

FACING INFERTILITY: DESIGN AND EVALUATION OF A MIND-BODY
PROGRAM FOR EFFECTIVE EMOTIONAL SUPPORT

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Submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY IN URBAN EDUCATION: COUNSELING

at the

CLEVELAND STATE UNIVERSITY

December, 2006

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ACKNOWLEDGMENTS

First and foremost infinite thanks to my children Sami and Beni and partner Haysam El-Dalati without whom I would not have forged this path in life or commitment to this work. They taught me what it means to love and be loved and what it is like to be a child who is truly wanted.

To the men and women who collaborated with me in this study and opened their hearts and world for me to share with them; to you I am indebted. To Professor Joanne Goodell whose personal journey toward motherhood has paralleled my own academic voyage; who knew? To Professor Carl Rak whose challenge led me to reflect on much more than the words within these pages; may I always be asked to think for myself.

Finally, to the Committee Members, CSU Professors and colleagues from Cohort XVII who offered support and kindness throughout, with a special mention to Niki Vasu without whom on many a night I might have killed my computer, thank you.

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ABSTRACT

The psychological impact of infertility is well documented in the scientific literature. Childbirth and parenting is universal and when denied to those who seek it generates feelings of tremendous loss and grief. This study explored the stress and distress associated with the experience of infertility within an historical medical and social framework, and evaluated the effectiveness of a one-day mind-body workshop to provide emotional support. Emphasis was placed upon a mind-body paradigm because of its demonstrated benefit in other stress-related health conditions and the emerging evidence that demonstrates an increasingly important relationship between emotional and physical well-being. Stress was explored according to its specific impact on personal identity and interpersonal functioning during the experience of infertility.

A mind-body program was developed specifically for use in the research design. This study was implemented in two phases and with two groups, women-only and couples. Phase I involved the collection of baseline quantitative data, implementation of a one-day workshop. Phase II consisted of in-depth qualitative interviews with all study participants conducted one-year later. The study's mixed-method and multi-methodological design challenged the medical model approach predominantly used to evaluate and provide psychological support for individuals and couples receiving infertility treatment.

The study's outcome revealed that both men and women report experiencing high levels of stress related to infertility and that the source of this stress differs according to gender. Involvement in the workshop led to a decreased level of perceived intra-personal and relationship-based stress and improved understanding between partners for participants who attended as a couple but not for women who attended alone. When compared to women-only participants couples reported higher rates of pregnancy and live birth one-year after participation in the workshop. In addition, men reported feeling equal or higher levels of stress than women after the birth of a child. The effectiveness of a one-day format and the implications of the study's overall findings on clinical practice are discussed.

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CHAPTER I

INTRODUCTION AND OUTLINE

This dissertation examines the emotional and psychological stress effects on individuals and couples facing infertility. The purpose of this study was to evaluate the effectiveness of teaching a one-day mind-body workshop as a method for providing effective emotional support. Evaluation of the teaching tool and its perceived usefulness as an intervention is reviewed and analyzed. The significance of the research and its findings, its relevant theoretical constructs, practice implications, and the study's limitations are also discussed.

A preliminary review of the medical history is offered in Chapter I and provides context to the way in which infertility has traditionally been framed socially, culturally, and therapeutically. Although the research demonstrates that stress is a significant factor in the treatment of infertility, what is less clear is the degree to which stress contributes to the diagnosis of infertility or influences its resolution (Csemiczky, Landgren, & Collins, 2000; Domar, Clapp, Slawsby, Kessel, Orav, & Freizinger, 2000). For the purpose of this study, stress and its physiological sequelae is defined generally, and then specifically, as it pertains to an infertility diagnosis (Demyttenaere, Nijs, Evers-Kiebooms, & Koninckx, 1993; Kemeny, 2003). Stress is also examined from the perspective of externally and

internally generated sources and a theoretical model for identifying those sources was applied to the design and development of the Phase I research intervention (*Minding Matters*), and is being qualitatively reviewed in this dissertation (Aneshensel, 1992; Higgins, 1987).

Numerous studies explore the significant psychological and physiological stress that accompany both the diagnosis and treatment of infertility, how to best respond to this stress continues to be less definitive (Boivin, 2003; Domar, 2004; Eugster, Vingerhoets, van Heck, & Merkus, 2004; Olivius, Friden, Borg, & Bergh, 2004; Schmidt, Holstein, Boivin, Tjornhoj-Thomsen, Blaabjerg, Hald, Rasmussen, & Andersen, 2003). In addition, the stigmatizing effect of an infertility diagnosis is well documented and is known to have negative effects on self-identity with or without successful resolution of the fertility crisis (McQuillan, Greil, White, & Jacob, 2003). This finding suggests the need to provide supportive intervention to individuals experiencing infertility that extends beyond the period of active family building and into the realm of ‘artful’ living. Supportive intervention also means developing ways to help educate families, friends, and the larger world about the painful and far reaching sweep of infertility’s mantle (Eugster et al., 2004; Gibson & Myers, 2002) .

How Stress is Examined in This Study

This study examines three major sources of stress encountered by individuals and couples experiencing infertility: (1) The challenge to personal identity that is reported as a result of being unable to fulfill a desire for biological parenthood (Letherby, 2002), (2) The disappointment and or conflict that develops within social relationships as a consequence of a perceived failure to meet role expectations (McQuillan et al., 2003), (3)

The perceived stress effects of treatment and treatment cost including allopathic and alternative intervention procedures, the style or method of how therapeutic care is delivered, and access restriction due to financial limitations (Leite, Makuch, Petta, & Morais, 2005; Olivius et al., 2004; Verhaak, Smeenk, Evers, Minnen, Kremer, & Kraaimaat, 2005a).

In addition to the emotional and psychological difficulties associated with these three conditions, brief attention is paid to the physiological and physical manifestations of stress that have driven the current theory behind mind-body medicine and infertility. A variety of well documented stress reduction techniques are explored (Ong, Linden, & Young, 2004).

Support for a Multidisciplinary Approach.

Traditionally, the study of infertility and its ancillary effects has been the eminent domain of medicine, therefore much of the literature that has been produced, even in the area of behavioral health, has tended to be published in medically grounded scientific journals. Given the broad based impact of infertility, and Boote and Beile's, (2005) mandate that, "... anyone earning a doctorate in education ought to know the literature in his or her area of specialization" (p. 10), this analysis strives to evaluate past and current research across a variety of subjects while moving the fertility discussion further into the field of counselor education.

A multi-disciplinary approach is important given that the bulk of the data collected is outside the scope of the counseling profession. The intervention tool (*Minding Matters Manual and one day mind-body workshop*), designed for evaluation in

this study, is dependent upon data gathered from fields of practice beyond infertility, making collateral analysis of several other content areas necessary (O'Donnell, 2004c).

Research continues to show that even when counseling and psychological support is offered to individuals and couples it is frequently not utilized (Boivin, Scanlan, & Walker, 1999; Domar, 2004). Some authors suggest that future research must address the need to discover what contributes to the apparent inconsistency documented between perceived need for supportive services and their actual use (Boivin, 2003; Boivin *et al.*, 1999; Greil, 1997). Understanding the complex mechanism of this profoundly existential, biological, emotional and psychological crisis is critical to the development of a healthy and cost-effective model for providing adequate care that is also likely to be utilized (Nakao, Fricchione, Zuttermeister, Myers, Barsky, & Benson, 2001b).

Defining an Effective Intervention

Effectiveness research, according to Kihlstrom "...attempts to extend the logic of efficacy research to more ecologically valid treatment settings" (Norcross, Beutler, & Levant, 2006, p. 26). However, Kihlstrom also warns that effectiveness research studies often rely on subjective evaluation related to clients' perceptions of satisfaction or assessment of improvement rather than documented or measurable change; the objective versus subjective methodological experience. This study does not challenge that position. This study makes the argument, supported by a growing abundance of evidence, that what people believe and how they construct meaning out of what they believe influences their course of action and action has both a direct and indirect relationship on thought process and problem outcome. The objective and subjective are given equitable

consideration rather than equal weight in this dissertation; observed, heard and discussed, rather than calculated and defined.

Given that the main and undisputed goal of infertility treatment is pregnancy and a successful live birth, it has been and is, tempting to associate all forms of collateral support as potentially contributing to this outcome. However, this is not the intention or capacity of this study. Hope is inherently linked to the struggle of infertility because it speaks to the intention behind any quest for treatment; to have a child. Hope as an enduring, unfulfilled expectation is also intrinsically linked to the probability of suffering anxiety and depression, perhaps as a secondary effect of fear (Bloomfield & Vurdubakis, 1995; Boivin et al., 1999). One only has to read poetry to understand the affliction that is unrequited love (Blake, 2002). Whether sadness and grief or anxiety and depression pre-exist infertility or are predicated on its diagnosis, does not alter the need for their effects to be addressed.

To develop a full respect for the impact of infertility on an individual's relationship with *self* and a couple's relationship with each other, appreciation for how people have matured through their lives to the point of 'diagnosis' is profoundly important. For many, infertility is their first point of crisis personally and frequently, in their primary relationship. This research provides a model for individual's to build upon their existing understanding of who they are; to gain new perspective at a time many report as life defining and which this study will demonstrate, can also be life affirming.

The Dissertation Structure

This chapter introduces several historical elements of infertility and the paradigm shifts and discoveries that have influenced treatment. In addition, the theoretical construct

(Higgins Self Discrepancy Theory), which serves as the framework for understanding the relationship between stress and infertility, is examined using a mind-body model “Mind Body interventions are so critical: they provide relatively simple, structured steps that individuals can take to assume a greater influence upon their own self-care” (Higgins, 1987; Pelletier, 2002, p. 5).

The study seeks to further the understanding of how the need for support is perceived by individuals experiencing infertility and examines how that support can be better provided. Integration of counseling methods that address both the external sources of infertility driven stress and their internal, emotional and physical effects on the body is critical to the delivery of comprehensive care. Most importantly, this research aims to expand the role of counselors in the field of reproductive medicine in providing a model of care for therapists and their clients whose traditional sphere of influence has been psychology and to a lesser degree, the medically based or independent social worker.

History of Infertility Research

Gynecology emerged as its own medical specialty in the latter half of the nineteenth century and by 1930 had joined with obstetrics to become the field of obstetrics and gynecology (M. Marsh & Ronner, 1996). Infertility physicians formed their own sub specialty within this discipline in 1944 and six years later began publishing a Journal devoted to the topic called *Fertility and Sterility*, which is still in distribution today (Medicine, 2000).

Defining Infertility

The current clinical definition of infertility most widely used is stated as: the inability to conceive after twelve months of unprotected sexual intercourse, although

some authors suggest that this definition should be expanded to twenty four months, merging the clinical and research classification of infertility into a uniform interpretation (Larsen, 2005). Recent statistics estimate that approximately thirty percent of infertility is attributable to male factor, thirty five percent female, twenty five percent combined, and ten percent unexplained (Larsen, 2005).

Prevalence

The World Health Organization places the global prevalence of infertility at between eight to ten percent worldwide, (an incidence that has remained relatively steady over the past fifty years), effecting about eighty million people of childbearing age (Vayena, Rowe, & Griffin, 2001). These figures are much higher in regions of the world experiencing an exponential rise in sexually transmitted disease, poor obstetrical care, culturally based female circumcision practice, none or minimal sex education, and limited diagnosis and treatment for its sexually active population (Giwa-Osagie, 2002).

Medical History

Chapter II's overview of the medical history of infertility examines the Western understanding of reproduction as it emerged from the time of Antiquities, in the hands of the ancient philosophers, to its present status, with focus being attended on the last one hundred years (Hunter, 2003; M. Marsh & Ronner, 1996).

There have been several critical periods in the history of infertility including identification in the eighteen hundreds of the exact function of the sperm and egg and development of the Sims Speculum for performing the internal pelvic exam (M. Marsh & Ronner, 1996). The early twentieth century brought discovery of the role of the pituitary in controlling hormones, the specific detection of estrogen and progesterone, and use of

the Rubin test to detect tubal patency (Hunter, 2003). By the nineteen thirties testosterone had been named and the first public announcement of a birth conceived via sperm donation was recorded (S. Smith, 1999). These combined events led to the use of animal and human pituitary products in the treatment of infertility and, by the nineteen seventies, sperm was available for legitimate purchase in the United States for use in artificial insemination (Barney, 2005).

A Critical Turning Point

The birth of the first baby, Louise Brown, by in-vitro fertilization, stands as the single most important contribution to reproductive medicine in the twentieth century (Henig, 2004). The work of Patrick Steptoe and Robert Edwards paved the way for a number of techniques that followed including: egg donation, gestational surrogacy, intracytoplasmic sperm injection (ICSI), and pre-implantation genetic diagnosis, all of which brought the ethical discussion surrounding the reproductive technologies to a new pinnacle of philosophical debate (Pfeffer, 1997). A review of current success rates and their implication on duration of treatment, therapeutic options, and repercussion to mental health is discussed in Chapter II.

History of Psychological and Stress Effects of Infertility

The American Society of Reproductive Medicine published an article on the relationship between emotions and infertility in one of its earliest issues of *Fertility and Sterility* entitled: *Possible Psychogenic Aspects of Infertility* (E. M. Marsh & Vollmer, 1951). Since that time several researchers have explored the psychological impact of infertility as well as the potential psychological contributors to infertility, both intra and inter personally, for example: (A. Abbey, Andrews, & Halman, 1995; Fouad & Fahje,

1989; Kee, Jung, & Lee, 2000). An article by Wischmann: *Psychogenic Infertility: Myths and Facts* (2003) brought the often contentious debate about what role the mind plays on the process of reproduction full circle, emphasizing that we are no closer to understanding the complex relationship between our head and our gonads than we ever were (Wischmann, 2003).

The Meta-Reviews

Several important meta analyses highlight the significant psychological distress that accompanies infertility and the conflicted discussion that continues regarding both its causes and mitigation (Boivin, 2003; Brkovich & Fisher, 1998; Eugster & Vingerhoets, 1999; Greil, 1997). Greil's review paid particular attention to the literature examining differences between genders as well as making a distinction between articles that discussed symptoms as a consequence of infertility and studies that see them as contributing to infertility. Greil's observation that much of the research was undermined by weak methodology, biased sampling, and poorly accommodated temporal factors, was a concern also raised by Boivin (2003) in her analysis of effective psychosocial interventions (as measured by reduction in stress symptoms and overall pregnancy rates).

Brkovich and Fisher reviewed psychosomatic infertility in particular, and looked at research that attempted to mitigate, pre medical treatment, any underlying psychopathology (Brkovich & Fisher, 1998). The influence of such treatment on subsequent pregnancy success rates and its reliability and validity is also evaluated. Eugster and Vingerhoets (1999) emphasized an almost exclusive use of retrospective study designs in the research literature. Despite the documented relationship between perceived levels of stress and pregnancy, the authors suggest a prospective design with

couples to determine “...whether psychological factors can predict infertility and outcome” (Eugster & Vingerhoets, 1999, p. 587).

A Breakthrough

Domar et al (2000) conducted the first “...randomized, controlled, prospective trial” that demonstrated a relationship between women who received some form of psychosocial support during infertility treatment and pregnancy outcome (Domar et al., 2000, p. 806). Domar’s study limitations reflect the difficulties that the previous authors document: lack of an adequate control group, homogeneous sampling, and insufficient consideration of duration of infertility. However, Domar’s findings that fifty five percent of the cognitive behavioral group and fifty four percent of the support group achieved a viable pregnancy compared to 20% of the control suggest “... that group interventions may lead to both improved psychological state as well as increased pregnancy rates...” (Domar et al., 2000, p. 574).

Research on other health related conditions demonstrates a strong association between stress, depression, vulnerability to disease and disease recovery (Austenfeld & Stanton, 2004; Pelletier, 2002). Authors in the field of infertility have also noted the correlation between depressive symptoms and fertility rates projecting that mitigation of those symptoms has the potential to improve reproductive success (Demyttenaere, Bonte, Gheldof, Veraeke, Meuleman, Vanderschuerem, & al, 1999; Ramezanzadeh, Aghssa, Abedinia, Zayeri, Khanafshar, & Jafarabadi, 2004). Despite these findings, few clinics uniformly offer their patients the kinds of psychosocial support that have demonstrated effectiveness (Boivin, 2003). Some authors have suggested that this in part due to the increased financial burden of providing this service, the stigmatization effect of

receiving mental health treatment, and the generally ambivalent stance toward mind-body medicine (Schroeder, 2004).

Data Synthesis

The purpose of this dissertation study is to develop an intervention based on evidence from the literature, which both steps out of the medical paradigm and can be presented in a cost effective group format or as a self guide, and does not use pregnancy outcome as its only measure of effectiveness (Eugster et al., 2004; O'Donnell, 2004c).

Social and Cultural Impact of an Infertility Diagnosis

Fertility is universally celebrated as the ubiquitous symbol of creation, a sign that things can and will continue. Fertility represents prosperity, favoritism, goodness, and eternity; to be fecund, in the words of Simone De Beauvoir, "...gives a woman a perfect sense of rich abundance" (De Beauvoir, 1952, p. 501). Fertility continues to be the yardstick by which women, and increasingly men, are seen to make their richest and paradoxically, most devastating contributions to the world (Menzies, 1995; Ruggerio & Loftus, 2000).

A Stigmatizing Experience

In many cultures a marriage without children is viewed as, "...a source of evil...an object of humiliation and shame; a stigmatizing experience as devastating emotionally as it is economically" (Daar & Merali, 2001, p. 16). Infertility is a condition of visible and invisible shame where the absence of children makes a statement that often belies this underlying pain. Given that childbirth is a biologically prescribed function, which is well within the identity that women also see for themselves, deviation from the

achievement of motherhood is fraught with personal trauma and the potential for social rejection (Ruggerio & Loftus, 2000).

Some infertility studies seek to understand the long-term psychological impact of being excluded from what is universally viewed as a generational rite of passage (Daniluk, 2001). Others examine the desire for a biological family within a social, cultural, and biological framework, hoping to better understand the wider individual and community meaning attributed to involuntary childlessness (Layne, 1999). Infertility is not therefore the precious domain of the reproductive endocrinologist.

An Existential Crisis

As a calamity of selfhood infertility calls into question the philosophical principles upon which individuals construct their lives (Besley, 2002). A perceived threat to *self* as well as loss of national, local, and group identity prevails upon the individual to find their own way of social and cultural belonging or, as Collins (2003) discusses in his analysis of Fuchs sociological network theory:

The individual self is not the building block of social organization but rather its result... groups...are pockets of repetitively reassembling solidarity...and social movements are groups that expand their solidarity, which eventually either dissolve back into unconnected networks or routinize into organizations (Collins, 2003, p. 72).

In other words, the collective desire to acculturate or move toward group norms results in the individual's establishment of core identity and what is respected by the community therefore becomes essential to the person. Wanting and having a child appears to fit this definition and supports Greil's assertion (1997), "...effort needs to be made to better integrate the empirical study of the experience of infertility with important social policy questions" (Greil, 1997, p. 1679). This study's intervention (*Minding*

Matters) provides a template for participants to understand better the social cultural implications of their experience with infertility (O'Donnell, 2004c).

Critical Points of Change in Treatment Approach

Standardized medical protocol, that included evaluation of the male partner in the initial infertility investigation, became more common place in the 1950s and shifted some of the burden of infertility from women toward a shared load (M. Marsh & Ronner, 1996). Also, during the 1950s significant advancements were made in the use of “human menopausal gonadotrophins” for the induction of ovulation, which led to the use of synthesized medications for stimulating fertility (Lunenfeld, 2004, p. 457).

Medical Advances

Most importantly, standards have been implemented that allow for a more individualized treatment approach and the improved understanding of the role of immunology in both reproduction and the therapeutic response has helped to reduce the incidence of adverse, sometimes life threatening drug reactions (Lunenfeld, 2004). The use of drugs that are increasingly more site specific and administered less frequently help to reduce the psychological stress and distress associated with infertility treatment (Lunenfeld, 2004).

The Shift from Freudian Theory

In the early nineteen fifties the prevailing opinion in the medical and psychological community with regard to unexplained infertility in particular stemmed from an essential commitment to Freudian psychological theory (Herman, 2005). Freud's view of sexuality in terms of essential masculine and feminine traits modified by social

and contextual constraints, presented women in particular with an untenable position: "...femininity (like masculinity) is a certain set of behaviors, that is, a constitutive performance, a contingent aesthetic construction with a long history"(O'Hara, 1999, p. 194). If it is the woman who mothers and she is unable to become a mother then how does she navigate the space between what *is* and an *ideal* (Strauman & Higgins, 1988)?

The Ongoing 'Gray' Zone

By the early seventies researchers had begun to see that the emotional impact of being stuck in this imposed 'maternal no-man's land' was comparable to being psychologically as well as physiologically infertile (Greil, 1997). The next decades reflect a period where the research data focused more on what people suffer emotionally during and after infertility, rather than what they might have contributed psychologically to earn the diagnosis .

The success of in vitro fertilization in nineteen seventy eight heralded the beginning of an era framed by the term 'assisted reproductive technologies', or ART as is it commonly known. Although these technologies have improved options for people struggling with infertility, they also represent a challenge to existing and emerging medical research, igniting both the abortion and stem cell debates. Particularly in light of a recent Harvard study that found almost eighty five percent of embryos transferred in the period between nineteen ninety five and two thousand and one did not result in a live birth (Kovalevsky & Patrizio, 2005). This reality has expanded concern regarding issues of cost effectiveness, informed consent, the right to self determination, and indeed whether or not there is even a right to parent, further demanding integration of the ethical, social, and political implications of infertility treatment (Pfeffer, 1997).

Mind-Body Medicine

Cartesian Dualism and the Mind Body Paradigm

In the mid seventeenth century Rene Descartes' concept of mind-body dualism ignited an intellectual storm that has howled and abated ever since (Serendip, 1994). Descartes' proposal that the world existed as separate physical and mental entities evolved in great part from his desire to explain a condition that was essentially unexplainable (Chesney, Darbes, Hoerster, Taylor, Chambers, & Anderson, 2005). Descartes' theoretical position that the body as matter was distinct from the processes of the mind, and his ultimate inability to reconcile that either might operate as a function of the other, or alternatively interact one upon the other, effectively left the mind-body model in the nebulous state in which it still rests today (van Gelder, 2005).

The Era of Enlightenment

The sixteenth century generated many philosophical challenges both to old ideas and old ideology, some of which were embraced as intellectually astounding while others were branded with the familiar heresy of the times (Statistics, 2002). Cartesian Dualism in some ways was an acceptable answer to the impasse that developed between newly emerging scientific beliefs and the role of God in the work of the universe. By separating substance from spirit it became easier to resolve the issue of faith, which demands a belief in something without proof of its existence (Dreary, 2005).

As twenty-first century science begins to deconstruct the brain, the ongoing philosophical discussion that strains the distinction between brain and mind as well as mind and matter, is making a forced re-entry into the world of psychology and medicine.

The resistance to deviation from the rationalist tradition is, according to Dreary (2005), its own form of dualism that persists in arguing for separation between the body and mind because it cannot unify a system of thought that seems to take action based mostly on assumption (Dreary, 2005). However, most of us take action based, at the very least on educated guesses if not on assumption, for the larger part of our day.

It is, according to Dreary, the ironic social and cultural legacy of what Jeremy Bentham called “fictions” and what Dreary and I have called ‘assumptions,’ that form the intransigent bedrock of mind body duality (Dreary, 2005). Still, in the twenty first century we continue to apply the positivist paradigm, (operationalized over three hundred and fifty years ago), to a system of practice that no longer bears resemblance to the world it was designed to fit while at the same time resorting to the ‘psychogenic argument’ when a better explanation for a somatic complaint is obscured; a sort of academic self deception (Pelletier, 2002).

Closing the Divide

Current theory attempts to negotiate the unresolved dichotomy between body and mind, which in many ways mirrors the historical separation of allopathic and alternative medicine, by finding new ways to explain the function and physiology of the brain (van Gelder, 2005). Anatomy and physiology is the observational tool of contemporary medicine. Now that positive emission tomography (PET) can localize certain types of thoughts to specific areas of the brain, and the effect of meditation on brain waves and

the immune response has moved from the fabulous to the fascinating, mind-body interaction is worthy of a new respect (Davidson, Kabat-Zinn, Schumacher, Rosenkranz, Muller, Santorelli, Urbanowski, Harrington, Bonus, & Sheridan, 2003).

A Working Definition of Mind-Body

This dissertation uses the following mind-body definition for the purposes of the research study, synthesized from multiple sources: the interactive effect between thoughts, feelings, spiritual beliefs and social conditions on the performance of the brain-body interface as it relates to general physical health and overall wellbeing (van Gelder, 2005). “Mind-body interventions employ a variety of techniques designed to facilitate the mind’s capacity to affect bodily function and symptoms (Pelletier, 2002, p. 4).

Mind-Body Medicine and Infertility

As Chapter II will show, mind body medicine’s philosophy is not new to the field of infertility. Although couched in the language of our ancient forefathers and embedded in terms like *hysterical*, *demonic*, *psychogenic*, and *inorganic*, the suggestion that deeply felt beliefs had some influence over the body’s physiology was showing itself in cogent as well as unimpressive ways throughout infertility’s history (van Gelder, 2005).

Personality Characteristics and Infertility

The unabashed refusal to combine the observed with the unobservable in the scientific tradition did not prevent rather creative ways of exploring the ‘psycho-physiologic’ aspects of infertility from developing. The use of projective tools like the Rorschach, Thematic Aperception Test (TAT), sentence completions, Draw a Person (DAP), and Minnesota Multiphasic Personality Inventory (MMPI), were integrated into research design in an effort to demonstrate the psychological disturbance it was predicted

one could expect to find in functionally infertile women (Abarbanel & Bach, 1958). Hypothesizing an intra-psychic cause for infertility, while offering no explanation for its physiological modifier, ensured that the burden of infertility remained in the lap of women.

Questions Regarding the Physiology and Psychology of Stress.

Contemporary researchers have begun to explore the specific relationship between the physiology of reproduction and psychosocial stress as a way to further understand peri-natal morbidity *and* infertility (Csemiczky et al., 2000; Lu & Halfon, 2003). As research that identified the significant stress effects on individuals undergoing treatment reached its saturation, a concomitant shift toward examining effective ways to mitigate the stress developed (Boivin, 2003).

The recognition by sufferers that emotional support was needed through their infertility crisis was not dependent upon a post hoc research analysis. *Resolve*, a national non-profit infertility organization, (established in 1973 by a nurse who had struggled with infertility), offers free support and educational services to men and women in approximately forty-two states (S. Smith, 1999). However, professional translation of the well documented stressors of infertility into an equally well delivered system of effective emotional care was not forthcoming.

Pregnancy as a Measure of Improved Psychosocial Outcome

It was Domar et al (2000), in their pioneering study that looked at pregnancy outcome as a function of psychosocial support, and ignited the current interest in utilizing a mind-body paradigm for infertility (Domar et al., 2000). Increasingly, there is a demand both from clients and clinicians, to provide programs of care that have some foundation

in evidence based practice (Boivin, 2003). The future of infertility research rests in its ability to demonstrate a relationship between the mood and misery of involuntary childlessness and the ‘sturm und drang’ of reproductive physiology.

One of the challenges that remains poorly recognized but essential, is resisting the urge to attach ‘successful intervention’ to pregnancy as an outcome, especially in light of Kovalevsky and Patrizio’s article on embryo wastage which speaks to the significantly high loss of embryos on the road toward the birth of even one baby (Kovalevsky & Patrizio, 2005).

Defining Stress

The term *stress* refers both to a generic medley of psychosocial symptoms and a series of biological reactions that occur in the body as a consequence of real or imagined stressors (Loucks & Redman, 2004). As a psychological definition *stress* and coping have recently been described by Lazarus as “...part of a complex, organized biosocial-psychological entity or whole which psychologists refer to as an *emotion*, such as anger, fear, shame, joy, or love...coping is an integral part of an emotion but not the whole” (Lazarus, 2000, p. 668).

External and Internal Stressors

According to Aneshensel (1992) stress is often considered within a medical framework that separates social stressors from both psychological and physiological stressors (Aneshensel, 1992). This study also considers the social and historical (inclusive of medical) treatment of fertility as one of the significant contributors to an individual’s stress experience and therefore, in agreement with Lazarus’ above statement, has a role in both the psychological and physiological manifestations of such stress. The greater

challenge, to integrate ways of identifying stress and reliably measure perceived levels of coping is, "...one of the most vexing issues of research" (Lazarus, 2000, p. 672).

Resistance to combining the social, psychological, and physiological mediators of stress resembles the ironic double jeopardy of mind-body dualism; how do we determine the influence of one thing upon another from the apriori position that they are unrelated? This study in part poses the question, how do we erect a stable bridge between observation of the body and what the body remembers?

Toward a Cohesive Definition

This dissertation examines the multiple ways stress is defined and researched, as well as the ways in which individuals report that they experience stress as it relates to their infertility. One of the main goals of this dissertation is the transfer of a cluster of ideas into meaningful action; what constitutes in real terms an effective and usable model for intervention?

Stress and Infertility

As previously documented in this dissertation there is an abundance of literature on the stress effects of infertility. Although there is no definitive research that has established a relationship between the type of stress experience that people have during treatment and pregnancy outcome, there is increasing evidence that patients with a prior history of depression have a higher incidence of infertility and lower treatment response rate (Domar, Penzias, Dusek, Magna, Merari, Nielsen, & Paul, 2005).

This research is interested in exploring the physical and physiological manifestations of infertility related stress, (as well as the emotional and psychosocial

symptoms), to further understand its emerging relationship with reproductive health and fertility treatment and aid in the development of a model for effective counseling.

Stress Reduction Programs

Like the term ‘stress,’ stress reduction programs represent an equivocal curriculum. A recent review by Ong outlines some of the reasons for this variability, which is also a reflection of the flexible interpretation of the definition, sources, and manifestations of stress (Ong et al., 2004). For the purpose of this study the six step protocol utilized in Domar’s infertility mind-body program model are incorporated, with considerable adaptation (access to the content of Domar’s syllabus was not available) (Domar et al., 2000).

The literature demands a progressive move toward evidence-based practice in the selection of clinical interventions. Review of the current available research in all six of the *Minding Matters Workshop* content areas is presented in Chapter II and consists of the following components: psychoeducational, cognitive behavioral, (see substitute definitions at the end of this Chapter), relaxation and meditation, yoga, narrative/journaling, inter/intrapersonal and group support.

Designing an Intervention

Theoretical Construct

The *Minding Matters Manual* utilizes at its foundation, Higgins (1987) Self Discrepancy Theory, situated within a feminist constructivist framework. Self Discrepancy Theory is built upon the longstanding sociological principle that people who hold beliefs that are incompatible, either with the way they see themselves or in the way others see them, will experience some form of emotional disturbance (Higgins, 1987).

Kikendal (1994) creatively introduced Higgins' Self Discrepancy Theory to develop a framework for therapeutic practice in the treatment of infertility (Kikendall, 1994). I take a similar theoretical position to further clarify the impact of infertility and expand the possible support approaches for modulating the distress reactions commonly seen in involuntary childlessness (Greil, 1997).

Critical Motherhood

The history of sexuality, marriage, and reproduction demonstrates a singular focus on the diagnosis and treatment of infertility as a woman's problem (Pfeffer, 1993). The placement of women as the central force impeding reproduction influenced the decision to use a liberal feminist constructivist (postmodern) epistemological framework for this study. Feminist theory developed in response to the absence of women's voice in the private and public discourse of what it meant to be something other than a white male (Bohan, 1997).

Feminist and constructivist theories form a critical base from which to examine the tension between gender and sexuality which is in constant flux: influenced by the dynamic conditions inherent to social practice, culture, history, and politics (Goldner, 2003; Schwandt, 2001). The feminist perspective is an important philosophical pressure that demands a struggle for balance between the internal and external forces that influence the experience of any group that is unfairly considered (Ulrich, 2000). The application of quantitative and qualitative methods in this study provokes the Socratic dialectic; exposes empirical contradictions and helps lay a foundation for development of a critical theory that speaks for infertility.

Infertility has long been viewed as a condition of shame; uncomfortably linked to the authenticity of sex and hopelessly dictated by the obligation of gender (Pfeffer, 1993). The social space in which infertility resides is a complicated milieu where the desire to have children is a universally accepted concept if not always compassionately, biologically, or emotionally well understood (Malin, Hemminki, Raikkonen, Sihvo, & Perala, 2001). The purpose of this research was designed to lift the veil of shame and give voice to those who suffer in silence.

Hearing his Voice

A feminist constructivist theoretical framework also supports exploration of the intrapersonal and interpersonal discovery and transformation that occurs as a result of men's experience with infertility (Throsby & Gill, 2004). In addition, it challenges patriarchal hegemony's unstable place in the lives of men who cannot beget children. According to Throsby and Gill (2004), "...both technology and gender are socially constructed," and are subject to the same vagaries of context and circumstance as the traditional patriarchal power structure that has fostered unique and distinctive relationships in the lives of women (Throsby & Gill, 2004, p. 332).

Figuring out where men fit into this paradigm is difficult in part because of what Throsby and Gill (2004) describe as, "...the general paucity of academic work on the meaning of fatherhood for men" (Throsby & Gill, 2004, p. 331). This dissertation also attempts to shed light on men's experience of infertility, both as the diagnosed individual and as a member of an infertile couple.

Workbook/Program Design and Content

The *Minding Matters* workbook was written using available research on the psychosocial effects of infertility, stress theory, relaxation and breath training, mindfulness based meditation, yoga, narrative therapy, cognitive behavioral strategy , group dynamics and learning (Beck & Perkins, 2001; Benson & Proctor, 1984; Folkman & Moskowitz, 2004; Iyengar, 2001; Kirkman & Rosenthal, 1999).

Evaluation in Clinical Practice

Evaluation of the *Minding Matters Program* as effective in achieving the program goal it states is an important aim of this research. Moon (2004) exemplifies this position in the following: “*Impact*, [italics are mine] has come to be a particularly valuable educational term for me because it supplies a word where none previously existed...if a course is short its design needs to be focused. Everything in it needs to work toward the achievement of impact” (Moon, 2004, p. 4).

The foundational principle of this research, as represented in the study title, *Design and Evaluation of a Mind Body Program for Effective Emotional Support*, is the development of a manual for self care that not only meets its own aim as a comprehensive mind body guide, but bridges the span between teaching and learning, mind and body, and quantitative and qualitative research for program participants. Examination of how this might be accomplished is provided in the Literature Review in Chapter II. The research in this dissertation is built upon a two phase study.

Research Background

Phase I Background

Phase I of this research, a pilot study, was designed to explore the pervasively acknowledged somatic and psychological symptom distress, infertility problem perception, and isolation experienced as a result of being childless without consent. The instruments used to collect and detail these findings represent typical self-report questionnaires, internally validated and reportedly reliable indicators of emotional disturbance or suffering (See APPENDICES). A pilot study is not ‘experimental’ and does not inform or examine research hypotheses; it serves to test the feasibility of an idea or intervention (Stewart, 2004).

Specifically, phase I of the research asked: (1) What is the study participants’ perceived level of general distress and specific fertility related distress prior to attending the workshop? (2) What are the most frequently utilized coping strategies? (3) How effective is a one day mind-body awareness program in mitigating those effects? Phase II of the research, intended to build upon the findings in Phase I, asks: How well do participants understand and apply the principles taught in the mind-body workshop to their life and emotional self care after completing the program? What are the benefits and limitations associated with a one day program? How can this format and the manual content be improved upon?

Initial Participant Recruitment and Workshop Implementation

Approval for the use of human subjects in research was sought from the Internal Review Board of Cleveland State University for Phase I of the study and granted January, 2005. Phase II approval was granted in March, 2006. Twenty seven subjects, divided into

two groups, were recruited for an eight hour (one-day) mind-body program that was designed and developed as a tool of self care during infertility treatment. Ten women participated in the first workshop, (n=10) held on Sunday, April 10, 2005 at the Five Seasons Country Club in Westlake, Ohio. Ten couples took part in the second workshop, (n=10) held on Sunday, April 17, 2005 at the Harmony Path School of Massage Therapy in Rocky River, Ohio. (Please see APPENDIX A for a detailed description of the workshop settings). Three women participated in both the women only and couple workshop. (Details on subject demographics are reported in Chapter IV). Participants were self referred during their attendance at a one-day infertility conference (of which this researcher was Chair), held at the Cleveland Clinic Intercontinental Hotel, Saturday, October 30th, 2004.

Survey Instruments and Data Collection

In Phase I evaluation and discovery was determined by participant self report. The Fertility Health History and Questionnaire (FHHQ-APPENDIX B) (O'Donnell, 2005) and The Fertility Problem Inventory (FPI-APPENDIX C) (Newton, Sherrard, & Glavac, 1999) was sent to each participant with a self addressed stamped envelope, and returned prior to each workshop day. On the day of the workshop the 1) Symptom Check List-Revised Ninety (SCLR-90-APPENDIX D) (Derogatis, 1977) 2) Ways of Coping Questionnaire (WCQ-APPENDIX E) (Folkman & Lazarus, 1988) were administered on site *prior* to beginning training and were intended as a baseline measure of generalized distress and coping style.

Data from the FHHQ provided necessary demographic information, and the FPI, a forty six item tool, was used to help identify participants experience with infertility

related stress. The SCL-90-R is a self report tool designed to distinguish psychological symptoms on nine different sub-scales according to their perceived severity. The SCLR-90 was completed a second time an average of 6-8 weeks after the workshop completion to provide a baseline comparison. A complete analysis of these survey instruments is provided in Chapter IV (**METHODS**). A brief review of the descriptive and statistical data obtained from Phase I is discussed in the early part of Chapter V (**RESULTS**) and helped to drive the Phase II, Part 2 research questions.

Objectives of This Study

Research Protocol

Phase II of the study, the subject of this Ph.D. dissertation, consisted of in-depth qualitative interviews with the Phase I participants: seven women, and ten couples. The couples were interviewed together resulting in seventeen total interviews. Participants were asked to discuss their experience in the *Minding Matters* workshop, the collaborative effect of participating in a group, the usefulness of the Manual, and the application of learning to their understanding of stress and emotional difficulty as it relates to their infertility and life in general.

Significance of this Research

While research on the multifarious effects of infertility is abundant, literature that reports on how best to alleviate those effects is sparse. In particular, evidence that supports what Moon (2004) calls “the idea of impact” or substantiation that an intervention works, and can be taught and learned well, is even more difficult to substantiate for individual clinicians (Moon, 2004).

The process of discovery that resulted in the material included in this dissertation in large part developed out of the need, as a mental health practitioner, to have access to a method of structured support for my own clients; a method of support that reflected the latest information on infertility and infertility treatment, and is delivered in a way that both complements and reflects my philosophical principles toward personhood and counseling. This research also explores the infertility experience of men as part of an involuntary childless couple and examines the role of partner support in the development and maintenance of ongoing intimacy despite significant relationship stressors.

Research Questions

Part 1

1. What are the study participants' perceived level of general distress and specific fertility related distress prior to attending the workshop, 6-10 weeks after completion of the workshop and at 12 months post workshop? What coping strategies are most commonly utilized to manage the stress?
2. What impact does a one-day mind body program for individuals and/or couples facing infertility has on their experience of infertility related stress?
3. How well do participants understand and apply the principles taught in the mind-body workshop to their life and their emotional self care after completion of the program?
4. What are the benefits and limitations associated with a one day program? How can this format and the manual content be improved upon?

Part 2

1. How well do quantitative measures of psychological, social and somatic distress reflect participants' qualitative experience and description of their distress?
2. What, if any, impact does labeling or categorizing of past symptom distress (reflective of a medical model), have on participants' perception of their current self?

Study Objectives

Developing an understanding of the deeply personal crisis, as well as a system of emotional support that is both effective and *utilized* by individuals and couples experiencing infertility, is the main objective of this research. Historically, the relationship between stress and infertility has been crafted to suggest that one had a causal effect on the other: that stress and psychological *distress* is a major contributor to childlessness (Rommer & Rommer, 1958). In the past twenty years the scientific community has redefined the nature of the relationship between stress and infertility as both condition dependent and treatment dependent; one does not cause the other, each is influenced by the other however, in exactly what ways is still not clear (Boivin, 2003).

Mind-body research asks, among other things: how does what we think influence what we do? This study works toward achieving a model of care that allows people struggling with infertility to consider and reflect upon this question in their own life, introducing comprehensive self care strategies within a counseling paradigm. A second critical objective therefore is in exploring the ways in which *Minding Matters*, as a teaching tool, can facilitate *and* maintain the participants' self-expressed and self directed desire for change.

Summary

Chapter I reviewed the rationale for developing a mind-body program for providing emotional support for individuals struggling with infertility, which is driven by a professional responsibility to support the use of clinical practice interventions. A history of the diagnosis and treatment of infertility within the positivist tradition is also presented. This Chapter acknowledges the well documented social, cultural, and psychological effects of infertility and respects the ongoing uncertainty regarding the nature of the relationship between stress and reproduction.

CHAPTER II

LITERATURE REVIEW

Making a Case: Mind-Body Counseling for Infertility

Chapter I introduced the main purpose of this research, offered a framework for addressing the questions the study confronts, and confirmed the well documented consensus that infertility is a profound crisis impacting emotional, psychological, physiological, and social factors (A. Abbey, Andrews, & Halman, 1992; Anderson, Sharpe, Rattray, & Irvine, 2003; Benyamini, Gozlan, & Kokia, 2005; Brkovich & Fisher, 1998; Domar, Friedman, & Zuttermeister, 1999a; Domar et al., 2005; T. Y. Lee, Sun, & Chao, 2001; Lukse & Vacc, 1999; M. Marsh & Ronner, 1996; S. Smith, 1999; Wilson & Kopitzke, 2002).

Given these findings, reiteration of the experience of infertility as a stressful or distressing life event is not warranted. The evidence is in: to be childless without consent is to suffer (Kirkman, 2003). How much suffering has been endured by this study participants' infertility experience is explored in Chapter IV. Attention is now paid to research that both challenges and supports the idea of mind influencing the body in relation to infertility, and how best to address these finding through a mind-body counseling relationship.

The first section of Chapter II provides a short chronicle of the medical milestones in infertility followed by an analysis of the relevant psychological literature. The object of this research is to evaluate a method of self-care created through integration of theory and techniques from evidence based psychosomatic psychology and medicine. Given that the predominance of the literature on stress and infertility is quantitative and yet it is the experience of infertility that is qualitatively perceived as distressful, this Chapter aims to provide substantial academic foundation on which to support selection of the mind-body approaches that are recommended. Interviews with the men and women who collaborated in this research aim to bridge the distance between infertility's medical and quantitative legacy, creating rich narratives that help eliminate infertility as a pathological model. Subsequent sections present supportive evidence for the counseling paradigm and intervention protocol utilized in the *Minding Matters Mind Body Program* and is extracted from a variety of disciplines.

Consideration is given to early research that explores the relationship between stress, distress, psychosomatic symptomatology, and coping. Review of the historical medical treatment of infertility as a stigmatizing condition is germane to current views of how the mind might influence the bodies of the involuntary childless and is also an attempt to provide some understanding of the later discussion on the physiology of emotion and thought processes (Benjamin & Ha'Elyon, 2002; Foucault, 1973; Goslinga-Roy, 2000; Penny, 2003; van Gelder, 2005).

Much of the research in the past 50 years concurs that infertility is a crisis that generates problems in the following areas: identity, self-esteem, grief and loss, social relationships, and general psychological, and sometimes physical, functioning (Domar et

al., 2005; Johnson, 1996; Jones, 2001; Kirkman, 2003; Letherby, 1999, 2002). It is suggested that *future* research should address the development of support programs that are effective, and cost efficient, in responding to these well established needs for women *and* men (Boivin, 2003; Greil, 1997; Verhaak *et al.*, 2005a).

Statistics and Definitions

It is estimated that there are 6.1 million women (no comparable statistic is available for men), of childbearing age (15-44) in the United States who experience some compromise to their fertility. Approximately 2.1 million *married* couples are considered to be infertile, which represents 7.1% of the married population, (this reflects prevalence rather than incidence), and is a percentage that has stayed relatively steady over the past fifty years (CDC, 1995). These numbers are the latest available statistics from the 1995 National Survey of Family Growth and are compatible with World Health Organization figures which quotes the prevalence of infertility as 8%-10% world wide (Resources, 1997; Vayena *et al.*, 2001).

Approximately 9.3 million people are reported to have sought some form of fertility treatment in the United States for the period of time that data is available (CDC, 1995). Some of these people will ultimately achieve pregnancy without intervention, do not meet the criteria for an infertility diagnosis, (12 months of unprotected sex), or decide not to pursue treatment and either adopt or remain childless. This means that the number of people who are receiving active treatment is likely much smaller, and the number of people using assisted reproductive technologies (ART), smaller still.

“In 1996 The Center for Disease Control (CDC) began collecting data on the number of assisted reproductive technology procedures (ART), performed in the United

States” (Clay Wright, Schieve, Reynolds, & Jeng, 2002, p. 1). This is considered a voluntary system of reporting (approximately 91% of clinics comply), and has been criticized on that basis by many scientists and clinicians because of what is often referred to colloquially as a case of ‘inflated or cooked statistics’ (Marcus, 2002).

The latest figures, published in June, 2004 document 115,392 ART procedures reported to CDC in 2002 resulting in 45,751 births, (a success rate of 39.6%), and reflects an increase of 11.9% from 1996-2002. (This statistic does not indicate either, number of attempts for each individual/couple trying to conceive, or percentage of clinical pregnancies that resulted in miscarriage). However, compared to a 2001 report from Finland, “...17.4% resulted in a live birth” this percentage is impressive (Gissler & Tiitinen, 2002, p. 942).

Pregnancy outcome is averaged across age ranges and shows a declining live birth rate from a maximum of 45% in women under age 35 to a low of 4% for women age 42 and above (CDC Center for Reproductive Health, 2004). Of significant relevance is the finding that 53% of the infants “...were born in multiple-birth deliveries” (CDC Center for Reproductive Health, 2004, p. 8). “Although ART accounted for 1% of the total births in the United States in 2002, the proportion of triplets or higher multiples attributed to ART were 16% and 44% respectively” (CDC Center for Reproductive Health, 2004, p. 11).

Consider the possibility that people with the most intractable problems, who most likely need to use reproductive technologies, is represented by the Center for Disease Control’s 2.1 million measure of estimated prevalence. Given the actual incidence of treatment success (live birth), in the last year for which figures are available, 45,751, this

number reflects only a 2.3% dent on the overall number of people who are at any one time struggling to conceive.

Traditionally infertility has been thought of as an ‘equal opportunity’ disease. However access to treatment, particularly in countries without a nationalized health service like the United States, tends to mostly reflect a White middle to upper class demographic, hardly reflective of an equal opportunity intervention (Greil, 1997). These facts, along with the ongoing indecision about the future of stem cell research and embryo storage, inflame the already pressured debate over the reproductive technologies (Lauritzen, 2005).

As documented in Chapter I, infertility has multiple causes and can involve either partner, both partners, or be categorized as unexplained. The particular interest in considering a psychogenic origin for couples with *unexplained* infertility developed in part, as a result of the influential impact of Freudian theory on psychotherapy in the early to middle half of the 20th century. In addition, a much larger percentage of individuals remained undiagnosed medically during this time due to inadequate investigative and diagnostic techniques.

According to Wischmann (2003), it was and is erroneous to use the term *psychogenic infertility* to describe individuals for whom we have simply not been able to attribute cause for their fertility difficulties (Wischmann, 2003). “In summary, the literature contains no well-founded indications of any relevant psychological difference between couples with unexplained infertility and organically infertile couples when the studies were conducted systematically and encompassed larger sample sizes” (Wischmann, 2003, p. 486-7).

This research does not attempt to differentiate between individuals who have a ‘definitive diagnosis’ for their infertility or have been told it is ‘unexplained’. It takes the position that being unable to have a child is emotionally, psychologically, and spiritually distressing, regardless of cause. Evidence that clearly describes *and* supports the type of intervention most likely to be effective and utilized is limited. This study’s purpose is to research and review a mind-body model of care as a potential counseling tool.

A Brief History of Infertility

“And this”, said the Director opening the door, “is the Fertilizing Room” (Huxley, 1932, p. 1).

Medicine and Infertility

The power and place of fertility in the human journey has been idolized and misunderstood throughout the world’s history (da Molta & Serafini, 2002; Thompson, 1999). In the earliest period of anatomical discovery, Herophilus of Alexandria, described in some detail the female ovary (Hunter, 2003). Still, accurate understanding of how the ovaries worked and their relationship to menstruation and conception came hundreds of years later in the nineteenth century (M. Marsh & Ronner, 1996). Between 450 BC and the middle 1500’s, it was legend and folklore that dominated what was believed about the creation of life (Thompson, 1999).

Running concurrent to fantastic stories of reproduction was the myth that within the belly of Woman nestled the potential for something to exist that was as destructive as it was life giving (Apfel & Keylor, 2002; Borossa, 2001). According to Lana Thompson, the ‘wandering womb,’ a term framed by the ancient Egyptians, explains the ‘dissatisfied

uterus's departure from the pelvis in the pursuit of satisfaction and contentment implying; wombs that wander belong to the disgruntled and melancholic (Thompson, 1999, p. 21).

Long synonymous with the wandering womb the word 'hysteria,' (derived from the Greek for uterus), became the designated term for many of the mental and emotional disturbances believed to afflict women (Thompson, 1999). Hysteria's legacy endures as one of the earliest manifestations of mind body medicine; soma reflecting spirit, a reification of the feminine (Borossa, 2001). The psychological and moral judgment projected onto the character of women who suffered with uterine problems contributed to how some still view fertility and childbirth today: as the making or demise of the female soul (Christianity Today, 2003).

When de Graaf discovered the ovarian follicle in 1672 he was under the impression that it *was* the human egg rather than what *contained* the human egg (Hunter, 2003). It was much later, (1827), that the follicle was distinguished from the egg and both their purposes identified (Johnston, 1963). Unable to find evidence of male involvement in the growth and development of a child in the uterus, seventeenth century scientists erroneously dismissed the idea that something from the man and woman came together to create a baby (Hunter, 2003). This flawed assumption helped to maintain the predominant attitude that women alone were responsible for the success and failure of human reproduction (M. Marsh & Ronner, 1996).

Although ancient cultures respected the significance of a 'man's seed' it was more as a function of the perceived importance of men in general rather than any biological appreciation for the role of male and female gametes in creating a baby: "...the practice

of medicine for the ancient Greeks was a conglomeration of religion, magic, and superstition...” (Johnston, 1963, p. 263).

With little accurate information about how conception occurred there was only a vague understanding of what contributed to its obstruction and medical interventions were largely unsubstantiated, primitive, frequently surgical, and sometimes even lethal (Brinker, 2005). Vaginal douche, ovariectomy, hysterectomy, and curettage were some of the procedures that became commonplace during the mid to late nineteenth century in the investigation of what was now becoming known as sterility (M. Marsh & Ronner, 1996).

By the late eighteen and early nineteen hundreds there was significant advancement in the study of the brain and endocrine systems, as well as the effect on fertility of diseases like gonorrhea, syphilis, tuberculosis, thyroid dysfunction and diabetes (Lunenfeld, 2004). Research on the female organs of reproduction helped to establish the mechanism by which eggs left the ovaries, traveled down the fallopian tube, and implanted in the wall of the uterus (Hunter, 2003). In nineteen ten researchers discovered that the gonads were controlled from somewhere other than the pelvis, by a tiny gland in the brain known as the pituitary. This period marked the beginning of the aggressive use of hormones in the treatment of reproductive disease (Hunter, 2003).

The underlying premise of many proffered remedies was akin to the old adage, “the hare of the hound,” i.e. whatever is the source of a problem holds the potential for cure within it (Barker, 2002; Lunenfeld, 2004). Once the variable secretions of the ovary were detected it became common place to see them utilized in several methods of infertility treatment (da Molta & Serafini, 2002; Hunter, 2003; M. Marsh & Ronner, 1996).

The role of follicle stimulating hormone, lutenizing hormone, and human chorionic gonadotrophin, and their relationship to the pituitary gland and the hypothalamus, as well as menstruation, ovulation and pregnancy emerged in the early nineteen thirties (Lunenfeld, 2004). This had a significant impact on the potential treatment of endometriosis, unexplained infertility, and disorders of ovulation (Hunter, 2003; Lunenfeld, 2004). However, the diagnosis and treatment of male factor infertility was still not being given its due attention (M. Marsh & Ronner, 1996).

American John Rock (1944) was the first scientist to report the successful fertilization of a human egg outside of the body and by the late sixties and early seventies there were several researchers working to establish a viable pregnancy using a sperm and egg united in vitro (M. Marsh & Ronner, 1996; S. Smith, 1999). Many opinions stood in opposition to this research, in particular the Catholic Church, which feared a slide into, "...dualistic pessimism, one which finds the individual human to have no more than a pragmatic value, to be only a thing whose worth is precisely measured by its fulfillment as a function" (Bertram & Shriver, 1975, p. 3).

It was against the backdrop of such emotionally and ethically charged debate that Louise Brown, the world's first 'test-tube baby' was born in Oldham, England on Tuesday, July 25th, 1978 weighing five pounds twelve ounces (Henig, 2004). "...We have brought hope to thousands of couples and interest to millions of others...these embryonic cells contain mysteries that can and must be solved...we know that our work is opening new horizons in human reproduction..." (Edwards & Steptoe, 1980, p. 186-7). In the words of Louise Brown's mother the world was able to hear vindication of that hope: "Louise is special because she never would have been born the normal way. It was

a miracle that I was chosen to have her...Whatever happens in her life, I'll always believe that Louise was truly meant to be"(L. Brown & Brown, 1979, p. 187-8).

Not only did a child conceived in vitro mean that absent or blocked fallopian tubes could be by-passed, scientists now had a way to observe life beginning which offered the potential to uncover other physiological or genetic obstacles to pregnancy, as well as offer close examination of the sperm's role in fertilization (Edwards & Steptoe, 1980). Louise Brown's birth propelled science and ethics down a steep path. Philosophers, clergy, medical liberals *and* conservatives challenged the inherent paradox that pitted what some perceived as a God given right to reproduce against the ecclesiastical mandate that framed creation as a right only God can give (Jones, 2001).

Mired in the complicated network of beliefs and attitudes was the emotional burden of infertility's perfidious history that held its sufferers morally, socially, and physically accountable for their own sorry struggle (Pfeffer, 1997). Teasing the heartache from the hard facts has been the elusive frontier; what price do we pay spiritually and physiologically for what the body remembers?

The scab was picked off a deep and festering wound exposing the profoundly intimate journey of a couple's quest for conception. "The most private, intense moments between a woman and a man were laid bare, through IVF, for lab assault and analysis. Scientists peered into sex cells, the heart of a species connection to its own future...They became a meddlesome third party in what was, until the advent of their ability to intrude, an eternal and sacrosanct duet" (Henig, 2004, p. 175). Global attention was focused on a tiny little girl whose parents would have otherwise slid into the predictable monotony that accompanies raising small children (Edwards & Steptoe, 1980).

At the beginning of the twenty first century reproductive medicine continues to make advances in fits and starts; periods of slavish inadequacy punctuated by vibrant bursts of profound success (Hunter, 2003; Lunenfeld, 2004). When Aldous Huxley wrote his prescient book 'Brave New World' in nineteen thirty two it was not only about the future ability to conceive a human being in vitro, it was also a comment on a social and cultural fantasy that imagined our destiny as truly within the power of our own hands (Huxley, 1932).

We have expanded the boundary of parenthood beyond the terms biological, foster, or adoptive parent. In vitro fertilization has blurred the notion of family and helps to create babies who have complicated filial arrangements; multiple mothers, invisible fathers, and unrelated siblings (Goslinga- Roy, 2000; O. B. A. van den Akker, 2001b). This too is part of the painful legacy of want and stigma that remains to be fully explained in the negotiation between the fertile and the infertile world as well as between the mind and the body (Ulrich, 2000). The following section reviews the psychosocial history of infertility, (including stress and coping), and the type of mental health support that has traditionally been provided, with discussion of both its effectiveness and utilization.

Psychology, infertility and the mind-body dilemma: The early years.

By nineteen fifty the three decade long influence of Freudian psychoanalytic theory had made its way into many aspects of mainstream medicine, education and sociology (Herman, 2005). Freud's position on attachment, identity, sexual development, and psychic trauma, and his belief in their potential for somatic manifestation, lent itself

well to the problem of infertility; "...the psychoanalysts have discovered some of the hidden psychologic effects of the sexual drives" (Rubenstein, 1951, p. 80).

Rubenstein's (1951) article *An Emotional Factor in Infertility: A Psychosomatic Approach*, offered a distinctly subjective analysis of unexplained infertility. "The psychodynamics of sterility in these 5 patients may be depicted as originating in their feeling of rejection by mother..." (Rubenstein, 1951, p. 85). In employing heuristic as fact Rubenstein is caught in the intrinsic double bind that has its origins within Cartesian Dualism and remains today, the oxymoronic bane of mind body medicine (Dreary, 2005). How does one support the argument that two things remain distinct and also insist that each has a fundamental capability to modify or influence the essential chemical structure of the other?

Rubenstein's work is interesting on a number of levels. First, he makes the assumption that when no organic reason exists in either partner to explain the couple's inability to conceive, that the psychogenic difficulty must therefore reside in the woman "...the female partners of 5 such couples, whose husband had no somatic impairment of their fertility, were chosen for psychosomatic study" (Rubenstein, 1951, p. 82). Given that the premise of this, and other articles of the time, is that emotional conflict and unresolved unconscious anxiety is an impediment to normal reproductive function, is it not possible that either partner could fall victim to such effects (Benedek, 1952; Rubenstein, 1951)? However the precedent to not only pathologize infertility, but to do so within the body of women, had long been set (M. Marsh & Ronner, 1996; Whiteford & Gonzalez, 1995). "...there was one common problem "...all described their mothers

initially as pleasant...yet all desired to be different from their mothers” (Rubenstein, 1951, p. 83). Mothers and non mothers it appears were equally maligned.

A further failure of logic is implicated when Rubenstein offers lack of pregnancy in the woman as *the* somatic condition and confirms the bias now well documented throughout the infertility literature (M. Marsh & Ronner, 1996; Pfeffer, 1993). Rubenstein’s argument in *Stigma Theory* would be comparable to holding African Americans’ responsible for racism because they are Black (Crocker, 1999). In such a climate it might seem impossible to women that they could extricate themselves from their reproductive burden. Despite evidence that has failed to establish such a causal link women are frequently still told to relax and it will happen (Ruggerio & Loftus, 2000).

Marsh and Vollmer (1951) declare that “...frequently sterility is a somatic representation of conflict existing in the unconscious” (E. M. Marsh & Vollmer, 1951, p. 71). Acceptance of such an interpretation today would require a large leap of faith and yet Marsh and Vollmer’s later clarification of this statement: “...In the center of her unconscious anxiety then is the ideal personality that she has learned to feel should be presented to the world, while in the unconscious is her more livable and realistic self that she would like to present...” does not move too far from what Tory Higgins, and others, claim contributes to the experience of emotional distress and discord, (Self Discrepancy Theory is the theoretical foundation upon which the *Minding Matters Program* is built) (E. M. Marsh & Vollmer, 1951, p. 74).

A year after Rubenstein’s study was published Therese Benedek wrote a paper called, *Infertility as a Psychosomatic Defense* which suggested that infertility that had no organic origin, now known as ‘unexplained infertility’, was an attempt, once again by

women, to protect against the real and imagined fears of motherhood and mature sexual identity formation “...to this we add the belief that the same factors which influence the emotional attitude toward sexuality modify, in varying degree, the physiologic processes that are involved in procreation” (Benedek, 1952, p. 528).

Although there was no significant empirical evidence to support this and similar claims, it was evident that the huge gaps in the numerous ways in which fertility could be enhanced, and diminished, fed such accusations (M. Marsh & Ronner, 1996). What was not in any doubt was the immense distress that developed within and between individuals whose attempts at procreation were repeatedly unsuccessful (Ford, Forman, Willson, Char, Mixson, & Scholz, 1953; Rommer & Rommer, 1958).

The challenge to describe a physical problem in the reproductive tract, secondary to psychogenic causes, (the attendant interest still focused entirely on the reproductive tracts of women), resulted in some exceptional investigations. William Bickers conducted an experiment in which he suggested that an involuntary fright/flight reaction in some women stimulated uterine contraction in addition to its well known effects on the cardiovascular and gastro-intestinal system (Bickers, 1956).

Operating under the hypothesis that fear was the affective manifestation of a physiological response Bickers deduced that the uteri of certain women in his ‘functional infertility’ group exhibited, “...persistent dysrhythmic, disorganized contraction patterns” associated with unexpected stress (Bickers, 1956, p. 272). Bickers’s far reaching conclusion was that, “...the clinical opinion long held that the emotions affect uterine physiology and play an important role in infertility has been shown to have valid basis in demonstrable physiologic changes occurring in the human uterus under the impact of

fear, pain, and disappointment” (Bickers, 1956, p. 274). Who might not be similarly afraid under such conditions?

Apparently, unhampered by the positivist dictate that cause and effect is infrequently an empirical given, a strong relationship between self blame and infertility was further established (S. Smith, 1999). Bickers article demonstrated the prevalent belief that psychic resistance to motherhood could be made manifest by the uterus which, through episodic abnormal contractions, attempted to reject or expulse a potential embryo (Bickers, 1956). One of Bickers closing points reveals the persistent blight of post hoc analysis without a comparison group and of research that is based on a pathologic model (Greil, 1997; G. Heiman, 2003). “... now, it must be emphasized that most uteri do not react in such a manner. The slammed door, the hypodermic syringe, the skin pinching induce no alterations in uterine physiology of most patients” (Bickers, 1956, p. 271).

From his small sample (3 cases) Bickers concluded that emotional liability played an important role in inorganic or functional infertility. Exploration of the multiple systemic contributors to the stress, well recognized as part of the infertility journey, was left unattended, as was the possible role of men and the marital relationship, in this tenuous equation (O'Donnell, 2005; Verhaak et al., 2005a; Verhaak, Smeenk, van Minnen, Kremer, & Kraaimaat, 2005b).

