

"CAUGHT BETWEEN TWO WORLDS":  
RENEGOTIATING THE BOUNDARY BETWEEN  
INFERTILITY AND FERTILITY.  
A STUDY OF WOMEN'S EXPERIENCES WITH  
INFERTILITY IN ST. JOHN'S, NEWFOUNDLAND

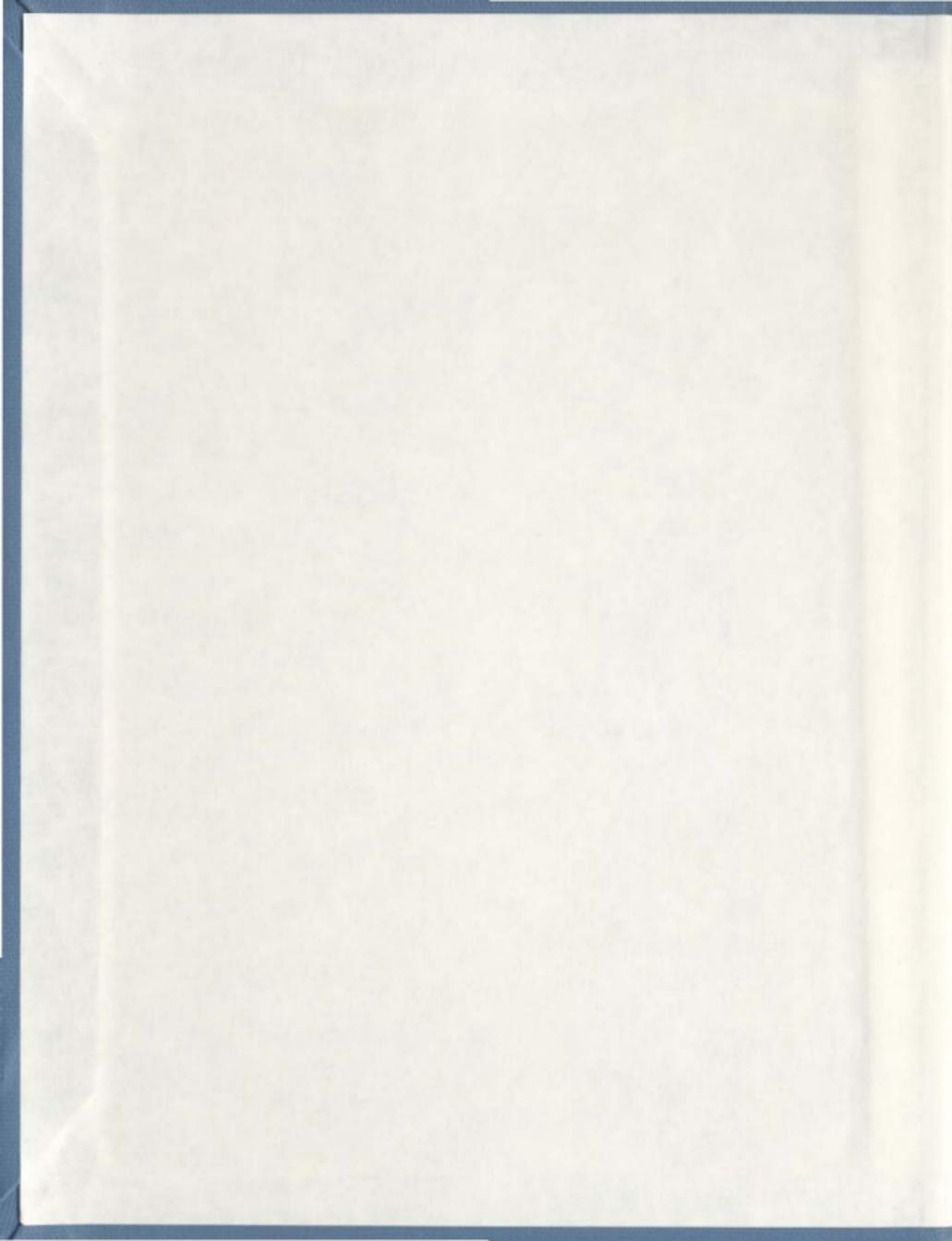
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**"Caught Between Two Worlds": Renegotiating the Boundary  
Between Infertility and Fertility.  
A Study of Women's Experiences with Infertility  
in St. John's, Newfoundland.**

by

Penny M. Dowdoff

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**Abstract**

One in ten Canadians of childbearing age experience infertility. Often, infertility is discussed in relation to new reproductive technologies and their ability to "treat" infertility as well as the legal, social and ethical consequences of these technologies for women, children and society. This thesis does not focus on these consequences but rather explores how the experience of infertility impacts on the daily activities of women living in St. John's, Newfoundland. This study examines the diverse ways in which women perceive, experience and make sense of their lives after receiving an infertility diagnosis. A phenomenological approach was used to gain a detailed understanding of the infertility experience from women's perspectives. The findings suggest that women and their partners living in St. John's and rural Newfoundland experience lack of choice and poor access to medical treatments and social support. Also, the impact of infertility stretched beyond the "medical aspect" by influencing the extended family, social and friendship circles, and work environments. Moreover, it disrupted how the women understood their life cycles and bodies.

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## **Chapter 1**

### **Introduction**

Infertility<sup>1</sup> affects a significant number of Canadian men and women. According to Infertility Awareness Association of Canada (1999), one in ten Canadians of childbearing age experience infertility. Generally, we tend to think of infertility in relation to new reproductive technologies<sup>2</sup> or NRT's and 'miracle' medical innovations such as the first 'test-tube' baby in 1978. Much academic activity has centred around NRT's used to 'treat' infertility and the ethical, legal, and social ramifications of this technology for society, women and children. The apparent increasing incidence of infertility is to some extent related to the availability of NRT's rather than the increase of infertility per se (Ziehl 1994: 138). By improving the chances of bypassing fertility problems, such technologies could create a demand for treatment, thereby enhancing the public's awareness of the extent of the conditions which require such treatments. (Ziehl 1994: 138).

In Newfoundland, research has focussed on developing resource material to detail the medical and non-medical options available to women and their partners (Redfern and

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<sup>1</sup>For brevity, I use the medical definition of infertility. Infertility refers to the inability to conceive after one year of unprotected, well-timed, sexual intercourse or after six months if the woman is over age thirty-five. A more detailed examination of the definition of infertility is provided in chapter four.

<sup>2</sup>New reproductive technologies (NRTs) refer to several different medical procedures designed to unite sperm and eggs, thus bypassing altogether some of the factors causing infertility. The most common NRT's are artificial insemination, in vitro fertilization, gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer (ZIFT) (Garner, Menning and Wentz 1997: 29).

Wyse 1987). Yet, the infertility experience among couples includes more than the use of NRT's to treat infertility. The experience of infertility affects the entire lives of women and their partners. From their own perspective, two women discuss the totality of the infertility experience:

Hannah: So people say, "relax, relax, it will happen." But it is hard to because you are thinking about it [infertility] every day. You are thinking about it every time when you and your husband are having sex. You think about it. It never leaves your mind. Especially when every day you are counting days and counting this, and you are taking pills everyday and you are taking injections every day. It is a reminder. Everyday.

Julia: Infertility really affects your whole life. The next thing you know, you are drawn into this vortex and then your life suffers. It is not supposed to be so mechanical. Babies just happen you know.

The above quotes also illustrate certain assumptions women have about infertility, their lives, their bodies and themselves. Such assumptions include being able to segment or bracket the infertility experience and that babies are supposed to happen 'naturally' with little or no medical intervention. Moreover, the stereotypical advice given to couples who experience infertility by family, friends, co-workers and even medical health care providers to relax in order to conceive a child is discussed by the women. Conceiving a child for couples who experience infertility involves more than relaxation: it involves a stressful and emotional regime of diagnostic tests and medical treatments which reminds the couple of their infertility every day.

This thesis presents the stories of thirteen women who experience infertility. It is an exploration of what it means to be an infertile woman confronting assumptions about

one's body, one's life and one's self. This thesis also explores the consequences of viewing infertility solely in terms of a dualistic framework which separates the mind from the body, emotion from science and infertility from fertility. This framework is constantly reworked and rewritten throughout the everyday lives of these women. Throughout this thesis, their stories will emerge along with certain themes and concepts. As much as possible, their narratives are presented from their own experiences, voices and emotions.

#### 1.1 Choice of Research Topic

My interest in studying infertility and the body was shaped by my personal experiences. Over the years, I have watched close family members make sense of their lives and bodies after being diagnosed with an illness such as cancer, multiple sclerosis and chronic arthritis. Often, we do not pay attention to the day to day activities of our bodies. However, when a disruption occurs such as being diagnosed with a chronic illness, our bodily routines are brought into the forefront. I have wondered how individuals understand their bodies before and after a disruption occurs.

In 1995, I would also face a disruption to my understanding of my body and confront assumptions I held about my body. After a year of being referred to different physicians, receiving numerous blood tests and pelvic examinations and repeatedly being told that the reason why I stopped menstruating was because of stress, I was finally diagnosed as having an "ovulatory disorder." One cold winter day, I heard my gynaecologist read out loud the results of a pelvic examination and blood test. In a calm

voice she said, "Penny, you may have difficulty having children because your body stopped ovulating." I was shocked. Although I knew that there could be a problem with my menstrual cycle, I never expected my gynaecologist to say those words. I always assumed that when I *chose* to have a child, I would be able to have one. I never thought my body could not "carry" or conceive a child.

The next sentence I remember hearing was, "don't worry, what you have is easily fixable with fertility drugs." The only word I focused on was fixable. My gynaecologist did not use the word treatable, but fixable. At that moment, my body had been viewed as a machine with a malfunctioning subsystem that the physician could fix. I did not feel or view my female body as being broken and in need of repair. For me, the term fixable not only referred to fixing my ovulatory disorder (my reproductive system), but referred to fixing my whole body in terms of being a woman.

After being diagnosed, I had contradictory feelings about myself. Although I knew defining my womanhood solely in terms of being able to have a child was reductionist and was a part of the social ideology that equated womanhood with motherhood, I nonetheless defined myself in those terms. The possibility of not being able to conceive a child, for me, struck at the heart of what it meant to be a woman. Like other women who have experiences with infertility, I was forced to confront assumptions I held about my body, myself and what it meant to be a woman.

Many women and their partners who experience infertility do not know they have fertility problems until they try to conceive a child. Today, many couples are deciding to

postpone having children until they are financially and socially secure. Couples who postpone childbirth may find "themselves in a situation where they are most capable of providing for-but unable to conceive or bear a child" (Zeihl 1994: 141). In other words, even though couples may be economically and socially secure and decide to have a child, their bodies are unable to bear or conceive a child. Therefore, many couples are surprised to learn that they have difficulty in conceiving a child. I wanted to know how other women who had different infertility experiences made sense of their lives and bodies after an infertility diagnosis.

The methodological and theoretical focus of this thesis is driven by my personal experiences with infertility. I disclosed my personal experiences with infertility when the women asked why I was studying their experiences. Smith (1987) argues that women's experiences of marginalization and exclusion make their lives epistemologically privileged starting points for conducting sociological research. Therefore, beginning from the standpoint of women who experience infertility will provide me with an entry point into the wider social relations that organize their experiences and will help give voice to women who have been previously marginalized in the discussion surrounding infertility and new reproductive technologies.

### 1.2 Outline of the Thesis

Chapter two begins by documenting the literature surrounding infertility from the perspectives of medicine, psychology, sociology and anthropology. The literature review primarily discusses how the body is viewed in each of these disciplines. I then look at

feminist writings on infertility and discuss a tension among them. Following that, I detail the theoretical perspectives used in this thesis, phenomenology and sociology of the body. The concept of the body is explored in detail and I argue that 'the body' consists of both the physical, experiential body and the objectified body. I also argue for the need to view the body in holistic and 'embodied' terms rather than a mind/body and science/emotion dichotomy. Finally, I explore the use of bodily metaphors in the construction of a gendered body.

Chapter three describes the research design and the methodology used in this study. It explains my research objectives and the reason I chose to use qualitative research techniques. I also discuss the difficulties I had in gaining access to the population I intended to study and the limitations of my study.

Chapter four gives a detailed demographic description of the participants in terms of age, occupation, income, marital status and education. This chapter gives background information about the infertility clinic, the medical and social services available in St. John's and explores the geographical impact of living in Newfoundland for women and their partners. Next, I provide an introduction to the infertile women's lives by providing a portrait sketch of five of the women I interviewed. The remaining portrait sketches of the women can be found in the Epilogue at the end of the thesis. Finally, I discuss how the women define infertility and what it means to them. I examine the interplay between the medical definition of infertility and the women's own definitions, noting that the women's experiences of infertility and the meaning they ascribe to it does not fit with the

medical profession's definition of infertility.

The fifth chapter explores the themes and concepts that have emerged from the women's infertility narratives. It discusses the 'regime' of diagnosing and treating infertility in order to document the processes by which the female body is objectified and fragmented into different biological systems. I also explore how the isolating and lonely experience of infertility contributes to the development of the 'emotional roller coaster ride' among the women. Within each of these sections is an exploration of how the women tactually, visually and emotionally experience their bodies. I also note how their understanding of their bodies is disrupted after receiving an infertility diagnosis.

The sixth chapter details the various ways in which the women experience loss in their daily lives. These losses include miscarriages, loss of control over their life cycles and bodies, the loss of specific reproductive organs, and the loss of a life dream, that of motherhood. Throughout this chapter I discuss how the women remake and rewrite their lives after an infertility diagnosis. I also explore how the body becomes a site of resistance for these women and how they negotiate between their actual activities and the images and discourses presented by popular culture and the medical profession.

In the conclusion, I discuss the overarching themes that have emerged from the infertility narratives such as: blurring boundaries between the dichotomies of science/emotion, mind/body, infertility/fertility, and otherness/sameness; the impact of using visual technology to (re)image the female body; and the experience of alienation from one's body, one's life and one's work. Finally, I provide some policy

recommendations that are based on the women's experiences of infertility.

As you read through the chapters, it will become evident that the women's experiences are filled with obstacles, mixed emotions and that they continuously redefine their bodies, their lives and themselves. Just like any story, there is a beginning, middle and end. However, some stories do not have a resolution and await a future that is unknown. Join me by entering into the lives of thirteen women who shared their stories. I hope that you, the reader will gain a deeper understanding of the infertility experience.

## Chapter 2

### Literature Review and Theoretical Perspective(s)

#### 2.0 Introduction

This chapter will review the infertility literature in medicine, psychology, sociology and anthropology. I will also explore tension among feminist writers in relation to how women's bodies are viewed and the use of new reproductive technologies to treat infertility. Next, I will outline the theoretical perspectives used in this thesis, phenomenology and sociology of the body. This chapter is not an exhaustive survey of the infertility literature, but instead offers a glimpse into how 'the body' is viewed and interpreted in each of these areas.

#### 2.1 The Medical Perspective on Infertility

Medical studies of infertility either discuss the cause(s) of infertility or deal with advances in technological innovations in infertility treatments such as new reproductive technologies. According to medical studies, infertility is as likely to be caused by a male factor as a female factor. Female related problems account for 40% of infertility and male-related problems account for 40%. Combined female and male problems account for 10%, and unexplained causes account for the remaining 10% (Garner, Menning and Wentz 1996: 4). The causes of infertility can range from behavioral factors, environmental and occupational factors to physiological factors. Behavioral factors may include inadequate diet and exercise, cigarette smoking, and the use of alcohol and drugs which can lower sperm count levels and cause irregular ovulation in women. Environmental factors include exposure to lead, repeated exposure to sources of radiation

like x-rays, and cancer treatments, which can affect sperm production and contribute to ovarian problems. Physiological factors for female infertility consist of abnormal ovulation, blocked fallopian tubes, endometriosis and coital/cervical problems.

Physiological factors for male infertility may be related to inadequate sperm count or abnormalities relating to size, shape and mobility of sperm. About 30% to 50% of male factor infertility relates to the presence of a varicocele, or varicose veins within the scrotum, which affect sperm quality and quantity (Garner and Patton 1996: 17). With the exception of references to psychological disturbance and stress (Keye 1984), medical literature rarely discusses the non-biological context of infertility: such as its impact on a marriage, family, relationships, career, or other aspects of daily life (Strickler 1992: 114).

The medical literature frames the problem of infertility in a narrow and clinical manner. For instance, physicians often focus on the causes and cures of infertility and not its psychological or social consequences. Discussions between physicians and infertile patients revolve around temperature charts, timed sexual intercourse, medication, and progress toward achieving the goal of pregnancy (Mahlstedt 1985: 341). Even though the patient's body is the primary focus, there is little discussion within the medical literature about how infertile women experience their bodies.

The medical literature on infertility is framed by a positivist view of science. The positivist scientific view assumes that there is a tangible reality 'out there' (including the body) that can be dissected into discrete parts, and is capable of being examined

independently from other factors. For example, the body can be dissected into specific biological subsystems where each system can be measured and tested independently from other factors. This dominant view of science is the basis for the medical model and has led to a medical discourse in which some maladies are seen as curable and fixable. In medicine, infertility is viewed as a disease and the medical model helps in explaining the components of this disease in order to select the appropriate treatment for the 'cure' (Glynn 1991: 152). In short, medical studies of the causes of infertility and the technological innovations used to diagnose and treat infertility does not assess the whole situation for infertility patients within their limited framework.

### 2.2 Psychological Studies of Infertility

Historically, psychological studies of infertility explored a possible link between infertility and personality. It was argued that infertility was psychogenic in nature where an individual's personality 'caused' infertility. For example, Eisner (1963) contended that infertile women experienced more emotional disturbance and were reported "to give more schizoid-type responses on projective tests than normal women; but other studies have rated infertile women as more hysterical or aggressive than normal women based on responses in psychodiagnostic interviews" (1963: 391-395). Mazor (1978) further elaborated that women have a "universal fear of not being able to conceive, hence, crisis is precipitated by the awareness that the dread fear is now a reality" (1978: 137-160). What these earlier studies fail to consider is the social and cultural context in which these women's experiences are embedded. The "universal fear of not being able to conceive"

and the report of infertile women being more "aggressive" and "hysterical" than normal women are socially constructed ideas that equate womanhood with motherhood. Within the psychological perspective there is little discussion of the discourse which equates womanhood with motherhood and how this may shape the experience of infertile women.

In contrast, later psychological studies of infertility focussed on the nature of the infertility experience itself, looking at the emotional aspects of infertility and the mechanisms by which individuals coped with the infertility experience (Ziehl 1994; Hartmann 1981; Lober 1989; and Mahlstedt 1985). The emotional aspects of infertility include the stressful regimen of daily temperature charting, regular doctor's appointments, medications, surgeries, the impact on an individual's self esteem and the social stigma associated with infertility. The experience of an emotional roller coaster ride is well documented in the psychological literature. The emotional roller coaster ride consists of a woman feeling hopeful and excited at the beginning of a treatment cycle followed by disappointment and grief if the medical treatment fails. Schoener and Krysa (1995:170) note that the grieving process is a continual focus for the woman and her partner, who must grieve at many stages such as the diagnosis of infertility, changes in life style and each new loss of an early pregnancy or miscarriage.

Other studies have documented the sense of loss women feel as they receive medical treatment. The sense of loss includes the loss of control over one's body and life course, loss of privacy, loss of a life dream, i.e. motherhood, and loss of one's self esteem (Needleman 1987; Mostyn 1986; Shapiro 1988; Humm 1989; McCormick 1980; and

Valentine 1986). The sense of loss is also present after any failed attempt to conceive a child or after the experience of a miscarriage. The sense of loss for such women has a profound impact on their lives. It can be an emotionally draining experience since one is dealing not only with a woman's reproductive capacity, which is something abstract, but also with her reproductive organs themselves (Ziehl 1994: 145).

While psychological studies of infertility often focus on the emotional aspects of infertility and medical studies focus on the cause(s) and physiological impairments of the infertile body, neither discipline pays much attention to the actual bodily experience of infertile women and how this shapes the emotional needs of these women. Consequently, each discipline maintains the mind/body distinction which is problematic in the study of the infertility experience.

Recently, some studies surrounding the psychological components of infertility have tried to incorporate a more holistic view of infertility and the patient's body. For instance, Schoener and Krysa (1995:168) use the Kalcaba theoretical model of comfort (the state of having basic needs for ease, relief and transcendence met) that involves four factors. These four factors include physical, social, psychospiritual and environmental aspects. The physical factor is how a woman experiences her body as she goes through the diagnosis and treatment of her infertility. This includes mastery of injection techniques, daily blood tests, side effects of the medication, and receiving daily ultrasounds. The social factor includes the relationships of the patient with her family, partner, friends, co-workers and support groups. Psychospiritual refers to the patients'

acceptance of the infertility diagnosis and the regime of the medical treatment, working through the stages of grief and maintaining self esteem. The environmental factor refers to the daily travel concerns of the patient, control of life events, and change of location of treatment for out of town patients (Schoener and Krysa 1995:169). Each factor focuses on different aspects of the infertility experience of the patient. The authors recognize that receiving an infertility diagnosis invades "one's body, one's personality, one's job and one's mind" (Mahlstedt 1985: 341). While this theoretical perspective incorporates a more holistic view of the body, it does not discuss the cultural aspects of infertility or how infertile women make sense of and construct their own meaning of infertility.

### 2.3 Sociological and Anthropological Studies of Infertility

Sociological and anthropological studies of infertility emphasize the social and cultural factors that shape the infertility experience. Popular narratives of infertility, such as those in the media, and the medical profession's representation of infertile women are examined in order to uncover the social construction of an ideology that furthers the process by which women see themselves as different from other women who can have a child 'naturally' and that stigmatizes them for failing to fulfil a societal norm (Whiteford and Gonzalez 1995; Pfeffer 1987, 1993; Martin 1989; Rapp 1987; Beagan 1989; Findlay 1996; and Stanworth 1987). These studies aim to document the social, cultural, political, medical and economic contexts in which the infertile couple's experiences occur. One area of particular importance in the study of infertility is medicine's relationship to political economy. It is argued that there is a link between pharmaceutical companies

which develop new drugs to treat infertility and the medical profession which markets such drugs and develops new technologies to 'help' treat infertility (Franklin 1997; Glynn 1991). Subsequently, these studies emphasize the social construction of infertility rather than the actual bodily experience of the infertile woman.

However, some recent anthropological studies have tried to incorporate the social construction of infertility without ignoring the body (Becker 1997; Martin 1989; Bury 1982; and Scritchfield 1989). For instance, Becker (1997:13) examines the process by which people attempt to create continuity after an unexpected disruption to their life such as an infertility diagnosis. She argues that the body is the medium through which people experience their cultural world, and bodily experience can reflect the culture in which it occurs. Moreover, Martin (1989) discusses how women's bodies have been historically viewed in the medical and scientific community. Martin stresses how metaphors of production inform medical descriptions of female bodies. Most of these metaphors clearly relate to familiar forms of mass production, where value is placed on "large quantities and on efficiency of scale" (1989: xiv). In each of these works, there is a commitment to the study of the larger social, political and cultural context in which the female body is embedded without ignoring the importance of how women actually experience their bodies.

Thus far, I have given a brief overview of the literature surrounding infertility. Although I have drawn artificial boundaries between the medical, psychological, sociological and anthropological studies of infertility, there are overlaps in how infertility

is studied and viewed, particularly among the social sciences. The study of infertility incorporates many different facets ranging from the medical causes of infertility and the emotional aspects of infertility to exploring the social, medical and political context in which the infertility experience occurs. In the next section, I will discuss a large body of feminist literature surrounding new reproductive technologies. Often, infertility is situated within the context of new reproductive technologies. In the following pages, I will highlight a tension that exists among feminist writers between how the female body is viewed and the use of new reproductive technologies to treat infertility. I will also note how my study is situated within this tension.

#### 2.4 Feminist Views of New Reproductive Technologies and Infertility

There are several different feminist perspectives surrounding new reproductive technologies. Broadly speaking, there are two main arguments: 1) new reproductive technologies provide women with choices in treating infertility and these technologies have the capacity to free women from the confines of the biological family; and 2) new reproductive technologies further medicalize women's reproductive capacities and increase the control over women's bodies by a predominately white, male medical profession, thus expanding patriarchal power over women's bodies. Central to this debate are theoretical assumptions about how the female body, technology and power are defined<sup>1</sup>.

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<sup>1</sup>Feminist writers have also debated the concept of motherhood. There has been profound division between feminists who reject motherhood because of its oppressive

With reference to the first argument, Firestone noted that modern medicine and its technologies rescued women from their biology. Firestone (1979), argued that when technology is able to perfect artificial ways for people to reproduce, the need for the biological family would disappear and, with it, the need to impose heterosexuality as a means of ensuring human production. Once women no longer have to reproduce, the primary rationale for keeping them at home would disappear; and with the entrance of women in the workplace, the family would no longer exist as an economic unit. Therefore, it is argued, that if technology could eliminate woman-the-reproducer, it could also eliminate the role of man-the-producer (Tong 1989: 75).

However, some feminist writers (Corea 1985a; Williams 1986; Walby 1990; Spallone 1989; Klein 1989; Sherwin 1992; Stanworth 1987; and Azizah al-Hirbri 1989) have noted that technological reproduction does not neutralize the patriarchal power structure, as Firestone argued, but it inverts it. It appropriates the reproductive power of women and places it in the hands of men who control new reproductive technologies. As Azizah al-Hirbri (1989) notes, "far from liberating women, reproductive technology will further consolidate men's power over women" (as cited in Tong 1989: 28). It is argued

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character and its presumed ability to capture the moral essence of womanhood (Davis 1994: 42) and feminists who embrace motherhood as a powerful, liberating experience of womanhood. It is argued that the "cult of motherhood" (Stanworth 1987: 17) attempts to press women in the direction of childbearing and in that sense, women's motivations for motherhood are socially shaped. In contrast, motherhood is viewed as an experience of great value for women and their children, where women are able to separate themselves from men. Rather than viewing motherhood as destiny for all women, motherhood and the experience of it can be seen as the epitome of womanhood.

that NRT's increase the medicalization of women's bodies and therefore, women's monthly cycles, pregnancies and menopauses become controlled by a predominately male medical profession. These men may pursue research directions which they feel are important, and which may or may not be beneficial to women (Williams 1986: 5).

Moreover, physicians controlling these technologies could restrict access to only those women who meet physicians' criteria for good mothers, criteria that may emphasize race, age, heterosexual relationships and middle class life style. The opportunity to use these technologies has political and social meanings and consequences regarding the role of women, and how women and children are viewed in society (Rodin and Collins 1991: 3). It is further argued that a woman who opposes the increased regulation of her body is defined as pathological, as a difficult patient or a pregnant woman who is working against the interests of the child she is carrying (Smart 1989: 113).

Other feminist theorists have noted that NRT's exist within a specific cultural, historical and medical context which shapes the development of these technologies (Smart 1989; Armstrong 1995; Rodin and Collins 1991; Jordanova 1980; and Oakley 1984). Historically, women's bodies, parental desires to procreate and the nuclear family have been depicted as being 'natural' within medicine and western culture (Jordanova 1980: 49). For example, in the Eighteenth century, female breasts were a powerful symbol of women's role in the family through their association with suckling babies. Women's destiny to bear children and suckle babies was used to define their whole body and mind, and therefore their psychological capacities and social tasks. This resulted in

women becoming a central part of contemporary social debates which focussed on the family as natural. It is necessary to consider some of the historical context of the medical profession's conceptualization of women and their bodies in order to gain an insight into the current concerns surrounding new reproductive technologies. As Jordanova (1980: 66) states:

while it is important to realize that nature was endowed with a remarkable range of meanings during the period of Enlightenment, there was also one common theme. Nature was taken to be that realm on which mankind acts, not just to intervene in or manipulate directly, but also to understand and render it intelligible. This perception of nature includes people and societies they construct.

