

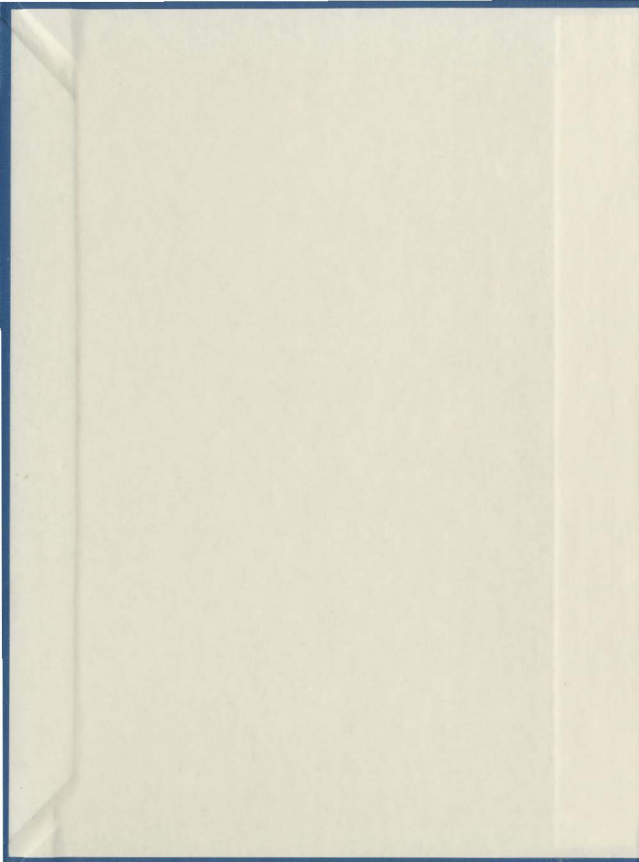
LEARNING TO LIVE WITH ENDOMETRIOSIS:
A GROUNDED THEORY STUDY

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ANN CAROLYN CARPAN





LEARNING TO LIVE WITH ENDOMETRIOSIS
A GROUNDED THEORY STUDY

by

Ann Carolyn Carpan

A thesis submitted to the
School of Graduate Studies
in partial fulfilment of the
requirements for the degree of
Master of Women's Studies

Women's Studies Programme Faculty of Arts
Memorial University of Newfoundland

October, 1996

St. John's

Newfoundland

ABSTRACT

This study examines the psychosocial processes involved in women's experiences of living with endometriosis. Ten women diagnosed with endometriosis participated in unstructured formal interviews. The researcher discovered that the respondents define endometriosis as a chronic illness and, consequently, they are undergoing a process of learning how to live with endometriosis. Grounded theory methodology was used to determine four stages in the process of learning to live with endometriosis: discovering the cause(s) of menstrual problems, getting treatment, dealing with doctors and living with symptoms. Phases in each stage of the process of learning to live with endometriosis are described. The social construction of endometriosis is also explored through an examination of popular magazine articles and self-help books about endometriosis. Endometriosis is primarily constructed as a fertility problem, whereas the participants regard endometriosis primarily as a chronic illness, and secondarily as a fertility problem. Women's lived realities of the disease, as described by the participants, are not usually included in the popular press.

Discussion focuses on the disjuncture between the lived realities of endometriosis described by the participants and the social construction of endometriosis in the popular press. By reconstructing endometriosis in a way that includes women's experiences of endometriosis, medical and popular knowledge of endometriosis could reflect women's lived realities of the disease.

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ACKNOWLEDGEMENTS

I would like to acknowledge the advice, support and encouragement of the members of my thesis supervisory committee, Shirley Solberg, Associate Professor, School of Nursing, and Dr. Patricia Canning, Associate Dean of Graduate Programs and Research, Faculty of Education. I would also like to acknowledge the advice and support of the faculty of the Women's Studies Programme, particularly Dr. Ellen Balka, and my colleagues in the Master of Women's Studies Degree Programme.

I would also like to acknowledge the financial support provided by the School of Graduate Studies, in the form of the Graduate Studies Support, for the years 1994-1995 and 1995-1996. The financial support provided by the Women's Studies Programme, in the form of employment in Graduate Assistanceship and Teaching Assistanceship positions, has also been greatly appreciated.

Finally, I would like to acknowledge the women who participated in this research project. This research would not have been possible without their participation and support. My gratitude is extended to these women.

CHAPTER ONE

Introduction

Endometriosis is a disease affecting women in their reproductive years. Approximately five and a half million girls and women in Canada and the United States are affected by endometriosis (Berger, 1993). Endometriosis occurs when some of the tissue that normally lines the uterus grows in other parts of the body. It usually develops on the ovaries, the lining of the pelvic cavity, ligaments and/or fallopian tubes. Other less common sites include the gastrointestinal tract, the urinary tract and the kidneys. Endometrial growths often respond to the hormones of the menstrual cycle, but unlike the lining of the uterus, endometrial tissue outside the uterus has no way of leaving the body. Endometriosis often results in internal bleeding, inflammation of the surrounding areas, and formation of scar tissue. The most common symptoms of endometriosis are pain before and during menstruation, pain during or after sexual activity, infertility, and heavy or irregular bleeding. Many of these symptoms are exacerbated every time a woman with the disease menstruates (Ballweg & Endometriosis Association, 1987, 1995; Boston Women's Health Collective, 1992; DeMarco, 1994; Lauersen & de Swaan, 1988, Weinstein, 1987). This study focuses on the psychosocial processes involved in women's experiences of living with the symptoms of endometriosis. This research also explores the ways in which endometriosis is socially constructed in the popular press and how this affects women's lived realities of endometriosis.

Background of Study

Diagnosis of endometriosis is considered uncertain until confirmed by laparoscopy.¹ One of the challenges women with endometriosis face, however, is getting the disease diagnosed. It can be difficult to diagnose endometriosis in women, even using laparoscopy, because endometrial implants can be so tiny they cannot be viewed via the laparoscope. Symptoms of endometriosis are often dismissed by doctors as normal or as a figment of a woman's imagination, and as a result, women frequently visit several doctors before a definitive diagnosis is made. Moreover, many doctors do not address the challenges that women experience due to endometriosis, such as side effects of medical and surgical treatments for the disease or the emotional aspects of endometriosis-associated infertility. Various challenges related to endometriosis are addressed in some of the popular self-help books that are available (Ballweg & Endometriosis Association, 1987; 1995; Weinstein, 1987), but there is a paucity of research on endometriosis from the perspectives of women with the disease.

Research Problem

There is a need for research that addresses women's lived realities of endometriosis. This study, therefore, investigates the problem of how women deal with

¹ Laparoscopy is a surgical procedure in which a laparoscope, a tube with a light in it, is inserted into a tiny incision in the abdomen. Carbon dioxide is used to expand the abdomen so the surgeon can check the condition of the abdominal organs and see any endometrial implants.

the challenges presented to them by endometriosis. Ultimately, the goal of this research is to discover how women learn to live with a chronic condition such as endometriosis.

Research Objectives

The research objectives were two-fold. First, the researcher explored and described the psychosocial processes involved in women's experiences of living with endometriosis. Second, the researcher explored and described the social construction of endometriosis through popular literature and self-help books.

Research Questions

- 1) What kinds of challenges does having endometriosis present in women's everyday lives?
- 2) How do women deal with these challenges?
- 3) How is endometriosis socially constructed through popular magazines and popular self-help books? Does the social construction of endometriosis reflect sexist attitudes that are prevalent in society?
- 4) Could the social construction of endometriosis affect the kinds of challenges endometriosis presents in women's everyday lives, and if so, how could this affect women's abilities to deal with these challenges?

Significance of the Study

It is important that researchers explore the kinds of challenges women with endometriosis face because, despite a plethora of medical information and self-help books about endometriosis, there is little information available describing women's experiences of the disease from women's perspectives. Preliminary research has found that women report initial reactions of relief at finally having a diagnosis but they later

report feelings of anger, frustration, loss of self-esteem, fear and uncertainty (Halstead, Pepping, & Dmowski, 1989). Research exploring women's experiences of endometriosis may produce information that could be useful to both women with endometriosis and to health care professionals. Women with endometriosis may learn how other women with endometriosis deal with the challenges presented by endometriosis. Health care professionals may also become aware of how endometriosis affects women's lives, and this knowledge may enable health care professionals to provide better support for women with endometriosis. Furthermore, the social construction of endometriosis has not yet been explored. This is significant because the social construction of endometriosis could affect the kinds of challenges women face and the ways in which women deal with these challenges.

Theoretical Review and Conceptual Framework

The Social Construction of Reality and the Sociology of Knowledge

The concept of the social constructionism is a contemporary sociological notion emphasizing the socially created nature of social life. Berger and Luckmann (1966) contend that "reality is socially constructed" (p. 1). The study of the social construction of ideas is called the sociology of knowledge. The role of the sociology of knowledge is to study how ideas are embedded in the social experience of their producers and the social and historical environments within which ideas are formed (Andersen, 1993). There are three components of the sociology of knowledge: a) knowledge is socially constructed, b) knowledge emerges from the conditions of people's lives, and

c) knowledge is embedded in ideological systems and, therefore, knowledge is generated from and tends to reinforce the belief systems that support the status quo (Andersen, 1993). Ideology is defined as a body of ideas that influence a person, group or culture (Webster's Dictionary, 1993).

One ideology that is prevalent in our society is patriarchy. Patriarchy is defined as a system of social structures and practices in which men dominate, oppress and exploit women. Patriarchy is an ideology that aims to explain and justify institutionalized inequality and oppression of women in society (Walby, 1990). The ideology of patriarchy is often demonstrated in society through sexist and paternalistic attitudes and behaviours. Sexism and paternalism are, therefore, consequences of patriarchal ideology. The sociology of knowledge creates a theoretical framework in which patriarchy, sexism and the generation of ideas about women can be understood by helping us to understand how ideas reproduce our definitions of social reality, who produces ideas, under what conditions ideas are made, and the consequences of ideas and beliefs that systematically define women and men in stereotypical and distorted terms (Andersen, 1993). For example, feminist theorists suggest that what we believe to be knowledge reflects the system of male domination in which it is produced (Smith, 1987, Walby, 1990).

The Social Construction of Medical Knowledge

The study of the social construction of medical knowledge has recently become a field of investigation for sociologists (Conrad, 1987, Conrad & Schneider, 1980a: 1980b,

Findlay, 1993; Miles, 1991; Riessman, 1983; Zola, 1978). The term 'social construction of disease' represents a method of analysis in which non-biological factors such as beliefs, economic relationships and societal institutions are seen as influencing our understanding of particular ills (Aronowitz, 1991). Various diseases, conditions and syndromes, including chronic fatigue syndrome, Lyme disease, premenstrual syndrome, menopause and osteoporosis, are socially constructed in a variety of ways (Aronowitz, 1991; Bell, 1987; Davis, 1989; Kaufert & Gilbert, 1986; MacPherson, 1985; Riessman, 1983; Rodin, 1992; Tavis, 1992; Ware, 1992; Zita, 1988).

The idea that medical knowledge has a "social character" is accepted in the sociological and anthropological literature on women and biomedicine (Findlay, 1993, p. 118). Several researchers examining women's reproductive health issues, such as pregnancy and menstruation, developed the idea that obstetric and gynaecologic knowledge about women can be socially constructed. For example, in her examination of the construction of obstetric and gynaecologic knowledge in the 1950's, Findlay concluded that women's reproductive capacities serve as a resource in the social construction of medical knowledge about women. Findlay reports this medical knowledge was subsequently used to "define the world in a way which included particular concepts of females and normal women" (p. 132). Women were thus defined as normal or abnormal based upon their reproductive capabilities. Despite interest in the construction of obstetric and gynaecologic knowledge, the social construction of endometriosis has not yet been explored in the literature on women and biomedicine.

Moreover, feminist scholars contend that the institution of medicine asserts authority over women by interpreting and implementing patriarchal ideology in women's lives via medicine (Findlay, 1993; Lander, 1988; Linden, 1994; Malterud, 1993; Martin, 1987; Miles, 1991; Mitchinson, 1991; 1993; Riessman, 1983; Sherwin, 1992; Smith, 1987). It is necessary, therefore, to determine if the social construction of endometriosis perpetuates some of the sexist attitudes that are prevalent in our society.

The Sociology of Knowledge and Feminist Standpoint Theory

Feminist standpoint theory was created for the purpose of theorizing women's experiences in the everyday world. Feminist standpoint theorists insist women's knowledge has been excluded from the construction of ideology and culture. Men create ideology, knowledge and culture based upon their own experiences (Smith, 1987). The standpoint of men is regarded as representative of the universal experience of all humankind, and thus, the male voice has been granted authority in our society. Women's voices, in contrast, have been silenced throughout history. Consequently, women are deprived of the essential basis for developing expressions of their shared situations. Smith describes a point of rupture in women's experiences, relative to social (i.e. male) forms of consciousness in the world, as "the line of fault" (p. 49). Women's experiences are not what they are often described to be and there is a disjuncture from which women's consciousness must emerge. Sociological researchers can study the everyday circumstances of women's lives by finding the line of fault and exploring this disjuncture. Moreover, women's specific location in patriarchal societies can be used as a

resource in the construction of new knowledge. For example, Malterud (1993) suggests a variety of strategies for empowering women's voices in the medical culture. These strategies include creating research methods that facilitate sensible observations and interpretations from women's voices, obtaining and refining knowledge of women's illness experienced by female physicians, investigating clinical approaches for empowering the voices of female patients, creating medical knowledge from the experiences of female patients and physicians, supporting female researchers and constructing a female epistemology that can inform medical culture.

Feminist standpoint theory can be used to elucidate, support and validate women's experiences of living with endometriosis in three ways. First, feminist standpoint theory allows the researcher to locate and explore disjunctures between women's lived realities of endometriosis and the social construction of endometriosis. Second, feminist standpoint theory allows the researcher to give primacy to the lived experiences of women with endometriosis, instead of supporting the perspectives of the male-dominated institution of medicine that informs the popular press. Finally, feminist standpoint theory, as articulated by Smith (1987), enables the researcher to account for women's experiences of oppression as they seek diagnosis and treatment for endometriosis.

Social Construction, Sexism and the Media

Definitions of reality are created and sustained by the mass media. A focus of media studies, therefore, has been particularly concerned with the media as agents of socialization (Wilson, 1981). Socialization of the audience is accomplished through the

models, values, ideas and attitudes the media conveys. Social construction theorists argue that images of the world generated by the media are used to construct meaning about political and social issues and, thus, social reality is constructed through the media (Andersen, 1993; Gamson, Croteau, Hoynes, & Sasson, 1992; Smith, 1987). Gamson, Croteau, Hoynes and Sasson contend:

the lens through which we receive these images is not neutral but evinces power and point of view of the political and economic elites who operate and focus it...the whole process [is made to] seem so normal and natural that the very art of social construction is invisible (p. 374).

Feminist scholars argue that aspects of women's lives are socially constructed by the media and they have offered various explanations to describe the depiction of women in the media (Tuchman, 1979). Tuchman outlines several theories including the reflection hypothesis, the role-learning theory and organizational theories of gender inequality. The reflection hypothesis assumes that the mass media reflect the values of the general population, role learning theory suggests that sexist and racist images in the media encourage role modelling, and organizational theories of gender inequality attribute sexism and gender inequality to the capitalist structure of media organizations. The existence of sexism in the media has been attributed to all of these theories separately. It can be argued, however, that all of these theories are pieces of the puzzle. The values of the general population, role modelling and the organizational structures of

the media all contribute to the social construction of sexism and gender inequality in the media.

Despite the uncertainty about exactly how the media infiltrates our social consciousness, there is no doubt that the media establishes the popular culture which influences our definitions of social reality. Endometriosis is usually constructed in the popular culture as "the career woman's disease" that will render women infertile and, therefore, unfeminine.

CHAPTER TWO

Literature Review

The literature on endometriosis can be divided into two broad categories: clinical discussion and health research. A brief review of each category of literature is included. A critique of the endometriosis literature, particularly the health research reported, follows and limitations of the literature are discussed. Recommendations for new research topics are also included. The literature on chronic illness is reviewed in order to understand the broader context of the endometriosis literature. The chronic illness literature can also be divided into two categories: health research and the sociology of illness experience. A brief overview of the literature on chronic illness is included. A critique of the chronic illness literature follows and limitations of the literature are addressed. Implications for endometriosis research and treatment are also discussed.

