

**BLAZING A TRAIL: A CONSTRUCTIVIST GROUNDED THEORY
STUDY OF THE EXPERIENCES OF CANADIAN WOMEN WITH
ENDOMETRIOSIS**

By

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BLAZING A TRAIL: EXPERIENCES OF ENDOMETRIOSIS

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ABSTRACT

The purpose of this constructivist grounded theory study was to explore women's experiences with endometriosis through diagnosis, treatment, and coping. Conducted using a health geography, medical sociology, and medical anthropology theoretical framework and a constructivist grounded theory methodology, the following research objectives guided this study: (a) document the experiences and consequences of receiving a medical diagnosis of endometriosis from the perspective of a group of women living in Hamilton, Ontario; (b) explore the iterative process the women experienced while seeking relief from the symptoms of endometriosis; (c) interpret the meaning of 'coping' that women on the journey for a reliable diagnosis and effective treatment for endometriosis experienced; and (d) formulate a coherent, middle-range interpretive substantive theory of the women's journey, in order to help others better understand the endometriosis experience from the patient's perspective.

Seventy women were interviewed, and the middle-range substantive theory that emerged from this study is grounded in their experiences. The results indicate that the women experienced endometriosis as a journey through constant interaction with the social worlds they had defined through diagnosis, treatment, and ultimately coping. Studying their everyday life experiences and mapping those in the context of their biomedical, personal, and informational social worlds allow for a broader understanding of the varying ways that the women interviewed perceived the treatment processes and their treatment options, made sense of their symptoms, and experienced uncertainty about the influence change could have on their everyday lives. By incorporating their individual experiences and knowledge, their social world and descriptions of these worlds reflect the entirety of the endometriosis experience. Finally, if one examines endometriosis only from the perspective of being diagnosed, treated, and learning to cope with the disease, many facets of the journey are missed. Understanding these individual experiences as a journey, instead of just diagnosis, treatment, and coping, has practical implications for healthcare providers treating endometriosis.

DEDICATION

This work is lovingly dedicated to the memory of my grandparents, Lewis Freeman (1920 – 2006), Mary Jane Freeman (1922 – 2007), and Ruth Emily Harrelson (1924 – 1999). Thank you for instilling the confidence to pursue my dreams and teaching me the value of education.

I also dedicate this dissertation to the memory of Susan Moore Morgan (1972 – 1999). Susan, you are missed, and loved by all those who knew you and your infectious laugh, warm heart, and tremendous kindness.

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CHAPTER 1: INTRODUCTION

1.1 Background of Study

Chronic illnesses such as endometriosis profoundly affect the lives of the people who suffer from such conditions. For women who have been diagnosed with endometriosis, the unpredictability of the symptoms, coupled with limited treatment options and an uncertain future, makes living with this condition physiologically and psychologically challenging.

This research focuses on the experiences of 70 women in the Hamilton, Ontario area who have been clinically diagnosed with endometriosis. I have chosen the metaphor of mapmaking, or cartography, to help capture the common thread of their experiences—a journey into uncharted territory in their search for a diagnosis, effective treatment, and validation from their medical, social, and personal communities, coping all the while with their symptoms as they unconsciously create a roadmap for those who will follow. By describing the journeys that the 70 study participants have taken, and the maps they have created along the way, I intend to provide a richer understanding of the life experiences of one group of women with a chronic health condition.

In this dissertation, I argue that, while biomedicine has focused on the **disease** endometriosis in its search for a better understanding of its etiology and effective treatment, it has ignored key features of the **illness** endometriosis, including the personal experiences of women with this health problem. It is important to make a clear distinction between these two crucial terms in order to understand how they are used throughout this dissertation.

Disease refers to a pathological condition or process, often exclusively treated by a biomedical clinician, and does not take into account unexplained or undiagnosed symptoms or how they impact the daily lives of those affected by the symptoms (Kleinman, 1988). The primary objectives of biomedical clinicians are to diagnose and treat disease. The approach they use is referred to as the “disease model” in much of the social science literature (i.e. Moss & Dyck, 2002). Although many health problems can be resolved through this approach, it is not a satisfactory model for individuals who have a chronic condition. In contrast, **illness** refers to the lived experience of a health problem as defined by a person’s own experience of being sick (Kleinman, 1988).

Unlike disease, illness captures the physical, psychological, social, and cultural dimensions of a disease (Kleinman, 1988).

When I use the term disease in reference to endometriosis in this dissertation, I am referring to the pathological process of endometriosis and how it is treated by biomedicine. When I use the term illness, I am referring to the study participants' experiences with endometriosis. In addition, illness captures the personal everyday understanding and experience of the chronic nature of endometriosis.

As a health geographer, I am intrigued by the construct journey, which aptly describes the process people with health concerns undergo in their search for help and validation. I took this metaphor further when I realized that the women I had interviewed were actually laying out the maps of their journeys in the form of illness narratives that described the steps they had taken as well as the advice they had for others who might follow in their footsteps. I have also come to realize that these maps are an essential component of any illness narrative of a person with a chronic health condition on their journey toward medical, social, and personal legitimization of their experiences.

At a theoretical level, this dissertation is a critically informed examination of the relationship between the experiences of women with endometriosis and their navigation of daily life within the context of trying to understand endometriosis. Using a constructivist grounded theory (C-GT) approach based on the work of Charmaz (2000 & 2006) and situational analysis, a postmodern development of grounded theory based on the work of Clarke (2003, 2005), I investigated the progress or journey of a group of women with endometriosis, within the context of their social worlds, and the maps they constructed along the way.

I also hypothesize that health geography offers a conceptual framework to advance our understanding of women's lives with a chronic health problem that extends beyond the traditional biomedical context. As such, this study contributes to a growing body of interdisciplinary literature examining the connections between the experiencing of the social world and illness.

1.2 Study Rationale

Endometriosis affects the emotional well-being and physical health of up to 10 percent of the female population in North America (Lobo, 2007). The symptoms of endometriosis include chronic pelvic pain, sexual dysfunction, menstrual irregularities, and infertility, any or all of which can

negatively impact the general, physical, mental, and social well-being of those diagnosed with the disease (Cox et al., 2003^b). Much of the literature on endometriosis has been quantitative and focused on the disease, specifically its clinical diagnosis and surgical treatment (Denny & Khan, 2006), with few studies actually focusing on the illness, specifically the life experience of having endometriosis (Manderson et al., 2008; Lemaire, 2004; Jones et al., 2004; Cox et al., 2003^{a and b}; Whelan, 2003; Whelan, 2000) from the sufferer's perspective.

Most of the clinical literature on endometriosis has suggested an increase in the incidence of the disease over the last 30 years (Lobo, 2007). Although the medical treatment for endometriosis has improved over time, there are still significant delays in diagnosis, an estimated 11.7 years in the United States and 8 years in the United Kingdom (Lobo, 2007). The prevalence of endometriosis in the general female population has yet to be definitively estimated. The suggested prevalence of pelvic endometriosis is 6-10%, although the incidence is much higher in women with chronic pelvic pain (33%) or infertility (30-45%) (Lobo, 2007).

In addition to the discomfort of the symptoms and some of the treatments that women with endometriosis face, sufferers come to learn that very little is actually known about the disease or how to treat it successfully. In particular, there is no known cause or cure. Endometriosis can be defined as the growth of endometrial cells that normally form the *inside* of the uterus in areas *outside* the uterus (Lobo, 2007). When endometrial cells attach themselves to tissue outside the uterus, they are known as "endometriosis implants." Although the implants are most commonly found on the ovaries, the fallopian tubes, the vagina, the outer surfaces of the uterus or intestines, and on the surface lining of the pelvic cavity, they are also found on the liver and old surgery scars and even in the lungs and the brain (Lobo, 2007). Most importantly, as in the uterus, these aberrantly located endometrial cells shed each month during menstruation (Lobo, 2007).

There are many enigmatic characteristics of endometriosis. Women who experience severe symptoms may actually have only a mild form of endometriosis, whereas women with advanced disease may be asymptomatic. Diagnosis, therefore, is extremely difficult, not only because the severity of the disease does not always correlate with the amount of pain experienced but also because its common symptoms such as pelvic pain or infertility might have multiple, other putative causes (Simoens et al., 2007). In addition, endometriosis is a progressive disease that has many different clinical presentations over its span (Lobo, 2007).

Given the high direct costs (e.g. expensive medical care) and indirect costs (e.g. lost employment income) associated with endometriosis, it is surprising how little is known about the prevalence or risk factors of this condition. The annual healthcare costs associated with endometriosis have been estimated at \$2,801 (USD) per patient and the costs of productivity at \$1,023 (USD) per patient (Simoens et al., 2007). In the United States, when these figures were extrapolated to the female population in 2002, the estimated annual cost of endometriosis was \$22 billion dollars (USD), assuming a 10% prevalence rate (Simoens et al., 2007). That figure alone makes this a significant and costly public health concern in Canada as well.

In 1999, the Society of Obstetricians and Gynaecologists of Canada initiated a Canadian Consensus Conference on Endometriosis (CCCE), charged with the task of reviewing the current medical literature and providing “a guide for patients and clinicians in the current management of this condition” (Rowe, 1999, p. 2). The working group consisted of medical specialists, surgeons, health economists, and representatives from the Endometriosis Association (a patient advocacy organization). The consensus working group decided to include the patient’s perspective in the consensus document, which was a first, as the consensus guidelines are usually exclusively focused on quantitative data. Commonly many of the consensus guidelines do not include the patient perspective, or research evidence to support the patient’s perspective. The majority of clinical guidelines are usually quantitative in nature and provide a review of the best research evidence available on the topic of concern (Browman et al., 1995). However, there was an acknowledgment from the consensus working group of the importance of including the patient’s perspective, and the reasoning for the inclusion, which follows, is important to this dissertation:

The patient perspective section relates many anecdotal examples spanning several decades of women’s experiences with their disease and with their treating physicians. It is obvious that for some women their management has been perceived as suboptimal. Thus, to the reader, many of the statements may paint a totally negative picture of the women who suffer from endometriosis. We must realize that many women are relieved of their symptoms or infertility with the use of current therapies. As physicians providing care for these women, we must be constantly aware of the need for a sympathetic and supportive approach, an issue which is vital from the consumer’s perspective. The committee eventually decided

to include this section, because it does bring to light the emotional and physical upheavals that are often associated with endometriosis. It has become very clear to us that good qualitative research in this area would be of great value (Rowe, 1999, p. 2).

The group also acknowledged that:

We must listen carefully to the patient through qualitative research tools in order to learn more about the experience of having endometriosis. This will allow for management to be directed appropriately (Rowe, 1999, p. 60).

Although initially the inclusion of the patient's perspective seems like a good approach, it is clear from this research that many of the recommendations from this consensus group have not made it to the clinicians treating endometriosis. While there was an acknowledgement of the women's experiences, it was not clear what role that would play in future treatment guidelines for endometriosis. The women's knowledge and experience still do not have the weight of quantitative research evidence, and I argue that we need to expand the inclusion of and weight given to these experiences. This is a critical position that, as a health geographer, I take, to expand the treatment of chronic conditions to include lived experience and patient knowledge.

Regardless of the debates within the biomedical literature around the use of clinical evidence, this is a starting point, and provides a strong rationale for examining the experiences of endometriosis from the women's perspective. The inclusion of the patient's perspective in the consensus document initiated a discussion around how to incorporate the patient's perspective in relation to other chronic conditions. In conclusion, the group determined, unanimously, that future research into all aspects of endometriosis is desperately needed but, in particular, into the effects of the disease on women's lives.

1.3 Study Aims

In this dissertation, I document the "experience of having endometriosis" in 70 women with endometriosis on their journeys toward a confirmed diagnosis, effective treatment, and validation from their medical, social and personal communities. With this in mind, I have created a C-GT and 'situational map' that contains elements of each woman's journey within her social world.

I have undertaken this work in order to move forward our understanding of the basic social processes that shape the experiences of women with chronic illness, specifically endometriosis, by examining the maps of their experiences within their individual social worlds through diagnosis, treatment, and coping. I look at how women's experiences of endometriosis are socially constructed in specific locations: the healthcare system(s) they have encountered, daily life (e.g. work, family, personal relationships), and their own personal social worlds positioned within a larger collective experience of endometriosis. These maps also document the circuitous, iterative route that a specific group of women with endometriosis faced on their journey towards effective diagnosis, treatment, and ultimately, living or coping with endometriosis (a process that will be referred to simply as their 'journey' throughout the dissertation).

1.4 Research Objectives

This research project is an exploratory study examining women's experiences with endometriosis. The main objectives of this research are to: (a) document the experiences and consequences of receiving a medical diagnosis of endometriosis from the perspective of a group of women living in Hamilton, Ontario; (b) explore the iterative process the women experienced while seeking relief from the symptoms of endometriosis; (c) interpret the meaning of 'coping' that women on the journey for a reliable diagnosis and effective treatment for endometriosis experienced; and (d) formulate a coherent, middle-range interpretive substantive theory of the women's journey, in order to help others better understand the endometriosis experience from the patient's perspective.

1.5 Significance of Study

This dissertation makes important practical and theoretical contributions to health geography, medical sociology, and medical anthropology. From a practical perspective, it gives women with endometriosis and their healthcare providers a better understanding of the experiences of living with a chronic condition. Methodologically, my research provides an example of the application of a C-GT research approach (Charmaz, 2006, 2000, 1990) to understanding the experiences of women living with endometriosis. Theoretical contributions come from drawing together insights from health geography, critical social theory, medical sociology, and medical anthropology literatures to develop a conceptual framework that may be extended to other chronic health conditions.

Ensuring that women with endometriosis have access to improved health care requires knowledge about their lives and the challenges they face while on their journey through the healthcare system and other social worlds. Applying theories from medical sociology and health geography, this research focuses on the women's responses to doctors' expectations (the physician–patient interaction), their coping with endometriosis within the context of their social worlds, and the subsequent impact this has on self-identity in their defined social worlds in daily life.

Finally, this is an important project at a time when the restructuring of Canadian healthcare services, focused on wait times, cost, and client services, is occurring (Beach et al., 2006). A key outcome of this restructuring is a shift toward a more "patient-centered" approach (i.e. Cancer Care Ontario's Ontario Cancer Plan 2008-2011) and an increasing awareness of the social determinants of health (i.e. Social Determinants of Health: Canadian Perspectives, Raphael, 2004). Patient centeredness is defined as:

Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care (Institute of Medicine 2001^a, p.41).

Patient centeredness is relevant to this dissertation, because of its focus on the individual experience of the healthcare system, is that it "encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient" (Institute of Medicine 2001^b, p.48).

Most healthcare providers, educated within the traditional biomedical framework, tend to know far more about the acute phases of chronic disease than they do about the ongoing, lived experiences of chronically ill persons as they struggle to manage their illness. The findings from my research can help practitioners better understand what their patients want and need (i.e. type of information and understanding), as well as the social forces that encroach on their daily lives.

1.6 Structure of the Dissertation

The following section outlines the structure of the remaining chapters of this dissertation. In Chapter 2, I present the theoretical framework that underpins this study by summarizing relevant literature in

health geography and medical sociology and anthropology and discuss the C-GT approach, situational analysis, and interpretive traditions in the social sciences. In Chapter 3, I describe my methodological techniques and how they were applied to this study. This includes defining the research question and sampling; creating the interview guide; collecting, analyzing, and interpreting the data; and presenting the final results and conclusions.

In Chapter 4, I set the context for the remaining chapters by presenting an overview of the analysis. In the overview, I explain in further detail how I applied the technique of situational analysis to my study, using the metaphor of cartographers or mapmakers to describe study participants' activities and experiences. In this chapter, I also identify the core concept, of "journey" towards understanding endometriosis through experiencing it, based on the data analysis of the study participants' experiences. In Chapters 4, 5, and 6, I focus on mapping the journey of women with endometriosis. By interpreting the daily experiences of these women, using the metaphor of being on a journey, I was able to capture the essence of an ongoing basic social process of navigating through personal illness and the multiple dialogues that begin with possible diagnosis and continue through repeated rounds of searching for a definitive diagnosis and effective treatment and, ultimately, living with the illness.

In Chapter 7, I present the C-GT model or map of these women's journeys towards health within illness. I also document the shared features of how these 70 women navigated the maze of the healthcare system on this journey. By depicting this process as an example of a chronic illness journey, I will have created a "meta-map" of several women's experiences that can contribute to our understanding of how people with other chronic conditions map their own journeys in an attempt to understand and explicate their experiences. This will be of value to both the health geography and the medical sociology literatures. In Chapter 8, I discuss the policy implications and potential impact of this C-GT, limitations of the study, and future directions of my own work.

CHAPTER 2: THEORETICAL FRAMEWORKS

2.1 Introduction

In this chapter, I present the theoretical underpinnings of this study and explain how they influenced decisions made when I conducted and wrote about the empirical results of my research. This approach is consistent with the interpretive and inductive aspects of qualitative research (Creswell, 2007).

To begin with, this chapter frames my current study within the disciplines of health geography and medical sociology, focusing on their importance to studies of both women and chronic illness. Next, I briefly describe qualitative research methods, including qualitative research paradigms, the types of health-related issues that are appropriate for qualitative inquiry, and the methods commonly used to collect and analyze data. This paves the way for a discussion on grounded theory (GT), the specific qualitative research approach used in this study. I start with a description of symbolic interactionism, the philosophical underpinning of GT, and the evolution of the approach since its initial appearance in 1967. I then draw attention to constructivist grounded theory (C-GT), developed by Charmaz (1990; 2006), which informed the study's framework and Clarke's (2005) situational analysis which informed the analysis.

I end this discussion with key concepts I used to link the above frameworks with my empirical data: illness experience and narratives. Finally, I address the suitability of the above elements to a study of the journey that women with endometriosis undergo while seeking diagnosis and treatment and, ultimately, coping with their illness.

2.2 Key Theoretical Frameworks

2.2.1 Health Geography

In this section, I provide a brief history of health geography, identifying the key features that distinguish it from medical geography, and its relevance for this study. Because of the differences between medical and health geography, it is important to discuss how health geography relates to my study goal of developing a substantive middle-range interpretive theory to explore how women experience endometriosis while seeking diagnosis, treatment, and coping strategies. As a health geographer, I next present how I used three core health geography concepts—'cartography', 'map-making', and 'narratives'—in terms of their

relevance to health and illness (how they are used to express both), notions of cartography (map-making by the women), and how the two are interconnected. My aim in this section is to firmly position this study within the health geography literature and to highlight its potential contributions to this growing interdisciplinary field.

2.2.2 Emergence of Health Geography

Medical geography as an academic sub-discipline within geography has a relatively short history, beginning in 1958 with the work of Jacques May on the ecology of diseases (Meade & Earickson, 2000). However, some could argue that the roots of medical geography go back as far as John Snow's work in 1854 in which he described how he identified the Broad Street pump as the source of an intense cholera outbreak in London, England, by plotting the location of cholera deaths on a dot-map (Meade & Earickson, 2000).

As an academic discipline, medical geography has historically focused on disease ecology, spatial patterning of diseases and health services research (Meade & Earickson, 2000). The types of topics analyzed within medical geography include the spatial analysis of diseases, locational analysis of health care systems, and diffusion of innovations (Meade & Earickson, 2000). However, this left issues such as the cultural and humanistic approach to health and illness, an awareness of place as socially constructed, and the role of social theory within geography and health, relatively unexplored (Kearns & Moon, 2002). To address this gap, a new perspective—health geography—emerged in the 1990s. Examples of early health geography research include: community responses to risk and threats to health, landscapes, social justice, and social inequities and power struggles as related to health (Kearns & Moon, 2002).

There are important yet subtle differences between medical and health geography that should be noted for the purposes of this study. According to Gatrell (2003) and Kearns and Moon (2002), there are three key factors that distinguish these two fields:

- **Theoretical position and qualitative methods:** Health geographers tend to be firmly embedded within the broader discipline of social geography, which addresses issues such as social difference, power relationships, illness narratives, and qualitative research, as opposed to medical geography, which has been accused of not focusing on social theory (Kearns & Moon, 2002). Health geographers tend to use qualitative approaches to

develop an understanding of a specific group of people's experiences with place through narratives using interview techniques (as well as focus groups and other qualitative methodologies). In contrast, medical geographers tend to use quantitative methodologies that employ spatial statistics to describe the distribution of a particular disease (Kearns, 1997). Historically, much of medical geography was driven by spatial statistics and theories of epidemiology. Elliott (1999) suggested that for both medical and health geographers, the more important consideration to researchers should be the research question. This study as a qualitative examination of women's experiences with endometriosis is, therefore by its topic, more aligned with health geography.

- **Focus on place:** Place refers to the subjective characteristics of particular places and how they are defined by the individual, as opposed to spatial variations (i.e. epidemiology) of disease which have historically been a topic belonging to medical geographers (e.g. Kearns and Moon, 2002; Curtis & Rees Jones, 1998; Eyles, 1985). There is also an acknowledgement that place can be a social construction; thus, place is not limited to physical location but also includes metaphorical space (Gesler, 2000; Kearns, 1997).
- **Scales of analysis:** There is a predisposition for health geographers to focus on micro-level issues emerging in the relationship between people and their local environments, rather than on the macro-level issues that involve the larger population over a larger geographical area commonly examined in medical geography (Gatrell, 2003). However, with the 'cultural turn' (Gesler, 1992) in health and social geography, this situation is changing; now there is ample research examining the larger socio-spatial/political forces and their influences both on the individual experience and within the global scale (Dummer, 2008; Gatrell, 2003; Curtis & Rees Jones, 1998).

Kearns (1993) highlighted the need to differentiate medical and health geography by locating the latter within the discipline of social geography. Some of the hallmarks of social geography are the recognition of social difference (i.e. socio-economic status, gender, sexual orientation, and gender identity) as opposed to focusing only on locations based on geographic differences; an increased focus on everyday life; and a concern with place, identity, power struggles, and social justice (Poland et al., 2005; Dyck, 2003; Gesler & Kearns 2002; Moss & Dyck, 1999).

The specific aspects of social geography that are most relevant to my study include focusing on the everyday experience of living with endometriosis (e.g. moving beyond the boundaries of simply experiencing diagnosis and treatment to actually living with the illness on a daily basis and understanding that experience); understanding how women with this condition attempt to navigate and make sense of that experience through illness narratives; and examining the placement of women within a larger social context to understand how the disease of endometriosis is treated (i.e. reproductive disease) and influenced by this social placement.

2.2.3 The Everyday Experience in Health Geography

The reorientation of medical geography into health geography has been described by many as medical geography's 'cultural turn' (Cutchin, 2007; Carolan et. al., 2006; Kearns & Moon 2002; Kearns, 1997), in which a more holistic and inclusive approach to understanding the health and illness experience developed through the integration of social and feminist geographies into health geography. The more holistic approach of health geography meant an acknowledgment that the social context of the illness experience can significantly influence the individual's daily life (Dyck, 2003, 1995). Another characteristic of the cultural turn within of health geography and that is useful to this dissertation is the use of qualitative methods (Poland et. al., 2005; Kearns & Moon, 2002; Baxter & Eyles, 1999) to understand experiences of everyday life, narratives, and metaphors.

As noted by Kearns and Moon (2002), a key reason why health geography uses a more inclusive approach than medical geography is the emergence of place as a theoretical framework for understanding health. The acknowledgment that place is socially constructed has allowed health geographers to examine the experiences of health and illness within particular places as they are subjectively experienced by the people who navigate those places (Kearns & Moon, 2002).

The experience of everyday places can be unexciting to someone not living with an illness, whereas it is often described as demanding and difficult by people with chronic illnesses who are trying to navigate that daily life (Moss & Dyck, 2002). Consequently to understand the women's experiences of diagnosis, treatment, and living with endometriosis, it is important to understand those places they subjectively navigate and deem important to their individual lives.

The everyday represents diverse things to different people, in part because it is linked to personal subjective experiences within places of

importance to the individual (e.g. being diagnosed with a chronic illness (Moss & Dyck, 2002); changing lifeworlds in living with a chronic illness (Dyck, 1995); and sense of place (Eyles, 1985)). In fact, Dyck suggests that this has been a key contribution by feminist geography to health geography and even proposes: “Clusters of work in these areas [storytelling and everyday spaces] are setting directions in emerging feminist geographies of health and illness” (Dyck, 2003, p. 364).

Dyck further discussed the importance of understanding the experiences of the everyday in women’s health. The acknowledgment of the experiences within the context of home, places of work, and embodiment is essential to understanding the experience of illness and health (Dyck, 2003). The experience of place (i.e. places of diagnosis, treatment, and coping, such as home and work), is influenced by the expectations one may feel and more importantly, the experiences that these places contain for a person.

Some women view their place of employment positively and others, negatively, based on their individual experience of how they have been treated by their employer with regards to managing their endometriosis. If the employer has accommodated concerns of chronic pain and flexible work hours, then the experience will be positive. However, if there is no understanding on behalf of the employer, then she may view the experience of employment as a negative one. Therefore, the everyday experience is multifaceted; resulting in a unique subjective experience of place based on the pathways navigated (i.e. home, work, and healthcare facilities) during the course of the day. With regard to my study, this is highlighted by the social meanings of endometriosis not only as a reproductive disease but also as the cause of a variety of health concerns and symptoms. Not only are the women navigating their everyday lives, they are also attempting to navigate a path while burdened with pre-existing notions of how a woman with endometriosis should interact on a daily basis with others.

One of the recent influences on health geography is feminist geography (Dyck, 2003). In the mid 1990s, feminist geographers began describing the experiences of women affected by chronic illnesses, examining such issues as the body as a geographical site, the experiences of home and work in relation to coping with a chronic illness, and the effect of place on women’s health status (Moss & Dyck, 2002; Dyck, 2003; Moss & Dyck, 1999; Dyck 1995). These threads are part of the fabric of this study that documents the experiences of coping with endometriosis in and through places of health care, work, and personal

relationships on their individual journeys, as described by a specific group of women.

A key term used in the interview guide for this project is 'lifeworld'; I would like to explain the term and its relation to 'lived world', a concept discussed in detail in Dyck's work (1995) and strongly associated with feminist geography. Dyck used this term to describe changes in the social and personal spaces of women diagnosed with multiple sclerosis. The lifeworld is the world people experience on a daily basis. One's lived world is often taken for granted until an illness or disease disrupts its ordinariness and renders it extraordinary (Dyck, 1995). It is important to note that this term is very similar to 'social world' as described by Clarke (2005) within situational analysis. Although the term lifeworld was initially used within the interview guide, I will instead use the term 'social world' to more closely align my study with the methodological framework described by Clarke (2005). According to Clarke (2005):

Social worlds (e.g., a recreation group, an occupation, a theoretical tradition) generate shared perspectives that then form the basis for collective action (Shibutani 1955, 1962, 1986, as cited in Clarke, 2005), while individual and collective identities are constituted through commitments to and participation in social worlds and arenas (Becker 1960, 1967; Strauss 1959, as cited in Clarke, 2005) (Clarke, 2005 p. 45).

As I explain in more detail in Chapters 4, 5, and 6, women with endometriosis navigate social worlds that lead them to one or more physicians who can strongly influence their experiences of how they and their families perceive their illness. While the women themselves are not collective actors (rather, they are individual actors with collective experiences), they "dwell in spaces in between" (Clarke, 2005 p. 117) their doctors, employers, families, and friends. Clarke goes on to state that within a social world "implicated actors are not physically present in a given social world but solely discursively constructed..." (Clarke, 2005 p. 46). It is how the women interact with the constructions of their social worlds (e.g. reactions of members of their family or an employer to their being diagnosed with endometriosis) and their individual interactions that shape their experiences with endometriosis.

In this research project, these 'implicated' actors are a key component of analysis. They are the 'others' who are not traditionally represented in understanding the holistic experience of endometriosis, or as Clarke (2005) suggests:

“if one seeks to understand a particular social world, one must understand all the arenas in which that world participates and the other worlds in those arenas and the related discourses, as these are all mutually influential/constitutive of that world” (Clarke, 2005 p. 48).

The knowledge and experience the women have with endometriosis is given little validity within biomedicine. The women and their social worlds become the implicated actors.

The social worlds of interest for this research project are those aspects or features of the women's experiences that are simultaneously individual and collective experiences of the women's journeys. It is the experience and knowledge the women have with endometriosis. This process is shaped by the social worlds and arenas that women engage in through negotiations and their development of strategies to understand their experiences. Each individual woman brings her own meanings and categories to the understanding of endometriosis, and it is through the interactions with their social worlds and arenas that their experience of endometriosis can be understood.

2.2.4 Women as Cartographers

One of the key tools that helps people navigate throughout a journey is a map. Maps have been defined in the geographic literature as “graphic representations that facilitate a spatial understanding of things, concepts, conditions, processes or events in the human world” (Harley & Woodward, 1987, p. xvi). This definition goes beyond the traditional view of a map as something that represents simply geographic coordinates and locations and allows us to think of a map as a tool that involves the discovery of new terrain, territories, and ideas, as experienced by individuals. That map allows for the visualization of connections that include the human experience.

Simply put, a map can be a visual representation of the illness experience, providing the readers with a reflection of the experiences of daily life. This expanded definition of maps has been used for over 30 years in modern urban and social geography, specifically referred to as ‘mental maps’ (Tuan, 1975; Gould & White, 1974). The concept of ‘mental maps’ acknowledges the personal point-of-view, or how the individual experiences their subjective place within the world (Tuan, 1975). In addition, and more recently, maps have been used within the field of health geography to map the subjective experiences of chronic illness (Mackian, 2000).

Those who make maps are referred to as cartographers. The women who participated in this study are cartographers who mapped out their collective endometriosis journey. A cartographer moves that which is intuitively sensed into the realm of what is visualized. This realm of visualization is provided through the illness narratives of these women and my interpretation as a researcher of their journey through endometriosis maps. As the study researcher, I had the opportunity to interpret the journey of women with endometriosis.

My reflection on their narratives, which I transformed into their maps, conjured up visions of traveling from place to place and an understanding of the main social worlds inhabited and experienced by these women. Through the work of these cartographers, I, as the researcher, had the task of exploring the endometriosis terrain. The women as cartographers, through the creation of situational maps, enabled me as the researcher to understand the totality of the endometriosis experience through their ability to capture and link social worlds.

In summary, it is important to note that the maps generated by the illness narratives do not reflect the traditional view of a map, as noted above. Nor do these maps fall within the traditional category of 'mental maps'. Rather, the maps generated by the illness narratives are meant to illustrate the women's experiences of moving across the terrains encountered in their daily lives. For example, while undergoing the experience of diagnosis or treatment, what kinds of territories did the women have to navigate to understand their own experiences? These maps are about the women's subjective and personal experiences and the weight they place on the terrains crossed. The legends for these maps include the social worlds and arenas navigated by these women.

2.3 Medical Sociology and Medical Anthropology

Other relevant conceptual work in the social sciences literature that I drew upon for this dissertation comes from medical sociology and medical anthropology. Specific issues related to medical sociology that were relevant to this study were how women navigate their way through chronic illness and how their perceived roles within society shape their daily experiences as chronically ill women. The relevant issue within medical anthropology focuses on Kleinman's (1988) work on illness narratives, the distinction between illness and disease (as discussed in Chapter 1), and the complex social dimensions of a chronic illness.

A vast amount has been written in the medical sociology literature about the illness experience, particularly *biographical disruption* (Bury, 1982) and *loss of self* (Charmaz, 1983). The concepts that are useful to this study include the impact of chronic illness on daily life, the influence of chronic illness on social negotiations, the changed self, and biographical disruption. Additionally, lay and medical knowledge are important, as the women define their experiences with endometriosis through a certain context and knowledge they have created through their interactions with experiencing endometriosis, and it is often at odds with the information provided by her healthcare provider. In a summary of the lay and medical knowledge literature within medical sociology, Prior (2003) suggests that while there are limits to lay knowledge, there should be an assessment as to what lay knowledge can offer the healthcare system and how this offering can improve patient care.