Similarly, this view of nature can be applied to contemporary debates surrounding new reproductive technologies. Women's bodies are viewed as 'natural' in terms of their ability to bear children. Medical science acts, not just to intervene with NRT's directly, but also to understand women's reproductive capacities and render them intelligible and visible. The female body literally became the site for the "exercise of masculinist engineering of reproduction" (Terry and Calvert 1997:6).

However, underlying this argument is an assumption of how the female body is viewed. Women and their bodies are viewed as being passive, manipulated and as victims of medical technologies. Feminist concerns with the medical profession and representations and images of the body ignore how women actually engage with these ideas in their daily practices. For instance, how does the controlling nature of the medical profession and the objectification of women's bodies get worked out in the daily routines

of women who seek out new reproductive technology? Moreover, the emphasis on the oppressive character of a male defined technology and its use limits our ability to understand women as being other than manipulated and passive.

In addition, technology is viewed as culturally masculinized and its uses are always circular, maintaining the hegemony of patriarchal relations (Mazzeo 1988: 214). In this view, technology exerts power toward the object and maintains power in a circular manner. Alternatively, technology both shapes and is shaped by the everyday activities of individuals. As human agents, individuals are able to shape technology itself, albeit within pre-given social relations. This latter perspective is further argued by Wajcman (1991: x). She states:

a recognition of the profoundly gendered character of technology need not lead to political pessimism or total rejection of existing technologies. The argument that women's relationship to technology is a contradictory one, combined with the realization that technology itself is a social construct, opens up fresh possibilities for feminist scholarship and action.

Recently, a few feminist theorists have questioned the unilateral characterization of medical technology and its effects on the body as being oppressive; they point out that a woman's body can also be a site of resistance, agency and empowerment (Rapp 1991; Martin 1989; Humm 1989; and Woollett 1996). Writing from her own experiences of infertility, Humm (1989: 45) notes:

infertility is problematic because of the ways in which it has been technologized by male-dominated medicine. Yet, an experience of infertility must be kept problematic, must deliberately not cohere, if the individual who brings it forward is to see the contradictions honestly. But to rely on the apparent passivity of infertile women as a basis for a feminist explanation of the development of

medical technology is the narrowest kind of rationalization.

Others such as Martin and Rapp have noted the complex relationship between women as victims or as agents. Rapp (1991) goes beyond the medical-control and coercion component of reproduction by uncovering and documenting women's resistance to routinized medical assessments of in utero disabling conditions. Similarly, Martin (1989: 178-179) notes there is resistance to dominant birthing practices in hospitals among young black women in birthing centres devoted to the creation of new birth imagery and woman-centered birthing practices. The complex and often contradictory relationships of women to new reproductive technologies are even documented with the use of imaging technologies such as the x-ray and the ultrasound. While these imaging technologies increase the medical control over women's bodies and assist in discrediting women's experience of pregnancy, one must also note the positive aspect of this technology, i.e. women's pleasure in seeing their babies and increased knowledge of their own bodies (Marcus 1990: 261).

Furthermore, there is little attempt to understand the diverse ways in which women make sense of and experience infertility, and the reasons why they might persist with or resist medical treatments. In this way, infertile women's voices have been marginalized in feminist writing and "given no part in developing an understanding of, for example, the diverse meanings of motherhood in western industrialized and other cultures" (Woollett 1996: 75). It is also important to note that the experience of infertility does not solely centre around the use of new reproductive technologies to 'treat' infertility.

but incorporates all the experiences of these women.

This thesis focuses on the everyday experiences of infertile women and details their infertility experience from their own perspective. It is hoped that this will help bridge the gap in the infertility literature by documenting infertile women's experiences which have been previously marginalized. One of the aims of this thesis is to document the ruptures or cracks in the ideological discourses surrounding infertility and note the spaces where women reproduce, transform and resist dominant discourses of infertility. All feminist theorists have made important contributions to the study of infertility. However, any analysis that wishes to explore the nuances and complexities of the experience of infertility and the meaning(s) surrounding infertility must be experientially based as well as politically motivated.

### 2.5 Phenomenology: Merleau-Ponty and Smith.

The theoretical approach used in this thesis is phenomenology. Broadly speaking, phenomenology refers to a method of inquiry that begins with the individual and his/her own conscious experience (Wallace and Wolf 1991: 290). Since the aim of this thesis is to document the everyday experiences of infertile women, it is necessary to begin the inquiry with their life world. The term lifeworld refers to the world of our common, immediate experiences. Specifically, phenomenology is defined as a descriptive science that offers "an account of space, time, and the world as we 'live' them and tries to give a direct description of our experience as it is" (Merleau-Ponty: 1962: vii). Individuals gain access to and experience the world through their bodies. Merleau-Ponty used 'lived'

experience to illustrate that the body and mind cannot be represented as separate and oppositional. The body and mind are not only interrelated with each other, but with the world. In fact, the body is viewed as belonging to a particular space and time. As Merleau-Ponty (1962: 140-141) stated, "I belong to space and time, my body combines with them and includes them."

Rather than beginning his analysis with the division between the objective world and the experiencing individual, Merleau-Ponty (1962: 242) starts with the "preobjective" experience of that individual, "in all its indeterminacy and richness." For Merleau-Ponty, the preobjective world is where one begins the inquiry into the social world. The preobjective world consist of individuals experiences before they are reorganized by a professional to fit the dominant ideology of a social institution. Merleau-Ponty points the social researcher not towards the end, but towards the starting point of analysis in the "preobjective" world.

Similarly, Smith (1987) notes that making the everyday world problematic, as a method of inquiry, begins with an individual's "actual experiences" and works out from there to see how social relations, organizations and structures shape their life. Although Merleau-Ponty uses the term "preobjective world" and Smith uses the term "actual experience", both theorists refer to studying activities of individuals before they are reorganized to fit with the professional's objectives. For instance, Merleau-Ponty views the experience of pain (physical and emotional) as beginning in the preobjective body. But, in a person's perception of that pain and in his/her verbal description of it, the

distinction between subject and object and mind and body are heightened. The mind and body, reason and emotion can be arbitrarily separated by an act of conscious reflection and objectification. Smith (1990a) also contends that the "actual activities" of individuals become a resource for scientific technologies that produce objects that are recognizable to a scientific discourse. Medical practices are designed to localize suffering in a discrete site in the body, a site which can be made visible and subjected to therapeutic procedures and objectified (Good 1994: 132). The technology of science such as the microscope, x-ray and ultrasound systematically produces objects and events which can be found and recognized as the same in the multiple settings of scientific discourse, including its research practices (Smith 1999: 122-123).

A further example of the objectification process is how an individual's experience is transformed into a factual account. According to Smith (1990a), it is a series of socially organized practices in the "relations of ruling" that enable the factual account to emerge. First, there is the actual experience of the individual, which exists before the individual tells his/her story to the professional associated with a particular organization. Then there is the telling of the story whose development the professional can shape. The experiences of the individual are then reflected upon by the professional. This is the entry point of the written text. This is the point of transition from engagement in the living to reflection on the lived from the standpoint of the text (Smith 1990a: 78). Then the text gets worked into a factual account. This occurs when the experience of the subject is made into a report which includes the concepts and terminologies of the professional

(1990a: 78). When the actual experience is reorganized into the factual account by the professional, there is a disjuncture between the world as it is known by the professional and the experiences of the individual. The experiences of the individual are reorganized and reconceptualized to 'fit' with the professional's policies and objectives. Accounts are shaped to fit the text called for within the legal, medical, governmental, or educational institutions.

Therefore, if we begin the inquiry at the level of objectification, we cannot see or study the processes by which the body and its activities are objectified. Phenomenology as a theory concentrates on the experiences of individuals, noting the different social and historical contexts of the individual or what Merleau-Ponty called studying the body in its particular time and space. In *Phenomenology of Perception*, Merleau-Ponty (1962) emphasized that perception is always undertaken from a particular place or perspective. He stated that our perception of everyday reality depends on a "lived body" because we, for instance, move around a room in terms of sight, touch and smell (Turner 1992: 43). The "lived body" refers to the perception of the individual and his/her surrounding. He counters the claim that the subject is autonomous and separate from the world. Merleau-Ponty re-unites the mind with the body which opposes Descartes, who argued that the mind and body are separate entities. However, it should be noted that Merleau-Ponty does not argue that the body has agency. In contrast, Smith argues for the acknowledgement of women's standpoint and their expertise in applying or resisting dominant discourses of femininity. Smith(1990b) draws attention to the role of dominant

ideology and “the relations of ruling” in the construction of knowledge but also leaves open the possibility of women’s agency and resistance to the “relations of ruling”. In this way, the body is active and is capable of perceiving and activating itself in organized ways in relation to the social world. The body is viewed as being actively engaged in the “lifeworld” and as an agent in its own world construction.

Gaining access to the “life world” of individuals can occur through their telling of their story. Language gives access to individuals’ experience in so far as language is brought to experience (Csordas 1994: 11). Therefore, telling one’s story can be a means through which bodily experience is expressed. For instance, when people experience health conditions requiring medical intervention, they monitor and discuss their bodies. In the case of infertility, women who ‘choose’ to seek out medical treatment often talked about their bodies in relation to the medical treatment. How they talked about their bodies can tell us about the nature of their experience and how gender, age and ethnicity influence their bodily experience (Becker 1997: 29). Since individuals experience the social world through their bodies, any disruption to their bodies can disrupt how they perceive the world around them. Prior to a disruption, people move through their everyday routines giving little attention to the inner functions of their bodies such as the reproductive system. However, a disruption cuts through this routinization of bodily experience (Becker 1997: 192). Once a woman receives an infertility diagnosis, how she perceives and experiences her body and the world around it becomes disrupted. Subsequently, the woman’s perception of the world is “unmade” (Good 1994: 13) or

altered as a result of the infertility diagnosis. Using Merleau-Ponty's view of phenomenology and Smith's theoretical perspective allows one to study the ways in which women actively engage in the 'remaking' of their lifeworld.

### 2.6 Body(ies) Defined.

Many theorists have viewed the body as being socially constructed by dominant discourses<sup>2</sup> (Turner 1992; Lyon and Barbarlet 1994; Lupton 1994; McWilliam 1996; Merleau-Ponty 1962; Foucault 1978 ; Martin 1989; William and Bendelow 1996). For instance, Martin (1989) has noted that the representation of sexual organs in medical discourse reflects dominant conceptions of the role of the two genders in society and that the language for describing reproduction has been shaped by the dominant ethic of industrial capitalism. Moreover, Foucault (1978; 1980) focused on how 'bodies' are produced by discourses and his primary theme was the normalization of the bodies and populations by the social sciences and social institutions with the use of scientific knowledge. He documented how the body was transformed into the "docile" body by various discursive practices of knowledge systems.

However, the body is more than a social representation of dominant discourses.

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<sup>2</sup>The term discourse refers to particular ways of organizing meaning-making practices. It is a constructed ideology with images, ideas, language and categories that are internalized by individuals and define their reality. A discourse is also a systematic form of regulation and legitimation of power. Discourse as a form of regulation acts to limit the range of possible practices of people and organizes the articulation of these practices within a particular historical and social context although differently and often unequally for different people (Lewis and Simon 1986: 457-458).

Theorists have noted that 'the body' consists of both the "actualities of experience" (Smith 1987) and as a social construct (Martin 1989; Turner 1992; Merleau-Ponty 1962; Ots 1994 and Williams and Bendelow 1996). The "actualities of experience" refers to all the immediate experiences of the body such as feelings, sensations, perceptions and emotions. The body also reflects the processes by which it is socially constructed and where dominant discourses are inscribed on the body. Defining the body in this way allows one to view the body as a lived experience and also as an objective presence. As Turner (1992: 61) notes, "the body is a product of knowledge which cannot exist independently of the practices which constantly produce it in time and space. Alternatively, the body exists separately from its social construction."

By viewing the body as a social construct and as the "actualities of experience" one does not view the body as passive, but instead active in its involvement in the social world. Theorists, like Foucault have only seen the body as a social artifact rather than as an active source of social processes. To acknowledge individuals as active agents in their social world does not deny that their bodily activities are a subject of (and subject to) social power. Yet, they are not merely passive recipients of social discourses and therefore external to it. As Lyon and Barbalet (1994: 54) contend, "the human capacity for social agency, to collectively and individually contribute to the making of the social world, comes precisely from the person's lived experience of embodiment." In relation to this thesis, I am not arguing that the women do not experience their bodies in a segmented, objectified manner. In fact, their bodies do become objectified through a

number of different medical procedures. However, to deny that the women have agency and that they actively make sense of their lifeworld is to deny their own perspective and experience of infertility.

#### 2.6a Emotions and the Body

Another aspect of the body which must be included is the concept of emotions. Emotions and their experience are central in the women's infertility narratives. Often, the experience of infertility is filled with mixed emotions ranging from hope to disappointment and a sense of failure. Historically, emotions, like the body, have had a peripheral existence within sociology. This peripheral existence is embedded in traditional western thought which sought to divorce body from mind, nature from culture, reason from emotion and public from private. Emotions have tended to be dismissed as 'private', 'irrational', inner sensations, which have been tied, historically to women's 'irrational thoughts' and 'hysterical bodies' (Williams and Bendelow 1998: xv). Rather than viewing emotions as private, 'irrational' thoughts and desires of 'hysterical' women, emotions are better viewed as embodied, purposive and meaningful expressions of individuals (Csordas 1994; and Denzin 1984).

Furthermore, emotions are a part of the social, personal, biophysical, situational and cultural factors of an individual. William and Bendelow (1996: 37) suggest, using Giddens' structuration theory, that the social structure can be seen as both the medium and outcome of "emotionally embodied practices/techniques it recursively organizes." For Giddens' (1976: 121-122) social structures are both the medium and the effect of human

action. They exist neither apart from the activities they govern nor from human agents' conceptions of these activities. At the same time, they are also a material condition of these activities. Therefore, social structure both enables and constrains human agents' activities. In this way, emotions are not viewed as passive or involuntary responses to the world, but rather as ways in which individuals engage actively and even construct the world (Jaggar 1989: 153). It is through activities that individuals' emotions have practical directions and force which connect them to the social world and to each other.

By solely concentrating on how dominant discourses shape the body, one runs the risk of ignoring the bodily sensations of individuals, including emotions, and of viewing individuals as passive recipients of a dominant culture. In order to build theories of the body, one must ground theories of the body in concrete embodied experiences and the practices of individuals (Ettore 1998: 554). For instance, biomedicine and its discourse has its own particular view of the body. The body is viewed as an object and medical practitioners deal with malfunctioning organs or other subsystems of the body but not with 'the body'. The medical view of the body is partial because it does not include the "actualities of experience". Even though this is a dominant view in medicine, individuals' interpretation of and experience of their bodies can allow the emergence of a different view of the body that counters the medical view.

### 2.6b The Gendered Body

Thus far, I have argued that a definition of the body must include the immediate experiences of individuals such as feelings, sensations, perceptions and emotions as well

as noting the processes by which the body is socially constructed. I have also argued that individuals are active agents in constructing their lifeworld, albeit within pre-given social relations. Yet, I have not specifically discussed the concept of the gendered body.

Feminist writers have noted the importance of placing women's bodies within a social and historical context. In feminism, there is a rejection of the view that the body can be understood outside the realm of culture, society or politics (Bordo 1993). In fact, the body is viewed as gendered. One cannot separate one's gender, sexuality, class and ethnicity from the experience of the body.

For example, the medical view of the body as being partitioned off in subsystems has consequences when specific *gendered* metaphoric meanings are attached to those subsystems. Often, the focus of diagnosing and treating infertility is on the woman's reproductive system and the process of menstruation, fertilization and pregnancy.

Women's reproductive organs have symbolic and metaphoric importance in representing what is female such as being nurturant, productive, natural, whole (in terms of having all reproductive organs) and healthy. Body metaphors provide a way to communicate bodily sensation as well as social, cultural, and political meaning (Becker 1997: 84). For instance, pregnancy is a cultural symbol of the discourse on womanhood. Pregnancy affirms that a woman is normal, that she is a woman and that her body is healthy (Becker 1997: 85). In medicine, menstruation has a particular symbolic meaning ascribed to it. Menstruation not only carries the connotation of a healthy, natural female cycle but also of a productive system that has failed, making products that are wasted and scrap (Martin

1997: 29). Martin (1997: 30) further elaborates:

one reason the negative image of failed production is attached to menstruation is precisely that women are in some sinister sense out of control when they menstruate. They are not reproducing, not continuing the species, not preparing to stay at home with the baby, not providing a safe, warm womb to nurture a man's sperm. I think it is plain that the negative power behind the image of failure to produce can be considerable when applied metaphorically to women's bodies.

In relation to infertility, women not only have the symbolic meaning of menstruation as unproductive but it also has a metaphoric meaning of failure because it confirms that they are not pregnant. This can impact how the women view themselves in relation to other women who can have a child without any medical intervention. It is well documented that infertile women's self esteem and self identity can be negatively affected when they do not 'fit' the social ideology that equates womanhood with motherhood (Becker 1997; Whiteford and Gonzalez 1995). In sum, women cannot separate their gender, sexuality, class and ethnicity from the experience of the body. There is a tension between women's 'lived' bodily experience and the cultural meanings inscribed on the female body that always 'mediate' those experience (Conboy, Medina and Stanbury 1997: 1). In other words, there is a "line of fault" (Smith 1987) between the women's actual experiences and what is represented officially by the dominant discourses surrounding infertility.

### 2.7 Conclusion

In conclusion, I have given a brief overview of the literature surrounding infertility. The study of infertility can take many different vantage points: documenting the medical causes of infertility; exploring the psychological impact of receiving an

infertility diagnosis on women and their partners; and noting the social, political and historical context in which the infertility experience is embedded. Few infertility studies have incorporated the actual experiences of women as they maneuver through the medical maze of diagnosing and treating their infertility.

Feminist writers have debated the impact of using new reproductive technologies in treating infertility. The debate centres around the concept of the female body and whether such technologies provide 'choice' to women who have difficulty in conceiving a child or increase the medical control over women's bodies and their reproductive capacities. Women who 'choose' to use new reproductive technologies enter into a complex relationship between women as victims of such technologies and as agents, actively engaging in their lifeworld.

This thesis aims to explore this complex relationship by documenting the actual experiences of infertile women. My particular vantage point starts from the women's own perspective and how they experience and interpret their bodies after receiving an infertility diagnosis. In the following chapters that focus on presenting and analyzing the women's infertility narratives certain questions about the experience of infertility emerge. For instance, how do the women experience their own and the medically constructed/defined body while receiving medical treatment, what role do emotions play in the development of the narrative, how does the ultrasound and x-ray imaging shape the experience of these women, what meaning(s) do the women attach to the term infertility and what is the social and medical context of their experiences? These questions and

others will be further explored in the data analysis chapters. In the next chapter, I will document the research design and methodology used in this study.

## **Chapter Three**

### **Research Design and Methodology**

#### **3.0 Introduction**

This chapter will describe the research design and the methodology used in this study. First, I will outline my research objectives and explain why qualitative research techniques were used. Second, I will detail the research steps involved in gathering the data. Third, I will discuss the difficulties I had in gaining access to the population I intended to study and the limitations of my sample. Finally, I will offer some personal reflections on the research process.

The purpose of this study is exploratory and descriptive: to gain a broader and deeper understanding of the infertility experience from the perspective of women. I wanted to explore the experiences of infertile women within the social and medical contexts in which they occurred. The emphasis was on how infertile women talked about their everyday lives and how they made sense of their lives after receiving an infertility diagnosis.

#### **3.1 Qualitative Research**

A qualitative research approach was chosen for this study. Qualitative research is a method of inquiry that involves the direct observation of social phenomena in their natural settings and the assumption that social phenomena cannot be easily reduced to numbers (Babbie 1998: 280). Qualitative research is based on methods of data generation which are flexible to the social context in which data are produced rather than rigidly standardized or structured, as in some forms of experimental and quantitative methods

(Mason 1997: 4). Qualitative research enables the researcher to explore complex social phenomena and to document social phenomena in rich and meaningful ways. Qualitative researchers are most interested in how individuals perceive themselves and their settings and how they make sense of their surroundings through symbols, rituals, social structures, social relations and social roles (Berg 1995: 4).

However, qualitative research is criticized for its limited generalizability. This criticism is countered by the claim that quantitative methodologies cannot adequately explain complex and contradictory realities of social life. Qualitative research has also been criticized for being nonscientific and thus invalid (Berg 1995: 2). Yet, knowledge and the production of knowledge are not neutral or purely objective. Smith (1992: 97) maintains that dominant forms of knowledge production are designed to reflect the interests of those with the most power - traditionally, white males in modern western society. Knowledge is neither value free nor value neutral; the processes that produce it are themselves value-laden and those values are open to evaluation (Smith 1990a: 204).

Since my research aims to detail the daily lives of infertile women and the various meanings they give to their lives, a qualitative approach provides the best means of studying the perspectives and experiences of infertile women. My study was also guided by my theoretical assumption that women's lives and their everyday experiences are a "good starting place" (Smith 1987:128) to begin social research. My study was not suited to a quantitative approach that emphasized a scientific method and objectivity.

### 3.1a Smith's Methodology: Making the Everyday Problematic.

Smith's methodology, making the everyday world problematic, guided this research. The inquiry begins with the actual activities and experiences of women and works out from there to see how social relations, organizations and structures shape their lives. Smith (1992: 91) argues that the standpoint of women begins one step before the Cartesian shift that divorces the body from the mind:

The body isn't forgotten; hence the actual site of the body isn't forgotten. Inquiry starts with the knower who is actually located; she is active; she is at work; she is connected with particular other people in various ways; she thinks, laughs; desires, sorrows, sings, curses, loves just here; she reads here; she watches television. Activities, feelings, experiences, hook her into extended social relations linking her activities to those of other people and in ways beyond her knowing. Whereas a standpoint beginning in text-mediated discourse begins with the concepts or schema of that discourse and turns towards the actual to find its object, the standpoint of women never leaves the actual. The knowing subject is always located in a particular spatial and temporal site, a particular configuration of the everyday/evernight world...When we begin with our experiences as women, however, we were always returning to ourselves and to each other as subjects in our bodies.

Instead of beginning the inquiry with the concepts and schema of those who are in power, one begins the inquiry with the immediate activities and experiences of an individual.

Moreover, starting from the experiences of women and seeing how their lives are socially organized provides a means of exploring the disjuncture between our experiences and the dominant ideologies shaping our experiences. Smith (1987) identifies a disjuncture or line of fault that divides what is officially presented by the "relations of ruling" and what women experience when their experiences do not coincide

with the official discourse. This disjuncture provides a point of entry into an examination of the social relations and structures that inform both everyday experiences and official discourse. The disjunctures between experience and officially legitimated facts can provide a 'point of entry' into understanding how knowledge is socially constructed (Smith 1990: 204). An example of this disjuncture is how infertile women experience the medical treatment they receive and what is officially presented to them in the form of pamphlets that explain the treatment.

Critics of Smith's methodology note that it privileges the site of the knower. Terms like 'experience' and 'standpoint' denote a notion that some knowers have a privileged position of knowing associated with their identities (Devault 1996: 39). However, the argument is not that women know better by virtue of occupying these positions, but that the research done from the standpoint of women must be part of any adequate account of how the social relations, organizations and structures shape the daily lives of women.

Others have noted that taking a standpoint invokes the particular experiences associated with some particular people located in society. Critics suggest that the idea of a single 'women's standpoint' provides an account of experience that fits for only some women, mainly white, heterosexual women (Collins 1992; Ingraham 1994). Yet, Smith (1992: 90) notes that making the everyday world problematic, as a methodology, works to make

a space into which anyone's experience, how various, could become a beginning place of inquiry. 'Anyone' could be an Afro-Chinese, or Caucasian Canadian, an individual from one of the First Nations, an old woman or man, lesbian or gay man, a member of the ruling class or any other man.

From different sites of people's experiences, different social relations and structures are brought into view and their organization is explicated. Smith's standpoint does emphasize the local, subjective experience of an individual and does not entail an absolute truth claim. There is no claim to a unitary or final truth. As Smith (1992: 91) states, "I am not aiming for the one truth." Other feminist researchers have noted that the aim of conducting research is not gaining the ultimate truth on a particular social phenomenon, but feminist social scientists center themselves in knowledge development and widening of the feminist knowledge community (Stivers 1993: 424). In my thesis, I do not claim to represent the entire infertile experience among the women I interviewed. However, what I can offer is a glimpse into the infertile women's lives and how they live them. Making their experiences problematic can provide a perspective that those in positions of power are normally unable to see.

Finally, critics have noted that a woman's telling of her experience may simply reflect the biases of the larger society (Devault 1996: 40). Women's experiences are always communicated in language and discourse. Smith (1990a) argues that women's "bifurcated" consciousness and the experience of the line of fault encompasses the knowledge required to participate in social relations, organized largely through ideological processes. She calls for analysis of how women's activities are connected to

the interest of those who rule and how the "ideological processes of ruling" shape, without fully determining, women's accounts of their experiences (Devault 1992: 96).

### 3.1b Narrative as a Methodology

Along with Smith's methodology, I used a narrative approach to guide this research project. Since experience comes into view in its telling, listening to women's narratives and what they say about their lives provides insights into how these lives are organized and the meanings embedded in them. Narrative is the retelling of an experience that has a temporal ordering of events and is associated with change of some kind. Most narratives consist of a beginning, middle and end (Hyden 1997: 50). The narrative mode is a form for women to express and retell a story based on their experiences of infertility. Narratives provide neither an 'accurate' nor 'inaccurate' description of preexisting experiences, but instead, help give experience form. According to Becker (1997: 25), experience is reshaped in the narrative process and narratives are subject to change with subsequent experience. One reason a narrative approach has proven useful to the analysis of conception, assisted conception and infertility among women is because of its generic composition of beginnings and endings, obstacles and resolutions and seriality of events (Franklin 1997: 12).

One main criticism of using a narrative approach in social research is whether the story told by the participant is true. In other words, how accurately does the narrative reflect the lived reality of the story teller? Margaret Anderson (as cited in Reinharz 1992: 29) argues that if researchers assume that the women's claims are inaccurate they are put

in an untenable position of being unable to believe the subjects' report. A more appropriate research strategy is to look at the actual conditions of the women's lives from various vantage points and the way those conditions and context shape the women's responses. The studying of the actual conditions of women's lives from various vantage points may include talking with collaborative sources, paying close attention to the non-verbal responses of the participants and receiving feedback from the participants throughout the research process (Reinharz 1992: 29). In essence, the researcher looks at where a woman is situated and the context in which her experience emerges to check the validity of the story.

Researchers using a narrative approach also note that situational factors play a decisive role in the construction of narratives and that individuals continually produce new narratives in new contexts. It is not a question of obtaining *the* narrative, but rather of different possible narratives which are determined by situational factors such as the social context of the narrator and the interaction between the narrator and listener (Hyden 1997: 52). It is important to note that I interviewed the participants at a particular moment in their lives. If I were to interview them a month or a year later, their narratives would change because they would be in a different context in which the retelling of their experience emerges.

The methodological focus of this research centres on developing concepts and themes through narratives. As such, the results are time and context specific. Specificity is extremely valuable when one is interested in clearly understanding the social space in

which the experiences of individuals are embedded (White 1997: 102). In addition, the women's narratives were so compelling and thick with detailed description that it was difficult not to believe their stories. For instance, women who received medical treatment described every step of their treatment process and the women who experienced a miscarriage retold their experience with such emotion and with graphic images that I did not doubt their experiences or stories.

### 3.2 Sample

The participants of this study were selected using purposive sampling. The boundaries consisted of those women who had been medically defined as infertile (inability to conceive after one year of unprotected, well timed, sexual intercourse or after six months if the woman is over age thirty-five) and lived in the St. John's area. However, it should be noted that two women defined themselves as infertile and another two lived outside the St. John's area. I tried to maximize variation in the sample by interviewing women who were both in and out of medical treatment, women refusing medical treatment, women considering adoption and women considering remaining childless. The length of time that they spent trying to have a child ranged from one to seventeen years.

