

**AN EXPLORATORY ANALYSIS OF SINGLE YOUNG WOMEN WITH
ENDOMETRIOSIS AND THEIR LIFE COURSE EXPECTATIONS**

by

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B.A., The University of British Columbia, 1996

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF

THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

THE FACULTY OF GRADUATE STUDIES
(School of Social Work and Family Studies)

We accept this thesis as conforming

to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

May 1999

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Abstract

This study explores how a chronic disease called endometriosis influences single young women's expectations for family, educational, and occupational careers. Previous research on this disease has focused primarily on the biological ramifications of its presence, and not the social aspects. This exploratory study attempts to not only analyse the effects of endometriosis on life course expectations of single young women, but also what variables might account for differences in expectations within this group. This study consists of two components: a questionnaire component and a semi-structured interview component; data collection was carried out via e-mail. The volunteer sample consisted of women who belonged to support groups on the internet. Seventy-two women participated in the questionnaire component; of those 72, 12 participated in the interview component. Five research problems are analysed; these assess the effects of endometriosis on life course expectations, and what might account for variations in expectations and experiences of living with endometriosis. Interviews are also carried out to address issues not suited to quantitative measures, and to further explore the influence of this disease on life expectations. Questionnaire results failed to find significant effects for time since diagnosis on varied experiences of living with endometriosis; no significant effects were found for type of treatment method(s) undergone, and degree of pain experienced due to endometriosis on life course expectations. Results also suggest that pattern of pain affects life course expectations, and that role strain also plays an important role in determining the effect of this disease on expectations. Interview findings suggest that although women with this disease may not deviate from societal norms in terms of expectations and sequencing of life events, they do find endometriosis creates asynchrony with their

own planned life paths. These results also reveal that the ramifications of this disease extend beyond biological effects. Results are discussed in terms of implications for future research, as well as for practitioners and support groups.

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Acknowledgments

My most profound thanks are due to all of the women who volunteered for this study, particularly the twelve women who participated in the interview component. These women graciously shared their stories, dreams, and fears; I am touched by their courage and grateful for their willingness to speak. I owe a debt of immeasurable gratitude to Dr. Catherine Allaire, without whom I would not have been able to undertake this research. I would also like to thank my thesis committee members, for their advice and encouragement.

Finally, I must thank my friends, who kept me sane through the entire research process, especially Sharon, Barb, Carmen, and Ali, as well as my family, in particular my mother, for their unwavering support and good humour.

Chapter I

Introduction

Life course expectations shape many important decisions, and motivate behaviours. These expectations can involve goals for family, educational, and occupational success. For young women today, expectations are not limited to marriage and the family: with access to higher education, women now have goals in the occupational and educational domains, as well as the family (e.g. Arnold, 1993; McBain & Woolsey, 1986). Barriers to achieving these goals, such as illness, disability or unanticipated events, can limit a person's expectations to varying degrees; how do people reassess life course expectations when faced with barriers?

One such barrier for young women is a chronic disease known as endometriosis, which can have profound effects on expectations and life choices. This disease, which primarily affects the reproductive system, has been neglected in social research; the focus of most research to date instead assesses the pathology of the disease, or its biological consequences. However, this disease affects more than a woman's ability to reproduce:

I know I must accept the fact that endometriosis is going to change the rest of my life and that it will prevent me from doing everything I wanted to do. Endometriosis is a lot more than just a physical disease.

(quoted in Weinstein, 1987, p. 138)

As the above quotation illustrates, living with endometriosis has implications for various areas of life, including social aspects. Unlike other chronic diseases, endometriosis is rarely recognised as such; it is an internal condition, affecting only women, that cannot be witnessed by others. As one woman put it, women with endometriosis look normal, despite the pain they endure: there is "...no outward evidence

of the disease to constantly remind our friends and families of how poorly we might be feeling” (Dutcher, 1994, p.100). Endometriosis definitely involves “quality of life” issues (e.g., Damario & Rock, 1995; Waller & Shaw, 1995), and can be quite disabling due to the symptoms of pain. For women who are not asymptomatic, endometriosis can become a focal point for all future plans (e.g., Ballweg, 1987, 1995; Jones, 1988; Weinstein, 1987, 1988). Most reports estimate that endometriosis affects around 10% - 15% of women, and although many researchers also concede that this is probably an underestimate (e.g., Brewer, 1995), this estimate reveals that research on the social consequences of living with endometriosis is due. Symptoms include pelvic pain (continuous, cyclical, or unpredictable), dysmenorrhoea, infertility, nausea, and back pain. Treatment methods are diverse, and include such things as dietary changes, pregnancy, and definitive hysterectomy. Endometriosis, like any chronic disease, has ramifications for various areas of a woman’s life and must be incorporated into the planning of life goals surrounding family, education, and occupation. These three areas of life are considered the main careers within the life course, according to Family Development Theory (Aldous, 1996; White, 1991).

This study explores how having endometriosis affects the life course expectations of single young women, as well as what might account for variations in expectations within this group of women. Specifically, the purpose of this study is to explore the effects of having endometriosis on expected family, occupational, and educational careers of these women.

What follows is a discussion of the disease: what it is, its treatment methods, and how common it is. This overview provides insight into some of the potential

consequences having this condition can lead to for women. Though no studies prior to this one have formally assessed the social consequences of having endometriosis, testimonials from women living with it provide some insight into the effects the disease can have, and are therefore included. Empirical studies that have some bearing on this exploratory study are also discussed.

Review of the Literature

Endometriosis: What is it and where does it come from?

“If a man had a disease which caused him to be unable to father a child and to have unbearable pain during sex and unbearable pain during bowel movements, treated by feminizing hormones and surgery, endometriosis would be a national emergency in this country.”

(N. Peterson, nurse, quoted in DeMarco, 1997)

Almost every article on the topic of endometriosis begins with words like “Endometriosis is a mysterious gynaecological disease....a puzzling disease...an enigmatic disease”. The adjectives are appropriate. There is no one agreed-upon cause of this disease, though several theories exist. It is most commonly found in women of childbearing age, though this is not always the case, and it has no known cure. Endometriosis can cause infertility, it can affect other organs, including the bowel and bladder, and treatment is often difficult and provides only short term relief. Symptoms are highly varied, though most involve pain: pain with menstruation (dysmenorrhoea); pain with intercourse (dyspareunia); chronic pelvic pain; or lower back pain (Brewer, 1995; Sutton, 1993).

The aetiology of endometriosis.

A brief foray into some of the more prominent theories of the aetiology of endometriosis is useful at this point. The three most common theories are: 1) retrograde menstruation; 2) coelomic metaplasia; and 3) abnormal immune function.

1) Retrograde (backward) menstruation theory is one of transplantation: live endometrial cells move upward into the pelvic cavity instead of being shed. These cells then implant themselves along various structures within and outside of the pelvic area, and grow (for a detailed discussion, see Kruitwagen, 1993). Though some studies do support this theory, retrograde menstruation appears to occur in women without endometriosis as well (e.g., Brewer, 1995; Rock & Markham, 1992).

2) The coelomic metaplasia theory, the oldest of these three, suggests that all women are born with endometrial tissue lining the pelvis; in some women this tissue remains dormant, but for others, it is somehow activated, resulting in the metaplasia (or transformation) of peritoneal mesothelium cells (which are naturally occurring in the area) into endometrial-like cells (which are not). Although this theory was commonly supported for around one hundred years (Brewer, 1995), recent work has pointed to several flaws in it. The main arguments against this theory are as follows: most metaplasticism increases as a person ages, yet endometriosis is rarely found in menopausal women, and if the mesothelium can simply transform itself without any hormonal influence, then endometriosis should be found in both women and men (see Olive & Schwartz, 1993).

3) The role of the immune system in women with endometriosis has only recently been researched, but it proves a promising explanation for the disease: women with endometriosis seem to have an increased activity of macrophages (cells which absorb

foreign bodies in the bloodstream and tissues), and a decreased activity of natural killer cells, and may have many allergies in general (Brewer, 1995; Rock & Markham, 1992). Some suggest that endometriosis is an auto-immune disease, but findings are still controversial (see Barlow, Kennedy, Fernandez-Shaw & Starkey, 1993; Evers, 1993, for a detailed discussion).

Whatever its origins, endometriosis involves the presence of endometrial tissues outside of their natural environment. These tissues can take the form of nodules, cysts, lesions, or implants; and like regular endometrium, these tissues will respond to a woman's hormonal cycle and bleed (Carol, 1994). Through whatever mechanisms, these tissues can become adhesive, holding organs together, or forming blockages. In rare instances, this disease can be life threatening, when an obstruction of the bowel or bladder occurs.

Some researchers believe endometriosis to be a progressive disease, while others feel it is a self-limiting one. Though there is no known "cure", studies show that for some women, the endometriosis simply disappears; for others, it subsides with menopause, and for still others it remains active for a lengthy period of time (Brewer, 1995). There is growing evidence that this may in fact be a hereditary disease (e.g., Kennedy, Hadfield, Mardon, & Barlow, 1996; Kennedy, Mardon, & Barlow 1995) with a genetic basis. Some lesser known theories suggest that contraceptive use (e.g., birth control pills, IUDs) is a possible risk factor (Brewer, 1995; Darrow, Selman, Batt, Zielezny & Vena, 1994; Kirshon & Poindexter, 1988). Confusing the matter further, some studies suggest that contraceptive use can actually decrease the risk of developing this disease (e.g., Vercellini, Ragni, Trespidi, Oldani, & Crosignani, 1993). Endometriosis was

characterised in the past as the “career woman’s” disease (Ballweg, 1987; Weinstein, 1987), and sadly often still is: the “typical” woman with endometriosis is described as single, childless, white, and “underweight”, sometimes “neurotic” (e.g., Weinstein, 1987). Some studies suggest that delayed motherhood is a risk factor (e.g., Moen, 1991), though this finding could merely be a misattribution of cause and effect (i.e., endometriosis causes a delay due to subfertility, and not vice versa). Others point to stress as a source (Brewer, 1995). These studies, though few in number and support, indicate that women may play a role in facilitating the onset of this disease, and some women may feel that they ‘caused’ endometriosis. The whole point of this discussion is to illustrate that the highly uncertain nature of the disease, and what is known of it, could result in life course expectations themselves being unstable, or unknowable.

Symptoms of endometriosis.

As mentioned, the symptoms of this disease vary. Indeed, there is no “typical” woman with endometriosis, just as there is no typical progression of the disease. Some women are asymptomatic, and do not realise that they are afflicted until they undergo surgery for an unrelated reason (tubal ligation, or abdominal surgery, for instance). Other women may have what is termed “mild” endometriosis, and yet suffer from extreme pain.

The four classic symptoms, as described by Dr. Brewer (1995), are as follows:

- painful periods (dysmenorrhoea)
- deep pain during sex (dyspareunia)
- pelvic pain (continuous or cyclical)
- infertility

(p.38)

Other common symptoms include: heavy periods (menorrhagia), abnormal bleeding, back pain, distension and abdominal bloating, abdominal pain, pain with urination (dysuria), nausea, insomnia, fatigue, and dizziness. Since endometriosis is a metastatic disease (Lancet editorial, 1992), it can be found almost anywhere in a woman's body. In fact, it has been found everywhere but the spleen (Brewer, 1995; Rock & Markham, 1992). For example, symptoms of chest endometriosis can include coughing up blood, blood in the chest cavity, breathlessness, and chest pain.

Not only do symptoms vary, but they are also often unrelated to the extent of the disease as classified by the former American Fertility Society (e.g., Damario & Rock, 1995; Naish & Barlow, 1997; Vercellini, Trespidi, De Giorgio, Cortesi, Parazzini & Crosignani, 1996), a confusing factor for women who are told they have "only a mild" case, but are in excruciating pain. This problem may soon be rectified, as the AFS (now known as the American Society for Reproductive Medicine) is now supporting a separate classification based on pain (Brewer, 1995).

The symptoms described above can have obvious effects in many areas of a young woman's life. School work may suffer due to an inability to concentrate because of pain (e.g., Kurth, 1994). A job may suffer because of excess sick time, often on short notice (since a woman can never be sure if it will be a "bad" day or a "good" one): "It's impacted (sic) my relationships, finances,...and my dreams. I even recently lost a job when the manager...refused to tolerate my absences." (quoted in Ballweg, 1995, p. 278). Sexual relations may be strained, and a woman may not know how to explain the problem to her partner, or be afraid that she may not be believed. Day to day living can be difficult, and relationships in general are often affected.

Perhaps one of the more disturbing aspects of this disease is the fact that surgery is the only certain method of diagnosis: many women face difficulties in being believed, not only by partners, as mentioned, but by family, friends and the health care profession. The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) of the American Psychiatric Association lists the symptoms of endometriosis almost word-for-word (pain during menstruation, irregular menstrual periods, pain during sexual intercourse, pain in the abdomen, nausea and bloating), and states that these symptoms describe a mental disorder called somatization disorder (*DSM-IV*, pp. 446 -50, quoted in Ballweg, 1995, p. 296). One woman states that between the ages of 13 and 17, the doctors “decided I had a mental problem - a conduct disorder...I was using this pain as a way to get attention...I was hospitalized in a mental hospital twice. I was given...heavy doses of tranquilizers.” (quoted in Ballweg, 1995, p.295). This problem seems even more pervasive for single women: “I was given the gamut of diagnoses from hypochondria to cancer to anxiety attacks to my age and marital status being a factor...told at one point that I had these problems because I did not have a date for that Saturday night!” (quoted in Ballweg, 1995, p. 296).

The one “classic” symptom that a woman may not notice is that of infertility. This is a topic tied to family career expectations, and necessitates a more detailed discussion. The relationship between endometriosis and infertility is still largely controversial. The common estimate now is that for couples *seeking* treatment for infertility, endometriosis is present in 20-50% of the cases (Brewer, 1995; Thomas, 1991). Because it is estimated that only 10% - 15% of the female population suffers from the disease, this finding suggests that endometriosis plays a role in infertility (Surrey & Halme, 1989). In some

cases, the reason is observable: endometrial tissue outside of the uterus has blocked a fallopian tube, or is holding organs together, preventing the proper functioning of the reproductive organs. In some instances, the reason is not so obvious: various theories implicate immune dysfunctions and leutinised unruptured follicle (LUF) syndrome (Brewer, 1995, Surrey & Halme, 1989; Thomas, 1991). For this reason, many women with endometriosis are considered "subfertile", not infertile (Brewer, 1995). Whatever the cause, the fear of infertility is a real one for many women with endometriosis. Though most doctors will not publicly recommend (i.e., publish a paper stating it) that a woman with endometriosis have children sooner than later, case profiles suggest that they privately do (e.g., Ballweg, 1987, 1995; Shore, 1994; Weinstein, 1987, 1988).

The issues involved in endometriosis are best summed up by Weinstein (1988):

A single woman may fear the reaction of future partners toward her potential infertility or her difficulties with sex. She may feel pressured to find a mate to test her fertility. Both single and married women may be so distraught by the possibility of infertility at a later time that they may rearrange their life plans to accommodate a pregnancy, whether or not they are emotionally or financially prepared. Whether single or married, fertile or infertile, a woman may begin to feel defective, not wholly a woman.

(p.868)

Prevalence of endometriosis.

The number of women afflicted with endometriosis is difficult to ascertain for many reasons. Some of the symptoms of endometriosis are also found in women with pelvic inflammatory disease, irritable bowel syndrome, and appendicitis (Brewer, 1995). Because of this, endometriosis can occasionally be misdiagnosed based on symptoms alone. Painful periods (dysmenorrhoea) are sometimes the only symptom; if painkillers

are prescribed (or birth control pills) and the pain ceases, that woman will not be diagnosed with endometriosis.

The main problem with determining an accurate count stems from the method of diagnosis: the only "sure" way of diagnosing this disease is through surgery (Apgar, 1992; Brewer, 1995; Cahill & Wardle, 1996). Though a woman's menstrual history, combined with a physical examination, may lead a physician to suspect she has the disease, a laparoscopy is considered the best method of diagnosis, the "gold standard" (Brewer, 1995), with the added bonus that if endometriosis is present, the doctor can treat it immediately. This operation consists of two small incisions being made in the pelvic and abdomen regions, with a small laparoscope inserted to view the reproductive and surrounding organs. Surgery, no matter how "minimal", always carries a risk, and therefore physicians (and patients) may be reluctant to perform one based on a few symptoms. As well, diagnosis is often based on the discovery of "typical" endometrial lesions, though studies have shown that there are many kinds of endometrial lesions (e.g., Brewer, 1995; Jansen, 1993). These two factors (the necessity of a surgical diagnosis, and the failure to recognise atypical endometrial lesions) lead some to suggest that this disease is more common than is currently thought (e.g., Brewer, 1995).

The necessity of surgery for diagnosis may also help explain the average delay of seven to eleven years between onset of symptoms and diagnosis (Brewer, 1995; Endometriosis Association (EA), 1998; Hadfield, Mardon, Barlow, & Kennedy, 1996). Many women feel that their symptoms started before the age of twenty, but probably were not operated on because of their age, combined with the notion (on the part of gynaecologists) that the pain would go away, that it was only "normal" (Beckman, 1996).

In their study, Chatman and Ward (1982) found an incidence rate of endometriosis of 65% in the 43 teenagers they assessed (these were all teenagers who were experiencing pelvic pain). At the time, it was estimated that adolescents accounted for 8.5 % of all endometriosis cases. The rate now is unknown, but the statement that it is “very rare” to find endometriosis in women under the age of twenty five is still made, despite evidence to the contrary, from both studies, and women with endometriosis themselves (Barber, 1995; Brewer, 1995; Emans & Goldstein, 1990).

Brewer (1995) states that endometriosis is the second most common gynaecological condition after fibroids. She suggests that the estimated 10% of women afflicted can be broken down into the following groups:

- Between 2 and 5 per cent of healthy women of childbearing age, who have already had a pregnancy have some degree of endometriosis, although many women do not notice any symptoms;
- Of those women who do have pelvic pain and who undergo a diagnostic laparoscopy....., endometriosis is confirmed in 10 -15 per cent;
- In women undergoing investigation for subfertility, endometriosis is diagnosed in 30-40 per cent of cases. (p.2)

A survey by the Endometriosis Society, in 1985, asked 726 women with endometriosis when they felt they had developed endometriosis, when they saw a physician about it, and when they were finally diagnosed. Table 1 offers a glimpse at the profile of women with endometriosis.

TABLE 1**Age at development of endometriosis, age at consultations, and age at diagnosis***

Age	Age when think first began to suffer	Age first saw GP	Age when Diagnosed
10 to 15	14%	5%	0%
16 to 20	21%	10%	2%
21 to 25	19%	25%	21%
26 to 30	17%	27%	29%
31 to 35	9%	17%	25%
36 to 40	5%	10%	15%
41 to 45	1%	3%	5%
46 to 50	0%	1%	2%

* Brewer, 1995, p. 16

Endometriosis is very rare in postmenopausal women, as this table suggests, but it can affect a woman at any age (note that 23% are diagnosed before the age of 26, while 35% felt they had been affected before the age of 21). It is therefore not so unusual to find many younger, single women with endometriosis.

Interventions.

Treatment for endometriosis varies. Due to this disease's nature, treatment is often highly individualised, and prolonged. Though there is no set intervention program, the progression from medical to surgical methods is typical. The surgical treatments are rarely mild in nature, and can consist of something as basic as a laparoscopy to something as drastic as a definitive hysterectomy. The "medical" treatment can be as simple as ovulation suppression or something as life-altering as a "therapeutic" pregnancy (Weinstein, 1987). Two "therapy lines" adapted from Jones (1988) chart the potential course of treatment for pain as a main symptom of endometriosis, and infertility as the main symptom (see Figure 1).

