rest divided almost equally between involuntary childless at 28% and those expecting children in the future, at 30%. This represents a slight increase in involuntary childlessness (Abma & Martinez, 2006).

### **Length and Impact of Treatment**

The length of time a couple attempts to conceive is variable. Including medical intervention, the pursuit of a child can span more than a decade, with the average being five years (Domar & Seibel, 1997). Reproductive technologies have become more complex since the first IVF baby in 1978. As options continue to increase, it becomes increasingly difficult for individuals and couples to feel they have done everything they can and comfortably terminate treatment. Treatment, although at times ending due to final medical failure, also often ceases as a result of emotional exhaustion and/or financial depletion.

Considering the trend toward delayed marriage and first child, and its association with infertility, more women will need to make difficult decisions regarding their reproductive options, including whether to use donors, a surrogate, adopt, or live without children. However, regardless of age, the impact of infertility and infertility treatment on women is usually profound, and has been well documented in the literature. For example, the stress of infertility treatment (Benyamini, Gozlan, & Kokia, 2005; Berg & Wilson, 1991; Eugster & Vingerhoets, 1999) and the negative impact of infertility and treatment on the marital and sexual relationship (Gerrity, 2001; Meyers et al., 1995; Peterson, Newton & Feingold, 2007) are well known among professionals that work with the infertile population. Also recognized is the finding that infertile women register levels of depression similar to those induced by cancer, HIV, and heart disease (Domar, 1992;

Domar, Zuttermeister, & Friedman, 1993). Considering this research, it is imperative to address the impact on the infertile of the ever-present pronatal ideology in the United States.

### **Pronatalist Ideology**

In American society, being a parent is often a fundamental part of identity. Most women grow up assuming they will be mothers, and, for many, the urge to have a child is a powerful and complex force. Social constructionism addresses the impact of culture and society on our choices; pronatalist ideology is a social construct that embodies the belief that a person's social value is linked to procreation (Ulrich & Weatherall, 2000).

#### **Idealization of motherhood and biology.**

In our pronatalist society, "biological parenthood and family life are considered normal, desirable and necessary for a successful transition to adulthood" (Parry, 2005, p. 276). This is illustrated by numerous studies over the past 30 years. According to a 1979 study, most Americans ranked becoming a parent as the most significant marker of adulthood, more than marriage or getting a job (Hoffman & Mannis, 1979). Greil (1991) stated that "the normality of parenthood is communicated and reasserted by the media's presentation that depict and define 'families' as people with children" (p. 52). Ireland (1993) stated that motherhood is universally seen as "intrinsic to adult female identity" (p. 1), "inextricable linked with women's creative capacity" (p. 12), and "prominently woven into the social construction of adult female identity" (p. 123). Bartholet (1993) encapsulated the social and cultural values that women with infertility encounter when she states "women are taught at birth that their identities are inextricably linked with their capacity for pregnancy and childbirth and that this capacity is inextricably linked with

mothering” (p. 35). Jordan and Revenson (1999) stated that despite the wide-ranging roles available to women in North America, motherhood is still emphasized as the primary social role for females. Rocha-Coutinho (2008) wrote “in spite of all the changes that have occurred in the last decades, it appears that our beliefs still are very tied to the idea that the mother-child unit is basic, universal, and psychologically more appropriate” (p. 69). Feminism has contributed to pronatalism as well, with numerous academic feminists writing about feminism and motherhood in recent years (Baraitser, 2009; Bulbeck, 1998; de Marneffe, 2004; O’Reilly, 2008).

A pronatalist ideology “embodies the belief that biological motherhood is the most valued path towards parenthood for woman”, and “within a pronatalist ideological context...a woman’s social worth is inextricably linked to her ability to achieve biological motherhood” (Parry, 2005, p. 276). Bartholet (1999) referred to the social construction of family as having a bias toward biology, “the assumption that blood relationship is central to what family is all about” (p. 7). According to Miall (1996), a traditional understanding of family being blood-related has led to the “social construction of infertility as a problem requiring high technology medical treatments to produce a biologically related child” (p. 310).

Parry (2005) found, in her qualitative study on conceptualizations of family in women diagnosed as infertile, that many had self-defined as reaching closure to their infertility through conception, adoption or choosing a childfree life. Those that had reached closure through biological conception seemed even more committed to traditional, biological ideologies of family. Letherby (1999), in her qualitative study that included addressing mothering after infertility, found that women who became mothers

through adoption and step-parenting reported being perceived as lesser to biological mothers.

### **Brief history of pronatalism.**

Motherhood, historically, has been portrayed as the primary role for women. At the beginning of the 20<sup>th</sup> century, “even the most radical advocates of women’s rights argued that motherhood conferred upon women the moral superiority that was the foundation of their public activism” (May, 1995, p. 69). Pronatalism seemed ubiquitous in the 1940s and 1950s post-war America: surveys taken in 1945, 1955, and 1960 indicated that zero percent said no children were the ideal family size (Whelpton, Campbell, & Patterson, 1966). The period of 1946-1964 is well known as the “baby boom” years, when birth rates in the U.S. skyrocketed and families with children were universal and romanticized. Adoption policies shifted as well in 1946, moving children’s need for parents secondary to childless couples’ desire for children; during this period, infertility was considered the only acceptable reason for adopting a child (Carp, 1992). The childless during this period were marginalized in “unprecedented ways” (May, 1995).

May (1995) addressed the 1940s cultural focus on children, and gave examples such as movie stars and celebrities of that time posing with their babies, making this lifestyle seemingly unrivaled. May (1995) believed that this emphasis on children and family life resumed in the 1980s, on the heels of the childfree movement of the 1970s. May (1995) argued “...reminiscent of the early baby-boom days, babies, children and parenthood began to permeate the nation’s popular culture. Plots of movies and television shows and even popular songs revolved around the baby quest” (p. 214).

To further illustrate May's (1995) point, in 1989, the highly successful movie *Parenthood* (Grazer & Howard, 1989) was released, which culminated with each of the three female leads, from two generations, giving birth after easily getting pregnant. Dianne Weist, one of the actors, was 41 at the time; Mary Steenburgen was 36. This trend continued with the television series "Friends". One of the most popular sitcoms of all-time, "Friends" ran from 1994-2004, and a prominent plot line involved pregnancy. Today, movies continue to reflect female hunger for babies, integrating society's growing acceptance of "alternative" lifestyles, which, despite being "alternative", celebrate family life. For example, in 2010, movies released included *The Kids Are All Right* (Gilbert & Cholodenko, 2010), about a lesbian couple and their two children conceived with donor sperm; and *The Switch* (Bergen, Yerxa, Speck, & Gordon, 2010), about a single woman who decides to have a child also using donor sperm. The messages are not understated.

Also similar to the 1940s is the spotlight on celebrities' glamorization of pregnancy and motherhood. In 1991, Demi Moore led this trend by notoriously posing nude and pregnant on the cover of *Vanity Fair* (Halpern, 2010). Today, Brad and Angelina are famously building their family, Jennifer Lopez had twins after years of trying to conceive, and many celebrities' pregnancies and births are deconstructed relentlessly by the media (Hammel, 2010; Shira & Tan, 2010; Taylor, 2010).

### **Pathologizing infertility.**

In 2009, the WHO, for the first time, defined infertility as a disease (Zegus-Hochschild et al., 2009). William Gibbons, President of the American Society for Reproductive Medicine (ASRM) responded:

For too long those suffering from infertility have had their condition slighted or

even ignored. Insurance companies don't pay to treat it, governments don't put adequate resources to study it and consequently patients suffer. We hope that this international recognition that infertility is, in fact, a disease will allow it to be treated like other diseases. (Tsigdinos, 2010, pp. 1)

Many responded positively to this, and certainly categorizing infertility as a disease will mobilize resources. However, the emphasis on medical intervention risks further devaluing women for accomplishments beyond reproduction, and may contribute to the social construction of motherhood as the superior form of womanhood. The medicalization of infertility communicates to infertile women that they have an "obligation to expose themselves to medical intervention, regardless of the financial, emotional and physical costs" (Whiteford & Gonzalez, 1995, p. 36).

Another development contributing to the social construction of motherhood as the ultimate role for women is the recent reworking of Maslow's famous hierarchy of needs, placing parenting at the top of the hierarchy (Kenrick, Griskevicius, Neuberg, & Schaller, 2010). This replaced "self-actualization", which allowed freedom for each individual to reach their potential in their own way.

In summary, pronatalist ideology is everywhere. It can be subtle or obvious, but its impact on the social and cultural construction of motherhood is powerful and compelling. Despite this, there are some women who remain immune to the pressure to reproduce and parent, and remain without children.

### **The Voluntary Childfree**

Historically, language has placed women without children in a context of deficiency or absence. "Barren", "infertile", and "childless" are familiar words to

describe women without children, and depict emptiness or something missing. Conversely, in the past 20 years or so, the term “childfree” has been used by a growing number of women who stress the legitimacy of this choice. However, both of these perspectives minimize what is for many women a complex process of deciding whether or not to have children. Although some women define themselves as “childfree”, suggesting contentment and pleasure with this choice, and the involuntarily childless may feel distressed and desperate at times, for many women there is a great deal of ambivalence.

### **Reflection, thoughtfulness, and ambivalence.**

For many women, choosing not to have children is a thoughtful and complex process, involving evaluation of their own personality characteristics and ability to parent; consideration of structural limitations such as money and time; and the impact of overpopulation on the planet (Campbell, 1999; McAllister, 1998). Morell (1994) observed in her interviews with voluntarily childless women that although many described their status as a choice, it was one determined by various circumstances, not necessarily a rejection of motherhood. Bartlett (1994) observed ambivalence as manifesting by failing to make a decision to have a child rather than actively making a decision not to have a child. McAllister (1998) observed that voluntarily living without children is a continuum, and includes those that were certain they did not want children, those who are ambivalent, and those who felt the decision was not their own although still describe themselves as voluntarily childless.

Morell (2000) found, in her qualitative study with 34 married, intentionally childfree women, that some chose to remain childfree and made this decision relatively



early; others decided later on, through much thought and consideration. For some, the decision was more passive, becoming finalized because of advancing age. She also refers to the “wavering nos” who have occasional rumblings or even tsunamis of desire to be mothers, and states “it is common for even the most dedicated intentional not-mother to have her temporary moments of wavering” (p. 316). Morell (2000) goes on to address maternal feminism in academia:

The problem is not maternal feminism per se, but the lack of interest in the subjective experiences of women without children, which would validate nonreproduction as an equally viable goal or state. Without a dual focus on reproduction and nonreproduction, the notion that motherhood is essential to women’s lives is confirmed. (pp. 316)

Ireland (1993) found that although some women actively choose not to have children, others delay making a decision to have children due to ambivalence about motherhood. These women passively drift into living without children until what ultimately may be age-related infertility (Ireland, 1993).

Letherby (2002) stated that

...it is a myth that all childless women are selfish or desperate but some have felt, do feel, or may feel in the future a loss through not producing a biological child or having a child to care for on a daily basis... (pp. 17)

**Actively choosing to be childfree.**

Several studies have shown that increasing numbers of women in Western Europe and North America are viewing non-motherhood as a valid choice, and actively choose to remain childfree (Bartlett, 1996; Casey, 1998; Mollen, 2006; Morell, 1994).

This trend began in the 1970s, when the voluntarily childless became increasingly visible and strident, and, tired of feeling marginalized, began seeking each other out as a result of their intense feelings of isolation (May, 1995).

Gillespie (2003), in a qualitative study, explored why some women reject motherhood and focused on examining the appeal of a childfree lifestyle. Her sample was comprised of 25 active deciders, and reasons given were freedom, including financial freedom; preserving relationships based on choice as opposed to obligation; increased autonomy; and the loss of time, energy and identity they associated with motherhood. There was also among some participants a more radical rejection of traditional activities associated with female identity based on motherhood. Some participants described the nurturing or caring roles associated with motherhood as unfulfilling or even repellant to them; the demands, hard work, responsibilities, sacrifices to their well-being and other activities associated with motherhood were viewed as simply burdensome. These women experienced a sense of female gender identity unattached to motherhood.

Mollen (2006), in her qualitative study, studied the experiences of nine women who also actively decided not to be mothers, dividing her results into internal and external factors. Internal factors influencing the choice to not mother included early resistance to societal gender expectations, messages of dissatisfaction from their parents' experiences of motherhood, and the freedom made possible by being without children. External influences included concern about genetically inheritable diseases and negative environmental conditions some felt were less than ideal for raising a child today.

### **Perceptions of women without children.**

Childfree adults report being perceived less favorably than those with children, experiencing pity, criticism, or feeling stigmatized in some way for not having children (Blake, 1979; Byrne, 2000; Gillespie, 2000; La Mastro, 2001; Letherby, 2002, Letherby & Williams, 1999; Mollen, 2006; Park, 2002). These studies indicate that despite growing numbers of the voluntarily childless, parenthood remains a powerful cultural norm.

However, in contrast to experiences of negative perceptions by women regarding their childlessness, over the past few decades, other research has indicated that public attitudes toward childlessness have become more accepting. The share of adults who disagreed that people without children “lead empty lives” increased to 59% in 2002 from 39% in 1988 (Livingston & Cohn, 2010b). Additionally, children are increasingly seen as less critical to a good marriage. In 1990, 65% of adults said that children are very important for a successful marriage; in a 2007 Pew Research Center survey, only 41% agreed with this (Livingston & Cohn, 2010b).

About half the public says it makes no difference one way or the other that a growing share of women never have children. Yet, in 2009, 38% agreed that this trend is bad for society, an increase from 29% in 2007 (Livingston & Cohn, 2010b).

In 2002, among women aged 40-44, 6% were deemed voluntarily childless, 6% involuntarily childless and 2% childless but hoping to have children in the future. Involuntarily childless older women have a distribution across race and ethnicity similar to that of the overall population of older women, in contrast to the voluntarily childless, who are disproportionately white (Abma & Martinez, 2006).

According to Thornton and Young-Demarco (2001), increasing tolerance among Americans of diversity in adult paths and lifestyles should render the childless lifestyle an increasing acceptable option. Yet, despite the increasing acceptance of a childfree life by society, the psychological consequences for someone desiring children do not necessarily decrease. For a woman desiring to be a mother and all the attending activity that role brings, forging a new identity and sense of meaning may present a challenge.

### **The Involuntarily Childless**

Although many infertile women adopt or use third-party reproduction to build their families, some women are either unable or unwilling to do so, and are childless. Other women might frame this differently, stating that they have chosen to be childfree. An extensive amount of literature is available on numerous aspects of infertility and infertility treatment. This includes, in addition to what has previously been addressed, the transition to parenthood when medical intervention has been successful (Glazer, 1990; Hjelmstedt, Widstrom, Wramsby, & Collins, 2004; McMahon, 1999); the ethical and moral dilemmas involved when contemplating alternatives such as using a donor egg/sperm, surrogate or gestational carrier (American Society for Reproductive Medicine 1997; Cooper, 1997; Horowitz, Galst, & Elster, 2010); disparities in rates of infertility and infertility treatment seeking attitudes and behavior by race and socioeconomic status (Becker, Castrillo, Jackson, & Nachtigall, 2006; Inhorn & Fakhri, 2005; Jain, 2006); experiences of positive and negative support during infertility (Domar, Clapp, Slawsby, & Kessel, 2000; Peterson, Feingold, & Gold, 2007; Smith & Smith, 2004); evidence that the emotional experience of infertility is similar in different cultures (Dyer, Abrahams, Mokoena, & Lombard, 2005; Gulseren, Cetinay, Tokatlioglu, & Sarikaya, 2006; Nasser,

2000); and many other aspects. However, the psychosocial consequences of treatment failure, the transition to biological childlessness, and the long-term impact associated with this transition has not been the topic of investigation (Daniluk, 1996; 2001; Daniluk & Tench, 2007; Johansson & Berg, 2005; Verhaak, Smeenk, van Mennen, Kremer, & Kraaimaat, 2005).

### **Transitioning to living without children after treatment.**

According to Verhaak et al. (2007) a systematic review of 25 years of research, using peer-reviewed journals in English, German, Dutch and French, reveals a disproportionate concentration on exploring the impact of infertility for women actively engaged in treatment, with only 2% of the literature dedicated to the post-treatment phase of the infertility experience. Verhaak et al. (2007) specifically identified a clear need for longitudinal studies that follow women from the last phase of IVF treatment through 2-3 years after ending treatment to learn more about the process of adapting and giving meaning to one's life without a biological child. According to Devereaux and Hammerman (1998), the transition to biological childlessness from an identity and life reconstruction perspective only starts when the active quest for pregnancy ends. In addition, there is little research in general that addresses how people resolve losses that do not intuitively make sense (Davis, Wohl, & Verberg, 2007).

This lack of research is particularly salient when we consider psychological functioning across "stages" of infertility treatment. Berg and Wilson (1991) examined psychological functioning at different stages of treatment for infertility, defined by amount of time pursuing treatment. They found those in earlier stages of treatment had an acute stress response to initial diagnosis and treatment, overlaid with chronic strain as

treatment was prolonged. Couples in their third year and beyond of medical treatment had particular difficulties with depressive symptoms, paranoid ideation, and interpersonal strain. Indices of marital adjustment and sexual satisfaction were at the lowest level overall, with marital adjustment nearing the maladjusted range. Amir, Horesh, and Lin-Stein (1999) also found duration of infertility to be positively correlated with psychological distress. There is little current data on whether the most distressed individuals/couples choose not to pursue treatment after diagnosis or terminate treatment relatively early due to the psychological strain, or become preoccupied with the desire for a biological child and are unable to terminate treatment. Furthermore, according to Matthews and Matthews (1986), parenthood is so fundamental to most people's identities that the infertile experience a real and stressful "transition to nonparenthood", despite this seemingly "non-event".

#### **Post-treatment.**

Seven of the following eight cross-national studies examined the short-term (all under three years) transition to biological childlessness after unsuccessful treatment for infertility, and includes one study that addressed emotional responses to IVF. One study examined the long-term transition to childlessness. Cross-national studies were included because, as noted previously, there is evidence that the emotional experience of infertility is similar in different cultures (Dyer et al., 2005; Gulseren et al., 2006; Nasser, 2000). This review will begin with four studies (three included women only, one included couples) that focused only on those who were living without children after infertility treatment. Next, three studies will be reviewed that included couples who had either adopted, were waiting to adopt, or were living without children after infertility treatment.

The final study addressed emotional responses to IVF, and included those for whom treatment was successful as well as unsuccessful.

In these studies, certain themes emerge repeatedly. These include difficulty integrating infertility into one's identity, reports of both growth and change in certain areas (relationships, priorities), and ongoing struggle in others, such as socially, and continued hope for pregnancy despite often years of trying to conceive. Consistently, those with better outcomes were those that had adopted; those that struggled and suffered the most were those that remained without children.

Wirtberg, Moller, Hogstrom, Tronstad, and Laos (2007), explored the long-term experience among involuntary childless Swedish women 20 years after giving up hope for a biological child. This study recruited subjects from a sample of 151 who had undergone tubal surgery in the period 1980-1984; part of the inclusion criteria was self-defining as "involuntarily childless." Ultimately, 39 women replied, of which 25 had conceived and/or adopted a child. This study focused on the 14 who never entered parenthood.

Findings included that infertility was still a major life theme, social isolation persisted, and at the time of the study the effects of childlessness were increasing as the women's peer group entered the "grandparent phase". Half of the women had separated from the spouses with whom they were with at the time of infertility treatment, and nearly all related the separation to the infertility; in every case, the men had left the women. Yet, 11 of the 14 claimed that they had made the adaptation to acceptance of the state of "none-parents." For the remaining three (21%), their life story remained dominated by their infertility and involuntary childlessness.

Johansson and Berg (2005), in their qualitative study, sought to learn about women's experience of ongoing childlessness 2 years after the end of fertility treatment. Eight Swedish women were asked to "describe their experience of infertility as deeply as possible". They found that childlessness and fertility remained a central part of life, taking up a large part of their existence; the women isolated socially, feeling they had nothing in common with similarly aged parents of small children; the hope of pregnancy still existed; and there were ongoing struggles to find other central values in life. The women described a "life grief", which included grief over being unable to reproduce and carry forward the family, and being unable to confirm their relationship through parenthood.

Bergart (1997) looked at the impact of infertility on 10 American women who had ended treatment at least six months prior, had not adopted and did not plan to. This study focused on subjects' retrospective experience of their infertility treatment, from entering the role of patient to deciding to end treatment. Nine of the women were still trying to conceive; most said their marriages and other relationships had been stressed by infertility. Women out of treatment under a year experienced intense and painful affect, felt angry about childlessness and impersonal care during treatment, and were afraid of an unknown future and old age without children. Respondents out of treatment over a year and a half described affect as more manageable. They were attempting to redefine their identities, and focusing on marriage, friendships, and activities. They felt happy, no longer thought about infertility every day, pursued interests with pleasure, and enjoyed spending time with friends and their children. Two women out of the sample of ten described having more difficulty. They still experienced painful affect, spoke more about



hoping for pregnancy than women out of treatment under a year, and continued to avoid pregnant women and children.

Lechner, Bolman, and van Dalen (2007) studied the association between coping, social support and psychological distress in involuntarily childless Dutch couples. Of the 116 subjects, half had known of their involuntary childlessness for less than 2 years; the average length of fertility treatment was 45 months. They found that women especially experienced more health complaints, more anxiety and depression symptoms, and more complicated grief than the general population; these symptoms were also positively correlated with a passive coping style and dissatisfaction with social supports. A more active coping style was negatively correlated with these same symptoms. The results from this study found that a substantial percentage of involuntarily childless people experience depression, anxiety, and, most of all, complicated grief.

Daniluk (2001), in her qualitative study, conducted multiple interviews with 37 Canadian infertile couples 2 months-3 years after treatment ceased. She found in the later interviews that when hope of a solution is extinguished, the process of integrating the reality of their infertility and biological childlessness into their identity was slow and painstaking, involving the willingness to reject the socially constructed link between fertility and self-worth. This seemed to be the most difficult for those who were unable to see the value of their own self and life apart from their ability to produce a child. Participants expressed a strong desire to “put this part of their lives behind them” (p. 8), although they were often at a loss as to how to achieve closure and move forward. This was especially difficult for those unable to accept either adoption or a life without children. Sexual spontaneity, pleasure, and intimacy remained an issue for many couples.

Subthemes that characterized the last interview included feelings of being a survivor rather than a victim; integration of their infertility into their self-structures; and a sense of normalcy and restored equilibrium in their relationships. Those who remained most distressed were those who were still waiting to adopt and those couples who were divided on the issue of adoption. This, too, was a self-selected sample, recruited through notices placed at infertility clinics and radio ads. A limitation of this study was the high percentage of participants (54% versus 10% in the infertile population) who had received the diagnosis of unexplained infertility. The literature suggests that receiving this particular vague diagnosis may make resolution more difficult (Nachtigall, Becker, & Wozny, 1992; Greil, 1991).

Daniluk and Tench (2007) conducted a longitudinal study of 42 Canadian couples transitioning to biological childlessness, with questionnaires completed 3, 13, 23, and 33 months after ending treatment for infertility. Findings included the similarity in adaptation over time to their biological childlessness, regardless of their gender, age, or diagnostic status; and significantly better adjustment for those who became parents through adoption versus those who had not by the end of the study, although most planned on adopting and remained on adoption waiting lists.

McCarthy (2008) did a qualitative study of 22 American women who were a minimum of one-year post infertility treatment. Although seven of the women had adopted and four had stepchildren, all of the women discussed the challenges to their identities and to the meaning of their lives. The paradox of coming to terms with the loss and finding hope for the future was apparent. The loss also had an enduring quality,

meaning that there continued to be reminders of their difference and their loss. There was continual awareness that their life was different from what they had expected.

Verhaak et al. (2005) studied the emotional responses to IVF and factors contributing to these responses, from pre-treatment to six months post-treatment in 148 Dutch IVF patients and 71 partners. Women showed increased anxiety and depression after unsuccessful treatment and a decrease after successful treatment. In the six months after unsuccessful treatment, women showed no recovery. Results supported the interrelationship between the personality characteristic of neuroticism with anxiety and depression. Social support determined the course of the emotional response, with the spouse determined to be the most important source of social support. There was no relationship found between focused, active coping and changes in depression or anxiety. It is important to note that the subjects in this study had not precluded additional treatment, only had not engaged in treatment for various reasons for six months.

### **Summary.**

All of these studies had various limitations, including relatively small sample size, selection bias, and little ethnic or socioeconomic variation. Although much of the research found that unsuccessful infertility treatment had significant psychosocial consequences, after ending treatment and with the passage of time, most women are psychologically adjusted and in stable relationships. However, these findings may be influenced by the fact that many of the participants were still hoping to conceive, had decided to adopt children, or had become mothers. Only one study examined the long-term impact of infertility on permanently childless women after undergoing treatment; in this study, all of the participants had learned of their infertility 20-25 years ago.

That there are few studies examining life without children after unsuccessful medical treatment is particularly salient considering the advances in Assisted Reproductive Technology in the past 25 years. Previously, infertile women transitioned into childlessness or turned toward adoption without medical intervention. Now, there are numerous ways to intervene, options are increasing, and, as a result, it is difficult to know when to stop pursuing treatment. Letherby (2002) emphasized the historical period in which individuals experienced their infertility, stating “it would appear that ambivalence was a more acceptable response before the development of technological ‘cures’” (p. 15). In addition, the use of reproductive technologies often results in greater feelings of desperateness for a child than existed prior to treatment (Franklin, 1998).