As a final point, by giving voice to the lay experience, this allows for a more inclusive understanding of the illness experience. For instance, medical sociology has highlighted that health is not merely the absence of disease but that people define health as their ability to manage everyday tasks and get through daily life (Freund & McGuire, 1999). For women with endometriosis, examining their experience with the illness, instead of focusing exclusively on diagnosis or treatment, allows for a fuller understanding of what endometriosis actually means in their daily lives. For example, are the symptoms related to either infertility or chronic pelvic pain, or for some women, to both? Depending on the answer, the experience within the healthcare system can be different, which can dramatically impact the everyday routine these women navigate.

2.3.1 Chronic Illness from a Sociological and Anthropological Viewpoint

No matter if an illness is acute or chronic, the person suffering from it is forced to confront life's unpredictability. With the diagnosis of endometriosis, a woman moves from being healthy, through new symptoms, to a state of having a chronic illness that can affect her fertility, challenge her femininity (Martin, 1992), and generate incapacitating pain. Charmaz (1983) stated that a fundamental form of suffering in chronic illness is the loss of self. This occurs when the person diagnosed with the illness loses his/her former self-image without developing an equally valued new image. This finding is relevant to women who have been diagnosed with endometriosis because their assumed identities and roles within the work place and home/family can be altered and can also be unpredictable. Specifically, their very identity of being female can be

challenged and changed, especially when infertility is involved (Martin, 1992).

Related to this changed life experience for women with endometriosis is that it may mean being unable to have children, a reality which can bring its own set of emotional responses (Huntington & Gilmour, 2005). There is also the difference between how a woman may understand endometriosis, how her clinicians treat her endometriosis, and how the people in her life may understand the condition, views which could be in conflict with one another (Carpan, 2003). In addition, the emotional response from a woman and her family, employers, co-workers, and friends can be difficult to face because of the complexity of the disease, the inconsistency of symptoms and treatment, and the lack of a clear prognosis (Lemaire, 2004).

Lastly, there are significant concerns with the biomedical treatment of endometriosis; since there is no cause or cure, the best that can be done is manage symptoms. For women with endometriosis, the treatment can bring added difficulties as time is spent traveling to healthcare providers and undergoing tests and treatments, (and the treatments themselves may be as difficult as the presenting symptoms) that may be physically and emotionally exhausting, and there is no defined end to what they are experiencing until a diagnosis can identify their symptoms (Kleinman, 1988). Several studies already exist that identify key emotional responses, the importance of documenting and using the illness narratives for understanding endometriosis, and difficulties women may face when diagnosed with endometriosis (Markovic et al., 2008; Manderson et al., 2008; Ballard, 2006; Denny & Khan, 2006; Huntington & Gilmour, 2005; Lemaire, 2004; Whelan, 2003).

Previous research suggests that the framing of endometriosis within the biomedical community is problematic for women (e.g. exclusively a reproductive disease), both when trying to obtain a diagnosis and receive the best treatments for the disease (Carpan, 2003; Capek, 2000). Both women with endometriosis and people who comprise their social support network (or those in their lifeworlds) seem to lack an understanding of how the experiences in one place (e.g. work) can impact the experiences in another place (e.g. home). There is also a lack of understanding of how the meaning and conceptualization of endometriosis by actors within the lifeworld impact the women's own experiences of endometriosis. Gaining more knowledge about the meaning of living with endometriosis from their perspective is therefore important. Beyond gaining more knowledge or information about the women's perspective, it is important to gain knowledge on how they try to navigate their daily lives. This allows for a

better understanding of the illness experience, which in turn can inform biomedical practice.

In order to understand the complexity of endometriosis, it is useful to discuss Kleinman's work in the context of defining the social worlds women navigate within the everyday experience. In particular, Kleinman (1988) stated that: "For the practitioner, as for the anthropologist, an inquiry into the meanings of illness is a journey into relationships" (p. 186). Kleinman goes on to further state that:

The study of illness meanings is not only about one particular individual's experience; it is also very much about social networks, social situations, and different forms of social realities. Illness meanings are shared and negotiated. They are integral dimensions of lives lived together (Kleinman, 1988, p. 186).

The meanings of illnesses are shared and negotiated, and form fundamental dimensions of the individual social worlds that women with endometriosis experience collectively. Kleinman stated in his later work that that healthcare providers often diminish the consequences of chronic illnesses in the "interpersonal space of everyday life" (1995, p. 184). If these everyday experiences are ignored by healthcare providers, this could lead to further suffering by the ill individual (Kleinman, 1995). A better understanding of the trials that women with endometriosis face and how they navigate the illness in relation to their daily social worlds is a basis for being able to facilitate an improved understanding of their experiences within daily life and to improve their health care experience.

Medically, some chronic diseases are stable in terms of the nature and frequency of symptoms, whereas others fluctuate in terms of the severity and intensity of symptoms (Freund & McGuire, 1999). Because of the uncertainty attached to endometriosis, for instance when symptoms might be experienced, the understanding of the everyday and the individual social worlds become necessary, in order to paint a complete representation of the endometriosis experience. For women with endometriosis, there is significant variability in symptoms (degree, type, and frequency), and treatment of the disease (Lemaire, 2004). Some cases of endometriosis are related to fertility concerns and other cases are an attempt to manage chronic pain and a whole range of additional symptoms, including intestinal pain, fatigue, and painful bowel movements. The effects of severe chronic pain are further compounded by the degree to which a person is able to take personal responsibility for addressing symptoms and has the discipline required for effective self-

management, a situation that is highly debated in the biomedical community (Lemaire, 2004).

People with chronic illnesses can be affected in many ways. Household routines are disrupted, which may result in isolation; symptoms may necessitate that a woman use outside services for household duties, which can be expensive; and physical impairment caused by the chronic illness may lead to a loss of function and curtailed activities (Moss & Dyck, 1999; Dyck, 1995, Charmaz, 1990). People with chronic conditions may not have sufficient knowledge about their disease and so may not be able to make decisions that could provide a certain level of freedom and control (Frank, 1991). This is particularly relevant for women with endometriosis, as there is a clear desire by women with endometriosis for more information about their disease and treatments.

2.4 Overview of Qualitative Health Science Research

2.4.1 Research Paradigms and Methods

Methodology is described as the way a qualitative researcher “conceptualizes the research process” (Creswell, 2007, p. 248). Creswell further clarifies the conceptualization process as: “For example, a qualitative inquirer relies on views of the participants, and discusses their views within the context in which they occur, to inductively develop ideas in a study from particulars to abstractions” (Creswell, 1994, as cited in Creswell, 2007, p. 248). The present study required a framework capable of exploring social processes and building a middle-range substantive theory. Much of the conceptual literature that has informed my work in this dissertation led me to decide I would conduct a qualitative rather than quantitative study. Qualitative research has often been advocated as the best strategy for exploring a new area and developing hypotheses (Miles & Huberman, 1994). Given that little is known about the everyday experiences of women with endometriosis, a qualitative research design is therefore a highly appropriate choice for investigating this issue.

Because qualitative research focuses on people’s lived experiences, or events in their lives—including the repetitive or mundane—it is “fundamentally well suited for locating the meanings people place on the events, processes and structures of their lives” (Miles & Huberman, 1994, p.10). My goal is to identify the basic social processes of the experiences of a group of women with endometriosis as they search for diagnosis and treatment, while coping with their illness, from their own perspective. Therefore, as explained earlier, I chose C-GT as the overall research approach because its aims are to explore, explain, and develop

theories about social problems and processes, as guided by the principles of symbolic interactionism (Charmaz, 2006; Dey, 1999; Strauss & Corbin, 1998; Glaser & Strauss, 1967).

Qualitative research is interactive, emergent, and interpretive (Dey, 1999). The qualitative researcher seeks to gain an understanding of meanings attached to people's actions and perceptions through observing, reading, or hearing about their thoughts, feelings, beliefs, values, and world assumptions (Creswell, 2007). In contrast to quantitative research, relevant variables are not defined a priori but instead emerge from the interactive and dynamic processes of collecting and analyzing data (Charmaz, 2006). The evolving and flexible design of such work allows researchers to construct a more all-inclusive picture of people's experiences and behaviors based on their worldview and understandings.

2.4.2 Qualitative Research Approaches

An important distinction in qualitative research is between approach (or tradition) and method. Although this is not a distinction made by all qualitative researchers, it is how I will be differentiating between the framework that guides how a qualitative study is done (approach) and the included guidelines on how to collect, analyze, interpret, and represent the data (methods). The hallmarks of qualitative research include: (a) an interest in naturalistic inquiry such that researchers go to participants in their settings, (b) an interest in capturing complex social processes, and (c) a view of data analysis and interpretation that is emergent and grounded in the data itself (Charmaz, 2000).

Given that my goal for this study was to develop a middle-range substantive theory that examines the processes women navigate when coping with endometriosis, I decided to use a C-GT approach to understand the experiences of women with endometriosis within everyday life. I will use the term 'middle-range substantive theory' to describe the end product of my C-GT. I would like to define exactly what I mean by middle-range and substantive theory. One of the defining features of grounded theory is the ability to develop a theory grounded in the empirical data of the phenomena of interest. The term middle-range was initially described by Merton in 1957 to describe the linkage between theory and empirical evidence. The term was later used by Glaser and Strauss in 1967 in their early work on grounded theory.

Specifically the middle-range theories "consisted of abstract renderings of specific social phenomena that were grounded in data" (Charmaz, 2006, p. 7). This is markedly different from the 'grand' theories

often used in the social sciences and Charmaz (2006) makes a clear distinction between the two: “[middle range theories] contrasted with the ‘grand’ theories of mid-century sociology that swept across societies but had no foundation in systematically analyzed data” (Charmaz, 2006, p. 7). In contrast to the ‘grand theory’, my middle-range theory will be a theory grounded in my empirical data collected from the participants of my study, hence, a grounded theory study of women’s experiences of endometriosis.

Charmaz suggests that most grounded theories are substantive theories because “they address delimited problems in specific substantive areas...” (Charmaz, 2006, p. 8). Charmaz goes on to describe the importance of substantive areas to grounded theory as:

The logic of grounded theory can reach across substantive areas and into the realm of formal theory, which means generating abstract concepts and specifying relationships between them to understand problems in multiple substantive areas.

The substantive theory is related to a particular domain of interest. For example, the domain of interest for this dissertation is women’s experiences of endometriosis within the scope of diagnosis, treatment, and coping. The substantive theory also represents a real-world situation with empirical data that highlights human interaction within the domains of interest (Charmaz, 2006). A hallmark feature of developing a substantive theory is the use of the constant comparative analysis, which is a key feature of the grounded theory approach.

To review, I have developed a middle-range substantive theory of women’s experiences with endometriosis, grounded in the women’s narratives, and examined through diagnosis, treatment, and coping. In the next section of this dissertation, I provide an overview of symbolic interactionism (the theoretical framework underpinning grounded theory) and the origins and evolution of GT, focusing on constructivist grounded theory (C-GT). I also discuss my rationale for choosing this approach.

2.4.3 Overview of Grounded Theory

The qualitative approach that guided this study was grounded theory, which has its disciplinary roots in sociology. Grounded theory resulted from the collaboration of two researchers: Strauss, a sociologist at the University of Chicago in the early 1960s where qualitative methods were embraced and Glaser, a sociologist at Columbia University, who came from a strong quantitative perspective (Charmaz, 2006). With the

discovery of GT, Glaser and Strauss “provided a powerful argument that legitimized qualitative research as a credible methodological approach in its own right rather than simply as a precursor for developing quantitative instruments” (Charmaz, 2006, p. 6). More importantly at the time, Glaser and Strauss (1967) challenged the methodological and theoretical assumptions within social sciences. Specifically, the following was challenged in their 1967 work:

- Beliefs that qualitative methods were impressionistic and unsystematic
- Separation of data collection and analysis phases of research
- Prevailing views of qualitative research as a precursor to more ‘rigorous’ quantitative methods
- The arbitrary division between theory and research
- Assumptions that qualitative research could not generate theory (Charmaz, 2006, p. 6).

At the time of their initial work, many of these issues discussed above were exclusive to GT; however, the many of the characteristics above now apply to the majority of qualitative research (Creswell, 2007). Since their seminal work in 1967, Glaser and Strauss, and many others have expanded the approach (Clarke, 2005; Charmaz, 2006, 2000; Strauss & Corbin, 1998).

It is important to understand the foundation of GT and its historical philosophical roots. Symbolic interactionism provides the philosophical foundations of GT. The basic assumptions of symbolic interactionism were initially described by Blumer (1969). The assumptions of symbolic interactionism include: (a) human beings act towards things based on the meanings they have for them, (b) the meanings of things arise out of human interaction, and (c) meanings are handled and modified through interpretive processes people use as they deal with things they encounter (Blumer, 1969). The idea of symbolic interactionism is important to this study, because I am attempting to understand the experience of endometriosis through the women’s experiences as they describe them.

2.4.4 Constructivist C-GT

The focus of qualitative research is to capture the complexity of human experience through an inductive process, the collection of data where participants experience their individual problems, and through an interpretive process (Creswell, 2007). I would like to clarify the differences between inductive and deductive analysis. Qualitative research tends to

focus on inductive analysis meaning, that the organizing of data and themes builds from the 'bottom up'; the results emerge from the data itself (Creswell, 2007). As compared to a deductive approach; this assumes a hypothesis before beginning data analysis. Because of the interpretive nature of qualitative inquiry and inductive analysis, rigid sample sizes determined a priori are not used; instead, data saturation is used to determine the sample size of the study (Creswell, 2007).

C-GT is an interpretive methodology in that it claims that the creation of knowledge is equally shaped by the participant and researcher rather than by the researcher developing preconceived hypotheses (Charmaz, 2006). C-GT was initially discussed by Charmaz in 1990 when she described a constructivist perspective on the GT research process. In particular she suggested that C-GT should be reflexive in design, and the relationship of the researcher to the research should be reconsidered (Charmaz, 1990). Constructivism holds that there are multiple realities in the world and each person creates or builds her or his understanding by linking new knowledge to existing cognitive organizational structures (Charmaz, 2006).

The C-GT approach is capable of accommodating the varying experiences and realities that characterize the illness experience and narrative most importantly from the participant's perspective. Specifically, C-GT, as described by Charmaz, recognizes the following basic principles: (a) it is crucial to enter another person's world in order to understand her/his experiences fully, (b) subjective experiences are situated within a social context that needs to be taken into account, documented, and understood during the research process, (c) acknowledgement of the differences in power relationships and distinctions between people, as well as societal hierarchies should be made, and (d) take a reflexive stance towards the research process and development of the theories should be taken (Charmaz, 2006, p. 130-131).

To summarize, a C-GT was most appropriate for this research as I as the researcher was seeking to develop an understanding of the coping process of living with endometriosis from the standpoint of women who live with the illness. The variation of GT most relied upon for this study was the constructivist approach by Charmaz (2000, 2006) and the postmodern approach by Clarke (2005).

2.4.5 Situated Knowledge within Constructivist Grounded Theory

I have been diagnosed with endometriosis and have undergone two laparoscopic surgeries to confirm the medical diagnosis and treat the visible sources of symptoms, as well as following various courses of medication to treat both putative causes and the symptoms. As have the participants in this study, I have been on a long journey, searching for diagnosis, treatment, and the means of coping with endometriosis. In addition, I bring to my study 14 years of experience working in the field of social support and education on endometriosis.

I started this research with the assumption that my own experiences with endometriosis would facilitate my developing a rapport with study participants and allow me to access more substantive information about their experiences. Instead of viewing my personal and professional knowledge and experience of endometriosis as sources of bias (as might be the case in a quantitative study), qualitative researchers would view it as “situated knowledge” (Moss & Dyck, 1999) and an asset to facilitating access to study participants. I had to “bracket” or set aside my ‘filtered experience’ in order not to overly color my perspective of the data or prematurely end my search for a reasonable explanation (Creswell, 2007). GT research, in particular, values the investigator’s ability to enter into the lives of study participants through her/his own life experiences and knowledge (theoretical sensitivity) (Creswell, 2007).

2.4.6 Clarke’s Situational Analysis

In this study, I decided to analyze data based on Clarke’s (2005) approach to GT using situational analysis. Clarke’s research builds on the previous versions of GT (Charmaz, 2006; Strauss & Corbin, 1998, 1990; Glaser & Strauss, 1967) but differs by focusing on the situation(s) of interest and the relationships between discursive components to that situation of interest (Clarke, 2005). Because the overall aim of this study was to understand the processes involved in coping with and navigating the endometriosis experience, I decided to conduct a situational analysis situated within the C-GT approach of Charmaz and using Clarke’s guidelines for developing a situational and social world/arena map to describe the journey experiences in daily life of women with endometriosis. Additionally, this dissertation reveals the ‘trailblazing’ role the study participants want to fill for other women with endometriosis, the relationship of illness identities of women to their everyday experiences, and the impact of being diagnosed with endometriosis and being identified as having a “reproductive disease”.

According to Clarke in her book, Situational Analysis (2005), doing a situational analysis on a phenomena of interest is a map-making activity. Broadly speaking, the researcher first writes down all the categories that emerged from the data, along with the discourses (language), technologies, and features of the setting that are deemed relevant (the “messy” or working map) (Clarke, 2005). The researcher then indicates how the various terms on the page are connected to one another and notes the relationships among key connections. Clarke describes three types of maps that are useful for identifying and situating key connections:

1. **Situational maps** as strategies for articulating the elements in the situation and examining relations among them;
2. **Social worlds/arena maps** as cartographies of collective commitments, relations, and sites of action;
3. **Positional maps** as simplification strategies for plotting positions articulated and not articulated in discourses. (Clarke, 2005, p. 86)

For the purposes of this research study only the situational and social worlds/arenas maps were used for data analysis.

One of the key concerns of this study was how to represent the women’s voices in a way that would capture the interconnections the women experienced within their social worlds. Clarke has highlighted why maps are a more useful tool in understanding these experiences that is a narrative analysis and goes on to discuss further that:

Maps also work more easily as discursive devices for making assemblages and connection—relational analysis. Maps are tools of control, appropriation, and ideological expression. Mapping opens up knowledge spaces (Clarke, 2005 p. 30).

2.4.7 Use of Maps in Situational Analysis

The maps provide insights into the variety of actors the women encounter in their daily social-world interactions. Mapping is an interactive and ongoing process that enables the researcher to continuously analyze data, refine emerging theories, and track the analytical processes (Clarke, 2005). From the analysis, the information gathered can be used to facilitate the process of understanding the endometriosis experience and, hopefully, identify the key areas that need to be addressed within the

larger social context so that a better understanding of the disease can be achieved. I will discuss the two types of maps used for the analysis of my empirical data below: the situational map, which builds on the final map, the social arena map.

2.4.8 Situational Map

In the development of a situational map, identification of all human and non-human actors in a situation can be extremely detailed and often begins as a “messy” working map (Clarke, 2005). It identifies the key actors but begins examining and identifying the relationships between the identified actors and the situation of interest. Specifically, “once these maps are drafted, they are used in doing relational analyses, taking each element in turn, thinking about it in relation to the other elements on the map, and specifying the nature of that relationship” (Clarke, 2005, p. 87). This step is important in identifying the key elements in the navigational journey through endometriosis and allows for a relational analysis of these navigational elements.

Clarke discusses how important these relational elements are to understanding the key process that is identified, suggesting that “as a part of doing systematic grounded analysis, we need maps of situations, maps that specify what is there empirically in considerable detail from multiple angles of perception” (Clarke, 2005, p. 72). The explorations of these relationships result in a complex and often times a “messy” map that is used for identification and does not mean all situations will be analyzed. I have used the situational map to identify the actors and their interactions in the social worlds, as told by the women.

2.4.9 Social World/Arena Maps

The social world maps illustrate the social organization, institutional and discursive dimensions as they are situated within a larger socio-political arena (Clarke, 2005). The interpretations may be personal to the individual actors who are navigating the social worlds but are influenced by the external situations and negotiations (Clarke, 2005). The social actors situate themselves within a social world, and that social world within various arenas, through their interpretations, navigations, and negotiations. Social world/arena maps are, therefore, based on those worlds as described by the women in their illness narratives and are situated within a larger arena.

The social world/arena map is also extremely important to the understanding of the components women use to navigate their journey

through endometriosis. As discussed previously in Chapter 2, the social world is being substituted for the lifeworld from the interview guide. In addition, the social world/arena map captures the idea that endometriosis is a chronic disease, and that, because there is no cause or cure, the experience of symptoms and treatment is iterative in nature and becomes a representation of an illness.

Clarke suggests that in order to understand a particular social process you must understand the context or situation of the social world in question (Clarke, 2005). For women with endometriosis, I am capturing the personal social world as mapped by the women themselves. Clarke further states that “if one seeks to understand a particular social world, one must understand all the arenas in which that world participates and the other worlds in those arena and the related discourses, as these are mutually influential/constitutive of that world” (Clarke, 2005, p. 48).

2.5 Illness Narratives

The final theoretical concept relevant to this project is the illness narrative, which gave me a way to frame the stories of women with endometriosis. Although the subjective experience of illness is important to all ill people, it holds a particular importance for those women with endometriosis because the contested nature of the disease makes their illness predominantly subjective and places them in circumstances where their symptoms are questioned (until a biomedical diagnosis confirms endometriosis). The disease itself is frequently viewed as subjective, lacking an objective diagnostic basis, without a major invasive surgical procedure, and with no known cause or cure; so until a woman experiences surgery for diagnosis, there is no definitive answer of endometriosis. In other words, there is limited biomedical understanding and treatment for endometriosis, and there are likely to be associated consequences for the everyday lived experiences of the women whom I was interested in investigating.

There has been a shift within medical sociology that focuses on the “individual’s perspective of illness, rather than that of the medical professional” (Turner, 1987, p.1). Illness narratives are the primary empirical data source for this study; the women’s narratives are analyzed using the techniques outlined by Clarke (2005). These narratives are extremely important because they focus on the women’s experiences and their interpretations of how they make sense of their illness. It is important to note that illness narratives have been documented within health geography and used within the context of narratives and metaphors (Kearns, 1997). The narratives are also important in the context of

developing interpretive middle-range theories, because they form the foundation for understanding how women explain their experience of their illness and how they navigate their lifeworld, as well as what is important to them.

Recently in the social sciences, a substantial body of work on illness narratives has emerged (Charmaz, 2006; Charmaz, 1999; Charmaz, 1990; Strauss and Corbin, 1998; Frank, 1991; Kleinman, 1988). In addition to understanding the illness narratives, Blaxter (1997, 2004) has highlighted the importance of understanding the lay perspective of health and illness as well. Specifically, Blaxter suggests: "Lay beliefs can be better defined as commonsense understandings and personal experience, imbued with professional rationalizations..." (Blaxter, 2004 p. 46). Therefore, the study of individual experiences of illness is necessary to draw attention to the perspectives of those who have lived with it. More specifically, it is necessary to recognize that women's experiences of endometriosis vary in many ways, and it is important to capture their individual stories.

2.6 Chapter Summary

In this chapter, I introduced the basic elements of health geography, medical sociology, and anthropology as well as qualitative research methods, in particular GT and situational analysis. I also explained why I chose to do a qualitative study—specifically, a C-GT study—and how illness narratives helped me do a situational analysis of the everyday experiences of women with endometriosis seeking diagnosis, treatment, and a means of coping with their illness. As is true of all experiences, the process of experiencing endometriosis unfolds in identifiable places, making it possible to map both the literal and figurative journeys of the study participants. From this explanation of several basic theoretical constructs that informed my decisions when conducting this study, I will now move to a description of the study participants' experiences of coping with endometriosis and the meanings they attach to them.

CHAPTER 3: RESEARCH DESIGN AND METHODS

3.1 Overview of the Chapter

The phenomenon explored in this study was the experience of 70 women with endometriosis in Hamilton, Ontario on their journeys through diagnosis, treatment, and coping with endometriosis. In this chapter, I will explain how I conducted my study and present information on how I applied Charmaz's (2005) vision of C-GT, with additional inputs from Clarke (2005), who strongly emphasized social mapping as a data analysis technique. I will also describe the overall design of this study, as well as the methodological decisions I made regarding the sampling and recruitment of study participants, data collection, and data analysis.

3.4 The Research Process

3.4.1 Sampling and Recruitment

I had to make several decisions about identifying my study participants and determining when I had included enough participants to be able to state with confidence that I had a saturated understanding of the issues under study. This meant that I first had to ensure that I had a wide range of viewpoints and in-depth descriptions of events and experiences from my participants. In addition, I had to ensure that any gaps in the theory I developed were filled in by collecting information from a second wave of study participants. I initially interviewed 35 women. After the initial analysis, identification of developing theoretical areas, and when additional funding was provided for the project, I interviewed a further 35 women, for a total of 70 participants.

Key decisions for the initial stages of sampling and recruitment included setting my inclusion/exclusion criteria and identifying relevant sampling and recruitment strategies, as well as the ideal sample sizes for both phases of the study. There were no differences in the recruitment of participants between the two waves of sampling. However, the decision to recruit an additional 35 participants was to determine if the developing theory was saturated and if there were any new areas or themes being identified by a new wave of participants. The decision to recruit and interview 35 additional participants was based partially on an increase in funding, which meant additional funds for interview transcription. And to further solidify the developing theory or determine additional themes with the new participants. The increase in funding for this research project was

from the Susan Moore Morgan Research Grant in Women's Health administered through McMaster University.

3.4.2 Inclusion and Exclusion Criteria

Before recruiting participants I decided on three inclusion criteria for women to be considered as study participants. The first was that they have a medically confirmed diagnosis of endometriosis by surgical laparoscopy. It was important that a participant have a biomedical diagnosis of endometriosis because, without such a diagnosis, presenting symptoms are similar to those of other conditions, including irritable bowel syndrome, ovarian cancer, and chronic fatigue syndrome (Lyons & Kimball, 2003). I wanted to ensure I was interviewing only women with a clinical diagnosis of endometriosis because the illness narrative was very specific to the endometriosis experience. The second criterion was that each woman would be aged 18 or older. I chose to include women who were able to speak and read English comfortably and who were long-term residents, in order to ensure I accurately understood their interview statements; because of the lack of resources for translation. Finally, it was critical that all participants in the study indicate their willingness to engage in active self-reflection and self-disclosure about their endometriosis experiences.

3.4.3 Setting of Study

Each participant was given the opportunity to select the interview setting of her choice, in keeping with qualitative research principles of collecting data in close proximity to a local setting (Creswell, 2007). For the purposes of this research project, only participants located in Hamilton, Ontario were selected for the final results of this research. 25 of the 70 participants opted to be interviewed off-campus, and 45 chose to be interviewed in a private faculty office at McMaster University, Hamilton, Ontario. The option of being interviewed in the home was a relief to several participants who had practical concerns such as how to travel to another research site, childcare, and possible negative consequences to their health.

3.4.4 Sampling Strategies

In qualitative research, purposive rather than statistical sampling is the norm. This means that the researcher actively searches for and selects the most information-rich sources of data possible from the pool of potential sources (e.g. people meeting eligibility criteria) (Morse, 1989). Since the specific characteristics, conditions, or variables associated with

women diagnosed with endometriosis were not known prior to the study, I could not identify who might be my best sources of information. Therefore I started with open sampling, which aims to expose the data through identifying concepts and provide an initial pool of potential participants.

Once the group of potential participants was established, the sampling method evolved into purposeful sampling to generate data that were progressively more able to clarify elements of the theory under construction. Given the limited research that has addressed the experiences of women with endometriosis, it was important that the data reflected the both the scope or range of experiences and the detailed nuances and patterns. With this in mind, I chose maximum variation sampling within the purposeful approach. As the study progressed, the sampling also including snowball sampling, as the participants told other women they knew who had endometriosis about the study.

This meant that I chose certain women as study participants because they both met the inclusion criteria and reflected a wide range of endometriosis experiences. Traits I deemed important enough to use as guides for this part of the study were degree and type of disease impact (for example, chronic pain or infertility and the stage of diagnosis), age (older versus younger), diagnosis (recent diagnosis versus longer), immediacy of social support (living alone versus living with others), and geographic location (living within the region of Hamilton, Ontario). Exploring differences through maximum variation allowed properties, dimensions, and conditions of categories and subcategories to materialize.

To sample theoretically means that a researcher allows sampling to evolve during the process of collecting data, rather than pre-determining a sampling pool. Charmaz (2006) provides a clearer definition of theoretical sampling as: "seeking and collecting pertinent data to elaborate and refine categories in your emergent theory" (p. 96). Theoretical sampling guided later data collection to examine initial categories as well as their properties and relationships, in order to ensure categories were representative of the range and specificity of participants' experiences. The decision to use theoretical sampling did not change my recruitment strategy. This led me to enroll additional participants who were then formally interviewed, interview three key informants (Ms. Donna Laux of the Center for Endometriosis Care in Atlanta, Georgia and Drs. Salim Daya and Warren

Foster at the McMaster University Medical Centre¹), and additional information from the initial literature review.

3.4.5 Ethical Considerations

Permission was obtained from McMaster University's Human Research Ethics Board prior to commencement of the study in 2001. Implications for participating in the study, as well as an outline of the study's purpose, were given to all prospective participants prior to collecting data from them. All participants were informed of the voluntary nature of their participation and that they could withdraw from the study at any time without penalty or disadvantage to themselves. Written informed consent was obtained from participants, a copy of which was given to each woman before entering into the study. Verbal and written permission to audio-tape the interviews were also obtained. The participants were reminded that they could stop the tape recording at any point during the interviews.

To ensure anonymity, participants' names were not used on the audio tape recording or on the transcribed data files. Instead, code names were used for the participants. The identities related to these code names, which were only known to the researcher, were written in a code book that was kept separate from the data in a secure location. The typist who was transcribing the interviews was unaware of the identity of the participants and was advised of the confidential nature of the transcripts. The audio-tapes were destroyed at the completion of the study to avoid voice identification and to ensure further anonymity of the participants. The participants are referred to only by numbers in this research study.

3.4.6 Recruiting Study Participants

The participants were recruited from six sources: two hospitals in Hamilton, Ontario, a local community health center, McMaster University (advertisements posted within university buildings), the Hamilton community, and through the WITSEND0 site on the Internet. In order to fully explore the phenomenon under study, I used the maximum variation purposive sampling technique, recruiting women whose medical diagnoses spanned the timeframe of 1 month to 25 years at the time of the interviews.

¹ These key informants expressly wished to have their names made known to readers of this dissertation or other reports on my study. Therefore, providing their names is not in violation of formal guidelines or my own personal ethics, which led me to carefully protect the identities of other study participants.

The purpose of the study and the benefits and risks were explained, and potential participants were given the opportunity to ask questions. The women were given an information sheet providing a brief overview of the research and were advised that participation was voluntary and that they could withdraw their consent at any stage of the study (Appendix A).

Following the assurance of confidentiality, the women were invited to be interviewed at a time and place convenient to them. It was also explained to them that a follow-up interview might be required. They were advised that, once their written consent was obtained, they would be asked a series of open-ended questions (Appendix B) during an interview that would be audio-taped and that the interview would take approximately an hour to complete. Furthermore, it was explained that the questions would focus on discovering women's perceptions of coping with endometriosis and their perceptions regarding their experiences of health care and their search for social support. They were also informed that they would be asked to complete a demographic data sheet (Appendix C) following their interview.

3.4.7 Sample Size

Following standard practice in qualitative research, my sample size could not be pre-determined. Instead, I used the principle of data saturation, or the collection of data until each analytical category or theme was full (saturated). The researcher can claim to have attained saturation when no new or relevant data emerge for each category, no new categories of data are found, and the resulting theory can account for all the data without any theoretical gaps (Dey, 1999; Strauss & Corbin, 1998). I was also fortunate in that this research project received additional funding as discussed previously that allowed for the additional collection of data that allowed me to reach both information saturation (develop my model or depiction of the theory) and theoretical saturation (filling in any gaps within the theoretical model thru additional data collection).