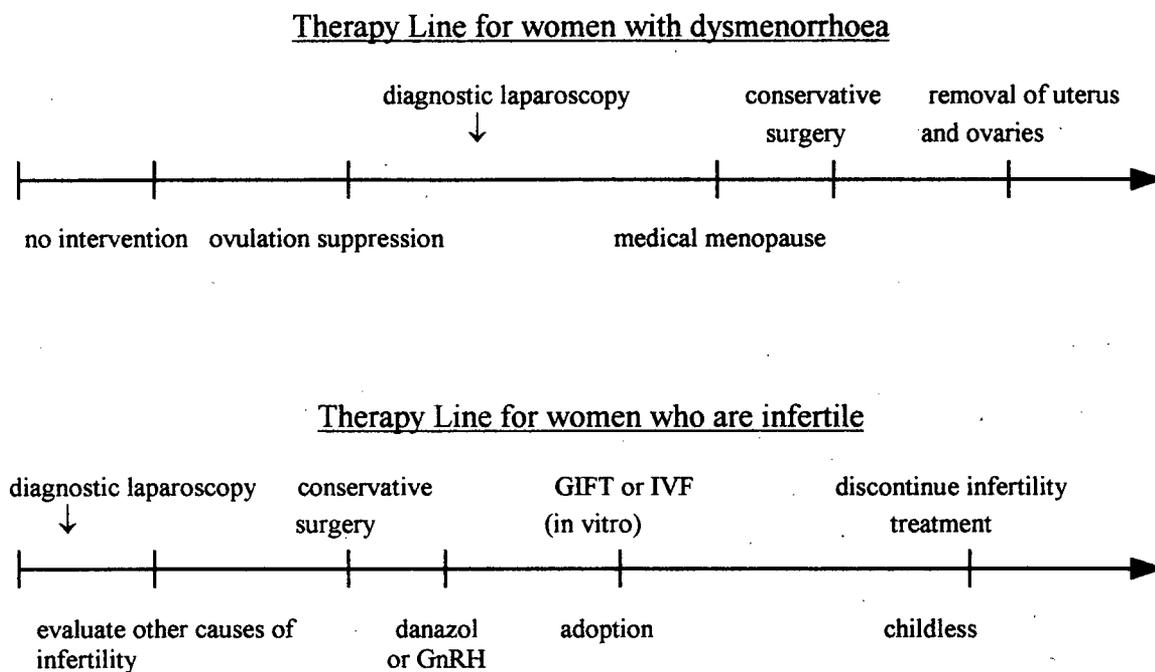
FIGURE 1

Figure 1. Two therapy lines for the treatment of endometriosis: i) for women with dysmenorrhoea (painful periods); ii) for women who are infertile. From "Emotional aspects of endometriosis: A physician's perspective" by K.P. Jones, 1988, *Clinical Obstetrics and Gynecology*, 31, 874- 882.

For some women, the first and only treatment received is ovulation suppression, also known as a pseudopregnancy drug. This is usually in the form of birth control pills (BCPs, combined estrogen and progesterone) taken continuously. When a woman experiences pelvic pain, BCPs are usually the first recourse. They are relatively inexpensive, and side effects are usually minimal. If BCPs are effective, as mentioned earlier, a woman may never be officially diagnosed with endometriosis. The popular use of BCPs to treat endometriosis stems from the fact that pregnancy seems to abate the symptoms of this disease, and in some cases, seems to "cure" it (e.g., Ballweg, 1987; Haney, 1991; Henderson & Studd, 1991; Weinstein, 1987). Since BCPs prevent ovulation, and in this manner, mimic pregnancy, their usage seems logical. Studies suggest that BCPs are only effective in about 30% of the women who use them, and so they are often prescribed for women who have dysmenorrhoea as a main symptom or for teenagers, because of the non-invasive nature (Brewer, 1995). Another common pseudopregnancy drug is MPA (medroxyprogesterone acetate), a high potency progesterone drug which is more effective than BCPs, but also has more severe side effects (including weight gain, back pain, fluid retention, heavy bleeding, depression, hair loss, fatigue, insomnia, and nausea). Other progesterone-based drugs include depo provera and dydrogesterone. These progesterone-only drugs lower the blood level of estrogen in the body, which may be important in relieving symptoms (Brewer, 1995).

The drug treatment most frequently recommended after the above treatments fail is commonly known as Danazol. This is a synthetic form of male hormone (testosterone) which lowers a woman's estrogen level to that of a postmenopausal woman. The beneficial effects of Danazol seem to cease when treatment ceases, or soon after (e.g.,

Ballweg, 1987, Carol, 1994). Because of the intense hormone-altering effects that occur with this and all other pseudomenopausal drugs, treatment is rarely for more than six months at a time, and usually is not repeated. Danazol is unique among the pseudomenopausal drugs in that it is a masculinating drug (and most likely the treatment to which nurse Nancy Petersen refers at the start of this article). Many women on Danazol have to stop before treatment is finished because of an inability to tolerate side effects. These side effects are often noticeable to others, and highly undesirable; they include drastic weight gain, hairiness, nausea, shrinking breasts, depression, and acne, among other things (see Brewer, 1995, for a detailed list). More serious side effects include: non-reversible voice deepening (Boothroyd & Lepre, 1990), and an increase in the level of harmful LDL cholesterol (Brewer, 1995). Despite these side effects, young women (including teenagers) are often advised to take this drug (Ballweg, 1987). For some women, this treatment is not worth taking:

I was on danazol for almost 11 months...my side effects included nausea,...fatigue (extreme), and hot flashes...I would wake up completely soaked almost every night...I also suffered...slight hair loss (my frontal hairline receded), and weight gain...By far the most severe side effect ...was depression...I have never felt so utterly worthless in my entire life...
(quoted in Ballweg, 1995, p. 185)

The more recent pseudomenopausal drugs do not increase male hormone levels; these are called GnRH agonists. They induce a menopausal state by overstimulating the pituitary gland. There are currently four varieties, differing usually in the method of induction (injection versus a nasal spray). Side effects include hot flushes, acne, short-term memory loss, joint pain, and headaches. These side effects subside when treatment ceases. However, there are possible long-term risks for women who use these drugs, as they result in bone-thinning, present even six months after treatment stops (Ballweg,

1995, Brewer, 1995). The long-term effects are unknown, and a woman can therefore only be on these drugs once, for a six-month term, and never again. New studies suggest that it may be possible to 'add-back' estrogen to prevent bone loss in order to repeat drug treatment, but there are no studies which assess the long-term or extended use risks associated with this therapy. Though these drugs are often as effective as, if not more so than, Danazol, symptoms often recur within a few years following treatment. As Carol (1994) points out, because the safety of continuous use of these drugs is unknown, this kind of drug therapy will only be possible for roughly two years of a woman's life. In general, the recurrence rate of symptoms following medical surgery alone is 50% within five years after treatment (Namnoum, Hickman, Goodman, Gehlbach, & Rock, 1995).

The next steps in treating endometriosis involve surgery. For women who are "officially" diagnosed with endometriosis, surgery is their first treatment in the form of a diagnostic laparoscopy. Conservative surgery treatment can include laser surgery, which can involve vaporising adhesions, draining cysts, and sometimes improving fertility (as reconstructive surgery). If endometriosis is seen to have encased an organ, or the bowel is involved, or drug treatment and laparoscopy have failed to alleviate pain or improve fertility, a laparotomy may be performed. This involves cutting open the pelvic region and removing visible endometrial tissue, as well as adhesions. Sometimes removal of an ovary or fallopian tube is necessary if endometriosis is extensive. A laparotomy incurs greater risks than a laparoscopy, including the potential for the formation of new adhesions. Though surgery may aid in fertility probability, it does little for pain symptoms in many women. According to Brewer (1995), it can relieve pain for up to only one year in about 75% of women. Carol (1994) notes that if endometriosis is

microscopic or atypical in appearance, it may be missed, thereby negating the benefits of surgery. It is not uncommon for women to undergo surgery every few years to maintain a tolerable pain level (Ballweg, 1987; Carol, 1994; Weinstein, 1987). The recurrence rate of symptoms following conservative surgery is 40% within five years of treatment (Namnoum et al., 1995).

There are two other treatments for endometriosis which both drastically affect a woman's future: pregnancy and a definitive hysterectomy. Recent studies have shown that the incidence of hysterectomy as a treatment for endometriosis is actually increasing (e.g., DeMarco, 1997; Pokras & Hufnagel, 1988). In a study on hysterectomies in the United States from 1965 to 1984, the number performed to treat endometriosis increased 176 percent (Pokras & Hufnagel, 1988). More startling and worrisome is the fact that during that same time period, hysterectomies to treat endometriosis in women between the ages of 15 and 24 increased 250 percent (Ballweg, 1995). The recommendation of a hysterectomy to treat this disease is controversial because its effectiveness is suspect. This is because many younger women who are nowhere near menopause are undergoing this surgery; to decrease the risk of osteoporosis and alleviate an immediate menopause, doctors often leave in the ovaries. A hysterectomy without the removal of the ovaries (oophorectomy) often fails to "cure" endometriosis. In their study of symptom recurrence after hysterectomy for endometriosis, Namnoum et al. (1995) found that women who had ovarian conservation had six times a greater risk for recurrence of the disease and had eight times a greater risk of reoperation for their condition than women who had had an oophorectomy as well. The more severe the endometriosis, the more likely it will recur in

women who have a hysterectomy only (Brewer, 1995), a particularly ironic fact, since these severe cases are the ones which are typically recommended for this operation.

A hysterectomy with an oophorectomy is supposed to be definitive in that the relief it provides should be permanent. For women with endometriosis, if even the slightest bit of ovarian tissue remains inside the abdomen, symptoms will continue (Brewer, 1995). Recurrence of endometriosis has been noted in many studies (e.g., Redwine, 1994; Revelli, Modotti, Ansaldi, & Missobria, 1995), suggesting that this is not a "cure" by any standards. As well, the surgically induced menopause cannot be treated with hormone replacement therapy for at least six months following surgery to prevent recurrence initiated by estrogen. Considering the many risks of radical surgery (risks of infection, and risks of recurrence), as well as the fact that it prevents a woman from conceiving, it is surprising to find that it is recommended as a treatment option for younger single women (Ballweg, 1987).

The second drastic treatment option is one that is rarely publicly endorsed by physicians: pregnancy. Endometriosis has often been labelled the "career woman's" or "single woman's" disease because mothers never seemed to have symptoms in the past (Weinstein, 1987). This is probably more likely due to the fact that mothers were often pregnant or lactating throughout their child-bearing years, and would not have noticed symptoms following menopause. As mentioned, the cause of endometriosis is unknown, but it is known that increased estrogen levels worsen the disease (Brewer, 1995). During pregnancy, estrogen is at a lower level due to increased progesterone in the blood. This is believed to somehow aid in softening and breaking down endometrial tissues, thus alleviating symptoms, but this finding is debatable. Still, some studies suggest that

postponing motherhood increases the risk of endometriosis because a woman will have longer hormonal cycles without the break a pregnancy provides (Moen, 1991; see Weinstein, 1987 for a detailed discussion). Pregnancy as a “therapeutic treatment” for endometriosis is an irreversible and desperate step, as Weinstein (1987) points out, for if a woman follows “the advice still given by many doctors and ha(s) a baby to “cure” endometriosis, chances are you will have a baby...*and* endometriosis” (p.93). From 1922 on, many doctors pointed to the benefits of pregnancy as therapy, though their conclusions often included the words “*may* possibly retard future growth”, or “*may* protect against endometriosis” (Weinstein, 1987). It is true that for some women, symptoms are relieved for up to seven years, and remissions are possible through pregnancy (Jones, 1988), but there is also evidence that pregnancy can worsen the disease (e.g., Weinstein, 1987). For the majority of women, pain symptoms return within ten months to a year following a birth (Ballweg, 1995). Despite the fact that there is no conclusive evidence of the benefits, many women report still feeling pressured to have a child, sometimes out of desperation to end pain, sometimes out of fear of possible infertility, sometimes both (e.g., Ballweg, 1987; Shore, 1994; Weinstein, 1987, 1988). For young, single women, this is a frightening choice to make. As Weinstein (1987) so succinctly notes, pregnancy “and childbirth will definitely make you a parent, but won’t necessarily free you of endometriosis” (p.96).

Alternative treatment options (e.g., hypnosis, herbalism, homeopathy) also warrant discussion. These are interventions that are not considered “medical” or scientifically proven (see Carol, 1994 for greater detail). These treatments seem to work

for some women, but they can be quite costly, as they are not covered by health care plans.

In summary, drug methods alone can provide temporary relief of symptoms, but this kind of therapy is a short-term solution that can be quite costly and frustrating due to side effects. Surgery provides a bit more relief, and seems to be helpful in some cases of infertility. However, it does not always help alleviate pain, incurs greater risks, and often is required more than once. It is important to be aware of the myriad side effects and the prolonged nature of treatments, for this long-term relationship between a woman, her disease, and its treatments, as with any chronic illness, is often draining emotionally and financially.

Implications for developmental careers.

My body is the destiny of our futures...my husband's career,
my own career, our parenthood, our far future goals....

(quoted in Ballweg, 1987, p. 193)

It has gotten to the point where my life revolves around endometriosis. It's getting harder and harder to work, and I worry about not being able to support myself...It's difficult holding down my job. After so much time off I've already been...refused a raise. I'm afraid I won't be able to get another job...I don't feel good about myself. I don't think any man could feel good about me...I'm terrified by the thought of a hysterectomy. Not having a hysterectomy terrifies me too. But if I can't have a relationship, a baby, a career, what's left for me?

(Leah, from Weinstein, 1987, pp. 162 - 163)

In her aptly titled chapter on dealing with symptoms ("Living with continuing symptoms: Lives on Hold"), Weinstein (1987) discusses the many ways in which this disease changes a woman's life, due to pain, infertility, and sexual difficulties. The implications for educational and occupational careers stem from the symptoms of endometriosis. If a woman is in constant pain, she may be unable to attend classes, and

end up in part-time studies, falling behind, or doing poorly as a result of an inability to concentrate (or because of prolonged absences due to recovery from surgery). As well, maintaining a full-time job, or any job at all, could be difficult (e.g., InTent, 1994). For example, a study by Boling, Abbasi, Ackerman, Schipul, & Chaney (1988) showed the disabling effect that this disease can have on careers: they found that women in the United States Army with endometriosis were not able to perform their duties at optimal levels. This problem with keeping a job could be compounded by a reluctance to tell co-workers or employers of the disease, in case it has a negative effect on career progress (e.g., Dutcher, 1994). As well, if a young woman feels that endometriosis limits her abilities, she may behave in a manner that proves this to herself and others (a self-fulfilling prophecy).

Endometriosis, as a reproductive disorder, has obvious and serious implications for family planning. For a young, single woman, this disease forces upon her issues she may not have thought about. She is confronted with grave decisions (e.g., treatment options, such as radical surgery) which can permanently affect the rest of her family goals. A 24 year old single woman detailed a typical struggle with such decisions:

At 24, childbearing was not an ambition of mine. It was not even something I thought about on a daily basis. Now doctors were haranguing me to consider my options and make my choices carefully. They spoke as though my chances for childbearing were rapidly passing me by - unless I tried to get pregnant in the immediate future, I might not be able to do it at all. Suddenly I found myself thinking about an issue that was deeply personal, and yet, still foreign to me... Would I want to have a baby and raise a child, dramatically changing the course of my adult life? ...The question of fertility, I decided, would have to wait until I was ready to consider pregnancy a real option....

(Shore, 1994, pp. 152-153)

For a young woman who has never tried to get pregnant, the uncertainty of her fertile status may force her to rearrange goals (Weinstein, 1987). If she is single, she may decide to take a "wait and see" approach, and direct her time and energy towards other, more stable goals.

There is another aspect of this disease involving fertility, and that is the fact that, as mentioned, many studies point to a genetic basis of endometriosis. If this disease really is passed down through mother to daughter (Marrs, 1997), then a young woman may also have to grapple with the risk of passing this disease on to her own daughter(s). As one woman states,

Why are so many...trying to become pregnant and joyfully having babies?
I am personally astounded at the idea that it is OK to go ahead and have babies as if infertility is the only obstacle. I am personally **not** going ahead with the old "Go have a baby, and it will help your endo" advice...because I have a great fear of producing a child...with endo-related health problems. I feel a responsibility to address this issue sensibly and objectively, much as I would like to have children...

(Michelle, from Ballweg, 1987, p. 76)

As this quotation illustrates, if a young woman believes that this is a genetic disease, she will face a moral dilemma regarding her decision to have or not have children.

The issue of childbearing is not the only one involved in family planning. For some young single women with endometriosis, marriage, even relationships may not be seen as an option. The fears expressed by Leah in the quotation above are echoed by many women in her position. Much of this fear seems to stem from fear of pain with intercourse: "I felt I couldn't handle it if I told someone about...sex pain and was rejected...Men sometimes think I am using it as an excuse. Some did try to be sympathetic..., but that did not make the pain go away" (Weinstein, 1987, p. 182). This

apprehension about relationships could also be due to a sense of not being a "real" woman because of potential fertility problems, or it could be an outgrowth from the unwelcome side effects that some treatments, particularly Danazol, can cause. As well, a chronic illness such as this would undoubtedly affect any relationship as a whole, causing strained communication and perhaps a lack of understanding. Women in relationships describe the difficulties of maintaining one: "If I were single right now, I don't think any man would want me." and "I have completely avoided being with him. I don't think I can be intimate...because I don't feel good about myself. I don't feel capable of loving anyone else, either" (quoted in Weinstein, 1987, p. 180). For some women, this disease led to their single status: "I am now separated after eight months of marriage...intercourse is very painful" (quoted in Ballweg, 1995, p. 323) and "Divorced from my first husband due to the illness", "My husband divorced me because of our inability to have children", and finally, "I had begun a serious relationship a month after learning about endo...and had told him about it. Unfortunately, or rather fortunately, I learned he was nonsupportive (sic) of my plight" (all quoted in Ballweg, 1995, p. 324). Single women may experience fears with even entering a relationship: comments such as "I cannot put myself through the turmoil of dating" (quoted in Weinstein, p. 182) and "But I'm not ready to settle down...So what am I to do? Wear a sign when I date that says 'Don't consider me unless you aren't sure you want children?'" (quoted in Ballweg, 1987, p. 162) show this problem.

For younger, single women, endometriosis can be a fixed reality, something that must be dealt with on a day-to-day basis, and something that can have profound effects on future plans. At some point, a woman must reach a resolution as to how to live with

this disease. This resolution will probably involve loss, both concrete and symbolic, in areas such as goals for family, career, and education (the focus of this exploratory study), as well as control; romance and intimacy; income potential; employment; energy and strength; predictability and normalcy; pride; privacy; productivity; body image and notions of femininity; and social status (adapted from Weinstein, 1987, pp. 184 - 185). A 33 year old single woman with this disease summed up the plight of a woman with endometriosis eloquently:

We all lose our fertility at some point in our lives. And to steal an image from poet Donald Justice: "We must learn to close softly the doors to rooms we will not be coming back to." Women with endometriosis may have to learn to close some doors early - and single women with endometriosis may have to learn to close these doors alone.

(Mormann, 1987, p. 180)

Though her comment is specifically about fertility, the sentiment expressed is applicable to all life goals.

Apart from studies on psychological functioning and endometriosis (e.g., Christian, 1992; Damario & Rock, 1995; Low, Edelman & Sutton, 1993; Peveler, Edwards, Daddow, & Thomas, 1996; Waller & Shaw, 1995), very little research has been done on the effects of this disease outside of the medical realm. However, some studies do exist on issues of life goals and other chronic illnesses (e.g., Schmitz, Saile, & Nilges, 1996), which allow a certain amount of extrapolation. Though the goal of this study, exploratory in nature, was not to test the hypothesis of any one theoretical orientation, two did help shape the direction of this study. Role blocking theory from symbolic interactionism as described by Matthews and Matthews (1986) provided a framework for identifying initial salient topics of interest. As well, literature on family stress and the life

course (e.g., Falicov, 1988; Rosman, 1988) illustrated the importance of life stressors such as a chronic disease, especially for the sequencing and timing of life events. These factors permitted the investigation of the question: "How do expectations for various life careers differ among women with this disease?"

In their study of chronic pain sufferers, Schmitz, Saile, and Nilges (1996) analysed the benefits of accommodative coping styles (flexible goals; attempts are made to adjust goals as a function of level of pain) compared to assimilative ones (inflexible goals; attempts are made to adjust pain to desired plans). Their research showed that accommodative coping styles and goal modifications are protective resources, preventing a loss in psychological functioning. This flexibility also allowed people to maintain positive attitudes toward life. In contrast, those who chose to keep rigid goals suffered in terms of depression and negativity. This study does not suggest that all people modify goals, but that this approach is a healthy one. As well, this study led the authors to hypothesise that people are more likely to use assimilative coping styles at the onset of a chronic illness and use a more accommodative one with time. This finding serves as a useful tool for explaining variation in these women's expectations for developmental careers. It suggests that younger women who accept the fact that they have a chronic illness (an accommodative skill) will likely modify their goals for family, education, and occupation. However, women who refuse to acknowledge limitations that this disease can incur, or who are unaware of the full impact of the disease, could fail to lower their expectations for certain roles. As well, the length of time a woman has been living with endometriosis could affect her expectations.

We all have preferred roles in life, roles in a family, in the academic world, in an occupation; endometriosis places limitations on the ability of a woman to take on certain roles. According to Burr, Leigh, Day, and Constantine (1979), many propositions can be tied to roles: propositions regarding role enactment, role strain, role expectations, and role transitions (see their chapter for more details). Though these propositions are well developed, Matthews and Matthews (1986) take issue with the approach, and suggest some modifications.

In their article on infertility and the transition to nonparenthood, Matthews and Matthews (1986) point out some of the limitations of Burr et al.'s (1979) original propositions: they are "founded on the premise that people have social choices to make....and that problems of role strain....and so on arise when choices must be made. Burr et al. do not seem to have considered the possibility that actors might be unable to assume the roles they desire most." (p.648).

Matthews and Matthews (1986) suggest a certain kind of role strain is experienced when an anticipated role cannot be fulfilled, through no fault of the person experiencing this strain: "role strains that are brought about by the inability to assume a desired role (W)e refer to such strains and problems of transition as "role blocking". " (p. 648). Role blocking is not limited to infertile couples; it can be applied to anyone who is prevented by whatever cause(s) from assuming a preferred role. Matthews and Matthews (1986) offer five hypotheses, as follows:

- 1) When involuntarily childless couples are unable to assume the anticipated and desired role of parenthood, there is an associated increase in their level of role strain.