### **Social Support**

Social support includes positive and intimate relationships we have with friends, family, and partners, as well as social networks we are a part of, including spiritual, religious and work. Increased social support has been positively correlated with emotional health, particularly during stressful life events (Cohen & Wills, 1985; Dalgard, Bjork, & Tambs, 1995). Social support as a coping mechanism for women in particular has also been established (Billings & Moos, 1984; Gibson & Myers, 2002; Stanton, Tennen, Affleck, & Mendola, 1992), especially in infertile women (Fouad & Fahje, 1989; Gibson & Myers, 2002).

Stress has historically been considered a psychological rather than a psychosocial issue, and attention to social factors has been neglected. Kemper (1978), writing from a social psychological perspective, argued that social relations are prime instigators of emotions, and that “situations may be more powerful than dispositions in accounting for

emotions” (Kemper, 1991, p. 332). Kemper (1991), invoking Darwin (1873), also reasoned that emotions are informative, providing necessary information about our environment. In addition, social relations “are the most frequent antecedents” (Kemper, 1991, p. 334) of four major emotions: joy, sadness, fear, and anger.

For women, connection to others through relationships is central to their psychological well-being. However, help during infertility has historically focused on the woman or couple experiencing the fertility problem, to the exclusion of their social networks (Blyth, 1999). The efficacy of social support in other settings has received much attention, including high stress situations such as bereavement, old age, pregnancy and negative life events in general (Sarason, Sarason, & Pierce, 1990). Within the context of infertility, support from others is often absent as the loss is often silent and secret, rendering the infertile vulnerable to direct and indirect comments from their close surroundings as they do not fulfill the social expectations of parenthood (Daniels, 1993). In addition, infertile women may feel estranged from pro-natal society in general. Childless persons have a feeling of marginalization and difficulties in affinity with persons of the same age with small children whose life consists of caring for them, and also speak of feeling marginalized at social events and family meetings (Lalos, 1985).

Previous research has found that infertile couples often have difficulty accessing social support (Abbey, Andrews, & Halman, 1991; Katz, Millstein, & Pasch, 2002). In addition, the source of support for couples facing infertility can also be the very source of strain. For example, not having children can impact sibling and peer relationships as similar developmental stages and milestones are no longer shared; there may be an imbalance in parental and/or community attention to families with children; family and

community members may not know how to respond to infertility; and infertile couples may avoid child-centered family activities (Ridenour, Yorgason, & Peterson, 2009). In summary, support systems, including families and communities, help to define the infertility experience for couples.

### **Complicated and Disenfranchised Grief**

Many women facing infertility experience a complicated form of grief. Prigerson et al. (1995) noted considerable differences between complicated grief and depression, observing that symptoms associated with complicated grief puts the bereaved at heightened risk for enduring social, psychological and medical impairment. These symptoms include chronic and disruptive yearning for the deceased (biological child), trouble accepting the loss, inability to trust others, excessive bitterness or anger, unease about moving on, numbness, and feeling as if life is meaningless without the deceased (child). Common with infertility is also a disenfranchised grief. Doka (1989) defined this type of grief as resulting from a loss that leads to intense sorrow which is unrecognized or minimized by others, and absent the usual customs, rituals, and validation that facilitate grieving and the healing process. Disenfranchised grief is “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publically mourned, or socially supported” (Doka, 1989, p. 4). Disenfranchisement refutes the mourner’s right to grieve, fails to appreciate the significance of what has happened or the consequent anguish and loss of sense to the mourner’s life, and imposes needless and unnecessary suffering (Attig, 2004).

Corr (2002) elaborated on the scope of disenfranchised grief, arguing that grief reactions and expressions of them can be disenfranchised when even the feelings,

thoughts, and behaviors related to bereavement are deemed inappropriate. For the infertile, the desire to avoid those who are pregnant, very young children, and the attendant activities (baby shower, first birthday parties, etc.) is often not understood and invalidated. Lost, as well, is the infertile woman's imagined identity as a mother. This concept of disenfranchised grief comes from a relational-cultural perspective, in that it considers interactions with others as well as societal and cultural expectations in expressions of bereavement, as well as the impact on our identity because of these interactions and expectations. Brabant (2002) emphasized that each individual is socialized by his or her culture in how to think about, feel, and process loss. Yet there are no clear norms for grieving the loss of a dream. For the infertile, cultural and societal expectations that result in silencing are often plainly conveyed. Common reactions to a woman who discloses her infertility include offers of advice ("relax", "adopt", "use a donor") and suggesting that if the woman really wants to bear children, she will eventually get pregnant.

These responses emphasize the woman's infertility, reinforce that the woman's grief, sadness, and distress has been passed over and unseen, and cause additional anguish and sorrow. When an emotion contradicts established cultural norms, validation by another that the loss warrants grief is critical to the healing process (Worden, 1991). When this validation does not occur, the infertile woman may become trapped in her sadness, mourning, and disbelief, impacting both her relationships with friends and family and her identity as defined within those relationships. Attig (2004) suggested that:

...disenfranchisement fails to appreciate the extent of the loss of wholeness that mourners experience: how their daily lives are devastated; how their life stories

are disrupted and veer off their expected courses; and how meaningful and sustaining connections in the world around them are threatened and undermined.

This misunderstanding of suffering actually compounds the loss and hurt that mourners endure. ...it induces and reinforces feelings of helplessness, powerlessness, shame and guilt. And it withholds support from, breaks connections with, isolates, and abandons the bereaved in their sorrow. (pp. 205)

Deck and Folta (1989) observed that society determines who is a valid griever.

For the infertile, the grief itself, the intensity of the grief, or the timing (e.g., excessive in duration) may render it inappropriate and, consequently, illegitimate: it is in contrast to established cultural norms. While an infertile woman cannot dismiss these norms, she may refuse to comply with them (Brabant, 2002). But at what emotional and social cost to her relationships and to her identity as it is shaped by those relationships?

In summary, infertility is increasing due to the delayed age of marriage and first births, and a possible environmental impact. Although many women are choosing to live without children, despite a presently strong U.S. pronatalist ideology, there is disruption to the lives of those who are involuntarily living without children after pursuing treatment for infertility.

The following chapter will address this disruption in women's lives within a theoretical framework of ongoing identity development. Literature on identity development, continuity, and discontinuity will be reviewed, as well as literature on growth after interruptions to identity during the life cycle. Finally, the research questions will be presented.



## Chapter II

### Theoretical Framework, Literature Review, and Research Questions

Parenthood, in American society, is central to many people's identities, and is usually their most salient identity (Thoits, 1991); few Americans want or expect to be childless (Thornton & Young-DeMarco, 2001). Infertility is especially stressful for women who have been successful in other aspects of their lives (Stritchfield, 1995.) Stress arises when people experience events for which their coping resources are insufficient (Pearlin, Lieberman, Menaghan, & Mulan, 1981). Stressors can also be nonevents, or failure to achieve life goals or wanted identities (Aneshensel, 1992). When circumstances external to an individual's control prevents them from achieving a desired identity, they face a challenge to their identity that is expected to cause stress (McQuillan et al., 2003). McQuillan et al. (2003) also found that the "strong, long-term effect of motherhood denied supports an argument that frustrated attempts to achieve motherhood threaten a central life identity" (p. 1015). The infertile face the stressful task of unclasping "mother" from female identity.

This chapter will examine infertility within a theoretical and developmental framework. First, Erikson's stage of generativity vs. stagnation will be discussed, along with his emphasis on the social and cultural aspects of ongoing identity development. Included as well will be the influences of communication studies and social psychology on ongoing identity development, followed by a discussion of Goffman's "facework". Second, Jean Baker Miller's Relational Cultural Theory will be discussed, along with various other feminist writers. Emphasis will be placed on the impact the experience of infertility has on relationships, and, in turn, the continuing development of a sense of self.

Third, Stigma Theory will be reviewed, addressing stigma's unintentional yet painful presence in the life of an infertile woman and its sociocultural impact. Fourth, Kohut's "self-object" and "mirroring" needs will be reviewed, and the possible disruption in these needs for a woman who is infertile. Following this will be a discussion of the possibility for growth after the experience of infertility, and, lastly, research questions.

### **Identity Formation and Development**

#### **Erik Erikson and psychoanalysis.**

Erikson (1959) was the first psychoanalyst to frame ego development and identity formation as occurring over the course of a lifetime, and the first to stress the influence of culture and society on our ongoing opportunity for growth. It is a useful theory within which to explore infertility, a major negative life event that usually has a deleterious impact on the identity of women. Erikson's (1959) epigenetic theory describes eight stages of development, each of which provides opportunities for growth with varying levels of success and failure. The seventh stage is adulthood, where our developmental challenge is Generativity vs. Stagnation. The core of generativity lies in concern for and raising the next generation, most often expressed through parenting or in some way caring for others. Erikson (1980) also believed that contributing to future generations could be accomplished by creating lasting physical objects. The developmental lapse at this stage is stagnation, where one becomes self-absorbed and emotionally stunted because of an inability to satisfy the need for generativity.

Erikson's (1959) inclusion of the social and cultural impact on ongoing identity development had previously been addressed by the symbolic interactionists, who suggested that people form their self-concepts through interactions with others, and that

positive interactions lead to positive self-concepts (Dewey, 1922; Mead, 1934). Identity development has been further elaborated on by theorists from diverse theoretical orientations, including communication studies, social psychology, and sociology.

### **Communication studies and social psychology.**

Eisenberg (2001), writing from a communications perspective, suggested that instead of viewing identity as a “fixed sense of self with rigid boundaries”, we consider a more fluid one that “more closely aligns with the shifting and fragmented quality of lived experience” (p. 537). Eisenberg further emphasized that our identity is shaped by all our “surround”, including our cultural, spiritual, economic, biologic, and interpersonal relationships. It is the “interplay among all these sources of information that provides the raw materials for the sense-making processes” (p. 544), and “life stories, however, can have great inertia” (p. 546). It is easy to get trapped in what should have been.

Stryker (2002), writing from a social psychological perspective, defined the goal of “structural symbolic interactionism” as understanding the relationship between social structures and self. Stryker (2007), drawing from the symbolic interactionist frame, stated that one premise of identity theory is that “person’s selves are shaped in interaction with others”; “selves are built upon responses to them made by others”; and “society shapes self, and self shapes social behavior” (p. 1089).

Stryker & Burke (2000) saw people as being part of small, distinctive social networks, “in roles that support their participation in such networks” (p. 285). For each network, there is the potential for a different role, or identity. Roles and identities are reinforced and internalized, and group cohesion is solidified, by the mutual granting and receiving of “status, respect, and esteem” (Stryker & Burke, 2000). Identities remain

stable as a result of continuity in roles within social networks; alterations in identities are a result of a changed relationship to an existing network, caused by either internal or external factors. Marriage, divorce, and having children are examples of such factors (Stryker, 2007).

Burke and Stets (1999) elaborated on the formation of groups, stating that when several people in a common situation mutually verify each others' identities, their commitment to each other increases. As this continues, they begin to see themselves as a new group or social structure. When verification of identities does not occur, structures either do not form or dissolve.

### **Goffman's "facework".**

Goffman (1959) illustrates well the difficulty an infertile woman may have in social settings. Writing from a sociological perspective, Goffman (1959) greatly elaborated on the central concepts and applications of symbolic interactionism. He coined the term "face-work" to address the "face", or persona, a person presents to each particular social interaction. He argued that an individual's feelings of confidence and assurance would be reinforced if his "face" was supported by others during social interactions; if the presented "face" was not supported, an individual may feel shamed or threatened. Important for impression management was attention to saving one's own face through social skill and diplomacy. Protection of others' faces was important as well; attention should be paid to avoid harming the faces of others through insults or faux pas (Goffman, 1959).

The woman grieving the loss of her fertility often becomes careful regarding the face she presents in her social interactions. If she reveals her sorrow, she risks feeling

unacknowledged and shamed if her grief is passed over; if she shows her displeasure with another's response, she risks committing a social faux pas in not preserving another's face. Most significantly, interactions that were previously easy and uncomplicated risk becoming complex and problematic. As a result, relationships may be interrupted, resulting in further limiting self-disclosure. Yet, self-disclosure is critical to integrating the loss into one's identity and assisting with the sense making process (Hastings, 2000).

To summarize, for the infertile woman seeking to develop her identity and fulfill the goal of generativity by having children, there are significant, unplanned, and difficult challenges to work through to successfully navigate this stage of life. This interruption in the expected developmental shift to parenthood is an immense psychological loss. An additional dilemma impacting self-esteem and identity in the infertile is the shift in perceived social supports and sense of self-worth that comes from being a vital member of a group. The crisis to be resolved is multi-faceted: who am I if I am not a mother? How do I define myself within my primary (spouse/partner) relationship, and with my friends, extended family and culture? How do I compare myself to peers that so far fared equally to me? These challenges will be examined within a framework that includes the concepts of Relational Cultural Theory and Stigma Theory.

### **Relational-Cultural Theory**

#### **Relationships and development of a sense of self.**

The concept of disenfranchised grief is particularly salient when we consider its impact on the relationships, and, consequently, lives and identities of infertile women. Chodorow (1974) emphasized the importance of relationships to women, attributing this to early development and emphasis on early childcare, a time when mothers are

especially empathic to their children. Girls experience themselves as similar to their mothers, and, as a result, “in any given society, feminine personality comes to define itself in relation and connection to other people more than masculine personality does” (Chodorow, 1974, p. 43-44). Miller (1976) addressed a different developmental line for women that stressed the impact of relationships on identity formation and sense of self, a departure from Erikson’s (1959) developmental themes of separation. In her Relational-Cultural theory, Miller stated that connectedness to and relationships with others is vital to personal growth, posits that healthy relationships require a sense of feeling part of others by sharing ideas and feelings, and emphasizes that people do not live in isolation from each other. According to Miller, “women stay with, build on, and develop in a context of attachment and affiliation with others”, “women’s sense of self becomes very much organized around being able to make, and then maintain, affiliations and relationships,” and “eventually, for many women, the threat of disruption to an affiliation is perceived not just as a loss of a relationship but as something closer to a total loss of self” (Miller, 1976, p. 83).

Gilligan (1993) directly challenged Erikson’s (1959) developmental theory as it applies to women, emphasizing that women’s growth, identity formation, and sense of self is not through separation and individuation but through “coming to know herself as she is known, through her relationships with others” (p. 12), that a female’s expanding network of connection impacts ongoing development and sense of self, and that survival is seen to depend on acceptance by others. Jordan, Kaplan, Miller, Stiver, and Surrey (1991) discussed women’s self-esteem as being related to “the degree of emotional sharing, openness, and shared sense of understanding and regard” (p. 57); that the

relational line of development entails that relationship and identity develop in synchrony; that empathy, developmentally, begins very early for girls, and that relational mutuality can provide purpose and meaning while lack of mutuality can adversely affect self-esteem.

### **Envy and self-care.**

When infertility shatters the wish for a child, it often disrupts the ability to identify with peers and the wish for sameness; as a result, it is common for infertile women to find themselves alienated from surroundings that were previously a great source of support. Many women report a consuming, powerful destructive envy of which they are hardly in control. Klein (1957) defined envy “as the angry feeling that another person possesses and enjoys something desirable – the envious impulse being to take it away or to spoil it...” (p. 181). In our society, envy is considered a “bad” or deviant emotion. Deviance conveys a departure from a culturally defined norm (Kalich & Brabant, 2006), and is created by society, meaning that social groups make decisions about what will be defined as deviant (Becker, 1963).

For infertile woman, envy and its accompanying sense of aggression and destructiveness can be experienced as real yet extremely uncomfortable, and manifests particularly where there is an expectation of relational behavior. This envy is observable in feelings of intense rage toward pregnant friends, high sensitivity to invitations to baby showers or parties involving children, and profound unwillingness to attend family gatherings where small children and/or pregnant relatives will be. These situations are common as infertile women are often in a stage of life where peers (including siblings, sisters-in-law and women of a similar age) are becoming pregnant or already have young

children. Their envy is usually highly ego dystonic and experienced as a loss of the known self. Suddenly, the infertile woman must choose between remaining true to herself and her feelings, which, in their intensity, are new and foster questioning of who she is, or potentially hurting others by avoiding situations that are quite difficult to bear.

Gilligan (1993) stated that, for women, “the inflicting of hurt is considered selfish and immoral in its reflection of unconcern, while the expression of care is seen as the fulfillment of moral responsibility” (p. 73). Gilligan (1993) also spoke of goodness in women being associated with self-sacrifice, a concern for feelings of others, and essentially doing what others are counting on her to do regardless of what she wants. For the infertile woman, the need to take care of herself is in conflict not only with societal and cultural expectations but with her own internalization of these expectations – what she herself has defined as a loving and good friend, sister, or daughter. Jordan et al. (1991) suggested that “many women do not develop dependable self-empathy because the pull of empathy for the other is so strong, because females are conditioned to attend to the needs of others first, and because women often experience so much guilt about claiming attention for the self, even from the self” (p. 30). As a result, women may struggle to take care of themselves and feel selfish when they act on their own needs. This may be exacerbated for the woman who has defined herself early, developmentally, as a “mothering” person or caretaker of others.

In summary, Relational Cultural Theory suggests that relationships and identity develop in tandem; that the self becomes known to oneself and to others through self-disclosure; and that relationships are vital to the construction of personal narratives. As women experiencing infertility may face a disruption in their relationships, it is possible



that there will be an interruption in their ongoing development of personal narratives and sense of self.

## **Stigma Theory**

### **Sociocultural impact.**

According to May (1995), a new pronatalism began its ascent in the United States and other western societies in the 1980s, just as medical technology was enabling women diagnosed as infertile to have a chance at pregnancy. In the U.S., this served to underscore the strongly encouraged group identity of parenthood. Government policies reinforced this identity, most obviously through tax deductions for children. Cultural references to children and families are ubiquitous, and are the focal point of movies, television, magazines, advertisements, and news stories. During the last decade, there has been much attention on celebrities well into their forties having children, with few disclosing the assistance they may have received in becoming pregnant, such as the use of donor eggs or donor embryos. The effect of this societal expectation to procreate on the involuntary childless is profound, and can be framed through Stigma Theory.

Stigma Theory helps us understand infertility as a cultural, societal, and existential experience. Goffman (1963) defined stigma as “an attribute that is deeply discrediting” (p. 3) and further characterizes stigma as arising due to physical deformities, individual character deformities, or from deviation from the group identity. It is this last piece – deviation from the group identity - that is attached to infertility. Crocker, Major, and Steele (1998), examining stigma from a social psychological context, defined it as occurring when an individual is believed to possess an objective attribute that conveys a devalued social identity within a social context, and is not located entirely within the

stigmatized person. Link and Phelan (2001) addressed social processes that take place within the sociocultural environment whose effects can be seen within the individual. Yang et al. (2007) referred to stigma as a situational threat, one that results from being placed in a social situation that influences how one is treated, occurs among interpersonal communication, and emphasize that stigma compounds suffering for the stigmatized. Yang et al. (2007) also argue that there is little research examining the interpersonal aspects of stigma, and that most current stigma research emphasizes individual psychological processes.

Pachankis (2007) referred to “stigma salience”, stating that a stigma is salient when it is “shared by many or shared by none in a given situation”, and that “situations in which an individual perceives herself alone in possessing the stigma may be more likely to lead to negative psychological consequences than those situations in which similar others are present” (p. 331). For example, baby showers may make one’s infertility salient, and research shows that baby showers are particularly difficult for the infertile (Whiteford & Gonzalez, 1995).

Pachankis (2007) further addressed the psychological implications of concealing a stigma, and the challenges of making regular disclosure decisions for those stigmas that are less visible, as is infertility. (Infertility is not completely invisible; for example, couples may be asked repeatedly when they plan to have children and may need to be increasingly deceptive to avoid revealing their secret stigma.) Those with a concealable stigma are further burdened with concern over revealing the stigma, worry that the stigma is suspected, and apprehension that one’s stigma is known (Pachankis, 2007). In addition, the shame of secret keeping has been made plain in U.S. culture through popular 12-step

programs, such as Alcoholics Anonymous. The dilemma for the infertile arises over whether to risk being devalued, among other threats, by revealing their infertility, (for example, Letherby (2002) studied women without children and found that involuntary childfree women were typically regarded by others as desperate) or continue bearing the emotional stress of concealment.

Research with gay and lesbian populations have found that avoidance of others is a frequent strategy for avoiding the negative cognitive and affective consequences of hiding a stigma (Corrigan & Matthews, 2003; Croteau, 1996). This combined avoidance of others as well as deciding to not reveal stigmas leaves fewer opportunities for social support.

According to Whiteford and Gonzalez (1995), the stigma of infertility extends to the social identity of the whole person, spoiling her other accomplishments, and transforms biological infertility into socially defined inadequacy. “For many infertile women in North America infertility is a secret stigma, distinguished from more obvious examples of stigmatization because it is invisible” (Whiteford & Gonzalez, 1995, p. 28).

The literature has well-documented the emotions associated with infertility, including shame, inadequacy, devaluation, failure, and incompleteness, that may contribute to feeling stigmatized (Greil, 1991; Miall, 1985; Whiteford & Gonzalez, 1995). In contrast to stories about the preeminence of medical technology and those who have overcome great odds to have a child, women who are unsuccessful in their pursuit of a biological child are often overlooked and unheard due to the socially and culturally defined stigma of infertility.

### **Everyday experiences.**

Depending on age, marital status, and degree of familiarity with the inquirer, women are frequently asked when they plan to have children, or whether they already have children or grandchildren. These questions are common icebreakers among unfamiliar women regardless of setting and socioeconomic status, and serve as an effortless way for women of childbearing age to quickly bond and create community. Having or planning to have children is often an expectation at this stage of life. The impact of this on the woman struggling with infertility is a feeling of exclusion from a social group. In the moment, this feeling may be brief or prolonged, depending on the woman's developmental history. Often, it is profound.

It is common for those with children to structure their social lives and holidays/vacations around children; children are also the source of many adult friendships, as parents link with each other and form bonds and friendships that include their children. It is easy for those without children to feel marginalized and discredited as they are often not included due to their childlessness. Stigma, in its everyday subtlety, manifests both interpersonally and relationally, deepens suffering, and ultimately serves to become internalized as part of the woman's identity.

### **Kohut: The Selfobject and Mirroring Needs**

Many infertile women, considering RCT, Stigma Theory, and disenfranchised grief, experience disruptions to relationships and risk not receiving the support that previously may have felt effortless in receiving. Kohut believed that “attempts to develop, maintain, and enhance the cohesion, autonomy, esteem, and emotional vitality of the self are the most important psychological issues in the life of the individual” (Cushman, 1995,

p. 263.) Kohut (1977) addressed the needs of infants developmentally, yet also emphasized that these needs did not disappear but continued in varying degrees throughout life. The self needs *selfobjects*, who provide psychological nourishment by fulfilling various psychological needs that aid in integrating the self. He spoke of the self as having three parts that have their own distinct needs: the grandiose self needs a mirroring selfobject to see one's uniqueness and individuality; the idealizing self needs a selfobject to idealize and emulate; and, finally, a self that seeks twinship to avoid feeling alone in the world (Berzoff, Flanagan, & Hertz, 2008). Kohut saw the integration of the self occurring through the use of selfobjects. For infants, failures, or optimal frustrations, of selfobjects are expected and result in the infant internalizing the various selfobject functions, resulting in *transmuting internalizations* and a building of the self-structure (Cushman, 1995). Kohut (1977) believed that pathology resulted when there is too great a deprivation of the selfobject functions, when selfobject functions are unregulated and overindulged, or when selfobject functions are inconsistent and unpredictable.

For an adult woman experiencing infertility whose core self-structure is essentially built and who depends on selfobjects for reinforcement and growth, this disruption can be highly distressing. The sudden lack of mirroring and twinship in the world may evoke feelings of deficiency or deviance, especially if there are unresolved developmental issues. Some women will find this exceptionally distressing, particularly if they have not yet integrated a sense of themselves as spouses, daughters or mothers (Rankin, 2009).

## **Resolution**

Each of the theories discussed above presents a result of a critical life stressor and the potential for emerging, changed but intact, with opportunities for mastering the stage of Generativity vs. Stagnation with a healthy balance of positive and negative outcomes. Infertility can be a transformational experience once the loss has been mourned. Central to a successful resolution of this loss is feeling validated in one's grief so that it is not disenfranchised and relationships have a better chance at remaining supportive and intact. The infertile woman very much needs friends, family or a therapist to receive the gift of "the accepting, confirming and understanding human echo" (Kohut, 1978, p. 705). If there is not opportunity for this, if a woman struggling with infertility is not able to ask for and receive what she desperately needs, growth is stagnant, thus heightening the developmental crisis of Generativity v. Stagnation.

Certain women are unable to move through this crisis and successfully resolve this developmental stage; they may remain in infertility treatment for many years, searching out the latest advance in technology, trying different doctors, and finally stop because there is no more money and/or no doctor that will continue to treat them. These women have failed to expand their view of "family" to include non-biological children or make an active choice to live childfree, and have been unable to integrate being infertile into their identities. Miller (2003) evoked Erikson (1959) when she said "for some women the inability to conceive a child can challenge their belief in a spiritual and a creative capacity and can also keep the infertile woman trapped in a timeless world where mourning is not possible and as a result nothing can change" (p. 48) and "an acceptance of their failure to conceive may not release them but keep them imprisoned in a state of

permanent failure” (p. 52). Freeman (2005) explained this timelessness as an experience of dependency, that “a person denies time as an adult because she is trying to hold the world still until she gets what she needed, wanted, or deserved as a child” (p. 56). It is not clear if identity becomes or is a continuation of feelings of deprivation and irrelevance.

### **Growth After Infertility Treatment**

Certain losses, including those that are unexpected or traumatic, often destroy dreams, shatter expectations and hopes, and deprive the bereaved of what had previously given meaning to life (Davis et al., 2007). According to Neimeyer, Herrero, and Botella (2006), losses can test fundamental tenets and belief systems that give our lives meaning and coherence. Bereavement may be the one universal stressor for human beings, and “...for a substantial minority the associated grief may become nearly a life sentence” (Neimeyer, Burke, Mackay, & Stringer, 2010, p. 82).