Early efforts to define possible interactive effects between the brain, hormones, emotion, and reproduction demonstrate the stagnation that has plagued research on the impact of stress upon fertility, which in part is explained by the inconsistent definitions of stress and stress's effects (Domar et al., 2000; Kemeny, 2003; Loucks & Redman, 2004). Unfortunately we have made little scientific ground since nineteen fifty eight when

Heiman made this observation about pseudocyesis or imaginary pregnancy, "...the psychogenic origin of the pseudocyesis has not been questioned, but the explanation of the mechanism by which psychic factors bring on the symptomatology, has evaded the observers" (M. Heiman, 1959, p. 172).

In Heiman's academic acceptance that physiological change, (specifically in the reproductive and neurosecretory hormones), occurs secondary to psychological distress, he establishes his commitment to a mind-body model once again invoking the unsustainable position of Cartesian Dualism (Dreary, 2005; M. Heiman, 1959). The location of the pituitary gland in the base of the brain, (attached to the distal portion of the hypothalamus), fed researchers suspicion that sensory and emotional neurologic pathways had the capacity to alter hormonal output and therefore by influence, reproductive function (Anonymous, 2005; M. Heiman, 1959). In 1960 Rutherford wrote:

...hypothalamic amenorrhea is now well established in our vocabulary...in which under the emotional stresses of forcible captivity...many women stopped ovulating...protecting the female from violent impregnation...until she is emotionally at peace (Rutherford, Banks, Coburn, Zaffiro, & Williams, 1961, p. 55).

Although the evidence that infertility was emotionally devastating and the negotiation between mood and thought and their physiological effect was under study, without clear answers the responsibility for unexplained infertility remained very much in the hearts and minds of those it wounded (Rutherford *et al.*, 1961).

Running concurrent to the clinician's frustration at being unable to establish accurate causality between hormones and emotions was the paradoxical finding: "...that many patients undergoing these tests express their relief and gratitude for such inquiries by the physician" (Rutherford *et al.*, 1961, p. 5). The subjective experience of being

‘cared about’ had transformative power, capable of producing hope from despair (Blenner, 1992).

Domar and others, in more recent research, demonstrated that physician attentiveness, patient attitude and spiritual well being are significant modulators of perceived and measured levels of stress both during and beyond infertility treatment (Domar et al., 2005; Verhaak et al., 2005a; Verhaak et al., 2005b). Traditionally such attentiveness has been thought of as ‘bedside manner’ and a current day measure of what Epstein describes as *mindfulness based practice*; the act of bringing reflection, compassion and engagement to the provision of care (Epstein, 2003). Many contemporary researchers studying cancer, cardiovascular, and immune disease have demonstrated the benefits of kindness, faith and emotional support on illness and recovery (Benson & Stuart, 1992; Nakao *et al.*, 2001b). Adler (2002) in an article discussing the sociophysiology of caring makes this observation based on his review of research that examines the healing potential of the doctor patient relationship: “...selected physiologic indicators of autonomic activity – heart rate...skin temperature, and muscle tension, varied together between patient and psychotherapist...they called this similarity of patterning a ‘physiological identification’...” (Adler, 2002, p. 884).

It is evident from earlier work such as Rutherford’s, as well as current studies, that people seeking infertility treatment place great emphasis on the their perception of ‘being attended to’(Penzias, 2004). As a result individuals seem to ‘feel’ and ‘do’ better emotionally, regardless of treatment outcome (Greil, 1997; Rutherford et al., 1961; Smeenk, Verhaak, Stolwijk, Kremer, & Braat, 2004; Verhaak et al., 2005a).

The attribution of psychopathology to individuals who were unable to conceive as noted, was specifically directed to women (and more rarely couples), in whom a cause for their infertility was not apparent (Eisner, 1956; E. M. Marsh & Vollmer, 1951). It seemed easier for clinicians to understand that people who had a definitive reason for being unable to have a child, although saddened by their reality, would be far less likely to harbor any underlying mental health disease (Rommer & Rommer, 1958).

By the late 1950's and early 1960's researchers had begun to conduct comparison studies on fertile and infertile women to see whether "...certain psychological factors play a central role in primary infertility" (Eisner, 1956; Seward, Wagner, Heinrich, Bloch, & Myerhoff, 1965, p. 535). Although the purpose of the sperm in conception was now acknowledged, medicine remained influenced by the psychodynamic tradition and men were still being studied vicariously through the transference effect of their wife's emotional distress and resulting dependency (Seward et al., 1965).

Efforts to demonstrate elevated levels of psychopathology was ongoing, and although interest in explaining infertility using a psychogenic paradigm waned somewhat given the general lack of understanding between the mind and body, as well as the mind and the brain, unsubstantiated theories persisted. Anecdotal evidence expounding the notion that previously infertile couples had higher rates of conception after adoption despite evidence to the contrary, fed the belief that all a woman had to do was 'relax' and she would simply get pregnant (Aronson & Glienke, 1963; Tyler, Bonapart, & Grant, 1960).

Attempts to link the limbic system and the hypothalamus to thought and emotion were attractive because of the close association this area of the brain had with the

pituitary, which it was now known had significant control over reproductive function (Lunenfeld, 2004). Seward et al (1965) made an effort to demonstrate this effect by utilizing subjective psychometric tests to support their hypothesis that elevations in psychological distress would manifest physically in the form of menstrual dysfunction (Seward et al., 1965). No such evidence, at that time, was found. Studies have persistently been plagued by what Greil describes an “either/or approach” rather than a collaborative design, in their attempt to demonstrate this univariate relationship of cause and effect (Greil, 1997).

Power, personality, and profiles in early mind-body treatment.

By the 1970’s researchers began to pay more attention to the idea that infertility was a couple issue although the prevalence, at least in medical journals, to use a disease model to identify and describe the personality traits of people struggling to conceive, endured (Mai, Munday, & Rump, 1972; Platt, Fischer, & Silver, 1973). Of particular interest to this thesis, (which uses Higgins Self Discrepancy Theory as a tool for clients to identify their variable sources of stress), is the use by Platt (1973) of internal/external locus of control and self-concept theories to explain the identity characteristics and experiences of *couples* who are unable to have a biological child (Platt et al., 1973). According to Platt’s findings, the previously established bias that women particularly, demonstrated higher rates of neuroticism, as well as the reality that couples perceived the most intimate aspect of their lives as not within their power, were confirmed (Platt et al., 1973). However, the single most unanswered question remained the same: “...infertile individuals differ from fertile ones... but what is the basis for the difference?” (Platt et al., 1973, p. 973).

It is this commitment to establishing mental and emotional dysfunction as the cause of some types of infertility that possibly gets in the way of people either seeking or accepting help during its crisis (Boivin, 1997). Once labeled 'infertile' being further labeled as depressed, histrionic, frigid, or unavailable adds to the culture of self blame that has followed infertility's history (Pfeffer, 1993). The documented prevalence of anxiety is as likely to be treatment dependent as it is condition dependent as well as a possible result of attempts to adjust to the ongoing 'non-pregnant' position (Salvatore, Gariboldi, Offidani, Coppola, Amore, & Maggini, 2001).

By 1983 the thrust of the research in psychological literature came from a desire to explain *how* and *what* was happening emotionally (descriptive), as a result of infertility rather than specifically *why* it was happening (diagnostic/epistemological). It was clear that being excluded from the 'fertile world' had significant consequence (Baluch, Nasser, & Aghsa, 1998; Benyamini et al., 2005; Cook, 1987; Daar & Merali, 2001; Dyer, Abrahams, Hoffman, & van der Spuy, 2002; Gannon, Glover, & Abel, 2004; Hirsch & Hirsch, 1995; Miall, 1994; Mindes, Ingram, Kliwer, & James, 2003; Sanders & Bruce, 1997). Still, recognition of the broad based impact that infertility had on individuals and couples did not necessarily translate into the provision of effective care, although clinicians were searching (Mindes et al., 2003).

In 1983 O'Moore et al hypothesized that the elevated prolactin levels detected in some women who attended their fertility center in Dublin, Ireland "...might be an indicant form of psychogenic infertility...It is known that prolactin may be 'stress related'" (O'Moore, O'Moore, Harrison, Murphy, & Carruthers, 1983, p. 145). Their study used a sample of 13 couples (N=13) who had been trying to conceive for longer

than 2 years and included identical examination of both *men and women*. Psychological and personality inventories (self-report), urinary analysis of free cortisol and plasma prolactin levels in the blood were measured prior to commencement of an 8 week workshop in autogenic training (AT), and were compared to controls (N=10). Of significance is the authors' decision to evaluate physiological parameters with psychometric measures and to apply an intervention between pre and post testing i.e. autogenic training. "Autogenic training consists of simple mental exercises designed to diminish the response to 'stress' and enhance the relaxation response" (O'Moore et al., 1983, p. 146).

The study results demonstrated mixed findings in that infertile women had higher degrees of anxiety and guilt when compared to controls but that infertile males showed a relationship in the opposite direction: decreased tension and frustration. The authors attribute this to a possible 'fake good' scenario, not unusual in psychological vulnerability research on men (Jordan & Revenson, 1999). However, it could also reflect the limited language that men have to describe feelings of sadness, fear, loss, or grief (O'Donnell, 2005).

Although O'Moore et al demonstrated a reduction in perceived stress and measured urinary cortisol and plasma prolactin post AT treatment, this evidence does not help them in determining whether 'stress' is causing the infertility or the infertility is generating the stress. Subsequent researchers continue to emphasize the ongoing instability of this dynamic (Bolle, Evandri, & Saso, 2002; Demyttenaere, Nijs, Evers-Kiebooms, & Koninckx, 1994; Harlow, Fahy, Talbot, Wardle, & Hull, 1996; Schenker, Meirow, & Schenker, 1992; Wischmann, 2003).

It is clearly tempting to define ‘success’ with respect to any intervention in terms of an expected outcome. For the most part, the literature identifies pregnancy as the most desired dependent variable in studies of infertility, which for O’Moore translated into a success rate of 7.69%, and might well be why his investigation did not, at the time, inspire any similar studies (Edelmann & Connolly, 1986; O’Moore et al., 1983). This is also largely why Domar’s work has received considerable attention because of her finding that people who participate in group psychological interventions achieve “...significantly increased viable pregnancy rates...” (54% compared to 20%) (Domar et al., 2000, p. 809).

Edelmann and Connolly’s (1986) meta-analysis of the literature prior to 1986 continued to expose the tenuous relationship between thought and physiology (Edelmann & Connolly, 1986; O’Moore et al., 1983). After most researchers began to abandon the psychoanalytic approach that had dominated discussion around infertility, focus turned toward examining differences on personality characteristics between individuals with organic versus an inorganic diagnosis. Edelmann et al.’s review concludes once again with “uncertainty” regarding the direction of mind on body and body on mind. They recommended a move away from anecdotal claims like: adoption as stress relief improves conception rates, that despair causes sterility, or that infertility in poor marriages is protective, stating instead that: “How therapeutic effectiveness can best be evaluated is a further matter in need of careful attention” (Edelmann & Connolly, 1986; O’Moore et al., 1983, p. 218). The tide was turning.

Stress, emotions, and infertility: A complicated relationship.

Demyttenaere et al (1992) reported their findings from a study that looked at levels of anxiety, depression and coping style, as well as reproductive hormone levels (luteinizing hormone, cortisol, prolactin, and follicle stimulating hormone), in women attending a Belgian IVF clinic (N=40). They concluded that women who had elevated “anticipatory state anxiety and high anticipatory cortisol” levels achieved pregnancy at a lower rate than women who were less anxious.

In addition to the documented changes in stress hormones the rate of rise of reproductive hormones stimulated as part of the treatment cycle itself was also predictive of pregnancy success (Demyttenaere et al., 1994). In this study’s subjects, increased levels of the stress hormone cortisol were negatively correlated with estrogen rise. This is significant evidence of a possible ‘psychoneuroendocrine pathway,’ thought influencing mood, influencing body, and was the impetus for some of the research that has followed (Csemiczky et al., 2000; Facchinetti, Matteo, Artini, Volpe, & Genazzani, 1997; Facchinetti, Tarabusi, & Volpe, 2004). Given the known association between both mood and menstruation and mood and pregnancy, and the increasing use of anti-depressants to treat cycle related disorders, is it not possible that these relationships are bi-directional (Di Ronchi, Ujkaj, Boaron, Muro, Pisella, & Quartesan, 2005; Loucks & Redman, 2004)?

In an article written in 1993 Wasser et al proposed the Reproductive Filtering Model (RFM) in support of a stress relationship, (psychosocial and physiological), that is causal for infertility (Wasser, Sewall, & Soules, 1993). Long used as a measure of stress and reproductive patterns in other mammalian species, Wasser et al (1993) suggest that the RFM:

...has naturally selected for physiological mechanisms that terminate reproductive attempts when the likelihood of producing viable offspring is relatively low” and supports “...the likely effectiveness of acute and/or long-term environmental therapy (e.g. diet, stress reduction, or psychosocial therapies) as treatment for some forms of reproductive failure (Wasser et al., 1993, p. 685).

Although Wasser’s speculation that what occurs in other mammals is also likely to occur in humans has merit, evidence that would fully support his extrapolated hypothesis was not forthcoming (Wilson & Kopitzke, 2002). Like many previous studies Wasser’s suffered from a lack of randomization, use of self-report measures that were subject to the vagaries of temporal and mood effects upon completion, and too few controls (N=6) (Wasser et al., 1993; Wilson & Kopitzke, 2002). However, his conclusion that “...psychosocial distress contributes significantly to the etiology of some forms of infertility” was further confirmed as observation, and deserving of ongoing review (Wasser, 1999; Wasser et al., 1993, p. 688).

Facchinetti et al (1997) implemented a controlled prospective study of 49 women preparing to undergo active infertility treatment in an Italian clinic. Independent variables were a cognitive stressor (the Stroop Color Test), and baseline and post stress induction measures of heart rate and blood pressure. Pregnancy was considered to be the desired outcome and a determinant of the reflected level of stress obtained at the study’s intervention stage. Faccinetti et al (1997) concluded that women who achieved pregnancy not only demonstrated a lower stress response rate but were also less likely to work outside the home, and *hypothesized* that the elevated cortisol levels (associated with stress), might interfere with an embryo’s implantation (Facchinetti et al., 2004).

It is critical once again to assert, that regardless of these findings attributing a cause and effect dynamic between stress and infertility is not academically or

scientifically sound (Lindheim & Sauer, 1997). In light of the historical precedence for self-blame and significant anguish of infertility that is clearly documented in the literature, examination of the multiple sources of stress, as well as the development of life skills to mitigate it, remains the recommended therapeutic approach (Domar et al., 2000; Facchinetti et al., 1997; Verhaak et al., 2005a; Verhaak et al., 2005b)

Brkovich and Fisher (1998) published *Psychological Distress and Infertility: Forty years of research* (Brkovich & Fisher, 1998). Several of the articles previously included in this study's literature review were examined (including Facchinetti et al.'s original 1997 investigation), and although no new evidence is revealed, the authors also make reference to the relationship between endocrine function, the limbic system, and the hypothalamic pituitary adrenal axis (Brkovich & Fisher, 1998). In the past decade research conducted in other disciplines has demonstrated increasing evidence for the association between depression, negative thought processes, cortisol levels, and immune system function, all of which have been implicated in infertility (Davidson et al., 2003; Domar et al., 1999a; Nakao et al., 2001b; Twardowska & Rybakowski, 1996; Wilson & Kopitzke, 2002). Utilization of some of the prescribed interventions for these 'other' conditions is discussed later in this literature review.

A Boom in Research and a Different Direction: A Big Picture

According to Greil, between 1986 and 1996: "At least 94 quantitative articles and 26 qualitative articles" on the "...social and emotional aspects of infertility" were published (Greil, 1997, p. 1679). It is likely that this increase paralleled expansion in the new reproduction technologies (NRT), as there were now many more cases of infertility that could be treated using in vitro fertilization, which by-passed blocked fallopian tubes

and circumvented low sperm counts using assisted fertilization techniques (M. Marsh & Ronner, 1996).

Greil's meta-analysis divided studies between two general areas: *psychogenic infertility* and *psychological consequences* of infertility. It also examined research methodology and study design placing specific emphasis on gender differences in the research findings (Greil, 1997). Many of the early articles in Greil's analysis proposing a theory of psychogenic infertility have been reviewed earlier in this Chapter.

Greil paid attention to studies that attempted to differentiate between fertile and infertile individuals based on personality measures (Greil, 1997). Given the challenge to separate distress as a cause of infertility from it likely being a consequence of infertility, and the finding that individuals with an identified reason for their inability to conceive still suffer such distress, continuing to focus on this area of research does not appear to be the answer. Greil (1997) recommends:

Instead of viewing the infertility experience as a *socially constructed life crisis*, the psychological distress literature transforms it into an *individual trait*, present in some individuals to a greater extent than others. Until research is guided by a more holistic and sophisticated theoretical framework, the result of efforts in this field will be disappointing (Greil, 1997, p. 1700).

As research is performed almost exclusively on 'clinic-based' samples' with no 'normative' comparison data, a *belief* that women are somehow responsible for their own infertility is not scientifically consistent with a quantitative research paradigm (Dreary, 2005). Just as there is no way to determine how many women become pregnant in the general population despite what could be a *clinically elevated follicle stimulating hormone level (FSH)*, it is not possible to determine birth rates among fertile men and women with undiagnosed anxiety or depression. Certainly we know that many people

under stress get pregnant and have children whether they want them or not, what makes the infertile population different (Greil, 1997)?

One recent attempt to challenge this dilemma was conducted by Berkowitz King (2003), who analyzed “fecundity status and anxiety from a 1995 sample of almost 11,000” women of childbearing age (15-44) (King, 2003, p. 739). Using a cross sectional measure from the National Survey of Family Growth this study includes racial and minority samples not usually represented in the infertility literature. King posed questions that met the criteria for a diagnosis of generalized anxiety disorder (GAD), if answered by respondents affirmatively. Subject pool was differentiated based on their fertility status: sterile, sub-fecund, and presumed or known fecund, as well as their desire for children, and miscarriage history.

King’s article suggests that women who had difficulty both conceiving and carrying a child to term, regardless of whether they sought infertility treatment, displayed elevated scores on measures of GAD. Current research shows a stronger association between depressive symptoms and infertility, rather than anxiety, in women who actively receive treatment (Domar et al., 1999a; Domar et al., 2005). However, this study is significant in that it revealed that women who have fertility difficulty but had no desire for a child also had higher anxiety distress than women who were fecund (King, 2003).

It is possible that this finding speaks to the stigma associated with childlessness in general and involuntary childlessness specifically (O. van den Akker, 2001a). “Infertility, unlike diabetes or rheumatoid arthritis, which has codified signs and symptoms, is defined by what it is not; it is not rich, fruitful, abundant or kind. Infertility is banishment and separation; a discounting that renders its sufferers unseen” (O'Donnell, 2004a, p. 6).

Acknowledging the Need for Psychological Support

Eugster and Vingerhoets (1999) examined the psychological literature pertaining to infertility and in vitro fertilization (IVF) only, with a view to determining the psychological *needs* of individuals during infertility treatment and after birth, as parents (Eugster & Vingerhoets, 1999). Their analysis of the data showed that people who present for infertility treatment are as stable psychologically, in terms of entrenched aspects of personality and physical well being, as the general population (Eugster & Vingerhoets, 1999). Although “ineffective coping strategies” likely contribute to the added problem of treatment related stress and the increased likelihood when pregnancy is achieved that people will suffer from anxiety during pregnancy and/or experience post partum depression. These authors also indicate that “...support has been found suggesting that stress reduction through relaxation training or behavioral treatment improves conception rates” (Eugster & Vingerhoets, 1999, p. 575).

Australian researchers have recently published similar data; women who become parents through IVF experience mood disorders at a rate almost 4 times higher than those who conceive without intervention (Fisher, Hammarberg, & Baker, 2005). It is Fisher et al’s belief that that previous infertility treatment as well as the risk of multiples and fear of miscarriage, contribute to this finding, it is also possible that such mood effects and their corresponding physiologic sequelae, had a role to play in the initial difficulty conceiving (Fisher et al., 2005). It appears this research is once again coming full circle.

The literature continues to be equivocal. Are individuals who are better adjusted emotionally more likely to seek out medical treatment or have an increased desire to implement effective coping strategies (Edelmann, Connolly, & Bartlett, 1994)? Does the

stigma of infertility send some people into hiding and drive up their sense of isolation and stress (Bergart, 2003)? Do people who are more vulnerable to stress have greater difficulty conceiving in the first place (Fassino, Garzaro, Peris, Amianto, Piero, & Daga, 2002a)?

Perhaps most importantly Eugster & Vingerhoets looked at articles that evaluate the impact of *treatment* stress and the elevation in depressive or anxiety symptoms that are known to occur between embryo transfer and presentation for the pregnancy test; euphemistically known as the two week wait (Eugster & Vingerhoets, 1999). The authors specifically point out the finding that couples experience of being unsupported is at its highest during the time period that they have no contact with the clinic providing treatment (Eugster & Vingerhoets, 1999). Being left alone to cope has been described by many infertility sufferers as contributing to their terrible sense of abandonment (Schmidt, Holstein, Boivin, Sangren, Tjornhoj-Thomsen, Blaabjerg, Hald, Andersen, & Rasmussen, 2003).

This addresses what Domar advocates for in a mind-body model of care; a self-directed method of coping that is internally recognized, personally driven, and group shared (Domar, 2002). Individuals and couples need help in identifying the ways in which they typically experience stress as well as developing effective methods to 'live' while they are *in* that stress and beyond (O'Donnell, 2004b). When Domar's pioneer article: *Impact of Group Psychological Interventions on Pregnancy Rates in Infertile Women*, was published in 2000, correlating attempts to decrease stress during infertility treatment with improved pregnancy outcome, the move toward a more integrated system of care had already begun (Domar et al., 2000). This move was driven in part by the

frustratingly stable levels of pregnancy success with ART, and infertile individuals and couples search for complementary and alternative methods of care (Coulson & Jenkins, 2005).

The finding that both men and women experience anxiety during IVF treatment although women at a higher intensity and rate, has been supported by several authors (A. Abbey, Andrews, & Halman, 1991; Boivin & Schmidt, 2005; Jordan & Revenson, 1999; T. Y. Lee, Sun, Chao, & Chen, 2000; Nakao, Fricchione, Zuttermeister, Myers, Barsky, & Benson, 2001a). The lack of literature examining the experience of men who suffer infertility is in part due to the historical emphasis placed on women and also, according to Throsby and Gill, reflects "...the general paucity of academic work on the meaning of fatherhood for men" (Throsby & Gill, 2004, p. 331).

A few qualitative studies in the past 5-10 years have specifically examined how men negotiate their infertility crisis (Inhorn, 2002, 2003; Menzies, 1995; O'Donnell, 2005; Throsby & Gill, 2004; Webb & Daniluk, 1999). O'Donnell (2005) noted in her unpublished research, *Hearing His Voice: Men's Experience with Infertility*, that: "...the personal tragedy of infertility, and its potential as a deeply transformative life experience is not determined by gender but rather by the human condition" (O'Donnell, 2005, p. 55).

The men in this study described feelings of loss, abandonment, failed gender expectations, isolation, powerlessness, and an inability to ask for the support that they needed (O'Donnell, 2005). In the words of one participant: "...I know that there's some issues here that we need to deal with and that *I* don't know how to deal with" (O'Donnell, 2005, p. 27). Perhaps this is confirmation of Boivin and Greil's position that although

psychological interventions are needed that the ones presented are possibly of the wrong type (Boivin *et al.*, 1999; Greil, 1997).

Judith Daniluk looked at the long-term emotional impact to couples of an infertility diagnosis and their transition to biological childlessness (Daniluk, 2001). Daniluk's longitudinal exploration of the lives of 37 couples over 3 years supports O'Donnell's finding (2005) that the process of being involved in the study, and being asked to share their intimate story was perceived by participants as therapeutic (Daniluk, 2001; O'Donnell, 2005). The act of sharing, listening, and bearing witness is itself healing, "...healing happens when we tell a story that allows us to make sense of our situation" (Harrington, 1997, p. 10). Perhaps this is what happens when individuals are supported through their infertility experience in ways that respect the social, cultural, physical, and emotional impact it has upon their lives.

Currently there is a call for researchers to view couples who experience infertility as a single relationship unit, as well as unique individuals, (regardless of gender). This will aid in the discovery of more effective ways to provide emotional and psychological support (Boivin & Schmidt, 2005; Verhaak *et al.*, 2005a; Wilson & Kopitzke, 2002). A paper published in April 2006 reviewed helpseeking behaviors in a randomly selected group of women (culled from a larger study by some of the same authors $n=196$ and who met the medical definition of infertility), in an attempt to better understand how problem perception influences the ways in which individuals seek out professional care and support (White, McQuillan, Greil, & Johnson, 2006). A variety of theoretical models have developed which attempt to breakdown the components that contribute to increased helpseeking behavior, these components include factors such as education, finances,

culture, health related attitudes, and locus of control. About 78 (40%) of the 196 women who indicated they had experienced infertility in this study reported that they had sought medical treatment. The authors hypothesized that the apparent lack of helpseeking behavior is in part due to the way in which infertility is defined and that some individuals identified as infertile simply see themselves as without a child rather than actively attempting to conceive without success. Only about 30-35% of the 196 women who met the medical definition of infertility actually perceived of themselves as infertile. This article's interpretation expands the role of problem perception to include internal factors, relationship issues, (are partners on the same page), resources at the time of problem identification, i.e. is there enough money to access care; is the timing right (White et al., 2006)? The study also identified a negative relationship between participants' overall health and their reduced perception that fertility was a problem, in other words good general health decreased the likelihood that individuals viewed a lack of pregnancy as medically significant. White et al make the point that this is a significant finding "...because it is precisely this group who is most likely to benefit from treatment" (White et al., 2006, p.1040). Precisely what this treatment needs to be remains elusive.

Bridging the Gaps

By 2000, when Domar et al published their research finding on the increased pregnancy rates in women who were attending a mind-body program for infertility, the Cartesian tension between medicine and psychology had begun to wane (Domar et al., 2000). This has been in large part due to people like Deepak Chopra, Bernie Siegel, and specifically, Herbert Benson whose work in the area of heart disease, stress, and mind-body medicine produced evidence for what is known as the relaxation response (Benson

& Klipper, 1975). Within the context of placebo and the placebo effect, mind influencing body had mostly been denigrated by Western Medicine, despite the well accepted belief that "...the physician himself is the most powerful placebo of all" (Whorton, 2002, p. 20).

Evidence of the adaptation response (the body's reaction under stress), was first described by Hans De Solye in the first half of the 20th century (De Kloet, 2003). Since then, the pressure for traditional medicine to open its own body and mind to consideration of alternative and integrated forms of care has slowly but consistently been on the rise (Fugh-Berman & Kronenberg, 2003; Jacobs, 2001; Whorton, 2002). According to Harrington "...we should explore all physiological and biochemical pathways by which the brain "talks to" the body, to see which would best explain the specific end-organ changes that appear to be attributable to placebo responses" (Harrington, 1997, p. 12).

Coulson (2005), reports that upward of 40% of women attending private infertility clinics in England are using some form of complementary or alternative medicine (CAM). These interventions include: relaxation, autogenic training, meditation, acupuncture, reflexology, massage, aroma therapy, yoga, homeopathy, hypnosis, nutrition, guided imagery, creative visualization, and meditation (Coulson & Jenkins, 2004, 2005).

A recent study in the United States explored, not only the use of complementary and alternative methods of treatment, but also looked at the influence of personality, coping style, and social support on people's decision to use them (Honda & Jacobson, 2005). The authors determine: "Understanding the relationships between psychological

factors and CAM use may help researchers and health care providers address patients needs more effectively” (Honda & Jacobson, 2005, p. 46). Although counseling and counseling psychology is not considered an ‘alternative’ technique, a mind-body paradigm that attempts to address somatic and psychological/emotional complaints, incorporates several of the above methods (Nakao et al., 2001b; Ong *et al.*, 2004).

An Accepted and Acceptable Method

Domar’s 2000 study on the effectiveness of group psychological interventions followed a mind-body paradigm and is considered to have broken new ground in the area of psychological support, most significantly because of the boasted success rates that this program delivers (Boivin, 2003; Domar et al., 2000; Domar, Seibel, & Benson, 1990). There are some methodological flaws to the study that seem to come with the territory in infertility research, in particular the high rate of participant attrition: 38 of the control group, 17 from the support group, (considered one type of intervention), and 9 from the cognitive behavioral group, the primary intervention, dropped out (final N = control 25, support = 47 and cognitive behavioral = 48) (Domar et al., 2000). Loss of study participants in control groups is due to the lack of desire by individuals striving to achieve pregnancy to *not* be involved in a strategy that could potentially improve those chances (Boivin, 2003).

Domar et al (1992), and others, documented in previous research that women presenting for infertility treatment who had an increased level of depressive symptoms did not achieve pregnancy at the same rate as their non-depressed counterparts (Domar, Zuttermeister, Seibel, & Benson, 1992b; Lapane, Zierler, Lasater, Stein, Barbour, & Hume, 1995). The use of group based psychological interventions was the first study of

its kind, to show that treating pre-existing depressive symptoms, and/or mitigating the emotional effect of treatment stress, impacted perceived level of coping as well as pregnancy outcome (Domar et al., 2000)

In 2004 Faccinetti et al conducted a follow-up to their 1997 research into stress as a mediator of IVF success. Their latest work looked at the impact of cognitive behavioral (CBT) group intervention and the development of coping skills on women who demonstrated cardiovascular and neuroendocrine vulnerability to an external stressor (Facchinetti et al., 2004). Women (N=45) who were *awaiting* IVF treatment were selected to participate in a 12 session program of CBT whose goals included: greater awareness and articulation of the treatment process, understanding of the emotional ‘roller coaster’ effect familiar to ART, and the influence of these dynamics on the couple relationship (Facchinetti et al., 2004).

The decision to conduct this research at least 12 – 18 months prior to treatment commencing was an attempt to control for effects of treatment strain: “...stress susceptibility has, therefore, to be attributed to their genuine coping ability” (Facchinetti et al., 2004, p. 171). Although evidence of a relationship between perceived stress, cortisol, and certain cardiac measures: blood pressure, heart rate, and respiratory rate, (BP, HR, RR) was demonstrated, the exact mechanism by which *mind influenced body influenced mind* remains inconclusive from the psychosomatic perspective. Nevertheless, Fachchinetti et al re affirm that “... the total experience of infertility is affecting stress response parameters at endocrine and cardiovascular levels (Wilson & Kopitzke, 2002, p. 196).

Authors continue to research the effect of stress on menstruation and reproduction specifically, and health in general, with particular focus placed on activation of the hypothalamic adrenal axis (HPA), the area of the brain responsible for managing the body's response to internal and external stressors (De Kloet, 2003; Loucks & Redman, 2004). Given the lag in knowledge between how the body works and the way the mind is capable of modulating its effect, the current push in infertility is toward the development of comprehensive support programs that are demonstrated to be effective. A brief review of the most recent interventions follows.

Psychosocial Interventions

Given the historical bias toward treating infertility as a women's issue early efforts to provide some foundation for either a 'couple' or 'group' approach toward the provision of psychotherapeutic support were at best contradictory (Abarbanel & Bach, 1958). In advocating that "the physician must evaluate two human beings, a man and his wife" Abarbanel and Bach (1958) present an optimistically enlightened view of the treatment of infertility as a conjoined mission (Abarbanel & Bach, 1958, p. 152). However, review of their study's participants reveals that *women only* were expected to participate in group meetings with the express task of "maintaining and sustaining the male ego" (Abarbanel & Bach, 1958, p. 156).

...it must be strongly emphasized that the wife must *never* tell her husband that the doctor wants them to have intercourse the night before. Rather, she should seduce him in whatever manner she has found to be most reliable in this respect. Her husband must never feel that she is having intercourse with him only because the doctor suggested it or only because she wants to get pregnant...command performances are never conducive a happy marriage, much less to a buoyant male ego (Abarbanel & Bach, 1958, p. 156).

With a psychodynamic approach principally in use in 1958 in both evaluation and treatment of the psychosocial effects of infertility, it was expected that part of a wife's role was the reduction of symptom distress in her husband. This was seen as a way to educate women as to the ego frailties of men as well as provide them with a group forum on which to project their own sexual hostilities and frustration; establishing a protection from isolation, ignorance, and further deterioration in their marital relationship (Abarbanel & Bach, 1958). The author's observed that group discussion enhanced problem solving and made the rather expansive claim that the non-present husband "became more actively interested as a result of his active participation in the problems raised by the group" (Abarbanel & Bach, 1958, p. 159).

By the 1980's the shift away from focusing on psychogenic causes for infertility was well established (Edelmann & Connolly, 1986). The parallel reduction in treatment that used a psychodynamic approach influenced the changing nature of the academic debate around infertility and its effects. Criticism of the limited medical view of involuntary childlessness and its impact on identity development, social and cultural isolation, as well as the relationship between treatment and stress effects were starting to be more closely reviewed (Matthews & Matthews, 1986). An appreciation for infertility and its multiple biopsychosocial consequences began to shape the overwhelming volume of material that was being written about infertility as a universal and profound life crisis (Cook, 1987; Gerrity, 2001).

Counseling Women

This literature review looked at approximately eleven articles that addressed how best to *meet* the specific emotional needs of women experiencing infertility and found

that the themes already discussed were consistently presented as reasons for advocating individual counseling. Those themes included: limited social support, anxiety, depression, reduction in self esteem, denial, anger, isolation, grief, a discrepant view of self, inadequate coping skills, relational conflict and alienation, stigma, powerlessness, and decreased sexual desire (Fouad & Fahje, 1989; Gibson & Myers, 2000, 2002; Gonzalez, 2000; Hart, 2002; Kikendall, 1994; S. H. Lee, 2003; Marshak, 1993; McQueeney, Stanton, & Sigmon, 1997).

A variety of therapeutic approaches were recommended, designed to mitigate the above listed emotional impact of infertility. Most authors stated as paramount the recognition of infertility as a 'life crisis' that places unreasonable burden upon sufferers with equally unreasonable expectations of treatment and treatment outcome (Fouad & Fahje, 1989; Gibson & Myers, 2002; Kikendall, 1994; S. H. Lee, 2003; McQueeney et al., 1997). Strategies suggested to counter these effects incorporate at least one, or a combination of several, of the following techniques: education, assertiveness training and reality testing, psychodynamic therapy, relaxation and stress management, cognitive behavioral intervention, grief counseling, sexual, marital and/or relational therapy, experientially oriented couples therapy, emotion versus problem focused group therapy, and crisis intervention (Fouad & Fahje, 1989; Gibson & Myers, 2000; Kikendall, 1994; Kleinplatz, 1999; S. H. Lee, 2003; McQueeney et al., 1997; Mindes et al., 2003).

Some of the articles utilized a case study format to review the impact of intervention on their personal clients providing clinical evidence to support either their own interventions or theoretical perspectives suggested by the academic literature (Gibson & Myers, 2000; Hart, 2002; Kirkman, 2001; Kleinplatz, 1999). Generally,

recommendations that were specifically identified for use with women were framed in feminist language and persisted in respecting the unfair weight that has been placed on women in traditional approaches to treatment (Gibson & Myers, 2000; Gonzalez, 2000; Kikendall, 1994; Klawiter, 1990). More often, the specific interventions were not clear or seemed to reflect the particular clinician's therapeutic style (Gibson & Myers, 2002). Others provided a theoretical template from which to approach the provision of emotional support without offering specific techniques or strategies (Gonzalez, 2000; Kikendall, 1994).

As more and more research conducted inside and outside the medical model is incorporated into the recommended comprehensive treatment approach this will, have a positive impact on psychological treatment. It is clear from the literature that individuals and couples express both a need for some kind of support as well as a perception of its emotional benefit (McNaughton-Cassill, Bostwick, Vanscoy, Arthur, Hickman, Robinson, & Neal, 2000). However connecting a particular treatment approach or therapeutic gain to pregnancy success is both misleading and likely to further elevate stress. Boivin and Schmidt (2005) recommend that rather than attaching specific interventions to pregnancy outcome they should be advocated because of their document impact on overall wellbeing (Boivin & Schmidt, 2005).

Counseling Men

As has been well noted, there is a lack of academic literature on the experience of fatherhood for men, and the infertility literature reflects a similar scarcity (Throsby & Gill, 2004). Increasingly authors are calling for research that is representative of the stress impact on both partner's individually and together, regardless of gender: "It is

important to understand the psychosocial issues in infertility from the woman's, the man's, *and* the couple's experience" (Jordan & Revenson, 1999, p. 355).

Martin Pook, a psychologist from the University of Marburg in Germany, has conducted several studies that examine personality, coping style and sperm concentration as well as whether there is any association between these factors and the subsequent need for, or use of, infertility counseling by men (Pook & Krause, 2005; Pook, Krause, & Drescher, 2002; Pook, Krause, & Rohrl, 1999, 2000; Pook, Rohrl, Tuschen-Caffier, & Krause, 2001; Pook, Tuschen-Caffier, Kubek, Schill, & Krause, 2005).

In Pook et al.'s 2000 article *A Validation Study on the Negative Association Between an Active Coping Style and Sperm Concentration* the authors' hypothesize that "there is a negative correlation between active forms of coping and sperm concentration and the correlation between active forms of coping and sperm concentration is higher than that between passive forms of coping and sperm concentration" (Pook et al., 2000, p. 250). Participants were infertile men "without organic causes for impaired spermatogenesis" (n=55) (Pook et al., 2000, p. 249). Evidence to support their first hypothesis was mild and not significant however this led the researchers to a follow-up study conducted on fertile men to determine whether removing the stress of an infertility diagnosis would still reflect similar results in terms of coping style and sperm parameters (Pook et al., 2005).

The relationship between personality and coping was evaluated using the Five Factor Inventory, which is the German Version of Goldberg's International Personality Item Pool, and the Stress Coping Questionnaire (L. R. Goldberg, 2005b). Participants were recruited after they had agreed to participate in a drug trial which required semen

analysis, and the psychological measures were tested only *after* completion of the primary investigation. Pook et al explains that of the 4 relationships that were significantly correlated “...the association between active coping and sperm concentration – is also in agreement with previous findings” (Pook et al., 2005, p. 33). In other words men who seemed to demonstrate an active coping style had better sperm concentrations than men who did not. This is important because it reflects, as the authors suggest, “...the consequences of behavioral modifications on sperm parameters” (Pook et al., 2005, p. 34). In addition, Pook et al make the distinction that rather than “try to identify personality characteristics associated with infertility” investigations should be focused on “...psychological aspects associated with physical factors essential for fertility” (Pook et al., 2005, p.34).

In Pook et al’s 2001 analysis of the reasons that infertile men might consider using infertility counseling the authors report the well recognized fact that “...there is a striking discrepancy between the number of patients who are interested in psychological counselling and the number of patients who actually use such services; only 18 to 21% of the patients accept the offered counselling” (Pook et al., 2001, p. 239). The need has been determined at closer to 50% - 70% by clients’ themselves (Boivin et al., 1999; Pook et al., 2001).

Male infertility patients (N=94) who were currently receiving counseling completed the SCLR-90 (German version), prior to the commencement of either brief problem focused psychotherapy or extended couple therapy (Pook et al., 2001). Male infertility patients who were not receiving counseling acted as a control group (N=134). Results indicate that men who were using psychological services had “...significantly

higher scores for both depression and anxiety” and this also correlated with higher numbers of “...impaired sperm parameters” when compared to controls (Pook et al., 2001, p. 241). Despite accounting for temporal factors that might have influenced participant responses, which could inflate SCLR-90 scores the authors determined: “...if a patient has little distress (T score for depression <40) and only one or two sperm parameters are impaired, he is less likely to use counseling” (Pook et al., 2001, p. 243). Conversely, the likelihood of using counseling increased with the severity of the problem or the *perceived* severity of the problem, indicating that interpretation and construction of meaning play a role in the level of distress experienced: “The therapeutic benefit of constructivism is in helping clients reconstruct new meaning about presenting issues, thus allowing for the creation of new solutions to deal with those issues (Trippany, Barrios, Helm, & Rowland, 2004, p. 39-40).

O'Donnell (2005) also noted that a man's willingness to participate in counseling was a function of his desire to be helpful:

I said yes [*to counseling*], number one my wife asked me to do it, and I don't feel like I've done anything to help...I figured there would be some questions that might make me feel uncomfortable...and I thought it would be good for me (O'Donnell, 2005, p. 30).

According to Pook et al, an evaluation of the kind of help men are subsequently offered, and whether it is effective, would be appropriate (Pook et al., 2001). What must also be re-emphasized here is that knowing which comes first, the behavior or the physiology, is not clear and applying the causal principle would remain, in Locke's words: “...intuitive uncertainty” (Kharmara, 2000, p. 339).

A 2004 article by Throsby and Gill helped to delineate why men may have difficulty either identifying their emotional needs or developing a language to talk about

them (Throsby & Gill, 2004). The predominant attitude of male partners in this small qualitative study, regardless of whether they have been diagnosed with the infertility problem, continued to reflect a patriarchal system of gender relations already highlighted earlier in this historical review (Pfeffer, 1993). "...it's that girly thing again, you know, I'm a guy I don't really want to know all the ins and outs of it, just fix it and get back to me" (O'Donnell, 2005, p. 40). Women therefore frequently feel separated in, and by, their suffering and men are further discouraged from participating in the relief of their partner's emotional stress as well as their own (Matsubayashi, Hosaka, Izumi, Suzuki, Kondo, & Makino, 2004). Deconstruction of the social and gender norms that continue to influence the perception of infertility as a condition of shame and shameful sexuality is critical if support from partners and important others is to improve: "Distancing unsupportive social interaction, indicate that an attempt was made to communicate...and the effort to communicate was, in essence, rebuffed...this rejection may intensify the stigma associated with infertility and corresponding psychological sequelae" (Mindes et al., 2003, p. 2175).

Counseling Couples

Most researchers who have examined the recent data on the psychological and emotional impact of infertility have come to a similar conclusion; this is a couple issue and should therefore be examined as a couple issue (Boivin & Schmidt, 2005; Throsby & Gill, 2004; Verhaak et al., 2005a; Wilson & Kopitzke, 2002; Wischmann, 2003).

Daniluk's 1988 study which explored the "intra and interpersonal" influences of an infertility diagnosis revealed that couples who do not have an explanation for their infertility report higher levels of sexual dissatisfaction in their relationship (Daniluk,

1988). Providing sex therapy or marital therapy that addresses potential sexual dysfunction has frequently been a part of infertility counseling (Leiblum, Aviv, & Hamer, 1998; Myers & Wark, 1996). However, Daniluk emphasized several other areas that needed to be addressed in her later paper, *Strategies for Counseling Infertile Couples*, these included: grief counseling, learning to relinquish and take control, relationship healing, reassessment of motivation for parenting, and moving on (Daniluk, 1991).

Toward the end of the 1990's a cognitive behavioral approach to couple therapy seemed to predominate (Myers & Wark, 1996). This was perhaps driven in part by the generalized demand for brief solution focused therapy in several different areas of mental health practice, as well as the mounting evidence that demonstrated that the way people think is related to their experience of anxiety and depression (Beck & Perkins, 2001). However, some authors continued to support infertility as a qualitatively profound psychological event requiring a comparable phenomenological approach, even documenting their own client's pregnancy success after such therapeutic intervention (Kleinplatz, 1999).

This approach goes beyond treating causes, symptoms or effects of either psychological or biomedical disorders: it opens the door to changes in behavior, relationships and in the body that could never have been anticipated from treating only the presenting problem (Kleinplatz, 1999, p. 32).

Eunpu (1995) recommended attention be given to identity issues in both partners and the impact these problems had on a couple's interpersonal relationship as well as their relationships with important others. The author suggested introducing an educational component to couple therapy which incorporated assertiveness training, stress reduction techniques, bibliotherapy, and "...referral to a support group such as

RESOLVE” (Eunpu, 1995, p. 124). This was seen as a way to mitigate the effects of stigmatization on self-esteem, help reduce stress and depressive symptoms, and reduce isolation within and between couples and their community

Stammer et al (2002) advocated removing the disease label from infertility counseling and blurring the distinction between ‘counseling and therapy’ (Stammer, Wischmann, & Verres, 2002). The authors do not offer their definition of either counseling or therapy, which whether intended or not, creates the sense of a fuzzy therapeutic boundary while reaffirming this researcher’s position that interventions that are deemed to be effective need to be clearly defined and described . They go on to emphasize the importance of goal setting, offering short-term or low frequency sessions, utilizing humor, and developing a plan for infertility resolution, i.e. moving toward adoption or childlessness as an option (Stammer et al., 2002).

A study published in *The Family Journal: Counseling and Therapy for Couples and Families* in 2003 addressed the research finding that suggests women experience infertility as much more stressful than men (A. Abbey et al., 1991; Jordan & Revenson, 1999; T. Y. Lee et al., 2001; Savitz-Smith, 2003). The article advocated for the counselor’s understanding of this effect as well as the multiple consequences of social isolation, personal despair, stigma and the need for support that goes beyond the active infertility period into parenting, whether through biology or adoption (Savitz-Smith, 2003).

A later review of the literature published in the *Journal of Counseling and Development* in 2004 placed infertility within a brief historical context and provided a basic introduction to the medical aspects of infertility treatment (Watkins & Baldo,

2004). The authors offer a guideline for therapeutic couple intervention using a case study model that addresses the following well documented issues: social isolation, identity development, relationship conflict, anxiety and depression, gender differences, sex and intimacy struggles, grief and mourning, self acceptance, and coping strategies (Watkins & Baldo, 2004). The therapeutic strategies described are designed to support the client at the level of their current distress and provide a framework of practice for the ‘inexperienced’ infertility counselor. The article provides no evidence that this strategy provided this or other couples specifically with a measure of effective emotional support (Watkins & Baldo, 2004).

Group Counseling Strategies

McQueeney et al (1997) took advantage of the some of the earlier coping research that demonstrated a difference in outcome between people who used a problem focused versus emotion focused response to emotional distress, as well as gender differences in response to infertility (A. Abbey et al., 1992; Wallbott & Scherer, 1991). These authors compared two different types of ‘coping skills educational groups’, (women only), emotion and problem focused, (N=30), conducted for 90 minutes a week over a 6 week period (McQueeney et al., 1997). A small control group comprised of women who signed up to participate in the study and were then unable to attend, was used for comparison. The authors determined that emotion focused skills set “...may be more effective in reducing distress for infertile women compared with problem-focused strategies”(McQueeney et al., 1997, p. 315).

This is an interesting finding given that some researchers have demonstrated that problem focused coping is more effective than emotion-focused coping in reducing the

stress associated with health related conditions, and that women tend to use emotion-focused coping more often than men (Jordan & Revenson, 1999). While still earlier studies revealed that women resorted to "...problem-focused coping and escape coping" far more than their male partners and that this was likely related to the elevated stress effect experienced by women when compared to men (A. Abbey et al., 1991, p. 304).

Once again the struggle to find a consistent voice throughout the literature is disheartening. On the one hand it impedes the likelihood of finding a particular type of support strategy that is considered more effective than any other, however, it perhaps also reinforces the notion that infertility is not experienced statistically but suffered individually, one heart broken person at a time (O'Donnell, 2004a).

Domar et al's (2000) study hypothesized that infertile women who participated in a cognitive behavioral/mind-body intervention group or alternatively, attended a regular support group (Resolve style format), would have differentially higher pregnancy rates than women who did not receive either type of emotional/psychological encouragement while actively trying to conceive, with or without the use of assisted reproductive technology (Domar et al., 2000). Domar's results reflect a significant difference in pregnancy rate between attendees of any kind of support program when compared to non-participating controls (55% vs. 20%).

Perhaps what is more interesting and not commented on by the authors, is that the rate of pregnancy success in the cognitive behavioral/mind-body group, in women who were trying to conceive *without* medical assistance, was 42% compared to only 11% in the support group and 20% in the control group (Domar et al., 2000). This speaks to the possible benefit of utilizing a well rounded comprehensive intervention program to help

women find effective methods of modulating their emotional and subsequently, physiological health, even reducing or eliminating the need for any other type of medical intervention.

As previously mentioned, RESOLVE, a non-profit Organization dedicated to providing education and support for individuals and couples experiencing infertility was founded in 1974 (RESOLVE, 1974). Since that time RESOLVE has established a presence in over 35 States offering a regular monthly meeting space for people to gather and share their experience. Although helpful, these groups are not designed to be *clinically* therapeutic. However, they have demonstrated effectiveness in providing a forum for people to reduce their sense of social isolation, burden of secrecy and shame, and develop a network of friendship (Boivin, 1997; McNaughton-Cassill et al., 2000).

A trial of “brief stress management support groups for infertility” was undertaken at Wilford Hall Medical Center, (a United States Air Force facility), in 1999 in an effort to mitigate the stress of waiting for, as well as receiving, medical treatment (McNaughton-Cassill et al., 2000). Couples were recruited via their treating physician (N=17) and intervention consisted of 1.5 hour meetings twice per week for 3 – 5 weeks. Couples were also allowed to attend separately or together to accommodate scheduling conflicts. Satisfaction surveys in the form of written questions answerable on a 5 point Likert scale was the only form of program evaluation. The authors determined “...that both males and females valued the social support derived from the group and that the groups helped them to deal with the stress of IVF treatment (McNaughton-Cassill et al., 2000). It is by now clear that some form of connection, identification, and mutual

witnessing is important for individuals and couples struggling to build a family (de Liz & Strauss, 2005).

Dayus et al (2001) proposed an infertility support group for couples that integrated Yalom's approach to group process with nursing theory. Sessions were 1.5 hours long and conducted over 7 weeks and the program content reflected several of the methods already discussed: relaxation, meditation, guided imagery, assertiveness training, journaling, and cognitive behavioral therapy strategies (Dayus, Rajacich, & Carty, 2001). Dayus et al offered evaluative participant feedback only as a measure of their intervention's effectiveness: "...the support environment...makes me really recognize that I don't do enough self nurturing" (Dayus et al., 2001, p. 112).

In 2003 Boivin published an extensive "...review of psychosocial interventions in infertility" which examined over 380 articles (in multiple languages), addressing the possible benefits of counseling or psychological support for people who are facing infertility (Boivin, 2003, p. 2325). Boivin determined that only 25 of the studies she examined qualified as "independent evaluations" and primarily consisted of one of the 3 following modalities: i) counseling (psychodynamic, cognitive behavioral, problem focused); ii) educational (coping/stress management, sex therapy, medical information), and iii) broad-based psycho-educational training programs that encompassed several different methods for reducing negative emotional affect, constructing meaning, understanding and mitigating somatic symptoms, and the development of a general overall health improvement plan i.e. a mind-body program (Boivin, 2003; Domar et al., 1990).

Boivin (2003) reported that although psychosocial interventions on an individual or couple level had some impact on the reduction of negative affect there was less evidence of their influence on interpersonal (relationship) dynamics. This finding and the fact that broad based group programs were overall, "...more effective in producing positive change across a range of outcomes" resulted in Boivin making the following recommendations for future studies. Larger sample sizes ($n > 64$), with randomized controls; well clarified intervention and evaluation techniques; adequate data collection and analysis, and pre and post intervention testing (Boivin, 2003, p. 2325).

In February 2005 de Liz and Strauss published a review of the differential efficacy of group and individual/couple psychotherapy with infertile patients. They included studies that provided at minimum: descriptive statistical analyses, pre-and post intervention measures, and randomization to both control and treatment groups (de Liz & Strauss, 2005). Specifically, efficacy was evaluated in terms of reduction of negative affect and by pregnancy as a possible function of treatment outcome, calculated using "...the proportion effect size statistic" (de Liz & Strauss, 2005, p. 1325).

The final number of included studies was 22, only 5 of which provided statistical data on both reduction of psychological symptom distress and conception rate (*not live birth*). These five studies were conducted in a combined academic-clinical site. Sample demographics reflected the "Caucasian, upper middle class couples and women" representative of the usual people seeking assisted reproductive treatment (de Liz & Strauss, 2005, p. 1325). The most common self report measures utilized intermittently across all 22 studies were the State-Trait Anxiety Inventory (STAI), the Beck Depression Inventory (BDI), The Profile of Moods Scale (PMS), the Symptom Checklist Revised

(SCLR-90), and the Hospital Anxiety and Depression Scale (HADS) (de Liz & Strauss, 2005).

Research which evaluated the effectiveness of psychotherapy based on pregnancy outcome revealed a combined 45% pregnancy rate at cessation of follow-up compared to only 14% in controls. From these authors perspective it appeared that neither the type of psychotherapy offered (cognitive behavioral, hypnotherapy, supportive sex therapy, psychoanalytic therapy, or stress reduction and coping strategies), or format: individual, couple, or group intervention, seemed to affect overall outcome and “yielded similar pregnancy rates” (de Liz & Strauss, 2005, p. 1330).

In their final analysis the authors’ propose “that psychotherapy (group and individual/couple) reduces anxiety and depression for infertile patients and possibly enhances conception success” (de Liz & Strauss, 2005, p. 1331). However, they also stipulated that the association of pregnancy success with counseling or any other kind of formal psychological support “...cannot be made at this point” because of the variable influences of infertility treatment, traditional or alternative and the multiple environmental factors that likely impact these conditions (de Liz & Strauss, 2005, p. 1330).

Both Domar (1999) and Boivin (2003) have noted that women who have a prior history of depression, or are more negatively emotionally affected by their infertility diagnosis, seem to benefit most from psychosocial support and mind-body interventions (Boivin, 2003; Domar et al., 1999a). Perhaps it is this that lends further support to the notion “that the total experience of infertility is affecting stress response parameters at endocrine and cardiovascular levels” (Wilson & Kopitzke, 2002, p. 196). Increasingly, as

already suggested, research that includes men and women in evaluation and intervention is critical.

A 2005 study exploring the effectiveness of a communication and stress management program for infertile couples (n=37 couples) concluded that structured psycho-educational support group intervention was effective in helping participants improve their level of communication about infertility with each other (Schmidt, Tjornhoj-Thomsen, Boivin, & Nyboe Andersen, 2005b). In particular, the authors discovered that providing couples with information on common infertility myths, stress and its impact on thoughts, feelings, and the body, as well as strategies for more effective methods of coping seemed to influence which topics surrounding their fertility were discussed between couples as well as outsiders (Schmidt et al., 2005b). Given that a source of significant stress is the sense of helplessness, stigma, and misunderstanding that surrounds infertility, this study supports the notion that educational programs that aim to develop a sense of choice and confidence over how, when, and with whom to discuss intimate fertility related problems, need to be available. Other particularly relevant findings in this study were that after participation in the psycho-educational workshop men tended to move away from fact focused discussion into more emotion based interactions with their partners, and women came to depend more on their partners and close family and less on colleagues for emotional support. Despite these positive conclusions the overall experience and/or reporting of stress was not significantly reduced. Previous surveys by these researchers indicated that a psycho-educational was the most likely format to be attended by men.

What's Next?

What is lacking in much of the previously mentioned strategies is a specific standard of care that offers clients the opportunity to resume expert status in their own lives. Sexual behavior and more specifically reproduction, is classically a private decision and private act that individuals and couples participate in without the need for professional debate or discussion. Infertility is the ending of that (Henig, 2004). In addition, infertility continues to be a poorly covered health care expense due to the ambiguous status it holds in terms of its medical definition.

The International Classification of Diseases (ICD-10) is a globally identified list of pathological terms, authored by the World Health Organization, and claims to recognize *infertility* and its organic contributors as a legitimate health condition (WHO, 1994). However, attitudinal surveys in countries such as the United States, Australia, United Kingdom, France, Germany, Italy, Belgium, and Sweden, indicate that as many as seventy five percent of these countries general population do not view infertility as a diseased medical state (Morgan, 1999).

It is this attitude that continues to marginalize infertility sufferers who are caught in the crossfire between scientific, social, ethical, and political discourse. Infertility has emerged in its time as a critique against the institution of medicine, the poverty of class, and the politics of race, sex, and gender (Ulrich, 2000). This Dissertation aims to develop a critical theory to deconstruct the complicated narrative that is infertility's history, in part to analyze the emotional effects of these painful cultural legacies. It becomes possible to have an impact on those effects and create alternative stories when the full power of their impact is understood. "Above all, critical, post-structuralism, and post

modernism are effective as *critiques of positivism* interrogating taken for granted assumptions about the ways in which people read and write science” (Agger, 1991, p. 106).

A recent attempt to do this was begun by Cousineau et al (2004) with their design of a “multimedia psychosocial support program for couples receiving infertility treatment” (Cousineau, Lord, Seibring, Corsini, Viders, & Lakhani, 2004, p. 532). The program is aimed to function as an interactive “...CD-ROM that uses audio, video, interactive tasks, and personalized feedback” providing information that reaches people who have both limited access to services and limited resources (Cousineau et al., 2004, p. 532).

Mind-Body: Chicken Egg

The chicken-egg dilemma has been a blight on infertility research on many levels. Early attempts to demonstrate psychological causality were presumptive and added their own secondary stress effects, so were mostly abandoned toward the end of the 1970’s (Wischmann, 2003). However, the struggle to identify factors that might increase people’s vulnerability to stress during treatment and can predict treatment success as well treatment failure continues, with pregnancy as the most desired outcome (Verhaak et al., 2005a). Once again reflecting the essential dilemma that is mind-body medicine: looking to the psyche to explain the performance of the body (Dreary, 2005).

Only preliminary investigation into the biopsychosocial impact of fertility has been performed and the paradigm shift that is occurring must also rely on projections of the mind-body effect learned from studies conducted in other disciplines (Davidson *et al.*, 2003; Demyttenaere *et al.*, 1993; Facchinetti *et al.*, 2004; Jonsdottir, 2000)

Building on the Research

The focus of this Ph.D. thesis is the design and evaluation of a mind-body workshop for individuals and couples experiencing infertility. In addition, the efficacy of a one-day educational group format is examined as well as the potential to utilize the program's accompanying Manual as a 'stand alone' self-help resource. To achieve this aim a pilot study was conducted (as outlined in Chapter I).

Participants completed a preliminary Fertility Health Questionnaire and Fertility Problem Inventory, (returned by mail *prior* to the program date), which included demographic data, height and weight, (to calculate BMI), general health, years of fertility, type of treatment, both alternative and complementary, previous counseling experience, and goals for attending the workshop (see Appendix for full details). The average number of years participants had experienced infertility was 3.2. Research shows that the stress of infertility alters as a function of how long someone has been trying to conceive (Boivin et al., 1999; Verhaak et al., 2005a).

The workshop was conducted by Liz O'Donnell and Helen Deneselya, (both professional clinical counselors), with the assistance of two female masters level counseling students from Cleveland State University. The *Minding Matters Program* was divided into 6 components:

- i) educational overview of mind-body medicine and its relationship to infertility
- ii) Identifying and differentiating thoughts, feelings and beliefs – strategies for change
- iii) Mindfulness and Meditation

- iv) Relaxation and Breathing
- v) Introduction to basic yoga principles
- vi) Sharing, writing, telling your story

In addition, the respect for group process and the power of the shared experience allowed for the continual integration of personal narratives, questions, dialogue, and contemplation throughout the day. This was accomplished using open discussion, reflective feedback, and the fishbowl technique. Conditions of confidentiality as they pertain to psycho-educational group process were reiterated along with a brief review of the code of ethical conduct for human research participants.

A follow-up day was conducted approximately 5-6 weeks after the workshop and (attended by 4 couples and 3 women from the women only group). An additional 2 couples and 2 women were seen in the private office of this researcher (Liz O'Donnell), and the remainder completed their follow-up information by mail. Preliminary analysis of the collected data reflects some finding that are compatible with the infertility research literature (Boivin & Schmidt, 2005). The following is a brief review of the *Minding Matters* program components and the literature that supports their efficacious use as part of a mind-body approach to chronic health conditions.

An Ecological Model

The *Minding Matters Program* follows the principles of an ecological model which allows that a defined problem is compounded by multiple levels of effect at the point of the individual, family, community, and culture: microsystem, mesosystem, macrosystem, and exosystem (Sidebotham, 2001). This is an important way to view infertility and facilitates greater understanding of the numerous ways in which people

have been seen to suffer (Greil, 1997). An ecological model also insists the utilization of interventions that expand insight of this multiple effect and can potentially have an influence at each stage of impact (Sidebotham, 2001).

A psychosocial Education Component

Several of the studies outlined in this literature review documented evidence of the importance for individuals and couples experiencing infertility to be accurately informed about their particular condition and its status regarding treatment (Boivin, 2003; Domar et al., 2000; Greil, 1997; van Balen, Trimbos-Kemper, & Verdurmen, 1996; Webster & Austin, 1999).

Webster & Austin (1999) conducted a quasi experimental study to determine whether it was possible to teach health related hardiness (HRH), loosely defined as the "...ability to resist illness when under stress" in people presenting with a chronic or persistent medical condition (Webster & Austin, 1999, p. 241). Their findings suggested that group instruction and support was effective in "fostering the development of thoughts, feeling, and behaviors associated with health related hardiness" (i.e. the ability to resist illness when under stress), and that such changes reflect improved commitment to adaptive coping strategies and a greater dedication to the challenge of destructive or negative behavior patterns (Webster & Austin, 1999, p. 246).

There are several key components deemed necessary to an individual's capacity to withstand the impact of chronic stress, described by these authors as *control* and *commitment and challenge* (Webster & Austin, 1999). *Control* is also a concept well recognized in stress research (discussed further below), and speaks to the concept of

helplessness, problem focused versus emotion focused, or avoidance coping, and the need for individuals in demanding situations to believe that they have accessible ways to modulate their stress (Folkman & Moskowitz, 2000). *Commitment* and *challenge*, as defined by Webster & Austin (1999), addresses the willingness of participants to dedicate themselves to approaching their particular life problem differently and to consider the possibility that there might be some unanticipated benefit to their crisis experience (Webster & Austin, 1999). A sort of ‘silver lining’ approach or ‘looking for the good in the bad’ which has been described as “...positive outcomes of stressful events, even though the events themselves might not have had favorable resolutions” (Folkman & Moskowitz, 2000, p. 647).