3.4.8 Demographic Information

The identifying information of the participants has been removed to preserve the anonymity of the women. In reporting the results, the participants have been assigned a number and will be referred to within the results sections by their assigned number. The participants ranged in age from 18 to 57 years, with a mean age of 33 years. A summary of the demographic information collected from the participants is found in Appendix D. Demographic information regarding the ethnicity, sexual orientation, and intimate relationship status was not collected on the demographic information sheet that the women were asked to complete.

However, much of this information was noted and collected during the individual interviews. While the actual time in living with endometriosis was not recorded, the time to diagnosis was it ranged from a low of 1 month to a high of 300 months (25 years), with a mean of 69 (5 years, 9 months) months. Also important was the number of doctors seen by the participants and the number of surgeries they had (it is important to note that all women in this study would have had at least one surgery for their endometriosis, as it is needed to confirm an actual diagnosis).

The range for number of doctors seen was 1 to 35, with a mean of 4.8; the number of surgeries ranged from 1 to 22, with a mean of 2.57. In fact, only 17 participants (24%) had only one surgery to diagnose their endometriosis. The majority of participants (n= 45) were employed, and the type of employment ranged from permanent full-time, to part-time or casual employment. Finally, the majority of participants were university or college graduates (n= 31), with an additional 23 participants having completed some university or college. There was one current university student. 11 women had completed their high school education, and 4 had not completed high school.

Finally, there were 51 women who indicated during the interview (as noted by the final interview question number 13, "If you are in a relationship, what difference has that made in your ability to cope with your issues?") that they were in a relationship. Of those 51 women, 3 openly identified themselves as being in a same-sex relationship. The remaining 16 women were not in relationships at the time of the interview. While the question regarding ethnicity was not asked of the women on the demographic information sheet, 18 women identified themselves as women of color, and 4 identified themselves as recent immigrants to Canada (range of time in Canada for the four recent immigrants was 6 months to 18 months in Canada). In particular one participant thought that her recent immigration status contributed to the delay in her diagnosis because of language barriers between herself and the healthcare provider she was referred to.

3.5 Data Collection

3.5.1 Overview of the Data Generation Process

Although data were formally gathered during scheduled interviews, in many cases data collection began during the first phone call with a participant. Many of the women immediately began discussing their experiences as sufferers of endometriosis during the initial call. I made

notes of such information, with the participants' permission, and incorporated this information into the first (or only) interview.

In addition to information provided by the statements that participants made during their interviews, I also made note of behaviors that indicated a particular topic or issue was very important (e.g. tears, excessive body movements, changes in facial expression). Once I had completed the pre-set portion of the interview (i.e. asked all relevant items on the interview guide), I asked each participant if she had any other issues to address or information she wanted to share. None of the participants appeared emotionally upset at the completion of the session, and the majority offered to help in any way they could in the future. After I left the interview site, I made notes of my thoughts and impressions, including descriptions of what I had observed, to assist me when reviewing and analyzing the interview data.

3.5.2 Developing and Using the Data Collection Instrument

While recruiting the first participants in September 2001, I was also finalizing the data collection instrument or interview guide. I included the items on this list of topics and questions based on the interview guide that was developed in conjunction with Dr. Cathy Charles at McMaster University. I then field tested the instrument by interviewing three women during October 2001. This resulted in my modifying the guide by including a question about the women's social support networks. The finalized interview guide was ready by December 2001.

In keeping with tenets of C-GT research, I used the interview guide as an evolving instrument, adding and deleting items, based on the information gathered in prior interviews. These decisions were made possible by closely following an iterative cycle of collecting and analyzing data and then re-evaluating my sampling needs and topics to be pursued in subsequent interviews (Charmaz, 2006; Strauss & Corbin, 1998).

As with the sampling strategies used in this study, data generation was also modified according to the advancing theory. This meant that I asked more theoretically driven questions in later interviews to help me better understand specific categories of data and linkages among them. For example, the women spoke about the idea of "travelling" from one doctor to the next, on a "search for diagnosis", and "what about my treatment" allowed for the identification of key allowed constructs of the journey. These codes of "diagnosis", "treatment" and "movement" between the two became a central theme for all of the women that built on the developing theory of "journeying". This was consistent with early GT

procedures as described by Glaser and Strauss (1967), who stated that the researcher should identify essential constructs from generated data so that the theory can evolve. The significant changes to the interview guide came from the early identification of diagnosis, treatment, and coping as the substantial issues of the women's experiences of endometriosis: so after the initial interviews, the interviews focused more on the identified areas of interest.

3.6 Data Analysis

In a GT study, the researcher analyses data by interpreting the words of participants to convert their individual narratives into theory. The challenge lies in protecting and communicating the participants' meanings while developing theory that also incorporates the researcher's perspective as the 'research instrument' (Creswell, 2007). As the researcher, I moved the narratives into a more abstract level of theory.

Through the GT approach, all factors relevant to the phenomenon of coping with endometriosis through diagnosis, treatment, and validation from the women's' perspective were sought, rather than focusing on specific factors selected by the researcher as being significant or meaningful. The constant comparative method of analysis was used throughout the study, which meant that the data was systematically examined and sorted into categories. This continued until theoretical saturation was attained (Morse, 1995; Strauss & Corbin, 1990; Glaser & Strauss, 1967). Saturation has been described as a situation where the researcher ceases to obtain any new data about the phenomenon under study (Morse, 1995; Strauss & Corbin, 1990). In keeping with the canons of GT, previous steps of the research process were continually checked through constant comparison while moving forward in the analysis.

3.6.1 Overview of Procedures Used in this Dissertation

In a GT study, the researcher uses specific data collection, analysis, and integration techniques, including memo writing (Strauss & Corbin, 1990), concurrently throughout the study. The major constructs are generated from the middle-range theory and so can be said to be grounded in the data. As noted earlier, as the study progresses and the proposed model reveals categories and linkages that need to be saturated, the researcher switches to theoretical sampling (Creswell, 2007) to guide further data collection, analysis, and integration.

The interview data from the women were coded using a constant comparative approach, initially by hand, and later imported into a

computer program. The interview data produced quotations that were a fundamental part of the data analysis for this dissertation. For purposes of this dissertation two types of coding techniques, as described by GT was used: open and selective. The open coding was done line-by-line to explore the data without any prior assumptions about the data (Creswell, 2007). The selective coding is a more abstract analysis of the data which links themes and categories to the overall theoretical structure identified in the analysis process. The coding procedures will be described in further detail later in this chapter.

Quotations are an important part of this dissertation, as they reveals the illness narratives in the participants' words. In keeping with practices of qualitative research, it is useful to provide a discussion of why quotes were selected for publication in this document (Creswell, 2007). The initial coding of the data was done line-by-line, in combination with memos from the interview; a more selective coding process followed. After the selective coding, the quotes were sorted according to the key themes. After all the data was analyzed and coded, a story line began to develop based on the narratives and the memo information and these results began to inform the larger themes of the project. This technique of analysis is described by Crabtree and Miller (1999) as:

Analysis involves the ongoing iterative spiral or organizing, connecting, and corroborating/legitimizing. Once an organizing approach for entering the text is determined, sense making continues at a new level and the connecting phase is soon entered. Sometimes the connections come as spring blossoms of inspiration. More often, they result from critical and patient reflection and persistent engagement with the text, analytic memos, sorted segments of text, team discussions, and disciplined organizing (pp. 135-136).

The process of analyzing the data, developing selective codes, and using the memos represented an iterative process of analysis. My preference for this study was not to include a quote more than once within the presentation of findings, so quotes are used only once. When I present the quotes, they are the participants' words, with minimal editing only for clarification. The participants have been assigned a number, and that number is used to protect the privacy of the individual participant. As a final point, the participant's quotes are single-spaced in an otherwise double-spaced document to separate the narratives from the written text of the document.

In the presentation of my findings, I use as many quotes as possible to illustrate and represent the middle-range substantive theory that was developed. The decision as to which quote is included is based on how well it captures the fundamental meaning of the theoretical construct and if it illustrates the key points of the relevant portion of data analysis (Creswell, 2007).

3.6.2 Theoretical Sensitivity

The interpretive approach of qualitative inquiry requires that the researcher be sensitive to the subtleties and issues inherent to the data. The term ‘theoretical sensitivity’ refers to the practice in GT studies of enhancing insight into the research process through acknowledging the theoretical background of the researcher (Dey, 1999). This involves the researcher first identifying herself as belonging to a community of researchers and/or educators in a specific academic field or fields. In the case of this study, there were multiple sources of theoretical sensitivity—the professional and disciplinary literature of health geographies, medical sociology, and medical anthropology; qualitative research methods; literary accounts of women living with endometriosis; publications by endometriosis support groups; conference proceedings (both biomedical and patient-driven conferences) such as material produced for the Endometriosis Association’s 25th Anniversary Conference; and media reports, as well as my own personal experiences with endometriosis.

In the case of the present study, I began my research with significant pre-existing knowledge of endometriosis, including the physical and psychosocial aspects of living with this condition. This, combined with my academic training in health geography as well as extensive reading in medical sociology and anthropology, formed my experiential knowledge base. Without this pre-existing understanding of the world and how women with chronic illness journey through it, I believe the explanatory power of this study’s theory would have been much more difficult to attain.

Prior to commencing the study, I had routinely kept abreast of the endometriosis literature, both from the patient and the biomedical perspectives, so in effect my literature review had been conducted over a number of years. The knowledge derived from the research strengthened my theoretical sensitivity, particularly in the early planning stages of: identifying and conceptualizing the area for investigation; demonstrating the value of the study; and deciding on the study design. Ultimately, all sources facilitated understanding through all stages of the study. Theoretical sensitivity, for example, contributed to the identification of potential problems in recruitment, to the development of the interview

guide, and to the conduct of the interview sessions. Throughout the analysis, the sources of theoretical sensitivity continued to inform, and were augmented by, method.

3.6.5 Overview of Data Coding Procedures

A professional typist produced verbatim records of the audio tapes from the interviews (transcripts), entering each transcript into the Atlas.ti[®] computer program. The interview data were formatted to provide a wide right-hand margin for coding. Data from transcripts of the participant interviews, examination of personal memos, demographic information, and the literature were included in the data analysis process to complement the interview data.

3.6.6 Open Coding

Coherently documenting these 70 women's journeys was made possible through C-GT analysis. During the first phase of analysis (open coding), I was able to begin making sense of the complex and confusing accounts and generate the initial codes (e.g. "what are my symptoms", "before diagnosis", "unpredictability of symptoms"). Participants told me about when they first became sick, looking for explanations but finding none, seeking help, pursuing a diagnosis, experiencing incapacitating pain, facing infertility, receiving multiple diagnoses, dealing with treatments, coping with early menopause, enduring slow improvement, gathering information, seeking more help, and trying to navigate daily life while living with the fear and uncertainty associated with their intermittent and changing symptoms.

The individual journeys documented in this study were chaotic, convoluted, complex, and iterative accounts of their endometriosis experiences. The women's histories of the journey were generally long; participants moved back and forth between time frames and defining events such as receiving the endometriosis diagnosis and surgery, pregnancy, or infertility, as well as a future full of uncertainties.

The goal of open coding was to initially describe the data through a broad, line-by-line approach that lead to the development of initial themes and categories (Charmaz, 2006). Open coding occurred initially when transcribing the interview tapes; however, I only transcribed the first three interviews, and afterwards a professional transcriptionist was hired. I did create memos and record early impressions and insights. Next, I engaged in deep textual analysis by coding line-by-line to capture the meaning and key concepts of each line of text (Charmaz 2006, 2000; Clarke, 2005;

Strauss & Corbin, 1998, 1990). During data collection, the line-by-line coding was recorded on printed copies of the interview transcripts and later refined and imported to Atlas.ti®, a qualitative research software program.

The purpose of open coding was to separate the initial data and give each discrete phrase or described event a theme or category that represented the experiences of women with endometriosis (Strauss & Corbin, 1990). The data were fragmented and examined phrase by phrase to determine codes that described the meaning of what was occurring. The code words used were sometimes the very words or phrase used by the participants, for example, “taking the pill” or “taking testosterone” was used by some participants to describe their perception that they should take a medical treatment for their endometriosis.

Phrases and sentences within the data were given multiple codes if they were identified as describing more than one meaning. For example, one data segment was coded ‘legitimation,’ ‘need a diagnosis,’ and ‘frustration with symptoms.’ Table 3.1 provides a summary of the results from the open coding exercise. This open coding process identified initially more than 70 codes, and these codes fragmented the data into small pieces. The constant comparative method, however, facilitated the reduction in this number as concurrent analysis of further data supported, modified, or discarded a number of the codes. The final list of the open-coded categories was reduced to 27 through further analysis. The definition of each code word was recorded in detail and stored in a separate file. This allowed for access to the abbreviated code word with its full meaning next to it, which facilitated the consistent use of the code word.

Table 3.1 Open-coding Categories

-Experiences of diagnosis	-Barriers to treatment
-Experiences of treatment	-Need for better understanding
-Living with endometriosis	-Unpredictability of symptoms
-Movement from diagnosis to treatment	-Social support groups
-Managing life with endometriosis	-Employers
-Effect of chronic pelvic pain	-Communication with doctors
-Results of hormonal treatment	-Other women’s experiences
-Anxiety	-Doubts about sexuality
-Fear of always having endometriosis	-What about family and friends
-Infertility	-Lifeworlds
-Identity	-Stigma
-How can I use the Internet	-Places of support

3.6.7 Selective Coding

In selective coding, categories developed through open coding are integrated to form a theory and identify the central phenomenon or the core category (Creswell, 2007). The core category is the category to which all the other themes and categories are linked. This forms the foundation of the basic social process (or processes) associated with the phenomenon of interest. In this research, the core category is journeying through diagnosis, treatment, and coping with endometriosis in everyday life. In the selective coding phase I generated thematic codes that contained many of the open codes but linked more abstractly with the developing theory. Selective coding identified the basic social process that women used in order to cope with endometriosis in daily life. This phase of the analysis yielded a description that encompassed both a qualitative and chronological account of the women's endometriosis experience on the journey.

During the selective coding phase, I integrated the open coding categories into coherent, more abstract themes describing the process embedded in individual and collective experiences of navigating the endometriosis journey. This story encompasses the participants' challenges and experiences related to their search for diagnosis and treatment for endometriosis, and an ability to better cope with having endometriosis. I have chosen to follow this path, laid out by the women themselves, while describing their journeys. Therefore, the major headings or 'landmarks' along this journey are: diagnosis, treatment, and coping. Table 3.2 provides a summary of the selective coding categories.

Table 3.2 Selective Coding Categories

-Experiencing symptoms	-Seeking treatment information
-Receiving a diagnosis	-What information do I need?
-Reactions to the diagnosis	-Decisions about treatment
-Recurrence	-Long-term versus short term relief
-Communication with healthcare providers	-Coping strategies
-What's wrong with me?	-Relative state of health
	-Future options of treatment?

3.7 Messy Situational Map: the Overall Experience of Endometriosis

For the purposes of using the situational analysis approach (Clarke, 2005), it was important to "situate" endometriosis within a larger context that included written memos and diagrams; specifically in both messy and ordered situational maps. Memos are written notes or records of analysis

related to the development of the theory (Creswell, 2007). The writing of memos and the maps assisted in asking further questions about what was happening with the phenomenon of women's experiences with endometriosis. For example, questions that were asked included: so what are the intervening conditions that facilitate coping? Who do you communicate with in the health care system? What was your diagnosis experience?.

I employed Clarke's (2005) situational analysis approach to GT for the analysis of my interviews. I then structured the presentation of my data to incorporate the mapping techniques described by Clarke (2005). The maps created for this research project allowed a charting of situations within the endometriosis experience and the social worlds traveled by women diagnosed with endometriosis. Additionally, this also allowed for the conceptual maps to be filled in empirically with the women's individual experiences.

The most important aspect of this project was to examine women's experiences of endometriosis within the context of diagnosis, treatment, and coping with their illness. Following in the analytic footsteps of Clarke (2005), I created a messy situational map that located endometriosis within a wider societal context, thereby situating the illness in a particular social world or arena. Clarke (2005) states that by constructing a situational map, the questions "who and what are in the broader situation" (Clarke, 2005, p. 94), and is the primary outcomes of interest. Furthermore, the messy situational maps represent the new "cartography" of situational analysis (Clarke, 2005).

It was important to understand all the discursive constructions of the women's experiences as they related to the social worlds that they developed around diagnosis, treatment, and coping. By "discursive constructions," I am referring to what Clarke notes when she wrote, "for Strauss, both individuals and collectivities are produced through their participation in social worlds and arenas, including their discourse" (Clarke, 2005, p. 55). She and I both concur that to be understood, individual experiences (micro-level) must be comprehended at a micro-level and then situated within a larger context of the collective experiences (the macro-level).

The women with endometriosis in this research project all navigated their social worlds on the journey towards understanding and coping with their experiences. Figure 3.1 illustrates the messy situational map that developed following the description provided by Clarke (2005, p. 95) in her book Situational Analysis. It is important to note that not all the categories

of their experiences and the concomitant social worlds were examined in this research project. Rather, this was an attempt to understand the various social interactions that influence the women's experiences along their journeys. Because of the complexity of endometriosis (both biomedically and socially), it was important to highlight any social area that could affect their journeys and provide the backdrop for discussing the results of this research project within the larger context of literature related to medical sociology, medical anthropology, and health geography.

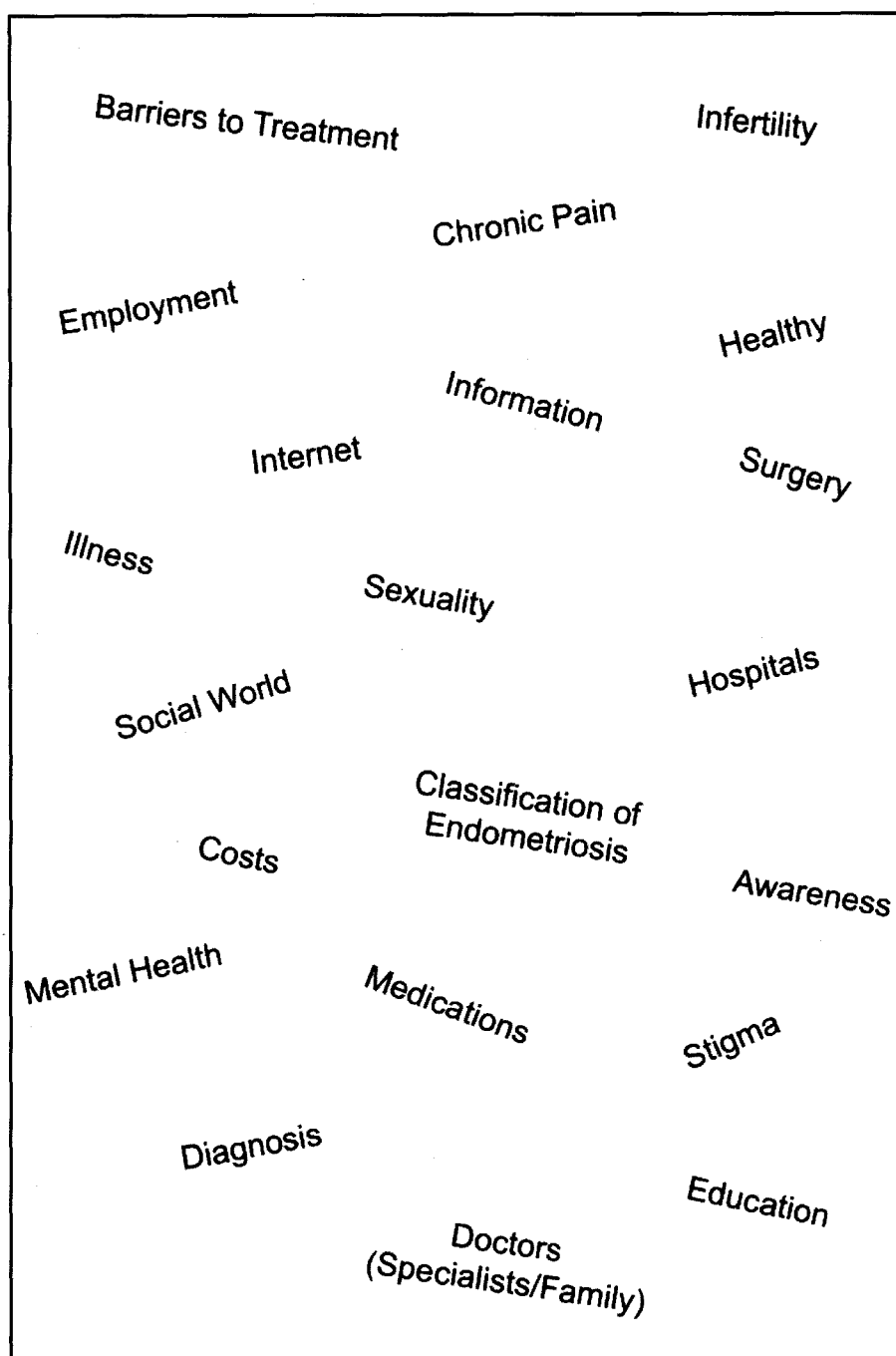


Figure 3.1 Messy Situational Map: Experience of Endometriosis According to 70 Women in Ontario, Canada

3.8 Ordered Situational Map: the Experience of Endometriosis

The messy situational map of the endometriosis experience captured the complexities of what the women experienced on their journey to their endometriosis diagnosis, search for treatment, and many of the macro-level societal situations that characterize the experience of endometriosis, not from a biomedical perspective but from the situated perspective of the women and their social worlds. The messy map was developed during the memoing and coding phases to highlight the situation of experiencing endometriosis. The ordered situational map is represented in Table 3.3. The ordered map goes a step further to identify key discursive elements of society that influence the endometriosis experience. The ordered situational map was created using a template described by Clarke (2005, p. 97) in her book Situational Analysis. This perspective enables us to examine endometriosis from a broad perspective that takes into account society's view of endometriosis and the politics of diagnosis of a chronic condition.

These are larger issues that are incorporated into the discussion (Chapter 7) and that will allow me to situate the endometriosis experience within a macro-level societal context. The maps are included in Chapters 4, 5, 6, and 7, as they were key in allowing me to think about how diagnosis, treatment, and coping are situated within a larger experience, and how that larger societal experience effects the micro-level for these women who are struggling with obtaining a diagnosis, treatment, and living with (coping) endometriosis.

Table 3.3 Ordered Situational Map: the Experience of Endometriosis

Individual Human Elements/Actor -Women with endometriosis/doctors -Employer -Family/friends/significant others Collective human elements/actors -Other people affected by the disease/diagnosis/treatment Discursive constructions of individual and/or collective human actors -Stereotypes of chronic conditions -Stereotypes of reproductive diseases -Stereotypes of endometriosis Political/economic elements -Politics of diagnosis -Health care system issues -Ontario Health Insurance Program's classification of endometriosis and limited treatment options Temporal elements -Time to diagnosis -Time to wait for treatment Major issues/debates (usually contested) -Meanings and consequences of diseases and illnesses -Gaps between understanding the disease and the illness experience -Epidemiology of endometriosis	Nonhuman Elements/Actants -Medical definition of endometriosis -Technologies to treat endometriosis Implicated/silent/actors/actants -People with a chronic condition/pain -Women with reproductive diseases Discursive construction of nonhuman actants -Gender -Socio-economic status -Diseases with no known cause/cure Socio-cultural/symbolic elements -Perceived role of women in society -Health/disease/illness perceptions and expectations -Infertility and women -Chronic pain and women Spatial elements -Navigation of the health care system -Navigation between social worlds/arenas Related discourses (historical, narrative, and/or visual) -Public health education -Media coverage/portrayal -Women as a reproductive being -Living with an illness and the "duty" to be healthy in society
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3.9 Chapter Summary

This chapter explains the methodological decisions I made when designing and conducting this qualitative study on the experiences of women with endometriosis. I also explained the theoretical and procedural approaches of a C-GT study and the implications they had for the present study. The methodology I used was consistent with my aim of exploring the meanings and experiences of women with endometriosis in their everyday lives.

Another aim was to create a middle-range theory grounded in the experiences of these women, through listening to their voices while facilitating the emergence of theory grounded in the data. In this way, I was able to provide a contextual understanding of endometriosis that is

uncommon in the quantitative clinical research on this health problem. As a health geographer, I also wanted to reinforce the centrality of the experiences of women who participated in this study, while further developing our understanding of endometriosis and the impact it has on women's lives. In the following section of this dissertation, Chapters 4, 5, and 6, I describe the core concept in the theoretical model, as well as map out key elements of the participants' experiences of journeying and navigating through the maze of endometriosis.

CHAPTER 4: SETTING OUT ON A DIAGNOSTIC JOURNEY

4.1 Introduction

In this chapter, I present an overview of the analysis used to develop the C-GT. The following chapters provide a coherent account of the journey through diagnosis, treatment, and coping with endometriosis and the subjective experiences of the women diagnosed with endometriosis. These chapters present a narrative description of those experiences. The chapters include sections of the participants' transcripts to illustrate, in the women's own words, the way in which they navigated their endometriosis experience. In Chapters 4, 5 and 6, I analyze the social process of '*navigating the journey through endometriosis*' and how the participants navigate common aspects of their everyday lives to describe their experience with endometriosis.

4.2 Situating the Endometriosis Narrative

This chapter lays out the boundaries of the endometriosis journeys experienced by the study participants, based on their descriptions of diagnosis. Two major narratives that defined their endometriosis experiences were generated during the C-GT analysis—the endometriosis narrative and the process of navigation.

The core illness narrative of journeying is the primary finding of this dissertation study. The narrative of the endometriosis journey provides a contextual basis for understanding the participants' experience of living with the condition. The image of navigation, trailblazing, and charting new territories while on the journey was a strong narrative for women with endometriosis. They made it clear that not only did they want to make sense of their own experiences but that they also wanted to leave a path or trail so that others on their own endometriosis journey could benefit from their experiences.

One theme that emerged from my analysis of transcripts was that many of the participants were both grateful for information gained from other women who had made this journey before them and felt a responsibility, in turn, to serve as trailblazers, providing details for an endometriosis road map that other women could follow. The final graphical representation of the endometriosis map can be found in Chapter 7 as part of a larger discussion around theoretical constructs related to the map.

4.3 Situating the Journey

Iterative journey is a term I use in this dissertation to refer to the repeated and ongoing movement through diagnosis, treatment, and validation in the context of coping with endometriosis. Table 4.1 provides a summary of the core category for this study. The term iterative journey is used in this study to highlight the fact that most women do not experience endometriosis as a linear process but instead experience its symptoms and treatments at unpredictable times. This becomes a cycle as the women move through many different symptoms, physicians, and treatments. The function of the term is to encapsulate a sense of the movement and repetition involved in the experience of coping with endometriosis. The term also captures the idea that information and experiences gathered in one place and time, is carried to the next, and may even determine the path for the future journey through endometriosis.

Table 4.1 Core Category Defined

The endometriosis experience is best understood as a traveled journey through diagnosis, treatment, and coping in which each path along the journey provides iterative feedback to the overall experience.

The term iterative also refers to the ongoing and dynamic experience of coping with this chronic illness. Specifically, the term iterative is defined by “the characterization of or involving repetition, recurrence, reiteration, or repetitiousness” (Merriam-Webster Online Dictionary, 2008). Of those, some women may experience this iterative or repeated cycle of unknown symptoms, new symptoms, treatment options, and validation. Some will only experience it for short period of time, while others may continue on their journey for longer periods of time.

In this research study, the participants all became expert navigators as they traveled on their individual yet collective journeys. The concept of the endometriosis journey includes the uncertainty of a diagnosis, the treatment options, and validation of having a chronic illness. The women involved in the study were active participants in the process of planning, understanding, and coping with endometriosis and undertook preparations for this journey, similar to those preparations travelers make when beginning a journey to a new place. Most of this analysis relies on the understanding and the construction of social worlds that the women experienced on their endometriosis journey. While obtaining a diagnosis, the women entered several social worlds, including the biomedical world, their family world, their intimate life world, and, for some, their employment world, all of which required careful navigation in order to understand and be within that world.

Re-reading the interview transcripts, I found the text very similar to travelogues or first-hand accounts of travelers' experiences as they tell of their uneasy journeys through poorly charted terrain. The reader is asked to both take a macro- (birds' eye) and micro- (footpath) level perspective when reading these accounts. In addition, I ask readers of this dissertation to look both at the overarching patterns identified in the C-GT I developed and the intimate accounts of the study participants' personal experiences.

4.4 Beginning the Journey: Seeking a Diagnosis

4.4.1 Experiencing Symptoms (What's Wrong with Me?!)

For most of the participants, the initial symptoms that resulted in medical visits were painful menstrual cramps (64/70 participants, 91%), painful menstrual cramps plus infertility (22/70, 31%), and infertility concerns (without painful menstrual cramps) (6/70, 9%). Table 4.2 provides a description of the background of the participants, including number of visits to physicians and number of surgeries before diagnosis. The participants visited a mean of 4.8 physicians and had a mean of 2.57 surgeries.

Table 4.2 Descriptive Statistics of Participants

Demographics	N	Minimum	Maximum	Mean	Standard Deviation
Age	70	18	57	33.04	9.405
Time to Diagnosis *months	70	1	300	69.77	73.839
Number of Doctors	70	1	35	4.80	5.353
Number of Surgeries	70	1	22	2.57	2.780

The participants had entered the world of unexplained symptoms. This meant the women were situated squarely into a world that they did not understand and could not make sense of and they felt an immediate need to move into a new experience that would help them make sense of their symptoms. The women desperately needed an explanation of why they were experiencing their symptoms. Table 4.3 provides a summary of the symptoms experienced by the participants, the majority of which were painful menstrual cycles that worsened over time, heavy bleeding, fatigue, low-grade infection, and bowel irritations.

Table 4.3 Summary of Symptoms

Symptoms	N
Dysmenorrhea	64
Dyspareunia	38
Infertility	28
Heavy/Irregular Bleeding	60
Bowel	55
Fatigue	51
Low-grade fever	51
Low resistance to infection	9

The women knew something was seriously wrong with them but were not sure what the symptoms they were experiencing meant to their lives. The vast majority of participants (n=65) described a progressive worsening of symptoms that eventually led them to their family doctors, such as painful menstrual cramps that became incapacitating over time or growing concerns about infertility as the number of 'missed pregnancy opportunities' increased over time. As participant #40 stated about the progression of pain:

Before my diagnosis there was always wondering if it was all in my head...being very frustrated with not having an answer and wondering how much worse can the pain get.

Participant #16 expressed concern over her age and her inability to get pregnant:

It was surprising because I was so young...and I was worried because if I am having these kinds of problems now, will I ever have a child of my own?

Many participants (n= 33) indicated they had heard about endometriosis prior to receiving their own diagnosis and had often wondered if that was what they had. At this point, many participants entered the information world, a place in which they began to gather information and formulate some opinion about what they were experiencing and what might be wrong with their bodies. For 33 of the women, this meant wondering if they had endometriosis, based on their readings and discussions with other people (e.g. sisters or mothers).

The main sources of information the women used to situate themselves within a social information world of trying to figure out what was going on pre-diagnosis were public messages in the media, stories

from family members, and co-workers. These are sources of lay knowledge, meaning they are not legitimate biomedical sources of information but knowledge created by the women themselves. Many participants reported that they had noted their symptoms were similar to those of other women in their family—particularly their mothers or sisters—and so thought their symptoms were normal rather than signs of a recognized disease, endometriosis. Participant #27 noted that, while her mother and sister had both experienced symptoms of endometriosis, no one had ever told them about it:

I didn't know about it; my sister didn't know about it; my mother didn't know about it. But all these things he [physician] was telling me and how it works, it was like I've heard all this before but nobody ever labeled it.

The majority of participants indicated their symptoms never fully disappeared but, rather, fluctuated in terms of type or manifestation, intensity, frequency, and location, varying during their menstrual cycle. For example, participant #4 said:

When I feel the pain coming on I have to catch it with medication or I'm in trouble. That's basically the bottom line for me, I have to be prepared.