Most people believe they have some control over their lives, and that the world is fair and benevolent (Janoff-Bulman, 1992). The trauma, and what can be the ambiguous loss (Boss, 1999) of infertility can undermine this conviction and lead to a more complicated grief. Infertile women, for whom adoption or third-party reproduction is not an option, are faced with challenging tasks after ceasing treatment, including reimagining their lives without children and integrating this loss into their life narrative. However, despite great loss and suffering, often compounded by disenfranchised grief, feelings of stigmatization, and disruptions in relationships, humans have great capacity for both resilience and growth. This growth, after trauma, has been referred to as *posttraumatic growth*, or PTG (Tedeschi & Calhoun, 2004).

### **Posttraumatic growth.**

Tedeschi and Calhoun (2004) defined PTG as “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (p. 1). They view PTG as requiring a “seismic” event that disrupts an individual’s sense of self and understanding of one’s place in the world, and link the degree of the trauma to the extent of the disruption to one’s understanding of the world. Growth occurs by reforming a coherent and meaningful narrative that integrates and makes sense of one’s loss. According to Calhoun and Tedeschi (2004), “...the individual’s struggle with the aftermath of trauma can produce negative, positive, and perhaps, more typically, a mixture of negative and positive experiences” (p. 93). In addition, “positive and negative effects of traumatic events probably exist in the same person and that when people perceive benefits they do not appear to deny the difficulties” (Tedeschi & Calhoun, 1996, p. 468).

Calhoun and Tedeschi (1998) identified five major areas of potential growth emerging from the struggle with major life difficulties. These included seeing new possibilities; changed relationships; being stronger yet more vulnerable; a greater appreciation for life; and shifts in spiritual and existential realms. It is also possible that some experience life changes after trauma that are less amenable to categorization (McMillen, 2004; Pals & McAdams, 2004; Park, 2004).

### **Meaning-making.**

Neimeyer (2009), writing from a constructivist perspective, argued that the desire to make meaning of life experiences through self-narrative is a fundamental part of humanity, and that our narratives reveal our core beliefs and assumptions about the world.



The loss of a loved one (hoped for child) “can challenge the validity of core beliefs and undermine the coherence of the self-narrative” (Neimeyer et al., 2010, p. 74). A significant part of grieving involves making sense and meaning of a loss, which can be complex for some, particularly when a loss is unexpected. For these individuals, it is vital to articulate a coherent life-narrative that assimilates the loss (Neimeyer et al., 2010).

According to Snyder and Ingram (2000), optimal functioning requires “coherence and adaptation to the world *as we know it*” (p. 411). As traumatic losses disrupt our fundamental beliefs about how the world is and should be, coping involves restoring or reworking basic beliefs disrupted by the trauma (Janoff-Bulman, 1992). Meaning making involves integrating the loss into these prior schemas (Davis et al., 2007).

Individuals often have longer and more intense grief reactions to those deaths that are “non-normative”, meaning those that are not expected and have seemingly little meaning. Deaths such as these most likely trigger an existential search for meaning and fairness (Currier, Holland, & Neimeyer, 2006; Neimeyer, 2005; Stroebe & Schut, 2001).

Attig (2004) addressed moving through, meaning making, and growth after grief, recognizing the need to respond to the suffering of the bereaved as well as the desire to return to embracing life again. Important is the “need to understand and appreciate the potential for thriving inherent in the bereaved” (Attig, 2004, p. 204). Grieving involves relearning how to live well again in our physical and social environments, and with our selves, in a changed world (Attig, 2000). Growth after bereavement includes “soul work”, which involves returning to what has historically been comforting, familiar and life affirming; and “spirit work”, reaching through the pain and finding new meanings and contexts, and making space once again for happiness. Support systems, too, must believe

in hope and resilience for the possibility of growth (Attig, 2000). Attig (2001) also argued that directly reengaging in life leads to meaning making, rather than purposeful or creative activity.

It is important to emphasize that there are many ways to adapt to a loss. Making sense of a loss and/or experiencing PTG are not necessary for everyone, nor essential to live a full or satisfying life after a traumatizing loss (Davis et al., 2007). Ultimately, everyone grieves in their own way.

### **Studies examining growth after infertility treatment.**

There are few studies specifically examining growth in women after infertility treatment, although women in some of the qualitative studies already referenced do refer to certain positive changes, particularly those who ultimately had a child (Bergart, 1997; Daniluk, 2001; Daniluk & Tench, 2007; Wirtberg et al., 2007). Two other studies specifically addressed the possible positive impact of the experience of infertility. Paul et al. (2010) studied posttraumatic growth (PTG) during treatment for infertility. Findings included an association between female infertility and posttraumatic growth, with higher PTG associated with the number of live birth deliveries and lower PTG associated with a diagnosis of unexplained infertility. There was no significant correlation found between the total PTG score and availability of social supports, and a small association between satisfaction with social support and PTG. This was the first study that addressed posttraumatic growth during treatment for infertility. Schmidt, Holstein, Christensen, and Boivin (2005), studied the benefit to marriage for couples undergoing infertility treatment. They found that about 66% of the women and 57% of the men in their study reported a marital benefit, strongly or somewhat agreeing that infertility had strengthened their

relationship and/or brought them closer to their partners. This study was divided into two timeframes. T1 was at the beginning of treatment; T2 12 months later. T2 was divided into those who were either pregnant or who had given birth, and those who had not. There were no significant differences in marital benefit between these two groups.

### **Conclusion and Research Questions**

In summary, our pronatalist society has focused on two groups of women: those who want to be mothers and do so through either biology, third-party reproduction and/or adoption, and those who are either ambivalent about motherhood or embrace childfree living. The long-term progression of those who transition from pursuing biological parenthood with medical assistance to living without children, and how women, specifically, cope after perhaps years of managing the ups and downs of hope and despair, remains relatively unstudied.

This qualitative study will attempt to address this gap in the literature by exploring the following themes:

What is the process for women who are not willing to make biology secondary to being a parent?

What can we learn from these women about their path through and beyond infertility?

Who is less resolved, and what has hindered this?

Who is more resolved, and what was their psychological process?

What has the impact been on their relationships and their identities?

What has their journey been in making sense of and giving meaning to their lives?

## **Chapter III**

### **Research Methods**

#### **Introduction**

Qualitative research focuses on people's individual stories, encouraging examination of the social, historical, and cultural contexts of participants' lived experience. This allows rich meaning and understanding to emerge, and gives context to individual narratives (Seidman, 1998). Such vivid accounts allow researchers to more fully understand participants' processes and actions, ultimately allowing clinicians to use these insights in developing and applying the most effective practices in the field (Seidman, 1998). As there are so few studies of women living without children after infertility, a qualitative study was appropriate to generate hypotheses regarding their process, how they made sense of their lives, and to discover what we can learn from them that may help other women that continue to struggle and are unresolved.

In this chapter I will discuss my recruitment strategy, address the different modalities used to interview (face-to-face, telephone, and email), inclusion and exclusion criteria, and the research design and setting. I will then review how I performed the analysis and confirmed the data. Finally, ethical considerations are reviewed, and a reflexivity statement is provided.

#### **Recruitment Strategy**

The researcher was in contact with Pamela Tsigdinos, who established and runs a popular website that focuses on the issues of women living without children after infertility ([www.silentsorority.com](http://www.silentsorority.com)). After communicating with her about this study, she offered to post about it on the blog section of her website (Appendix A), along with the

researcher's contact information. A Facebook page was also established, which Ms. Tsigdinos also listed. Potential recruits were able to contact the researcher through an email account specific to this study ([infertilitystudy1@gmail.com](mailto:infertilitystudy1@gmail.com)), through Facebook, or by phone. Other bloggers that focus on this population reposted from or linked to Ms. Tsigdinos's blog post.

Ultimately, upwards of 70 women expressed interest in participating in the study, contacting me either through email, phone, or Facebook. Everyone was personally responded to and thanked for their interest. Initially, I was hoping to be able to interview participants face-to-face, limiting my travel to the East Coast. This resulted in four participants being selected, after screening for eligibility, based on my ability to travel to them.

After encouragement by my dissertation chair to do phone interviews, an additional eight participants were selected randomly. Of the 12 (total) participants, three interviews were in-person (one in-person interview was changed to a phone interview), seven were by phone, one was done through Skype (video chat), and one was done through email.

The interview done through Skype was ultimately not able to be included due to recording difficulty; at this point, an additional participant was selected, and this interview was done by phone. The email interview was initially going to be done through Skype. Upon reflection, the interviewee, due to her location, believed the connection would be spotty, and we discussed doing the interview through email. I was comfortable with this, particularly since all email communication with her had been quite clear, and I

had experienced her as quite expressive. The participant expressed comfort with this method as well. Differences in interview modalities are discussed below.

Ultimately, six women were from the northeast and Mid-Atlantic States, and the remaining six were from all parts of the country (south, southwest, west, and mid-west). Included in the sample were one European who had permanently relocated to the United States, and one American temporarily living abroad.

After initial contact by participants, a phone call was scheduled. During these calls, eligibility for participation was confirmed; the purpose of the study and consent were reviewed; participants were given the opportunity to ask questions and express concerns, and a time for the interview was scheduled. It was also an opportunity to develop rapport and become acquainted prior to the actual interview.

Following this introductory call, those being interviewed by phone were mailed a cover letter, two copies of consent forms (Appendix B), a self-addressed stamped envelope (to mail back one signed consent form), and a \$10 Starbucks gift card as a token expression of gratitude and consideration of their time. For those being interviewed face-to-face, consent forms were signed and a gift card was given at the time of the interview. For the participant living abroad, although confidentiality was assured during the interview, formal consent forms were signed and a gift card was mailed upon her return to the country.

### **Interview Modalities**

This study ultimately collected data using three different modalities: face-to-face interviews and phone interviews, both of which consisted of one interview within a prearranged timeframe; and one email interview spread over four months. Research

comparing the various modes of data collection in qualitative interviewing show that there are both pros and cons for each method, yet all can be completed successfully.

Sturges and Hanrahan (2004) found no significant differences in interview results in a comparison of face-to-face and phone interviewing. In addition, Holt (2010) argued that telephone interviewing should in no way be considered “second best”, but that there may be “sound ideological, methodological, and practical reasons why it may be a more favourable mode than the often ‘default mode’ of face-to-face interviewing” (p. 120).

Kazmer and Xie (2008) concluded that qualitative interviewing can be successfully completed using face-to-face, telephone, email, and I.M. (instant messaging). They identified potential issues with each modality, including interview scheduling and participant retention; recording and transcribing; data cleaning and organizing; presentation and representation of data; and the detection/presentation of affective data. Busher and James (2006), in their research addressing on-line interviewing, found that this method brought about an increase in reflexivity beyond what was expected, provoking a “richness of reflection”. This was also consistent with the findings of Berger and Paul (2011).

My experience using the three different modalities reflected the research. Each method had benefits and disadvantages, although I believe they were minimized considering the context and emotional subject matter of the interviews. In addition, although on-line communication risks being devoid of affective communication, making it potentially more difficult to “hear” someone’s voice, this was not my experience. I was fortunate that the interviewee who participated on-line was quite expressive with her language.

## **Inclusion and Exclusion Criteria**

Criteria initially included women, aged 35-60, with primary (no children) infertility, who pursued treatment for infertility, are now living without children (either biological, conceived with the use of donor eggs or via surrogate, or adopted), and have not pursued treatment for at least three years. The criteria requiring actual “treatment” was changed to “pursued treatment” after it became apparent, upon screening, that unsuccessfully pursuing treatment was also traumatic and didn’t minimize the experience of infertility for someone desiring biological children.

Age was limited to this group since they are a population that most likely had access to some infertility treatment and made a decision to live without children. It is also an age group that was raised with many options for women (e.g., motherhood, education, career) as well as cultural pressure to procreate. All women in this age range were invited to participate, regardless of sexual orientation, race, ethnicity, or marital status.

Despite this well thought-out argument limiting the age of participants to 35 and over, I was challenged on this in the comments section of the silent sorority blog. After carefully considering the argument, I believe the challenger is correct: an experience is valid, regardless if the woman is 25, 30, or 35. In addition, there is always the possibility that a woman will change her mind and adopt at age 45, despite feeling that this was not a viable option at 35. This challenge was brought after all participants had been selected; had it been brought earlier, the criteria would have changed.

Women who were still undergoing infertility treatment, still considering such treatment, were pregnant, had adopted, or were planning to adopt were excluded. Also excluded were those who may be infertile but did not pursue treatment for infertility



(unlike Ireland (1993) this study did not include those who did not pursue treatment). Those who had suffered a non-infertility related current or recent-past crises (recent death or serious illness in family) were also excluded.

### **Research Design and Setting**

The sample size was limited to 12 women. The sampling procedure was purposive. Purposive sampling involves the selection of participants that will contribute to an in-depth understanding of the study's focus because they share an experience or can contribute to the study in some meaningful way (Charmaz, 2006).

Each participant was interviewed individually. Eight participants were interviewed via telephone; two were interviewed at their offices, and one woman was interviewed in her home with one very minor interruption. Interviews ranged from 30 minutes to two hours. One woman participated via email; a total of 28 email exchanges took place over four months.

The researcher was prepared to do semi-structured in-depth interviews using an interview guide (Appendix C). However, after beginning with the statement, "please tell me how you came to learn you were infertile and what that experience was like for you", almost all the women were able to tell their story from start to finish with little prompting. The interview guide was consulted minimally for almost all interviews. During each interview, I took notes and asked clarifying and probing questions at appropriate times. At the conclusion of the interview, demographic information that had not been organically disclosed was collected. Participants were also asked to reflect on their experience being interviewed, and were invited to contact the researcher by phone or

email if they wanted to elaborate on anything they had shared or had more to say. Four women did so.

The interview completed through email necessitated, because of its nature, more activity on my part. Here, my questions were often dictated by the participant's answer (probing) or from the interview guide.

Many of the women cried at certain points of the interview, recalling some of the more intense and emotional moments of their journey. Their reactions felt appropriate to the sensitive nature of the particular area being discussed. At no time did I feel interviews needed to be stopped for this reason, nor did participants express this. Almost every woman, at the end of the interview, thanked me for doing the study. Many specifically mentioned that they had never told their story before from start to finish, as they had just done. All expressed a desire to read the study when completed.

It was necessary for me to contact three participants at a later time to gather additional demographic data I had neglected to collect at the time of the interview. This was done through email; all responded promptly.

All participants knew of my own infertility; this had been disclosed in the original recruitment posting for the study on the silentsorority.com blog. I believe this was relevant; knowing that the researcher shared this history may have provided a comfort that aided participants in disclosing particularly sensitive information.

## **Analysis**

Interviews were audio recorded, and took place from April 2011–August 2011. Notes were taken immediately following each interview, reflecting the interviewer's initial thoughts, feelings, and anything else that felt particularly relevant about the

interview. Recordings were promptly downloaded to a password protected computer and file, and labeled with a number. Each file was then uploaded to a transcription service that had encryption software in place to ensure confidentiality. Two women asked if it were possible to have copies of their interviews emailed to them, hoping to have another record of this time in their life. This request was honored once transcription was complete.

Each interview resulted in four separate sources of data: demographic information; an audio recording; a typed verbatim transcript of each interview; and the researcher's notes recorded after each session. The researcher read through each transcript while listening to the audio shortly after each interview to ensure accuracy, take notes and write memos. Each interview, subsequently, was listened to once more and read numerous times, resulting in the researcher fully immersing herself in the data and being able to easily recall each woman's story and voice.

The researcher used principals of grounded theory to analyze the data. Grounded theory "consists of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories that are grounded in the data themselves" (Charmaz, 2006, p. 2). Following the principles of grounded theory, data analysis began as soon as the first piece of data was collected, and involved a careful and repeated comparative analysis of the participants' responses. This constant comparison of participants' responses facilitated the ability to adapt questions accordingly and listen for particular "markers" in subsequent interviews in order to gather the most relevant information.

Data were analyzed using line-by-line coding for the first four interviews, followed by sentence-to-sentence coding for the next three. Coding "distills data, sorts them, and gives us a handle for making comparisons with other segments of data.

Grounded theorists emphasize what is happening in the scene when they code data” (Charmaz, 2006, p. 3). This was followed, for the remaining interviews, by focused coding, which uses “the most significant and/or frequent earlier codes to sift through large amounts of data” (Charmaz, 2006, p. 57). As constructs took shape, the data was collapsed into categories and subcategories, from which theoretical codes were developed. Theoretical codes identify potential relationships between categories developed in focused coding (Glaser, 1978). From here, a theoretical framework began to emerge.

Memo writing was employed throughout the study, and proved to be a rich and valuable resource. Memos assisted in clarifying coding, defining categories, exploring ideas, and comparing the data. Analysis continued throughout and following the data collection process based not on frequency of codes but on scrutiny of the data.

### **Confirmation of the Data**

Data analysis was approached from a constructivist grounded theory point-of-view. This method sees data and analysis created from shared experiences and relationships with participants (Charmaz & Mitchell, 1996). Resulting theory “*depends* on the researcher’s view; it does not and cannot stand outside of it” (Charmaz, 2006, p. 130). Considering this, it was important to ensure that my own worldview, although important, did not take over the data analysis.

To ensure confirmability of the data, I worked closely with two colleagues, each of whom independently coded four interviews (with all identifying data deleted). One colleague had been through infertility and had adopted, although was not versed in the infertility literature. The other had no prior knowledge of infertility. As a group, we studied and examined our coding, challenged each other and made adjustments. As

coding progressed and a theoretical framework began to emerge, data was checked and rechecked, and findings were adjusted. This served to confirm the data and validate emerging themes.

As this was qualitative research, results are not generalizable and apply only to participants in this study. Whether the results are transferable to a different context is up to the judgment of the person making the transfer. The transferability was enhanced as much as possible by attempting to do a thorough job describing the context of the interviews, assumptions of the research, and potential biases of the researcher.

### **Ethical Considerations**

The confidentiality and protection of participants was of paramount importance, something this researcher is accustomed to as a practicing psychotherapist. Approval was obtained from the Institutional Review Board of the University of Pennsylvania, and informed consent was received from each participant.

All paper data generated by this study, including consent forms, has been kept in a locked file drawer in the researcher's locked, private office in a secure building. Computer data, including audio files and interview transcripts, is stored on the researcher's personal password protected computer in a password-protected file. At the conclusion of this study, all paper data will be destroyed and all computer data will be erased.

### **Reflexivity Statement**

Grounded theory necessitates the researcher be aware of her own biases, assumptions, and values, and imagine how they affect the research. I have approached

this study mindful of this, and have attempted to maintain awareness of these potential issues throughout this study.

I became interested in this research well before beginning this study. I had been ambivalent about having children, yet found myself surprisingly distressed when I discovered I wasn't able to. Failing to intuitively understand my reaction, and failing, as well, to find a therapist that could assist me, I turned toward my historical coping style of reading and becoming well informed on the topic. Yet, I was unable to find research that addressed infertility for those who were not interested in adopting or third-party reproduction. I also attended numerous conferences and workshops on infertility; all focused on increasing one's fertility, IVF, donor eggs, and adopting. It seemed, and felt, that deciding to not have children after infertility was as isolating as living on Mars.

As I worked through this part of my life, friends and colleagues began to refer women to me (as a psychotherapist) that were struggling with infertility. This population has now become a small but steady part of my practice. Most of these clients eventually have a child, whether biological or not. I have also encountered a few women who are unable to have children, are uninterested in non-biological children, and are trapped in sadness, unable to move forward. These are the women that most needed this research.

One of my strengths is in listening; this has served me well as a psychotherapist in private practice. This skill also assisted me in my role as a researcher. The two roles have other things in common as well, such as the ability to probe for deeper meaning and the capacity to put others at ease in order to facilitate safety and disclosure. There are other aspects, however, of being a therapist that I needed to be aware of and hold in abeyance while conducting the interviews. These included offering my own thoughts to facilitate

deeper understanding, wondering and inquiring about relevant history, providing education, and offering, however mild, an interpretation. This was not an easy process, and may have resulted, at times, in being quieter than was necessary.

My training as a therapist served me particularly well while analyzing the data. During practice, I attempt to listen, as Freud (1912) said, with “evenly suspended attention” (p. 111). This means not focusing on anything in particular that a client says, but giving equal notice to everything. Freud meant that one should allow for the therapist’s own unconscious memory to arise for the purpose of interpretation. Although I wasn’t interpreting data in the Freudian sense (during the interview), I was certainly using this skill while reading over the data, making connections, and developing theory.

Finally, since the research on the experience of infertility while going through treatment is well documented, I approached this study with the pre-conceived notion that all participants had suffered greatly. I was aware of this bias while interviewing and analyzing the data. I was also aware that despite not having children, I was quite happy with my life. I needed to be mindful of my hope that I would find more of the same.

## **Chapter IV**

### **Findings**

In this chapter, core themes that emerged from the data analysis are presented, in accordance with the methods reviewed in the previous chapter. Except as indicated, these themes reflect commonalities found among most of the research participants, “most” meaning 9-10 of the 12 participants. These ten themes include experiencing trauma; actively ending treatment; moving into living without children; experiencing profound loss and grief; processing the grief; acceptance and choice; reestablishing identity and turning toward the future; growth and opportunity, improved spousal relationships, and enduring issues. Themes will be defined, then further clarified with verbatim quotes from the transcripts. When there was a broad range within a theme, that range is illuminated with appropriate examples. Participants often used medical terminology and abbreviations. A glossary of terms is provided (Appendix D), as well as brief bios of study participants (Appendix E).

#### **Experiencing Trauma**

All of the women described powerful feelings of traumatizing grief and loss over the inability to conceive or carry a child to term. This trauma began either at a first miscarriage prior to awareness of their infertility, when first learning of being infertile, or after an unsuccessful treatment cycle. Despite some of the women being aware they were having difficulty conceiving, and seeking medical attention for this, receiving a concrete diagnosis was devastating. Many felt robbed that a simple birthright had now abruptly become more complex or taken away completely. Others reported feeling further traumatized by their treatment by doctors and various fertility clinics.



### **Traumatic responses to miscarriages, diagnosis, and treatment.**

Miscarriages were often experienced as traumatizing. Patricia, 54, described her traumatic response upon learning her pregnancy was not viable:

*It was the most horrible, horrible day of my life, really, one of the most horrible days... It was almost like an out of body experience. I don't know how else to describe it. I just was so upset because I knew then that there was something wrong, that something had happened... I don't really remember sleeping or whatever...I remember, I kept saying the whole time, "I don't think the baby's dead. I can't let them just go in there and scrape out my baby." I was so in denial about the whole thing. It was just totally devastating, it really, really was.*

Many of the women described feeling traumatized by receiving a diagnosis. Sara, 38, went for testing after unsuccessfully trying to conceive for one year. Here, she described her experience after learning (incorrectly) that her fallopian tubes were blocked:

*... I have two sisters and my mother were on the phone silent. And I'm on the other end I'm hysterical...I was so traumatized coming home thinking my tubes were blocked...he scheduled actually a second HSG and so I did that but in the meantime I was developing some severe upper neck and shoulder pain...I'm really psychosomatic and so I think it was from the stress and anxiety and I had never been in such pain before...*

Shortly after, Sara learned this diagnosis was incorrect, and had surgery to correct a different issue. She describes her follow-up visit after this surgery:

*I remember going and the doctor saying, "No, that really isn't the problem. You just have unexplained infertility and you have a five percent chance of getting pregnant," instead of the regular what, I don't know, 20 percent or whatever. "And we suggest you start intrauterine insemination." And I remember just being, "What?" I felt like the rug had been pulled underneath...And I remember getting in the car after that appointment and I went by myself to that and just shrieking in the car to God like he owes me an explanation for this and just to make this go away.*

Others described failed treatment cycles as traumatic. Lauren, 42, recalled:  
*And actually that phone call is worse than the ectopic, when they said, "It didn't take." And they don't even tell you-- they give you a phone call. You go in for blood work, and they call you four hours later: "It didn't take." And you're devastated, because you spent six weeks doing everything you can do to make this happen, and you get so excited and they get you excited, and then it doesn't take, and there's no one there for you.*

### **Trauma compounded by doctors.**

Many of the participants recalled negative experiences with multiple reproductive endocrinologists. Reported was a pattern of poor communication and lack of information provided on the part of the doctor, a feeling of being rushed through appointments with little opportunity to ask questions, and inadequate attention given to the heavy emotional toll of infertility and infertility treatment. Although most of the participants ultimately found doctors they trusted and with whom they were comfortable, the memory of poor treatment lingered and contributed to the overall traumatic experience of infertility.

Rachel, 38, described the insensitivity by her fertility doctor when learning she was not a candidate for infertility treatment using her own eggs:

*...she didn't even do an exam or bloodwork. She just read my chart from my obgyn, said yes I have POF, I have a 5% chance of getting pregnant naturally, I need to be on hormone replacement therapy, here are the meds in one hand, and by the way we can do egg donation here is information on loans and payment schedule in the other hand, come see us when you want to do egg donation, I have nothing more to say to you, as I am sitting there shocked and crying, bye bye...and who the FUCK was this RE, daring to give me info on egg donation in the next breath after telling me I couldn't have my own children, showing no compassion as my husband and I sat there, watching our future die in front of us?*

Danielle, 40, described her clinic's abhorrent communication with her:

*...after the second cycle, we went back to the doctor. We left with a plan for round three, of what was going to happen, and I literally walked out of there with my medication sheet, and what the plan was. A week later, I get a letter from this clinic, saying, "The board has decided we can't treat you." I was like, "What?" Like, first of all, this isn't even my doctor picking up the phone to tell me this. I walked out with a medication sheet, thinking that in a month or so, I was going to be doing another cycle...It was just awful. I got the-- one of the head nurses on the phone, and she tried to tell me, you know, "Well, given your past two cycles, we don't feel that IVF is the right route for you." I'm like, "That's fine, you can have your opinion, but I left there-- I left that appointment with the expectations that I was going into another cycle." I'm like, "This is just totally inappropriate,*

*the way you had handled this.”*

Miscarriages, and the diagnosis and treatment of infertility resulted in layers of traumatic experiences. These layers were often compounded by disrespectful treatment by fertility doctors and clinics. For many participants, the psychological toll of this trauma was a major contributing factor to the decision to terminate treatment.