Review of Endometriosis Literature

Review of Clinical Reports

Clinical reports or discussion on endometriosis written by health care practitioners focused on a variety of issues including histogenesis, epidemiology, diagnosis, symptoms of pain and infertility, medical and surgical treatments, and recurrence of endometriosis after treatment. Clinicians also debated particular issues such as whether endometriosis is actually a disease, what patients with endometriosis expect from their doctors, what is important to these patients and the approaches and perspectives of doctors on the treatment and management of endometriosis. Prior to the

widespread use of laparoscopy as a diagnostic technique, clinical discussion featured issues such as the etiology and histogenesis of endometriosis, diagnosis, medical and surgical treatments, the relationship between endometriosis and infertility, and epidemiological factors such as race and class (Aimalahu & Osunkoya, 1971; Kistner, 1959; Meigs, 1938; Ridley, 1968; Weed, 1955; Yin, 1945).

Clinical reports written in the 1980's and 1990's expanded upon these issues and broadened the scope of the discussions of endometriosis. Clinicians continued to discuss the origins and nature of symptoms of endometriosis, such as pain and infertility, and various diagnostic techniques including clinical, laparoscopic and histologic diagnosis (Barlow & Glynn, 1993; Dmowski, 1984; Haney, 1993; Metzger & Haney, 1988). Particular emphasis was placed upon the revised American Fertility Society² classification system, a scale devised to show the relationship between endometriosis and infertility at various stages of the disease (Brosens, Donnez, & Benagiano, 1993; Canis, Bouquet De Jolineres, Wattiez, Pouly, Mage, Manhes, & Bruhat, 1993; Crosignani & Vercellini, 1994; Dubuisson & Chapron, 1994). This scale uses a four-stage classification system which assumes that the higher the stage of endometriosis, the less fertile a woman will be. One problem is that this scale is not based on the relationship between endometriosis and fertility; instead, it focuses on the extent of the disease without considering other factors such as age or other fertility factors (Haney, 1993).

² The American Fertility Society is now called the American Society for Reproductive Medicine.

Moreover, the reliability of this scale has not yet been established (Rock & ZOLADEX® Endometriosis Study Group, 1995). Although medical clinicians argue that the American Fertility Society classification system should be revised again, they disagree about exactly how to do this (Brosens et al., 1993; Canis et al., 1993; Crosignani & Vercellini, 1994; Dubuisson & Chapron, 1994).

Medical clinicians also question whether endometriosis should always be considered a disease (Brosens, 1994; Evers, 1994; Koninckx, 1994; Koninckx, Oosterlynck, D'Hooghe, & Meulemen, 1994; Moen, 1995; Wardle & Hull, 1993). Although some argue that all women develop endometriosis and only some women develop endometriotic disease, most medical clinicians generally regard endometriosis as an endocrinological disease requiring medical and/or surgical treatment (Canadian Consensus Conference on Endometriosis, 1993; Koninckx & Martin, 1994; Magos, 1993; Martin, 1995; Nezhat, Nezhat, & Nezhat, 1994; Rock & Moutos, 1992; Shaw, 1994; Thomas, 1992). The majority of the clinical reports highlighted reviews and opinions of various medical and surgical treatments of endometriosis (Kauppila, 1993; Martin, 1995; Rock & Moutos, 1992; Shaw, 1994; Thomas, 1992; Wingfield & Healy, 1993).

Medical clinicians frequently examined medical and surgical therapies to evaluate their effectiveness in the treatment of endometriosis. Medical treatments reviewed in the clinical literature include oral contraceptives and other hormone

treatments, such as androgens³ and gonadotrophin-releasing hormone (GnRH) agonist analogues⁴, which temporarily suppress menstruation (Canadian Consensus Conference on Endometriosis, 1993; Kauppila, 1993; Rock & Moutos, 1992; Shaw, 1994; Thomas; 1992; Wingfield & Healy, 1993). Medical clinicians usually concluded that various medical treatments were beneficial in alleviating symptoms and treating microscopic endometriotic lesions and they recommended, therefore, that other clinicians use these treatments.

Medical clinicians reported that surgical techniques used to remove endometriotic implants include lasers, electrocautery, endocoagulation and sharp excision (Malinak, 1993; Rock & Moutos, 1992). Surgical treatments were generally regarded as beneficial from the clinicians' point of view because they could perform surgical treatments at the time of diagnostic laparoscopy (Wingfield & Healy, 1993). Clinicians disagreed, however, on the effectiveness of surgical treatments. For instance, some clinicians argued there was no evidence indicating that results using lasers were better than those obtained using the other surgical techniques, while others argued that lasers produced better results (Nezhat, Nezhat, & Nezhat, 1994; Rock & Moutos, 1992). Some medical clinicians insisted that new techniques such as videolaparoscopy and

³ Danazol[®] is an androgen that is often prescribed for the treatment of endometriosis.

⁴ Lupron[®] and Synarel[®] are two GnRH agonist analogues that are often prescribed in the treatment of endometriosis.

videolaseroscopy were improvements upon laser laparoscopy and these techniques could revolutionize gynaecological surgery (Nezhat et al., 1994). Definitive surgery, in the form of the total abdominal hysterectomy, was usually recommended by physicians for patients with symptoms that were unresponsive to medical treatments and/or conservative surgical treatments (Magos, 1993; Malinak, 1993; Rock & Moutos, 1992). The combination of medical and surgical therapies was also commonly used by physicians (Kauppila, 1993; Thomas, 1992). Medical clinicians recommended that the choice of treatment be governed by a variety of issues including doctor and/or patient preferences, severity of symptoms, side effects of medical treatments, cost of medical therapies, the patient's previous experiences with certain therapies, the patient's desire to preserve fertility and/or reproductive organs, the likely need for long term therapy and the availability of medical and surgical resources (Kauppila, 1993; Magos, 1993; Shaw, 1994; Wingfield & Healy, 1993).

Some clinicians argued that neither medical, surgical or combination therapies were effective treatments for endometriosis because they did not address the etiology and/or pathophysiology of the disease (Gleicher, 1995; Rock & Moutos, 1992). This would account for clinical reports of recurrences of endometriosis after treatment (Fedele, Bianchi, Di Nola, Candiani, Busacca, & Vignali, 1994; Revelli, Modotti, Ansaldo, & Massobrio, 1995). Gleicher and Rock and Moutos suggested that future medical and surgical treatments for endometriosis may be based upon the notion that it is a systemic disease which causes immune dysfunction. Gleicher argued that researchers

should concentrate their efforts on determining whether or not there is a gene that predisposes women to develop endometriosis.

Finally, medical clinicians have tried to determine what is important to the patient with endometriosis and what the endometriosis patient expects from her doctor (Kennedy, 1991; Weinstein, 1988). Since very little research has been done in these areas, these reports tended to be opinion and anecdotal evidence. Physicians also discussed approaches to treating patients with endometriosis, with particular reference to how doctors can help women deal with the emotional aspects of the disease (Jones, 1988; Miller & Rebar, 1988). Miller and Rebar's discussion differed from the other clinical reviews of medical and surgical treatments only in its brief mention of the importance of patient education and the need for medical practitioners to be aware of the psychological impact of endometriosis. Jones, on the other hand, suggested models of treatment for physicians to help women who have minimal emotional stress deal with symptoms of pain and infertility.

Review of Health Research

Epidemiological Studies

Health research on endometriosis has produced a large body of literature. Prior to the 1980's, health researchers focused on epidemiological factors of endometriosis including age, race, class and fertility patterns (Cavanagh, 1951; Chatman, 1976a; 1976b; Lloyd, 1964; Meigs, 1953; Miyazawa, 1976; Scott & Te Linde, 1950). Health researchers often found ideas for epidemiological research projects in the clinical

reports. For instance, Chatman studied the incidence of endometriosis in Black women because he wanted to know if, as medical clinicians had argued, endometriosis was rare in Black women. He discovered that endometriosis was not, in fact, rare in Black women.

Health research studies conducted in the 1980's and 1990's continued to feature epidemiological factors of endometriosis such as age, race, class, fertility patterns, reproductive factors and familial factors (Arumugam & Templeton, 1992; Arumugam & Welluppilai, 1993; Chatman & Ward, 1982; Darrow, Selman, Batt, Zielezny, & Vena, 1994; Houston, Noller, Melton, & Selwyn, 1988; Lamb, Hoffmann, & Nichols, 1986; Matorras, Rodriquez, Pijoan, Ramon, Gutierrez de Teran, & Rodriguez-Escudero, 1995; Moen, 1994; Moen & Magnus, 1993; Osefo & Okeke, 1989; Wheeler, 1989). Researchers have examined the incidence of endometriosis among women of different age groups. Traditional clinical opinions maintained that endometriosis was rare in teenagers, so Chatman and Ward studied the incidence of endometriosis in a group of teenage women. They examined forty-three teenagers, who complained of disabling pelvic pain and/or abnormal bleeding, using laparoscopy. They found a 65% incidence of endometriosis. Chatman and Ward suggested that endometriosis occurred more frequently in teenagers than previously thought, and they suggested that use of laparoscopy as a diagnostic technique may make it easier to diagnose endometriosis in teenagers in the future.

Health researchers continued to study the incidence of endometriosis in women of various races. Osefo and Okeke (1989) conducted a retrospective study of endometriosis of the Igbo of Nigeria. Using reports from 5,995 gynaecological operations, they discovered a 4.3% incidence rate, the highest incidence reported for Nigeria. Arumugam and Templeton (1992), on the other hand, studied the incidence of endometriosis among 202 infertile women in Kuala Lumpur, Malaysia and 464 infertile women in Aberdeen, Scotland. Although they did not find a difference in the severity of the disease in one group of women compared to the other, endometriosis was significantly more common in the patients from Kuala Lumpur. Arumugam and Templeton argued that their clinical impression that Asian women have a significantly greater risk of developing endometriosis than Caucasian women was confirmed in their data.

Only one recent epidemiological study focused on the social class distribution of endometriosis. Arumugam and Welluppilai (1993) studied the social class distribution in 147 Asian patients with endometriosis. Two hundred and eighty-one patients who did not have endometriosis were used as controls. Social class of the patients was designated according to the Registrar General Classification scale, with social class one at the top of the scale and social class five at the bottom. Arumugam and Welluppilai concluded that endometriosis was significantly associated with women in social classes one and two, but there was no association between social class distribution and the severity of the disease.

Health research has also featured the epidemiology of surgical treatments for endometriosis. For example, researchers studied the incidence of symptom recurrence

after hysterectomy for endometriosis. Namnoum, Hickman, Goodman, Gehlbach and Rock (1995) conducted a historical prospective study of 138 patients with endometriosis to determine the risk of symptom recurrence and/or additional operations after hysterectomy with ovarian preservation for the treatment of endometriosis. They concluded that patients who had hysterectomy with ovarian conservation had 6.1 times greater risk of developing recurrent pain and 8.1 times greater risk of having additional operations than women who had oophorectomy for endometriosis.

Health researchers also examined the incidence and prevalence of endometriosis among certain populations of women. For instance, a group of researchers from the United States Army studied the active duty records of 6, 456 female Army officers to evaluate the amount of lost duty time due to endometriosis over a five-year period (Boling, Abbasi, Ackerman, Schipul, & Chaney, 1988). These researchers determined the prevalence of endometriosis among the female United States Army population was 6.2% and the estimate of lost duty time was 21, 746 days. Boling et al. realized that endometriosis can be a disabling disease, and as a result, women's work lives may be disrupted by endometriosis. They recommended that women with histories of endometriosis and women who are diagnosed with endometriosis at their recruitment examination should not be eligible for entry into active duty in the United States Army. They encouraged the United States Army to adopt a policy that discriminates against women with endometriosis, instead of suggesting ways of helping women soldiers so their work lives are not disrupted by endometriosis.

Health researchers also studied the epidemiology of endometriosis-associated infertility and reproductive factors in predicting endometriosis. Matorras, Rodriguez, Pijoan, Ramon, Gutierrez de Teran and Rodriguez-Escudero (1995) conducted a case-control study of 174 infertile women with endometriosis and 174 infertile women without endometriosis to assess epidemiological factors linked to endometriosis in infertile women. Although their results showed that age, menstrual cycle characteristics and reproductive history were similar among both groups of women, Matorras et al. discovered the proportion of women with menstrual cycles of twenty-seven days or more was higher in the endometriosis-associated infertility group. Previous studies suggested that age, age at menarche, duration of menstrual cycle, duration of menstrual flow, intensity of flow, social class, family history and delayed childbirth were risk factors in the development of endometriosis-associated infertility. They concluded that the only risk factor related to endometriosis-associated infertility was a menstrual cycle of twenty-seven days or more. This information is not very useful, however, because most women who menstruate have a cycle of twenty-seven days or more, so this information will not enable researchers or physicians to predict who is likely to develop endometriosis or its associated infertility. They also found that smoking seemed to have a protective effect against endometriosis, but they argued the adverse effects of smoking outweighed the potential protective benefits on endometriosis, and they did not encourage women to use smoking as protection against endometriosis.

Another study examining reproductive factors focused on the popular clinical notion that endometriosis strikes career women who voluntarily delay childbirth (Darrow, Selman, Batt, Zielezny, & Vena, 1994). These researchers investigated sexual activity, contraception and reproductive factors in predicting endometriosis. They compared data collected from a survey of 104 women newly diagnosed with endometriosis and two control groups totalling 198 women. Darrow et al. concluded their results did not support "simplistic assumptions" that characterized women with endometriosis as career women who voluntarily delay pregnancy (p. 500). Instead, they argued there is a complex relationship between endometriosis and reproductive, sexual activity and fertility related factors. Studies of the epidemiology of endometriosis-associated infertility and reproductive factors did not produce any predictive measures regarding who is likely to develop endometriosis or endometriosis-associated infertility.

Finally, researchers conducting epidemiological studies examined family histories in order to determine familial risk of endometriosis. Lamb, Hoffmann and Nichols (1986) also conducted a study of family traits to determine lineage patterns of women with endometriosis. A control group was composed of the best friends of the women. Most of the cases involved the maternal lineage with an overall expectancy rate of 4.9% for first-degree maternal relatives. Second-degree maternal relatives, including grandmothers and aunts, showed an overall risk of 1.9%. Based upon their results, Lamb et al. concluded a familial trait does exist, but they were not sure if the familial trait was genetic or was related to shared lifestyles and behaviours.

Moen and Magnus (1993) also studied the familial risk of endometriosis. They interviewed 563 patients with endometriosis to find out if their mothers or sisters have endometriosis or adenomyosis. A total of 515 cases of endometriosis were located among the mothers and sisters of 522 patients. A control group of 149 women without endometriosis was included in the study. Moen and Magnus found a seven fold increase of risk of endometriosis in mothers and sisters of patients with endometriosis. Like Lamb, Hoffmann and Nichols (1986), Moen and Magnus were not sure whether familial aggregates of endometriosis could be explained by a common genetic trait or by similarities in lifestyle. Moen (1994) pursued the possibility that a common genetic trait causes endometriosis in families. He studied the incidence of endometriosis in eight pairs of monozygotic twins. Six pairs of the monozygotic twin sisters (75%) had endometriosis. Five pairs of the twins had the same severity of disease. Three mothers (38%) of the monozygotic twins also had endometriosis or adenomyosis. Moen concluded his data supports the notion that the development of endometriosis is influenced by genetic factors.

Studies examining familial risk of endometriosis have not gleaned much useful information. Researchers have vaguely concluded that a family trait probably exists, thereby increasing the risk of endometriosis, but they are unable to determine if the family trait is due to genetics or to something related to shared lifestyles. Clearly, more research needs to be done to determine if there is a gene that predisposes women to developing endometriosis (Gleicher, 1995).