Limitations therefore increase role strain.

2) This strain is likely to be directly proportional to the role privileges and rewards that such couples attribute to parenthood.

Role salience therefore increases role strain.

3) The role strain produced...will, in most cases, lead such couples to redefine their situation in such a way that their desired goals become more congruent with the range of possible alternatives still available to them.

4) Such redefinitions will in turn lead to a series of role transitions. However, the greater the perceived role strain that arises from involuntary childlessness, the more difficult will it be for such couples to make such transitions.

5) The more time involuntarily childless couples have to adjust to such strains, the more likely they are to receive anticipatory socialisation to such transitions, and thus the easier will such transitions become.

(five hypotheses from Matthews & Matthews, 1986, p.

648)

Though all five of these hypotheses were designed with involuntarily childless couples in mind, the themes can be readily applied to women with endometriosis, both because of fertility issues, and because of the inaccessibility of desired roles. The revised hypotheses, as they apply to young women with endometriosis are as follows:

- 1) The inability to assume an anticipated role will increase level of role strain;
- 2) This role strain will likely be proportional to the salience (value) a woman attaches to said roles;
- 3) The strain produced will usually lead a woman to find substitute roles to reconcile her goals with the limitations of her disease;

- 4) The ease of finding substitute roles will depend upon the salience of the desired role, and the perceived role strain experienced by the inability to perform that role; transition procedures (as detailed by Burr et al., 1979, proposition 4 of role transitions) therefore influence the achievement of substitute roles, and therefore the ease of transitions;
- 5) Duration as measured since time of diagnosis increases the likelihood of receiving anticipatory socialisation, which is positively related to role substitution, and therefore the ease of role transitions.

These hypotheses and concepts address issues of ease of transitions into a role; however, these were not the only concepts which helped to guide this study.

Family Development theory assesses the probability of transitions from stage to stage for the individual and family life courses (White, 1991). Role transitions serve to mark these transitions: new roles are added, old ones are cast off at each transition event. Burr et al.'s (1979) theory of role transitions describes the individual level process of role transitions; two variables not included in Burr et al.'s theory are derived from Family Development theory at the social/ life course level: asynchrony and duration.

Duration does emerge as a concept in Matthews and Matthews' (1986) hypotheses in an indirect manner as "anticipatory socialisation". For instance, as mentioned, adaptation to an illness appears to develop over time. As well, duration is a key concept in Family Development theory: the probability of a transition decreases with time (White, 1991). For example, the longer the duration since diagnosis, the less likely a woman may be to achieve a natural pregnancy. For this study, duration was measured as "time since diagnosis".

“Asynchrony” is the experience of an individual diverging from the “normative” social path. This can occur in two ways: being “off-time” or being “out of sequence” compared with the social norm. Social norms are rules regarding social behaviours (White, 1991), and there are sanctions against “deviance”. Being socially “off-time” means that one has departed from a timing (age) norm. An example of an off-time event would be a woman bearing her first child at age 50, or at age 15. “Out of sequence” divergence involves straying from socially supported cross-institutional norms (norms developed across institutions to decrease strain; White, 1991). For example, the accepted social norm of sequencing life career developments, such that there is no cross-institutional strain, is as follows: education, job, marriage, children (e.g., Klein & White, 1996; White, 1991). An example of being “out of sequence” might be an unmarried woman dropping out of college to have a baby. The institutional “sanction” against asynchrony is in the shape of “life chances” (White, 1991, p. 168). “Life chances include access to the opportunity structures in each institution, such as education, family, and work...people who do not follow the modal pattern of social behavior have differential access to institutional opportunities” (White, 1991, p. 168).

Literature on life stressors has reflected much of what is known from coping literature: adaptation is healthiest, and more successful than denial. But a woman with this disease still has choices within her adaptation: she may choose to have a child though unmarried, or she may decide she does not want children, or she may wait until she is married and then adopt. She may lower her standards for educational achievements, or she may attend school part - time instead. Single young women with endometriosis (a stressor) may experience a ‘domino effect’ in their developmental careers, depending on

the choices made. For example, if a single young woman suffering from this disease opts for a pregnancy, she is already out of sequence in terms of her life events (e.g., White, 1991), and perhaps off-time compared to the normative age as well. This deviance will affect the rest of her life and family development, as it is difficult to return to normative transitions following a non-normative one (e.g., White, 1991).

Research Problems

Considering the myriad effects of endometriosis, and in conjunction with the propositions mentioned, the following research problems regarding single young women's experiences with endometriosis were developed.

1) How does the experience of having endometriosis vary as a function of time since diagnosis?

It seemed likely that time since diagnosis might affect a woman's life course expectations, by the effect it might have on her experience of living with the disease. As mentioned, medical treatment options can be exhausted in approximately two years. A woman who has just been diagnosed, and has yet to embark on her treatment interventions, may have different expectations than a woman who has no options remaining (e.g., she may be more optimistic in her experience of having the disease, and perhaps not feel it necessary to rearrange goals). The study by Schmitz, Saile, and Nilges (1996) led them to believe that, over time, a person living with a chronic condition changes her approach to coping (i.e., coping can come with time). And Matthews and Matthews' (1986) hypothesis regarding adjustment also illustrates the important role of time.

2) Differences in the expectations of single young women with endometriosis will vary as a function of degree of pain and pattern of pain (cyclical versus constant and/or unpredictable).

Studies on chronic pelvic pain (e.g., Damario & Rock, 1995; Low et al., 1993; Mathias, Kuppermann, Liberman, Lipschutz, & Steege, 1996; Peveler et al., 1996; Waller & Shaw, 1995) suggest that degree and pattern of pain might affect women's expectations. These studies are important because most of them compare women with endometriosis to women with chronic pelvic pain of other origins. In their study on pelvic pain and psychological functioning, Waller and Shaw (1995) compared four different groups of women: 1) women with asymptomatic endometriosis, apart from infertility; 2) women with pelvic pain as a symptom of diagnosed endometriosis; 3) women with a normal pelvis and no pain symptoms (control group); and 4) women with pelvic pain of no known origin. Their results showed that when women with the same degree of endometriosis were compared across groups 1 and 2, women with pain seem to have substantial distress leading to difficulties in psychological functioning. This finding is relevant, as it suggests that the pain from endometriosis has a greater effect than the knowledge of having the disease does.

In their study on the prevalence of chronic pain and health-related quality of life issues, Mathias et al (1996) also found evidence that chronic pelvic pain is highly disruptive. In this study, women who knew the source of their pain was endometriosis did report being the most severely affected. However, all women who reported chronic pelvic pain (of whatever origin) reported a decrease in productivity at work, less energy, and

interference with activities when compared to women with menstrual cycle-related pain. This suggests that pattern of pain is also important.

Peveler et al. (1996) also analysed psychosocial factors comparing two groups of women: women with endometriosis experiencing chronic pelvic pain, and women with unexplained pain. Their results indicated that although women with endometriosis reported slightly higher overall pain levels, the "worst pain" levels for the two groups did not differ.

Finally, a discussion by Damario and Rock (1995) on pain as a quality of life issue for women with endometriosis emphasises the fact that pain from this disease seems to have the greatest impact on physical activity, mood, sexual activity, and work capabilities.

These findings all suggest that limitations based on pain can seriously hamper a woman's abilities. Chronic pain is a constant reminder of poor health, and in such a way, it is tied to limitations based on knowledge (i.e., it reminds a woman constantly that she has this disease), but it is the pain, and not the knowledge, that has a greater impact. For example, a woman with severe pain symptoms is probably more likely to lower expectations compared to a woman who is relatively asymptomatic, and whose diagnosis may have been quite by chance. But it is not only the degree of pain that affects abilities: the pattern of pain is also relevant. Women who experience pain as a symptom can either have cyclical pain (occurring, usually, solely with menstruation, or with menstruation and ovulation), or they can experience constant pain. It is reasonable to suspect that constant pain will have a greater effect than cyclical. Cyclical pain is to some degree predictable, and though still disruptive, it can be planned around. Therefore, it is possible that a

woman with moderate constant pain will have different expectations and experiences than a woman with moderate cyclical pain.

3) When expectations regarding life roles do not differ from normative roles in society, the routes to such roles may differ.

Matthews and Matthews' (1986) hypothesis 3), involving the redefinition of a situation, and the revised proposition 3), helped shape this problem. Women with endometriosis can have limitations on their access to certain roles that may prevent them from taking traditional routes to various roles. For example, a woman with this disease may still have expectations for motherhood, but she may envision achieving this role through adoption or in vitro fertilisation, based on biological limitations.

4) The type of treatment method chosen may affect life expectations.

This is a statement of common sense. If a single woman opts to have a definitive hysterectomy, then she has taken a drastic step with ramifications for health and fertility. If she chooses to become pregnant, she has chosen a non-normative path that could disrupt her entire life course. Other treatments, such as drugs, may not have any effect, or their side effects may result in subtle changes. For example, many of the drugs prescribed create depression; some result in anorexia; some result in drastic mood swings. These side effects could influence expectations insofar as they definitely affect a woman's quality of life.

As well, it is important to bear in mind that it is not unusual for a woman suffering from endometriosis to undergo three to five surgeries in a five to ten year time frame. The weariness and stress of such procedures, as well as financial and emotional costs, can influence a woman's goals.

5) Women with endometriosis may have sequencing differences in their expectations compared to social norms.

The accepted norm of life career developments, such that there is no cross-institutional strain is as follows: education, job, marriage, children (e.g., Klein & White, 1996; White, 1991). For women with endometriosis, the fear of infertility may force a rearrangement of events: a woman may drop out of college to have a child, or marry before finishing school, or give up occupational aspirations to have a child, or even have a child before marriage. This kind of deviant sequencing is probably not common for young single women, because being "out of sync" can affect the rest of the life trajectory. For example, Rodgers and White (1993) propose that "contradictory timing and sequencing norms for family stages lead to greater deviation from the normative paths" (p. 244). Individuals within families who deviate in one area will likely disrupt the balance among various institutions, thereby creating an incongruity that extends beyond the one deviation (see Rodgers & White, 1993; White, 1991, for greater detail).

Although the main focus of this exploratory study was life course expectations, two other variables, depression, and satisfaction with social relationships (including familial), were also assessed. Living with a chronic condition can be challenging physically and mentally; when things seem hopelessly unresolvable, depression may occur. Depression may also be an outcome of poor coping mechanisms, and a lack of adaptation or modification of goals. As well, depression can be an outcome of dissatisfaction with one's perceived quality of role enactment. For example, Burr et al. (1979) describe quality of role enactment as how well a person perceives her

performance of a role in comparison to expectations (p. 58). It was therefore prudent to also analyse the effect of this disease on depression levels.

Bearing in mind the symptoms of this disease (pain with intercourse, pain in general), and some of the side effects of treatments, it seemed likely that social relationships might also be affected. Burr et al. (1979) also suggest that one's perception of one's own quality of role enactment affects satisfaction with relationships (p. 70). So if a woman perceives herself as being a poor student or girlfriend, she is likely to be less satisfied with these particular relationships. These were therefore important variables to explore.

CHAPTER II

Method

The effect of endometriosis on the expectations of single young women can be explored and assessed in diverse ways. A combined quantitative and qualitative approach was used for this study. Although the purpose of the study was exploratory in nature, certain aspects of endometriosis, as a chronic condition, can be measured. Though there is little research on the experience of endometriosis, findings from other literature on chronic pain, and chronic conditions allow for a certain degree of extrapolation. The untested hypotheses by Matthews and Matthews (1986) discuss issues of fertility highly relevant to living with endometriosis, and their paper illustrated potential areas of interest for this study. Due to the nature of this chronic condition itself, its symptoms and its treatments, as well as the literature cited previously, there was enough information to warrant the use of quantitative measures, yet at the same time qualitative measures were also appropriate, as this was an exploratory study.

Procedure

A questionnaire and an interview guide were developed for this study. Details on these two forms are discussed later in this chapter. A pre-test of the questionnaire was first conducted. Volunteers for this pre-test included graduate students and women with endometriosis who were not eligible to participate (e.g., women related to the researcher, married women, older women); this pre-test helped assess the validity of the questionnaire. Twelve pre-tests were completed; these were analysed to ensure that women who did not have endometriosis did not respond to those questions meant to analyse aspects of having the disease and that women with endometriosis who

participated in this pre-test answered these questions appropriately. The pre-tests were analysed for variation in responses (e.g., varying levels of depression). These pre-tests were also analysed to ensure that women understood questions asked; pre-test participants were asked to make suggestions for confusing wording or questions, and changes were made accordingly.

An introductory letter providing a brief description of this study and the criteria for participating was sent out to support groups, newsletters, and health forums on the internet (see Appendix A for letter). Women who were interested in participating sent their e-mail addresses, and a questionnaire was e-mailed to them (see Appendix B for the questionnaire). Women whose completed questionnaires indicated that they were either a) married, b) over 28, or c) never surgically diagnosed with endometriosis were excluded from the study. Initially, the interview component was designed to take place in person; however, many women indicated that they wanted to participate, but geographically, this wasn't feasible. In the interest of increasing the choice of participants (and therefore, increasing diversity), the interview component of the study was also carried out via e-mail. Women who indicated an interest in this second part, an in-depth "interview", were selected in such a manner as to increase the diversity of responses (see Appendix C for the "interview" guide). The three independent variables of time since diagnosis, degree and pattern of pain, and treatment methods undergone were used initially to sort through the thirty-nine of the seventy-two participants in the first portion who expressed interest in the second portion. From these piles, sixteen questionnaires were randomly drawn (it was anticipated that some of these sixteen women would not have the time and/or energy to complete an interview, and so four more than the desired

number were chosen). As anticipated, not all sixteen responded. Only twelve interviews were ultimately completed. E-mail interviews were carried out by designating a mutually agreeable time frame in which to exchange questions and comments; women were asked only one question at a time, and this allowed for probing questions and clarification when necessary.

As with the e-mail questionnaire, the return of interview questions constituted consent to participate; for member checking, women who took part in the interview component were asked to keep their own responses as transcripts of the interviews.

Sample

As mentioned, the participants in this study were recruited via support groups on the internet for women with endometriosis. The membership lists for these support groups are private, and the exact number of women on these lists is therefore unknown.

The sample selection was guided by three criteria: marital status, age, and surgical diagnosis. The sample was limited to currently single women. Marital status is a variable of obvious consequence: a married woman's experiences with this disease are likely to be different from those who are single. Obviously, a married woman will be more likely to see pregnancy as a real possibility in the future than a single woman who is not in a relationship. These research problems and this study were therefore limited to exploring the experiences of single young women. However, this criterion did not exclude women who cohabit; although cohabitation is more common than in the past, it is still not the "norm" of society.

The sample was also limited to young women. For the purposes of this study, "young" was defined as the age of 28 or under. This is an arbitrary number, but single

young women under this age are unlikely to be well established in an occupation, and may still be sorting out educational planning. Because of this, these women (in comparison, for instance, to a woman in her thirties) are less likely to be focusing exclusively on any one area of their developmental careers. It was believed that this limitation would provide diversity in responses.

This study was limited to women surgically diagnosed with endometriosis. This limitation was in place for two reasons. First, this limitation ensures that women in the study were indeed suffering from endometriosis and not another condition with similar symptoms (e.g., pelvic inflammatory disease, IBS, Crohn's); in such a manner, the validity of the study is increased, because it assessing the experiences of women *known* to have endometriosis. As well, there is a distinct possibility that women who suspect they have endometriosis, with no accompanying formal diagnosis, will have different experiences with family, with doctors, etc. For example, a woman who has chronic pelvic pain with no diagnosis may feel her pain is less validated than another woman with the same degree of pain, who can attach a medically recognised name to her condition.

Sample: Questionnaire Component

A total of seventy-two women fitting the criteria participated in the questionnaire component of this study. The average age of participants was 24 (SD 3.12), with a range in ages from 13 to 28. Sixty-four percent of participants lived in the United States (n= 46), eighteen percent (n= 13) lived in Canada, thirteen percent (n= 9) lived in Australia or New Zealand, four percent (n= 3) lived in the United Kingdom, and one percent (n=1) lived elsewhere (Philippines).

The sample for this study was limited to currently unmarried women. Ninety-four percent of participants were never married ($n = 68$); of these, 11 (16%) were engaged and thirty-two percent ($n = 22$) were cohabiting. Six percent ($n = 4$) of the sample were divorced; one of these women was cohabiting. A total of thirty-two percent ($n = 23$) of the sample were cohabiting at the time of the study. Twenty-eight percent ($n = 20$) of participants were living alone, twenty-four percent ($n = 17$) were living with parents, while eleven percent ($n = 8$) and five percent ($n = 4$) lived with a female roommate and a male roommate respectively.

The average annual income of participants falls between \$11,000 and \$20,000 (Canadian). Note that this does not include parental aid, a common source of income for the many students who participated. Occupations were assessed as per the Pineo, Porter, and McRoberts scale (1977), with new categories created for students and the unemployed. Seventy-eight percent of participants ($n = 56$) were employed at the time of the study; twenty-two percent ($n = 16$) were not. Of those sixteen currently not working, only 4 (5.6% of the entire sample) listed their occupation as "currently unemployed". The other 12 listed "student" as an occupation. The modal occupational category was student, with 34.7% ($n = 25$) of participants.

Many of the women participating in this study had some post-secondary education. Fifty-eight percent ($n = 42$) of participants had a diploma, bachelor's degree, or master's degree (the breakdown of these categories can be seen in Table 2).

Table 2 shows the breakdown on all the above characteristics of the sample.

TABLE 2**Sample characteristics: Questionnaire component**

Average Age		24
Residence		
	Canada	18% (n = 13)
	USA	64 % (n = 46)
	UK	4% (n = 3)
	Australia/New Zealand	13% (n = 9)
	Other	1% (n = 1)
Occupation (Pineo et al, 1977)		
	Student	35% (n = 25)
	Unemployed	6% (n = 4)
	Clerical	4% (n = 3)
	Semiprofessional	11% (n = 8)
	Middle management	13% (n = 9)
	Technician	1% (n = 1)
	Professional	29% (n = 21)
	Self-employed Pro	1% (n = 1)
Marital Status		
	Never married	94% (n = 68)
	Divorced	6% (n = 4)
Education		
	Grade 7	1% (n = 1)
	Grade 10	1% (n = 1)
	High school	39% (n = 28)
	Diploma/Vocational	13% (n = 9)
	Bachelor	39% (n = 28)
	Master	7% (n = 5)
Average Income/yr.		\$11,000-\$20,000

Sample: Interview Component

A total of twelve women participated in the interview component of this study. These women ranged in age from 19 to 28 (average age: 24). Five of these women were from Canada, six from the United States, and one from England. Two of these women were cohabiting at the time of the study, one was engaged, two were divorced, and nine were single, never married; note that these were not exclusive categories.

Eight of these women held professional or semi-professional jobs, while one was currently unemployed and two were students.

Three women had completed high school, six had a bachelor's degree, two had completed a diploma or vocational program, and one had a master's degree.

These twelve women were selected, as described previously, initially on the basis of diversity of experiences of the three independent variables (time since diagnosis, degree and pattern of pain, and treatment methods). The breakdown of these particular characteristics is described in the Results section of the Interview component.

Table 3 illustrates a comparison of demographic characteristics of the questionnaire and interview participants. Note that there was some degree of oversampling, especially in regards to residency, marital status, and education level; the women who participated in the interview component were all volunteers, and it was therefore not possible to have an interview sample which perfectly reflected the same characteristics as the pool from which they were drawn.

TABLE 3**Comparison of key variables of sample characteristics for questionnaire and interview components**

	Questionnaire Component	Interview Component
Average age	24	24
Residence		
Canada	18% (n = 13)	42% (n = 5)
U.S.A.	64 % (n = 46)	50% (n = 6)
U.K.	4% (n = 3)	8% (n = 1)
Australia/New Zealand	13% (n = 9)	
Other	1% (n = 1)	
Occupation		
Student	35% (n = 25)	25% (n = 3)
Unemployed	6% (n = 4)	8% (n = 1)
Clerical	4% (n = 3)	
Semipro	11% (n = 8)	17% (n = 2)
Middle	13% (n = 9)	8% (n = 1)
Management		
Technician	1% (n = 1)	8% (n = 1)
Professional	29% (n = 21)	33% (n = 4)
Self-employed	1% (n = 1)	
Professional		
Marital Status		
Never married	61% (n = 44)	75% (n = 9)
Divorced	6% (n = 4)	17% (n = 2)
Engaged	15% (n = 11)	8% (n = 1)
Cohabiting	32% (n = 23)	33% (n = 2)
Education		
Grade 7	1% (n = 1)	
Grade 10	1% (n = 1)	
High school	39% (n = 28)	25% (n = 3)
Diploma/ Vocational	13% (n = 9)	17% (n = 2)
Bachelor	39% (n = 28)	50% (n = 6)
Master	7% (n = 5)	8% (n = 1)
Average income/ yr.	\$11,000 - \$20,000	\$11,000 - \$20,000

Measures

Questionnaire Component

In order to explore the research questions posited, as well as the potential mediating and moderating variables, several techniques were used. The measures used will be discussed for each of the research problems, as well as dependent and independent variables, and the moderating variables. The main dependent and independent variables as established in the previous chapter (depression, life satisfaction, and asynchrony of life events; and time since diagnosis, degree and pattern of pain, and type of treatment method, respectively) are discussed in greater detail. Analysis of data is discussed in the Results chapter (Chapter 3).