### **Actively Ending Treatment**

Of the 12 participants, treatment ended for one due to an emergency hysterectomy; another decided against using donor eggs, her only viable option after diagnosis. The remaining 10 women made difficult, conscious decisions at some point to end treatment with reproductive endocrinology and the medical community. This was initially, for many, a temporary decision made to take time to reevaluate; for others, it was a permanent turning away from Western medicine. For everyone, the emotional toll, both personally and on their relationship, had become extraordinary.

The next treatment step for these 10 women would have been beginning or continuing with IVF or donor eggs. The prohibitive cost of treatment for this, with no guarantee of success, and the likelihood (due to statistics) of failure and further emotional turmoil were factors that contributed and overlapped in participants' decisions to delay or end treatment. The desire for less suffering and a better life was critical.

Finally, six of the women reported an additional trauma between their infertility diagnosis and shortly after ending treatment. These traumas included events both related to and separate from infertility, and added to participants' suffering.

### **Emotional toll.**

All of the women reported feeling traumatized by their infertility diagnosis; this trauma was compounded with each failed treatment cycle and/or miscarriage. Nancy, 50, ended treatment after three IVFs and multiple miscarriages. She recalled the emotional and physical toll:

*...I was just like, I can't keep on doing this. I can't-- it was just too much. Even if I had more money, let's say I had another 100,000 dollars, to put into it. Just physically and mentally, it was just too much. I couldn't-- it was the emotional toll, it was not worth it at that point, and I knew that, for myself and for my husband, that we just-- it was enough. And I think the only way I would have done it again, is if someone could guarantee me 100 percent, that-- and they told me my odds were, like, five or ten percent, and I just-- you know, at some point, you have to understand statistics and be like, okay, that's it, done. And you know, I love my husband, and I wanted to have a different life than what we had been having.*

Beth, 48, succinctly stated why she took a break from treatment:

*...we were pretty much out of money and out of our minds.*

Rebecca, 35, and a stepmother, spoke of an element of self-preservation and a desire to return to happier times that motivated her decision to end treatment. Here, she described her process after her doctor recommended she begin IVF:

*...I really came to the conclusion that I had been through enough. And while I knew I could handle the physical challenges, I didn't think I had it in me anymore to deal with the emotional ones. And I also kind of had come to realize that there had been a time in my life when I had been happy and I didn't have children--*

*biological children. And so if that was possible at one time in my life, then that should still hold true today, and that it was not worth it for me to put myself through everything that had happened, potentially damage my marriage and the family that I currently had, to pursue treatment and put my family under financial strain-- which I knew we could have handled, but that's also a huge load to carry. And so I think around that time, I said, "No more."*

### **Turning away from ivf.**

Six of the participants chose not to do IVF for various reasons. This decision was often difficult; many felt that despite this advance in science, it was still against nature to conceive outside of the womb. Sara, 38, described her decision to not pursue treatment with IVF. She addressed the financial piece, but ultimately it is the personal cost to her that was the deciding factor:

*...my husband did not want to do IVF. It just didn't feel right to him. He didn't-- the whole unnatural, he just wasn't into it...I get anxious about money issues, was scared about putting so much of a financial investment possibly into it even with a grant...But I didn't want to go back, after a while I realized I didn't want to go back to the person I was during the fertility treatments that I did do... I just remember, oh God, just sitting on the kitchen floor, I can't open a package and I'm so angry and I'm-- I was like getting temper tantrums and I know it was the hormones but I just don't-- part of me says it's not worth it to me. And it's kind of like an emotional self preservation. And I go back and forth between feeling guilty that I guess you don't want it enough and saying, no this is because I care about myself and I care enough about myself not to go walk down that road again.*

Four of the participants underwent IVF and one pursued a donor egg. Those who pursued IVF did so with much thoughtfulness. For some of these women, spousal discomfort with the process needed to be resolved as well. The lack of a guarantee, combined with the emotional cost, was also problematic. Samantha, 43, ultimately decided to end treatment after an honest assessment of her chances, statistically. She recalled her ambivalence about IVF, the stressful nature of it, and her difficulty coming to terms with ending treatment:

*...three years into this process of trying to conceive and we go with IVF options... I did my IVF cycle, my one and only IVF cycle. And it was just a really bad experience, sort of start to finish... There was just nothing-- well first of all there's nothing natural about it... It's just my husband was very uncomfortable with his part of the requirements for that and I just was trying to manage my working full time and managing him because he had a lot of anxiety about the whole thing. And it just didn't-- I was very ambivalent about it to begin with and it just didn't feel right to me. I also didn't have high hopes for it. And it took me a really long time to come to terms with that decision to not do another IVF cycle because there was a sort of sense like well if you don't do it it's your own damn fault. So who are you to complain? Don't complain. You chose not to do it. So it was this vicious sort of ping-pong game in my head.*

For Jill, treatment with Intra Uterine Insemination (IUI) came to an end when she was no longer producing viable eggs. Prior to this, the high-cost of IVF would have required a lifestyle change that was not an option for her:

*So we got to a point where we were talking about in vitro fertilization but our insurance wouldn't cover it. We'd have to take out a loan. I always wanted to have kids and stay home and, if I took out a loan, I'd have kids and have to go to work.*

**Additional discrete traumatic event.**

Six of the women suffered an additional discrete traumatic event between their infertility diagnosis and shortly after ending treatment. Only one linked this additional trauma to adoption no longer being an option. These events included one woman's donor accidentally becoming pregnant while mid-cycle, then having an abortion; another experienced spousal infidelity after her first miscarriage. One participant's infertility journey ended with an emergency hysterectomy; she had also participated in an egg-sharing program (with her own eggs) to defray treatment costs. At the time of the interview, she did not know if this had been successful and whether she had a biological child somewhere. One woman's mother, with whom she was very close, was diagnosed with stage 4 metastatic breast cancer between IVF cycles, and passed away within 3 months. Another participant suffered major hemorrhaging after a procedure to remove a fetus that was no longer viable, requiring paramedics taking her to the hospital. She reports continuing somatic memories of this event. It is not possible to know how much, if at all, these additional traumas influenced subsequent decisions. In addition, another participant's husband suffered a traumatic brain injury one year after ending treatment. His subsequent long-term rehabilitation and altered mental capacity removed adoption as a possible option, something this participant had been undecided on.



Participants took different paths once the decision was made to delay or cease treatment with Western medicine. Some pursued alternative medicine; others explored adoption and/or fostering. One knew immediately she would be living without children.

The following eight findings are presented linearly, but, like any developmental or stage model, moving through these stages is less systematic.

### **Moving Into Living Without Children**

At the time of the interviews, ten of the women had come to terms with living without children, one had mostly decided, and another was still hoping to be a foster parent once she retired. One of the participants came to an immediate decision to live without children after learning that fully biological children were not an option for her. The remaining 11 began personal journeys of “letting go”, lasting from a few months to years. This journey included attempts to conceive naturally, sometimes with the assistance of Eastern or alternative medicine (e.g., acupuncture, herbs, dietary changes); contemplating more treatment; and considering fostering and/or adoption. The women spoke of letting go of hope, and why they ultimately decided against fostering or adoption. Much thought, insight, and self-awareness contributed to this process; often numerous smaller decisions led to significant, life-altering outcomes.

#### **Letting go of hope for a biological child.**

Many of the women continued to try to conceive naturally, often seeking out alternative therapies for assistance. Sara, 38, had acupuncture for a year after ending treatment. She recalled her husband’s frustration and her own magical thinking, both which contributed to her process of letting go:

*...a year after the fertility treatments we agreed we were just going to stop trying to get pregnant naturally kind of thing because when I was doing the acupuncture we were still trying in a way and (spouse) was just like, "I draw the line, I can't do this anymore," and so we said, okay. And my mom saying on the phone to me, "Oh now that you're really quitting, I'm sure you'll get pregnant now." It was infuriating hearing that. And a part of me agreed with her. I had a lot of wishful thinking, that magical thinking where I thought if I just try to let go as much as possible maybe I will get pregnant and it was hard for me to let go of. But just gradually it just kind of I guess one by one my fingers let go of the cliff kind of thing.*

Christine, 41, ended treatment, then continued trying to conceive with the assistance of acupuncture and other alternative therapies. She and her husband would agree to stop, but for six months she would “slip” back into trying. She recalled the impact this had on her relationship:

*...in the craziness that took over me and this determination to make this thing work we'd started to lose track of our relationship and I could tell that we were starting to drift in different directions.*

Christine gradually let go of pursuing alternative treatments:

*I kept going even when I knew that it wasn't going to work. I just kept going and then bit by bit I canceled an appointment and then I didn't go one week and then I didn't go to all of them and then finally I just knew that it wasn't going to work and I was just clutching at straws.*

Danielle, 40, ended treatment, then vacillated for over a year between more treatment, adopting, or living without children. She recalled a turning point after receiving a call from a friend informing her of her pregnancy:

*...that was my meltdown stage ...I got off the phone with her and I just literally, I sat in the living room just bawling and bawling. My poor husband didn't know what to do...we talked through a lot, what does this mean to us. His point was, "Well your friends are going to get pregnant, how are you going to deal with this or how are we going to deal with this going forward?"...it was sort of that turning point that I knew I couldn't keep living my life with going through this, we had to stop at some point.*

#### **Deciding against adoption.**

11 of the women considered fostering and/or adoption. Deciding against this path was complex; none gave just one reason. Factors included the risk of further loss, the importance of biology, the high cost, participants' mental health, and a prioritizing of their marriages. Critical for many was reconciling guilt over deciding against adoption due to the desire to begin living life again. Patricia, 54, explored adoption on and off for 3-4 years. She, like many, objected to the cost, privileged biology, and struggled with guilt:

*It was like \$30,000. "How can 30,000--?" you know. It just seemed like a baby racket... ...we struggled with this for years. We'd go back and forth...we wanted our child to be a product of our love and our union and conceived that way... other people can do that and feel that the child is their very own. We couldn't do that... he knew sooner than I knew that it wasn't going to make us happy, that it*

*wasn't really the path that we were supposed to take. But I held on for a longer time than like, "I should be a mom at all costs. I should just do it. I should do it".*

Danielle, 40, recalled feeling exhausted as well as adoption not feeling right for her, a sentiment shared by many:

*We did end up going to talk to a woman who counsels couples going through this. Adoption...wasn't one that was jumping out for either of us. And by the time we went to talk to this woman we were sort of in that stage of where-- is this what we want to do, do we want to adopt, do we not want to have kids...we were so burnt out from all of this that our minds were-- I think our minds were made up but we sort of felt like we needed confirmation about it all that we were going to go this route without children... my friends would always ask, "Well why don't you adopt?" And I sometimes feel like, "Well why don't you adopt?" People think that's the end all solution to things and it's not. It's a wonderful choice for people but it's not for everyone...it wasn't pulling at our heart strings so we went with our gut.*

Lauren, 42, seriously considered adoption. She ultimately decided against it, fearing further loss and desiring a turn toward life:

*...we thought adoption...god, probably up to like the second interview with a lady that was pregnant-- a young lady. And came home, everything was looking good, and I just broke down to my husband. I said, "You know what? If we go through this, nine months of her being pregnant and she says no, she takes-- I can't. We have to live our lives. We have spent most of our entire marriage, the first seven years of our marriage trying to have a baby. We haven't lived our life. Let's live*

*our life. I don't care what other people think." And he agreed. Thank god. I go, "We have nieces and nephews that we love, godchildren. Let's focus on that. Let's live our lives." And it was easier said than done. There was a few times I'm like, "Why didn't I do the adoption route?" But at the end of the day, I'm grateful. I'm finally at peace.*

Continuing to consider adoption was common for a few years after ending treatment; it was part of the healing process. Also imperative for healing was taking time to process all of the loss and grief that accompany living without children after infertility.

### **Experiencing Profound Loss and Grief**

All of the women reported continuing experiences of overwhelming and profound grief and loss. These losses usually began with diagnosis, were cumulative, and become layered as time passed, treatment ended, and the process of moving into living without children began. These losses included denial of motherhood as a rite of passage; doubting one's womanhood; feeling a lack of control over one's life; the anticipated life with children; loss of one's religious environment as a support system, and changed and broken friendships. For 10 of the women, the intensity of their grief abated gradually, with a marked shift 3-4 years after ending treatment (or after the initial diagnosis if no treatment). One woman reported a shift five years after her hysterectomy, although also reported being in denial for two years. Another was just beginning to glimpse this shift; she had ended treatment five years prior and had then fostered children. Her last foster child left her home 2 ½ years prior.

### **Denial of motherhood as a rite of passage.**

All the women addressed their feeling of having “missed out” by not being a mother, emphasizing the universality of motherhood and their resulting sense of feeling isolated and like an outsider. Sara, 38, described this loss:

*...her husband told her once, “Before kids, I didn’t get it, but, now...I look around at other parents, and I feel like I’m in the club,” and, when I think of that now, it feels really bittersweet, because I know that club, and I’m not in it, and I don’t feel like I’m a part of that club...I feel like I’ve been denied this rite of passagehood, and that kind of gets me, it really does, and, being denied that, I’m denied membership in something that so many women are in, and so that makes me feel even more alienated.*

Patricia, 54, similarly:

*I just always still feel in a way that society values mothers more than non-mothers...people don't come right out and say that, but I think it's true, and I feel left out because of that. I feel like I'm not in the club. I'm just not in the club. I'm not in any club. Like I don't have that sense of identifying with anybody. I identify with me and my husband. It's still a little isolating. I think it probably always will be.*

Christine, 41, addressed the loss of connection with her friends:

*...there’s something that you’re never going to have in common with your friends, and you know, somehow they’ll find other friends who, you know, who they can talk to their children about.*

### **Doubting one's womanhood.**

Many expressed a sense of feeling broken because their bodies could not do what comes easily to the majority of women. Debbie, 36, spoke of being unable to experience pregnancy:

*It feels earth shattering...what would it have been like just to feel the feeling of being pregnant? I mean, I will never know that feeling and to not be able to have that simple thing that so many other people are able to do naturally. That's really hard to take...and it makes me question being a real woman...I don't feel complete. I don't feel whole-- those types of comments have, certainly, come out of my mouth.*

Samantha, 43, similarly:

*There's something really wrong about the fact that my body doesn't function in the way that it was born to function. There is a sense-- I mean I know there's a sense of me that feels less than, you know, that my body failed me and I try not to sort of allow that to take over my mindset because it's not particularly healthy, but I do feel that...in certain circles, makes me feel like I don't have any credibility.*

### **Loss of control over one's life.**

Many of the women addressed, both directly and indirectly, having had a sense of control over their lives prior to infertility, believing anything was possible with hard work. Experiencing infertility challenged this confidence. Jill, 40, described her response to feeling powerless for the first time:

*I was pretty angry and pretty hurt and I didn't understand why I couldn't make it*

*happen, because in my entire life, if I wanted it, I got it...Never did I ever think that there was ever going to be something that I was not going to be able to attain if I wanted to, ever.*

Samantha, 43, described her attempts to gain control over her fertility with various remedies:

*I had stayed so hopeful for so long and so vigilant and had worked so hard to make this happen and believe me, you name it, eastern, western, I went to shamans. I went to acupuncturists. I went to Mayan massage. I mean I tried this supplement. I mean you name it I did it to try to-- I meditated. I didn't meditate. I ate wheat grass. I didn't eat wheat grass. Like I just did everything under the sun to make this work. I journaled. All of this stuff.*

#### **Loss of anticipated life.**

All of the women addressed the loss of the life they thought they would have and had already been preparing for. This particular loss involved almost every aspect of the women's lives. Initially, it was traumatizing. Rachel, 38, described how she felt in the first few months after learning she was infertile, was not a candidate for any treatment other than third-party reproduction, and would never have biological children:

*I felt dead. Dead inside. I felt like I wanted to die. All of a sudden I felt 30 years older than I was, as if I blinked and lost all those years with nothing to show for it. The future I had imagined, the life I had expected to have with my husband, was shattered... I think it was like what people who are about to die experience, where their life flashes before their eyes – however, instead of reliving moments from my life, I was seeing moments of a future life that would never be mine, that I would*



*never experience.*

As time passed, the initial traumatic response was replaced by sadness and awareness of what else, specifically, was lost. For many, it was the loss of the ordinary, daily life, as Samantha, 43, described:

*I think there will always be things that bring it up, whether they're holidays or they're weddings or even where I work or just something I hear on the radio... And I am such a sucker for tradition and family. And I'm not-- listen, my family's as dysfunctional as the next one. They're all kind of crazy in their own right, but I wanted my own still. I wanted to have that experience. I wanted to be able to walk up the backyard and go see Grandma or whatever, get my kid on the school bus or go to Thanksgiving dinner and whatever... no weddings, no grandchildren, none of that. That just stinks. It just stinks.*

Jill, 40, addressed the loss of a hoped-for Christmas. She reported hating her first Christmas after ending treatment, and now, eight years later:

*...Christmas morning sucks for me, because I have a really large family, and it's something I always wanted to do, was to have everybody over and all the grandparents and watch my kids open their Christmas presents and I don't have that. I wake up Christmas morning and it's my husband and I, and he is wonderful and I absolutely adore that man. But that's not where I saw my life going and that's not the life I planned...I don't think they will ever understand how much Christmas morning hurts.*

### **Loss of religious environment as a support system.**

Although some of the women reported a changed relationship with god, none reported a crisis of faith due to their infertility. However, for the women who attended church and were more actively involved in religion, church attendance became difficult because of its focus on families with children. Danielle, 40, felt isolated from her church yet still had her faith:

*I remember going to church on Mother's Day one day and they, "All the mothers stand up." And I'm in a puddle on the floor, I'm like, I can't do this, this just isn't working for me. So we found we were also pulling away from going to church because everything was so family, children centric and that wasn't-- we were trying to take care of ourselves and figure out where our place in the world was...I don't feel like I've questioned my faith, I feel like I still have my faith, it's more of being in that central area and it was just like once again, the isolation, I don't fit in here, we don't fit in here...it was the one place where when I thought I would be sort of feeling okay on things, it would-- being in there it just, I don't know, I seemed to be falling apart in there.*

Patricia, 54, was disappointed in and angry with her priest when she actively sought out recognition for her miscarriages:

*I'll tell you who annoyed me the most is the priest. We're Roman Catholic...I wanted to have some type of a recognition for the babies, like a baptismal or something...and what he told me was I just have to accept this dark time in my life, and accept that I'm not going to have children, and that there isn't any religious ritual or anything to do. And I remember saying to him, "Okay, if it's such a crime*

*and a sin to have an abortion in any stage, why-- and that's acknowledged as a baby-- why is not a miscarried baby acknowledged as a baby in the eyes of the church to be blessed?" And that made no sense to me whatsoever, and I was really, really, really put off by that. And I think at that point it almost-- I felt isolated from religion. And I think we stopped really going to church then, because also church became a very painful experience. Let's face it: It's families. It's mothers. It's babies. I couldn't stand it. And then like Mother's Day: "Will all the mothers stand?"*

### **Changed and broken friendships.**

11 of the 12 women reported experiencing a lack of empathy and support from close friends, both during infertility treatment and after. Many spoke of their desire for friends to understand what an enormous loss this was, or, at the very least, to be able to see and respond to their tremendous pain. This often did not happen, resulting in strained friendships. Sara, 38, addressed one such loss:

*I had a best friend and that friendship has fallen apart basically. It's limping along, we pretend we're still friends and email each other once in a while. But she didn't handle the situation well and so that has been a really painful thing for me because she's ended up not being as supportive as I wanted.*

Danielle, 40, addressed her loss of friends and her inability to address it due to her exhaustion:

*...checking in would have been nice...my sort of core group of friends, I don't know, I guess we've sort of gone our different ways...to this day, I still think they just don't get it. And I went through a stage though that I was really angry about*

*that...when I had been going to a therapist, we talked about, you know, well why don't I call them up and you know, talk about this or write a letter or something like that. And I thought about it, but I just didn't have the energy to do it.*

Friends had often become parents, were busy with their children and had little time available for others. Amplifying this was the women's own reluctance to be around pregnant women and young children. Samantha, 43, described the impact on three of her close friendships, as these friends moved into parenting:

*They had families. I didn't. It was painful for me to sometimes be at these family gatherings in the middle of all these fertility treatments or whatever we were going through...the third friend adopted a child from China, and she just could not get her head around the fact that-- why we didn't just adopt. And that ended up being a source of stress for me. I'm like "You know, it's not helpful. That might be your choice. That doesn't have to be my choice." But she ended up taking it personally, and it just got a little bit difficult, and that friendship definitely became strained.*

Rachel, 38, similarly:

*My friendships have suffered - almost all my friends have kids, and over time, as they have become more involved with their kids and as their life and social activities have revolved around them, I have been excluded...it is isolating being childfree. I finally got my friends to stop talking to me about hope and/or adoption. With most of them, I am "friendly" but the quality of our friendships has changed, and we can never do things together as we used to.*

Healing involved becoming fully aware of all the grief and loss, and finding a safe

place to express one's sadness. These two processes complemented each other.

### **Processing the Grief**

For almost all the participants, the first year after ending treatment was a time of loss, depression, anger, and trauma; many isolated. As time passed, these feelings remained yet became less intense as the women found voice, began expressing themselves, and moved into accepting their decision to remain without children. This was a gradual process that lasted, on average, 3-4 years. Almost all of the women reported this gradual shift, often followed by a marked shift in their thinking toward the end of this period.

For all of the women, having witnesses to one's sorrow and finding like-minded others was critical to processing their grief. Although half of the women had attended groups sponsored by Resolve (the National Infertility Association) during treatment for infertility, all of the women spoke of how difficult it was to find help once treatment ended. To move forward, it was necessary to be resourceful, persevere, and take risks in creating an individualized supportive structure.

Healing, for all of the women, included a combination of finding a way to speak of the issues, or "finding one's voice"; fully acknowledging the grief and loss; having the support of family and friends; taking risks in disclosing; managing one's environment; therapy; and on-line support. Much self-awareness and personal growth was achieved during this period.

### **Finding one's voice.**

All of the women spoke of their desire for privacy and/or discomfort expressing emotions, either explicitly (describing themselves as shy or introverted, or stating that

this is how their family functioned, e.g. “my mom was a doer and didn’t talk about emotions”), or implicitly (remarking that their on-line group or class was “closed”). To work through their emotions, particularly shame regarding infertility, the women were compelled to learn how to give voice to very personal internal processes. Each participant found their voice in a unique way. This often resulted in permanent internal change and an increase in self-esteem. Christine, 41, reported that for two years, bad days shifted gradually into both good and bad days; now, three years later, she has mostly good days. She found her voice and tackled feelings of shame through writing a blog, a means of communication more comfortable for her:

*I keep my cards pretty close, and don't really pull people into the really, you know, emotional side of what's going on. But writing it is different...it's much easier to put down what's going on in writing rather than sitting across the table from somebody and tell them face to face...I knew that on the other side of things people that I knew would be reading it. And there was some discomfort with that, because it was okay for the people that were good friends to read it, but I realized that anybody who knew me at all... could read what was going on in the deepest most personal parts of my life. So there's a lot of discomfort with that, but I just kept thinking, I've got to talk about this. Nobody talks about this. It's really still such a taboo subject and it needs to be talked about. So I just need to get over that, I don't know if you want to call it shyness, but discomfort with telling the truth, you know, the absolute truth about what's going on with me. But it has also helped as well...now I'm not afraid to talk about it and it's much easier, ultimately, doing it that way than feeling ashamed or uncomfortable or*

*embarrassed about, you know, what happened and the reason why I don't have children... people understand it to be a shameful thing...But if you can find a way to boldly say, yes this happened to me. I couldn't have children, but it's okay, then people will kind of think well, you know, it's not such a shameful thing to talk about. I hope.*

Rachel, 38, reported a three-year depression (part of the constellation of complicated grief and trauma) after learning she would never have biological children. She worked through destructive emotions by finding her own voice, fostering greater self-awareness in the process. She then used this voice to help and educate others:

*Well, I noticed that I was harder and harder on myself, feeling shame, feeling pity, feeling ostracized...and I realized that I was enabling others to make me feel that way, and they couldn't make me feel that way unless I let them. A few things have helped me work on this, including therapy, and just getting sick of hearing people speak empty words about prayer, hope, 'it will happen if it is meant to be' - I HATE that!!!! I started to figure, do they realize how they are making me feel? How they are making others feel? Ignorance is not permission. So, I decided to provide education...I started out of anger, and I was terrified. I'm sure I came across as bitter or depressed, but I didn't care. It really started out of the pain I felt from questions about adoption...I realized that I needed to be open and communicate my feelings, or else I would have no one to blame for my upset except myself. If I can help someone else by being open myself, even better.*

For many, finding voice simply meant becoming comfortable speaking to others about their experience. Samantha, 43, was in a deep depression after ending treatment.

She had disclosed little to others out of respect for her husband's desire for privacy.