Participant #3 describes the uncertainty associated with her symptoms by stating:

It all depends on how, like to me, my endometriosis is how I feel. Like, some days I have good days where I feel fine and other days when it's acting up I feel bad: I have cramps, my back aches, I feel nausea, dizzy. So it all just depends on what kind of day I'm having.

Regardless of how long a participant had been affected, unpredictability and uncertainty remained primary characteristics of the experiences of their symptoms. For 42 of the women, unexpected and worsening menstrual cramps occurred. Participants described this experience of constant variability according to the time of the month (or stage of their menstrual cycle) and used the degree of pain and discomfort as a gauge by which to assess their health on a particular day. Participant #40 described scheduling her entire day around her symptoms:

Basically [coping with endometriosis is] just being able to make it through my day. I have to make sure I'm not sweating in public or usually if I get that fever with it [endometriosis] and I'm near the washroom like the first day I

have to be near the washroom for sure because sometimes I'm doubled over. Sometimes I'm vomiting so, as long as I catch it early and I'm okay with it and I feel comfortable that as long as I'm not the sickly girl and I can go ahead with my day.

The participants discussed obtaining the diagnosis as an iterative process, involving: a). experiencing symptoms, b). seeking of information, c). medical testing and surgery, d). receiving the diagnosis, and e). discovering treatment options. Figure 4.1 provides a graphical summary of this experience and situates the experience of endometriosis symptoms within the larger arena of illness, because at this point, the links between symptoms within the experience of illness are unclear. The women were unable to classify their experience other than as a general perception that something was wrong, recognizing they were on a quest to figure out what was wrong based on the symptoms and information gathered.

Figure 4.1 provides a summary of the social worlds the participants enter into, based on their symptoms and where they are along the course of their iterative journey. Mapping the women's experiences involved making a value judgment by me as a researcher as to which social worlds were clearly defined and discussed by the participants using their narratives. To understand the map in this chapter (Figure 4.1) and the subsequent maps, it is important to describe the map legend. The larger-dashed circles in the maps represent the larger social arenas that are external to the women. These arenas are the larger socio-political forces that the experience of endometriosis is played out within.

For example, these arenas include society's view of endometriosis and biomedicine's treatment of endometriosis. The women experience several different arenas as they navigate endometriosis. For instance, within their social world, and before diagnosis, they are navigating an illness arena, but the illness is unknown. The smaller circles represent the individual social worlds the women navigate in daily life. These circles represent not only their experience individually, but, also, how the external forces within the arenas impact their experience as well. So the social worlds represent the individual experiences of endometriosis within the arenas that are the collective experiences of endometriosis for these women. The arrows represent the paths that the women travel along within their social worlds and inside the arenas.

Each social world will be further discussed in the subsequent sections. The map also provides a construction of the illness arena and in the process, identifies the key social worlds the women experienced and moved through in trying to make sense of their symptoms. The social

worlds experienced all influence the ultimate end point, which is diagnosis and a movement into the endometriosis arena, based on the results of the biomedical tests that confirmed endometriosis.

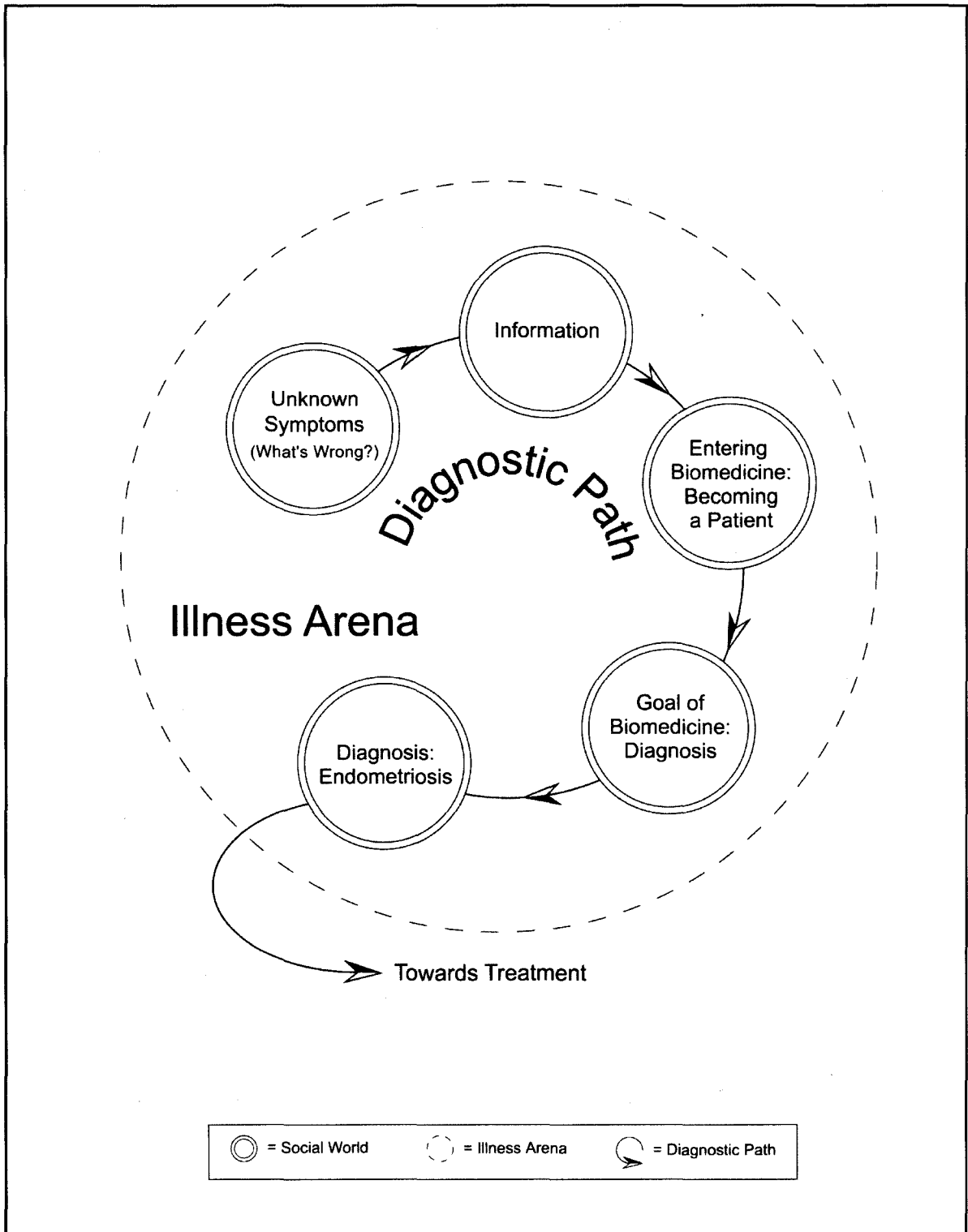


Figure 4.1 The Endometriosis Journey: Part One – Diagnosis

4.5 Traveling Along the Diagnostic Path: Pre-Diagnosis Illness Arena

The diagnostic journey was typically a long, difficult, and complicated experience. The time between the onset of symptoms and diagnosis ranged from as little as one month to 25 years (mean=5.8 years; see Table 4.2). Without a diagnosis, participants had no way to enter the biomedical world where treatment and prognosis reside. Consequently, participants' narratives included reports of long periods of time in which the pre-diagnosis experience was part of their journey, with no externally recognized label for what was happening or only a very useless diagnosis (i.e. irritable bowel syndrome). Participant #42 described what her experience was like in this stage of her journey:

Life when I had the symptoms but wasn't diagnosed was very frustrating. I was in so much pain but didn't have a name for it. Every test came back 'normal' which added to the frustration. I spent most of my time in the recliner.

Diagnosis required many consultations with a variety of medical practitioners, although a firm diagnosis of endometriosis can only be confirmed through surgery. The most common facilitator to having a medical diagnosis was the family physician providing a referral to an obstetrician-gynecologist to follow up on symptoms. Many participants felt that their family physicians simply did not have enough information about or awareness of endometriosis to make the proper referrals to a specialist. Participant #3 summed up her experience with her doctors as:

It would be nice if more people were made aware of it [endometriosis], especially my doctor. I'm not saying that he's not aware of it, but because it took so long for me to be diagnosed with it, it always seems to be the last thing that they think of. So maybe some more support from the community and the healthcare community [would be helpful]- more reading material made available [to the patients].

When the women entered into the biomedical world for a diagnosis of their symptoms, which included medical tests and surgery, they began to more intensely wonder what was wrong with them and if what they were experiencing were serious. Participant #6 asked the following questions:

Am I going to be able to have children? What kind of steps are we going to take? What kind of medication are we looking at? What are we going to do?

The social consequences of not having a medically confirmed

diagnosis were significant: for example, sick leave from work was often not granted, and there was significant doubt from friends and families of the legitimacy of the symptoms experienced by the women. Participants' descriptions of symptoms were often met with doubt and disbelief by family and friends because the women had symptoms but no recognized biomedical label to validate them. The women knew something was wrong with them, based on their subjective experience; however, they had no evidence for the doubters in their lives. Participant #41 was frustrated during this stage of her journey because she started doubting herself as did everyone around her:

Before I was diagnosed, I was frustrated with myself for always not being able to do things and I didn't really believe myself about my own pain. I saw myself through the doubting eyes of everyone else. I knew something was wrong, but I could not prove it to myself or my family.

Thus, for many reasons diagnosis was a key landmark or stage for the majority of participants. Unfortunately, many of the women lived many years in a diagnostic limbo.

While on the path to diagnosis, participants suffered through not only varying cycles of pain and frustration but also multiple rounds of consultations, tests, and misdiagnosis by several healthcare providers. Figure 4.2 provides a cartographic representation of how the women experienced moving between the social worlds of being a woman with an unknown condition into the biomedical world of becoming a patient. This movement between the two social worlds was, in fact, the typical experience of the participants entering into the biomedical world as an endometriosis patient. Participants spoke of the growing frustration they felt at the lack of a clear path from symptom to diagnosis and treatment. Participant #9 summarized her experience of seeking a diagnosis as follows:

I just think generally if I were to sum it up there was little time allotted. I've spent hours waiting to talk to a surgeon in his waiting room trying to get in. I spent eight months on a waiting list to see the second surgeon before I got in to see him. And I just feel that there's a huge time delay, little information given, and just overall 'shuffled in and shuffled out' with no real solution or plan, no direct path from symptoms to what is wrong, to being given a sure diagnosis.

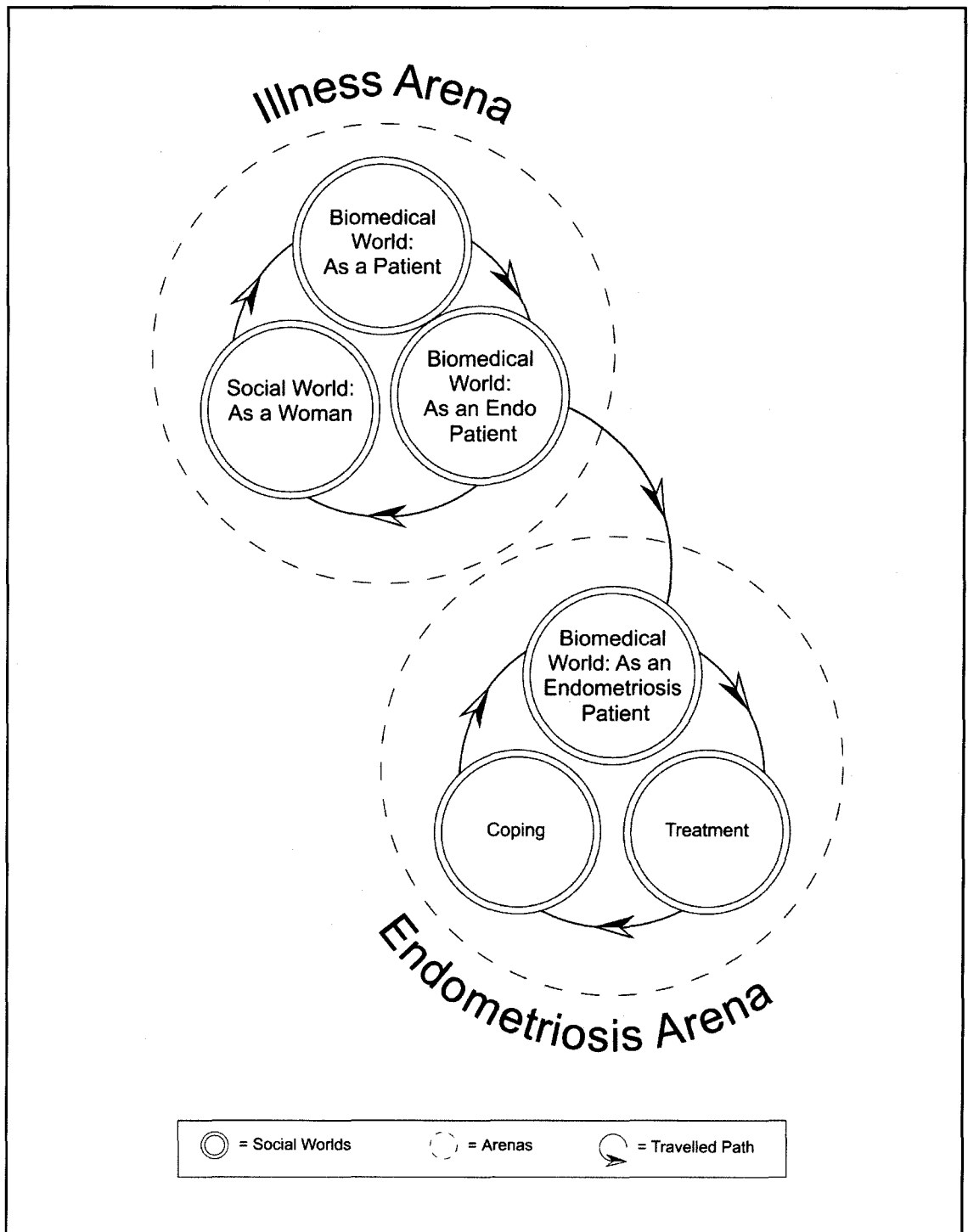


Figure 4.2 Micro-map of the women's experiences of moving between the social world as a woman and the biomedical world as a patient

4.6 Diagnostic Phase of the Journey (the Biomedical Arena)

One of the inclusion criteria for this study was that there be a medical (surgical) diagnosis of endometriosis. Therefore, each participant had undergone the experience of locating a healthcare provider who could finally arrive at a clear and useful diagnosis of endometriosis as the explanation of symptoms. Invariably, this brought a sense of relief to the participants, whose experience can be summed up by that of participant #12:

I've had the door slammed in my face a lot with docs saying they don't know what is wrong with me. On my last visit to a new doctor, I pulled in to see him the first time and I just burst into tears and I said, "If somebody else tells me there's nothing wrong with me, I'm going to freak! I'm going to lose my mind." I haven't been coping [well] emotionally because nobody's really identified it for me. And I haven't been able to identify it for me. Last month was the first period that I've ever had that I've been able to say, 'Yeah, I have endometriosis. That's why I feel so bad.'

Another woman (participant #14) described her reaching the signpost of diagnosis in these words:

Because of my symptoms, they [physicians] kept telling me it was in my head. They sent me to a bunch of different specialists, and my symptoms just kept getting worse and worse, so I left all these doctor's offices going, "Oh, my god, I am crazy. There's something wrong in my head." One night, I was having a really bad pain day and I took two bottles of LorazepamTM and chased it with a 40-ounce [shot] of rye, straight. And it was only after I did that that they investigated my pain more seriously and I was diagnosed with Stage 4 endometriosis.

Despite the overall similarities in the passage from pre-diagnosis to diagnosis (the movement from the social arena into the biomedical arena) there was a great deal of variation in the amount of relief the women felt upon receiving the diagnosis of endometriosis. On the one hand, the diagnosis reaffirmed the participants' beliefs that there were legitimate reasons for their symptoms and validated their experiences of 'real' symptoms for themselves and others (e.g. status as 'not normal' with family, significant others, coworkers, bosses). Participant #20 struggled with the lack of diagnosis and described the experience as a very difficult process because she felt like everyone around her was labeling her as 'crazy':

Because of going through all these doctors and being so insistent in saying, you know I'm not crazy. I really felt like I had to spend the majority of my time proving myself you know, like see, see, I'm not crazy, right, I really do feel sick, or I would have another test done and I would go home, I would be like see, this was wrong and I was right there is something wrong with me. I still didn't know what was wrong. But when I guess I first found out about it I was confused, I mean I didn't know, I thought thank goodness finally something was wrong with me. Not that I wanted something wrong with me but I at least had an answer. I didn't have to try and convince my family, my boss, and my husband all the time.

The diagnosis was an important step in the illness narratives of the women because it signified entry into a biomedical world characterized as having endometriosis that provided social legitimation to the doubters in their lives. Nevertheless, while the women now had a medically sanctioned label, others in their social worlds were skeptical of their symptoms and experiences: could endometriosis really be *that* bad? Even with a diagnosis, they inhabited a contested social world, compromised in their ability to operate within the bounds of 'normal' social functions by continuing to suffer physically with endometriosis.

There was also movement from the world of the 'normal' to taking on the 'sick role'. While the 'sick role' (Parsons, 1951) has been criticized for its applicability to chronic illnesses, the notion of the 'sick role' is relevant in the case of these participants; as they move in and out of the sick role, it's not a clearly defined role. With the 'sick role' comes rights, duties, and obligations on the part of those who are 'sick' (Parsons, 1951). Most importantly, the 'sick role' exempts those affected from normal social duties; however, it also comes with an understanding that the 'sick' individual will seek help in getting better (Parsons, 1951). So, while the women in this study were not 'healthy' at certain times, there was an indication from the narratives that the women moved between the 'normal and healthy' and 'sick' worlds.

The women in this study not only experienced suffering and uncertainty during their pre-diagnostic lives but were also aware that they faced many challenges ahead in terms of journeying to effective treatment and symptom relief. Many women described the future as a difficult journey that was just as uncertain and difficult to manage as their lives before their diagnoses. These women realized that they had to prepare for possible infertility issues or painful menstrual cycles that would become progressively worse with time. The women also described in detail two

very different reactions to receiving a diagnosis: not surprised and surprised.

4.7 Reaction to Being Diagnosed with Endometriosis

4.7.1 No Surprise

The majority of the women (n= 58) were not surprised by their diagnosis of endometriosis. Although many (n= 45) of the women had described symptoms related to endometriosis for years before receiving an actual diagnosis, the surprise was the very long time to diagnosis and that physicians were so slow to reach the diagnosis of endometriosis. The women themselves had read about and researched the disease and were not surprised by their actual diagnosis. Participant #4 discussed her reaction when diagnosed:

When I was diagnosed I really wasn't too surprised because I had been hearing stuff about and reading a little bit about it. And thinking, gee it sounds like something that I might have and when I was diagnosed I really wasn't surprised.

Participant #4 was not alone in wondering about her diagnosis before receiving one from the biomedical community. Participant #5 reflected on her diagnosis this way:

I wasn't at all surprised with my diagnosis. [But I was surprised] because it had been mentioned so many times throughout my life and there wasn't a doctor that wanted to take the time to diagnosis me.

When participant #22 first heard the word *endometriosis*, she felt it was validating her experience. After years of being dismissed by physicians, she revealed:

A diagnosis has given me permission to acknowledge that I have a disease, [that] something is wrong with me. I was not surprised by my diagnosis.

Endometriosis can lead to debilitating pain, which is often times invisible to those who are not suffering. This invisibility can lead to dismissal by family, friends, and health care providers. Participant #2 describes her experience of having pain and being reminded that endometriosis is constantly with her:

For me, the disease is devastatingly painful...with every moment that passes, I am aware that it is with me.

Although both participants #2 and #22 felt the diagnostic

experience to be validating, neither was surprised that they had the disease. They had long known something was wrong with them, and they had accumulated knowledge about the disease in their pursuit of a diagnosis.

Another participant, #29, describes her journey to diagnosis as important for legitimating her experiences with this 'invisible disease':

I only talk about this to people who understanding because otherwise you get the rolling eyes and you can tell the person is thinking 'she's just complaining, female problems, low tolerance for pain. Some people just make me feel like I'm making the whole thing up. Part of why I originally considered surgery even though my symptoms are not severe was because I wanted to be able to tell people 'Look I have endometriosis. It's REAL.'

Again, while participant #29 felt it to be validating, she was not surprised by the diagnosis.

4.7.2 Surprise

Only 12 of the 70 (17%) women were surprised by their diagnosis. Usually this was because after experiencing so many symptoms over a long period of time, no one, not even their family physicians, had suspected endometriosis. For these 12 women, they felt as though endometriosis was the last thing suspected by their physicians. Interestingly, although these women had thought they had the disease, no one along their diagnostic journey had any information or discussed their symptoms in relation to the endometriosis with them. Participant #28 discussed her reaction to the diagnosis as the following:

When I was diagnosed, my doctor discussed two extremes: either we are going to take the cysts out or we are going to do a hysterectomy. I wasn't prepared for a hysterectomy; it's not even an option [for me]. And when the doctor said that, I just saw in her eyes that she was surprised that I was surprised. Do they not understand if you're not diagnosed, if no one tells you that you might have this, and it was never, ever mentioned to me in my medical history that you might have endometriosis and you are diagnosed with it, how shocking that is?

Participant #1 was also surprised:

I had such extensive endometriosis because I had ignored the ages at which my relatives had their hysterectomies - about 35 - since I tied it in more to the fact that they'd [already] had their children than their age.

Endometriosis had been in participant #1's family, but because a biomedical or socially understood label wasn't attached to the experiences, she didn't think she had this condition.

Similar to the experience of participant #28, the women who were surprised experienced shock along with their surprise, because the doctor had not discussed the diagnosis or even the disease as a possibility during the long search for a useful label. What also surprised them was the vast amount of unknowns about what endometriosis means, in terms of future symptoms, treatments, or even options. For participant #64, her doctor never even mentioned the word '*endometriosis*' during her diagnostic journey:

Not even the word [endometriosis] was mentioned. I didn't even know what endometriosis was. I had no idea what I had. All I knew was that I was in pain every month and that my swelling and everything else was due to the fact that it's a 'normal' thing for women.

Participant #14 was surprised because she was diagnosed at such a late stage in the disease process (stage 4):

Well, I was surprised that more doctors didn't know about it. And I was surprised that I was at stage 4 and nobody knew about it. That was my surprise. I kind of felt that I had it because of the research that I had done, so I guess my only surprise is that I was at Stage 4 and nobody [had] caught it earlier.

Many of the women were fearful because of what they had heard in the media or from family and friends, such as requiring a hysterectomy to treat the disease, becoming pregnant to alleviate symptoms, or never being able to get pregnant because of the age at diagnosis. Participant #18 describes her fear of being diagnosed but also the surprise she felt because the disease was also in her family:

It was surprising because I was so young [22 years old], and I was scared; could I have children? One day I talked to my mother about it and she was like, she had endometriosis;

she had [had] some problems, too. I guess it was surprising that my mom had it and no one thought I might have it too!

Participant #13 was afraid of her own experience with endometriosis because of what she had heard from friends who had been diagnosed with the disease. Was she going to need a hysterectomy? What kind of treatment would she have to choose? As she stated:

Because, with my experience of women that had endometriosis I knew of two at the time they were in excruciating pain and one of them worked in the same building that I worked in, in another office, and she used to be off work three days at a time because of her endometriosis. And even after the surgery she had a full hysterectomy because they left half her ovary and she was still getting the pain even after the surgery.

It was clear from the participants' endometriosis stories that, regardless of their response (surprised or not), a definitive or correct diagnosis for many provided legitimization. This, in turn, allowed them to move from the unknown illness arena to the endometriosis arena, a defined territory that could be mapped with existing information from those who had passed through the terrain previously or by making a new map for themselves and others who would follow.

4.8 Entering the Endometriosis Arena

Obtaining the diagnosis was a key factor on the journey toward understanding what was wrong for the women. It also provided an entry into the endometriosis arena, which will be discussed in Chapter 6. But more than anything, by entering into the biomedical social world, the women started gaining knowledge, accurate test results, and more information that provided landmarks for their journey into treatment.

The next major social world in the map presented in Figure 4.2 is that of receiving the key to the biomedical world, the endometriosis diagnosis. The women began their journeys as a woman with symptoms, but then, once diagnosed they entered the biomedical world as a patient. The overwhelming majority of the women (n=65) described feeling relief that there finally was a name they could attach to their symptoms. However, with that label came the fear of recurrence, new treatments, possible infertility, and unpredictability of symptoms, because they had a disease that had no discernable cause or cure.

Participant #30 described the process of receiving her diagnosis

and how it changed her entire existence yet allowed her to navigate a known terrain in this way:

I think before I was diagnosed I didn't really know what was going on. I was in a very blank space, a space where you kind of dealt with the pain, you kind of dealt with whatever's going on with your body, not really knowing what was happening to me. After I was diagnosed, it became easier to do that, to work through it and to go on with my daily life, because now I knew what was happening and there were steps that I could take to actually do something about it. I had a label for symptoms...it was easier being diagnosed because now you know what's wrong, and I can live my life and try to figure out how to cope with this disease.

There were some exceptions to this pattern. Participant #47 clearly described her difficulties in trying to manage her symptoms before her diagnosis, noting that not all people in her social world understand and accept her even after a diagnosis:

Before the diagnosis, I was treated like a drama queen looking for attention. No one took the pain and difficulty I was having seriously. Since I was diagnosed, I have had to explain it seems like to everyone why, and what it is. Half of those I meet are concerned and take endometriosis seriously; the other half look at it as no big deal. They have no idea what it is like to live with endometriosis day in and day out.

Not only did the label of endometriosis bring validation and legitimation to 65 of the participants, it also brought about an entirely new way of navigating daily life. These women now faced a multitude of decisions about treatment options, negotiating the effect of the illness in their employment settings, the reactions of friends and family members to their diagnosis, and the overall uncertainty that the illness brought. Their treatment and coping experiences are discussed in further detail in Chapters 6 and 7.

4.9 Chapter Summary

The more successful the women were in finding information about their symptoms during the pre-diagnosis phase of their journey, the more they were able to engage in actively navigating the endometriosis journey. The diagnosis experience also provided the impetus for movement from the illness arena into the endometriosis arena. They began their navigation of the terrain by making an educated guess about what the

ongoing symptoms meant, gaining information that suggested endometriosis as a possible diagnosis, and becoming armed with information to share with healthcare practitioners over time.

These three factors not only influenced the direction toward diagnosis that their journeys took but also defined the length and difficulty of the terrain navigation along the journey. The maps constructed for this dissertation illustrate the collective experiences of the participants. Although the interviews were focused on the individual, lived experience of endometriosis, the maps constructed the larger social world experience that allows us to situate endometriosis within a greater context of living with the illness. In addition, the acknowledgment of other views of the illness experience is keenly important. For example, the individual social world is impacted not only by what the participants experienced but also by how others, such as co-workers and family, members viewed their experiences as well.

Some women were better navigators than others, receiving their diagnoses sooner and more useful information from healthcare providers. This was directly linked to finding a physician early after their symptoms appeared and receiving a quick diagnosis of endometriosis. Having a quicker diagnosis allowed their journey to follow a more direct route. The participants noted that the unpredictability of symptoms greatly influenced the navigation of their journey, particularly through treatment and coping with the illness.

As the participants traveled further, they became more competent navigators, as demonstrated by their coping strategies and search for information on treatment options. Knowledge of the endometriosis landscape and its associated journey led to a better understanding of the need for awareness, resources, and information. In Chapter 5, I discuss the impact of treatment options, how the paths to treatment were determined, and how the women moved along their journey of assimilating and merging their diagnosis and treatment together as they headed into the final phase, coping with endometriosis.

CHAPTER 5: TREATMENT EXPERIENCE

5.1 Introduction

Women embarked upon their diagnostic journey with varying degrees of experience with the healthcare system. The status of 'beginner,' in the context of the journey, was quickly lost once the participants received the diagnosis of endometriosis and set out on the initial path through treatment. At the other end of this journey are those participants who had become familiar with the treatment journey; they had previously navigated the journey after diagnosis and were, therefore, no longer beginners. The women had entered the biomedical social world but were still within the illness arena described in the previous chapter.

In this chapter, I describe how these women are still occupants of the biomedical world, but are now within the endometriosis arena, because the diagnosis provided a biomedical label that assisted with navigation through both the social world and the arena.

In terms of their current health, the women usually had an "illness narrative" that was strongly linked to their "diagnosis narrative," which in turn was often connected with their "treatment" narrative. The narratives provide an understanding of how all the experiences are connected and need to be understood in terms of that interconnectedness. As previously discussed, women reported sometimes having various symptoms of endometriosis and of other health conditions such as allergies, low-grade fever, and chronic pelvic pain that can also be associated with endometriosis. As described in Chapter 4, most the women had been living with endometriosis for many years ($n = 5.8$ years) with complicated treatment plans and options.

The treatment experience focused on several social worlds, including seeking information, making decisions, and living within a biomedical social world. This chapter will focus on the experiences of the women during their experiences with trying to determine the most effective treatment for endometriosis, considering their initial symptoms, the decision process, and actually moving through the treatment journey, in other words, undergoing the treatments. The majority of the participants ($n = 68$) found this difficult as the treatments were determined by symptoms and a "best guess" estimate of what might happen in the future with little to no certainty.

5.2 Seeking Information About What's Available to Treat Endometriosis

Once the participants were diagnosed with endometriosis, they were then faced with choosing a treatment based on their primary and most troublesome symptoms. All participants in this study had undergone at least one surgery for diagnosis. However, 63 participants had at least two surgeries (mean number of surgeries was 2.57, range 1-22). The women also had a difficult time finding doctors and other healthcare providers who possessed adequate information about treatment or who they felt were confident in discussing treatment options related to endometriosis. The women visited a mean of 4.80 doctors (range 1-35). The lack of information on treatment options is a key theme that will be discussed later in this chapter.

The participants discussed in detail the strategies used for finding information on treatment options. The key information social worlds described by the women included: the Internet; social support groups (on-line); family, friends, and co-workers; local libraries; and other women with endometriosis. In fact, 56 of the 70 participants mentioned that they wanted to be involved in this research project so that they could help other women going through the diagnosis process find information and a diagnosis sooner. Participant #14 described her feelings about this as follows:

I hope that someone out there can learn from my experience with this disease. There should be no excuse for anyone going through this horrible disease not knowing anything, or having any information. This has to change for women.

5.2.1 The Information Social World: What do I Need?

The women described a range of information they needed in order to make their treatment decisions. The primary information focused on the side effects of medications (n=55), chances of infertility (n=60), medication options (n=65), and types of alternative treatment available (n=35). The treatments experienced by the women included hormonal therapy, additional surgery, pain medication, and alternative therapies. The alternative therapies, for this research project, are defined as massage therapy, acupuncture, homeopathic remedies, and diet changes. A summary of treatments that were experienced by the women can be found in table 5.1.

Table 5.1 Treatments of Participants

Treatment	N
Hormonal	54
Pain Medication	47
GnRH agonists	46
Surgery	70
Alternative Treatment (Massage therapy, acupuncture, homeopathic remedies, diet changes)	29

Many of the participants (n= 40) collected a significant amount of information and developed a detailed understanding about their endometriosis and its treatment options. The women found that sharing information helped to relieve fear and anxiety and helped in their own treatment decision processes. If the women knew what to expect from biomedical treatment and what options were available, this significantly reduced anxiety. For example, participant #28 was told to go on the Internet and find information about endometriosis, but not only did she find information, she found a vehicle through which to share her experience and compare it to others:

Well when I was diagnosed, I was told to get on the internet and find out as much as you can about this disease. That was it. There was no questions you know mostly when you walk out of the doctor's office you have the information that the doctor handed you. I'm coping with it well because I'm trying to get as much information, telling my story to other women, and comparing what I am going through to them. Maybe I can learn what medication I should take. I don't want a hysterectomy; maybe I can find information on how not to have one.