Research problem 1: The experience of having endometriosis as a function of time since diagnosis

The experience of having endometriosis was measured by the following variables: level of depression; general life satisfaction; work changes; rearranging goals; and reanalysing goals. The measures of depression and life satisfaction are discussed below, as is the measure of time since diagnosis. Work changes were measured by asking women if, since diagnosis, endometriosis had caused changes in work patterns (see Questions 41 and 44). If women answered yes to any of these questions, she was considered to have experienced work changes. Women were also asked if, since diagnosis, they had reanalysed life goals (Question 24), and if they had rearranged life goals (Question 25). Reanalysis and rearrangement of goals would indicate that endometriosis has had some effect on expectations, though a woman might not actually

carry out what she has considered (i.e., a woman might reanalyse her expectations, but in the end, still decide to pursue her former goals) Acting on that reanalysis and changing expectations in some way (rearranging) may be linked to time since diagnosis, and in turn, affect expectations.

Dependent variable one: Depression

Depression was assessed using one of the short forms of the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). This scale ranges from 0 to 7, and asks such questions as: "On how many days during the past week did you feel you could not get going?". The short form of this scale had an alpha of .86 in a previous study (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993).

Dependent variable two: Life Satisfaction

A Likert-type scale was designed for this study to assess satisfaction with various areas of life. Women were asked to rate, on a scale of 1 to 7 (1 being "extremely satisfied", 7 being "extremely dissatisfied"), how satisfied they were with their educational activities, for example. Five general areas of life (education, family, social relationships, work, recreation) were chosen as an index to general life satisfaction. The higher a woman's score, the less satisfied she would be. Although these five areas are not exhaustive, they are broad enough to cover many of the areas of living that previous research suggests are affected by living with a chronic condition (e.g., Damario & Rock, 1995; Ruta, Garratt, Leng, Russell, & MacDonald, 1994). As this particular scale was created for the purposes of this study, reliability of the scale will be discussed in the Results section (Chapter 3).

Independent variable one: Time since Diagnosis

Time since diagnosis was measured simply, by asking women when they were *surgically* diagnosed. The inclusion of the word “surgically” is crucial, as women may suspect, or have doctors who suspect, the presence of endometriosis, but until that presence is verified and tissues analysed, the diagnosis is not certain. As mentioned, there is often a delay in diagnosis. A recent survey by the Endometriosis Association found an average delay of 9.28 years (EA Survey, 1998). With this in mind, it was prudent to ascertain when women first experienced symptoms from endometriosis. The delay in diagnosis might play a role in differential experiences of having endometriosis, and so women were asked when they felt they first experienced symptoms of endometriosis. This variable is not as reliable as time since diagnosis for the obvious reason that it is a judgement call, and not possible to prove. It is, however, still an important consideration, and was therefore measured.

Research problem 2: Differences in expectations as a function of degree and pattern of pain

Differences in expectations were measured by first measuring expectations for various life events. Categories of events were created based on responses given to a time line (Question 18) that was filled out by all participants. These categories are discussed in detail in the Results chapter (Chapter 3). A quantified time-line was given to participants to measure their life trajectory. Time lines, sometimes known as “life charts” or “life drawings”, are usually retrospective in nature (e.g., de Vries, Birren, & Deutchman, 1990; Wacks, 1989), and serve as a visual representation of major events that have already occurred in a person’s life (e.g., marriage, divorce, first “career” job). However, it

is possible to use time lines as representations of *projected* life events (see de Vries & Watt, 1994; Whitbourne & Powers, 1994, for an incorporation of both retro- and prospective time lines), as well as events that have already occurred, and the time line used in this study served this function. This time line included life events that fit normative experiences (from Hogan, 1978, 1981; White, 1987), such as birth of first child, completion of highest degree, entrance into full-time occupation, and marriage. In the interest of maintaining content validity, when a woman experienced two or more events in a given year, she was asked to give approximate month as well, in order to determine sequence of events. Thus each event (such as marriage) was uniquely tied to a date. The pre-test responses also helped assess the face validity of this measure. Details of analysis are given in Chapter 3. The measures of degree and pattern of pain are discussed below.

Independent variable two: Degree and Pattern of Pain

Women with endometriosis have to deal with a number of negative factors both before and after a diagnosis is given. Despite evidence that there is no correlation between level of pain and extent of endometriomas, lesions, etc., women are still told that they "can't be" in too much pain if there is only a "little endo". A recent article (September, 1998) on the Better Health web-site on natural approaches to endometriosis suggests that women with endometriosis experience pain because the disease "may be connected with a conflict between a woman's innermost needs and desires and the demands of the outside world. Working with a counsellor to identify your inner needs and find ways to fulfil them may be helpful. If you are in a position to start a family soon, you may want to consider doing so" (Burch, 1998). Both these examples suggest that

women with endometriosis may experience a lot of difficulty convincing others of their pain. Perception of pain is an individual thing; no one can tell another person that her pain is not "that bad". Because of this, it is important to illustrate that these women are not merely "overly sensitive" to pain, or that this pain is in their heads (as the last quotation suggests).

One way to do this was to assess their pain tolerance for more common aches and pains: headaches, toothaches, and stomach aches. After consideration, the stomach ache item was rejected, as many women with endometriosis are mistakenly diagnosed with IBS, which suggests that their "stomach" problems have as much to do with symptoms from endo as anything else (especially since the symptoms of endo often manifest themselves in 'lower abdominal pain'). By creating a general variable of "pain tolerance" based on the individuals involved in this particular study, the potential to attribute perceptions of pain of the general populace to these women's perceptions is eliminated. Their level of pain associated with endometriosis is therefore compared to their own experiences with varying degrees of pain. This measurement also assisted in ensuring validity of the sample; it was possible (though highly unlikely) that all the women who volunteered for this study were extremely sensitive to pain. With a "pain tolerance" measure, it was possible to assess whether or not there were varying levels of felt pain for the participants.

Pattern of pain was assessed by one single item which asked women to choose the statement which best described their pain symptoms (e.g., "my pain is constant and moderate", or "my pain is cyclical and mild"). "I do not experience pain" was also given as an option. Women were also asked to assess current level of pain (as they filled out the

questionnaire) on a scale of 1 to 5, one being “mild” and 5 being “excruciating”. This scale was also used to assess the pain items mentioned above, for general pain tolerance (“the worst headache you ever had” and “the worst toothache you ever had”).

Finally, pain interference was assessed by asking women if they experienced trouble falling asleep due to pain, needed medication to fall asleep due to pain, and were awakened by pain; they were asked to rate these occurrences on a scale from never to always. Pain interference was also addressed by asking women if symptoms of endometriosis (in this instance, pain) resulted in work changes or educational changes.

Research problem 3: Routes to roles

This research problem analysed whether or not women with endometriosis find substitute paths to normative roles, such as being a wife or mother. Women were asked if there were roles they had planned on having that they felt were no longer viable because of endometriosis, what those roles were, and whether and what substitutes were found (Question 26). Women who had not rearranged goals were not asked this question; if they had not rearranged goals, then presumably nothing had changed in terms of role expectations, and therefore routes to those roles.

Research problem 4: Differences in expectations as a function of treatment methods undergone

The measure for expectations has already been discussed. Type of treatment method undergone, the third independent variable, is discussed below.

Independent variable three: Type of Treatment Method

Type of treatment method undergone for endometriosis was analysed using a list of treatment options (Question 18 on the questionnaire). This list included common

treatments (such as birth control pills) and less common treatments (hysterectomies, pain mapping), and had an option for no treatment at the time of the study. This list provided a time line of treatment, as women were asked to give the date(s) of treatment next to each option. In this way, it was possible to determine the extent of treatment sought prior to surgical diagnosis, a variable that could very well affect women's experiences of having endometriosis, and in turn affect life expectations.

Research problem 5: Expectations and asynchrony

The measure of life event expectations has already been discussed. Asynchrony of events was measured in comparison to both social norms (through the use of comparison of expectations to census data, for example), and to one's own planned life path.

Dependent variable three: Asynchrony of Life Events

Asynchrony of life events has been previously described in this study as the experience of an individual diverging from the normative path, in one of two ways: being off-time, or being out of sequence. Although asynchrony in comparison to social norms is a worthwhile phenomenon to explore, this study also analyses asynchrony in comparison to one's own expectations for a life trajectory.

To address the issue of asynchrony with one's own planned life path, several open-ended questions were included. Women were asked if they had reanalysed goals since diagnosis, if they had rearranged goals since diagnosis, and if there were things they wanted to do or be that they felt endometriosis has prevented them from doing or being. These open-ended questions, along with the interview portion of the study, helped to assess the effect endometriosis has had on women's own expectations for a proper life trajectory (as opposed to a societal normative one).

Mediating variables

As this area of research is vastly underexamined, several other variables which could play a role in differential experiences and expectations were assessed. Perceived prognosis was determined by asking women how they felt about their future with this disease (optimistic, depressed, or neutral). Social support was also assessed several times: women were asked to list the three people with whom they felt most comfortable discussing endometriosis, if they felt others believed their difficulties with the disease, and if others were even aware they had this disease.

Another important variable that was measured was role strain; based on Matthews and Matthews' (1986) previously discussed untested hypotheses, it was reasonable to expect that degree of role strain (manifested as "role blocking" - the 'inability' to assume a desired role) affects a woman's expectations and experiences living with endometriosis. Role strain was measured by asking women two separate questions: "how important are the following roles to you?"(mother, wife, daughter, student, etc.), graded on a Likert-type five point scale. This measured role salience (the value of a role). Women were then asked: "to what degree do you feel endometriosis has affected your ability to perform as (a mother, a wife, etc.)?", graded on a Likert-type ten point scale. This measured the direct effect of endometriosis on these particular roles. This one item did not however, capture role strain; role strain is linked to role salience. Role strain was therefore measured by multiplying role salience for any given role by the effect endo had on said role. This was deemed the most appropriate way to assess role strain; it is impossible to know, for example, if role salience increases because of the inability to assume a role

("wanting what one cannot have"), or if the inability to take on a role is influenced by an already established role salience.

As mentioned, delay in diagnosis was measured by determining the difference between a woman's age at first symptoms and age at diagnosis; however, since delay is a perception, women were also asked "Did you experience a delay in diagnosis due to..." and given 6 options, one of which was "I did not experience delays". This variable addresses a personal perception of delay, rather than a measurable experience.

Several other variables that could possibly affect women's differential experiences were: family history of endometriosis (measured by one item, "does anyone else in your family have this disease?"); women's greatest concerns with the disease (Question 17, with concerns such as infertility and chronic pain); current medications (as many hormonal medications affect depression level); and current relationship and relationship history (women were asked the duration of a current relationship, when they told their partners of the disease, and if they felt endometriosis played a role in the ending of or lack of involvement in a relationship).

Potential control variables identified in previous research (e.g., Christian, 1992; Low et al., 1993; Peveler et al., 1996) were also assessed. These included age, socio-economic status, and household structure, as well as marital status (Questions 2 through 9).

Interview Component

As this study was exploratory in nature, the interview portion was designed to expand on some of the issues addressed in the questionnaire, as well as issues that were not suited to quantitative measures. At the same time, the interview component provided

the opportunity to discover variables that may affect a woman's experiences, but which were not identified in the questionnaire. The interviews were semi-structured; that is, women were all asked the same questions in the same order, but there was a certain amount of flexibility in deviating from a question, or in expanding on a particularly interesting response (see Appendix C for a copy of the interview guide). Morse and Field (1995) state that a semi-structured interview may be used when the "researcher knows most of the questions to ask but cannot predict the answers...this technique ensures that the researcher will obtain all information required..., while at the same time gives the participant freedom to respond" (p. 94).

Women were all asked eight identical questions; three other questions regarding relationships were adjusted according to relationship status at the time of the study. Some of the questions asked women to consider the effect of having endometriosis on views on having children, on marriage, and the effect on life expectations in general; these were issues addressed to a lesser extent in the questionnaire component. Women were also asked to discuss the experience of waiting for a diagnosis, the effect of having endometriosis on family relationships, coping "helps" and "hurts", and if and how endometriosis affected their outlook on various areas of life.

The analysis process and development of themes followed procedures for cross-case analysis as detailed by Patton (1990). Cross-case analysis involves grouping together answers to common questions from different people, as opposed to doing a single case study for each interview. This kind of analysis is possible with a semi-structured interview, as each individual is asked essentially the same questions. The interviews were read over several times, and themes were developed based on these readings and notes

made during and after the interview process. Cross case analysis involves looking for recurring comments and regularities, which form patterns and themes. These themes were then sent to the interview participants (“member checking”), and they were invited to comment on the validity of the themes. Of the twelve participants, nine gave detailed comments on the themes, and these comments and thoughts were also incorporated into the final interview results.

To address the issue of “trustworthiness” (comprised of four elements that approximate internal and external validity, and reliability in quantitative research; see Rodwell and Byers, 1997, for a detailed discussion), an audit trail was created, and an audit carried out on the interview findings. An audit trail, as defined by Rodgers and Cowles (1993), is “comprised of a variety of researcher-generated data that must be consistently...recorded and...organized throughout the research process”. An audit trail typically includes four basic types of documentation: contextual (descriptive accounts, usually created as the observations occur rather than created on reflection); methodological (decisions made regarding the methodology throughout the process of conducting the study); analytic (notes on the researcher’s thought processes in sorting and analysing the data); and personal response (e.g., a reflexive journal). This documentation was kept, and then shared with an auditor. The auditor’s task was to assess the trail left, and prepare an evaluative report (see Appendix D for this report). Although methodological proficiency is often a consideration in choosing an auditor, so too is familiarity with the issues of the study (Schwandt and Halpern, 1988). The person chosen for auditor was familiar with qualitative methods and analysis, and also had knowledge of endometriosis.

Chapter III

Results: Questionnaire component

Endometriosis characteristics of participants

The average age at diagnosis for these women was 21.6 (standard deviation of 3.9 years). Age at diagnosis ranged from 13 years to 28 years old. Two modal ages were found: 20 and 22, with 11.1% (n=8) of participants being diagnosed at each of these ages. The average age at symptoms of endometriosis tells a different story: the mean age at first symptoms was 16 with a standard deviation of 4.7 years. There were again two modal ages: 11 and 14, with 14% (n=10) of participants experiencing symptoms at each of these ages. Only one participant did not experience symptoms prior to diagnosis.

Seventy-nine percent (n=57) of participants felt they had experienced a delay in diagnosis. The most common reasons given for a delay were: misdiagnosis (n= 22) and being told/thinking the symptoms were "normal" (n= 21). Lack of health coverage was an issue for only one woman, which suggests that differences in the health care systems of various countries did not affect women's initial experiences of living with endometriosis.

Key descriptives of the dependent and independent variables are discussed below. Table 4 illustrates the means, standard deviations, and alphas, where applicable, for the main dependent and independent variables (depression and life satisfaction; and time since diagnosis, respectively). These are discussed in detail under the appropriate headings. Table 5 illustrates the bivariate correlations between the dependent and independent variables, where applicable. Degree and pattern of pain has a significant effect on depression and general life satisfaction (note that the life satisfaction scale is reversed; i.e., the higher one's score, the *less* satisfied a woman is). This is unsurprising,

if one considers previous literature and common sense. Time since diagnosis, on the other hand, has no significant effect on either of these variables. There was no significant relationship found between the two independent variables of time since diagnosis and degree and pattern of pain ($r = -.004$).

TABLE 4Key descriptives of dependent and independent variables

<u>Variable</u>	<u>Mean</u>	<u>SD</u>	<u>alpha</u>
<u>Dependent:</u>			
Depression (CES-D)	3.0718	1.7213	.9146
Life Satisfaction	3.5	1.1399	.69
<u>Independent:</u>			
Time since diagnosis (in years)	2.3611	2.7898	N/A

TABLE 5

Bivariate correlations between dependent and independent variables

	<u>Dependent</u>	
	Depression	Life Satisfaction
<u>Independent:</u> Time since diagnosis	-.006	-.095
Degree and Pattern of Pain	.440**	.350**

** significant at the .01 level (two-tailed)

Dependent Variables: Depression, Life Satisfaction, and Asynchrony

Depression

The depression level of participants was assessed using a short form of the CES - D scale (Centre for Epidemiological Studies Depression Scale) (Radloff, 1977). This scale had an alpha of .9146. in this sample. The mean level of depression was 3.0718 (on a scale of 0 to 7, where 7 indicates severe depression), with a standard deviation of 1.7. There was little skewness (.168). There was no relationship between level of depression and being on any medication with the potential to elevate depression ($r = .048$).

Satisfaction level

General life satisfaction was assessed using a five item scale with an alpha of .69. This alpha level was the highest possible; the removal of any of the five items decreased the alpha. The mean level of life satisfaction was 3.5 (on a scale of 1 to 7, where 7 indicates extreme dissatisfaction), with a standard deviation of 1.1. Levels ranged from 1.6 (satisfied) to 6.4 (dissatisfied), and there was very little skewness (.178; s.e. of .283); this suggests, despite a lower alpha, that distribution is fairly even.

Asynchrony

Asynchrony was assessed in the questionnaire component by forming categories of events based on the time line (Question 18). Categories were as follows: sequence of events prior to symptoms; sequence of events after symptoms (sequence of events until diagnosis); sequence of events after diagnosis (to the date of the study); and expected events (as of the date of the study). Each event listed on the time line was given an arbitrary code number (e.g., high school = 01; full time occupation = 05), and thus

sequencing of events was coded in one string of numbers for each of the four categories mentioned above. For example, for expected event sequencing following diagnosis, one cluster of responses might be "0105" ("high school - full time occupation"), while another sequence cluster could be "0910" ("cohabitation - separation"), or "05" ("full time occupation"). Events which were not expected in the next five years were not included in this string, as it was not possible to determine sequencing. Sequencing of expected events was then further broken down into 12 categories. Table 12 illustrates the breakdown of these categories; it is further discussed under research problem 5.

Independent Variables: Degree and Pattern of Pain, Time since Diagnosis, and Type of Treatment Method

Degree and Pattern of Pain

Two participants (2.8%) experience no endometriosis-related pain; one of these women has had a definitive hysterectomy. Slightly over one quarter of the sample (n = 19) experience constant, moderate pain, while 22% (n = 16) experience cyclical and moderate, 18% (n = 13) experience constant and severe, and 19% (n = 14) experience cyclical and severe. 4% (n = 3) of participants experience cyclical and mild pain, while 7% (n = 5) experience constant and mild pain. Only one woman's pain patterns did not fit into the categories given. Table 6a gives a breakdown of exact numbers for each category.