Folkman and Moskowitz (2000) note “...most models of stress do not emphasize positive affect” as a result there has been little emphasis in the research of how it emerges, it’s adaptive effect, or discussion of particular coping strategies that might be useful in supporting it (Folkman & Moskowitz, 2000, p. 648). Although coping mechanisms have traditionally sought to minimize negative affect it is the goal of this research to further understand the ways in which the difficulties associated with infertility might be understood by its sufferers more constructively; identification of a creative versus procreative power.

The psycho-educational element of the *Minding Matters Workshop* provides a forum to teach participants what is currently known about mind-body medicine in general, and its possible relationship to fertility, specifically. Each element of the program is reviewed and presented according to the theoretical principles governing its inclusion and the latest evidence supporting their potential benefit.

Stress

As discussed in Chapter I, *stress* is a broad term that refers to the physical, physiological, emotional, sociological and psychological health and wellness of human beings (Aneshensel, 1992; De Kloet, 2003; Kemeny, 2003; Millan, 2003; Somerfield & McRae, 2000). It is because of the number of domains upon which stress has influence and that the perception of stress is as important as the ability to objectively observe and measure stress, that the term has remained both expansive and somewhat nebulous (Hobfoll, Schwarzer, & Chon, 1998).

The psycho-physiological effects of stress are generally well understood as a sequence of events that come under the umbrella of the fight/flight response (Kemeny, 2003). Both real and imagined stressors, frequently with their foundation in a sense of fear or danger, triggers the neuroendocrine reaction that occurs in the body to prepare an individual to manage an incoming threat; a stimulus-response utilization of the term stress (Hobfoll et al., 1998).

A sense of crisis or danger is quickly followed by activation of the adrenal medulla (under the control of the autonomic nervous system ANS), which releases norepinephrine into the body. Norepinephrine is a hormone that has a stimulating effect on the sympathetic nervous system, (the SNS governs the body's involuntary reflex response to a perceived threat), promoting the release of epinephrine (adrenalin). Epinephrine is responsible for the elevated heart rate, respiratory rate, and redirection of glucose away from the liver to the muscles for mobilization; the common experience of a stressful condition (Benson & Klipper, 1975; Kemeny, 2003).

It is now believed that activation of this stress pathway also influences the function of the hypothalamic pituitary-adrenal axis (associated with reproductive function), inciting the release of cortisol into the system (Kemeny, 2003; Wilson & Kopitzke, 2002). In addition, evidence suggests that there is also a concomitant decrease in immune function secondary to the “cumulative toll of chronic over-activation of the physiological systems that are designed to respond to environmental perturbations” (Kemeny, 2003, p. 126). Individuals experiencing infertility live with a considerable amount of low grade stress, punctuated by exacerbations in that stress during active treatment and the potential for subsequent treatment failure (Watkins & Baldo, 2004). Given the multiple collateral effects that such stress is shown to have, development of a template of care that is comprehensive and well understood, is critical.

Thoughts, Feelings, and Beliefs

Psychopathology remains the oracle of psychiatric medicine and within its definitions we find disease, disorder, dysfunction and despair (WHO, 1994). Yalom and other authors assure us that although organization of clinical symptoms may be of benefit with a ‘confused’ client, within such structure we must also make room for reconstruction or self construction (Yalom, 1998).

Each individual brings their personal history to bear on their explanation of the past as well as their struggle to live with an uncertain future (Breitbart, Gibson, Poppito, & Berg, 2004). It is in the breakdown of these private narratives to their simplest form that we create the space for a new tale to emerge (Hodges, 2002; Zubair, 1999). Viewing ‘symptom manifestation’ within this framework is less about cataloging idiosyncratic behavioral and psychological features and more about discovering a mechanism for

observing and discerning the fundamental scaffolding upon which people support their mental, emotional, and spiritual health (O'Donnell, 2005).

There is increasing evidence that how we think not only influences our emotions but also impacts our physiology (Carrasco & Van de Kar, 2003; Davidson et al., 2003; van Gelder, 2005). Davidson and Kabat-Zinn's work on mindfulness based meditation and its relationship to decreased activity in the right side of the pre-frontal cortex was one of the first studies to demonstrate that quieting the mind had a beneficial effect on the body (Davidson et al., 2003). Davidson and Kabat-Zinn's research using positron emission tomography (PET scans) revealed that people who ruminate or have negative thought patterns not only activate different regions of the brain but stimulate different types of neurotransmitter activity (Davidson & Irwin, 1999; Davidson et al., 2003).

The impact of these brain changes is also felt to influence certain chemical messengers in the endocrine and sympathetic nervous system, which play a role in the body's immune response, as well as reproduction.

The findings from this study are the first to suggest that meditation can produce increases in relative left sided anterior activation that are associated with reductions in anxiety and negative affect and increases in positive affect (Davidson et al., 2003, p. 569).

Specifically, Davidson et al were interested in documenting that "emotion-related brain activity" provokes different kinds of brain waves and in different parts of the frontal cortex (Davidson et al., 2003). In particular, they hypothesized that because positive emotion is associated with increased left sided brain activity that an intervention designed to facilitate this effect, i.e. meditation, would demonstrate this benefit (Davidson et al., 2003). The results of their work suggest that, "...left sided anterior activation is

associated with more adaptive responding to negative and/or stressful events” (Davidson et al., 2003, p. 569).

An earlier study by Davidson and Irwin (1999), (which looked at the role of the pre-frontal cortex and amygdala in the interpretation and expression of emotion), attempted to demonstrate a relationship between approach/avoidance styles of emotion and their location in the brain (Davidson & Irwin, 1999). According to a coping model, approach and withdrawal behavior is mediated by factors like motivation, desire, goals, as well as fear associated with not meeting those goals and, “...includes a variety of strategies such as avoidance, seeking emotional support, and positive reappraisal (Austenfeld & Stanton, 2004, p. 1137).

Past research has shown that individuals who suffer damage to the left side of the pre-frontal cortex often go on to suffer depression and other types of negative mood affect (Davidson & Irwin, 1999). In addition, the role of the amygdala in the experience of anxiety and response to anxiety has shown that stimulation of this small structure, (situated in the brain’s medial temporal lobe), is strongly associated with fear based or anxiety provoking conditions (Carter, 1998). Davidson and Irwin go on to explain that the changes in blood flow associated with stress or the perception of stress “...indicate that the pattern of functional connectivity between these two regions is altered as a function of emotional expression...” (Davidson & Irwin, 1999, p. 14).

Therefore meditation, as an intervention “...has demonstrable effects on brain and immune function” (Davidson et al., 2003, p. 569).

This is particularly important to the issue of infertility and infertility treatment because it has been shown that the cycle of hope and despair, as well as the attitude that

one brings to make sense of this cycle, contributes to an individual's ability to cope as well as their overall sense of wellbeing (Boivin & Schmidt, 2005; Domar et al., 2005; Gibson & Myers, 2002). It is this "...conceptual bottom line...the relational meaning that an individual constructs from the person-environment relationship" that is so important to "...personal goals, beliefs about self and world, and resources" (Lazarus, 2000, p. 665).

It is also critical to underscore that coping is impacted by the length of time that people have struggled with infertility as well as the degree of grief that they have suffered, and is also tempered by general constraints such as "...individual differences in personality traits...the interpersonal and cultural context" (Lazarus, 2000). Lazarus goes on to explain that a fundamental understanding of how people negotiate crisis in their lives is linked to how well clinicians are able to facilitate and mitigate its effects. Given that the effects, as discussed, are multiple and multi-layered, Lazarus advocates John Dewey's model of *synthesis* or dialectic, which rather than promote a 'cause effect' approach to the experience of stress, suggests a comprehensive view "...in which any of the variables can serve as an antecedent, a mediator, a moderator, or a consequence" (Lazarus, 2000, p. 668). This requires a respect for the unique phenomenological identity of each sufferer as well as studies that are "meaning centered...longitudinal...in a framework that is process centered and holistic" (Lazarus, 2000, p. 665). A reflection of critical theory in research and "the hermeneutic act of interpretation" (Denzin & Lincoln, 2000, p. 285).

Stress and Coping

Numerous studies have examined the relationship between stress and coping and in particular the impact that some coping processes appear to have on stress (i.e. problem)

management and health related outcomes (Austenfled & Stanton, 2004; Beasley, Thompson, & Davidson, 2003; Hobfoll et al., 1998). A smaller number of studies have explored specific infertility related stress and the relationship between certain types of coping processes and the experience of psychological distress in this population (McQueeney et al., 1997; Mindes et al., 2003; Peterson, Newton, Rosen, & Skaggs, 2006; Zwick, 2003). The tendency to view infertility as a problem to be solved i.e. eradicated by the production of a baby is self explanatory. However, many life circumstances present themselves more as difficulties to be lived through rather than obstacles that will certainly be overcome, death being the most obvious inescapable event. Infertility is often described by its sufferers as a type of death and its resolution through childbirth or adoption does not necessarily eliminate that definition from the experience (O'Donnell, 2005). Coping processes that use problem focused strategies to mitigate stress have traditionally been viewed as the most adaptive throughout the coping literature (Austenfled & Stanton, 2004). This view is being increasingly challenged by evidence from several fields of discipline that demonstrate emotional processes and processing as an important positive variance in the mitigation of psychological distress in response to stressful life conditions (Austenfled & Stanton, 2004; Folkman & Moskowitz, 2000; Lazarus & Folkman, 1987). Equally, personality, disposition, relationship and the environment creates a complicated intersect within and between individuals who are attempting to understand and reduce stress. According to some authors this might have an important influence on infertility related stress reduction as well as be predictive of infertility treatment outcome for both men and women (Lancastle & Boivin, 2005; Pook et al., 2000).

It has also been demonstrated that social isolation is a critical condition of the infertility experience (Hart, 2002). This is ironically both as a consequence of infertile individuals being unable to participate in the social and cultural experience of parenting and as a self-imposed method of withdrawal by sufferers to create emotional protection. Therefore a complicating factor in the development of professional services for individuals and couples experiencing infertility is how to best provide the social support that research indicates is a necessary part of their ongoing physical and emotional wellness and long term healing (Verhaak et al., 2005a). Recent research on coping and infertility has attempted to understand the influence that variable coping processes has on the level of distress reported within the couple dyad (Petersen, Newton, Rosen, & Schulman, 2006). Peterson et al's study emphasized that regardless of which partner is diagnosed infertility is a shared struggle and needs to be considered within a relationship based framework.

Coping, by implication, suggests the presence of someone, something or some condition that necessitates toleration; a kind of 'putting up with.' Typically coping processes have been reduced to emotional versus problem focused strategies to limit the levels at which data must be interpreted. Peterson et al maintained the eight original coping scales from Folkman and Lazarus's Ways of Coping Questionnaire (WCQ) which examines how thoughts and action change during the experience of life stressors. The WCQ, according to Folkman and Lazarus, "...differs from traditional trait or disposition approaches, which attempt to identify what the person usually does or is most likely to do" (Folkman & Lazarus, 1988, p.7). In their study Peterson et al found that three particular coping practices, distancing, self controlling, and accepting responsibility, were

significantly linked (positively) to couples' experience of increased infertility related stress, poorer marital adjustment, and depression (Petersen et al., 2006). The implication of these findings suggests that understanding how couples might perceive and negotiate their infertility differently is critical to the provision of effective psycho educational support. This study is a continued effort to further address this problem.

Self-Discrepancy Theory

As a way of helping individuals to define not only how they view their world but also the various sources of internal and external sources that might influence that view, I have used *Higgins Self Discrepancy Theory* (Higgins, 1987). Higgins has organized his model on two thought levels which he calls 'domains of the self' and 'standpoints of the self.' Domains of the self include the *actual*, *ideal* and *ought* self and reflect what one believes is the real, perfected, and obligated or expected role or duties of the self. There are two *standpoints* of the self: *own* and *other* which represent how the individual self evaluates and how they are viewed by an important outsider. Bringing the three domains and two standpoints together produces Higgins, "...six basic types of self-state: actual/own, actual/other, ideal/own, ideal/other, ought/own, and ought/other" (Higgins, 1987, p. 321).

Ultimately it is the conflict that arises between the domains and the standpoints, as well as previous incident exposure and priming events, which determine the type and degree of psychological or emotional stress that a person experiences. For example a significant 'mismatch' between an individual's actual self (actual/own) and the perception of them by a significant person in their lives, (actual/other), could create

enough internal discord to generate worry, fear, or some other psychological suffering (Higgins, 1987, 1999).

Higgins theory and study findings suggest that the degree of discrepancy is highly correlated with the amount and type of perceived stress, a result that has been replicated by other researchers (Kikendall, 1994; Strauman & Higgins, 1988). According to Higgins it appears that the conflict between, and within, particular self states is associated with a certain type of emotional distress, for example: discrepancy between a person's actual sense and ideal self tends to lead to feelings associated with disappointment, discontent, or disinterest (supported by subject responses on a depression scale). Alternatively, a discrepancy between someone's actual self and ought self is more associated with feelings of responsibility and guilt as reflected by overt worry or anxiety (Higgins, 1987; Strauman & Higgins, 1988).

Self Discrepancy Theory not only provides a map to help people understand the events and circumstances that contribute to their distress, but it also provides a mechanism for identifying people's mental models and coping styles, and is therefore helpful in establishing specific, individualized, effective, interventions (Boldero, Williams, & Robins, 2003). Robbins and Boldero conclude that self discrepancy theory, "...offers a potentially useful tool for understanding different types of interpersonal relationships and the outcomes of these relationships for the individuals" (Boldero et al., 2003, p. 71).

In other words, it is possible to not only help individuals to better understand their own mental models and ways of coping but also those of their partner and the culture. This helps in mitigating some of the discord and relational effects so frequently

documented in the infertility literature and provides a template for reconstructing emotional intimacy and cultural congruence (A. Abbey et al., 1992; Boivin, Andersson, Skoog-Svanberg, Hjelmstedt, Collins, & Bergh, 1998; Hurst, Dye, Rutherford, & Oodit, 1999; Newton et al., 1999).

Yoga, Meditation and Relaxation

Given the increasing use of *mind-based* modalities in both physical and psychological health conditions a standardized approach to defining what constitutes a particular practice is important (Cardoso, de Souza, Camano, & Leite, 2004). Meditation and meditation training is often further broken down into a specific approach which for the purpose of this research is known as mindfulness based stress reduction, defined by Kabat-Zinn (2003) as:

...the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment (Kabat-Zinn, 2003, p. 145).

The concept of mindfulness has its beginnings in "...Eastern meditative practices" and is considered a particularly useful strategy for reducing stress. Participants are taught to bring their full attention to the cognitive, spiritual, and physical experience of being fully present to their internal and external world (Baer, 2003, p. 125). In order to accomplish this goal a variety of relaxation techniques are utilized to facilitate an individual's development of both somatic (body), and mental (mind), awareness (Baer, 2003). Autogenic training, (described earlier in this review), deep breathing exercises, progressive muscle relaxation, and Hatha yoga postures, become mechanisms through which self regulation skills are taught (Grossman, Niemann, Schmidt, & Walach, 2004).

To a large extent, the purpose of mindfulness is to counteract the consequences of mindlessness, which Langer suggests restricts movement of thought and perspective and keeps us locked in destructive patterns and paralyzing behaviors (Langer, 1997). Therefore as an adjunct to analysis of individual thought process (e.g. Higgins Self Discrepancy Theory), and a technique for evoking Benson's earlier described, *relaxation response*, and reducing the physiological and emotional effects of stress, mindfulness meditation should include the following techniques:

- i) an established meditative technique
- ii) a muscle relaxation exercise to promote physiologic lessening
- iii) non-judgmental approach to observation of thought process
- iv) an ability to *self-induce* the meditative state

It is precisely because the state of meditation is spiritual and elusive that the scientific community has begun to examine what is occurring on a physiological level in the bodies and brains of people who meditate (Peng, Henry, Mietus, Hausdorff, Khalsa, Benson, & Goldberger, 2004; Wolf & Abell, 2003). Although several studies have looked at the effect on galvanic skin response, salivary cortisol, heart rate and breathing rate, as a function of the use of a meditative practice, only recently has examination of neuroendocrine function been examined in terms of its impact as a learned meditative stress reduction technique (Davidson et al., 2003; Peng et al., 2004).

Ellen Goldberg's (2005) recent article, 'Cognitive Science and Hatha Yoga,' attempts to bridge the span between our knowledge of the science of the mind and its relationship to the body (E. Goldberg, 2005a). Goldberg was particularly interested in addressing the increased use of alternative techniques and the introduction of religious

and eastern traditions into the healing potential of mainstream medicine. A study by Domar (2005) also evaluated the role of faith in the coping response. Specifically, faith's role in mediating the mental and emotional wellness of women with infertility; Domar determined that there was a positive relationship between depressive symptoms and people's level of religious conviction (Domar et al., 2005)..

Further, according to Goldberg, "...cognitive studies of religion hypothesize that religion is also related to human physiology and... informed by current research in cognitive science" (E. Goldberg, 2005a). In other words, recent exploration on the impact of religious faith on what individuals believe may have significant implication for the physiology of conscious and unconscious thought. A similar challenge to behaviorism and the Cartesian model of mind body dualism has been heralded at different times by different theoreticians, argues Goldberg (E. Goldberg, 2005a). It is this same challenge that a mind body program takes on when it utilizes a variety of physical practices to facilitate emotional strength, spiritual growth, and mental stability. How do we accommodate the concept of spirituality as integral to our physiology and continue to uphold the conviction that the soul as ethereal entity has existence that exceeds the death of the body (van Gelder, 2005)?

The field of neuro-emotional science is attempting to respond to this question building upon previous challenges by researchers in linguistics, philosophy, neurophysiology, and metaphysics (Damasio, 1999; E. Goldberg, 2005a; van Gelder, 2005). Yoga, as a form of meditative and physical practice reflects the essential nature of mind-body-spirit assimilation. Yoga, which in Sanskrit means, to connect, join, or balance (a union between our true and imperfect self), defies the western notion of

dualism, instead respecting the body's influence on, and interaction with, the power of the mind (Whicher, 1997). A metaphor perhaps for Higgins integration of the ideal and actual self (Higgins, 1987). Yoga, as an integrative practice helps to bridge the distance between the perception of *self* that is unattainable by grounding one in the here and now experience of movement and engagement with one's body and challenging the belief that might undermine this experience (Iyengar, 2001).

Although there has always been a strong relationship between the performance of yogic principles and postures (*asanas*), and the function of various organ systems, empirical evidence supportive of those claims has been scarce (Iyengar, 2001). However, it is believed that certain physical poses stimulate particular areas of the body and that it is release of tension from these areas that has a concomitant effect on the release of tension in the mind (Pelletier, 2002). Effort has been made in recent years to demonstrate the benefit of yogic breathing practices and meditation on the cardio-respiratory system, (oxygen consumption), the brain, (eeg activity), and the endocrine system, (melatonin production) (Aftanas & Golosheykin, 2005; Peng et al., 2004; Telles, Reddy, & Nagendra, 2000; Tooley, Armstrong, Norman, & Sali, 2000). As evidenced in these studies it is possible to translate the perception of 'feeling better' into the physiological performance of 'doing better' and that somatic symptom distress is often alleviated when the head and the heart are no longer in conflict (Pelletier, 2002).

Broken hearts.

In June 2005, researchers discovered a mechanism by which grief is manifested as a life threatening cardiac complication, a condition they have named 'myocardial stunning or 'broken heart syndrome' (Wittstein, Thiemann, Lima, Baughman, Schulman,

Girstenblith, Wu, Rade, Bivalacqua, & Champion, 2005). Patients presenting to the Johns Hopkins Emergency Department with suspected myocardial infarction, and coronary failure fully recovered after appropriate medical support without evidence of permanent damage to the heart, a finding which is inconsistent with a heart attack (Wittstein et al., 2005).

What the authors discovered instead was that each of these patients (18 of 19 were women), had recently suffered an “...acute emotional distress” which resulted in changes to cardiac enzymes, cardiac rhythm, and plasma catecholamines and neuropeptides (Wittstein et al., 2005).

It has also been observed post mortem in people who died under terrifying circumstances such as fatal asthma, suggesting that catecholamines may be an important link between emotional stress and cardiac injury (Wittstein et al., 2005, p. 546).

Who has ever needed to be told when they have been paralyzed by grief and bereft from inconsolable loss that their heart is indeed broken? Now it seems, evidence is emerging that can confirm what human beings have known in their soul all along.

Healing narratives.

As a final element to the *Minding Matters Program* participants were encouraged to share and bear witness to their own and each others stories. These stories are a reflection of the places and spaces within which people construct meaning from their lives. A story that is shared becomes a collective memory and a connective strategy; a way to “...move the moral stance of the counselling out of the therapy room and into the global community” (Speedy, 2000, p. 366). Infertility is a macro problem, a crisis with a universal theme, extensive social and cultural implications; a worldwide story of exclusion, abandonment and isolation (Daar & Merali, 2001).

Akin to the critical phenomenological experience, narratives serve to provide a rich template for the building of personal meaning as well as functioning as the shape against which individuals push and mould to become better acquainted with their unique self; a micro level challenge (Guilfoyle, 2005). Narrative therapy then is:

...a way of working, involving the telling and retelling of stories and alternative stories...perceived as encouraging, thick, rich or multistoried, rather than thin or 'deep' descriptions of, and conclusions about people's lives (Speedy, 2000, p. 365).

Alternative stories lead to what Michael White refers to as 'unique outcomes;' an ending that is different from past experience and alters future expectation (Carr, 1998). Narratives, according to Wrubel et al (2001) also "...assume that people's life experiences make sense to them and they can articulate their understanding through narrative account of biographical events" (Wrubel, Richards, Folkman, & ACree, 2001, p. 176). Narrative therapy technique is also interested in deconstructing the politicized discourse that tends to pathologize people rather than describe them as subjects within their own experience and emerged from Michael White's interest in the work of Michel Foucault (Carr, 1998).

Personal as political.

Foucault introduced the body as a politicized domain in his discussions of power and its natural marriage to the development of the subject. Foucault has written extensively on the histories and institutions that both memorialize and legitimize the way in which we do business with ourselves and each other (Pryor, 2002). Foucault's deconstruction of power and the body politic serves to underscore the inescapable burden placed on all human beings, and people suffering illness or separation, in-particular (Foucault, 1994b).

In ‘The Birth of the Clinic’ Foucault discusses the constructions and nosology of the body’s pathology or disease. Disease is organized according to a catalogue of symptoms that are as independent of the person in whom they exist as paradoxically, they are reliant. Disease (infertility), as entity is itself an end and serves as the object through which doctors are able to practice the development and acquisition of medical knowledge. In Foucault’s depiction knowledge is a unit of functioning that is removed from the person upon whom it has impact. Knowledge is a framework for practice and the gradual approximations or discontinuities that shape and change the meaning of knowledge therefore influence what is ultimately available to be seen (Foucault, 1973). This, according to Guilfoyle (2005) is a reflection of the language of power that removes personal agency from individual experience and places it in the hands of the people and organizations that are the “*evidence, outcomes, or products of power*” (Guilfoyle, 2005, p. 103).

The body then becomes the vessel through which illness speaks, and the discourse between medicine, therapy, morality, and the law only a few of the parts that exceed the sum of the body’s whole. In this context disease is the mind’s representation of what is visually *unseen*. Individuals no longer experience infertility they become infertile; unproductive, non-contributors, hidden and ashamed (Whiteford & Gonzalez, 1995).

Summary

This Dissertation aims to form a critical theory that exposes this legacy of shame while providing an example of self-support that is not attached to a pathological framework or disease model. Despite the experience of infertility as predominantly a

‘woman’s problem’ recent research has demonstrated the importance of viewing it within the context of the couple dyad (Verhaak et al., 2005b). Men have been mostly missing from the experience of parenting and continue to have little voice in the literature with respect to their individual response to involuntary childless (O'Donnell, 2005). This research also works to address this inequity. As a problem that affects the minds and bodies of each partner it is critical that both are considered in the delivery of care, whether the care is physical, emotional, traditional or complementary.

CHAPTER III

METHODOLOGIES AND THEORIES

What strikes me is the fact that, in our society, art has become something that is related only to objects and not to individuals or to life. That art is something which is specialized or done by experts who are artists. But couldn't everyone's life become a work of art? (Foucault, 1994a, p. 109)

Introduction

Chapter I reviewed the underlying principles that support the design, development and utilization of the *Minding Matters* mind-body intervention for effective infertility related emotional support. Chapter II exposed the substantive need to address more effectively the complex emotional distress that results from infertility. An integration of theories is offered in Chapter III to clarify the methodological approach used to explore this study's qualitative research premise and provide the broad based evaluation of the *Minding Matters* program.

The research for this study was divided into two phases: Phase I data collection included a demographic questionnaire and 3 survey instruments while Phase II consisted of 17 in depth qualitative interviews. A full description of the demographic questionnaire

and quantitative scales used in Phase I and the Phase II interview protocol is provided in Chapter IV (**METHODS**). A review of the important findings is included in Chapter VI (**RESULTS**). The following theoretical analysis serves as the scaffolding upon which the qualitative (Phase II) data has been constructed.

Building a Methodological Argument

The expansion in research on the causes of infertility coincided with advancements in treatment; specifically development of the assisted reproductive technologies (ART) (Wischmann, 2003). Despite improvement in the conception and pregnancy rates for certain kinds of conditions, there remains a chasm between functional or unexplained infertility and the influence of stress, as well as the consequence of diagnostic and treatment related pressure on all forms of involuntary childlessness (Wilson & Kopitzke, 2002). As a result of this chasm, well documented and effective psychosocial interventions for infertility are poorly represented in the literature (Boivin, 2003; Schmidt et al., 2005b). There is also a tendency to associate ‘effective interventions’ with pregnancy success (Domar *et al.*, 2000). This increases the burden on those who experience infertility as well as care providers, and confounds the role of therapeutic counseling (individual, couple or group), as a method of adequate care (Kleinplatz, 1999).

According to Frankel and Devers (2000): “Qualitative methods are needed when the questions being asked pose puzzles that are difficult, if not impossible, to address using conventional research approaches” (Frankel & Devers, 2000, p. 253). “Qualitative research generally is often questioned by positivists, perhaps because their concepts of validity and reliability cannot be addressed in the same way in naturalistic work”

(Shenton, 2004, p. 63). This research employs some of the same principles recommended by Guba and Lincoln and include but are not limited to i) credibility, ii) transferability, iii) dependability, iv) confirmability, and are discussed in Chapter IV (Guba & Lincoln, 1989; Shenton, 2004, p. 64).

Qualitative research provides a dynamic background against which difficult questions can be asked and its specific framework the scaffolding upon which a new theory might emerge. Theory is useful in that it can be applied to individual cases rather than linearly across a predicted developmental trajectory. Theory also allows for modifications to occur to the research questions and design as new information is revealed (Frankel & Devers, 2000).

Evaluating Art

ART is the ironic acronym for assisted reproductive technology. Art is also an elusive concept in the hands of great thinkers. Art is creative and created, and defined by some as an aesthetic structure distinctly different from that which can be found existing freely in nature (O'Donnell, 2004b). Art is about imagination, fantasy, appreciation and evocation. For many who suffer the experience of infertility a view of themselves as artistic or productive, worthy or indeed worthwhile, is sacrificed to the belief that without the ability to procreate they are damaged individuals (Roy, 2000). "...I think of it as an illness, you know like when a spouse becomes incapacitated or paralyzed like Christopher Reeve" (O'Donnell, 2005, p. 34). As a corollary to this and other predominant themes infertility, (with or without biological resolution), requires a well described, dynamic method of addressing emotional and physical struggles (Daniluk, 1988; Greil, 1997; O'Donnell, 2005; Wilson & Kopitzke, 2002).

It is recognized that this study is brought about by the equivocal nature of mind-body medicine in general and the micro-macro impact of being infertile in a pronatalist culture, specifically (Park, 2002). In addition, the task of developing and evaluating new intervention methods while meeting the requirements of *evidence based practice* and consumer demands remains “...problematic” (Tolson, 1999). Evidence based practice for the purpose of this research is defined as: “...the integration of the best research evidence with clinical expertise and patient preferences and values...” (Barlow, 2004, p. 870). Best research evidence is reflected by the comprehensive literature review and sets the foundation for developing ‘clinical expertise’. Client evaluation is critical to determining whether an intervention achieves its stated purpose. This study respects the power of participatory research and adheres to the principal that, “...user involvement in mental health service evaluation is seen as essential if service provision is to be responsive to their needs” (Truman & Raine, 2001, p. 217). This research works to:

- i) construct a bridge between the object of ART and the subject’s life as an artful experience;
- ii) engage participants’ in the work of evaluation and practice development;
- iii) decrease the distance between research and clinical practice.

Minding the Research Gap

Since Greil’s work in 1997 there has been some pressure to respond to the increasing awareness of the social implications and pressures of the infertility experience (Greil, 1997). The most recent research continues to inform us that a lack of partner and network support is negatively correlated with a sense of wellbeing and confidence regarding treatment success (Boivin & Schmidt, 2005; Peterson et al., 2006; Verhaak et

al., 2005a; Verhaak et al., 2005b). In addition, evidence produced in other areas of medicine and the health sciences has demonstrated a link between physical health conditions, perceived levels of stress and adaptive coping (Davidson et al., 2003; Kosslyn, Cacioppo, Davidson, Hugdahl, Lovallo, Spiegel, & Rose, 2002; McEwen & Milliken Hatch, 2005; Mindes et al., 2003; Rosenkranz, Jackson, Dalton, Dolski, Ryff, Singer, Muller, Kalin, & Davidson, 2003; Solberg, Halvorsen, Sundgot-Borgen, Ingjer, & Holen, 1995).

Clinics that integrate these findings into the development of psychosocial support programs are poorly described in the academic literature. Research that discusses from the ‘client’ perspective, how well these kinds of programs work although limited, has begun to demonstrate the need to include meaningful participant voices in healthcare program evaluations (Truman & Raine, 2001). This dissertation is an important effort to close the present gap.

Combining Methodologies and Theories

The literature review in Chapter II documented the history of infertility. Significant technological advances have driven the ongoing dependence on positivist research methods for justifying infertility’s current medical and psychological treatments (Boivin & Schmidt, 2005; Wilson & Kopitzke, 2002; Wischmann, 2003). However, the elusive relationship between *stress* and reproduction remains (Wilson & Kopitzke, 2002). This section of Chapter III forms an argument for utilizing a comprehensive and inclusive qualitative research approach by integrating elements of feminist, constructivist and critical theory. This study’s questions and research design is viewed as a guide to personal clinical practice rather than a definitive response to “what is *best* counseling

treatment?” Giving evaluative consideration to the voices of those who must navigate infertility implies that “...the client becomes the one holding the required knowledge about the treatment, rather than the one looking for some useful knowledge” (Shamai, 2003, p. 457).

Beyond Positivism

This study sheds light on a phenomenon that has been principally understood through a medical or positivist research approach and aims to provide support for a profile of emotional care that goes beyond that approach (Anderson et al., 2003; Benyamini et al., 2005; Berghuis & Stanton, 2002; Boivin et al., 1998; Cwikel, Gidron, & Sheiner, 2004). It is likely that the abundant use of quantitative research design in the infertility literature has been driven by the compelling argument that western medicine is the point of last resort for many couples struggling to conceive a child; an example of the end (dependent variable), justifying the means (independent variable) (M. Marsh & Ronner, 1996). It is also the heritage of post Enlightenment rationalism which stands grounded in a positivist system of *knowing*; a system that sees reason as truth and science as progress (Bogdan & Biklen, 2003).

Perhaps the most persuasive argument for conducting research in the positivist tradition is the tendency for people trying to conceive to view therapeutic options that are intrinsically linked to the outcome of live birth as the only ones that are effective (O'Donnell, 2004b). Until we fully understand the complex nature of both the mind and body on an individual's physiology we cannot afford to continue to isolate the effect of one upon the other (van Gelder, 2005). Nor must it be forgotten that with or without an

achieved pregnancy people who experience infertility can continue to suffer emotionally and that this has long-term consequences for family development (Fisher *et al.*, 2005).

Taking a Risk

By examining the mind-body concept this research takes a controversial position. The contentious relationship that exists between the medical search for answers, homeopathy sits as the monolith that continues to further divide and separate the mind from the body (van Gelder, 2005). The language of science and medicine is a systemized global method for presenting conditions as observed and the body is the vessel through which these symptoms speak (Foucault, 1973). Personality is also representative of cumulative behaviors and thoughts that forge to reflect the human character, which science has also attempted to define (P. Robbins & Jack, 2006). However, the concept of spirit, faith, and soul remains vague and elusive sitting somewhere between theology and the 5th dimension (van Gelder, 2005). There is no challenge to the belief that these concepts exist. What they consist of is what remains in doubt. This research opens the door to theoretical perspectives that challenge the post Enlightenment modernity position that makes measurement the master and mind distinct from body. Rather than provide answers this research is inquiring into the less considered practice questions.

How do we decide what to do with our clients as counselors and how effective is what we ultimately do? This dissertation is a beginning effort to respond to this complex question. Most importantly, the theoretical perspectives included in this study design insist on: "...recognizing our engagement in partial meaning making, recognizing that

our research actions will change others, and understanding that we too must be open to change” (Ropers-Huilman, 1999, p. 24).

A Multilevel Problem: A Multi Theory Approach

The literature review contained in Chapter II revealed the extensive amount of academic interest that has been focused on the problem of involuntary childlessness. By its very nature this attention is not limited to the work of scientists and theoreticians; we all have a stake, *and are therefore stakeholders*, in human reproduction, all delivered from the universal belly of ‘mother’ (Guba & Lincoln, 1989). Public opinion has weighed in over the centuries on the claimed rights of human beings to reproduce (Warnock, 2002). Social, cultural, religious and political voices lent their perspective to what Thompson described as “...ideas about women, steeped in ancient humerol theory...disguised as science or unexamined in the wake of changing worldviews (Thompson, 1999, p. 19).

It is important to reveal the historical template that has given rise to the current discussion of both infertility and parenting as it is framed within the larger discourse of what it means to be a man or a woman, male or female (Goldner, 2003). The condition that the *subject* finds itself in today is a function of that legacy and cannot be viewed through the singular lens of either medicine or psychology or medical psychopathology. In order to describe the distress that develops in people’s lives as part of this journey it is imperative that its many origins are well understood.

Liberal Feminist Theory

The magical thinking that has surrounded fertility over the centuries has been on a crash course with radical feminist theorists, some of whom claim that, "...many young women make conscious decisions to bear children in order to convince themselves that they are alive and creative human beings" (Davis, 1993, p. 362). This study adopts a liberal feminist/constructivist critical approach. This is an academic effort to challenge the status quo of empirical research, (whose objective stance runs the collateral risk of losing contact with its subjects), as well as broaden the audience with mind-body medicine (Agger, 1991).

Although liberal feminist discourse might acknowledge the cultural imperative that continues to brand women as productive only if producing children, it also recognizes the academic dishonesty in abandoning its principle of freedom of choice by chastising women who want to become mothers, at any cost.

...the overwhelming majority of women who become mothers do so without having their moral worth scrutinised. Their affairs and innermost secrets remain private, unlike women seeking medically assisted procreation, who are often denied treatment because they are considered unsuitable as mothers (Pfeffer, 1997, p. 2).

Pfeffer's statement points a finger at the painful 'double whammy' that strikes particularly at women who have been unable to conceive. Not only are they held to a higher standard of moral integrity but in the eyes of radical feminism have allowed themselves to remain victim to the patriarchal mandate that says you are no one until you have birthed someone (Davis, 1993).

It is remarkable, despite some of the significant advances of the 20th century, that the relative success rate of the assisted reproductive technologies (ART) is not higher (Resources, 1997). Evidence to support the conclusion that infertility generates

significant emotional, relational, and social stress is vast (Boivin, 2003; Boivin, Takefman, Tulandi, & Brender, 1995; Domar, Broome, Zuttermeister, Siebel, & Friedman, 1992a; Domar et al., 1999a; Eugster & Vingerhoets, 1999; Greil, 1997; Miall, 1994). Deductive reason tells us that most people who struggle with infertility suffer a psychic toll. Not a psychiatric disease, or even a psychopathologic dilemma, but an ache of the spirit that is expressed through a human being's affective barometer; measured by scientists with depression scales, symptom checklists, state versus trait inventories, and personality profiles.

Although there are some researchers who have provided rich and powerful narratives of the lives of the men and women infertility has touched, there is an urgent call to unite the divergent research paths of quantitative theory and qualitative paradigms in the quest for greater understanding of the search for children (Daniluk, 2001; Greil, 1997; Inhorn, 2004). Feminist, critical, and constructivist theory all represent modems of challenge in our current age of technological abstraction (hyper-reality); where the particular hegemony of the science of medicine has managed to cloud medicine's intrinsic art.

A Critical Constructivist Theory

Critical constructivism stands in direct challenge to the standards of positivism not because of an attempt to disprove, that would mean employment of its own philosophy against itself. A critical constructivist theory has a mandate to seek out the conflict inherent to undisputed principles and to make links between what *is* and what is socially constructed (Agger, 1991; Schwandt, 2001). Critical theory is represented by the work of post modern writers such as Habermas and Foucault whose work is seen as an

extension and expansion of the Frankfurt School: "...the theoretical tradition...developed by a group of writers connected to the Institute of Social Research at the University of Frankfurt" (Denzin & Lincoln, 2000, p. 279). Social construction in post-modern thought has particular relevance in the medical technologies which make it increasingly possible to transcend the function of the physical body (Barnard, 2000b).

The critical tradition makes space for multiple avenues of thought; dialectic as a method of academic democracy. Critical theory insists that social, historical, and cultural forces are inseparable effects on how individuals come to view themselves. Feminist theory according to Hutchings (2005) "...is, by definition critical theory. That is to say it is premised on a critical approach to understanding and judging the world" (Hutchings, 2005, p. 157). It is also interested in women's relational ways of knowing that Gilligan describes in her seminal work 'In a Different Voice' as "...seeing in the dilemma not a math problem with humans but a narrative of relationships that extend over time" (Gilligan, 1982, p. 28).

This researcher takes the position that the qualitative experience of infertility for men and women, as well as its multiple treatments play a role in the therapeutic impact of those treatments. In other words, it is as important to explore the *meaning* attached to any positive or negative effects of treatment intervention *as well* as the individual's primary struggle with involuntary childlessness. A critical constructivist inquiry demands that the cultural, social, historical and economic interests are considered in problem analysis. Such analysis serves to demystify the deductive logic of the positivist strategy which seeks to comment only on what it knows it can measure (Agger, 1991). Inductive

reasoning seeks to address universality rather than generalizability; humanity as the common experience rather than the typical response.

Hope and Critical Theory

Smith (2005) brings attention to the elusive concept of 'hope' and its philosophical exploration by critical theorists. Hope represents a quest for wish fulfillment; a desire not yet met and a state traditionally critically maligned "...it deals with an unsatisfactory present not by practically engaging with it, but by projecting an imaginary future in which satisfaction is miraculously secured" (N. H. Smith, 2005, p. 47). The instillation of hope is also, according to Yalom a principle tenet of the counseling relationship and that "...high expectation of help before the start of therapy is significantly correlated with a positive therapy outcome" (Yalom & Leszcz, 2005, p. 4). A tender negotiation of the preservation of hope and its relationship to anxiety as well as passivity, i.e. the wait for something to happen, and its particular relevance to the unfulfilled desire to have a child supports the use of critical theory as a tool for analysis of this unique position.

Critical theorists are in some ways as uncomfortable with the elusive notions of hope and faith as positivist researchers who would rather leave alone abstract human beliefs that defy rationalization. However, the majority of research participants in Phase I of this study (approximately 70%) stated "I hope to have a baby" as their number one reason for attending a mind-body workshop. Participants also spoke of the hope that their suffering would be understood by their larger social network and society as a whole; a

form of 'social hope' that addresses their desire to be included in the greater circle of life with or without children (N. H. Smith, 2005). Matching this participant expectation to a realistic intervention outcome is imperative. Recognition of the obstacles to achieving both reasonable expectations and therefore an achievable outcome will be examined through the participants' and researcher's collaborative voice. Hope, like expectation is attached to the potential for disappointment. Bearing in mind the statistical evidence in Chapter II, which reports an overall pregnancy rate of anywhere from 4% - 45% depending on age, for individuals or couples receiving assisted reproductive treatment, a great number of people have their hope devastated each month (Clay Wright *et al.*, 2002). This dissertation explores that devastation and its impact on the relationship between client and provider; participant and researcher.

Evaluative Research

Both feminist and critical theory shed light on the power relations that exist between research observer and research participant (Deveaux, 1994). These theories also acknowledge the divergent goals and influences of different stakeholders in those relations and bring attention to the impact that third party interest might play in deciding whether a treatment is either bona fide or 'effective' (Norcross et al., 2006). Given that program evaluation is one of the aims of this study it is important to distinguish between the interests of program providers and program consumers, (Tolson, 1999). When evaluation is collaborative it unites the needs of participants with research evidence and brings further attention to the frail connections between hope and expectation, and what constitutes an 'effective' intervention.

Evaluative research also places the researcher in a position of risk. The risk that what they ‘believe they know’ can be called into question and challenged. Evaluative research helps to address the difference between an effective intervention and simply an effective policy (Atkinson, 2004). Evaluative research can also help take the lid off what Atkinson describes as the double bind of “...public scrutiny,” viewed as the temptation to support a democratic ideology rather than a commitment to the performance of democratic acts (Atkinson, 2004, p. 115). In other words, we convince ourselves that by conducting research we have respected the mission of movement toward a practice of greater certainty. What we fail to recognize however is that this mission is only as valid or reliable as its foundational belief. Atkinson asks: “...for whom is this transparency intended? Is it for us to look *out* or for those regulating, controlling, (and where they deem fit), punishing us to look *in*?” (Atkinson, 2004, p. 116).

Guba and Lincoln (1989) point out that, “...*every act of evaluation becomes a political act*” (Guba & Lincoln, 1989, p. 35). For the purpose of this research ‘political’ refers to how evaluation alters as a function of the relationship between the social, cultural and political impact of differing stakeholder positions. For example: how is what I want different from what the research participant, their extended family, or society might want? Even quantitative research is not value free; it is imbued with the passion and interest of the curious observer, “...to approach evaluation scientifically is to miss completely its fundamentally social, political, and value oriented character” (Guba & Lincoln, 1989, p. 7). This research design brings together elements of measurement, description, and interpretation in a way that places knowledge back into the hands of the

participant while accepting that such knowledge is limited by what the researcher has chosen to examine.

What is at once critical about Guba and Lincoln's fourth generation strategy is the mandatory respect for the absence of 'pure objectivity' in any form of empirical research. Construction of meaning is situational, value dependent, socially and culturally influenced, runs the risk of helping and hindering all impacted parties, and drives the long-term action recommendations of any research (Guba & Lincoln, 1989). Constructivism runs a parallel path to critical theory, expanding and expounding on various methods of viewing, interpreting and evaluating the world, creating room for what can be as much as for what *is*. Taking note of the power relations that influence how people can be in the world informs the researcher of her own role in this dynamic (Hutchings, 2005).

As clinicians working in the area of infertility we are bound by our professional commitment to engage in our client's experience, expand their and our knowledge of what it means to suffer infertility, and develop and apply a form of therapeutic intervention that does justice to the struggle; "...to devise solutions with local meaning and utility" (Guba & Lincoln, 1989, p.47). Guba and Lincoln suggest that an inflexible commitment to positivist methodology and the principles of generalizability obstruct the researcher's ability to seek explanations that can provide comfort and support on an individual level.

Bridging the distance between theory and praxis, participant observer, deduction and induction is a large project. This research takes a small step toward that by utilizing traditionally quantitative measures and descriptive techniques and incorporating them

into the participant interviews in systematically unorthodox ways. This treatment is the researcher's way of remaining connected to critical theory and hermeneutics ; "...to develop a form of cultural criticism revealing power dynamics within social and cultural texts...combined with an analytic flow between abstract and concrete" (Denzin & Lincoln, 2000, p.286).

Identifying stakeholders is paramount when using an evaluative paradigm. There are many stakeholders invested in infertility: the individual, the couple, the family, the physician, the lawyer, the clinic, the drug company, the insurance company, the multiple voices that speak for God, the child who is yet to be born. Stakeholders therefore can have conflicting interests, exposing those interests and providing information is critical to the disbursement of power. Allowing stakeholders to have voice through this process ensures a mutual respect for invested parties and ultimately ensures that the evaluative process has credibility.

Clearly the multiple parties who have interest in the problem of infertility are not all represented given the particular scope of this research. However, using the literature review as a system of discovery helps to highlight the various claims that have been made on their behalf and also highlights the power disparities that exist, most significantly with respect to access to diagnosis and treatment and its collateral effects (Pfeffer, 1993, 1997). Who I am in this negotiation is an important part of the theoretical challenge to search, discover, and report sincerely on what we, the researcher and participant collaborator find when we venture 'out there'.

Evaluation for the purpose of this research is primarily theoretical (rather than statistical) in that the mind-body intervention is built upon a series of principles that have

demonstrated success in supporting individuals who struggle with stress and its multiple emotional and social effects. Utilization of the selected methods in the *Minding Matters Program* is based on selection criterion extracted from evidence in psychotherapy in general. These criterion, as outlined by Norcross et al (2006) should include: best fit intervention for stated condition, best fit intervention for client/therapist style, best fit intervention for circumstances and settings (Norcross et al., 2006).

Researcher Perspectives

Tierney describes the ability to place the researcher within the construction of his or her work as requiring “undaunted courage” (Denzin & Lincoln, 2000). Courage is needed, according to Tierney because it “...allows the author to reach across boundaries within him or herself” (Denzin & Lincoln, 2000, p. 550). Despite the caution that is often weighted against introducing one’s own story into the text of any research, the feminist and critical theory position suggest that “subjectivity is considered a part of all research, and moreover is an important aspect of the work” (Bogdan & Biklen, 2003). Therefore, my own interest in infertility and the personal narratives that have guided me to this project are *also* critical.

I am a triplet, born 10 days early sandwiched between two boys, the last 3 of 7 children. My mother was 43, tired, un-partnered and daunted by her own failing courage. It hardly mattered in those early years that my name was never used. The three of us remained connected to each other through the word that defined children born of the same mother on the same day in the same year; the triplets. As Guba and Lincoln (1989) have said, constructivism is relative, and I only had my own circumstances to compare things against (Guba & Lincoln, 1989).

I thought life was hard as a little girl, and particularly hard because my mother was a single parent, bi-racial, and most of the time quite mentally unstable. I certainly developed an early understanding for power relationships and that I was likely on the wrong side of an unfathomable equation. All of my mother's children left home at unholy ages, some as young as 9 years old, only intermittently to be heard from again. I began to ask early what it meant to be a family, to be a child, to want a child, or to have a child. I committed in my own mind to simply not needing to have *that*. I cringed on many occasions when it was suggested to me that my parents must have really "gone at it" to have had 3 babies all at once. Fertility seemed to be more the problem in my house growing up.

When I left high school at 18, the last child in the house and the only one to go on to college, I had made a tacit agreement with myself to never reproduce. Offspring were synonymous with tremendous burden. It hardly mattered that some unanticipated circumstance or unpredictable desire would loiter with the intention of destroying this pact. When I found out at 23 that I would not be able to conceive, "...you will not have a baby of your own," he said, my heart temporarily held its breath. This is not an easy thing to endure.

It was as though the words represented something far deeper than the truth of my anatomy. They sat like sharpened barnacles ready at any and all moments to penetrate my skin. I wrestled with this new urge and urgency that enveloped me, which upon reflection had very little to do with wanting a child and everything to do with being denied consent. I frequently made the journey from passionate despair to the logic circuit in my head that told me I would be able to have a family in some, as yet unknown way.

I began actively looking for medical solutions to circumvent my frozen tubes, anticipation is preparation I thought. I finally found someone who would resurrect my fertility by operating for 6 hours on the area of my body I believed held my only hope of living a truly productive life. It didn't work. No babies came and my drive to become a mother began to steer my life down a narrow path toward an insecure destination.

I followed Louise Brown, the world's first test tube baby, as she started nursery school, pre-school, dance classes, just like all the rest of the little girls. By 1986 I had my own attempts at in-vitro fertilization. "We can't get to those eggs...they are bunged up...this is probably not going to work for you." I felt bunged up, stuffed inside a definition that told me only what I didn't have, couldn't be, shouldn't want, and mustn't mind. To be sure this was not always the way in which I was treated but after it became the way I felt it was mostly all anyone could ever see. Who or what would want to impregnate that?

As irony would have it, although I left England and went to Canada when I finished high school it seemed England was where I would have to return with my partner if we were to ever have a baby. So many people held my power in the capricious palm of their own hands. The Consulate who would not give my partner a visa, the first clinic in the United States which stated "we do not treat unmarried couples" we were married but did not share the same name, and the company that fired me because I needed too much time off. No matter it was all for a good cause.

If I sound cynical then it is surely because I was. I did not conceive through the first attempt in England either and was told my frozen embryos were 98% likely not to survive the thaw. However, between packing them in ice and unpacking my own soul,

something remarkable happened. I sat on my hands for the first time in 7 years. I did not cycle watch, clock stop, take my temperature, or feel my breasts. I loved my husband, moved my limbs, fed my heart, and stopped holding my breath. It didn't matter that this would not unblock my fallopian tubes it was releasing my spirit. The onerous weight of pregnancy had somehow been lifted and even though it did not mean the wish for a baby was gone, the belief that I would die if I was asked to live a life without children changed. Most importantly, it was a decision that I made.

It didn't matter anymore what I named this thing, or any other thing. It mattered what it was and did to me and who I could be despite it. I was no more barren than I was an irritable bowel. Finding a way to make sense of it all hit me while on a flight across the Atlantic. When I disembarked from the plane I recorded its name, 'Maid of the Sea,' and watched pregnant and in horror as it was blown from the sky in Lockerbie, Scotland some 16 months later. Life is and always has been fragile.

What I also took away from the science and technology that gave me my sons was a remarkable gratitude for Robert Edwards and Patrick Steptoe, without whose work and words, and the labor and love of the inquiring minds who came before and since them, we might still be stuck with frozen tubes. Their stories did not begin with in vitro fertilization, anymore than mine. When Patrick Steptoe and Robert Edwards successfully helped Lesley and John Brown create their first child it was after years of collaborative research, numerous trial patients, and indeed the development of a relationship of intense importance between all of the participants (M. Marsh & Ronner, 1996). The faith inherent in these relationships it would seem was every bit as vital to the outcome of a

healthy baby as a mature follicle, stable hormones, ambitious sperm, and a receptive uterus. The marriage between faith and truth is important to this research.

The philosophical tension between these two positions reflects not only who I am but the point I have chosen to take on the qualitative research spectrum; between the critical and post-modern position. I am raising questions and wanting some method for evaluating those questions, not to provide definitive answers but to stimulate the inevitability of further questions. I am also trained as a physical therapist and yoga teacher and bring to bear that perspective to my critical understanding of the impact of one's emotional state on physical health. Through my years of clinical practice as a developmental specialist working with families who have experienced infertility and extremely premature birth I have witnessed the tremendous loss that surrounds not having children as well as having them, and having them too soon.

CHAPTER IV

METHODS

Introduction

This two-phase study is viewed from the premise that the inability to conceive when desired, either as part of a couple or individual, male or female, is a profound and transforming life experience (Greil, 1997). Specifically the study examines three major areas of stress encountered by individuals and couples experiencing infertility: (1) The challenge to personal identity that is reported as a result of being unable to fulfill a desire for biological parenthood (Letherby, 2002); (2) The disappointment and or conflict that develops within social relationships as a consequence of a perceived failure to meet parental role expectations (McQuillan et al., 2003); (3) The perceived stress effects of infertility treatment, treatment cost, and exploration of the strategies that are implemented to cope with this stress (Leite *et al.*, 2005; Olivius *et al.*, 2004; Verhaak et al., 2005a).

Development of the Research Questions

The research questions are divided into two parts and were constructed to address one particular type of counseling intervention as designed by one researcher. The development of the research questions evolved from the existing literature on stress and its relationship to infertility and the desire to better match a method of effective emotional support to what people who struggle with infertility say that they want or need. Information from the Phase I demographic questionnaire and surveys establish context and provide baseline data on participants' perceived level of generalized distress, infertility specific stress, as well as typical coping processes. The Phase I data collection and analysis responds to the first research question only: What is the study participants' perceived level of general distress and specific fertility related distress prior to attending the workshop, 6-10 weeks after completion of the workshop and at 12 months post workshop? What coping strategies are commonly utilized to manage stress?

Mixing Methods

Descriptive statistics provided the mean scores for each subscale on the survey instruments. Results were tabulated and explored for first and second survey administration, gender, and between group differences using SPSS 11.5 statistical package. Univariate analysis were to detect outliers and skewed scores. Scores from studies conducted with individuals experiencing infertility (Domar, Friedman, & Zuttermeister, 1999b) provide a reference point for the level of specific infertility related distress and generalized stress in this particular study's participants' (Domar et al., 1999b; Petersen et al., 2006). Due to the small sample size and exploratory nature of this study in general, noteworthy findings were examined from the perspective of plausibility

and fallibility: i.e. how accurately are study participants' experience of infertility reflected in this research and how well are those findings tracked, documented, and represented? Infertility is a story of exclusion from a universal cultural norm and requires understanding across the multiple levels at which it has an impact. According to Schwendt (2001) qualitative

...research should be a kind of cultural criticism – both a better way of understanding ourselves and our society, and a way of changing or transforming same...the understanding or knowledge that one acquires in interpretation is already a kind of action-oriented self-understanding...we study the particular case to...permit the application of general knowledge.”(Schwandt, 2001, p. 265-266)

Independent and paired sample t. tests/one way ANOVA, and bivariate correlation were performed on the data. Although relationships are discussed due to the small sample size and type (convenience), definitive conclusions are not drawn (CHAPTER VI). These results cannot be generalized and are provided to add challenge, contrast, and support to the qualitative text.

The time lapse between Phase I and Phase II of the research was one year and created a reflective distance for participants to assess how much of the material from the workshop they found useful over time. The second set of research questions were built around a narrative summary and graphic representation (APPENDIX G) of each participant's responses to the Phase I surveys, and was provided for participants to read at the time of the in-depth interview. The following model (Figure 1) is a breakdown of the mixed method sequential design used in the data collection. Words that are capitalized and/or bolded reflect the relative importance of the research approach used in this dissertation. The model is adapted from Ivankova, Creswell and Stick's (2006) study.

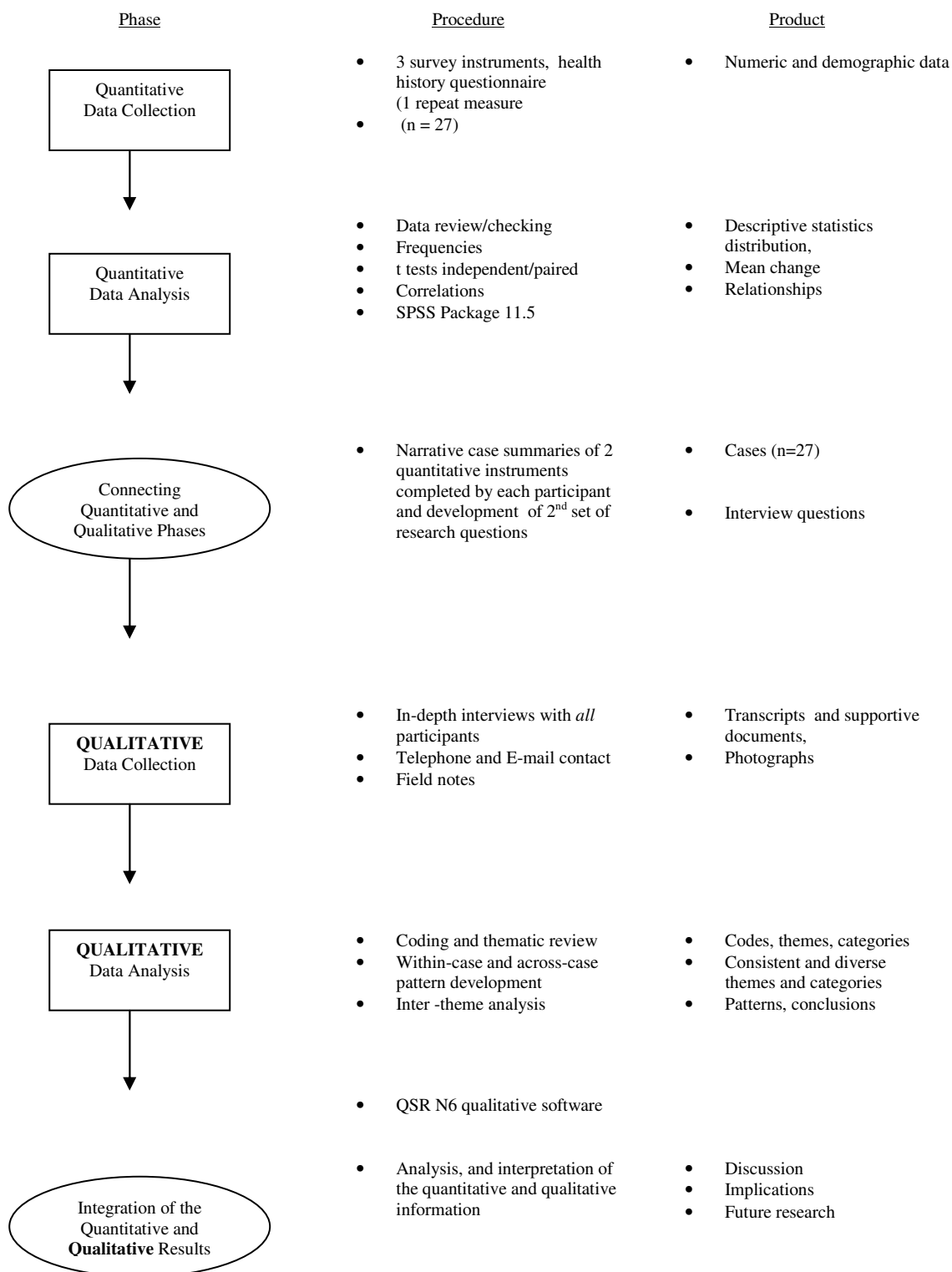


Figure 1. Visual model of mixed-method sequential design

Phase II of the study consisted of evaluative in-depth qualitative interviews. A deep level of collaboration helps to diffuse the role of researcher and participant and supports partnership in the research. From a constructivist position the sharing in participant knowledge also influences the direction of power in the research relationship. This is especially important for clients' whose emotional experience with infertility has created isolation and a sense of personal failure related to culturally driven social identity norms.

Research Questions – Part 1

1. What are the study participants' perceived levels of general distress and specific fertility related distress prior to attending the workshop, 6-10 weeks after completion of the workshop and at 12 months post workshop? What coping strategies are most commonly utilized to manage the stress?
2. What impact does a one-day mind body program for individuals and/or couples facing infertility have on their experience of infertility related stress?
3. How well do participants understand and apply the principles taught in the mind-body workshop to their life and their emotional self care after completion of the program?
4. What are the benefits and limitations associated with a one day program? How can this format and the manual content be improved upon?

Research Questions - Part 2

The following two questions were intended to evaluate how well the Phase I surveys captured participants' reported memories of their stress and coping at the time of

instrument completion and facilitate phenomenological discussion between individual participants and researcher as well as between couples.

1. How well do quantitative measures of psychological, social and somatic distress reflect participants' qualitative experiences and descriptions of their distress?
2. What, if any, impact does labeling or categorizing of past symptom distress (reflective of a medical model), have on participants' perception of their current self?

Participants

Most of the twenty seven participants (10 men and 17 women) were recruited for either a women only or couple workshop during a one day infertility conference (RESOLVE of OHIO), held at the Cleveland Clinic Intercontinental Hotel and Conference Center on October 29th, 2004 in Cleveland Ohio. Two women were referred by reproductive specialty practices in the Cleveland area and two couples from Toledo self referred after hearing about the study from their local Resolve support group. Three women requested that they attend both workshops. Approval was given as it was felt that these women might serve as key informants (assist in describing differences between each workshop), in the follow-up phase. Participants did not have to be in active treatment but had to have received an infertility diagnosis, either primary or secondary, from a medical professional. Female participants were required to be within acceptable reproductive age (18 – 45). There was no similar limitation placed on men.

Cleveland is a Midwestern city of just under 500,000. The urban population is approximately 51% African American and 41% Caucasian however the surrounding

suburban communities reflect a substantially different racial demographic. The majority of attendees at the conference were Caucasian and non-residents of the city of Cleveland proper. Participants were self referred and declared their interest in the project by placing their name on a sign-up sheet posted at the Conference Center. Initial approval to conduct Phase I of this study was requested from the Internal Review Board (IRB) at Cleveland State University October 22nd, 2004 and was granted November 4, 2004. The Phase II IRB was approved March 26th, 2006. After Phase I approval participants were contacted and informed of the prospective workshop dates (April, 2005).

Participants were sent a letter explaining the purpose of the study and were provided with an informed consent requiring their signature (APPENDIX F). Participants were also assured that all information would be held under the strictest confidence and notified of any potential risks associated with their participation. Counseling and/or psychological support was also made available throughout the duration of the study from an independent clinical practitioner. The informed consent was returned prior to the workshop day in a self addressed stamped envelope. At this time participants were assigned an ID number and all other data collection was conducted using this as confirmation of identity.

Demographics

The following information was collected via mail in Phase I of the study and before the workshops using the *Fertility Health History Questionnaire* (APPENDIX A), which was specifically designed for this research. The instrument asked general demographic information as well as details regarding fertility history, medical history,

social support, and if relevant, counseling history, and objective for attending the workshop. All twenty seven questionnaires were completed and returned.