I contacted the administrator of the St. John's Women's Centre, The Care Centre for Women, and the Fertility Management Services (infertility clinic) at the Grace hospital to inform them of the project and gain their cooperation and permission in placing an advertisement in their establishments. Advertisements were placed in each of

these organizations, in the Evening Telegram and in a newsletter published by the St. John's Women's Centre. However, gaining access to the infertility clinic at Grace Hospital was difficult.

### 3.3 Gaining Access

The difficulty in gaining access to the infertility clinic was an unexpected hurdle in the research process. Although I had already had ethics approval from the Arts Ethics Committee at Memorial University, it was strongly suggested by Fertility Management Services that I go through medical ethics approval before my advertisement would be placed in the infertility clinic. After waiting seven weeks, I was informed by Patient Research at the Health Care Corporation of St. John's that I would not have to go through medical ethics. They based their decision on two main factors: i) my research was not going to cost the Health Care Corporation of St. John's any money; and ii) I was not asking for the participants' medical records.

The experience of having to wait to place my advertisement in the infertility clinic even though I had ethics approval from Memorial University raised an important question: was one ethics committee more qualified and therefore more valid than the other in making a decision as to whether my research was ethically sound? Since my research is a phenomenological study of infertile women's experiences, one could argue that the Memorial University Faculty of Arts Ethics Committee would have a better understanding of the complexities and nuances of this research method. Moreover, the criteria used by Patient Research of the Health Care Corporation of St. John's to

determine that I did not have to go through medical ethics was not based on whether the participants' were voluntarily involved and informed of any potential risks. In contrast, the criteria focussed on whether I was asking for subjects' medical records and if my research was going to cost the Health Care Corporation of St. John's any money.

Obtaining participants for this research project was also difficult. I hoped that after interviewing a few women about their experiences with infertility that they would inform other women they knew about my study in order to gain more participants. Yet, only one woman gave me a name of a friend who shared a similar experience. Some women found it difficult to tell their friends about my study because infertility and the experience of it were considered to be a private issue and not something that was readily discussed. Others noted that they did not know of any friends or acquaintances who had difficulty in conceiving a child. In total, I interviewed thirteen women for this study. Six saw my advertisement in the Evening Telegram, three in the infertility clinic, two in the Care Centre for Women, one in the Women's Centre Newsletter and one was referred to me by a friend.

#### 3.4 Initial Contact with Participants

Initial direct contact with potential participants was conducted by telephone or email. Further elaboration on and discussion of the project such as how long the interview would take and the approximate schedule of interviewing were presented to each woman. Issues of confidentiality and the woman's right to withdraw from the project at any time were also discussed by telephone or email prior to the interview. It

was important to allow the women some time to consider carefully their decision to participate before making a commitment. I conducted the interviews either at my home or the participants' homes. However, one interview was conducted in the sociology graduate room at Memorial University. The time and place of the interview were scheduled around the participants' work schedules and their personal preferences.

Establishing rapport and trust with the women was extremely important. In a study which aims to capture the phenomenological perspective of the infertility experience, it is necessary that the setting maximize trust and rapport between the interviewer and participants. As Erikson (1986: 142) notes, "trust and rapport in fieldwork are not simply a matter of niceness; a noncoercive, mutually rewarding relationship with key informants is essential if the researcher is to gain valid insights into the informant's point of view." One way that I established rapport and trust with the participants were by disclosing my own experience with infertility. The women were sharing intimate and sometimes painful experiences with infertility and I felt that I had a responsibility to be open and honest with them when they asked why I was conducting this research. Some feminist researchers note that self disclosure helps establish the interview as a 'true dialogue' rather than an 'interrogation'. As Reinharz (1992: 33) states, "self disclosure initiates true dialogue by allowing participants to become co-researchers." I tried to encourage an open dialogue where the women felt free to ask me questions about the research project and my own experiences which I believe promoted a meaningful conversation between myself and the women.

### 3.5 The Interview Process

A semi-structured interview schedule was used to interview the participants. Individual interviews allowed me to gain access to the women's narratives and provided me with an immediate, rich source of data. One of the benefits of interviewing is that it offers researchers access to people's ideas, thoughts and memories in their own words rather than in the words of the researcher (Reinharz 1992: 19). The goal of this research was to try to understand what it means to be infertile from the perspective of people experiencing it. I assumed that the women would have a better chance of telling me about their experiences as they saw them if their active participation in defining the dialogue were encouraged. Although I had specific questions that I asked the women, I allowed the interview to follow the natural order in which it occurred.

The interviews were tape recorded with the written consent of each participant. Each participant completed an Interviewee Release Form (see Appendix iv). This form provided the participant with relevant information about the study. It also informed the participant that her participation was voluntary and that she could at any time withdraw from the study. Names of the participants have been replaced with pseudonyms and I have altered the age and occupation of the women to conceal their identities. I also provided information about the infertility support group and a name of a psychologist at the Fertility Management Services if the women requested further information about support services in St. John's.

The shortest interview lasted two hours while the longest lasted four hours. Each interview was transcribed verbatim. I did not selectively transcribe for two main reasons: 1) I did not want to interrupt the flow of the narrative; and 2) I did not want to change the sequence of events in which the women told them. It was important to let the themes and concepts emerge from the data rather than imposing an external order on the narrative.

Once transcriptions of the interviews were completed and copies made, I began reading through the interviews and making notes in the margins. Having listened to each tape several times already, I found that I had sketchy ideas about some of the possible themes emerging from the interviews. I started coding each interview using letter categories. Coding refers to the process whereby the rationale for naming and conceptualizing data is developed and used. For instance, I used "BI" for body image, "F" for financial concerns of the medical treatment and "LCB" for the loss of control of one's body. At certain passages, I used multiple codes because the women discussed multiple categories in a single passage. I also analyzed the interviews by sectioning out large passages that dealt with one particular theme such as the meaning of infertility. Once all quotations from the women were separated, I began to analyze the passages. Certain key words were emerging from the data. For instance, all the women I interviewed used terms like frustration, alienation and loneliness to describe what it meant to be infertile.

For some women, particular themes emerged as more important than others. For

example, in Cindy's narrative, her experience of three miscarriages in a row was central to her story because it shaped how she defined infertility and how she viewed her own body. Furthermore, Jane's self identity as a lesbian, the experience of an ectopic pregnancy and her feelings of difference framed the development of her narrative.

I also interviewed a nurse who worked at the infertility clinic. This allowed me to see another 'point of view', that of a person who worked at the clinic. It also gave me an opportunity to ask questions about the diagnosis and treatment of infertility which clarified any ambiguities that I had about the process. Due to the busy work schedule of the infertility specialist and time constraints, I was unable to interview the infertility specialist.

Furthermore, I read numerous articles and pamphlets and watched informational videos provided by the infertility clinic to couples receiving medical treatment. This provided me with another source of information about the infertility experience presented by the medical profession. As I began to analyze the interviews, I returned to the text provided by the medical establishment with "new eyes" (Smith 1992: 93) and identified points of disjuncture or lines of fault for women who were diagnosed with infertility and who were receiving medical treatment. I also toured the infertility clinic to get a sense of the physical setting of where some women received medical treatment. I viewed the waiting room, individual examination rooms and the various medical equipment used to treat infertility such as the vaginal ultrasound used to track the development of the follicle and the medical equipment used to perform artificial insemination. These different

methods of 'points of entry' into the infertility experience provided a more substantive picture of the reality, and a richer, more complete array of symbols, concepts and meanings surrounding the infertility experience (Berg 1995: 5).

### 3.6 Limitations of the Sample

Since this research is exploratory in nature and there exists no list to use as a sampling frame for this population, I cannot generalize to the larger population and, therefore, this project will forego generalization in favour of exploration. Moreover, my sample for this project was limited to interviewing women who were white, middle class and had at least two years of post secondary education. I did not interview any women who were from a visible minority or who were economically disadvantaged. Due to the lack of medical insurance coverage for infertility treatments and the expense of them, it would be unlikely that women who are economically disadvantaged would be able to obtain medical treatment for infertility. These factors limit the accessibility of this group and draw attention to the socioeconomic complexities of 'choice' in their wish to have a child. The fact that my sample did not include women from a visible minority group may be largely due to the fact that St. John's has a low percentage of ethnic minority groups. Racism in Canadian society has a complex impact on infertility issues and this merits a separate investigative study.

### 3.7 Personal Reflections on the Research Process

During the interviews, I tried to promote a sense that we were learning together and no one has a monopoly on 'the truth'. For instance, I did not claim that I was an

"expert" on infertility issues and when the women asked why I was researching their experiences I replied that my personal experiences with infertility prompted me to do this research. I fully disclosed my personal experiences with the women I interviewed. I also asked the women if they had any questions about myself or the research process. Moreover, I asked the women to clarify any medical and technical terms that I did not understand. If further clarification was needed, I recontacted the women and also contacted the nurse at the infertility clinic to help me understand some of the diagnostic tests and medical procedures that the women received. All women I interviewed were from Newfoundland and I asked all the women the same questions.

Most women commented that participating in the study was helpful in that it gave them an opportunity to share their narratives with others. For instance, Cindy noted that one reason she participated in this study was to "contribute to somebody else's experiences" and knowing this, she "would be happy that [she] did." Wendy, in a similar tone stated "it is really good for women to talk about their experiences and get them out there because it helps you feel less alone and isolated."

Moreover, after each interview, I wrote extensively in a journal about my experiences interviewing the women. This served three functions. First, it allowed me to write about my personal thoughts and ideas about infertility or what Kirby and McKenna (1989: 32) called a method of tracking your "conceptual baggage." Through my writing I attempted to sort out my own feelings and experience of infertility from those presented in the interviews.

Secondly, I wrote on the themes, issues and concepts that were emerging from each individual interview. For instance, in Cindy's narrative, her experience of three miscarriages in a row was central to her story and Jane's self identity as a lesbian framed the development of her narrative. I also wrote about themes that were emerging across the interviews, such as the experience of the emotional roller coaster ride and the experience of multiple losses among the women.

Finally, writing a journal allowed me to 'debrief' after each interview where I wrote about my feelings. Every woman retold experiences that were traumatic and filled with emotional and physical pain. I was physically and emotionally drained from hearing their narratives and, at times, I wanted to escape the images that the women painted as they told their stories. I also relived the narratives when I began to transcribe the interviews. I could see the woman's face, tears sliding down her cheek and hear her declarations of pain. For me, the research process was an embodied experience.

### 3.8 Conclusion

In sum, I used a qualitative approach in this study because it best suited my research aims: to gain a deeper understanding of the infertility experience from the perspective of women and how they made sense of their lives after receiving an infertility diagnosis. The research process presented me with a number of challenges, that of gaining access to the infertility clinic, obtaining participants for this study and the 'stress' of interviewing the women who retold their stories that were filled with physical and emotion pain, joy and hope. The remaining chapters are devoted to the presentation and

analysis of the narratives. The narratives provide a glimpse into the daily lives of these women and what it means to be infertile.

## **Chapter Four**

### **Shaping the Infertility Experience: The Meaning of Being Infertile in Newfoundland.**

#### **4.0 Introduction**

This chapter has four aims: 1) to provide the reader with a demographic description of the participants in terms of age, occupation, income, marital status and education; 2) to describe the infertility clinic and the impact of 'living on the rock' for these women; 3) to provide a portrait sketch of the women's narratives and 4) to discuss how the women define infertility.

#### **4.1 Demographic Information**

All the women I interviewed were white and middle class, with at least two years of post secondary education except for one woman who had a high school diploma. The age of the women ranged between 26 and 45 years old. Eleven of the thirteen identified themselves as married, while one was single and another was in a same sex relationship. At the time of the interviews, seven of the women had children and six did not.

In terms of employment, eight women worked on a full-time basis outside the home in a variety of occupations such as nurses, teachers and social workers. The remaining five women worked in their homes doing childcare and housework. Out of these five women, three were homemakers and took care of their children, one was on maternity leave and another was unemployed. Income levels varied depending on whether the household was relying on a single income, usually that of the partner, or if the household had dual incomes. The single woman had an income between \$10,000 and

\$14,999, whereas the income of dual income couples ranged from \$15,000 to \$110,000. Specifically, one couple had a single income between \$15,000 and \$19,999, four couples had dual incomes between \$40,000 and \$69,999, four couples had dual incomes between \$70,000 and \$89,999 and three couples had dual incomes of \$90,000 or more. It is important to note that the women I interviewed for my study were relatively affluent compared to the average income of families living in St. John's. According to the 1996 Canadian Census, the average income of married or common-law families for St. John's and the metropolitan area was \$57,114 a year (www.statcan.ca; 1996). Except for the single woman who had an income below the poverty line, ten of the twelve couples were either slightly above or well above the average income reported in the Canadian Census. Due to the lack of medical insurance coverage for fertility treatments and the expense of them, it would be unlikely that I would interview a high number of women who were economically disadvantaged because they would be unable to obtain medical treatments for their infertility. Lack of medical insurance and the high cost of fertility treatments both limit the accessibility of the poor to fertility treatments. This points to the socio-economic restriction of their choices in their attempts to have a child.

#### 4.2 The Infertility Clinic

There is one infertility clinic in St. John's, Newfoundland. At the time this thesis was written it was located on the second floor of the Grace Hospital where other gynaecological and obstetrical clinics were held. As a result, women undergoing medical treatment for their infertility may be waiting in patient rooms with other women who are

pregnant. The infertility clinic is staffed by one infertility specialist or a reproductive endocrinologist and one RN nurse who works part-time. The infertility clinic handles approximately 500 appointments annually, including some repeat visits. There is a four to six month waiting list to see the infertility specialist. The medical treatments that are available at the infertility clinic include ovulation induction<sup>1</sup>, artificial insemination<sup>2</sup>, and an in vitro fertilization satellite program.

In vitro fertilization or IVF involves a technique in which an egg is fertilized in the laboratory and the resulting embryo is then implanted by a doctor in a woman's uterus. The in vitro fertilization satellite program allows the woman to start the procedure of taking the fertility drugs to induce ovulation before she and her partner travel to another province to get the actual procedure done. This may reduce the time and cost of staying in another province by two or three weeks. The nearest infertility clinic that provides IVF is located in Halifax, Nova Scotia. The infertility clinic in St. John's does not offer sperm banking (freezing of sperm) or artificial insemination by donor. Artificial insemination by donor involves taking sperm from an anonymous donor and placing it into the uterus of the woman. For women having this procedure done, they must either see a gynaecologist that does not work at the Grace Hospital or travel to another infertility

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<sup>1</sup>Ovulation induction is a procedure in which oral or injectable fertility drugs are given to stimulate ovarian activity in women who are not ovulating normally.

<sup>2</sup>Artificial insemination is a procedure in which a sample of sperm from the male partner is prepared and placed either in the cervix or high in the uterus of the female partner through a fine catheter.

clinic outside Newfoundland and Labrador.

Women living outside St. John's have the added cost of travelling to and staying in St. John's while they receive medical treatment. One woman noted the difficulties she had taking time off from work to travel to St. John's for her medical treatment. Although she had family living in St. John's, she decided to stay in a hotel because she did not want her family to know she was infertile or receiving medical treatment. For women living outside St. John's, obtaining medical treatment for their infertility is difficult because of the added cost, time and energy. Some women discussed the limited number of choices in receiving medical treatment at this clinic compared to other clinics across Canada. For instance, one woman commented that "the service for women at the time was poor compared to what was available to other places. If you are poor and infertile that is worse. It is really bad because when you are in this province, there was nothing. It was really hard." Another woman added, "I found here too that you are so limited in Newfoundland to what you can have done and just your knowledge of it all."

For many of the women, seeking out medical treatment requires taking injectable fertility drugs on a daily basis. However, the availability of the injectable drugs at pharmacies in St. John's is problematic. No pharmacist in St. John's specializes in fertility drugs. Therefore, many of the injectable drugs have to be shipped in from other pharmacies across Canada and the United States. This impacts all the women who need to take injectable drugs in two ways. First, women have to travel all over the city locating one particular fertility drug. Secondly, women have to wait for the injectable drugs to

come in from another pharmacy. One woman noted that travelling throughout the city was difficult because the "appointments and pharmacies were scattered all over the city. If we didn't have a car, it would have been another stressor." Since many of the injectable fertility drugs have a short life span, it is difficult for the pharmacies to keep them on hand all the time before their shelf life expires. Women who are taking fertility drugs may find themselves losing not just days or weeks during medical treatment, but whole months because they have missed the starting date of their menstrual cycle and have to wait for another menstrual cycle to begin.

"Living on the rock" and having one infertility clinic and specialist located in the capital city shapes the everyday experiences of these women. It not only affects what treatment is available to them in this province, but it also affects their choices - the choice to consider IVF as an alternative, the choice of which medical doctor to see and where to go for medical treatment. The women face many delays while seeking out medical treatment for their infertility. These delays include waiting four to six months to see the infertility specialist, to stopping the medical treatment altogether when the infertility specialist is on vacation and waiting for the appropriate fertility drugs to come in at local pharmacies.

#### 4.3 Her/Stories

Between the months of January and June 1999, I interviewed thirteen women for this study. All shared the common bond of experiencing infertility, but all had unique characteristics as well. The range of infertility experiences included women who had

already adopted, women considering adoption, women both in and out of medical treatment, women refusing medical treatment for their infertility and women who were successful in having a child after receiving medical treatment. Ten of the thirteen women had been medically defined as infertile and three are partners in marriages with unexplained infertility (where there is no known medical reason for the couples' infertility). The narratives of these thirteen women reflect this variance. They give a rich and complex description of their experiences and individual perspective on the world. In the following pages, I will present a portrait sketch of five women. These five women were chosen to give the reader a sense of the difference of their stories in terms of their social context, medical history and the experience of being infertile. The five narratives are also drawn upon to discuss how the women define infertility in the next section of this chapter. It should be noted that these five narratives in no way exhaust the descriptions of the infertility experience among the thirteen women in the study. The remaining portrait sketches of the women can be found in the *Epilogue*.

### **Jody's Story**

At the time of the interview, Jody was 35 years old, married and working full-time as a legal secretary. After seeing many doctors including family physicians, gynaecologists and specialists, Jody was diagnosed with pelvic inflammatory disease. It is an infection and inflammation of the pelvic organs which is caused by bacteria or viruses which left her fallopian tubes blocked with scar tissue. Jody's pelvic inflammatory disease had been misdiagnosed and left untreated for five years. In total, it

had been ten years of blood tests, two surgeries to remove cysts from her ovaries and a number of stays in the hospital to monitor the infection. Jody is angry at the fact that she was misdiagnosed for five years and that she did not have the option to choose to have a child. The decision was made for her. As she stated:

I was not given an option. It is different when you are given the option. You can say, "I am not going to have any more children", but when you cannot have the choice it is very difficult. You feel like there is a piece of you missing...by the time it was caught it was too late. I was finished. I was lucky that I didn't have to end up having a hysterectomy.

Jody and her partner decided that ten years of trying to have a child was long enough and they would not seek out any medical treatment for Jody's infertility. Jody succinctly stated:

I was not willing to sacrifice no more a part of me that I had already sacrificed over the past ten years. I was not going to lose anything else that was a part of me. If I want a child, I will find another way...It's a barrage of tests. It's physically and emotionally draining; so you have to be prepared to be pricked and prodded at. I think I have been through hell and back again. Fifty times with doctors, tests, the different personalities of doctors, and to them I am just a number. I am not a woman trying to have a child. I am one of thousands here in this province who are having difficulties. I am 34 now, and I don't want to go through any more crap. I am not going to try. I am not going to put myself through it. I don't want to **torture** myself. I want to **heal** myself and move on.

The healing process began when Jody realized that it did not matter if she did not give birth to a child. Having a child and being a parent was much more than that. Jody and her partner decided to look into foster care and be a part of the lives of children around them: their nieces and nephews. Jody and her partner have thought about adoption, but she noted that the waiting list is too long and international adoption is too expensive.

Although Jody has come to some resolution, this journey was a long and difficult one and is still without a final ending.

### **Wendy's Story**

Wendy was 31 years old, single and has an arts degree. She was unemployed at the time of the interview and waiting for another project to begin. Wendy is a free lance writer. Wendy's story is different from the other women's stories because she was single and she was the only woman who was not actively trying to have a child. When Wendy was three years old, she had a hysterectomy (removal of the reproductive organs) due to a hernia. Wendy has not sought out any medical treatment for her infertility and she noted at this time in her life, she does not feel she is ready to have a child through adoption.

She explained:

I think that having a child is such a huge responsibility. I don't think that I would be able to live the creative life I like to live. I like to be able to do what I want to do on that day and be able to pursue creative projects, you know, the theatre, music or activism. I would like to have a child, but I don't think now is the time. If I had a more secure lifestyle, then I would consider adopting an older child. I don't feel incomplete without a child you know; like some women I know would be devastated, devastated if they knew that they could not have a child in their life time. I don't feel that way.

Through her creative projects and by doing research on hysterectomies, Wendy explored what it means to be a woman and what infertility means to her. Although Wendy has a different experience from the rest of the women I interviewed, she also shares a commonality with them: the experience of infertility can be an isolating process. Wendy recalls going through puberty as a particularly isolating process because she did not share

the same experience with other young women. Wendy did not menstruate and needed to take hormones to induce puberty. For Wendy, taking hormones to develop breasts and develop as a woman felt unnatural and shameful because it was a very taboo thing to talk about with her friends and family.

### **Jane's Story**

Jane is 34 years old, has a university degree and works full-time in the social services sector. Jane is in a common law relationship with her same sex partner. She and her partner have been trying to conceive a child for four years. At the time of the interview, Jane had received fourteen artificial inseminations by donor. One of the artificial inseminations was successful, but it resulted in an ectopic pregnancy<sup>3</sup> where she lost the fetus and her left fallopian tube.

For Jane, the experience of the ectopic pregnancy was central to her story. Not only was it a traumatic experience and a sense of loss, but it brought together her identity not as woman who lost a pregnancy, but as a lesbian who lost a pregnancy. In this passage, she discusses her loss, being a lesbian and in a room with other women who had miscarriages:

Like you are in this room with all these women who miscarry or are in with DNC's or all this gynaecological problems which was really good for me to be there because it was almost comforting for me to know that other women were

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<sup>3</sup>An ectopic pregnancy is when a woman's pregnancy occurs in her fallopian tube rather than in her uterus. An ectopic pregnancy can never come to term. It is a dangerous condition and always requires surgical intervention to save the woman's life. She will always lose her fallopian tube.

going through the same thing as me. So it was good to know that other women had lost their babies too. It was almost a comfort thing because other women knew what I was going through...The nurses came with information for the father, things that the father would be feeling and no one came out to give things to Patty about what she was going through. Like she is not even recognized that we are in pain as a couple and that was really hard, that was. It was an insult to injury. So you are grieving, grieving the loss of your baby and then you are not being recognized as a couple who lost a baby. No one asked, you know.

After Jane's ectopic pregnancy she had a few more artificial inseminations by donor, but they were unsuccessful. Jane explains that in the last few months it has been difficult to schedule a doctor's appointment to get an artificial insemination by donor because her timing has been off in regard to the egg releasing on her left side where she has no fallopian tube and she has had to work around two doctor's work schedules. When I interviewed Jane, she and her partner were waiting to schedule another appointment.

#### **Cindy's Story**

Cindy is married, between the age of 35 and 39, has a degree in education and works full-time as a teacher. Cindy and her partner have two children without any medical intervention. However, between her first child and second child, there was a period of time where Cindy miscarried three times in a row. It was not a question of getting pregnant, but staying pregnant. Cindy described this period of time as being "pregnant or getting over being pregnant for about six years." The three miscarriages were physically and emotionally difficult on her body. Cindy recalled being told by a medical doctor to go home and wait to miscarry for the third time. Cindy described the waiting period as being filled with disbelief and doubt: "I knew of course, my rational

mind knew that I was not carrying a live baby or anything, but my irrational mind-every time I had a twinge of gas or something like that, I thought they were wrong, I thought that they were wrong.” After having the third miscarriage, Cindy noted how she officially fit into the category of a high risk pregnancy and the services that became available to her when she got pregnant for the fourth time. She stated:

First of all, there was no indication that we would fall into the category of, it is called the repeat, repeat miscarriage or missed abortion, or high risk pregnancy. Like there are all sorts of labels on it. Then because I had been officially fit into their category of *officially* of a high risk pregnancy I was referred to a specialist. Before that, they said anything under three times, it is not officially high risk. Anything after that was officially high risk. So you could avail the other services after. So I was referred to a specialist who saw me every week and watched everything from my hormone counts to have blood work done. Every week I was monitored, just like a baby myself. Every single week. And that was a successful pregnancy which I went three weeks late of all things. So, that's ten years now this year, or it seems like ages ago.

During the six-year period of being pregnant and getting over being pregnant, Cindy and her partner considered adoption. However, Cindy noted that she had to first get past the part that her body would not do what it should have done and then she would be ready to adopt.

### **Julia's Story**

Julia is the last woman I interviewed and we had to reschedule our meeting numerous times because she does not live in St. John's. Julia is 31 years old and has been married for six years. She works full-time as a secretary and her partner is self employed. As soon as Julia and her partner got married, they started to try to have a child. It was not until the third year of trying to conceive a child that Julia and her partner decided to go to

their family doctor to seek out medical treatment. After Julia had a few blood tests and her partner had a sperm count, they were both referred to the infertility specialist by their family physician. Last year, Julia received one artificial insemination and it was unsuccessful. While taking the injectable fertility drugs needed for this treatment, Julia experienced side effects such as mood swings, weight gain and vomiting. For Julia, this was too much at the time, and she explained that now, "we are officially not trying because you are not having a life and you are not healthy mentally either."

Julia also discussed the frustration she felt when the infertility specialist diagnosed her and her partner as having unexplained infertility . She stated:

When we found out there is no problem you are annoyed. Like there is nothing to get fixed. It is frustrating and it is just this big wonder, a big question mark. It is difficult not knowing a cause because if you knew, then you would know what not to do. You would gear your life around it and say, "Well, I am being my own worst enemy. I should do this instead." You are barking up the wrong tree. I think part of the purpose of us being so busy is probably to divert our attention from not being able to have a baby...Like I work full-time, and my partner has his business. I also do my sewing and crafts and everything and courses as well. Like, how does that affect your mind? Is your mind telling your reproductive system that this person has way too much on the go and now is a bad time to get pregnant. Is that what is going through my body, you know?

Julia and her partner have put their names on the adoption list and wonder if they will ever get a chance to adopt an infant. If Julia and her partner have not adopted a child by the time Julia is 35 years old and she is not pregnant, they will consider in vitro fertilization. For Julia, the age of 35 years old is the best time to have in vitro fertilization because she will consider herself to be in the most 'fertile' period in her life. This view is

connected to how she defines infertility and fertility.

#### 4.4 Definition of Infertility

Defining infertility is problematic. Scientists, physicians and lay persons do not agree about the 'normal' length of time it takes to get pregnant or what infertility is. According to some scientists, infertility is a "disease of the reproductive system often diagnosed after a couple has had one year or more of unprotected intercourse, or if the woman has been unable to carry a pregnancy that results in a live birth" (Resolve 1996). On the other hand, physicians typically define infertility as "inability to conceive after one year of unprotected, well-timed, sexual intercourse or after six months if the woman is over age 35" (Garner and Patton 1996:20) or "a couple's failure to conceive after regular unprotected intercourse for a period of at least one year" (Ziehl 1994: 137). Lay persons are more simplistic in their approach to defining infertility. They define infertility in terms of a couple having difficulty in conceiving a child or the inability to get pregnant.