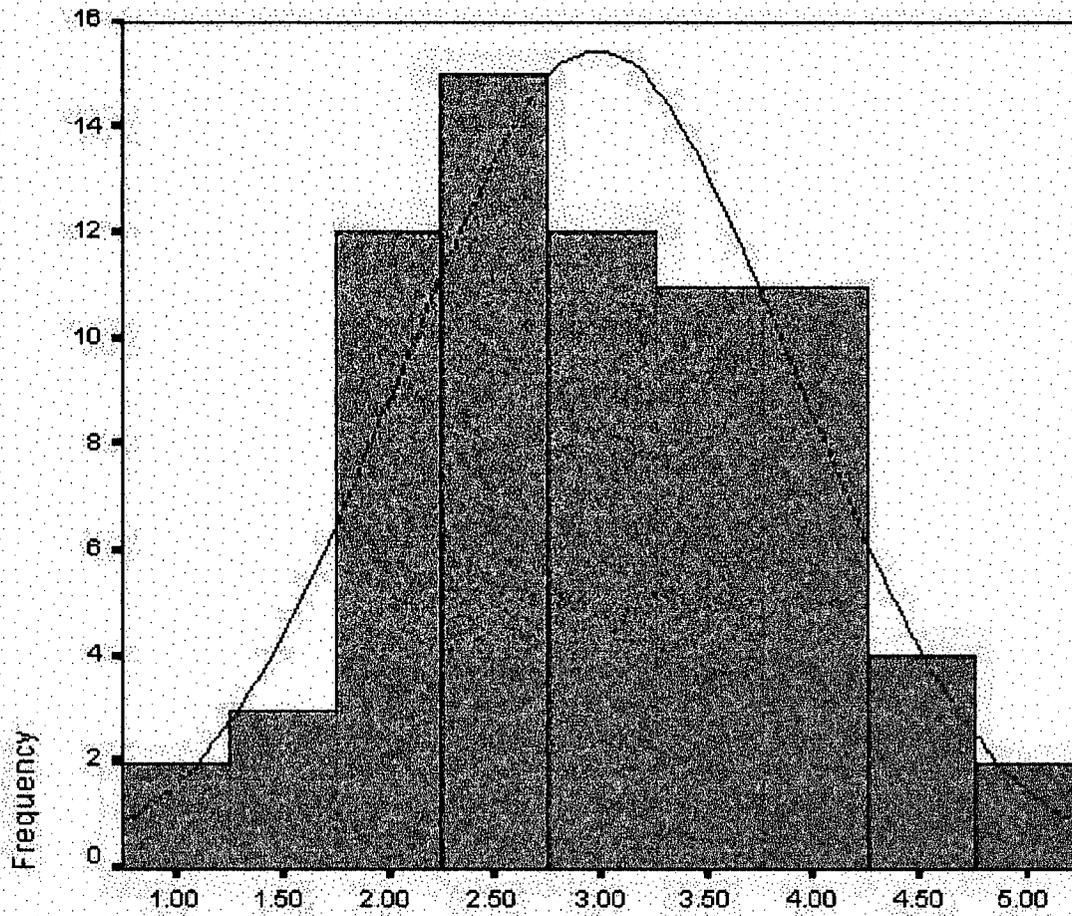
TABLE 6a

Degree and pattern of pain: Questionnaire component

<u>Degree/Pattern of Pain</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Percent</u>
no pain	2	2.8	2.8
cyclical mild	3	4.2	6.9
cyclical moderate	16	22.2	29.2
cyclical severe	14	19.4	48.6
constant mild	5	6.9	55.6
constant moderate	19	26.4	81.9
constant severe	13	18.1	100.0
Total	72	100.0	100.0

To address the issue of pain tolerance, a new variable of normal pain levels was created, as mentioned in the previous chapter (p. 49). Worst toothache and headache levels were summed, then divided by two, to give a general "worst pain" level, on a scale from 0 - 5. The mean level of general pain was a 3 ("distressing"), standard deviation of .93, with very little skewness (.103) and a wide range of responses (from 1 to 5). Then, the worst pain experienced due to endo *relative* to other pains at their worst was assessed by subtracting the general "worst pain" level from the worst endometriosis pain. The relative pain of endometriosis was often worse, with a mean of 1.6 degrees of pain worse than the general "worst pain" level. Only 8% of participants (n = 6) felt their worst endo pain was less than or the same as their worst general pains from other sources. For a visual representation of the general pain (worst toothache and worst headache) tolerance results, refer to the chart in table 6b. Table 6b shows a wide range of results, and suggests a varying degree of pain tolerance levels for the women in this study.

TABLE 6B

General pain tolerance levels: Questionnaire component

Pain interference was also assessed using a three item scale. The alpha for the pain interference variable was extremely low (.40), and there was very little variation in responses (most of which suggested every participant had experienced some interference due to endo pain). This variable was thrown out due to the low alpha.

Time since diagnosis

Time since diagnosis was measured by asking the year and month of surgical diagnosis. In terms of time passed since diagnosis, there is not a lot of variety in these women's experiences. This should not be too surprising, as these are younger women. Since most women experience a delay in diagnosis of 9.28 years (1998 Endometriosis Association Survey), most endo sufferers are not being diagnosed at young ages (i.e., the sample pool for younger women is probably smaller to begin with). Time since diagnosis ranged from 0 to 12 years. Table 7a illustrates a more detailed breakdown of time since symptoms and time since diagnosis characteristics of the questionnaire sample. Table 7b gives a detailed breakdown of age at first symptoms and age at diagnosis for the questionnaire component.

It should be noted in Table 7a that a full 22% of participants were diagnosed in 1998, and a further 33% were diagnosed in 1997. Just under half of the sample (44.4%) has been living with the diagnosis of endometriosis for two years or more (as mentioned in Chapter 1, after 2 years, most non-invasive treatment options will have been exhausted, and this could lead to re-assessment of living with endometriosis). Table 7b shows that time since symptoms is much more varied: the mode is 12 years (15.3%, n= 11), with another large group at two years (11%; n= 8).

TABLE 7ATime since symptoms and diagnosis (in years): Questionnaire component

Years	<u>Since</u> <u>Frequency</u>	<u>Symptom</u> <u>Percent</u>	<u>Cum. %</u>	<u>Since</u> <u>Frequency</u>	<u>Diagnosis</u> <u>Percent</u>	<u>Cum. %</u>
0				16	22.2	22.2
1	1	1.4	1.4	24	33.3	55.6
2	8	11.1	12.5	11	15.3	70.8
3	6	8.3	20.8	5	6.9	77.8
4	7	9.7	30.6	5	6.9	84.7
5	5	6.9	37.5	1	1.4	86.1
6	4	5.6	43.1	2	2.8	88.9
7	3	4.2	47.2	1	1.4	90.3
8	5	6.9	54.2	2	2.8	93.1
9	5	6.9	61.1	3	4.2	97.2
10	2	2.8	63.9	1	1.4	98.6
11	4	5.6	69.4			
12	11	15.3	84.7	1	1.4	100.0
13	5	6.9	91.7			
14	1	1.4	93.1			
15	3	4.2	97.2			
16	1	1.4	98.6			
N/A	1	1.4	100.0			
Total	72	100.0	100.0	72	100.0	100.0

TABLE 7B

Age at first symptoms and diagnosis: Questionnaire component

Age	<u>At</u> <u>Frequency</u>	<u>Symptom</u> <u>Percent</u>	<u>Cum %</u>	<u>At</u> <u>Frequency</u>	<u>Diagnosis</u> <u>Percent</u>	<u>Cum %</u>
9	1	1.4	1.4			
11	10	13.9	15.3			
12	6	8.3	23.6			
13	4	5.6	29.2	2	2.8	2.8
14	10	13.9	43.1	2	2.8	5.6
15	6	8.3	51.4	2	2.8	8.3
16	7	9.7	61.1	3	4.2	12.5
17	1	1.4	62.5	4	5.6	18.1
18	2	2.8	65.3	2	2.8	20.8
19	3	4.2	69.5	5	6.9	27.8
20	8	11.1	80.6	8	11.1	38.9
21	2	2.8	83.4	5	6.9	45.8
22	5	6.9	90.3	8	11.1	56.9
23	1	1.4	91.7	5	6.9	63.9
24	3	4.2	95.9	4	5.6	69.4
25				7	9.7	79.2
26	2	2.8	98.6	7	9.7	88.9
27				6	8.3	97.2
28				2	2.8	100.0
N/A	1	1.4	100.0			
Total	72	100.0	100.0	72	100.0	100.0

Type of Treatment Method

Women in this study have undergone a variety of treatments, both medical and surgical. Table 8 gives a detailed breakdown of all treatment methods undergone.

TABLE 8

Treatments methods undergone: Questionnaire component

<u>Treatment Type</u>	<u>Frequency</u>	<u>Percent</u>
none (currently)	11	15
dietary changes	38	53
yoga	17	24
acupuncture	14	19
therapy/counseling	24	33
birth control pills (bcps)	64	89
diagnostic	72	100
laparoscopy/tomy		
subsequent laparoscopy	49	68
laparotomy	12	17
danazol	13	18
pregnancy	1	1
pain mapping	6	8
GnRH agonists	33	46
removal of ovary	8	11
removal of fallopian tube	5	7
hysterectomy	3	4
definitive hysterectomy	3	4

**Note: Frequencies will not total 100%, as none of these treatments is exclusive. Table does not include frequencies of treatments (e.g., laparoscopy) undergone for any one individual.

By far the most common treatment was birth control pills: only 11% of participants had never been on birth control pills at some time. One third of participants had undergone counselling, almost 20% of those in the past year. The average length of counselling was one year. Only 15% of participants were not taking any treatment at the

time of study (n= 11). 68% had more than one laparoscopy. 40% of women had at least one subsequent laparoscopy following surgical diagnosis, while almost 20% had two subsequent laparoscopies. Note that 51.4% of participants were diagnosed since 1997, so this high percentage of subsequent surgeries illustrates that some women are undergoing surgery yearly, or even twice a year. This is not to suggest that yearly surgery becomes a pattern, but it may indicate the lack of any one effective treatment. The range of subsequent surgeries spans from none to 9. Almost 17% of participants (n= 12) had also had laparotomies for treatment. Two of the most drastic of treatments, hysterectomies and/or definitive hysterectomies, were undergone by a total of 4 participants (two of these women had hysterectomies first, then went on to have their ovaries removed as well); three of these women were 23 or younger at time of this surgery. Only one of these women is currently not experiencing pain related to endo.

Pregnancy was also listed for these women to choose as a potential treatment. Though many women plan to try to conceive, 17% (n= 12) mentioned it specifically as a treatment option. One woman had already had a pregnancy as a treatment.

In terms of drug treatments (apart from birth control pills), responses were varied. Only 18% of participants had been on danazol; while almost 50% reported using GnRH agonists at least once (n= 33).

Since all participants were surgically diagnosed with endometriosis, surgical intervention at least once was a given. Treatment methods other than this diagnostic laparoscopy were collapsed into nine categories, as follows: 1) no treatment other than a diagnostic laparoscopy; 2) alternative (counselling, dietary changes, acupuncture, yoga; 3) medical (birth control pills, danazol, GnRH agonists); 4) surgical (laparoscopies,

laparotomies, colectomies, pain mapping, removal of organs); 5) a combination of surgical and alternative; 6) a combination of surgical and medical; 7) a combination of medical and alternative; 8) pregnancy as a treatment option (over-riding any other treatment types); and 9) surgical, medical, and alternative. The category of surgical was thrown out, as no woman sought solely this type of treatment.

Only 3% ($n = 2$) of these women fell into the "no treatment" category. Many women's treatment methods belonged in the surgical, medical, and alternative (i.e., all types) category ($n = 28$, 39%). These categories will be further discussed in Research Problem 4.

Research Problems

Research Problem 1

How does the experience of living with endometriosis vary as a function of time since diagnosis?

The experience of living with endometriosis was measured by the following variables: level of depression; general life satisfaction; work changes; rearranging goals; and reanalysing goals. Control variables, as mentioned earlier, were: age, family history of endo, household structure (dummied as living alone or not), and SES. Three other potential independent variables also entered into the equation: role strain, time since symptoms, and the difference between time since diagnosis and time since symptoms. As well, the variable which addressed a personal perception of delay was also included (dummied as 1 = yes; 0 = no).

Bivariate correlations were first assessed. There were no significant relationships between duration variables and the five dependent variables (see Table 9 for a breakdown of correlations).

TABLE 9

Bivariate correlations between select dependent and independent variables: Research problem 1 (N= 72)

Independent:	Dependent:				
	Depression	Life Satisfaction	Work Change	Reanalyzing Goals	Rearranging Goals
Time since diagnosis	-.006	-.095	-.139	.097	-.072
Time since symptoms	-.082	.122	-.117	.076	.000
Dif. tsymp and tdiagnosis	-.082	.190	-.028	-.059	.048
Role Strain	.246*	.261*	.157	.041	.366**
Family History of Endo	.004	-.047	-.014	.104	-.049
Age	-.189	.078	-.214	.062	.000
SES	-.315**	-.058	.141	-.018	-.153
Perceived Delay	-.070	.112	.007	.067	.309**
Living Alone	.736	-.121	.226	.177	.092

* Correlation significant at the 0.05 level (2-tailed).

** Correlation significant at the 0.01 level (2-tailed).

Note: dif = difference tsymp = time since symptoms tdiagnosis = time since diagnosis

Table 9 illustrates that there was a relationship between the variable of personal perception of delay in diagnosis and rearranging goals ($r = .309$, $p = .01$). There was also a relationship between role strain and several dependent variables: between role strain and depression ($r = .246$, $p = .05$), role strain and general life satisfaction ($r = .261$, $p = .05$), and role strain and rearranging ($r = .366$, $p = .01$). These relationships will be discussed in the Discussion chapter (Chapter 5).

Because there were no significant relationships between duration variables and the five dependent variables, no further statistical analyses were carried out for this question. The lack of a linear relationship here suggests that the mean for these dependent variables (depression, life satisfaction, et al) is the best predictor across time duration. The only duration variable that was significantly related to any of the dependent variables was a perceptual one, that of perceived delay in diagnosis. This suggests that using a perceptual measure of duration is better suited to analysing the effects of duration on women's experiences of living with endometriosis. The relationship between perceived delay and women's experiences is further discussed in the Discussion chapter (Chapter 5).

Research Problem 2

Differences in the expectations of single young women with endometriosis will vary as a function of degree of pain and pattern of pain (cyclical versus constant and/or unpredictable)

Table 10 depicts the results of a cross tabular analysis of the variables of degree and pattern of pain and expectations of the women in this sample. This matrix represents the number of women experiencing various patterns of pain categorised by their

expectations for different events (the development of these expected events is discussed under research problem 5). This matrix was used instead of correlational analysis due to the large number of subcategories for each variable (i.e., dummifying variables was not a feasible option). Percentages of women expecting to experience different events are discussed below.

TABLE 10

Cross-tabulation of pattern of pain and expected events: Research problem 2

Expected Events	no pain	cyc-mild	cyc-mod	cyc-severe	con-mild	con-mod	con-severe	Total
None			2	2	1	5	2	12
high school		1			1			2
m - hd	1		3	2		3	3	12
hd				1	1	2		4
c before			1			1	4	6
m								
co-m			1	1				2
c no m			2				1	3
no child			1	1		1		3
f/t job						4	3	10
m-job		1	2			1		2
hd-adopt	1			1		1		3
m-c		1	4	5	2	1		13
Total	2	3	16	14	5	19	13	72

Notes: m= marriage hd= highest degree c= child f/job= full-time job
 cyc=cyclical mod = moderate con = constant

Most of the women expecting marriage then a child (i.e., a normative sequencing of events) did not experience constant pain, regardless of degree of pain: 77% (n = 10) of women expecting this normative pattern experienced some form of cyclical pain; no woman with severe and constant pain expected this sequence. 31% (n = 4) of women with severe and constant pain expected to have a child before marriage; these women made up 67% of the participants expecting this particular sequencing. Note that this sequencing of events was the modal category for these women.

Women with constant pain, regardless of the degree, also made up the largest portion of women who did not know when to expect events in their lives: 67% (n = 8) of the women in the category of "none" had constant pain. This was also the modal category for women with constant and moderate pain (26%; n = 5).

Women with constant as opposed to cyclical pain were also more prominent in categories for expectations that did not involve relationships (marriage, cohabiting, children): they made up 70% (n = 7) of women expecting a full time job and 75% (n = 3) of women expecting their highest degree in the next five years.

Of the two women not experiencing pain, neither expected an entirely normative sequencing; one expected to continue school after marriage, and the other expected to adopt outside of marriage.

These results suggest that pain experiences do have an effect; specifically, pattern of pain (i.e., cyclical or constant) affects women's expectations more so than degree of pain (i.e., mild, moderate, or severe) does. These findings are further discussed in the Discussion chapter (Chapter 5).

Research Problem 3

When expectations regarding life roles do not differ from normative roles in society, the routes to such roles may differ

This research problem analysed whether or not women with endometriosis may find substitute paths to normative roles, such as being a wife or mother. The focus of this question was most specifically on the roles of wife and mother. In the questionnaire component, women who had rearranged goals were asked if there were roles they had planned on having that they felt were no longer viable because of endometriosis, what those roles were, and whether and what substitutes were found. Women who had not rearranged goals were not asked this question; if they had not rearranged goals, then presumably nothing had changed in terms of role expectations.

50 of the 72 participants had rearranged goals. Of those 50, 66% (n = 33) felt they had given up roles. The role women most commonly felt they had given up was that of "natural" mother (14 of the 50; 28%). "I divorced because my husband did not want to adopt...I can now adopt as a single mom. Eventually I'll be a mom with or without someone else!" wrote one participant who had had a hysterectomy.

Many women mentioned that they would adopt if they could not have biological children. 78% of participants (n = 56) planned to adopt at some point. Adoption rates in the general population are difficult to ascertain (see Sobol & Daly, 1994 for a detailed discussion). Not only do most statistics fail to distinguish between nonrelative and relative adoptions, they also neglect to analyse the characteristics of adoptive parents; i.e., how many women who adopt included in those general population rates have endometriosis, and further, how many have this disease and are unaware of that fact?

Bearing this in mind, the rate of anticipated adoption among the women in this study seems high; Sobol and Daly (1994) state that "clearly the trend emerging...is one of decreasing use of adoption as a means of family formation..."(p. 497). Some of this is due to a lack of children available for adoption, though it is difficult to determine exactly how much of this trend can be attributed to this lack.

But not every woman who had given up a role found a replacement (or a suitable substitute). Of the 33 women who had given up roles, roughly half had substitutes and roughly half did not. Some women redirected energy: one participant said she had given up the role of mother and had replaced it with being a baby-sitter. And even women who still hoped for normative roles expressed fears of never seeing them realised. "I always assumed that I would be a parent. Since being diagnosed...I am now more aware that might not happen", said one woman. "I have had to look at what I will do in the event that I cannot have children, either at all or naturally." And another said, "I have thought of adoption because I fear that I may not be able to conceive- sometimes afraid I will never find a significant other because of this..."

The mother role is a valued one for the women in this study, and the above findings suggest that these women are indeed searching for other routes to motherhood, or, failing that, the experience of being a mother (i.e., the comment about babysitting). As well, the comments made by many women in response to the open-ended questions reveal that these women are also willing to substitute roles if an expected or preferred one is not achievable. These findings are discussed further in the Discussion chapter (Chapter 5).

Research Problem 4

The type of treatment method chosen may affect life expectations

The creation of categories of treatment type was discussed earlier under the type of treatment method section (p. 67). Table 11 depicts the results of a cross tabulation of treatment type and expected events. This matrix describes the number of women who have undergone various treatment methods categorised by their expectations for different events (the development of these expected events is discussed under research problem 5). This matrix was used instead of correlational analysis due to the large number of subcategories for each variable (i.e., dummyming variables was not a feasible option). Percentages of women expecting to experience different events are discussed below.

TABLE 11

Cross-tabulation of treatment types and expected events: Questionnaire component

	Treatment Type				pregnancy	all types	total
	none	alt	med	surg/alt			
Expected							
none		1	1			3	12
high school			1			1	2
marriage-high degree		1	1			5	12
marriage-child	1		5			1	13
highest degree			1		1	2	4
child-marriage	1					3	6
cohabit-marriage					1	1	2
child-no marriage					1	2	3
no child						3	3
full time job		1	1	1		4	10
marriage-job			1			1	2
highest degree-adopt						3	3
Total	2	3	11	1	1	28	72

Notes: alt = alternative med = medical surg = surgical

Women who have undergone all (i.e., surgical, alternative, and medical) treatment types (though not necessarily all methods) make up the majority of this sample (39%; n = 28); they also expect “non-normative” event sequencing and expectations (if we define “normative” as education, then occupation, then marriage, then child): of the 29 women who fit this non-normative definition, 55% (n = 16) have undergone all treatment types.

There does not appear to be any other significant effect of treatment methods on expectations; women who have had to undergo a variety of treatments do not seem to be any more or less likely to have no expectations compared with other women in this sample.

Research Problem 5

Women with endometriosis may have sequencing/timing differences in their expectations compared to social norms

Sequencing expectations

As previously mentioned, there is a normative sequencing of life events that aids in reducing cross-institutional stress. That normative sequence is as follows: highest degree, full time occupation, marriage, child (Hogan, 1978, 1981; White, 1987, 1991). This research problem analysed whether or not women with endometriosis adjusted their sequencing, both compared to the normative sequence, and to their own previous expectations.

As shown in Table 12, 12 categories of events women expected to experience in the next five years were created from the data. As mentioned (p. 61), events which were expected beyond the next five years were not included in the formation of these categories. After creating the sequence strings (again, as detailed on p. 61), these codes

were further collapsed and clustered into common expected events. The clusters do not include more than two events, for the sake of simplicity (and the creation of categories with an N greater than one). Women who expect a normative sequencing of events (i.e., school, job, marriage, child) were all clustered into the category of marriage – child, as this cluster reflects normative sequencing. All non-normative sequences were clustered to indicate at which point the sequence was deviant (e.g., “child-marriage” may include school and job prior to these two events, but only the non-normative cluster is represented).

TABLE 12Expected events: Sequencing

	EXPECTED	EVENTS
	<u>Frequency</u>	<u>Percent</u>
None	12	16.7
High school	2	2.8
Marriage-highest degree	12	16.7
Marriage-child	13	18.1
Highest degree	4	5.6
Child-marriage	6	8.3
Cohabit-marriage	2	2.8
Child-no marriage	3	4.2
No child	3	4.2
Full time job	10	13.9
Marriage-job	2	2.8
Highest degree-adopt	3	4.2
Total	72	100.0

Six of these categories are deviant when compared to the regular sequence laid out above: marriage-highest degree; child-marriage; child-no marriage; no child; marriage-job; and highest degree-adopt/child. Forty percent of the 72 participants (n = 29) expected a sequence that fell within one of these six categories. This percentage cannot easily be compared to rates of non-normative sequencing in the general population, as such rates are not usually calculated; besides, how many of those women who are 'deviant' have endo and don't know it? Still, the modal category of expectations among these women is marriage-child (n = 13, 18%), though this is followed closely by marriage-highest degree (n = 12, 16.7%), and the default category (events expected, but more than five years from now) (n = 12, 16.7%).