All of the participants self described as Caucasian, one couple was Jewish and the remaining reported as Christian (Catholic, Protestant, Lutheran, and Presbyterian). All participants disclosed as heterosexual. All but one couple was married and all but one woman in the women only group was married (this same individual participated in both workshops and was in a long-term relationship > 6 years). The majority of the female participants from both groups reported a college education, 6 had a master's degree, 11 had a bachelor's degree, 1 had an associate degree and 2 were high school graduates. Among the male participants 1 had a master's degree, 5 had a bachelor's degree, 1 had an associate degree and 3 (30%) were high school graduates. Approximately 37% reported a household income of \$100,000 or above, 30% between \$75,000-\$100,000 and 33% between \$50,000-\$75,000.

Table 1.

Summary of Basic Demographic Data

Participants	N	Age Range	Mean	Years of IF	Mean	Education Range yrs	Mean
Women	7	30- 42	36.2	2 - 8	3.85	12 - 18	17.6
Both	3						
Couples	10	28 - 47	33.8	1 - 4	2.35	12 - 18	16.55
Men	(10)	29 - 47	35.1			12 - 18	16.4
Women	(10)	28 - 42	32.4			16 - 18	18.1

Note. Years of IF = number of years considered infertile
Both = women who attended both workshops

Fertility Status

The majority of female participants (95%), reported experiencing primary infertility. In the female only group 40% described female factor infertility, 30% combined, and 10% unexplained (one participant declined to respond to the question). In the couple group 50% reported female factor, 20% combined, 10% male factor, one couple described a genetic problem, and another couple declined to respond.

Participants also responded to questions about their diet and exercise habits and provided height and weight information for estimation of *Body Mass Index* (BMI). Body Mass index is calculated by dividing weight in kilograms by height in meters squared and reflects the muscle mass to body fat ratio (Wittemer, Ohl, Bailly, Bettahar-Lebugle, & Nisand, 2000). Elevated BMI is believed by researchers to have a negative influence on fertility status, particularly in men and women who have a BMI greater than 30, i.e. in the obese range (Barbieri, Sluss, Powers, McShane, Vitonis, Ginsburg, & Cramer, 2005; Koloszar, Fejes, Zavaczki, Daru, Szollosi, & Pal, 2005; Qublan & Malkawi, 2005).

Table 2.

<i>Body Mass Index (BMI – kg/m²)</i>			
BMI Range	18.5 – 24.9 (< 25) Normal Range)	25 – 29.9 (< 30) Over Weight	30 or Greater Obesity
Women Only Group	n = 4	n = 3*	n = 3
Couples			
Men	n = 2	n = 5	n = 3
Women	n = 4	n = 3	n = 3

Note. * This represents some duplication for the 3 women who attended both workshops

The BMI's are reported for descriptive purposes only and with the caveat that BMI calculations in people who have a large percentage of muscle mass to body fat ratio will have a falsely elevated BMI index due to differences in critical threshold for men, women, or athletes when compared to more sedentary individuals (Halls, 2005). As indicated by Table 2 two thirds of participants had a BMI over the 'normal' threshold and almost 50% of those had BMI's in the obese range. (This appeared to be somewhat equivalent for men and women).

Treatment History

Three of the women only group and five of the couples had attempted at least 1 in vitro fertilization procedure (IVF), some as many as 3. In addition, three women reported having tubal reconstruction surgery and one male underwent a repair for a varicocele. Several of these same participants had also undergone two or more intrauterine inseminations (IUI) using clomid or a combination of clomid and injectable drugs.

In the women only group one woman reported using nutritional supplements as a method of enhancing her fertility (this participant did not have a cause for her infertility and was 42 years old). Four women reported using acupuncture in addition to receiving traditional medical treatment and two were participating in a yoga/meditation class sporadically.

In the couple group four women reported receiving acupuncture (not with their partner), and one woman had received Clear Passage Therapy (a manual technique designed to help break up pelvic adhesions). Three men reported using vitamins C and E to help with "...sperm production" and with the exception of the male who underwent repair of his varicocele no other men were receiving medical treatment.

Counseling History

Six of the women in the women only group reported having been offered counseling and two of those women indicated that they had used it and found it to be helpful. The remaining women stated that this was not a service that was offered but that they would have liked it to have been.

In the couple group there was a disparity between men's and women's responses and it was not clear whether partners had participated in couple sessions. (The three men who responded yes to this question were in relationships with women who also sought mental health support; it is possible that these couples attended at some point together). Only three men reported that they were offered counseling and had attended several sessions and seven reported it was not offered and that it was a service that at least four of them stated they would have wanted. Women reported being offered counseling much more often (seven women responded yes to this question) and five indicated they had

seen a mental health professional. Of the three women who indicated counseling was not made available to them only one stated that she would not choose to use it if it had been.

Social Support History

In the women only group the majority found confiding in a friend was their most likely form of social support (> 60%). Approximately 40% found they could talk to their partner, however several noted that “he just did not understand.” Several women also had family members that they could confide in and two were participating in on-line chat rooms or attending a support group (RESOLVE). Social support is a concept that is acknowledged by researchers to have an impact on physical health and emotional wellbeing. Social support in the context of this study is defined as: “...the assistance and protection given to others, especially to individuals...tangible as in financial aid, or intangible as in emotional help” (Hinson-Langford, Bowsher, Maloney, & Lillis, 1997, p.95).

In the couple group only 40% of women reported that they confided in their spouse some of the time, the majority seeking social support from friends (90%), and 40%, on occasion from family. (Clearly there is overlap between categories). Men indicated (50%) that they confided in their wife, and 40% found it easier to talk to a friend or other family member. One man indicated he had no one to confide in and another reported “it is easier to talk to strangers; they don’t judge.”

Women, Couples and Groups

Although all participants collaborated in the Phase II interviews, either individually or as couples, text analysis for the purpose of this study and in the interest of information management is conducted on two main levels: 1) the experience of attending

the women's only workshop; 2) the experience of attending the couple workshop. Within each of these two main levels themes emerged that were relevant to individuals, women and men separately and collectively, as well as within and between couples, and these themes are also evaluated and discussed (CHAPTERS V and VI).

Participants as Collaborators

Often research results become the property of the researcher. In particular, an individual's survey responses used to inform research conclusions and interpretations are often not shared with participants. This study is interested in peeling back this shroud of mystery for participants and challenging the discursive practice that seeks to, label and define, rather than hear an individual's infertility experience (Kleinplatz, 1999). More importantly there is evidence to suggest that when participants are included in these critical components they are able to expand on or "...identify problems" and researchers "...were able to build upon this dialogue and make users more active partners in the research process" (Truman & Raine, 2001, p. 217).

Researcher Interviewer

The researcher collaborator is a multi-racial (Nigerian, English, Irish) female with a bachelor's degree in physical therapy (University of Toronto) and a master's degree in community counseling (University of Wisconsin Oshkosh), currently completing her Ph.D. in Urban Education (counseling emphasis) at Cleveland State University. She is a professional clinical counselor licensed in the state of Ohio and a Nationally Board Certified Counselor. She is currently licensed to practice physical therapy in Wisconsin, Ohio, and California, has her 200 hour Registered Yoga Teacher (RYT) certification, and

earned her Neonatal Developmental Care and Assessment Planning (NIDCAP) certification in 1996.

The researcher has two children conceived through in vitro fertilization and experienced several years of infertility (six) prior to the birth of her children. This is respected as a potential source of bias in her interest and application of the infertility research literature. In an effort to reduce this bias an exhaustive review of research that pertains to stress and infertility has been performed. (Participants were made aware of the personal association this researcher has with the problem of infertility during the Phase I process).

The participant/collaborators have now been known to the researcher for almost a year and during that time there has been periodic e-mail, telephone, and some personal contact with the researcher; essentially updates on fertility status and ongoing treatment concerns. This contact could have influence on how participants respond to the research questions as well as influence their ability to distance themselves from wanting to possibly *please* the researcher (Merriam, 2002).

Participant selection was established through a sample of convenience and participants were receiving treatment in a variety of clinical settings from a variety of health care providers. It is therefore not possible to establish to what degree participation in the *Minding Matters Program* influenced any perceived change in emotional support. However, feedback on the perception of positive long-term effects and ongoing utilization of concepts learned at the workshop can help examine strengths and weaknesses and aid in the future development of the Program.

The following four interview questions evolved both from the literature review and Phase I research and were designed to respond to the overarching research question: Does the *Minding Matters* mind body program provide a method of offering effective emotional support for people experiencing infertility? These questions functioned as an initial starting point for our conversations together.

The Interview Questions

1. Describe your experience of being in the Workshop?
 - a) How did you experience the group format and/or couple format?
 - b) What did you think of the location and environment?
2. What is your understanding of mind-body principles and infertility-related stress as a result of your participation?
 - a) Were your learning objectives met?
 - b) What skills have you been able to apply to your life?
 - c) How did participation effect your ability to understand and respond differently to your (& partner's) emotional needs?
3. How was the construction of the workshop and manual helpful to you?
 - a) How often have you read the material in the Manual and/or reflected back on something you learned in the Workshop?
 - b) What would improve this experience for you?
4. Please describe where are you now in your family building journey?

The three additional interview questions were posed after participants received and read a two page narrative summary of their responses from two of the Phase I quantitative survey instruments and questionnaires taken almost a year ago (SCLR-90

administered twice, and the FPI). The summary provided an abbreviated review in graphical form of the participant's overall survey scores as well as a description of the content analysis. Individual subscale names on the SCLR 90-R were changed for this purpose from clinical terms to lay terms (see APPENDIX G). The narrative was shared with participants to foster a collaborative climate around the research to: a) evaluate how well the survey instruments appeared to have captured participants actual experience of stress; b) allow participants to reclaim ownership of quantitative data from the measurement domain; c) to explore how labeling might impact participants' views of their current emotional states as well as their ongoing emotional needs.

Additional Interview Questions

1. How closely does what you have heard from these survey results match your memory of how you felt at that time?
2. How closely do you believe this summary reflects where you are with your infertility today?
3. How does it feel to you now to hear the survey results and is there anything that you might believe differently about yourself after reviewing this summary?

Phase I Data Collection and Measures

The Fertility Health History Questionnaire, (FHHQ – APPENDIX B), provided the background demographics, treatment history, and historical framework for each participant.

Fertility problem inventory.

The Fertility Problem Inventory (FPI - APPENDIX C) was constructed as "...a multi-domain measure specific to infertility" (Newton et al., 1999, p. 54). The authors

address the particular difficulty of evaluating infertility stress and note that the use of measures designed to assess global levels of functioning are not sensitive enough for this specialized problem (Newton et al., 1999).

The FPI contains 46 items divided into 5 subscales: social concern, sexual concern, relationship concern, need for parenthood, and rejection of a childfree lifestyle. The global stress score is an overall measure of infertility related stress. Responses are recorded on a 6 point Likert scale (1 = strongly disagree - 6 = strongly agree), and some items are estimated using reverse scoring. The global stress score is calculated by totaling each individual sub scale score (Gibson & Myers, 2002). The scale was tested on a mixed gender sample ($n=1,151$) and test re-test reliability coefficients were reported at .83 for women and .84 for men with Cronbach alpha coefficients of internal consistency ranging from 0.77 to 0.93 for the each subscale (Newton et al., 1999). The authors used several "...standardized measures of depression, anxiety, and marital adjustment" to determine convergent validity and suggest that "...the FPI is a reliable and valid measure that taps five homogeneous and relatively independent infertility-related domains" (Newton et al., 1999, p. 59). Evaluation is determined by raw score values and percentiles. The Fertility Problem Inventory was administered once as a baseline measure of infertility related distress.

Symptom checklist ninety revised (SCL-90-R).

The Symptom Checklist Ninety Revised (Derogatis, 1977) (SCL-90-R - APPENDIX D) is a self-report survey measure containing 90 questions designed to check for the presence of a variety of psychological distress symptoms (Derogatis, 1977). Answers are accommodated by a five-point Likert scale (4 = extremely – 0 = not at all).

The instrument is divided to provide 9 separate subscale scores for the following dimensions: somatization, obsessive compulsive, interpersonal sensitivity, depression, anxiety, anger-hostility, phobic anxiety, paranoid ideation, and psychoticism (Schmitz, Hartkamp, Brinschwitz, Michalek, & Tress, 2000). The non-clinical normative validity and reliability studies were conducted on a sample of "...494 males and 480 females...and represents a stratified random sample from a diverse county in a large eastern state" (Derogatis, 1977, p. 19).

The instrument was originally intended to discriminate between particular kinds of psychopathology but has since been used more frequently to indicate more global measures of emotional distress in community as well as clinical populations. The tool is written to a 6th grade reading level and a minimum age of 13 years. The SCL-90-R was selected because it reflects symptom distress commonly reported by people struggling with infertility: somatic disturbance, rumination or obsessive thinking, a conflicted sense of self, anxiety or depressive symptoms, anger, avoidance, and feelings of guilt and self blame (Anderson et al., 2003; Brkovich & Fisher, 1998; Csemiczky et al., 2000; Downey & McKinney, 1992; Fassino, Piero, Boggio, Piccioni, & Garzaro, 2002b; Gibson & Myers, 2002).

Finally, the three global indices: i) the Global Severity Index (GSI), ii) Positive Symptom Distress Index (PSDI), and iii) Positive Symptom Total (PST) reduce a person's overall measure of psychological distress to reveal the general depth, intensity, and extent of their current level of difficulty (Derogatis, 1977). Scores are reported with raw scores and T values against a normative non clinical and clinical sample.

This tool was selected because of its extensive use in mind-body research generally, and studies of infertility specifically (de Liz & Strauss, 2005; Nakao et al., 2001b). The purpose in Phase I was to determine whether there were differences in scores between the two SCL-90-R administrations, (approximately 6 weeks apart). The data is included in the Phase II interview for discussion and to review participants' experiences of having their distress framed in this way. It is particularly critical given the impact that the 'infertility 'label' is known to have on an individual's sense of identity (McQuillan et al., 2003). One of the persistent challenges posed by psychodynamic clinicians against using psychometric tests for evaluating infertility related emotional distress is that they are unable to access the deeper meaning attributed to endorsement of a particular response item (Wharton, 1987). The research questions in this study are interested in exploring that deeper meaning. The SCL-90-R was completed twice by participants, once at the workshop and again approximately 6 to 10 later. A repeat measures was performed for this instrument for each participant.

Ways of coping questionnaire.

The Ways of Coping Questionnaire (Folkman & Lazarus, 1988) (WCQ – APPENDIX E) is a 66 item self report measure that examines coping processes and is intended to explore the behavior and attitude that individuals adopt to manage stressful situations. Items are recorded on a 4 point Likert scale (0 = does not apply or not used - 3 = used a great deal). This instrument was designed by Folkman and Lazarus and evaluates condition specific responses to internal and external stressors rather than a particular coping style across several life domains or established personality traits (Folkman & Lazarus, 1988). The differentiation the authors make between coping

process and coping style parallels their distinction between coping management and coping mastery. According to the authors, "...allowing coping to imply mastery results in an inevitable confounding of the process of coping with its outcome" (Folkman & Lazarus, 1988, p. 8). For the purpose of this study coping process is a much more relevant indicator of how people manage the presence of fluctuating stress in their lives.

Fifty of the 66 items are used to achieve 8 coping sub scales:

confrontive coping; distancing; self-controlling; seeking social support; accepting responsibility; escape-avoidance; planful problem-solving; positive reappraisal. Participants were asked to focus on a fertility related problem that occurred in the previous seven days before responding to the test items. This questionnaire was completed once to provide a baseline measure and explore the relationship between participant perception and management of stress.

General communication.

All participant/collaborators in this study were originally notified that Phase II would commence approximately 10 – 12 months after completion of Phase I. Participants were encouraged to contact the researcher with any follow-up questions between these two phases. Fourteen of the female participants made at least one contact by e-mail with this researcher *after* the initial workshop was conducted. One male made direct e-mail communication and one male asked a question indirectly through his female partner. Questions tended to involve how to integrate stress reduction strategies into a particular life situation and general comments regarding how the workshop was personally experienced. Follow-up phone calls and e-mails to facilitate maximum involvement of the original twenty-seven participants was diligently pursued.

All interviews were conducted in a private office space located at 24629 Detroit Rd. #8, Westlake, OH, in the participant's home, or by telephone or e-mail with the study's single researcher. Interviews were recorded using a digital recorder and backup audio tape, uploaded and transcribed within 72 hours by an independent *paid* transcriber not involved in this research (The Transcription Network, Vermilion, OH). No identifying information was provided with the audio files, to which participant identification numbers were assigned. Participants were invited to review their own audio tape and manuscript and make any changes or clarifications that they felt necessary. Member checks were offered several times throughout the coding of the data.

Due to the intimate nature of the topic and the collaborative nature of the research it was not possible to retain anonymity between participants and observer/interviewer. Confidentiality however was assured and all recordings and written versions of taped sessions were given an ID # and stored in a locked filing cabinet and locked office. Contact phone numbers (Chair, Dr. Carl Rak and Cleveland State University Internal Review Board) and relevant e-mail addresses were made available to participants for questions, concerns, or a general need for follow-up.

Interview scheduling.

Initial contact was made with all participants via e-mail and/or telephone. There was a brief conversation to re-establish connection and build an appreciation for what had been happening in the lives of participants in the several months since the last meeting. General discussion concerning the interview format and location, signature requirement for informed consent, and terms of confidentiality were reviewed before any research interviews were scheduled. All twenty seven research participants agreed to be included

in Phase II of the study (100%). Of the couple group: seven couples were interviewed in their home, two couples came to a private office, and one couple completed the interview by telephone. In the women only group: four women came to a private office, one woman was interviewed in her home, one woman was interviewed on the telephone, and one chose to respond to the questions via e-mail. All interviews were completed within a 30 day period and were scheduled to best accommodate participants' work and home life. Most interviews were therefore conducted during the week in the later afternoon/evening or on the weekend.

Field notes.

Field notes were collected from the beginning of this project (October 2004). Copies of e-mails and written comments pertaining to telephone inquiries were placed into a computer file. Several of the original candidates who declared an interest in the workshop dropped out of consideration before the research was underway because they had already become pregnant. Notes on these individuals were transferred to an inactive folder. As the research continued contact between the researcher and participants became more frequent and continued to include periodic telephone calls, e-mails, and occasionally referral to outside professional resources.

The interview protocol.

Qualitative data collection takes a "bottom up" approach that reflects an inductive rather than deductive method of analysis (Bogdan & Biklen, 2003, p.6). The methodological theories outlined earlier formed the scaffold upon which the larger picture was built. The research questions served as a template to both guide initial

discussion and develop evaluative potential for the *Minding Matters* workshop. Participants were also encouraged to explore and expand on issues and themes that they determined to be important, or were revealed as a result of the ongoing dialogue.

A brief conversation to re-establish connection, continue to build rapport, and review the research protocol was conducted prior to formally beginning the interview and turning on the recording device. Participants were assured that they could request to have the tape turned off at any time during the discussion. The interviews took an average of between 1.5 and 2 hours. Couples were interviewed together, asked identical questions, and encouraged to respond by alternating their comments between each other. This system worked exceptionally well and dialogue was documented using a different color print for men and women in the transcription process (blue=men and red=women). This insured that all comments were accurately attributed to the appropriate partner.

In keeping with the theoretical perspective of this study (feminist/critical/evaluative), the research questions were designed to "...give voice" to the concerns of men and women living this intensely personal struggle (Merriam, 2002). Participants were invited to ask questions throughout the interview. This process provided an opportunity for individual experience to emerge and unique themes of importance were established. Notes were not taken during the taped interviews. However, observations were made regarding any physical, behavioral, or emotional gestures. These observations facilitated the direction of some of the 'off topic' discussion that emerged during the interview process. Formal and informal signals were documented at the completion of each interview. The written observations served as researcher memos and helped to refine and explain textual nuance.

As previously noted, interviews were conducted in a variety of locations and environments. This variability contributed to some discrepancy in participant/researcher comfort and influenced the range of minor distractions that emerged during the dialogues (e.g. briefly leaving to take care of an infant or pet). In particular, the two telephone interviews required several logistical adaptations to guarantee that all parties could be heard over speaker phone and that the recording device was adequate to pick up everyone's voice. This impacted question presentation, which was slightly less seamless, sometimes repetitive and demanded greater explanation. However both of these interviews concluded in a time frame comparable to in-person conversations. One female participant elected to complete the questions by e-mail. Her responses were structured as single, closed ended sentences and although are included in the Chapter V analysis offered little personal insight or feedback on her experience in comparison to the in-person in-depth interviews.

Information Analysis

Jacelon and O'Dell (2005) state that "...data analysis in any research is based on the research questions and guided by the theoretical framework of the study" (Jacelon & O'Dell, 2005, p. 217). Deconstructing hegemony as it relates to medical and psychological labels is an essential feature of this research, as is deconstructing thoughts, actions, and beliefs. Exploration of the discrepancies between self, self and relationship, and self and social structure can lead to the discovery of "...unique outcomes;" a way of seeing and being in the world differently (Freedman & Combs, 1996).

The semi formal interview structure and research questions were based on a priori assumption that infertility is a distressing experience that impacts several areas of an

individual's physical, emotional, and social health. Due to the large number of participants ($n=27$), one woman and one couple from each workshop is presented as sample case studies in this results section of this document. However, responses from all participant interviews are woven into the text and often specific details of a participant's story, an essential element of the qualitative research experience, assumes center stage.

The literature review demonstrated a consistent pattern of psychological stress facing individuals and couples struggling with infertility. In order to evaluate the effectiveness of the *Minding Matters* program in modulating this stress, content specific questions were asked. However, individual narratives were respected in keeping with the constructivist position that one creates understanding from one's own particular set of circumstances (Schwandt, 2001).

A commitment to observer/participant collaboration was vital to this study's methodological principles: "A productive hermeneutic dialectic negotiation thus requires that certain conditions be met if it is to be a successful process" (Guba & Lincoln, 1989, p.149). These conditions include respect for the multiple collateral influences that modulate people's experience of themselves in the world, willing and open communication, shared realities and shared power (Guba & Lincoln, 1989).

The engagement between parties (shareholders) aided in the development of a richly woven narrative that placed individuals at the center of their own socially constructed story. The research questions were important in that their answers provided a measure of the competence of the mind-body workshop to meet participant goals. In addition, use of the interview as an evaluative technique to examine participant response to results of the quantitative measures used in Phase I of the research was a way to

explore and negotiate the constructed meaning within and between conflicted ideals (ideal/actual, self/other). How do people see themselves? How do they believe they are seen by others? How might this further influence what they think, how they feel and the choices they make; an example of the hermeneutic dialectic in practice. The interview also provided a way for collaborators to act as witness to each others' rendered experiences and to discover "...how different people make sense of their lives" (Bogdan & Biklen, 2003, p.7).

Phase I: Developing Codes

Phase I of the content analysis and interpretation of the interviews/dialogues began approximately one month after data collection was complete. To effectively organize and manage the large amount of interview text, (over 500 single spaced pages), the women's interviews were printed on white, and the couples' on colored paper (each couple was assigned a different paper color). This made it easier to classify and analyze the interview responses within couples and between non-related participants.

The research questions were given individual color codes. Text that was identified as being a response, partial or complete, direct or indirect, to a particular research question was highlighted in the same shade as the question. This protected the uniqueness of each story while connecting participants' dialogue. Participant ID numbers and first name pseudonyms were entered into a permanent page header on the corresponding transcript to insure against loss or contamination of material. The use of pseudonyms rather than ID numbers maintained the humanity of the text and preserved confidentiality. The auditory files were cross matched to document headers and page numbers and made

instantly accessible via the researcher's computer desktop, allowing written text that needed deeper contextual analysis to be conveniently retrieved.

As evaluation of the text began, and the transcripts were reviewed over and over, global issues became apparent. The emerging issues were organized according to their question specific content. The chunk of text that pertained to a particular question or important topic was electronically cut and paste and put into individual folders given designated headings. Frequent re-examination of categories helped to adequately saturate the text for additional content codes and themes until the subject relevant data appeared to be exhausted.

Phrases or comments that applied to similar themes were paired or collected under specific sub headings, linking associated concepts while minimizing category overlap and redundancy of ideas (Bogdan & Biklen, 2003). For example words like *identification*, *normalizing*, *shared*, and *common*, were related to the theme '*needing to belong*' and were accumulated under this category as sub headings. This form of open coding accommodated the expanding narratives and helped to maintain the richness of the text as the stories unfolded.

Phase II: Condensing the Data and Identifying Themes.

Once multiple observations and themes were identified axial coding reorganized and streamlined intersecting categories (pruning the qualitative tree). For example, '*needing to belong*' was associated with the themes '*isolation*' and '*feeling misunderstood*'. The strategy of axial coding generated an interconnected map of reduced themes, subjects, and ideas related to commonly used phrases, events, behavior, and social and personal relationships. When analysis using these selective coding methods

was complete, the critical responses to each interview question, as well as discovery of additional important topics, was reduced into essential content areas and reviewed for final interpretation (Creswell, 1994). These essential content areas will be discussed in Chapter V using the integrated perspectives of liberal feminist, critical, and evaluative theory.

Throughout the coding process the story of the participants' lives became apparent. Although the data was partitioned to provide coherence and structure, preservation of the uniqueness of each narrative was imperative. The individual construction of meaning applied to infertility influenced how each participant shared who they were as well as their workshop experiences. Capturing subtle as well as apparent meanings, differences between couples, within couples, and between groups helped to identify "...*emergent* themes as well as *anticipated* themes" (Ziebland & McPherson, 2006, p. 405). The discovery of unanticipated themes as well as unexpected omissions, according to Creswell, places research participants in their own historical and contextual perspective (Creswell, 1994). This also helped to explain discrepancies between the literature and this particular study's findings, and to clarify previously misunderstood phenomena.

Key informants.

The Chapter I introduction was shared with professor (Dr. Peggy Kleinplatz, Ottawa Canada) who teaches outside of the researcher's academic institution and specializes in working with the emotional and stress effects of infertility. Dr. Kleinplatz offered critical feedback in the beginning phase of this study. In addition, Dr. Jeffrey Goldberg, Section Head Reproductive Endocrinology and Infertility at the Cleveland

Clinic Foundation, is a non-voting member of this Dissertation Committee. Dr. Goldberg represents a medical opinion position in the infertility field and his valued input allows for active dialogue to occur between counseling and medical professionals and embraces this study's integrative premise. The 3 women who participated in both workshops provided a critical analysis of each setting and situation as well as a comparative process experience (with and without their partner). In order for sufferers of infertility to be regarded and supported as whole people rather than dysfunctional parts, productive conversation needs to exist between all concerned individuals.

Member check.

Participants were offered an opportunity to read and edit the transcript of their interview within 2 weeks of its completion. According to Guba and Lincoln (1989), member check "... is the single most crucial technique for establishing credibility" (p. 239). Out of 17 interviews 14 people requested a copy of the typed document. Five participants acknowledged receipt of the document and verified that there were no changes to be made, although several expressed the experience of re-reading their words as an emotional experience.

As stakeholders in research it is important that the researcher's interpretation of participant responses reflects synchrony between what was said and what was meant during the interview experience. A summary of the coded data, categories and themes, was e-mailed to participants prior to final data analysis. This data was explained according to the researcher's understanding of what was revealed during the interviews and represented a condensed analysis of the most important discoveries. No requests for edits or alteration were received.

Ethics

Of overriding importance in any research using human participants is the ethical concern and consideration for the protection of their full welfare. Informed consent for this project was sought and required. Complete disclosure of the possible risks and benefits of all procedures was reviewed. Confidentiality and identity protection, absence of coercion, reimbursement of travel, and full admission of the conditions of the research, as well as access to, and discussion of, the research findings were provided (Bogdan & Biklen, 2003). Due to the intimate nature of the research topic and the possibility that participants might disclose information in the workshop that required additional processing, the names of three mental health professionals who had agreed to provide follow-up care were provided: Helen Deneselya, LPCC, Mary Kay Lawson, LISW, Anthony Pizzuti, PC.

Fundamental to the ethical principle is appreciation of the power differential inherent to a relationship where the sharing of personal information is predominantly unilateral. Respect for this dynamic acknowledges the privileged position afforded researchers who negotiate and dialogue with collaborator without whom, they could not add to existing knowledge or generate new ideas.

Limitations of Current Study

This study used a sample of convenience and a previously unexamined intervention (*Minding Matters*), to evaluate the effectiveness of a mind body program for providing emotionally supportive care during infertility. It is possible that individuals who self-referred have generally higher levels of distress than couples who elect not to participate in a mind body program and might have benefited from any intervention

perceived to be supportive. In addition, it is well known that individuals experiencing infertility are willing to try several things simultaneously to improve their chances of pregnancy success, therefore it is not possible to deduce that participation in the *Minding Matters Program* had any effect on pregnancy outcome (Coulson & Jenkins, 2005). Although it was not the intention of this research to examine possible cause and effect relationships it is important to underscore that no such conclusions can be made from the study's findings.

Evaluation scores for each workshop, the presenter(s), and the Manual is provided (APPENDIX H). However, evaluations conducted at the completion of a workshop can be influenced by temporal learning effects when information is new and participants might still view the intervention as favorable (Shamai, 2003). Also, the experience of being in a psycho-educational group with others who are struggling with similar difficulties itself provides temporary respite from the sense of social isolation and lack of understanding that the research indicates is a large part of the infertility and group experience (Yalom & Leszcz, 2005). Therefore workshop evaluations collected on the day are only briefly considered as a source of participant satisfaction.

Evaluative research that relies on direct feedback from program participants in the form of an interview also has the potential to provide a therapeutic effect as a function of the interview process and is considered a potential conflict in this research. Through the process of retelling any life experience, the participant has the opportunity to reconstruct and to

...re-experience it, both from another position and another context...In the qualitative evaluation interview, the participant is invited to explore the treatment in detail and to assign a place to different voices in treatment (Shamai, 2003, p.459-60).

Shamai goes on to state: “When people seek help from professionals, they often experience some feeling of failure in being unable to solve their own problems. Clients often feel helpless. In contrast, helper’s knowledge ensures a position of power” (Shamai, 2003, p.457). The collaborative nature of this research was one attempt to mitigate power. However, possible bias exists due to the researcher’s personal experience with infertility and the closeness that developed with participants during the period under study. These issues will be considered in the evaluation and discussion of the workshop’s impact.

Several areas of research have demonstrated the benefit of a mind body approach to the management of psychological distress (Baer, 2003; Davidson et al., 2003; Nakao et al., 2001b; van Gelder, 2005). The exact mechanism of effectiveness in mind body interventions for infertility remains equivocal and beyond the scope of this study’s premise (Boivin & Schmidt, 2005; Domar et al., 2000; Facchinetti et al., 2004; Schmidt et al., 2005b).

The concepts of internal validity: “...the certainty with which an observed event can be attributed to an earlier intervention” and external validity: “...the extent to which the effects observed could be generalized to the populations and setting of interest” do not meet established standards for statistical analysis (Norcross et al., 2006, p. 97). Statistical data therefore was provided as an additional method of observation as well as an avenue of contrast; a descriptive measure that helped to challenge and explain the particular circumstances of individuals attempting to build a family. These results are not intended to be definitive. They are intended to provide new ways to consider a timeless problem.

This is an exploratory study. One which looks for dependability rather than reliability as a measure of its “stability over time” (Guba & Lincoln, 1989, p. 242). Dependability refers to “the accuracy and comprehensiveness of the data...rather than consistency across different observations” (Bogdan & Biklen, 2003, p. 36). Significant effort was made to ensure the accuracy of all included data with the use of key informants, member checking, detailed coding, and a transparent document trail.

Current infertility research attempts to define infertility related stress according to pre-established psychological categories and constructs that might or might not represent a person’s lived experience. This study is an effort to explore the veracity of those constructs using previously established evaluative tools and newly acquired descriptive information.

Summary

This Chapter outlined the research methods and strategy for analyzing and interpreting the research questions that emerged from the literature in Chapter II. The study’s mixed method sequential design is reviewed and explained and the researcher’s perspective considered. Discussion regarding participant selection, data collection and data analysis is also presented.

CHAPTER V

EXPLORING THE INTERVIEW QUESTIONS

Introduction

Chapter V is divided into two parts. Part I is a text analysis of the in-depth interviews and is organized according to each interview question and group type: women only or couple. When appropriate or for added clarity, feedback offered from women who attended both workshops (*Key Informants*), is included under a separate sub-heading. The interview questions were constructed to acquire insight into participants' family building narratives and experiences of being in the *Minding Matters* workshop. The dialogue is explored and presented from the perspective of the individual/couple and the individual/couple within the group. Participant/collaborators are introduced personally through their private words and collectively through their shared stories. Part II presents the important themes that emerged during the interview questions and sets the foundation for responding to the specific research questions (Chapter VI). All twenty-seven original participants responded to the interview questions and sample a case description of one participant and one couple from each group is provided below.

Sample Case Descriptions

Hillary is 33 years old and describes herself as Caucasian. She works full time as an attorney and has been with her current partner 6 years (married). Hillary has a teenage stepdaughter and at the time of the Phase I data collection Hillary's partner had recently been laid off and Hillary was the primary breadwinner. Hillary had been trying to get pregnant for the previous 3 years. She described herself as always wanting to be a mother "...it was never a question of if, only of when." Hillary is a very private person and for the first several months while she was trying to conceive she was reluctant to see her physician because she felt uncomfortable exposing the details of her sex life to inspection. However, after about 10 months she found herself increasingly distressed, tearful, avoiding many things she had previously enjoyed, and her menstrual cycles appeared to be more erratic. At this point Hillary decided to see a reproductive endocrinologist.

Hillary underwent a laparoscopy (examination of the abdomen and pelvis under anesthetic) that was reported as normal. Hillary also had evaluation of her fallopian tubes at this time and it appeared that both were open. A uterine biopsy was 'inconclusive.' Hillary was informed that analysis of her hormone function indicated that her ovarian reserve (eggs available for conception) appeared to be low. This generated a great deal of anxiety in Hillary and she began to experience difficulty at work and at home, particularly dealing with her teenage stepdaughter who was struggling through adolescence. Hillary's husband was still unable to find employment and Hillary reported the stress of trying to juggle so many things as overwhelming. At about this time Hillary experienced changes to her bowel function; fluctuating periods of constipation, diarrhea,

and bloating, which her doctor told her was likely Irritable Bowel Syndrome. In addition, Hillary was diagnosed as hypothyroid and started on medication to treat this problem. Hillary's sadness and disappointment continued and she asked for a referral to a therapist. Hillary went to see a clinical psychologist and a psychiatrist who recommended that she take anti-depressant medication. Hillary was given Ambien (a sedative, Klonopin (a benzodiazepine to help with anxiety,) and Zoloft (an anti-depressant). Hillary decided to only take the Zoloft. She felt dissatisfied with the psychotherapy she received feeling that it was too focused on her mental health and did not help her to address the multiple areas in which she felt distraught, both physically and emotionally. Hillary had been accustomed to exercising 3-5 times per week prior to trying to conceive and she reduced her exercise to 1-2 times per week. (Hillary's weight was well within normal limits for her height and she had a body mass index of 21.8). Hillary also began acupuncture therapy and taking nutritional supplements to help with her reproductive hormones and depressed mood.

At the time of Hillary's participation in the mind body workshop she had tried 5 cycles on the infertility medication Clomid, had 3 intra-uterine inseminations using her partner's sperm and injectible fertility drugs, and underwent one in-vitro fertilization procedure. After all of these interventions Hillary decided to discontinued her anti-depressant medication and was looking for a more holistic approach to her care; a different way, as she stated, to begin to heal the immense pain she was feeling.

Graham (couple #6) is 33 years old and has been married for 3 years to Bethany who is 35. Both partners are Caucasian and had been trying to have a baby for over two years. Graham is a paramedic/firefighter and Bethany is a speech and language

pathologist. Bethany was referred by her primary care physician to a reproductive endocrinologist and underwent laparoscopic investigation. Bethany was informed that although her fallopian tubes appeared to be open the ends were clubbed, making it very difficult for an egg to be propelled into the tube for fertilization. Graham indicated that analysis of his sperm appeared to reveal no problems. Bethany's general health seemed to be moderate she was borderline diabetic and had begun taking the medication Glucophage to help regulate her blood sugar. She was not sure how she had developed scar tissue in her abdomen. She did not smoke or consume alcohol although she was very overweight with a body mass index (BMI) of 31.2. Graham did not smoke and estimated that he had about 3 beers a week. Graham felt he was in good health and had a BMI of 28.7.

After Bethany's surgery her physician recommended that she try again to get pregnant having intercourse with Graham and adding the infertility drug Clomid, to see if recruiting more eggs at the time of ovulation would increase the likelihood of one of them entering her fallopian tube. Bethany and Graham found scheduled sex increasingly miserable. Bethany indicated that she felt more distant in her relationship than she ever had and that she was struggling to contain her anger. Graham also expressed that they had withdrawn from each other and that he had difficulty understanding all the emotions Bethany was going through.

After the trial with Clomid did not result in Bethany becoming pregnant the couple progressed to injectible medication and Bethany underwent 2 intrauterine inseminations with Graham's sperm. Graham was becoming increasingly frustrated with his inability to know how to support his wife. He only knew that simply hugging or

holding Bethany never seemed to be enough. Bethany also indicated that she felt she was “losing it” and that she was increasingly defining herself in terms of her failure to become pregnant and this was isolating her. Bethany came to the workshop looking for greater personal insight and a decrease in her anger. Graham was looking for a way to moderate Bethany’s temper, to understand her more; and ultimately to “get pregnant.”

PART I: Text Analysis

Participants were interviewed in their home ($n = 7$), the researcher’s private office ($n = 7$), on the telephone ($n = 2$), and by e-mail ($n = 1$). Two women from the women-only group were interviewed in their homes and one of them (Bethany), had participated in both workshops. Approximately 60% of couples elected to conduct the follow-up in their home compared to 14% of women. Interviews took an average of 1.5 hours to 2 hours (range 65 to 115 minutes) with the exception of the participant from the women-only workshop (Kit), who responded to her questions in an e-mail and provided predominantly single sentence answers.

It was important for participants interviewed in their own environment to make sure the researcher was welcomed. A space was designated by them for the discussion and refreshments were frequently provided. These interviews lasted approximately 20 minutes longer than those that took place in the researcher’s office. (The telephone interview with Hillary was an exception and had lasted almost 2 hours). A brief conversation described the purpose of the interview and reminded participants that they had consented to being audio-taped and also offered an opportunity for any last minute questions prior to beginning.

Question 1: Describe your experience of being in the workshop

- a) How did you experience the group format and/or couple format?
- b) What did you think of the location and environment?

Women-only workshop.

Question 1 was phenomenological and designed to encourage participants to describe how they felt about their day in the workshop. It also inquired more specifically how the group format and location might have influenced their experience. From the perspective of critical theory, the shared insights are seen as methods for achieving greater self-reflection. The communal setting reflects the social and cultural reality that each person will experience the same thing differently according to context, history, and personal construction of meaning (Agger, 1991).

The most frequent response to Question 1 (a) was related to the perception that participants were in a place emotionally where they fit in; a place where there was no need for them to explain themselves and their infertility or justify their childless status. Katherine had been diagnosed with premature ovarian failure and had been trying to conceive using an egg donor for 4 years. She expressed little patience anymore for the invasion on her intimate life that questions about her lack of children represented, especially as she considered the inquiries less about genuine concern and more a desire from outsiders to simply be in the know.

It was a comfort to be around other people, other women struggling through similar situations...I just get sick of the questions from people saying, where are you at? What are you doing now? (Katherine, April 8, 2006)

Being connected to others on a similar journey and therefore less isolated was important to a majority of the women. The language of disclosure and mood that women chose to express their feelings appeared to be a measure of how long they had been on their family building journey. Fatigue and irritability took the place of sadness and depression as participants passed three years of infertility. The desire to share was still present but to share with people who needed no background data and simply 'got it'. Deborah, who has a 5 year old daughter and had been experiencing secondary infertility for over 3 years, stated:

Anybody who's dealing with infertility is always looking for a comrade, somebody else who shares your problems. (Deborah, April 4th, 2006)

Also critical to the discovery of comradeship was the theme of separation that occurred within the group despite the commonality of infertility that had brought them together. The separation represented on the one hand, compassion and empathy for the struggle of any woman experiencing difficulty conceiving a child, and on the other hand a wish to see oneself as different from; i.e. unique when compared to others. This appeared to serve both a supportive and challenging function in particular for Sarah, who had also been trying to conceive for more than 3 years. Sarah was 40 years old and described her age and her partner's sperm motility as contributing factors in their infertility. She expressed some ambivalence toward the group experience; although glad to be there was disappointed it was necessary.

I definitely feel like I clicked in the group...not just because of our joint reason for being, but my experience of infertility has alternated between being very isolating, feeling isolated, then wanting to isolate and the difference in that energy you know, not wanting to be part of *that* group. (Sarah, April 8, 2006)

Conflict was also expressed in terms of the alternating impact that hearing other people's stories had on participants. For Deborah and Ruth it was affirming to be in an environment where they felt they had been listened to, particularly as they believed their concerns were not heard in their personal relationships and supported their perception that their male partners would not have wanted to attend:

I really wanted to come to the women's only group...I have no-one to talk about this with, and my husband, he's always sick of hearing about it.
(Deborah, April 4, 2006)

Ruth and her husband had been trying to have a baby for almost 5 years. Ruth was one of two women who had decided not to use assisted reproductive techniques to try to achieve her family. She had spent a great deal of money (\$5,000) in the previous year attending an acupuncture infertility retreat, which she had also gone to without her partner. Ruth indicated that it was her decision not to include her spouse in either of these activities. This was related to what she described as his uneasiness about being there which she felt superseded her need for them to participate in something together.

It was nice to be around women experiencing the same issues, to be able to relate to each other...I know he gets uncomfortable talking about his feelings around other people...so I didn't ask him to come. (Ruth, March 31, 2006)

In retrospect Ruth felt she had assumed the weight of many of their infertility decisions and her insistence that her partner did not have to attend to the workshop was one of them. She had some regrets about this after she saw couples together at the follow-up session (where women and couples had completed the second Symptom Checklist).

Just to see the husbands there and that support, I think it's just really important I think so many times the women take the burden on themselves – it is all their fault and they feel like the failure. So if the husbands are there to realize that women think that way, you know, I think it would be beneficial (Ruth, March 31, 2006)

For Hillary and Alice the group format presented something of a risk; exposure and another opportunity not to measure up. Hillary had multiple stressors in her life. She was a busy attorney and the primary bread-winner. She was also stepmother to a teenage daughter. Prior to her diagnosis with infertility Hillary had guarded her privacy and the scrutiny infertility placed her under medically and emotionally was difficult territory for her to negotiate.

I often end up comparing myself to what the other women were going through...for me, I find that somewhat detrimental...I found the group format personally, a little bit intimidating. (Hillary, April 29, 2006)

Alice, was diagnosed with infertility the longest of any of the study's participants (8.5 years). She was currently on a hiatus from treatment, in part because she had been told that to pursue a biological child she would need to consider using an egg donor, and she was having a difficult time integrating this information. She was also on an egg donor waiting list and needed to be in a better place financially to move forward with any treatment.

Sometimes it is really difficult to be in a room, listen to people, and hear their successes when I am not really doing anything. (Alice, April 12, 2006)

Question 1(b) was posed to explore which aspects of the physical space contributed to and detracted from participants' emotional safety during the workshop. On the day of the women's program, unknown to the researcher, a baby shower had been scheduled in an adjacent room. We became aware of the shower as lunchtime approached and Kit, (the only participant who responded to the interview questions by e-mail) and Alice, appeared to have been the most distressed by this event. Kit was 30 years old and had been trying to have a child since she was 25. She was diagnosed with severe

endometriosis and had undergone a significant surgery to reduce the amount of endometrial tissue in her abdomen and pelvis. Kit was visibly upset at the workshop. This was expressed mostly by her body language and facial expression, (slumping shoulders, sighing, and tight-lipped disappointment.

The location and environment wasn't the most comfortable, mostly because there was a baby shower in the room next to our location. (Kit, April 28, 2006)

Even after a year I can significantly tell you that the one thing I can distinctly remember is there was a baby shower in the next room and it was very upsetting. (Alice, April 12, 2006)

Sarah was sensitive to Kit and Alice's discomfort and spoke insightfully of her own tendency to take on the self-appointed task of protector/defender, a role that Sarah adopted frequently in other areas of her life.

What struck me about the day was the different point at which people were in the process...it probably triggered my shepherd energy more than anything. I do remember the absolute irony that there was a baby shower going on. I do not remember it in a way that was intrusive to me initially, but I did feel protective of some of the other women in the group. (Sarah, April 8, 2006)

This was a pattern that Alice recognized in herself too She saw the ways she had allowed the level of distress in some workshop participants to impact her own reactions. Alice shared that she had spent a lot of time in the year since then stepping back from the position of hero or savior in her life in order to decrease the emotional and physical burdens she assumed from others and take more time for her own healing.

Researcher: Did you feel supported by the other women in the group or did you feel more as though you were giving?

It was a combination of both. I felt like it was good to be in that room and to have them know that you can go through this and you can still survive...I have always tried to take other people's feelings into consideration very much over mine and if I let that dictate my life I will never do anything. (Alice, April 12, 2006)

I was concerned that the baby shower would be disruptive and painful to participants. Experience and research taught me to expect a spectrum of emotion, and in varying degrees, from women who received birth announcements and shower invitations. Not all participants voiced the same level of distress. However, during the interviews Katherine (infertile for over 4 years) and Alice made this observation about my own reaction to the baby shower:

I remember you being more worried that it would bother everybody but I do not specifically remember one person being upset. (Katherine, April 8, 2006)

I remember that you were trying to figure out how people felt and if people were not saying it they were certainly feeling it. (Alice, April 12, 2006)

This was an accurate perception of my concern at the time. I was sensitive to the possibility that some participants might have been reticent to speak their mind. Exposure to these types of social events are, for the majority of women dealing with infertility, extremely distressing (Schmidt, Holstein, Christensen, & Boivin, 2005a). The decision to move the afternoon session to a more private room was met with unanimous approval. A baby shower is a critical trigger for the emotional pain that is provoked daily by the pregnancy success of others. The workshop was intended as refuge and a respite from the fertile world. It seemed cruel irony to continue the afternoon's relaxation techniques within earshot of infant party games. The baby shower was a consistent topic in the interviews and served, as Yalom would say, as 'grist for the mill' (Yalom & Leszcz, 2005).

I think the exposure and knowing that group was next door may have left an impact, I am not saying it did but just the fact that I haven't thought about it for a year and it came back to me that quickly means it did make an impact. (Hillary, April 29, 2006)

Hillary recalled the baby shower as an event that provoked a lot of in-group discussion. Hillary also believed it was necessary for the physical environment of the workshop to parallel the intimate nature of infertility itself if it was to facilitate open sharing. Hillary needed her surroundings to be more organic and private and to flow from the natural order of things. Several women expressed a shared sense of personal abandonment during their experience of infertility and stated that their recovery had as much to do with resurrecting the body as healing the head and the heart. The setting, viewed as a metaphor for the body by Hillary, was a potential anchor that could give her emotions a softer place to fall.

Fertility is such a personal, intimate issue that I think the space worked against me opening up...maybe the seating arrangement needed to be more natural, you know where things are uncertain like how life kind of happens..(Hillary, April 29, 2006)

Sarah also felt that the size of the room, the style of the chairs, and the seating arrangement, (a circle), reflected a business like atmosphere that made self-disclosure for her more difficult. Emotional processing might have been less risky, according to Sarah, in a more contained and soothing physical space.

I think if the room were smaller it would have been conducive to me just at a very personal level so that I did not have to self-focus a lot or block things out. (Sarah, April 8, 2006)

The group transitioned to a downstairs yoga room after lunch that had not been available for the morning session. This area was smaller, equipped with flexible lighting, and better protected from other activities going on in the Facility. Changing the venue provided Alice with an 'in vivo' experience of stress reduction directly related to the opportunity to be in a more secure physical space.

Everybody was really happy we were not in that room that we had moved...that was a great sense of relief of stress. (Alice, April 12, 2006)

Couple workshop.

Couples were provided with pseudonyms and each pair assigned a number from 1 to 10, (in addition to their research ID), this made it easier for responses to be examined within and between pairs. David and Laura (# 8) stated at the beginning of the interview that although it was “neat” to be in a room with people struggling through the same thing, in retrospect they had not been ready to participate in such a diverse group because the level of difficulty expressed by other couple’s did not feel comparable to their own. The research literature demonstrates that the experience of infertility-related stress is associated with the period of time since diagnosis and the types of intervention sought to achieve pregnancy (Schneider & Forthofer, 2005).

David and Laura had suffered an ectopic (in the fallopian tube) pregnancy in the previous twenty-four months and had been trying to conceive again for just over a year. For David and Laura the workshop served as a yardstick against which they were able to be more definitive about their own circumstances, gain perspective, and appreciate that their situation was less dire than imagined. This couple also highlighted the difference in perception that existed within partnerships regarding fertility related problems and that sometimes mitigating those different needs can generate coping conflicts. Laura was anxious about her potential for future pregnancy success hence her desire to participate in the workshop. David had more optimism that things would work out for them and felt that their particular circumstances were less likely to benefit from the group experience, although there had been agreement between them to attend.

I went in thinking that it was one more thing that could help us, and it was free. It was a little overwhelming to hear some of the problems people were having. I just wanted to block that out of my mind and be thankful that we weren't in their situation (Laura, couple # 8, April 7, 2006)

I didn't feel like lumping us in with people who were having real infertility challenges was going to be beneficial to us because Laura isn't the kind of person who goes "oh, I'm better than that...she doesn't do that, that's not her way of thinking (David, couple # 8 April 7, 2006)

The majority responses to Question 1 (a) were concentrated around two themes: firstly, what it was like to address the infertility issue together and secondly, how couple's experienced being part of a group. Jeanette and Karl had been married 3.5 years and trying for a child most of that time. Jeanette was diagnosed with endometriosis and had undergone several medication protocols to try to get pregnant. Jeanette and Karl both indicated that the toll of infertility had impacted their relationship and that this was one of the main reasons for attending the workshop, as well as learning how to see their circumstances from each other person's perspective.

I thought it really opened up our lines of communication and gave me a little more insight into what he was going through versus what I was going through. (Jeanette couple # 7, April 4, 2006)

You know, doing it as a couple, that I think definitely helped us, you know bond quite a bit there over the whole situation, you know and made things easier, helped us to relax (Karl, couple # 7, April 4, 2006)

Jill and Howard had been married almost 5 years. Howard had 2 children from a previous marriage (girls age 14 and 16), whom the couple had full custody of. Although Howard already had biological children he had been told by his physician that his sperm count was low and Jill was being treated for hypothyroidism. Jill was particularly distressed because she felt Howard's lack of understanding of how painful infertility was for her had a great deal to do with Howard already being a parent. However, their mixed

diagnosis was also creating more confusion for them both and Jill hoped that a couple workshop would help to bring them together.

What I really appreciated more was that we did it as a couple. We sat and talked and shared, but up until that point had been kind of separate ...so being together as a couple really meant a lot (Jill, couple # 1, April 25, 2006)

Howard was extremely anxious about being part of a group. He acknowledged that he had difficulty understanding what Jill was going through but he was also fearful that this was only his experience. It was important for him see himself in the narratives of others. Howard found the shared stories helpful in confirming that he was not isolated in his pain and that there was potential to emerge from the crisis of infertility with his relationship intact.

That's what helped me to relax. Knowing that other people are going through the same thing and that we can still have a good marriage even though we couldn't have kids. (Howard, couple # 1, April 25, 2006)

Many men in this study had little prior experience discussing the emotional aspects of their infertility status and frequently reported that their motivation for attending was to support or accommodate the wishes of their partner. They expressed surprise when the opportunity to connect with others also helped them to reduce their own tension.

Peter and Stephanie had been trying to conceive for almost 3 years and were the only couple who reported having male factor infertility. Peter had undergone surgery to repair a varicocele (a swollen testicular vein) in the previous year. For Peter the group format alleviated the pressure to be engaged in the conversation on an individual level, which he thought would be demanded in couple therapy. He had worried that he would

have to carry the dialogue within the group and it had been a relief for him to find out this was not necessarily the case:

The group experience was comforting for me...It wasn't just our issue so it helped make things a little easier... I didn't feel like I had to answer every question every time. (Peter, couple # 3, April 8, 2006)

Graham and Bethany had been trying for a child for 2 years. Bethany indicated on her demographic questionnaire that her biggest emotional struggle during this time was her anger which she felt had driven a wedge between her and Graham. She was trying to address these feelings and her physical lethargy using yoga and moderate exercise (mostly walking to help bring down her weight). Graham's motivation for attending was related to not knowing how to support Bethany, he had little expectation he would gain anything personally from the group. He had not anticipated learning something new, discovering alternate ways to manage difficult situations, or that observing other couples' relationships might help him to navigate his own:

The overall experience for me was kind of like eye opening to the point of hearing other people's aspects of what they were going through, how they handled it...you are probably picking up a new method or trying to maybe tackle the problem that you weren't doing a very good job at. (Graham, couple # 6, April 30, 2006)

Peter also shared that he was unaware of how alone he had been feeling until he was presented with an opportunity to listen, explore, and bring his voice to the workshop. For Peter, hearing his own words and being witness to the pain of other's seemed to resurrect and normalize a flagging part of his and Stephanie's relationship.

You actually physically and emotionally understand where they are, could see how it was affecting them [other couples] and it helped open my eyes to thing that were going on in our relationship that made it normal and you can relate to them [partner] again...I felt when we left there, we left with something else.(Peter, couple # 2, April 8, 2006)

This tension between isolation and connection was consistently present in the men's dialogue in particular. Karl also expressed fear that he would be the only man in the group who was not coping well with his situation and it was validating for him to recognize his own struggle in the stories of others.

I kind of felt like I was alone, you know, until then and I hear, you know, the other guys concerns and everything and I was like "oh" I am not the only one going through this and that really did help. (Karl, couple # 7, April 4, 2006)

Brian and Caroline had been together four years and actively trying to conceive for almost two. Caroline was diagnosed with polycystic ovarian syndrome. She had experienced two miscarriages, undergone laparoscopic surgery, intrauterine insemination and in vitro fertilization. Brian attended the workshop to learn some useful techniques for dealing better with his emotions. Learning to deconstruct his own behavior (as opposed to trying to analyze his partner Caroline), was to be a new activity for him. Brian felt powerless to change the reality that it is the woman who has the baby and this had been feeding his belief that a man's only function was to support his spouse. Through his own process analysis and self-reflection he began to see his role in their relationship differently and developed an appreciation for addressing his own feelings toward their infertility.

I probably came to the workshop not really knowing what to expect but at the same time I think, seeing how the exercises helped – you know seeing, why do I feel this way...or how do I approach things? Just because the wife's having a hard time doesn't mean the husband is fine. (Brian, couple # 3, April 15, 2006)

This was a familiar theme for men who reported they agreed to attend the workshop at the behest of their wife. Howard stated several times that he had worried putting himself

into a situation with which he was unfamiliar (a group), to discuss a subject that he felt powerless to control (infertility), filled him with trepidation.

I was looking for an answer or a solution when I first came, I was really judgmental at the beginning I think. I was like, “how are they going to help me with my problem?” I saw by then end of the class it is not just me it is a whole bunch of people who have same problem...after the workshop I have opened up more, talked to people about it. (Howard, couple # 1, April 25, 2006)

Victor and Wendy were the only couple who were not married and reported they had been in a committed relationship with each other for almost 4 years. They were also not living together at the time of the workshop although this was not made clear until the follow-up interview one year later. There were some combined male and female factors influencing this couple’s fertility. Wendy was forty two years old, reportedly ovulating regularly and had been told that her hormone levels were within normal limits. She also said that she was participating in yoga 2-3 times per week and walking regularly. Victor had indicated that he was looking for more information on infertility in general but had no listed specific objectives for attending. He appeared disconnected from the group and often disengaged from his partner Wendy throughout the workshop. Although he responded to one or two direct questions from Wendy during the day his affect remained mostly flat. When Wendy was upset with Victor her voice became strident and terse and their relationship dynamic was noticed by other participants. Wendy and Victor’s relationship helped Graham put his own reasons for participating into better perspective.

I remember looking at the body language of one of the guys and its like, you know, “he doesn’t want to be here, and I *wanted* to be there. (Graham, couple # 6, April 30, 2006)

At the interview session Victor shared that he felt “...uncomfortable talking to strange people in a crowd” and acknowledged that he was clinically depressed and had been for

several years (this was not indicated on his demographic questionnaire). Victor's partner Wendy sighed deeply when Victor made this disclosure and admitted to the exasperation she had felt during the workshop.

I somewhat anticipated that and I think the most frustrating part for me was that I *know* he was tired. The one time we were lying down during one of the yoga sessions...he was starting to fall asleep. (Wendy, couple # 5, April 30, 2006)

Wendy said she had participated in both workshops to get as much information as possible but also to increase the opportunity to receive emotional support from other women and get a sense of what other people were doing to cope.

It helped me going to the first session and getting to meet the other women first....that really made me feel comfortable although in the group session we got to see other types of partnerships and relationships so they were both advantageous for me. (Wendy, couple # 5, April 30, 2006)

The couple workshop was held in a different location than the women-only workshop. Feedback was focused on the seclusion of the building and contained atmosphere of the space, (i.e. privacy). Many expressed the positive benefit of having so much natural lighting (it was a corner space with several windows on two of the exterior walls), and overall they were content with the availability of blankets, mats, refreshments, and accessibility of the restrooms. David thought that the layout of the space influenced his ability to participate. His observation also reflected the position David and Laura's stated earlier, that a smaller group size that was problem specific might have been more helpful to them personally as a couple.

I thought the group was too spread out in the room and also too large to really get that kind of close, sort of therapy relationship I was looking for. (David, couple # 8, April 7, 2006)

Other critical (negative) feedback related to prolonged floor sitting, in particular that the option of moving between rooms, changing the seating arrangement, or even taking an

extended break between activities would have helped them to stay better focused and engaged:

Um, the only thing is the long time sitting and my rear started to get a little bit sore after a while, but that was probably the only discomfort. (Jeanette, couple # 7, April 4, 2006)

It was good that there were mats available...the other thing I liked was that it was big enough that you could be in a circle so you could see everyone (Emily, couple # 10, April 18, 2006)

Key informants: Women who attended both workshops.

Three women attended the women-only and couple workshop. Each of these women had a different reason for wanting to attend both workshops. Bethany described feeling that she needed the protection and comradeship of other women because she felt they implicitly understood her journey. However, she also discovered after attending the couple workshop that listening to other couples and observing their responses was important for her partner to see, and more powerful because they experienced it together.

With the women-only I felt like it was just me, you had the support of other women...but when you were at the couple one you had the spousal support and he learned some things I had been thinking but never told him (Bethany, couple # 6, April 30, 2006)

Stephanie described each workshop as relaxing although the women's workshop seemed more formal and felt more public. Stephanie had received most of her support from other women prior to the couple workshop and it was this familiarity that prompted her to attend both. In retrospect she found that the absence of partners' in the women's group became pronounced when she compared it to her couple experience. Having her partner by her side helped Stephanie to appreciate that he was involved on a different level emotionally than she previously realized.

I He did care as much as I did about it. I don't think that I really truly grasped that before that. I think having him there helped to show me, not just words that he said...It was two people doing things to get to a common goal...in the couple workshop the men were really in it! They were up to their necks in it...I remember many of the men talking about heir feelings and it just being overwhelming, you know, all that love...(Stephanie, couple # 2, April 8, 2006)

Wendy was on a mission to learn more information and found the women's workshop was an opportunity to discover what other people were trying to do to get pregnant. She reported feeling misunderstood by her health care providers, employer, and her partner. Although Wendy brought her partner (Victor) to the couple workshop he appeared distracted and withdrawn (which he later confirmed) and when Wendy compared his involvement in their relationship to what she saw between other couples she was disappointed.

In the women's group it was somewhat reassuring that there are other women out there...but the couple session we got to see different partnerships, that was advantageous for me you know it educated him, it was great, but there wasn't much that we did afterward...it took a lot for me to get all the information, it is always more on my side. (Wendy, couple # 5, April 30, 2006)

Question 2: What is your understanding of mind body principles and infertility related stress as a result of your participation?

- a) Were you learning objectives met?
- b) What skills have you been able to apply to your life?
- c) How did your participation affect your ability to understand and/or respond differently to yours or your partner's needs?

Women-only workshop.

All participants were asked to share their learning objectives prior to attending the workshops (this item was included on the demographic questionnaire). The majority

indicated that they were looking for a way to resurrect hope, develop a more positive attitude and reclaim faith. Deborah and Katherine both indicated 'get pregnant' as their main objective, albeit with humor. The mind-body concept that women participants reported as being most helpful was mindfulness; living in the present moment. Deborah and Katherine described what they learned in the following way:

One of the main things I took away from the whole thing was your terminology of trying to be mindful., not thinking about what's going to happen, you know what you going to do later that day...enjoying that moment, I think that's the biggest thing I've learned (Deborah, April 4, 2006)

The workshop was good for me because it gave me a place to talk...I have struggled all my life with negative self talk ...I have been working on letting things go and not letting them bother me...after the workshop I had a better mindset going into treatment. (Katherine, April8, 2006)

The breathing exercises, which were used to elicit the relaxation response, helped to solidify the concept of mindfulness and were viewed by Sarah and Hillary as an immediate and effective way to become aware of, or modulate, their feelings of anxiety.

I hugely underserved myself in terms of breathing. I think that was one of the things I remembered most, consciously and subconsciously, after the workshop, in particular when we were on the yoga mats. Yes, being more cognizant of how often I held my breath and changed my breathing to isolate – to not feel something. (Sarah, April 8, 2006)

There was one breathing exercise...it kind of helped me cement the process, the mindfulness exercise, just feeling the connection between like a physical thing and an intentional thing, that helped me, has helped me quiet my mind. (Hillary, April 29, 2006)

Women had varying degrees of familiarity with mind body principles. Several saw it as an umbrella term that included all forms of complementary and alternative medicine e.g. acupuncture, herbal medicine, energy work, vitamins, yoga, and/or therapeutic martial arts. The common link for the majority of participants was their understanding that mental stress could be influenced by, and have influence on, how they

think about things. The believed that discovering a way to relax physically held benefit for their body physiologically, and their head and heart emotionally. Sarah spoke passionately about her understanding of these elements in her life.