As stated in chapter three, I adopted the medical definition of infertility to set the parameters around the population I intended to study. However, it is important to note that this definition, as well as the other definitions, are inherently gender biased. Phrases such as the 'inability to conceive' or 'difficulty in conceiving a child' and the inability to 'carry a pregnancy that results in a live birth' associate infertility with women because only women are able to conceive a child and carry a pregnancy. According to Steinberg (1990: 91), underlying these definitions is a bias which situates responsibility for infertility where it has historically been located, with women. This assumption is at the

base of many contemporary sexual stereotypes surrounding infertility. The underlying notion is that anything to do with children is a woman's concern, that women are responsible for both contraception and conception, and thus the tendency is to see infertility as a female problem.

In addition, the medical and scientific definition of infertility is limited in its view. Infertility is viewed as a disease that is physiological and the body is the sole focus of inquiry. Informing this view is a biomedical assumption that views the body as separate from the mind. This assumption has provided a base upon which scientific medicine rests which has sought to separate body from mind, reason from emotion, rational from irrational and biology from culture or what Bordo (1986: 134) calls the "masculinization of Cartesian thought." The body not only occupies a separate sphere from the mind, but it also occupies a superior position to the body. Other dualisms such as male and female, reason and emotion, and culture and nature were also a part of the mind/body dualism. In biomedicine, the body, emotion, and nature were associated with women and the mind, culture and reason were associated with men. This philosophical paradigm equated women with nature and its unruly forces, whereas men were equated with culture and reason. William and Bendelow (1996: 27) argue that this dualistic conceptualization of the body is still present in medicine today. Instead of the 'incarnate body' it is the 'somatic body' which is emphasized.

Among the thirteen women interviewed, ten defined infertility using the medical definition and three did not. However, all the women noted that the medical definition

alone was inadequate in defining infertility and what it means to be infertile. To them, infertility was not just a medical problem located inside the body. It was a part of their whole lives, socially, economically and psychologically. In short, the medical definition did not 'fit' with their actual lived experiences. The women themselves noted the separation of science from emotion and the body from the mind. They also noted the emotional and social aspects of infertility in their definition of infertility and what it means to be infertile.

For instance, when I asked Rachel about her definition of infertility, she defined it as being "unsuccessful in becoming pregnant without any medical interventions. Just natural." But when I asked her what words she used to describe her condition Rachel replied, "fragile, depressed and devastated" and she went on and stated, "This is not just a medical issue. It is a very emotional issue. You are not just treating a disease or symptom." Rachel clearly made the distinction that infertility was not just a medical, physiological issue, but an emotional one as well. Similarly, Teresa noted the scientific and medical definition, but also stated that infertility is a lonely disease and that "science is not an emotional thing." When the women discussed what it meant to be infertile, they discussed it in terms of emotions and feelings of frustration, alienation, annoying, devastating, challenging, stimulating and in terms of bitterness, loneliness, grief, fragility and pain. The women did not include the emotional and social aspects of infertility when they focussed on the medical definition of infertility.

The clearest distinction between the medical definition and the emotional and

social aspects of infertility was made by Lauren. When I asked how she defined infertility, she stated, "when a couple has a difficulty in having a child, during a period of time, a year of infertility and they have to have treatment for their infertility." However, Lauren's definition of involuntary childlessness included the emotional and social aspect of infertility. She explained:

[Involuntary childlessness is] wanting to have a child and it doesn't matter how much effort you put into it. I guess the despair that you feel every time it doesn't work out. That is pretty hard thing, going through the tests and money and so on and in the end it does not work. It is something you really want and it is something that you can't get...I think there is a difference between infertility and involuntary childlessness. I mean a person could find out that they have an infertility problem and not be affected. I think involuntary childlessness is if you really want children and you just can't have one. No matter what you do. I guess infertility is more a medical, to me it is more of a medical term, a medical definition, whereas, involuntary childlessness there is the emotional thing attached to it. That is the difference if that makes sense.

The question on defining involuntary childlessness gave Lauren an opportunity to discuss the emotional aspect of infertility. Other women have meshed the physical and emotional aspects of infertility and the mind and body distinction in their definitions of infertility. For example, Kathy defined infertility as the inability to conceive children "whether it was physiological or psychological in nature." Kathy also noted that she did not like the use of the term infertility because of the negative connotations surrounding it. She preferred to use the term "child free" to describe her condition.

Wendy, who had a hysterectomy at a young age, chose to define her condition not in terms of infertility, but in terms of fertility. She redefined what it meant to be fertile even though she noted that she was physiologically 'infertile'. In the following quote

Wendy succinctly explains why she chose to look at the ways she is fertile and how being 'infertile' has been a frustrating and challenging process. She stated:

It is challenging, frustrating and stimulating in a sense because I feel like in some ways I have come to terms with it. I have allowed it to lead me into certain directions. So I think in a sense I have grown from it. But all those negative and positive things, it has been extremely, extremely frustrating in a lot of ways. I have tried to look at it in a positive sense. So I consider it a challenge...Infertility is really interesting because it is something that I have thought about a lot and I have been trying to write about. To me, infertile is to be sterile or barren. You know, all these other connotations come to mind, desolate or barren. Many years ago, I mean if a woman was not able to bear children then, that is what exactly you were considered. You can be considered worthless. With some of the things that I have read from the Victorian Era, a woman would be of little value if she could not bear children. So to me, the concept of fertility and infertility is really an interesting concept. So for me, I have been exploring the opposite, fertility. Fertility for me is creativity. I am looking for other ways that I can explore my creativity and bear children in another sense. Writing music, writing poetry, writing songs, creating a nice home or just, you know through activism in the sense of maybe trying to build a better world for all children, that sort of thing. I am looking for ways to balance that limiting definition of infertility with other ways of being fertile or creative.

Wendy further described what it meant to be 'infertile' and 'fertile' with the use of a metaphor of a barren in Newfoundland. For Wendy, the barren is both a desolate and lush place. She noted:

barrens here in Newfoundland are really, they are, sometime when you look at them during the year they can be rugged and desolate, and sparse and cold. Then at other times a barren is really a lush and colourful and hearty place you know. So things grow there, but they just grow differently. They grow strong. Anything that grows on a barren, the trees are very, they might be twisted and stuff like but, they are strong and they can withstand the elements. There are berries and all sorts of things like that on the barren and those are the sorts of things that I am exploring.

In this quote, Wendy described the barren and 'infertility' as sparse, lush and colourful.

places place where things grow differently and can withstand the harsh elements. According to Wendy she is neither infertile nor fertile, but she experiences both as the seasons change from winter to summer. Wendy along with the other women noted the limiting aspect of the medical definition of infertility. They found ways of redefining it which 'fit' with their experiences of what it means to be 'infertile'.

Moreover, the women's social context and their experiences with infertility became a backdrop which the women drew upon to define infertility and discuss what it meant to be infertile. Two examples that illustrate this were given by Cindy and Jane. The social contexts of these women's lives were different and their definition and meaning of infertility stem from their experiences. As previously noted, Cindy gave birth to a child 'normally' and then had three miscarriages in a row. I asked Cindy if she considered herself infertile and her following response included how she defined infertility. She stated:

I think we did [consider ourselves infertile] even though getting pregnant was not the problem. Staying pregnant that was the problem. So I don't know, like the strict definition is, for some people it would include not being able to conceive, but for us, it included not being able to actually give birth to a live baby. I mean, before that happened to me, I was like any body else. As soon as you find out that you are pregnant you tell people, but sometimes you just don't know. I just learned to be cautious about that sort of thing. You are not clear about it until that baby is in your arms because you don't know.

For Cindy, experiencing the three miscarriages was a sign of infertility even though the medical doctors could not find a reason for her difficulty in having children. Cindy's definition of infertility not only included the inability to conceive, but not being able to

carry a pregnancy to a live birth.

In contrast, Jane defined infertility both in terms of external and internal factors. Before she had an ectopic pregnancy, she defined infertility as having external barriers or problems in getting pregnant. The barriers included working around the schedules of two professionals. However, after Jane had the ectopic pregnancy and then lost both the fetus and one of her fallopian tubes, the term infertility made more sense to her. She explained:

*So now, like to me infertile makes more sense in my reality because I think of infertility as a barrier to getting pregnant. Ok, now I have a barrier in getting pregnant because I have one fallopian tube and it makes my chance much more, it lessens my chances in becoming pregnant. I didn't know. I guess I am starting to come to grips that maybe I am infertile or I got unexplained infertility or maybe that was the case, but it wasn't a term I used readily. It is only now that I have sort of saying ok, maybe I am infertile or I do have problems because of the barriers. One might be the actual barriers of one fallopian tube, one insemination per cycle and part of that is the financial because it costs me \$325 every time I try to get pregnant...Infertility, I guess, for me is issues, problems, concerns that prevent you from getting pregnant and staying pregnant and sometimes it is internal and sometimes they are external. Maybe I have external infertility. I don't know (laugh). That is where I am. That is what it means to me.*

Included in Jane's definition of infertility and what it means to be infertile is the physiological problem of having one fallopian tube and how this lessened her chances of getting pregnant. However, it also included external factors such as the schedules of two doctors and the financial cost of the actual insemination procedure. Jane also noted that she does not really know if the term infertility is appropriate for her and does not know exactly when she is infertile and when she is not.

For some women, trying to fit their experience with that of the medical definition

was difficult. For the women who were 'successful' in achieving a pregnancy, the question arises as to whether or not they still considered themselves infertile. I asked the women who had children if they still considered themselves infertile. The women noted that they did not consider themselves infertile per se, but had infertility issues or problems because they knew that if they tried to conceive a child again, they would have difficulties and it would not happen on its own or naturally. They would need some kind of medical intervention.

The binary opposition of infertility and fertility was a problem for some women in the study to negotiate and understand. For the women, this dichotomy was too limiting and they viewed their experience of infertility as a continuum where the markers or boundaries between infertility and fertility were blurred. One clear example which illustrates the blurred boundary between infertility and fertility was Julia's definition of infertility. Not only was the experience of infertility a continual process, but also cyclical. At certain stages in Julia's life, she was more fertile than at other times. She explained:

I don't really think of us as infertile. I kind of think that we are going through an infertility stage right now. There has been studies done about how at different life cycles in a women's life your fertility might have peaked at 18 and in your 20's and it might drop and come up again when you are 35. So I am thinking that I might be like that. Whereas everybody else is the other way, your peak reproduction time is in your twenties. And then I look at my mom. My mother had me when she was 18, my brother at 19 and my little sister when she was 36. So I am thinking that I am like her. Maybe her twenties was not her peaked time. Maybe my good time was when I was 18 then and it won't happen again until I am 35.

For Julia, the experience of infertility occurs in stages or cycles and depends upon how old she is. Julia does not necessarily have a clear distinct boundary where she leaves the 'world' of infertility and travels to the world 'fertility' never to return again. For her, it is a continual, cyclical process until she reaches the age of menopause. This is similar to Wendy's use of the metaphor of infertility as a barren which changes from a sparse place to a lush place as the seasons change throughout the year.

Since there were no distinct boundaries that the women drew between being infertile and fertile, it became even more difficult for them to 'fit' into society as they experienced it. The women used key phrases and terms to identify themselves as being different from other women in society who could have children without any medical intervention. Identifying themselves as being different and the feeling of otherness contributed to the ambiguity they felt as they relate their personal experiences to the social and medical context in which it occurs.

Hannah defined infertility in the following way: "Infertility to me is more um, well, it means that I am not normal. It's you know, I just can't have a baby. I have to go on drugs. I have to go on regimes. It is just awful. At this point it doesn't mean I will never have a child." What is interesting in Hannah's definition is that she defined herself as not being normal, not being like other women who can have children. Kristine also identified herself as not being normal with this statement: "When you don't feel normal, how else can you go on and be normal? You know what I mean. When you don't feel [normal], how can you be normal? I will never be normal." Other phrases the thirteen

women used when discussing their experiences and what it means to be infertile included "I am abnormal," "no one can relate to you and you feel like you are alone, you are abnormal," "something is wrong with me," "I am different," "I feel different," "I am different from normal" and "I am not the norm." These phrases were used by the thirteen women to identify themselves as being other than normal in regard to their self identity and the way their bodies should be working.

For Jane and Wendy, identifying themselves as being different from other women was an important part of their narratives. I would like to quote a passage from each in order to give a glimpse into their interpretations of what being 'other than normal' is like. Jane talked about the feeling of difference when she decided to have a child with her lesbian partner. She explained:

I never thought I would be a lesbian. I guess as a kid I just thought I would be a mother. I always knew. I just always knew I wanted to be a mother. And then I went through puberty and grew up and as a young adult I had attractions to women. My thoughts were this, this is just inconvenient you know, not being lesbian, that's fine I have no problems with that. But, it is just puts a real wrench in having kids. I never thought: "Gees I can't have one." I just thought this was going to be more difficult. For me to be, I don't want to be noticed. I don't want to stand out. I just want to be like everyone else. But, sometimes I feel that it is not the same. Our situation is **so different from theirs**<sup>4</sup>. It is not always **the same** and I mean, I need to be around people who are like me. I need to be the same and I am not. I don't know where I fit, just sort of glide along.

Jane recognizes her situation as different from other infertile women, but at the same time she wishes she could be like everyone else and she does not know where she fits in.

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<sup>4</sup>I have bolded these words to indicate a change in the tone of voice of the participant. The participant raised her voice when speaking these words.

For Wendy, the feeling of otherness was accentuated by the fact she had a hysterectomy at a young age and never menstruated:

For most of my life, I have felt very much outside the women's experience. I felt very isolated and alone and alienation might be another adjective. I mean as a teenager, it was very difficult because I was not able to participate in the conversations and I didn't feel that I could express my experience in relation to theirs because it was a very taboo thing...When I am in a conversation with a group of women and they may be talking about their periods and saying "My period is so irregular and mine is right on time. Oh, I have a heavy flow or oh I thought I was pregnant the other day." So when I hear women talk about this. I think, "Well gee whizz." You know, I should be able to talk about my experiences in the same way, to include myself in the conversation. But, instead I would just be quiet, just not say anything and allow the conversation to go on. And I think, "Well gee, I should not be ashamed about this. This is not something to be ashamed of..." But, a lot of the shame I would say stems from feeling different as I mentioned before and you know, not feeling, not feeling I was like other girls. Not being able to participate in all that growing up stuff and that type of thing that women go through. And shame about my body. Shame about the scars. I have scars on my belly. Shame I guess in terms of my body. Feeling different. You know, the feeling that I was different from others.

Like Wendy, the other twelve women I interviewed came face to face with a core cultural construct: that biological reproduction is expected to be a naturally occurring event, one considered to be part of the natural order of life. Failure to fulfil this cultural expectation was disruptive to their lives because they had assumed that they would be able to have children with little or no difficulty. In essence, they struggled to find a fit between the dominant cultural model and their own experience. They recognized that they were different from women who could have children without any medical intervention. In Wendy's case, she faced another core cultural construct: that menstruation is a 'naturally' occurring biological event that marks the transition to

womanhood.

The feelings of alienation, isolation, difference, and being abnormal among women who experience infertility were heightened when the women recognized the discrepancy between the cultural script and the personal reality of infertility that they were forced to confront. Sandelowski (1988: 148) argues that although infertile women conform to cultural expectations by wanting children, they violate behavioral norms by not having them. In some sense they have become culturally 'deviant'.

The women's sense of feeling other than normal was reinforced in strained interactions in which they were forced to act differently and in which others, whether it was family and friends treated them differently by withholding information about pregnancies or by avoiding them when they experienced a miscarriage. For instance, Hannah recalled that while she was at work one day, a co-worker apologized profusely to Hannah for announcing her pregnancy among her co-workers. Hannah stated that it was not the fact that her co-worker announced her pregnancy that made her feel different, but the fact that her co-worker felt like she needed to apologize for it. Similarly, Wendy's sense of difference was reinforced when she felt that she could not engage in the conversations women had about their menstrual cycles.

Most of the women I interviewed felt like they lived and experienced both the 'deviant' and conventional worlds. This was heightened by the ambiguity experienced concerning the reasons for infertility which obscured the lines between fertility and infertility. Women who had achieved a pregnancy and motherhood were, at times, still

confused about where they fit in, recognizing that they did have a child, but also recognizing that if they wanted another child they might need medical intervention. These women appeared to exist between two worlds, identifying with both sides. For Jane, it was a matter of trying to find where she fit in, being a lesbian trying to conceive a child and identifying external and internal factors for her infertility. As Sandelowski (1988: 160) notes, the unclear boundaries "between fertility and infertility and between childlessness and parenthood highlight the confusion of identities and the uncertainty of place that the infertile must face as they negotiate these worlds."

Moreover, the medical treatment the women sought out to solve or fix their infertility contributed to the feelings of difference and abnormality. The medical treatment heightened their sense of abnormality and gave it a highly specific focus, the body. Often during the diagnosis and treatment of infertility women were compared to a medical standard of 'normalcy'. What a normal period should be (between 28 and 30 days), what a normal fallopian tube looks like and what the normal size and shape of an ovary and follicle should be. If the women deviated from the 'normal' standard, they viewed themselves and their bodies as being different, abnormal and not functioning as they should. This was evident when the women discussed how their menstrual cycles did not function normally and how they did not ovulate normally with such phrases as "my period is not normal," "I don't ovulate like normal women," "my hormones are imbalanced," "it is irregular," "my body is not producing the eggs that it suppose to be" and "my body is not working properly."

#### 4.5 Conclusion

In sum, the women noted that the medical definition of infertility was limiting and it did not accurately reflect their experiences. The dualities of mind/body, science/emotion, rational/irrational and fertile/infertile were limiting in the conceptualization of what infertility is and how the women experienced it. What it means to be infertile included more than the "inability to conceive after one year of unprotected, well-timed, sexual intercourse or after the six months if the woman is over age 35". It included the emotional aspects of frustration, alienation, devastation, loneliness, bitterness, painfulness, challenging and fragile. As Lauren noted:

No medical doctor ever asked me, "How are you coping with this? Is this difficult for you? Would you like to take a break from this? Would you like to talk to a psychologist? Would you like to see a therapist?" Not once, ever. They are just there to give you the treatment.

The women identified themselves as being 'other than normal', deviant from a cultural norm which stated that to reproduce biologically is a naturally occurring event. The women often found themselves living in two worlds: that of the fertile (conventional) world and the infertile (deviant) world, where the boundaries between infertility and fertility are blurred. In the next chapter I will discuss how the women experience their bodies as they maneuver through the maze of diagnostic tests and medical treatment.

## Chapter 5

### The Embodied Experience of Infertility

#### 5.0 Introduction

As argued in the previous chapter, infertile women viewed themselves as different, abnormal and alienated from other women who could have a child 'naturally' without any medical intervention. The medical definition of infertility did not accurately reflect the women's experiences. They did not experience infertility as a set of dualities of the mind and body, science and emotion, rational and irrational, and fertile and infertile but rather as an embodied experience<sup>1</sup>. I use the term embodiment to denote the holistic view of the body that incorporates both the mind and body. The body is viewed as a living structure where the individual actively experiences the world through his/her body both physically and emotionally. Here, the body is viewed as a 'mindful', 'emotionally' 'expressive' body (Scheper-Hughes and Lock 1987; Williams and Bendelow 1996; Leder 1990). This view of the body constitutes a theoretical departure from the traditional Western mind/body distinction. As Scheper-Hughes and Lock (1987: 21) argue, "we lack a precise vocabulary with which to deal with mind-body-society interactions and so are left suspended in hyphens, testifying to the legacy of the Cartesian view of the body."

This chapter will explore how women experience the mind-body-society interactions as they go through the diagnosis and treatment phase of their infertility.

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<sup>1</sup>The embodied experience is used to incorporate the emotional, sensual, tactual, visual and cognitive ways in which the women experience their bodies as they maneuver through the diagnosing and treatment of their infertility.

Specifically, this chapter will describe the procedure of diagnosis and treatment of infertility in order to illustrate the processes by which a woman's body becomes objectified. This will be contrasted with the ways in which women's experiences of infertility is described as an embodied process.

### 5.1 The Regime: The Process of Diagnosing and Treating Infertility.

The physician's task is to render the patient's body (and the patient) transparent so that the true disease can be directly apprehended.

- Richard Zaner (1988).

I had a couple of laparoscopies. I had a hysterosalpingogram and that was awful. There was the endometrium biopsy where they take a chunk of uterus. And then there were the ultrasounds to see if I was ovulating. I was closely watched and that was awful.

-Vanessa.

The above quotes illustrate two different perspectives, that of a physician and that of a patient. In medicine, the dominant ideology that prevails is one which views the body and mind as separate and distinct entities. The body is understood as a complex biological organism that can be partitioned into specific parts and systems and made transparent through a number of different diagnostic tests. However, the women do not view their body and mind as separable. The body and mind are not seen as distinguishable entities: rather, they form a continuum. Therefore, changes in one produce and cannot be separated from changes in the other (O'Neil 1985: 122). In other words, the women enter the medical maze as an integrated whole person, where the mind and body are not separable.

The diagnosis of infertility involves an infertility work-up for both the female and

male partner. The infertility work-up is used to identify fertility problems and is composed of three elements: medical history, physical examination and laboratory testing. The giving of the medical history is the first step toward rendering the body transparent to the physician. Both partners will be asked to give a detailed medical history, either privately with the physician or together as a couple. The medical history includes current health status, diet and lifestyle, past medical and surgical events, occupational and environmental risks, sexual development from adolescence through adulthood, use of birth control, sexually transmitted diseases, any previous pregnancies and sexual issues within the current relationship such as frequency and timing of intercourse (Garner, Menning and Wentz 1996: 13-23). The barrage of questions asked by the physician is intrusive to the lives of woman's and her partner's. The sole focus of investigation is on the body and its actions. The inquiry about the body and its actions begins the separation of the mind from the body by turning the woman's attention to her body as an object.

The physical examination, laboratory testing and subsequent medical treatment finalize the process whereby the body is rendered an object. From the perspective of the woman, the examination table may be seen as a bed on which to lie, but from the perspective of the physician it is seen as something to help inspect things (Young 1997: 26). The examination of a woman consists of a general physical including a breast examination and a comprehensive pelvic examination. Women with a history of irregular or absent menstrual cycles may have blood tests to measure hormone levels and to

determine hormonal profiles. The pelvic (internal) examination is helpful in providing information about the size, shape and position of the reproductive organs. During the pelvic examination, the sole focus is on the woman's uterus, ovaries, vagina and cervix which can be future sites of medical treatment. Although the woman cannot see what the physician sees, she does experience the pelvic examination tactually. She feels the insertion of the speculum, the scrapping of the uterus wall and abdominal pressure as the physician pushes down on her stomach to feel her ovaries. As Young (1997: 58) notes, the woman has tactile experience of just those parts of her own body from which she is visually excluded.

Before a woman undergoes more time consuming and intrusive diagnostic tests, the male partner has a general physical and detailed examination of the testes, penis and scrotum as well as a semen analysis. The semen analysis is useful if the cause of infertility is an obvious male factor. It is important to note that the men's bodies are also rendered transparent and objectified as they too maneuver through the medical maze.

Additional diagnostic tests for women may include a basal body temperature chart where a woman takes her temperature orally each morning before she gets out of bed, a hysterosalpingogram (HSG), laparoscopy, hysteroscopy, endometrial biopsy, ovarian drilling and ultrasound testing. Of the thirteen women I interviewed, eleven had hysterosalpingograms, four had laparoscopies, one had an endometrial biopsy and another had ovarian drilling. With each of these diagnostic tests, the sole focus is on the woman's reproductive organs and their ability or inability to function normally. The women

discussed the process of having their infertility diagnosed as be physically and emotionally difficult and filled with uncertainty. They were also unprepared for the lengthy time it took to locate where the fertility problem(s) lie.

All the women preferred to see a female family physician, gynaecologist and infertility specialist. Eleven of the thirteen women had a female family physician and gynaecologist. The infertility specialist in St. John's is female. However, for some women in this study, they viewed this as a negative experience because they expected more from a female physician than from a male physician. For example, two women commented that they expected the female infertility specialist to take into account their emotional needs more than a male physician. However, from the women's perspectives, their emotional needs were not addressed throughout the diagnosis and treatment phase of their infertility.

The hysterosalpingogram or HSG was the most vividly remembered and retold diagnostic test reported the women. The hysterosalpingogram is used to detect structural problems. Blockages and other problems of the uterus, the fallopian tubes and the pelvis may be diagnosed through an x-ray study or film. The HSG is preformed in an examination room. The woman undresses, wears a hospital gown and lies on a metal examination table with her legs spread apart. Only the physician, radiologist and nurse are present in the room with the woman. A small tube is inserted into the cervix and a blue dye is slowly injected. The dye flows into the uterus, out through the fallopian tubes and into the pelvis and can then be viewed on a television monitor. The lights are

dimmed in order to enhance the image on the screen. The television monitor is connected to a metal arm which can be maneuvered in place where both the physician and the woman can view the flow of dye through her reproductive system. As the dye is injected into the woman's body she feels pain, intense pressure and uterine cramping that may last several hours. After the test, there is a sticky discharge which lasts for several hours as the dye is expelled from the uterus.

Rachel described the HSG as very painful and explained that she was uncomfortable with all the medical tools in the room:

So I had that done and that was painful. [It was] the most painful. It is a procedure that had to be done in the hospital. I was awake and in this room and there was a nurse who was assisting the doctor. I was squeezing her hand most of the time. I would not let go of her. It hurt. I think what hurt more than anything was all the tools and gadgets that were there. I guess similar to the kind that would be there for a pap smear. But, all that was really painful and when the dye was put in it was painful. For me, I think the equipment and getting set up was much worse. So, I actually watched it on the monitor and they were trying to get me focussed on it because I was in so much pain. I watched. I watched the left tube almost instantly fill up and that was open. But the right one was touch and go for a while...It was pretty tense for a little while because I am thinking ok, one tube is blocked and my chances were obvious slim. I was just thinking no, but eventually the dye did appear so we knew they were both open.

Rachel's description of the HSG clearly illustrates that this diagnostic test is painful. It is also important to note that Rachel and the other women actually see the dye flow through their inner reproductive organs. They are able to see the results of this test instantly as the image is projected onto the television monitor in front of them. Rachel even notes feeling tense when the dye did not fill up the right fallopian tube instantly. The impact of viewing their inner reproductive organs and instantly seeing the results of this test will be

further discussed later in the chapter.

Once a diagnosis is made, a woman may seek out medical treatment. Although there is a range of medical treatments available to the women, I will only discuss ovulation induction, artificial insemination and artificial insemination by donor because they were the only medical treatments that the women received and they were the only medical treatments offered in St. John's. Women usually begin with less invasive treatment and progress to more invasive ones which are more time consuming and increasingly intrusive on the body. One of the first options for women who have polycystic ovarian disease, a development of multiple cysts in the ovaries which inhibits follicle growth, is ovulation induction.

Ovulation induction is a procedure in which oral and/or injectable fertility drugs are taken daily to stimulate ovarian activity. The aim of this treatment is to stimulate the ovaries to produce a single mature follicle (17 mm in diameter), to induce ovulation and to allow fertilization to occur by sexual intercourse or by artificial insemination. Women beginning ovulation induction usually start by taking an oral fertility drug called clomiphene citrate or clomid. If a woman does not ovulate within three to six months, the physician may increase the dose of clomid or change the fertility drug to an injectable fertility drug.

The switch to an injectable fertility drug for a woman means that she is more closely watched by the infertility specialist and the number of different steps that she goes through increases. For instance, a nurse must teach the woman how to inject the fertility

drug into her fatty tissue and she is required to take daily blood tests to monitor hormone levels. The injectable fertility drugs are taken daily at the same time every day. This can be emotionally stressful for women trying to schedule in the daily injection at the right time of the day. As Kathy noted, "Emotionally it is difficult because you have to get everything right. The timing has to be right. If you start taking injections at 7 o'clock at night, you have to make sure that you always get them at 7 o'clock at night. If you are going out somewhere at six, you need to take the stuff with you or you don't go out. Or you try and come back." Scheduling the daily injection gets more complicated and intrusive in the woman's life if she is required to switch to an injectable fertility drug that must be injected into the muscular tissue. The woman cannot inject this particular fertility drug herself. A physician or nurse must give the injection. As a result, women taking this drug either have to go to the infertility clinic or another physician's office to receive the injection. However, on the weekends when most of the physician's clinics are closed, the women must go to the emergency room at a hospital where a nurse will give the injection. This is extremely inconvenient and intrusive because they have to explain why they need someone to give the injection. As one woman described it, "I had to go to the hospital and bring in all my medication. It is not very convenient and everyone else kinda knows in that regard. The process is intrusive to say the least."