Psychosocial Studies

Health research on endometriosis also featured psychosocial studies examining the relationship between mood disorders and endometriosis, the involvement of personality in the expression of pain, the relationship between pelvic pain caused by endometriosis and psychological functioning, and the relationship between women's symptoms of endometriosis and self-esteem (Christian, 1992; Gomibuchi, Taketani, Doi, Yoshida, Mizukawa, Kaneko, Kohda, Takei, Kimura, Liang, & Kaibara, 1993; Lewis, Comite, Mallouh, Zadunaisky, Hutchinson-Williams, Cherksey, & Yeager, 1987; Low, Edelmann, & Sutton, 1993a; Low, Edelmann, & Sutton, 1993b; Walker, Katon, Jones, & Russo, 1989; Waller & Shaw, 1995). Two studies examined relationships between affective disorders and endometriosis. Lewis et al. (1987) evaluated sixteen women diagnosed with endometriosis for mood disorders. An interview schedule was produced from materials in the Hamilton Rating Scale for Depression, the Schedule for Affective Disorders and Schizophrenia - Lifetime Version, the Beck Depression Inventory and the criteria listed in *DSM-III*. The researchers determined that twelve of their sixteen subjects met *DSM-III* criteria for mood disorder and they concluded, therefore, that endometriosis and mood disorders may be related. Although Lewis et al. included a lengthy explanation about how there could be hormonal commonalities between the two illnesses, they did not actually test for this possibility.

Walker, Katon, Jones and Russo (1989) performed psychiatric evaluations of sixty-nine women in order to compare their data to the results found by Lewis, Comite,

Mallouh, Zadunaisky, Hutchinson-Williams, Cherksey and Yeager (1987). Thirty-nine women had chronic pelvic pain, fourteen of whom had been previously diagnosed with endometriosis, and the other thirty women made up the control group. In an effort to have unbiased results, the interviewers were not advised which of the women had been diagnosed with endometriosis. They also used a different interview questionnaire than Lewis et al. In contrast to the findings of Lewis et al., Walker, Katon, Jones and Russo concluded there is no direct relationship between endometriosis and affective disorders. Methodological differences, however, may account for the different findings in these two studies.

Two studies examined personality profiles of women with endometriosis. Gomibuchi, Taketani, Doi, Yoshida, Mizukawa, Kaneko, Kohda, Takei, Kimura, Liang and Kaibara (1993) studied fifty-eight women with endometriosis, using the Rosenzweig picture frustration study, to determine if personality affected the expression of pain. The Rosenzweig picture frustration study measures the direction of aggression and classifies it into three categories: a) extraggression, b) intraggression, and c) imaggression. Furthermore, aggressive personality was analyzed in this study according to three types of aggression: a) obstacle-dominance, b) ego-defense, and c) need-persistence. The researchers concluded that the pain caused by endometriosis was influenced by personality types. It was not clear exactly how they reached this conclusion, however, because the results of this study were confused by the jargon that was used in the research report. Moreover, Gomibuchi et al. explained that the term "aggression" used in

this study did not mean an attack or hostility, but instead represented assertiveness. By changing the meaning of words, the researchers added to the confusion surrounding their study.

Low, Edelmann and Sutton (1993a) studied forty women with endometriosis and forty-one women with other gynaecological problems to investigate the possibility of a specific psychological profile associated with endometriosis. Each patient completed six standardized psychometric tests to assess personality, psychopathology, marital state and pain. Low, Edelmann and Sutton concluded that the endometriosis group is more anxious than the women with other gynaecological problems. They believed this may be due to the anxiety caused by endometriosis-associated infertility or the uncertain prognosis associated with endometriosis. Nevertheless, they also suggested that anxiety may make more women prone to endometriosis.

Two studies examined the relationship between pain symptoms and psychological functioning. Low, Edelmann and Sutton (1993b) examined the short-term psychological outcome of surgical intervention for endometriosis. Thirty-seven women were tested using a variety of questionnaires to determine pain intensity and psychological functioning. Low, Edelmann and Sutton concluded their results suggested a statistically significant short-term improvement in both psychological state and pain experienced by endometriosis patients treated during laparoscopy. They could not confirm, however, if the short-term gains were maintained or improved in the longer term. Waller and Shaw (1995) investigated psychological differences between women with symptomatic and

asymptomatic mild endometriosis. Women with pelvic pain symptoms, whether they had mild endometriosis or not, scored significantly higher on the Beck Depression Inventory scale than women with asymptomatic mild endometriosis. Waller and Shaw concluded that certain psychological features did not appear to make women vulnerable to developing endometriosis. Instead, they argued that women who suffer from chronic pain may be in a state of distress that leads to abnormalities of psychological functioning, and they suggested that some women with endometriosis may benefit from a management team that includes a gynaecologist and a psychologist.

Finally, Christian (1992) used the Rosenberg Self-Esteem Scale to study the self-esteem levels of twenty-three women with endometriosis. She determined that there was no relationship between women's symptoms of endometriosis and self-esteem. Christian suggested her research instrument may not have been sensitive enough to pick up differences in the group, even though the title of the Rosenberg Self-Esteem Scale was changed to "Women's Health Study" to reduce subject bias of the research instrument. Silverton (1990) also examined the self-esteem of women with endometriosis in her study of the psychosocial adjustment and coping strategies of thirty women with endometriosis. She used an illness-specific typology that was devised to measure subjects' repertoires of coping strategies, the Ways of Coping questionnaire, the CES-D Scale, the State-Trait Anxiety Inventory and the Rosenberg Self-Esteem Scale. Silverton discovered there were significant relationships among medical factors, coping and adjustment. She determined that reattribution of healthy functioning was significantly

associated with lower depression and anxiety, while passive-dependent coping was associated with worse adjustment.

Halstead, Pepping and Dmowski (1989) examined the help seeking behaviours of twenty-five women with endometriosis. Semi-structured interviews focused on symptom history, actions by the women to seek help, and reactions of family, care givers and self to symptoms. The women reported initial reactions of relief at finally having a diagnosis and current feelings of anger, frustration, loss of self-esteem, fear and uncertainty of the future. Halstead et al. concluded that women with endometriosis continue to experience significant delays in diagnosis and treatment, and as a result, they suffer considerable disruption of their lives.

Finally, Ballweg (1992) identified the need for research on endometriosis from the patient's perspective. In a research based article that included information from focus groups conducted for the Endometriosis Association, Ballweg outlined what it is like to have endometriosis. Ballweg's work suggested researchers should begin to explore the psychosocial processes involved in living with endometriosis.

Limitations of Health Research on Endometriosis

Health research on endometriosis is limited by several methodological problems. First, health research on endometriosis has been criticized in the clinical literature for its use of the revised American Fertility Society classification scale for endometriosis. It has been suggested that this scale does not actually measure the relationship between endometriosis and infertility, as it purports to do (Hancy, 1993). Moreover, the reliability

and validity of this scale have not yet been established (Rock & ZOLADEX® Endometriosis Study Group, 1995), so there is no way to determine if researchers are using the scale in the same way. Many researchers, however, continue to use this classification scale in their studies. For instance, Matorras, Rodriguez, Pijoan, Ramon, Gutierrez de Teran and Rodriguez-Escudero (1995) used the revised American Fertility Society classification scale in their study of the epidemiology of endometriosis in infertile women.

Another methodological problem is that health researchers referred to endometriosis and adenomyosis interchangeably or they suggested a connection between the two diseases without explaining the association. For instance, Moen and Magnus (1993) claimed to be studying the familial risk of endometriosis, but they actually examined the incidence of endometriosis and adenomyosis in families without distinguishing between the two diseases. Most of the other epidemiological researchers only studied endometriosis, excluding adenomyosis as a separate disease entity. The fact that some researchers conflated endometriosis and adenomyosis is problematic because the results of research on endometriosis become confused, distorted and unreliable.

Methodological errors were also evident in several of the psychosocial studies of endometriosis. For instance, in their study of endometriosis and affective disorders, Walker, Katon, Jones and Russo (1989) examined histories of adult and childhood sexual abuse in the lives of their subjects without explaining why this is important information, nor do they explain how they gained this information. Another methodological problem

occurred in psychosocial research when Lewis, Comite, Mallouh, Zadunaisky, Hutchinson-Williams, Cherksey and Yeager (1987) used the *DSM-III* criteria for mood disorder to determine that women with endometriosis also suffered from mood disorders. *DSM-III* criteria for mood disorder requires "that symptoms not be explainable by physical illness" (Robins, Helzer, Croughan, & Ratcliff, 1981, p. 381), yet Lewis et al. did not consider the possibility that mood disorders could be the result of physical illness caused by endometriosis. Psychological difficulties could also be compounded by medication used to treat endometriosis that can cause mood changes in some women (Waller & Shaw, 1995), but Lewis et al. also failed to consider this possibility.

Finally, health research on endometriosis is limited by research questions that do not address the effects of endometriosis on women's everyday lives. Ballweg (1992) and Kennedy (1991) suggested that studying the effects of endometriosis from women's perspectives is a significant area of research that has been ignored by researchers. Most researchers studying endometriosis focused on clinical, health or psychosocial issues as separate areas of research. An interdisciplinary approach to endometriosis research would allow researchers to focus on the interaction between each dimension of the experience of living with endometriosis. Moreover, an interdisciplinary approach could enable us to explore new fields of endometriosis research including sociology and women's studies. The knowledge gained by sociological and women's studies researchers could inform clinical, health and psychosocial knowledge of endometriosis. For example, sociological and women's studies researchers could study women's knowledge

of endometriosis and incorporate this new information into the general knowledge of the disease. New ideas about how to care for women with endometriosis may also become evident based on women's experiences of the disease.

Review of Chronic Illness Literature

Review of Health Research

Chronic illness is defined as a disease process which is progressive, enduring, and recurrent (Strauss, 1975). Illnesses that are considered chronic in nature include diabetes, arthritis, cardiovascular disease, muscular dystrophy, cancer, stroke, cystic fibrosis, epilepsy, multiple sclerosis, renal failure, emphysema and Alzheimer's disease (Curtin & Lubkin, 1995; Gregg, Robertus, & Stone, 1989; Thome, 1993). Silverton (1990) and Thome identified endometriosis as a disease that should be included in this list. In the past, health researchers were encouraged to study particular aspects of diseases. This approach denied the experiential nature of chronic illness, and thus, commonalities among chronic illness sufferers were invisible.

Recently, biomedical, nurse and psychological researchers explored the similarities between chronic illnesses and the common effects of chronic illnesses on individuals. Common elements of the chronic illness experience have been identified as lifestyle adaptations, gaining control over medical treatment, managing emotions and acquiring information. Chronic illnesses often result in problems such as intrafamilial stresses, sexual stresses, social isolation and economic problems (Curtin & Lubkin, 1995;

Thorne, 1993). Chronic illnesses also have in common the problem that they cannot be cured by modern health care methods.

Research on chronic illness usually focused on the adaptation of patients and their families to chronic illness. Research has also explored the relationships between health care providers and their patients, the attitudes of health care professionals towards their patients, and the illness behaviours of the chronically ill. Social interaction, especially with health care professionals, "features powerfully in the lived experience of chronic illness" (Thorne, 1993, p. 9). Researchers have also found that the individual's self-concept, emotional resources, family relationships, sexual behaviour, social adjustment, career, leisure activities and/or finances can be affected by chronic illness (Charmaz, 1987; Gregg, Robertus, & Stone, 1989; Strauss, 1975). Theories of adaptation, adjustment and coping were, therefore, prevalent in the literature on chronic illness.

Psychologists often focused on stress, adjustment and coping strategies of the chronically ill. Lazarus and Folkman (1984) defined psychological stress as a "particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). Psychologists have identified various stages of emotional reactions to chronic illness including shock, realization, denial, mourning and adaptation (Athelstan, 1981; Livneh & Evans, 1984). Coping was defined as "purposeful efforts to manage or vitiate the negative impact of stress" (Jensen, Turner, Roman, & Karoly, 1991, p. 250). Two kinds of coping strategies were identified as ways of dealing with the stresses induced by

chronic illnesses (Hymovich & Hagopian, 1992; Jensen et al., 1991). First, problem-focused coping was directed at solving or relieving problems. Second, emotion-focused coping was directed at managing the negative emotions associated with stress. Coping strategies were defined either as active, requiring a person to initiate action to manage the physical illness, or passive, involving a person's withdrawal or giving up control to an external force or agent (Jensen et al., 1991). Various measures were used to study the relationship between coping strategies and adjustment. For example, Jensen et al. (1991) found that measures such as the Vanderbilt Pain Management Inventory, the Coping Strategies Questionnaire and the Ways of Coping checklist are often used to study people's abilities to cope with chronic pain.

Finally, the concept of adjustment referred to the psychological well-being or adaptive mental functioning of the chronically ill person. This concept has been expanded to "include multiple dimensions relating to the ability to carry out normal physical and psychosocial activities" (Jensen, Turner, Romano, & Karoly, 1991, p. 250). Theorists and researchers proposed various adaptation or adjustment models (Hymovich & Hagopian, 1992). Shontz (1975), for instance, identified four stages of adjustment to chronic illness. These include: a) onset of illness with no functional impairment, b) early signs of medical complications which may or may not be accompanied by temporary impairment, c) major medical complications accompanied by permanent functional impairment, and d) catastrophic medical complications resulting in death or severe functional impairment. Safilios-Rothschild (1970) identified several factors of

adjustment including personality, body image, previous experience with illness and attitudes of care givers. Parets (1967) argued that adjustment to chronic illness is marked by various emotional reactions such as fear of death, incapacitation, pain, abandonment and of spreading disease. Coping and adjustment strategies must be flexible in order for people to be able to deal with issues such as fear. People with chronic illnesses are always in the process of adjusting and the adjustment process is never complete (Gregg, Robertus, & Stone, 1989; Stone, Gregg, Kelner, & Coates, 1978).

Review of Research on the Sociology of Illness Experience

The sociology of illness experience considered people's everyday lives living with, and in spite of, chronic illness (Conrad, 1987). Sociological research on chronic illness usually focused on the problems of chronically ill people and their families (Bury, 1991). Conrad insisted that sociologists study the subjective aspects of illness experience in order to determine the meaning of illness, the social organization of the sufferer's world, and the strategies used in adaptation. Sociological approaches to chronic illness included four stages: a) initial disruption of illness, b) explanation and legitimation, c) treatment, and d) adaptation (Bury, 1991).

Researchers focusing on the initial disruption of illness usually examined the consequences and significance of the illness for the individual. Conrad (1987) suggested that relevant questions at this stage include how people first notice "something is wrong," what it means to them, and what kinds of theories and explanations they develop to make sense of these unusual events (p. 5). Explanation and legitimation focused on the

gathering of information about a medical condition and repairing disruption in order to "establish an acceptable and legitimate place for the condition within the person's life" (Bury, 1991, p. 456). Relevant questions at this stage include what people do about their problem, how they come to seek medical care (and with what concerns and expectations), what impact diagnosis has on them and how they cope with a medical label. The treatment stage focused on the impact of treatment regimens and how people manage treatment regimens. Finally, the adaptation stage focused on how people adapt or adjust to chronic illness, including coping, strategy and style. The term 'coping' was defined as the cognitive processes that allow the individual to learn how to tolerate the effects of illness. In contrast, the term 'strategy' directs attention to the actions people take in the face of illness. Lastly, the term 'style' referred to the way people respond to, and present, important features of their illnesses or treatment regimens. Ultimately, people with chronic illnesses must learn to adjust their lifestyles in order to "live as normal a life as possible in the face of...disease" (Strauss, 1975, p. viii).

In sum, sociological research provides us with additional knowledge of the experience of chronic illness (Bury, 1991; Conrad, 1987). Knowledge of the experience of chronic illness is useful because it will enable us to better understand and care for people who live with chronic illness.

Limitations of Chronic Illness Research

Chronic illness research has been criticized for its emphasis on coping, adjustment and adaptation. Browne, Byrne, Roberts and Sworcl (1995) argue that the

field of coping and adaptation is based on the notion that accepting challenging circumstances is "a good thing" (p. 90). Instead, they suggested that not coping with circumstances was not always a failure, but rather a part of life for people who live with chronic problems such as chronic illness. Moreover, coping and adaptation research is limited by research questions that do not clearly specify the context of coping and phases of the coping process. For example, the phase of the stressful event is rarely addressed in research questions, leaving us to wonder exactly where the coping efforts are being directed (Browne et al., 1995). Coping and adaptation research is also limited by biased research methods and conclusions. For example, in their literature review on research on coping with chronic pain, Jensen, Turner, Romano and Karoly (1991) concluded that methodological limitations, such as invalid and unreliable measures, prevented them from "drawing definitive conclusions" about relationships between stress, coping and adjustment (p. 280).