Integration for me of mind/body/spirit...it was an important piece of the workshop for me to be able to kind of break those out a little bit...the experience of infertility has left a wound that has not healed. I did not expect that – physical pain. All those places enter – mind, body, and spirit, they are wounded in some way (crying). (Sarah, April 8, 2006)

The workshop served to reinforce what some participants already knew and were only sporadically attending to. For Katherine it was a foundation upon which to build a personal practice of self care: self care that did not separate fertility out for special attention but integrated it into her personhood.

The workshop confirmed what I was coming to realize...I was blaming everything on my job, my body was aching and hurting and it kind of helped me to say that it was not those other things and that if I stopped the negative self talk and things like that, that things might start turning around or that I might start seeing things differently. (Katherine, April 8, 2006)

Sarah's experience with infertility was the trigger that got her to attend to herself. The struggle to expand the attention beyond infertility and include other aspects of one's life was a common and sometimes overwhelming thread for all the women. Coming to the realization that the mind-body relationship is about understanding, as well as deconstructing, existing beliefs was expressed in the following way by Sarah:

Researcher: How do you construct meaning out of things you don't understand?

For me, I move away, I pull it apart like a piece of taffy. For me, the piece of taffy is all the things that go into creating a child for our family and then having to extricate certain things from that process. I can make sense of them individually. Then they are not quite as powerful and volatile for me emotionally when I am able to pull them apart a bit. That helps me understand, as soon as I put it all back together...[sigh]. (Sarah, April 8, 2006)

The concepts of mindfulness and deep breathing were also the most useful strategies that Ruth took from the workshop and that she continues to apply in her daily life:

I just remember, you know that relaxation response and that I *can* breathe in any situation, that's helped me out a lot...to stop and remember to breathe. (Ruth, March 31, 2006)

Breathing was not a new skill to acquire but rather a reflex to refine. Ruth recognized deep breathing as a technique that provided an immediate response, allowing something that she did to be linked simultaneously with a change in her body's resting state. Although yoga can facilitate awareness of the body during relaxation yoga is viewed as a more specialized practice than deep breathing or mindfulness and takes longer to learn as a strategy for reducing stress (Ghoncheh & Smith, 2004). Nevertheless the effectiveness of yoga as a mechanism for integrating physical, mental, and emotional health and awareness is well documented (Arambula, Peper, Kawakami, & Gibney, 2001). Ruth would have liked to have spent more time on the yoga portion of the workshop.

I especially liked the yoga aspect, I think if we could have done more physical things like that I would have been pleased with it. (Ruth, March 31, 2006)

She reported during the in-depth interview that she had been laid off from work and was currently under a lot of stress. She was also experiencing numbness and tingling in her left arm and was scheduled to undergo an MRI scan of her brain.

Hillary also found the yoga to be helpful but she had so many situations that she was struggling to negotiate, having a clear vision of what to do about any one of them at times seemed insurmountable to her. Hillary realized she needed more emotional support than a one day workshop could provide, and her quest to find adequate help persists.

I've gone through my infertility journey alone and I still am...I am always going to things like workshops or things on my own...I started seeing an

infertility counselor, well I can't see her right away so I have been relying heavily on my sister who is an ob/gyn. The yoga does help me, because it is something I have continued to practice, but seeing myself as *not* just a fertility patient I am still not making good progress there... [chuckling]. (Hillary, April 29, 2006)

The biggest challenge participants had was committing to a program of self-care that was meaningful, practical, and effective for them. As Alice indicated, finding the time to do for yourself what you know feels good is one thing, committing to it and then being hit with another devastating blow can be the catalyst that derails this process.

The yoga, yeah I thought wow, I need to do this more often...I remember thinking I really wish I had this knowledge before I had done one of my in vitro's because I think I would have gone in with a different perspective. Not saying to myself this is going to fail, but saying what do I do if it does fail? But then, having the devastation of losing my brother I kind of let life, other things, impact my decisions. (Alice, April 12, 2006)

The transfer of information from the workshop into life in general and relationships (with self or others) shared parallels for Hillary and Deborah, who were raising children in their home (biological and step). Hillary believed that being able to step back and gain perspective in her relationship with her teenage stepdaughter was enhanced by what she learned in the workshop about 'letting go'. Seeing this concept as quite different from 'giving up' was an important part of her learning process.

That whole concept of letting go, I tried to apply that to my stepdaughter... I think that time in my life when I was trying to control her most was when my life was so out of control with fertility (Hillary, April 29, 2006)

Deborah saw mindfulness as synonymous with being present in her own life and the lives of her partner and her child. She continually referred back to the many periods during her treatment for secondary infertility when she was unavailable to them and only able to focus on her pregnancy losses and disappointments.

I have evolved a lot from this...I wasn't looking at the big picture...it was one of the things you had said in the seminar "people come to the families that they want or need, I forget the terminology that you used and that's what I began thinking with this journey, that you just have to evolve through it you know egg donation or adoption, my daughter doesn't care she just wants a sibling. Do I really care? I've been looking at this all wrong. (Deborah, April 4, 2006)

Ruth's retrospective analysis of the workshop during our interview provoked new thoughts about how participating in the couple workshop might have had a positive influence on her relationship with her husband. Ruth expressed regret that they had not attended together and wondered whether this could have given them both an opportunity to be in their infertility experience differently?

I think if I had the chance to do it all over I would have liked him to have done the couple workshop because I think he could really benefit from some of the things we talked about. (Ruth, March 29, 2006)

Couple workshop.

Participants reported a more developed understanding of global infertility-specific stress after attending the workshop. Although couples indicated they had some knowledge of the mind-body connection they were not necessarily applying this knowledge to their own physiological and emotional functioning. Bruce and Nicole had been married 4.5 years and trying to conceive for almost 3. Nicole was diagnosed with severe endometriosis and at the time of the workshop they had completed 2 intrauterine inseminations and 2 in vitro fertilization cycles. Nicole described herself as extremely emotionally fragile and without hope. She also viewed her body through a prism of negativity and portrayed her infertility as the death of the biggest dream of her life, the shattering of which had left her devastated. Brian felt enormous pressure to try to change that perspective for her. Although Brian and Nicole were familiar with the mind-body connection and how mental health can influence physical health, neither one of them had

been effective in relating these principles to their own lives. Nicole's sensitivity to the comments of others often resulted in anger and self-blame and had been obstructing her ability to experience infertility or herself differently.

I had experienced the mind-body connection before but I hadn't really applied it to us. (Bruce, couple # 4, April 5, 2006)

It was the first time I realized that there was such a connection between the mind and the body, that stress could possibly play a part in it...I mean people would say insensitive things like, "well you just need to relax, that's your problem" that's the only context I heard it in. (Nicole, # 4 April, 5, 2006)

Brian recognized that the relationship between mind and body needed to be integrated into his lifestyle to have adaptive relevance. He understood it would be necessary to generalize skills across different situations and over time and to address his own issues rather than simply trying to heal Nicole.

I realized that you need to apply these things out of this process to get any benefit out of it, it kind of helps you to train yourself so that can do that when those moments arise. (Brian, couple # 3, April 15, 2006)

Nicole's despair momentarily lifted during the workshop and she reported feeling encouraged. She expressed awareness of how significantly her mood, health, indeed life had changed since she been trying to have a baby.

I was really ashamed. I had a lot of self-esteem issues. I always loved babies now I couldn't talk to people at all. I had shut down totally because I couldn't function. (Nicole, couple # 4, April 5, 2006)

The practice sessions provided an in-vivo experience of the body in a state of relaxation and helped to solidify or reinforce mind-body concepts. They also allowed individuals to make links between their own situations, personal thoughts, and particular pattern of manifesting stress. Bea and Kevin had previously been diagnosed with a genetic translocation, had suffered 2 miscarriages and were scheduled to undergo vitro

fertilization and embryonic pre-implantation genetic diagnosis. For Bea, the opportunity to rehearse the skills being taught was an important part of her recovery process.

What I liked was that we were practicing everything right then. (Bea, couple # 9, April 16, 2006)

I definitely think the practical was the most important part...the coping skills because I remember that we actually kept using them over the next few weeks. (Kevin, couple # 9, April 16, 2006)

Stephanie found that participating in the workshop as a couple helped her partner Peter to recognize how she experienced stress in her life. Peter's progressive ability to intuit when Stephanie was worrying or not doing well fostered a renewed confidence in their relationship and helped to convince Stephanie that she was understood by him.

If your mind is constantly going then your body is a wreck. I think he recognizes that in me more from the workshop when my mind doesn't shut off...like last night, I wasn't saying a word but he said to me, "you know you need to do something to shut your mind off. (Stephanie, couple # 2, April 8, 2006)

Much of the research literature has demonstrated that men and women cope with the stress of infertility differently: problem versus emotion-focused coping (Gibson & Myers, 2002; Petersen et al., 2006; Schmidt et al., 2005a). One of the consistent themes that arose in the interviews was that couples learned during the workshop that infertility was not always a problem to be fixed but a life circumstance to be lived through. Jeanette and Karl discovered new methods for supporting themselves emotionally, each taking responsibility for the different ways that they identified and subsequently mitigated their distress.

For me it was the breathing exercises and looking at my body posture to see, ok, am I tensing up? (Jeanette, couple # 7, April 4, 2006)

For me it was basically putting into effect a different thought process...thinking things through before I act right away (Karl, couple # 7, April 4, 2006)

It is well recognized that women undergo a majority of the treatment associated with infertility regardless of which partner has been diagnosed (M. Marsh & Ronner, 1996). For some couples this had translated into unspoken resentment. Bethany believed that Graham had little appreciation for the pain she was subjected to during treatment. Graham expressed frustration at not being able to influence this perception and tended to withdraw from Bethany's anger that provoked more rather than less conflict in the relationship. Exploration of this issue at the workshop, and feedback from couples who had successfully incorporated different communication strategies, helped to change this experience for Graham.

I remember the things that were said about taking your partner's face in your hands and stuff like that on decreasing the anger. I think hearing how some other guys have dealt with their wives...I noticed some guys that did a better job [than me] dealing with everything. (Graham, couple # 6, April 30, 2006)

Modeling and peer support played a large role for participants, sometimes proving beneficial and other times less productive. Laura expressed mixed emotions about her experience in the workshop.

If David and I had been able to talk more on a personal level in the group, you know things would have come out, but most of the people had some major stuff going on so it was important to hear *them* process *their* stuff. When there was a question asked, I did like say what was on my mind because I know that it would help other people. (Laura, couple # 8, April 7, 2006)

Her partner David was fearful that Laura might be infected by other people's grief and that the therapeutic intimacy they had hoped to achieve had not been possible because of the size of the group.

I believe as men we could have identified with each other more in a smaller group...in a larger group I am able to isolate more "oh that's not

happening to me” I am not even listening to that. (David, couple # 8, April 7, 2006)

Men and women noted several differences that occurred within their relationship as a result of participation in the couple workshop: improved listening (rather than giving advice), an appreciation for the fertility struggle within the large life picture, a commitment to pursue more counseling together, and the tendency to respond rather than react to difficult situations.

Stuart and Emily had been married for 6 years and trying to conceive for the last two. Emily was diagnosed with endometriosis and had undergone several cycles with the drug Clomid, had 2 intrauterine inseminations and was getting ready to try her first IVF. For Stuart being in the workshop broadened his perspective of his and Emily’s quest for a family. He described that prior to the workshop he might have expected to experience the following event as a more stressful situation.

We were definitely less stressed after the workshop because when the lady called with, you know, the positive test, we weren’t really as worried as before...I think I was tunnel vision before, I am so much more in tune to what’s happening right now. (Stuart, couple # 10, April 18, 2006)

For some couples a one-day workshop was clearly not enough. Though Bruce reported less cross contamination of anxiety between himself and Nicole after he began to recognize certain stress related patterns that had developed between them, he was overwhelmed by the depth of Nicole’s sadness. Bruce and Nicole both knew that the workshop was only the beginning of what they would need to support them through their infertility.

I felt like I was fighting for air...my only concern was Nicole, so when I left there, yeah, I felt like we had gained some, but we were in deep. (Bruce, couple # 4, April 5, 2006)

I remember thinking “oh my God, this could be the start to something that I haven’t had before, but it wasn’t enough (Nicole, couple #4, April 5, 2006)

For this couple the workshop was a starting point; a place from which to push forward differently. Bruce and Nicole made the decision to stop medical treatment after participating in the program and began weekly couple therapy, which they continued for the next 6 months to address their deep emotional pain.

Nicole had this whole way of looking at other people and saying “this thing is too big for me. I see other people can accept this but they are not feeling what I am feeling; they are not hurting as bad as I am.” She was on a mission to prove that in every instance...so I was so focused on her and trying to make her feel better that I wasn’t really seeing a lot of anything anymore. (Bruce, couple # 4, April 5, 2006)

that day (the workshop) I felt really encouraged...I read the manual page by page, the whole entire thing...then just day after day, it didn’t work for me anymore. Then I got too depressed and became too hard for me...until that day I hadn’t really met anyone who knew what I was feeling. I remember feeling like I wanted more and I needed more. (Nicole, couple # 4, April 5, 2006)

Question 3: How was the construction of the workshop and manual helpful to you?

- a) How often have you read the material in the Manual or reflected back on something that you learned in the workshop?
- b) What would improve this experience for you?

Women-only.

The overwhelming response to this question again addressed the issue of camaraderie and the participants’ search for a sense of belonging and identification.

It always makes me feel better when I hear about other people and can relate situations ‘cos I’m thinking “oh I am not so abnormal.” (Katherine, April 8, 2006)

Sarah, Hillary, and Alice had picked up the manual to read certain sections in the first few weeks following the workshop (breathing exercises, yoga postures, dealing with anger). As energy that had been gained from the supportive group atmosphere and the learning of new skills began to dissipate, it became more difficult for participants' to maintain their commitment to the workshop's recommendations. Even though there was an expressed sense from Alice that revisiting the text and doing some of the exercises would help her feel less stressed, she tended *not* to use it at the times she stood to reap the most benefit.

At times when I am feeling low I have to be honest, I do not reflect back on it because it is a constant reminder, at other times when I am feeling motivated which has been more recently to be honest with you, I find myself wanting to read it more. (Alice, April 12, 2006)

Some common ideas and recommendation were suggested to make the manual content and workshop experience more accessible and give the shared stories and relaxation strategies longevity. Katherine spoke for the majority when she said:

If the manual could have been on CD or something like that I definitely would have put it in and listened to it...I would have definitely used it over and over again, and you know, something explaining the breathing exercises (Katherine, April 8, 2006)

For Hillary the group format was not as effective as she had hoped in providing a source of support. Hillary felt a less formal atmosphere or unstructured setting might have been safer for her and although Deborah found the structure comforting and familiar she too wondered whether a more intimate setting might also have been more productive:

For the first 20 years before I had my daughter I was a CPA and all I did was attend workshops and environments like that, it's what I am used to. Would I learn more or have taken away more from a more intimate setting, probably! (Deborah, April 4, 2006)

Sarah thought that the construction of the workshop, presentation of the material (including graphics), registration, and pre-planned lunch, helped her to prepare for the day. The manual was symbolic of being included in the group and indicated that she had been expected, rather like a guest at a dinner party; first the invitation and then a place set for her at the table.

I am all about logistics...planning, getting a book, somebody knowing you are coming - the manual was a part of that even though it was prepared for everyone. For me it was part of the inclusiveness of the experience...everyone had a manual and you could refer back to it whenever you wanted to. (Sarah, April 8, 2006)

For Hillary, Alice, Deborah, and Sarah one day was not adequate to meet their needs. They expressed a desire to get to know themselves and each other better and thought an extended weekend or weekly sessions would allow them to consolidate the information and provide opportunity to integrate skills more effectively.

Longer, yes longer would have been okay, but not any shorter, I could see doing it over a weekend or something like that (Deborah, April 4, 2006)

I think that had there been more workshops, maybe things could have been different for me. (Alice, April 12, 2006)

Couple workshop.

Once again the overarching theme was the chance the workshop offered to be a part of a supportive group. For couples the experience of participating together was critical, allowing them to unify over a problem that was causing tremendous pain and sometimes separation.

That day was an eye opener it did get us closer together. I learned what she was going through and I'm hoping she learned what I was going through. (Howard, couple # 1, April 25, 2006)

I think I was feeding off her sensitivity...wanting to take on the role of protector and shield her from hearing or doing things and afterward I didn't feel the same burden or anxiety. (Peter, couple # 2, April 8, 2006)

The majority of men reported they had not opened the Manual since leaving the workshop. David, Stuart, and Brian all wondered whether they had actually received one. The exception was Kevin, who had periodically referred to the breathing exercises and yoga components in the first several months afterward, and stated:

We used a lot of the coping skills right at the beginning and I remember it was the first time that we actually relaxed. (Kevin, couple #9, April 16 2006)

Although men acknowledged that they hadn't touched the Manual since the workshop a few had adapted or were still applying some of the various techniques.

Everything was out of my control and I had a hard time letting go of that. It took someone else pointing that out to me. I realized that I was doing that and to enjoy the moment we were in. When I sense that's happening to me now I'm able to do the breathing techniques. (Peter, couple # 2, April 8, 2006)

We didn't really put like the yoga techniques and stuff like that into effect but I think the taking more time and having a little bit more patience with each other helped to lower our stress level...I am able to take a deep breath and just think things through before reacting. (Karl, couple # 7, April 4, 2006)

Women were more inclined to pick up the Manual, particularly to review the breathing exercises, a yoga posture or principles for guided meditation, even using it as a teaching tool to help others who had not attended.

I looked at mine. It lived up by the computer and stuff for quite some time. I guess I used it more to try and help other people, like friends or whatever if I was trying to explain the relaxation response you know. It helped spread the wealth. (Emily, couple # 10, April 18, 2006)

Sometimes it was not the material from the Manual itself that was used as a reference instead it served as the prompt to pursue a particular piece of the workshop content in more depth. Women participants who found a strategy helpful or had been successful in

identifying how they personally manifested or alleviated stress seemed more likely to apply their discovery across life domains.

The guided visualization was something I used after the weekend workshop and I find myself going to that for a different purpose now. I know I do more deep breathing now because I have had a lot of trouble sleeping...I felt like there was this higher standard of you know, our baseline should be higher, like no matter how bad it is we are not allowed to be like that all day long. (Bea, couple # 9, April 16, 2006)

I've opened the Manual a few times, just to remind myself of some of the techniques imagery and that kind of thing. The breathing, I use that *a lot*. (Stephanie, couple # 2 April 8, 2006)

The most common suggestion for improving the workshop was shorter sessions over a more extended period of time. Breakouts or topic specific discussions were also proposed, and an opportunity to come together at the end of the workshop to review individual objectives and the tasks of the day.

I think shorter sessions over the long run so you had the Manual in your hands more often. I'm someone who needs to manipulate more, not necessarily more in one day, but more times. (Jill, couple # 1, April 25, 2006)

I think more talking and more communicating with the other couples would have been really helpful, and I also think a chance for more one-on-one with your partner.. (Howard, couple # 1, April 25, 2006)

Cost consideration was less of a factor for women however men were more inclined to discuss this in their recommendations. Men and women suggested an interactive CD, something that they could listen to in the car that included intervention strategies, (relaxation and breathing techniques), and personal stories and vignettes.

Question 4: Please describe where you are now in your family building journey.

Women-only.

Two of the three women who attended both workshops (Bethany and Stephanie) had recently delivered children and their responses, along with Wendy's are included under the *Couple* sub-heading. Kit was in the process of completing a domestic adoption and gave this as her reason for not participating in the in-depth interview in person. Baby Anthony had already been in her home approximately 4 months at the time of the follow-up and Kit was waiting to have the paper work finalized.

Deborah had undergone two more IVF procedures since the workshop, had become pregnant both times and suffered two miscarriages at around six weeks gestation. Deborah felt that she experienced these losses differently (less traumatically) than she had in the past. She attributed her transformation to a change in perspective that she believed developed over the course of the year and had helped her to accept that infertility was a part of her journey; not something she wanted simply something that *was*. She was also considering other family building options such as adoption and egg donation, both of which had also represented failure or loss at earlier stages in her infertility. She expressed feeling strong emotionally at this point in her life.

One of the things you said in the workshop was that people often find a way to arrive at or accept the families that they need, or something like that, it just stuck with me. I have realized now that perhaps there *are* all these other possibilities. (Deborah, April 4, 2006)

Sarah had also suffered an early miscarriage since the workshop, (her second after an IUD), and decided against taking any more fertility drugs or using assisted reproduction. She was still trying to conceive naturally and pursuing adoption. Sarah found the increasing powerlessness that she experienced as part of her treatment

overwhelming to her and led to her decision to stop. Like many of the women she was used to working hard to achieve her life accomplishments and infertility was one challenge that she discovered could not be overcome by simply being more industrious.

There is nothing intimate, spontaneous, fun or joyful about the whole process it becomes scientific or medical, that is part of why I wanted to stop. It became this obsession that working harder didn't fix. (Sarah, April 8, 2006)

Sarah was sad yet philosophical as she talked about the child she still longed to bring into her family. She also referred back to earlier struggles in her life and drew an analogy between previous wounds she had suffered and the complexion she was bringing to her ongoing infertility.

One of the things I know is that having a child is just one piece of this [life]....it is not as if having a child somehow fixes all those infertility wounds or heals them automatically the wounds will still exist and require healing and growth. (Sarah, April 8, 2006)

Alice had experienced an extremely tough year since we had last met. Approximately six months after the workshop her younger brother was found dead in his bed of an undiagnosed brain tumor. Alice had also lost her father the previous year. Alice called me during this time and asked for a referral to a mental health professional. She was suffering tremendous grief and anxiety and described several episodes of uncontrollable anger that scared both her and her husband. She had just completed six months of weekly therapy sessions at the time of our interview. She reported feeling very positive about moving forward with her life. She had put infertility treatment on the back burner during her year of tumult but was now talking once again about using an egg donor. It continued to be important for Alice to have a child and possibly experience pregnancy with her partner but she was no longer looking through a narrow tunnel without hope of ever seeing light.

We are definitely going to do donor, not that we aren't open to other things. In the past we shut our selves off from adoption but now we are being very open... (Alice, April 12, 2006)

Hillary had recently completed another IVF (her third). She had relocated to a new city since the workshop and was still the main breadwinner, although her husband was now employed. Doctors had also recently told Hillary that she would need an egg donor to achieve pregnancy because of an elevated hormone (follicle stimulating hormone or FSH), however she was still committed to attempting one more stimulated IUI cycle with her own eggs. Hillary had also participated in a six-week mind body workshop and was currently searching for an infertility counselor. She was still experiencing tremendous emotional pain and described her anguish as stemming from this one enormous loss in her life and continued to search for ways to support her wounded spirit.

I know I need to get the emotional support first. My heart has been broken. I know I will get through this. Something I learned through the workshop is that infertility is grieving...I don't believe anybody who already has a child could ever understand not having a child. I mean he [my husband] sees the sadness in me because I have been crying more in the past but he doesn't know what to say so he's quiet. (Hillary, April 29, 2006)

Hillary resisted describing what she was experiencing as depression. Her emotional pain was a corrosive force in the center of heart and she continued to find putting back what infertility was stripping away extremely hard.

Katherine described herself as "taking a break." She had applied to nursing school and was scheduled to begin classes later in the summer. She was also open to the idea of using a gestational carrier sometime in the future. However, for the first time since she was diagnosed with infertility she and her partner were considering not bringing children into their relationship. This was an active decision Katherine felt she was making. She

reported that she was in a much stronger place in her life. She had also decided to begin taking the anti-depressant medication Lexapro, although she did not feel this was only as a direct result of her infertility but related to a strong family history of depression. Katherine believed that her change in perspective had liberated her and she was finally able to consider her own life rather than the life of a baby she had yet to create.

At this point I would be okay with anything. If we did nothing that would be okay, I think I am still healing emotionally and still taking time. I just wanted to take time for myself and I think that is good. (Katherine, April 8, 2006)

Ruth continued to describe her infertility as a roller coaster ride. She was also experiencing lots of other physical symptoms in her body and was awaiting a brain MRI. Ruth considered her family building to be on hold and had decided early on in the journey not to use assisted reproductive techniques to help get pregnant. She had recently resumed her yoga practice and was also visiting a chiropractor for problems she was having in her neck. At the time of the interview Ruth's job loss and general physical health was overshadowing her concern about having a baby. She was beginning to see that focusing on a child she did not have was another way in which avoided addressing some other pressing issues in her life.

I *need* to do something and change the way I handle stress because I don't want to keep doing what I am doing – it is amazing the power that stress has over me physically. I was doing so well with exercise and then I noticed as soon as this happened (losing my job) I stopped exercising. (Ruth, March 31, 2006)

Couple workshop.

Howard and Jill (couple #1) had one more IUI in the 12 months after the workshop and then decided to discontinue their medical infertility treatment because the stress and financial cost was simply too much for them. They also confided that between

the workshop and completion of their second SCL-90-R Howard discovered that his sperm count was significantly abnormal and his physician thought it unlikely that he would father a biological child. This threw the couple into a tailspin as Howard had two children from his first marriage (that Howard and Jill were raising) and he began to doubt that they were biologically his. Howard disclosed that they were conceived while he was completing military service in the Middle East. He also feared that his current fertility problem and erectile dysfunction was related to medication that the army had given him to take during Desert Storm.

When we went to the doctors and I found out that it was also me I was like how do I know my children are even my children?" I mean, there are a lot of things that build up and there is a lot of anger and, you know, the marriage I had with my children's mother was not a good one at all, I was in the Service and she was back in the States. How do I know she didn't cheat on me and let me believe they were my kids? (Howard, couple # 1, April 25, 2006)

Howard shared that his experience in the workshop helped him decide to go to couple therapy with Jill. His military background and current occupation (prison guard) was based on what he described as "structure and organization; always knowing the rules and what's supposed to come next." Howard had believed he had no safe ground on which to explore painful emotional issues. After participating in the workshop his philosophy changed to the benefit of both of them.

I remember at the workshop, when we were leaning against each other. Just feeling and that whole thing physically to me was the expression "I've got your back" I think maybe if we didn't state that goal to each other that has been our goal and that is what we have worked through. (Jill, couple# 1, April 25, 2006)

The couple has not ruled out adopting a child in the future but for now they are focused on supporting each other and raising Howard's teenage children. They have reached a

place as a couple where the term ‘family’ is not represented by biological ties but committed relationships.

Peter and Stephanie (couple #2) shared that they conceived their daughter Lillie the month following the workshop. They had been trying to get pregnant over 3 years when Peter underwent a varicocele repair in November 2004. (Lillie was born at 38 weeks in February 2006 and came with her parents to the interview). Peter shared that seeing other couples at the workshop, hearing their stories and then integrating them into the narrative of their own lives helped him to appreciate how much stress Stephanie had been under when he left her to deal with their infertility alone. He also began to see that the guilt he felt about being the partner with the identified problem had contributed to his discomfort talking about it. Peter’s fear of not being able to conceive a child with Stephanie kept him trapped in self-sabotage and emotional withdrawal.

In hindsight looking at it now it was almost like an ignorant thought that I don’t want to try something because why try if you’re just going to fail.
(Peter, couple # 2, April 8, 2006)

Stephanie’s struggle to bring Peter into their fertility discussion often ended up with her lashing out at him in anger and then a further retreat while he licked his wounds. Although Peter knew he was avoiding a conversation that needed to occur he had no strategy for entering, or staying in it.

He didn’t want to take any steps at first and I just remember that being the hardest thing for me...I’m the type of person that wants to talk and he’s the type of person, “well let’s just wait and see if it goes away first.”
(Stephanie, couple # 2, April 8, 2006)

Now one year later, with their child between them, they see their journey toward parenthood as a life lesson that brought down many intrapersonal and interpersonal walls and broke open their ability to see each other clearly for perhaps the first time.

I totally forgot in the beginning of our relationship how you had these little walls built up...since then, and since going through these different experiences, you are more you. There are no little shields of protection. (Peter, couple # 2 April 8, 2006)

Stephanie and Peter both work full-time and co-ordinate the majority of Lillie's care between them by maintaining flexible works schedules.

Caroline and Brian (couple # 3) had recently experienced another miscarriage after IVF (3rd miscarriage and second IVF procedure). They had frozen embryos remaining and were planning to have these transferred some time in the summer. Caroline also talked about beginning to think about adoption more seriously. Brian had been less open to the idea of adoption because he felt, in part, it reflected Caroline's desire to have plan B on the go in case plan A was failed. For Brian, any consideration of failure during an IVF cycle represented a loss of faith that he believed fed his wife's anxiety. However, for Caroline plan B was the safety net that assured her that the chance of motherhood was not permanently eradicated by miscarriage or a negative pregnancy test. Brian and Stephanie had learned in the past year to recognize and respect their own and each other's coping strategies. Brian also began to see that the tools they used to get them through infertility needed to be applied across their lives.

I worry, but I do not worry as much about worrying, if that makes any sense? (Caroline, couple # 3, April 15, 2006)

I think it is important, you know, you do need to have a positive attitude. I believe if you have a negative attitude people pick up on that. (Brian, couple # 3, April 15, 2006)

During the workshop Nicole and Bruce (couple # 4) described their relationship as "in a dark place". Nicole was deeply distressed over her infertility and had already experienced 2 IUI and 2 IVF cycles. At her own admission she held little hope that anything was going to work out for them. Nicole was stuck in her conviction that she

could not become pregnant but she nevertheless continued to pursue assisted reproductive treatment. The inherent conflict of her position severely elevated her anxiety and Bruce took on the role of ‘anxiety reducer’ in the relationship. He spent a great deal of energy trying to reframe Nicole’s negativity eventually realizing that his efforts at cheerleader were futile. After the workshop Brain and Nicole agreed to discontinue medical treatment and committed to participate in weekly counseling session for a period of 6 months. In November, 2005 they found a new reproductive endocrinologist and completed another IVF cycle. At the time of the interview (April 15, 2006) Nicole was 5 months pregnant with fraternal twin boys. Nicole, who is a grade 4 teacher, plans to quit working after the boys are born and stay home full-time to raise them.

Victor and Wendy (couple # 5) were still in a relationship with each other but continued to live apart. Wendy had been pregnant once before the workshop (with Victor’s child) and miscarried at 6 weeks. They had been to see two different infertility specialists in the previous 6 months who once again informed them that Victor had a low sperm count. Victor and Wendy described their experience during their infertility evaluation as disorganized and dismissive. They were disillusioned with the level of compassion they felt they had been shown and frustrated that any help they were likely to benefit from would be cost prohibitive. Victor had several other health related difficulties he was trying to cope with; back and foot problems, high cholesterol, elevated blood pressure and intermittent bouts of depression. He was also taking a lot of different medications to manage these conditions and had recently begun to see a mental health professional.

Victor lost his younger brother to a heart attack and expressed his anxiety that this would be his fate if he didn't get his life under better control. Fear for his own mortality was much more important for him at this time than trying to conceive.

I am just trying to correct my health problems. My blood pressure was incredibly high. I don't want to have a heart attack or something. I just lost my brother last year so I am trying to take care of my own health and eat better. (Victor, couples # 5, April 30, 2006)

Although Wendy was ovulating regularly and in what she reported as "good health", she was extremely overweight with a body mass index (BMI) of 36. Wendy expressed gratitude that she was not the cause of their infertility and although discouraged that Victor did not take more initiative over their fertility issues, or the relationship generally, she worried that her desire to be pregnant was contributing to his pressure.

It made me feel really good and relieved that it was not all me...but when he told me he was having a lot of medical problems, I was hoping this wasn't caused because of me stressing him out or anything. (Wendy, couple # 5, April 30, 2006)

Graham and Bethany underwent their first IVF procedure in the month following the workshop and their daughter Charlotte was born full-term in February, 2006. Within twenty four hours after her delivery Charlotte was diagnosed with a congenital heart defect called Tetralogy of Fallot; a complex system of cardiac abnormalities that require surgical repair. At the time of the interview Charlotte was home with her parents and doing well on about 40% oxygen (room air is 21%) and was scheduled for heart surgery approximately one week later.

Some significant changes had occurred in Graham and Bethany's relationship since Charlotte's birth and subsequent medical problems. As the primary caretaker Bethany often slept on the floor next to Charlotte's crib during the night to monitor her

breathing and provide the frequent feedings that were helping her gain strength for the heart procedure. Bethany described herself as transitioning from “fix it mode” to “taking care mode” and Graham had now assumed the role in the partnership of researcher/medical investigator.

I probably did more of the research looking into IF stuff, finding things to do or treatments or something. I don't know why I haven't researched this stuff. It would probably scare me. I think okay, her health is in their hands and I'll just take care of her until the surgery. (Bethany, couple # 6, April 30, 2006)

That's the whole thing. We *can* do something together whether we're both doing some research or whether just one of us does the research. It doesn't matter because we can *both* make the ultimate decision where with the infertility problems I still had to be the one giving *her* the shots. (Graham, couple # 6, April 30, 2006)

The transition to parenting also saw shift in the couple's emotional synchronicity with respect to their daughter. They continued to recognize that they had different coping strategies and personality styles but described greater unity and a shared depth of concern for Charlotte health. Each better understood the degree of pain and worry the other felt as a result of Charlotte's upcoming surgery. This had not been their experience through infertility when Graham struggled to understand Bethany's anger and she reported feeling discounted and ignored. The couple's initial plan had been for Bethany to return to her job as a speech pathologist part time when Charlotte was 3 months old but because of Charlotte's health needs Bethany had stopped working outside of the house and was taking care of her daughter full-time.

Karl and Jeanette had been trying to get pregnant since their marriage in 2002. Jeanette used the fertility drug Clomid early on in her treatment but discontinued it due to an adverse reaction. The couple felt that their options were extremely limited because of financial restraints. They attended the workshop as part of an effort to introduce positive

lifestyle/behavioral changes into their relationship, which they thought might impact their overall physical and emotional health.

I was looking for something to either help us get pregnant or if not, to give us the patience until we got there. (Jeanette, couple # 7, April 4, 2006)

After the workshop Jeanette felt she was able to take some pressure off herself and described being more aware of how she held tension in her body. She also began a regular practice of breathing and relaxation exercises. Although both of them were significantly overweight they introduced only modest dietary changes and Karl cut down from 1 pack to 6 cigarettes a day. In May/June 2005 Jeanette completed a cycle on the drug Femera, (an estrogen inhibitor currently approved in the USA for the treatment of post menopausal women with breast cancer), and became pregnant. Jeannette delivered her daughter Brea at term on March 23, 2006 and by the time of the interview Brea was almost 2 weeks old and the couple was still adjusting to the circumstances surrounding the delivery and being new parents. They both believed there had been a significant reduction in their stress level in the 2 months prior to their conception

The workshop definitely opened the door for us to talk more during the pregnancy. The delivery was quite a traumatic experience, things didn't go to plan, I think if he hadn't been open to the idea of going to support groups or workshops, try whatever may be needed to get us to this point...then she wouldn't be here. (Jeannette, couple # 7, April 4, 2006)

Karl acknowledged being particularly overwhelmed with the financial responsibilities of being a father and provider. He continued to be dissatisfied with his job but he also felt that they were now at a stage in their relationship where they were much better able to manage their stress.

Being open with each other and sharing our problems and emotions...that's the biggest thing that's changed and I think that transfers through the whole entire family unit...you know a man and a woman

being there for each other *and* for the children. (Karl, couple # 7, April 4, 2006)

Jeanette was on a twelve week unpaid maternity leave at the time of the interview and had not yet begun to look into daycare or in-home child care services. Along with Karl, she was anxious about finances and shared that she did not want to return to work but felt she had no other option because as a family they relied on two incomes.

David and Laura (couple #8) had also become new parents at the time of the interview. Laura conceived in early June 2005 and gave birth to their son Keenan on March 17th, 2006. David and Laura felt that the disparity between their fertility related distress (lower) compared to the other study participants made the workshop less productive for them. Laura disclosed high levels of anxiety generally and David was concerned that Laura's tendency to over-identify with the pain of others could have a negative effect. Laura's recovery from her ectopic pregnancy and subsequent difficulties conceiving were compounded by her tendency to ruminate and inclination to second guess herself. She also experienced several somatic symptoms as a manifestation of her stress. Laura frequently relied on playful problem solving and positive reappraisal (as per WCQ) as coping methods and her registration for the workshop was representative of that. The couple began to better understand their intra and interpersonal dynamics as they progressed through their pregnancy. They took charge of their prenatal care, decided against circumcision for their son, and began to see the value in heeding their own counsel.

Half the girls (at the workshop) were going to the same acupuncturist ... it took a bit of the credibility away from that... maybe I had to stop running to all these different doctors and go within, to listen to my own physician? During the pregnancy I tried to practice that and not scare myself with every symptom. (Laura, couple # 8 April 7, 2006)

It was important for Laura and David to have the uniqueness of their situation, their individuality, and distinct relationship needs recognized and respected. David observed a significant change in Laura as she became less reliant on the expert advice of others and looked more inward to find her own personal power and it was this message that they wanted the study to take away from them.

I think the older we get and the more experience we have the more disappointed we are by the titles doctor and Ph.D. and the more times you go and ask a specific question and you get feedback that is incorrect, inappropriate or just doesn't make any sense, it bring more questions into your mind than answers. So I've notice that Laura sees a lot less people that she used to see for counseling, doctors and things like that. She is a lot more self-contained. (David, couple # 8, April 7, 2006)

Laura took maternity leave from her job as a flight attendant and is Keenan's primary caregiver although David is also very involved in the care of their son. Laura plans to be a stay-home mother through Keenan's infancy and young childhood and hopes to open a massage therapy and yoga business in the future.

Bea (Beatrice) and Kevin (couple # 9) called the day before the workshop to say that they had just received a positive pregnancy test and could they still participate? They had experienced 2 prior miscarriages due to a genetic defect and were originally scheduled to undergo IVF and pre-implantation genetic diagnosis the month following the workshop, when they got pregnant on their own. The couple felt that despite their pregnancy they still needed to attend the workshop. They were looking for group support, a method for identifying how they manifest stress, and some coping skills to help get them through the next few weeks of pregnancy until they completed their chromosome testing.

We didn't consider our issue solved by a positive pregnancy test by any means if anything the stress worsened for us. (Bea, couple # 9, April 16, 2006)

The couple went on to have a healthy pregnancy and their daughter Kelton was born in late December, 2005. At the follow-up interview Bea and Kevin recalled many of the strategies they had learned that helped them through the pregnancy and delivery, as well in their new role as parents.

The prenatal yoga came in part from doing it at the workshop. We did long extended childbirth classes and also DVD's. The experience from the workshop made us more invested in just seeking out ways to be prepared together, and then we also used some relaxation CD's. (Bea, couple, # 9, April 16, 2006)

Although this couple's situation was unique Kevin appreciated being part of a group of people with diverse stories. Kevin also shared that as a result of their workshop experience they made some different early pregnancy decisions than they otherwise might have.

Prior coming to the workshop we said we were going to tell everyone we were pregnant, then after listening we decided against doing that at all. There was enough difference involved in everyone's story that I think that really helped us out. (Kevin, couple # 9, April 16, 2006)

Bea was currently on unpaid maternity leave from her job as a psychotherapist and although she had primary responsibility for Kelton's care both partners viewed themselves as active involved parents with major influence in the day-to-day progress of their daughter's development.

Emily and Stuart underwent their first IVF procedure the month following the workshop (May, 2005). Emily developed Ovarian Hyperstimulation Syndrome during the treatment cycle, (associated with marked shortness of breath, reduced urination, fluid retention, and eventually chest pain), for which she had to be hospitalized.

For me, I was so sick I had made peace with the fact that it was probably going to be negative because my body had been under so much stress. I was like “okay where will we go from this, I can handle this” and then it was positive, that was actually more shocking. (Emily, couple # 10, April 18, 2006)

Emily and Stuart were extremely surprised when Emily’s pregnancy test was positive. She described the first two months of her pregnancy as extremely difficult and relied on several of the workshop’s relaxation techniques to help stay calm (breathing exercises, meditation, and guided imagery). It was not until after Emily passed the fourteenth week gestation (when she felt she had a reduced risk of miscarriage) that her anxiety level began to come down. In December, 2005 at almost 35 weeks pregnant Emily’s water broke and she was admitted to the hospital. Her son James (Jimmy) was in a frank breech (feet first) position and delivered by cesarean section 5 weeks premature. After ten days in the neonatal intensive care nursery he was sent home with a breathing and heart monitor, which he continued to wear for the first two months of his life. At the time of the interview Jimmy was doing well and Emily had returned to her job as a nurse (approximately 30 hours per week). The couple was working varied day, evening, and weekend shifts to accommodate Jimmy’s schedule, and alternated being the primary caregiver for their son.

Figure 2 shows the ratio of participants who became pregnant, delivered, miscarried, or adopted during the 12-month period between the workshop and follow-up interview. A total of seven women became pregnant and proceeded to have a live birth (eight infants had been delivered at the writing of this dissertation). Stephanie and Bethany represent the only participants in the women’s group who had babies and they also attended the couple workshop.

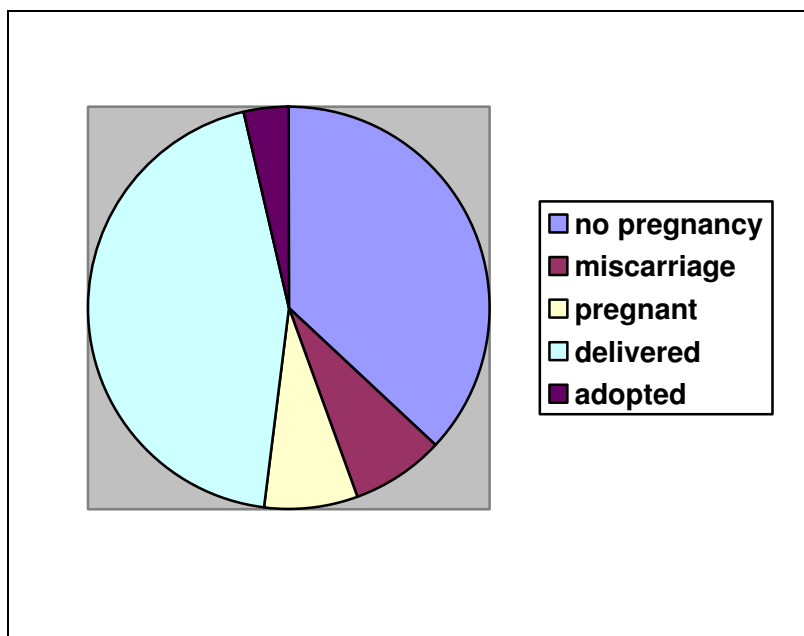


Figure 2. Pie chart of pregnancy outcome

PART II: Interview Questions

Prior to being asked the final 3 questions participants were given a narrative summary of their responses to the SCL-R-90 and FPI survey instruments (Appendix G). The individual sub scale items on the Symptom Checklist had been converted from clinical to lay terms, e.g. anxiety became worry, and hostility became anger. The Symptom Checklist is a self report measure intended to capture an individual's perception and experience of a particular set of circumstances at a particular point in time (Derogatis, 1977). Rank scores (0 to 4) are accumulated for each item to reveal scale elevations and provide the global severity index. For this reason low scores on a particular dimension are not so much a reflection of positive self-regard as they are an absence of distress or psychopathology. Therefore it was not possible to share with participants their possible psychosocial strengths but rather what they reported having few personal struggles with. The language in the narrative was designed to frame low

scores in a neutral light, i.e. it “it appeared that you had few difficulties with....” High scores were similarly reported: “it looked as though a particular area of concern for you was...”

A second administration of the SCL-R-90 was conducted to produce a comparison between participants for two separate time frames. No estimate was made by the researcher that variation in the responses would be predictive. It was anticipated that an instrument designed to measure the perception of stress over a seven-day time period would likely reflect the inconsistency of experience. The summary was intended as a method for provoking self-reflection, temporal discussion, and some analysis of the instrument’s usefulness, not as a measure of the intervention’s effect. A graphical representation of an individual’s change score between the first and second SCL-R-90 was also provided.

The FPI narrative reviewed the categories that produced an individual’s highest score i.e. greatest areas of infertility related concern. A comparison between participant scores and norm referenced percentile rankings was provided for perspective. The FPI is designed as a measure of infertility specific stress and although values on this scale can vary with time, its authors have found global stress scores to be relatively stable over at least a one month period (Newton et al., 1999). As initial follow-up was to be within six weeks it was not expected that fertility specific stress would show much fluctuation therefore this instrument was not repeated. A review of the relationship between categories on the SCL-R-90 and FPI is discussed in Chapter VI.

The Ways of Coping Questionnaire was not included in the narrative summary. The coping scale gave a single portrait of the coping processes used by participants to

modulate their perceived stress at one particular point in time. According to its authors: “Coping when considered a process, is characterized by dynamic changes that are a function of continuous appraisals and reappraisals of the shifting person-environment relationship” (Folkman & Lazarus, 1988, p. 7). Coping therefore is not a skill that is mastered but an inconstant; an adaptive set of responses to impermanent people and situations. The workshop was a pilot study that on one level was designed to collect feedback and information to share later with participants and on another, develop material for expanding and improving the Minding Matters workshop. Discoveries and implications from these analyses are presented in Chapters VI and VII.

Question 1: How closely does what you have heard from these survey results match your memory of how you felt at the time?

Women-only.

After reading the 2 to 3 page narrative a preponderance of participants began by offering an explanation for what was going on in their lives a year ago when they completed the instruments. It appeared there was an overwhelming need for justification. In order to clarify why she thought her responses on the Symptom Checklist had gone down between the first and second completion Deborah shared the following:

I think all the fertility drugs and everything they put you on – they’re all hormones and plus it adds weight and I think all of that compounding in the miscarriage really sends you toward being anxious and depressed. I started exercising and I am not on those drugs anymore. I think all that helped. (Deborah, April 4, 2006)

Deborah matched the memory of events in her life one year ago to the description presented in the words before her; creating and expanding meaning to give both herself and the researcher greater context. Similarly, Sarah remembered feeling that she had

some difficulty focusing at the workshop and placed this interpretation on the narrative summary:

This is how I would have liked to have said how I felt. This is deconstructed for me, yeah, not overwhelming I'm able to look at it in pieces and feel some humor, which of course when I am in a state of being overwhelmed I do not feel. (Sarah, April 8, 2006)

For Sarah it was important to reflect back on the specific sadness she had expressed about her fertility, which was actually quite low when compared to others, and the way in which she now saw how sadness had managed to permeate her life generally at that time.

Infertility is one slice of the pie but when you are in that slice it is overwhelming like this is the only thing in my life and it takes up all my energy. It is my only focus. (Sarah, April 8, 2006)

Alice and Hillary had greater difficulty recognizing themselves in the text on the page though neither challenged the veracity in the words used to describe them. Alice was experiencing multiple stresses at the time of the workshop including the recent death of her father that resulted in her mother moving into her home.

It is very eye opening...I knew I was at a really low point...but reading it...it fits exactly... I don't think I ever saw myself at the time as falling apart but it was really a bad time. (Alice, April 12, 2006)

Rather than question either the authenticity of the questionnaire or accuracy of the interpretation Hillary built a story to fit the description she was reading and worked hard to reconcile conflicting ideas.

Was this really me? I wonder what I was thinking. I immediately remember being dissatisfied with the IVF team at the hospital but what I am reading seems even worse than what I'm feeling in some areas, but in general I would say it is pretty accurate. (Hillary, April 30, 2006)

Katherine expressed amusement when she read her narrative and was relieved it was in the past and did not reflect her current mood or situation. She recognized herself in the

words but was glad to see that she could now observe the experience from a distance, with her memory intact and her emotions contained.

It matches how I felt at the time, yeah I *remember*, and I am proud of myself for making it through. (Katherine, April 8, 2006)

However Ruth expressed some ambivalence. She continued to be experiencing a great deal of general stress in her life and expressed disappointment that she had not done a better job identifying and dealing with it, particularly in light of her current physical symptoms (chest pain, numbness and tingling in her arm).

I look at the stress situations and they are the same or maybe even intensified...the fertility issue is probably the same, stress does weird things to my body I mean it's just very obvious. (Ruth, March 31, 2006)

Couple workshop.

David and Laura (couple # 6) was the only couple that decided not to review a summary of their responses. Laura had recently given birth to their son Keenan (March 17, 2006) and both of them felt that the circumstances surrounding their difficulty in conceiving were not as extreme as same as many of the other workshop participants. They were committed to practicing the tenet of mindfulness; being present in the day. This was a pledge the couple established prior to the workshop and was reinforced by their subsequent pregnancy experience. Their understanding of mindfulness included striving for personal power, conscious living, and movement forward. The couple indicated that there was little benefit to them in looking back at where they had come from.

I don't really need to read it for my own application that was a different point in my life, like your opinions change from new information. I have new information now so, you know that time in my life has passed. (David, couple # 6 April 7, 2006)

Yeah, I don't feel, now that I have a chance to have new information, I don't feel the need to read it or go back, I am not even really curious.
(Laura, couple# 6, April 7, 2006)

David and Laura viewed the interview as an opportunity to share what they had learned about themselves and potentially help others and they wanted to add their voices to the research. Having power over their reproductive decisions; pregnancy, delivery, and care of their son, was of paramount concern to both of them. They expressed a general dissatisfaction with the philosophy of Western medicine and considered it overly interventional and indiscriminately applied. David and Laura had also recently decided against circumcision and vaccination for their son.

The urologist said to us, "it [circumcision] is a nose job for your penis," well that made our decision pretty clear [laughing]. (Laura, couple # 6, April 7, 2006)

In general, couples approached questions differently from the women-only group due to the presence of their partner. In addition, responses to the Part 2 questions revealed greater interest from women than men in partners' answers to the earlier questionnaires. Women often asked to read their partner's summary, asked for clarification, offered feedback, and suggested new interpretations. The majority of participants, regardless of sex, agreed with how their global and specific fertility related stress was represented in the narrative.

Jill and Howard (couple # 1), had decided to stop medical treatment by the one year follow-up. A review of their summaries confirmed the reasons for them that they had made this decision: loss of control, heightened anger, feelings of shame, and the need to maintain confidence in their intimate relationship. Although Jill continued to experience heightened sensitivity to the comments of others she felt that her sexual life with Howard only resumed its previous strength after they discontinued treatment.

It matches! I mean it's interesting because it just depends on where you are at. One of the areas I still have difficulty is feeling critical of others and criticized by others...being either hurt or misunderstood and quite self conscious or judged, I feel that...but now that we have chosen to be done I would say our sex life is back to being a strength for us. (Jill, couple # 1, April 25, 2006)

Howard confirmed his elevation in anger between the first and second SCL-90-R and shared that this was when they discovered he had problems with his sperm count and that he had begun to question the paternity of his own children.

My anger went up after the first time because I felt I wasn't in charge, I wasn't in control of what was going on. We had to listen to the doctors and kept on doing the same thing and the result as the same. I felt like I was being hurt. (Howard, couple # 1 April 25, 2006)

Jeanette (couple # 7) also provided additional explanation for clarity and to broaden the context of her specific situation. She reported that she frequently revisited the breathing techniques and used reframing strategies to challenge her tendency to ruminate and rigidly fixate on her fertility. Progress was incremental and non-linear; circumstantial and multi-layered.

Pretty much the narrative's dead on, although I did progress later and become a little bit more relaxed and hopeful. I had become trapped in a mindset that it would never happen (Jeanette, couple # 7, April 4, 2006)

Couples responded to each other during the interview and made observations or offered an interpretation of some aspect of their partner's narrative. Women were frequently surprised by the degree of stress that their partner reported and believed that at the time of the workshop it had been their perception that their own emotional struggle was the more significant. Women's experience of distress was focused around not being able to get pregnant and it was common for them to assume that their partner did not suffer this loss at the same magnitude. It was necessary for women to proffer an explanation when this

appeared not to be the case. Nicole (couple # 4) presented the following analysis after reading her partner's summary:

Oh my goodness Bruce, you were worse than me... I am surprised. He's very introspective. Bruce is the type of person who really tries to self-improve at all times. I remember when he was working at LM as an engineer, on Sunday night he would practically be rocking. (Nicole, couple # 4, April 5, 2006)

It was also revealed that what Nicole had evaluated as strength in their relationship, (the ability to depend on her partner), Bruce had encountered as vulnerability or a threat. It seemed as much as women felt disconnected from their bodies, men described feeling disconnected from their spouse.

How Nicole was doing was all of my stress, almost all of it. Only when I saw Nicole feeling better, only during those times did I ever get sad about not being able to have children. It was by myself, not when she was around. (Bruce, couple # 4, April 5, 2006)

I was feeding off her sensitivity and wanting to take the role of protector. I was stressed out because you were stressed out. There was no way for me to get you to stop thinking about it. If I couldn't fix it I didn't want to talk about it. (Peter, couple # 2, April 8, 2006)

For several men, stress was discussed as an externally provoked event rather than an internal experience; something that was done or visited upon them. Men's absorption of stress as it related to infertility appeared to be mediated by how well their partner was managing her own emotions and they often saw themselves as the conduit through which her stress eventually traveled and subsequently had to be mitigated.

I remember working really hard on doing everything I could to make it as stress free as possible for her. It didn't really seem like it was important how high my stress level was, it was all about her stress level and how her body was feeling. (Kevin, couple # 9, April 16, 2006)

Kevin (couple # 9) had the perception that his partner did not understand how hard he had tried to console her during some of the most difficult periods of their marriage. The

observation that his stress appeared to rise as his partner Bea's came down appeared to vindicate this position for him.

I think we are both probably surprised that my stress decreased at all...[laughing]. (Bea, couple # 9, April 16, 2006)

I do remember waking up and thinking "how is Bea doing, you know, wondering how to make sure she's not going to cramp or something else...(Kevin, couple # 9, April 16, 2006)

The impact of social events, celebrations, and commitments was remembered as especially painful. For couples who were pregnant or had delivered children since the workshop the sensitivity was greatly reduced, but appreciation for how difficult it had been for them to attend occasions where they would be exposed to the fertile world, remained.

The three couples still trying to build their family were all at different places with respect to their desire to pursue treatment and for Caroline (couple # 3), the specter of pregnancy success amongst the workshop participants loomed large. Although Caroline understood that every couple was working toward achieving the same thing the fear of being left behind as others moved on was enormously painful. Caroline had struggled to maintain her confidence throughout the diagnosis and treatment of her infertility and frequently experienced periods of panic when she was convinced that a biological child would never happen for her. One of the strategies she admitted using to help bolster her self esteem at the workshop was 'downward comparison', a technique described in the literature as: "...the propensity for people who are harmed to compare themselves to less fortunate others" (Stanton, 1992, p. 389). During the interview Caroline recalled how impacted she was by the amount of grief and sadness that Nicole had expressed. She shared that she had used Nicole's poor level of functioning to compare favorably to her

own, as if to say “at least I am doing better than that.” Caroline was keen to find out how she was doing now in contrast to Nicole.

I wondered how you found some of the other people who have responded, how are they doing, like are people generally feeling better...they probably all have babies? How is the girl doing who was so sad? (Caroline, couple # 3, April 15, 2006)

It was difficult for Caroline to hear that several women from the workshop became pregnant. Participants had agreed to share their current status if a direct question was asked about them by other group members. Caroline was visibly upset when she heard the news that she and Brian were one of the few couples who had not yet conceived. Immediately noticing Caroline’s distress Brian stepped in to try and console his wife. While he offered rationalization and tried to project a more positive spin, Caroline appeared dejected and resigned, almost disappointed that she had agreed to participate in the follow-up if it meant hearing the positive news of others.

It’s going to be okay. There are people I mean in better places and worse places, we’re somewhere in between. (Brian, couple # 3, April 15, 2006)

It just feels like everybody else – like it eventually works out for. I mean I was looking forward to today [the interview] but I felt like “well gosh, probably everybody else is pregnant from that group.” (Caroline, couple# 3, April 15, 2006)

The narratives served as a bridge between the scored survey items and helped to generate a three dimensional picture against which the story of each participant could begin to emerge. The narrative did not assume to reflect an accurate representation of an individual’s life, or infertility specific distress, but provided a reference point from which to explore and discuss important themes. What began to materialize from between the lines of the text was a complex dialogue that exposed the multiple layers of impact the quest for children has on intra and interpersonal relationships.

Question 2. How closely do you feel this summary reflects where you are your infertility today?

Women-only.

Despite the fact that none of the women who participated in the women-only workshop (excluding Bethany and Stephanie who attended both), had given birth to a biological child in the previous year, most reported that their survey responses no longer reflected how they were experiencing their infertility. With the exception of Hillary and Ruth, the five remaining women described feeling stronger, more confident, and less powerless over their life direction specifically and their body generally. This appeared to be related to an alteration in their perception of what they had influence over rather than a circumstantial, physical, or reproductive change.

I'm a lot better today...I do realize logically that I was beating myself up about something I have no control over, that I have no power to change. I was so mad at my body, I am still mad but its nothing compared to then (Deborah, April 4, 2006)

Alice, who had the longest infertility history of more than 8 years, appeared to have undergone a significant transformation. Reading the narrative summary of her responses from a year earlier helped put that transformation into perspective for her. The tremendous grief that she experienced after the death of her father and brother helped her to understand infertility as a form of chronic loss and brought her closer to her own humanity.

I think I have come a long way. I am a very different person. This is a different person I am reading about. I now know I am as human as anybody else, some days are good and some are bad but therapy has helped me to realize that this is okay. (Alice, April 12, 2006)

Katherine also expressed that she had moved on in her life. Although she was not completely beyond the desire to bring children into her relationship she felt she was finally able to see the value of her own existence and what her experience of infertility had prepared her for. She no longer took her own or others health for granted and had learned that life was neither fair nor predictable.

In the future, no matter what I have to deal with, whether it would be cancer, a death in the family, or whatever, at least I have the skills to deal with stresses and what life throws. (Katherine, April 8, 2006)

Sarah struggled to maintain her composure several times while reviewing her narrative summary yet reported that she was in a sturdier place emotionally. Sarah felt her tears had been provoked by the words that she read. She described herself as an ‘energy healer’ and somebody who was used to exploring the karma of others and the process of having her experience reframed and manifested in the moment helped to reaffirm the role she played in the lives of others.

It’s interesting to read about myself through someone else’s eyes, through interpretation, and it still be me on paper because this is what I do frequently for others. (Sarah, April 8, 2006)

Kit was raising her adopted son Anthony and no longer self-identified as infertile. The Kit of the previous year bore no resemblance to the person she knew before her diagnosis of severe endometriosis, and it wasn’t one that she wanted to know again. Kit was actively involved in the adoption community and described herself as being “in a completely different place.”

Ruth felt that her general life problems had intensified since the workshop but that there was little change in her fertility specific stress. She had recently lost her job and was struggling financially. She also disclosed that she was experiencing numbness in her arm and hand which had provoked considerable alarm and discomfort. Reviewing the list

of bodily symptoms she had endorsed on the SCL-90-R made her aware that stress often manifested itself in her physical health. She also noticed that when she was distracted from her stressful circumstances that the pain in her arm would dissipate.

Today I see, I took the day off and I notice that I don't have any of those symptoms. (Ruth, March 31, 2006)

Hillary had stopped practicing any of the mind-body techniques and stated it was because she wanted to be more connected to what she was actually feeling. She expressed conflict over what she thought a more integrated approach to her experience of infertility might do for her. She expressed her belief that using mind-body strategies could allow her to better tolerate her infertility and appeared unable to make the connection between 'living in' and merely 'avoiding' her circumstances. Although she described feeling much worse than she had a year ago she insisted that she knew she could survive. She had intentionally isolated herself from social interaction because of the recent relocation and didn't want to have to explain herself again to new people, but at the same time Hillary longed to make a connection.

I don't remember the headaches as much from last year but I have recently felt all those symptoms, the headaches the stomach upset. ..this is life altering it changes you forever...I don't know how to balance things these days. I need to really reflect if I am going to be that person who looks at myself from afar. I need to do that until I am closer, so that person from afar is *within me*. (Hillary, April 29, 2006)

Couple workshop.

For couples who had delivered ($n = 6$) or were expecting a child ($n = 1$) the narrative summary of their Fertility Problem Inventory (FPI) responses was not reflective of their current infertility specific stress. For women in particular, being pregnant or having a child had been healing.

It doesn't reflect anything of where I am today. (Nicole, couple # 4 April 5, 2006)

Researcher: So all of the stresses you felt were infertility-related and have been resolved because that's resolved?

[Laughing]. Yes, uh hum, definitely. (Nicole, couple # 4, April 5, 2006)

However the resolution of infertility did not guarantee the elimination of other types of life stress. The shift from a family building to a family raising focus invited different kinds of tension including: relational, occupational, gender/role specific, and financial. This was especially intense for Bruce whose partner Nicole was expecting twins.

If I had to guess at where I'd be today I feel a lot of stress right now. I'm working a lot. I feel a lot of pressure to make a living. (Bruce, couple # 4, April 5, 2006)

Bethany and Graham, whose two month-old-daughter Charlotte was awaiting surgery, were plunged head first into their parenting responsibilities. Charlotte's serious congenital heart defect required the couple to make an immediate and grave emotional shift; from longing for parenthood to negotiating decisions that could mean life or death. However, they remained appreciative that they had conceived after only one attempt at IVF. They were optimistic that they might avoid the pain and financial hardship of going through a future IVF and hoped to achieve a subsequent pregnancy on their own.

It's [the narrative summary] is where I was before. I think that the only thing I really do worry about now, and we did have good success with in vitro, is if we end up having to go back and do it again....although we were told by her doctor that sometimes right after infertility you end up getting pregnant it's almost like it teaches the body, sort of like it's therapeutic. (Graham, couple # 6, April 30, 2006)

Karl (couple # 7) and Jeanette's daughter Brea was only two weeks old when they completed the interview. For Karl infertility specific stress had been completely usurped by fatigue and the anxiety he was experiencing regarding his ability to adequately

provide for his family, while Jeanette was learning to put her role as a new mother into perspective.