In conjunction with taking the injectable fertility drug daily, the women are monitored using blood tests and vaginal ultrasounds to track the growth of the follicle. The monitoring of the woman's body is important because "it maximizes the chances of a

successful pregnancy and minimizes any risks" (Balen 1996: 6). These risks may include developing too many eggs which can lead to the chance of multiple pregnancies and the development of ovarian hyperstimulation syndrome. This occurs when too many follicles grow which enlarges the size of the ovary and may cause it to burst or rupture. A treatment cycle may be suspended if there is danger of either of these two conditions occurring and the woman chooses to stop the medical treatment.

The infertility specialist monitors the development of the follicle with a vaginal ultrasound. The ultrasound is performed by placing a probe in the vagina. The infertility specialist sheaths the ultrasound probe in a sterile condom, coats it with cold jelly and inserts the probe in the woman's vagina (Cussins 1996: 584). By rotating the probe in different directions, the infertility specialist brings first one ovary into view on the screen and then the other. Both the infertility specialist and the woman can see the follicle on the screen. As the follicle grows and reaches the appropriate size (17mm) for ovulation to occur, the frequency of the vaginal ultrasounds and blood tests increases. During a two to three week period, the woman will have blood tests every day and vaginal ultrasounds every second day.

At the infertility clinic, blood tests are scheduled at 7:30 in the morning and the vaginal ultrasounds are performed in the afternoon. Women receiving ovulation induction often find themselves travelling back and forth to the infertility clinic twice in a single day. The structure of the infertility clinic directly impacts how the women structure their day. The time of day that the women are required to have the blood test

and vaginal ultrasound are not flexible and delays can occur. At times, the women find it difficult to schedule these medical appointments within their work schedules. Often, they ask their co-workers to cover for them, take sick days or tell their bosses why they will be late.

The women not only find it difficult to schedule this medical treatment within their work schedules but the treatment is also difficult on their bodies and their marriages. For instance, Kathy described receiving ovulation induction as being like:

a pin cushion...the bruising and soreness of my stomach and the doctor basically says when you can have intercourse...You need to be ready to have intercourse at that time you are supposed to. It's like do we really have to do this because I am really too tired to do this. You think if you don't do it now, it means this month, taking the medication is all for nothing...I mean it kinda of gets a little bit personal you know. You are stripping down, you are getting a vaginal ultrasound and everyone is there. They are watching you and you are looking at the screen and carrying on a conversation. At one point my partner came in and started talking with the doctor about the equipment.

When Kathy spoke about everyone being in the room with her, it included the infertility specialist, her partner, a nurse and two to three medical intern students. One of the medical students got to practice performing the vaginal ultrasound on Kathy. Lauren also commented on how she felt about having the medical intern students in the room with her. She explained:

It felt like I had every resident that went through medical school for about four years examine me. They would tell me that they need to do this but it was difficult. You are continuously, every second day taking your clothes off for someone else which I never got used to...I don't know how many of those I had, probably a hundred and thirty. Usually the resident would get to do that. But not always. And the infertility specialist would look at the ovaries to see if a follicle was developing or if there were too many. She could see it on the screen right

beside you. So I got used to seeing my ovaries and seeing follicles.

With the use of the vaginal ultrasound, the woman's body is rendered transparent.

The ultrasound provides a means to view inner body parts such as the ovaries and follicles. Also, the women's bodies are closely monitored with the use of the vaginal ultrasound and blood tests in order to 'see' the progress of the treatment. The women even monitor their own bodies by taking their basal body temperature every morning, noting any changes in vaginal mucus discharge and making sure that they take the fertility drugs at the appropriate time of day. These various steps and procedures are designed to monitor the body, they render it visible and segment it into different parts.

However, the women do not experience the diagnosis and treatment of their infertility solely in terms of segmented body parts being displayed on screens in front of them. One clear example is Jane's description of receiving artificial insemination by donor. As Jane describes the steps involved in receiving artificial insemination by donor, she weaves a complex narrative which incorporates her self identity as a lesbian, how she finds it difficult to schedule this treatment with her work schedule and how she feels about having artificial insemination. Within this passage all these issues are brought to light:

Physically it is painful...They take a very long thin catheter, just a little plastic tube and then they put it up through your cervix. Then they get a syringe and put the sperm inside the syringe and push it in. It really hurts- a sharp pain, but it does not last very long...[It is] really difficult to do some of that scheduling. And there are times when we walked away and thought, I am not going to get pregnant because I am too rushed. It is Christmas and I am not going to enjoy Christmas day because I got to get back to work and that is not fair. I feel like I waited so

*long* for this and I got to try and squeeze it in between 12:30 and one. I get sort of resentful. It is not fair that I got to go back because even after the inseminations for me, I don't know the word, it is not dirty. But, I don't feel clean because there's KY jelly on my underwear. You might think this is gross, but for me, some of the sperm might come on my panties and I am not used to that. That's foreign to me. To have that inside of me first of all. I mean I had some experiences with men when I was younger but most of my adult life I have been a lesbian. So having the feeling of sperm like rush down my body is not a good feeling to me. It feels icky to me even though I need to do this. So I have to go back to work and I am feeling icky when I get inseminated. I just want to go home. I would like to do sort of clean up and lie on the couch and think that it is happening now, you know. I don't want to do a whole lot. I got to rush through it and go back to work and I think it is not fair. I should be able to enjoy this time.

For Jane, the artificial insemination by donor procedure is an embodied experience. It is filled with mixed emotions of wanting to 'enjoy' this moment and feeling resentful that she has to schedule this procedure 'between 12:30 and 1:00'. She also noted how the artificial insemination procedure affects her body, the pain she felt as the sperm was being injected into her and how she felt when some of the sperm 'rushes' down her body. There is also a tension between her self identity as a lesbian and receiving artificial insemination. Even though she required this procedure to achieve a pregnancy she felt the 'ickiness' of the sperm rushing down her body, which is foreign to her.

Thus far, I have described the process of diagnosing and treating infertility and how the women's bodies are rendered transparent and segmented into different body parts and systems. However, the women also experience the medical treatment in terms of an 'emotional roller coaster ride' to which I now turn.

### 5.2 Emotional Roller Coaster Ride

It is almost like being manic depressive: One minute you are up and the next minute you are down.

-Grace

The emotional roller coaster ride consisted of feeling hopeful and excited at the beginning of a treatment cycle and then disappointed and devastated when the medical treatment is unsuccessful. At the start of a new cycle of ovulation induction, a woman is hopeful that the fertility drug is causing the follicle to grow. But, when the vaginal ultrasound shows that the follicle is not growing or responding to that particular fertility drug, the woman feels disappointed and frustrated that the treatment failed. The emotional roller coaster ride is directly related to the results of the medical treatment. As the medical treatment is more invasive and the woman is monitored more closely, the frequency and intensity of the emotional roller coaster increases.

For instance, Hannah makes a clear distinction between the emotional roller coaster ride she experienced when she was taking an oral fertility drug (which does not require her to have daily blood tests and a vaginal ultrasound every second day) and when she was taking an injectable fertility drug:

When you are on clomid it is different. I had side effects every day with hot flashes and stuff. You were not on the roller coaster ride because you don't know if it was working or wasn't working. So you don't think about it. But when you are on the injectables every two days you are seeing the results of what you are doing. So if those results are good, you are good. If they are bad, you are down. So it all got to do with results. When you take a pill, the only thing you do is get a progesterone level to start your cycle. And that takes a week or more for you to know if you ovulated. So you are going blindly really. But, with the injectables you are not. You are seeing everything that is happening inside of you. So that's

when the roller coaster comes in. It is more of an everyday roller coaster. With the other drugs, it's not because the roller coaster ride come at the end when your period starts.

It is also important to note that the women experience the emotional roller coaster ride over and over again each time they start a new treatment cycle. By writing in a diary, Hannah chronicled her daily emotional coaster ride as she went through one treatment cycle of ovulation induction. I would like to present a few excerpts from Hannah's diary to illustrate how the presence of a screen, the results of the blood test and vaginal ultrasound shape the emotional roller coaster ride she experienced. Hannah was not separated from her family, partner, friends and co-workers while she was receiving this medical treatment. She wrote:

Day 7: Today was my first ultrasound and blood work after 3 injections. The follicle isn't growing yet, however. I am usually upset by this, but it's too soon to tell if the drug will work yet. I had to get up at 7:30 AM and get blood work done and then go back at 11:00 AM for the ultrasound. I am doing nights tonight. It doesn't get any easier injecting the drug. It's like waxing your upper lip. I hesitate over and over again before I make that jab. Everybody thinks that injections are easy but it is not.

Day 12: Today has been the worst day of my cycle so far. I went for the ultrasound today and the drug is still not doing its job. My left ovary was only slightly active. My dose is increased to 75 mg. My doctor asked me today if we considered ovarian drilling as an option yet. I told her we had. If this drug does not work, that is my next option. I don't think there are any options after that. I feel so depressed and desolate today. It looks like my sister may be pregnant after all. I found out my sister-in-law is pregnant and my best friend is pregnant. It seems like everyone around me is getting pregnant but me. I can't take all this news at once. It is killing my spirit.

Day 17: I am still feeling numb and depressed.

Day 18: Today I saw the infertility specialist again. I went thinking the worst but

something is turning out right. The doctor did not show me the ultrasound screen today which makes me feel kind of iffy about the kind of good news that she is telling me. I hope it is not false hope.

Day 19: A miracle has happened. I have a follicle that is 15 mm in diameter. I only have to take today's injection and the beta HCG [a hormone that is given midway through the cycle which encourages the dominant follicle to release its egg] on Sunday. My estradiol has tripled to the target range. This is terrific news. I am so excited.

Day 23: My period started today. Ok, so I am very disappointed but no tears shed. I am just happy that I ovulated and maybe I will get pregnant. The doctor warned me that it may take a few months to get pregnant. But, I am so impatient now from waiting so long...Today I told my husband I am sorry that I still haven't had a baby. He told me that he will love me forever no matter what and as long as he has me, he is content. I hope he was telling the truth.

Through Hannah's diary entries we see the daily roller coaster ride from feelings of depression and desolation because the follicle was not growing and everyone around her was pregnant to excitement and happiness when she had ovulated. The dominant theme in Hannah's diary is whether or not her body can grow a follicle large enough so that the egg can be released. It is also interesting to note that when the infertility specialist tells her good news about the follicle, Hannah does not believe it because she did not see the screen herself to confirm what the doctor had said. In this instance, the screen provided the visual evidence of what was happening inside her body. Both Hannah and the infertility specialist relied on the screen to show the results of this medical treatment.

While Hannah and the other women were having the vaginal ultrasound, the infertility specialist used medical phrases to describe what she seen on the screen and what a normal follicle, ovary and uterus should look like. Such phrases include "starting

to see good mucus build up", "what the lining of the uterus is supposed to be like". "how big the follicle is supposed to be" and "the shape of a normal healthy egg." If however, a woman deviated from this medical normalcy or the follicle did not grow, the result of the ultrasound was perceived negatively. Furthermore, as the women invest more time, energy and money in the medical treatment, the downward swing of the emotional roller coaster ride was intensified. For instance, Jane commented on the incredible disappointment she felt when the infertility specialist told her (with the aid of the vaginal ultrasound) that she ovulated on the wrong side where she did not have a fallopian tube. At this point, Jane had waited four months to receive her twelfth artificial insemination by donor. In the doctor's office it was Jane's "heart that hurt" which was quite separate from her body. As she explained, "I was just so sad and empty and hollow. I felt empty, sad and it was horrible. Maybe next month, maybe next month. But, right there, when you find out the news, it is your heart that hurts...[and] it does not always get taken care of."

For both ovulation induction and artificial insemination, women were reduced to mere body parts. In ovulation induction the sole focus was on the body's ability to grow a follicle and then release the egg. Artificial insemination provided additional help for the body by increasing the likelihood that conception will take place. This not only maintains the dichotomy between the mind/ body and science/emotion but also separates the self from the body. In the next section of this chapter I will explore the impact of reducing women to mere body parts and how the presence of video screens shape the subjective

experience of these women.

### 5.3 The Visual and Tactile Body

With the aid of the video screen, in both the hysterosalpingogram and vaginal ultrasound, the women see themselves from a very close, yet remote, machine created location where they witness their own bodies from the examination table. The women are able to see parts of themselves that would otherwise not be possible without the aid of this medical technology. The women commented that this technology offered a new and interesting way of seeing their bodies. For instance, Julia stated "it was kind of interesting though because they gave you a monitor to watch it. You see the blue dye coming up through your tubes and it was like oh, cool," and Kristine added "it is interesting, exciting just to see what she [infertility specialist] was looking for because she showed me everything." Yet, this same image that is projected onto the screen is also subjected to an external medical gaze. The women have noted that they are objects to be viewed by others with such statements like, "having people talk about you and you are not quite sure what they are talking about", "knowing that you are an open book to strangers is hard" and "I felt like a calf going to slaughter. All these people watching you like a spectator--that was difficult." As a result, this medical technology enables the women to view themselves in a new way and also renders their bodies transparent for others to view.

However, the body is more than a visual object. As Maxine Sheets-Johnstone (1990) argues, the body is a 'tactile-kinaesthetic body' capable of feeling and touching the

world around it. The body is "always in touch, always responding with an intimate and immediate knowledge of the world around it" (Sheets-Johnstone 1990: 46). Not only do the women experience their bodies visually, but they also experience their bodies tactually.

For instance, in the hysterosalpingogram, the women feel the thin catheter being maneuvered up through their vagina, the coldness of the examination table and the pressure and pain of the flow of dye as it moves through the uterus and up into the fallopian tubes. With the vaginal ultrasound, the women feel the pressure of the probe being rotated around in their vagina, the coldness of the examination table and of the probe, and the feeling of K Y jelly leaking down their inner thigh. During each medical procedure, the women experience their bodies first tactually and then visually. They move from one state to another as their inner body parts are being projected onto the screen in front of them. The television monitor acts like a mirror and it is "by the means of image of the mirror, [she] becomes cable of being a spectator of [herself]. Through the acquisition of the specular image the [woman] notices that [she] is visible for [herself] and others. The passage from the introceptive me into the visual me...is the passage from one form or state to another" (Merleau-Ponty 1964: 136). The mirror is the screen displaying the visual pictures of the woman's ovary, follicle, fallopian tubes and uterus. The passage from the 'introceptive me' is how the women tactually experience their bodies and the passage to the 'visual me' is how the women visually experience their bodies.

Since the women experience their bodies both tactually and visually, how do they move from one state to another? In other words, how do the women mediate between their tactually experienced body and the visually body experienced? It is through the experience of physical pain. The instrument probing gestures of the hysterosalpingogram and vaginal ultrasound cause physical pain ranging from discomfort, pressure, sharp jabbing pain lasting a few minutes, to intense menstrual cramping lasting for a few hours. It is through the experience of pain that the women are tactually bound to their bodies. As Young (1997: 53) suggests, "pain binds the woman to her body in the realm of medicine. To permit her to express her pain is to permit herself to reconstitute herself as a [subject]." I would like to quote a few excerpts from the women's narratives to illustrate how the women experience their tactual and visual bodies:

Jody: It is like your insides are going to pop. The dye cannot go anywhere. It is pushing on a door that it can't go through and that was probably the worst pain ever. That was my screaming episode.

Vanessa: very embarrass[ing] and intrusive. They shoot dye in your fallopian tubes and it is the most intensive pain you ever felt in your life. You are on the table and there are other people and they push you up on the table and they look at you. And you are looking at the screen and you see your spine go past the machine. You are in this pain. You are thinking you are in the twilight zone, on the table.

Lauren: I am not exactly sure what they did. They inject the dye. When they put it in that hurt. When you put the dye in it was just a very sharp pain. It was painful and they were doing x-rays the whole time. So no one was paying attention to the fact that I was in pain and weak. They were trying to get the x-rays at the right time. So they didn't even know that I was lying there in pain and cold. So when they finished, I just stayed there for a while. Then I got dressed. My husband was waiting outside the room.

In these excerpts, which describe the hysterosalpingogram procedure, the women use certain terms to describe the pain they experience. These include "insides are going to pop", "door that it can't go through", "they shoot dye in your fallopian tubes", "push you up on the table", "it was just a sharp pain", "they didn't even know that I was lying there in pain and cold" and "you are thinking you are in the twilight zone". The women talk about their bodies in terms of an 'object' that is capable of feeling pain such as a door through which the flow of dye cannot go and the pain is described as sharp where your insides are going to pop. The women themselves objectify their bodies when they speak of their pain. According to phenomenology, in the everyday world, individuals do not experience their bodies as objects. However, when individuals try to pay attention to pain or to talk about it, to make sense of it, then individuals objectify it (Leder 1990: 69-102). While the women are physically feeling the procedure, they are witnessing their inner body parts being displayed on the screen which is void of any tactile experience. The women note a disjuncture between what they are feeling and what they are seeing in front of them with terms like the "twilight zone" and phrases like "they didn't even know that I was lying there in pain and cold." The procedure itself and the image on the screen objectify and segment the woman's body into mere body parts that are displayed on the screen.

However, the experience of pain binds the woman to her body and permits her a space where she can reconstitute herself as subject in the realm of medicine. Pain is a lived, embodied physical and emotional experience. Pain by definition is simultaneously

bodily experience and mental-emotional experience. By consisting of both "sensation and emotion, by simultaneously thinking and doing, pain blurs the mind/body dualism" (Jackson 1994: 208). The woman also does not passively experience the diagnostic test and medical treatment but she is actively responding to them tactually, visually and emotionally. As the women move back and forth from their tactual and visual body, they are experiencing the emotional roller coaster ride. The image on the screen in both the hysterosalpingogram and vaginal ultrasound display the results of the diagnostic test and medical treatment in front of them. Therefore, if the image shows no blockages in the fallopian tubes and the follicle is growing, the women experience the upswing of the emotional roller coaster. But, if there are blockages in the fallopian tubes and the follicle is not responding to the medical treatment, the women experience the down swing of the emotional roller coaster ride. For the women, the boundaries between the mind and body, self as object and self as subject are blurred. They experience both as they maneuver through the maze of diagnostic tests and medical treatment.

#### 5.4 Conclusion

In this chapter, I have described some of the consequences of viewing the body in terms of subsystems that can be partitioned off into specific parts and made visible. This systematic view of the body is rendered visible by obtaining a medical history of the women and using imaging technologies to diagnose and treat infertility. In contrast, the women in this study do not experience the diagnosis and treatment of their infertility as a biological system. They experience infertility as an integrated, whole person. In the case

of the hysterosalpingogram and vaginal ultrasound, the women experience the tactual, visual and emotional body. The women see the visual image of their ovaries, fallopian tubes, and follicles, they physically feel the pain and discomfort of the procedures, and they experience the emotional roller coaster ride. Moreover, the women are not separated from their families, friends, co-workers and work environments while they experience the diagnostic tests and medical treatments. The medical maze involves a stressful regime of monitoring the body within a rigid schedule which often conflicts with the women's work schedules. It requires that the women monitor their basal body temperatures, take daily fertility drugs and receive numerous blood tests and vaginal ultrasounds. This medical regime is also filled with delays, uncertainties and mixed emotions of hope and disappointment. The women do not live their lives as a set of dualities but often blur the boundaries between the self and body, science and emotion, and subject and object. In the next chapter, I will explore further the interaction between the self, body and society in the context of the women experiencing multiple losses.

## Chapter 6

### **The Experience of Multiple Losses and Renegotiating the Concept of the Life Cycle and the Body.**

#### 6.0 Introduction

The women interviewed for this study experienced loss on multiple levels and this loss had many different meanings for them. The multiple losses included miscarriages, the loss of specific body parts and how this impacts their self identity, the loss of control over their bodies and life cycle, and finally, for some women, the loss of a life dream, that of motherhood. This chapter will explore the impact of experiencing loss on multiple levels and how this affects the women's understandings of themselves, their bodies and their life cycles. I will also discuss how the women renegotiate their life cycles after an infertility diagnosis and how their bodies become sites of resistance. Throughout this chapter it will be made evident that there are spaces where the women reproduce, transform and resist dominant discourses of biomedicine, womanhood and motherhood.

#### 6.1 Loss of Control Over One's Life Cycle

I use the term "life cycle" (Kahn 1995: 20) instead of life course for two reasons. First, it is important to emphasize that women do not experience the life course in a linear pattern of progression from one event to another. The word course denotes "onward movement in a particular direction", "progress" or "advance" (Avis 1989: 309). In contrast, the definition of cycle stresses a regularly, repeated sequence of events (Avis 1989: 332). Therefore, throughout this thesis, I use life cycle to refer to the women's actual experiences of infertility. I want to highlight the fact that a woman's life cycle is a

repeated sequence of events, yet not without change, such as the experience of the emotional roller coaster ride. I also want to draw attention to the nature of the medical treatment itself. Medical treatment often requires repeated tries in order to find the 'right' dose of the fertility drug to stimulate ovulation.

After an infertility diagnosis, the women were forced to confront many of the assumptions they held about their life cycles and bodies. As Rachel stated:

Like everybody takes for granted that anybody can have a baby. They think anybody can have a child. If you are a woman you will get pregnant. People decide when they want children and how many and this is what I am going to have. But people take for granted you do, you don't realize. And then you get married and you decide...You prevent, you spend all those years preventing and then you try. Then you try, try and try. All your dreams get messed up and then you start all over again. Start from scratch again.

As Rachel illustrates, infertility involves a profound disruption in that it challenges individual's taken for granted assumptions that they can have a child of their own on their own (Sandelowski 1988: 148). All but one woman interviewed assumed they would be able to have a child, although the importance of children and motherhood varied among the women. There was a belief that life should be predictable, knowable and continuous. A person's life should occur in a series of events and transitions that have an order, sequence and timing. For instance, one should obtain a university degree, establish one's career, fall in love, get married and then start a family. The women expressed this assumption in various ways with such statements like, "I am sort of a planner. I had to get my education, get a permanent job that I liked and buy a house. And then have a child. So that's what I did and everything worked out except for this. Everything I had

under control except for this part" and "my goal was, I finished my degree and get married and get pregnant right away...we had it all picture perfect planned out."

However, the life course assumption was dispelled by the diagnosis of infertility and subsequent medical treatment. The women's experiences did not fit with social ideology and their own expectations of how their life should be. The women experienced a disjuncture between their lived reality and the social ideology which shaped their experiences because real lives are more unpredictable than the social ideal (Becker 1994: 387). When expectations about the life course are not met, people may experience a disruption.

This disruption in the life course can manifest itself in the experience of loss of control over one's life. For some women, the future, or the thought of it, could not be foreseen and they felt that their life was in limbo, unable to proceed to the next phase or the next event. Jane illustrates this feeling of limbo and putting her career plans on hold while receiving medical treatment. She stated:

We have really become one of those couples that are so focussed on having a child that I wonder where I would be if this didn't come up. Would I have done other things with my life? I put things on hold. I would not apply for jobs or opportunities because I thought I would become pregnant. We are investing this money in a child or into a pregnancy and we are not taking trips or travelling the way we would have wanted to do. So there is this sort of delay on everything and both of us would like to go back and do our master degrees out of the province and try something different. We won't do that. We say, "No, No we will probably get pregnant and the baby is going to come." So things are just put on hold.

It is interesting to note that as Jane discusses putting her life on hold she wonders what

her life would be like if infertility had not intervened. Would she take that job and travel more? There is an expression of what if, what if infertility was not in her life.

The experience of living one's life in limbo is also heightened by the very nature of the medical treatment. The medical treatment the women receive is often filled with delays ranging from delays in seeing the infertility specialist, delays in getting blood tests done and delays in obtaining injectable fertility drugs from local pharmacies. These various obstacles delayed the treatment process not in terms of days, but months. The women are bound to their monthly menstrual cycle. The women must wait until they can begin another treatment cycle which begins at the start of a new menstrual cycle. Therefore, when a woman speaks about having eight or nine treatment cycles, this means that she is receiving treatment for at least eight or nine months. This does not include suspending the treatment due to serious side-effects of the fertility drugs. The treatment process can stretch out over a number of years with no visible end in sight. Moreover, some women in the study saw ovulation induction as a way of revealing what their infertility problem was: the infertility specialist might figure out what would work on the basis of what did not work in the previous cycle. For instance, the physician might be able to find the 'right' dose of the fertility drug that would induce ovulation. Therefore, the women viewed the next treatment cycle as possibly the *one* that would be successful.

Julia expressed how her life plans have been put on hold while receiving medical treatment. However, Julia also noted her feeling that her life cycle was out of control:

It [infertility] has put my career on hold. If I knew then what I know now, I probably wouldn't even get married when I was 23. I don't know about that. I don't regret that but I would have put my career first, put it that way. I would definitely put my career first rather than thinking about I want to have a child. You fall in love and you get married and have a child...But it's like this whole block of time, six years has put everything on hold. And you feel out of control. You don't really. This is my life, I want to be in control, you know, work hard, get whatever you can, what you deserve. So, it has put things on hold, put on the brakes on really.

Julia stated the taken for granted assumption that a woman's life should occur in an ordered sequence of events such as falling in love, getting married and then having a child. Yet, Julia's life did not unfold in this way. The diagnosis of unexplained infertility and subsequent medical treatment have contributed to putting her life on hold. Julia further discussed the loss of control over her life cycle by contrasting the fact that she and her partner work hard, are doing everything right, but still cannot have a child. She stated:

I have always felt that no matter what your life station [is], you could work as hard as you want at anything and reap the benefits. Sometimes bad things happen but if you work hard enough you should. I mean we take care of ourselves, we are fit, we look after ourselves and we work hard. We are decent and honest people. We have so much to give and this baby and this thing is so elusive...And then when nothing happens, it drags you down...I am losing everything that was important to me. I could not study. I wasn't into my fitness.

Julia's words are a clear example of the discourse surrounding the protestant work ethic: if you take care of yourself, work hard, be honest and decent you should be able to reap the benefits. To work hard connotes more than physical labour; work is the "continued activity, whether physical or mental, directed to some purpose or end" (Avis 1989: 1547). That purpose could be buying a house, being a decent and honest person, or wishing for a

baby that is still elusive.

When the "baby thing" is still elusive, despite how hard the women and their partners work at it, the women's self identity and self esteem can be affected. As

Vanessa explained:

This is not the way you started out thinking that your married life would be like. And it really takes a toll on your marriage. It affects your self esteem. Another thing is that you sort of, you can't control infertility, and you can be as good a person as you want. You can be as smart as you want. You can have all kinds of accomplishments and dreams but you can't have a baby. It makes your self esteem go out the window...You look at yourself as a failure and it is very difficult emotionally.

Vanessa and the other women expressed a sense of failure when an anticipated life event was not achieved. As Becker (1997: 395) suggests, a sense of failure to live up to societal norms of the idealized life may be present during times of transition. In addressing their infertility, women come face to face with a core cultural construct: that biological reproduction is a naturally occurring event, one that is part of the natural order of life. Failure to fulfil this cultural expectation was disruptive to the women's lives. They struggled to find a fit between the cultural model and their own experience. Although the women were trying to conceive a child, they still perceived themselves as different from other women who could have children without any medical intervention.