Despite limitations in the coping and adaptation research, Silverton (1990) believes that women with endometriosis can benefit from medical and mental health care professionals who are knowledgeable about endometriosis and the coping process. While many medical and mental health care professionals may be knowledgeable about the coping process, they are not necessarily knowledgeable about endometriosis or how the coping process could help women with endometriosis. Perhaps this is because endometriosis is not often defined as a chronic illness. If medical and mental health care professionals would recognize that endometriosis can be a chronic illness in women's

lives, they could apply models of coping and adaptation to the treatment of women with endometriosis. In doing so they might discover that current models of coping and adaptation are not useful in the treatment of endometriosis, but health care professionals could be encouraged to help women with endometriosis develop new coping strategies. Further studies are needed to determine a greater understanding of the kinds of emotional issues women with endometriosis face and how these issues can be resolved (Low & Edelmann, 1991; Silvertown, 1990; Waller & Shaw, 1995).

Finally, researchers rarely focus on the interaction between various dimensions of the chronic illness experience (Bury, 1991; Thorne, 1993). Bury concludes that sociological studies of chronic illness "suggest the need for a multidimensional view of its impact on every day life" (p. 463). An interdisciplinary approach to research on chronic illness could enable us to better understand chronic illness and care for the chronically ill. For example, if sociological, biomedical, nursing and psychological knowledge of endometriosis and related issues were combined, we could gain a better understanding of how endometriosis affects women's lives. New insights into how to care for women with endometriosis may also become apparent.

CHAPTER THREE

Research Methodology

Grounded Theory

Grounded theory, a qualitative research technique developed by Glaser and Strauss, is rooted in the symbolic interactionist school of sociology (Baker, Wuest, & Stern, 1992; Chenitz & Swanson, 1986; Glaser & Strauss, 1967). Grounded theory offers researchers a systematic method for collecting, organizing and analyzing data. The goal of researchers using grounded theory is to identify and explain basic social or social psychological processes (Fagerhaugh, 1986a; Hutchinson, 1986). A basic social or social psychological process is also called the core variable. The core variable recurs constantly in the data, connects the data together and explains variation in the data. Data is gained from the lived experience of research participants, allowing researchers to attend to how research participants construct their worlds (Kirby & McKenna, 1989).

Grounded theory uses the constant comparative method of analysis. Comparisons are made continuously during data collection and analysis. The constant comparative analysis method "emphasizes theory as a process - theory as an ever-developing entity" (Simms, 1981, p. 356). Simms summarizes the four stages included in the constant comparative method: a) comparing incidents applicable to each category, b) integrating categories and their properties, c) delineating the theory, and d) writing the theory.

Using the constant comparative method of analysis, grounded theorists create theoretical categories from data and then analyze relationships between key categories

Coding occurs during the process of analyzing the data. Relationships between categories are developed until a pattern among relationships is conceptualized (Charmaz, 1990; Chenitz & Swanson, 1986; Glaser & Strauss, 1967; Kirby & McKenna, 1989). The group of theoretical codes referred to as the "6-C's" - causes, contexts, contingencies, consequences, covariances and conditions - helps conceptualize how the data is related (Glaser, 1978; Swanson, 1986a). Data collection continues until categories become saturated. Eventually, the grounded theory researcher is able to integrate "the multiple parts of the problem under study into a logical and understandable whole" (Fagerhaugh, 1986a, p. 134).

Writing is done throughout the research process (Chenitz & Swanson, 1986; Corbin, 1986b; Kirby & McKenna, 1989; Strauss & Corbin, 1990). Memos are the written records of analysis related to the formulation of theory. Memo writing and sorting point out areas for further clarification, refinement, and verification, and lead to further data collection. Diagramming can also be helpful. Diagrams are visual representations of relationships between concepts and they are useful to the analyst at any stage of the analytical process (Corbin, 1986a; Corbin & Strauss, 1990). Ultimately, the various processes involved in grounded theory research are aimed at theory development that "furthers the understanding of social and psychological phenomena" (Chenitz & Swanson, 1986, p. 3). Grounded theorists have studied various issues including the coming out process of young homosexuals, the integration process in stepfather families, crisis intervention and evaluation of the United States community

mental health system, women's experiences of hysterectomy, mothers' involvement in their adolescent daughters' abortions, women's experiences of pregnancy while using crack cocaine, and the psychosocial processes involved in leaving the psychiatric hospital (Chasse, 1991; Kearney, Murphy, Irwin, & Rosenbaum, 1995; Kus, 1986; Lorencz, 1991; Norris, 1991; Stern, 1986; Wilson, 1986). People's experiences of chronic illnesses such as emphysema, rheumatoid arthritis, ulcerative colitis, chronic renal failure and diabetes have also been examined (Benoliel, 1975; Fagerhaugh, 1986b; Reif, 1975; Suczek, 1975; Wiener, 1975).

Library research is an important component of grounded theory studies (Glaser & Strauss, 1967; Glassner & Corzine, 1982; Kirby & McKenna, 1989; Simms, 1981; Strauss & Corbin, 1990). Technical and non-technical literature play a significant role in grounded theory research. Technical literature, such as reports of research studies and theoretical or philosophical papers, can be used to stimulate theoretical sensitivity, to stimulate questions, to direct theoretical sampling, or it can be used as secondary sources of data or as supplementary validation. Non-technical literature, such as biographies, diaries, documents, manuscripts, records and catalogues can be used as primary sources of data or as supplementary data. Although the non-technical literature can be used for the same purposes as the technical literature, it is important to verify the findings from the non-technical literature by comparing these with other sources of data (Strauss & Corbin, 1990).

Kirby and McKenna (1989) describe two key aspects of grounded theory research they believe will expose the oppression of people on the margins of society. First, they stress that research from the margins requires intersubjectivity. Intersubjectivity is defined as "an authentic dialogue between all participants in the research process in which all are respected as equally knowing subjects" including research participants, researchers, documentation and theory (p. 129). Second, Kirby and McKenna believe that research from the margins requires critical reflection on the social context. They argue "that if we are to fully understand the data and effect change, we must try to understand contextual patterns and how they are sustained and controlled" (p. 129). Intersubjectivity and critical reflection on social contexts are significant because these processes enable researchers to affirm the words and experiences of research participants throughout analyses and, at the same time, researchers can critically reflect on the social structures that influence their lives. Furthermore, Kirby and McKenna recognize that women are among the people on the margins of society. They advocate a research methodology that combines grounded theory with feminist standpoint theory in order to document women's varied experiences of oppression in society.

Research Design

This study was both exploratory and descriptive. The chosen research methods were consistent with the combined methodology of grounded theory and feminist standpoint theory. Interviews enabled the researcher to determine the kinds of challenges endometriosis presents in women's lives and how women deal with these challenges.

Content analysis of self-help books and popular magazines, on the other hand, allowed the researcher to explore and describe how endometriosis is socially constructed.

Data Collection

Data for this study was collected through interviewing and content analysis of popular literature about endometriosis. First, interview data was collected through unstructured formal interviews. An interview guide containing a set of brief and general questions was constructed by the researcher (see Appendix A for interview questions). The researcher was not limited by the interview guide, however, and participants were allowed to report on issues that were not covered by the interview questions. The interview guide was modified after several interviews were completed in order to improve the quality of the interviews.

Second, materials were collected for the content analysis of popular literature on endometriosis using various indexes and bibliographies. During the collection of materials for content analysis, it became obvious that the popular press only began publishing magazine articles about endometriosis in 1975. The first popular self-help book on endometriosis, on the other hand, was not published until 1984. Over the course of a year, the researcher located all available materials about endometriosis published in the popular press in various university libraries at Memorial University, local public libraries and from libraries outside Newfoundland via interlibrary loans at the Queen Elizabeth II Library. Content analysis data was collected through systematic enumeration and interpretation of themes in the popular press.

Interviews

Eleven interviews were conducted with ten participants between November, 1995 and January, 1996. One participant was interviewed twice. The interviews took place in locations convenient for the participants. Interviews were usually conducted in the participants' homes or the researcher's home. Several interviews were also conducted at the student office of the Women's Studies Programme at Memorial University and the St. John's Status of Women Council Women's Centre in St. John's, Newfoundland. Each interview took approximately one hour to one and a half hours to complete. Permission was received from the participants to tape record all interviews so the interviews could be transcribed. After each interview, transcriptions were produced by the researcher. Upon completion of the research project, all tape recorded interviews were destroyed.

Participants

The interview population was delimited to women who have obtained a medical diagnosis of endometriosis. The researcher met many women who had been diagnosed with endometriosis through friends, by chance and by participating in a self-help support group for women with endometriosis. Several of these women expressed interest in participating in this study. When it was time to interview participants, the researcher had a list of names of women to call who were interested in participating. Many of these women consented to participate in an interview, and convenient times and locations were arranged for the interviews. In total, ten women were interviewed in order to identify the challenges of living with endometriosis and to learn how women cope with these

challenges. Theoretical sampling guided the number of participants interviewed. Interviews continued until no new categories were identified. The participants ranged in age between twenty-five and forty-eight years and they had been diagnosed with the condition anywhere between two and ten years. Most had been living with endometriosis for approximately five years.

Data Analysis

The data gathered in the interviews was analyzed using the constant comparative method described by grounded theorists (Baker, Wuest & Stern, 1992; Charnaz, 1990; Chenitz, 1986; Chenitz & Swanson, 1986; Corbin, 1986b; Glaser, 1978; Glaser & Strauss, 1967; Kirby & McKenna, 1989; Simms, 1981; Swanson, 1986b). The data was coded as each interview was transcribed and categories were developed from this data. Relationships between categories were analyzed and these relationships were developed until a pattern emerged. Data collection continued until the categories were saturated. After the data was collected, the researcher described and wrote the theory. Memo writing and diagramming were used to help clarify, refine and verify the data collection process. A model was developed based on the four stages of the process identified. This model, discussed fully in the findings chapter, captured the interrelationships among the stages.

Attention was also paid to the credibility of the research project. The researcher adhered to Sandelowski's (1986) criteria for establishing the credibility of qualitative research studies. First, the coding categories and examples used to present the data were

checked to ensure they were representative of the data as a whole. Second, the researcher also checked to ensure that descriptions, explanations and theories about the data contained typical and atypical elements of the data. These two criteria were met when the researcher went back over the data after the first draft of the interview data was written. Third, the researcher obtained validation from the research participants. The participants were given a draft of the chapter of the findings from the interview data and they were invited to comment on the theory the researcher developed from the data. The researcher received only positive remarks from the participants.

Content Analysis

Researchers conduct content analysis by systematically counting or interpreting themes within a set of objects, cultural artifacts or events (Reinharz, 1992). Content analysis has proven to be a useful technique for evaluating print materials and has frequently been used to examine the popular press (Chrisler & Levy, 1990). Although people rely on the mass media as a major source of information on health issues, very little research has been conducted examining information about women's health issues presented in the media (Elliot, 1994; Weston & Ruggiero, 1985).

Several studies have been conducted to determine the general content of women's health issues published in women's magazines in the United States and Great Britain (Elliot, 1994; Lepley, 1994; Weston & Ruggiero, 1985). Only a few studies have been conducted on self-help books for people dealing with physical health problems, however, and none of these studies focus specifically on women's health issues. Many self-help

books offer women advice regarding psychological and emotional problems, and researchers have focused their efforts on examining the content of these books (Jiminez & Rice, 1990). Topics of study in the area of medical self-help include studies of books recommending various diet therapies to relieve symptoms of chronic fatigue syndrome, consumer satisfaction and prescriptive practices of doctors (Morris & Stare, 1993; Starker, 1986; 1988; 1990). Weston and Ruggiero recommend researchers conduct in-depth examinations of the content of health-related material in the popular press. Recently, researchers have explored menstruation and premenstrual syndrome by interpreting themes in various magazines, magazine articles and advertisements (Christer & Levy, 1990; Coutts & Berg, 1993; Parlee, 1987; Pugliesi, 1992; Tavris, 1992). As far as the researcher knows, however, no one has yet studied endometriosis by analyzing the content of material published in popular magazines or self-help books.

The researcher attempted to identify all articles about endometriosis published in Canadian and American magazines during the time period between 1975 and 1995. Various periodical indexes including *Reader's Guide to Periodical Literature*, *Canadian Magazine Index*, *Canadian Periodical Index* and various bibliographies were used to locate fifty-four magazine articles on endometriosis. Magazines that have published articles about endometriosis can be categorized as women's magazines, news magazines, health and fitness magazines, and feminist magazines. Magazines such as *l'hebdomadaire*, *Flare*, *McCall's*, *Mademoiselle* and *Glamour* are classified as women's magazines because they contain advice specifically for women on topics such as fashion, beauty and

health. News magazines such as *Time*, *MacLean's* and *Newsweek* report recent newsworthy events. Health and fitness magazines such as *American Health*, *Women's Sports and Fitness* and *Prevention*, on the other hand, focus on issues related to health and fitness. Finally, magazines such as *Healthsharing*, *Ms.*, *Waterlily* and *Horizons* are classified as feminist magazines because these magazines analyze a variety of women's issues from feminist perspectives. The popular press published the first book about endometriosis nine years after the first magazine article appeared. Since then, there have been many books published in the popular press about endometriosis. The *Books in Print* index and various bibliographies were used to identify and locate eight self-help books about endometriosis.

A review of magazine articles and self-help books about endometriosis was conducted and the following questions were addressed: a) What kinds of information do popular magazines offer women about endometriosis? b) How does each type of magazine (i.e. women's magazines, news magazines, health and fitness magazines and feminist magazines) construct endometriosis, and how do they differ? c) How do the self-help books construct endometriosis? d) Does the popular press perpetuate sexist biases that are prevalent in our society, and if so, how are these biases revealed?

Magazine categories, titles, number of articles and publication years were determined for the articles published in popular magazines. Publication years of the self-help books were also checked and compared with the publication years of the magazine articles to determine if any trends were apparent. Themes that appeared in the popular

press were systematically counted and percentages were calculated, where possible, to determine the frequency of these themes. The significance of these themes was interpreted by the researcher to determine how endometriosis is socially constructed in the popular press. Finally, media coverage of endometriosis was evaluated in terms of the possible effects the social construction of endometriosis could have on women's lived realities of the disease.

Ethical Considerations

Four significant ethical considerations were addressed during this research project. First, the researcher sought approval of the project from the Memorial University Arts Faculty Research Committee. The research proposal was approved by this committee in October, 1995 (see Appendix B). The researcher complied with the recommendations of the committee. Since the project did not involve obtaining participants through health care institutions or health care practitioners, nor was any treatment (medical or other) associated with the study, ethical approval from a Health Sciences/Medical Ethics Committee was not required. One of the supervisors was an experienced nurse researcher, so any health care issues that arose could be discussed with her.

Second, a letter of consent was distributed to potential research participants explaining the purpose of the research project, and anyone who participated in the project was required to sign this letter (see Appendix C). In each case, two copies of the letter were signed, one for the researcher to keep on file and one for the participant to

take home. Third, in order to protect the confidentiality of the research participants, anonymity was preserved. Moreover, the names of any physicians, hospitals or health clinics mentioned in the interviews were omitted. Fourth, the researcher was aware of the sensitive nature of certain areas covered in the interviews. For example, half of the participants experienced fertility problems as a result of endometriosis, and for some of these women, infertility was difficult to discuss. The researcher handled painful matters, such as infertility, by listening and by being sensitive to the women's concerns.

CHAPTER FOUR

Research Findings

The research findings of this study includes data from interviews and content analysis of popular literature about endometriosis. The findings are separated into two sections. First, the data from the interviews is described using grounded theory methodology. Various stages and phases of women's experiences of living with endometriosis are explored. Second, popular literature about endometriosis is examined using content analysis. Various themes in the literature are counted, interpreted and described.

Interviews

The basic psychosocial problem identified for women with endometriosis was learning to live with the disease. The process of "learning to live with endometriosis" was, therefore, identified as the core analytic variable in this study. According to *Wehster's Dictionary* (1993), "learning" is "the process of acquiring knowledge, understanding, or mastery of a study or experience" (p. 273). The process of learning to live with endometriosis was defined as the process of acquiring knowledge, understanding and mastery of the challenges experienced in living with endometriosis. The process of learning to live with endometriosis consisted of four stages: a) discovering the cause(s) of menstrual problems, b) getting treatment, c) dealing with doctors, and d) living with symptoms of endometriosis. The phases of each stage are described below. Coping with emotions was classified as a subsidiary category that was

present in each stage of the learning process. Participants usually initiated the learning process in the discovery stage when they realized something was wrong. Respondents described the process of learning to live with endometriosis as circular, with the four stages of the process overlapping each other (see Figure 1). The four stages of the process overlap because the participants usually had to focus on dealing with two or more problems at the same time. Some participants progressed through all of the stages in the process of learning to live with endometriosis. Other participants only passed through two or three stages. In some instances, participants only needed to progress through certain stages, and in other cases, participants became stuck in one stage and they were unable to move to another stage. In many cases, the psychosocial processes involved in learning to live with endometriosis were never completed. Learning to live with endometriosis is a process that takes place over time.