I am figuring out what the priority is, you know, I guess the hierarchy of what it really is worth getting upset over...there are some things that I can allow myself to really take personally and other things that I have to say are no big deal. (Jeannette, couple # 7, April 4, 2006)

It was useful for Karl to review how he had reported experiencing stress as it reminded him that his problems had not been eliminated with the birth of his daughter. It was still important for Karl that he develop a firmer understanding of who he was and how he operated in his life.

I hold things in a lot I think that's why sometimes I have a short fuse, just because I know that not everybody sees it my way. I've always worried about people looking at me. That's been another thing I have dealt with like my whole life so that hasn't changed. (Karl, couple # 7, April 4, 2006)

Peter and Stephanie (couple # 2) also identified important reductions in their relationship strain after the workshop. This continued to improve during Stephanie's pregnancy and after Lillie was born, particularly as they were both optimistic but realistic about their chances for having another child naturally in the future. Breathing exercises remained the mainstay of this couple's emotional tool kit during periods of elevated tension and helped them to modulate their interpersonal reactivity and maintain their objectivity.

The things that would upset me still upset me maybe just to as quickly as they were during that time. Now I might tell him about it instead of snapping on it or reacting to it so aggressively. (Stephanie, couple # 2, April 8, 2006)

For couples who had children, the experience of infertility had been integrated into the tapestry of their lives; something that was but not necessarily is. The once raw wound of

childlessness had begun to heal, at least around the edges, replaced by new areas of vulnerability that most couples appreciated also had the potential to one day bleed.

Wendy & Victor's (couple # 5) response to question 2 continued to reveal a fertility journey that was led by Wendy and intermittently followed by Victor; a story of parallel paths that didn't seem to intersect. Wendy believed she was in a different place than a year ago with respect to her general level of stress. She had a new job and the good news about her own fertility had triggered a sense of hope and optimism. Victor in contrast described escalating pessimism and fear for his own mortality. His disclosure that he felt unheard by his family, medical professionals and to some extent his employer, played itself out during the interview in his relationship with Wendy. While Wendy pursued motherhood Victor searched for a safety net. They were speaking about each other but neither one appeared to be truly listening.

It's hard to survive anymore and I'm trying. (Victor, couple # 5, April 30, 2006)

We have our difficult times but I see him being a great father and I hope he can understand that and realizes that too...the way I'm looking at it has to be this year, most definitely. (Wendy, couple # 5, April 30, 2006)

Howard and Jill (couple # 1) found new strength in their relationship since they had decided to abandon infertility treatment. They were still considering the possibility of adopting a child together, committed to their marriage, and far removed from the peak of emotion that had risked sending them retreating to separate corners. Participation in the workshop had encouraged Howard to agree to pursue couple therapy with Jill. His earlier cynicism toward talking about problems rather than finding some way to fix them had been replaced with a new philosophy. Infertility had taught them both that although they

might know what they would like, finding a way to like what they have was far more critical.

I always lived that the answer's going to be there and if it's not there I am going to get it. Now I can't do that so I have to wait and see what the next day brings. I mean I had to learn to live that way. I mean it wasn't something that came easily, and it's still not easy. (Howard, couple # 1, April 25, 2006)

Jill had expressed her own reservations about attending a workshop with people she did not know to discuss a profoundly intimate topic however, the isolation and sadness she had been experiencing, particularly within her relationship, prompted her to take that risk. Jill feared the judgment of others and felt certain that she would not have elected to disclose her personal life had she not experienced infertility. Ultimately, the decision they made to share their difficulties was viewed by Howard and Jill as extremely productive; a path not chosen and definitely not avoided.

Well, it's hard when there are two people and then two different genders...I didn't want to feel like I was dragging him...either this could pull us together in a stronger marriage or it could pull us apart, you could look at a lot of life crisis that way and this is ours right now and we are just kind of living in the answers. (Jill, couple # 1 April, 25, 2006)

Caroline (couple # 3) found it difficult to evaluate how she was currently experiencing infertility without clarification of some of the descriptions from her narrative summary. (To provide participants with some perspective regarding how they were functioning in one area of their lives compared to another, qualifiers such as: above average, moderate, noteworthy, and important were added to the condensed text). Caroline sought validation and confirmation that these discriminators did not suggest that she was doing poorly when compared to others. She was often stuck knowing that seeking external support was important to her while also realizing that discovering it within herself was more likely to offer longevity and conviction. It appeared that for

Caroline pregnancy was the only outcome by which she could measure her own or others success. Infertility was a scourge that continued to contaminate much of Caroline's thinking and cross infected her partner too.

I mean yesterday an insurance bill came and I think he was scared, not because of the insurance bill but because of my reaction...yeah even our new car, our trip to Italy we never go on. I guess I am feeling kind of upset when I talk about it right now because [laughing] we don't have a baby. (Caroline, couple # 3, April 25, 2006)

It was often Brian's job to point out the inconsistencies in Caroline's argument and he frequently responded to her statements implicitly by taking a position without linking it directly to something Caroline had just said.

I think you have to go through that situation, you can't just say okay I am feeling bad. I think you have to kind of have to allow your emotions to kind of flow though...and then take a step back...it's okay if you want to be upset, but don't be upset for 3 days. (Brian, couple # 3, April 25, 2006)

Question 3. How does it feel to you to hear the survey results and is there anything you might believe differently about yourself after reading this summary?

Women-only.

Responses to question 3 overlapped with some of the preceding questions and expanded on their existential themes. For some women the follow-up functioned as a form of creativity; a discovery or rediscovery of self that would have never happened in quite the same way without the experience of infertility. The written narratives became the mirror in which their reflected image had sometimes been a surprise for them to see.

It's weird to see yourself on paper. This is me in words; this is a lot of what I try to express sometimes to my husband or to my mom or my sister, and I've even attempted to write things to them, but this kind of summarizes...I think I would show it to my husband. (Hillary, April 29, 2006)

Deconstructing the experience *of* infertility from the person who *had* infertility was an insidious struggle. The stories of anguish committed to the page became shared tales, recounted by participants and documented by the researcher in as collaborative act. It was in the process of recalling those tales that sometimes the wisdom of self presented itself.

I do not think I realized how fragile I was. I feel like I have been led through a lot of challenges and made it through. This is going to sound weird but I wonder if I had to go through those tragedies? God put me here for some reason I am not sure what it is but I understand that now. As bad the experiences I have been through have been, I think *I* have been able to help people. (Alice, April 12, 2006)

Alice not only believed something different about herself she believed she *was* different. Unrecognizable from the person presented in the summary she was still careful to embrace the ‘old’ Alice whose existence had made it possible for her to now see herself as someone other than an ‘infertile woman’. It appeared to be irrelevant that the Symptom Checklist and Fertility Problem Inventory were instruments designed to produce a generic and rather imprecise measure of stress and its effects. The narrative summary provided a template for participants to fill in the blanks; the subscales represented the bones, global scores the developing flesh, and the interview became another opportunity to add more substance to the human frame.

While I’m talking to you on a cordless phone probably the first half of our conversation if not greater I’ve moved around the house but for the past 30 minutes or so I have been in one place. I don’t know if is existential or just the movement that I’ve experienced talking to you. It has invigorated me to think I am capable of achieving small steps. It’s like a symbol this telephone call, it represents more than just a year later follow-up. It’s been meaningful *now* that I’ve just thought about it, what I’ve just gone through talking to you, *without* moving. (Alice, April 29, 2006)

Researcher: Keeping still and yet not being paralyzed.

That’s it exactly...I’m not paralyzed. My lungs are full of air, my heart is pumping. I’m here, I’m still alive...that’s reconnecting. (Hillary, April 29, 2006)

Katherine now expressed pride in herself. She had been unaware at the time of the workshop of how courageous she was and how resilient she would later become. Her faith in God, which had been challenged when she was first diagnosed with infertility, once again formed the foundation of her spiritual life. Katherine's road back to her religion was fraught with potholes and cracks and she had survived them all, resurfaced, and was now confident in her belief that her own life, with or without a child was "blessed." The ache for motherhood that had so tested her heart was replaced with a desire to protect and nourish herself.

Just talking to you today brings up a lot of stuff and reinforces it. It reminds me I have to appreciate myself, treat myself well, relax. That is what the workshop did! I notice myself really trying to get my hands on things that will remind me of that and I know I have come a long way.
(Katherine, April 8, 2006)

Deborah recalled vivid memories of feeling anxious, misunderstood, marginalized, and alone. She was also aware that as far along as she had come in her own infertility processing there was still the potential to experience those feelings again and that this potential was worrisome to her. She had not put down her wish to conceive and carry a child but had let go of that child needing to be of her own biology. This was an enormous change in Deborah's perception of what it meant to be a family. Deborah described herself as an organized thinker, someone who did well when life followed a plan and deviation of any sort was an anathema. Deborah initially viewed her decision to participate in the workshop like her decision to seek treatment for infertility: as a choice between several things she did not want. In the year since then she had come to see that life offers no one a guarantee. For Deborah finding a way to accept the things that had

happened to her was no longer a confirmation of her failure or a sign that she was giving up, it was the commitment she needed to make in order to move forward.

My neighbor down the street just got pregnant for the fourth time and my daughter said to me “well maybe they’ll give *us* the baby?” I am so glad it was dark because I just started crying, I thought “how selfish am I?” My daughter wants a sibling she doesn’t care if it’s black, white, or came from down the street. Do I really care? Would I love my mother any less if I found out she wasn’t my genetic mother? No. I just had never thought about it that way. (Deborah, April 4, 2006)

Ruth’s language and body posture changed as she responded to this question. She used the terms “disappointed and negative” to describe what she was feeling about herself. She had acknowledged several times that she had recently lost her teaching job and she believed much of what she was currently experiencing was related to this loss rather than the loss of children, but it was becoming difficult for her to tease all of these issues out from each other. She identified personal themes in the summary that pre-existed both her marriage and her infertility diagnosis. She also admitted that part of her had felt optimistic about participating in the interview because it would help her to get her mind off her job and her numb arm however the discussion unexpectedly brought her full circle.

Researcher: were you feeling differently about yourself when you first came in?

Probably yeah, I mean, you know it’s always in my head but Wow, these are things that I still need to deal with – to admit it and see it in black and white. So, if I leave here today thinking, okay this is something that I will need to work on – then I am still a work in progress. (Ruth, March, 31, 2006)

Couple workshop.

For the majority of couples who had a child, looking back over the past year was centered on constructing meaning around the circumstances of their baby’s conception

and their journey through infertility. Despite giving birth, ‘infertile’ was a label with which Nicole and Bruce (couple # 4) still self-identified; a proud label that was once symbolic of a group to which they had begrudgingly belonged. In Nicole’s world the transition from “I am infertile” to “I had infertility” was connected by a tenuous thread that could easily be broken should she want to try for a child again. However pregnancy had begun to heal Nicole’s soul and brought her back together, back to her family, and back to her friends.

I was really ashamed, I had a lot of self esteem issues around not being a *real* family, alienation and isolation from peers, friends, and loved ones and since I am pregnant we have reconnected and people have shown me such mercy. (Nicole, couple # 4 April 5, 2006)

Nicole expressed feeling considerable humility over the way in which her sister Liv had forgiven her for leaving her life so abruptly when Liv gave birth to her son. She also recognized a side of herself that she needed to face as unkind and acknowledged the desire she once had to inflict as much pain on others as she had suffered in her own heart.

I feel I’m so much more of a compassionate person now. I’m very humbled with friends and family members that so graciously took me back in...I feel very much like a changed person. I mean I didn’t have any faith, I wasn’t capable of it, I had faith that life couldn’t be anything but crap. (Nicole, couple # 4, April 5, 2006)

Bruce also struggled with the concept of faith. This couple described themselves as religious (Nicole’s father is a minister) and their turn from God affected them both deeply. Bruce reminded himself and Nicole that their walk out of the wilderness had involved considerable therapy and it was important for Bruce to see that where he stood now had a great deal to do with where they had both walked.

Going to counseling was literally like being in the desert and just dying of thirst then we would get more information about ourselves and learning about ourselves was like drinking from a well each week. It was really something that we needed as a couple and I need it s much as Nicole did.

When we went to counseling I knew he was okay because the counselor had her and I could let her go. (Bruce, couple # 4, April 5, 2006)

The notion of change might have seemed implicit for couples who had finally become parents yet negotiating new roles after having struggled so long to become pregnant required some suspension of disbelief. Karl and Jeanette (couple #7) were anxious to establish a routine with their two week old daughter, dealing with sleep deprivation, and trying to manage on only one income. Jeanette spoke of motherhood as though it continued to be outside of her realm of experience despite the baby in her arms.

I was pretty much in denial throughout the entire pregnancy regardless of the ultrasounds, even throughout the surgery, even now. So I went from thinking it will never happen to now being in denial that it did happen. So I think I'm the same person but I can't get my mind around it right now – so I am taking a step back and not stressing about it. (Jeanette, couple #7, April 4, 2006)

Karl was reflective and quite anxious about his new role as a father. He certainly had a clear idea in his head of how *not* to raise his child. He also believed that one of the ways in which he had changed was in his ability to express this. Karl shared that he had often suppressed his feelings in the past because his earliest memory of speaking up was that it got him into trouble. Karl had a poor work history that included several jobs in the last 5 years and he was feeling the pressure to knuckle down and measure up. Karl grew up without his own father and believed that he was already giving something to his daughter that he had not had but he remained dissatisfied with work and continued to experience a significant amount of stress.

I've had so many jobs in my lifetime you would think that I was already like 60 years old. Me, I'm still looking for the one job that, you know, that interests me, so that's why my job has always basically been – stress! I can't see myself staying at this job, again it's just a job, yeah I need a whole different kind of stress relief program. (Karl, couple # 7, April 4, 2006)

Peter and Stephanie (couple #2) were sharing the child-care for their daughter Lillie who was 2 months old. Peter was enjoying being an active parent and he had to a large extent pushed infertility to the back of his mind. Revisiting where he was a year ago during the interview proved a powerful reminder that he often chooses avoidance as a way to cope with situations that are emotionally painful. He also understood that it was this pattern that had caused much of the conflict between himself and Stephanie and that since the workshop their relationship had changed considerably.

I have finally realized what [my not talking] was doing to us and what I was doing to her...I had no idea what level we were at. I think things are a lot better from that aspect I think that I could see that in the [summary] responses but I think that they are tenfold [improved] now, it's still there the sensitivity to infertility, but it's not a crushing blow. (Peter, couple # 2, April 8, 2006)

Stephanie began to recognize that the intra and interpersonal sensitivities she struggled to negotiate during infertility continued to play themselves out in her current relationships. As she listened to Peter some of the familiar feelings that had erupted between them before they got pregnant began to flood back. With a baby between them and the source of her grief no longer an active part of their lives she was able to see that what infertility had provided was the crisis through which they had learned to see themselves and each other differently.

I was sitting here going through everything while he was talking thinking, "oh, you know, maybe I wasn't feeling criticized by others, but maybe I was feeling pretty criticized by myself and maybe that's something that really is me?" (Stephanie, couple #2, April 8, 2006)

Graham and Bethany's (couple # 6) had traversed their infertility crisis, resolved much of the anger that had developed between them, and were now united in their commitment to ensure that their daughter Charlotte received the best possible medical care. Since Charlotte's birth there had been a significant shift in their relationship and

Charlotte had become the fulcrum around which much of their interaction occurred. It appeared that the strengths they discovered in themselves and each other were not only triggered by becoming parents but by the special circumstance of parenting a sick child. Bethany spoke of her own change with a certain amount of magnanimity, as though she had always known that this is what mothers do, take care of their children, but it was also a fact in which she took some pride.

I think I'm stronger than I gave myself credit for but I just never gave it a second thought...I mean you just kinda sleep with one eye open. I think that we are a lot stronger than I what I thought we could be. (Bethany, couple # 6, April 30, 2006)

Graham felt that many things had improved between them in the previous year although he still acknowledged the toll that infertility specifically placed on their relationship. It seemed that Charlotte's health crisis had inspired confidence in Graham's belief that he could do something to make a difference i.e. find an excellent surgeon. Bethany's anger during their infertility had contributed to Graham's sense of impotence in the relationship. When he realized that other women and many couples struggled with similar issues it had become easier for him to feel that even without fixing the problem he could make a difference in how it was experienced, that he could support rather than repair. However, Charlotte's heart condition was fixable, it had a solution and it was after all, Graham's job to provide perspective, take the heat out of the fire, and save lives. Graham was finding it easier to give Bethany reassurance and Bethany was now more open to receiving it.

I've seen that Bethany is stronger. I've noticed that the meltdowns have decreased. I think just my whole informing her that she [Charlotte] is doing well, she looks good, everything like that, and that I've taken over researching Charlotte's problem. I've done it...I believe we are a lot closer than what we were at the whole start of the infertility. (Graham, couple # 6 April 30, 2006)

After reading the narrative summary Bea (couple # 9) shared that she had forgotten how absolutely bereft she was. She had punctuated her life with the grief of each loss, the period at the end of increasingly bleak sentences. As Bea slipped toward despair Kevin had worked harder to try and maintain them in a steady position. It seemed that the couple's biggest change represented the shift they had made in this dynamic, although Kevin and Bea are still a couple who tend to experience life in extremes.

During the pregnancy we really banded together in a healthy way. I think then when we do apply ourselves now we probably come to a supportive solution quicker than before but it's probably a little bit of both, like when it's good it's 100 times better than it's ever been and when it's off we're both extremely unhappy. (Bea, couple # 9 April 16, 2006)

Bea described their earlier relationship as a discordant dance where if Kevin was up Bea was almost certain to be to be down. This began with their move to the Cleveland area which had required Bea to make a significant professional compromise (which Bea was not happy about), and continued during their difficulties conceiving. Breaking this pattern began with deconstructing old habits and finding effective ways of supporting each other which meant releasing Kevin from the assumption that relieving stress was his job in the relationship.

My biggest stress reliever has been soccer and it's something we've kept in my time, our budgeted time so Bea's aware of it, I'm aware of it, so yeah we probably don't talk about it often but it's there and *we* know that it's important for me to do. (Kevin, couple # 9, April 16, 2006)

Several of the women, despite looking forward to becoming mothers, were surprised at how well they transitioned into parenting. With the exception of Bea, who had suspended practicing psychotherapy indefinitely, and Nicole (who had not yet delivered), all of the women were planning to return to their jobs. Emily had a lot of trepidation about leaving her son with Stuart while she was working and was fearful she

would be unable to manage her hectic schedule and be able to decompress Stuart's tension around parenting. There had been multiple changes since Emily conceived including selling their business, Stuart's new job, and his recent promotion.

We had been at a sort of standstill for two years, so much has changed now. I guess I see that I am handling all the changes better than I would've thought. Stuart [looking at him] you have had a harder time controlling your temper. I think his response to the stress of Anthony is similar to his response to the stress of infertility. (Emily, couple, # 10, April 18, 2006)

Stuart's adaptation to parent was more difficult than he had expected. He had always viewed himself as the placid partner in the relationship, (not an opinion shared by Emily), and expressed frustration with being home alone, sometimes as long as eight hours, with his son. He struggled to read Anthony's cues and was often impatient with Anthony's bouts of prolonged crying and irritability. Stuart developed a new appreciation for his own stress threshold since becoming a father and rediscovered that stopping and taking his own deep breaths allowed him to be less reactive with his son.

He definitely stresses me out at about eight hours...That's just, I guess who I am. If I'm mad I will just, I don't know, I'll sleep or I'll exercise or do whatever. If I can't figure out something with Anthony then he just gets to stay in his crib and I go in the other room. (Stuart, couple # 10, April 18, 2006)

It appeared that infertility does not simply go away or resolve with pregnancy but rather takes up residence in large and tiny corners of the mind, body, and spirit. How well those corners were inspected, cleaned, utilized or ignored became the successive approximations that participants made toward change; slow approximations toward a different place or maybe the *art* of becoming a parent.

Jill and Howard (couple # 1) were one of three couples in the group who did not become pregnant. Although Jill new she had made progress in her relationship with

Howard (their renewed commitment to each other superseded the disappointment she felt about not conceiving), the memory of expectation and the hope for something different, still held its own pain.

Seeing all those doctors appointments on the calendar, it is bittersweet looking back a year ago because we were hoping we would be at a different point right now but I think we are stronger for it, I mean there are ups and downs in life but I am kind of shocked with this infertility and some of the other stuff we had to live through, but at least I am kind of calm in my heart now. (Jill, couple #1, April 25, 2006)

The interview for Jill and Howard was the catalyst that got them to take stock of how much they had been through in the previous twelve months, where they had started and how far they had come. It was an opportunity to explore the evidence and confirmed for them they were doing okay. This couple learned that suffering doesn't discriminate and that what hurts one of them inevitably hurts the other. Stuart no longer believed compassion to be another word for submission. He now believed in the sanctuary of his relationship and had begun to honor his own heart.

We have made a place where we can go in and be away and forget about everything. We did that and I think that is how we live our life now. We live our life by the way we can support each other. (Howard, couple # 1, April 25, 2006)

Caroline and Brian (couple # 3) were still raw from their recent miscarriage. During the interview Caroline in particular had difficulty hearing about other people in the group who had become pregnant or delivered since the last time we met. She described feeling as though she was often taking two steps forward and three steps back and that recently even being in a group with other couples experiencing infertility had the potential to elevate her distress. She was tired of seeing life pass her by while she believed she was stuck in a childless limbo. In Caroline's eyes it appeared as though everyone else had moved on and she had to work hard to resist the temptation to stay in

social seclusion. Caroline was a planner, and planning was a strategy that kept her prepared and less likely to be knocked off her feet. Planning and pregnancy for Caroline were supposed to go together but she hadn't found that firm ground. She even worried that it was her worry that set her apart. It had always been important for Caroline to have a backup plan for anything she did but she was learning that this strategy also kept her from being securely connected to the moment she was in.

You'd like to apply the principles of what we learned but I feel like when you are in that awful place, like when I was finding out we were having a miscarriage, it is very hard to do it right then. I even worry that if we end up adopting when we do the home study we will have to get the dog out of here. (Caroline, couple # 3, April 15, 2006)

Brian recognized that many of the traits that had been Caroline's strength in her studies, work, and their relationship together were partial liabilities in their treatment of infertility. Brian had often stepped back from Caroline's preoccupation with getting things just right because he appreciated that this was how she made peace with herself. Since they had been trying to have a child he saw the detriment to both of them in her continuing to do that. Infertility was not about trying harder it was more about trying to do things differently. Although Brian believed that how he faced challenges had a great deal to do with how well they turned out he also respected there was no direct cause and effect relationship between attitude and outcome. Brian was beginning to see that sometimes the only place where human beings have power is in owning the sensibility that they bring to their pain.

It is very easy as you are going through this to kind of look back and just say, throw your hands up in the air and just let it affect everything that you do, your friends, to your family, to your work, to how you just, you know view the world. It's kind of easy to sit and feel sorry for yourself but you don't change things when you let that happen. (Brian, couple #3, April 15, 2006)

Wendy and Victor (couple # 5) seemed to be at a crossroad in their relationship and introspection toward their infertility was a luxury that Victor could not afford. He was negotiating the medical system on many levels and had made contact with few care providers who had offered him real comfort. Hope was in short supply. Victor appeared directionless, lost to his own life, and emotionally depleted. He rarely spoke to Wendy during the interview and responded to questions with lateral and rambling indignation. His perception of their experience with infertility specialists was alienating and dehumanizing.

Dealing with the medical profession right now it is like, “when do we get paid?” It is not Marcus Welby, M.D. I see the prices for this stuff, they botch tests, they both other stuff. It was \$10,000 and then *maybe* they could get Wendy pregnant, if not you’re out ten grand. I don’t have that kind of money. It’s hard to survive anymore and I’m trying. (Victor, couple # 5, April 30, 2006)

Wendy was feeling the pressure of time. She described motherhood as a place of anticipated calm, an opportunity for her to bring to another human being her capacity to nurture, but it seemed hard for Wendy to offer Victor empathy when she believed it was his agony that directly contributed to her pain. Wendy wanted a baby more than she wanted Victor’s baby. She had independently explored donor insemination and placed a six month timeline on her decision to pursue this road. For Wendy making a unilateral decision *was* a way to alleviate her stress. As she described, counseling hadn’t worked.

Unfortunately he blew up at the counselor and it was a really bad situation and I felt bad about that. I wasn’t there to point fingers at him. I wasn’t there for him I was there for us. (Wendy, couple # 5, April 30, 2006)

It appeared that infertility does not simply go away or resolve with or without pregnancy but rather takes up residence in large and tiny corners of the mind, body, and spirit. How well those corners were inspected, cleaned, utilized or ignored became the

successive approximations that participants made toward change; slow approximations toward a different place. Is that part of the *art* of becoming a parent?

Reflective Commentary

Several of the workshop participants attended Resolve of Ohio's Annual Infertility Conference (2004), where initial sign up for the research took place. Although couples registered, all communication was conducted through the women with the exception of Bruce (couple # 4). Bruce and Nicole were referred to me by their counselor and Bruce admitted that he was at his wits end with how to help his partner Nicole, who he felt was perpetually sad and had changed considerably since they had been trying to have a baby. Bruce effectively said, "I don't know what to do with her, you figure her out."

In addition, a majority of the participants had attended a one-hour concurrent session about infertility and mind-body medicine given by me at the Resolve event. The upcoming study was announced during the concurrent session and an opportunity was provided for people to ask questions and personally meet me. Approximately 60 people or 30 couples made direct inquiries and several more e-mailed or telephoned their questions in the following months. During that time a 'quasi' relationship began to develop between us, intimate exchanges occurred, which is not unusual during the process of infertility where people become accustomed to sharing personal information rapidly and with relative strangers.

For women who attended the workshop alone I was their only familiar point of reference. All other participants were relatively unknown to each other and the atmosphere surrounding the first several minutes of orientation was clearly

uncomfortable for some individuals. Although every effort was made to provide private access to the seminar room, music was playing and refreshments were available, the additional burden of being alone, until encouraged to join, was evident.

Although most couples were also unknown to each other before the workshop coming with a partner made a distinct difference in the level of community that appeared to develop before the days activities began. This was significant at the time, in part because men also joined in this experience of camaraderie despite having had very little contact with me over the preceding months (all contact having been made through the female partner). My assumption that men were less interested in attending, or at the least came with trepidation, was partially responsible for my surprise at their level of interaction. Several women had told me on the phone that their husbands were worried about attending and were coming to please them. Although men did not appear to initiate conversations with other men as readily as women did with each other, women who attended the workshop alone seemed to have a harder time talking to other group members before formal introductions. In other words, women who participated with their partner seemed, at least initially, to find it easier to talk to other women.

Reflecting back there were other differences between the workshop days. Perhaps the most compelling was that the absence of partners allowed women to discuss their relationships in the third person, and several women expressed that they felt misunderstood by their partner or that he had reached his limit with respect to talking about infertility. Although the comments were not all complaints, the solo environment fostered an atmosphere that supported the sharing of critical feedback in a more complaining fashion, and did not allow for reflective input from the other person in the

relationship. Women in the couple group appeared to put more energy into talking about themselves and their role in feeling misunderstood e.g. "...I have difficulty feeling critical of others and criticized by others at times, feeling hurt or misunderstood," (Jill, couple # 1, April 25, 2006). Those in the women-only group made relatively more comments that were generated by externally perceived causes for their conflict "I have gone through my infertility alone and it is still a sore subject, I don't think he has the resources within him to try to battle with me" (Hillary, April 29, 2006).

It appeared that men were able to offer input about their own situation after listening to a woman, other than their partner, share her feelings. When men demonstrated insight into how their behavior might be misconstrued, or were able to show compassion toward someone else's partner it seemed that a channel had been opened for new healing "...I think I was more relieved it was me and that it wasn't something for my wife to feel like the other women" (Peter, couple # 2, April 8, 2006).

I observed this again in the follow-up interviews, at which women-only workshop participants continued to make comments about their situation without benefit of their partner's point of view. As the human being on the other side of these interactions I was aware of my own temptation to step into that void, not only to provide a compassionate voice but to gently present the possibility of another perspective. Although this was a temptation I worked diligently to resist the inclination to join in the participant's beliefs was also just as dangerous, not because of a judgment that they were either wrong or right, but because being alone in my office somehow conveyed a greater depth to their loneliness. Was this my counter-transference or was I engaging with an experience of

truth? Perhaps the reality is a place between the two rather like the relationship between the positivist and post positivist position?

Similarly, couple interaction presented a unique opportunity to observe a relationship dynamic that was more intimate and self focused than the group format. The interviews, as one might anticipate with qualitative inquiry, were self-perpetuating one comment led to another and took a direction that was unique to individuals and the individual dyad. The tendency for women-only participants to remain engaged at the level of their own understanding was influenced by the fact that this, at that moment, was all they had. We were engaged in the present. The power of the phenomenological is that life unfolds within the framework of conscious experience. Bracketing of text was an essential feature of my own academic process. What was women-only workshop participants' construction of 'being alone,' what did couples mean when they said they had been brought together? Conclusion deferment is the cornerstone of all solid research and particularly antithetical to qualitative inquiry. Infertility is an especially powerful metaphor of this qualitative principle because it calls the heart to task each time it tries to get ahead of itself, wishing for something that isn't, and suspending living until it is. I had to step back from that angst ridden position myself on many occasions, suspend judgment and get to know better how the social implications of childlessness in our historically, politically and culturally constructed world had taken us to where we were; different yet still related to where we now are. Does it ultimately always come down to life and death?

PART III: Emergent Themes

The critical themes that emerged from the interviews are presented according to the interview questions, and for each group. This study's aim was to determine which aspects of a mind-body program are effective in evaluating distress and providing emotional support for individuals and couples experiencing infertility. The overlap and difference in themes between groups is noted and the difference in themes between men and women in the couple workshop is also clarified. Categories with characteristics common to both groups are discussed. These differences are reviewed at length in the Discussion and Conclusion sections (Chapter VII) of this dissertation.

Utilizing feedback from participants is one way to ensure that their expectations and perceived need for support is adequately met. The survey instruments, narrative summaries, workshop experience, document analyses, dialogues, and direct participant collaboration have collectively contributed toward identification of the following themes:

Women-Only

Identification and belonging.

Women who participated in this study were searching for a normalizing experience and an opportunity to connect with others who were also suffering from infertility. Previous studies have demonstrated the therapeutic benefit of bringing together individuals with similar difficulties for supportive and educational purposes (McGuire, 2003). For some of the women in this group the decision to attend alone had been made unilaterally with the tacit assumption that their partner would not want to attend (although for at least one person there had been a scheduling difficulty). Women often expressed that their partner was sick of talking about infertility, or that he didn't see

talking as solution, but that they still needed to express their emotions. The workshop was an opportunity for them to do that. There is a well documented risk of social isolation and relationship discord associated with infertility and recent research suggests it may also influence pregnancy outcome (Boivin & Schmidt, 2005).

According to Yalom, "...all individuals seeking assistance from a mental health professional have in common two paramount difficulties...1) establishing and maintaining meaningful interpersonal relationships and 2) maintaining a sense of personal worth and self esteem" (Yalom & Leszcz, 2005, p. 64). Although the mind-body workshop was not presented as a 'mental health' intervention but rather a program of self-care, its construction was based on research developed within a variety of mental health fields.

Several studies have documented higher levels of stress and depressive symptoms in women experiencing infertility when compared to men (Peterson et al., 2006). A few studies have explored the contribution that relationship based stress has on pregnancy and the post partum and parenting periods (Fisher et al., 2005). There is an increasing call for research to address the multiple contributors to this stress which include: "...social, historical, economical, political and cultural aspects" (Hardy & Makuch, 2001, p. 272). The workshop was constructed with consideration and respect given to these various influences: stigma and marginalization of the childless; predominance for infertility to be seen as a woman's problem; extreme cost of treatment; access to services; religious and/or cultural bipartisanism.

Location, setting, and participant selection.

Financial consideration (this research was conducted at no cost to participants), adequate privacy, deemed essential for fostering an appropriate environment for intimate disclosure, and physical comfort, were all reported as essential by women participants. Women frequently described feeling victimized when they attended their fertility specialist's office especially if the medical practice included general obstetrical care. If reception rooms were occupied by pregnant women and small children participants reported their level of stress steadily rose as they approached their scheduled appointment time and that this impacted the quality of their office visit.

Participants were looking for a workshop location that was restful and protected them from bombardment by the fertile world and allowed them to relax their hyper vigilant stance. This was of particular significance to the women-only participants because a baby shower had been scheduled for the room next door necessitating moving the afternoon session to a different location. (This event also prompted the researcher to move the couples' workshop to a different venue entirely).

Also important were the following group member factors: length of time since diagnosis, type of diagnosis, and likelihood that the duration of the workshop was adequate for the problem being presented. Women who had a longer history of infertility felt protective toward participants who had only recently received their diagnosis. On the one hand this served an educational purpose in that some women functioned as guides and role models and on the other hand it was potentially overwhelming.

I often end up comparing myself to what the other women are going through, or what their experience is compared to mine. For me, I find that somewhat detrimental. (Hillary, April 29, 2006).

Hillary self disclosed during the interview that she needed more one-on-one attention than the workshop was able to provide. However she also believed that it was her attendance at the workshop that allowed her to reach that decision. In this capacity the workshop functioned as a yardstick against which Hillary was able to consider her additional needs.

Mastering mindfulness.

The mind-body principle that women reported as most helpful and expanded their understanding of how they personally manifested stress, was mindfulness; the concept of being present and staying aware of one's thoughts without passing judgment. Mindfulness has the potential to impact the experience of anxiety, a commonly reported stress effect of infertility, because it requires pulling back from a future oriented focus e.g. moving from what will I do if treatment doesn't work, to what can I do to have more confidence in where I am? Paying attention rather than living in anticipation. A recent review in the literature on the effectiveness of mindfulness training as a strategy for managing different types of health-related stressors supports its use as a psychotherapeutic technique (Allen, Chambers, Knight, Blashki, Ciechomski, Hassed, Gullone, McNab, & Meadows, 2006).

The construct of mindfulness enjoys a close relationship with cognitive therapy because both adopt the philosophy that ruminative thought which is often negative, self defeating, and hypercritical, obstructs the healthy processing of life experience. For many sufferers of infertility there is a strong temptation to concentrate their emotional energy in the direction of outcome, i.e. pregnancy. This leaves an infinite dead space for individuals to navigate as they save for treatment, prepare for treatment, go through

treatment, and then recover from treatment. Mindfulness teaches that there is value in being connected to where you are, whether in ecstasy, pain, or emotionally treading water. A second mind-body technique that women consistently utilized, and is a practical introductory for teaching mindfulness, was deep breathing.

Deepening the breath.

Deep breathing has a long history in Eastern health practices. Frequently used in the management of diseases such as chronic obstructive pulmonary disease, cystic fibrosis, and asthma, its effectiveness in several stress-related conditions is also now well recognized in Westernized medicine. Herbert Benson's (1975) pioneering work, which explored the relationship between negative emotion and heart disease, helped bring the benefits of slowing and deepening the breath to the American mainstream (Benson & Klipper, 1975).

Yogic breath, or pranayama in Sanskrit (literal English translation, "control of energy"), is estimated to have been in use as a technique to enhance and maintain health for over 8,000 years (R. P. Brown & Gerbarg, 2005). Oxygen is a primary necessity for life, being deprived of oxygen causes an immediate cascade of physiologic events in the body that are designed to protect the brain from potential compromise. The art of deep breathing has developed into a complex discipline that belies the basic premise that breathing is instinctual. To breathe is instinctual, to deep breathe is learned. "Yogic breathing provides a unique and powerful tool for adjusting imbalances in the autonomic nervous system and thereby influencing a broad range of mental and physical disorders" (R. P. Brown & Gerbarg, 2005, p. 190). So deep breathing as a strategy for slowing down the pace of our own physiology as well as our thinking is relatively undisputed in the

scientific community. However, the relative power of the breath's relationship to the experience of calm in the mind and body is either not well understood or not routinely practiced by the average person. Key to this study's participants' deeper appreciation of the power of deep breathing to quiet the thoughts and steady the heart was the opportunity to practice it in real time. Practice forms the utilitarian bridge between theory and application. Without the advantage of performance i.e. experiential learning, theory only remains at the level of possibility. Several participants reported that deep breathing or slowing down their breathing helped them to stop in the moment, modulate thought processes, and take the time necessary to reframe their circumstances to gain a different perspective.

Hope and optimism.

Many women participants listed 'hope' as one of their learning objectives from attending the workshop (men were more likely to say coping skills or ways to help my partner). Hope, as previously discussed, is an elusive concept; it keeps human beings engaged in life at times when they feel their most desperate. Hope for women-only participants was intimately linked to their ability to remain positive not only about the likelihood of having a baby but toward thriving with or without a child. How hope was generated or sustained appeared to be related to participants' ability to see other people in similar or worse circumstances doing the work of living. Women who used downward comparison as a self-reflection strategy were less critical of themselves and more optimistic about how the future might turn out and seemed better able to respond 'hopefully.' Hope seemed suspended for women who were either too early in their infertility experience or were easily upset by the difficult stories of others. For

participants like Hillary the development of hope was inversely proportional to the degree with which she was negatively impacted by the infertility difficulties of others. Clearly for downward comparison to occur someone in the group had to be perceived as doing less well, at least by the individual doing the comparison. Inspiring hope across circumstances and personalities however was an important desire for all participants. Externalizing the problem of infertility from the experience of being infertile is vital to the establishment of hope. If our problems *become* us and those problems are perceived as intractable, then resurrecting hope becomes a relatively hopeless task.

Sharing stories.

Each participant in the women-only workshop, either in the demographic questionnaire or at the follow-up interview, listed the chance to be in a group with others experiencing the same problem as one of their main reasons for agreeing to be in the study. A key component of the need for identification with others was the opportunity to experience the shared story. Shared stories have power because they have the potential to undermine the unspoken assumptions that develop as part of dominant worldviews. Infertility is historically bound by the cultural, political, religious, and social practices that define us as human beings. The tales we tell and how we are permitted to tell them emerge according to the custodial rules of particular discourse relationships. Who owns what, how, where and when? The women shared that they often felt reduced to a label; a shrunken ovary or a battered uterus. They also worried that seeing a mental health professional might mean acquisition of another label; depressed, anxious, personality disordered, or psychotic. They were invested in the power labels had to change the

effective authority that they had over their own lives because labeling *had* already changed them.

Listening to one other without adherence to labels allows us to see the humanity behind the discourse. Infertility is the loss of something one has never had and its sufferers often shuffle between being analyzed to being reconstituted, and perhaps never coming out the same at the other end. This is likely not entirely a bad thing. Speaking aloud is one way to render the invisible visible, and the once hidden seen. According to many researchers, listening is the most important thing we give to our participants and “...itself constitutes a revolutionary act” (Freedman & Combs, 1996, p. 45). The experience of being heard helped to alleviate the need for participants to justify themselves “It makes me feel better when I hear about other people...okay, I am not so abnormal” (Katherine, April 8, 2006). Several elements of the stories that were shared influenced how participants believed they could move forward. Hearing different narratives helped them gain perspective and open up new lines of communication with themselves and others.

According to Foucault, “...we need a historical awareness of our present circumstance;” to understand how thought, language, and imagination become observed in the subject as performance (Foucault, 1994b, p. 124). What we tell ourselves and what we absorb from the messages all around us becomes the substance from which our characters grow. Description is a natural antidote to the destructive capacity of labeling. Description cannot be limited by branding or reduced to categorization. Even the categories that have emerged through the telling of participants’ stories must remain fluid if they are to retain both integrity and texture. The use of the narrative summaries rather

than technical titles on the Symptom Checklist and Fertility Problem Inventory served to further flesh out participants' experience and people seemed able to better see themselves in the words on the page. The descriptions also served as a reference point against which to clarify or expand upon who they know themselves to be. Is that perhaps also part of the art of becoming human?

Refractive reframing.

At the one-year follow-up participants in the women only group were beginning to see themselves through a prism of possibility, becoming active performers in their own lives rather than relinquishing themselves to something they had previously perceived as a parasitic host condition. "I don't have cancer but I have felt violated like there's the scarlet letter, like there's this giant 'I' and I want to get to a place where I see myself as something other than an infertile women" (Hillary, April 29, 2006). Reframing experience was more than a verbal exercise or even a guided vision. It was the ability to change the eye's refractive lens thereby changing the angle at which the image of 'self' could be seen "I am not defining myself by my loss but by my contributions (Alice, April 12, 2006). This ability *was* the creative experience for Alice because she was finally able to see her life as different from, rather than less than; still creative despite not yet procreative. Refractive reframing [the researcher's term] developed in the period between the diagnosis of infertility and the experience of infertility. They are distinct entities because one position identifies the person as the disease and the other seeks to find the person despite the disease. Thoughts, feelings language, and cognition all appeared to play a role in mediating the progress from one-stage to the other and an individual's life circumstances was the medium through which this progress was recognized or seen.

The discrepancy between what participants viewed as important elements of a productive life and the life they were actually living became the container for their emotional distress (Higgins, 1987). Understanding which belief constructs contributed to what particular experience of distress was an educative goal of the mind-body workshop. Placing infertility in a historical, social, and political context was a step toward accomplishing this goal, deconstructing personal myths and constructing new meaning another. Refractive reframing like personal growth of any kind is subject specific, temporal, and provoked and influenced by life's circumstances. Refraction in purely technical terms refers to the angle and speed at which light is transmitted from one medium to another. The more dense the media the less acute the angle of refraction (Wilkinson, 2006). Light as a physical phenomenon is the electromagnetic radiation emitted from the sun that becomes visible to the naked eye (as reflected images) at a particular wavelength allowing us to see. Of course seeing is not only about light, it is about depth of focus, environment accommodation, perception, and age; it is about our ability to train the eye as well as our capacity to interpret what we see (Wang & Ciuffreda, 2006). Light is also a creative metaphor; a process of intellectual or artistic illumination; a source of information that we use to tell us and the world about ourselves. Infertility is a dense medium clouded by the external influences of society, custom, history and politics. The angle at which light hits this medium is different for each participant. Rather than portray a general image of infertility, refractive reframing seeks to define a unique image that distinguishes the person from the condition. It is not about mirroring back what the rest of the world sees. Fertility is ubiquitous. It is the norm reference point against which childlessness is invariably seen. Infertility doesn't reflect

the norm it bends and arcs through grief and isolation, misunderstanding and despair, anger and solitude, judgment and evaluation.

Some women were still in a significant place of loss one year after the workshop and struggling to reconcile several aspects of their life. They were deconstructing their own story and working to eradicate the stigma of infertility and participation in the interviews was a big step toward accomplishing that. Refractive reframing is a dynamic process. Like the angle of light changing as it meets the boundary between two mediums the perception of infertility shifts when individuals can see themselves and are no longer hostage to this stigmatizing experience.

“I want to say thank you for doing this on infertility, because it is a very important subject and people need to know, it’s too close for me to be public, In your research I am just you know participant # so and so, anonymous, but I’m glad that people like you are publishing things that will talk about it. (Deborah, April4, 2006).

Couple Workshop

Identification and reconnection.

One year later couples (both men and women) shared that the most profound impact of the mind-body workshop was the opportunity to identify with others also experiencing infertility. Identification influenced the experience of isolation that many participants had disclosed as a significant source of their stress. Women often stated ‘finding a place to belong’ as a primary reason for participating in the workshop. This was more likely to be an unanticipated discovery of attending the workshop for men.

I learned from going to the workshop, was I hesitant at first, yes I was, but would we have gone and got the medical done if we hadn’t gone to the workshop, maybe not. It helped me to relax and see I am not the only one with this problem. (Howard, couple #1 April 25, 2006)

There were some unique differences between the women-only and couple group because the majority of women who attended alone had decided unilaterally that their partner would not want to participate. Perhaps previous resistance from their partners informed this decision but nevertheless most came alone because they felt that their relationship had been saturated by the topic of infertility and they were still looking for a safe place to speak.

Identification in the couple workshop was experienced individually and in partnership. Women recognized themselves in other women and compared their relationship against the perceived relationship strengths and fallibilities of the other couples present, although they were less likely to look at other men as a way to better understand their own spouse.

Men looked for points of reference between their partner and other women as often as they did between themselves and their same sex peer. How is she doing compared to my wife? How am I doing compared to him? For men, comparing their partner to other women helped to modify a previous belief or to generate a new perspective on their partner's struggle. It was as though the true distress of infertility did not become real for these men until the isolation of their experience had been reduced through sharing. Men were surprised that the act of sharing brought them closer to understanding their partner or had an immediate personal impact.

I needed to see my wife and the other women there and what they were experiencing for that raw emotion for it to be there – for it to affect *me*!
(Peter, couple # 2, April 8, 2006)

Women's perception that they were better understood fostered a feeling of intimacy and helped to decrease the emotional distance present within the relationship. Several women mentioned that although they realized that the physical burden of infertility treatment was

theirs by virtue of their sex, they were resentful that the emotional burden was not more equitably split with their male partner. (This played itself out in the research study also as 90% of women acknowledged that they had assumed the responsibility of registering for the *Minding Matters* workshop). Ultimately men's participation in the workshop helped to lessen this burden for women and also provided concrete ways for men to step in and provide comfort and support. The three women who attended both workshops emphasized the importance that facing infertility as a couple had on developing or maintaining unity in their relationships.

The fact that he sat there with me, he was in it with me, no matter what, he was there. It created a different intimacy. I mean the sex act changed. It just became different...it was a deeper more meaningful act. (Stephanie, couple # 2, April 8, 2006)

Identification for couples appeared to be less about finding commonality amongst group members struggling with infertility and more about finding the point of intersect between each partner in the couple relationship despite the experience of infertility. The workshop was described by participants as an opportunity for men to normalize their partner's experience, to bring partners together, and to recognize the humanity of each individual beyond their struggle to create a child.

Negotiating and respecting differences in coping.

Researchers have demonstrated differences between how men and women process stress generally and infertility related stress specifically (Jordan & Revenson, 1999; Matud, 2004). These differences are influenced by the complicated negotiation between, age, environment, social, situational, and cultural context, as well as experience, and education. The term 'coping' suggests temporary status is given to a stressful situation i.e. that handling, putting up with, or getting through, is the goal of coping, and that

stressful conditions are impermanent. Coping seen through this lens is sometimes experienced as a Bandaid, a way to protect the wound until the wound has healed and regular activities can once again resume. For a majority of men in this study coping had been experienced as a search for a Bandaid and the Bandaid they were hoping to apply was more often to their partner than to themselves. How can I patch her up and make her feel better or help her heal?

Men's view that their primary task was to heal or fix their partner clouded the secondary gratification that emerged through the interview discussion i.e. men's perception that they would be okay if only their partner was okay. Men discovered that relieving their partner from despair was not a realistic goal and did not necessarily do anything to alleviate their own suffering, but that sharing more fully in the mutual experience of infertility itself *was* a worthwhile way to offer support and allowed them to see *each others* suffering.

...it was her stress I was trying to help, but I wasn't doing a very good job. I was doing most things to help my partner but then I realized it goes 50/50 there are some things I can do to help my partner and then there's some things that I can't. (Graham, couple # 6 April 30, 2006)

Women often experienced their partner's desire to fix or mitigate infertility through abstract problem solving as a dismissal of their distress, particularly as this was not a problem that could be fixed through traditional problem solving means. In addition, when men realized that their usual coping strategies neither fixed the problem nor consoled their partner they began to withdraw which often fueled anger and increased isolation. The couple workshop provided a unique opportunity for these dyadic stressors to play themselves out and to be witnessed and confirmed by others as an additional

course of relationship stress. Sometimes it was only through the observation of others that participants were able to finally see themselves.

You get to the point where sometimes you don't see anything in yourself. You're trying to tell somebody "this is how I respond to something" and then your partner can be like "oh no she doesn't." (Nicole, couple # 4, April 5, 2006)

Women who were absorbed by their own distress were less likely to be aware of how infertility was impacting their partner and expressed surprise upon discovering that their partner's perception of stress was as high if not higher than their own. However, women were more likely than men to recognize that something had to change in the relationship and were prepared to take steps toward initiating that change. Other than Bruce (couple # 4) female partners took responsibility for registering for the workshop, responding to all post workshop and pre interview communications, and ensuring that their partner completed each research instrument.

After one year men reported an increased awareness of their own behavior and its impact on several important relationships in their lives including their partner, colleagues, parents, and in some cases children. Women described being less disappointed in themselves and more satisfied with their partners' efforts to demonstrate compassion. Women also began to see the larger impact of stress in their lives beyond infertility, particularly as many of them were now pregnant or already mothers. Attending the workshop together also helped couples to stay on task, to call each other on what they had learned and to recognize old patterns and habits. The crisis of infertility extended beyond infertility and provided a paradigm for facing future difficulties. Couples reported fewer parallel conversations, an increased ability to read each others cues, a reduced tendency to lecture and berate each other and a willingness to accept the inevitability that

life is an unknown.

What has helped me a lot is realizing that 10 years from now this will be way Behind us and we'll just be living our lives. They are all (the women in the workshop) going to be mothers one day and it won't hurt like this because they'll be living the life they want, it's just, how are the going to get there, you know, it's a huge experience. (Bea, couple # 9, April 16, 2006)

Coping processes were better understood when partners developed an appreciation for the factors that influenced an individual's experience of stress. Role identification, personality characteristics, financial constraints, information or knowledge base, guilt-blame ratios, and contextual interpretation all impacted the way in which infertility was manifested within the relationship. Expressing distress within a group format decreased the likelihood that couples would tune each other out and provided an opportunity for unrelated observers to also participate as active listeners. According to some coping researchers, it is the ability for partners to share an emotionally charged experience productively that can help to reduce the experience of marital distress (Austenfeld & Stanton, 2004). Emotion focused coping has traditionally been correlated in the literature with increasing rather than decreasing levels of stress. However stress, like coping, is a fluid process, is experienced on an individual level, and fluctuates according to time and situation.

The couple workshop provided a forum for issues to be explored and created a template against which partnered individuals as well as unrelated participants could examine and adapt their particular emotional approach and avoidance strategies. The interactive process between and across relationships was an important feature of the couple workshop's educational experience.

Mindful response versus mindless reaction.

The concept of mindfulness appeared to be internalized differently by participants in the couple workshop. Although paying attention without judgment was a construct that was emphasized equally at both events, couples were more likely to apply the concept across their relationship than women who participated alone. For men, being present in the moment meant attending to what they were being told and thinking before they proceeded to speak. The cognitive process of identifying an image, contemplating the image, and responding to the image was a construct that both men and women were able to grasp, but to varying degrees. Mindfulness was about gaining perspective, attending to language, recognizing impatience, suspension of criticism of self and others, and acknowledging rigid patterns and themes. Mindfulness was binary; practiced by the individual and between individuals wherein awareness of self stimulated an awareness of other. Mindfulness was about delaying reaction, taking things less personally, and reducing the tendency to minimize or maximize the interpretation of events.

Like sometimes I react to one thing whether it's a comment or a behavior and then I make it represent the whole relationship. I am a better judge now of when it's the wrong moment so I think "I really want to discuss this, but this isn't the time" and I'll wait. (Bea couple # 9 April 16, 2006)

For men mindfulness translated into tangible benefits not only in the primary relationship but across relationships and domains i.e. work and home. Thinking before one speaks was more than a reflective exercise to guarantee damage control it was a way to develop synchronicity between thought and action. How does what I do reflect what I say about what I do; establishing concordance between attention and performance. This is an important notion to master as it relates to infertility because it is easy to become

distracted by the treatment plan; to lose sight of the approach and stay focused only on the elusive goal of pregnancy.

Mindfulness for couples was also about recognizing the infectious nature of a partner's mindlessness; preventing cross contamination of anxiety while remaining supportive, not an easy progression. Distinguishing between mindfulness and simply staying quiet to stay out of trouble was difficult for Karl who equated mindfulness with "watching his P's and Q'.

I think I have learned what not to say from my mother because she is not afraid to say whatever is on her mind no matter how it may affect someone that she is saying it to...I've always been able to watch what I say and how I react to other people's thoughts and stuff, you know, so I don't hurt their feelings. (Karl, couple # 7 April 4, 2006)

Like many men Karl struggled to identify his own feelings and held a critical view of himself in the eyes of others. Since the workshop Karl had put energy into reflecting on his own emotions rather than getting caught up in his partner Jeanette's.

The experience of infertility (particularly as reported by women) has been described in the literature as frantic or desperate, is known to generate variable amounts of anxiety, and can contribute significantly to marital distress (Verhaak et al., 2005a). Women in this study were familiar with the pattern of rage and despair associated with the beginning of an unwanted menstrual cycle or the progression of treatment and were looking for a different way to live in their struggle as well as mitigate the stress childlessness was placing on their relationship. Providing a background history of infertility and the variable factors that influence its place in the culture as a stigmatizing event helped validate couple's personal experience. Female participants who self disclosed that they needed much more support than could be gleaned from a one-day

workshop expressed greater difficulty paying attention in the moment and applying the construct of mindfulness.

I know that there's nothing in the moment that is going to make me feel better, um I wish I could apply those principals right then but I find it's, like impossible, because it is so awful. (Caroline, couple # 3, April 15, 2006)

At the follow-up interview, despite receiving periodic counseling, Caroline continued to worry about and ruminate on several aspects of her treatment and past pregnancy losses. However, her partner Brian was more consistently identifying his own emotions and allowing them to guide his behavior rather than suppressing them in order to modulate Caroline's.

Mindfulness was also about relinquishing control, letting go rather than giving up and creating the space necessary to acknowledge each other's needs. Mindfulness did not occur in a vacuum it was predicated on past experience and current events. In other words couples anticipated that old habits would emerge around familiar dialogue and that their work was to listen differently, to identify and take responsibility for their own needs.

Deep breathing and relaxation.

Deep breathing was frequently utilized to self-calm and helped men in particular get better acquainted with their body at rest. Deep breathing was seen as a way to slow down thoughts, to respond rather than react, and was a concrete way for participants to see that something they were doing had an immediate effect on the way their body felt i.e. a slower heart rate. A few participants took a pre-relaxation baseline and post relaxation pulse however this information is not included as the study design did not lend itself to verification or interpretation of any physiological measures

As in the women-only workshop, breathing was assumed to be a reflex activity rather than a skill to be mastered, yet mastery was critical to achieve full comprehension of the relaxation response. Participants were instructed in two simple deep breathing techniques and each participant had an opportunity to demonstrate their individual understanding with the researcher. Deep-breathing was considered the most effective and easily transportable relaxation tool and was often applied by male participants across domains. Peter, a firefighter noted:

Taking deep calming breaths makes a big difference when I am working with a patient who is being physically or verbally aggressive. It's a way for me to step down and separate from what's going on and o get more centered in myself. (Peter, couple # 2, April 8, 2006)

Some men initially approached the deep breathing and relaxation component of the workshop with skepticism. The introductory exercise involved progressive muscle relaxation (PMR), which incorporates graduated muscle tightening and letting go as a method for familiarizing participants with the areas in the body in which they hold the most tension. Research has demonstrated that a maximum sustained contraction of fast twitch muscle fibers facilitates greater relaxation in the muscle upon release of the contraction (Ghoncheh & Smith, 2004).

Three restorative yoga postures were also incorporated into the format. Restorative yoga is designed to facilitate relaxation by supporting the body toward postures that facilitate a stable physiological state. Restorative yoga requires no special expertise to practice but can be intimidating to beginners who have the perception that any form of yoga requires significant flexibility. Restorative yoga is not dynamic in the sense of being active or involving stretching. It is quiet, contained, and a method for grounding, both the body (on the floor) and the mind and spirit in present time (attention

or awareness). For example, simply lying on the back (see Appendix H) with hips and knees bent and neck and low back supported takes pressure off the spine and positions the peripheral joints in a neutral and or non-weight bearing position (Lasater & Pullig Schatz, 1995).

Deepening of the breath accompanied by increased awareness of the body under tension and relaxation helped participants recognize how and where they experience stress physically. Emotional arousal is often precipitated by the perception of an external or internal threat. Deep breathing is utilized as a strategy to attend to the thoughts and cognitions that identify the source and meaning of a perceived threat. This technique is particularly helpful during infertility where the body itself can be perceived as the threat.

One of the things relaxation (when I could do it) helped me to see about myself was how I spiraled. I would get on this horrible spiraling vessel or tornado down and just bury myself into the ground. I was able to learn techniques and identify “okay I’m going here, what triggered this?”
(Nicole, couple # 4, April 5, 2006)

Infertility treatment is often perceived as a threat despite its intention to heal. Many women described the relationship between seeking medical help and accepting medical help as conflicted. The reality of not being pregnant was compounded by the fear that it might not be possible to get pregnant and treatment failure confirmed this terror. Verbalizing the turmoil that contributed to women’s experience of emotional paralysis was often difficult and fostered discord between partners; women felt misunderstood and men believed it was not possible for them to “get it.” Deep breathing and simple relaxation strategies were effective in helping couples attend to themselves and each other differently.

Back to back and supporting each other.

The theme of isolation and feeling misunderstood permeated many aspects of participants' lives, including their primary relationship. For the majority of couples, attending the workshop together was an opportunity to connect with each other differently around their infertility. Women were seeking greater understanding from their partner and men were hoping to gain insight into how to best provide that understanding. The male role at the commencement of the workshop appeared to be facilitative and ancillary, as noted in the majority objective men listed for participation "to find ways to support my wife." However, men were encouraged to engage in each exercise and they asked questions and provoked discussion for the most part as often as their female partner. (Victor and Wendy remained the one exception to this observation. Victor fell asleep during the PMR and guided imagery component of the workshop and Wendy asked only limited questions throughout the day).

The use of yoga, as described in the previous section, served two main purposes: 1) greater body awareness and 2) mental and physical relaxation. As time was limited and most participants had not participated in yoga previously, only simple postures were incorporated into the program structure. Included in the couple day was a posture that could be performed with a partner (see Appendix H). This was designed to function as both a physical awareness exercise and a spiritual and emotional metaphor. The direction was given to close the eyes, deep breathe, and bring awareness to the points of contact on the body using each other's back for support. After several minutes participants were asked to describe how this felt. Several participants spoke poignantly at the time of the

workshop, a few women were tearful, and men also expressed the observation that this was the first time they felt someone had their back.

That whole thing physically for me was the expression “I’ve got your back.” I think maybe if we didn’t state that goal to each other, that has become our goal and that is what we worked through. (Jill, couple # 1, April 25, 2006)

Uniting on a common goal might seem to be intuitive to creating a child however many couples reported feeling disconnected both from themselves and each other. Women in particular struggled to maintain a positive relationship with their body that they typically viewed as having failed them. Women reported feeling alone and experienced the procedures used to evaluate and treat infertility as invasive and dehumanizing.

Using the back-to-back posture as metaphor couples talked extensively about wanting to find a way to be on the same page or as Stephanie said to her partner “hey, you have to be in this with me.” This exercise served to epitomize the difference between the women-only and couples workshop. Women who attended alone had to use more energy to hold up their own back. The exercise also highlighted the pattern of involvement experienced by men during a couple’s infertility crisis. Men frequently assumed the role of bystander until asked by their partner to take a more active role in treatment; however determining what the active role could be was both frustrating and intimidating. Menstruation, rather like infertility, is a shrouded mystery from the male form. There is no experiential point of reference from which to understand how blood leaves the body on a monthly basis if you are not a woman. Although men in partnerships with women might report familiarity with the symptoms of premenstrual tension and associate a corresponding shift in mood to the changing phase of their partner’s cycle, they are unable to *know* what it is to actually have a period. They often described feeling

helpless and inadequate and for men inclined to use problem focused coping as a stress reduction strategy, trying to stem the flow of an unwanted menstrual cycle is viewed as both futile and overwhelming. Figuring out an alternative method of support was where men and women persisted to struggle.

Listening to women other than their partner describe what it was like to fear arrival of a period, anticipate its imminent flow, check multiple times to see whether it had started, and then plummet into a cavern of grief when it begins, helped men to see that this was part of the sadness that is experienced differently by women than men. A woman can never escape her body or the threat of impending child loss. Men may also be devastated but their body provides their soul with a natural reprieve. When men tell their women partners “I’ve got your back” they are also saying stay steady, lean on me, feel my presence, I am not going anywhere. Women in turn are saying we need each other, I will count on you and you can count on me, it is hard but let us combine the strengths we have to sustain us rather than use them to decimate each other. One year later this was still a prevalent theme, even with two of the couples who had not yet conceived:

“...and the trick is bringing us together so we can experience each other’s [journey] and that is what the workshop did for me” (Howard, couple # 1, April 25, 2006)

Refractive reframing.

There had been significant changes in the lives of the couple participants in the year since the workshop. Six of the ten couples had already given birth to children and a seventh was approaching her sixth month of a twin pregnancy. For all intents and purposes, these couples no longer fit the classification ‘infertile’ as currently defined in the literature (Larsen, 2005). However, the experience of infertility and the memory of

loss that accompanied this struggle continued to be a part of each couple's personal identity. The question of visibility and invisibility remained a constant theme throughout the participants' dialogue. The absence of children when they are desired is a virtual scar that speaks to the world; the non-pregnant body an image reflected that represents something not there. The body *perceived* as lifeless; mind-body dualism at its most conflicted. It is in this essential contradiction that infertility continues to lumber because creating a baby is not simply about joining sperm and egg. Creating a baby is about building futures, synthesizing the past, integrating families, constructing lives, pursuing dreams, and confronting death. It is about sense and reason as much as it is about science and form and it is almost certainly about art.

I just have the biggest sense of relief that this terrible time in our life is over...the pregnancy for me has been everything because this is my biggest dream but I have had a lot of guilt over my pregnancy in myself and feeling like I didn't go through it well enough, and I don't deserve this. (Nicole, couple # 4, April 5, 2006)

Nicole, like many women, wanted to hide herself away during the years that she had been unable to get pregnant. She closed out her family and friends and in many ways shut the door to her real and ideal self. Negotiating the space between desire and reality seemed impossible; a discordant lurch that only barely kept her hanging on. Her pregnancy brought her out of her own shadow and presented to the world a silhouette she could now live with. While her growing belly framed the children growing inside her and reflected to the world the concreteness of her own desire, she was acutely aware of how deeply she had neglected her own life during her craving to create another.