Moreover, the women's sense of failure was accentuated by the fact that they confronted a social discourse that equated womanhood with motherhood. In other words, to be a 'real' woman, one must be a mother. The women noted this discourse surrounding womanhood with statements like "You are a woman and you should be able to have a

baby, no ifs, ands, or buts. You are a woman, that's what women are made for" and "I could not see myself not having children. I mean that is every woman's dream. I am a woman and I can't do it. I think it is harder on women to accept failure because you can't have a child and it is the most natural thing." This discourse was further evident when the women discussed why they wanted a child. The most common response was that they always knew that they wanted children and that a child was an extension and product of the love they shared with their partners.

Being able to carry a pregnancy to a live birth acted as a cultural symbol of womanhood which affirmed that a woman was 'normal', that she was a woman, that nothing was wrong with her and that her body could function as it should. The discourse of womanhood also emphasized that getting pregnant is easy, required no medical intervention and, once pregnant, women were supposed to be happy. As Becker (1997) suggests, pregnancy is not only a cultural ideal but also "an embodied metaphor for womanhood; that is pregnancy stands for a body that is nurturant, natural and healthy and these qualities represented womanhood and [femaleness]" (1997: 85). Because the women deviated from this idealized social norm, they viewed themselves as failures.

The sense of failure was expressed even when women had successfully achieved a pregnancy but only after receiving medical treatment. Kristine and Teresa noted the feeling of failure after they required a caesarean section to deliver their child. For Kristine, the caesarean section was seen as another failure because she "could not even do this normally." Teresa further added, "I ended up having an emergency c-section. I was

very depressed after that because I felt like I could not get pregnant on my own and I could not even deliver the child on my own. I felt like here I am, I could not do anything right."

### 6.2 Loss of Confidence in One's Own Body

The sense of failure was associated not only with inability to live up to the idealized social norms of womanhood and motherhood but also with the women's perception of their bodies as not functioning normally. The loss of confidence in and control over one's own body was a part of the women's narratives. All the women acknowledged some degree of loss of confidence in their body's ability to function 'normally', though the extent to which their self esteem and self image was affected varied.

One way in which the women viewed their body as not functioning normally was when they miscarried. The five women who experienced miscarriages felt it was not enough to get pregnant; one had to stay pregnant. All were told to go home and wait to miscarry by their physician. The waiting period sometimes lasted over a week and was filled with confusion as to whether the women had really miscarried. Three of the five, including Cindy, experienced multiple miscarriages. Cindy miscarried three times in a row and this affected her self image and how she viewed her body. I would like to quote a lengthy passage from Cindy's narrative in order to illustrate that having a miscarriage is an experience filled with feelings of loss and grief especially after physically feeling the fetus being expelled from the body:

I got pregnant and everything seemed to be fine until the fifth month of pregnancy. I went for an ultrasound and I knew from just the way they were moving the equipment around that they hadn't found the heartbeat. I was told that I should go home and just wait to lose it before they would do anything...Anyway, I didn't lose it on my own. So they put me in the hospital and tried to stimulate labour with a hormone. The way they tried to do it was they would come in every eight hours and insert ten tabs of this hormone on my cervix. It felt every time like being raped. You are in your hospital bed and they come in and there is three or four of them. They didn't take me down into the examination room. They did it right in the hospital bed. They would have to put these things right on my cervix. Really, it was so uncomfortable and it happened like four times everyday. I was in the hospital for ten days before I finally went into labour and of course I had full labour. They delivered the baby and it was *dead*...The physical memory of going through that labour stayed with me for such a long time afterward. There were certain foods I couldn't pass, the meat section in the grocery store because I remembered all the, just the whole visual sight. I saw the baby being born and being put in a beef bucket. That is what they did, put it into a beef bucket to take it to wherever it needed to be taken. Just being, how it felt in my body stayed with me for a long time. There was no counselling available at that time in the hospital or anywhere nobody really...It was hard to come home from the hospital without a baby after you had been pregnant. And you had gone through it all because your body is still in baby state. You are lactating. My pregnancy had gone far enough so you have started to lactate. Your body is still sort of, whatever extra weight, your hormones are still going nuts. It is hard to come home from the hospital like that without a baby.

There are a number of points I want to highlight in Cindy's statement. First, Cindy noted the use of the ultrasound to visually confirm that the fetus she was carrying was dead because of the 'way the equipment was being moved around'. Second, she described the physical act of placing the hormones on her cervix as being raped: her body was repeatedly violated in order to force the body into labour. Third, Cindy recounted the physical and visual imagery of that night, how the fetus felt inside her body, how she experienced her body during and after the miscarriage. She also stated how it was

difficult to go home without a baby after going through the miscarriage and how no counselling available to her. Cindy experienced the miscarriage both physically and emotionally. Grieving the loss of a 'baby' and a life dream and physically feeling the forced delivery of the 'baby'.

After the discovery of an infertility diagnosis and the experience of a miscarriage, the women's sense of self and knowledge about their bodies was challenged. Prior to the infertility diagnosis, the women assumed that their bodies would function normally which would allow them to have a child. However, the diagnosis of infertility was a disruption to how they viewed their bodies. As Becker (1997:83) suggests, after a disruption which challenges a woman's perception of her body, the body becomes an unknown terrain that needs to be relearned and becomes the focus of identity in which a new conceptualization must be built. The women viewed their bodies as becoming unpredictable, unknowable and uncontrollable.

For instance, Cindy discussed how after giving birth to a child normally, the miscarriages affected her perception of her body as becoming uncontrollable. It is important to note that Cindy was not medically diagnosed as infertile, but she defined herself as such because of the three miscarriages. Cindy explained:

Yes, there is a lot about control over your body. You should have control. I always thought that I was healthy, I never had anything wrong with me and then we decided to have a child. Our first child was planned. It was a planned pregnancy. We got married, we had a baby and everything was fine. Like my body works thank you very much. But, after that it was, what's wrong? It is not working. This isn't supposed to be working like this. I really felt um, there was a period where I really was angry at myself and my own body because it couldn't do

what it should be doing. It couldn't do what I wanted it to do. It could not be relied on to do what it was made to do or so I thought. And that sort of thing that I think helped me sort of understand women who are never able to get pregnant must feel. At least I think for me, having the experience of having a child was a good thing and a bad thing. I knew I could have one but it didn't make the other times any easier. I understand how someone feels when your body is not doing what it is supposed to be doing. It is like it is out of control and that really bothered me.

Cindy viewed her body as healthy, controllable and working normally before the miscarriages. Cindy did not pay much attention to her body's ability to carry a pregnancy before she miscarried. It was something that her body was able to do. However, when carrying a pregnancy to live birth became difficult, Cindy became self-consciously aware of her body. The body was not working normally and it could not be relied upon anymore. The experience of the three miscarriages disrupted how she viewed herself resulting in a lack of control over her body. Other women in the study have also expressed the lack of control over their bodies with statements like "why can't my body do this?", "Why doesn't my body work?" and "my body is not doing what it is supposed to be doing."

The women also expressed a sense of failure and shame about their bodies because they could not make them function normally and because they did not fit the idealized social role of motherhood. As Jane noted, "sometimes I get disappointed. I feel why can't my body do it? I say what is wrong with me, why won't my body do it?...I don't feel really good about me. I can't do it right. Why won't my body let me do it? There is frustration, anger, sadness and hurt." Although Jane perceived she could not

control her life cycle and she was living in limbo, she did assume that she could exert some control over her own body. In contrast, for Wendy, the feeling of being ashamed of her body was connected to viewing herself as different from other women: "A lot of shame stems from feeling different. Not feeling like I was like other girls. Shame about my body. Shame about the scars, I have scars on my belly...Shame of my body feeling different."

Wendy's shame about her body feeling different was associated with having a hysterectomy at a young age. The loss of reproductive organs such as a fallopian tube, an ovary or the whole reproductive system affected a woman's self image. Wendy had a poor self image and as she stated "I was alienated from my body." Jane reports that the experience of the ectopic pregnancy and then the loss of a fallopian tube was just as traumatic as losing the embryo. Her hope that she would become pregnant was dashed and her self image was negatively affected. Other women have noted the symbolic importance of having all reproductive organs in order to feel like a whole and complete woman. For instance, Jody clearly noted that she is "lucky to have everything, even though it does not work. I told my gynaecologist, 'You won't have it either. You will not be given the opportunity to take it out of me. I will go to the grave with it. It is a part of me and as long as it is still producing cells and multiplying it is going to stay. It is what makes me, me.' " Even though Jody noted that her reproductive organs do not work, they are still a part of her and she equates the symbolic meaning of the reproductive organs (nurturant, femaleness and healthy) with what it means to be a woman. For Jody, the loss

of any reproductive organ is associated with not being a complete woman.

Furthermore, infertility often disrupts the body as it is known and experienced, thereby disrupting not only a sense of wholeness of the body, but the understanding of specific body parts and systems. The body became the central character for the women who sought out medical treatment. The medical treatment often focussed on specific body parts, such as a blocked fallopian tube, the development of a follicle or the ovary itself, disconnecting the self from the body and reducing the women to mere objectified body parts. For some women, their self identity was viewed in terms of specific body parts. For instance, Jane viewed her right ovary as being useless to her and all her focus was on the other ovary's ability to release an egg on the left side where she had the remaining fallopian tube. She explained:

I really want to get pregnant right. Do something. Give me injectables, I don't care what you do. But, they would say, "Oh, no, no. You don't need any of that. Wait! wait!" and I would come away so frustrated. I said, "Take my ovary on the right side. I am not using it. It has no purpose to me. Take it." But, ethically they can't do that. Because if the right one was gone, the left one would have to produce the egg. It would be forced into it. And ethically they are saying no, they won't because it might cause problems during menopause. But, the way I am feeling right now, it is like I am not using it. It is going to waste. Get rid of it. It has no purpose for me. So that is where my thinking has gone. I am not thinking long term right now, about how healthy I will be when I go through menopause. Sometimes you lose all sense of reality. It is not a good place to be when I start thinking like that.

For Jane, the right ovary is the key body part in achieving a pregnancy. She understands the removal of the right ovary as increasing her chances of getting pregnant and not the long term effects of its removal during menopause. Jane's understanding of her

reproductive system and the function of her ovaries has been disrupted by the medical treatment she is receiving and her desire to have a child sooner rather than later. The main goal in ovulation induction is to stimulate the ovary to grow a follicle and then release the egg. Jane sees whether or not the follicle is growing every second day of that treatment cycle and the infertility specialist can tell her which side she is going to ovulate on. Since this medical treatment solely focuses on one particular body part, the ovary, Jane views herself in terms of her ability to grow a follicle and ovulate. It is also important to note that Jane views the possible removal of the right ovary as a way to force the left ovary to ovulate. Perhaps, this is a way to regain control over the body or manipulate the body to ovulate.

Thus far, I have discussed how the women experience multiple losses in terms of miscarriages, loss of control over one's body, loss of reproductive organs and the impact on the women's self image and how the women understand and view their own bodies as they receive medical treatment. The final loss I wish to discuss is the loss of a dream: motherhood. As previously stated, the women had an assumption of how their life course should unfold. One should establish a career, fall in love, get married and then start a family. However, not achieving a pregnancy disrupted their life cycle and the women were confronted, at the same time, with the fear that they would not become a mother. The women confronted the loss of their dream every time they miscarried, started their menstrual cycle, or when the pregnancy test came back negative. The loss of a dream was connected to the emotional roller coaster ride that the women repeatedly experienced.

Every time the medical treatment failed, the women experienced sadness, disappointment and the fear of not becoming a mother. For some women in the study, the start of their menstrual cycle symbolized the loss of their dream. As Teresa noted, "I still every month, like going to the bathroom and like phew, I did not start. And then you start and there is twenty four hours of sadness...And then you go back to the drawing board. Every time I start it is gross." Instead of the menstrual cycle being viewed as something the body normally did, the menstrual cycle was equated with the death of a dream.

Although seven women eventually had a successful pregnancy and the delivery of a healthy child addressed their loss of their dream, they still characterized the 'period of time of trying' as a painful and lonely experience which they would never forget. The pain and memories of repeatedly trying to have a child may diminish with time, but it remains a permanent marker in their life cycle.

### 6.3 Infertility : An Isolating and Lonely Experience.

I mean you get married and all that. Everyone asks when you are going to have children. Like it is not that easy. Nobody could understand, unless you go through it. And the pressure was like why aren't you pregnant. But, it hurt, I mean no one could understand...We just didn't want other people to know about it. You feel bad enough yourself. Talking to someone else about it could make it more real.

-Grace

Like the men too, they take a toll differently. Like my husband, he shies away from it because he doesn't want me to feel bad. He doesn't want to have to say, "Look what you are going through." And we get together at our friends and he had to go through a sperm analysis. And it is a big joke around the table right. So it becomes funny for men. Like it is a funny experience for them. And then like they're saying my sperm count was this, what was yours. Like it becomes like a

big joke. And then the women are laughing along with the men and yes, it is funny. But at the same time, that is all you have to do. That is all you have to go through. I got to go through this test, that test and I get stabbed in the arm a dozen of times, more than a dozen of times... You do need someone, especially when your partner don't want to talk about it. He doesn't want you to feel bad because he knows that there is nothing wrong with him. So he is not going to come out and say anything and talk about it because he is afraid he is going to say the wrong thing.

-Hannah

The above excerpts from Grace and Hannah succinctly capture why infertility is an isolating and lonely experience. First, infertility is not a widely discussed topic among individuals who do not share the experience. The women noted that "nobody could understand, unless you go through it." Likewise, when the women perceive themselves as not fulfilling the social role of motherhood, they may feel a sense of failure and do not wish to talk about their experience. Second, twelve of the women did not immediately tell their families, friends or co-workers about their difficulty having a child. Of those twelve, four never told their families, whereas eight eventually did tell, but later regretted that decision. The women did not tell their families and friends about their infertility because they did not want the added social pressure to have a child, nor did they want any 'helpful' advice on how to conceive a child. Infertility and sex were also subjects not discussed in their families and were viewed as private issues. Even when the women told their families and friends about their difficulty in having a child, they never received the social support they wanted because their families and friends could not understand what it was like to be infertile and at times they were insensitive to

what they were experiencing.

Third, the women noted that it was difficult to talk to their partners about infertility because it placed a strain on their relationship. For instance, the spontaneity of having sexual intercourse was hampered because the couple had to have sexual intercourse on an 'absolute schedule' which matched the time the woman ovulated. The women also noted a difference in how men and women experienced infertility. Women have been socialized to express their feelings and concerns regarding their health, whereas men are typically encouraged not to do so (Draye, Woods and Mitchell 1988: 165). This can contribute to experiencing infertility in isolation because the women found it difficult to bring up the subject of infertility with their partners. As Hannah noted, "You need someone when your partner doesn't want to talk about it."

Moreover, the women discussed how they felt guilty about not being able to have a child. Even if the fertility problem is not associated with the woman or the couple is diagnosed with unexplained infertility, the woman tends to locate the fertility problem with herself because pregnancy and the majority of diagnostic tests and medical treatments happen to her body. Therefore, she may feel more responsible because the medical treatment and pregnancy are directed toward her own body. The women also felt guilty for foregoing certain things such as buying a house or a car because of the added expense of the medical treatment.

Most of the women in the study did not know of the infertility support group in St. John's or other support services such as counselling available to them. Even if the

women did know about the support group, some women chose not to go because they did not feel comfortable in that setting. For instance, Jane stated that she would not go to the support group because she did not want to disclose her sexual orientation to the group. Two other women could not attend the infertility support group because they did not live in St. John's and there was no service available to them in their home towns. All these factors contribute to the experience of infertility as an isolating event for the women. However, it is important to note that the women and their partners, did negotiate the boundaries as to when and how they discussed infertility with each other, their families, friends and co-workers. Each woman decided when she wanted to talk about her experience and found a person she was comfortable talking to, whether it was her partner, mother, sister or friend. The women also redrew the boundaries between their own isolating experience and the experience of other women by reading women's infertility stories and by developing friendships with others who had a similar experience. Subsequently, the women were able to identify with other women and realize that they were not alone. This will be further discussed in the next section of the chapter.

#### 6.4 Power, Agency and Resistance: Resistance to Dominant Discourses and Finding a Sense of Community.

I can reconnect myself. I don't feel isolated and alone. I realize that no, I am a woman just like every other woman. I am a goddess too. It is a magical thing to be able to recover a sense of wholeness when you have felt that separation.

-Wendy

Thus far, I have discussed how various discourses shape the daily lives of the

women in this study. These discourses range from the biomedical discourse of viewing the body as an organism and thereby maintaining the mind and body distinction to discourses surrounding motherhood, womanhood and the life course more generally. However, I have only told one aspect of these women's stories. The body is not just a site of surveillance, control and manipulation where the various discourses shape it into a particular form, but it is also a site of resistance and agency. The women are not mere passive victims of the medical technology and treatment they receive. They are active human agents engaging in and interacting with their social environment. As Dorothy Smith (1990b) notes, femininity as a discourse has "disclosed a double subject, a subject-in-discourse who appears passive, lacking agency, awaiting definition by a man and a second layer of organization positioning an active and competent subject. While the subject-in-discourse is deprived of agency, the subject at work behind her is active and skilled" (1990b: 205-206). This section of the chapter will explore the spaces where the women are active agents resisting and transforming the medical concept of the body and the development of their life cycle.

The act of bodily resistance can take many different forms. For instance, after years of negative experiences with physicians and subjecting their bodies to various diagnostic tests, both Jody and Vanessa decided not to have any medical treatments for their infertility. Although the dominant biomedical discourse stated that medical treatment provided the only means of having a child that was biologically linked to them, they nonetheless decided not to seek out medical treatment. Jody noted that she was not

willing to sacrifice any other part of her or subject her body to any further manipulation: "I was not going to lose anything else that was a part of me. If I want a child, I will find another way." Vanessa further added, "The doctor look[ed] at me that day like I was a flake. I wasn't a flake. It was the most important thing in my life. I was at the end of my rope, reaching out to this doctor. And I just thought, 'That is the end. This is all that I can expect to receive out of doctors. Well, that is it. I don't need ya.'"

For women seeking out medical treatment, bodily resistance and agency came in the form of throwing away and refusing to take the prescribed fertility drugs due to the numerous side effects. Kristine noted how she flushed her prescribed oral fertility drug down the toilet after learning about the drug's side effects. Although Kristine viewed biomedicine and its technology as providing the sole means in achieving a pregnancy, she nonetheless threw away the fertility drug that could help her achieve a pregnancy. Becker (1997: 13) suggests that people are able to ground their resistance to powerful social norms in bodily experience. At the same time Kristine noted the discourse surrounding motherhood and womanhood in the statement "it is every girl's dream to have a child." She grounded her resistance to this discourse by throwing away the fertility drug.

Other women have sought out non-medical treatments (such as herbal remedies, relaxation and breathing techniques, and yoga) to reduce stress, and to rediscover the mind and body connection. For example, Lauren notes that seeing a non-medical practitioner for her infertility enabled her to explore the root cause of the infertility instead of imposing therapy that only treated the symptoms. Similarly, Wendy practised

yoga to become "in tune to [her] body" again and to unite the mind with the body.

The women also gained a sense of empowerment and had agency in treating their infertility when they actively researched the medical treatments they were receiving. The women became knowledgeable 'experts' on the medical treatment and on their own bodies. They learned about the different phases of their menstrual cycle, the process of fertilization, the function of the reproductive system, the various medical treatments for infertility, and how it affects their bodies and they learned about the different side effects of each treatment. At times, the women were prompted to do their own research into the medical treatment of infertility and its possible short term and long term side effects because they were not satisfied with the information provided by their physician. The women gathered information about infertility from social science and medical journals, magazines, books, articles and the internet.

They also searched for other women's stories that focussed on the actual lived experiences of other infertile women. Vanessa described the process of connecting her own isolating experience with other infertile women as "biblio therapy." Jane commented that she researched other women's stories about infertility that centered around women's experiences rather than the medical description of the cause(s) of infertility.

In addition, the waiting room of the infertility clinic provided an area where the women could meet other women who shared similar experiences. For instance, Kristine and Lauren discussed how they developed friendships with women while waiting in the

infertility clinic. Kristine commented, "I don't know why I thought the first time I was going there I would be the only one going to see the [doctor]. And you see all these women and then you say hello. And you get to know them. You get to know about their problems and I realized I am not alone." In a similar tone, Lauren added, "Eventually, I did meet another woman at the doctor's office because often the appointments, you would have to wait maybe an hour or even longer. So after a few years of going there, you start to recognize the other people there. So I started talking to this other woman one day and we became friends. Other than her, I did not talk to anyone." Although infertility can be an isolating experience, the women found ways to connect with other infertile women.

Wendy also discovered a sense of community with women by reading women's hysterectomy stories and by talking to women who had hysterectomies. Wendy succinctly discussed how otherness and difference became a shared experience among women:

I think it was good for me to read that book. It answered some questions for me regarding how other women feel after a hysterectomy and to compare it to my own experience because I haven't been able to talk to any other women. Although lately I have been talking to some women who are middle age and who are having or had a hysterectomy. And that is an interesting thing because I am a lot younger than they are but we still compare notes. And in a way that was a valuable thing about that book was hearing about other women's experiences. And sometimes you don't know it, when you feel that separate, you don't know if your own experiences are your own or if they are common with other women. Are these problems I am having just me? It does help you identify with other women. Even as having a hysterectomy that's a woman's experience. The same as having children is a woman's experience or the same as having a period is a woman's experience. For a lot of women, having a hysterectomy is a woman's experience. So in that sense, in an interesting way it connects me to other women's experiences, whereas, for the most of my life I have felt very much

outside the women's experience...I am finding a sense of community with other women again.

By reading other women's experiences with infertility and developing friendships, the women are actively reconnecting their own isolating experience with other women.

Although the women label themselves as being different and abnormal, this otherness is a shared experience among infertile women.

Moreover, the women who had experienced miscarriages talked about finding a secret club among women. For Jane, this secret club provided an opportunity for her to talk about her experience with other women. She stated:

Since I lost the baby it is almost like I found this secret club because women that I hardly knew [would] come up to me and tell me their miscarriage stories or their infertility stories. I am really glad because it really helped me. And it was sort of I found this secret club and now I was in the club because I miscarried. Before, I never talked to these women and now it is like some sort of a friendship. Most of my talking has been with heterosexual women who had miscarried. My lesbian friends um, I don't think that some of them listen to me. I don't think that they understand. I don't think it registers with them because it is not their reality. Children are not part of their lives. They are not looking for kids.

Most of Jane's sharing of her infertility experience has been with heterosexual women who had a miscarriage. Jane does not find a 'secret club' among her lesbian friends because it is not their reality. As previously stated in the last chapter, Jane did not know where she fitted in because she did not identify herself as being infertile. However, the experience of the ectopic pregnancy was an experience that connected her to other women. Jane is not only a lesbian woman trying to conceive a child, but also a woman who lost a pregnancy.

Whether it is through reading about women's infertility experiences or talking with infertile women, the women find ways to identify their own experience with others and recognize that their experience is a shared one. They negotiate the boundaries as to when they tell their stories and when not to tell them. It is through the sharing of the infertility experience that the women actively blur the boundaries between sameness and otherness and isolation and community.

Another way in which the women have a sense of empowerment and agency is when they renegotiate the development of their life cycle. All the women shared the common bond of experiencing infertility but were also at different stages of their life cycle. For instance, women were at different stages of their medical treatment. Some had set limits to how long they would seek out medical treatment while others did not, and some women had a resolution to their story while others did not. The women's narratives about their life cycle are not complete. As Good (1994: 146) notes, in many instances, individuals are still engaged in the striving for a cure and imagining alternative outcomes, evaluating the potential meanings of the past and seeking or not seeking medical treatments.

The options, choices and means available to each woman to negotiate her life cycle is shaped by social, cultural and economic constraints. For example, some women in this study noted that it was important to have a child that was genetically linked to them so they would not consider adoption. Whether the couple had medical insurance that covered the medical treatment was also a deciding factor for the women in

determining how long they would seek out medical treatment. For other women, the cost of an international adoption was too expensive and some viewed it as buying a child.

All the women, to some degree, discussed setting limits to how long they would try to conceive a child. What emerged from the narratives were instances where the women were trying to make sense of their infertility. Women's statements ranged from "I was learning life lessons", "We have come to that fork in the road", "We have done what we can and have to move on" to statements that indicated their uncertain futures such as "How long can you put your life on hold for something that may never happen?" and "How far am I going to go this time?" Other statements included a resolution to their fertility problem such as "We have come to terms with it. It is time to stop this and move on to some other things", "I could live just as happily without a child" and "My path is going to be different."

Some women actively acknowledged that they were different and that this difference was not necessarily a negative self label. For example, as Jody told her story, she defined herself as being different and not the norm. However, at the end of the interview, Jody discussed how being different was a positive attribute which enabled her to gain a sense of resolution. She explained:

Just because you are not the norm doesn't mean you are abnormal...My purpose is different from everybody else's. You are just different and it is ok too because everybody is different. And I know that I am not alone anymore and it took me a long time to realize that...I can say I am ok, there is nothing wrong with me. I don't need to torture myself anymore.

Jody's statement of difference can also be seen as an act of resistance because she takes a

stance toward issues of normalcy and difference. Individuals' statements of difference and statements that say this is how I am or am not, statements that question the status quo or the status of a particular medical treatment, are all statements of resistance (Becker 1997: 17). Jody acknowledges that she does not fit the dominant ideology surrounding the concept of women as defined by motherhood and this is fine with her.

Even though the women experience their life cycle as being in limbo, they do redraw the boundary between otherness and sameness. Infertility is a disruption in the women's lives where they actively rewrite and create new meanings to their stories, and reinterpret events, relationships, feelings and self identity in the face of attempts to achieve an uncertain goal: motherhood. As Kathy explained:

For my experience, for our experience with infertility...we think, we feel that we are in a win, win situation. If we have a child and we go down that road and life will be happy. It will be *different* but it will be happy and it will be hopefully everything we wanted it to be. But, if we don't have a child, we will go down the other road. We would just live the way we have been living, doing our travelling and all that sort of stuff. So we feel we cannot lose either which way.

### 6.5 Conclusion

As the women proceed through the diagnostic tests and medical treatments they experience multiple losses. These losses include miscarriages, loss of control over their life cycles and bodies, loss of privacy, loss of reproductive organs, and loss of a dream, that of motherhood. The women interact with and confront many discourses surrounding biomedicine, womanhood, motherhood and the life course which reflect dominant ideologies about how one's life should be lived. Failure to fit with these cultural scripts

and social norms disrupted how the women viewed their bodies and life courses. Often, the women experienced a sense of failure and loss when their bodies did not function normally and when they did not conform to the social norms of motherhood and womanhood. Yet, in their everyday lives, the women did find spaces to transform and resist these discourses and the medical concept of the body. Some women refused medical treatments or refused to take prescribed fertility drugs for their infertility. Other women sought out non-medical treatments in order to unite the mind with the body. Still others found a sense of community and connection to other infertile women despite the lonely and isolating experience of infertility. All the women in the study (re)made sense of their lives after receiving an infertility diagnosis and renegotiated their life cycles. It is through listening to the women's infertility narratives that the complexity and often contradictory meanings of the experience are revealed as a complex social interplay between the body, self and society.

## **Chapter Seven**

### **Conclusion**

This thesis explored the experiences of infertile women in St. John's, Newfoundland. I have argued that the women experienced a 'line of fault' between their actual experiences and the dualistic framework presented by the medical profession. This dualistic framework was disruptive to the women's lives because it shaped their experiences within a narrow framework which did not address the holistic experience of infertility. The women did not experience the diagnosis and treatment of their infertility in terms of fragmented body parts which divorced the mind from the body. Instead, the women experienced the medical treatment as whole persons where there is no separation between mind and body. In fact, the persistence of conceptual dualisms such as mind and body, science and emotion, rational and irrational, fertile and infertile, sameness and otherness, body and self, and object and subject alienated the women in terms of reorganizing their experiences within conceptual frameworks that disregarded their voices.