Seeking information also helped the women cope emotionally with endometriosis. However, as discussed previously, women gathered information in different ways: some used the Internet (n=42), others relied on local information sources (doctors, nurses, or local libraries) (n=15), and others (n=13) preferred not to search for further information but to trust their healthcare provider to give them all the information they would need to make a treatment decision. As participant #9 explains:

Well, I found answers on the Internet. There are a lot of people there who seem to be in the same situation or coping in the same way I am. And information which I can't really find anywhere else. But I don't know if I should trust it. Whether it's right or wrong I don't know. So in the end I always let my doctor really decide.

Entering into the information social world meant navigating from one physician to another, full of new explanations about symptoms and gathering information to make new decisions. These movements between physicians and healthcare providers are a key part of the endometriosis journey. For each woman, information was obtained and a clinical encounter was experienced. That encounter set the tone for the current and future treatment. The additional information gained became an important navigational tool through the journey. It became clear that if one examines endometriosis only from the perspective of being diagnosed, treated, and learning to cope with the disease, many facets of the journey are missed.

Participant #13 discussed how she used the Internet to gather information and why she wanted the information:

I basically went on the Internet to look up information on the LupronTM. And to see what kind of a drug it was, what it did to you, what the side effects were. And I wanted to find, I had questions and I wanted to find resources where it was experiences from women who actually went through this, not from somebody who didn't know. Like I felt more comfortable in reading stuff from people who actually went through it and knew you know what they were talking about. So you know I had questions, Do I need a hysterectomy for this? If I need a hysterectomy can I keep my ovaries? You know questions like that. Basically finding out what endometriosis was, the doctor just told that I wanted more information what the LupronTM was, what it did. What kind of changes your body goes through? What kind of lifestyle changes I should be making because of this change? Like should I be eating differently? Should I be taking herbal stuff?

The journey is multidimensional throughout treatment. The prior treatment experience impacts the future treatment of endometriosis. For example, deciding to continue current treatments or finding out what the specific treatment options are that will be available in the future became a concern for the women. The goal of the majority of the participants was to seek a diagnosis and find treatment for their presenting symptoms. However, the layered opinions of the biomedical communities they encountered became the frame in which to situate endometriosis, given that it is not a disease that is diagnosed and treated very easily. In short, this is a complex arena to navigate. Participant #30 talks about not only the information she needed but situates her search for relief within the larger context of understanding endometriosis and the resulting need for

information:

I think we live in a world where especially with disease, like even the common cold, what the medical community says [about the disease] it validates anything that they say, the labels that they come up with are what we use to decide things. And the general public, we really don't know on a daily basis what these things [diseases] are. And with something as obscure as endometriosis it isn't a broad disease where people really think a lot about it. It's so specific to women. It's so specific to your reproductive system, it's just isn't something that a lot of people are interested in. So I think that the more knowledge that comes out for the general public the better it is because then people become interested and realize that here's something that maybe a lot of people go through. Here's something maybe a lot of women have. Even numbers—like statistics [might help]. People really tend to look at those things [statistics].

The information women gathered was used to structure an opinion about which treatment option might be the most effective, given the primary symptoms of either infertility or chronic pelvic pain. The women spoke about being categorized, based on these symptoms; some of them felt as if this categorization reduced their treatment options. Participant #52 felt that because she suffered primarily from chronic pain, the doctors and those within her social world did not take her seriously—in the larger endometriosis arena, many view it as a reproductive disease that is just “painful cramps”, without an acknowledgment that the underlying disease is much more complex. Participant #52 commented:

Emotionally with endometriosis you take a beating. People think they understand, but have no idea. Women say to me all the time, oh I had that as if it was no big deal. Then when I say I am having a lap [laparoscopic surgery] they don't even know why and say they never did. It seems to me that doctors use endometriosis as a reason to justify pain in women. And because of this it is not taken seriously for those who have and suffer from it.

The larger implications of participant #52's comments will be discussed in Chapters 6 and 7; the specific decision-making process around treatment will be discussed in the next section of this chapter.

5.2.2 The Decision Social World: What's Right for Me?

All the women had to make decisions about their treatment, based on their primary symptoms. As discussed in Chapter 4, the majority of women (n=64) had symptoms of chronic pain, as compared to only 6 who had fertility concerns instead. This caused problems for those trying to navigate the system to treat one or the other symptom. Because the women were now within the endometriosis arena, which has larger socio-political implications, this fact changes and influences the personal social world of these participants. The larger socio-political implications of this will be discussed in Chapter 7. But for this section, the most important finding is what choice needs to be made: will they need to live with infertility or chronic pain or both?

For many of the participants, the interviews revealed biomedical encounters that had been laden with difficulty and conflict for the women. Participants sought out medical practitioners (and for 29 women, alternative therapy practitioners) to make sense of their symptoms and to provide treatment. They frequently found (n= 51), however, that their symptoms were doubted or minimized, by their healthcare providers; therefore treatment options were limited. The vast majority of participants perceived that their healthcare providers were for the most part unable to treat women with endometriosis, although, three women described positive experiences with their healthcare providers that led to better treatment outcomes.

In particular, all three women described an interactive treatment decision making in which their opinions and life circumstances were considered in the process and information was made available to them by their healthcare providers. It is important to note that these three participants were educated women (college/university graduates) who had full-time employment. Participant #63 describes her experience as:

He [her doctor] really encourages interaction and he lets you be a participant in your own treatment. I think that's really important. He outlines what the different treatment options are and what the pros and cons of each of them are and you choose what's best for you.

For other women, their symptoms seemed to guide their treatment options. Twenty-three of the 70 participants had experienced symptoms as adolescents (10-16 years of age). They had been forced at an early age to start navigating the uneven terrain of an uncertain illness, with parents and healthcare providers who often were unsympathetic. Participant #27 started menstruating at age 10 and says this about her experiences:

When I first started menstruating, I thought the part of the pain was just normal, but it was tenfold to what it should have been. Once I found that out. I wish someone had listened to me and helped earlier.

Participant #28, a 38-year old stay-at-home mom, reveals her experience of endometriosis that began when she was 15:

Well, you know what? Women are so dismissed so much. I've had this since I was 15. I remember being in emergency rooms when I was 15 years of age in pain, and it was basically, put a band aid on it and take her home, she'll be fine.

Interestingly, most of the women who received some type of medical intervention for treatment were critical of the medical community, although they usually held their personal healthcare providers in high esteem, often because s/he was seen as being sympathetic, competent, or caring. Participant #21 discussed how she felt when she received her diagnosis. She thought her healthcare provider did a good job providing her a diagnosis but was more critical of the biomedical community as a whole. She states:

At least as being acknowledged was a start. That I was dealing with something real and definite and something that they can do something about. At least put a name to it a face to it. And the more communication, the more different ideas. It just gives you more to go into to look at and consider. I don't think there's any one thing that I can do to make me feel better. My doctor was great. It think it's just a whole combination of things, with the system as a whole. And you know who knows if it's all together or if it's a couple of things together and as long as it's not hurting myself overall, it's worth a try.

However, counseling to cope with chronic pain or fertility issues was seldom recommended by any healthcare provider.

Participant #30 discusses the impact that seeing a mental health provider had on her experience of endometriosis:

I've seen a psychologist that was recommended by my family physician, which has been very helpful. I think a lot of the times when I would be depressed when I was first diagnosed I didn't really consider the mental and emotional strain that I

would be going through and when I was going through it I didn't consider that part of a treatment.

Although participant #25 was diagnosed with both infertility and chronic pain, her comments about the disease suggest how the disease is perceived in the wider arena of society:

Somebody referred to this as the 'career woman's disease'. I guess I'm guilty of having waited too long to have a kid. I didn't know if I even wanted kids when I was younger, why am I forced to make this decision when other women are not.

Because the women had obtained a biomedical diagnosis, this meant they now had a possible treatment, although a cure for endometriosis does not yet exist (Lobo, 2007). It meant, too, that others have lived with the illness and that there might be an existing body of knowledge that doctors and the women themselves could access.

For the women who continued along the treatment journey, every day resulted in uncertainty and disrupted self-identity, because they never knew when the symptoms might hit. The women also did not know how to present their identities, as ill or healthy. Their identities were literally formed moment by moment based on the symptoms they were (or were not) experiencing that day, which added to the complexity of their identities and experiences. This uncertainty around symptoms added significant stress to managing their daily lives. In fact, most women (n=41) would have preferred some schedule or routine for experiencing symptoms that was more predictable. Participant #4 discusses her strategies to manage her symptoms and its impact on her everyday life:

I work around it usually. If I know it's coming I make sure that I'm not doing anything really strenuous or that I'm basically near home so that if I needed to lie down or anything but that's usually without drugs. Usually if I'm on the medications and I catch it on time I'm a lot better off than if I didn't.

For participant #16, she faced a great deal of frustration finding a doctor who would take her seriously and treat her symptoms:

I don't see anything happening. I mean, I've been to 5 different gynecologists and out of the 5, one has only been really good and supportive about it, where they sit down and

talk to you, make you think like you're normal instead of like you're crazy.

Because there is still no cure for endometriosis, women are forced to resort to a variety of short-term treatments that only temporarily stave off symptoms and slow disease progression. Hormonal treatments (i.e. the birth control pill, Lupron™, Danazol™, and Depo-Provera™) were the most common treatments (n=54), but many participants complained of side effects and unknown future effects of these medications. For participant #41, her experiences with Depo-Provera™ have been challenging, as she describes below:

I'm on Depo-Provera™ to hopefully stop it from returning but it doesn't seem to be working and the side effects are not fun. I feel horrible all the time. I don't know what is worse, this disease or this drug. I think the big unknown to me is what do I do after this drug? I don't think anybody's really offered me very good or very much information about that.

Participant #53 also is concerned about the hormonal treatment she is taking, especially as it relates to her fertility:

I'd like to see more specifics on things like infertility, especially related to the *Depo-Provera™* that I'm taking.

While conservative surgery involving removal of the endometrial implants can help reduce pain and improve fertility, but recurrence is likely (Lobo, 2007). Pain medication was the second most popular treatment offered by physicians, as reported by the majority of participants (n=47). However, participant #12 discusses her concerns over taking pain medications:

I don't believe that I would be able to function if I were taking Demerol™, whatever the max dose of things that you can take for endometriosis. So that's not really an option for treatment.

Participant #14 described what it felt like to ask for pain medication, then to be judged by the doctors:

A lot of the doctors that I've come in contact with over the years don't believe that you're in pain. And you know to get a measly Percodan™ once a month; they make you feel like you're a drug addict. And I mean I feel very uncomfortable

talking to my doctor about pain management. But when I was in the height of my endometriosis problems I felt very uncomfortable talking to my doctor about pain management because I felt like I was a drug addict you know.

Fourteen of the 70 participants were encouraged not to delay pregnancy, in order to experience a temporary remission of symptoms and because infertility becomes more likely as the disease progresses. Participant #16 discusses her experience with her obstetrician-gynecologist, who encouraged her to have children, even though she was not at a point in her life where she could support children financially or emotionally:

The worse [*sic*] advice I received was from a woman gynecologist. She's the one who stressed for me to have kids....and I'm thinking, yeah, 'If you're having a baby, she's great. If you're in my position, no.

Participant #5 described her experience with co-workers misunderstanding the treatment for endometriosis and assuming that her only concern was fertility issues, not chronic pain:

There are a few people at work and the common conversation is that she's trying to have kids and has endometriosis and hasn't had any luck and that's the rationale for it. And I'm saying it's not happening. And that's because at this point I'm not trying to have children, but if that's truly the case, I'm going to be in a different situation. Right now it's pain.

There was an overarching concern about chronic pain and infertility for the women when discussing endometriosis, often stemming from their experiences with family, friends, and popular culture's representation. Participant #16 described the lack of awareness and how society viewed endometriosis as:

Like I just keep thinking, like I'm not a female chauvinist by any means, but if this happened with men, would more research be done. I honestly believe this. If this was male, like you always hear about prostate cancer, you always hear about heart disease in men. Where is the women part of it? When was the last time you saw an ad about endometriosis on television? Like never. I've never ever. And not that I go around telling everybody that I have endometriosis, but the nice thing now is I find when I do talk to people and I say I

have female problems and they say, oh is it endometriosis?

Participant #23 also described her frustration with the public awareness of endometriosis as:

I think there is a lot of misunderstanding with the public, as people suffering from PMS, or not wanting to go into work or wanting to just lie in bed all day and not be in pain. I think that's probably the biggest misunderstanding.

Participant #45 discussed how she perceived endometriosis and its representation in society:

Because endometriosis is related to menstruation and fertility (and infertility) it seems like it is a taboo topic. There is not much out there. People don't know about the disease. More specifically, MEN don't know about the disease. It's a female thing. How do you explain to your male boss that you have to take time off due to cramps?

The apparent fear of endometriosis was strongly associated with the nervousness that it was a recurring disease with no cure. Participant #28 described her perceptions of endometriosis within the larger socio-political arena this way:

If doctors were more compassionate and they didn't jump to...the word hysterectomy it is terrifying to me. Knowing that this wouldn't cure the disease why is it an option? That's what I want. I want the information out there. I want what you're doing. I want studies. I want funding. I want the government to take an interest in women. Not just because, I'm sorry to say it, but if this were a man's disease, we would know more.

The perceived inevitability of infertility, additional surgeries, and chronic pain along with the fear that the endometriosis would eventually recur, even in those who received quick and successful intervention at an early stage, revealed a strong need for follow-up and support at the end of treatment, not only by the specialist but the family doctor as well. Participant #11 discussed her experiences with her doctors and the frustrations she has felt over her prognosis:

So I wasn't very satisfied with that and I ended up going, I guess in that sense I felt really not listened to because I explained to them, all of them, that my number one priority is, I can live with some discomfort and I can live with some pain,

but my number one priority is to make sure that having a family down the road is an option for me. And but that didn't seem to matter too much. My friends have been wonderful, but my major frustration has been doctors.

For the majority of the women in this study, there was an attempt to make the treatment decision individualized depending on their symptoms with endometriosis. The women wanted to be treated based on their symptoms, not on how the doctor thought they should be treated. The women battled cultural misrepresentations and expectations of those with endometriosis, which influenced the treatment decisions and expectations. At this point in their journey, the women have re-entered the biomedical social world; because they have their diagnosis, they are re-entering for their treatment. But this re-entrance is now situated within the endometriosis arena, which brings an entirely different set of socio-political considerations into the journey process. The next section will discuss the participants experience with re-entering the biomedical world.

5.3 Entering the Endometriosis Arena

Having a confirmed diagnosis of endometriosis provided the women with a compass or directional aid to point them in the right direction for the next part of their journey. However, the fact that the women now knew what was wrong with them did not necessarily mean an immediate treatment and end to the disease. They quickly learned that endometriosis is a chronic condition accompanied by preconceived notions and expectations of how one copes with it. In Chapter 3, the ordered situational map addresses how endometriosis is situated within society. Figure 5.1 is the situational map for the treatment journey and illustrates the social worlds and arenas traveled by the participants. These women have moved from an unknown illness arena into the known arena of endometriosis. This final section addresses the experiences of the women as they move into this arena. The key themes of the biomedical world situated within the endometriosis arena focus on the movement into the larger socio-political context of the condition, facing uncertainty and the future treatment options.

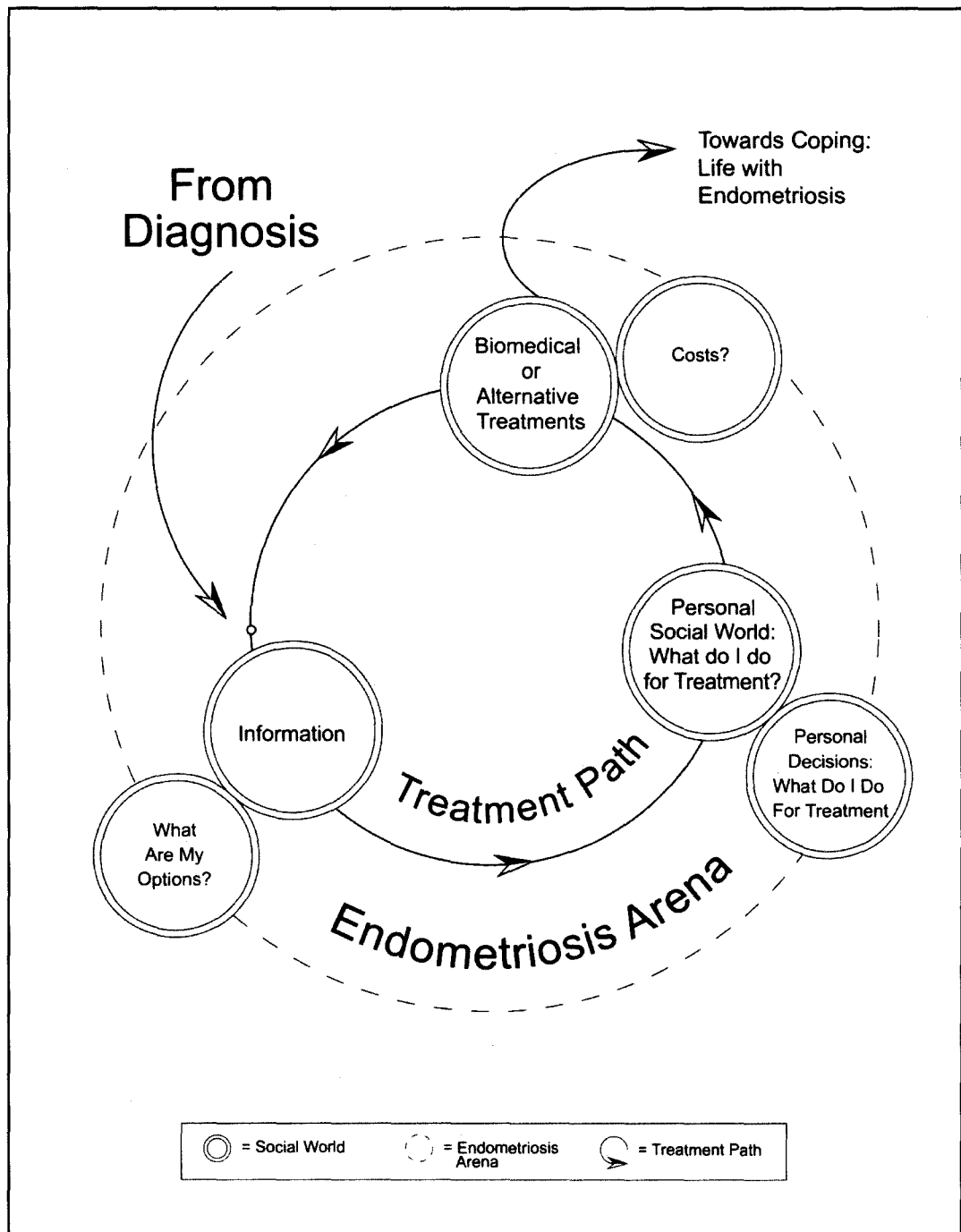


Figure 5.1 The Endometriosis Journey: Part Two - Treatment

Biomedical health care providers within our society are considered experts and thus are seen as holding power and authority (Freund & McGuire, 1999). Therefore, the participants generally tried to comply with the prescribed treatment for fear that they might be judged by their physician and risk being rejected and no longer a patient. This is a major difference between being in the unknown illness arena and now being within the endometriosis arena, for along with the diagnosis, there was an expectation to follow prescribed treatments. Participant #5 expressed fear about rejecting the treatment offered in hospital on the grounds that she would be rejected universally by “the biomedical system” in Ontario, even though she considered the treatment completely useless and risked suffering from severe side effects:

I was diagnosed with endometriosis in September of 2001. This disease has basically taken over my life. It controls what I eat, what I drink, and my activity level due to the pain. Over the past 12 months, I have been trying to locate a doctor in Ontario that will remove this disease and have been told that I will not find one. Through friends in the U.S., I have located two facilities that specialize in this procedure and now have spoken with two different doctors regarding excision surgery. I would prefer to stay in Ontario to have this surgery completed, but if it is not available I have no choice [but to go elsewhere]. I cannot continue to let this disease control my life. But also, I have been told if I go to the United States for surgery, I will no longer have a family doctor.

Another theme related to moving into the endometriosis arena is that of uncertainty. Uncertainty is a key component of the journey through endometriosis and comes not only from the symptoms, diagnosis, and treatment but also from the future: what does the future hold was a key question posed by the participants. While some participants experienced a great relief when they were diagnosed with endometriosis, they also experienced a new set of uncertainties. Even with relatively predictable trajectories, symptoms do not appear and disappear within a certain time frame; endometriosis is far from a predictable disease, unlike, for example, the flu or the common cold. An example of an unpredictable, uncertain situation is illustrated in this statement made by participant #3, a 31-year-old investment-banking manager:

Just the feeling of...feeling lousy. Like when you get that nauseated feeling or that upset stomach feeling you do not know. It is just a constant all day you don't know whether that feeling of nausea, you don't know whether you are actually

going to throw up or if you are just going to feel that way all day. It takes a lot out of you all day. And then you get paranoid. You think, oh I'm going to work, am I going to get sick? Am I going to make it through the day?

Unanimously, these women demonstrated, through reference to comments made to them, the lack of education and ignorance that the public has about endometriosis, the chronic pain, and the infertility, as well as the inability of women with endometriosis to openly address the reality of their struggle, what this illness is like for them.

The other critical aspect of how society viewed illness to these women was that there is no public interest or policy group related to promoting the rights of women with endometriosis. In addition, every participant interviewed expressed the importance of believing the person and of validating or acknowledging their illness experience. The women made frequent reference to phrases such as, "it is not in my head" and "I'm not crazy", to describe their experiences with a doubting society. Sometimes, they were skeptical to the point of doubting their own feelings of pain. Participant #45 said that "being diagnosed was a sort of relief," because of her own self-doubt.

Finally, a key theme for all the women was an uncertain future. Because treatment options are limited with endometriosis (i.e. hormonal treatments can only be used for a limited time, as with pain medications), the women were fearful that, as they aged, their options would become more limited. For example, participant #14 expressed fear over not being able to take Depo-ProveraTM any longer:

I'm fearful of the future. I'm fearful of what's going to happen when they say you cannot have Depo-ProveraTM anymore. I mean I've changed my life so much. I used to be a huge red meat eater and I went to see a naturopathic doctor and he was telling me all about the fats and the hormones that go into our meat and etc. etc. And so I became a vegetarian and that made a big difference in my pain level but I wasn't pain free. So I guess for the future for me, I'm terrified when they take away my Depo-ProveraTM, what's going to happen.

Participant #1 goes on to describe what the future means to her as:

This is where I don't like the uncertainty. Many WITSENDO [We're Interested in Treatment and Support for Endometriosis Internet on-line support group for women who have endometriosis to communicate with other women from

around the world] people have had repetitive surgeries. I expect (as does my gynecologist) to have a hysterectomy when I'm about 40 – I'm 32 now – although I don't want to because I had such a bad experience on LupronTM and on HRT.

Participant #23 is fearful that, because she is young and has been on treatments for several years, her fertility options may be limited:

I do not want to stay on the medication for too long. I've been on some sort of medication for 4-5 years now and it worries me that that will affect me being able to get pregnant later on in life, as well as endometriosis. Aside from the medication, I think my biggest concern is having an effect on my fertility. And so I think that's a fear for me, you know, nothing else will work and it will come to a point where that may have to be done.

Finally, participant #9 is also fearful not only about treatment options but also about what endometriosis means for other health conditions and future health benefits:

Future options? Well no, not really options but sort of band aids. And I think as well the future lies in terms of health I'm wondering I'm taking hormones now what's it going to do in the future? Is it going to increase my risk of cancer? What if I lost my job and I don't have medical benefits?

As these participants move into the endometriosis arena, they are left to cope with the disease since there is no cure at the time of this study. The next chapter will focus on the women's experiences of coping with endometriosis, which includes how they live with a chronic illness, the uncertain world they face, how they manage that uncertainty, and what the future will bring if new symptoms appear—will it mean beginning the journey at the first step again?

5.4 Chapter Summary

This chapter has illustrated the women's experiences of endometriosis treatment in navigating their social worlds as they exist within the context of the endometriosis arena. Examining their daily life experiences and situating them within the context of their biomedical, personal, and informational social worlds allows for an understanding of the ways that the women interviewed perceive the treatment process, and options, make sense of their symptoms, and experience uncertainty about the influence of endometriosis on their daily lives. By incorporating their

individual experiences and knowledge, their social world and descriptions of these worlds reflect these treatment experiences.

The women's narratives articulate the frustration and difficulties that are, in part, due to the puzzling symptoms of endometriosis and the lack of treatment options available. Those interviewed discussed the external social and cultural forces that influenced their navigation and the paths they took along their journey through endometriosis. The experience of living with endometriosis involves paths to treatments that are not direct routes but instead are navigated in response to the symptoms experienced by the individual woman.

Furthermore, the journeys are multi-dimensional. The biomedical treatment of endometriosis and the women's individual experiences are dimensions of the current endometriosis arena—the dominant view of endometriosis and biomedical treatment are intertwined in different social worlds that are separate social worlds for the women in the context of their individual daily lives, but they represent other worlds (biomedicine and treatment) the women are required to navigate.

The women participating in this study described navigating their social worlds, entering into a known disease, trying to find as much information as possible, using that information to make treatment decisions, and then moving into the arena of coping with a known illness of endometriosis. In addition, the symptoms of endometriosis can reoccur at any time or can manifest as new symptoms; hence, it becomes an iterative journey of navigating one's experience with endometriosis. As one set of symptoms becomes controlled or managed, the same symptoms (or new ones) may emerge, leading to an entirely new diagnosis and treatment experience.

The journey through treatment describes how women with endometriosis navigate through the pain, infertility, fatigue, and medical treatments that they routinely face. I approach their progress through the journey in Chapter 6, with greater emphasis on the movement and change that occurs over the course of the endometriosis, which becomes a coping issue.

CHAPTER 6: LIVING WITH ENDOMETRIOSIS

6.1 Introduction

The intent of this study was to examine women's experiences of endometriosis. The experiences as described by the women were revealed as a journey through endometriosis; experiences the women collected through their journey ultimately influenced their ability to cope and manage the chronic condition. The women created pathways as they journeyed to being able to live with endometriosis, or 'coping'. The pathways they traveled included those made while seeking a diagnosis and the factors that had contributed to determining a pathway for future treatment. As the women moved into the arena of being diagnosed with endometriosis, the social worlds that they navigated shifted to reflect their long-term or chronic illness experience. These social worlds navigated by the women include: 'life with endometriosis world', the 'uncertain world', and 'management world', which leads directly into the unknown arena. The unknown arena represents the uncertain futures of endometriosis; will it return, remain stable, or will new symptoms develop?

6.2 Coping Strategies: How to Manage the Social World of Endometriosis

As discussed previously, the women have now moved into a known arena, yet are still navigating new social worlds. The first social world described by the participants was just living with endometriosis. The participants discussed several strategies they used for coping with this illness, which influenced how they navigated their life within the endometriosis world. The key strategies discussed included learning as much as possible about the disease, dealing with the disease on a daily basis (taking a one-day-at-a-time approach), and trying to cope with a changed identity. These coping strategies were both emotionally and action-based strategies. Figure 6.1 graphically illustrates the social worlds and arenas navigated by the women. Although this may seem like an endpoint after being diagnosed and treated, the map has a clear feedback loop that can begin again with new symptoms or the need for new treatment options. The main representation of this map is to highlight the iterative nature of the endometriosis experience through visualization of the women's narratives.

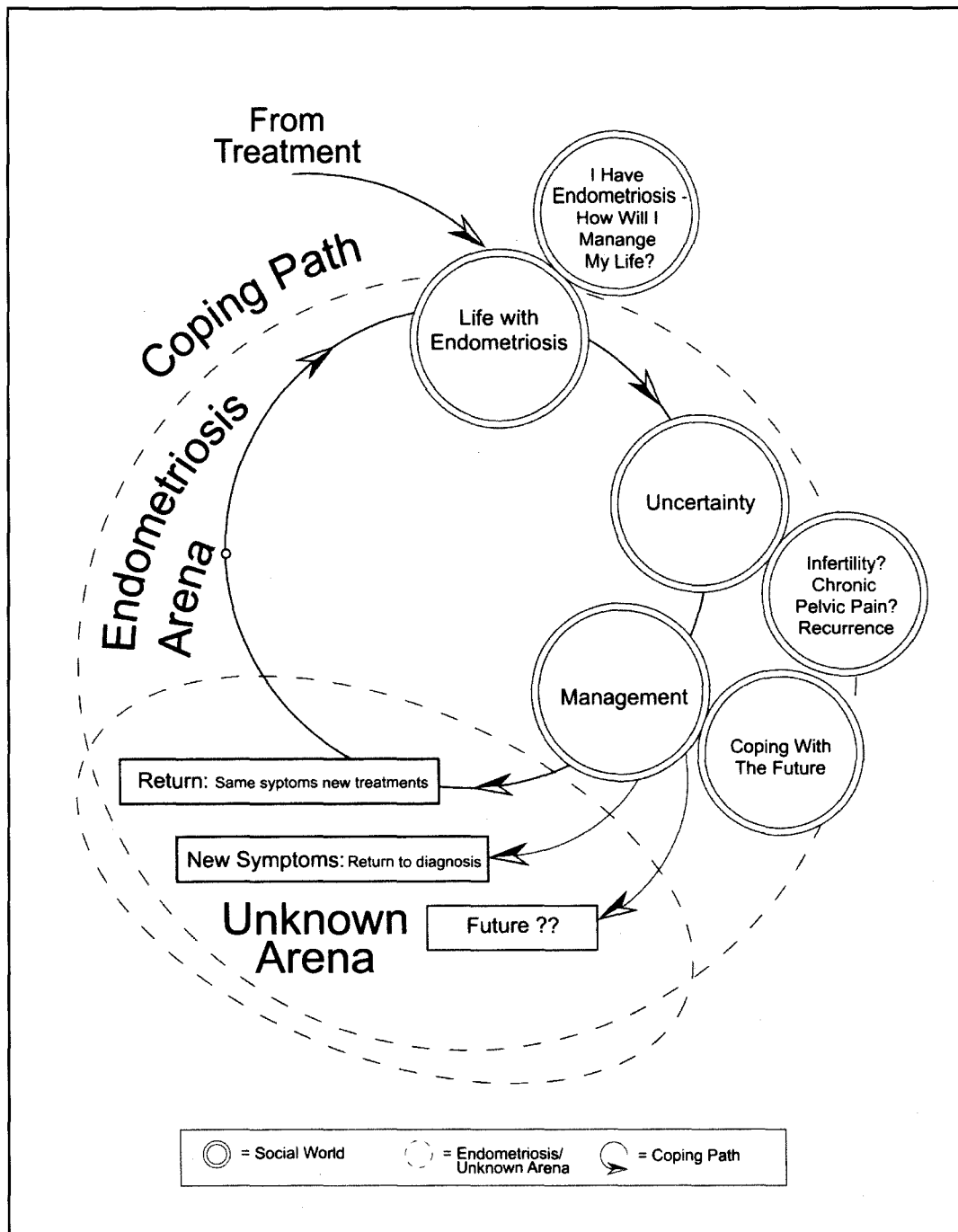


Figure 6.1 The Endometriosis Journey: Part Three - Coping

Participant #28 describes her coping strategy as one of gathering as much information as possible but also discusses her initial reaction to being diagnosed and treated:

Initially I went through mourning, a mourning period. And it's gone very quickly but now I'm ready to fight back and find out all the information and that's how I'm going to cope.

Participant #27 echoes a similar sentiment in trying to cope with endometriosis:

I would take the most information that I could find on endometriosis, and to see if I could better improve the situation, to exhaust all avenues.

Participant #38 said that, for her:

I've gone through several stages with endometriosis. One with the pre-endometriosis, I didn't know I had it and then I found out I had it and so it explains the pains that I have and my periods and so I think that once I was diagnosed with endometriosis I felt relieved because then I understood why I bled heavier than other people and my periods were more excruciating. So I think coping with endometriosis is really just doing more research and finding out as much as I can about it, you know.