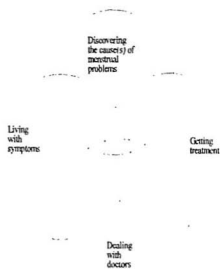


Figure 1: The Process of Learning to Live with Endometriosis

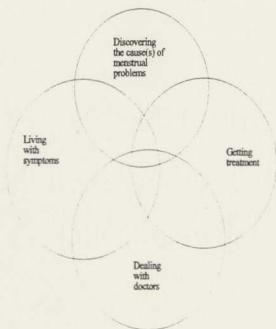


Figure 1: The Process of Learning to Live with Endometriosis

I started my periods when I was thirteen...I started realizing that my periods were too painful, they were lasting too long, anywhere from two to three weeks at a time...I didn't really know if it was normal or not.. my aunt came home...one summer...just after I turned fourteen and she...realized that this wasn't normal.

Only one participant started experiencing menstrual problems when she was in her late thirties. Two other participants realized something was wrong when they experienced painful periods and were unable to conceive. One respondent said, "I was trying to get pregnant. I was off the pill for about a year and a half and the pain was really [bad]." Three more participants noticed something was wrong when problems persisted, or got worse, over time. One respondent explained, "I had been having a lot of problems for...a long time...heavy, heavy bleeding, excessive pain." Another participant said:

Ever since I was a teenager...there was always a lot of discomfort...[T]he first time I thought something was wrong was...one month [when] I had a particularly painful period with lots of blood, lots of clotting...This time...was different...I was in a great deal of pain...it was a stabbing pain...I could barely stand, so I knew something was wrong because I had never had a period like that before...Subsequently, each period I got was just as bad.

The other participants noticed something was wrong when a new problem occurred. These problems included vaginal discharge, heightened pain or a swollen abdomen.

Phase 2: Seeking medical assistance

Participants usually sought medical assistance when they recognized something was abnormal from what they thought should be occurring with a menstrual period. Although all of the respondents reported experiencing menstrual problems, only three respondents went to their family doctors to find out the cause(s) of their menstrual problems. These participants were prescribed medications, such as Anaprox®, Motrin® and Atasol 30®, to relieve menstrual pain. The rest of the participants sought help for other gynaecological and/or medical problems. For example, two participants sought help because they were unable to conceive. One respondent thought she had appendicitis, another participant had a swollen abdomen and a third respondent wanted to know the cause of vaginal discharge. Another respondent went to her family doctor because she did not feel well. After visiting their family doctors, participants were usually referred to gynaecologists. Gynaecologists then had various tests performed including ultrasound and dilation and curettage.⁵ Two participants were admitted to hospital immediately for surgery because gynaecologists suspected they had ovarian cancer. Another respondent was also admitted to hospital on an emergency basis for surgery to treat an ovarian cyst. Most of the respondents, however, were scheduled for a

⁵ Dilation and curettage (D and C) is a surgical procedure in which physicians dilate the opening of the cervix and insert a long, thin metal instrument called a curette through the cervix into the uterus to scrape out some of the uterine lining. Dilation and curettage is used to find the cause of uterine bleeding and to diagnose uterine fibroids, endometrial polyps and uterine cancer.

laparoscopy because their gynaecologists suspected they had endometriosis. One respondent was scheduled for a hysterectomy to treat cervical cancer.

These respondents sought help either when they realized something was wrong or they felt they could no longer tolerate their menstrual problems. Participants reported feeling anxious to know the cause of their menstrual problems. All of the respondents reported seeking help for their menstrual problems because they thought something was wrong. Five respondents, including two women who realized something was wrong when they were teenagers, persisted in seeking help for a long period of time. These participants visited many doctors, continuing to change doctors, until they found someone who was able to help them. One participant visited different doctors for ten years before she found a doctor who was able to help her. She explained:

I've had [menstrual problems] since I've been seventeen...at nineteen I went in with the same problem[s]...and the doctor said that he'd do a D and C. So I went under for the D and C and...he couldn't do it...he decided to do nothing else...Ten years later I was finally diagnosed [with endometriosis] by somebody else.

Two other participants received the help they sought only after they were unable to conceive. Finally, it was not always menstrual problems that got participants the help they desired. Three respondents only received help upon the appearance of a new problem such as a swollen abdomen, vaginal discharge or the possibility of appendicitis.

Phase 3: Obtaining a diagnosis

All of the participants were diagnosed with endometriosis during surgery. Six participants had diagnostic laparoscopies because their gynaecologists thought they had endometriosis. Five women were diagnosed with endometriosis at the laparoscopy. One woman was told by her gynaecologist she thought she had endometriosis but she could not locate it during the laparoscopy. The other participants were diagnosed with endometriosis during surgery for other gynaecological problems.

Respondents reported that obtaining a diagnosis of endometriosis evoked a variety of emotions including depression, anger, helplessness, frustration, fear and anxiety. One participant said, "I'm worried all the time." She worried about not being able to get pregnant and about getting sick. Another respondent reported, "I really lost control of my emotions...I didn't have a clue what I was doing...I remember...the day that my sister said to me, 'You have to do something about this...you can't continue like this.'" Several participants had been told by their doctors that endometriosis can cause infertility and they reported feelings of fear and anxiety about the progression of the disease and its effects on their fertility. One participant said, "I think...the uncertainty of the infertility was worse than the actual infertility itself." Another respondent explained, "I was totally depressed for months after [being told I had endometriosis and I was infertile]." A third respondent reported she was shocked to discover she had "chronic" endometriosis. Most of the respondents, however, reported feeling relieved to finally know what was wrong with them.

Stage 2: Getting Treatment

Phase 1: Treating endometriosis medically and surgically

The participants reported that medical treatment of endometriosis began soon after diagnosis was confirmed. Treating endometriosis medically involved two components. First, medications were used to try to alleviate physical symptoms of the disease. Second, medical and/or surgical treatments were used to try to eliminate symptoms and/or slow the progression of the disease. Participants reported that medical and surgical treatments occurred alone, at the same time or in sequence.

The first phase of treating endometriosis medically usually involved continuing to take over the counter and prescription medications to relieve menstrual pain. Six participants reported they continued to use pain killers to try to relieve their symptoms of endometriosis. Respondents reported that various hormone medications, including oral contraceptives, Lupron®, Synarel® and Danazol®, were usually prescribed next. Hormone medications were used to stop the menstrual cycle for a limited amount of time to try to slow the progression of the disease and ease symptoms. Six respondents reported using hormone medications. Oral contraceptives were the most commonly prescribed hormone treatments among the women interviewed, with four respondents reporting they had used them. The respondents who used oral contraceptives reported various results. For example, one respondent reported that oral contraceptives relieved her symptoms of endometriosis, while another woman reported oral contraceptives only had a moderate effect. Two participants reported oral contraceptives were totally

ineffective. Three participants reported taking Danazol®, while another woman took Lupron®, but these medications were useless. One participant was recently prescribed Synarel® and she reported that it relieved her pain:

I was put on Synarel® because they discovered through [medical] tests...my estrogen levels were still as high as someone who still had ovaries. So I was put on Synarel® to reduce the production of estrogen...for seven months....the seven months that I was on Synarel® I felt good. I didn't have any adverse side effects to the drug...And then I was taken off that drug and I've been okay since.

Some participants reported suffering from unbearable side effects of the hormone medications including migraine headaches, mood swings, fluid retention and muscle cramps. One respondent described the side effects of Danazol®:

Danazol®...didn't agree with me at all...I had no control over my emotions whatsoever, I retained so much body fluid that I just couldn't wear any of my clothes any more (and the) muscle cramps were beyond belief. By the time I got home from work in the evening, I could barely stand and I would even get the muscle cramps in my chest if I turned a certain way...the side effects were...too much for me to handle...when the three months were over, I [decided] I'll suffer with the disease before I'll suffer with the cure.

Most of the respondents also had surgical treatment for endometriosis. Eight respondents had endometriosis treated surgically via laparoscopy or laparotomy. Four participants reported they had both medical and surgical treatments concurrently. Four respondents had multiple surgeries for diagnosis and treatment of endometriosis. One participant had four laparoscopies for diagnosis, re-diagnosis and treatment of

endometriosis. Two participants reported they had hysterectomies; one woman had a hysterectomy to treat endometriosis, the other woman had a hysterectomy to treat cervical cancer. Although one of these women reported she felt healthier after her hysterectomy, the other woman reported a recurrence of endometriosis symptoms. Several participants reported they felt healthier immediately after surgical treatment but most of them reported a recurrence of their symptoms after some time had passed. One respondent described the surgical treatment as giving her a stage of relief:

The symptoms are starting...to reoccur...it starts on ovulation and it progresses...until I'm finished my period...so I get about one good week a month...But...it's still not nearly as severe as it had been prior to the surgery...It's been a relief stage.

Although the various medical and surgical treatments were effective for some of the respondents, they reported that medical and surgical treatments usually only alleviated symptoms of endometriosis temporarily. Moreover, participants reported that side effects of medical treatments caused new physical problems. The respondents reported that medical treatments alone did not usually help them to manage physical symptoms. Several respondents reported seeking other methods of managing symptoms.

Phase 2: Integrating old management strategies with medical and surgical treatments

Respondents reported devising management strategies to relieve their menstrual problems including the use of over the counter and prescription medications, the application of heat to sore muscles and exercise. The participants reported that they continued to use these management strategies after endometriosis was diagnosed. First, five participants reported that over the counter and prescription medications such as Anaprox[®], Motrin[®], Atasol 30[®] and oral contraceptives helped to relieve menstrual pain. Some respondents reported that these medications "help[ed] tremendously," while others reported that when the pain was "at its worst," no medications would alleviate the pain. Two participants described an aversion to taking pain medications. One respondent explained, "I'm not one to take pills, I hate taking pills...but...when the pain is so bad I have to take [them]." Another participant believed she was becoming addicted to pain killers, so she stopped taking them:

I just couldn't deal with the pain, so I turned to pain killers...[F]inally one morning...I was in incredible pain and I went to the medicine cabinet and I remember seeing just a bunch of pain killers there...I was so confused, [I thought], "Which one do I take first?" So that's when I decided...to stop taking them...I flushed them all down the toilet...and I said no more pain killers.

Second, three respondents reported using hot water bottles, heating pads and hot baths to soothe and relax their sore muscles. One participant said, "It was nothing for me

to get up out of the bed in agony...[at] three and four o'clock in the morning...and go and take a hot, hot, hot bath...it was so hot you could just barely stand getting into it "

Third, four respondents reported that exercises such as running and aerobics eased physical pain. One respondent also reported that regular exercise helped her cope with the emotional stresses provoked by endometriosis:

I run...I...notice a big difference when I don't [run]. I notice that I can't cope as well...I'll just put on my running shoes and go out the door and say "I've got to get rid of this." [I]t helps with the...physical pain as well as the emotional stress.

Participants reported they combined the management strategies they had devised prior to diagnosis of endometriosis with the medical and surgical treatments prescribed for the disease.

Phase 3: Finding new alternative therapies

Several respondents reported the combination of medical treatments and their old strategies did not always relieve their endometriosis symptoms, so they sought alternatives. Alternative therapies helped several of the participants relieve their symptoms of endometriosis. For instance, three respondents reported they changed their diets, to exclude red meat and dairy products or to include vitamin and mineral supplements, with the help of nutrition counsellors or naturopaths. Although two participants reported they noticed improvements in their health, one respondent reported the dietary changes recommended by a naturopath cost her too much money and made

her illness worse. Another participant reported that changes in her diet, with the help of a naturopath, was the next step in her efforts to cope with the physical symptoms of endometriosis.

Two participants reported using other alternative therapies. One participant reported reading literature on positive thinking and "self-directed healing." She believed using these healing techniques helped ease her physical symptoms for a few months. Another respondent reported that acupuncture and Chinese herbs relieved her pain and allowed her to function every day:

The only thing that's working for me at this moment is acupuncture...from a Chinese doctor who studied acupuncture in China...that's really made a difference with my pain...she takes away my pain...If you can take away the pain, I'm quite happy.

Although alternative treatments can also be combined with medical and surgical treatments to try to improve women's general health, the women interviewed only used alternative treatments after medical treatments failed to help them. Respondents reported turning to alternative treatments when they were feeling desperate enough to "try anything" that would alleviate their symptoms.

Stage 3: Dealing With Doctors

Phase 1: Visiting doctors

Participants reported that "dealing with doctors" was one of the most challenging aspects of learning to live with endometriosis. Learning to deal with doctors was necessary, however, because many participants reported they continued to visit doctors frequently, even after they were diagnosed with endometriosis. Participants described their meetings with doctors as "frustrating." Most of the respondents were frustrated with doctors for four reasons: a) they believed doctors did not listen to their complaints, and therefore, did not take their complaints seriously, b) doctors were often unable, and sometimes seemed unwilling, to help them, c) doctors often believed they were suffering from psychological disorders when they described symptoms of endometriosis, and d) many doctors displayed paternalistic and sexist attitudes.

Five participants reported that doctors would not listen to their complaints and questions. For example, four participants reported that doctors refused to listen to their complaints because the doctors believed menstrual problems such as pain and heavy bleeding were normal. One participant reported that visiting doctors about menstrual problems was like "talking to a wall." Another respondent reported she was not even allowed to ask her gynaecologist questions after he diagnosed her with endometriosis. Five participants reported they were frustrated with doctors because they were unable, and sometimes seemed unwilling, to help them. For instance, three respondents reported that gynaecologists frequently prescribed pain medications and sent them away. Two

other respondents reported their doctors refused to see them on certain occasions. Although it is a doctor's right to choose not to treat someone, these participants felt abandoned by their doctors when they needed them:

I had one doctor who refused to see me on one occasion...I didn't go back to that doctor...by that time I'd already been diagnosed with endometriosis...yet [the doctor] still refused to see me...her attitude was that...there wasn't anything else she could do for me.

Respondents reported that doctors frequently thought they were suffering from psychological disorders when they described various symptoms of endometriosis. Two participants reported they were treated for depression and endometriosis simultaneously. Another participant visited a gynaecologist who recommended that she see a psychiatrist to deal with her mood swings. Several other participants believed their doctors thought they were "crazy."

Finally, respondents encountered paternalistic and sexist attitudes upon visiting doctors. One participant explained that her doctor's paternalistic attitudes affected her interactions with him because he yelled at her, refused to answer her questions and only treated her with respect when she brought her boyfriend to their meetings. Several respondents also reported incidences of sexist behaviour during physical examinations. For example, one woman reported that the gynaecologist pinched her on the stomach and commented on her figure during an examination:

I was lying on his table...and...he grabbed my stomach, gave me a little pinch and he said "Oh, you're still the skinniest patient I have. I see you're still nice and skinny"...I thought [it] was extremely inappropriate for him to touch me when I didn't want to be touched.

Another participant reported that when she refused to let a doctor at a hospital examine her "interesting case of endometriosis," the doctor said he would just wait until she was in surgery. The respondent felt violated by this doctor: "That's assault....when I say no, he doesn't respect [my wishes]...[T]here wasn't any respect at all for me as a...person." Participants also reported that doctors sometimes told them pregnancy was the only thing that would cure their endometriosis and they should, therefore, consider pregnancy as a treatment option. One participant felt pressured by doctors to get pregnant in order to alleviate the symptoms of the disease. She explained:

[T]here seems to be a lot of pressure to [get pregnant] when you have endometriosis...even when I was seventeen...[pregnancy] was posed as an option...we went with the birth control pills and after...I noticed...they weren't working...the doctor finally said, "You're going to have to try something else"...then I seriously considered having a baby...Right now, I've put it on the back burner again because I'm still in school...I'm going to finish school, I'm going to have a career and eventually get married and...have children *if* that's still an option for me.