Timing expectations

Table 13 shows the timing expectations of this sample for various life events.

Timing is calculated as the average age at which these women expect an event to occur.

TABLE 13

Expected life events: Timing averages

	high school	marri- age	di- vorce	highest degree	1 child	2 child	3 child	adopt	cohab -it	Separ -ation	full time job
Mean	17.6	25.7	21.3	25.5	27	29.8	32.6	28	23.1	24	23.07
Med	18	26	21	26	27	30	33	27	25	23	23
Mode	18	26	19(a)	26	27 (a)	30	33	24 (a)	26	23	21 (a)
Never	0	6	52		8	10	27	17	6	48	3
+5 yrs	0	31	16	23	31	44	40	52	23	19	12
Total	72	72	72	72	72	72	72	72	72	72	72

a Multiple modes exist. The smallest value is shown.

For some of the expectations assessed, average age statistics are available for the general population. These expectations are: age at marriage, and age at first child .

In Canada, the average age at first marriage for women is 27.3 (Statistics Canada, 1996 data). The average age at marriage (first or otherwise) is 31.3 (1997 data). It should be noted that since some participants in this study have been previously married once or twice, looking at both these average ages is appropriate. In the United States, the median age at first marriage for women is 26.7 (Monthly Vital Statistics, 1990), while average age at marriage (first or otherwise) is 29.3 (MVS, 1990).

For the women in this study, the average expected age at marriage (first or otherwise) is 25.7, lower than both the average actual age for Canada and the United States.

In terms of age at first birth, statistics for Canada in 1995 indicate an average of 28.8 years (Statistics Canada, 1995). No comparable data for the United States is available. The average anticipated age at birth of first child for the women in this study is 27.1.

These findings suggest that younger women with endometriosis are, on average, anticipating to experience events such as marriage and birth of a first child at slightly earlier ages than North American societal averages. These findings are discussed in the Discussion chapter (Chapter 5).

Asynchrony with one's own planned life path

But the goal of this study was not solely to compare these women's life expectations with those of the general population: this research problem also assessed the effect endometriosis might have on women's own planned expectations. Most of these women clearly felt that they had changed expectations of personal sequencing or timing: 50 of the 72 women (69%) indicated that they had indeed rearranged life goals since diagnosis (see table 14 for a breakdown of rearranging patterns). The most frequent rearranging patterns were: changing priorities (32%; n = 23), having children earlier than planned (15%; n = 11), and a change in career goals (14%; n = 10).

TABLE 14

Rearranging life goals: Questionnaire component

	Frequency	Percent
Changed priorities	23	32
Increase import of family	4	6
Decrease import of career or education	5	7
Family earlier than planned	11	15
Increase import of career or education	3	4
Change career goals	10	14
Marriage earlier than planned	9	13
Other	15	21

*Note: Percentages do not equal 100. Women often gave two or three descriptions of rearranging, so they could be categorized in two of the explanations above, but no woman was given the same code for a rearranging pattern more than once.

“My path in life has completely changed,” one woman said, and this sentiment is echoed by others. “Concerned with the ability to meet all my goals in life, and I almost feel as though my life has been turned upside down.” “I realise that I may not have the life I always dreamed of.” “I feel like I have to forget about the life-script with the nice house full of kids.”

Most of these women changed their priorities. Many planned marriage and/or children earlier: “I now want to get married, have kids at the earliest possible time” “Family comes before career now” “I have had to put having a family #1, instead of graduating college and finding a career.” “I came to <name> to try and save my troubled relationship with my boyfriend... It was not the best choice for myself or for my career, but I felt under pressure to make things work because of this disease.” “Prior...CAREER

was the #1 item on my goal list... during my twenties. Then I will get married, etc. Now, I'm not married, have no intention on getting married anytime soon- yet would be thrilled if I got pregnant!"

But for others, the importance of having children or a family life decreased: "I do not want to have children. I am afraid that if I have a daughter she will get it too." "I always thought I'd have kids but I've had to realise that I may never have them so I've changed priorities from family to school." "Since I am always tired...I have certainly delayed getting involved in a serious relationship. I no longer view marriage and giving birth to a child/children as a major goal." "I no longer feel that I **have** to have kids...Having kids no longer seems required to me."

The increase in importance of having children or a family life appears to lead to an acceleration of events, and compression of timing, whereas a decrease in the importance of children and/or a family life leads to a rejection of normative events.

For others, education paths changed: "Putting off college since I couldn't work with the pain and afford to go." "Pulled out of college," "...I have decided against pursuing further education in order to try and have kids." "I had to drop out of university because the pain was too much to handle. This made me change my life goals concerning career." "I decided not to get my Master's Degree because I couldn't handle working and going to school and having this disease."

For some, career paths also changed: "I had a full navy scholarship and commission. I was diagnosed... I was going to be an astronaut...because of my endo, my doctor removed me from the Navy and said I could not go further." "I was studying to be a nurse, but am now looking into careers that don't require me to be on my feet for long

periods of time.” “I have changed my program of studies that I may research Endometriosis...I am also considering cutting short my academic career to get a job, get married and start a family.” “I have begun looking for alternative but related careers for the time when I cannot teach.” “I wanted to be a doctor, but I can’t do that much schooling, so I’ve switched.”

And for some women, there was a realisation that endometriosis hadn’t changed only their life paths: “My boyfriend and I decided to get engaged and to start having children earlier than we had planned.” “I just ended my 2nd marriage...because of the endo and having to rearrange my plans in life.” “I was happy with my current boyfriend before. Now I look at him and know that I don’t want him to be the father of my children so I feel as if I’m wasting my time.” “...My boyfriend and I had to move in with my parents, 300 miles away from where we were living before. All of our goals got rearranged for us.” “I ended a relationship with my live-in significant other because he wasn’t who I felt would make the right father for my kids and I can’t waste any more time.”

Some women were determined not to let this disease disrupt their life goals, though they also sometimes mention that endometriosis had changed some things: “I still plan on doing the things that I have always wanted to - it’s just going to be a lot harder.” “I refuse to let this disease control and/or change me or my life. I will not live my life around endo, I will continue to live it for me.” “I have the same goals...but their importance and the feeling of urgency to get them accomplished has increased.”

Expectations in general

Of the 37 women who did not give an age at marriage, 31 expected to marry at some point, while 6 never expected to marry. Of the 39 women who did not give an age at birth of first child, 31 expected to have a child (though it should be noted that many of these women were not certain of their ability to bear a child), while eight never expected to give birth (note that only four of these women were incapable of bearing children, due to hysterectomies).

The issue of a lack of choices, or limitations in abilities, also became apparent: Some women mentioned giving up favourite activities, and worried over the future: "I'm scared I'll have to live my life surgery to surgery...Will I be able to ride horses again?" One woman mentioned giving up the right to "have children when I choose". Another said "I always assumed I could have a family and settle down when the time was appropriate for me. Now I feel as though I don't have that luxury anymore." Another woman wrote: "I have come to realize that I am limited in what I can do."

Summary

The results of the questionnaire component suggest that time since diagnosis and treatment methods undergone do not significantly influence women's life expectations. Analysis suggests that role strain and pattern of pain may play important roles in affecting women's experiences of living with endometriosis as well as their expectations. The findings also reveal that although living with endometriosis may not necessarily lead to asynchrony with societal expectations, it does create a sense of dissonance with women's own planned life paths.

Chapter IV

Results: Interview Component

The twelve women who participated in the interview component of this study had varied experiences with the disease, in terms of time since diagnosis, degree and pattern of pain, and treatment methods undergone as well as planned. Table 15 shows selected characteristics of the women who were part of this portion of the study.

Endometriosis characteristics of participants

The average age at diagnosis for these twelve women was 22.5 with a range between 18 and 27. The average age at first symptoms was 17. The breakdown of characteristics for the three independent variables follows.

Degree and Pattern of Pain

Two women experience cyclical and moderate pain, two experience cyclical and severe, one experiences constant and mild, three experience constant and moderate, and four experience constant and severe pain.

Time since diagnosis

The largest group of these women (5) were diagnosed in 1997, as were the women in the larger sample. Two were diagnosed in 1994, two in 1995, two in 1996, and 1 in 1998.

Treatment Methods

These 12 women have undergone a variety of treatments for endometriosis. The treatments listed in table 15 were valid at the time of the study and interviews only (many of these women have since had further treatment).

TABLE 15

Select characteristics of participants: Interview component

Pseudo- nym	Age	Marital Status	Educatio n	Occupation	Diagnosis	Pain Level	Treat ment
Anna	24	Never married	Master's	Speech Therapist	1998	cyc-s	lap yoga diet Δ med (c) lap (p) 3 lap
Jasmine	19	Engaged; cohabiting	Diploma	Student	1997	con-s	bcps preg (p) laparotomy ovary yoga bcps thera- py yoga
Shirley	25	Never married	Bachelor's	Student	1997	cyc-s	therapy med 3 laps bcps (c) 5 laps
Brittany	20	Never married	High school	Student	1995	con-s	therapy bcps med preg(p) 2 laps
Monica	24	Divorced cohabiting	High school	N/A	1995	con- mod	bcps med(c) 5 laps
Karen	23	Divorced	High school	Computer Systems Rep.	1997	con-s	therapy bcps med preg(p) 2 laps bcps med(c)

Jenna	26	Never married	Bachelor	Consultant	1996	con-s	diet Δ (pre) thera- py bcps 3 laps yoga (pre) preg (c) med (5)
Susan	27	Never married	Bachelor	Paramedic	1994	con- mod	2 laps bcps lap (p) 2 laps
Meg	25	Never married	Bachelor	Computer Analyst	1996	con- mod	bcps med (c) diet Δ (c) lap
Dawn	27	Never married	Bachelor	Nurse	1997	cyc- mod	diet Δ (c) lap
Charlotte	28	Never married	Bachelor	Project Manager	1997	con- mild	bcps (c) lap
Ingrid	24			Paralegal	1994	cyc- mod	pain map diet Δ bcps (c) preg(p)

** Notes: pre = prior to diagnosis c = currently (time of study) p = planned
 med = medication preg = pregnancy bcps = birth control pills lap = laparoscopy
 Δ = change ovary = ovary removed s = severe

Numbers in parentheses indicate number of times a particular treatment was undergone

Themes of living with endometriosis

One of the purposes of the interview component of this study is to explore issues that do not lend themselves easily or well to quantitative inquiry. As well, the effect of having endometriosis on expectations was further investigated in these interviews. Questions focus on either the explicit effect of the disease on expectations, or on areas that might influence expectations (e.g., the effect of endometriosis on a woman's outlook on life, or what negative or positive effects the disease has had on previous relationships). Several themes emerged as data analysis progressed. Themes are listed below, and clustered with respect to the interview question asked.

Question 1. The experience of waiting for a diagnosis and receiving a diagnosis

Responses to this question revealed that diagnosis was a two-part process for these women: pre-diagnosis and the actual diagnosis.

Misdiagnosis.

The common theme that emerges for pre-diagnosis is misdiagnosis, whether through lack of knowledge on the physician's part, health professionals' explanations that make no sense, or lack of understanding of symptoms (e.g., symptoms as psychological in nature).

Ingrid, for example, experienced all three components of misdiagnosis:

"I was diagnosed with appendicitis by two different doctors...and one said it was bad menstrual cramps. However, I hadn't had a period in over a year so how was that to be true. After about a year of pain, the doctors began to say they had no explanation and hinted to my mom that it was in my head."¹

Getting the right diagnosis was difficult for Charlotte as well:

"I was going into emerg almost every month. At first, there wasn't really

¹ Corrections of spelling, grammar, and typographical errors have been made for ease of reading.

a pattern with the pain, so every time I went...a different diagnosis was offered...I had absolutely NO idea what was wrong, and was sick of being informed that the pregnancy test was negative!!! Umm, I could have told them that!"

Shirley was initially diagnosed with something more sinister:

"I had been having severe pelvic pain that would cause me to pass out... after a few months a large growth showed up on my left ovary during an ultrasound. My next appointment (she) informed me that I might have cancer..."

Pre-diagnosis therefore was difficult for these women because they were doubted (e.g., the implied psychological nature of the disease; health professionals' explanations that were implausible) or misdiagnosed. None of the twelve women indicated that the wait for a diagnosis was an easy one. That is to say that no-one felt that she had been diagnosed in a timely, efficient manner.

Following diagnosis, women felt a variety of emotions, including relief, fear, anger, and confusion.

Relief: It has a Name; It's not in My Head.

One common emotion was that of relief; these women were often relieved to know that there was a medical explanation for their pain, that they were not psychologically unwell. This was especially true for women who had been misdiagnosed. For many women, diagnosis was a validation of their prior symptoms; in this sense, they were relieved to have a title to attach to their disease. Diagnosis was seen as proof that these women had the right to feel their symptoms.

For example, Anna said, "I felt totally relieved to hear that I had endo - it seems weird to say this, but finally I knew that I wasn't going crazy...I'm glad to know the reason for everything I went through: pain, anxiety, depression..."

Her sentiments are echoed by many of the other women in this study. Shirley was relieved to know that this disease was not cancer: "It was a relief after having lived with the idea that I had cancer...", while Dawn, a nurse with some knowledge of the disease prior to diagnosis, felt "relieved by the diagnosis because it explained so MANY of my symptoms. I knew it wasn't in my head!".

Meg said, "I was glad that it was endometriosis, as this meant that at least I was not imagining the pain that I was experiencing. I had been so worried that they would find nothing and they would say that I was making everything up..."

Ingrid, who had been told it was "in her head", also felt this way:

"When I was finally diagnosed, I was relieved. It was such a psychological game to have people tell you the pain is in your head. My mother never doubted me, but I'm sure she got tired of me complaining all the time, and in the end I...would not see a doctor anymore for the pain, and thus ended up in the hospital. It is also nice to finally know you're not crazy and there is a reason for the pain. It is very hard to cope with misdiagnosis and disbelief."

Fear and Anger: What Does Endometriosis Mean?

Fear was also an emotion some of these women experienced. For some women, even diagnosis did not assuage concerns; if they knew little or nothing of endometriosis, the diagnosis was frightening.

"When it was first mentioned to me, I was scared to death," said Monica. "I had no idea what this was...It isn't like there are pamphlets for this disease in the doctors office."

“I was relieved in one way,” said Brittany, “that there was finally something to call this disease. But in another way I was so scared, I had no idea what it was...In one way my diagnosis was a nightmare, and it continues to be.”

Fear of the known (i.e., that endometriosis has no cure, that it is poorly researched) was also experienced. For Karen, knowing about endometriosis already, the diagnosis was scary. “I had done some reading on endometriosis and knew what it was and that there was not a cure. This made me start worrying...”

Some women also mentioned feeling angry following diagnosis.

For example, Shirley said that although she was relieved it wasn't cancer, “I didn't know what it was or what it meant. I was confused, but mostly angry.” Charlotte was more blunt: “As relieved as I was to finally discover what illness I had been suffering from all that time, I did not want endo. I was pissed off to put it mildly.”

There was a sense with these women that although they were relieved, they were also, paradoxically, upset at the discovery. The notion of “finding something there” is important to validating pain: no matter how angry or frustrated these women might be with having a chronic condition, it is important to them to know that they do have *something*. For example, in a later discussion, Dawn mentions having another laparoscopy to treat pain symptoms. When she was told no endometriosis had been found, she was surprised: “The nurse in recovery was wondering why that made me cry. “Isn't that good news?” she asked...How do I explain the relief of this, plus the frustration – what, then, has been causing all the pain...I'm feeling confused, frustrated, angry.....”.

Confusion: But What Is Endometriosis?

And finally, confusion, (largely due to ignorance of the disease) was also a common emotion. Physicians often did not explain what endometriosis was (possibly because they themselves were not familiar with the disease). As well, these women typically had no prior exposure to the disease (e.g., family members with endometriosis). Both factors combined to create a sense of uncertainty about what diagnosis actually meant.

“Diagnosis still didn’t mean that much --” said Jenna, “BECAUSE MY DOCTOR TOLD ME NOTHING ABOUT THE DISEASE!”

Susan also was confused as to what the disease was:

“Endometriosis was mentioned as a possibility...but I didn’t find the diagnosis any scarier than when they told me I had Dysfunctional Uterine Bleeding or fibroids. I didn’t realize that endometriosis is a chronic and progressive condition; I just thought it described my insides.”

Meg had no idea what to expect; like Susan, she was unaware of the chronic nature of the disease:

“At the time of diagnosis, endo was just a name and I did not really know much about it. I thought that it was a case of they found endo, it was treated, so therefore I was cured. I did not realise that it was a chronic disease.”

“When I came to (after surgery),” said Jasmine, “and he (the doctor) said I had Endo, I had no clue what it was and it sounded like no big deal.” Or, as Brittany succinctly put it, “ENDOMETRIOSIS! What the hell is that?”

Question 2. The effects of endometriosis on one's outlook on life

Women were also asked if and how they felt having endometriosis had affected their outlook on life. Most women interviewed feel endometriosis has changed their

outlook in some way, and the effect was not always negative. The common threads are uncertainty regarding the future and learning to live with and accept endometriosis.

Uncertainty.

Endometriosis has created feelings of uncertainty about the future, particularly about developing/maintaining relationships, for many of these women; this feeling was especially strong for women who were not in relationships at the time of the study, or had never been in a relationship. Women who experienced uncertainty were also less hopeful regarding relationships.

“I’m scared I won’t be able to find a life partner because of endo,.....I’m just plain scared of not knowing where this disease will take me,” said Anna, who had never been in a relationship and felt that endometriosis was largely responsible for her single status.

“I cannot see any way of having a successful relationship whilst suffering from endo,” said Meg. She had also never been in a relationship, and mentioned her disease as one reason for this.

“As content as I am with being single,” Charlotte said, “I also feel that I am too afraid to become involved with a man because of endo.”

Learning to Live with Endo.

All twelve women believe that learning to adapt to and accept this disease was (and is) important and necessary. Themes include negative components such as: a sense of helplessness, of resignation, and of urgency to complete goals.

Resignation and helplessness were reflected in several comments.

For example, Anna wrote, "I know I will be battling with many surgeries, medications, and ignorant doctors...", while Meg noted that "To me, it is now 'normal' to not feel well and to have pain." Both women's comments illustrate resignation to the probability of living with the disease for a long time.

Brittany was more ambivalent about whether endo had affected on her outlook on life, and although she would not commit to a definite answer, she acknowledged that whether she liked it or not, her disease did and would affect her:

"Yes and no...I've been trying hard to beat this thing, and not let it run my life, but unfortunately it usually has the upper hand...I realize things will be hard, but life is, so I'll be a little more prepared when life is dealt to me. This is a hard question..."

"When realizing the seriousness of my endo, it made me truly depressed," Jenna wrote, "My outlook on life became melancholic because there is no cure for endo...I have to admit that I felt helpless..."

Charlotte also noted that the disease had made her less optimistic about life, especially relationships:

"I never thought I would be in this position, and it saddens me. My social life has gone completely downhill, and although my friends say they understand,...they will never know how it feels to experience what I have been going through...it is just that I have felt like I have been dying at times, and nobody I know really gets that. So, all in all, I can see friendships deteriorating."

Some women also felt an urgency to achieve certain goals and thought more carefully about what they wanted from life.

"I've always wanted children," Jasmine said,"...and I want to make sure I'm still able to have them...I was always a person to put things off until I was diagnosed, and now I want to make sure I can do everything I want to while I'm still able to do things."

Shirley said, "I now think much more seriously about marriage and children than I did before. I had always assumed that when I was ready I could and now I feel like the longer I wait the less chance I have of being able to get pregnant."

For these two women (both in relationships at the time of the study), a "wait and see" approach to life is not an option: endometriosis was the impetus to reconsider what they want, and when they want to experience various life events.

Despite the negative aspects of having this disease, some women found it had some positive side effects, including learning patience, acceptance of life and the unknown in life, and learning to be strong.

For example, Meg wrote, "I have learnt (or trying to learn) to make the most of the good days...and to try and take every day as it comes."

Brittany felt that endo "made me more aware of my body ...it also helped me to become a stronger person...it helped me to learn I'm in charge...Endo has also made me realize that I should appreciate everything..."

Jasmine found that the disease made her closer to her family, and Ingrid felt she was "more accepting about things that are dealt to me. I just take my life for the way it is now...why worry because I can't change it."

For Monica, endometriosis led to the end of a marriage, and then she found

"a WONDERFUL man...and my life (even though I have pain with my periods) almost couldn't be better...So endo has made me think about what I really want ...and I think I had to become stronger with this."

For these women, endometriosis has been something that makes them reflect on their lives, and how they want to live them (a reassessment of their life philosophies).