Finally speaking of her loss provided relief and validation:

*I wish I had opened up sooner to people and learned how to dodge the negative stuff or the unhelpful things because I do think there's-- I've received so much benefit from the people who did say the right things and were empathetic and did listen to my story and were truly sorry that this is how it worked out for us. I think it actually soothed me in ways that I wish I'd had access to sooner because I do think it helped me finally breathe...I always wonder like is there some level of embarrassment that I had. You know, you think there's something wrong with you, right? So, do you really want to like, you know, bare that to everyone? I don't know. But yeah, I do think opening up to people, especially women - I mean I work with largely women - and having them validate me and even my dad. Having that validation that this does stink and I'm really sorry was really healing to me. It really was.*

### **Fully acknowledging the grief and losses.**

Some of the women struggled to acknowledge the loss. Lauren, 42, was in denial after her hysterectomy. For two years, she was absorbed with advancing her career, giving little thought to her losses. Mourning began suddenly:

*I had went to get a baby gift at Babies 'R Us, and I remembered calling a friend. And I'm like, "I'm literally on the floor crying. I think they're going to call the cops on me. I am just insane." And she was like, "You've never grieved. Allow yourself time to grieve the losses you've been through." And I think that was the best words anyone had ever said. I allowed myself to cry. I allowed myself to look*



*at the pictures of the ultrasounds from the ectopics to finally--for the first time-- to go read all the medical records, to write letters to them, to do a little scrapbook for each one. I allowed myself to grieve. And I think grieving is an important part of moving on. If you don't grieve your losses, no matter how insignificant other people may think they are, I don't think you truly ever move on and get over it...(My spouse) and I decided every anniversary of the ectopic we would do something.*

Acknowledging the loss was an important step for Christine, 41:

*I didn't see it as a loss at first and I didn't understand that it was just the same as losing someone who had existed because in my mind those children had existed. They had names. I had plans for them. They existed in my mind but I didn't- it took me a while to make that connection that I had lost something and I needed to grieve that just as if I had lost a loved one who had lived. And so when I realized that and was finally able to do that and acknowledge that loss that was really important for me.*

Samantha, 43, allowed grief to surface once she was able to acknowledge the loss:

*So it was-- looking back on it now I was in a really bad way. I just was in a really bad way. I mean I'm so much better now but looking back I just think it was more than a bad flu. I was really depressed. I just could not-- and I kept journaling. And I kept trying to take care of myself the best I could and continued with yoga and I just wasn't there. I wasn't fully present in any of those things. And as the months wore on just sorrow just started to pour out of me. I think that was what it was. I kind of kept it together for so long I hadn't allowed the emotional parts of*

*these losses to really come up front yet because it wasn't a loss yet until I started to come to terms with the loss. And then it was a combination of just sheer disbelief.*

**Actively seeking the support of family and friends.**

Many of the women spoke of the need for empathy and thoughtfulness from family and friends. For some of the women, having one close friend provided enough sustenance. Others needed broader support. There were limits, however, to how much they would tolerate if they did not find this. Rachel, 38, read aloud to gain her mother's understanding of why she did not want to adopt:

*I finally started using a section of "Silent Sorority" which seemed to put all my jumbled feelings into words. In fact, I still remember when my mom mentioned adoption and just asked her to listen to me read a passage, don't interrupt - and she finally got it, and she's never asked about adoption again... It was very important to have my family's support, considering the huge impact it would have on the rest of my life. Then again, if I didn't have their understanding, then I would just pull back. One thing I have learned through all of this is how important my personal health and mental health are to me. Some may call it selfish, but I call it healthy boundaries.*

Lauren, 42, an avid reader and writer, took an idea from a book and wrote a letter educating friends and family:

*One time, I sent a letter to all my family and friends. And it was a pretty harsh letter. It said, "This is how we feel. These are the things you can do to help us. If we don't come to a party, we're having a bad day." And I hit the Send*

*button...And for the most part, it worked...there was a couple of friends that-- in the back of my mind-- that they're no longer friends. They responded in a negative way, that I should be grateful for what I have and that I'm being selfish. Which they totally didn't-- I just responded back, "Please reread the letter from \_\_\_and I," and that's it.*

Jill, 40, had a remarkably open and supportive family. She received sustenance after her final treatment cycle failed:

*I called my grandmother and I think that was the worst... she was so upset and so supportive. It was amazing. She had five children and she said to me, "This isn't fair," she said. "I'm going to church right now and I'm going to go yell at god."... She went to church, yelled at god...then she wrote a letter to the pope and yelled at him...Which was fun, you know? That's the sweet, wonderful thing about my family is that they were willing to go anywhere they needed to go to correct and fix this problem. So that was kind of nice, you know?*

### **Taking risks and opening up.**

Taking risks and opening up often led to surprise sources of support. This surprise support was remembered as highly beneficial, and often led to a crucial support system throughout the healing process. Rebecca, 35, pushed herself to take an on-line class that focused on loss two years after ending treatment. She then created her own on-line class to address losses specific to infertility:

*I created my assignments based on sort of things I needed to get out...Another assignment I did was: What did you want to name your kids? What did you really look forward to doing with your children? Because nobody wants to listen to you*

*talk about your nonexistent kids...Again, being seen and being heard, even if it's in a protective community, was very therapeutic. And I had people write assignments on: What would you like to really tell your loved ones about what you're going through? Whether you say it or not. What would you really like to tell your mom that you can't really seem to explain to her? It was very therapeutic for me to sort of address these issues and find a way to work through them.*

Sara, 38, described herself as an introvert. She took a risk by attending a weeklong retreat where she knew no one, 3 ½ years after ending treatment:

*I was too scared to go... the money...scared about going by myself... ..there was a lot of sharing, a lot of oversharing, a lot of opening up and journaling and reading out loud what you've journaled, in addition to learning and saying out loud your poem...at one point, we had to say in a microphone around the circle-- that was just 10 people, the thing that I'm afraid to say to other people, and I talked about my infertility, and I cried and stuff like that, and it seemed like such a whoo, whoo, oh, there we are, Kumbaya kind of thing, but it was a very powerful experience for me.*

During the same week, Sara heard something that resonated in a life-affirming and life-changing way:

*Through the week, now and then, we'd have to pair off with someone to do some kind of exercise, and I kept being paired off with this woman...She's my mom's age, and we did a lot of exercises together, and I told her, actually, earlier in the week about my infertility, 'cause it was just the two of us, and it was very hard for me, and I was crying, and she said to me, at one point that week, and she has two*

*grown sons, "I'm really sorry for what you've been through, but I think you're going to be all right, because I've heard you laugh," and that has been one of the most helpful, healing, supportive things I have heard about my infertility. She's like, "I think you're going to be okay no matter what. You're going to be all right," because not only can I laugh, but she's heard me laugh, and she's heard the quality of my laugh, and it's good, and I hold onto that, and I felt like it was a gift.*

Beth, 48, was extremely private about her infertility, speaking only to her husband and one close friend. She discovered a colleague was going through infertility concurrently, and found a positive experience when she risked opening up to another in similar circumstances:

*...one of the teachers of the rooms I was with was a young teacher... using a surrogate to get pregnant-- well, to have a baby...So we were kind of doing it at the same time, so we would talk...she was successful and she has a baby and that's great but it was nice to at least have somebody, you know what I mean, that knows relatively what you're going through.*

### **Managing one's environment.**

Many of the women addressed a need to manage or change both their work and personal environments; being around pregnant women, new mothers, and attending baby showers was too painful. Samantha, 43, managed her day-to-day environment in the first few years after ending treatment by retreating, both at work and personally:

*I had a hard time being with my friends with their kids...And I finally gave in to it. I couldn't any longer pretend oh look at your beautiful baby...So I think what I did was sort of more of an opposite extreme was I just cut everybody out. If you*

*had kids, if you had babies, if you were pregnant, if you had toddlers I cut you out...If the conversation at work, at lunch became around babies I'd get up and leave, maybe not every time but if that was the sole focus I would eat in my office. I couldn't deal with it.*

Jill, 40, left her job prior to treatment ending. After, she embarked on a new career that bolstered her confidence, and put her amidst young men:

*...because I was pretty angry at the world for a good two years that I couldn't have kids. Angry at myself, angry at the world, angry at other people that they were able to have them... culinary school kind of saved me in certain ways. Going to school with young kids who were arrogant and men and--I don't know how else to explain it, but I wasn't in a room full of women, sitting around talking about kids. I was in a room full of 18 year old boys who were talking about getting laid and where they could go find pot and where they could find alcohol. And I wasn't sitting in an office at lunch hours, planning baby showers for co-workers. I didn't do any of that for two years.*

Rachel, 38, had worked with at-risk prenatal women and toddlers. She left when she became too angry:

*I found that I was too angry - angry at these families who were taking things for granted, angry that these women with little to no resources were able to have kids while I had every ability and capability to provide for children, as well as a strong understanding of child development. I was so angry at the mothers who were able to get pregnant over and over again (one had 7 kids with 6 different fathers) and only complained about the mouths to feed. I realized that I couldn't*

*do it anymore; I wasn't helping myself, and I wasn't helping the families...*

### **Therapy.**

Nine of the 12 women sought therapy for infertility, and four supplemented individual therapy with couples therapy. All who did ultimately reported a positive experience with therapy, often considering it one of their primary sources of support. Sara, 38, found therapy particularly helpful. Her therapist was able to hold some of her more troubling emotions, sparing her husband:

*...at one point a couple of years ago, something freaked him out. I don't know what I said, but it freaked him out a little and realized that I should reserve that for my therapist...*

Almost all reported having difficulty finding a therapist that was familiar with infertility. Lauren, 42, found therapy quite helpful, but finding someone who understood and was able to offer guidance was a challenge:

*I wish that it was a requirement to see a therapist as you're going through IVF, even before IVF, to really understand what you're about to go through, the rollercoaster that you're about to go through...And I went to a therapist who knew nothing about infertility, nothing about ectopic loss. Finding someone to understand what you're talking about is really hard. They don't-- they don't really get what you've been through.*

Rebecca, 35, had a very positive experience in couples therapy, where she expanded on the empathy she had for her spouse, and recognized their different styles of communication, particularly regarding their love for each other. Her couple's therapist was unable to help once it was time to address the infertility:

*I went to a marriage counselor, and that really helped in terms of dealing with all the stuff with our marriage. But once we got beyond that, and I really realized how much the whole infertility issue was an issue, I found a counselor here locally who's an infertility specialist counselor. And having her, someone who truly understood my issue, was so key for me. And that's just something I just want to really bring out, because I don't feel like there's a lot of therapists out there that understand. My first therapist, he was really great. But once it got to that issue, I didn't feel he could help me. And I had spoken to another therapist, and I just felt like she didn't get it....my infertility specialist was excellent, and I think her helping sort of really see that truth of that I did have a family, that I did have people that loved me.*

Ultimately, the women who sought therapy were successful in finding a therapist that was helpful. For almost all of these women, therapy was a critical component of their support throughout their infertility journey.

### **On-line support.**

All of the women spoke of on-line support being a central component of their healing. Since the women's situation was so uncommon, on-line support provided interaction with those in similar circumstances, critical for normalizing emotions, feeling less alone, and offering hope for the future. On-line support usually involved reading and/or participating in various blogs, closed groups, and websites. For Nancy, 50, and five years post-treatment, relief was found in a closed on-line group:

*...being able to talk within a community who understood as well what it is that you were going through was very, very helpful...I had just finished treatment and*



*I found it and it was, like, oh, my god. There's people out there who understand 100% what it is, what I've been through, the emotional rollercoaster...So our community is very small or it's just not out there and publicized...it's like people either they choose to talk about it or they don't talk about it. And is it because it's a very personal and private thing, or is it because of the emotions behind it? I always wanted to talk about it, but found that a lot of times, people didn't want to talk about it, I think because they didn't know how to deal with the emotions and the feelings that I had. So I was very happy when I found this.*

Beth, 48 and four years post-treatment, is not a big talker, nor is anyone in her family. She found reading, both books and on-line, to be helpful:

*...I read a lot of blogs from people...maybe for the last year or so I read a lot of blogs on people who have just decided to end treatment. And reading books too. Just seeing, you know what I mean, that I'm not the only one out there and that people are living-- so that's really-- it's been helpful.*

Only one person struggled greatly with finding the support she needed, feeling she received very little, if any, from family and friends. It is notable that this person, although currently on-line, ended treatment 14 years ago. There was no access to on-line support, fewer resources and less information available at that time.

Almost all of the women reported having a creative outlet to help them access their grief and find their voice. As already addressed, this included blogging and creating an on-line class. Another wrote and published poetry in a local paper; still another participated in a “fertility fairy” exchange, where she compiled a book of her favorite poems for another infertile woman she met on-line. Two of the women twice participated

in healing workshops at a yoga retreat. Others journaled extensively, which assisted them in accessing profound sadness. Many reported looking back on their writing with wonder at how far they have come.

As the women slowly worked through their grief and found voice, healing began and shame diminished. Taking risks led to increased support, and, ultimately, a stronger voice. As this continued, and the women grew stronger, acceptance came.

### **Acceptance and Choice**

Themes of acceptance and choice emerged regularly. Often a series of minor decisions led to life-altering outcomes. Participants spoke of the necessity of *accepting* one's reality, and the ability to *choose* one's path. One could opt to live in sadness for what might have been, or decide to value and cherish one's life. A great deal of grief work preceded defining moments. Samantha, whose spouse suffered a traumatic brain injury one year after ending treatment, realized she had a choice three years after ending treatment. This led to having hope for the future:

*...these are my sister's children. I certainly can provide input, but they're not mine, and that was a realization for me...I just started to cry, and I cried and I cried and I cried and I cried. And finally I heard a little voice in my head...it's almost like this black cloud just lifted, and it was as if I finally was able to say "Okay, it's not what you wanted. It's not your first choice. But in fairness to myself and in fairness to (spouse), I have got to live the life we have and not stay stuck in this place that I don't have." So that was huge. I had already sort of started coming along. I had lightened-up quite a bit. I had been working with this therapist for a little over a year and had done a lot of work... finally look at that whole thing and*

*make a choice. I said "You know, (spouse), for the first time in a really long time, I have hope for the future in a positive way, that I feel like, okay, infertility and brain injury or not, we are going to make a life for ourselves. We are."*

Sara, 38, had a "kayak vs. canoe epiphany" 2 ½ years after ending treatment.

Intentionally not making a decision allowed her to turn toward life again:

*...we always wanted to get kayaks or a canoe... with a canoe you can put a kid in there but with kayaks you can't...I had this, I call it my kayak epiphany. It was a real turning point for my life especially in regards to infertility is that I realize I don't have to make a decision right now...the kayak was a huge thing for me. What am I waiting for? I mean so what, what if something happens, we finally had a family down the line then we just sell the kayaks and get a freaking canoe. But just this idea that live your life now, living now, not feeling like I have to make a decision or schedule a decision or if I don't know the answer now then why am I forcing myself to come up with an answer. And it was a huge thing for me...It's like you're in this car that's so fast moving that you have to make a decision right now what turn you're going to make. And instead I just decided to get out of the car, just go walk in the field kind of thing and just not make a decision. And it was a really freeing thing. I don't have to decide if I want to adopt or whatever.*

With time, Sara did make an active choice, realizing that not choosing would leave her in limbo:

*...Another big issue...is the fear of regret that, in 20 years, we're going to say, what were we thinking, but, if you don't feel it now, the adoption thing, then I*

*can't force myself to want to do something I don't want to do, and I think that it's better if you make the decision than if we had said, let's not make the decision 'til next year, let's not make the decision 'til three years from now, because then I think it's easier to have regret if you never make a decision than it is when you do...That's what I'm hoping, that's what I'm really hoping.*

Christine, 41, and 3½ years post-treatment, actively chose to let go of any ambivalence, however miniscule:

*I hit a point very recently, within the last six months...where, you know, my husband and I sat down and had a conversation about what are we going to do about contraception...obviously we're not trying anymore, but we are not taking precautions to not have children either. And while it's very, very unlikely that that would happen, it's still in the realm of possibility, but we have reached a point now where we have-- we don't want to have children anymore, and so that was kind of a big shift in that feeling and thought process.*

Debbie, 36, five years after ending treatment and 2 ½ years after her last foster child left her home, still vacillates between acceptance and moving forward. She is able to see the necessity and value in acceptance:

*I certainly have days where I feel like-- out of-- I wouldn't want children anymore. I feel like I've got too many things that I'm already doing or that I'm so used to the way my life is now that it seems okay that I don't have kids...I am kind of sad still, but I am working through it and maybe by having more support in that area that I will get to a place where I don't think about it every day or I don't still think, "Oh,*

*well, it could happen." I just accept that it probably won't, and then I start doing other things-- moving in a different direction.*

Actively making a decision to live without children went along with or was followed by concrete change, such as selling family homes, disposing of baby clothes and furniture, and essentially what one woman referred to as “lightening the load”. Only one woman of the 12 spoke of ongoing hope of conceiving, stating that she was “still ovulating”. This was tempered with a quick statement of the odds and acknowledgment of her age.

### **Reestablishing Identity and Turning Toward the Future**

Almost all participants felt a need to add or change something in their lives in order to rebuild and reestablish their identity as a “non-mother”. The women approached this in different ways, including reaching out to help other infertile women; charity and volunteer work; engaging in creative outlets; and reinvesting in and/or recreating careers. An advantage of some of these outlets was the decrease in social isolation they provided, a potential chronic issue if not actively addressed. Almost all participants addressed the implementation of self-care and the ongoing journey of identity formation.

#### **Implementing self-care.**

As previously addressed, participants, to process their grief, needed to “find voice” around it. This led to changes in thought and behavior. For Samantha, 43, and almost four years post-treatment, this manifested in letting go of certain perceived social obligations:

*...this may be a projection, but I feel like, “Well, you don't have kids, so you can be anywhere at any time.” And the answer is no. I can be there if I want to be there, or if I can make it, if it works for my schedule, but I don't have to be there*

*just because I can be there, you know? And it's been really kind of empowering a little bit for me in the past six months especially to say "You know what, I might not have three kids and artwork all over the walls and soccer practices to run to and dance classes," I said, "but I also feel like I am very busy, and we have a full life." ...probably the most helpful thing for me was just allowing myself the space to finally just say "Okay" to myself, that it's okay to opt out of a social engagement and not feel guilty about that. I basically have a policy that I don't go to baby showers to this day, and I don't know if that policy will ever change, but that's a decision I've made.*

For Rebecca, 35, and over three years post-treatment, knowing and actively taking care of herself was paramount:

*I had to make sure that I knew myself outside of my role as a wife, my role as a stepmother, my role as a daughter. I had to make sure I knew Rebecca for Rebecca, because those other roles had that pain attached to them. And I had to feel okay with me. And the other things is when kind of all the-- everything went poorly for me personally and in my marriage, what I found really is that I disconnected from myself. And when I reconnected with myself and I started doing things again to make myself happy, everything else started to fall back into place. My marriage came back. My relationship with my parents was better. And that's I guess what I found. That's why it's so important to sort of know you within whatever world you live in, and what makes you tick.*

Sara, 38, became more comfortable asserting herself. For example, here she addressed a woman who suggested acupuncture when she revealed sadness about her infertility:

*...she tried to talk about an acupuncturist she knew, and I quickly was like, "You know what? I'm not trying to get pregnant anymore. I should be allowed to feel sad about it, though, from time to time".*

### **Reaching out to other infertile women.**

Some participants discovered their voice around infertility, then broadened and shifted this voice, reaching out to other women in various stages of infertility. For some, this included speaking at local Resolve meetings about their own journey and sharing what had been helpful for them. Others did this by reaching out on-line through women they had "met" in chat rooms. Christine, 41, helped in a more global way, committing to continue blogging about infertility:

*...in some ways be a role model of someone who, you know, went through this and came out the other side, and that there is a life after this and that you can come through this and still have a good life, even if motherhood is something that you always wanted. There are other things. You can still have a good life without that.*

Rachel, 38, did this more locally. She spoke of purposively reaching out to a woman she suspected was struggling to conceive:

*...this is the first time I have been open at work about my infertility - I think it is important...to discuss these issues openly...Maybe I can be an example of a different way of seeing it. In fact, some new staff started yesterday, and as we were introducing ourselves, I mentioned that I was married - immediately got the*

*question from one new staff, "and kids?" When I said no, the reply was "not yet". A different new staff introduced herself and mentioned she's married, and no kids yet. I made a point of going to her afterwards in private and asking if it was by choice - or not, and that I was infertile but learning to live with it. She admitted she's been trying, how hard it is, how isolating - and I offered her my understanding and support. I mean, I "get it".*

### **Charity and volunteer work.**

Many participants spoke of the importance of “giving back”. Giving back provided a way to be seen, heard, and acknowledged apart from their identity as “infertile”. This resulted in an internal lessening of what had become the dominant identity of “infertile”, and helped them rebuild and reestablish their sense of self. Giving back also decreased isolation by increasing social outlets. Danielle, 40, developed a love for cycling, then combined it with charity, 3-4 years after ending treatment:

*...I started cycling. I did the \_\_\_\_, which is a big charity event...biking became my thing. I felt like I needed the hobby. I needed something. And the thing with biking, I met wonderful people...we sponsor a pedal partner who's a young child who's currently in cancer treatment...I'm finding things that can help redefine myself.*

Lauren, 42 similarly:

*I do go to the nursing homes here locally... I go to a local shelter and I pick up a pet-friendly dog, and just their faces-- they hold them, and it's-- that really helps me...I bring a dog in, and they're like-- it makes their day. They hold that dog and they tell me stories...I love going to the retirement homes...they tell some great stories, and they don't ask you a thousand questions. They're just grateful that*



*you're there. The first question out of their mouth isn't, "How many kids do you have?"*

Debbie, 36, was 5 years post treatment, and 2 ½ years after her last foster child left her home. She is working toward rebuilding her identity, and planned on volunteering, a previous activity that contributed to her self-worth:

*...I've thought about volunteering and needing to do things. I used to do that a lot in college-- feel like I'm doing something that's worthy... It's like I have to be taking care of something in order to make me feel like I'm making a difference... I probably will get into volunteering again soon at a homeless shelter or something that makes me feel like I'm doing something positive with my life.*

#### **Engaging in a creative outlet.**

Some participants reported becoming absorbed in various creative and active outlets. Sara, 38, spoke of reconnecting with her creative side and how helpful and healing that has been:

*If I found anything good out of the experience of infertility, that I've gotten back in touch with my creative self...I kind of lost touch with that. When I was in college, I vacillated between being an English major and a history major, because I liked to write...I stopped writing creatively, and then I kind of picked it up again with my therapist's encouragement and doing that and then the poetry thing and doing the little journals that I've done. It's been a really nice healing thing to get in touch with something, some other part of yourself.*

Rebecca, 35, thought about what she would have done with a child and put this into action:

*I kind of started thinking, "Well, if I'd have had a girl, I would have maybe liked to do cheerleading with her." Some random thing that I really like. So I went and started coaching a young girls team locally, and I did that for a couple years, and I really enjoyed it. And I love ice skating, so I took my nieces ice skating. And I love horseback riding, so I took my nieces and a little neighbor girl horseback riding. So instead of suppressing something I wanted to do, I found a way to make it work.*

Nancy, 50, planned to reconnect with previous artistic outlets:

*I will probably take up some fine arts again, which I went to college for, painting and drawing.*

### **Turning to careers.**

Some of the women made a conscious decision to turn to their careers after deciding to live without children. A few made a complete career change; others remained in the same field but shifted their focus. All were quite aware and deliberate about their choices and decisions. Patricia, 54, and 14 years post-treatment, worked in a social service agency. She began a private psychotherapy practice seven years after ending treatment, consciously deciding to shift her focus once she decided against adoption. She was happily surprised at this being so fulfilling:

*...I started the practice in 2004. I guess in a way I just tried to shift my focus but I was still grieving. I would find that sometimes it would become less important for whatever reason, because there were other things that became fulfilling to me, like I really loved developing my practice.*

Rachel, 38, knew that her work gave her meaning. She had previously worked

closely with at-risk children and families, and found, after diagnosis, that continuing in this position was untenable. Initially, accepting different work that required travel was an escape, but over time became a “condolence prize”.

*...I see the ability to travel...as my 'condolence' prize from my infertility...I am still working to support children, but a few degrees away from the families and children themselves.*

### **Identity as an ongoing journey.**

Many of the women described their identity as still evolving and an ongoing journey. They spoke of the need to actively define themselves apart from the role of mother. Sara, 38, in a follow-up email, contemplated the definition of “mother”:

*...when I was diagnosed as infertile, suddenly my identity as a woman flipped out or something. Suddenly the idea of women and motherhood became important...I feel less connected to other women--maybe even most women now, because most women are mothers. This has felt kind of devastating...Before, I didn't see motherhood as such a strong or necessary aspect or facet of womanhood...I guess now, I do. And that makes me sad. I'm trying very hard to change that, to go back not to the same I ideas I had (because I'm not the same person I was 6 years ago) but to something similar at least... I'm not Wiccan or pagan but there's this concept of the goddess as three parts--the maiden, the mother, the crone. It's hard to say where I belong now...I've been thinking about this and wondering if I can redefine that Mother aspect of the goddess... I can think about ways I can be nurturing and mothering without having my own children...what is it about that Mother phase of life besides the words "nurture" and "mother"? How can I*

*incorporate creativity, inclusiveness, open-mindedness, efficiency, mastering of skills, the idea of becoming someone who can look outside of herself--expanding what I think of "mother"? In a sense, I have to redefine myself as a woman. That's hard. I'm still working on it...*

Danielle, 40, recalled her numerous lifetime roles, an exercise she learned while going through infertility treatment. She continued to draw from this exercise as she reimagined her identity:

*...we did a life map, which I found was really helpful because you like have this big sheet of paper and plot out from when you were a child until now and the accomplishments that you have. And it made me realize, like, all that I had done in my life, like the being a mom and going through the infertility, I didn't-- those things-- it wasn't the only thing that was going to identify me. I had to look back and say, you know, at a young age-- fairly young age, I took care of both of my parents that had terminal illnesses. I went to graduate school while working full time. I've been successful in my career. You know, all these other things that were other ways to identify me. So that's where I'm trying now.*

Beth, 48, and four years post-treatment, still struggled with her identity as a non-mother. She had not yet made changes in her life:

*I always thought from the time I was little that I'd have kids and it was just a given. I babysat all the time, it was just, if anybody's going to have kids, Beth's going to have-- you know what I mean, everybody thought... so I think that you have your vision of how your life's going to go and then you have to change that. So it's sort of making a new path...sort of have to change your picture of how you*

*were going to be in your head. You always had that picture that you're going to be a mom...some days are better than others.*

Again, the women were forever changed by their infertility experience. Necessary was changing course and incorporating something new into one's life. As this happened, most of the women were able to grow and, with time, embrace the opportunity that living without children offered.