Refractive reframing, as described earlier, reflects process rather than product. Refractive reframing also respects the multiple influences that determine how we ultimately see what we see. Refractive reframing as a concept also respects the no-mans

land that infertility finds itself in because it recognizes that we are often asked to fit a distorted image of ourselves into a system of inflexible social, cultural, political, and religious rules.

Refractive reframing is about making sense of the senses. It is about placing the grief of despair and the elation of joy on a shared footing with the physiological rush and plummet of human endocrinology. Refraction is the process by which reflection is seen and can only occur in the presence of light. Refraction shrinks the distance between reality and reflection, the objective and subjective, by considering the medium through which light must travel and in this scenario the medium *is* the narrative and the narrative life's circumstances. Shedding light on their lives is the work of all participants in this study, whether with child or still on the road toward defining their family.

Review of the narrative summaries was not about proving an instrument right or wrong anymore than it was about correcting distortions. The summary was a textualized interpretation of item endorsement as seen through the reflected reality of the researcher. Perhaps this is where their (the instruments) power lays, in their ability to generate words from numbers, descriptions from categories and stories from abbreviated summaries. For the most part people wanted to talk about their own world. Yes they answered the research questions but they went on to describe themselves, to flesh out the real and ideal image, to shed light and in doing so add substance to the page.

Even reading my original responses I mean it was so sad, you know how I was feeling at the time...there's something to be said for what we've been through and there's such mixed feelings about having had such a long road and I think that road, it's now part of who we are. (Bea, couple # 9, April 16 2006)

Gaining perspective was difficult for participants who continued to see the image of what they didn't want reflected back at them, a sort of negative photography where color and shade is recorded in its inverse form.

I feel like, I mean I was looking forward to today but I felt like probably everyone else is pregnant from that group and we still don't have a baby. (Caroline, couple# 3, April 15, 2006)

For couples who had conceived during the previous year, having a child had healed a large wound but offered no protection from future pain. Graham and Bethany's daughter had a significant congenital heart defect which required extensive surgery, Karl and Jeanette were struggling to meet financial obligations, and Emily and Stuart found managing both their work schedules and an infant to be increasingly stressful. The transfer of stress in couples with children had been ceremoniously passed in some cases from the woman to the man. The burden of fulfilling the role of provider, parent, lover, and friend left some men feeling as overwhelmed with fatherhood as their partners had been during their loss of motherhood.

My stress has always been about bills and money, you know, where's the next paycheck coming from? That's where my level of stress comes from and I am still basically at the same point. (Karl, couple # 7, April 4, 2006)

Others saw infertility as the turning point in their relationship; a crisis that aimed them in the direction of themselves. Rising to the challenge that life presents was like an obstacle course for the head and the heart, an emotional and mental stress test that built cardiac endurance and expanded their sense of purpose.

I don't know if it's growing older or learning more or now being in a situation where I am responsible for someone else, but all of a sudden I seem to be able to see the underlying reason for things more easily. (Peter, couple # 2, April 8, 2006).

What made this journey so powerful for couples was that they were witness to each other's declarations often hearing a sentiment from their partner for the very first time.

She has been an outstanding parent to my two kids that she has nothing biologically in common with...she has done a lot in their lives. I think she would make a great mother to our child. If it was her biological child or adopted child, I think it would be a good choice...so I think it is very sad that she cannot have her own child. (Howard, couple # 1, April 25, 2006)

Howard had learned to express himself differently. He wanted to talk, about his past, his military background, his first wife, his children, his country, and his heart. What emerged in Howard's dialogue was his profound respect for where he had been and his larger hope for where he still might go. This position serves as the intersection between what *is*, and what is possible, a meeting of the objective and the subjective, the qualitative and the quantitative, the mind and the body. Not quite monism but not dualism either (D. Robbins, 2003).

Summary

This Chapter was divided into two parts. Part I explored the interview questions by conducting an in-depth text analysis of participant dialogues and was organized according to interview question and group type (sex and gender implications were discussed where appropriate). Part II presented the emergent categories and themes and sets the foundation for responding to the study's specific research questions presented in the Chapter VI.

CHAPTER VI

RESPONDING TO THE RESEARCH QUESTIONS

Introduction

This Chapter begins by examining participants' survey results. Although the predominant direction of the research is qualitative and therefore inductive, descriptive statistics, comparison of means, and correlations are provided. This approach is relevant to the first research question. Integration of the quantitative findings across the research is discussed when appropriate. Chapter V was an introduction to the lives of the participants and explored the themes, categories and relationships discovered within the narrative text. Application of those themes to the specific research questions is reviewed in this Chapter.

Positivist methods of exploring causes and consequences using quantitative information rely on strict rules that govern sample size, hypothesis testing, collection, and interpretation of the relevant data. The descriptive statistics used in this study serve as a foundation upon which to both build and deconstruct each participant's infertility story. They cannot be generalized beyond the experience of those to whom they apply. It is well

recognized that temporal effects influence the level of response on summary data therefore this data may not be a true measure of an individual's overall distress or infertility related stress, nor be reflective of the experience of people who struggle with infertility generally, and no such claim is made.

The art of qualitative inquiry is in the establishment of a narrative that generates new understanding. The development of new understanding is the primary purpose of this study. Responses to research Questions 2-4 (Part 1) and 1-3 (Part 2) are presented qualitatively along with additional ideas and discoveries that emerged during the in-depth interviews.

The Research Questions - Part I

Question 1

What is the study participants' perceived level of general distress and specific fertility related distress prior to attending the workshop, 6-10 weeks after completion of the workshop and at 12 months post workshop? What coping strategies are most commonly utilized to manage the stress?

Descriptive statistics and baseline measures (pre-workshop).

Descriptive statistics were performed to establish baseline: means, standard deviation, range, skewness and kurtosis for the SCL-90-R, FPI, and WCQ.). Fifty percent (n=14) of participants' mean global distress scores on the SCL-90-R were considered moderately high (> 84th percentile) and twenty nine percent (n=8) were very high (above 98th percentile) when compared to normative samples (non-patients, see Table III). Several researchers have documented elevated levels of stress in individuals experiencing

infertility therefore this alone is not a unique finding. The skew value and kurtosis for this instrument revealed relatively normal distributions for most scales except Psychoticism, which had a platykurtic distribution; Interpersonal Sensitivity, which was negatively skewed and Phobic Anxiety, which was positively skewed.

Although there were no significant gender differences in mean scores for men and women on each subscale, mean scores (using one way ANOVA), between the couple and women-only group were significantly different ($p < .05$) for 3 subscales: 1) Interpersonal Sensitivity ($F_{(1, 25)} = 4.8, p < .05$); 2) Hostility ($F_{(1, 25)} = 5.1, p < .05$); 3) Psychoticism ($F_{(1, 25)} = 5.6, p < .05$ Table 3). In order to provide some perspective and relativity to the values obtained, a comparison of baseline mean scores was made between this study's participants and baseline scores for a sample of women (n=132) participating in a 10 week cognitive behavioral program for fertility (Domar et al., 1999b). Overall mean score differences on all SCL-90-R subscales in this study's sample, when matched to Domar et al's (1999) were significantly higher, ($p < .05$). These scores are recorded in Table 3. When comparative scores were analyzed for between gender, and between group differences, there was less variability between the women-only workshop participants and Domar's sample.

Table 3.*Gender and Group Means for Symptom Checklist 90 Revised*

Source	Mean Women	Mean Men	Mean W/W	Mean C/W	Mean Domar et al
Somatization	57.2	59.9	57.4	58.5	52.0
Obsessive Compulsive	64.8	64.8	62.9	65.7	57.3
Interpersonal Sensitivity	65.4	67	59.7*	68.2*	58.8
Depression	65.2	67.2	62.9	67.1	60.9
Anxiety	63.4	63.0	62.7	63.5	56.2
Hostility	61.7	63.5	55.6	64.7*	56.5
Phobic Anxiety	52.65	57.8	49.6	52.7	49.7
Paranoid Ideation	56.1	61.8	50.6	60.9	51.0
Psychoticism	63.1	63.2	54.7	66.1*	57.4
Global Score	64.6	66.6	61.3	66.8	58.9

Note. WW = women-only workshop; C/W = couple's only workshop

* $p < .05$ mean difference between women-only and couple group

Fertility specific stress was estimated using the Fertility Problem Inventory (Newton et al., 1999). Descriptive statistics revealed relatively normal distributions on all scales with a slightly positive skew for Relationship Concern. Mean global infertility stress scores in this study were higher than the normative mean for both genders ($p <$

.001), however below the 84th percentile which is considered average. Newton reported mean global stress scores in his sample as 117.0 for men and 134.4 for women (Newton et al., 1999). A one-way ANOVA conducted to examine differences by gender was significant for Social Concern ($F_{(1, 25)} = 10.36, p < .05$) with women reporting a much higher level of social stress than men (Table 4). Pearson's correlational coefficient indicated a positive relationship between social stress and female gender ($r = 0.54, p < .01$).

Table 4.

Fertility Problem Inventory

Source	Mean Men	Mean Women	Mean W/W	Mean C/W
Global Score	141.90	165.18	152.71	157.90
Social Concern	28.90*	41.65*	37.71	36.65
Sexual Concern	20.22	27.18	24.43	24.89
Relationship Concern	26.30	26.53	28.71	25.65
Rejection of Childfree Life	28.10	28.03	24.57	29.28
Need for Parenting	39.70	41.79	37.29	42.33

Note. WW = women's only workshop; C/W = couple's only workshop

* mean difference for gender significant, $p < .05$

Results from the Ways of Coping Questionnaire were reported using relative scores (which reflect the percentage or proportion of time a particular coping process was used rather than its frequency, see Table 5). Women sought Social Support as a way to

cope the majority of the time while men employed Planful Problem Solving (20% and 16% respectively). One way ANOVA revealed significant differences for gender on the Seeking Social Support sub scale only ($F_{(1, 25)} = 5.45, p < .05$). The Pearson correlation coefficient confirmed that seeking social support as a coping process (a strategy used most frequently by women) was negatively related to Interpersonal Sensitivity on the SCL-90-R ($r = -.40, p < .05$). This finding was not repeated between the women-only and couple group. However, between group differences were noted in the use of Positive Re-appraisal with members of the couple group using this coping strategy almost twice as often as women who attended alone ($F_{(1, 25)} = 6.41, p < .05$). The Pearson correlational coefficient indicated a moderately strong relationship between use of Positive Re-appraisal and attendance at the workshop as a member of a couple ($r = .45, p < .05$).

Table 5.

Ways of Coping Scale

Source	Mean Men	SD	Mean Women	SD	Mean W/W	SD	Mean C/W	SD
Confrontive Coping	.10	.03	.10	.05	.08	.04	.11	.04
Distancing	.12	.05	.10	.06	.10	.03	.11	.06
Self Controlling	.14	.03	.14	.05	.15	.07	.13	.03
Seek Social Support	.12*	.04	.20*	.09	.20	.08	.16	.08
Accepting Responsibility	.12	.05	.08	.08	.11	.11	.09	.06
Escape Avoidance	.10	.04	.12	.08	.11	.05	.11	.07
Planful Problem Solving	.16	.04	.16	.06	.19	.07	.15	.05
Positive Reappraisal	.13	.04	.11	.07	.07*	.03	.13*	.06

Note. WW = women's only workshop; C/W = couple's only workshop

* Between group mean difference significant $p < .05$

A follow-up Symptom Checklist 90 Revised was completed by all 27 participants approximately 6 - 10 weeks after the one day workshop. Paired sample t tests were performed for each subscale. The mean change score for Interpersonal Sensitivity (IS) was significant ($t = 2.073$, $df = 26$, $p < 0.048$, two tailed). All other subscales showed some reduction in score however not to the level of significance. Mean change scores on

the Interpersonal Sensitivity scale were explored for gender and between group differences (women-only versus couple group). The women-only group's IS score increased and the couple group's decreased, these two changes combined contributed to the overall reduction in the repeat measure IS score (Table 6).

Table 6.

Mean Change Scores for Interpersonal Sensitivity for Women-Only and Couple Group

Source	Mean W/W	SD	Mean C/W	SD
IS – 1	59.71*	8.04	68.20*	9.04
IS – 2	62.14	7.13	63.20	11.50

Note. * Significant difference in mean scores at $p < .05$ level

12 Months Later

Exploration of the perceived level of global and fertility related distress as well as general life events that individuals and couples experienced in the 12 months since the workshop, was accomplished through the interview questions. The majority of participants did not approach the subject of stress, either general or fertility specific, until directly asked to comment on the content of their narrative summary. Coping was explored as a one-time process at the beginning of the workshop. For coping processes to reflect an individual's coping style over time versus their adaptive response to a particularly stressful condition, multiple assessments over many situations are considered necessary (Moos & Holahan, 2003). The Ways of Coping Questionnaire (WOC) specifically explores coping in terms of symptom management rather than mastery of

condition (Folkman & Lazarus, 1988). It is used in this study to explore a possible relationship between perceived levels of stress and implemented coping strategies over one seven-day period (pre-workshop). Individuals who rated themselves as high with respect to interpersonal sensitivity were far less likely to seek social support as a way to mitigate their stress and reported significantly higher social concern on the Fertility Problem Inventory (FPI). This finding is consistent with research literature that suggests a relationship between perceived social support and optimism about treatment outcome (White et al., 2006)

Women-only.

Twelve months after the workshop the participants in the women-only group who continued to report feeling isolated and significantly impacted by their inability to conceive a child were also experiencing several other additional life stressors. For these women in particular review of the narrative summary confirmed their current experience and in some cases brought their attention to issues that had worsened since that time or that they were still trying to avoid. Despite initially reporting fewer difficulties in some areas on the SCL-90-R than either men or women from the couple group, these women were also less likely to have made any interpersonal changes in their primary relationship, reported high levels of work related concerns, and were experiencing considerably more somatic distress than previously reported or when compared to other women in the group.

Women who were feeling much better about their life in general, despite not being pregnant, were able to reframe their circumstances and had rediscovered their own inherent value independent of having a child. Alice disclosed that she believed the

significant improvement in her emotional health was the result of intensive individual psychotherapy and review of her narrative summary helped her to put her overall progress into perspective. She had also begun to relinquish responsibility for others in her life, an interesting contrast to her original WOC summary which indicated her most frequently used coping process was *accepting responsibility*. Katherine had a newly developed confidence and was about to begin nursing school and was no longer nursing her own previously unhealed wounds. However, the theme common to all participants in this group was a continued pursuit of emotional and mental support that did not include their partner.

Couple workshop.

At the commencement of the workshop couples reported significantly higher interpersonal sensitivity, anger, and disconnect from self than women who participated in the workshop alone. However the reported relationship stress on the FPI was actually slightly lower on average when compared to the women's group (25.65 compared to 28.71). The most important finding 6 weeks after the workshop was a large reduction in the interpersonal sensitivity scores for couples compared to a slight elevation for women-only participants (this change in score reached the level of significance at the .05 level). In addition female partners with a significantly higher perception of infertility related and global distress were far less likely to seek social support as a coping process and were more likely to be feeling anxious and depressed.

At the 12-month follow-up several couples who had reported a high degree of intrapersonal difficulty, as reflected in their narrative summary, indicated an important change in this perception. Bethany (couple # 6) was experiencing much lower levels of

anger (despite having an infant who was scheduled for heart surgery). Graham, her partner attributed this in part to his commitment to stay engaged in the relationship rather than resort to escape or avoidance as a coping mechanism, a strategy they both reported using frequently in the past. In addition Bethany was more inclined to ask for help and less likely to use self-control as a way to try and influence stress. In general, extremely elevated global distress scores amongst couples had initially been associated with a lower use of social support as a coping process. By the end of the 12-month follow-up period couples who had made the most progress in their stress reduction had made important changes in their intrapersonal and interpersonal functioning, were more likely to be unified with family members, and were experiencing less relationship conflict.

Perhaps one of the most noteworthy observations was the increase or status quo in global stress that some men reported despite the majority having become fathers. In contrast, women who had become mothers reported much less fertility specific stress and their perception of global distress was also reduced. For women childbirth appeared to be a mechanism for healing, while for Karl (couple # 7) and Bruce (couple # 4) it also triggered new stressors and additional sources of existential angst. These stressors were primarily related to work-related dissatisfaction and appeared to become more pressing as their female partner's perception of stress declined. Prior to their pregnancy Bruce had functioned as the conduit for his partner Caroline's stress and at the follow-up interview this dynamic had reversed and Caroline was trying not to function as the container for Bruce's difficulties while providing much more of the relationship support.

Couple's who were still trying to conceive appeared to be managing their ongoing wish for children in different ways. Jill and Howard (couple # 1) reported that choosing

to stop infertility treatment and to place their energy into something they had more power to influence, e.g. their relationship, had been of considerable benefit. They were still considering expanding their family through adoption, had also reclaimed their sex life which had been abandoned to timed intercourse, and they reported sharing much higher levels of emotional intimacy. Caroline (couple # 3) reported ongoing difficulty managing her worry about getting and staying pregnant, although she had several positive things going on in her life which helped mitigate that stress. She also described her relationship with her partner Brian as extremely supportive. Victor and Wendy (couple # 7) had ongoing intrapersonal and relationship difficulties that pre-existed their attempts at conception. Victor's reluctance to have a child was rooted in the difficulty he had making sense of his own life while Wendy's desire to have a child was an attempt to give her life meaning. One year later this couple was still attempting to bridge the chasm that these two positions had created.

Question 2

What impact does a one-day mind-body program for individual and/or couples facing infertility have on their experience of infertility related stress?

Women-only.

The impact on the experience of infertility related stress most frequently cited by women-only workshop participants was the opportunity to be in a group with others struggling through infertility. The majority described feeling less isolated, comfort in being able to identify with others, a sense of belonging and camaraderie, and a reduction in their need to maintain a façade of coping or competence. Women also reported that the opportunity to see how others were dealing with their circumstances gave them a gauge

against which to compare their own progress. This had both beneficial and detrimental effects. Women who perceived themselves as doing well were more likely to implement downward comparison, an observation also confirmed in the literature ((Stanton, 1992). In contrast, women who were experiencing more distress reported feeling overwhelmed at certain times throughout the day (Nicole, couple # 4).

Being provided with any chance to attend a seminar or workshop related to infertility was an important factor for many participants. This made a particularly lasting impression on women who believed that a large part of their stress was tied to a belief that infertility was ignored by society in general; ipso facto they also felt ignored. Most women listed being with others and the development of self-awareness as an objective for participating in the study. Participants reported retaining at least two strategies from the workshop that still had influence in their lives one year later (commonly mindfulness and deep breathing). At twelve months they were also invested in helping others newly struggling, contributing to a change in the public's attitude toward infertility, and seeing medical intervention take on a more integrated (mind-body) treatment approach. Workshop participation appeared to confirm that how one feels about a condition can be influenced by the perception one brings to a condition and that understanding this dynamic was an important component of healing.

Couple workshop.

Couples also indicated that the opportunity to be in a group with others experiencing similar difficulties had a significant impact on their perception of infertility related stress. Observing how other couple's negotiated infertility helped participants to evaluate their own intra and interpersonal relationship strengths and fallibilities. Men in

particular believed that hearing a woman other than their partner speak about infertility helped to normalize the experience and gave them a new point of reference. It also helped men to see that they were not the only one struggling to navigate this difficult terrain and that it was possible to offer support without bearing the onerous burden of ‘fixing the problem.’ Subsequently, women participants reported being less focused on themselves as well as feeling less resentful, and were more likely to view their partner as a source of comfort. Couples also acknowledged that they were better able to attend to the ways in which they had chosen to isolate, seemed more able to take responsibility without applying blame or judgment, and therefore had a heightened awareness of the impact infertility was having on their partner. This was especially true for women, many of whom did not realize how much their partner was personally affected by not being able to have a child.

Couples also tended to engage in downward comparison as a way to evaluate their own relationship status. Men were more likely to be positively influenced by upward comparison, e.g. using the example of other men who appeared to be doing better as a model for their own behavior, while women participants tended to describe other women whom they perceived to be coping better, as a threat.

Each couple brought their unique history to the workshop and left with personally valuable information. Jill and Howard (couple # 1) valued the opportunity to physically and emotionally explore each other differently; to touch and be touched. For Nicole and Bruce (couple # 3) the workshop represented a door opening into a larger support system they began long-term couple counseling. Peter (couple # 2) reported “I felt when we left there, we left with something else. We created another portion of ourselves in either the

way we deal with things or the connection that was made....” David and Laura developed more confidence in how well they were doing despite their recent miscarriage and committed to pursuing a path that honored their own counsel. The degree to which individuals and couples were impacted varied according to how long they had been trying to conceive, how they typically sought our supportive resources, to a lesser extent who had been diagnosed as infertile, and how receptive they were to the process, their partner, other group members, and the researcher.

Question 3

How well do participants understand and apply the principles taught in the mind body workshop to their life and their emotional self-care after completion of the program?

Women-only.

Women typically reported that they had ‘believed’ in the concept of a mind-body connection before they attended the workshop. Several could identify times in their life when they had felt sad about something and then experienced that sadness as a physical symptom in their body. Hillary, Alice, and Ruth had suffered such deep emotional pain in their past that heartache for them was synonymous with the heart actually breaking. What was most important for participants was development of an appreciation for how they personally manifested stress whether through rumination, misreading or avoiding their own cues, the creation of unrealistic expectations, headaches, or other somatic symptoms. The first hour of the workshop was spent discussing the relaxation response and generating understanding of the physiological sequence of events that occur when the body perceives itself to be under stress. This was followed by an explanation of mindfulness and a group activity that facilitated integration of the concept of staying

connected to the present. The relationship between mindfulness and movement of the body to a more relaxed state was then reinforced with a deep breathing exercise.

Deep breathing and mindfulness were the two mind-body principles that participants continued to use in their everyday lives. Mindfulness was intimately connected to the perception of fear for most women in the workshop, and fear is a well documented consequence of infertility and its treatment (Lancastle & Boivin, 2005). Deep-breathing was frequently described as a transportable and efficient calming device that had an immediate effect on participants' worry or trepidation. Understanding the physiology of respiration and its relationship to heart rate, blood pressure, and the production of stress hormones helped women better understand the benefit of doing something as simple as stopping to take a deeper breath.

At the beginning of the workshop women had been looking for a way to mitigate their tendency to get ahead of themselves and wanted to stop living in infertility's no-man land of 'if only' or 'when'. The nature of trying to conceive makes it a waiting game where time is literally punctuated by the almighty period. Women's appreciation of the cumulative effect of stress helped them to understand how the character of one experience can influence the complexion of another when attention isn't given to their overall physical, mental, and emotional environment. Eventually the constructs of mindfulness and deep breathing were applied across multiple domains.

The restorative yoga postures were introduced as secondary reinforcement of the deep breathing and mindfulness activities and provided another opportunity for women to experience how quieting the mind had the effect of calming the body. However, most women (with the exception of Hillary) had not pursued a more formal yoga practice.

Yoga was viewed as more of a specialized intervention that took work and effort. Although philosophically most women could talk about the published benefits of yoga they were not applying those principles to their own self care practices.

Couple only.

Implementation of the couple program was different to the women's for several reasons: 1) alternate location 2) two presenters (see Appendix G) 3) twice as many group members) 4) participants attended in dyads. Although the identical manual was used for both groups, less time was spent on each concept in the couple workshop to allow for the increased number of member questions and afford presenters an opportunity to review exercises individually with each participant.

Time was spent exploring the synchrony between thought and action and promoting self understanding because of its impact on interpersonal skill development. How do you identify emotions in your body? What thoughts are connected to which emotions? How do you express what you feel and how accurately is what you express being received? How much attention is given to your physical self when you are experiencing emotional difficulty?

At the twelve-month follow-up men expressed that the concept of listening without necessarily having to *do* anything with the information they were given had been a new experience. Several men shared at the beginning of the workshop that their reason for attending was that they wanted information on how to better support their wives. The implication being that this new information would give them something to do or provide a tool to help them mitigate their partner's pain. An unanticipated gain from attending was the discovery that *being* rather than *doing* was a more likely answer. Given that each

couple had their own unique relationship style couples were encouraged to see themselves as their own best relationship expert. To listen actively was strategically linked to the teaching of mindfulness because it became self evident to participants in real time. How present am I now? What do I see? What do I hear? What do I say? Once men understood the concept of mindfulness it became easier for them to recognize it as performance in themselves as well as others.

Mindfulness overlaps the therapeutic phenomenon of here and now processing because both insist on awareness of what is happening in the moment (Yalom & Leszcz, 2005). However mindfulness based education is more structured and does not call for reflective insight as much as it demands non judgmental attending (Kabat-Zinn, 2003). “Oh this is what I am thinking now” rather than what does that mean and let me bring this to the group process. The distinction between ‘therapy’ and ‘technique’ was an important one for many men, especially those who had never been to a counselor before or engaged in a similar type of group format. Mindfulness was translated into listening, acknowledging what they heard, and staying engaged.

Women used mindfulness and deep breathing to slow down their thought processes, particularly as their partners were now stopping to listen to what they had to say and this demanded more contemplation and less spontaneity. Women reported that when they paid attention to their own reactions and self talk they were able to see how they contributed to their partner’s sense of helplessness. By first asking “what am I asking from him” it became easier to recognize when their requests were unreasonable.

Mindfulness required engagement and acceptance and engagement and acceptance interfered with many of the coping processes that some couples reported

using to manage their stress. For example, couples who used escape avoidance, distancing, or self control reported greater improvement in their relationship when they incorporated mindfulness as a way to remain connected. The couples who had integrated the practice of mindfulness into their lives reported fewer fights, quicker recovery from disagreement, more emotional intimacy, and an enhanced ability to read each others cues.

While men and women utilized deep breathing to self soothe, women (with the exception of Peter (couple # 2) were more likely to use relaxation methods such as yoga, guided imagery, and progressive muscle relaxation to calm their entire body. Whether women were in active treatment or not, they reported an overwhelming responsibility toward maintaining their own health. Initially this had presented a conflict for women participants who were struggling to see beyond an inevitable question: would I be doing any of this if I was not trying to have a child? There had also been some struggle to make peace with what many women perceived as an unfair biological burden that required they take more care with their health than their partners did with theirs. Five of the women who had children since the workshop reported using the breathing techniques they had learned during their labor and Peter (couple # 2) specifically stated:

Without going through the mind-body experience the breathing techniques that we learned in the birthing class I would never have been able to relate. To me this has been a real good experience and hopefully something I can retain for a while. (Peter, couple # 2, April 8, 2006)

Question 4

What are the benefits and limitations associated with a one-day program? How can this format and the Manual be improved upon?

There was significant overlap between groups with regard to this question therefore women and couple data is presented together. The majority of participants reported that the primary benefit of a one-day program was the opportunity to be with others who were experiencing infertility. The need for like-minded support was repeated several times throughout the interviews by both men and women.

Maybe it's all a little bit different situation, but the pain is right there all the time. Having a place where other people understood that and you can talk about it...where you know you are actually understood, that was tremendously helpful to me. (Stephanie, couple # 2, April 8, 2006)

Holding the event over one eight-hour day limited ongoing scheduling conflicts and increased the likelihood that people would make time in their calendar to attend. For people who traveled extensively for their business, scheduling the workshop for a Sunday meant it was more convenient for couples to participate together. Men were particularly interested in the risk of attrition and believed that they would be more prone to *not* completing a program that was organized over a weekend or several evenings. Although this workshop was free, participants were aware that a program that was any longer might incur considerable expense, both in travel time and provider fees. A one day format was also perceived as more flexible and something that could be offered several times a year and would make it easier for people to integrate emotional support with their medical care.

It was also important that the workshop had been offered at a separate location from where people were receiving treatment and accessible to individuals from different medical facilities. This gave couples an opportunity to compare treatment protocols, learn about other institutions, and share concerns or criticism about their care without fear of retribution. Several women reported feeling sad and anxious when they had to return to a

clinic where they had received several cycles of fertility drugs that had not ended in a pregnancy. The workshop facility needed to represent a place of respite and comfort, not be reminiscent of despair.

The biggest limitation for the majority of participants was program duration. There was a large amount of material to cover in one-day and little opportunity for people to solidify their skills with practice and solicit feedback. Most participants recommended extending the workshop over a two-day weekend possibly including a Friday evening for an informal dinner and introductions. Men were more interested in having shorter sessions over a longer period or including breakouts with alternative speakers. Although extending the length of the session would incur cost, it would also allow for a more inclusive program that offered the potential for individual or couple sessions, and a women's and men's group format.

Men overwhelmingly reported that they did not look at the Manual once the workshop was completed despite the fact that there was a section that specifically addressed concerns men might have. Approximately 45% of women participants reported reading the Manual for the first two or three months afterward and another 15% in the first few weeks. Several people indicated that they were more interested in the experiential format of the workshop and had retained the most critical elements from the day from participating in the activities themselves. Both men and women felt that learning would be enhanced by including a DVD or interactive CD-Rom that gave instructions on deep breathing, mindfulness, and deconstructing beliefs. Participants were also interested in hearing the stories of others; living examples of what it was like to listen to the narratives of others who had walked in their shoes.

Finally, participant selection had significant influence on group dynamics and was influenced by mental health status, number of years infertile, personality characteristics, as well as type of diagnosis.

Research Questions – Part II

Participant response to the narrative summary demonstrated consistency across groups and gender and the following three questions are presented according to this finding.

Question 1.

How well do quantitative measures of psychological, social, and somatic distress reflect participants' qualitative experience and description of their distress?

Two of the surveys used in this research, the Symptom Checklist 90 Revised (SCL-90-R) and Ways of Coping Questionnaire (WOC) have a long history of use in the scientific literature (Derogatis, 1977; Folkman & Lazarus, 1988). The Fertility Problem Inventory (FPI) is a lesser-known tool designed to be used as a screening instrument for identifying infertility related stress across several domains.

Folkman and Lazarus recommend that the WOC tool be viewed as “an evolving strategy for measurement rather than, strictly speaking, a test” (Folkman & Lazarus, 1988, p. 6). The WOC was used in this study as a method for exploring the relationship between participants' perceived stress (as reflected by the SCL-90-R and in-depth interviews) and self identified coping processes.

The SCL-90-R is a self-report inventory that is frequently associated with clinical assessment and diagnosis and therefore more readily identified with a medical model. One of the intentions behind administration of a self-report measure is to garner direct

feedback from the test-taker i.e. an experiential model. However, several researchers who explore both the concept of satisfaction in health care delivery and the measurement of perception using questionnaires caution that perception does not necessarily equal outcome and is also significantly influenced by gender, culture, class, and context (Barr, 2004).

Qualitative inquiry is a search for explanation; investigation of phenomenon, and “...requires in-depth participant observation of relatively small scale social aggregates” (Miller, 1982p, 282). It is not enough to know that something happens the edict is to understand the essential nature of the experience (Robinson, 1951). As a group, study participants’ survey responses on the FPI and SCL-90-R were above or well above average when compared to values reported in other studies for individuals who are experiencing infertility. What did this really mean?

Few study participants took exception to the narrative summary that represented their item endorsements on the questionnaires. Rather than challenge its veracity participants often acknowledged what was presented on the page as an accurate reflection of themselves at an earlier time in a different location. However, a small minority, regardless of whether they had achieved pregnancy, also still believed that what they had said about themselves one year earlier reflected their current perceptions. These six participants (Hillary, Ruth, Bruce, Caroline Karl and Victor) reported still feeling stuck at a similar place and in some life areas considered their stress to be at a higher level.

Participants appeared to instinctively justify any difference in score between the first and second test measurement according to the direction of the change, e.g. “oh it went up then because...” These sorts of statements were usually followed by an in-depth

explanation of what was happening in their life at the time the survey was completed. A particularly poignant example was provided by Howard who disclosed that between the first and second SCL-90-R administration he had been told it was unlikely that he could have fathered any biological children. This news generated tremendous rage and anxiety and caused him to question the paternity of the children he was still raising from his first marriage. (Howard's second SCL-90-R hostility measure increased 10 points or about 16% over his earlier score).

Women and men were more likely to clarify their responses on the SCL-90-R than they were the FPI. Participants appeared to be comfortable with the perception that infertility was a stress producing experience but expressed some conflict over how other areas of their life might have influenced, or been influenced by, their fertility.

This is a different person I am reading about. I think I let a lot of issues overtake. I did not realize how significantly I had let them impact my life. There are so many words that are describing what I am feeling but I am kind of having a hard time saying it, only because I almost feel like this was two different people. (Alice, April 12, 2006)

Alice and Howard's descriptions provided frame and content to their experience which altered the interpretation of their narrative summary both for themselves and the researcher. Numeric values on the Symptom Distress Scales appeared to have little between subject relevance when compared to the qualitative description of an individual's stress. For example, Nicole (couple # 4) expressed considerable despair in the couple workshop which provoked concern from several group members. She reported feeling hopeless, desperate at times, and passively suicidal "if I don't have a baby I don't see my life as worth living, I mean I might as well die." However, Nicole's global distress score was the lowest of all study participants (GSI=51) and of the 27 subjects 19 also recorded a higher depression score.

Nicole described her pre-infertility personality as energetic, positive, trusting, and to a large extent innocent of life's traumas. Infertility, which was her first experience with personal crisis, had prompted her to stop all communication with her sister, (for over a year), develop a phobic association with sex, and experience post-traumatic like symptoms when she attended her fertility appointments. However, Nicole's responses to the first SCL-90-R were recorded in a mood of optimism only 30 minutes prior to the beginning of the workshop. "I felt I was finally doing something that might make a difference" (Nicole, couple # 4).

As the day progressed Nicole appeared to others to become more and more despondent although her own memory of the time was that she left that day feeling guardedly optimistic. Nicole's SCL-90-R was significantly impacted by temporal and contextual effects that did not jibe with her later emotional presentation. Her second SCL-90-R demonstrated several scale elevations and a 54% increase in her overall global distress score (this appeared to be more representative of how she and others experienced her mood at the time). Nicole also explained that she had been operating under the assumption that the reason only four couples returned for the follow-up meant that the others were pregnant and that she would continue to be the one person for whom infertility treatment would not work. It is therefore perhaps a mistake to assume that the process by which information is presented in questionnaires, including sentence structure and timing of the surveys, is an accurate reflection of actual experience. It is also however, possible that Nicole's pre-infertility personality would have reflected such low item endorsement on the SCL-90-R scales that even below average norm referenced scores could be considered elevations for her.

It appeared that the consistency between infertility related distress and the qualitative experience of that distress was in part a function of category limitations i.e. the FPI was only looking at one type of stress and therefore appeared to be more representative across participants. Coping processes were often context and personality specific and reflected a strong association between social isolation and the limited use of social coping to mitigate stress. In other words couples who reported feeling alienated from each other, emotionally disconnected and often angry or irritable acknowledged that they intentionally withdrew from contact with others when they were under duress. It was not until Bethany participated in the workshop that she both recognized this as a tendency and also experienced the immediate benefits of receiving social support.

In sum it appeared that while each instrument had the potential to capture certain elements of an individual's level of functioning it was in the telling of the tales that the richness of people's circumstances could be fully considered and understood.

Question 2.

What, if any, impact does labeling or categorizing of past symptom distress (reflective of a medical model) have on participants' perception of the current self?

Quantitative values for each participant were transformed into a narrative by the researcher using identical language for each summary and applying the term below average, average, or above average to distinguish between perceived levels of stress. This was done to avoid giving mental health designations such as depressed, anxious, phobic, or hostile to individuals who had higher scores and helped to maintain uniformity between the narratives.

Infertility is traditionally viewed in the west as a medical condition and as such is accorded the same kind of scrutiny as other health concerns. The gaze under which infertility finds itself has expanded in the past decades, in part because of the increasing interest in embryonic research, but also because the use of technology in medicine continues to push the boundary between disease and health (Pryce, 1999). The majority of participants in this study did not only view their desire for children as a condition to be fixed but also as a developmental trajectory that had been kidnapped from them on their course through life. Explaining, justifying, or accommodating their wish for children made no sense when positioned against the fertile world. It appears after all that ninety percent of the populated universe fulfills their longing to make babies.

According to Foucault it is the work of human beings to construct facts about themselves and that within those facts it is important to remember four discrete levels of technological influence: a) the technology of production which allows us to alter or influence products of our environment, b) the technology of sign which impacts how we construct meaning, c) the technology of power which insists on the respect of hierarchy and authority and d) technologies of the self which reflects the numerous ways in which mood, cognition and behavior change our understanding of self (Rabinow, 1994).

For the purpose of this study's formal labels were removed from the narrative content that represented participants' survey responses. However all words become a language of power when placed in the hands of scientists or researchers. Consider the following disclosure by Laura (couple # 8) given in response to one of this researcher's statements:

Your feedback is really helpful to me and I respect and appreciate the time you have given me with you and your family. (Researcher, April 7, 2006)

Well I still have the “I want to be liked and I’m the good girl.” [Laughing]
(Laura, couple # 8, April 7, 2006)

Laura and David (couple # 8) was the only couple who elected not to read their narrative summary. They were also the most vocal about their negative perceptions of science and medicine before and since the birth of their son Keenan. Laura and David tied together several of their thoughts from the workshop day that personify Foucault’s call to respect the four levels of technological influence cited above. This couple was not willing to pursue interventional technologies, reported disappointment with the scientific position that commands all boys must be circumcised and babies given vaccinations, deferred themselves to the voice of a perceived higher order (they nevertheless completed the workshop and participated in the follow-up with this researcher), and were continuing to navigate their way through their own mental, emotional, and behavioral mediums.

The reduction of human beings to the material body is an essential feature of science and medicine (Barnard, 2000a). How else to explain the vastly inexplicable or measure the weight of the things that people do? Contemporary psychologies and philosophies of counseling follow a similar path of reification. By relying on labels to describe performance language rather than people *become* the performance. Feminist and constructivist theories focus attention on the problem of essentialism wherein character, condition, and circumstance can be defined. However feminist, constructivist, or post-modern theories are rarely represented in the discourses of medicine. Mind-body, Cartesian Dualism, this remains the predominant lens of medicine’s focus and the body rather than the person the medium of refraction.

Despite the removal of technical labels from the narrative summaries the transfer of survey items from ratings to relativities still demanded that individual experience be

contained by an externally imposed description. Of the 25 of 27 study participants who read their narrative summaries none rejected the depiction of themselves. Several found an ongoing identity in the lines that streamed the page, while others looked upon the words using their own clinical gaze:

I almost felt like I should be committed (laughing) I felt like it described a very, very, distressed and anxious person, like extreme. (Hillary, April 29, 2006)

So who is *that* person? It appears she wasn't Hillary perhaps a version of Hillary mutated through the fractured lens of my own desire to find something of the person in the discussion of infertility. Several participants shared similar externalized perceptions of the person represented before them and it strikes me now as I shuffle pseudonyms that I too have materialized, broken down, reconstituted and reconstructed if you like, 27 human beings.

I almost feel like this was two different people...wow I have really come out the other side. (Alice, April 12, 2006).

It seems that is what we do in part when we ask questions that are self defined, limited in context to a chain of statement upon a page designed perhaps to meet more mine, the clinician's, expectation. Perhaps then it is in the answer to this question that the greater question begs to be asked. How will *I* then use all that I have learned?

Summary

This Chapter responded to the specific research questions and integrated participant feedback on their experience in the *Minding Matters* workshop with the designed goals of a mind-body program. This Chapter also examined the results of several quantitative instruments used in the study and explored qualitatively the causes and attributions the use of such instrumentation has on research participants. The

following Chapter will consider and discuss the implications of this study's findings as they relate to the current direction of mind-body therapies and clinical practice in the area of reproductive medicine.

CHAPTER VII

DISCUSSION AND IMPLICATIONS

We must try to proceed with the analysis of ourselves as beings who are historically determined, to a certain extent, by the Enlightenment. Such an analysis implies a series of historical inquiries that are as precise as possible; and these inquiries will not be oriented retrospectively toward the “essential kernel of rationality” that can be found in the Enlightenment, which would have to be preserved in any event; they will be oriented toward the “contemporary limits of the necessary,” that is toward what is not or is no longer indispensable for the constitution of ourselves as autonomous subjects. (Foucault, 1994b, p. 51-52)

Introduction

This study's aim was to evaluate the effectiveness of a one-day mind-body program designed to provide emotional support for individuals and couples experiencing infertility. Construction of the teaching tool was guided by current standards of practice in mind-body medicine and included consideration of the multiple influences that impact the diagnosis and management of infertility. The study also examined three major sources of infertility related stress 1) the challenge to personal identity (internal) 2) social isolation and/or relationship conflict (external) 3) stress effects of treatment (historical, cultural, and political). The literature review in Chapter 2 outlined the history of infertility and its psychosocial effects and formed the academic foundation for this

research. The voices of this study's participants are a new addition to the literature and serve to further inform the direction of infertility counseling. This Chapter reviews the study's major content areas including: 1) limitations of the study; 2) the study's finding of important differences between the Women-only and Couple group; 3) relevant methodologies and emergent theories and themes; 4) practice implications; 5) implications for future research; 6) researcher reflections, and concludes with a final summary.

Study Limitations

This study had several constraints. The *Minding Matters* manual and mind-body workshop were designed specifically for this research and had not been used previously by anyone other than this researcher. In addition, mind-body techniques and their precise application to infertility are not well identified or validated in the literature therefore the methods and methodologies used in this study have little precedent. Each principle incorporated into the workbook has its own strict requirements of acceptable skill acquisition and teaching standards. For example yoga, as a long standing mind-body-spirit Eastern tradition requires years of self practice and mastery before teaching is undertaken (Iyengar, 2001). This researcher has had a personal yoga practice for more than ten years, uses yoga as a therapeutic intervention in the application of physical therapy/mind-body techniques in clinical care, and earned a 200 hour registered yoga teacher certification (RYT) prior to the commencement of this research. Although yoga incorporates some of the meditative aspects of mindfulness, mindfulness is also considered its own area of specialization. Therefore, according to Kabat Zinn:

...it becomes critically important that those persons coming to the field with professional interest and enthusiasm recognize the unique qualities

and characteristics of mindfulness as a meditative practice, with all that implies, so that mindfulness is not simply seized upon as the next promising cognitive behavioral technique or exercise decontextualized, and plugged into a behaviorist paradigm with the aim of driving desirable change, or of fixing what is broken. (Kabat-Zinn, 2003, p. 145)

The principles of mindfulness used in this study adhered to the definition outlined in Chapter II of this dissertation:

...the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment. (Kabat-Zinn, 2003, p. 145)

It is also respected that the understanding of this concept by participants is predicated on the facility of the person teaching, as well as the epistemological framework through which an individual might best learn.

Infertility is classically referred to as a medical condition and consequently crosses from the domain of counseling into the field of physical health. This research did not reach the scope of a mind-body study that can examine the internal physical structures and physiology influencing reproduction, the brain, or indeed the mind. For the purpose of this research mind-body referred to the subjective experience of thinking and feeling, speaking and doing. It is well recognized by the researcher that the notion of empiricism in the positivist tradition questions the authenticity of narratives of being. It is this conflict that sits at the center of involuntary childless; a crisis of *self* mediated through the prism of physical pathology (infertile), as reflected by a medical model. The non-traditional approach employed in this study is used as metaphor and represents the belief this researcher holds: that a strict adherence to tradition does not allow room for the continuities and discontinuities that smudge the linear relationship between cause and effect. Despite the prolific amount of literature produced on the topic of infertility the familiar questions persist and while some things change others remain the same. This

dissertation has its own continuity and discontinuity, abstraction and actuality, visibility and invisibility, despair and possibility. It is its own attempt to make one small change to the order of things.

...the empirical domains become linked with reflections on subjectivity, the human being, and finitude, assuming the value and function of philosophy, as well as of the reduction of philosophy or counter philosophy. (Foucault, 1970)

The quantitative instruments selected for use were designed to provide baseline data and serve as a reference point against which to explore the relevant use of these particular questionnaires and summaries in the experience of infertility. The information gleaned is intended to inform clinical practice and makes no generalizations about infertility and its influence on individuals beyond those who have participated in this study. Participants self-selected for this research and as a result might suggest a somewhat biased group with respect to the degree of difficulty they report experiencing, the extent to which they represent people who suffer with infertility across race, gender, class, and culture lines, and the type and duration of their self-disclosed medical diagnosis. It is well documented and noted in the literature review that individuals presenting for infertility treatment reflect only a small proportion of those actually suffering with infertility (Greil, 1997; King, 2003; White et al., 2006). This study's participants' have a demographic profile common to other types of infertility-related research; Caucasian, moderately well educated, and predominantly upper middle class (Greil, 1997). Although all of the participants in this study were White, there was some variability in socioeconomic status as reflected by combined household income and level of education. Infertility treatment is costly and cost prohibitive and it had been this researcher's hope that recruitment for the study would attract a more diverse group of

participants who need not be limited by finances. However, specialized community education and awareness of infertility's causes and treatment is not well established across different ethnic populations and this study demonstrated that. Despite the low cost of the Resolve Infertility Conference where participants initially signed up to attend the *Minding Matters* workshop, (\$20 including lunch and valet parking as well as the availability of scholarships), this event had an under-representation of minority groups hence the relative homogeneity of the study participants'.

Finally, research informs us that individuals on a quest to make a baby will go to remarkable lengths to meet this desire and are far more likely to want to participate in research of this kind if it is their perception it might help them to achieve a pregnancy (Domar et al., 2000; White et al., 2006). Although the *Minding Matters* program made no such claims, several participants, albeit couched in humor, indicated that this was one of their reasons for participating. This elevation in motivation to do anything to get pregnant might also cloud the factors that contribute to an individual's infertility and experience of stress and make it difficult for the researcher to make assertions about how future workshop participants are likely to be impacted when cost is a consideration. It is also impossible to tease out the principles taught in this study from the multiple sources of information currently available to people experiencing infertility. Several participants also disclosed that they were receiving complementary care in the form of acupuncture and herbs, yoga or Qigong as well as their traditional medical treatment. To what degree this study added new information was an important research aim, however no claim is made that participation in this research had a direct influence on the participants' pregnancy outcome. This study served to inform rather than predict.

It was known to participants that the researcher had also experienced infertility that was resolved through the use of assisted reproductive technology (ART). The story of this research therefore is a collaborative epic located within the multiple realities and hyper realities of twenty-eight (including the researcher) examples of the lived experience. I am not separate from, or incidental to, the intimacy of the subject or the influence of subjectivity. I have come to this research from my own point in history and proceed under the caveat: bias beware.

Study Findings

The extensive literature review in this dissertation was performed in an effort to understand the historical, social, cultural, medical, and psychological factors that impact an individual's contextualized experience of infertility. The desire to have and birth children was noted in Chapter 2 as a universal phenomenon, a norm reference point against which childlessness has often been viewed as deviance (Letherby, 1999; Remennick, 2000; Whiteford & Gonzalez, 1995). It is this loss of inclusion that contributes to the distorted image that may then become an individual's new representation of self as expressed by many of this study's participants (Joachim & Acorn, 2000).

Exclusion and isolation is the character of stigma and as previously documented, stigma characterizes infertility (Letherby, 1999). Overcoming stigma required a change in the internal beliefs as well as a discounting of the external labels imposed on the individuals in this study by society. The multiple sources of stress associated with infertility and the development of stigma were explored. Stress is both a physiological and psychological event; an experience of the body mediated by the interpretation of the

mind; no exclusive cell's function no singular thought rather, a cacophony of human history and incidents. Stress and coping were examined according to the definition provided in Chapter I: "...as part of a complex, organized biosocialpsychological entity or whole which psychologists refer to as an emotion, such as anger, fear, shame, joy, or love...and coping is an integral part of emotion but not the whole"(Lazarus, 2000, p. 668). The process of coping, like stress, was influenced by an individual's perception of their difficulty and was time sensitive and context specific. It was important for this researcher to place the problem of infertility outside of the individual with infertility in order to understand how they coalesce and often present themselves in the 'infertile person' as in "I am infertile" rather than I am Susan or I am Steve. This was in part accomplished by juxtaposing positivist measures of construction within a postmodern dialectic.

In the twenty first century Cartesian Dualism's tension is in conflict with itself. Mechanisms of inquiry continue to lean toward the seen and the tested with the use of functional magnetic resonance imaging (fMRI) and positive emission tomography (PET). However, infertility is also experienced as a rupture of the spirit and a hemorrhage of the heart, the break between the mind and body that leads many into despair. Knowing what we do not know is the double entendre of science and medicine. If we didn't see it then it didn't happen. Does that tree in the forest ever truly make an unheard sound? Philosophy it appears exists because we exist and serves to fill the dark space between guarantee and doubt. Infertility asks those who suffer at its hand to live in that dark space and this study's participants' were looking for a way to turn on the light.

Qualifying the quantitative.

From a descriptive perspective the following observations can be made about participant responses on the survey instruments. They are included as important findings with the caveat that they inform rather than explain; enlighten Enlightenment rather than clarify cause. Self-administered surveys are often portrayed as client-driven and less directive than other methods of quantitative evaluation. However, self-report measures are context specific, depend upon the elegance of their construction to capture the individual rather than the generic, and are subject to a broad range of interpretations.

...both qualitative and quantitative data can be very useful. While each can stand on its own it is possible to show that the two types of data can be bridged. (O'Rourke & O'Rourke, 2000)

The couples who elected to attend the workshop together reported experiencing more interpersonal sensitivity, feelings of anger, and disconnection from *self* than women who attended the workshop alone. This was an important finding. The Chapter 2 literature review reported that a 2005 study conducted in Denmark shows a demonstrable benefit to couple communication after participation in a stress management program for infertility (Schmidt et al., 2005b). Yet although researchers have documented an increase in relationship stress during infertility few if any (as far as this researcher has discovered), compare findings between women who participated in an intervention alone, and couples (Boivin et al., 1998; Fassino et al., 2002a; Peterson et al., 2006; Schmidt et al., 2005b). More importantly, because infertility treatment is also predominantly performed upon women's bodies, they are more likely to be identified as the person needing psychosocial support.

However this study demonstrated that both men and women are experiencing relationship difficulty to the same degree although not always over the same things. Men tended to report greater distress over not being able to support their partner rather than only the inability to have a biological child. Women had far more sorrow over being unable to become pregnant and did not express as much confusion over how to mitigate their partner's perceived despair. For some women the level of their partner's despair only became apparent as a result of the workshop and in some cases not until the study's interviews. Although both men and women indicated that they struggled with feelings of hopelessness men struggled to find a way to be useful utilizing their typical problem solving and coping strategies. This usefulness seemed to be focused on making their partner feel better and because feeling better was tied into having a child, which in the experience of infertility is an uncertain goal, men reported high levels of intrapersonal difficulty. Women on the other hand were far less aware of how their partner was struggling and were absorbed by their condition of non-pregnancy and the interventions that their body had to be subjected to in order to have a child. This disparity in perception within and between partners in their relationship was the most important difference that emerged between the women-only and couple group. It is possible that the ongoing conflict that develops as a result of not addressing these differences in perception contributes to the experience of increased psychological distress which has a possible secondary effect on physiological stress. In addition, the distance that develops between partners as a result of this conflict likely influences how many other decisions are made in the relationship unrelated to infertility and underscores the importance for couples to participate in emotionally supportive care together.

Overall, women from both groups reported much higher levels of social stress related to the experience of infertility than men and were more likely to seek social support to mitigate that stress. Women reported higher levels of infertility related stress generally when compared to men, a finding that is also confirmed by many other researchers (Anderson et al., 2003; Jordan & Revenson, 1999; Newton et al., 1999; Zinn, Hondagneu-Sotelo, & Messner, 2005).

Approximately 6-10 weeks after completion of the first surveys, responses from the second questionnaire revealed a decrease in couple reports of interpersonal sensitivity. No observed changes were documented by women who attended the workshop alone. Lest the researcher fall prey to the temptation to take credit for an essentially positivist structure of cause and effect: i.e. that attending the workshop was the cause in stress reduction, it is suggested that couples who came together are also possibly more connected to each other in other life areas, or alternatively less disconnected from their partners than women who attended alone (this was disclosed as part of the subjective experience of many of the participants who attended the women-only workshop). There is ample evidence to support the theory that discussing conflict rather than avoiding conflict is more likely to have a beneficial effect (Akgun, 2004; Mindes et al., 2003). In addition, the mean length of time that the women-only group had been experiencing infertility was 3.85 years (range 2 to 8 years) compared to 2.35 (range 2 to 4 years) years for couples. Several studies have documented that the third year of infertility appears to be critical to the level of stress experienced and on the decision to discontinue treatment (Domar et al., 1992a; Olivius et al., 2004; Rajkhowa, McConnell, & Thomas, 2006). It has also been documented that the timing of when emotional support is

offered is also a critical feature of its effectiveness (Boivin, 2003) This difference in the experience of interpersonal sensitivity as well as isolation between the women-only and couple group seemed to bear itself out in the in-depth dialogues and was expressed by Hillary with particular poignancy:

I feel like work is tainted beyond belief because I have had to tell people. I guess I could have lied and made up some other health problem but people know about my infertility, people I never wanted to know. By law they don't have a right to know but infertility doesn't work like that. I feel so violated that I despise them. It's embarrassing. I feel embarrassed to go to work. (Hillary, April 29, 2006)

Hillary's expression of violation was neither unique to women nor resolved between the couples who reported less distress. What made Hillary's disclosure so powerful was the story of loneliness and isolation that fell from her words. To give better perspective to Hillary's dialogue consider *our* exchange through the following angle of refraction.

It is 9:00 PM on Saturday April 29th 2006 and I pick up the phone to dial Hillary's number and she is not in. Minutes later she calls me back and we begin our interview, neither able to see the other, hearing our breathing between bouts of conversation. Hillary sounds tired, is she tired or am I too tired to listen? Never mind, we go on. Hillary like Laura (couple # 8) is a "good girl," she responds to my questions and they lumber along. About 10 minutes into the interview, (page 9 in fact), something begins to happen and it coincides with Hillary's reading of her narrative summary and her observation "was this really me?" Surely that was a rhetorical question?

Hillary and I were now connected beyond our telephonic transmission. Was there a precise moment when it happened, maybe, but it hardly mattered because inside my own heart was a core rumble that is resurrected as I sit here to type my feelings on the

page. I heard her strip herself before me and in her vulnerability I became vulnerable. Is that I wondered, good research?

Me: You know, you said that you struggle with your words, but your words have been so powerful this evening. I don't know whether you hear that when you say them but *I* hear it when I hear them.

Hillary: I've been told that before, but mostly through writing, that my words are powerful, but it seems rare that I hear them for myself. I don't have many people to talk to and this is so life altering, absolutely the most and it changes you forever.

It seemed unfair that I was also in the process of being changed forever by the impact of Hillary's words, sounds that without her grief I would not otherwise be privileged to hear, Hillary wasn't suffering from interpersonal sensitivity, Hillary was suffering.

Perhaps it is the ease of this suffering that couple's experience when they begin to listen to the sound of each other's hearts. This is a large leap to make because it is a large thing to do. Human beings don't hit infertility on their way to somewhere else, infertility hits them while they are reaching for something else. The stigma associated with infertility affects prior identity and challenges role formation, often confounding the loss of a child with the loss of one's previous self (Haslam, Jetten, O'Brien, & Jacobs, 2004; McQuillan et al., 2003; O'Donnell, 2005). Women and men are frequently left asking "who will I be if I can't be that" or "who will still want me if I can't do that" (O'Donnell, 2005). Without an answer to this question individuals frequently find themselves living in a reproductive limbo land; a procreative purgatory where barren souls and bodies are sent to lament. Whether purgatory exists is determined by subjective experience and maybe participating in the workshop with a partner helped couples to see something other than a sure path to Hell? The level of anger that couples reported on the survey instruments was explained by them in the interviews as a function of feeling misunderstood, helpless, and

often criticized. This is in part the product of two individually constructed realities that remain unlinked when couples become distant and withdrawn from each other, further disrupting the potential for meaningful conversation. (This is an ironic development of separateness given the ultimate goal of procreation). It is possible that the opportunity to listen and be heard, observe others and also observe themselves, and discover new ways of interacting helped to reduce the areas of conflict that had been contributing to couples relationship stress (Schmidt et al., 2005a; Schmidt et al., 2005b).

The Symptom Checklist, Fertility Problem Inventory, and Ways of Coping Questionnaire might well have their place because as Foucault reminds us, they are also products of a constructed reality (Foucault, 1972). Our responsibility as researchers is to seek out the truths not necessarily to define them. The larger question of whether these tools should be used or can be used *usefully* is situated within the context in which they are applied. As structures against which the density of an individual's circumstances can be explored or understood they become a device of relativity. If employed as a way to label or define, questionnaires run the risk of being unilateral methods within an existing medical model where:

....we have been and are asked to think of the discontinuities of life as symptoms, to think of the psychodynamic processes of which discontinuities are a product as pathology, and to search for some traumatic event in the person's life as the etiological cause of the pathology. (Hyman, 2004)

To rule surveys out as contributing anything of value would be to refute Foucault's advice to consider ourselves within the history of our Enlightenment traditions. However, to award surveys and measures the dominant voice undermines an equal imperative to engage the subject in the understanding of their own experience.

What is effective?

Effectiveness research according to Borkovec and Castonguay (2006) “...attempts to obtain knowledge about psychotherapy outcomes in real-world clinical situations” (Norcross et al., 2006, p. 89). To some extent I would challenge the oxymoronic position that research can reflect the real world for it is organized, premeditated, and although unfolding, bounded by the constraints of investigative hegemony. The researcher cannot simply say and do as they want. They must define purpose, satisfy aims, delineate methods, record a course, and interpret and construct meaning. However, this research was an attempt to evaluate the use of a one-day mind-body program for providing individuals and couples experiencing infertility with effective emotional support. The participants as collaborators have aided in determining what can ultimately be considered effective.

The camaraderie and belonging that was reportedly shared by group members during the workshop was considered by them to be the most important aspect of their participation; an experience of inclusion that reformed isolation. There is considerable research on the psychotherapeutic benefits of various kinds of group support to reduce the feelings of stigma and loneliness that are associated with difficulty or difference, and this study confirms those findings (Boivin, 2003; Domar et al., 2000; Tarabusi, Volpe, & Facchinetti, 2004; Yalom & Leszcz, 2005). Infertility as illness is a difficult zone to straddle because it is both visible and invisible. The absence of family is comparable to the mark of stigma and reflects the physical manifestation of an internal shame. Being in an environment that was free from judgment represented a mental and emotional free zone.

That's what helped me to relax...Seeing that I am not the only one with this problem. Knowing that other people are going through the same thing and that we can still have a good marriage even though we couldn't have kids. (Howard, couple # 1, April 25, 2006)

The most significant distinction between groups was the opportunity for couples to unify around a shared difficulty and to observe each other and their relationship from a different perspective. For men this translated into much more emotional sharing and for women the opportunity to be listened to *and* listen. Although participants in the women-only group had a forum in which they acknowledged feeling heard, they also reported much less carry over to their real world.

I definitely felt like I clicked in the group. I felt like I participated and belonged in the group per se, not just because of our joint reason for being there. There were other things that kind of had me click; at the same time I was kind of pulling back from that I am like "okay, need to go back out in the real world tomorrow get up and go to work." (Sarah, April 8, 2006)

Women who participated in the workshop without their partner often used the argument, "well it's my body having treatment" or "he doesn't get it," to rationalize their reason for living so much of their infertility experience alone. It was also important for these reasons to be validated because this is the context in which infertility has been researched, recorded, and interpreted for centuries: as a problem that is resolved primarily within the woman. Attending as a couple helped to alleviate the emotional stress and stigma experienced by both partners, although not necessarily for all couples. It also encouraged participants to claim ownership of what happened in the workshop and it was ownership that appeared to be instrumental in the mitigation of some couples relationship stress.

Although participants in the women-only workshop reported benefit from attending there was less impact on their overall experience of intra and interpersonal

stress that might have been related to the ongoing unilateral nature of their experience with infertility. A particular exception to this finding was Kit who chose not to pursue medical treatment for her infertility and by the follow-up had a four-month-old son through adoption and perceived her struggle to conceive a biological child as “over.” Perhaps it is the reclaiming of choice; deciding when to stop treatment or to not initiate treatment that is an example of what Foucault described as: “...no longer indispensable for the constitution of ourselves as autonomous subjects” (Foucault, 1994b, p. 52)

Understanding the mind-body paradigm.

Participants came to this research project with multiple levels of understanding of, and facility in, mind-body practices. Several women were still using complementary and alternative methods as adjuncts to their medical treatment including: acupuncture, energy healing, dietary restriction, and herbs (50% in the women-only group and 40% in the couple). The only alternative treatment men reported using was vitamins and herbal supplements (20%). Although nutrition was beyond the scope of this workshop a majority of participants reported a body mass index in the overweight or obese range, although Wendy was the only participant who indicated that this had been given as a contributing reason for her hormonal dysfunction. (Wendy was also the oldest female participant at age 42 and disclosed that she had gained weight in the past 12 months as a direct function of work and fertility related stress and recorded a BMI of 36). Although research has demonstrated that BMI is increasingly considered an unreliable indicator of true body fat to lean tissue ratios, women in the extreme weight ranges (very thin or very overweight) and men who are extremely overweight, have been shown to have slightly

reduced fertility rates (Fratarelli & Lee Kadama, 2004; Koloszar et al., 2005; Tahmasbi Rad, 2004).

One of the main objectives of the workshops was to provide participants with the information to apply the circumstances of their own life into a mind-body template. This included modest education on diet and exercise, as well as discussion of the main principles of mindfulness, yoga, meditation, narratives, breathing exercises and deconstructing experience. Although it was reinforced that participation in the workshop was neither an indictment of traditional methods for providing emotional support or confirmation of a mind-body approach, respect for infertility as a condition of the body experienced through the mental and emotional, i.e. the field of the mind, was highlighted. The interactive construction of one upon the other, although not measurable in the objective, was respected throughout the presentation of the workshop material.