Another respondent reported she was willing to ignore the paternalistic and sexist attitudes of her doctor because he was knowledgeable about endometriosis. Most of the participants, however, found this difficult to do.

Phase 2: Changing doctors

Participants reported it was necessary to visit many doctors, changing doctors frequently in order to find doctors who listened to them and who tried to help them. Seven participants reported changing doctors. One participant visited seven gynaecologists, another visited five gynaecologists, and a third participant changed family doctors three times and gynaecologists twice. Respondents reported they devised a strategy of changing doctors in order to find someone who could help them. Changing doctors allowed participants to avoid doctors who prevented them from discovering the cause(s) of their menstrual problems and managing their symptoms of endometriosis.

Five respondents reported the strategy of changing doctors enabled them to find new doctors who were good listeners, who respected them and who trusted their knowledge of their own bodies. Participants reported their new doctors allowed them to be equal partners in decisions about their medical treatments. One participant explained, "I finally think I've found [doctors] who [are] willing to listen to me...[they] seem more willing...to concede to my knowing as much or more about my medical problems as [they do]." Three participants also reported that being more assertive and decisive in their interactions with doctors helped them to communicate with doctors. One respondent insisted, "You can't be a passive patient with this disease." Another participant reported that by asking questions and informing doctors of her treatment needs, she learned to become an effective communicator:

I've...been more inclined to question doctors and...what they've decided to do with my treatment, whereas before I had all these medical problems I would go to a doctor, and if the doctor said, "Take two aspirins and call me in the morning," then that's what I would do. But now...I question. I'll say "Well, do I need to take two aspirins? Maybe I can just go to bed and call you in the morning." I've had no problem with the two doctors I'm dealing with now on a regular basis.

Several participants reported they were still not entirely happy with the care provided by their doctors, even after changing doctors, and they would continue to change doctors.

Stage 4: Living with Symptoms of Endometriosis

Respondents reported that the two most troublesome symptoms of endometriosis were pain and infertility. All of the respondents reported experiencing symptoms of pain. Only half of the participants, on the other hand, reported experiencing fertility problems. Although the participants reported coping with emotions was a significant part of each stage, this phase predominated the final stage in the process of learning to live with endometriosis. Respondents reported that symptoms of endometriosis, especially pain and infertility, were particularly stressful. Respondents reported that the symptoms of endometriosis caused them to experience anxiety and mood swings. For example, nine participants reported that pain symptoms gave them unpredictable mood swings. They reported that mood swings encompassed feelings of extreme happiness and severe depression. One participant reported that every mood "was really at its peak." Four participants reported that fertility problems contributed to feelings of depression.

These participants reported fertility problems were the most difficult aspect of living with endometriosis. They described infertility as "devastating":

[The] fact that I may never have children is something I find very difficult to live with because I'm getting older now and biologically it's getting more and more difficult...and...less and less safe...for me to have a child...Not having children is definitely the most devastating [part of having endometriosis] for me.

[The doctor]...[told me] the day before I turned thirty...that the fertility was irreversible....this was...devastating to me...[N]ow [the doctor] says that...I may be able to get pregnant...I have tried constantly [to get pregnant] with no success...I was totally depressed for months after [being told that I was infertile]...every month when my period comes, [it is] a big disappointment for me...the year before I was diagnosed [with endometriosis] I finally decided...I [did want children]...So that [was] disappointing.

Another young participant reported that the possibility of infertility made her feel depressed. She explained, "Right from the beginning I was told that there was a possibility...I could be infertile...For a long time I let that worry me...I just felt there's never going to be any hope for me." Only one participant reported she easily accepted the possibility of infertility. Four other respondents already had children and they were not concerned with the effects of endometriosis on their fertility.

Participants devised two strategies for living with the symptoms of endometriosis: managing pain symptoms and accepting infertility. First, respondents reported that alleviating pain symptoms through a variety of medical, surgical and alternative methods enabled them to live more comfortably with endometriosis. For instance, one participant

reported that Synarel®, a hormone medication, alleviated her pain symptoms. Another respondent reported her disease symptoms were alleviated by a hysterectomy, and as a result, her emotional stress eased. Finally, another participant reported that acupuncture and Chinese herbs relieved her pain and enabled her to function every day. Each of these participants tried various methods of management until they were able to find a way to relieve their physical symptoms, and thus, dispel emotional stress caused by chronic pain.

Second, five participants reported that accepting infertility was a lengthy process involving time and finding alternatives to bearing children. First, the passage of time allowed respondents to get used to their fertility problems. One participant explained, "[T]he best thing...that helped us with coming to grips with [infertility] was...just time...it turns out that cliché, time heals wounds [is] true." The passage of time enabled respondents to get used to the idea that they might not bear children and to reevaluate what was important in their lives. It also gave participants a chance to decide if they wanted to find alternatives to bearing children, and thus move into the next phase of this stage. Several respondents reported that after some time had passed, they realized there were alternatives available besides having one's own children. For example, one participant reported surrounding herself with children as much as possible:

I try to surround myself with children...I've worked as a daycare teacher...as a nanny...as a summer camp counsellor [and] a baby sitter...I have a lot of friends [who are] single parents [and] I try to help them out as much as I can and take on this...auntie role. Surrounding myself with

children makes me feel like I'm not missing out...I can still be around [children] and...enjoy them...I don't see why I have to divorce myself from children if I can't have them physically, I think that would be foolish and worse for me.

Four other respondents reported that adoption was an alternative to having their own child that they would consider. One of these respondents explained she would like to adopt a child, but due to lengthy waiting lists, an adoption could take many years and she did not know if she was willing to wait. Participants suggested lengthy waiting lists could be avoided by arranging private adoptions or adopting a child from another country. One young respondent reported that she and her husband already put their names on waiting lists, despite the fact that they do not yet know if she is infertile.

The Process of Learning to Live with Endometriosis

The interview data demonstrated that women with endometriosis struggle to cope with the challenges of living with the disease every day. These women had learned to live with endometriosis by focusing on the part or parts of the process that were important to them, suggesting that women involved in the process of learning to live with endometriosis may focus exclusively on one stage or phase at a time, in sequence, or they may concentrate on two or more stages or phases at the same time. For example, some chose to manage their physical symptoms before they tried to discover the cause(s) of their menstrual problems, or they learned to deal with doctors and manage their physical symptoms at the same time. Since the process of learning to live with endometriosis was not linear, some women focused on the parts of the process in a different order than they

are organized here. Some women already had been able to handle certain aspects of living with endometriosis. For example, one participant while very young had accepted the fact that she would never bear children. Other women, on the other hand, still needed to learn to accept that they may never bear children. Learning to cope with one problem also eliminated other problems. This was the case for the respondent who found that her emotional stresses dissipated and her health returned after she had a hysterectomy. Learning to live with endometriosis took place over time and for some the psychosocial processes involved in learning to live with endometriosis may never be complete.

Content Analysis

There were fifty-four magazine articles about endometriosis identified in the popular press since 1975. Popular magazines articles about endometriosis were found in four categories of magazines: a) women's magazines, b) feminist magazines, c) news magazines, and d) health and fitness magazines (see Table 1 for magazine categories, titles, number of articles and publication years). The popular press has also published eight self-help books that were used in this study (see Table 2 for titles and publication years). The majority of the self-help books and magazine articles about endometriosis were published between 1985 and 1993. During this time period, forty-two magazine articles and five self-help books were published.

Content analysis of popular magazine articles and self-help books about endometriosis also revealed they offered women information about medical aspects of endometriosis including obtaining a diagnosis, symptoms of pain and infertility, medical

treatments, alternative therapies and how to find information and resources. One area of importance only discussed in the self-help books was coping with emotions. Women's stories of living with endometriosis were also included in popular magazines and self help books. The following sections highlight these findings.

Table 1: Magazine Categories, Titles, Number of Articles and Publication Years

<u>Magazine Categories and Titles</u>	<u>Number of Articles and Publication Years</u>
<u>Women's Magazines</u>	
Canadian Living	1 (1990)
Châtelaine	1 (1985)
Flare	2 (1987, 1993)
Glamour	2 (1990, 1991)
Good Housekeeping	2 (1980, 1987)
Ladies' Home Journal	1 (1975)
Mademoiselle	3 (1978, 1985, 1987)
McCall's	4 (1981, 1985, 1987, 1989)
Parents	1 (1991)
People Weekly	1 (1985)
Redbook	2 (1982, 1986)
Verve	1 (1987)
Working Woman	1 (1979)
	Total: 22
<u>Feminist Magazines</u>	
Healthsharing	7 (1981, 1988, 1990, 1991, 1993)
Henzoris	1 (1994)
Ms	2 (1981, 1995)
Waterlily	2 (1990)
	Total: 12
<u>News Magazines</u>	
MacLean's	3 (1982, 1988, 1989)
Newsweek	1 (1986)
Time	1 (1986)
Western Report	1 (1989)
	Total: 6
<u>Health and Fitness Magazines</u>	
American Health	1 (1988)
FDA Consumer	1 (1986)
Health	2 (1986, 1988)
Health News	1 (1993)
Let's Live	2 (1989, 1992)
Prevention	3 (1979, 1987, 1990)
Today's Health	2 (1987, 1990)
Vegetarian Times	1 (1992)
Women's Sports and Fitness	1 (1986)
	Total: 14
	Total Number of Articles: 54

Table 2: Titles of Self-Help Books and Publication Years

<u>Title</u>	<u>Publication Years</u>
<u>Endometriosis</u>	1984
<u>Overcoming Endometriosis: New Help From The Endometriosis Association</u>	1987
<u>Living With Endometriosis: How to Cope With The Physical And Emotional Challenges</u>	1987
<u>Coping With Endometriosis</u>	1988
<u>The Endometriosis Answer Book: New Hope, New Help</u>	1988
<u>Fibroid Tumors And Endometriosis: A Self-Help Program</u>	1993
<u>Alternatives for Women With Endometriosis: A Guide By Women For Women</u>	1994
<u>The Endometriosis Sourcebook</u>	1995

Medical Aspects of Endometriosis

Self-help books and the different kinds of magazines offered women information about the medical aspects of endometriosis, including diagnosis, symptoms, and medical and surgical treatments. Self-help books, however, presented more detailed information than the magazine articles. Endometriosis was generally constructed by the popular press as a physical health problem in which the symptoms of pain and infertility could be controlled by medicine or surgery.

Obtaining a diagnosis of endometriosis

Women's magazines, feminist magazines, and news magazines addressed women's difficulties of getting an accurate diagnosis of endometriosis. Nineteen percent of magazine articles about endometriosis considered this problem. Women's stories of living with endometriosis reflected the phenomenon of misdiagnosis and the difficulties of getting an accurate diagnosis of endometriosis. For example, Latta (1988) was informed that she had an ovarian cyst, while Lane's (1990) menstrual problems and pain went unaddressed for many years. Although Lane experienced pain, she did not know there was something wrong:

As a teenager I dreaded the approach of a period. It was like being tossed into a torture chamber each month...I didn't bother checking with a doctor because I figured it was normal - 'all teenage girls go through it...' (p. 26).

News magazines and feminist magazines reported that misdiagnosis was common. For instance, Rooney (1989) reported women with endometriosis were often misdiagnosed as having psychosomatic disorders. In an edition of *Healthsharing*, Williams (1993a) reported that a study of Black women with endometriosis found that as many as 40% were previously misdiagnosed as having a sexually transmitted pelvic inflammatory disease. Williams explained that Black women were often misdiagnosed as having pelvic inflammatory disease because of racial biases in medical textbooks that suggested Black women were more sexually promiscuous than women of other races and, therefore, they were more likely to get a sexually transmitted disease such as pelvic inflammatory disease. *Healthsharing* magazine, a feminist publication, was the only magazine article that addressed the issues of race and racism in the diagnosis of endometriosis in women of colour.

One article published in *McCall's* warns women to beware of doctors who over diagnose endometriosis (Nolen, 1981). Women's stories of endometriosis in all the different kinds of magazines did not, however, reflect this phenomenon. Williams (1994) reported the use of laparoscopy as a diagnostic technique probably resulted in the discovery of thousands of previously undiagnosed cases of endometriosis, thereby providing medical confirmation of the pain that many women had been told they were imagining.

Like the popular magazines, self-help books also described the surgical techniques used to diagnose endometriosis. Self-help books, however, included more

detailed information than the magazines about women's anatomy and the relationship between menstruation and endometriosis (including illustrations and diagrams) in their explanations of endometriosis and diagnostic techniques. Five of the self-help books, in contrast to the popular magazines, offered women practical advice on how to find a doctor to diagnose and treat endometriosis (Ballweg & Endometriosis Association, 1995; 1987; Breitkopf & Bakoulis, 1988a; Lauersen & de Swaan, 1988; Older, 1984). Glossaries were also found in four of the books to explain medical terminology used in the diagnosis and treatment of endometriosis.

Symptoms of endometriosis: Pain and infertility

All of the self-help books and the majority of the magazine articles identified both pain and infertility as symptoms of endometriosis. Self-help books, however, identified infertility as the most difficult symptom of endometriosis. Thirty-three percent of the magazine articles also identified infertility as the most problematic symptom, while 30% of the magazine articles indicated that pain was the most troublesome symptom. The different kinds of magazines, however, usually emphasized one symptom more than the other. For instance, feminist magazines usually mentioned that infertility was a possible symptom or side effect of endometriosis, while the other kinds of magazines stressed the threat of infertility (see Table 3). In contrast, 67% of articles in feminist magazines emphasized that pelvic pain, rather than infertility, was the most troublesome symptom of endometriosis (see Table 4).

Table 3. Frequency of Emphasis on Infertility in Articles about Endometriosis

<u>Magazine Category and Number of Articles</u>	<u>% Articles</u>
Women's Magazines (10 of 22 articles)	45%
Feminist Magazines (0 of 12 articles)	---
News Magazines (4 of 6 articles)	66%
Health and Fitness Magazines (4 of 14 articles)	29%
Total: 18 articles	Total: 33%

Table 4: Frequency of Emphasis on Pain Symptoms in Articles about Endometriosis

<u>Magazine Category and Number of Articles</u>	<u>% of Articles</u>
Women's Magazines (1 of 22 articles)	4%
Feminist Magazines (8 of 12 articles)	67%
News Magazines (3 of 6 articles)	50%
Health and Fitness Magazines (4 of 14 articles)	29%
Total: 16 articles	Total: 30%

The emphasis on pain in self-help books and feminist magazines was explicit in discussions of the nature of the pain associated with endometriosis and pain management techniques. For instance, Ballweg and the Endometriosis Association (1995) included in their book an article reviewing research on the nature and the causes of pain associated with endometriosis. All of the self-help books offered women practical information about pain management. Only feminist magazines described in detail the kinds of pain associated with endometriosis: "The pain is usually described as sharp, stinging and burning in nature, and is not necessarily associated with menstrual periods" (DeMarco, 1991, p. 18).

The emphasis on infertility in self-help books was evident in two ways. First, the self-help books usually devoted whole chapters to the topic, compared to a brief discussion of pain. They provided women with useful information about medical aspects of infertility such as how physicians determine infertility and its causes, possible ways in which infertility could be caused by endometriosis, medical and surgical treatments for endometriosis-related infertility, and ways of circumventing infertility via reproductive technologies and fertility drugs. Second, most of the authors of self-help books about endometriosis discussed the fact that endometriosis is commonly known in society as "the career woman's disease." Although most of the books dismissed "the career woman's disease" as myth, two of the self-help books on endometriosis examined in this study continued to perpetuate the notion that endometriosis is "the career woman's

disease." Lauersen and de Swaan (1988), for example, maintained that "working women are most likely to succumb to endometriosis" (p. 7).

Only the books written by Ballweg and the Endometriosis Association (1995; 1987) did not feature infertility. Ballweg and the Endometriosis Association (1987) downplayed infertility by calling the chapter on fertility issues in their first book "Fertility and Pregnancy Considerations." In their second book, Ballweg and the Endometriosis Association (1995) reported on the results of a study of pregnancy, labour and postpartum experiences of women with endometriosis. Furthermore, the self-help books written by Ballweg and the Endometriosis Association were the only books that contained separate chapters about the symptoms of infertility and pain.