### **Growth and Opportunity**

Processing grief, acceptance, actively choosing how one wants to live, and reimagining identity were vital components of the ability to once again find meaning in life. All of the women in the study were continually navigating this road in different ways. Many reported personal growth as a result of their ongoing journey.

Opportunity was also addressed. Most of the women generically addressed the ability to travel, financial freedom, and overall spontaneity that living without children allowed. Many also spoke more specifically about their excitement about the future, discrete areas of personal growth, a sense of liberation, and certain life changes and plans that financial freedom allowed.

#### **Excitement about the future.**

At the time of the interviews, two participants were at critical junctures, about to embark on life changes as a direct result of infertility and deciding to live without children; others who were less than five years from ending treatment were moving in the direction of something new. Samantha, 43, and five years after ending treatment, was excited about seeing the world in a new way:

*...there's sort of a light that's getting a little bit brighter I feel. There are other things I can do, other passions to pursue...I hate this term, but other things to birth... more and more there is a piece of me that's starting to see the value of being a childless woman. There is value in that. There's lots of things that my husband and I can pursue that our peer group can't, do you know what I mean, in whatever form that may be...I can pursue the things I want to do and honestly, like sometimes I do feel like the infant, sort of just coming out, waking up and sort of seeing the world with a fresh new set of eyes because I do have to look at the world in a different way now. I can look at it differently. I can sort of engage with it differently than my peers are with kids. I can. So, that can be a good thing if I choose to make it that way.*

Danielle, 40, and five years after ending treatment, had just sold her home in a family-oriented community. She was moving to a more mixed community (singles, couples, families) in two weeks, and planned to buy a vacation home:

*...my husband and I decided, you know what, our lifestyle is different than everyone around us and we need to move forward on what our lifestyle is and trying to fit into the rest of society. So that's when we really started looking on selling our house and moving...we bought a townhouse and had decided we love going to \_\_\_ in the summer...so I'd have to say the first time in a long time it's like we're okay with everything that's happened and just really looking forward to what's ahead for us... you know, sometimes it's I think we're always wanting for what we don't have at times. And that was one thing that I learned through all of this is you know, life is about living, and what-- you can't spend your life sort of*

*wallowing with you don't-- what you can't have and what you don't have because otherwise it's sad. It makes for long days. So the fact that we're in a place-- my husband's very excited about the move too. We're just-- I feel like this whole part of, you know, this process of we have to re-identify ourselves because we didn't go the route after infertility of adopting. We made the decision not to have kids. So we have to-- we're in the stage of redefining our whole life. So it's exciting right now.*

### **Personal growth and finding meaning.**

Although “personal growth” is discussed in the section “Processing the Grief”, here it is discussed in the context of specific areas of growth and change that gave new meaning to participants’ lives. Samantha, 43 and almost four years after ending treatment, learned how to express her emotions:

*...also a big thing for me is the progression that I've had in a good way of learning how to cry, learning how to sort of express my emotions more openly and more readily and being able to cry in front of people...I wasn't particularly good at the emotional expression of things. It wasn't allowed growing up...by coming to terms with infertility, I also have come to terms with who I am. It's actually helped me know myself in ways that I don't know that I would have known myself before. ...I have been able to draw upon a resilience that has been very clear. It's very apparent that I have it. And so, there's something really empowering about that as well...I have been able to kind of break an unhealthy just even an emotional cycle in my family of women by learning how to say no, by*

*knowing myself better, by allowing myself to express my emotions in healthier ways.*

Nancy, 50 and five years after ending treatment, became a more empathic person:

*I think I'm much more sympathetic and understanding of people because we don't always know or understand what it is, what they're going through because they may not be as open and vocal about it. Meaning everyone I encounter and meet, they don't know what the hardships are that I've been through and what the heartache is or what has made me what I am today. So, likewise, when I meet a new person or someone on my staff or something, you don't know everything there is to know about that person so I choose to give people the benefit of the doubt and not take everything at face value. I try to understand individuals better and what makes people tick, which maybe before all this, maybe I did just take people at more face value than-- it was very black and white and going through all this, I understand that things are not as black and white as they may seem.*

Rebecca, 35 and 3¼ years since ending treatment, learned to take agency over her life. She applied the lesson of making a choice to the care of her parents:

*...I've also come to realize, somewhat through therapy, that it's not an obligation; it's a choice that I've made, and I want to be there for my parents. So that's a choice I make. And that I can't really count on my siblings' acknowledgement as to why it's worth it. It's worth it because I decided it was worth it.*



### **Financial freedom.**

Some of the women spoke of the financial freedom living without children allowed. Sara, 38, and over four years since ending treatment, captured the day-to-day freedom of no longer fretting about money:

*I don't have to worry about saving it. I'm not thinking at all I need to save money, I might get pregnant. No, I don't think that at all. We should save for adoption. I don't think that at all, so we started living that way before we actually said to each other we're not going to adopt, we're not going to do IVF, pour me another margarita, 'cause we're not having kids!!*

Debbie, 36, and five years post-treatment, was unsure if her marriage would survive infertility. Still, she imagined retiring early as she gradually moved into accepting that she would live without children:

*...we are totally, totally looking forward to the day that we don't have to work. I mean, we've already been planning the whole thing, and so then I think-- and back to the kid thought-- I think, "Well, God, we're planning on retiring in ten years from now." The house will be paid off. My husband will have his pension hopefully if the economy doesn't die...we're planning on buying a camper and hitting the road full-time. So we'd do that now, I think, if we didn't have a job and didn't have to have the money...*

Jill, 40, eight years post-treatment, had always planned on being a full-time mom. She spoke of the benefits of her unplanned earnings:

*...our house will be paid off in the next two years...when I quit my job and went to culinary school and we were only living on one salary, it was perfect because we*

*could afford it and now that I'm working again, that's why we're able to put so much more money on our house. So we can retire early. We can do whatever we want to do and we haven't physically outgrown the house.*

**Sense of liberation.**

Many participants spoke of a newfound self-acceptance and liberation from societal and cultural expectations as a result of their journey. For Rachel, 38 and four years post-treatment, this began as recklessness:

*In a way, infertility has made me, or given me permission to be, reckless - I don't have a child I have to get home to, so I have no reason to drive slow....*

Gradually, as time passed, this transformed into authenticity:

*Infertility has also changed me by giving me a greater sense of distance to others' opinions of me. I am already on the outskirts of society as an infertile woman/woman without children, society doesn't know how to deal with us, we are walking the unbeaten path already - so I feel I have the freedom to be completely authentic, say and do what I want, and I don't care what others may think.*

Lauren, 42 and ten years post-treatment, spoke of caring less and less of others' opinions of her:

*...I really cared what other people thought about me. (Spouse) is the total opposite. He could care less. If you like him, you like him. He doesn't care. And I've found through this-- I found that part of me. I don't care if I have makeup, if I cut my hair shorter-- I don't care. If I'm happy, that's all that matters. I don't care what other people think, which is another big, huge, aha moment to get to that*

*didn't-- for me especially, being raised in the South. I mean, you just-- you're always made up when you went out. So it was hard for me to get that.*

### **Improved Spousal Relationships**

10 of the 12 women reported consistently supportive spouses, highly invested in their happiness and welfare. 11 of the 12 women expressed that the experience of infertility had ultimately brought them closer to their partners, resulting in a deepened commitment to their relationship and increased respect for their spouses. The process of growing closer was complex. Themes included experiencing spousal support; facing one's fears; the ability to see and respond to distress in one's spouse; accepting limitations and responsibility, and embracing one's identity separate from one's spouse. Learning how to effectively communicate and a sense of mutuality was critical to all of these themes.

#### **Experiencing spousal support.**

Most of the women reported great appreciation for their spouses' support during such a difficult time. Critical to growing closer was sensitivity to and awareness of this support, particularly during the initial diagnosis and treatment phase. Danielle, 40, was attuned to her husband's reaction when comments from an insensitive doctor resulted in her breaking down in tears:

*...my husband's very easy going, I thought he was going to get up out of his chair and ring the doctor's neck, he was just so frustrated.*

Lauren, 42 recalled her husband's consistent support:

*I think it really has brought us closer. We share such a bond that I could never share with anyone else. He was there at the hospital with me every time. He was*

*giving me shots. He was there when I was crying, when I was grieving, when I needed his support. He never once has not supported me.*

Patricia, 54, similarly:

*...he was there through thick and thin. I could grieve my heart out. Like he never, ever, ever once criticized me. Never once made me feel-- if anything, he was always saying, "It wasn't your fault. You are not less of a woman".*

Experiencing spousal support was critical. Notable was participants' awareness of the ways, both large and small, that spouses offered support.

### **Facing one's fears.**

Most of the women were relatively early in their marriages when going through infertility. For some of the women, internal conflict arose due to their frustrated desire to please their partners by having children. Many had not yet developed the tools to effectively communicate during challenging times, resulting in the first period of significant conflict within the marriage. Working through this conflict involved much self-reflection, openness and the willingness to be vulnerable with spouses. Therapy was often sought. Rebecca, 35, felt that she had disappointed her husband. She recalled the period of time after her second miscarriage:

*I very much shut down...and very much pulled away from everybody, including my spouse, and within a matter of months our marriage crumbled. We started having a lot of problems, and we almost got divorced...I also subconsciously wanted out of the marriage because I couldn't have a child... I wanted children, but I think my husband wanted children more. So there was a lot of guilt over failure...and that was a big sticking point that I think we had to get over, that he*

*was okay with us not having children, and me accepting that, and not trying to take on that I failed that piece of it.*

Rachel, 38, after learning she would never have her own children, struggled with believing her husband wanted to stay with her:

*I didn't feel worthy of him, and I knew he would never leave me – so I tried to push him away. I treated him awfully. I almost had affairs with others – to prove to myself I was a woman, and to try to drive him away.*

It wasn't until the fourth year after her infertility diagnosis, and much work on both of their parts, that her relationship began to recover. She again believed that her husband was happily and willfully choosing her and the marriage. Here, she spoke of her desire to work abroad, and her husband's decision to come with her:

*When he first told me his feelings, I was scared – I was terrified he would regret his decision and hold it against me in the future. I was very surprised. I kept asking him if he was sure, and don't do it for me but for him. As we talked more, I became more relieved – that no matter what, we would do it together – and excited...as we talked about the future, my husband also helped me see how the common assumption of life and work doesn't have to fit us - and that is a freeing thought. His excitement was contagious!*

Lauren, 42, had multiple ectopic pregnancies that resulted in a complete hysterectomy. She addressed the bond between her and her spouse:

*I remember one time saying to him, "I wish you would just leave me. Leave me and go have a baby. Why are you staying with me? Just leave. You're such a good guy. You deserve kids. You're so good with them. Why are you staying with me?"*

*And I remember him just holding me so tight and saying, "Because I love you. It doesn't matter. I love you." And like I said, I'm very blessed to have him. It's definitely a forever bond.*

Others were less concerned about losing their partners over not being able to have children, but were fearful or avoidant in other destructive ways. Christine, 41, and her spouse disagreed over when to end the search for alternative remedies. This was quite painful; they previously had a very open relationship and rarely disagreed:

*...for the first time...we were not in agreement and I was afraid that if we talked about it we were going to fight about it. And we're not a couple that really fights so I think that I wasn't willing to have that conversation...*

For Samantha, 43, her husband's desire for privacy and her desire to please him by maintaining that privacy created a tremendous burden for her:

*...he's also just very private...it actually created a divide between us and it put a tremendous amount of stress on me trying to keep him happy but meanwhile I'm dying inside because I just need to talk to somebody about this.*

Ultimately, all of the women above were able to find voice for their concerns and fears, and begin talking about these issues with their partners. This contributed to feeling closer, more committed, and a greater sense of trust within their relationships.

**Ability to see and respond to spouse's distress or sadness.**

Many women reported becoming aware of their spouse's distress, and sometimes depression, during the treatment process itself, or later, when coming to terms with not having a family. The men were frequently either not aware of their sadness or not open about it, and expressed their upset in different ways. Critical to the process of growing

closer was the women's ability to see their partner's distress and respond to it. For example, Lauren, 42, learned of her husband's grief and then developed a new appreciation for him:

*...for a long time, I thought he didn't grieve. Like, "I know you're supporting me, but do you think of our babies? Do you?" And he actually wrote a letter to them, and I found it, by accident. He hadn't showed it to me. And I realized, he's hurting too. He's really hurting too. He physically didn't go through what I went through, but he still has given up having a baby by staying with me.*

Patricia, 54, was grateful for her husband's caretaking and subsequently responsive to his delayed depression:

*Because of him taking care of me for so long, he never dealt with all of his stuff because he was always taking care of me. Then once I got better, then he got really depressed for a while. Then he got better, but it was a lot of us really taking care of each other.*

Sara, 38, recalled witnessing her spouse's distress for the first time, empathically recognizing how difficult it is to see the one you love upset:

*...when he cried it just, it broke my heart and so I imagine him on the other side seeing me despondent, how hard that was for him, but still being such a support.*

Essential for growth was having empathy for and giving support to one's spouse. As this happened, participants were able to accept spouses' limits and take responsibility for developing other supportive outlets.

### **Accepting limitations and responsibility.**

Addressed, too, was the realization that partners were unable to meet all needs, particularly emotional ones. Sara, 38, addressed how respecting limits and boundaries within her relationship served to bring them closer:

*Well, I think we have gotten closer, but I've seen the lines. I don't have to tell him my deepest, darkest thing, and I learned that through our experience with infertility, and I think that's actually a gift.*

Jill, 40, described how she and her husband respect each other's limits and take care of each other:

*...he doesn't know how to handle me when I get upset because he can't fix it. My husband is very, very good at fixing things...so my husband and I don't talk about it a whole lot because it affects him, that he knows that I'm upset. He understands. He knows when I go to a baby shower that I'm going to come home and it's going to be an ugly afternoon...I'm probably not going to eat that night, you know? But he also knows that, if you just leave me alone, give me a little time, I'll deal with it then we'll be fine. So he's very good about it. He really is. But he just doesn't know how to deal so I don't make him deal. This isn't his issue and-- not that it's not his issue but, you know, it's the way I handle it, right, wrong or indifferent, whatever and it's not the way he handles it and that's fine. So we've learned to work around each other and how we handle it. He's very, very good to me and I try very hard to be good to him.*



Mutual respect for boundaries led to increased self-worth and improved relationships for the participants. This assisted in the women's embracing an identity separate from their spouse.

**Embracing identity separate from spouse.**

Some of the women found themselves struggling to find their voices within their marriage. This most likely corresponds with the traumatic and overwhelming experience of infertility combined with the early years of marriage. Rebecca, 35, spoke of the importance of getting back in tune with her identity:

*You know, I don't know how much it was expanding my identity as much as getting back in tune with my identity. I think when you get married, you lose a little bit of yourself, because you become part of a partnership, and that sort of becomes what you know yourself as and other people know you as.*

Samantha, 43, discussed her conflict, early on, regarding her husband's desire for privacy and her need to share:

*I wish I had been stronger in the beginning, more assertive with him at the beginning and insisted that we do (be less private)...I do think maybe we wasted some time early on and there was a lot of unnecessary angst....he's got a pretty strong personality when it comes to saying what he wants and what he needs. That's actually been a benefit to me, to learn to say what I need. This whole experience has helped us communicate better I have to say because we would have some probably pretty unhealthy conversations early on, either not have them at all or have them be just really volatile and not very healthy.*

Of the 12 participants, all were still married, and 11 reported solid, mostly happy, committed marriages. All 11 reported varying degrees of the above components. Only one of these 11 participants reported a spouse who was initially unsupportive and “didn’t get it”; eventually he did become supportive. This participant later needed to address anger toward her spouse for feeling abandoned during such a difficult time. At the time of the interview, she felt they were on the right track and were mostly recovered.

Only one participant was in a marriage that, at the time of the interview, was at high-risk for divorce. Few of the above components, in this marriage, were present, and this participant was clear that although infertility was the biggest problem, it was not the only problem.

### **Enduring Issues**

Although almost all of the women worked through much of their grief and emerged stronger, two issues persisted that were thematic for many. These included residual grief and ongoing isolation.

#### **Residual grief.**

Fully reengaging in life necessitated integrating the loss into one’s narrative, and included feeling occasional sadness. Jill, 40, and eight years after ending treatment, recalled incidents that were similar for many:

*One of the weird things that bothered me was my girlfriend’s daughter went to prom and I thought, “Hmm. I will never have a daughter that goes to prom.” So it’s things like that, that kick you in the teeth when you least expect it. Of course you get arrogant and you think, “I’ve dealt with this. I can’t have kids. That’s my life. Sorry. We’re good. Let’s go forward,” because I tend to be that kind of a*

*person. Then life just goes, "Yeah! I'm going to kick you in the teeth right now!"*  
*When you get a little arrogant, life has a way of just making sure you understand your position again.*

Nancy, 50, and five years after ending treatment, shared her latest post with her closed, on-line support group. In it, she described her process poetically, and ends with a statement that she will not go to baby showers, a sentiment expressed by the majority of participants:

*"... If you go back and see my older posts, it has not always been easy, but it is a process journey that we are on and go through. The process is dark, gloomy and stormy at the beginning, and it was that way for quite a while. Then there is a bit of clearing, with constant gray skies, with some storms sprinkled in. This phase went on for quite a while. Then it clears a bit, still gray skies, but now sprinkled with sunny skies and fewer storms. Then it progressed to sunny days, with a few clouds, and some gray skies sprinkled in, and a rare storm. I think I can live like this, and accept this. I will not go to baby showers, though."*

Christine, 41, and 3 ½ years post-treatment, who blogged extensively about her experience, stated:

*Sometimes I feel as if I've missed a chapter in my life and I've just skipped right over it and didn't get to experience, you know, motherhood, didn't get to experience pregnancy, didn't get to experience all of those things. So there's still kind of a-- sometimes a, you know, a lingering, kind of longing for that experience, but it's not something that I feel on a day-to-day basis.*

### **Ongoing isolation.**

As previously addressed, many of the women spoke of feeling apart from peers who had children. This isolation continued as time passed, and the women struggled to find their place. Friendships did not organically develop, as often happens between first-time mothers, but had to be worked for. Many participants wished to meet others that had experienced infertility and were living without children. Sara, 38, and over four years after terminating treatment, described this:

*It's almost like I need to find another infertile woman who decided not to have children, too, because it's like they still don't get it kind of thing...I probably will connect again with other women closely, and it doesn't have to be the infertility, but it's been such an intense experience...I almost feel like I need it, I don't know, and I think that's kind of a barrier for me. It's been hard.*

She further addressed the isolation of being a childless couple in her demographic area:

*(Spouse) is like, "Where are we going to find other couples like this?" And I think it's a good question, because, if we find another childless couple, they're just going to go get pregnant, aren't they, or something like that, and it's lonely, it's really lonely, and that's one of the lingering painful things.*

Lauren, 42, and 10 years after her hysterectomy, described her difficulty finding others similar to her or even those without children by choice:

*It would be great if we could go out to dinner with a couple that didn't have kids, whether they just didn't want to or they've gone through the process and they can't have kids. That would be great. But I can say we have no friends like that. All of our friends have kids, or are single...And it's like I know they're out there. I just*

*don't know how to find them and reach out to them. We have one friend, a gentleman, we used to go out a lot on Saturday nights...and so we enjoy his company, and he doesn't-- we have fun together. We don't have to hear about this school, this school this, or this child did this. It's just a nice break.*

## **Summary**

Living without children after experiencing infertility is an ongoing, complex journey for each participant, resulting in a life-altering, unplanned path. The data indicated that this voyage impacted every area of participants' daily lives. Most significant were the experiences of multiple and often concealed traumatic losses, the importance of finding a way to identify and express these losses, and the participants' resilience in being able to take agency over their lives, doing their best to change course.

The following chapter will discuss these findings in the context of clinical and theoretical significance. The concept of defining infertility as a traumatic experience will be addressed. Recovery from this loss will be discussed as a stage model, and a time frame of recovery will be introduced. The loss of support systems, particularly religious supports, will be reviewed, followed by the connection between healing and articulating losses. Also addressed will be the relevance of on-line communities functioning as a crucial support system. This will be followed by a discussion on acceptance and choice, identity, post-traumatic growth and finding meaning, relationship growth, and ongoing issues. Finally, clinical implications, limitations, and recommendations for future research will be reviewed.

## **Chapter V**

### **Discussion**

#### **Introduction**

The purpose of this study was to explore the long-term transition to living without children, either biological, adopted, or through third party reproduction, after pursuing treatment for infertility. It was hoped that this study would contribute to a greater understanding of what impact living without children after pursuing treatment has had on marriages, relationships with family and friends, and identity, and what is involved in the long-term psychological process of transitioning to living without children. Only one other published study was found that explored this specific population; that study addressed women whose infertility experience was 1980-1984 (Wirtberg et al., 2007). This gap in the literature is particularly relevant considering the abundance of infertility treatment options available today and, as reviewed in Chapter I, the environment of pronatalism that has reemerged and dominated our culture for the past three decades. In this chapter, significant findings of the study will be compared to the existing literature reviewed in Chapter II, and elaborated on. Clinical implications will then be addressed, followed by recommendations for future research.

#### **Losses and Affective Responses**

Consistent with the literature reviewed in Chapter II, the participants all described their experience of infertility, during treatment, as highly distressing (Amir et al., 1991; Berg & Wilson, 1991; Peterson et al., 2007). Initial diagnosis, each failed treatment cycle, and each miscarriage was experienced as yet another traumatizing event. Participants experienced painful empathic failures and insensitivity by family and friends; almost all

were affected by thoughtless doctors and clinics during this time of crisis, before finding doctors with whom they felt comfortable. Compounding this were disenfranchised grief, social losses, identity challenges, and ancillary losses (loss of one's anticipated life path, loss of control, etc.) common to the infertility experience. For some, there was great financial burden. These losses, together, overwhelmed participants' senses and ability to function, and contributed to decisions to end treatment.

An unspoken layer of trauma for the participants may be the timing of its occurrence. Participants' marriages were new; motherhood was the next expected and significant developmental stage in the women's lives. Suddenly, the imagined new self of mother, however fragile and unformed, was withdrawn, triggering an assault on the women's ability to self-actualize. Traumatic response is consistent with such a significant and unexpected developmental disruption and challenge to one's expected life course.

For the participants in this study, the bulk of these losses, and resultant affective responses, did not resolve as they would for those that experienced infertility, then conceived or adopted. This, too, is consistent with the literature, which has addressed this population primarily through inclusion in studies that addressed transitioning to *biological* childlessness after infertility (Daniluk, 2001; Daniluk & Tench, 2007; McCarthy, 2008; Verhaak et al., 2005), or studied this population's experience up to three years after ending treatment (Bergart, 1997; Johansson & Berg, 2005). Unknown was the long-term (greater than three years) progression of those who transition from pursuing biological parenthood with medical assistance to living without children.

## **Significance of Trauma**

Every participant used language (“trauma”, “end-of-the-world”, “wouldn’t wish this on anybody”) and tone evocative of trauma to describe their infertility experience. The women repeatedly described avoidance responses, depression, affect dysregulation, feelings of stigmatization, and cognitive disturbances including low self-esteem, hopelessness, guilt, and shame. This constellation of symptoms, in combination with the length of time participants struggled, exceeded those of complicated grief, and are indicative of traumatic responses (Briere & Scott, 2006).

The preponderance of the literature addressing the psychological impact of infertility use descriptors of “depression”, “anxiety” and “distress”; few, in comparison, use the word “trauma”. In the Chapter II literature review, only one of the cited papers that addressed the infertility experience used the word “trauma”; that paper specifically addressed Post Traumatic Growth in individuals with infertility (Paul et al., 2010). The lack of a strong association in the literature between “trauma” and “infertility” may be a result of the struggle to define psychological trauma. Weathers and Keane (2007) addressed this difficulty:

Achieving a consensus definition of trauma is essential for progress in the field of traumatic stress. However, creating an all-purpose, general definition has proven remarkably difficult. Stressors vary along a number of dimensions, including magnitude, complexity, frequency, duration, predictability, and controllability. At the extremes, i.e., catastrophes versus minor hassles, different measures may seem discrete and qualitatively distinct, but there is a continuum of stressor severity and there are no crisp boundaries demarcating ordinary stressors from traumatic



stressors. Further, perception of an event as stressful depends on subjective appraisal, making it difficult to define stressors objectively, and independent of personal meaning making. (pp. 108)

The unique and complex experience of infertility clearly does not fit easily into a predetermined trauma “category”. As a result, the cumulative overwhelming losses and extended nature of infertility result in psychological trauma that is understood by few working outside the field of reproductive endocrinology.

### **Letting Go**

Almost all participants made difficult, conscious decisions at some point to end treatment with reproductive endocrinology and the medical community. (One participant ended treatment due to an emergency hysterectomy; another never started after her initial diagnosis, her only option being donor eggs.) This was initially, for some, a temporary decision made to take time to reevaluate; for others, it was a permanent turning away from Western medicine. The prohibitive cost of treatment, with no guarantee of success, and the likelihood (due to statistics) of failure and further emotional turmoil were critical factors in this decision. Six participants chose not to do IVF, expressing discomfort with the odd nature of it. The desire for a child, no matter how strong, did not result in a complete letting go of personal values, beliefs, and self. For everyone, the emotional toll, both personally and on their relationship, had become extraordinary.