The women in this study experienced alienation on several different levels including alienation from their bodily experiences, from other individuals and alienation owing to geographic isolation. For example, the diagnostic phase in determining infertility is characterized by a series of questions posed by the physician to obtain the couple's medical history which emphasizes the body and its actions. The subsequent physical examination, laboratory testing and medical treatment further objectified and

alienated the women from their bodies by concentrating on the abnormalities of the reproductive system without addressing the social, economic and emotional aspects of the infertility experience.

The most vivid example of the medical treatment alienating the body from the self was ovulation induction. The nature of ovulation induction emphasized the close, daily monitoring of the body through blood tests, basal body temperature charting, taking oral or injectable fertility drugs and receiving numerous vaginal ultrasounds. Writing on the effects of routine work, Johnson (1983) notes how one's life shapes and disrupts one's body and perceptions. Although Johnson writes about the experience of a worker in a factory his analysis can be applied to the women's experiences of ovulation induction. He (1983: 78) states:

a worker on an assembly line or a secretary in an office, performing only one kind of action throughout the day, begins to get a sense of their bodies as machines with a narrow range of movement and little feeling. The reduction of the body's capacities to the specific range required by the habitual work correspondingly diminishes the scope of one's perceptions.

Johnson names this kind of work the "technology of alienation" (1983: 80), a way of applying techniques that disconnect people from their sensual being. The medical regime of ovulation induction is designed to manipulate the body to ovulate. In fact, this regime scheduled a woman's life and her activities into a pattern that fits with her monthly menstrual cycle.

The habitual work of taking fertility drugs and receiving blood tests and vaginal ultrasounds emphasizes one particular function of the female body, that is, to grow a

follicle, ovulate and then possibly conceive a child. Reducing women's bodies within this narrow framework negatively affected how women perceived their bodies and themselves. To some degree, all the women in this study viewed their bodies and lives as being out of control and they defined their self worth in terms of the ability to grow a follicle, ovulate and become a mother.

The use of visual technology such as the vaginal ultrasound and the HSG diagnostic test further alienated the self from the body. The women experienced a split orientation to their bodies. They experienced their tactile body when feeling the medical treatment, the visual body when seeing inner body parts being displayed on a screen and the emotional body when they experienced the emotional roller coaster ride. While the women were waiting to know the results of each procedure, they travelled back and forth from their tactile body to the visual (objectified) body by experiencing physical discomfort and pain. The results of the medical treatment and diagnostic test directly impacted the development of the emotional roller coaster ride. As the body is monitored more closely and the women invest more time, money and energy into conceiving a child, the frequency and intensity of the upswing and downswing of the emotional roller coaster ride increased. Instead of the roller coaster ride being spread out over a month, it occurred daily.

Feelings of grief, disappointment and despair were also expressed by the women with every loss they experienced throughout their emotional roller coaster ride. These losses included the loss of control over one's life cycle and body, loss of privacy, loss of a

life dream, i.e. motherhood, loss of a pregnancy, loss of reproductive organs and the loss of social relationships with family and friends. The loss of social relationships contributed further to the feeling of alienation among the women. They noted that interactions with family, friends and co-workers reminded them of their infertility. These reminders include seeing nieces and nephews, seeing children in malls, seeing empty child seats and strollers, and being invited to baby showers. All these reminders acted as symbolic cues that they were 'infertile'. Consequently, the women were continuously reminded that no matter how hard they worked at becoming pregnant, they still did not fit the prescribed cultural and social norm of womanhood.

The feeling of otherness and difference is further heightened because the experience of infertility is often lonely and isolating. The women discussed how, unless someone else experiences infertility, no one could understand what it is like. They felt that no matter how supportive their family and friends were, these people could not understand what they were experiencing because 'you really had to be there.' Furthermore, gender differences contributed to experiencing infertility in isolation for the women. Women have been socialized to talk about their own health, bodies and feelings whereas men have been discouraged from doing so. Discussing infertility with their partners was difficult because the women felt guilty that their bodies were not functioning normally and that the financial expense of the infertility treatments meant that they had to forego other amenities such as buying a house, a car or taking a vacation. Even though the infertility might be officially unexplained or diagnosed as a male fertility

problem, the women still felt responsible, because the majority of the fertility treatments were directed towards their bodies and pregnancies, and miscarriages happened to their bodies.

Finally, the women experienced geographic isolation by living in Newfoundland. The one practising infertility specialist for the entire province works in St. John's. The only infertility clinic, which offers limited fertility treatments for women and their partners, is located in St. John's. Women wishing to receive IVF must travel to another clinic outside the province. Moreover, women living in rural Newfoundland experience a compounded effect of geographic isolation because of the added expense of travelling and staying in the capital city. It is important to note that the nature of the fertility treatments, such as inducing ovulation with injectable fertility drugs, requires women to be monitored on a daily basis. Therefore, women living in rural Newfoundland must stay in St. John's for at least two to three weeks. Even if a woman has family or friends living in the St. John's area, she and her partner may decide not to stay with them to maintain privacy and not disclose a 'condition' that often carries a social stigma. Consequently, many couples living in rural Newfoundland may find it difficult to obtain fertility treatments because of the added financial and social costs. In short, couples living in St. John's and in rural Newfoundland experience lack of choice and poor access to treatments and social support. There is lack of choice of which infertility specialist to see, lack of choice of obtaining fertility treatments, lack of choice of which infertility clinic to go to and lack of choice of social services such as the infertility support group which is also

located in St. John's.

Despite the experience of alienation and isolation among these women, they did find creative ways to reconnect the body and self, reconnect with other women in the community and rewrite their life cycles. Often, the women blurred the boundaries between the body and self, mind and body, infertility and fertility and otherness and sameness. This allowed them to explore new ways of defining womanhood and infertility. For instance, the women did not define themselves as being completely infertile but in some ways fertile as well. They identified with and experienced both worlds by noting that infertility was cyclical and not a permanent state experienced throughout their entire lives. The women also combined the emotional and physiological aspects of infertility in order to discuss their experiences holistically.

In fact, the expression of mixed emotions of excitement, hopefulness, frustration, anger, despair and grief prompted some women in the study to reevaluate the development of their life cycles. These emotional responses were not expressions of irrational and desperate women seeking to have a child, but rather meaningful and purposeful responses to their experiences. These responses prompted the women to decide rationally whether or not to continue with medical treatment or set limits on how long they would try to conceive a child. For other women, the experience of the medical treadmill and frustration and anger at the medical profession prompted them to refuse medical intervention in treating their infertility.

Another means by which the women reconnected the body and self was seeking

out non-medical treatment for their infertility. Usually these treatments emphasized the unity between the mind and body and attempted to discover the root cause of the infertility rather than solely treating its symptoms. The non-medical appointments were longer in duration where the women could explore the emotional and social aspects of the infertility experience.

Moreover, the women reconnected with other women who experienced infertility by actively searching for other women's stories on the internet, in books, magazines and journal articles. By researching out other infertility stories, the women recognized that their experiences of alienation, isolation, otherness and difference were shared experiences among infertile women. A few women in the study developed friendships with other women by meeting them in the waiting room of the infertility clinic, by staying in hospital rooms where women had miscarried and by attending the infertility support group. What developed was a communal sharing of joys, concerns, losses and a sense of empowerment among the women.

The body also became a site of empowerment and resistance where the women actively transformed and resisted the dominant discourses of biomedicine, motherhood and womanhood. Such resistance took the form of refusing medical treatment, seeking out non-medical treatment, refusing to take fertility drugs, researching the long term and short term side effects of fertility drugs, learning about their bodies and the process of menstruation, fertilization and pregnancy, and deciding to remain childfree.

Throughout this thesis I have shown that the women's infertility narratives are complex, often consisting of mixed emotions, social, financial and medical factors shaping their experiences, futures that are unknown and full of contradictions. One significant contradiction involved experiencing infertility holistically but having it reorganized within a medical-scientific paradigm that render the body as passive and objectified. Another involved the female body as a site of both objectification and resistance. And finally, there was the contradiction of medical technology that segmented and objectified their bodies, while at the same time providing the women with a sense of hope of becoming pregnant and offering new ways of viewing their bodies. Within these contradictions the women rewrote, reevaluated and redefined their lives while trying to achieve an uncertain goal--motherhood.

#### 7.1 Areas for Future Research

Generally, women's health, particularly women's health in Atlantic Canada, has been under researched. The experience of infertility among women is included in this lack of attention. According to the Maritime Centre of Excellence for Women's Health, (MCEWH 2000: 7) the overall health and well being of women, children and their families in Atlantic Canada remains far behind the rest of Canada. Therefore, furthering women's health research which includes the experience of infertility will help us make the best strategic investments for the health and welfare of women living in Atlantic Canada. In particular, further research on infertility must include the voices of women and their partners who live in rural Newfoundland. Researching the impact of geographic isolation

and lack of access to fertility treatments and social support will further identify the needs and concerns of these women and their partners.

Among the thirteen women I interviewed, ten were diagnosed as having irregular ovulation or polycystic ovarian disease. Although this is the most common physiological cause of infertility among women, a high number of women in Newfoundland are diagnosed with this disease. Future research should investigate whether the high number of women being diagnosed with polycystic ovarian disease is "normal" given the population in Newfoundland and Labrador, as well as explore regional differences in the delivery of medical treatments among infertility clinics in Canada.

Finally, future research into the infertility experience must examine the impact of medical technology on the experience of embodiment. For instance, how does the introduction of visual imaging technologies (ultrasound and x-ray) shape the subjective experiences of infertile women? More specifically, how does the introduction of the ultrasound and x-ray shape the development of the emotional roller coaster ride? The women in this study have discussed the differences in the experience of the emotional roller coaster ride once the visual imaging technologies were used to monitor their bodies. Such research would further explore these differences and the impact visual technologies have for (re)imaging the female body.

## 7.2 Policy Recommendations

According to the World Health Organization, health refers to "a state of complete physical, mental, spiritual and social well-being, and not merely the absence of disease"

(as cited in Colman 2000: 9). The following policy recommendations focus on emphasizing the physical, social, mental and spiritual well being of women who experience infertility.

First, physicians, nurses, ultrasound and x-ray technicians and other health care providers who see infertility patients must recognize that women and their partners experience infertility holistically. Women experience the diagnostic and possible treatment phase of their infertility as whole persons. Women are more than uteruses, vaginas, ovaries, fallopian tubes and wombs. Moreover, health care providers need to be more empathic to the women's emotional needs after an infertility diagnosis and during any subsequent medical treatment—more specifically, when they are discussing the results of the HSG and the vaginal ultrasound because the results of these tests impact the development of the emotional roller coaster ride. Health care providers also need to provide *detailed* descriptions of the steps and procedures used to diagnose and treat fertility problems in order to better inform patients of any side effects and about what is actually involved with these procedures. Medical appointments could be scheduled for a longer period of time to allow the women to discuss their emotional needs with their physician and any other concerns they have about the diagnostic tests and the medical treatments.

Second, the availability of fertility drugs in Newfoundland should be increased by having a pharmacist specialize in dispensing these drugs in order to minimize delays in the treatment process. Third, counselling materials that are provided to women and their

partners after they have experienced a miscarriage or ectopic pregnancy should include the diversity of experience among single, bisexual, lesbian, and ethnic minority women. In addition, resource material should be provided to women and their partners who wish to seek out alternatives to receiving medical treatment for their infertility, such as adoption, international adoption, non-medical treatments and information about remaining childfree.

Fourth, Canadian women and men who are directly impacted by government policies designed to regulate reproductive and genetic technologies (RGT's) should be included in policy formation. For instance, during February and March of 2000, Health Canada officials met with provincial colleagues to discuss federal legislation surrounding reproductive and genetic technologies. The participants included "provincial and territorial colleagues, as well as with representatives of selected stakeholder organizations" and the purpose of such discussions was for "Health Canada to gain a fuller understanding of provincial, territorial and stakeholder views on proposed federal approach to RGT's" (Health Canada 2000: 1). However, the absent voices in such discussions were women and their partners who were directly affected by this legislation. Reproductive and genetic technologies are performed on women's and men's bodies, and therefore their voices and experiences should be included in any policy recommendation on reproductive and genetic technologies.

Finally, the women in this study noted the importance of sharing their stories with other women because they could identify their own isolating experience with them. They

also felt that the support they received from the women was qualitatively different from that received from individuals who did not have difficulty in conceiving a child.

Therefore, increasing the opportunity for women to talk about their experiences with others will help minimize the isolation felt by these women.

Increasing the social support and networks of infertile women could happen in a variety of different ways. For instance, another meeting time for the infertility support group which meets every second Tuesday of the month could be scheduled for couples who cannot attend because of conflicting work schedules. However, it should be noted that not all women can or wish to attend the infertility support group. Women living in rural Newfoundland often have to travel long distances to attend the support group and this can sometimes be expensive and even impossible to consider. Others may not wish to share their personal stories in such a 'public' space. Therefore, developing an on line listserv for women could help connect women across the province and provide another medium where women could discuss their infertility experiences.

Similarly, the use of audio teleconferencing technology can facilitate social support among women. This medium would connect women from different areas of the province, including Labrador, and provide an added means of being able to talk to other women face to face. Church, Curran and Solberg (2000) have noted the benefits of such audio teleconferencing meetings among women who have been diagnosed with breast cancer in Newfoundland. They noted that this teleconferencing network helped the women to deal with the "tremendous emotional upheaval they were experiencing" and

was "invaluable in lessening both family and community burdens of dealing with the disease process" (Church, Curran and Solberg 2000: 22). Having a facilitator also present for the audio teleconferencing would be beneficial because the facilitator would be knowledgeable about infertility and could discuss with the women the latest in treatment options or alternatives to receiving medical treatment (Church et al. 2000: 22). On-going or coming events related to infertility could also be discussed. The infertility support group, an on line listserv and the audio teleconferencing network would all help bring together women's voices in an informative and supportive way and help foster connections among women in different areas of the province who are in need of support.

Bringing together women's stories of infertility is important because all the women interviewed for this study expressed feelings of isolation, alienation and difference after an infertility diagnosis. They also noted how important it was for them to be able to talk with other women who knew what living with infertility was like or reading about women's infertility stories. Such stories included women currently receiving medical treatment, women refusing medical treatment, women who sought out adoption and women who remained childfree. This diversity of experience could provide optimal support for the women because it is comprised of women who had a variety of experiences with infertility and different ways of rewriting their life cycles after an infertility diagnosis.

Moreover, sharing their stories with other women can be an act of resistance. As Welch (1985: 41) writes:

as women share stories of their own lives, a common experience of oppression and resistance is recognized. This politicization gives women the courage to persist in resistance, recognizing their difficulties have not only individual basis but social and political basis as well.

Therefore, without the communal sharing of life experiences, the solidarity and social support Welch writes about cannot develop and the possibility for change is limited. This thesis has been about bringing together fourteen stories of women who experience infertility. Their stories offer unique insights into the infertility experience as well as sharing the common experience of oppression and resistance, and despair and hope. The women confronted assumptions about their bodies, themselves and their life cycles while redefining what it means to be a woman and infertile. I end this thesis with a quote from Wendy because her single statement succinctly captures how sharing one's story can be an act of resistance.

I am a woman...I have found fertility beyond just my body.

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**Appendix I****Epilogue**

The infertility stories of the eight women not included in chapter four are presented here. Names of the women have been replaced with pseudonyms and I have altered the age and occupation of the women to conceal their identities. I hope these vignettes can do some justice to illustrate the uniqueness of their incredible stories and illustrate the common bond they share. In each vignette, I have tried to choose experiences, thoughts and feelings that were central to the woman's narrative.

**Rachel's Story**

Rachel (26) was the youngest woman I interviewed. She is married, has a Bachelor's Degree and works part-time as a teacher. Rachel was diagnosed with polycystic ovarian disease or syndrome (a complex hormonal problem in which the ovaries fail to ovulate and instead form numerous tiny cysts) at the age of sixteen by an endocrinologist. The endocrinologist told her that she would need drug therapy to make her body ovulate. Rachel and her partner did not seek out medical treatment right away. They waited until she was ready to have a child and Rachel viewed this as a mistake because the waiting list to see the infertility specialist was a year. This was devastating news for Rachel. She then decided to ask her family doctor to refer her to a gynaecologist.

It was with this gynaecologist that Rachel started receiving medical treatment. It was a year full of physician's appointments, blood tests, taking oral fertility drugs, and

receiving ultrasounds. Rachel's partner also had a sperm analysis done and it revealed that his sperm motility was low. Rachel thought that this was the end of the world because there were two contributing factors for her and her partner to overcome and she wondered if she would ever have a child.

Rachel also recalled a vivid interaction with a medical doctor that dashed all hopes of conceiving a child. She stated:

It was the most devastating doctors' appointment I ever had in my life. She proceeds to tell us that because my husband's sperm motility and sperm count was low, we had to have sperm donation and that was not done here. It just came to us out of the blue...I could not control myself any longer. And she was absolutely confused as to why I was crying. She said to me, "I don't understand why you are so upset. You are so young. You are only 26 years old, why are you so upset? If you were 36, I could understand you crying. But you have no right to cry at the age of 26." And that was a big thing. And to me, I did not think I was *that* young to want to have a baby. But, in the medical profession I guess I was. You know, I was not at the last chance in my late thirties. I think I was discriminated against. I think I really was because of my age. I long to have so many years ahead of me. Like what good was that when you want a baby you know.

After this medical appointment Rachel and her partner decided to plan a trip to Toronto to investigate the option of IVF. When they were planning to go, Rachel got pregnant without any medical intervention and miscarried soon after. As a result, they cancelled the trip to Toronto and Rachel decided to see a different gynaecologist for her infertility. Under the supervision of this gynaecologist, Rachel started taking clomid, which is the mildest oral fertility drug used to induce ovulation. After being on this drug for one cycle (a month) Rachel got pregnant again and stayed pregnant. Rachel and her partner have a daughter and are thinking of trying to have another child.

**Hannah's Story**

Hannah is in her early thirties, married and is employed full-time in the health field. Hannah and her partner have been trying to have a child for five years. In 1995, Hannah was diagnosed as having polycystic ovarian disease and was prescribed clomid for three months by her gynaecologist. On the third month, Hannah got pregnant and miscarried a few weeks later. After taking clomid for another three months, Hannah was referred to the infertility specialist. The infertility specialist prescribed an injectable fertility drug to induce ovulation. At the time of the interview, Hannah had been taking the fertility drug for one month and was waiting for her next cycle to begin. Hannah described her medical treatment as a regime of frequent ultrasounds and

like at the same time the doctor did not say to me, "Well, this is going to be the regime." I had no idea in the beginning that every second day I would have to have blood tests and an ultrasound until that cycle started. She was like, "You got to come back in two days and track the cycle"...So every second day I went up to see her and it was like another disappointment. Everyday I go through another failed attempt to have a child and all my friends around me are having babies. There are babies all around.

Hannah also discussed how impatient she became as she progressed through the different stages of her medical treatment and it was nearly impossible to relax:

I am a very impatient person. I want things done immediately. But it's a slow process and that makes it harder. You want results immediately and you can't...You are bound by this 28 or 30 day cycle you know, what they call a normal cycle. And it takes that long to try something so it's a month that's gone. It's not like days, but it takes months because we are working with the cycle. And you don't know if it worked until the cycle is done.

Hannah and her partner do not have a child and they do not know how long they will continue to try to conceive a child.

### **Grace's Story**

Grace is 28 years old, a university student and is married. Her partner is also a university student. Grace and her partner have been trying to have a child for three and a half years. Grace was diagnosed as having polycystic ovarian disease by her gynaecologist and was prescribed clomid. After being on clomid for 18 months, Grace decided to go back to university. This was a needed distraction from the 'regime' of the medical treatment and the pressures associated with it. She explained:

Actually I think that it helped. I started university in January of 1992. I think it took my mind off of it. It took the edge off because I was devoting my time on something else... I was enjoying part of my life. If I can't have a baby I will have it later. I was reaching to a point that it would be ok. A couple of weeks before I found out that I was pregnant, I [wanted] to give up for a while because I was tired. I just wanted a break from the pressure because everybody knew we were trying. You know everybody was expecting a baby to happen. I mean people are asking you, "Are you pregnant yet." You know, just take a break for six months, see how university goes. And because being on the fertility drugs, having to take your basal body temperature, and trying to chart it, going to see the doctor every three months time, and having your period. It was all hard because you knew why you were doing it.

Grace vividly remembers the day she found out she was pregnant and rushing out to a pharmacy to buy a pregnancy journal and a teddy bear. In the journal she wrote all her thoughts and feelings surrounding the pregnancy as well as the difficult time she had trying to get pregnant. The journal served as a reminder of what she went through and she hoped that one day her daughter would read it and know that she was really wanted.

Grace also set up a time capsule. In the wooden box she placed the rest of her fertility drugs, the pregnancy test and all the basal body temperature charts. She added, "I am really sentimental about everything, but I will never forget that. I mean it was just, how hard we tried to get pregnant."

### **Kathy's Story**

Kathy is 37 years old and has been married for 14 years to her high school sweetheart. She has a university degree and teaches in a college. Kathy's partner has a PhD and works in the health field. Kathy and her partner were married for four years before they started trying to have a baby. After having unprotected sex for about a year, Kathy went to her family physician and she was diagnosed as having irregular menstrual cycles where she did not ovulate. At the time of the interview, they had been trying to conceive a child for three years. During the three years, Kathy has been on numerous medications to induce ovulation including clomid and injectable fertility drugs. When I talked with Kathy, she noted that this would be the last time she would be on fertility drugs and it was the last try to get pregnant. As she stated, "If we can't produce ourselves, it will be us and our dogs." I asked Kathy how she and her partner decided that this would be the last time for seeking out medical treatment. Kathy simply replied that she did not want to go through the emotional roller coaster ride again. Kathy and her partner both felt that it was time to say enough is enough. Kathy also noted how she felt different waiting for the last treatment to begin:

I think this time around is different because we are both going to be, I don't know

about Frank, but for myself I feel so much more relaxed almost as if a cloud has been taken off my head. Just knowing that this is going to be the last time. The emotional aspect of constantly being up and down and everything is not there this time. And I guess the only thing I can contribute that to is if it doesn't happen now, we came to the fork in the road and the road that we are going to go down on now is living child free. Life is going to be good. So I think in that regard I have started the process of detaching myself away from it.

### **Teresa's Story**

Teresa is 28 years old, married and has a child after receiving medical treatment. Teresa and her partner experienced the shortest length of time trying to conceive a child, one year. Teresa works at home taking care of her son and her partner is employed full-time in the health field. After six months of trying to get pregnant, Teresa went to her family physician because she thought it was taking too long to get pregnant. Her family doctor told her it was too early to do anything and the easiest thing to do was for Teresa's partner to get a sperm count done. This however, started a journey of confusion for Teresa and her partner as they both encountered the issue of unexplained infertility. After Teresa's partner had the sperm analysis done which showed a low to normal sperm count, Teresa was referred to a gynaecologist. It was here that Teresa felt she had no control because she was being given different explanations and reasons for her and her partner's difficulty in having a child. She stated:

I thought I had no control at all. I did everything he [the gynaecologist] said. And then, I just felt when I went to the doctors, here she comes again and then they would say, "Some have been trying for five years and they still don't have a baby." I know that. I mean, I got pregnant and it was only a year. I am so lucky. But still, and like first we were told that my husband would never father a child. Then I was told I had polycystic ovary disease. Then we were told that nothing was wrong and go home and have a bubble bath and a glass of champagne. So it

was just, how can you go from telling us, he is never going to father a child to I am having polycystic ovarian disease, to neither of us have anything, right.

Teresa's gynaecologist prescribed clomid, and after taking it for one cycle Teresa got pregnant. However, the confusion surrounding the diagnosis and living in an environment where everything was a reminder that they were childless was difficult.

Teresa noted how everything became a symbol that they were childless, from orange juice to baby seats in cars. She explained:

Everything, the orange juice [drinking orange juice supposedly increases a man's sperm count], everything, it use to drive me insane when people would say, "forget about it, stop thinking about it and relax." But, when you are going through it, at least for me, everything is a reminder. You get into your car. A car drives by and you see a child seat in it. You go for a walk and there are strollers. You get invited to baby showers. You've heard people getting pregnant all the time in your family...And it got to the point where I hated the number two because we would look out the window in the summertime and there would be two lawn chairs there. Everything was too neat and tidy. It was just really, everything was a symbol.

Teresa and her partner are trying to have another child, but neither of them has sought out further medical treatment.

### **Kristine's Story**

Kristine is 41 years old, married, has a high school diploma and works at home. Kristine and her husband have been trying to conceive a child for 17 years and were successful five years ago with the birth of their daughter. Kristine started having irregular menstrual cycles when she was sixteen and this began a process of going to see family physicians, different gynaecologists and specialists to find out what the problem was. One gynaecologist told her that she would never conceive a child. To Kristine, this was

not an option. As she noted:

Like years go on and I wanted to know what was wrong with me. One doctor said, "You will never have children." I went back to another specialist, you say my ovary is fine, but why can't you find out what is wrong with me. There are no answers and I would not accept that I could not have children. I just wasn't going to accept it. And then I went to \* place. They were trying to help us cope with it and understand it, and accept it. But I will not accept it. So, I would not go there anymore. I could not see myself not having children. I mean that is every woman's dream. You know, get married and have children.

Kristine took a number of different fertility drugs to help her ovulate, but none of them worked until she saw the infertility specialist and together they found the right dosage that induced ovulation. Kristine noted how she was the first one in her family to get married and the last one of her siblings to have a child. This was difficult for Kristine because she watched her siblings start their own families and she felt like a failure:

I felt like a failure. Here I am, a married woman for so many years and I can't have one. I use to say it is so unfair, not right. Then I use to say, "What did I do?" You know, not that wasn't the reason I wasn't having one. It was a medical reason. Then it took *so long* to find out what it was, all those wasted years and all the wasted money. I am disappointed that I was not diagnosed earlier, that I was not helped earlier because I always wanted to have one more child. And I am thankful for what I got, but now it is too late. I mean it took us 17 years to get her and I am not, I can't wait for another 17 years to have another one, right. And now I am not in a position to pay for my drugs you know, for another one...I just don't have the money or the resources to go back to see the infertility specialist and try again.

### **Vanessa's Story**

Vanessa is 35 years old and married for six and a half years. She worked full-time as a research analyst and her partner works full-time in the entertainment field. Vanessa and her partner tried for four years to have a child. During these four years, Vanessa

miscarried twice and went through a variety of diagnostic tests such as blood tests, a laparoscopy and a HSG. Vanessa cites a number of different factors contributing to her infertility, endometriosis, a lot of adhesions on her ovaries and an incarnate uterus where the uterus is shaped as a heart instead of an oval. After Vanessa had a negative experience with a medical doctor, she and her partner decided not to seek out any medical treatment and instead pursue international adoption because it was a 'sure thing':

I realized that I couldn't go through any more at this point. We thought ok, this is going to be very expensive if you go through with IVF. You had to go to the mainland and spend endless amounts of money and you are not sure that it is going to be successful in the first, second, or third, fourth go around. And we thought, ok, if we are going to spend all this money let's go through a sure thing. It wasn't important that the child was biologically connected to us, so why not go. It was a sure thing. We don't have to worry about if it was going to be successful or not. So, that is why we went that route. We just couldn't spend, the thought of it, we just decided it was enough.

After Vanessa and her partner internationally adopted their daughter, Vanessa got pregnant on her own and gave birth to her daughter. This led Vanessa to question the original diagnosis and she does not really know the reason why she had difficulty conceiving a child. She also felt shock surrounding her pregnancy. As she explained:

Not so much shock that I was pregnant. I was pregnant before, but shock that I was still pregnant. We were kinda of in denial going through the pregnancy. We had been through so much you know, we were in total denial. We could not believe it until she was born. We just couldn't get our hopes up.

In a few years, Vanessa and her partner will try to have a third child. Right now, they are concentrating on getting their 'lives back on track' after adopting their daughter and having another child only a year apart. As Vanessa stated, "We will just wait and see."