The significance of infertility was also conspicuous in women's magazines, news magazines, and health and fitness magazines. First, several of the articles in women's magazines were particularly frightening. For instance, one article published in *Mademoiselle* described endometriosis as "one of the scariest health problems facing many young women today...it is a 'silent' [disease] that can rob them of their fertility" (Morice, 1987, p. 94). It was also assumed by reporters that all women want to bear children and, therefore, they must be concerned with preserving their fertility. For example, Cherry (1991) advised women that if endometriosis was diagnosed early, it could be treated "before you experience any symptoms and can be prevented from spreading, thus preserving your ability to conceive a child" (p. 184).

Second, there were several articles in women's magazines, news magazines, health and fitness magazines and feminist magazines that focused on the notion that endometriosis is "the career woman's disease." Of the articles examined, 30% described endometriosis as "the career woman's disease" (see Table 5). This notion stems from the belief of medical doctors that if a woman with endometriosis delays childbearing in favour of her career, then her chances of becoming pregnant *may* decrease. The idea that there was an endometriosis-prone personality was encompassed in the concept of "the career woman's disease." Women with endometriosis were reported to be intense and ambitious career women with demanding jobs (Gray, 1981; Norwood, 1985; Smith, 1979; Zimmerman, 1975). Like some of the self-help books, these articles stressed that women who postponed childbearing because they wanted to establish careers were more likely to develop endometriosis. Many of these articles were written in the 1970's and 1980's, however, and some of the later magazine articles suggested that "the career woman's disease" was a myth:

Once thought to be a "career woman's disease," largely because those were the women who sought medical help and were diagnosed with it, endometriosis is now known to be common among women of all ages, races and economic levels (Morson, 1991, p. 84).

Several of the magazine reporters writing for women's magazines and health and fitness magazines in the late 1980's and early 1990's, however, failed to recognize that the notion of "the career woman's disease" was outdated and they perpetuated this myth.

Table 5: Frequency of Discussion of Endometriosis as "The Career Woman's Disease"

<u>Magazine Category and Number of Articles</u>	<u>% of Articles</u>
Women's Magazines (8 of 22 articles)	36%
Feminist Magazines (1 of 12 articles)	8%
News Magazines (4 of 6 articles)	67%
Health and Fitness Magazines (3 of 14 articles)	21%
Total: 16 articles	Total: 30%

For example, Rogers (1993) informed readers that endometriosis was "known as the career woman's disease [because] it is usually found in women attempting to conceive during their career-forming years" (p. 54). Although many of the later articles in women's magazines, health and fitness magazines and news magazines reported that endometriosis was once thought to be a career woman's disease, reporters were still using the phrase "the career woman's disease," thereby contradicting their intentions of dispelling this myth (Cherry, 1991; Clark & Carroll, 1986; Monson, 1991; Morice, 1987; Rogers, 1993; Wallis, 1986). Readers could still go away with the idea that the development of endometriosis was somehow related to being a career woman. Johnson (1985) argued "the label has stuck" (p. 71). Only feminist magazines, such as *Healthsharing*, *Herizons* and *Ms.*, successfully eliminated the notion of endometriosis as "the career woman's disease." For instance, an article published in a 1981 edition of *Ms.* referred to endometriosis as "the career woman's disease." There was, however, no mention of "the career woman's disease" in an article published in a 1995 edition of the magazine. In *Healthsharing* magazine, DeMarco (1991) addressed "the career woman's disease" myth without using this particular phrase.

Titles of articles, subtitles and section headings in the magazines also emphasized a connection between endometriosis and infertility. For example, several of the titles revealed the emphasis on infertility: "Can't get pregnant?" "Endometriosis: A growing cause of infertility in women," "The baby blues: How late should you wait to have a child?" "Fitness and infertility: Exercise as an antidote to endometriosis,"

"Endometriosis is a common cause of infertility in women...", "Endometriosis: The new young women's infertility disease" and "They said I couldn't have a baby." Articles in all the different kinds of magazines included the phrase "the career woman's disease" in the titles, emphasizing the supposed connection between career women and endometriosis. Although Bird (1987) tried to dismiss the notion of "the career woman's disease" as a myth, the location of her article under the section heading "Work Alert" in *Flare* magazine contradicted this effort. Moreover, the subtitle attached to Bird's article stated: "Infertility caused by endometriosis will strike thousands of women this year - and working women are high on the list of victims" (p. 93). Cherry's (1991) article on endometriosis and infertility was inappropriately located in a section called "As They Grow: Pregnancy and Birth" in *Parents* magazine.

Medical and surgical treatments of endometriosis

Popular magazine articles and self-help books discussed medical and surgical treatments of endometriosis. All of the self-help books covered a variety of medical treatments including medications and surgery and most of the books offered women as much information as possible about all treatment options. Authors of self-help books occasionally promoted one treatment for the disease, such as Lauersen and de Swaan (1988), who favoured the hormone medication Danazol[®] above the other available treatments. The other authors provided as much information as possible about every available medical treatment.

There were, however, significant differences in the kinds of information women received from different types of magazines about the medical treatments of endometriosis. For instance, health and fitness magazines and feminist magazines offered women more detailed and more accurate information about the medical treatments of endometriosis compared to articles in news magazines and women's magazines. In reports about the side effects of various medical treatments for endometriosis, for example, health and fitness magazines such as *Vegetarian Times* and feminist magazines such as *Healthsharing* were more candid than women's magazines and news magazines. They included descriptions of possible side effects and the experiences of women who suffered side effects of medical treatments. When side effects of medical treatments were presented in women's magazines and news magazines, however, they were often minimized and readers were not informed of women's experiences with these treatments. Moreover, news magazines such as *Time* and *Newsweek* only published short articles when a new medical or surgical treatment was available, whereas women's magazines, health and fitness magazines and feminist magazines all reported on treatments in conjunction with other aspects of endometriosis.

Alternative Therapies

Self-help books and popular magazines also featured information about alternative therapies. Six self-help books included information about alternative therapies, while 15% of the magazine articles published about endometriosis focused on the topic. Alternative therapies suggested in these articles and books included diet and

nutrition, acupuncture, herbs, homeopathy, visualizations, affirmations, relaxation, detoxification, massage, reflexology and exercises such as yoga and tai chi. Feminist magazines and health and fitness magazines, for example, investigated the use of alternatives to medical treatments for pain relief and healing. Reporters argued that women could heal themselves by using alternative therapies and maintaining a healthy lifestyle. Valverde (1981) suggested, for example, that "self-healing might mean changes in living and eating habits, as opposed to taking a prescribed drug" (p. 14). Challem and Lewin (1989), on the other hand, recommended certain vitamins and minerals that could reduce the amount of estrogen in women's bodies, thereby relieving symptoms of endometriosis. One woman reported she healed her endometriosis through the self-prescribed use of vitamin and mineral supplements (Karnes, 1979).

Four self-help books contained one chapter briefly describing alternatives to medical and surgical treatments. Two other books focused exclusively on alternative therapies. These books emphasized that alternative therapies can help women to manage pain symptoms of endometriosis and ease emotional stresses. Most of the information on alternative therapies included in these books was very brief, however, and the authors usually informed readers how to locate further resources on alternative therapies. Lark's (1993) self-help program for relief of symptoms of endometriosis and fibroid tumors contained more detailed information on dietary changes and stress reduction techniques. Menus, meal plans and recipes were provided in order to help women make dietary changes. Lark's stress reduction techniques also contained instructions on how to do the

various kinds of exercises. Carol (1994), on the other hand, briefly discussed the benefits of various alternative therapies used by women with endometriosis. Carol provided readers with evidence that alternative therapies helped women live with endometriosis by including women's own accounts of their experiences with alternative therapies. Carol also referred to studies of the effects of alternative therapies, such as traditional Chinese medicine, in the treatment of endometriosis. Lark, on the other hand, based her techniques on her medical knowledge and her experience treating women in her medical practice.

Information and Resources for Women

Self-help books and magazine articles about endometriosis were written in order to provide women with information about the disease. Much of this information has already been discussed. Feminist magazines and self-help books produced by the Endometriosis Association, however, offered women information that was not found elsewhere. Ballweg and the Endometriosis Association (1995; 1987) and feminist magazines, for instance, reported on the possibility that environmental toxins contribute to the development of endometriosis. Ballweg and the Endometriosis Association also investigated the growth of endometriosis in men and the notion that endometriosis may be linked to other health problems. The most recent book written by Ballweg and the Endometriosis Association (1995) also incorporated new information on the incidence of endometriosis in the intestines and the urinary tract, the patient's perspective of endometriosis and how men can help women to cope with endometriosis.

Women's magazines, feminist magazines, news magazines, and health and fitness magazines all considered the need for information and resources for women with endometriosis. In total, 11% of the magazine articles published about endometriosis addressed the issue of information and resources. Women's magazines, feminist magazines, and health and fitness magazines suggested that women required more information about endometriosis than they received from their doctors, so they researched the disease on their own (Coudert, 1987; Good Housekeeping, 1980; Karnes, 1979; Lane, 1990; Latta, 1988; Shimer, 1990). Some health and fitness magazines and feminist magazines reported that women were sometimes unable to find information about endometriosis (Karnes, 1979; Lane, 1990; Latta, 1988). For example, Karnes was unable to find a book to help her learn about endometriosis, so she had to rely on available information about hormones. Women's magazines, feminist magazines and health and fitness magazines also offered women information on other resources such as titles of books and addresses for support groups. Feminist magazines such as *Healthsharing*, *Herizons* and *Waterlily*, in contrast to the other kinds of magazines, addressed the issue of the availability of adequate information for women about endometriosis.

Self-help books, feminist magazines, and occasionally news magazines and women's magazines, reported that support groups were a good source of information for women. Support groups could offer women information on how to deal with the problems of paternalism in the patient-doctor relationship, obtaining a diagnosis and lack

of available information about endometriosis. Self-help books, women's magazines and news magazines occasionally reported on the political action of support groups and women's efforts to educate women, health care professionals and the public about endometriosis, while feminist magazines focused on how women could be empowered in order to cope with their endometriosis (Kalma, 1990; Valverde, 1981; Williams, 1994). For example, Williams reported that a support group in Winnipeg was working on changing the traditional patient-doctor relationship by empowering women with knowledge and informing them they had choices regarding physicians and treatment options. Ballweg and the Endometriosis Association (1995; 1987) also discussed the development of endometriosis support groups in countries such as Britain, Australia, Brazil, Germany, Japan, South Africa and Taiwan.

Coping with Emotions

One significant issue that went unobserved in the popular magazines was coping with the emotional stresses provoked by diagnosis and treatment of endometriosis. All of the self-help books claimed to provide women with information on how they could cope with symptoms of endometriosis, and thus, ease the emotional stresses of living with endometriosis (Ballweg & Endometriosis Association, 1995; 1987; Bretkopf & Bakoulis, 1988a; Carol, 1994; Lark, 1993; Lauersen & de Swaan, 1988; Older, 1984; Weinstein, 1987). All of the authors acknowledged there is an emotional component to the physical problems related to endometriosis, such as dealing with infertility, loss of reproductive organs, chronic pain and sexual difficulties, that the traditional medical

approach ignores. Breitenkopf and Bakoulis argued women could learn to manage endometriosis instead of allowing it to control or ruin their lives, but they did not offer practical suggestions for coping like the other authors recommended. Weinstein, for example, suggested a variety of ways women could cope with the emotional aspects of endometriosis. Her suggestions included learning to manage pain and stress, taking control of medical care, gathering information about the disease, developing assertiveness and decisiveness, improving general health and finding ways to restore emotional equilibrium.

Women's Stories of Living with Endometriosis

Women's stories of living with endometriosis were included in popular magazines and self-help books. Women's stories comprised 15% of the articles about endometriosis in the popular magazines. Women's stories were included in feminist magazines such as *Healthsharing* and *Waterlily*, health and fitness magazines such as *Prevention*, news magazines such as *Maclean's*, and women's magazines such as *Redbook* and *Good Housekeeping*. Women's magazines focusing on women's stories of dealing with endometriosis usually emphasized the threat of infertility, women's desire to have children and the grief that women experience as a result of their infertility (Good Housekeeping, 1980; Pogash, 1982; Smith, 1986). For example, Pogash reported she "was willing to undergo anything to have a baby" (p. 82). Smith, on the other hand, felt she had been "attacked and savaged in the most fundamental and frightening way a woman can be. I had been told that I was no longer a woman" (p. 128). In contrast to

women's magazines, women's stories of living with endometriosis recorded in feminist magazines, news magazines, and health and fitness magazines emphasized medical treatments and alternative therapies. Only the feminist magazines conveyed women's experiences of paternalism and sexism in the medical sphere. Latta (1988), for instance, reported in *Healthsharing* magazine that she encountered paternalism in her relationships with two doctors.

Feminist magazines and women's magazines reported that women with endometriosis often felt frustrated, angry and humiliated because they suffered for a long time before they were diagnosed with endometriosis. For instance, Pogash (1982) stated that "one insensitive doctor suggested that my problem might be that I really didn't want to become pregnant, a remark that infuriated me" (p. 84). Wilcox (1990) reported women were angry and frustrated because they suffered from a disease that "has been for so long ignored, mistreated and misunderstood simply because it is a woman's disease" (p. 129). One woman reported feeling relieved when she was finally diagnosed with endometriosis (Good Housekeeping, 1980).

Women's accounts of learning to live with endometriosis were difficult to locate in the self-help books. There were only three books located for this study that included women's entire stories. Ballweg told her own story in the books produced by the Endometriosis Association (1995; 1987), while Carol (1994) enabled women to share their experiences of alternative therapies. Authors of self-help books usually included excerpts of letters or interviews instead of including women's complete stories

Physicians who co-authored self-help books, such as Lauersen and Breitkopf, often invented fictional women based on women they encountered in their medical practices, and these accounts were awkward and unnatural.

CHAPTER FIVE

Discussion

The results of the interviews indicate that participants are learning how to live with the challenges presented by endometriosis. Respondents identify both pain symptoms and infertility as significant challenges presented to them by endometriosis. Respondents also identify a variety of challenges involved in the process of learning to live with endometriosis including discovering the cause(s) of menstrual problems, getting treatment, dealing with doctors and living with symptoms. The psychosocial processes involved in learning to live with endometriosis feature the need to manage chronic symptoms so participants can function every day.

Respondents want to learn how to manage pain symptoms. Since medical and surgical therapies usually only temporarily relieve pain, participants devise their own pain relief strategies. These strategies include integrating their old pre-diagnosis management strategies with medical and surgical treatments. When these combined strategies no longer help, participants search for new alternative therapies that may relieve their pain. Participants are usually able to obtain temporary pain relief from medical and surgical treatments, integrating their old management strategies and/or finding new alternative therapies, but they want more than just short-term relief from pain. Participants also want to find something that will completely eliminate their pain and cure their endometriosis. Most of the participants realize this is unrealistic, however,

so they continue to devise new pain management strategies and search for ways to relieve their pain.

Learning to live with endometriosis, however, encompasses more than just dealing with disease symptoms. Respondents want to learn how to live with all of the effects of endometriosis on their lives. For instance, the psychosocial processes involved in learning how to live with endometriosis also include coping with the emotional stresses provoked by chronic illness. Some of the participants have had to learn how to cope with the emotional stresses of infertility. The participants want to learn to accept infertility instead of seeking medical assistance circumvent. Although researchers reveal that women often perceive infertility as a secret stigma they may never overcome (Whiteford & Gonzalez, 1995), the respondents demonstrate it is possible to accept infertility. Moreover, the participants show that endometriosis and its associated infertility does not have to ruin women's lives. Although the participants describe both the notion and the reality of infertility as devastating, they realize over time they may need to accept infertility and proceed with their lives.

These research findings also indicate that the participants define endometriosis as a chronic illness because in their experience it is a progressive, enduring and recurrent disease. Many medical and mental-health care professionals, however, do not regard endometriosis as a chronic illness. There is, therefore, a disjuncture between the reality of women's lived experiences of endometriosis and how medical and mental health care professionals view the disease and the women in this study experienced this disjuncture.

For instance, the participants usually find that doctors try to help alleviate some of their symptoms through various medical and surgical treatments, but they do not help them deal with the emotional stresses of living with endometriosis. Several of the participants want their doctors to help them deal with the emotional stresses of endometriosis, but many doctors are often unable or unprepared to do so. If doctors recognized that endometriosis is a chronic illness that encompasses more than just diagnosis and symptom management, they could refer women to other health care practitioners who could help them deal with the psychosocial issues of endometriosis. For instance, some of the participants could benefit from the expertise of medical and mental health care professionals such as doctors, psychologists, psychiatrists, nurses and counsellors who are knowledgeable about the emotional stresses of endometriosis.