After ending treatment, all participants began an intense grieving process, and journeyed toward accepting a life without children in stages. Like any developmental or stage model, progressing through these stages is not systematic; participants moved back

and forth between feelings and sometimes vacillated about decisions. Often, issues reemerged after participants thought they were fully worked through.

In this study, the time frame of “greater than three years” proved significant. Participants reported pronounced distress that lasted years. This anguish slowly and subtly shifted and lessened, with a notable internal change, for most, 3-4 years after ending treatment. This change was primarily experienced as no longer feeling that being infertile was their foremost identity. This was followed, in years 3-5, with a turning toward life, and seeing the possibility of embracing it once again.

The first year after ending treatment, many of the women continued to try to conceive naturally, usually with the help of alternative therapies such as acupuncture, herbs, etc.; some considered further treatment. Eventually, most ceased actively trying to conceive due to the stress this had on their lives and relationships.

Contemplation of adoption and/or fostering, which usually lasted years, began during the first year as well, and was part of the healing process. All but one participant considered this route. Deciding against this path was complex; none gave just one reason. Factors included the risk of further loss, the importance of biology, the high cost, participants’ mental health, and a prioritizing of their marriages. Many expressed just not feeling drawn to or excited about adopting. Infertility, and, as addressed above, the resulting trauma, had been the primary theme of the women’s lives for many years (mean of 3.2, median of 4, plus time trying to conceive naturally), consuming a great deal of energy and resources. Critical for many was reconciling guilt over deciding against adoption with the desire to turn toward life again. Resolving this guilt appeared to be more difficult and complex for those with a strong religious background.

## **A Sense of Diminishing Supports**

For almost all of the participants, the first year after ending treatment was a time to endure. Many withdrew and “shut down” emotionally. In addition to motherhood denied, losses also included disruptions to almost all support systems, and interruptions to personal narratives that shaped participants’ sense-of-self and imagined future. Particularly painful for many was the sense of “twinsip” – that there are others like me in the world – disappearing, inducing feelings of utter aloneness and deficiency (Kohut, 1977).

While much of the loss around infertility has been documented in the literature, loss of connection to one’s religious support system has not been addressed. In this study, no one reported a loss of faith due to infertility. However, places of worship, regardless of denomination, were experienced as among the least supportive environments, revolving around families and exhibiting no sensitivity or awareness of the difficulty some may have conceiving. Compounding this was the deep-rooted biblical teaching that it is a duty to procreate; much shame and guilt was experienced over not being able to do so. Religious settings became not a place to heal but a place to be reminded of this obligation. No comfort was found there, rather a skipping over the loss and encouragement to adopt. Lauren, 42, addressed the lack of support she felt at her church:

*...it's kind of strange, but you would think that's the one place you would get the most support would be at your church or whatever place of worship. But I found that, in my case at least, not to be the story. It was more questions and more feeling guilt and shame. So I just-- I go, but not like I used to go every Sunday. And my husband and I will share our thoughts and read the Bible, but it just-- for*

*some reason, we don't get that comfort. I would have thought that would have been the place I got the most support...actually, that's the one place I feel the most outcasted.*

Especially difficult was the singling out of mothers on Mother's Day ("will all the mothers please stand up"). This traumatized participants, which contributed to a decision to decrease attendance or no longer attend services at all, if temporarily. Eventually, many did return to formal attendance at a place of worship, although usually at alternative and less orthodox institutions. Often, there were caveats, such as no longer feeling obligated to attend every christening, and not attending church, ever, on Mother's Day.

### **Giving Voice To Loss**

*"Give sorrow words; the grief that does not speak knits up the o-er wrought heart and bids it break."* — William Shakespeare, *Macbeth*

Almost all of the women intuitively knew they needed to find a way, no matter how difficult, to speak of their infertility. Giving voice to very personal internal states assisted in deeply processing grief, essential for healing from trauma. This served multiple purposes. First, it assisted in moving unconscious and implicit aspects of the self, including trauma, into awareness through verbalization, turning suffering into speech. This is a fundamental tenet of Freud's "talking cure". The field of neuropsychology later elaborated on this, addressing the neurobiological processes and resulting affect regulation that can occur through psychotherapy and other healing adult relationships (Fosha, Siegel, & Solomon, 2009; Schore, 2011).

Second, as addressed in the literature review, in order to integrate a loss into one's life-narrative, it is critical to be able to articulate the loss (Neimeyer et al., 2010). Finding voice served to elucidate and concretize some of the more ambiguous losses (Boss, 1999), such as the loss of one's imagined life.

Finally, and most importantly, speaking of their infertility decreased the shame almost all participants spoke of by providing opportunity for the "the accepting, confirming and understanding human echo" (Kohut, 1978, p. 705). Finding voice around infertility was a constantly evolving process, and continued for years. Sometimes it was spoken of carefully and protectively; others took more risk in disclosing, and were greatly rewarded. For example, Rebecca, 35, surprised herself by taking an on-line bereavement class two years after ending treatment:

*I took an online class... never in a million years would I have thought I'd take an online class and be spilling my guts to people I don't know. But it was truly another little turning point for me...it was really just kind of like seeing yourself in different ways...And actually some of those women became very close friends for me...several of us actually went and met. And that was just a very powerful experience.*

Finding a safe place to speak of one's infertility, other than with one's spouse, was fundamental for becoming aware of and integrating the many losses into one's narrative. It also served to decrease the shame many felt about their infertility, and provided opportunity for hope. Participants did this in many ways.

## **Moving Through Grief**

Participants approached finding voice, identifying losses, and working through shame in a variety of ways, including a combination of journaling, writing and publishing poetry, blogging, classes, workshops, and reading. One wrote a book; nine sought therapy. Some approaches were purposeful and directed (writing a letter to one's imagined daughter), others more organic (allowing for sadness to emerge at unexpected moments). Everyone used on-line support.

Almost all participants spoke of their difficulty finding others in similar circumstances. Helpful resources, including knowledgeable therapists, were scarce as well, leaving participants abandoned and brokenhearted in their grief. One participant referred to this period after ending treatment as a "real no man's land". Consistent with the literature on disenfranchised grief, participants were unable to receive recognition for their losses, negating their right to grieve and compounding their sorrow (Attig, 2004; Doka, 1989). Many participants also described what Goffman (1963) defined as stigma, feeling that their childlessness was a deeply discrediting attribute, and that they deviated from the social norm. Compounding this stigma was participants' feeling devalued within various social situations (Crocker et al., 1998), including, at times, with close friends and family.

Discovering on-line communities, mostly consisting of various blogs, open and closed groups, and websites, were a "breath of fresh air" for the women. Instead of feeling abandoned in their sorrow, on-line support facilitated interaction with those in similar circumstances, offering a refuge from disenfranchised grief and stigma by normalizing emotions and facilitating a shared group identity. On-line communities also

provided advice, served as a container of emotions, and offered the possibility of hope, enabling participants to see that it was possible to live a good life without children. With time, communities also provided opportunity to altruistically give back. In addition, as discussed in Chapter II, depending on how much one actively participated, it assisted participants in giving and receiving the social support and environmental feedback critical to ongoing identity development (Jordan et al., 1991; Stryker, 2007).

Group support from those facing similar challenges has long been a staple in 12-step programs such as Alcoholics Anonymous and health care settings. The power of these groups comes from members' ability to provide first-hand knowledge that comes from personal experience. Ultimately, these types of groups assist participants in finding voice, help them to clearly articulate losses and needs, and, in doing so, provide the potential for friends and family to meet those needs.

Only one participant ultimately was not able to find needed support separate from on-line communities. She received very little from family and friends and knew no one in similar circumstances. Although currently on-line, she ended treatment 14 years ago. The Internet, as we know it today, was in its infancy, making support, and "how-to" advice (e.g. how to ask for support from and communicate with family and friends, how to navigate baby showers and pregnant friends, etc.) from others in similar circumstances impossible to find. It is not possible to overestimate the value of this resource for those who are disenfranchised.

Finding voice, deeply processing grief, and working to speak openly about one's infertility was enormously healing, particularly in working through shame. The more risk one took, the more support one received, and the easier it became to find voice. All this

contributed to participants' rebuilding and further developing identity. This process was both cyclical and progressive, and essential in order for the women to begin reimagining their identity and a life without children.

### **Acceptance and Choice**

For almost all participants, the uncertainty of their situation – whether to adopt, foster, or in some way still hope for a child – kept them in a stagnant, depressed, and traumatized position. As the women grieved and began shifting into acceptance, intense and chronic grief gradually abated; again, this was, on average, a 3-4 year process. Most participants sensed a palpable internal “lightening” toward the end of this period. Some experienced this suddenly, like an awakening; others moved into this more slowly.

With the passage of time and much grief work, concepts of acceptance and choice began to emerge. Most participants spoke of the necessity to *accept* one's reality, the ability to *choose* one's path, and the importance of *taking agency* over one's life. Actively deciding to live without children was vital for the women to turn toward the future and imagine embracing life once again. Reframing marriage as a “family of two” was often part of this process.

This did not mean that the women were happy about this. However, almost all came to the realization, eventually, that not having the life they planned did not mean they could not lead a good life.

### **Reimagining and Rebuilding Identity**

Almost all of the women felt very much changed by their infertility journey. Many spoke of feeling as if they had skipped a phase, or were “missing a chapter” in their lives. The actual time spent planning and preparing to become a mother, pursuing



treatment, and the psychological “space” made for a child created a void that challenged one’s sense of self. Remaining the same person was not possible; healing involved actively reimagining, rebuilding, and reestablishing identity as a non-mother, and finding one’s place in a changed world. Thoughtfulness, self-reflection, and determination were necessary components of this explorative and restorative phase.

Participants were motivated to reengage in life and find a place to fit in; the desire for affiliation was synchronous with rebuilding identity. Consistent with the literature on identity developing within a social and cultural context (Eisenberg, 2001; Erikson, 1959; Stryker, 2007), and its dependence on interactions with others (Gilligan, 1993; Miller, 1976), affiliation provided a way to be seen, heard, and acknowledged apart from the negative, dominating, and shaming internalized identity of “Infertile”. Most were compelled to actively search out new and/or additional social connections and supports, regardless of the extent to which their existing social support networks were disrupted.

The search for identity and affiliation, and actively reengaging in life, led to what Erikson (1959) called generativity. As addressed in the literature review, Erikson (1959, 1980) spoke of the life stage of adulthood, when we are faced with the developmental challenge of Generativity vs. Stagnation. Most participants were aware of the need to be productive in this capacity.

The women fulfilled this need in a variety of ways, some of which required creativity and risk-taking. This included offering assistance, care, and camaraderie to other infertile women, either locally or globally (through on-line support); creative activity, in the form of writing, blogging, and fine arts; becoming involved with charities and volunteer work; and/or somehow being involved in the care of others, including

through work and with family and friends. One woman was an administrator in a mental health setting. She opened a part-time private practice after infertility, further committing to the care of others, and was happily surprised at this being so fulfilling; another served as a mentor in her place of employment. Almost all the women were already actively generative, or specifically named how they planned to be.

Danielle, 40, who had lost her mother suddenly during treatment, combined charity with creativity after beginning a food blog. Here, she described how she began to address her lack of affiliation and search for identity. Her active engagement in life, by hosting an event, led to a social outlet that potentially influenced her identity, and also resulted in generativity:

*...I'm like what do I do now, where do I fit in?...I made a lot of friends online with other food bloggers. There is an organization called \_\_\_\_, and the idea is to get a group of people together, bake some sugar cookies, decorate them and then donate them to a local charity...I'm like, you know what, this Mother's Day, I'm not going to be moping in the corner. I'm going to do something positive for me, and I'm also going to honor my mom in the interim. So I held an event at my house. I invited, I think I had like 10 friends over. And I baked a lot of cookies...we had an awesome time. And it was such a positive experience out of something-- out of a day that had become such a heartache for me...*

As identities, both old and new, emerged, voices discovered by the need to speak of infertility grew stronger. Many elaborated on that voice by looking inside themselves, discovering what was important and true, and expressing this both verbally and behaviorally. Becoming more comfortable with oneself led to behavior that nourished

and reinforced this newfound confidence, assisting in internalizing one's legitimacy and life as a non-mother. Jill, 40, asserted her legitimacy with family; like many, she began to actively practice self-care without remorse:

*My mother in law got ill. My sisters-in-law both said, "Well, you don't have kids. Why can't you go over there every night and make her dinner and sleep over there?" and that kind of thing. "Well, because I also have a life...can't we do a rotating schedule, that kind of thing?" They didn't understand that just because I don't have children, does not mean that my life is not full. I have a whole life. It just doesn't include children.*

To summarize, continued healing and turning toward the future involved a combination of self-knowledge, engaging one's voice, and actively taking agency over one's life. Recovery also included reconnecting with the various identities that existed prior to infertility, and the search for new identities through affiliation; this ultimately led to generativity. Almost all of the women were either planning on becoming or were already engaged in various creative, philanthropic, and/or other caring activity that ranged from mildly to greatly different from what they had done prior to infertility. Again, this process was circular, reinforcing, and progressive, resulting in changed, stronger women with clearer voices. From this emerged the opportunity to find meaning.

### **Post Traumatic Growth and Finding Meaning**

Deeply processing grief, acceptance, reimagining identity, and generativity were critical components of the ability to once again fully embrace life. Participants spoke of the various ways in which they found opportunity, personally grew, and discovered meaning in their lives.

Opportunity was addressed as much more than the obvious advantages of less responsibility and more financial freedom. For many, there was the desire to transcend this enormous disruption to identity and existentially seize the life they had been given. There was a sense of openness to what the future may bring; a few used language evocative of birth. Christine, 41, and 3 ½ years post-treatment, spoke of as-yet undefined opportunity with curiosity and hope:

*...I feel as if I've been given kind of another option. I've kind of been given a pass to go do something else and I don't really know exactly what that is yet. But what I'm hoping is that down the road, later in my life, I will look back and see paths that I took that I wouldn't have been able to have taken if I had children. And it's more than just being able to travel, you know, to sleep in, being able to go out for dinner whenever I want... I don't know what it's going to be yet, but my feeling is that at some point I will look back and see that my life took a different and positive path because I didn't have children...I feel very positive about it to be honest. I feel as if I-- like I said, like I've been given an opportunity to do something bigger or different, something different. I don't want to say bigger, but something different than I would have done if I'd have had children.*

Many spoke of discovering a newfound or more profound sense of emotional intelligence and self-acceptance during their journey. As a result, many felt kinder and more empathic to themselves and others, as well as a wide-ranging sense of personal authenticity and freedom. Some were excited about what the future may bring. Rachel, 38, at the time of our interview was eagerly planning a new adventure with her husband:

*The way he explained his thoughts, why should we limit ourselves to the*

*American 9-5, limited vacation days, mortgage, debt to our eyebrows lifestyle that everyone else limits themselves to pay for the kids, only to hope for retirement on a beach somewhere - when there is really NO REASON we need to do that?*

*I guess you could say that the American dream - house, white picket fence, 2.5 kids, dog and yard; parents working their asses off to afford it all, and buy the kids everything they want; keeping up with the Jones - that doesn't fit us anymore, it actually limits us by judging us based on what is missing. There is no reason for us to play along anymore, so once you take the need for those things out of the equation, what remains? Anything!*

Many had grown and learned enormously from the disruption to their expected life and developmental course. What had grown for almost all participants was their marital relationship.

### **Relationship Growth**

Literature that addressed the impact of infertility on marital relationships is mixed, reporting either positive or negative impact particular to individual participants (Bergart, 1997; Schmidt et al., 2005; Wirtberg et al., 2007). What remains unexplored is *how* couples living without children after infertility navigate this immense life challenge, not only during and shortly after ending treatment, but over years.

In this study, almost all expressed that the experience of infertility had challenged their relationship. Despite the “ups and downs”, most felt closer to their partners, resulting in a deepened commitment to and increased respect for their spouses. The process of getting to this point involved much mutual work, whether the couples experienced minimal disagreement or much conflict. Three themes emerged that

contributed to growth, including a deep and broad sense of mutual empathy and appreciation, a willingness to be vulnerable, and participants' individuating within their relationship.

Empathy is understood to be a fundamental component in healthy relationships; in couple's therapy, developing mutual empathy between spouses is often a primary goal. In this study, participants reported a deep and broad mutual empathy developing over time. Participants conveyed this by speaking of how spouses responded to them over the years, and how it was necessary to care for spouses' when they entered a period of mourning.

An additional way empathy appeared was the realization that certain needs overwhelmed spouses, and that these needs could and should be met outside the relationship. This was an acknowledgment of spouses' boundaries and limitations, and, when done with love and respect, served to enhance both the relationship and the women's self-esteem. Sara, 38, addressed this:

*I don't have to dump every horrible thought on him or every depressing thought I have on him. There should be other venues for that, and I've used those venues, and that's worked a lot better. I feel we've gotten closer, just the fact that our talking about it, respecting each other's boundaries, our limits.*

The second theme that facilitated growth in relationships was participants' willingness to be vulnerable by talking with partners about their fears. Almost all were early in their marriage and had not yet developed the tools to effectively communicate during challenging times, resulting in the first period of significant conflict within the relationship. Working through this conflict involved much self-reflection and emotional honesty; often, the process was quite painful.

The third theme that contributed to relationship growth was participants' ability to individuate within their marriage. Some of the women, despite having strong voices and successful careers, struggled to find these voices within their relationship. It is possible that this, too, is common in the early years of marriage, and that many struggle to find a balance between their own needs, their husbands' needs, and the needs of the relationship. Samantha, 43, described this process well:

*I just wish I had been able to not worry about him so much in the early days and worried about myself and what I needed...it takes a long time sometimes to find out who you are and to find your own sturdy feet to stand on and say what you need, you know, and speak your truth. And I think if anything, you know, that's been a benefit for me is I've been able to speak my truth more as the years have evolved.*

All participants' remained married, although one was not yet clear that her marriage would survive infertility. This is in stark contrast to current U.S. divorce rates of 50% (Tejada-Vera & Sutton, 2010). Participants' mean length of marriage was three years, the median two, at the time of first diagnosis or miscarriage, and many were still getting to know themselves as a "wife", an identity not yet fully consolidated. It is possible that being early in their marriage served as a protective factor for these couples. The chronic crisis and trauma of infertility at times introduced intense and destructive emotions into fairly new relationships. Patterns, particularly less functional ones, had yet to be established. These relationships may have had more elasticity, providing an opportunity to successfully work through, not disavow, the negative emotions that inevitably arise in long-term relationships.

The resilience and evolution of almost all of the women is consistent with the literature on growth after a traumatic loss (Tedeschi & Calhoun, 2004; Attig, 2004). Most of the women reported positive shifts in significant areas, including relationships, within themselves, and in their overall sense of connection to the world. Of course, this did not apply to everyone. Although almost all had made significant adjustments, one participant had made few changes and was much less verbal. While it was difficult to discern how she felt about her circumstances, it is important to remember that everyone has diverse needs, and works through grief differently.

Almost all of the women were able to work through their trauma and grief, reestablish identity, experience personal growth, and have hope for the future. Many were embracing the freedom of a life without children. However, a few issues persisted.

### **Residual Grief**

Acceptance, taking agency over one's life, and rediscovered identity facilitated the ability to live a good life; it did not, however, completely eliminate sorrow over what was lost. All the women addressed a residual sadness that sometimes emerged. Although predictable, holidays such as Christmas were often difficult, serving to remind participants of what they didn't have. Other times were more surprising, one woman describing being overcome with sadness as if she had been "kicked in the teeth". These could be moments like a niece or a nephew learning how to drive, or events such as graduations or marriages. Nancy, 50, recalled:

*...my nephew got married a year ago March. I cried at the wedding. Now I'm going to cry. I cried because this is an experience I'll never experience (crying). I'll never have a son or daughter to walk down the aisle, to give away.*



Almost all continued to find baby showers difficult to tolerate, and some were quite clear that they would never attend another.

Fully integrating the loss included participants being at peace with feeling sad sometimes. Weaving this occasional sadness into the narrative of their life contributed to participants' expanding emotional world.

### **A Continuing Sense of Alienation**

An additional enduring issue was the alienation many continued to feel. Although almost all found affiliation in various ways, many continued to feel isolated from their peer group, almost all of whom had young children. This loss was acutely felt; missed was the intense bonding between women that organically develops with meaningful shared experiences, such as pregnancy, childbirth and parenting, or that could have developed had they known someone physically close in the same position. Many desired a return to the easy intimacy enjoyed in friendships that existed prior to infertility. This was yet another loss resulting from the developmental disruption of infertility. It was also a loss for the couple. Debbie, 36, and five years after ending treatment, stated:

*I don't know anybody else who didn't have kids that's my age...I don't have a lot of friends, I guess. We hang out with a lot of older people, and all of them-- all their kids are grown. The people that are my age that I've tried to become friends with over the years all ended up having kids...the friendship was too hard to keep it going. I mean, we'd end up going to these children's birthday parties, my husband and I, and it was just kind of awkward. And we did that a couple times and we had kind of had enough of that, so we kinda keep to ourselves...*

Those who remained connected to old friends did so with caveats: friends may not have grasped the loss of infertility, but this was okay as long as they had been empathic to their pain. Others expressed being fine with friends not understanding, stating that they “wouldn’t wish that on anyone”. Those who were not struggling with alienation had long-time friends who had either remained without children, or whose children were grown; these women found that the connection and comfort they received from knowing others in the same situation, although on-line, was enough.

The following section will address what this integration of findings and theory imply for clinical practice. First, the importance of creating a safe emotional and physical environment will be addressed, followed by a discussion on the role of and working with denial. Helping the client to develop a narrative, articulate the loss, and rebuild identity will then be addressed. Following this, the significance of being an analytically informed and attuned clinician will be discussed, as well as relevant issues when working with couples. Finally, a brief discussion on implications for education will be reviewed, followed by recommendations for future research.

### **Clinical Implications**

There are numerous issues facing women who have begun the infertility journey. In addition to the numerous losses and challenges to identity already reviewed, there are often substantial decisions to be made. These include deciding which treatments to pursue, if any (including third-party reproduction); whether fostering or adoption is an option; and, finally, moving into living without children if none of these options are, for any reason, not viable. These decisions are difficult enough on their own, and can be

overwhelming when we consider the psychological distress most endure during this process.

In this study, nine of the 12 participants sought individual therapy at some point during their infertility journey; of these nine, four sought couples counseling as well. The reasons for seeking therapy were directly related to the confusion, disruption, and trauma caused by infertility. Although everyone who sought therapy eventually found a therapist, most struggled initially to find someone knowledgeable about infertility. An additional participant had sought therapy for depression previous to infertility, and reported using tools she had learned then during her infertility process. Because this study focused on those living without children after infertility, the following discussion on clinical implications will, for the most part, address this population.

#### **Creating a safe space and being fully informed.**

The therapist should provide a Winnicottian “holding environment” - a safe physical and psychological space - to facilitate the expression of intense, and, at times, frightening, emotions. Therapists have the ability to hold and contain these feelings, serve as a witness to one’s process, provide empathy, and validate emotions, particularly those that are ego dystonic.

Creating a holding environment is especially relevant due to the disruption in social supports and disenfranchised grief most experience. Particular losses, especially the selfobject loss of “twinship” (Kohut, 1977) that many experience, both locally and globally, may result in a temporary regression to an earlier level of psychological functioning. The loss of a sense of kinship is most likely why an infertile woman needs her therapist to deeply grasp the extent of the losses and resulting psychological impact of

infertility, and be well versed in literature that addresses loss. Feeling deeply understood can be powerfully healing, and potentially serve as a stabilizing force that aids in integrating, or reintegrating, the self, one of the functions of a selfobject. When a therapist does not grasp the loss, she risks adding yet another layer of trauma to her client by once again depriving her of an opportunity for twinship and a healthy holding environment.

### **Working with denial.**

Providing a safe holding environment and “starting where the client is” can be quite challenging, requiring patience and artfully timed interventions. The first year after ending treatment with Western medicine (the medical field of Reproductive Endocrinology), almost all participants remained hopeful they would be able to conceive naturally, and continued or turned toward alternative therapies (e.g., acupuncture, diet, etc.). This was especially true for those who were still well within childbearing age. A therapist knowledgeable about infertility, for whom it is apparent that the odds of conceiving greatly counter hope, needs to contain this wisdom and gracefully accept that the client is not ready to accept this. Sara, 38, recalled her own process of letting go, and her therapist’s response:

*I remember the first time I realized I couldn't remember when my period started... I thought that was such a huge step for me emotionally when I just kind of let go of that constant vigilance, so, for a while, I thought that was my inner voice telling me, you're going to get pregnant. I really, really felt it. I really strongly felt it, and my therapist is such a person that, I mean, she'll challenge me on thinking a certain way, but she's not going to be like, "You need to be realistic,"*

*or anything like that, so she didn't really push it, and I think maybe I was in serious denial, and she's like, "Well, you're kind of protecting yourself," and I can't remember what else she said to try to make me feel better. I just finally realized I'd just kind of been leading myself on, and it was really upsetting.*

Therapists should assume that infertility clients have been well-informed by their doctors about their odds of conceiving. Assessing how much or how well they have metabolized this information can be determined simply by inquiring as to what she was told, if she hasn't shared this already, and listening for what follows. If the client is continuing to actively pursue pregnancy and carrying hope beyond what is realistic, she is most likely in denial.

Like any defense mechanism, denial is unconscious, and serves to disavow events or their connected meanings that are threatening and potentially destabilizing to the ego (Freud, 1966). In this sense, as Sara's therapist said, they are protective; breaking through a client's defense mechanism before they are ready may result in regression (e.g. Kleinian splitting), disorganization, and, possibly, leaving therapy. Again, the denial serves a purpose, and should not be pathologized so long as other reality testing remains intact. With time, as clients recover, the need for denial will gradually diminish.