For others, the main strategy used was to navigate daily life the best they could, given the limitations of endometriosis. Participant #23 said that coping, for her, means: "Being able to function in my everyday activities with minimal amounts of pain." Although participant #65 discusses her coping strategies in the context of the everyday, she also situates it within her entire social world, including the interactions she encounters:

It's dealing with the disorder. Dealing with it on an everyday basis. The things you do in everyday life. How the disorder surrounds those things. The interactions that you have with your family and friends, how it changes you and how you deal with those changes in your interactions.

Participant #32 felt strongly that coping with endometriosis was linked to her everyday experience:

Coping is the ability to function in my daily life. It is being able to realize that the circumstance in which you are in will

and can change in the future.

Even though the women struggled to navigate the terrain of their social worlds and cope with endometriosis, other issues became apparent. Their self-identity was fundamentally changed, and there was a disruption in their lives. All these women felt that their self-esteem was very low and that their self-identity had changed. Many suggested that they had become a “different person” because of the unpredictable nature of the illness and because they were unable to develop a consistent identity. As a 29 year-old participant #33 noted:

I feel completely abandoned by my friends when I have these bad period pains. I can't go out at all for the week of my period sometimes. I am staying at home a lot lately, I'm just exhausted after work and taking painkillers makes me really groggy. I couldn't be bothered trying to make myself look well and go out.

Compare this to how participant #7, a university student, described her life with the condition:

It's one of the most debilitating diseases you, as a woman, can have. It affects your mind, relationships, career, academics, life and achievement of goals...the list goes on and on...I just hope I can pursue my dream of a Master's degree and have this disease.

6.3 Information and Lay Understanding for Coping

Many of the women discussed their coping strategies, which were divided into two distinct categories: getting through daily life or finding as much information as possible to help them get through their daily life. For many of these women (n= 41), they simply wanted to be “normal” and able to do things such as “household chores,” “cooking dinner,” “attending classes,” “holding a job,” and “getting out of bed”. The women also wanted their families, friends, and employers to understand that they had a serious condition so they would no longer need to cope in a vacuum. Their ability to cope was very much affected by external forces and interpretations of others. For example, participant #18 discusses her strategy to cope:

For me it's not just about how I cope. I could cope just fine, without my family, my husband, and my employer. But I feel that I have to help all those other people to cope. It's my duty. But I have found that going on to the social groups on the Internet have been extremely helpful. I don't feel alone in

my duty to help everyone cope. I just wish others would get this is a serious condition.

The sentiment of “not feeling alone” was also reflected by other participants who found that social support groups on the Internet provided not only a place to discuss strategies on how to help other people in their lives cope but also provided legitimation for the knowledge the women themselves had about their illness and experiences with endometriosis. In fact, overwhelmingly (n= 65) the women suggested that there needs to be more social support groups for women with endometriosis, not only on the Internet but support groups that they could attend in person.

The women also spoke about how they did not understand the treatment options, full-range of symptoms, or side-effects from the treatments (n= 67). As participant #60 discussed:

I cannot understand the options my doctor discusses. How am I supposed to know which will be the best option? I do like the fact that I can go to other women with endometriosis and they will be honest and tell me their experiences. That is the only way I feel I can get the honest answer to some of these treatments. My doctor told me I should go on LupronTM. When I went on WITSENDO, most of the women told me not to because of the side-effects. How was I supposed to tell my doctor this. In the end, I couldn't afford it, so it wasn't an issue. But what do I do when other women tell me not to try something, but my doctor tells me it is fine.

Participant #60's narrative reveals that there is a contested issue between what women with endometriosis believe and experience and what the biomedical community understands and ultimately how endometriosis is treated. Participant #50 also comments on the need for a balance between the information provided by the biomedical community and women with endometriosis:

I would like to see more information from the doctors as to what they are prescribing. Are they safe? What are the side-effects? Will this harm my fertility? How long can I take the medication? How many surgeries will I need? When I go on the Internet, I find that what the doctors say and what women say are different, and for me, how do I figure it all out? How do I know what to take with me?

23 of the participants identified gaining knowledge and information from other women with endometriosis as a positive influence on their coping abilities. For example, participant #26 commented on her feelings:

I always felt so much better if I spoke to any other woman with endometriosis. I felt I was understood, that I didn't have to explain myself. I just wish I could get that unconditional understanding with everyone in my life. This is where I think more information to doctors on how women really live with this disease would be helpful, like with this study. Maybe it will help them [doctors] understand.

Two other participants noted how they wanted to be able to discuss their treatment options with their doctors, as well as a support group that interacted with doctors (e.g. questions could be answered by doctors). These sentiments were also reflected by 11 other participants. Participant #4 discussed this issue as follows:

The best way for me to cope is just to be proactive. I have to look up my options and see where I stand. If I don't know where I stand, I cannot cope. I just wish my doctor was open to discussing my options with me and it was less of a one-sided conversation.

Participant #28 discussed how she would like the opportunity to ask questions to doctors and receive a legitimate answer to her questions about endometriosis:

Endometriosis specific support groups that interacted with doctors. Like where you could e-mail with questions and you could get an honest answer that isn't filled with medical terms.

The request for information, the opportunity to ask questions of healthcare providers, and understanding the knowledge the women had about their own experiences with endometriosis was a key theme from this analysis.

6.4 Living in an Uncertain World: Relative State of Illness

Perhaps one of the most interesting findings from this research project is the concept of a relative state of illness, or movement in and out of the "sick role". The "sick role" wasn't necessarily applicable at all times for the study participants. In fact being "sick" was described by many of the participants, as an intermittent role. 68 participants, when asked if they identified themselves as healthy or ill, identified themselves as healthy, and when asked if they were able or disabled, identified themselves as able-bodied. This is after revealing the very tough days of incapacitating pain and of re-negotiating their daily lives because of symptom uncertainty and how they felt that particular day. This is an important finding to note, because it reveals a separation between the personal social world

navigated by the women in their everyday lives and the larger endometriosis and unknown arenas, which have larger social implications for identifying oneself as ill or disabled. Within their personal social worlds, the women stated that the way they felt on a particular day was relative to other days, hence the concept, relative state of illness. They did not identify themselves as being 'ill' or 'disabled' people but only that way on certain days or at certain times; they were very careful not to adopt that label overall.

Recalling a relative state of illness is the process of reflecting and talking about the life the women lived prior to beginning their illness journey. This previous life was used as a foundation for how life was for them in the present and how it changed on a daily basis. Each woman's story made her experience unique and provided a backdrop for later experiences, how she experienced her individual social worlds. One strategy some women used was to reduce the overall effect of endometriosis in their daily lives. This involved making the illness process as normal as possible, as participant #1 suggests:

With any hopes, I cope by just being able to do your day-to-day things, you know, being normal.

Participant #18 described a similar experience in trying to navigate her daily life with endometriosis:

I guess mainly I just try to keep a positive attitude about my life and how structured in terms of having a physical disability and having endometriosis. I guess coping to me is not only an individual process but also part of my family and so for helping them to deal with how I feel about when I get sick or when I feel ill.

Participant #65 discusses the fact that, in navigating her experiences with endometriosis, her main guide is to be as normal as possible, which was a key theme among all the women:

Basically to cope, I go through it. I try to be 'normal' and I would say dealing with the present issues [endometriosis] in a manner that helps you get over something; like for me I think coping is a personal thing it's trying to be as normal as possible while I live with my endometriosis.

In their search for a "healthy" life inhabited by their family, employers, and doctors many women discussed coping with life on a variety of levels. Specifically, participant #30 discusses her process of trying to understand and cope with endometriosis this way:

For me it's a process of gathering research, understanding the disorder for myself and then being able to pass on that understanding to people who surround you in your life. Also, part of that understanding is with the medical community, my doctors. There's a family that develops when you have this type of disorder with everybody who's involved in this. From doctors, psychologists, people who help you to deal with it on a daily basis. And those are your main strengths when you are trying to cope with something like this. It's definitely culminating everything together, putting everything together, organizing your life on a daily basis and incorporating all of those factors, family friends, relationships as well as with the disorder.

A different way women described being "healthy" and perhaps one of the most important aspects of this notion, was that they were in control of their lives. The boundaries of navigation were not imposed by the biomedical definition of endometriosis; instead, the boundaries of navigation were set by the women. As participant #2 explained:

I cope with endometriosis by setting limits, trying to be as normal as possible but still getting up every day and doing what needs to be done, keeping a sense of humor, which helps a lot, and reminding myself that so many other women like myself are going through this, and living with this disease also. That helps me cope and gives me a lot of hope, I also keep focused on awareness of endometriosis and letting people know about it and how many women do live with this disease. But most of all, I try to do everything I can without having to worry about medicine and things like that.

Finally, the way the women viewed their health changed over time. During the diagnosis and early treatment phase, as well as at times during their menstrual cycle, participants saw themselves as ill, which was their relative state of illness. Following diagnosis and during times of stability, the women saw themselves as essentially healthy. This is highlighted by participants #7 and #4 comments on health and illness. Participant #7 identified herself as a healthy woman but qualified her statement this way:

I would say health. I would definitely say health. Sometimes I don't even think about the endometriosis. It doesn't cross my mind as an illness. Like if we were having a conversation, it wouldn't really even cross my mind.

Question (Researcher): What about times in which you actually have cramps? That's different. That's different

because I guess you tend to feel sorry for yourself and you start thinking maybe I am really sick. Maybe I'm not as healthy as I like to think I am. It brings you back down to reality maybe a little. Knock you off your high horse you know. So I would say that's definitely different.

Participant #4 also qualified her experience by identifying herself as being healthy but went on to say certain days had limitations:

Actually you are probably going to find this funny, but I would describe myself as being in excellent health. Now it's really only for 3-4 days of the month that I would say that I'm ill. I actually am. I do have really good days. Like I have I really am in excellent health the rest of the month. It's just those 3 or 4 days that I'm just a write off.

35 of the women spoke about the negative impact of chronic pelvic pain upon their social life, and in particular, not being able to attend social events because of the unpredictability of the pain. Some women explained how they had "put off" starting new activities because of their pain. For example, participant #45 discussed her social life as follows:

My social life was fine as long as it wasn't around that week to 10 days. I wouldn't want to go out then because I didn't feel well, felt nauseous. The pain wouldn't let me go out for start. I would have a couple of days definitely where I couldn't function properly at all.

Two main reasons were identified for not wanting to participate in events or functions. First, as 30 of the women described, feeling worried about the pain starting in public was a concern because when the pain occurred most of the women "wanted to be by themselves" and not surrounded by other people. Next, 5 of the participants were prevented from attending social events as they did not want to be in places where there was a likelihood of children attending, because of their psychosocial issues and infertility. Due to the incapacitating nature of the endometriosis pain, the women described having to make plans around holidays or attending social events to avoid the times their pain would be severe. 20 of the women found this frustrating: they described feeling "ruled" by endometriosis and stated that it was "taking away their life".

The unpredictability of the pain added to the frustration. Consequently, in 3 cases the women kept a diary of their symptoms in an attempt to predict when would be the best time to attend social functions, again moving into a relative state of illness, not ill all the time but trying to predict the times when it would be a problem. Participant # 9 describes

how it impacted her life:

It is just the restrictions it puts on you. You just have to think before you do anything. If you are invited for a night you have to say, how am I going to feel. Am I going to be able to make it work and at the moment being ill fits into my schedule. It is part of my life. And I write down when I have my period so I know how to prepare for my days, otherwise I am scared.

These problems frequently led to a lack of confidence. Many women described how they felt less confident because they were unable to go out as often as they would like or they were not able to mix as easily when out in public because they were constantly worried about their condition. 35 of the women felt that the endometriosis pain controlled their lives. They described feeling “frustrated” that they could not control or forget their symptoms, either because the pain was constant or because it occurred at times in the menstrual cycle other than during menstruation. All these descriptions of their experiences expressed how they were held hostage by the unpredictability of their symptoms and how their illness, while not impacting them all the time, was relative to where they were in navigating daily life.

6.5 Managing Life with Endometriosis

The difficult terrains navigated by those with endometriosis often begin at different starting points but ultimately end at the point of having to manage and live with endometriosis. The women described moving from the “normal” world without endometriosis into the “sick” world, and this movement might not be the chosen detour; rather it was one dictated by the illness. The journey through endometriosis is a physically travelled journey, through doctor appointments, medical treatments, and employment. There is also an element of the journey that represents the personal and subjective everyday experience within the individual woman with endometriosis that becomes represented by their social worlds.

Endometriosis is the starting point from which many different journeys are navigated for these women. For women with endometriosis, the symptoms represent the compass for the journey and dictate which terrain (chronic pain, infertility, or both) will be travelled. While the symptoms for some women may seem similar, as I have presented them here, many of the women do not have symptoms in common; some were infertile, some were both infertile and dealing with chronic pain, and some had a combination of low-grade fevers, diarrhea, nausea, vomiting, and low resistance to infections.

Just as journeying through endometriosis represents the process of beginning a search for diagnosis and treatment, that same journeying can also represent the process of exiting that experience because a biomedical diagnosis has been obtained and treatment of their symptoms is manageable. Although there may be an end to the journey temporarily, the iterative path that endometriosis so often takes provides a context for the women who have had unsuccessful diagnosis and treatment experiences, endings that typically have negative implications for future experiences. This fact is extremely important to recognize, because it can lead to the recognition of patterns and functions that will influence the iterative feedback loop of the journeying experience. Therefore, if a woman had a negative experience early in the journeying process, (such as those associated with delayed diagnoses), it will affect her future experiences in seeking out treatment from the biomedical community for endometriosis-related symptoms.

For example, the place of diagnosis for many women can be a positive experience or a negative one, if many attempts to obtain a diagnosis were unsuccessful. Participant #7 describes that she felt negatively towards going to her doctor's office because she felt like it was a waste of time because she never got any answers:

I hated going to his [her doctor's office] because I was very frustrated with not having an answer. I began associating his office with anger because he could not do anything to help me. But after my diagnosis I became angry because nobody bothered to do a damn thing about it before when I was in so much pain. I eventually asked my family doctor for a new referral because I could not stand going back to his [her doctor's] office.

Participant #7's experience illustrates why it is so important to explain the theoretical construct of "journey" as both a literal and metaphorical term to understand the illness experience. A journey through illness can be understood as a literal journey of physically travelling between healthcare facilities, the home, work, and the community. But there is also a metaphorical element, which includes the perceived notions of health care, home, and work held by the women and the people they interact with along the way. This metaphorical place is represented by the social worlds of the participants. For participant #38, the diagnosis of endometriosis left her social worlds very difficult to navigate, not only the physical places in which she travelled but also the reaction by her friends to the diagnosis:

My life before endometriosis was very different...I had college friends and went to dances and sporting events. The year that I was diagnosed and told everyone, I lost my college friends because they couldn't handle me having endometriosis and the restrictions it put on my life. I didn't know if I could go out on some days because of my symptoms and when they my strike. Some of my high school friends don't understand endometriosis and we aren't close any more. I cried that year...not because of getting the diagnosis of endometriosis but losing so many of my friends.

As participant #38's experience reveals, for women with endometriosis, the everyday experience is no longer an objective category but instead subjective and relative, multiple and dynamic, and that everyday experience can become a dimension of their experiences that can be associated with chronic pelvic pain and/or infertility, or both. And it is through these illness experiences that we can begin to understand the concept of journeying. We can also begin to understand the difficulties faced by these women on a day-by-day basis, especially regarding the uncertainty of symptoms and how others treat women with endometriosis.

6.6 Moving into the Unknown Arena

The women have now moved from being diagnosed with endometriosis to experiencing medical treatments to now living with the illness. They described three key themes that influenced how they coped and continued to live with endometriosis: the need for advocacy for other women who have endometriosis, the search for information and support from healthcare providers and other women with the disease in order to navigate the unknown future, and the need for better communication between women and healthcare providers.

A key theme identified by the women focused on the need for good information and communication skills to both convey and explain the information given. This was extremely important to the women in order to cope and to understand future options. Many participants talked of biomedical professionals as being hard to talk to and not wanting to listen. They felt that not only did doctors or the biomedical professionals not want to listen but when explanations were given, they were not necessarily at the appropriate level. For example, participant #19 said:

I found they were all talking above my head. They are using these big flaming words and yet they weren't speaking English. I thought 'This is all beyond me.'

Participant #14 described a difficult interaction with her doctors and how she felt:

I just don't feel comfortable. My physicians that I've had over the course of my endometriosis have been very technical and I find with me anyway that I'm very emotional when it comes to my pain. And it's hard to get across those emotions to somebody that's being very technical and that makes me feel uncomfortable to talk about you know the depression that comes with endometriosis and you can't have sex and you can't do this at certain times of the month and it's very difficult, it's always been very difficult for me to talk to my doctor about that kind of thing.

However, wanting a non-technical explanation did not mean that participants did not want large amounts of information. Participants did want to know about endometriosis, specifically, what their options were and how to manage symptoms and treatments. Participant #63 discusses what she viewed as limitations in the interaction with her doctor and what she would like from her doctor:

I think, I don't really think very much could have changed so far, but I guess it's the...I have a lack of knowledge about what happens from here. I'm on Depo-ProveraTM to hopefully stop it from returning but it doesn't seem to be working and I'm also considering you know, do I want to have children and when do I want to have children and what's the big impact on that. So I think that's the big unknown and I don't think anybody's really offered me very good or very much information about that. And I do want more information, it's not like I haven't asked for books, sources on the Internet and groups in Hamilton.

They wanted to feel comfortable and to be able to discuss issues relating to the condition with their own health professional, who in most cases was a family doctor. The women wanted reassurances about their future and to move into a known arena. In many instances, that comfort level did not exist. As participant #22 put it:

There seemed to be a bit of a communication breakdown. I didn't feel like I could sit and sort of have a proper discussion about my condition. Yeah, he's not really accepting to that. Just cause it's kind of stepping on his toes. Although I'm a nursing student, he would probably think, well, you don't

know everything. It's not generally received well. He would probably come back and say, well yes there's a study that says this and this and this, it's not always the best way. The odd time he's said it's worth giving a try, try that. Like I said I want to take Vitamin E and he said well that's been disproved in studies.

An important part of health professionals having the whole picture was the biomedical professional actually having time to get the entire illness narrative. Participant #27 discussed her opinion:

I guess there are some family docs you could sit down with, but it hasn't been my experience. I feel like you are using up their time and they want to whip you in and whip you out. I don't think they are really interested in your opinion about things.

Many participants expressed, in different terms, this sense of being herded in and herded out, especially because there is a shortage of gynecologists in the province of Ontario and an even smaller number who specialize in endometriosis. Finally, participant #21 discussed her concerns about the lack of consistency of treatment and information among gynecologists:

The only thing that really surprised me is the knowledge difference between different doctors. Whereas my family doctor, once we had gone through a certain series...she goes, this is what I really think you have and this is what you need. I go to a specialist and she's like, no that can't possibly be. Every other kind of specialist tried to rule things out before allowing me to go through the diagnostic process. That surprised me, how different doctors can see the one disease totally differently. And then I went to an endometriosis specialist in Toronto and absolutely know everything about it. Different knowledge base.

Finally, the participants wanted healthcare providers to believe their symptoms and knowledge, be aware of the complexities of endometriosis and the entirety of symptoms it can present as, provide information, and recognize that each woman has individual needs regarding their treatment of endometriosis. These themes are reflected in the following comment from participant #40 about the support from a physician she has received:

My gyn [gynecologist] has been very sympathetic and has never questioned whether my pain really exists or not. He has tried his best to answer all my questions. He has treated

me like an intelligent person and has told me what he can do, and what he CAN'T do. Being kept informed about my condition has given me a feeling of some control over this problem.

Over a period of time and through their navigation of health care, home, and work, changes occurred in the needs of participants, related to the type of information and support they requested. As the women continued along their journey, many found there simply was not any information available from their healthcare providers, leaving an information void. The women spoke of wanting more awareness not only from the biomedical community but also from the general public so that they were not battling preconceived notions of endometriosis. For example, three participants discuss the impact of endometriosis awareness; for these women, it was about blazing a trail for those who would come after them. They wanted to make sure that others had the information and awareness that they did not have, and they wanted to share their experiences with other travelers along the endometriosis journey. Participant #3 discussed how she would like not just more awareness in general but more awareness specifically about the symptoms of endometriosis:

It would be nice if more people were made aware of it. Especially my doctor. I'm not saying that he's not aware of it, but because it took so long for me to be diagnosed with it, it always seems to be the last thing that they think of. So maybe some more support from the community and the healthcare community—more reading material made available. More about symptoms other than cramps and fertility.

Participant #30 suggests that she would like more people to know about the disease, more research to be done, and for that information to be disseminated:

The one thing I would like to happen is that more people know about endometriosis. I think it becomes easier to cope with people, especially for myself when you have a huge network. There's a lot of knowledge. When the research is done and it's out there for the public and it becomes easier to talk about because people have something to talk about, they have a basis.

For participant #27, information in the doctors' offices would help, especially given the amount of women affected by endometriosis:

This is a major disease and it does affect unbelievable amounts of women, you know you just don't have a normal period and that's the way you are. If there were just more, whether it is a little small poster in the doctor's office saying, if you think you have it, talk to your doctor. Just to enlighten them.

Information was discussed as a key component of social support for the women, as many felt that more information for not only themselves but the public could make a difference in understanding and bringing awareness to the illness. Although some women stated that they had never received any specific information about endometriosis, most had seen advertisements that were part of a media campaign and had picked up brochures or leaflets, or talked to friends, or used the Internet, all sources that suggested severe menstrual cramps could be endometriosis. Participant #10 discussed that she had no idea endometriosis existed:

Well, first of all I didn't know anything about endometriosis. I had no idea that it even existed. That it was even something that could possibly be wrong with me. I initially just thought that I had major cramps, that I was someone that had heavy bleeding and a lot of cramps. It wasn't just heavy cramping and it was an actual disease.

The participants shared what they wanted from other women with endometriosis. The women wanted to network with other women and compare their experiences with endometriosis, empathize, gather information, and be recognized as an individual, as illustrated by the following comments of participants #14 and #54:

For me, knowing that there are other women with the same problems as me is really one way I can cope with endometriosis, and I don't feel so alone with this disease and Listening to other women gave me hope, in that they had been there before, and if they made it, I know could. Some women do well with treatment. I wanted to hear what worked, so I could tell others.

Finally, the need for information was greatest during times of uncertainty; specifically during diagnosis, when making decisions about treatment choices was central to the women (e.g. treatment for chronic pain and related symptoms or infertility) and during recovery from laparoscopic surgeries. Because there was a significant chance that the treatments were only temporary, the need for information fluctuated based on which symptoms were being treated and what would be the future

options. In times of stability, the amount of information required decreased and/or remained constant because there was not an immediate decision that had to be made about treatment courses.

The times when women faced new symptoms (or if old ones re-appeared) or when they had to make a specific decision regarding treatment decisions was when the need for information and social support was the greatest. Participants identified healthcare providers, other women with endometriosis, and the Internet as their primary sources of information but wanted more information particularly from their healthcare providers about the disease process (e.g. an explanation of what exactly endometriosis was) and treatment options (e.g. hormonal versus surgery). Many of the women (n= 35) found that the information that was provided did not adequately address the psychosocial aspects of living with endometriosis or any information about coping with the disease. The majority of participants (n=67) expressly stated that more information from their healthcare providers would have helped them cope much better with the disease. When participant #16 was asked what would help her cope and live with endometriosis the best, her response was:

A cure, but there is none. I think more recognition about yes, we realize what you have and we understand instead of, you know what, there's only treatments, there's no cure, so there's nothing we can do for you. I think more, no, we can't do anything for you so we understand but more positive. Like recognize it that it is an issue. I think that would help me cope.

Finally, participants #49 and #9 described what they thought were the major problems with having endometriosis:

Lack of awareness and understanding from the professional communities; perceived continued "taboos" about "women's problems"; lack of effective treatments, lack of research and research funding, and a cavalier attitude expressed by many (doctors and society at large) concerning endometriosis. I think it's a bit discouraging cause I know that like I said there's no long term cure. Before I was in a bit of denial in terms of I knew there was a problem and I was in pain I thought, oh I hope I don't have to have surgery maybe I don't have to have surgery. But now I just know that I'll probably be going to have to have the surgery and I'll feel better afterwards.

The women of this study have now arrived in the unknown arena of

their journey. After experiencing diagnosis and treatment, this is now the point along their journey where they leave the trail that others will follow and try to make sense of their own experiences of living with endometriosis.

6.7 Chapter Summary

As a chronic illness, endometriosis is similar to conditions such as fibromyalgia and chronic fatigue syndrome in that it is a contested chronic condition. However, because of the biomedical beliefs, encounters, and socio-political situational placement of endometriosis, it has features that not shared with most other chronic illnesses. That is, endometriosis is associated with unique symptoms and treatments related to its historical, socio-political, and medical contexts (Carpan, 2003). Endometriosis has been historically treated as a reproductive disease, and because the disease may not affect two women the same, there is room for societal doubt over the legitimacy of the symptoms experienced. It is difficult for society to think about endometriosis outside of being something that causes painful cramps and infertility. But for many of these women the symptoms went beyond those that are widely recognized. Until the understanding of endometriosis is expanding, it will be difficult for women to have the authenticity of their symptoms taken seriously.

Markovic et al. (2008) specifically state that: "Endometriosis is one of the many conditions in which health professionals often discredit patient's experiences and label them as psychosomatic..." (p. 359). As a consequence, the women's social worlds were exposed to terrains not found with most chronic illnesses. They not only had to navigate their own personal social world but also that within the endometriosis arena, which leads to the navigation of the socio-political discursive practices that dictate the view of endometriosis within the larger society, which in turn can influence the individual social worlds of the women.

The previous chapters outlined a journey through endometriosis that included the navigation of uncertain terrain, changes in self-identity, navigation of life within the context of endometriosis, and need for additional information and awareness. Empirical analysis of endometriosis as a journey illustrates how the experiences of illness from onset and through the progression of symptoms, diagnosis, and treatment can be described through that metaphor, specifically one of traveling through the social worlds that affected experience. The concept of journeying captures how the women navigate their social worlds within the context of the larger arena (macro-level) and at the individual level (micro-level) of their perceived social worlds.

Being diagnosed with endometriosis changed life in varying ways for the women in this study. These changes did not take place immediately but can be thought of as guideposts that provided key experience points along a traveled journey. Not only were there new experiences within their social worlds but also these experiences might have connected them with the past and aided or hindered them in the upcoming experiences, whether it was with a new diagnosis or a new treatment.

The most important thing to note is that the concept of a journey is about the movement from one place to another, traveling and experiencing detours, reroutes, and road blocks and blazing new trails. The journey through endometriosis is about change, relocating the woman diagnosed in new treatment experiences and trailblazing a path for others to understand their own experience, giving the others a road map to find shortcuts for coping with endometriosis within everyday life. Chapter 7 will discuss the findings of this study within the larger context of the medical sociology and health geography literatures.

CHAPTER 7: THE ENDOMETRIOSIS EXPERIENCE

7.1 Introduction

The overall theme that emerged from my analysis was that participants have been on three interlinking journeys—seeking a useful diagnosis, seeking effective treatment, and learning to cope and live with the condition.

The “journey” has become an interesting medium to capture the complexity of endometriosis and has allowed for the exploration of how the diagnosis affects the treatment relationship, and how this in turn affects the way the women themselves cope with endometriosis. The messy and ordered situational maps in Chapter 4 provide a guide that will form the discussion around situating the endometriosis experience. But before discussing the women’s experiences within the larger context, it is important to describe empirically how the women lived and coped.

The notion of journeying is expressed both as a process that helps affected women navigate metaphorical places as well as travel across both time and physical places (e.g. healthcare offices, employment, and home). It is a complex concept that allows for the understanding of endometriosis not only in the present but allows us to capture and understand women’s earlier experiences with this illness and how that earlier journey has affected their current travels involving seeking a diagnosis, treatment, and coping. Since the concept of a journey captures all aspects of the travel experience, it is a suitable metaphor, for it encompasses all components of the women’s experiences.

In developing this C-GT, the participants were also documenting the process by which they were becoming both successful navigators and also cartographers, leaving clues as to how best to make this journey for other women at earlier stages in their own journeys. The women in this study acknowledged that their lives were complex and at times paradoxical: indeed, several of them who described experiencing severe bouts of chronic pain and other symptoms still identified themselves as being healthy.

In this chapter, I will present how the concept of being on a journey captures the intricacies of endometriosis and allows for an all-inclusive understanding of this chronic illness. I will begin by explaining the C-GT that emerged regarding women’s journey towards diagnosis, treatment, and effectively living with endometriosis. I will explore the theory in the context of the original research questions, the relationship of the theory to existing relevant literature, and the implications for theory and future

research, as well as the strengths and limitations of this study, and my personal reflections on my own journey as the recorder and co-creator of the collective map for the study participants.

7.2 The Endometriosis Journey

The way a woman with endometriosis navigates everyday life may be quite different at the end of a long search for a definitive medical diagnosis than how she navigated prior to diagnosis. The more she interacts with other women with endometriosis, the healthcare system, friends, family, and the community, the more her views, meanings, and experiences of self in relation to this chronic condition will alter over time. Additional knowledge and information will be obtained over the course of the journey that will also impact the experience with endometriosis. This is the personal knowledge the women have developed from their experiences and the knowledge obtained from others during the course of their journey.

Bury (1982) referred to this knowledge as “lay knowledge,” and it allows for the validation of the knowledge and experience she has obtained over the course of her journey. In more recent literature, specifically related to endometriosis, Whelan (2003) described how women organize themselves, use their knowledge and information to navigate the illness experience and, ultimately, reorganize in a way that challenges the biomedical establishment. The dialogue between the lay and expert community, specifically related to endometriosis, has been discussed by Whelan (2003; 2000).

Whelan examined the knowledge of endometriosis patients in the United States and Canada and the knowledge of healthcare providers and their influence on each other (Whelan, 2000). The knowledge and experience each of the communities (the women with endometriosis and doctors) bring to the table offer a unique perspective that needs to be heard and understood (Whelan, 2000). While this study did not examine the specifics of the lay and expert knowledge issue, many of the women discussed how these issues influenced their ability to cope. It was also clear from the women that information was a key factor in influencing their ability to cope with endometriosis.

The concept of mapping is not new to health geography or constructivist research frameworks and is a highly fitting analogy for the present study, one that can be thoroughly revealed using Clarke's (2005) situational analysis. This dual strategy of using a C-GT and mapping allowed me to explore the complexities associated with both the commonalities of the illness experience with endometriosis and the unique

experiences of the study participants while journeying along their illness paths. In addition, I have been able to map out the paths taken by the women who contributed to this study, thereby visually capturing the meanings, contexts, and realities related to experiences of the self while journeying through a chronic illness. Given the lack of previous research on the experiences of endometriosis in everyday life, the study was essentially exploratory and best served by an approach that did not impose any predetermined theoretical model.

Using the journey metaphor, the experiences within endometriosis is conceptualized as a process of gathering information while moving from one place to the next, and these experiences determine the paths within the journey and the type of information gathered. Women diagnosed with this illness are conceptualized in my study as metaphoric mapmakers, creators of maps of the endometriosis experience. Using these maps allows for the documentation of the women's experiences with endometriosis through symptoms and into the struggle for diagnosis, treatment, and validation. This journey becomes an exploration of the experience of endometriosis, as seen by the women, and the physical experience of the places they explore. While on this journey, the women use the information and experiences gathered along each point of the journey to determine the future navigation of where to go next with their endometriosis experience. ***Navigating through the journey*** is the core social process that emerged from the data in this grounded theory study of the women whose navigation was directed by the demands of their illness.

The concepts of 'journey' and 'navigating' are especially suitable for describing the social process that emerged from women's descriptions of living with endometriosis. A 'journey' can be defined as "an act or instance of traveling from one place to another" (Merriam-Webster Online Dictionary, 2008). For the study participants, although they described the difficulties faced by traveling from one healthcare provider to another while seeking diagnosis and treatment, the focus of their journeys was not on geographical movement per se but rather on the movement from one life stage and process to another (i.e. diagnosis, treatment, and coping), and the loops between these three destinations.