Question 3. The effect of endometriosis on one's relationship with a partner

The main theme that emerges here for women in relationships is that of endometriosis “putting the relationship to the test” – with both positive and negative results.

Women in relationships.

Seven of the women interviewed were in a relationship at the time of the interview. The notion that endometriosis “tested” a relationship’s quality and strength was mentioned by several women. Considering the symptoms of this disease, and the side effects of treatments, this theme is not surprising.

For example, Shirley wrote, “We have always had a good relationship so I would say Endo has actually enhanced it...He is a very caring and nurturing person...I think it was a good test of the strength of our relationship.”

For Ingrid, her relationship initially failed “the test”:

“I was going out with my boyfriend for about 4 months before I was diagnosed and then after I had been on Depo Provera...I began to become very psychologically unstable...it was the scariest thing I ever did...it split my boyfriend and I (would have been my fiancé) up and I never even cared...I couldn’t understand how he could put up with me. Well, there is a happy ending, as 3 years later we are back.”

Jasmine also was diagnosed soon after her relationship with her now-fiancé started, and she admitted that this “test” was a hard one:

“He went through the shock of finding out also. He’s been very supportive, but things have changed, though I think mostly for the good.... There’s a bit of strain on our intimate relations...I think that’s a bit hard on him, and he worries so much about me being in pain...I usually try to pretend I’m not in pain. It makes him “mad” (not that he really gets mad - it’s more of a hurt).”

And Jenna also spoke of the positive effects endometriosis has had on her relationship. Endometriosis has tested the quality of the relationship by giving her partner an opportunity to show how caring he can be: "I think there are some positive things that came out of my endo suffering - and him feeling like I needed him to take care of me, and needed someone to understand."

Monica also felt endometriosis helped reveal her partner's supportive side, and it put their relationship to the test before there even was a relationship. "I did tell my boyfriend about my endo before we even discussed having a relationship," said Monica, "...It leaves it open. My boyfriend is very interested in hearing about it (but)...I don't know how long it will last that he is so supportive (hopefully forever)." The fact that her partner wanted to go out with her even after learning of her disease, Monica mentioned elsewhere, was proof of his feelings for her.

Unlike the other women in this study who told their partners about endometriosis after they had started dating, Monica was the only one who told her boyfriend about her disease prior to pursuing a relationship with him. Her desire to "leave it open", as she describes it, by letting a potential boyfriend know about endometriosis prior to dating, is echoed by some of the single women in this study, and emerges as an issue of concern (see the section on "Endo and the Single Woman" below).

For other women, the strain of dealing with endometriosis has been too much for their relationships; they have failed the test.

Karen, who was in the process of breaking off her relationship at the time of the interview, said that the relationship had been through so much already, and endometriosis was the final straw:

"He has always tried to help me through everything...After awhile, he could no longer handle taking care of me...he decided he was too unhappy with the situation to continue to deal with it. I was no longer the same person...He then broke up with me after having been together for 3 years."

Susan, who is in an on-again, off-again relationship, said:

"There were already difficulties due to the age difference and the fact that he's black and I'm white, but I blame endo for the real problems that set in over time...I hid my "female troubles" from him for the first few years because it seemed wimpy to complain. Then I got pregnant (happily but unexpectedly) with our son... I quit (her job) but ended up losing the baby...The next year or so was awful. With no job, I felt I wasn't contributing to the household...I felt this was no time to get married, so the wedding just faded into the distant future. I now know that the dissolution of the wedding plans made R** insecure and let worries of infidelity creep into both of our minds...when he missed being with me during a surgery and hospitalization, I got angry and left him...Now we are "dating"...but we are very wary of all the old fights."

And even Jenna, who thought endometriosis had some enhancing effect on her relationship, was cautious about the long-term chances of her current relationship:

"There is an insecurity that goes along with having a relationship with endo involved. It takes women's strength - and breaks it in half. My partner is now so thrilled that I'm pregnant...I'm closer to him than ever before - but I definitely see potential for endo ruining our relationship as well..."

These women's comments reflect a lack of support from their partners, or a fear of their own ability to make a relationship work. All three of these women indicated that their relationships had survived a lot of turmoil (e.g., divorce, family illness/death, pregnancy). In spite of this history, all three women cited endometriosis, its symptoms or treatments, as the source of conflict (real or potential) in their none too solid relationships.

Endo and the single woman.

For the five currently single women in this interview, endometriosis had a mostly negative effect on potential relationships: concerns about how to go about disclosing information about the disease to potential partners, and fear of reaction/rejection were two main sentiments. Three of the five women expected they would tell potential partners about the disease prior to pursuing a relationship (something that only one person in this study currently in a relationship, Monica, had done). These three women fretted over what to say, how to say it, and what reactions they might encounter.

For example, Anna said,

“Although I have no trouble talking about this disease to male friends, I think I would find it very difficult to go into more personal details with a potential partner - i.e., talking about painful intercourse...Will it drive them away, or will I be lucky enough to find someone understanding who will look beyond the obstacles and help me deal with endo.”

Meg also felt it would be awkward to explain her disease to others, and did not think any man would want to hear about it: “I have so far not managed to find any potential partner who I would wish to even begin to try and explain endo and all its implications...I am willing to try and explain further if they ask more questions but usually, the mention of poor health is enough!”

Dawn took a humorous approach to her feelings about discussing endometriosis with a potential partner, prior to a relationship:

“I’m at the point that this endo is a fact of my life and I’m not going to hide it. I’m certainly not going to advertise it on a billboard over my head, though, but as situations permit...I’ll share bits of information about it...I have no problem explaining it...when it’s appropriate, taking into consideration how much HE really wants to know. ;)”

But while those three women, though not entirely sure of what might happen, were willing to discuss the disease, two were uncomfortable with even getting involved in a relationship, or discussing the topic with men.

Brittany said,

“It’s very hard for me to discuss this with anyone let alone potential partners, ...I tend to stay away from getting involved with men, because I don’t want to explain it. It seems unfair to keep it a secret, I need to be honest with everything, but it’s certainly not something you can bring up on the first date...To make it short, I stay away from relationships because of my endo. It’s too complicated to explain, and I can’t stand being hurt anymore. I didn’t ask for endo, it’s not my fault.”

And Charlotte, who had already mentioned being afraid of becoming involved, said although she would have to say something (“It is something I certainly cannot hide, therefore I believe it is critical to disclose some of the facts”), she was extremely worried about what her potential partner’s reaction might be:

“I just don’t feel or look, for that matter, like the woman I was say 3.5 years ago. I suffer from...pain...What kind of relationship would I be able to have under these conditions?!”

Like Anna, she wondered what kind of person would “put up” with endo.

Again, as with their comments about their disease’s effect on their outlook on life, these women seem less optimistic about relationships in the future.

Question 4. Endometriosis’ Role in Ending Relationships

Five of the women interviewed felt endometriosis had played a role in ending a previous relationship. There were two main themes here: the strain of dealing with endometriosis (symptoms and/or treatments) was too much for women; it made them undesirable partners: they had mood swings, were hostile, and generally difficult to live with; or the strain of dealing with the disease was too much for their male partners, and

these women felt let down by a lack of support and caring on the part of their partners. The stress described here is similar to that described by the women experiencing difficulties with current relationships.

Both Charlotte and Jasmine fall into the former category; their last relationships ended, they felt, because of their own inability to deal with the disease and its symptoms. Jasmine felt that although her own behaviour had ruined her last relationship, neither person was "equipped" to handle the disease:

"We did pretty good in our relationship for awhile, and then I started having REALLY bad pains. I became really cranky...and was in CONSTANT pain (this was the summer before I was diagnosed). My boyfriend at the time couldn't handle it. He seemed to think I was yelling at him and got mad when I was over there and couldn't do things...He was a sweet guy, but didn't know how to help me through my little attacks...It's hard when *I* had a hard time coping!!"

Charlotte also felt that the symptoms of endometriosis, and her difficulty in coping with them, had ruined her last relationship:

"I was just starting to feel the symptoms of endo fairly early into the relationship...I was beginning to get really moody and was probably scaring the hell out of him! I did not want to go out very often, as I was always tired and experiencing discomfort. Essentially, I was not very much fun to be around - oppressive sums it up I suppose! Needless to say, as much as he tried to salvage the relationship, with the mental state I was in, there was no hope."

For these women, their own difficulties with the disease created too much strain.

Monica, who divorced her husband in part because of endometriosis, also talked about the inability to deal with having the disease. Her experience reflects more of a melding of the two themes mentioned: her own troubles coping were exacerbated by her former husband's lack of support and caring.

"If I would have known that I had this disease when we got married and known that it was going to affect my life the way it has, I would have never gotten married. It wasn't fair for me to expect him to be there for me "ALL the time" or for him to feel obligated to...take care of me (Even though that is part of

marriage). Being diagnosed also affected the aspect of having children...we weren't ready at the time. That put a lot of stress on us. I couldn't ask him to give me a child if he wasn't ready to be a father and our marriage was just starting out it was nowhere near stable enough to handle the stress of a newborn....He was as supportive as he knew how to be at 19," Monica said.

Four years later, he left her.

Jenna and Karen's last relationships fall into the latter theme; their partners did not care enough, or stopped caring, or were tired of providing support.

Jenna's description of her last relationship suggests that her previous boyfriend did not understand her disease, and was never there when she needed him to be; he failed to provide her with the emotional support she needed.

"I was dating a guy...July 1997 through October 1997 when it ended due to endo - and all the emotional complications that go along with it! R** never understood when I didn't feel well. He thought himself an expert on the female problems because (a girl he knew) had a cyst!...I got news from the doctor that I needed to have surgery again when R** had just left for a trip. I called his hotel room and left a voice mail...I explained that although the doctor wanted to do the surgery within the week to relieve my pain, I would wait for him to come back (I thought he'd naturally be concerned if I underwent surgery in his absence). He didn't call back for 2 days... I think I didn't forgive him for ignoring my phone call...I don't know how irrational it is for me to break up with someone for something that seems so small...then again, endo seemed small to him until I left him."

Although Karen had categorised herself as dating at the time of the questionnaire, she had begun ending her relationship at the start of the interview. She therefore discussed the effect of endometriosis on ending the relationship:

"It broke up a three year relationship that had survived through a lot....a divorce, my dad being hospitalized twice, my dad having brain surgery, my mom having a hysterectomy, me having 2 laparoscopies. After having made it through this along with a break up one year ago, I figured we could make it through anything. We only fought about one thing - getting married. I wanted to, he wasn't sure...when I began taking Lupron, I changed...Lupron put me on the emotional roller coaster from hell...P***** could no longer handle it...He was tired of taking care of me all the time...and he was still unsure if he ever wanted to get married. As he was unhappy, he didn't think that the relationship should continue, so he broke up

with me 9 days before our 3rd anniversary.”

Like Monica, Karen also felt that the blame rested neither on herself nor her partner entirely; endometriosis, however, was considered the main problem.

Question 5: The effect of endometriosis on views on...

Dating and/or Marriage.

Endometriosis has made some women avoid relationships, or feel nervous about having them, for fear of rejection. Many women, especially those not in a relationship, felt men might not accept the limitations endometriosis put upon them (e.g., the fatigue or pain preventing activities).

“I refuse to get rejected - therefore I never put in 100% into the relationship,” Jenna said, “And I’ve always been extremely fearful of marriage...I need my partner to reassure me that I’m needed - regardless if I can have children or not. Regardless of whether 2 weeks of every month I would rather lie around and rent videos...”

Her worries are echoed by many of the single women in this portion of the study.

“It makes me a bit nervous about dating AND marriage because I wonder how the guy would respond to a girlfriend/wife who has chronic pain,” said Dawn.

“I have no desire to date and I have turned a number of men away over the last couple of years that’s for sure :o,” Charlotte said.

And Brittany also voiced concerns:

“I tend to try to stay out of relationships because I don’t want to even begin to try to explain endometriosis...Marriage, wow....Someday I’ll find a guy who accepts me for everything I come with. I hope. But I try not to get ahead of myself, or that leads to depression. What guy would want to put up with all of this any how.”

Particularly for single women (some of whom had never had relationships, and others who had not been in a relationship since diagnosis), the fear of how a potential boyfriend or spouse might react was strong. These women have not yet had a chance to see what kind of effect endometriosis might have on a relationship; unlike women currently in relationships, these women really do not know what to expect, and their uncertainties are reflected in their comments.

Women in relationships also felt endometriosis had affected their views on those relationships, and what they expected from them. Specifically, women noted that on the positive side, endometriosis helped them make concrete decisions (e.g., "I've decided more firmly to marry earlier," wrote Jasmine); on the negative side, it made some women feel inadequate as potential girlfriends and wives.

Monica saw a positive side to having endometriosis: "It's affected my view of dating but in a positive way...I'm more selective :)."

Although Shirley did not say it was a positive thing, she did note that endometriosis had "affected my views on marriage by making it a more immediate issue than a remote one. I have always known I wanted to get married but I wanted to do it on my own terms when I was ready." Elsewhere, Shirley comments that she does not mean this as a negative thing; it is just different than what she had originally planned, and endometriosis is the cause of this.

For others, the disease has made them feel that they might not be successful as partners:

"On a bad day, I figure I should just give up on being with him since I feel like I'm not any good as a wife (*Susan has been in an on again-off again relationship for*

eight years, and feels she has adopted a wife role over time),” Susan said, “...there is fatigue, frequent illness and mood swings. It affects many of the roles...If I didn’t already have a partner, I worry that telling someone new...might affect how they thought of me as a potential mate...”

Karen also worried that she would not be a good wife or girlfriend:

“Endo has greatly changed my views on dating and marriage. As I am unsure if anyone else is willing to go through the crap that endo takes you through. And, if I do find someone who is willing to put himself through all of the emotional stress, ...is it right for me to allow someone I love to go through that pain? Relationships are hard enough as it is without adding a chronic disease. Marriage...I take a great deal of strength to deal with on a daily basis, let alone when I am having an enormous amount of pain or surgery. As for dating, why would anyone want to date anyone with a chronic disease? There are tons of wonderful women out there who do not have to deal with endo, it would be much easier for a man to decide that endo was more than he can deal with. It is not fair to tell someone that they must deal with a disease that can determine whether or not the future that he wants will ever be possible.”

Both of these women cite symptoms of endometriosis (fatigue, pain) or its chronic nature as reasons for feelings of inadequacy or unworthiness.

A few women felt endometriosis hadn’t affected their views on these relationships. Meg said, “I have always been of the opinion that I do not want to get married (and this was before endo) and so far, I have not had any reason to change it. I like having my own independence and being able to do what I want.”

And Anna (diagnosed in 1998) wrote, “I guess that since I’m still new to this endo stuff, it hasn’t really sunk in.”

Sexual Relations.

One theme that emerged here was a concern for affecting someone else’s life. There was concern expressed for disappointing one’s partner, of being “inadequate” - a concern tied in with the fear, mentioned previously, of rejection from a partner.

“Part of feeling like I’d make a bad wife is the fear of being sexually inadequate,” Susan said, “...I worry about not being as good at those roles (of mother, lover) because of the physical effects endo has had on my body....Males seem very intimidated by a woman with complex health problems, like it’s too much to deal with in a girlfriend.”

Ingrid recalled that certain medications affected her view: “I didn’t like the person I had become and it wasn’t fair to him...plus to be honest, I had no sexual desires whatsoever...”

“It can be very taxing at times with pain and not being able to do what you want,” Jasmine said. “I’m always afraid K*** will get angry that we’re not doing something he wants, and it makes a lot of stress.”

Another theme was avoidance of sexual relations. The concern here was not for someone else’s feelings, but the very real fear of experiencing pain:

“I think I am afraid to face the inevitable,” Charlotte said, “that being intimate will be too painful. I honestly believe that I am avoiding having sex so I do not have to face reality.”

Brittany was once again blunt: “Sex is painful and I don’t even like to or have the want to do it anymore.”

Dawn said, “I do worry about pain with sex...”. Her worry was echoed by others:

“I am fearful that endo will have an affect on my sexual life in the future,” Jenna said.

Meg also worried, “Endo has probably made me more nervous. I am worried that I will find it extremely painful as my endo, so far, has mainly been on the utero-sacral ligaments... so I know sex is likely to be painful.”

Having Children.

This particular area was one in which most of these women shared the same sentiments: Fear and Longing. The fear of infertility or subfertility was evident in comments; the importance of having children and/or of being a mother was frequently mentioned as well. One other main theme emerged, that of learning to accept alternatives to a natural pregnancy.

For example, Karen said, "I want children very badly. It hurts every time that I think I may not be able to have them. It isn't fair to a man who wants children if I can't...If I am unable to have children, we would adopt. But it's not the same."

"I'm terrified I won't be able to have children and I want to try having them a lot sooner than I might have otherwise..." said Jasmine.

"Having children - I always thought that I would one day, and never imagined I would be faced with this fear of perhaps not being able to. This I feel is very unfair, and makes me bitter," said Charlotte.

Jenna, who was pregnant at the time of the interview, said,

"This was my biggest fear. Would I ever be able to have kids - or get pregnant for that matter?? Now that I am pregnant....I am absolutely overjoyed about this - and I'm not married! I don't care either. I can love and appreciate this child MORE now because I feel SO BLESSED to have conceived at all. I am truly fortunate."

"I also worry about the fertility thing," Dawn said. "YES I WANT KIDS!...I do sometimes become concerned about how I'll cope with kids...how the fertility issue WILL present itself...I actually try not to think about it too much."

"As for having children," said Shirley, "it's the same as marriage. I had always thought I would have them but now it seems like a more immediate issue."

For other women, learning to accept alternatives emerged as a theme:

"Children is a question for me as I've been told both that I can and can't have them...It was very hard to accept at first," wrote Ingrid, "...I've thought that when we're ready adoption is always an option."

Monica said,

"I've always wanted them (children) and try to keep a positive attitude about someday becoming pregnant,...The doctors keep telling me that I need to get pregnant (right now) or have a hysterectomy...If for some reason this relationship doesn't work and I'm alone, I would probably consider adoption or having a sperm donor, because I want children and would do anything to have one."

Elsewhere, she said,

"What if I can't have kids at all? He (her boyfriend) told me something before we ever started "dating" that has stuck in my head. That he wouldn't EVER be with a woman who couldn't give him a child of his own. Now that we are closer he "says" that we will "deal" with it when the time comes..."

Brittany said,

"Children. I guess I'm a lucky person in that aspect. All my life that I can remember I have always wanted to adopt children from around the world...Now that I'm older I often think maybe I do want to have a child of my own too. But in some respects I also don't want to have kids because, what kind of a place is my uterus for a growing fetus...I would never want to feel responsible for passing this horrible nightmare onto my own children either. It's good that I want to adopt because some people can't emotionally do that and need counseling. So if I'm infertile, I'm ready and I'm okay with it."

Apart from these emotions, some women spoke of ambivalence of a kind:

Meg said, "My views on having children vary considerably. Every so often, I feel that it would be nice to have a child one day but then most of the time, I feel that I do not want children. I am still at the stage where children are nice when you can hand them back to the parents!"

And Anna said,

“The hardest for me was learning that my fertility is severely compromised...I *might* have a 4 year window of opportunity to have children. Four years isn't that much. I don't want to feel pushed in 1) finding a partner and 2) having kids as soon as possible! But I know that it will have a huge impact on the way I will be planning my family life. If I wait too long and can't have kids I'll kick myself for not trying sooner - If I have kids right away, I'll feel rushed and unprepared financially and emotionally. Let's say endo has stuck me between a rock and a hard place ;-).”

Both these women are currently single and have never had a relationship; having children was perhaps therefore not as salient or pressing an issue for them at the time of the study.

Question 6. Endo and Family Relationships

Three themes emerged on the topic of family relationships: for some, endometriosis strengthened family ties; for others, endometriosis created strain or exacerbated existing stress. Finally, some women indicated no change in family relationships.

Creating Openness and Validating Pain.

For some women, especially following diagnosis, the disease brought them closer to family members, or reassured them of family support.

For these women, there is a sense that the diagnosis of endometriosis in particular validated their symptoms and convinced family members of the severity of their disease.

For example, Shirley said, “My sister used to think I was a hypochondriac since I complained of being in pain all the time but now that there's a reason for it she takes me seriously.”

“Once they understood what it was (endo),” said Monica, “they have all been supportive. At first, they used to call and make sure I was okay all the time. Now they are

concerned and ask...but it isn't like they act like I'm going to break like they did before. I do feel comfortable talking to my grandma because she also has endo."

Anna said,

"They have always been supportive. They just ask more questions now...Although my mother acts very positively and supports my every decision, she is probably sad I might not experience the joy of having kids of my own. Come to think of it, my mom seems to 'accept' the pain I go through now a bit more than before I was diagnosed. She was sort of the type who thought "She's feeling sick...again". Things all seem to fall into place now - everything I went through is much clearer to us now."

For a few women, endometriosis brought them closer to mothers. This was especially true for women whose mothers had experienced similar, undiagnosed symptoms.