If medical and mental health care professionals were to define endometriosis as a chronic illness, they could bridge the gap that exists between their knowledge of endometriosis and the experiences of women with the disease. Health care practitioners could apply current models of coping, adjustment and adaptation to try to help women deal with endometriosis. Health care professionals could also help women with endometriosis develop new coping strategies. Presently, the women who participated in this study rely on their own ingenuity to learn how to live with endometriosis as best they can. Health care professionals are in a position, however, to assist them in their efforts of learning how to live with endometriosis.

The results of this research also indicate that the popular press constructs endometriosis primarily as a fertility problem. Self-help books and magazines generally focus on the threat of infertility and the damage it can do to women's lives. The popular press does not, however, suggest practical ways women can come to terms with infertility. For example, articles in women's magazines often stress the destructive effects of infertility on women's life goals without suggesting how women can mitigate these negative effects. Self-help books, on the other hand, usually suggest that women can circumvent infertility through reproductive technologies and fertility drugs, rather than recommending strategies for learning how to accept infertility. Although there are differences in how the magazines and self-help books portray infertility, neither medium suggests how women can come to terms with their fertility problems. Moreover, self-help books and popular magazines prominently feature endometriosis-associated infertility, while only briefly discussing other symptoms such as pain and pain management techniques.

Finally, this research demonstrates that the participants experience a reality of endometriosis that is not reflected in the popular literature about the disease. Respondents insist that pain, rather than infertility, is the most troublesome symptom because it disrupts their lives on a regular basis. There is, therefore, a disjuncture between the reality of endometriosis portrayed in the media and the reality of the participants' lived experiences of the disease. For instance, the popular press claims to report what is important to women with endometriosis, but the results of this research

indicate that the popular press does not always rely on women who have endometriosis to gain this information. This disjuncture illuminates the social construction of knowledge about endometriosis. The popular press does not normally attend to women's lived experiences of the disease. Instead, knowledge of endometriosis created in the popular press is usually produced *for* women with endometriosis rather than *by* women with the disease.

The popular press publishes information on endometriosis that reporters and doctors think women need to know, instead of asking women how endometriosis affects their lives and what they need in order to be able to live with the disease. For instance, most of the materials produced by the popular press about endometriosis suggest that endometriosis is primarily a fertility problem. Women with endometriosis interviewed for this study, however, regard endometriosis primarily as a chronic illness that disrupts their lives, and secondarily as a fertility problem. Moreover, the popular press frequently publishes information about endometriosis that is contained in the professional literature. Research findings reported in the popular press usually indicate that certain women are more prone to endometriosis. The popular press often distorts research findings, however, and research findings that are not generalizable to *all* women become "facts" in the popular press. Ideas become fixed and perpetuated in the popular press such as happened with endometriosis being translated into "the career woman's disease."

We need not, however, dismiss all of the media coverage of endometriosis. The feminist press exists to oppose the oppression and domination of women that is portrayed

in the mainstream media. Women can also learn about what other women are doing by reading materials produced by the feminist press (Coffey, 1991). Only articles and books published in the feminist press offer women a balanced presentation of the symptoms of endometriosis and inform readers of what it is like to live with endometriosis from women's perspectives. Furthermore, the feminist press alerts readers to the problems of sexism and paternalism that permeate the medical treatment of endometriosis.

In sum, the findings of this research demonstrate that the participants define endometriosis as a chronic illness and they are, therefore, learning how to live with the challenges presented by endometriosis over a prolonged period of time. Participants are learning to live with endometriosis on their own, usually without the continued help or support of health care practitioners. Moreover, the social construction of endometriosis in the popular press does not facilitate the respondents in learning how to live with endometriosis because the popular press describes a narrow perception of women's experiences of endometriosis. Much of the material published in the popular press is not useful to women with endometriosis due to this limited understanding. Consequently, participants have to create their own constructions of endometriosis so they can come to terms with the effects of the disease on their lives.

These research findings are significant because researchers rarely focus on the question of "what is important" to women with endometriosis (Kennedy, 1991). This study begins to explore what is important to women with endometriosis by investigating the psychosocial processes involved in learning how to live with endometriosis. These

research findings are also important because they indicate that women view endometriosis as a chronic illness, demonstrating a disjuncture between the knowledge of health care practitioners about endometriosis and women's experiences of the disease. Women's experiences of endometriosis emerge from this disjuncture and their experiences reveal they have gained knowledge of endometriosis that could be useful to health care practitioners.

Finally, this study contains the first analysis of the social construction of endometriosis in the popular press. This is significant because it is likely that the social construction of endometriosis influences women's experiences of the disease. For instance, the social construction of endometriosis as a fertility problem could easily affect the kinds of challenges presented in the lives of women with endometriosis. The social construction of endometriosis could compel women to be concerned about their fertility, perhaps before it is even a real problem for them. Women may also feel forced to bear children before they are actually ready to raise them. The emphasis on infertility in the popular press could also affect women's abilities to come to terms with their infertility. This investigation of the social construction of endometriosis is also important because it reveals that the media describes a limited understanding of women's experiences of endometriosis, and therefore, self-help books and magazine articles about endometriosis are of limited use to women.

CHAPTER SIX

Conclusions

Causes and Consequences of Women's Inability to Learn to Live with Endometriosis

The respondents in this study have actively sought means of learning how to live with endometriosis. Women may fail to learn to live with endometriosis, however, for a variety of reasons. First, the emphasis on infertility in the popular press does not enable women to learn how to deal with infertility or any other symptoms of endometriosis. Second, women may fail to learn psychosocial processes that could help them to live with endometriosis because they may be very ill and lack the energy to cope with the disease. Third, women may also be discouraged by their inability to discover the cause(s) of their menstrual problems and they may not pursue the problem. Fourth, women may not be able to navigate the obstacle course that exists in the medical sphere. Inability to locate or create the conditions necessary for learning how to live with endometriosis may cause the learning process to be incomplete.

A failure to learn how to live with endometriosis could have dire consequences. Some women may never learn the cause of their menstrual problems and continue to suffer. Other women may remain sick and in pain if they are unable to manage their physical symptoms. Women may always feel frustrated if they are unable to discover the cause(s) of their menstrual problems, manage their symptoms or learn to deal with doctors. Women who experience infertility may never be able to come to terms with

their infertility if they are unable to cope with their emotions. If women are unable to learn how to live with endometriosis, they may never be healthy or happy.

Consequences of Women's Ability to Learn to Live with Endometriosis

Women can learn social and psychological skills that could ultimately help them to live with a chronic illness such as endometriosis. The psychosocial process of learning to live with endometriosis is essential to the health and well-being of women with the disease. Although the process may never be complete, women can regain physical health and/or emotional strength during the learning process. By learning how to live with endometriosis, women can also gain a certain amount of control over the disease and its effects on their lives.

Women with endometriosis, as well as health care professionals, should be educated about this process. Health care professionals could gain valuable information about how to help women deal with various symptoms and emotional stressors of endometriosis, and thus, better assist them in learning to live with the disease. Women with endometriosis, on the other hand, could glean useful and practical information about how other women learn to live with the disease. Women and health care professionals should be encouraged to develop innovative strategies that could be added to the process of learning to live with endometriosis.

Improving Media Coverage of Endometriosis

Media coverage of endometriosis plays an important role in shaping public discourse on the topic, and thus, influences women's experiences of living with the disease. The major problems with the coverage of endometriosis by the popular press are the emphasis on infertility, the limited perspective and the perpetuation of sexism.

Recommendations for improvements in the media coverage of endometriosis include:

- a) Accurate information about the relationship between infertility and endometriosis must be included in the popular press. The method used to address the issue of infertility could also be modified to include information on how to accept infertility, for example, by adopting children or living without children.
- b) Information about symptoms of endometriosis other than infertility, such as pain, must be readily available in the popular press.
- c) Women's stories of dealing with pain and other symptoms of endometriosis, as well as infertility, should be included in the popular press.
- d) Reporters must be careful not to perpetuate sexist and paternalistic attitudes found in the medical sphere.
- e) A more balanced tone and point of view would improve the press coverage of endometriosis.

By following these guidelines, the popular press could incorporate women's lived experiences of endometriosis in their accounts of the disease. Moreover, adhering to these recommendations would enable the popular press to produce materials that could help women learn to live with endometriosis, instead of being useless or harmful. The popular press could become an indispensable resource for women learning to live with

the disease. In the future, the popular press must publish more reports of endometriosis that encompass women's lived reality of the disease. Furthermore, the popular press must reconstruct endometriosis based upon women's knowledge of the disease. Instead of constructing endometriosis as a fertility problem, for instance, the popular press could construct endometriosis as the participants in this study experienced it. By reinterpreting endometriosis from the perspectives of women with the disease, the popular press could construct endometriosis as a chronic illness that women can learn to manage with the help of health care professionals.

The Social Construction of Medical Knowledge of Endometriosis

Women's experiences, however, must not only be included in the popular conception of endometriosis. Medical knowledge must also be created from the experiences of women with endometriosis. Women's voices must, therefore, be empowered so that women's experiences of endometriosis can be incorporated into medical knowledge about the disease. Malterud's (1993) strategies for empowering women's voices in the medical culture could help achieve this goal. For example, new research methods could be created to facilitate sensible observations and interpretations of women's experiences living with endometriosis. Clinical approaches investigating ways of empowering female patients with endometriosis could also be explored.

Furthermore, practical knowledge could be obtained and refined from the experiences of female physicians who treat women with endometriosis. Female researchers investigating endometriosis should also be supported by the medical sphere

All of these strategies will contribute to the construction of a female epistemology of endometriosis that can inform the medical culture. Malterud's strategies will enable women's knowledge of endometriosis to become a part of the medical consciousness of the disease. Health care professionals knowledgeable about endometriosis would also be in a better position to inform the popular press about the disease, thereby improving the media coverage of endometriosis.

Limitations of the Study

Limitations of this study include inaccessible information from the popular press and difficulties in ascertaining exactly how the social construction of endometriosis actually affects women's everyday lives. First, the researcher was unable to locate several self-help books about endometriosis, and therefore, the content analysis of self-help books on endometriosis is incomplete and some alternate views may have been present in the popular press but were missed. Second, the researcher experienced difficulties in discovering how the social construction of endometriosis may have affected these women's lives. Although some women reported the use of self-help books or had remembered reading articles on endometriosis, how much these readings shaped their experiences if at all is difficult to discern. Therefore, the researcher reflected on the work of other researchers studying how the social construction of reproduction and infertility affects women, and then applied this to the social construction of endometriosis. The social construction of endometriosis relies on how infertility is constructed in our society, however, so the conclusions drawn in this study are not based

upon conjecture. Instead, the conclusions are based upon the conscientious work of other researchers. Moreover, these conclusions enhance the work of other researchers studying the social construction of reproduction and infertility in our society.

Directions for Future Research

There are a variety of areas for future research on women's experiences of endometriosis. Further research could be conducted on the psychosocial processes involved in learning to live with endometriosis. Researchers could also conduct research on how health care professionals can help women to learn to live with endometriosis. This research could lead to the development of practical strategies that could be implemented by health care practitioners to help women learn to live with endometriosis. Researchers should also examine how women with endometriosis actually deal with various aspects of the disease in their every day lives. For example, research on endometriosis could include investigations of women's experiences of endometriosis-related fertility problems and infertility treatments. Finally, studies on chronic illness should address endometriosis to determine if, as Silverton (1990) suggests, existing coping, adjustment and adaptation strategies could be applied to help women with endometriosis.

Studies of endometriosis must also include further investigations of the social construction of endometriosis. This could be accomplished through a broader review of materials published in the popular press, as well as materials published in the medical press. This study has determined that an important aspect of women's experiences of

endometriosis includes the effects of the social construction of endometriosis. It is necessary, therefore, that researchers further study the effects of the social construction of endometriosis on women's lives. Health care professionals could also be surveyed in order to determine how their constructions of endometriosis affect women's experiences of the disease. Finally, further research on women's experiences of endometriosis could be conducted by people working in a variety of professional fields such as medicine, nursing, psychology, psychiatry, sociology and women's studies. Interdisciplinary research could enable researchers in various fields to combine their knowledge of endometriosis, thereby expanding the boundaries of endometriosis research.

Finally, future research on women's experiences of endometriosis depends on valid, reliable and credible research methods. Future directions for research may also include locating or creating research methods that will enable researchers to study the effects of the social construction of endometriosis on women's lives. Future research of women's experiences of endometriosis must also include the use of non-sexist research methods.

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APPENDIX A

Interview Questions

- 1) When did you first think something was wrong?
- 2) How were you diagnosed with endometriosis?
- 3) What are your symptoms of endometriosis?
- 4) What medical/surgical treatments have you tried?
- 5) Have you tried any alternative treatments?
- 6) How would you describe your meetings with doctors?
- 7) What kinds of information have you found about endometriosis? What did you think of this information?
- 8) Has endometriosis caused you to feel any specific emotions?
- 9) Has endometriosis presented any challenges in your life? How do you deal with these challenges?
- 10) What is the most difficult aspect of endometriosis for you? How do you deal with it?

APPENDIX B



Department of Linguistics

Miss Ann Carolyn Carpan
Women's Studies
Memorial University of Newfoundland

30 Oct 1995

Dear Miss Carpan,

Re: Your project Women's Experiences of Living with Endometriosis:
A Grounded Theory Study

Your thesis project has been approved by the Memorial University of Newfoundland Arts Research Committee. Since yours is an unfunded project, you are not required to obtain a certificate of ethical acceptability from our committee.

The Arts Faculty Research Committee asked me to convey the following observations/recommendations to you:

- (i) Your Consent Form should refer to our committee as Arts Faculty Research Committee.
- (ii) Your Consent Form should state that this project is part of your degree requirements.
- (iii) Since your project is in a medical area, i.e. outside of our mandate, we strongly advise you to approach an appropriate Health Sciences/Medical Ethics Committee.
- (iv) It would seem to us to be a good idea to state in your Consent Form that no physicians/hospital staff will be interviewed and that there will be no direct access to medical records.

With our best wishes for your research,

Sincerely,

Dr. Vit Bubenik
Acting Chair
Faculty of Arts Research Committee

APPENDIX C

Letter of Consent

My name is Carolyn Carpan and I am a graduate student in the Master of Women's Studies Programme at Memorial University. I am conducting a study to learn about women's experiences dealing with endometriosis. This project fulfils part of my degree requirements. This study has been approved by the Women's Studies Graduate Committee and the Arts Faculty Research Committee at Memorial University. My supervisor, Shirley Solberg, an Associate Professor at the School of Nursing, Memorial University, can be reached at 737-6873. If you would like to speak to someone else who is familiar with my research, Dr. Rosonna Tite, Chair of the Graduate Committee of the Women's Studies Programme, can also be contacted at 737-8617.

You have identified yourself as a woman with endometriosis either by your expression of interest in my research or by your interest in the endometriosis support group based in St. John's. You are invited to join me in my efforts to learn about women's experiences of endometriosis.

If you decide to participate in my study, I will conduct an interview with you sometime between November and February 1995 at a location convenient for you. The interview will last approximately one and a half hours. It may also be necessary to conduct a second interview of the same length at a later date. During the interviews, I will be interested in learning about the kinds of problems endometriosis has presented in your life and how you have handled these problems. With your permission, I will tape record the interviews so that the interviews can be transcribed. When I have completed my programme in September 1996, the interview tapes will be destroyed. I will give you a summary of the findings of the interviews when I have completed all of the interviews. Please feel free to contact me after you have read the summary to clarify any points or issues raised in the interviews.

Every effort will be made to ensure confidentiality and to protect the anonymity of anyone who participates in my study. I will change your name and the names of any doctors, hospitals or health clinics that are mentioned during interviews.

A summary of the results of this study will be available to you when it is completed. The results of this study will also be made available to relevant groups or individuals who have an interest in endometriosis.

APPENDIX C

You are free to withdraw from the study at any time. Although you are now consenting to participate, you may withdraw this consent after it has been granted to the researcher. If you are willing to participate in my study, you can reach me at 753-0481.

I, _____, understand the terms of this study, agree to abide by these conditions, and consent to participate.

Principal Researcher (Carolyn Carpan) _____

Date _____ Witness _____