**Lauren's Story**

Lauren is 34 years old, married and has a Master's Degree in education and teaches full-time. Lauren was diagnosed with polycystic ovarian disease when she was 22 years old, but, it was not until she was 29 that her family physician referred her to the infertility specialist. Lauren and her partner tried for four years to have a child and in 1999 Lauren gave birth to her daughter. During the four years of medical treatment, Lauren took a number of different fertility drugs including clomid and injectable fertility drugs. She also had a HSG and ovarian drilling done. The years of medical treatment were physically and emotionally difficult on her body and travelling back and forth from her hometown to St. John's was very tiring. After she gave birth to her child, Lauren and her partner decided not to have another child because the treatment process was just too tiring and she experienced a difficult pregnancy where she could have lost both the baby and her own life.

Moreover, Lauren was one of the few women I interviewed that sought out non-medical treatment while she was going through ovulation induction. I asked her why she sought out the non-medical treatment and she explained:

[I went to] a nurse practitioner and she prescribed some naturopathic remedies and different things like that. I also did meditation and visualization...I enjoyed talking to her and she allows a lot of time for her appointments. They are more than an hour so you don't feel that you are rushed. You could just sit there and ask questions and talk. I think her approach to disease is obviously different from the medical doctor. I think if a medical doctor is often, they are trained to treat the symptoms whereas a naturopathic practitioner I think will often try to find the cause, the root cause of the problem and treat that rather than imposing therapy that treats the symptoms. They are open to the fact that the mind, spirit is a part of

the treatment of disease. Whereas, the doctors, not that they are not interested in it, they don't have time to sit down and discuss those things with you. But, sometimes I think that is exactly what you need.

Having the non-medical treatment along with the medical treatment complemented each other and helped Lauren go through the treatment process. Lauren also discussed how she was concerned about the long term effects of the injectable fertility drugs she took over the four years, especially the high doses. This concern stemmed from the fact that her mother was recently diagnosed with ovarian cancer and Lauren wondered if there was a connection to the fertility drugs she was taking and the risk of developing ovarian cancer.

**Appendix II****List of Medical Definitions<sup>1</sup>**

Artificial Insemination: A procedure by which sperm is placed in a woman's vagina as close to her cervix as possible.

Artificial Insemination by Donor: A procedure by which sperm from a donor male is placed in a woman's vagina as close to her cervix as possible in the hope of conception and successful pregnancy.

Basal Body Temperature: Temperature of the woman, taken orally upon waking in the morning before any activity. Used to help determine if ovulation is occurring.

Cervix: A ring of flexible muscle at the base of a woman's uterus which extends into her vagina.

Clomid: A trade name for clomiphene citrate which is an oral fertility drug. It is administered to induce women's ovulation.

Ectopic Pregnancy: A woman's pregnancy which occurs in her fallopian tube rather than her uterus. An ectopic pregnancy can never come to term. It is a dangerous condition and always requires surgical intervention to save the woman's life. She will almost always lose her fallopian tube.

Endometrium: Lining of the uterus.

Endometrial Biopsy: A procedure where a small portion of the endometrium is removed

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<sup>1</sup>These definitions were taken from Harkness (1987); Klien (1989) and Garner, Menning and Wentz (1996).

from wall of the uterus. The diagnostic test is used to detect any abnormal cell growth in the endometrium.

Endometriosis: A painful condition of the female reproductive system in which the lining of a woman's womb sticks to other organs in her body. It often leads to fertility problems and can cause a woman very painful periods and pain during intercourse.

Fallopian Tubes: Two tubes which lead from the top of a woman's uterus and end with fine finger like projections near her ovaries.

Fertilization: The union of egg and sperm.

Fetus: The developing embryo from the second month of gestation to birth.

Follicle: Structure in the ovary that nurtures the developing egg and from which the egg is released.

Gamete Intrafallopian Tube Transfer (GIFT): A variation of in vitro fertilization in which eggs collected from a woman (with the same procedures as in IVF treatment regime) and sperm are injected into the woman's fallopian tube so that fertilization can take place there instead of the laboratory dish.

Hormone: Chemical produced by the endocrine gland that circulates in the blood and has widespread action throughout the body.

Hyperstimulation: Overstimulation of a woman's ovaries as a result of the administration of fertility drugs to induce ovulation. Hyperstimulation can lead to ovarian enlargement or rupture of a woman's ovary(ies).

**Hysterosalpingogram (HSG):** X-ray examination of a woman's uterus and fallopian tubes using radio-opaque dye injected into her uterus under pressure. This technique is performed on women without general anaesthetic in order to detect anatomical abnormalities.

**Hysteroscopy:** Viewing the inside of the uterus through a narrow fitted telescope.

**Iatrogenic Infertility:** A condition of physiological infertility that has resulted from medical intervention.

**Infertility:** The inability to conceive after one year of well timed, unprotected intercourse.

**Infertility Specialist:** A gynaecologist who has received further experience, education, and training to specialize in the diagnosis and treatment of infertility.

**In Vitro Fertilization (IVF):** IVF is the original 'test-tube baby' technique. In vitro fertilization removes several eggs from the ovary, fertilizes them in the laboratory with sperm from the male partner, and transfers a small selection of the resulting embryos to the womb for implantation and pregnancy.

**Laparoscopy:** Visual examination of women's ovaries (or other abdominal organs) by inserting a laparoscope (light guide) through a small incision in a woman's abdominal wall.

**Menopause:** The last menstrual period after years of diminishing or erratic menses, commonly occurring between the ages of 45 and 55.

**Menstruation:** Shedding of the uterine lining by bleeding that, in the absence of pregnancy, normally occurs about once a month in the mature female.

New Reproductive Technologies: New reproductive technologies refer to several different medical procedures designed to unite sperm and eggs, thus bypassing altogether some of the factors causing infertility. Collectively these medical procedures are referred to new reproductive technologies.

Ovarian Drilling: A surgical procedure where tiny holes are drilled into the ovaries. Women who are diagnosed as having polycystic ovarian disease may have this procedure done because it sometimes helps stimulate ovulation.

Ovaries: Female reproductive organs that store and release eggs during ovulation, as well as the hormones estrogen and progesterone.

Ovulation: The release of a mature egg, usually about the midpoint of the menstrual cycle.

Pelvic Inflammatory Disease: In women, any infection and inflammation of their pelvic organs which is caused by bacteria or viruses. The infection often localizes in a woman's fallopian tubes and can cause irreparable damage from scarring. This scarring is a cause of fertility problems.

Polycystic Ovarian Disease: A hormonal problem in which the ovaries fail to ovulate and instead form numerous tiny cysts.

Primary Infertility: Inability to conceive after one year of regular, unprotected intercourse (after 6 months if the woman is over age 35) for a couple who has never had a baby.

Secondary Infertility: Inability to conceive after 6 months of regular unprotected intercourse, or carry a pregnancy when at least one partner has successfully conceived or

carried one or more pregnancies.

Sperm Count: A laboratory investigation of a sample of a man's semen to ascertain the number of sperm. Other sperm tests include those to determine the shape, size and ability to move.

Superovulation: The process whereby a woman is administered a regimen of fertility drugs and hormones to induce her to mature and ovulate more than one egg at a single menstrual cycle.

Ultrasound Testing: The use of high frequency sound waves to show visual outlines of internal body structures.

Unexplained Infertility: A term used to describe infertility when no medical reason can be found to explain the cause of a couple's infertility.

Uterus: The female reproductive organ that nurtures the fetus from implantation until birth.

Vagina: The muscular passage between the uterus and exterior vulva.

Varicocele: A varicose vein of the testicle.

Zygote Intrafallopian Transfer (ZIFT): ZIFT combines aspects of both in vitro fertilization and gamete intrafallopian transfer. Eggs are collected and fertilized by the partner's sperm in the laboratory. What makes ZIFT different from IVF is that the embryo is placed into the woman's fallopian tube via laparoscopy instead of the uterus.

**Appendix III*****Researching Women's Experiences with Infertility***

*My name is Penny Dowedoff and I am a graduate student in Sociology at Memorial University. I am interviewing women about their experiences with infertility. To my knowledge there exists no research into infertile women's accounts of their own experiences in St. John's. This research project will increase the awareness of the needs of infertile women as well as showing how infertility impacts women's lives. All precautions will be taken to ensure the confidentiality of the subject. Your participation is really important to my research. If you are willing to take part in this study, please contact me at*

*754-4171*

*Penny Dowedoff.*

This project is not affiliated with the Health Care Corporation of St. John's.

**Appendix IV****Interviewee Release Form****An Exploratory Study of the Everyday Experiences of Infertile Women in St. John's, Newfoundland.**

The purpose of this form is to provide you with information about this research project and how the interviews will be conducted. I request that you read this form carefully and sign it if you agree to participate in this project.

First, I would like to give you a little information about myself and the research project. My name is Penny Dowedoff. I am a graduate student in sociology at Memorial University of Newfoundland. This project is a requirement for my master's thesis. The primary objective of this study is to explore women's experiences with infertility and their social context. To my knowledge there exists no research into infertile women's accounts of their own experiences in St. John's. It is hoped, therefore, that this research project will increase the awareness and understanding of the daily experiences of infertile women and their needs.

Your participation in this study is voluntary. You may refuse to answer questions and you are free to withdraw from the study at any time. Please feel free to offer comments and suggestions on topics covered in the interview and on issues not covered that you think may be relevant. With your permission, I prefer to record the interview to ensure accuracy of information. However, you may request that I turn the tape recorder off any time during the interview. The interview will be subject to strict confidentiality.

It is my responsibility, therefore, to ensure the protection of both your identity and answers to the questions you provided. I would be grateful if you would sign this form to show that you consent to be interviewed. Your assistance in this project is very much appreciated.

Sincerely,

Penny Dowedoff

M.A. Candidate

Department of Sociology

I, \_\_\_\_\_, hereby agree to take part in the aforementioned project.

(Signature) \_\_\_\_\_ Date \_\_\_\_\_.

**Appendix V****Diary Entry Release Form**

Since this research project is focussed on your daily experiences with infertility, I feel that writing a diary is another way for you to tell me your thoughts and feelings about infertility. In short, how infertility has impacted your life. You may describe any new ideas or thoughts you've had since the interview or any new experiences. Writing in the diary is a place where you can describe your own experiences and what it means to be infertile. It is your story to tell.

I would like to ask you to write in the diary for a whole week and during one that is particularly significant to you. For instance, during a week where you have a doctor's appointment, receive medical or non-medical treatment or when your experiences of infertility are central in your life.

Writing a diary is completely voluntary and you are free to withdraw from the writing any time. Like the interview, it is my responsibility to ensure the protection of both your identity and what you write in the diary. Once my work is finished, I will either give the diary back to you or destroy it. Are you comfortable with writing in a diary and willing to participate? If you are willing to participate, I would be grateful if you sign this form to show that you consent to write in the diary.

Sincerely,

Penny Dowedoff

M. A. Candidate

Department of Sociology

I, \_\_\_\_\_ hereby agree to take part in the aforementioned project.

(Signature) \_\_\_\_\_ Date \_\_\_\_\_

Do you prefer to have the diary returned to you or destroyed? \_\_\_\_\_

**Appendix VI****Semi-Structured Interview Schedule.**

Date:

Place:

Time of Interview:

End of Interview:

Where did the participant learn about my study and how did she contact me:

Interview number:

**Section A.**

First, I would like to discuss your marital status and educational background.

1. What is your marital status? (Single, Common-law, Married, Divorced, Separated, Widowed). If the participant identifies herself as single, ask if she has a partner.
2. To which age category do you presently belong (under 24; 25-29; 30-34; 35-39; 40-44; 45+).
3. What is your highest level of formal education?
4. (If married or has a partner) What is your partner's highest level of formal education?

**Section B.**

Now I would like to discuss your employment history (and your partner's).

1. Are you currently employed, self employed, or not employed?

2. (If employed, or self employed). Are you employed on a full-time, part-time, or casual basis? Do you put in any overtime work? (Yes / No).

If yes, how much overtime do you put in?

3. What is your current occupation?

4. Do you do any unpaid work? (Yes / No). What type of work is it? Probe (i.e. housework).

5. What type of work schedule do you have? Please describe your schedule in terms of paid and unpaid work you do?

6. According to the letter categories on the cards, what is your personal income before taxes? (A, B, C, D, E, F, G, H, I, J).

7. (If married or has a partner). Is your partner currently employed, self employed, or not employed?

8. (If partner is employed or self employed) Is your partner employed on a full-time, part-time or casual basis?

Does your partner put in any overtime work? (Yes / No).

If yes, how much overtime does he or she put in?

9. What is your partner's current occupation?

10. Does your partner do any unpaid work? (Yes / No). If yes, what type of work is it? Probe (i.e. housework).

11. What type of work schedule does your partner have? Please describe your partner's schedule in terms of paid and unpaid work he or she does?

12. According to the letter categories shown on the cards, what is your partner's personal income before taxes? (A, B, C, D, E, F, G, H, I, J).

**Section C.**

Next, I would like to discuss the subject of infertility.

1. What words do you use to describe your condition?
2. What do these words mean to you?

For the purpose of this interview, I will use the medical term infertility.

3. Some medical doctors use the term infertility to discuss a person's difficulty in having a child? What do you think of the use of this term?

How would you define infertility?

4. Some medical doctors also use the term involuntary childlessness to refer to a person's difficulty in having a child. What do you think of the use of this term?

How would you define involuntary childlessness?

5. Do you think there is a difference between infertility and involuntary childlessness?

(Yes / No). If yes, what is the difference?

6. What kinds of information have you found about infertility?

7. Have you read any books or articles about infertility? (Yes / No). Can you remember the names of them?

What specific aspects of infertility did the books or articles discuss?

What did you think of this information? ( i.e. was the information helpful).

8. Have you looked on the Internet for information about infertility. (Yes / No). If yes,

what did you find?

What did you think of this information?

9. For how long have you tried to conceive a child?

10. Why do you want a child? Probe. ( personal choice; it is the right time; social pressure).

11. If you cannot have a child, have you decided to adopt, remain childless or have you considered any other options? Why?

#### **Section D.**

In this section, I would like to discuss whom you talk to about your infertility and how your infertility has affected your life.

1. Have you talked to anyone about your infertility other than medical personnel? (Yes / No).

2. Who have you talked to about your infertility?

Is there anyone else you talked to about your infertility?

3. What specific aspects of your infertility do you talk about?

4. Do you find it difficult to discuss your infertility with any persons you mentioned above? (Yes or No). Who?

How come?

5. In your opinion, does your partner find it difficult to talk about your infertility with you? (Yes / No). Why?

6. Has your infertility changed your relationship with your partner in any way? (Yes /

No). If yes, in what ways?

7. Has your infertility changed your relationship with your family in any way? (Yes / No). If yes, in what ways?

8. Do you find it difficult to attend family gatherings? (Yes / No). How come?

9. Do you know of a support group for people who experience infertility? ( Yes / No). If yes, what is it?

10. Do you belong to a support group? (Yes / No). If yes, do you feel free to discuss your difficulty in having a child within this group? Why?

11. Has infertility presented any challenges in your life? (Yes / No). If yes, how do you deal with these challenges?

12. What is the most difficult aspect of infertility for you?

How do you deal with it?

13. Has infertility caused you to feel any specific emotions? Probe.

14. In what other ways has your infertility affected your life? Probe.

### **Section E.**

Now I would like to discuss your contact with professionals concerned with infertility.

1. Have you seen your general practitioner (GP) about your difficulty in having a child? (Yes / No). If yes, what is his or her name?

If no, how come?

2. Did the general practitioner (put in name) refer you to a specialist? (Yes / No).

3. (If yes to #2) What is the specialist's name?

4. Which medical doctor is currently treating you?
5. Did your partner come with you to see the general practitioner the first time you went to discuss your difficulty in having a baby? (Yes / No). Why?
6. Did your partner come with you to see the general practitioner at any other time? (Yes / No). If yes, when?
7. Is your general practitioner male or female?
8. Do you have a preference for a male or female medical doctor? (Yes / No). Why?
9. Within the medical profession, doctors use a process called an 'infertility work up' to identify fertility problems. It includes a variety of tests performed to determine where the problem or problems lie. Did your general practitioner (put in doctor's name) do an 'infertility work up' with you and your partner? (Yes / No). What was involved in this procedure?  
If no, how were you diagnosed?
10. How would you describe your meeting(s) with the general practitioner?
11. Did the general practitioner give you any books or pamphlets on the subject of infertility? (Yes / No). If yes, can you remember what they were?  
Have you read any of them? (Yes / No). If yes, which ones?  
What did you think of this information?
12. Has the general practitioner given you a reason for your difficulty in having a baby? (Yes / No).  
What was his or her reason?

13. Do you agree with the medical diagnosis?
14. (If the participant was referred to a specialist ask the following questions) What is the specialist's name?
15. Is the specialist male or female?
16. Did you experience any difficulty in getting the appointment with the specialist?  
(Yes / No). If yes, what was the difficulty?
17. Did your partner come with you to see the specialist the first time you went to discuss your difficulty in having a baby? (Yes / No). Why?
18. Did your partner come with you to see the specialist at any other time? (Yes / No).  
If yes, when?
19. Did the specialist do any 'infertility work up' with you and your partner? (Yes / No)? If yes, what did it entail?
20. How would you describe your meeting(s) with the specialist?
21. Did the specialist give you a reason for your infertility? (Yes / No).  
What was his or her reason?
22. Do you agree with the medical diagnosis? (Yes / No).
23. (Ask this question for everyone) What is your own explanation for your infertility?

**Section F.**

Now I would like to specifically discuss your medical treatment.

1. Have you sought out any medical treatment for your infertility? ( Yes / No). If yes, please describe the procedure of your medical treatment? What did it entail?

If no, how come?

2. Are you currently receiving treatment for your infertility. (Yes / No).

If yes, please describe the procedure of your medical treatment?

3. Do you find the medical treatment is physically difficult on your body? For instance, does the treatment hurt; do you feel any discomfort or experience any side effects such as vomiting, mood changes or nausea? (Yes / No). If yes, how is the medical treatment physically difficult?

4. Do you find the medical treatment is emotionally difficult? (Yes / No). If yes, how is the medical treatment emotionally difficult?

5. Do you think you were well informed about the medical treatment before you received it? (Yes / No).

Did the physician or nurse carefully explain what the procedure/treatment entailed and any side effects of it? (Yes / No). Was their explanation adequate? (Yes / No). Why?

6. Did the physician or nurse hand out any articles or pamphlets that explained the procedure to you? (Yes / No). If yes, what were they?

Did you read any of them? (Yes / No). If yes, which ones did you read?

Were they helpful? (Yes / No).

7. Have you heard of in vitro fertilization? (Yes / No).

8. Do you know if in vitro fertilization is available in St. John's? (Yes / No).

**Section G.**

Next, I would like to discuss the financial cost associated with infertility treatments.

1. Have you personally had to pay for infertility treatment offered by a medical doctor (Yes / No). If yes, do you know the total amount of money you paid?
2. Do you anticipate needing any other treatments that you have to pay for? (Yes / No). If yes, what are the treatments?
3. Is there any other medical treatments you would like to have, which you cannot afford? (Yes / No). If yes, what are the treatment(s)?

How much do they cost?

4. Do you have medical insurance that specifically covers the infertility treatment(s) offered by your medical doctor? (Yes / No).
5. If you are not covered by medical insurance, how do you pay for the infertility treatment(s)?

**Section H.**

Now I would like to discuss your contact with other professional people regarding your infertility.

1. Have you sought out any non-medical treatments for your infertility such as seeing a herbalist, acupuncturist, chiropractor, therapist or any other therapist or counsellor? (Yes / No). If yes, who have you seen? If no, how come?
2. (If yes, to #1, ask the following questions). Are you currently receiving non-medical

treatment for your infertility? (Yes / No). Who are you seeing?

3. Please describe what this treatment entailed?
4. How would you describe your meeting(s) with the non-medical practitioner?
5. Do you find the non-medical treatment is physically difficult on your body? For instance, does the treatment hurt; do you feel any discomfort or experience any side effects such as vomiting, mood changes or nausea? (Yes / No). If yes, please explain how it is physically difficult on your body?
6. Do you find the non-medical treatment is emotionally difficult? (Yes / No). If yes, please explain how it is emotionally difficult?
7. Do you think you were well informed about the non-medical treatment before you received it? (Yes / No).

Did the person performing the treatment carefully explain what the procedure/treatment entailed? (Yes / No). Was his/her explanation adequate? (Yes / No). Why?

8. Did the person performing the non-medical treatment hand out any articles or pamphlets that explained the procedure/treatment to you? (Yes / No).

If yes, what were they?

Did you read any of them? (Yes / No). If yes, which ones did you read?

Were they helpful? (Yes / No). Why?

9. How much does your non-medical treatment cost?
10. How do you pay for your non-medical treatment?

**Section I.**

Now I would like to discuss any difficulties you experience in scheduling appointments.

1. How long does it take to travel to the general practitioner?
2. How long does it take to travel to the specialist?
3. If you have seen non-medical practitioners, how long does it take to travel to the non-medical practitioner?
4. How do you physically travel to the general practitioner? (I.e., own car, someone else's car, public transit, taxi, bike or cycle, walk).
5. (If the participant has seen a specialist). How do you physically travel to the specialist? (I.e., own car, someone else's car, public transit, taxi, bike or cycle, walk).
6. (If the participant has seen a non-medical practitioner) How do you physically travel to the non-medical practitioner? (I.e. own car, someone else's car, public transit, taxi, bike or cycle, walk).
7. Do you find it difficult to schedule (and keep) medical appointments to see your general practitioner? (Yes / No). How come?
8. (If referred to a specialist) Do you find it difficult to schedule (and keep) medical appointments to see your specialist? (Yes / No). How come?
9. (If participant has seen a non-medical practitioner) Is it difficult to schedule (and keep) appointments to see the non-medical practitioner? (Yes / No). How come?
10. If employed, does your employer know that you are trying to have a child? (Yes / No). Probe.

11. If employed, does your employer know that you are receiving treatment for your infertility? (Yes / No). Probe?
12. If employed, is it difficult to get time off work for medical appointments for your infertility? (Yes / No). If yes, how do you explain your need for time off to your employer?
13. If employed, is it difficult to get time off work for non-medical appointments for your infertility? (Yes / No). If yes, how do you explain your need for time off to your employer?
14. Have you ever been fired from a job because an employer presumed or in fact knew that you were trying to have a baby? (Yes / No). If yes, how do you know this?
15. Have you ever been refused a promotion because an employer presumed or in fact knew that you were trying to have a baby? (Yes / No). If yes, how do you know this?
16. Have you ever received an unfair work evaluation because an employer presumed of in fact knew that your were trying to have a baby? (Yes / No). If yes, how do you know this?
17. Did your employer give you any specific reason(s) why you had been fired/ refused a promotion / received an unfair work evaluation based on your decision to try to have a baby? (Yes / No). If yes, what was the reason(s)?

**Section J.**

In closing....

1. Is there anything else you would like to tell me about your experience with infertility?
2. Are there any other women you know who experience infertility , that I could talk to?  
(Yes / No). If yes, do you know their names and telephone numbers?
3. Once my work is finished, I will either return the cassette tape and transcript to you or erase it. Do you prefer to have the cassette tape and transcript returned to you or erased?
4. Thank you for taking the time out from your schedule to talk with me and your patience. I am deeply sorry if you found any of these questions offensive in anyway.

Your participation in this study is greatly appreciated.

**Appendix VII****Semi-Structured Interview Schedule (Health Care Practitioner).**

Date:

Place:

Time of Interview:

End of Interview:

**Section A.**

Marital Status and Education Background

1. What is your marital status? (Single, Common-law, Married, Divorced, Separated, Widowed).
2. To which age category do you presently belong (under 24; 25-29; 30-34; 35-39; 40-44; 45-49; 50+).
3. What is your highest level of formal education?

**Section B.**

Employment History.

1. What is your current occupation?
2. Are you employed (at the infertility clinic) on a full-time, part-time or casual basis?
3. Who is your employer (supervisor)?
4. Do you put in any overtime work (Yes / No). If yes, how much overtime do you put in?
5. Do you do any unpaid work? (Yes / No). What type of work is it? Probe.

**Section C.**

## Employment Related Activities.

1. How long have you worked at the infertility clinic?
2. Why did you choose to work in this area?
3. Please describe in detail what types of activities you preform in a given day?
4. Do you see any of the women who come to the infertility clinic? (Yes / No). If yes, ask the following questions.
5. How many women do you see in a day?
6. How much time do you spend with each individual woman you see?
7. Please describe what activities you do with the women?
8. Do all the women who are referred to infertility specialist come to see you? (Yes / No).
9. When the women come to see you, do they bring their partner, a family member, or friend to the appointment?
10. Do you work closely with the infertility specialist? (Yes / No).

**Section D.**

## Social Support and the Infertility Clinic.

1. Does the infertility clinic provide any social support for women who are infertile? (Yes / No). If yes, what kinds of social support does the clinic provide?
2. Do you provide any reading material on the subject of infertility to the women and (men) who come see you? (Yes / No). If yes, what types of material do you provide?

3. Do you provide any information about non-medical treatments for infertility such as seeing a herbalist, acupuncturist, chiropractor, therapist or any other therapist or counsellor? (Yes / No). How come?

4. In your opinion, is the infertility support group benefiting the women and men who attend it?

5. What do you view as the most important aspect of the infertility experience for these women?

#### **Section E.**

Medical Treatment and the Infertility Clinic.

1. What medical treatments are available at the infertility clinic?

2. What medical treatments are not available at the infertility clinic?

3. Are any of the medical treatments offered by the infertility clinic covered by medical insurance?

4. How do the women get referred to the infertility clinic?

Have the women been initially diagnosed by their general practitioner?

5. Is there a waiting period to see the infertility specialist? (Yes / No). If yes, how long is the waiting period to see the infertility specialist?

6. Of the women you see, what stages are they at in their medical treatment?

#### **Section F.**

Background Information about the Infertility Clinic.

1. How long has the infertility clinic been operating in St. John's?

2. How did the infertility clinic become established in St. John's?
3. How is the infertility clinic funded?
4. Do you think the infertility clinic is adequately funded (Yes / No). How come?
5. Do you think there is enough funding for social research on infertility?
6. What is the Health Care Corporation of St. John's?
7. Is the infertility clinic connected to the Health Care Corporation of St. John's? If yes, how is the infertility clinic connected to the Health Care Corporation of St. John's?
8. What is the Fertility Management Services/ Women's Health Program at the Grace Hospital?
9. What are the business hours of the infertility clinic? (Is the infertility clinic open on the weekends for medical treatments?)
10. In your opinion, are there any services that are lacking at the infertility clinic? (Yes / No). If yes, what are the services that are lacking at the infertility clinic?
11. How did the infertility support group become established in St. John's?  
What procedures or steps did you have to go through to set up the infertility support group?
12. If you wanted to change any of the (social or medical) services offered at the infertility clinic, how would you go about doing this? What steps would you have to go through?
13. Do you think that there should be another infertility specialist in Newfoundland?  
How come?

**Section G.****Infertility and Your Experiences Working at the Infertility Clinic.**

1. How would you define infertility?
2. What does infertility mean to you?
3. How would you define involuntary childlessness?
4. Do you think there is a difference between infertility and involuntary childlessness?  
(Yes / No). If yes, what is the difference?
5. Has working at the infertility clinic presented any challenges in your life? (Yes / No). If yes, how do you deal with these challenges?
6. Is working at the infertility clinic emotionally difficult? (Yes / No). If yes, in what ways is it emotionally difficult?
7. Is there anything else you would like to tell me about your experiences working at the infertility clinic?
8. Once my work is finished, I will either return the cassette tape and transcript to you or erase it. Do you prefer to have the cassette tape and transcript returned to you or erased?
9. Thank you for taking the time out from your schedule to talk with me. Your participation in this study is greatly appreciated.