### **Articulating the loss.**

It is essential for women to develop a narrative specifically regarding their infertility in order to fully grieve. This involves identifying and articulating social, identity, and ancillary losses, and understanding what these losses mean to them.

Developing a narrative around infertility leads to being able to articulate this narrative, or "find voice". Many women feel shamed by their infertility; speaking of it

coherently provides an opportunity for others to respond in a non-shaming way, offering the potential for a new experience, thus reducing shame. The therapists' role is to explore the shame, provide psychoeducation about the potential for healing in speaking of it to others, wonder with the client about potential safe places to disclose, and teach communication skills so clients can best be heard. Psychoeducation may also include directing clients to on-line support forums and encouraging active interaction (not lurking) to assist in developing one's narrative and articulating one's voice.

**Identity work.**

With time, as women are able to fully understand the extent of their losses, and how these losses have impacted their sense-of-self, the therapist may begin to address rebuilding and reimagining identity. This is vital: as the hoped-for identity of mother slips away, an emptiness remains that requires filling with something new, valued, and, ideally, self-esteem building. Without this nourishment, continued growth and development are at risk.

Reimagining identity involves assisting clients in reconstructing selves that have been lost or forgotten in the pursuit of pregnancy, and actively imagining, with the client, what a life without children may look like for her. The therapist may introduce themes of acceptance and choice; like any well-timed intervention that is attuned to the client, this can be experienced as life-affirming. It is also vital for the therapist to instill hope by conveying that it is possible to live a good and rewarding life, although different than what was expected, without children. The therapist *must* believe this, making sure her own biases have been thoroughly worked through.

### **Analytically informed treatment.**

Regardless of one's theoretical orientation, it is always helpful to listen with an analytically informed ear. The psychoanalytically oriented therapist can assist a client in constructing her life story, or narrative, that existed prior to infertility; help to access incomplete and less understood aspects of these histories; and, finally, provide understanding of how the loss of fertility and its ancillary losses interact with her narrative.

Being analytically trained and attuned is particularly relevant when working with clients that remain trapped in sorrow and despair, unable to imagine a life without children. The analytically attuned therapist, for example, may wonder whether being deprived of motherhood is a repetition of earlier losses and traumas, leaving a woman in a chronic and familiar state of longing and deprivation. This is particularly relevant if previous losses also occurred at developmentally vulnerable times.

The analytically skilled therapist may also become curious about the role shame has played in a woman's life. If a woman was raised in an environment of disavowed shame, she may disavow the shame of infertility. Disavowing any emotion keeps it trapped in her body, making it unavailable to be metabolized and worked through, and hinders the ability to fully integrate the loss into her life story.

These are illustrative examples of how times past can impact the present. Infertility may stir up numerous, complex, and unresolved issues from one's history. Analytically informed treatment can assist clients in reorganizing their narratives and integrating infertility into their life story. This allows for the possibility of continued identity development and the potential to lead a full, productive, and thriving life.

### **Interventions with couples.**

The crisis of infertility provides an opportunity for couples to grow closer, and consolidate their identities as separate, differentiated individuals invested in their relationship. The therapist working with couples can assist them in developing a mutual, far-reaching, and profound empathy for each other. Empathy impacts most aspects of relationships, including priorities and boundaries, and is the foundation of an essentially strong relationship. With infertility, although a man cannot know what it is like for a woman to be infertile, he can be empathic to her need for comfort, her need to find other women to speak with, respect the time it takes to heal and give her the space to do so. Infertile women can be empathic to their partners' need for infertility to not be a constant focus, and attempt to fill certain emotional needs elsewhere.

Communication skills can also be taught, which may result in couples deepening their connection to each other. Infertility results in intense affect; managing the expression of such feelings in ways that do not disrupt the relationship (from withdrawing to attacking) is vital. Empathy plays a critical role here as well, as couples discover and appreciate different styles of communication. For example, withdrawal, for one, may communicate anger. For another, withdrawal may indicate feelings of shame. As couples learn about how each communicates, they will hopefully be able to be responsive, rather than reactive, to one another.

It is important to note that all participants except one reported, ultimately, being in agreement about living without children. For those that are not able to come to an agreement, the analytically attuned therapist can, again, assist couples in individually forming their life narratives, help to integrate the loss of fertility (and ancillary losses)



into the narrative of their relationship, and wonder with the couple if there are underlying issue(s) that prevents them from coming to a decision that is best for the relationship.

### **Implications for Education**

Current Social Work education incorporates themes of loss, resiliency, narrative and analytically informed therapy, and the impact of trauma, both in theory and in practice. This study, although specifically addressing one population, indicates that there is a way through overwhelming sorrow and despair after traumatic loss. Although the journey through this type of loss is highly personal, common themes did emerge that may be applicable to other populations and incorporated into the social work resiliency curriculum. These themes may serve as a guide for working with those who face life-changing circumstances due to traumatic loss. In addition, social workers must believe in recovery and convey hope; this can often be challenging, particularly when we are drawn into the abyss of the client's presented world-view. This study provides evidence that the injured can once again live a valuable and good life, despite their transformed world.

In addition, there is clearly a need for further training in theological education. Considering the emphasis on procreation in religion, and the sudden loss of connection many experienced in their places of worship, religious leaders require further education regarding the psychological and psychosocial consequences of infertility. Churches, temples, and other places of worship have the potential to be tremendous sources of comfort for those struggling with this issue.

### **Limitations**

Again, like all qualitative research, these results are not generalizable to all women that fit the eligibility criteria for participation, but apply only to the women in this

specific sample. Limitations of this study include variables that are unable to be fully assessed in the context of a qualitative study. These include coping and stress management styles, support systems, mental health status, physical health, access to resources, and other strengths and weaknesses less amenable to categorization.

This study, like most studies that addressed infertility, consisted of participants that were white, married, heterosexual, highly educated and/or quite successful in their chosen careers and professions, and over 35. Transferability of this study is not possible to minorities, unpartnered women, same sex couples, those less educated and/or without investment in careers, and younger.

An additional limitation is this study's self-selection bias, an inherent issue in all qualitative research. It is possible that those who chose to participate felt good about their lives, had worked through many of the issues raised by infertility (including shame), and were therefore more open to disclosing highly personal aspects of their history and current life.

It is also possible that being willing to participate indicates a previously existing characteristic of the desire to help others; results indicated this was an important part of healing for many. (I would discount the characteristic of "outspokenness" as a reason to participate, since so many self-described as "shy" and "introverted" prior to infertility.)

An additional factor related to the self-selection bias is the positive state of almost all participants' marriages. It is possible that the ability and willingness to participate draws partially from the strength and security of one's marriage. Those in less supportive marriages, or those who have separated after infertility, may not feel as comfortable revisiting painful moments that may not yet be healed. In addition, although there were

disagreements about which treatment options to consider and when to cease pursuing treatment, all but one couple arrived at the decision to not adopt with minimal disruption to their relationship.

Almost all participants learned of the study from a blog post on [silentsorority.com](http://silentsorority.com). It is fair to assume that the majority of those who read this are drawn to it because the writer's posts resonate for them, or that they are benefiting in some way by reading this blog. All remained connected to the infertility world. Those who do not know about this blog, or for whom it does not resonate, are not in this study and may present differently than those who participated. In addition, there may be a subset of women who did read the blog, found it helpful, and moved on. They, too, may present differently.

### **Future Research**

A theme consistently raised during many of the interviews was the dearth of resources and knowledge available to guide the women through their process, including therapists, books, and organizations. Clearly a need for more research on the process of recovery for this particular population is needed. There is also a need to study the very long-term (20-30 years) progression of these women, particularly as peers move into the grandparenting phase of life.

This study, as most studies that address the psychological implications of infertility, focused primarily on a white, educated, married, middle-class population. There remains an urgent need to address ethnically and socioeconomically diverse populations, those who may not have access to medical treatment, and women whose ethnic or cultural background greatly privileges fertility and for whom there are few other role options available. The women in this study are mostly secular who come from

privileged position and who found solace in career or hobbies. Such privilege is not shared by all women and as such future studies should be expanded to include such women.

This study was open to all who fit the criteria; due to the small population, it was difficult to distinguish discrete differences in the impact of the various layers of trauma. For example, the two women in this study with the longest time post-treatment, falling well outside the mean, both had multiple miscarriages and identified religion as being quite important in their lives. What is the significance of this combination and its impact on grieving and recovery? In addition, two participants had their physical health permanently impacted by infertility, resulting in the need for daily and expensive medications. It would be desirable to know what impact this has on the adaptation process.

During the interviews, all of the women referenced, to varying degrees, the significant role of their husbands. Many spoke of their spouses support. A few reported that their spouses became depressed at some point. At this time, there is a dearth of research that addresses men's experience of infertility, and certainly none that addresses the long-term (after three years) experience of living without children after infertility. More research is needed in this area. This can serve to inform therapists working with men as well as couples.

In addition, since the role of spouses was so prominent and vital, research focusing on women who have divorced after infertility is also needed. This can help us understand how this population processes and/or integrates the loss, and how they begin to make sense of and rebuild their lives.

Since articulating the loss was found to be so critical in moving through grief, it would be helpful to examine the process of this in-depth. Charmaz (2006) spoke of who, what, when, where, and why questions. For this population, studying who the women disclose to, when and why they speak of infertility, where they tell, and what exactly they reveal may provide useful information for others in their search for voice.

## Appendix A: Recruitment Write-up on silentsorority.com

How many of you once bounced around looking for someone — *anyone* — with counseling credentials who knew even a *smidgen* about what you were going through? Someone who actually *heard* you when you explained your dogged pursuit of parenthood...and now your need for a bit of guidance as you pivot to a life without children? Let's see a show of hands.



Not surprised in the least. That's what led one therapist — after her own experience with infertility and, in particular, her difficulty finding help — to add infertility to her specialty.

Listen to Marni's story (and learn how you can make a difference and expand the body of knowledge on this topic.) In addition to working full-time, Marni is a doctoral student at the University of Pennsylvania School of Social Policy and Practice:

*"I sought out a number of therapists, all of whom were unable to hear that I was not interested in adopting or using third party reproduction. All thought it was a 'not interested yet,' and seemed to be on a mission to convince me that 'a child is a child.'*

*"Who knows - maybe clinical training vanishes around this subject; perhaps I had bad luck. In the end, I ended up working through much of my grief and sadness alone, with the support of my husband and whatever reading I could do on the subject.*

*"I have always admired how "out there" you have been with your struggle, which is incredibly brave and courageous. My dissertation topic is **Living Without Children After Infertility**. The dissertation topic will attempt to discover how women who sought treatment for infertility, were unsuccessful, and for whom adopting or 3rd party reproduction was not an option (for whatever reason) rebuild their lives after ending treatment. There are shorter term studies about this, most of which include women who have adopted, but nothing longer-term. I am curious to discover how women not only fare over the longer-term, but most importantly, how they get there - what is their process? What helped, what didn't? Are there any patterns for women who are doing*

*better? Anything that stands out for women who aren't doing well?*

Marni just received IRB approval, and is at the recruitment stage. She needs to interview 10 women who fit the criteria. If you have any interest in helping, you've landed at the right blog post. You'll find more detail below:

**You may qualify for a research study examining the long-term process of pursuing parenthood with medical assistance to living without children if you:**

- Experienced infertility
- Completed treatment at least 3 years ago (“treatment”, for purposes of this study, is defined as any type of medical intervention to enhance fertility, e.g. using Clomiphene or other ovulatory stimulant, IUI, IVF, etc.)
- Are living without children
- Are between the ages of 35-60 (all women, of any sexual orientation, race, ethnicity, or marital status, are invited to participate).

Participation involves one 1-2 hour interview to be done at your convenience.

Participants will receive a \$10 gift card to Starbucks and travel expenses.

Principal Investigator: Ram Cnaan, Ph.D.

For more information, please email Marni: [infertilitystudy1@gmail.com](mailto:infertilitystudy1@gmail.com). All inquiries are strictly confidential. The study even has a Facebook page: [Infertility Study](#).

I cautioned Marni that getting women to open up on this topic is difficult. That's when she assured me:

*"I completely understand any hesitation to go on record. Since this is a dissertation topic that required Institutional Review Board approval from UPenn, I am held to the highest standard of confidentiality. Please know that all interviews are strictly confidential; no personal information will be known by anyone but me."*

If you personally don't qualify, you may know someone who does. Would you care to join me in making history?

## Appendix B: Consent Form

**IRB Approval From: 04/04/11 IRB Approval To: 04/03/12**

### **University of Pennsylvania Informed Consent Form**

**Title of the Research Study:**

A Study Of Women Living Without Children After Infertility

**Principal Investigator:**

Ram Cnaan   
Professor and Senior Associate Dean  
School of Social Policy & Practice  
University of Pennsylvania   
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**Interviewer:**

Marni Rosner, LCSW  
315 W. 57th Street, Suite 307  
New York, NY 10019  
(212) 262-9041; cell (917) 318-2950  
marni.rosner@gmail.com

You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if decide to participate. The research team is going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with friends, family doctor and family.

If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form; in it you will find contact information and answers to questions about the study. You may ask to have this form read to you.

**What is the purpose of the study?**



The purpose of the study is to learn more about women who have experienced infertility and are now living without children. This study is being conducted for a doctoral dissertation. □

### **Why was I asked to participate in the study?**

You are being asked to join this study because you have identified yourself as a woman living without children. You have also identified yourself as someone who was diagnosed with infertility, sought treatment, and ceased pursuing treatment at least three years ago. You have also identified yourself as someone who is not considering further infertility treatment in the future, is not currently pregnant, and do not have plans to adopt. In addition, you are not experiencing a non-infertility related current or recent-past crises (recent death or serious illness in family).

### **How long will I be in the study? How many other people will be in the study?**

The study will take place over a period of one year. Your participation will be limited to one interview lasting approximately one to two hours. You will be one of 10-12 people in the study. □

### **Where will the study take place?**

The interview will take place at a place of your choosing, either your work (office) if convenient, your home, or my office. □

### **What will I be asked to do? □**

The interview will last about one to two hours. I will ask you questions about your experience with infertility treatment; why you stopped treatment; how infertility has impacted your life, from the time you ceased treatment until today. The interview will be audio recorded.

### **What are the risks?**

The ways that confidentiality will be protected have already been described. The risks of participating include becoming upset due to revisiting a difficult time in your life. In the unlikely event that you find that what you discussed in the interview is upsetting to you after the interview is over, please be in touch with me. I will provide you with some names and numbers of individuals or agencies that can provide further assistance.

### **How will I benefit from the study?**

It is possible that having a chance to share your experience will be an interesting and possibly even a rewarding experience for you. In addition, you will be assisting in generating information about the experience of women living without children after ending treatment for infertility, which may be helpful for other women in the future. □

### **What other choices do I have? □**

Your alternative to being in the study is to not be in the study. □

**What happens if I do not choose to join the research study? □**

You may choose to join the study or you may choose not to join the study.  
Your □ participation is voluntary. □

**When is the study over? Can I leave the study before it ends? □**

The study is expected to end after all participants have completed all visits and all the information has been collected. The study may be stopped without your consent for the following reasons:

- o The PI feels it is best for your safety and/or health-you will be informed of the reasons why. □
- o The PI or the Office of Regulatory Affairs at the University of Pennsylvania can stop the study anytime.

You have the right to drop out of the research study at anytime during your participation.

**How will confidentiality be maintained and my privacy be protected?**

The PI will make every effort to keep all the information you tell her during the study strictly confidential, as required by law. The Institutional Review Board (IRB) at the University of Pennsylvania is responsible for protecting the rights and welfare of research volunteers like you. The information you share will be kept strictly confidential. Nothing with your name or other identifying information (names and places mentioned in the interview) will be seen or heard by anyone but me and a Europe-based transcription service that is also bound by confidentiality. I will never use □ your name, personal information or information about where you live or work in my write-up of the interview. Once I have analyzed the interview and written my dissertation, I will destroy the audio recording, interview notes, and interview □ transcript. I will remove anything that might serve to identify you, including □ geographic locations and names of particular individuals you might mention in the interview. □

**Will I have to pay for anything? □**

There is no cost to participate in this study. □

**Will I be paid for being in this study? □**

If you decide to participate you will be given a \$10 gift card to Starbucks when the interview is completed. You will also be reimbursed for any money you spend to travel to the interview site.

**Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?**

□ If you have questions, concerns or complaints regarding your participation in this □ research study or if you have any questions about your rights as a research subject, you □ should speak with the Principal Investigator listed on page one of this form. If a member □ of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any □ question, concerns or complaints at the University of Pennsylvania by calling (215) 898-□2614. □

When you sign this document, you are agreeing to take part in this research study. If you □ have any questions or there is something you do not understand, please ask. You will □ receive a copy of this consent document.

**Signature of Subject:**

**Print Name of Subject:**

**Date:**

## Appendix C: Interview Guide

1. Please tell me how you came to learn you were infertile and what that experience was like for you.

If not addressed, and if applicable, follow-up with:

- a. What kind of support did you have during this period? Who did you tell? Were they supportive?
- b. Tell me how this impacted your relationship with your spouse/partner. Did this change over time? What helped? What didn't? What about friends and family?
- c. Tell me about how you arrived at no longer pursuing treatment.

2. Tell me the story of how you came to know you would live without children.

If not addressed, and if applicable, follow-up with:

- a. Please tell me how your thinking about living with or without children has changed over time.
- b. What were your thoughts about adoption or other alternatives to biological children?
- c. How open have you been about your process with your friends and family? How have they responded? Have their responses changed over time? How have their reactions impacted you?
- d. Was there any particular moment or event that pushed you toward this decision? Was there any particular "hangup" or thing that kept you stuck?
- e. What was most/least difficult about this?
- f. What was most helpful during this process? Least helpful?

3. How has your life changed since experiencing infertility and then realizing you would not have children?

If not addressed, and if applicable, follow-up with:

- a. How has this affected your relationship with your husband/partner? Has this changed over time?
- b. How has it impacted your relationships with your friends, both with and without children?
- c. How do you think about your life, now?
- d. What are your thoughts and feelings about the future?

4. How has infertility most changed you? How has it impacted your identity as a woman?

How much is being an “infertile woman” part of how you define yourself? Has this changed over time?

5. What, if any, emotion do you most struggle with and what has been helpful in alleviating this?

6. Any residual thoughts about your treatment by doctors?

7. How has this affected your life goals or philosophy of life?

8. Have you found purpose in this experience or made sense of this experience?

9. How does infertility still impact you today? Has it gotten easier or harder with time?

10. What would you do differently? What would have made this easier?

11. What do you wish your friends had said?

12. Is there anything else you'd like to share that we haven't talked about?

13. What advice would you give to others in this situation?

## Appendix D: Glossary

**ART:** Assisted Reproductive Technologies. All fertility treatments in which both eggs and sperm are manipulated. In general, ART involves surgically removing eggs from a woman's ovaries, combining them with sperm in the laboratory, and returning them to the woman's body or donating them to another woman.

**Blocked Fallopian Tubes/Blocked Tubes:** when an obstruction prevents the egg from traveling down the tube. This can occur on one or both sides, and is also known as tubal factor infertility.

**Children/Child:** for purposes of this research, “child” or “children” refers to fully biological children, unless otherwise specified.

**Clomid:** this is an ovulatory stimulant and is used to induce ovulation (egg production) in women who wish to become pregnant. It is very inexpensive and comes in tablet form. It is often used in combination with IUI.

**Ectopic Pregnancy:** An abnormal pregnancy, where the embryo implants outside the uterus, typically in the fallopian tube. An ectopic pregnancy can be life threatening and must be treated by a doctor immediately. This is not a viable pregnancy.

**Egg Donation:** surgically extracting eggs from the ovaries of a fertile woman and donating them to an infertile woman for use in an assisted reproductive technology procedure.

**Egg Sharing:** an arrangement that enables infertile patients who cannot afford the cost of IVF treatment to receive free or lower-cost IVF treatment in return for donating a proportion of their eggs to matching paying recipients.

**Endometriosis:** a condition where endometrial tissue, which normally grows inside the uterus, grows abnormally and may be present on the ovaries, fallopian tubes, and other nearby organs in the pelvic area, causing scarring, bleeding, pelvic pain and infertility.

**Fallopian Tubes:** two thin tubes, one on each side of the uterus, which lead the mature egg from the ovaries to the uterus. Fertilization usually occurs in the fallopian tube.

**Fibroids:** benign tumors that grow from the muscle layers of the uterus.

**HSG:** Hysterosalpingogram. An X-ray test that is performed by placing an iodine-based dye into the cervix. This determines whether the fallopian tubes are open or blocked and where the blockage is located.

**IUI:** Intrauterine Insemination. Also known as artificial insemination (AI), IUI is a medical procedure that involves placing sperm into a woman's uterus to facilitate fertilization. IUI is not considered an ART procedure because it does not involve the

manipulation of eggs; however, intensive monitoring and numerous trips to the infertility clinic are still required.

**IVF:** In Vitro Fertilization. A procedure that involves removing eggs from a woman's ovaries and fertilizing them outside her body. The resulting embryos are then transferred into the woman's uterus through the cervix.

**Ovum:** the mature female gamete cell, or egg. Ova is plural for ovum.

**POF:** Premature Ovarian Failure. The loss of normal function of the ovaries, causing a woman to have irregular periods or no periods at all.

**Reproductive Endocrinologists:** Physicians specializing in reproductive endocrine disorders and infertility.

**Resolve:** the National Infertility Association. Provides education and advocacy for men, women, and couples struggling with infertility.

**Surrogate:** a general term that refers to a woman who carries a pregnancy for another person.

**Third-Party Reproduction:** refers to the use of *eggs*, *sperm*, or *embryos* that have been donated by a third person (donor) to enable an infertile individual or couple (intended recipient) to become parents.

**Treatment Cycle:** refers to a typical IVF procedure. First, fertility drugs are used to stimulate the ovaries. Then, the eggs are retrieved, and placed together with sperm in a special nutrient rich cocktail. Finally, after fertilization takes place, embryos, usually one to three, are placed inside the woman's uterus. A typical treatment cycle is 33 days, but can be shorter or longer.

**Unexplained infertility:** infertility whose cause remains unknown even after medical evaluation. It is the most common cause of infertility.

## Appendix E: Brief Bios of Study Participants

**Beth:** Beth is a 48-year-old professional with a Master's degree. She was diagnosed with high FSH and a clotting issue at age 39, and had one miscarriage. She had been married for one year at the time of her diagnosis, pursued treatment for 3-4 years using donor eggs, and was 4 years post-treatment at the time of the interview.

**Christine:** Christine is a 41-year-old professional with a Master's degree. She was diagnosed with high FSH at age 34. She had been married less than one year at diagnosis, pursued treatment for 2 years using IUI and alternative therapies, and was 3.5 years post-treatment at the time of the interview.

**Danielle:** Danielle is a 40-year-old professional with a Master's degree. She was diagnosed with high FSH at age 34 and had multiple miscarriages. She had been married 2 years at the time of diagnosis, pursued treatment for 2 years using IUI and IFV, and was 5 years post-treatment at the time of the interview.

**Debbie:** Debbie is a 36-year-old with a Bachelor's degree working in the medical field. She was diagnosed with unexplained infertility at age 28. She had been married 2 years at the time of diagnosis, pursued treatment using clomid and IUI for 3-4 years, and was 5 years post-treatment at the time of the interview.

**Jill:** Jill is a 40-year old employed in the hospitality industry with a vocational degree. She was 27 when she was diagnosed with endometriosis. She had been married 2 years at the time of diagnosis, pursued treatment with IUI for 5 years, and was 8 years post-treatment at the time of the interview.

**Lauren:** Lauren is a 42-year-old employed in marketing with a Bachelor's degree. She suffered three ectopic pregnancies before a complete hysterectomy at age 32; she also had endometriosis, and a heart shaped and tipped uterus. She was engaged to be married at the time of her first ectopic pregnancy, pursued treatment for 7 years with IVF, and was 10 years post-treatment at the time of the interview.

**Nancy:** Nancy is a 50-year-old employed as a manager with an Associate's degree. She had her first of multiple miscarriages at age 39, and was ultimately diagnosed with unexplained infertility. She had been married 10 years at the time of diagnosis, pursued treatment for 5-6 years using clomid, IUI, and IVF, and was 5 years post-treatment at the time of the interview.

**Patricia:** Patricia is a 54-year-old professional with a Master's degree. She had her first of three miscarriages at age 37. She had been married one month at the time of her first miscarriage, pursued treatment for 5 years using clomid and IUI, and was 14 years post-treatment at the time of the interview.



**Rachel:** Rachel is a 38-year-old professional with a Master's degree. She was diagnosed with PCOS and POF at age 34, and was not eligible for treatment using her own eggs. She was married 10 years at the time of diagnosis, and was 4 years post-diagnosis at the time of the interview.

**Rebecca:** Rebecca is a 35-year-old entrepreneur with a Bachelor's degree. She was diagnosed with unexplained infertility at age 30, and had multiple miscarriages. She had been married for 2.5 years at the time of her diagnosis, pursued treatment over 2 years with clomid and IUI, and was 3.25 years post-treatment at the time of the interview.

**Samantha:** Samantha is a 43-year-old professional with a Master's degree. She was diagnosed with high FSH, fibroids, endometriosis, and a septated uterus at age 34. She was married 2.5 years at the time of her diagnosis, pursued treatment for 4-5 years with IUI and IVF, and was 3.75 years post-treatment at the time of the interview.

**Sara:** Sara is a 38-year-old professional with a Master's degree. She was diagnosed with unexplained infertility at age 32. She had been married 3 years at the time of diagnosis, pursued treatment over 2 years with clomid and IUI, and was 4.25 years post-treatment at the time of the interview.

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