It became clear that these women were moving between being diagnosed, to initial treatment after diagnosis, then living with endometriosis, and ultimately wondering what happens if it returns or new symptoms develop. Hence, the use of a journey was very important, as each step represented a "passage" from one phase to the next in understanding and living with endometriosis.

It is perhaps this second meaning of a journey as “something suggesting travel or passage from one place to another” (Merriam-Webster Online Dictionary, 2008) that best captures the lives of women searching for some anchor point, a diagnosis, that would help them better define their treatment choices and expectations about what life might be like with such a painful chronic condition. Above all, the journey revealed by the women in this study was loaded with uncertainty about diagnosis, treatment, and living with endometriosis, and their maps were much like the maps of early explorers who traveled through unknown lands, marking dangerous territories or terrains so that others might avoid the precarious path.

Regardless of the definition used, the concept of navigating a journey through uncharted (or poorly charted) territory is a frame of reference that links a known past to an unknown future. For the women, the journey is not linear but cyclical and iterative, with earlier phases of the journey shaping later passages through time and place. I use the term “iterative journey” in this dissertation not only to refer to the repeated and ongoing movement the women made through diagnosis, treatment, and coping but also to highlight the fact that most of them did not experience the endometriosis journey as a linear process. Symptoms, diagnoses, and treatments are unpredictable, at times leading the women on a dead end path forcing them to start again without a reliable diagnosis or useful treatment along with dashed hopes and an increased sense of frustration.

The women experienced this iterative cycle of unknown symptoms, new symptoms, treatment options, how to cope with the uncertainty of the future, and possible recurrence each in their own way, and so it will be for other affected women. Some will only experience it for short period of time, while others may continue on their journey for longer periods of time, depending upon the following characteristics based on this study: 1) time to diagnosis, 2) type of treatment (hormonal or surgical), and 3) concerns about fertility.

Figure 7.1 represents the overall map of the women’s experiences with endometriosis: through diagnosis, treatment, and coping, including an iterative feedback loop. The purpose of the map was to capture and visualize the chaotic experiences of the women as they navigate through their individual social worlds situated within the societal arenas representing their collective experiences.

The overall map also represents places travelled by the women; hence, the map reveals a travelled journey with a starting point to a temporary end. While this map, as represented here in 2-dimensional,

could be thought of as a 3-dimensional map. The 2-dimensional represents the graphical journey the women endured, at a single time. A 3-dimensional view of the map could be thought of as the women's experiences and represented by the children's stretchable toy the Slinky™ (K. Szala-Meneok, personal communication, November 14, 2008). The 3-dimensional properties are represented by the iterative journeys women make; for those women in this study, it wasn't simply just one journey through endometriosis, the journeys were layered. This 3-dimensional view would represent all the experiences the women have had during the course of her endometriosis journey; hence, the Slinky™ is an interesting way to represent the collective experiences of the women because the journeys are connected and all would be visible. This representation of the journeys also captures the movement in time for these women, in particular the women are always moving forward with each experience they have along their journey, so when the Slinky™ expands vertically, all of the collective experiences add up for the women.

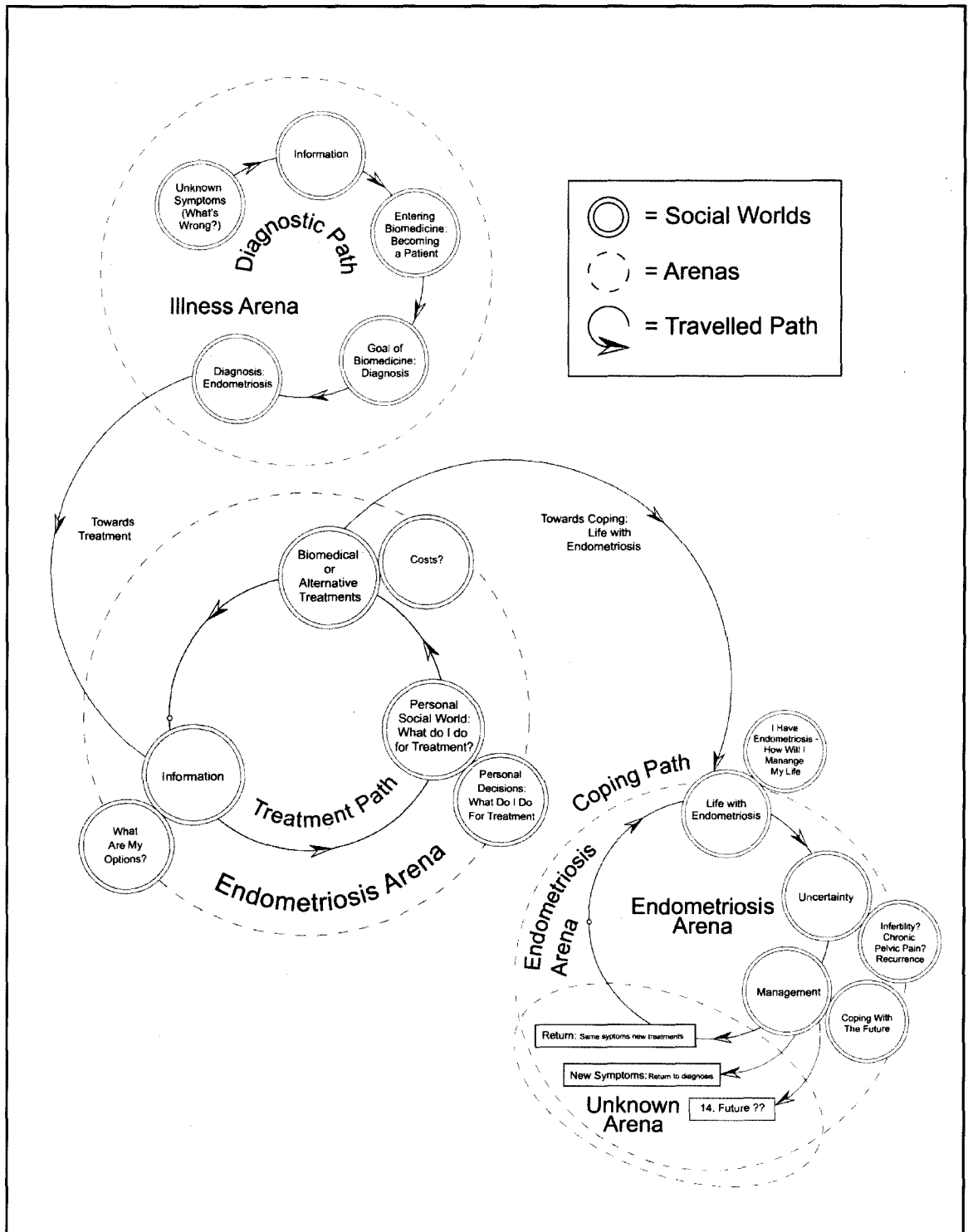


Figure 7.1 The Overall Endometriosis Journey

Conceptualizing the endometriosis experience as an iterative journey is crucial to experiencing it. A traveler on a journey picks up information from one place to another, information that can influence the trip travelled, and the women's stories reveal the complete and interconnected picture of the endometriosis journey, made up of their collected information, collective experiences, and personal interactions. The journey concept is one that the participants themselves allude to when describing their multiple diagnoses, treatment, and coping experiences and is, therefore, well grounded in the data. As participant #12 stated:

I always feel like I'm on a journey... my friends at work and my friends in my life, my family have all been through this journey with me.

7.3 Review of my Grounded Theory in Relation to Research Objectives

This research study had two main objectives: 1) to explore the experiences of women with a confirmed medical diagnosis of endometriosis based on their narrative accounts of diagnosis, treatment, and coping; and 2) to identify the core social processes underlying their experiences.

This research demonstrated that the women define their life with their illness through the three goals. They each maintain their identity, which is referred to as a relative state of illness, by learning to navigate along their journey. By seeking out information during their diagnosis and treatment, balancing uncertainty, developing strategies for coping and defining what is needed along the journey, the women maintain some sense of normalcy throughout their endometriosis experience.

The study specifically explored the following two issues during the interview process: 1) examining the impact of the diagnostic and treatment journey on the women's capacities to cope with and understand endometriosis; and 2) determining the role of social support (type and degree of validation) in shaping their capacities to negotiate the endometriosis experience in everyday life. This study found that the women had various reactions to their diagnosis, which included being surprised versus not surprised; experiencing difficulties in receiving a diagnosis versus being relieved; and finally, expressing the cumulative effect of navigating the diagnosis.

The participants were intensely committed to both legitimating and

validating their symptoms and what they were experiencing on their search for a diagnosis. Their experiences of treatment varied but tended to be determined by their initial symptoms of infertility or chronic pelvic pain. These women were highly motivated and organized when it came to understanding their treatments and options, particularly what kind of treatment were needed, any possible side effects, and the effectiveness of the treatment. Many of them relied on information from other women with endometriosis and from the Internet. In general, the women in this study found their family, friends, and workplaces to be supportive of their experiences with endometriosis but felt that society in general was not supportive, both in its policies and general understanding of the condition, a view which oftentimes came from the popular press or media representations of the illness. It should be noted many described their family and friends as influenced by the popular views of endometriosis in society as well, which left the women frustrated with not having their condition entirely understood. The flexibility and support of their family and friends along with that of their workplace seemed crucial to their coping with endometriosis and feeling of social support.

Again, study findings led to the identification of three key areas for understanding the experience of endometriosis that must be taken into consideration: diagnosis, treatment, and living with endometriosis (coping). The C-GT allowed for a holistic understanding of the endometriosis experience by allowing the further development of an understanding of those three areas as an iterative process based on prior experiences and of the fact that the future management and experience of endometriosis could be affected by those prior experiences.

When healthcare providers are considering interventions and treatments for women with endometriosis, it is important to think about all aspects of the disease and not just the clinical presentation. The women involved in this study made it clear that they wanted more information on their condition, available treatments, and future recurrences they could expect. The desire for information to reduce uncertainty and to become involved in treatment decision-making is supported in the literature on endometriosis (Jones et al., 2004; Lemaire, 2004; Cox et al., 2003^a) and cancer (Charles et al., 1997; Charles et al., 1999). In addition, although information and decision making are obviously important to the women, another area of expressed concern related to the treatments for endometriosis, the side effects, and the options available. It is clear from the literature that endometriosis and its associated treatments can be difficult on the individual women (Lemaire, 2004; Prentice, 2001).

For these women, coping with everyday life is a priority, as they struggle with anxiety, side effects, uncertainty, unpredictability of

symptoms, and trying to manage work and family. While there was not a formal definition for coping in this study, it is important to note that, when the women were asked about their individual definition, their responses reflected the two types described by Folkman and Lazarus (1984): problem focused and emotion focused. All the women described their coping as trying to solve a problem, which was trying to get through everyday life with minimal influence from endometriosis.

Finally, in envisioning how endometriosis awareness should be represented, study findings indicate that the women affected and their related needs of diagnosis, treatment, and coping do not exist in isolation but rather intersect with all their other life needs. For instance, a lack of information and understanding about treatment can create uncertainty and fear in women over their future options. Another example is the delay in diagnosis experienced by many of the participants. Not having a definitive diagnosis or information contributed significantly to their daily struggle with their symptoms and trying to understand their experiences. The interrelationships among diagnosis, treatment, and coping are shaped by the complexity of the information gained or not gained, the uncertainty faced, and the daily struggles experienced. This complexity supports the need for a more inclusive approach to the care of endometriosis; for more time spent with the individual woman, leading to an individualized treatment plan; and for an even greater understanding by family, friends, and employers of what both the disease and illness entails and encompasses.

7.4 Establishment of the C-GT within Existing Literature

The key categories of the C-GT were the initial diagnosis of endometriosis (beginning the journey), the treatment options and experiences, and living (coping) with endometriosis. These intersected to form the core category of journeying, which captures the cumulative experience that is based on everything experienced during diagnosis and treatment and ultimately influences how one copes with endometriosis. Furthermore, this is a process that could repeat itself based on recurrent or new symptoms. This research study does not focus on traditional medical geography, such as spatial analysis nor does it rely solely on social theory to explain the experiences of women with endometriosis. Instead, a multidisciplinary approach involving medical sociology, qualitative methods, health geography, and medical anthropology informs the experiences of these women. The following sections of Chapter 7 will discuss the findings in relation to illness narratives, conceptual metaphors, and living with a chronic illness.

7.4.1 Illness Narratives: the Women's Stories

One of the key reasons chronic conditions such as endometriosis cannot be adequately understood by using only the biomedical model is because it suggests to patients and families that although the journey to a confirmed diagnosis is often fraught with uncertainty, decisions about treatment and outcomes should become clear once the patient is diagnosed. This is certainly not the situation described by the participants of this study. Although the source of uncertainty and worry differ pre- and post-diagnosis, the endometriosis journey is actually sometimes more difficult after diagnosis because the struggle continues for adequate treatment that addresses individual concerns. The difficulties faced after diagnosis are also discussed in the endometriosis literature (Manderson et al., 2008; Lemaire, 2004; Jones et al., 2004; Cox et al., 2003^{a and b}; and Whelan, 2003) and within the larger social sciences literature related to other contested illnesses, for example, rheumatoid arthritis (Fair, 2003), medically unexplained symptoms (Nettleton, 2006), lupus (Stockl, 2007), and chronic fatigue syndrome (Whitehead, 2006).

To inform the basis of this research study, illness narratives played a key role; they were the women's stories as told by them to the researcher. The women's illness narratives allowed me to examine how women who are diagnosed with endometriosis experience everyday life. The narratives were based on a semi-structured interview focused on the experiences of endometriosis. Pierret (2003) reviewed the literature in relation to the illness experiences within medical sociology and suggests that the macro-level of analysis is the least researched within the discipline. Specifically, Pierret states that: "the central question in sociology arises about the interrelation between subjectivity, cultural factors and social structure" (Pierret, 2003, p. 14). Eighty percent of the women in the study discussed how the views of endometriosis varied not only within biomedicine but in society. Endometriosis has been labeled for many years as 'the career woman's disease' (Capek, 2000), and many of the women in the study felt as if their friends and family also held this opinion. This same opinion not only exists within popular press but also within biomedicine, as described by Carpan (2003), who says "clinical reports have continued to foster the idea that career women develop endometriosis, instead of disputing this sexist (career woman's disease), outdated notion" (p. 2).

This dissertation has not exclusively focused on the macro-level experiences, or attempted to describe all of the identified contextual influences on the endometriosis. However, it has at least acknowledged that these women's individual experiences of endometriosis are situated within society and within the collective experiences of other women and it

must be recognized if we are to understand the entirety of the endometriosis experience. It is the linkages between the subjective experience, the social worlds of the women, and the social structures these women navigate that we must understand in order to improve health care for chronic conditions.

There are debates within the endometriosis literature about how the disease should be defined by biomedicine and the popular press: infertility, chronic pain, or both (Carpan, 2003). Carpan (2003) examined articles on endometriosis between 1975 and 2001 in the popular press and found that most followed the biomedical model of endometriosis, and that medical doctors were seen as the experts. Carpan's (2003) findings indicate that endometriosis is represented in the medical and popular press as:

a frightening disease causing infertility in women.
Furthermore, women in our society have been blamed in the medical and popular literature for contracting endometriosis by delaying childbirth and pursuing careers. Women seeking information about endometriosis may be alarmed by the information they find in the popular press (p. 8).

As Kleinman (1988) and Kearns (1997) have suggested, illness cannot be studied or understood without understanding the sufferer's cultural context. Endometriosis brings the woman diagnosed to the divided nature of the disease (chronic pain and/or infertility) and into a larger discussion; which is "that each of us *is* his or her body and *has* (experiences) a body" (Kleinman, 1988, p. 26). In this formulation, the woman affected has a bodily experience that is different from her experiences with navigating her individual self through endometriosis. Kleinman goes on to state that cultural values and social relations shape the experience of illness (Kleinman, 1988). This is important for understanding the women's experiences because the diagnosis, treatment, and coping are a part of a social and cultural experience. In summary, I suggest that if we can describe health and illness experiences from the individual's perspective, we can begin to formulate strategies for coping that do not conflict with the individual's social and cultural world (also referred to in this dissertation as 'lifeworlds').

The use of narratives in geographic research is described by Kearns (1997) as the:

(re)legitimation of the personal pronoun within writing in geography generally which highlights a return to the geographer as teller of tales, an embodied reporter from the research frontier (p. 269-270).

Kearns (1997) also points out that “one promising outcome of metaphorical explorations by health geographers is likely to be a continued release of new connections and understandings” (p. 272). He further suggests that the use of narratives and metaphors in health geography is a reflection of the “cultural turn” in health geography that allows for the development of a deeper understanding of health and healing by using the examples of how landscape became a metaphor within health geography (Kearns, 1997).

The importance of mapping the individual experience was highlighted by MacKian (2000), who suggested that individual mapping can assist with the understanding of illness management and of the illness experience within a social context. She goes on to describe what the features of a map of the illness experience would include, specifically “aspects of the physical and social world, it has links with institutions, structures and other collectives and it has purely subjective elements” (p.99). The importance of these maps for understanding chronic illness is described as being necessary because “society is facing complex syndromes which biomedicine and medical professionals are presently ill-equipped to deal with” (p. 102). This is particularly relevant for the case of endometriosis as it is a contested disease, an illness within biomedicine that has a history of difficult diagnoses, with no known cause and no known cure, just a management of symptoms.

Other chronic illness studies within health geography, medical sociology, and anthropology document the use of illness narratives, the understanding of a chronic illness as a journey or trajectory, and how chronic illness causes disruption of the body or what Bury (1982) calls “biographical disruption” (i.e. Moss & Dyck, 1999; Charmaz, 1995; Frank, 1991; Corbin & Strauss, 1987). The disruption to the body experienced by women with endometriosis was described as deferring having children, attending graduate school, gaining full-time employment, and interacting with friends and family. The women in this study tried to navigate around the disruption, attempting to regain a sense of normalcy in their lives. Corbin and Strauss (1987) referred to this as “biographical accommodation” along the chronic illness trajectory.

Faircloth et al. (2004) describe how disrupted bodies are influenced on a daily basis as “it is the comings and goings of everyday life that the body responds [to], either in ways that are non-problematic to one’s self or in ways that force the self to reformulate its meaning” (p. 75). This description is of particular importance to women with endometriosis, because as the women journey through diagnosis, for example, a negative interaction will influence future experiences with the healthcare system, employers, friends, and/or family members. To further illustrate that point,

Becker (1997) commented on how past experiences influence the future experiences within chronic illness as: “people experience illness and impairment from a perspective determined by their historically situated and contextually informed bodies” (p. 39). This comment resonates with the concept of validation and legitimation for women with endometriosis as their journey is an iterative one: if the journey repeats portions of itself, the previous endometriosis experience will influence the new journey. The initial journey through endometriosis will inevitably influence the new journey through endometriosis. The journeys are layered with each experience influencing the previous and future journeys.

7.4.2 Conceptual Metaphors: Journeying

Metaphors are an effective means of communicating the lived experiences of illness and useful in describing the individual significance and impact of everyday experiences (Lakoff & Johnson, 1980). In particular, conceptual metaphors shape the way we think about and interact with both the physical and the abstract world. The importance of metaphors for understanding the experiences of daily life have been described by the work of Lakoff and Johnson in *Metaphors We Live By* (1980).

Metaphors are used in language to express ideas about daily life. In fact, Lakoff and Johnson suggest that “a great deal of everyday, conventional language is metaphorical, and the metaphorical meanings are given by conceptual metaphorical mappings that ultimately arise from correlations in our embodied experience” (Lakoff & Johnson, 1980, p. 247). The idea of mapping the everyday experience as grounded in the conceptual metaphor of a journey is a way of capturing all the complex experiences the women navigated, in their language, and how they understood the processes.

In this study, the metaphor of journeying is used to capture the women’s experience of moving through physical and metaphorical social worlds to find a diagnosis, treatment, and ways of coping with the illness of endometriosis. The journey through endometriosis is both a physical journey that the women travel along and a journey that exists within the subjective social world, or in other words, a metaphorical path. In describing these paths, Johnson states that “Our lives are filled with paths that connect up our spatial world...some of these paths involve an actual physical surface that you traverse...[and] certain paths exist, at present, only in our imagination” (Johnson, 1987, p. 113).

These women with endometriosis experience two internal journeys that direct them along an internal path of their subjective experience and an external path of navigating daily life, the healthcare system, employment, family, and friends. And Johnson describes three characteristics that are relevant to both paths travelled: “Whatever the path that is traveled, there is a (1) source or starting point; (2) a goal, or endpoint; and (3) a sequence of contiguous locations connecting the source with the goal” (Johnson, 1987, p. 113). The starting point for these women was a diagnosis, the goal was treatment, and everything in between was an attempt to cope with endometriosis.

Using the geographic metaphor of a journey and the women as cartographers, I have conceptualized the experiences of endometriosis as a process by which its sufferers gather information and experience while moving from one place to the next. Furthermore, those experiences and information gathered determine the path of the journey. I think of the women who have been diagnosed with endometriosis metaphorically as mapmakers, creators of maps of the endometriosis experience. Through these maps, women begin their journey through endometriosis with the onset of symptoms and move on through a struggle for diagnosis, treatment, and coping. This journey is also the manifestation of the task of exploration of endometriosis, as seen by the women, and the physical experience of the places the women explore through their experiences.

7.4.3 Navigating the Journey through Endometriosis

Metaphors help us describe both the material and abstract world and the interaction between both. If we consider the way in which key metaphors, such as journey, shape our thinking and understanding of complex and dynamic experiences, the metaphor can highlight the impact it has on these experiences. For example, Lakoff and Johnson (1980) suggest that the basic metaphor of journey can be represented by the “various types of journeys that one can make: a car trip, a train trip, or a sea voyage” (p. 45). The authors further state that: “there is no single consistent image that the journey metaphors all fit. What makes them coherent [coherent systems in terms of conceptualizing experiences] is that they are all journey metaphors, though they specify different means of travel” (Lakoff & Johnson, 1980, p. 45). The most relevant aspect of this definition to this study is the idea that the journey implies movement, and it is the movement that is emphasized and captured by these women’s experiences.

The endometriosis journey can be understood as the literal movement between healthcare facilities, home, and work, and also as a metaphorical construct that includes the perceived notions of how one was

treated within the healthcare system, the personal impact of that treatment, and coping with the diagnosis and treatment, all of which occur along an iterative journey. The metaphor of journeying has been used in previous health and feminist geographic literature. For example, Gesler described how metaphors and illness narratives can “enhance our understanding of health in place” (Gesler, 2000, p. 125). He used the concept of “journey to knowledge” to describe how knowledge and information is gained during an attempt to understand health and illness (Gesler, 2000).

In the feminist geography literature, Moss and Dyck (1999) explored ways of thinking about the identities of women with chronic illness such as chronic fatigue syndrome through the metaphor of a journey. In their work, they define this term as moving through the rites of passage in one’s life, explaining that:

Applying a rite of passage as a marking of the transition between illness and health implies a sense of wholeness, in that at one point a person is complete but ill with X and, at another, complete and healthy without X. (p. 158).

They also suggest the usefulness of metaphors in explaining how women diagnosed with a chronic illness make sense of their everyday lives. They describe the diagnosis as a “cultural marker...[that] acts as the ticket for the journey” (p. 164). Moss and Dyck (1999) suggest that using the concept of journey alone “implies some sort of direct movement from point A to point B” (p. 158), whereas sufferers’ reality is better captured if we describe the journey of having a chronic illness as “indirect, sprinkled with what can be considered side trips on rough terrain” (p. 158).

Moss and Dyck (1999) have combined the concepts of journey and rite of passage to describe the experience of chronic illness, especially as related to identity. What is more important to this research study, however, is the description given about how the two concepts combine to describe the illness experience, for:

...by using the concept of rite of passage in the context of journey, we can think through how diagnosis can mark a body and how that shapes the daily life of a woman with chronic illness and launches her journey from a state of health, to one of illness, and, perhaps, back again... (p. 158).

They argue that by thinking in terms of a journey, plus moving through a rite of passage, one can describe a process whereby women with chronic illness move on an indirect journey through diagnosis, treatment options,

and self-understanding in terms of their illness, all of which impact issues of identity (Moss & Dyck, 1999). This research study goes a step further to explain how those changes through places of everyday life (and through the specific experience of diagnosis, treatment, and coping) can be iteratively related if the symptoms of endometriosis reoccur or if new symptoms appear.

The use of journeying has also been described in the biomedical literature to help clinicians understand the complete world patients have to navigate. An editorial written in the *British Medical Journal* (BMJ) (Lapsley & Groves, 2004) described key characteristics of what a journey through chronic illness captures, stating that the journey “should encompass how it feels to face a difficult diagnosis and what that does to relationships and quality of life” (p. 582). The editorial (BMJ, 2004) goes even further to suggest that the concept of a journey captures the diverse and long-term experience of the chronic illness experience.

Baker and Graham (2004) write that to prepare for a journey through a chronic illness a map is needed and suggest that the diagnosis and treatment form the map to navigate through illness. The authors begin by describing the importance of having a map and knowing where one is traveling:

When we begin any journey, we need a map. We need to pack and prepare for the journey. We need to know what to expect along the way. The telling of the diagnosis and the explanation of the disease and its treatment form just such a map (Baker & Graham, 2004, p. 611).

They examined the experience of Parkinson’s disease and compared the navigation of the map of Parkinson’s to a map “from the medieval world...full of unknown territories and nameless threats” (Baker & Graham, 2004, p. 611). They suggest that the traveling companions of those experiencing Parkinson’s disease include family, friends, and the healthcare providers. The key message from Baker and Graham (2004) is that everyone starts their journey at a different point, depending on several key factors, including education, socio-economic status, and the stage of the disease. Ultimately, for all a timely diagnosis is needed and “clear maps and signposts along their journey, to help them cope” (p. 614).

They also suggest the use of multidisciplinary teams to manage Parkinson’s disease and an understanding that not everyone around the patient, including the physician, may want to travel along the journey; patients may find guidance along the journey from other patients who have been diagnosed with Parkinson’s disease (Baker & Graham, 2004). While

this example is related to Parkinson's disease, the relevance to the concept of the journey through endometriosis is similar in that the diagnosis and treatment define the journey. It is also important to identify key people who will be on the journey with the individual who is ill, as sometimes it is as much their journey as it is the ill person's journey. The idea of unknown threats and difficult terrain is useful to the endometriosis experience, particularly when discussing the theme of uncertainty around symptoms and future treatment options.

Another example of the use of journey for understanding health is from Reisfield and Wilson (2004), who described a journey through cancer as one that "encompasses possibility: for exploration, struggle, hope, discovery, and change. Importantly, the journey continues throughout cancer treatment and beyond" (p. 4026). In describing what a journey through cancer might look like, they suggest that the:

roads may be bumpy and poorly illuminated at times, and one may encounter forks, crossroads, roadblocks, U-turns, and detours. The pace, route and destination of the journey may change, sometimes repeatedly. The road may not be as long as one had hoped, and important destinations may be bypassed (p. 4026).

Again, the description of the actual journey is important for this dissertation, as the common theme among participants discussing journey and endometriosis is that it is a continuum that does not have a defined end point, that it can involve more than just the individual experiencing endometriosis and that the road and maps for the journey are not always clear, concise, or direct.

7.4.4 Living with Endometriosis: How to Make Sense of a Diagnosis and Medical Treatment

In cases of an uncertain diagnosis there are important compromises that should be made between the biomedical perspective (what the clinician can explain or diagnose) and lay perspectives (what the individual who is unwell feels and experiences) as described by Kleinman (1988). Biomedicine involves clinical data and diagnosis, whereas lay perspectives symbolize subjectivity of the ill individual (Kleinman, 1988). For women with endometriosis, as discussed previously, they are unable to access the endometriosis arena until they have received a clinical diagnosis of endometriosis, which is always through an invasive surgical procedure. In this dissertation, diagnosis is viewed as the portal to the journey through endometriosis. The receiving of a clinical diagnosis legitimates the women's symptoms and allows her to seek out strategies to cope with her own version of endometriosis in everyday life.

The journey through endometriosis is not only distance traveled or time spent traveling to and from physician offices, but also the things that happen along the way that shape a person. There is also an internal subjective journey, one with its own momentum that occurs, as a woman with endometriosis navigates herself through everyday life. However, within the internal journey, the perception by others of her illness experience and of how she should navigate everyday life also have a significant impact on her; her experience with endometriosis becomes a journey of performance based on self-expectations and the expectations of others in society.

The women in this research study described endometriosis as an interference to their lives. This might be because, when things truly are going well with endometriosis (i.e. predictable symptoms that can be managed), in their reality, it is truly only an interference when the symptoms cannot be managed. Conversely, this might mean that, by keeping the illness at arm's length, the women are able to experience some sense of normalcy, by not acknowledging the "sick role" or the disruption of the illness at all times, just certain ones in which the illness cannot be managed. The women varied in their experiences of living with endometriosis and in the degree to which they regarded managing it as an issue.

Many women indicated that the concept of 'ill' or 'disabled' was too extreme to describe the management demands, and even went on further to describe themselves as being healthy. This was despite the descriptions of pain, the use of pain medication, of not being able to complete daily tasks, or of needing to stay at home. Some of these women who were experiencing control over the physical, emotional, social, and related symptoms described the illness as being "something they had to live with." This might be because of the way the women represented the illness to themselves as a relative state of illness depending on the time, day, place, symptoms and the ability to manage the symptoms.

Charmaz (1991) suggests that "Experiencing illness as interruption, intrusion, or immersion depends upon the person's definitions of the experience. Illness cannot exist without such definition, for its meaning derives from the person's bodily feelings, thoughts, and sentiments" (Charmaz, 1991, p.10). This resonates with the women's experiences with endometriosis as the women defined the state of their endometriosis based on if it interrupted their daily lives and routines, which was dependent upon the progression of symptoms and the progress of the disease (e.g. if symptoms were predictable). Charmaz further suggests that "Not everyone experiences a linear progression of illness. Some

people define intrusive symptoms long before they have a major disruption or crisis. Thus, their illnesses start in the background of their lives and move stealthily into the foreground as they demand more attention and time” (Charmaz, 1991, p. 11). This is central for women with endometriosis because the symptoms are not experienced continuously but rather, intermittently, depending on the phase of the menstrual cycle. Charmaz concedes that:

Certainly, the possibility of denying illness still exists. If ill people persist in defining their illness as acute, but it long continues, they plant the seeds for denying illness. Likely, these people stretch their ‘allowable’ duration of an acute illness, because they do not wish to acknowledge that illness has become something more than an interruption (Charmaz, 1991, p. 20).

This might be an accurate description of the women in this study, as many of the women (n=65/70) rejected the ‘ill’ and ‘disabled’ label being attached to their endometriosis and instead, labeled themselves as ‘healthy’ with some bad days caused by endometriosis.

The women labelled themselves as ‘healthy’ if their symptoms could be accurately managed and if this allowed them to navigate their life with minimal disruptions. This was a problem for so many of the participants (n= 46/70) because the symptoms were highly unpredictable. The unpredictability of symptoms was directly linked to the uncertainty of the disease and how the disease might progress. For example, Lemaire (2004) noted that the highest levels of uncertainty were related to women’s perception of the changing course of their illness, of not knowing how bad the pain would be, or the unpredictability in symptoms. Lemaire also found that emotional distress increased with uncertainty and noted that women felt as if they did not have enough information about endometriosis and treatment options. Lemaire (2004) suggested that patient education, specifically obtaining written information or sharing educational videotapes or electronic resources, and the addition of nursing assessments might increase women’s knowledge about endometriosis and might reduce stress and uncertainty about the future progression of the disease.