Participants overwhelmingly indicated that mindfulness and breathing exercises had been the most beneficial mind-body principles reviewed in the workshop. These concepts were more consistently applied by participants to reduce infertility stress, as well as across other life domains. Mindfulness was also linked to changing beliefs or more accurately changing perspective. Mindfulness required attention and attention helped participants to reduce reactivity and explore without judgment the mental and emotional legacy that contributed to their current conviction. Mindfulness and deep breathing were also constructs that could be experienced and evaluated in real time and were viewed as readily transportable and applicable skills.

I made a connection that when one is racing it does affect how you feel, how you function, and everything else...so just taking deep, calming breath makes a big difference (Peter, couple # 2, April 8, 2006)

In the “unfolding of experience” mindfulness also begs consideration of the unspoken historical, social, and political influences that color people’s encounters with the world and themselves. How do we get to this day, this moment, this belief this attitude? How does seeing something differently change feeling, and how does feeling something differently change performance?

Mindfulness is not simply a thought stopping strategy or deep breathing a stop - gap to reduce anxiety. Mindfulness is observation; an examination of the present that helps to elucidate and unbridle the past. Infertility is not simply a void to be filled by a child. Infertility is a history of *being* punctuated by the crisis of life interrupted. Mindfulness is a method for negotiating the emotional turmoil that develops when individuals find themselves wishing they were anywhere but where *here*. This is reflected cognitively by the term rumination, experientially by the condition of anxiety and despair, and physically by a state of a symbolic creative paralysis where the body is encountered as frozen. Infertility has been described by many as “...the loss of human potential, the unrealized self submerged in the medical quest for reproduction” (Whiteford & Gonzalez, 1995, p. 35). Mindfulness brings the individual’s attention back to the power of their own potential; there is no more power than awareness of the moment one is in.

According to the latest evidence from functional magnetic resonance imaging and as discussed in the literature review, practicing mindfulness and deep-breathing over the long term can have an effect on brain and immune function although their impact on reproductive physiology remains unknown (Aftanas & Golosheykin, 2005; Davidson et al., 2003; van Gelder, 2005).

These neuroimaging studies suggested that the ruminative thinking often found in depression and anxiety may result from the failure of the frontal lobe to inhibit regions of the limbic system such as the amygdala. (Hamilton, Kitzman, & Guyotte, 2006, p. 126)

Mindful performance also requires a marriage between thought and action: what am I doing and what am I saying about what I am doing? The distinction between cognitive reframing and mindfulness is that cognitive reframing is based on Beck's "...view of psychopathology that stipulates that people's excessive affect and dysfunctional behavior is due to excessive or inappropriate ways of interpreting their experience" (Weinrach, 1988, p. 68). Thought becomes the antecedent of stress, and changing thought its successor. Mindfulness does not emphasize the changing of thought but rather "...*not* to judge or evaluate the veracity of a thought, but merely observe it and thereafter set it aside" (Hamilton et al., 2006, p. 128). Thinking differently about a circumstance that *is* doesn't necessarily help individuals feel differently about it. However observing and accepting the difficulty of life, developing an appreciation for its importance in the relative scheme of things, and finding a way to be engaged at the level of immediate pain does help to mitigate the pointless drive to "wish that everything would simply go away." Wishing in this circumstance is a hopeless endeavor like holding one's breath in the moment of crash; the difference between being afraid to die and not dying afraid. This is perhaps one of the most powerful of human dilemmas. One of the main purposes of the workshop was to help participants distinguish between letting go and giving up and separating acceptance from resignation.

I mean it was just so simple. I just never thought about it. I just never thought about it that way. It was at that moment I thought "now there are all these other possibilities" (Deborah, April 4, 2006)

Deep-breathing, as described in Chapter V, was employed as a physical exercise for demonstrating the propinquity of mind to body. Thinking about breath, becoming aware of breath, and deepening breath changes the way the muscles contract, the rib cage expands, the lungs inflate, and the body begins to relax. In order to accomplish one there has to be an attendance to the other. This research does not utilize or examine specific types of breathing techniques or their physiological correlates and outcomes. However, it operates on the assumption that the subjective experience of feeling relaxed is in large part a function of being relaxed and that this promotes more reflective personal analysis and a calmer state of being (R. P. Brown & Gerbarg, 2005). The majority of participants overall found this to be a useful technique.

Room for improvement.

There is an overwhelming abundance of evidence that demonstrates the effectiveness of support groups for people experiencing infertility (Boivin, 2003; Dayus et al., 2001; Domar et al., 2000; Domar et al., 1990; Greil, 1997; McNaughton-Cassill et al., 2000). This research is an attempt to build upon prior knowledge and to inform clinical practice at the micro level. It was discovered that one day was not enough to generate and maintain the type of group cohesion most participants reported that they wanted or needed. A two-day or two-and-a-half day workshop, or overnight retreat, was recommended instead. In addition to the longer duration, participants felt that shorter sessions with larger breaks between sessions and alternate speakers would help to shift and maintain group energy. Women participants in particular perceived a lack of privacy from their workshop setting, a lack of privacy that for Hillary and Kit translated into reduced physical and emotional comfort. The need for a more private space is voiced

frequently by men and women attending an infertility specialist's office situated within a general obstetrical practice. In this setting the experience of being 'other than' is magnified through the spectrum of bodies that are presenting as fertile and already pregnant. The presence of the baby shower in the adjoining room at the women's workshop was a reminder of *other* rather than the reprieve from *other* that women had anticipated the day would be. It is therefore incumbent upon the researcher, therapist, or clinician to place themselves in the frame of experience of those struggling with infertility lest they become yet an additional source of pain or stress.

Twenty percent of participants felt greater consideration needed to be given to the duration of infertility and type of diagnosis, to create more homogeneity amongst group members. However, from the social demographics perspective this *was* a homogeneous group; Caucasian, well educated, and middle class, a familiar representation of the kind of participants typically involved in infertility studies. This request perhaps emphasized the degree of sensitivity associated with people early on in the experience of infertility and a need to protect those individuals from over exposure to the myriad of treatment options and outcomes until they are better prepared.

A manual was provided to all participants and specifically referred to intermittently during each workshop. It was used more often in the women-only workshop due to the number of participants and fewer time constraints, and picked up more often by women than men in general after the workshop. Although the majority of men and women still wanted to have a physical text they also requested a CD-ROM component which would allow them to continue to revisit the concepts from the workshop as an interactive participant. Women also requested the inclusion of personal

audio narratives to re-create the sense of camaraderie and belonging that was experienced in the group format; an extension of the in vivo experience of group participation and shared stories.

A year later.

The purpose of this study was to determine the effectiveness of a mind-body program for providing emotional support for individuals and couples experiencing infertility. Evaluation of the program content and the application of learned skills during the time of active treatment and beyond have been reviewed throughout the discussion of the study's findings. This Chapter explored both the limitations and benefits of the Minding Matters Workshop. There was no expectation that involvement in the research could or did influence pregnancy outcome for these participants. The finding that seven of the participants from the couple group conceived and had children, and none from the women-only group, (apart from the two women who attended both workshops) is documented as an important observation from the perspective of what this could mean for future research. An interesting discovery at the one-year follow-up for couples who had children was that men in these partnerships reported experiencing as much, if not more stress in their lives, as they had during the period of active infertility. Fertility-specific stress for women was compounded by a 24-hour need to live in the disappointment of their body, and men by virtue of their biology did not share this experience. Often the conflict that erupted between couples was associated with this lack of understanding. Having a child was healing for most women and dissipated the grief of mother loss. However having children represented a financial and parental burden that men often found overwhelming.

What also became clear from the discussions with men was the shift in responsibility and ownership that occurred once their child had been born. For many men delivery of their son or daughter was a tangible reality and replaced the nebulous mystery of menstruation, infertility, pregnancy, and birth that had surrounded their experience of trying to conceive. Being able to see, touch, and know their child was often the missing link that solidified their engagement in the building of their family, here was something they were finally, once again, able to fully do together. In the case of Graham and Bethany, whose daughter Charlotte was born with a cardiac condition, Graham took over the role of fact finder, fact checker and treatment seeker, a role that Bethany had primarily assumed during their struggle with infertility.

For women who attended alone and had not conceived or had children there was not a similar opportunity to move together as a couple; to transition to the stage in their relationship that made room for getting to know each other as parents. This did not mean that growth and development had not occurred, for Katherine, Sarah, Deborah, and Alice, personal growth had been significant, although its influence on their relationships was far less dramatic than for couples. Hillary and Ruth described their relationships at a status quo, and reported much greater personal stress than they had a year ago. This stress was not only a function of their persistent experience with infertility but was compounded by work and/or extended family struggles. Similarly, Wendy and Victor, who disclosed personal and relationship difficulties independent of their fertility concerns continued to describe a complex arrangement of life circumstances while Brian and Caroline were gradually moving toward the possibility of adoption and making continued meaning out of their grief that they might not have a biological child of their own

Emergent Theories and Themes

Multiple theories have driven the direction of this research. However, new theory has also emerged as a result of the new information learned and is integrated in this Chapter beyond the methodological approaches outlined in Chapter 3. Manias and Street (2000) describe this approach to methodology as the ‘toolbox’ approach; a term they borrowed from Foucault who encouraged that his work be used as an instrument to fine tune, challenge, and validate dominant social discourses (Manias & Street, 2000). In this study Critical Theory was the bridge between the social, political, and cultural constructs of infertility and the practical art of healing the ache of involuntary childlessness. Critical Theory also demands that the researcher respect the dominant role they play in the development of constructed meaning and its implication to a study’s findings. What the researcher sees and experiences becomes as much a part of the outcome as what the participants report themselves. The degree to which this occurs is not known until the study is in process and it is in this process of change that the potential of a new direction can surface. Critical Theory and the work of Foucault has held its place through the course of this study because it provides a framework that includes the participatory and dynamic voice and this has important practice implications. Foucault’s examination of the constructions of power has also earned the embrace of the feminist epistemologies which also seek to understand hegemony and the acquisition of knowledge as an exercise in power (Merriam, 2002). Feminist Theory informs Critical Theory and both hold an important place in this study’s growth and development. The mind-body model utilized in this study emerged from the shadow of science and medicine’s Cartesian legacy. Infertility is not a wound that bypasses the head or the heart. The ache for children must

be held with the same care and deference as sperm and egg in a fragile dish. When the heart speaks the body listens (Wittstein et al., 2005). The scope of this research did not include ‘evaluation of the body’ within a positivist schema of evaluation: no blood was drawn, ovaries examined, or uteri scanned. In this study the body or person is the subject i.e. “this is my body and this is how it feels to me to be struggling to have a child, this is my experience”. The individual is neither objectified as the patient nor interpreted as the analysand; the individual is listened to and is heard in an effort to better understand.

Qualitative research is fundamentally descriptive, rich in content, deeply contextual and demands respect for narratives of pain. The participants’ stories wound their way into every electronic message, phone call, and note in the mail, workshop day, and poignant interview. It was important that the life being created in the form of this dissertation also take full account of the lives being shared by giving due diligence to the participants’ constructions of meaning. To that extent this dissertation has been their phenomenological journey.

Participant dialogues produced several overlapping themes. Many of those themes are specifically related to development of the *Minding Matters* workshop, they outline its strengths and flaws, program content, and direction for growth. Others emerged through the fractures in the research literature. This research was undertaken in part to address those fractures at a praxis level. What is the relationship between stress and infertility? How do we as providers of care to people experiencing infertility respect the multiple sources of such stress? Who decides what defines effective care? How can that care best be provided? Participants deemed the following components important to their understanding of mind-body principles and their ability to impact the experience of

infertility related stress: i) identification and belonging ii) mastery of mindfulness iii) deep breathing and relaxation iv) maintenance of hope v) sharing of narratives vi) partner support. However, expanding across categories and within the fabric of people's lives was a broader theme that I have called refractive reframing. Visual metaphor is present throughout this research in the constant challenge between what is seen and unseen, there but not there; a way of looking altered by perspective, focus, nightmare, dream, image, darkness, and light.

Deconstructing visibilities and invisibilities

This dissertation began with a discussion of the visible and invisible shame associated with infertility (Daar & Merali, 2001). The act of making visible that which is invisible has been placed in the center of multiple academic discourses (McDonald, 2004; Oksala, 1998; Zitzelsberger, 2005). Invisibility refers to the marginalization inherent to circumstances of difference and extends far beyond the physical body. It is the juxtaposition in the relationship between people, places, and things that configure to form the essential nature of lived experience. The lived experience is seen as outcast within the structure of post Enlightenment positivism because it cannot be observed according to the standards of objective measurement. According to Foucauldian thought it is this lack of recognition that also submerges the development of personal identity and relegates it to a back corner resulting in a legacy of shame and stigma (Oksala, 1998). Infertility is both visible and invisible and affords those who suffer little compassion from a world over populated, under nourished, and ultimately judgmental. Infertility and infertility treatment has also shed new light on the social constructions of gender and family and the ongoing discourses of the body politic as they relate to sexuality, reproductive rights, and the

biomedical technologies (Birenbaum-Carmeli, 2003). However, being seen as infertile is not the aim of people who suffer its wrath, being seen as suffering, this is the ideal. This does not translate into pity, sympathy, or even necessarily empathy, but the recognition that each human being has an accordant right to manifest their own destiny; gay lesbian, transgendered, heterosexual, single, married, rich, poor, of color or white. Utopia revisited.

In Foucault's discussion of heterotopias he introduces us to the idea that in the reflected image of our real life i.e. the subject or setting that we see in the mirror, we also experience our own utopia; the presence of something seen but that in reality does not truly exist (Foucault, 1967). We all understand shadow and light, likeness and representation. They imitate the parallel universes in which we all sometimes live. It is the experience of a parallel universe I propose that exemplifies the struggle of infertility and perhaps many other distressful life conditions. In the following section I present a format for explaining and applying this concept to the process of finding effective emotional support for individuals facing infertility.

Defining refractive reframing.

Where is the cognitive? Where is the behavioral, I asked myself throughout this research? I began with a mind-body premise that was informed by the work of Alice Domar who is credited with pioneering complementary approaches in the psychological support of infertility (Domar et al., 2000). I was also guided by the wider psychological literature and my own clinical practice which convinced me that at the base of people's despair when infertility strikes is the struggle to make sense of the perception of self that shifts from view (Baer, 2003; Benson & Klipper, 1975; O. van den Akker, 2001a).

Higgins Self Discrepancy Theory, which had been applied previously to the study of infertility, presented a comprehensive model for examining the multiple sources of stress that have influence upon the internal constructions of self during the experience of infertility (Higgins, 1987; Kikendall, 1994). Self discrepancy manifests as a function of conflict between the actual, ideal, and ought self. According to Higgins, the domain identified to be in conflict is predictive of a specific type of emotional distress (Higgins, 1987; Kikendall, 1994).

However, Self Discrepancy Theory is both complex and imposed and the experience of infertility is already an imposition. As my contact with participants developed and our dialogues progressed I observed them doing their own work to reduce the distance between what they wanted and what they had and it was this negotiation that produced their new construction of self which I am calling *Refractive Reframing*. Reframing requires the identification, deconstruction, and re-establishment of beliefs. It is essentially cognitive, driven by thoughts and perceptions. Refractive reframing includes thought, feeling, performance and language and the social constructs of culture, politics, race, and class; circumstances that combine to form the medium through which the self can be seen. Infertility viewed from this perspective becomes another condition of circumstance, external from the self but recognized for its powerful influence.

Vygotsky's discussion of the reflection/refraction metaphor as an application to psychology is introduced in an article by Robbins (2003). Although my discussion of refraction emerged from the work of this dissertation, a literature search found the term used in reference to culture and social relations and in Robbins paper (Alexander, 1984; D. Robbins, 2003). However *refractive reframing* is an original term that describes the

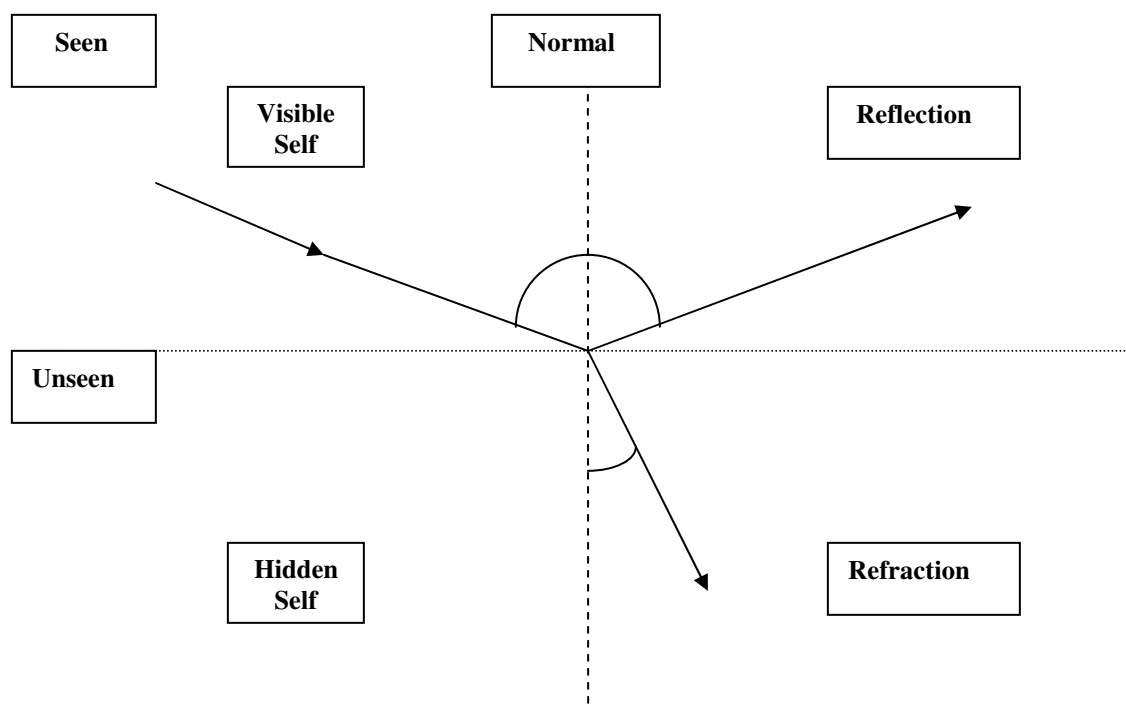
deconstruction and reconstruction of self an individual performs to achieve understanding of their experience of infertility, as expressed by the participants in this study. External and internal sources of stress, defined as circumstances, determine the density of the media through which light must travel in order for the image of self to be seen. The more complex the circumstances and the more stigmatizing the condition, the further away from the 'normal self' an individual sees themselves to be. The individual must first identify what they see of the world which in turn gives rise to their perception of how the world sees them; image and reflection. It is in the negotiation between these constructions of reality and virtual-reality that a sense of Self begins to come into view.

Using Snell's law of refraction diagram I have constructed a model of how visual constructions of reality and virtual reality, juxtaposed against the internal medium of person and circumstance, organize to become the experience of Self. I propose that it is in the deconstruction of these representations and images that we can best facilitate clients' in achieving a greater understanding of themselves. Deconstruction does not imply removal of conditions. Deconstruction is about education, recognition, acceptance, and reclaiming personal agency.

The refractive model is useful because it places the certainty of light and light travel against the perceived realities of human experience. According to Snell's law of refraction: "...when light passes from one transparent medium to another it bends" away from the normal (Reed, 1998). The normal is an imaginary perpendicular line that intersects the surface of both mediums and serves as the reference point against which the speed of light hitting changing densities is measured. It is at the boundary of these two mediums, existing in differing densities, that the angle of refraction is determined (Reed,

1998, p. 1). It is also the density of the mediums that determines both the angle of reflection and the critical point at which neither light nor images continue to be seen (for a more detailed explanation of refraction please refer to the previous reference).

In the following model, depictions above the horizontal represent the visible i.e. how the individual sees themselves according to a normative world view and how this normative world view is reflected back in the way the world sees them; a system of optical illusions. Depictions below the horizontal represent the invisible i.e. the particular circumstances and conditions, social, cultural, political, relational that contribute to how an individual begins to build their view of Self. I am suggesting that this is the phenomenological experience shared with me by the participants in this study; infertility weighted against the normative view of fertility and reflected back as an image that is subsequently defined as 'less than.' In addition, how individuals are oppressed or controlled by their internalizations held from view i.e. below the surface might, well be the 'measure' that decides who they are and who they can become.

**Seen:**

Visible Self: represents how the individual sees the world

Normal: point of intersect between the outside and inside self

Reflection: represents how the world sees the individual

Unseen:

Invisible Self: represents what the individual knows about self which is unseen by the world

Refraction: represents the change in view of Self that occurs as a function of particular circumstances and conditions

Figure 3. Refractive model of visibilities and invisibilities

This model could potentially be used as a framework for identifying and organizing the internal and external structures and stressors that contribute to an individual's experience of infertility.

Practice Implications

This dissertation set out to examine the emotional and psychological stress effects on individuals and couples facing infertility. The purpose of the study was evaluation of the effectiveness of teaching a one-day mind-body workshop as a method for providing

effective emotional support. This research has essentially been an exploration into the ‘art’ of praxis and an attempt to answer the questions: i) Who determines what constitutes effective support? ii) What labels do we use to define the boundaries of psychological and emotional distress? iii) Do problems or people determine the strategies or theories chosen? iv) How do we evaluate the process of counseling whether in a one-on-one or group setting? Given that several researchers have demonstrated both a need for counseling by people facing infertility as well as an underutilization of counseling services when offered, discovery of a valuable and utilized method for providing support is necessary (Boivin et al., 1999; Rajkhowa et al., 2006). Designing any intervention for use with clients requires a commitment to a philosophy of practice. Such commitment can help clinicians to establish professional accountability, bridge the distance between theory and application, and lead to the development of a specialization identity.

An important finding in this study was that both women and men are looking for a sense of belonging and a reduction in the isolation and exclusion that is part of the experience of infertility. However more importantly it was discovered that participants who attended in partnered relationships (for the purpose of this study heterosexual partnerships) reported higher levels of perceived relationship-based stress and greater diminishment in that stress after attending the workshop together.

The opportunity to be part of a group was a partial response to this need. However, a group format is not necessarily appropriate for everybody or an adequate method for providing the help that some individuals disclosed that they needed. The screening of participants for this research was based on self-referral and completion of the demographic questionnaire. This was not sufficient for identifying individuals or

couples who might be better suited to personal therapy of longer duration, or a less intensive group format. It is recommended that a pre-screening interview, preferably in person, or alternatively by telephone be conducted to ensure a good fit between group members and establish their readiness to be part of a group setting. Several studies also indicate that the duration of the infertility experience influences the type and degree of problem stress experienced and that people at different parts of the process are looking for different forms of support (Domar, 2004; Olivius et al., 2004; Penzias, 2004; Smeenk, Verhaak, & Braat, 2004). Prescreening also provides the counselor or clinician with an opportunity to clearly state the goals and objective of the workshop, its limitations and applications, and informs participants what to expect. Although pre-screening establishes some preliminary points of cohesion between potential members, in order to meet participants at the level at which they indicate their most need, another form of information gathering is necessary.

The surveys used in this dissertation were this researcher's attempt to uncover the multiple sources of stress that people indicate they are experiencing. To some extent the surveys met this purpose however, they were also limited by the temporal and finite nature of quantitative instruments in general as well as the medical model upon which they are based. The literature clearly supports the marriage of stress to involuntary childlessness (Domar et al., 1999b; Matsubayashi et al., 2004; Tarabusi et al., 2004). Nevertheless, assessments that adequately discriminate between the multiple lifestyle effects of infertility on the perception of stress are not currently unavailable. (There is an instrument being developed which has undergone multi-site international testing and is scheduled to be available sometime in 2007). The refractive reframing model described

in this dissertation has the potential to be developed into a qualitative tool that provides a view of an individual's perception of *self* in relation to multiple internal and external stressors. Infertility does not occur in a vacuum, it is framed by a history of prior events and relationships that all come to bear on how infertility negotiated. Understanding these relationships is essential to an individual's construction of meaning.

Men and women do not experience stress or cope with stress in the same ways (Anderson et al., 2003; Matud, 2004; Zinn et al., 2005). With respect to infertility specific distress this might well be a function of biological imperative; men simply do not know what it is like to live in a non-pregnant, menstruating body with no escape. Differential experience and differential coping styles also contribute to the relationship discord that many couples report, and yet this study, as well as others, indicate that these couples are also the most likely to benefit from supportive intervention (Schmidt et al., 2005b; White et al., 2006). Making some form of counseling or education available is therefore imperative. In addition, women who participate in counseling alone report less change in relationship factors, social stress, and interpersonal sensitivity generally than couples who attend together. Educating both women and men on this finding is a critical part of informed consent. There is no evidence to suggest a conclusive relationship between being a woman and attending an infertility-related workshop alone and achievement of pregnancy. It is however possible that women who have experienced infertility longer or are more estranged from their partners and other social support systems, are generally experiencing more overall stress. It is also possible that this stress pre-dates the infertility and is certainly likely to be exacerbated by the infertility. Women presenting for counseling or psychological support who are in partnered relationship must be advised of

the potential benefit to pursuing this support as part of a couple. No inferences can be made about single women or same sex relationships with regard to this finding. Indeed it might well be that the additional conflict that occurs within a relationship is more stressful than the experience of trying to become a single parent or at the least presents as a different set of stressful conditions which should therefore be investigated differently.

The techniques incorporated into a program of care should be relevant, broad based, and personalized. A group format does not imply generic treatment. The principles that are introduced require a cogent structure and appropriate application. Mindfulness is an imprecise term that has repercussion across thought and action. Intersecting thought and action is therefore a critical aspect of mindfulness training and is especially significant for people who are facing infertility where the common lament is: “I am doing this but I know it won’t work.” Mindfulness is about bringing attention to the discord between these two positions beyond reframing using positive language. Mindfulness is about bringing synchrony to what one says and does; being aware in the moment of both mind and body. For mindfulness to be taught well it must also be practiced. Similarly, deep breathing is more than a command it is an exercise in anatomy and physiology and a link between reflex and deliberation. Clinicians who wish to teach these skills must therefore understand the mechanism behind their action.

A mind-body workshop is not a guarantee of pregnancy and it is incumbent upon the practitioner to re-state this position. In fact mind-body is about teaching people how to take their eye off the goal and find a way to live in the present, as best they can, despite the condition of non-pregnancy. Therefore mindfulness, breathing exercises, and interpersonal education are not the domain of the female body anymore than they are the

married or heterosexual one. Counselors as well as psychologists are trained to respond to the complex web of emotions that contributes to the experience of despair. Infertility is not about categories or labels as much as it is about the human condition. We are not the gatekeepers of reproductive rights, nor the custodian of aberrant emotion. Our practice command is to meet those who collaborate with us in their care at the level at which they state their greatest need.

Currently few infertility clinics in the Cleveland area offer an ongoing educational format that addresses the issues outlined in this study. Although not all individuals receiving medical treatment declare a need for psycho-educational support, those that do are often deterred by the mental health stigma attached to seeking care (O'Donnell, 2005). Despite individual counseling being made available to some of the participants prior to this study, including those who chose to obtain additional counseling after the workshop, many reported previously feeling resistant to attending therapy. A group format eliminates the need to use diagnostic criteria to establish eligibility for service and creates a much-needed forum for people to share their own stories and hear the stories of others. Consideration of the spectrum of topics to be covered and degree of intimacy that participants wish to establish suggests that workshops should be held over a weekend or in a series of sessions over a few weeks.

Finally, close attention should be paid to the environment in which care is offered as well as the sensitivity of care providers. External sources of stress are environmentally situated and participants in this study reported that physical space was as influential on setting the tone of conduct as emotional or verbal tone.

Implications for Future Research

This study consisted of a small sample size that was extremely homogeneous. Future research should be conducted with larger groups that are more culturally and racially diverse and include participants across broader social and educational levels. A study that looks specifically at the long-term stress on women who attend infertility treatment alone as compared to women who participate with partners would help highlight particular areas of relationship concern, and their possible impact on infertility distress and treatment outcome. In addition, studies of single women, single men, or same sex couples experiencing infertility would help to establish the relationship and identity/role effects on this essentially human crisis. A comprehensive study that evaluates both the physiological and psychological/emotional correlates of stress is much needed and would require the same integrative approach to the research as recommended in this dissertation.

Finally, infertility and infertility treatment includes the involvement of a large number of people in a fundamentally private decision. This form of personal exposure is a significant source of the stress that individuals report experiencing and is often exacerbated by the way treatment is delivered or provided. Educating professionals working in the field of infertility about the multiple sources of relationship stress that magnify the experience of infertility would help them to better consider their own role in this dynamic. The desire to achieve pregnancy is both a shared goal and a shared disappointment during infertility treatment however, a physician who does not achieve 'success' must navigate this loss quite differently from the couple who does not become pregnant. Often it is this prism of difference and the need for each participant in the

relationship dyad to protect and preserve differing identity needs that generates greater conflict. Workshops utilizing similar mindfulness and relaxation techniques could help care providers better navigate this vulnerable territory for themselves; a sort of bi-lateral communication approach that truly brings together the art and science of infertility.

Further research on the refractive reframing model that emerged from this study might aid in defining its use as a qualitative tool for describing factors that contribute to an individual's view of *self* and the relationship dyad. This is a model that is not limited in scope to infertility; it is a method for seeing the multiple ways in which we view ourselves in the world, and the world in ourselves; not limited by title or delineated by others definitions or who we are or can be.

Researcher Reflections

I began my career as a physical therapist. I learned early on in the profession that the difference in recovery time between patients who underwent identical procedures sometimes had more to do with their emotional well being than the rehabilitation demands made upon a joint that had been replaced. Returning to school to study counseling was my attempt to attach a practice license to a skill that I believed had already become an essential part of my treatment plans. I quickly discovered that integrating physical and mental health within a unified approach to patient care was far more complicated than I had anticipated. Touching the heart, even metaphorically does not automatically lend itself to touching the chest. My hands-on physical therapeutics became a liability when extended beyond the boundary of the psychotherapeutic alliance.

I left the world of adult medicine and found my niche working in an intensive care nursery; an environment as humanly frail as it is technologically manic; a sort of

mechanical hyper reality begging to be saved by soulful connection. My mission included the heady ambition of changing care-giving philosophy, reshaping clinical identity, and placing infants and their families at the center of the care paradigm. Grieving parents needed no convincing that such a model of care held promise, offered hope, and gave them back the confidence that been annihilated the day that their child came into the world too early. Convincing modern medicine was not a struggle for the faint of heart but with statistics, dialogue, and systems thinking convince is what I did.

Fast forward ten years. My work in infertility emerged from my personal experience with this struggle and after almost 6 years of trying to conceive and finally succeeding using assisted reproductive technology (ART), I had two sons now 15 and 17. My relationship with the neonatal intensive care nursery was intimately linked to my understanding of infertility; family building gone awry; babies lost to unknown causes, arriving in multiples, or simply challenged by environmental derailment (nothing truly replaces a uterus). Watching families struggle to come together I learned their personal narratives: tales that were every bit as important to an infant's survival as ventilators, arterial lines, and sophisticated medications. These stories contained the belief systems of generations. It seemed to me that it was in the meaning that people created from their life circumstances that they were able to find their greatest link to faith. Not the religious faith we supplicate at times of deep fear but in the discovery or rediscovery of personal trust; knowing without *knowing* that you can get through this. It is perhaps what it is at the essence of the definition of resilience.

Of course it isn't enough to have been where one's client has been to declare one self-expert or even competent. I needed first to understand my own story, which though

rich in diversity had still not fully established itself as a worthy frame upon which I thought I could construct both personal and professional success. Breaking into the field of reproductive medicine in many ways has reflected my journey to build a family. A series of door knocks intermittently met with dismissal, curiosity, compassion, hopelessness, and exaltation. Was I looking for comparison or was there a relationship between the experience of exclusion so interwoven into involuntary childlessness and the theme of impossibility that I hit against when trying to get a job as an infertility counselor? It hardly matters if it's true. My certainty was the belief that I held, which ultimately dictated what I thought I could do. I believed I could do the work. What the work should look like was the broad research question I began to ask myself. What is infertility counseling? Who determines both the process and the outcome? Is resolution through infertility counseling about finding peace, making a baby, becoming a parent? Exploring these questions using a mind- body premise is deeply anchored in what I believe it is to be human; organically sentient, emotionally elaborate, physically and physiologically remarkable. Integration of these elements into the care giving paradigm is essential to my development of a sound therapeutic practice in any field of care. My theoretical position is existential in that I support the notion that the construction of meaning is critical to how people see themselves in the world and that this personal view both influences what individuals believe they can do about their circumstances as well as what they will do. This research has been a testament to that philosophy.

Final Summary

This Chapter reviewed the limitations and findings of this study, relevant methodologies, emergent theories and themes, and implications for clinicians. The

marriage between research and clinical practice is tenuous, punctuated by periods of cordiality, disdain, parallel thinking and not surprisingly, brief moments of passionate compatibility. It is Borkovec and Castonguay's statement that "...effectiveness research should be used to determine and guide effective practice" which has served as the underpinning to this dissertation (Norcross et al., 2006, p. 90). As a result of this study's important research findings my own clinical practice has changed. I encourage partners to work together to develop an emotionally supportive path through their experience of infertility. Although this does not preclude the possibility that one partner might need more support than another it also affirms that creating a child is a decision that by necessity requires involvement of at least two individuals and in the case of infertility sometimes many more than that. It is often in the variable construction of meaning that participants bring to their understanding of family and family building that additional sources of conflict are generated and it is in the deconstruction of that meaning that they may might be fully explored and understood.



The Artist's Mother

“Use your talent to possess whatever it is that is happening to you” (Dugdale, 2006).

John Dugdale is a contemporary photographer who began losing his eyesight as a result of AIDS in the nineteen nineties. He is currently considered legally blind and

continues to pursue his art. His commitment to his work, despite his failing vision emphasizes the necessity and possibility for human beings to find a way to be creative within the perceived confines of their own life circumstance.

Most people when they think of losing their sight are so blown out of the water they can't even think. They think it's the end of their life. But if you ask any person who's comfortable being blind, or nearly blind, you'll hear that something else takes over - your heart and your intuition. And it makes up for what you're not using your eyes for. It sounds kind of cliché, but it's absolutely true...Ultimately, I realized that the clarity of my vision was intact and had nothing to do with what was filtered through my eyes and my problems there. (Dugdale, 2006, p. 1)

Update

On July 13th, 2006 Bethany and Graham (couple # 6) shared that they had conceived naturally (reportedly with a 2% probability of this occurring) and that daughter Charlotte was robust and recovering well from her heart surgery. On July 17th 2006, Nicole (couple # 4) gave birth to twin boys at 34 weeks, Drew and Jeremiah. Drew was diagnosed with a congenital anomaly of the hands known as brachydactyly but is nevertheless doing well, and both boys have been discharged home from the neonatal intensive care unit.

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Unpublished Doctorate, Drexel University, Philadelphia.

APPENDIX

Appendix A – Research Settings

Setting 1: April 10, 2005 - 5 Seasons Country Club

Five Seasons Country Club is a private fitness, tennis, and banquet facility situated on approximately 8 acres of land located west of Cleveland. The women's workshop was held in an upstairs banquet room. The room was located next to a private dining area and had been divided to reduce its size. Opaque glass doors and mobile wall panels created the room's perimeter. The room was approximately 1000 square feet and the ceilings 25 foot high. The floors were carpeted. Several metal frame chairs with upholstered seats were situated in a circle and the room was wired for laptop power point and overhead sound. Exercises mats, eye masks, and towels were provided and participants were instructed to bring pillows or blankets for general comfort and to use during the yoga/relaxation exercises. Bathroom facilities were located close by although had to be shared with people attending other activities. Lunch was provided by Five Season's Country Club (charged to the researcher), and participants elected to eat on an outside patio area (despite it being April the weather was moderate). The workshop was conducted by this researcher and two Cleveland State University graduate students provided administrative support throughout the day.

Setting 2: April 17th, 2005 - Harmony School of Massage Therapy

The Harmony School of Massage Therapy is an independent educational facility located on the third floor of a five storey building. The school occupies about 4000 square feet which represents a reception area, kitchen, office, small library, moderate size classroom and free floor space area (site of the workshop). This floor space was carpeted. Blankets, yoga mats, pillows and bolsters were available throughout the room and several large windows provided a generous amount of natural lighting. Bathroom facilities were

located on the main landing and because the workshop was held on a Sunday the rest of the building was unoccupied which guaranteed both accessibility and privacy. Lunch was catered by a local store and picked up by one of the graduate students. This workshop was conducted by two female licensed professional clinical counselors (including this researcher).

Appendix B – Fertility Health/Family History and Questionnaire

Fertility Health/Family History and Questionnaire – CONFIDENTIAL

Name:	Address:
Phone:	E-mail:

Workshop #		Date: / /	Location:
-------------------	--	---------------------	------------------

Subject ID #:		Sex: M F	Age:	DOB:	Religion:
Race/Ethnicity:	White	A/A	Hispanic	Native A	Other
Education:	HS/GED	Associate Degree	Bachelor's	Master's	MD/PhD/JD

Please circle the appropriate response (If you choose not to respond to **Religion** please put N/A)

Are you married or in a committed relationship? (Please indicate which) _____ Length: _____

Do you have any biological/adopted children from this or a previous relationship?

N/A [] or Number: _____ Ages: _____ Sex: _____

Cause and nature of your infertility: (if known) Primary [] Secondary []

What type of treatment have you had? (please list all) _____

How long have you been trying to conceive? _____ Date of Diagnosis: _____

Have you ever had a miscarriage? Yes [] No [] # of weeks pregnant: _____

Have you ever had a preterm delivery and your baby did not survive? Yes [] No []

of weeks pregnant? _____ Did you receive counseling? Yes [] No []

Wt: _____ Ht: _____ Cigs: Yes [] No [] (#/day) _____ Alcohol: Yes [] No [] # day _____

Do you have any other current or chronic health concerns? (Please specify type and duration as well as any treatment/medication administered) _____

Do you follow a *regular* exercise program? Yes ☐ No ☐ (Please describe) _____

Please describe your family of origin – check where appropriate or respond in the space provided.

Parents: Father living: Yes ☐ No ☐ Mother Living: Yes ☐ No ☐

Divorced: Yes ☐ No ☐ Separated: Yes ☐ No ☐ Remarried: Yes ☐ No ☐

Siblings: (Please list sex and ages only and include half siblings) _____

Are you adopted? N/A ☐

(If yes, please describe how you found out and whether you have ever met your biological parents) _____

Where are you in the family? (youngest/oldest/middle etc.) _____

Is your family aware of your fertility difficulties? _____

Who have you found that you have been able to confide in the most and why? (This can be friends, family, professionals). _____

What has been the most difficult part of your infertility? _____

How do you believe you might have changed, if at all, as a result of your infertility?

How do you believe your relationship might have changed, if at all, as a result of your infertility? (A diagnosis may refer to either you or your partner or both). _____

Are you happy with the medical treatment you have received thus far? (Please explain yes or no).

Have you been offered or received any counseling or psychotherapy? Yes [] No []

If no, would you have liked to receive these services? (please explain) Yes [] No []

If yes, were you happy with the services provided? (Please explain). _____

Would you take advantages of these services again? Yes [] No []

What would you like to see offered that you believe is not currently available where you are receiving your treatment? _____

Are you currently receiving any alternative treatment e.g. acupuncture, naturopathic medicine, clear passage, nutritional supplements? (Please describe and include length of time on treatment).

What do you know or believe about mind body medicine and infertility? _____

What do you hope to take away from this workshop? _____

What do you hope will improve for you as a result of participating in this study? _____

Please take some time and describe below what having a child means to you. _____

Please use this space for any additional comments, requests, or concerns? _____

Appendix C – Fertility Problem Inventory

Fertility Problem Inventory

The following statements express different opinions about a fertility problem. Please place a number on the line to the left of each statement to show how much you agree or disagree with it. If you have a child, please answer the way you feel **right now, after** having a child.

Please mark every item. Use the following response categories:

- 6 = strongly agree
- 5 = moderately agree
- 4 = slightly agree
- 3 = slightly disagree
- 2 = moderately disagree
- 1 = strongly disagree

1. ___ Couples without a child are just as happy as those with children.
2. ___ Pregnancy and childbirth are the two most important events in a couple's relationship.
3. ___ I find I've lost my enjoyment of sex because of the fertility problem.
4. ___ I feel just as attractive to my partner as before.
5. ___ For me, being a parent is a more important goal than having a satisfying career.
6. ___ My marriage needs a child (or another child).
7. ___ I don't feel any different from other members of my sex.
8. ___ It's hard to feel like a true adult until you have a child.
9. ___ It doesn't bother me when I'm asked questions about children.
10. ___ A future without a child (or another child) would frighten me.
11. ___ I can't show my partner how I feel because it will make him/her feel upset.
12. ___ Family don't seem to treat us any differently.
13. ___ I feel like I've failed at sex.

14. ____ The holidays are especially difficult for me.
15. ____ I could see a number of advantages if we didn't have a child (or another child).
16. ____ My partner doesn't understand the way the fertility problem affects me.
17. ____ During sex, all I can think about is wanting a child (or another child).
18. ____ My partner and I work well together handling questions about our infertility.
19. ____ I feel empty because of our fertility problem.
20. ____ I could visualize a happy life together, without a child (or another child).
21. ____ It bothers me that my partner reacts differently to the problem.
22. ____ Having sex is difficult because I don't want another disappointment.
23. ____ Having a child (or another child) is not the major focus of my life.
24. ____ My partner is quite disappointed with me.
25. ____ At times, I seriously wonder if I want a child (or another child).
26. ____ My partner and I could talk more openly with each other about our fertility problem.
27. ____ Family get-togethers are especially difficult for me.
28. ____ Not having a child (or another child) would allow me time to do other satisfying things.
29. ____ I have often felt that I was born to be a parent.
30. ____ I can't help comparing myself with friends who have children.
31. ____ Having a child (or another child) is not necessary for my happiness.
32. ____ If we miss a critical day to have sex, I can feel quite angry.
33. ____ I couldn't imagine us ever separating because of this.

- 34. ____ As long as I can remember, I've wanted to be a parent.
- 35. ____ I still have lots in common with friends who have children.
- 36. ____ When we try to talk about our fertility problem, it seems to lead to an argument.
- 37. ____ Sometimes I feel so much pressure, that having sex becomes difficult.
- 38. ____ We could have a long, happy relationship without a child (or another child).
- 39. ____ I find it hard to spend time with friends who have young children.
- 40. ____ When I see families with children I feel left out.
- 41. ____ There is a certain freedom without children that appeals to me.
- 42. ____ I will do just about anything to have a child (or another child).
- 43. ____ I feel like friends or family are leaving us behind.
- 44. ____ It doesn't bother me when others talk about their children.
- 45. ____ Because of infertility, I worry that my partner and I are drifting apart.
- 46. ____ When we talk about our fertility problem, my partner seems comforted by my comments.

Used with the permission of Christopher Newton, Ph.D., University of Western Ontario, Canada

Appendix D – SCL-90-R

SCL-90-R

The SCL-90-R consists of a list of problems people sometimes have. Read each one carefully and select the answer that best describes **how much that problem has distressed or bothered you during the past seven days, including today.**

Key: **0** = Not at all **1** = A little bit **2** = Moderately
 3 = Quite a bit **4** = Extremely

How much were you distressed by:

- | | | | | | |
|--|---|---|---|---|---|
| 1. Headaches | 0 | 1 | 2 | 3 | 4 |
| 2. Nervousness or shakiness inside | 0 | 1 | 2 | 3 | 4 |
| 3. Repeated unpleasant thoughts that won't leave your mind | 0 | 1 | 2 | 3 | 4 |
| 4. Faintness or dizziness | 0 | 1 | 2 | 3 | 4 |
| 5. Loss of sexual interest or pleasure | 0 | 1 | 2 | 3 | 4 |
| 6. Feeling critical of others | 0 | 1 | 2 | 3 | 4 |
| 7. The idea that someone else can control your thoughts | 0 | 1 | 2 | 3 | 4 |
| 8. Feeling others are to blame for most of your troubles | 0 | 1 | 2 | 3 | 4 |
| 9. Trouble remembering things | 0 | 1 | 2 | 3 | 4 |
| 10. Worried about sloppiness or carelessness | 0 | 1 | 2 | 3 | 4 |
| 11. Feeling easily annoyed or irritated | 0 | 1 | 2 | 3 | 4 |
| 12. Pains in heart or chest | 0 | 1 | 2 | 3 | 4 |
| 13. Feeling afraid in open spaces or on the streets | 0 | 1 | 2 | 3 | 4 |
| 14. Feeling low in energy or slowed down | 0 | 1 | 2 | 3 | 4 |
| 15. Thoughts of ending your life | 0 | 1 | 2 | 3 | 4 |
| 16. Hearing voices that other people do not hear | 0 | 1 | 2 | 3 | 4 |
| 17. Trembling | 0 | 1 | 2 | 3 | 4 |
| 18. Feeling that most people cannot be trusted | 0 | 1 | 2 | 3 | 4 |
| 19. Poor appetite | 0 | 1 | 2 | 3 | 4 |
| 20. Crying easily | 0 | 1 | 2 | 3 | 4 |
| 21. Feeling shy or uneasy with the opposite sex | 0 | 1 | 2 | 3 | 4 |
| 22. Feelings of being trapped or caught | 0 | 1 | 2 | 3 | 4 |

23. Suddenly scared for no reason	0	1	2	3	4
24. Temper outbursts that you could not control	0	1	2	3	4
25. Feeling afraid to go out of your house alone	0	1	2	3	4
26. Blaming yourself for things	0	1	2	3	4
27. Pains in lower back	0	1	2	3	4
28. Feeling blocked in getting things done	0	1	2	3	4
29. Feeling lonely	0	1	2	3	4
30. Feeling blue	0	1	2	3	4
31. Worrying too much about things	0	1	2	3	4
32. Feeling no interest in things	0	1	2	3	4
33. Feeling fearful	0	1	2	3	4
34. Your feelings being easily hurt	0	1	2	3	4
35. Other people being aware of your private thoughts	0	1	2	3	4
36. Feeling others do not understand you or are unsympathetic	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	0	1	2	3	4
38. Having to do things very slowly to insure correctness	0	1	2	3	4
39. Heart pounding or racing	0	1	2	3	4
40. Nausea or upset stomach	0	1	2	3	4
41. Feeling inferior to others	0	1	2	3	4
42. Soreness of your muscles	0	1	2	3	4
43. Feeling that you are watched or talked about by others	0	1	2	3	4
44. Trouble falling asleep	0	1	2	3	4
45. Having to check and double-check what you do	0	1	2	3	4
46. Difficulty making decisions	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	0	1	2	3	4
48. Trouble getting your breath	0	1	2	3	4
49. Hot or cold spells	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4

51. Your mind going blank	0	1	2	3	4
52. Numbness or tingling in parts of your body	0	1	2	3	4
53. A lump in your throat	0	1	2	3	4
54. Feeling hopeless about the future	0	1	2	3	4
55. Trouble concentrating	0	1	2	3	4
56. Feeling weak in parts of your body	0	1	2	3	4
57. Feeling tense or keyed up	0	1	2	3	4
58. Heavy feelings in your arms or legs	0	1	2	3	4
59. Thoughts of death or dying	0	1	2	3	4
60. Overeating	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	0	1	2	3	4
62. Having thoughts that are not your own	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	0	1	2	3	4
64. Awakening in the early morning	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	0	1	2	3	4
66. Sleep that is restless or disturbed	0	1	2	3	4
67. Having urges to break or smash things	0	1	2	3	4
68. Having ideas or beliefs that others do not share	0	1	2	3	4
69. Feeling very self-conscious with others	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or a movie	0	1	2	3	4
71. Feeling everything is an effort	0	1	2	3	4
72. Spells of terror or panic	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	0	1	2	3	4
74. Getting into frequent arguments	0	1	2	3	4
75. Feeling nervous when you are left alone	0	1	2	3	4
76. Others not giving you proper credit for your achievements	0	1	2	3	4
77. Feeling lonely even when you are with people	0	1	2	3	4

78. Feeling so restless you couldn't sit still	0	1	2	3	4
79. Feelings of worthlessness	0	1	2	3	4
80. The feeling that something bad is going to happen to you	0	1	2	3	4
81. Shouting or throwing things	0	1	2	3	4
82. Feeling afraid you will faint in public	0	1	2	3	4
83. Feeling that people will take advantage of you if you let them	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	0	1	2	3	4
85. The idea that you should be punished for your sins	0	1	2	3	4
86. Thoughts and images of a frightening nature	0	1	2	3	4
87. The idea that something serious is wrong with your body	0	1	2	3	4
88. Never feeling close to another person	0	1	2	3	4
89. Feelings of guilt	0	1	2	3	4
90. The idea that something is wrong with your mind	0	1	2	3	4

Appendix E – Ways of Coping Questionnaire

Ways of Coping Questionnaire

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the *past week*.

By “stressful” we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind.
Read each statement carefully and indicate, by circling 0, 1, 2 or 3, to what extent you used it in the situation.

Key: **0** = Does not apply or not used **1** = Used somewhat
 2 = Used quite a bit **3** = Used a great deal

Please try to respond to every question.

- | | | | | |
|---|----------|----------|----------|----------|
| 1. I just concentrated on what I had to do next – the next step. | 0 | 1 | 2 | 3 |
| 2. I tried to analyze the problem in order to understand it better. | 0 | 1 | 2 | 3 |
| 3. I turned to work or another activity to take my mind off things. | 0 | 1 | 2 | 3 |
| 4. I felt that time would have made a difference –
the only thing was to wait. | 0 | 1 | 2 | 3 |
| 5. I bargained or compromised to get something positive
from the situation. | 0 | 1 | 2 | 3 |
| 6. I did something that I didn't think would work,
but at least I was doing something. | 0 | 1 | 2 | 3 |
| 7. I tried to get the person responsible to change his or her mind. | 0 | 1 | 2 | 3 |
| 8. I talked to someone to find out more about the situation. | 0 | 1 | 2 | 3 |
| 9. I criticized or lectured myself. | 0 | 1 | 2 | 3 |
| 10. I tried not to burn my bridges, but leave things open somewhat. | 0 | 1 | 2 | 3 |
| 11. I hoped for a miracle. | 0 | 1 | 2 | 3 |
| 12. I went along with fate; sometimes I just have bad luck. | 0 | 1 | 2 | 3 |

13. I went on as if nothing had happened.	0	1	2	3
14. I tried to keep my feelings to myself.	0	1	2	3
15. I looked for the silver lining, so to speak; I tried to look on the bright side of things.	0	1	2	3
16. I slept more than usual.	0	1	2	3
17. I expressed anger to the person(s) who caused the problem.	0	1	2	3
18. I accepted sympathy and understanding from someone.	0	1	2	3
19. I told myself things that helped me feel better.	0	1	2	3
20. I was inspired to do something creative about the problem.	0	1	2	3
21. I tried to forget the whole thing.	0	1	2	3
22. I got professional help.	0	1	2	3
23. I changed or grew as a person.	0	1	2	3
24. I waited to see what would happen before doing anything.	0	1	2	3
25. I apologized or did something to make up.	0	1	2	3
26. I made a plan of action and followed it.	0	1	2	3
27. I accepted the next best thing to what I wanted.	0	1	2	3
28. I let my feelings out somehow.	0	1	2	3
29. I realized that I had brought the problem on myself.	0	1	2	3
30. I came out of the experience better than when I went in.	0	1	2	3
31. I talked to someone who could do something concrete about the problem.	0	1	2	3
32. I tried to get away from it for a while by resting or taking a vacation.	0	1	2	3
33. I tried to make myself feel better by eating, drinking, smoking, using drugs, or medications, etc.	0	1	2	3
34. I took a big chance or did something very risky to solve the problem.	0	1	2	3
35. I tried not to act too hastily or follow my first hunch.	0	1	2	3
36. I found new faith.	0	1	2	3
37. I maintained my pride and kept a stiff upper lip.	0	1	2	3
38. I rediscovered what is important in life.	0	1	2	3

39. I changed something so things would turn out all right.	0	1	2	3
40. I generally avoided being with people.	0	1	2	3
41. I didn't let it get to me; I refused to think too much about it.	0	1	2	3
42. I asked advice from a relative or friend I respected.	0	1	2	3
43. I kept others from knowing how bad things were.	0	1	2	3
44. I made light of the situation; I refused to get too serious about it.	0	1	2	3
45. I talked to someone about how I was feeling.	0	1	2	3
46. I stood my ground and fought for what I wanted.	0	1	2	3
47. I took it out on other people.	0	1	2	3
48. I drew on my past experiences; I was in a similar situation before.	0	1	2	3
49. I knew what had to be done, so I doubled my efforts to make things work.	0	1	2	3
50. I refused to believe that it had happened.	0	1	2	3
51. I promised myself that things would be different next time.	0	1	2	3
52. I came up with a couple of different solutions to the problem.	0	1	2	3
53. I accepted the situation, since nothing could be done.	0	1	2	3
54. I tried to keep my feeling about the problem from interfering with other things.	0	1	2	3
55. I wished that I could change what had happened or how I felt.	0	1	2	3
56. I changed something about myself.	0	1	2	3
57. I daydreamed or imagined a better time or place than the one I was in.	0	1	2	3
58. I wished that the situation would go away or somehow be over with.	0	1	2	3
59. I had fantasies or wishes about how things might turn out.	0	1	2	3
60. I prayed.	0	1	2	3
61. I prepared myself for the worst.	0	1	2	3
62. I went over in my mind what I would say or do.	0	1	2	3
63. I thought about how a person I admire would handle this situation and used that as a model.	0	1	2	3
64. I tried to see things from the other person's point of view.	0	1	2	3

65. I reminded myself how much worse things could be.

0 1 2 3

66. I jogged or exercised.

0 1 2 3

Appendix F – Informed Consent Minding Matters Mind Body Program

Informed Consent Minding Matters Mind Body Program

Welcome back to all of you! In March and April of 2005 you were each participants in the *Minding Matters* mind-body research workshop designed to explore how best to provide effective emotional support to men and women who receive an infertility diagnosis. This letter is an invitation to you to participate in a follow-up interview regarding your experience in the workshop. You will also have the opportunity to discuss your responses to several questionnaires that you completed during and after the workshop day and ask questions you might have about your participation in, and contribution to, this important research.

Interviews are expected to take between 1.5 and 2 hours and will be conducted in a private office: 24629 Detroit Rd. #8, Westlake, OH. It is also possible (for those of you who prefer) to be interviewed in your own home, or another more convenient location of your choosing. I will follow-up this letter with telephone contact and you can make your meeting preference known at that time. In addition, some participants who are no longer in the Cleveland area will be able to participate in the follow-up through the use of a land line telephone. All interviews will be conducted at the researcher's expense and reimbursement for traveling will be provided (gas/mileage).

Interviews will be tape recorded and transcribed for accuracy. You will be invited to review the written transcript and make any changes or corrections that you feel are necessary and retain a copy for your own records if you wish. Each participant was provided with an ID number during the original research and this number, ***NO NAMES***, will be used to file the audio recordings and transcripts. These files will be kept in a locked office. Federal Guidelines mandate that this information is stored for a minimum period of three years, at which time it will be destroyed. Women who participated in the *women only* workshop will be interviewed individually. Couples who attended the workshop together will be interviewed together.

Some of you might currently be expecting a child as a result of your ongoing desire to build your family, or be breastfeeding a child you conceived and birthed in the year since we first met. The researcher respects the privileged nature of your agreement to continue to collaborate in this research and assures privacy and therapeutic integrity at all times. The questions addressed in the follow-up interviews are designed to explore your past experience in the workshop, the application of any skills you feel that you learned, and your recommendations for continued improvement of this method of support. A possible risk to you is that some of the questions posed might trigger unexpected emotions associated with your experience of infertility and family building. In the event that this occurs you are free not to respond to those questions. Should you decide to, and subsequently develop ongoing concerns related to a reaction you might have, you may be referred to one of several counselors (excluding research staff) with whom you could discuss this issue further. (This discussion would not be included in any research data).

Your participation in this research is considered voluntary and you are free to discontinue your involvement at any time during the research process.

Please read the following paragraph and sign and date below:

I have read fully the information that has been provided regarding this research project and am aware of the process, my particular involvement, and any risks that might be incurred as a result of this project. I also understand that I am a voluntary participant and am free to discontinue my involvement at any time. I may contact the Institutional Review Board (IRB) at Cleveland State University, or individual members of the research team, if I have any questions or concerns regarding any of the above information: Cleveland State University IRB Office: 216.687.3630 – Dissertation Chair: Dr. Carl Rak: 216.523.7146 - Methodologist: Dr. Joanne Goodell: 216.687.5426. Principal Investigator, Liz O'Donnell: 440.212.2595.

Signature

Date

Sample Question:

How was construction of the workshop and manual helpful to you?

- a) How often have you read the material in the Manual or reflected back on something that you learned in the workshop?
- b) What would improve this experience for you?

Appendix G – Summary of Survey Responses from Minding Matters Workshop

Summary of Survey Responses from Minding Matters Workshop: Participant #11

This is a summary of the responses from the surveys that you completed *prior* to participating in the *Minding Matters* Workshop held at Five Seasons Country Club on Sunday on March 17th, 2005. The first questionnaire (taken twice one-month apart) inquired about several different areas in your life that might have been a source of stress for you at the time of the workshop.

Symptom Checklist: #1

You indicated that you were experiencing a high degree of difficulty in the following areas of your body: symptoms such as headaches, upset stomach, chest pain, generalized muscle fatigue and occasionally an overall feeling of physical weakness. Of particular concern was the degree to which you reported feeling both critical of others and criticized by others, being easily hurt, misunderstood, and often quite self conscious or judged. You also indicated that you had periods of very low energy and at times felt trapped by your life circumstance which you tended to blame yourself for and which often led to tearful episodes and frequently, worrying thoughts and moments of deep isolation. You also reported feeling fearful or panicky which at times was accompanied by a sense of impending doom that left you shaky and nervous and generally keyed up. Overall your responses seem to tell a story that reflected a very high level of generalized distress with quite a high degree of intensity to that distress and having impact on several different areas of your life.

Fertility Problem Checklist

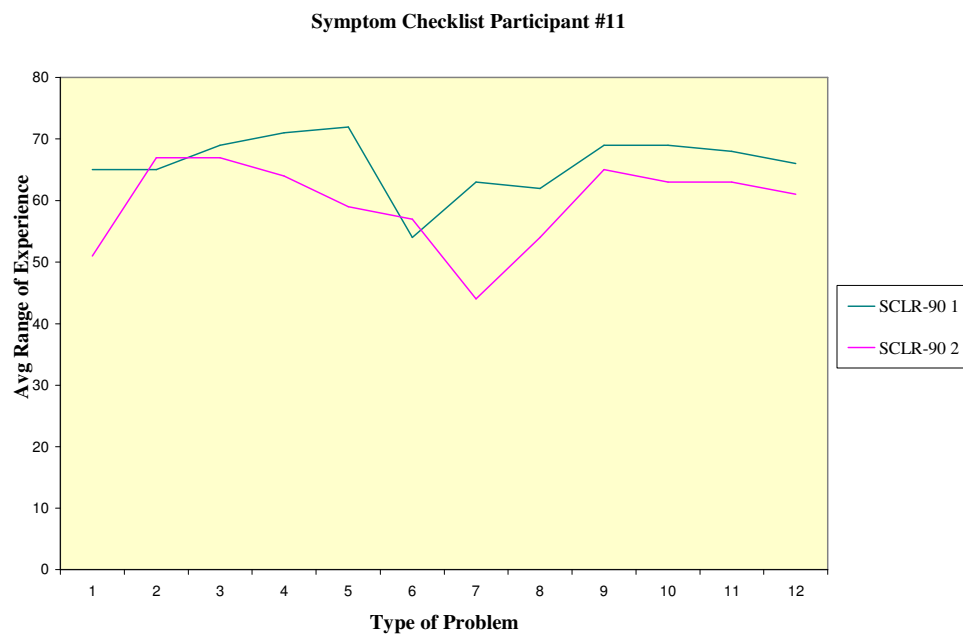
This questionnaire asked you more specific questions related to your struggle to build the family that you want. The area in which you indicated the most concern was in

social relationships for example: sensitivity to others comments, and questions about your fertility as well as feelings of alienation or isolation from peers/friends and family, and increasing difficulty with social activities and commitments. The second area in which you indicated you had a higher degree of difficulty was in your loss of enjoyment in your sexual relationship, loss of sexual self-esteem, and tremendous feelings of pressure to schedule sex.

Symptom Checklist #2

Approximately 1 month after the Workshop you completed a second Symptom Checklist questionnaire by mail. Your overall responses appeared to have improved considerably in the month since you answered the first questionnaire with the biggest change in distress appearing to be related to your physical symptoms such as headaches, stomach upset, and a general feeling of being run down (your responses indicated a greater than 20% improvement). Your feelings of anxiety also improved about 18% and your sadness and struggles with self blame, loneliness and worry appeared to be about 10% better. Overall you still indicated that you were experiencing a high degree of distress however the intensity seemed to be somewhat reduced and appeared not to interfere with as many areas of your life.

Please take some time to reflect on how you feel about what you have read and then I would like to ask you some additional questions.



1 = bodily symptoms (Somatization)

2 = Sensitivity (Interpersonal Sensitivity)

3 = Blue or sad (Depression)

4 = Worry (Anxiety)

5 = Anger (Hostility)

6 = Fear (Phobic Anxiety)

7 = Mistrustful (Paranoid Ideation)

8 = Feel unlike self (Psychoicism)

9 = Overall stress level (Global Score)

SCLR90-R Scales were changed from clinical to lay terms as recorded above.

Appendix H – Restorative Yoga Posture

Restorative Yoga Posture: Reclining Butterfly Pose (Purna Titali Asana)



Supported Child's Pose



Back to Back Supported Sitting in Easy Pose



Appendix I – Photographs

Photograph Gallery