Huntington and Gilmour (2005) note that the time to diagnosis was 5 to 10 years. Although a general practitioner might misdiagnose the endometriosis, once there was a referral to a gynaecologist, the diagnosis was usually made very quickly. They discussed in detail how the lives of women in their study were shaped by their experience with endometriosis and how chronic pain influenced their everyday lives and restricted their future lives and their socio-economic prospects.

Lastly, Cox et al. (2003^a) examined women's experiences of living with endometriosis through a series of focus groups. Her work supports the idea that there are a variety of issues that women with endometriosis face that are not yet sufficiently addressed: specifically, a lack of support and living with endometriosis (Cox et al., 2003^a). In addition the focus groups revealed a picture of "struggle and loss, trivialization and dismissal" (Cox et al., 2003^a, p. 3). Her work conceptualized the endometriosis experience as a "merry-go-round", in which the women had a long struggle for diagnosis, visited many doctors, and wanted to take control of their lives (Cox et al., 2003^a).

7.5 Chapter Summary

In this research study, the women with endometriosis became expert navigators as they traveled through their individual yet collective journeys of diagnosis, treatment, and living with endometriosis. The social process of navigating the journey through endometriosis includes the uncertainty of a diagnosis, the resulting treatment options, and living with a chronic illness. The women involved in this study were active participants in the planning around, understanding of, and living with endometriosis and undertook preparations that were similar to those travelers make when beginning a journey to a new place. However in this study, the preparations for travel over the terrain of endometriosis included a search for information and knowledge about their condition and a prediction of symptoms during their daily lives that could guide them through the process of journeying. The final chapter will summarize the dissertation, discuss the contribution to knowledge, acknowledge the strengths and limitations of the study, and make suggestions for future research for women with endometriosis.

CHAPTER 8: CONCLUSIONS

8.1 Dissertation Summary

“Navigating the journey of living with endometriosis” was the social process identified through my analysis of the interview data. The process of ‘navigating a journey’ captures how women who have been diagnosed with endometriosis coped with their experience of being diagnosed and treated for endometriosis, and how that affected on their everyday lives. The social process of navigation has a relational connection to the subsequent categories of: 1) Diagnosis, 2) Treatment, and 3) Coping. Within these categories, the relational themes to all of them focused on: a) seeking information, b) validating the experience, c) needing awareness, and d) educating the lay public and health care providers.

The actual journey for these women depended on the first two key categories, which followed the varied progression of the disease and determined the path. First was their diagnosis, which often provided women with guidance about where to go next, specifically with treatment options. Second was the treatment plan. The path that the women would take was governed by whether their symptoms led physicians to classify them as patients with infertility or painful menstrual cycles (additional symptoms included fatigue, chronic pelvic pain, low-grade fever, and abnormal bowel function). For the majority of the participants, the journey was iterative, meaning that although it began with diagnosis and continued on to treatment, there was a recurrence of the disease that led the participants back on a path of searching for a new treatment that might work better for their recurring (or even new set of) symptoms.

Chapter 3 provided the reader with a description of the methodology used in this study and described why qualitative research, in particular C-GT, was the most appropriate approach given the research objectives of this study. Chapter 4 began to situate endometriosis within a larger societal context; in particular, the experience of the struggles to diagnosis was explored. The women described beginning the journey to find out what was wrong with them and find an explanation for their symptoms. The women clearly identified the diagnosis as the starting point for their endometriosis journey. Chapter 5 found that the next “mile-marker” along their journey was the decision over which treatment options would be most helpful for their individual situation. The women found it difficult to receive an individualized treatment plan based on their symptoms. In this chapter the women also described their need for information and the experiences and knowledge they were gathering along their journey. In Chapter 6, the women’s experiences through diagnosis

and treatment led them to the later step of their journey, coping with a chronic condition. The women described their strategies for coping with endometriosis, their need for information and awareness, and most importantly, their hopes that in describing their experiences they might help other women who will also embark on this reluctant journey through endometriosis.

8.2 Contributions of the Dissertation

Several key points emerged through recognising that the women in this study understand endometriosis as something experienced and grounded in daily life. The number of women living with endometriosis is expected to increase in Ontario as the awareness of symptoms related to endometriosis increases, and as better technology to diagnose this disease develops. Women with endometriosis have individual healthcare needs related to the diagnosis, treatment, and coping as documented by this study; specifically they need to be treated according to their presenting symptoms and not just based on what a clinician assumes the symptoms of endometriosis to be.

The first theoretical contribution of this dissertation was the development of a C-GT to explain women's experiences of living with endometriosis that adds to the social science literature on this topic. In particular, this dissertation makes recommendations on how to improve women's ability to navigate the journey of endometriosis by using a theoretical framework grounded in health geography, medical sociology, and medical anthropology that allowed for a more complete understanding of endometriosis. Out of that understanding, I was able to develop recommendations for improving the journey. This study's findings contribute conceptually to several debates within health geography, medical sociology and anthropology, specifically in the understanding of the everyday experience of illness, geographic metaphors, illness narratives, and the use of women's voices to understand the illness experience.

This dissertation has mapped out the experiences of women using the situational analysis approach (Clarke, 2005), which allows for a more individualized understanding of the endometriosis experience. By situating the individual experiences of endometriosis within a larger societal context, and then documenting the collective experiences of individual women, we are able to understand how a group of women experience endometriosis, and what directly (and indirectly) influenced their experiences. The women provided valuable knowledge as to what would improve the experience of endometriosis: increased awareness, availability of more information, and shorter time to diagnosis. The

substantive contribution of this dissertation adds to the larger discussion of endometriosis outside of biomedicine, highlights the importance of illness narratives to understanding the endometriosis experience, and to a lesser extent, contributes to the discussion of the lay versus the professional knowledge of endometriosis.

The illness narratives from the women in this study suggest that women with endometriosis have three specific issues: (1) they would like to advocate and act as trailblazers for other women who have endometriosis, (2) they want more information and support from both healthcare providers and other women, and (3) they recognize a strong need for better communication between women and healthcare providers so that women can receive individualized care and treatment. The ensuing message—that the healthcare sector needs to shift from thinking about endometriosis as simply a reproductive disease and start examining the interconnections of a woman's social world is vitally important.

This dissertation is the first to highlight how difficult and enigmatic endometriosis can be. It also discusses the complexities of endometriosis in its entirety, from the difficulty of diagnosis, to confusing treatments and while living with the illness, the myriad of issues to be faced. This dissertation has demonstrated that endometriosis is much more complicated than is currently understood by the healthcare system and society at large. The illness narratives highlight the need for additional awareness about endometriosis—a well-informed biomedical community is needed to raise awareness of endometriosis in society, so that employers, family, and friends can understand the complexity and dynamic ever-changing nature of endometriosis. The endometriosis is intertwined with social, political, biomedical, and personal struggles, all of which equally contribute to the experience of living with the condition.

In this dissertation, I address the specific categories related to the journey. The first is the diagnostic experience, which contained several key themes: the experience of symptoms, seeking of information, the diagnosis, reaction to the diagnosis, and treatment options. The key themes related to treatment were: decisions about which treatment to undergo, the treatment process itself, side effects, and the relative state of health. The final category was related to coping or living with the illness. The most important themes identified here were the possible recurrence of the illness, management of present symptoms and possibly new ones, uncertainty, and management of future treatments. Even though the diagnosis was the beginning of the journey for the women, treatment and the third category, coping, were the sign-posts to the next phase of the journey. The sign-posts of coping highlighted the effect of identifying

endometriosis as a reproductive or chronic pelvic pain disease in the lives of women, which can influence the treatment and legitimization of the women's experiences. If a biomedical cure is not possible for endometriosis in the next several years, the best possible recommendation for minimizing the effects is the understanding and awareness of the disease as being something more than "painful cramps," a "career woman's disease," or a disease that causes infertility.

Beginning with the onset of puberty until menopause, which represents roughly 40 years of a woman's life, menstruation is a regular part of a woman's life and impacts her everyday life. Endometriosis is not just a diagnosis; it is something that a woman will live with for her entire post-diagnosis life in some form or another. The effects of endometriosis on a woman's entire lifetime have not yet been adequately addressed through biomedical or social science research. There is no doubt that our understanding of endometriosis will continue to develop; however, it is more evident from this research that the psychosocial effects of endometriosis are as important as biological symptoms and pathology. The women who participated in this study clearly expressed that by not having their psychosocial needs met (e.g. no information or social support), the anxiety and stress of endometriosis was as great as experiencing the symptoms and side-effects from treatments.

Finally, it is also clear that stereotypes and misinformation about endometriosis must be addressed. For example, it is often assumed that endometriosis primarily impacts women from more well-educated and higher socio-economic groups which is why the "working woman's disease" label has been attached to endometriosis (Carpan, 2003). Some investigators note this is simply because these women have been more visible and vocal in seeking medical intervention (Ballweg, 2003). In reality, as seen from the previous chapters in this dissertation and from Ballweg (2003), endometriosis impacts women in all social groups, including minorities and lower socioeconomic groups. All the women in this study had a collective experience with endometriosis that highlighted the importance of understanding processes associated with diagnosis, treatment, and coping with the illness. Future research should expand on the individual experiences within the collective experience. For example, did lesbian-identified women have a different diagnostic journey than heterosexual women? The second stereotype is that endometriosis is just "cramps" or infertility, not a disease which can have serious, life-altering symptoms. Both of these stereotypes need to be addressed within the biomedical community and the popular representations of the disease. For the most part, the women felt this would evolve out of a greater awareness from the biomedical community, which in turn, would inform the popular

representation of the disease.

8.3 Strengths of the Dissertation

The strengths of this study come from procedures that were consistent with a C-GT approach and the women's open participation in the study. I followed the procedures of a C-GT approach in the framing of the study, data collection, data analysis, and theory development. The situational analysis approach also guided the data analysis by allowing for the development of maps capturing the women's experiences and situating their experiences within a larger societal arena.

This qualitative in-depth research is one of the few comprehensive examinations of the experience of living with endometriosis in North America. I conducted individual 60 to 90 minute-long, semi-structured interviews with 70 participants and verified results by asking for additional feedback from 30 of the participants. By using many of the participants' own words in the data analysis, the resulting middle-range theory is based on an actual portrayal of their experiences with endometriosis.

This study offers an understanding of the diagnosis and treatment of women with endometriosis. In addition, this project allows for an understanding of how women cope with their illness and provides an opportunity to discuss how they develop such strategies. The women in this study have suffered through difficult diagnoses, treatments with horrendous side effects, and uncertainty about the future. Overall they developed strategies to help with coping and provided information to the researcher about how to improve the experience. This research demonstrates that by supplying what the women requested, which is information, awareness, and a connection to other women with the illness, the experience of endometriosis can be improved.

In addition, this study shows how women from different types of socio-demographic backgrounds experience endometriosis. Further, it illustrates how there is a collective experience even among women from different backgrounds who have received a diagnosis. Through the women's experiences, coping strategies, behaviors, thoughts, and feelings of women with endometriosis are described in detail. This study allows the reader to see how one subset of women live and manage their daily lives with endometriosis.

This study also adds to the insufficient discussion of a disease that has affected many women but has been discussed very little within the endometriosis research community. Most of the research that has been done has focused on finding a cure, a cause, or new treatment option, but

there has been limited research into women's experiences and mainly within the medical sociology and nursing literatures. The results from these limited studies need to be integrated into the biomedical world so that a dialogue can begin of how to understand and improve the quality of life for women with endometriosis. Explicitly, Huntington and Gilmour (2005) suggest in their review of the literature that "little research has been undertaken into women's perceptions of living with this condition, its effects on their lives and the strategies they use to manage their disease" (p. 1126).

Finally, during the interviews, many of the women commented about how useful the process of discussing their experience was to them. They told me that no one ever asked them about their experiences with endometriosis—a few recently diagnosed women shared with me that they had never even discussed the fact that they had endometriosis with someone other than their doctor. At the end of the research project, the women were particularly open to participate in an information session with Dr. Warren Foster, a well-known endometriosis researcher at McMaster University who allowed the women to ask questions about the disease. Dr. Foster was able to provide them with explanations that helped many of them understand their own situations and answered questions for the women that their own doctors had not taken the time to.

As a researcher it was surprising to witness the interaction between the women and Dr. Foster; because the interaction made it clear to me that if more information were available in an understandable format, this would greatly reduce the anxiety and stress that many of these women had experienced. The women knew exactly what they needed and wanted and through their narratives they shared that fact with me as a researcher. It was remarkable to watch it unfold during the information session. This recognition left me feeling as if my research was significant and could make a difference for women in the future with endometriosis.

8.4 Limitations of the Dissertation

As with any research study, this study also had limitations that should be acknowledged within the context of doing a qualitative research study (Creswell, 2007). The first limitation is my role as a researcher and as a woman with endometriosis. I am sure my own experiences as a woman with endometriosis facilitated a sincere and open dialogue and allowed the women to be frank in their responses. If a woman asked why I was doing the research study, I answered honestly that I had been diagnosed with endometriosis. This study was also exploratory in nature as very little was known about the whole endometriosis experience or about what individual women thought were the most important aspects of

their endometriosis experience.

The next limitation is that this study only examined women in one geographic location, Hamilton, Ontario, Canada. By examining only one geographic location, it is difficult to determine how the experiences and interpretations of the women in this study might be unique to the locale and to the Ontario provincial health care system. However, there is no way to know if the same themes and categories would have emerged from other women in a different geographic location. The women did represent a diverse background, in particular socio-demographic, for age, time to diagnosis, type of treatments, and number of doctors seen, and for including women of color and lesbian-identified women. While differences among social categories were noted, their narratives told of the commonalities of their experiences. While I did not specifically recruit women for the study based on age, sexual orientation, ethnicity, or race, the sampling did allow for these women to be included; however, it is difficult to state the select experiences of women of color or lesbians because those issues were not explored further in this study.

As the researcher of this study, I had tremendous influence on the process and the product of this research. I turned the illness narratives told by the women into maps that I felt represented their journey through endometriosis. I framed the study, conducted the interviews, acknowledged my own experiences with endometriosis, and developed a middle-range substantive theory based on the experiences of the women as they told them to me. Any other researcher conducting the same study would certainly have fulfilled this role differently, with possibly different results, especially if the researcher did not have the background of their own endometriosis experience. By studying the lives of 70 women through the use of qualitative methods, I was able to gain a detailed, saturated understanding of their diverse experiences with endometriosis.

8.5 Recommendations for Future Research

The women diagnosed with endometriosis who participated in this study demonstrated resilience in combating their illness, through diagnosis, coping with limited treatment options, surgeries, and ultimately living with a chronic illness. However, the healthcare services provided to women need to be better organized to draw attention to and strengthen this resilience. Women should be given information and organized healthcare services that demonstrate an understanding of the complexity of endometriosis so that they can have minimal impact to their lives from poor healthcare services and thus be allowed to focus on living a quality life. Most of the issues and problems identified by the women related to

time to diagnosis, understanding medical treatments, having better choices of medical treatment, and coping with endometriosis.

Simply put, many of the women in this study did not have the information, treatment resources, or social support that would have assisted them in living with endometriosis, whereas having had access to this support would have assisted these women in understanding their condition and the journey they were about to travel along. These results are similar to the findings of Cox et al. (2003^a) who suggests “Much of what was uncovered in these focus groups can be alleviated with knowledge, understanding and compassion” (p. 8).

Information about the diagnosis and treatment of endometriosis should be made available by doctors, nurses, and other healthcare providers and should be more effectively integrated into the overall medical treatment of women. Specifically, Cox et al. (2003^a) hopes that her work “will encourage nurses to be compassionate when dealing with these women [women with endometriosis] in any context” (p. 8). Endometriosis should not be the last suggestion any doctor makes to a woman; just building a better understanding and awareness within the healthcare community could reduce time to diagnosis. However, this will require more innovative healthcare practices, better organization of healthcare services, and more holistic understanding of endometriosis as not simply a reproductive disease but something much more complex (Sinaii et al., 2002). There also has to be an acknowledgement of the expansion of symptoms associated with endometriosis to beyond that of a reproductive disease (e.g. autoimmune concerns and bowel complications) (Sinaii et al., 2002).

There desperately needs to be an examination of the patient–physician interaction so that communication between patients and physicians can be improved. The roles of nurses, nurse practitioners, and physician assistants should also be examined, exploring how they might impact the women’s experiences of endometriosis, as these professionals are often the front line healthcare workers women encounter during their office visits and often the workers who spend the most time with the patients. If these front-line workers are aware of endometriosis and understand the complexity of the symptoms, there could be a significant reduction in the time to diagnosis for many women.

Current health geography research has focused on health disparities experienced by people who share a neighborhood environment, housing, and socio-economic status (e.g. Dunn & Hayes, 2000). Health disparity research focuses on differences in health outcomes for people

based on socio-economic status, geographic location, sexual orientation, race/ethnicity, gender, and gender identity. Social capital, specifically social support, has been a key factor in reducing or eliminating such disparities and is now a key factor in the discussions around health policy and healthcare planning (Cohen, 2008; Elliott, 2000). Future research on the experiences of women with endometriosis based on these social differences is needed to determine whether disparities in treatment and diagnosis exist, and if so, how they can be eliminated. There should also be a further examination of the role of social capital on coping with endometriosis, and whether this is based on socio-demographic characteristics (e.g. access to social capital).

Health geography is a key discipline for determining if these disparities exist, as well as for identifying other disparities based on geographic location. For example, 12 women in this research study stated that if they lived in the United States, their treatment options would be greater than what is available to them in Ontario. Further research is needed to determine if this was a localized experience for just these 12 women or if key differences exist in treatment and diagnosis between jurisdictions. Because of the treatment options available to women outside Ontario and Canada, there needs to be an economic or cost-benefit analysis of ensuring those treatment options are available to women in Ontario or that they have access to the outside resources so that the disease can be effectively managed more quickly and its effect on quality of life lessened.

The results of this dissertation have provided specific areas that should be followed up for future research on understanding the endometriosis experience. While this research has highlighted that diagnosis, treatment, and coping with endometriosis are essential to understanding the entire experience, there are other components of the experience that should be further examined. These specific future research recommendations include the following:

- The completion of a full needs assessment for women with *suspected* endometriosis and one for those *diagnosed* with endometriosis;
- More research into individualized care for affected women, care that should focus on which symptoms actually need to be treated and managed and not on assumed symptoms;
- Research into patient satisfaction with the treatment(s) and options;
- Determination of the geographic locations that offer best practices related to the treatment and encouragement of those best practices in Ontario, Canada;

- A qualitative comparative study examining the social differences of women with endometriosis to determine the role (if any) socio-economic status, sexual orientation, race/ethnicity, and gender identity play in the diagnosis and treatment. This should be further extended to examine if there are differences in ways of coping among these groups as well.

8.6 Chapter Summary

To summarize, this study contributes to a little-researched topic, which is the experience of endometriosis from a lay perspective. Much has been written in the biomedical literature about endometriosis, specifically its treatment options and diagnostic procedures, but it is important to understand how women themselves, from their perspective, experience endometriosis. This study demonstrated that the women viewed diagnosis, treatment, and coping as the most important components of the experience. Previous research had focused solely on diagnosis, treatment, coping, chronic pain, and infertility as separate topics, whereas this study highlights how they are very much interconnected to form the entire experience.

The lack of connection between the biomedical definition of endometriosis (i.e. the pathology) and the symptoms subjectively experienced by women makes understanding endometriosis very difficult. The combination of the limited treatment options for women and the lack of social support have made the experience of living with endometriosis enormously complicated. The women have identified the difficulties they face during their endometriosis experience and have expressed a need to help others who will follow in the journey through endometriosis. By identifying these difficulties and helping those who will follow, these women became trailblazers, leaving behind signposts of information and awareness of the disease to make the journey a much easier one to navigate for future travelers.

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APPENDICES

APPENDIX A

CONSENT FORM

Endometriosis: Women's Experiences of Spaces of Health Care and Social Support

Ph.D. Dissertation Research Project

Emily Freeman

I, _____, agree to be interviewed by Emily Freeman at a place of my choosing regarding my experiences of coping with endometriosis in the health care system, workplace, and through local support networks and information and support provided through the world wide web. ***I understand that I have the right to withdraw from this study at any time, and accept the terms of participation outlined below.***

Signature of Participant

Terms of Participation in this Research Project

1. The identities of research participants ***will not*** be revealed.
2. Only the project investigators and interview transcriber will have access to interview tapes.
3. Participants may choose not to have their interviews recorded and to have notes taken by the interviewer instead. Only the project investigators will have access to these notes.
4. Participants will be invited to review interview transcripts or notes for errors or to clarify the points made prior to data analysis.
5. Participants have the right to withdraw from the study at any time, including after the focus group is completed.
6. Project reports, published and unpublished, will refer to participants by false/nick names to protect their privacy and identity.
7. Project participants are regarded as experts on experiences of disablement, and their input on all aspects of the project, including follow-up research and using research findings to promote positive social change are encouraged and highly valued.

APPENDIX B

INTERVIEW GUIDE

- 1). How do you define coping?
- 2). How do you cope with endometriosis?
- 3). What would you want to cope better?
- 4). What are specific issues you perceive in coping with endometriosis?
- 5). How do you cope with endometriosis in spaces/places of daily life?
 - i.e. In what spaces do you find your most support?
 - i.e. What is it about that space/place that makes you feel support?
 - i.e. How would you describe your lifeworld before/after your diagnosis of endometriosis?
- 6). Do you use Internet Technologies in your coping process or for social support? If so, how?
- 7). How do you see yourself coping with endometriosis in the future? What do you see as your future options?
- 8). Reflecting back on your diagnosis, are there any particular aspects that was surprising to you?
- 9). Tell me about the way in which you communicate your concerns to your physicians and who do you talk to within the health care system. Are any of these interactions especially helpful or not in your ability to cope and why/why not?
- 10). Do you describe yourself differently after your diagnosis to other people?
- 11). Would you describe yourself as a healthy/ill/able/disabled woman?
- 12). When you are discussing your health to others is it in the context of health/ill/other?
- 13). If you are in a relationship, what difference has that made in your ability to cope with your issues? What role has your partner played in helping with your support, if any?

APPENDIX C

DEMOGRAPHIC INFORMATION

Name: _____

Preferred nickname for the project: _____

Age: _____

Postal Code: _____

Employment Status: (Please circle)

Permanent full-time

Permanent part-time

Contract

Casual

Other

If you are employed did you ask for accommodations at your workplace because of your symptoms related to endometriosis?

If you are not employed is this status related to your endometriosis? If you are employed, were you not properly accommodated? (i.e. flexible work hours, etc.)

Have you ever been unable to carry out your normal work and activities? NO / YES

How would you describe your past work experience? (i.e. clerical, administrative, laborer, professional)

How would you describe your current work situation? (i.e. clerical, administrative, laborer, professional)

Your highest level of education completed: (Please circle)

Some High School

High School Graduate

Some College/University

College/University Graduate

Post-Graduate Work

Post-Graduate Degree (M.A., M.Sc., Ph.D., etc.)

In what year did your endometriosis symptoms begin? How old were you?

Date you were medically diagnosed with endometriosis: _____

How many health care providers have you seen in relation to your endometriosis? _____

Please check the form of treatments you have received for endometriosis:

_____ Hormonal: i.e. oral contraceptives, progesterone drugs

_____ Pain medication: over-the-counter pain relievers including aspirin and acetaminophen, as well prostaglandin inhibitors such as ibuprofen, naproxen sodium, indomethacin, and tolfenamic acid. In some cases, prescription drugs.

_____ GnRH agonists: i.e. Lupron, Danazol, and Danazol

_____ Surgeries (please indicate number): i.e. laparoscopy, laparotomy, or hysterectomy

_____ Alternative Treatments: complementary treatment options may include traditional Chinese medicine, nutritional approaches, homeopathy, allergy management, and immune therapy.

_____ Other (Please list or describe)

Please circle all the symptoms you have experienced as a result of endometriosis:

Dysmenorrhea and/or pain throughout the menstrual cycle
 Dyspareunia (Painful sexual intercourse)
 Infertility
 Heavy or irregular bleeding
 Nausea, stomach upset at time of menses
 Diarrhea, painful bowel movements, or intestinal upsets w/menses
 Fatigue, exhaustion, low energy
 Low-grade fever
 Low resistance to infection
 No symptoms
 Other symptoms (please write in)

Pain profile relative to menstrual cycle: (Please Circle)

No pain relative to menses Varies	Mild	Mild/Moderate	Moderate/Severe	Severe
At time of menses only Varies	Mild	Mild/Moderate	Moderate/Severe	Severe
At ovulation only Varies	Mild	Mild/Moderate	Moderate/Severe	Severe
Throughout the menstrual cycle Varies	Mild	Mild/Moderate	Moderate/Severe	Severe

Have you had any involvement with the Endometriosis Association or been involved with other types of lobbying for government support for women with Endometriosis?

_____ YES _____ NO

APPENDIX D

SUMMARY OF PARTICIPANT DEMOGRAPHIC INFORMATION

ID	Age	Time to Dx (months)	Number of DR's	Number of Surgeries	Employment ^A	Education ^B	Painful Menses ^C	Infertility ^D	Treatments ^E	Symptoms ^F	Lobbying ^G
3	31	60	35	22	1	3	1	1	1,2,3,4,5	1,2,3,4,5,6,7,8	1
4	40	21	3	3	2	3	1	2	1,2,4,5	1,2,4,5,6,7,8	2
5	36	264	4	2	2	4	1	2	1,2,4	1,2,3,4,5,6	2
6	28	144	8	2	2	4	1	2	1,2,3,4	1,2,4,5,6,7	1
7	22	12	3	1	4	3	1	2	2,4,5	1,4,5,6,7,8	2
8	33	24	2	1	2	4	1	2	1,2,4	1,2,4,6,7	2
9	31	36	5	2	2	5	1	2	1,2,3,4,5	1,2,4,5,6,7,8	1
10	28	36	7	3	2	4	1	1	1,2,3,4	1,2,3,4,5,6,7,8	1
11	24	24	5	2	2	3	1	2	1,2,4,5	1,2,4,5,6	2
12	33	192	8	2	2	4	1	2	1,2,3,5	1,2,4,5,6,7	2
13	45	48	3	2	2	3	1	2	2,3,4	1,4,7,8	2
14	27	48	11	9	2	1	1	2	1,2,3,4,5	1,2,4,6,7,8	2
15	36	24	1	2	2	5	1	2	4	1,5,6	2
16	32	60	6	4	2	3	1	1	1,2,3,4,5,6	1,2,3,4,5,6,7,8	2
17	45	24	2	2	2	2	2	1	1,4	3,4	2
18	26	12	5	2	3	2	1	1	1,3,4	1,2,3,4,6,7	1
19	32	48	3	9	2	4	1	1	1,2,3,4	1,2,3,4,5,6,7,8	2
20	26	60	26	2	2	3	1	1	1,2,4,5	1,2,3,4,5,6,7,8	1
21	31	240	6	2	2	4	1	2	1,4,5	1,4,6,7	1
22	22	12	2	2	4	3	1	2	1,2,4,5	1,2,4,6,7	2
23	18	24	3	1	4	2	1	2	1,3,4	1,2,4,5,6,7,8	2
24	35	72	3	2	2	4	1	1	2,4,5	1,2,3,4,5,6,7	2
25	34	156	3	2	2	4	1	1	1,2,3,4	1,3,5,6	2
26	54	60	3	2	2	5	1	2	1,2,3,4,5	1,2,4,5,6,7	2
27	42	180	1	2	2	2	1	2	1,2,3,4	1,2,4,5,6,7	2
28	38	120	3	1	5	2	1	2	1,2,4,5	1,4,5,6,7,8	2
29	23	60	12	2	2	5	1	2	1,4,5	1,2,5,6	1
30	26	72	4	2	2	4	1	1	1,2,4,5	1,3,5,6,7,8	1
31	46	12	7	2	2	3	1	2	2,3,4	1,2,4,5,6,7,8	2
2	42	300	10	4	7	2	1	1	1,2,3,4,5	1,2,3,4,5,6,7,8	1
1	32	192	3	1	2	5	1	2	1,2,3,4	1,2,4,5,6,7	1
32	39	6	2	3	2	3	1	2	1,3,4	1,4,5	1
33	28	36	3	4	1	1	1	1	1,2,3,4,5	1,2,3,4,5,6,7,8	2
34	36	264	13	2	2	5	1	2	1,2,3,4	1,2,4,5,6,7	2
35	34	204	5	2	7	4	1	1	1,2,3,4,5	1,2,3,4,5,6	2
36	27	84	5	1	7	4	1	2	1,2,3,4	1,2,4,5,6	2
37	36	240	10	2	2	4	1	1	1,3,4	1,2,3,4,5,6,7	1
38	29	3	2	1	2	2	2	1	1,3,4	3	2
39	37	60	2	1	2	3	2	1	3,4	3,4	2
40	31	108	2	1	2	4	1	2	1,2,3,4	1,2,4,5,6,7	2
41	33	123	2	5	2	4	1	1	1,2,3,4,5	1,2,5	2

42	37	6	1	2	2	3	1	2	1,2,4	1,2,4,5,6	2
43	46	1	1	1	2	4	1	2	1,2,4	1,4,5,6,7	2
44	31	6	2	2	1	4	1	2	1,3,4	1,2,4,5	2
45	26	96	4	2	2	4	1	1	1,3,4,5	1,2,3,4	1
46	39	96	2	2	2	3	1	1	1,2,3,4,5	1,2,3,4,5,6,7	1
47	25	24	2	3	3	4	1	2	1,4	1,4,5,6	2
48	33	12	1	1	2	3	1	2	1,4	1,4,6	2
49	45	72	3	3	7	1	2	1	3,4	3	2
50	34	48	2	3	2	2	1	1	1,2,3,4,5	1,2,3,4,5,6,7	1
51	51	168	5	4	6	2	1	2	1,2,3,4	1,4,5,6	2
52	27	60	2	2	4	5	1	2	2,4	1,4,5	1
53	42	84	9	4	7	1	1	1	3,4	1,3,4,5,6	2
54	31	36	1	1	7	2	1	2	1,4	1,4,5	1
55	23	24	5	4	4	3	1	2	1,2,3,4,5	1,4,5,6	1
56	19	12	2	2	4	3	1	2	1,4	1,4,5,6,7	1
57	22	6	2	2	4	3	1	2	1,3,4	1,4,5,6	1
58	34	24	3	2	2	2	1	1	2,3,4	1,3,5	1
59	33	36	2	2	2	4	1	1	3,4	1,3,4,5,6	2
60	42	72	2	3	7	2	1	2	2,3,4,5	1,4,5,6	2
61	21	3	1	1	4	3	1	2	2,4	1,4,5	1
62	23	12	3	2	4	3	1	2	2,4,5	1,4,5,6,7	2
63	21	9	2	1	4	3	1	2	1,3,4	1,4,5	2
64	19	8	3	1	4	3	1	2	4	1,4,5	2
65	56	48	8	2	5	2	2	1	1,2,3,4,5	1,3	2
66	57	65	11	3	6	5	2	1	3,4,5	1,3	2
67	34	24	4	2	2	4	1	1	3,4	1,2,3,4,5,6	1
68	54	48	5	2	2	4	1	1	2,3,4	1,2,3,4	2
69	19	7	2	1	4	3	1	2	4	1,4,5,6	1
70	21	12	3	1	4	3	1	2	4	1,2,4,5	2

^AEmployment: 1 Part-time, 2 Full-time, 3 Contract, 4 Student, 5 Home, 6 Retired, 7 Other

^BEducation: 1 Some High School, 2 High school, 3 Some college/univ, 4 College/univ graduate, 5 Postgraduate

^CPainful Menses: 1= Yes, 2= No

^DInfertility: 1= Yes, 2= No

^ETreatments: 1 Hormonal, 2 Pain medication, 3 GnRH agonists, 4 Surgery, 5 Alternative treatments

^FSymptoms: 1 Dysmenorrhea, 2 Dyspareunia, 3 Infertility, 4 Heavy/Irregular Bleeding, 5 Bowel, 6 Fatigue, 7 Low-grade fever, 8 Low resistance to infection, 9 No symptoms

^GLobbying: 1= Yes, 2=No