"I'm a lot closer to my family now than I was before...I mean, I was always close to them," said Jasmine, "but now I am a lot more...my mom and I have always had a pretty good relationship, and she went through something similar (not diagnosed as endo, but pretty sure it was)...everyone has been pretty supportive with this."

"My mother and I talk about it and now she wonders if that is what causes her pain," Ingrid said, "...It has made me believe that my family is there for me no matter what."

For both Meg and Jenna, endometriosis put family relationships to the test as well.

Meg said that, "If there has been any effect, it has brought us closer as I often have to rely on them when I am not well."

"I have become more distant," Jenna said, "but I also have found those who really care about me and genuinely want to be with me - even when I'm in bed at home, feeling

and looking like shit! My sister and I live together - and are closer than ever! She is the best support...there is!"

Creating Stress and Strain.

For some women, this disease did not help relations with family members (particularly mothers). Despite diagnosis, these women continued to experience difficulty making their families understand their disease.

Brittany was again ambivalent about the effect endometriosis had; as she wrote, it became obvious that she did indeed feel the disease had exacerbated strain:

"I guess...in some ways (it has changed). My parents have always been supportive...but they just don't understand. It took my DAD until recently to start being more supportive...My mom can be the most and least supportive too. When I first had it,...and was in terrible pain, all she could say was "You're so selfish. You're not tired you're just being a bitch."...I was going in for my 3rd lap and when I told her I might need to stop working, she got really pissed. ..she suggested I miss first semester instead of this summer job, yeah, that would be a brilliant idea...Whenever I'm in pain (especially after surgery) she always says "I've had 5 c-sections, I know what you're going through and I never sucked it up this bad."...endo doesn't help our relationship...I think she blames me for having it...My older sister thinks I act sick for attention...My brother doesn't want to hear about it...My family is close, I know that sounds farfetched, but when it comes to living with endo every day, the support I need is not there."

"I'm not too sure about this one (the effect)," Charlotte said, "I think we are all frustrated about it...My mother is a nurse and I would totally expect her to understand, but I always get, "You've got to be strong". This really pissed me right off!...I know that my family totally cares for me and worries, but once again, do they truly understand what I'm going through?"

Susan has also experienced difficulties with her family because of the disease:

"They all know I have health problems, but when I try to give them information about endo...they never look at it. In the last couple of years, I attended 2 family reunions which were wrecked...by pain and illness...I really wanted to attend this fancy dinner so I held off the drugs and ended up

collapsing in the restaurant. I couldn't hide my problems and I felt like such a burden...I did learn that my aunt had endo and she confessed it nearly ruined her business and marriage...She had a hysterectomy at 39...She still pushes me to have a hyst. (hysterectomy) and believes it is the only way I'll get on with my life. I'm 27...I wish she could be more supportive, but she looks at it like I'm just stubborn...I'm much more withdrawn from my family since I've been sick...My mom tried to mend fences and fuss over me...When I did let her know about surgeries, she proved to be a huge stressor...so I don't tell her about my health much anymore. If I were very ill...I doubt I'd even call my mom or dad."

And although Jenna felt endometriosis had brought her closer to her sister, the rest of her family relationships were adversely affected:

"It unfortunately has made me "more to myself"...I am the only one who understands this pain, emotional and physical NO MATTER WHAT ANYONE SAYS TO ME!...My family thinks I'm an independent "working girl" who doesn't enjoy their company as much as my brother and sister do. That isn't true...but I don't want to take the time when I feel healthy to have my family pressure me - and soak up every ounce of energy I have left."

For these women, endometriosis had certainly not enhanced family relations. The problems experienced, especially with other female members, suggest that the ability to understand the symptoms of endometriosis is perhaps very difficult for other women, who may compare the general description of "pain" with their own experiences (as reflected in the comments made about "being strong" and "I've had 5 c-sections") and think that women with endometriosis just cannot handle their pain.

The Non-effect.

The non-effect occurred for one of two reasons: 1) some women with endometriosis just don't talk to their families about it, and 2) for some women, it really has had no perceived effect.

For instance, Dawn said,

"Family...hmm...I don't even bother talking to either of my two sisters about endo. They don't understand at ALL and think I'm being negative...My dad's a

sweetie...(but) never really wants TOO much info...Mum has always been stoic...if a lot of emotions come with it (being sick) from me, she's really lost."

And Ingrid said, "Not with my father, as we don't talk about it."

Question 7. Endometriosis and Work, Education, and Ambitions

Endometriosis and Work.

The women in this study, whether currently working or not, had concerns about this disease's effect on their jobs. Themes that emerged include: fear of one's ability to maintain a full-time occupation; and "tied to work" (dissatisfaction/frustration at work).

"I am not really ambitious and have never really had any career goals," Meg admitted, "My only worry is that the pain will get too bad for me to be able to continue going to work and as I now have a mortgage and other debts, work is a necessity."

Charlotte said,

"I have always wanted to be an independent career woman who could obtain everything on her own...I sometimes wonder if I will end up living with my parents if all of a sudden one day I can no longer work full time....I worry about whether or not I will be a complete success. Unfortunately, endo may create some problems in the future, and if I am unable to work to my full potential, then I'm not sure what I will do."

Both these women, currently employed, express concern for their ability to work in the future, and not at the present time.

For women working part-time or not at all, fears for their ability to find work or to work competently in the future were also expressed.

For example, Jasmine said, "I'm a bit more afraid to get a job now than I was before my endo got really bad. I'm afraid that I'll get sick during work or not be able to make it to work. I'm now working on a few plans to work at home most of the time."

“Wow, my outlook on working,” said Monica, who is currently unemployed, “If I could find a job with a flexible schedule...depending on how bad my pain was for that day...But that just isn’t realistic. (My last job) ...it came to the point where they threatened my job...every time I called in I had to have a doctors note if I was going to miss a day. I think it easier to bring up the fact that I have endo with people I meet on the street than with prospective employers.”

Some women are working where they are because they have to; and they felt “tied to the job”. These women typically work for medical coverage and benefits necessary to allow them to treat their endometriosis – a situation that made them further resent the disease, and led to dissatisfaction and frustration with a job these women do not necessarily want.

For example, Susan said,

“I’ve had to quit good jobs and been threatened with dismissal due to frequent absences so I have changed my job due to physical problems...I’m currently working in a less than satisfying job with bad hours and even worse pay (no raises in 3 years!) because it gives me health benefits and pays my medical bills. I look at the benefits package before anything else now when I consider changing jobs. It’s very stifling. I frequently feel trapped, afraid of being unemployed and sick.”

Karen said,

“Endo has changed my outlook on working in the fact that I HAVE to work and can’t consider going back to college...as I have to have health insurance and pay for health care...If I didn’t have a job, I would not be able to afford insurance,...If I didn’t have insurance, I could not afford to go to the doctor and have the treatments done (My current treatment is Lupron, and costs \$400 per month). So, in that respect, endo has changed my outlook on working.”

Comments made by other women in the questionnaire component indicate that working for medical coverage is a common reason for keeping unsatisfying or stressful jobs.

Dawn expressed frustration with the disease's effect on her current occupation; she was the only one, aside from Susan, who had experienced lost opportunities at work because of endometriosis.

“When I was really sick last spring/summer around the time my cyst burst and I was diagnosed with endo, my outlook on work was not too great. I was calling in sick more than 40 percent of shifts and had my job threatened. I was passed over for a permanent position in the fall, which I fought,...and won the fight, got the job. That made me a bit bitter, okay, a lot, about this disease.”

Non-effect.

Two women felt endometriosis would not or had not yet affected their occupational pursuits:

“Anyway, nothing not even endo will stop me from being a speech and language pathologist,” said Brittany.

“I always knew I wanted a research career and that hasn't changed,” said Shirley.

Endometriosis and Education.

Women who responded in their questionnaires that they felt that endometriosis had an effect on education were asked to explain what this effect was.

The most common themes were self-doubt and “taking things more slowly” in the educational sphere. Another less common theme was that of “speeding up” education, or rearranging educational paths.

For some women, endometriosis created self-doubt about the ability to pursue educational desires. Pain was often mentioned as a debilitating, interfering component in this self-doubt.

For example, Susan said, "When I first met my boyfriend, I was very independent, in school and I knew what I wanted. The pain and worrying has beaten me down. I lost that confidence I had as a pre-med student."

Charlotte said,

"I am so glad I made it through university...I am not sure I could have finished my degree if I was experiencing the symptoms I have been suffering from over the last three years. I am now taking (a course) and even though it is totally correspondence, I was beginning to worry that I may not be able to hand in my assignments on time because I was feeling sick."

Anna said,

"I have (with a lot of difficulty, tears and weight loss) finished my Masters program in Speech-Language Pathology in 1996. I almost quit before my last year because I could not handle feeling sick....at the time I didn't know I had endo...I have wanted to do my Ph.D. or go do my Medicine, but I really don't think I can go through that kind of stress knowing what I went through with my Masters - it's just not conceivable to me that I would be able to live through it now. So, for now, those plans are on hold, maybe permanently, all because of endo."

For these three women, symptoms of endometriosis resulted in a loss of confidence in ability.

Other women were determined not to let the disease prevent them from achieving their goals, even if the disease might slow them down somewhat. For them, endometriosis interfered by slowing the process, but it did not stop it, or lower or change their aspirations.

Jenna, for example, stated, "I still want to go back to school and get a masters in psychology,I just keep thinking everything will take longer than before."

"I had to take a year off from school to rest with endo...Yes endo has slowed me down, as far as school, but it hasn't stopped me," said Brittany.

Monica said,

“As for school, it (endo) has put a hindrance on that aspect of my life as well. I would love to go but if I can’t make it to work daily how am I going to make it to school?” But she continues, and adds, “I have a dream to someday have a degree in elementary education and I’m not giving up on that just because of this disease.”

Two women rearranged their educational goals, and chose different educational paths than they had originally planned:

“Probably the most significant change has been in my studies,” said Shirley, “I used to be in mathematical physics and in January I officially changed to mathematical biology (to most of the world there’s very little difference...but it is actually quite a leap). I now have a new supervisor and a completely new direction, to study cell population and tumor growth...now I’m in a field that could potentially help people in a very real and immediate way...The path I thought I would take...is slightly different.”

“I’m taking a 15 1/2 month course to get a degree instead of taking something longer...I wanted to become a doctor, but I can’t do that much schooling, so I’ve switched to a Medical Assisting program,” Jasmine said.

Endometriosis and Ambitions, Personal or Otherwise, Big or Small.

Women also talked about how endometriosis had affected other ambitions. Here, they were free to reflect on any aspirations they held. For some women, living with endometriosis has led to doubts over their abilities to be or do certain things (their abilities to fulfil roles). Some spoke of mother roles, while others mentioned more idiosyncratic roles (e.g., dancer, traveller)

For example, Susan lamented,

“I just haven’t figured out how to handle school, work and keep my health and home together. I want to have a baby ASAP but without a career in place I fear I won’t have enough money...I never thought about being “just” a mom. I believed

that a woman could bring home the bacon, fry it up and keep her family happy...now I'm not so sure...I'm on a journey right now, dealing with infertility and how to find my calling in life. Do I want to be a doctor or a mom? Do I spend my time in school or at home? There are no easy answers..."

"I worry about whether or not I will be a complete success," said Charlotte.

"It (endo) has also affected...my travel plans....I have always wanted to go across and live in Australia," said Meg, "Until my health becomes more stable, I don't feel that this is viable."

"I'm more nervous and worried about never having kids and doing what I want to do. I've decided I want to do as much as I can now before my endo gets worse and I'm unable to move and do things without pain," said Jasmine.

Karen focused on the smaller things in life:

"The little things that others take for granted are sometimes very difficult for me to accomplish. I work out very little any more...as I am in pain and tired all of the time. I am unable to pursue my interest in Middle-Eastern dance (hobby, not professionally)."

Jenna said,

"I would like to exercise more yet rarely have the energy...I used to believe that I could conquer the advertising market out here by the time I turned 30...I can't imagine having the endurance to conquer anything...I think I doubt myself more now - and I don't know why. It's like something killed my spirit for anything long-term and worthwhile."

For two women, endometriosis has not had a significant effect on life ambitions in general:

"I don't think it's affecting my goals no," said Dawn, "I've been off Danazol for over 2 months now, so I'm playing the "wait and see" game as to how my body will react being off...already using narcotics with my latest period..."

“No, it (endo) didn’t change my goals,” said Ingrid, “it made them more difficult, but I put my mind to it and went for it.”

Question 8. Life Events and Endometriosis

Women were also asked to talk about how endometriosis had affected any of their life expectations. They were encouraged to talk about issues previously discussed, as well as any other areas of life that had been affected. The two main themes that emerged here were: reassessing life goals, and changing expectations for relationships.

Reassessing Life Goals.

For many of the women interviewed, a reanalysis of life goals and expectations occurred due to living with endometriosis. Most women talked about motherhood and fertility specifically, and how endometriosis made them feel about these issues. Some women talked about how they felt about their goals.

Susan contemplated her health, her relationship, her goals:

“My goals have been to help people, to be in a helping profession...I don’t want glamour or money, and I want to be married only once...I was planning on marrying the man I’ve been with for 8 years, figuring I’d been with him long enough that the marriage would be sure to last. Just recently he has betrayed me and expressed pent - up frustration that were both painful and cleansing... The question is - can our relationship survive?.....I want a legacy of my values and ethics and drive to continue. Children are not the only way of doing that, so I may continue investigating alternatives. Teaching was something I considered. I want to be pregnant, I want a healthy baby...*(Susan had had three previous pregnancies; two ended in miscarriage, one was a stillborn preemie)*. I’ll investigate adoption no matter what happens...That is a future goal.”

Concerns about fertility and being a mother also arose for Anna:

“For kids, I have thought a lot about the possibility of adopting if I am unable to have my own. I had never really thought about it before I was diagnosed - now I feel very open and comfortable with making that kind of decision. I’ve also thought about having children (my own or adopted) as a single parent - you can see I really want kids ;-).”

Ingrid also commented on motherhood, as well as goals in general:

"I now accept things for what they are and try my best to help myself...The other thing I learned quickly was that I couldn't put my life on hold because of endo. If I want to do something I just do it...pain and all...I have also learned that being a mother is more important than I thought, but more than that I think I realized how much I took it for granted that I could (be a mother)."

For Karen, reanalysis and reassessment of her life expectations was a difficult and trying process:

"I am always afraid...I will not be able to live a normal life...I am always afraid that when I plan to go on vacation or do other things that are enjoyable, the endo will be a problem...I want to be able to lead a normal life without worrying when I will next be in pain," she said, "I am also afraid that when I am finally in a position to start trying to have children that I will be unable to get pregnant...I don't mind the idea of adopting, but I would like to experience at least one (healthy) pregnancy and birth (healthy baby). I already wonder if I am really worthy of being a woman sometimes...When I look ahead at the rest of my life, it looks like one long fight...I know that I will always be fighting the endo... By the time I am 30, I will be a very strong woman. You have to be to deal with endo. As they say, "what doesn't break you, will make you stronger."

Jasmine also thought more seriously about her goals, and how to reconcile her desire for children into the possibility that she might be unable to have her own:

"I used to want to be a doctor to help people...but the more I think about the endo and how it could possibly rob me of my ability to have kids, I want to go into helping out with childbirth more and more, so I can help others experience what I can't...I've thought quite a bit about what my goals in life are...My goal of being a wife, mother, and having a good paying job is a bit harder to attain now."

Endometriosis also made Shirley contemplate various aspects of her life; she spoke more about general things in life, as well as the effect endometriosis had on her priorities in life:

"I have also decided to become more involved with people in terms of starting up a support group...I'm much less driven than I was before, I always thought I had to dedicate myself entirely to my work and forget about everything else. I appreciate my time much more, taking walks with the dog or simply sitting on

the back deck and enjoying the breeze. Many things seem very trivial now that used to be very important to me (like work).”

Expectations and Others.

For some women, their expectations for various relationships have changed because of living with endometriosis, its symptoms, and its treatments. There was some anger expressed, as well as frustration and sadness.

Jenna, for instance, said,

“I expect a lot LESS from other people in my life - due to the fact that the very same people I grew up relying on, hardly believe how difficult this condition is. They constantly give me the “Oh, that sounds like a bummer..” NO! NO! NO! This disease takes my energy...I’m exhausted mentally and emotionally, too - - BECAUSE NO ONE WILL ACCEPT THE FACT THAT “PERFECT JENNA” IS REALLY SICK! I expect MORE of myself... ‘giving up’ didn’t work for me...I decided I will constantly work at something and TRY as hard as I can.”

“Marriage is not necessarily in the cards for me,” said Charlotte. “I often tell people that I will probably never get married...It may upset me when I reach my 30’s, who knows. I think endo has played a part in this.”

Meg felt endometriosis had changed her expectations for a successful relationship, and said she did not expect to have one, feeling that “it is unfair to inflict Endo on anyone else. I could only enter a relationship/marriage if I was 100% committed to it and as my health (or trying to regain it) is now my top priority, I feel that I wouldn’t be truly committed to the relationship.”

And Monica felt that the disease’s greatest impact was on her expectations for relationships, and her timing of events:

“I think that it (endo) has changed my expectations of relationships more than anything,...having endo I think puts a stress on relationships that most people don’t have to deal with....People in your life who are close to

you don't want you to hurt everyday and go through everything that us women with endo go through, but they don't know how to fix it and I think it makes them...feel "inadequate" because there is literally nothing they can do...unless you've been there and experienced it, I don't think you can understand...after a failed marriage that I blame mostly on endo for the problems it caused, I am scared to get married again...I feel like endo is almost "rushing" us (her and her partner) into it...I can't help but think sometimes am I doing this so quickly because "my time" might be running out?...I couldn't handle losing someone so dear to me because of a disease that I have no control over."

Two women interviewed felt endometriosis hadn't made much of an impact on their expectations, but both note that this perception could change in time. For instance, Dawn said, "From where I'm sitting right now, I don't think my expectations are different than if I didn't have endo, other than the frustrating temporary things...but then again I've just had several months of feeling good, ...SO where are my expectations? Perhaps a little of "get it all in while I'm feeling pretty good"... (not at all) close to how I felt last year at this time..."

"I never really thought about it," said Brittany. "I guess the answer is no. I already had my goals planned before endo became a part of my life...So the answer is definitely no, or not yet anyway..."

Question 9. Coping Helps and Hurts

Women were asked to talk about the things and people that and who helped them cope with endometriosis, and what did not help in coping. Previous literature (e.g., Schmitz, Saile, and Nilges, 1996) points to the importance of coping styles in explaining healthy adjustment to chronic illness, and how these styles may change over time. This question is meant, in part, to see first what helps these women cope, and second, if there are significant differences in what helps them cope.

Women mentioned several things that helped them cope with endo, and responses were often identical; regardless of degree/pattern of pain, what treatment methods these women had undergone, and how long it had been since diagnosis, these women cited common sources of comfort. Family and friends figured prominently as “coping helps”, as did support groups and self-pampering. Some women also mentioned that learning about or working with endometriosis also helped them.

For example, Monica mentioned family: “I think that the support of my grandmother, my best friend, and my boyfriend make my day to day life easier to cope with.”

“(My friends) let me baby-sit their baby daughter. It’s nice to play mommy for an evening,” said Karen.

“My parents have helped me cope with endo greatly...taken time off work to look after me,” Meg said. “Knowing that if I need their help in any way, they are willing to come down (she lives about 150 km away from them) and do their best, has helped with coping with endo.”

“My mom has really helped me out. We believe she has/had endo, though she was never diagnosed. She can understand a little bit what my pains are,” Jasmine said.

Support groups were also a source of comfort:

“I have met many wonderful, supportive women...These women know exactly what I am going through and have been a tremendous support!!” said Karen.

“The endo forum has been the best....It makes me feel better to know that I am not the only one going through this hell,” Charlotte said.

For some, learning about the disease, or working on it in some way, also aided in coping:

“Working on Endo has also helped me a lot. I feel less helpless and it gives me more insight into what’s going on inside my body,” said Shirley.

“Books on Endo have been wonderful...answered a lot of questions,” said Dawn.

These women seem to be taking control of the disease in a sense, by working on it, or studying it. The notion of control over the disease may be important in successfully coping, and is discussed in Chapter Five.

Taking time out for their own welfare was important to many of these women:

“I have a list taped to my fridge that says “hot baths, favorite scents, back rubs and candles” as a reminder for when I get too stressed and can’t deal with my symptoms anymore,” said Susan.

“I do yoga...and little things every week just for me: facial, massage...also my cat,” said Anna.

“Setting aside time to “do nothing”...I like to have the rest time to take a walk sit on the beach, or read a novel,” said Jenna

Women also mentioned several things (and people) that and who were most unhelpful - and often hurtful. Doctors, acquaintances, and family all created distress for many women. Pain symptoms were also listed by women (“Pain” said Jenna), as were medications and their side effects (“Lupron,” said Karen).

“My first gynecologist...was a very cold an unresponsive person and offered me no control or even a say in my treatment,” said Shirley.

“People (doctors) who tell me “just deal with it” and “women are supposed to have this pain!” make it difficult,” said Jasmine.

“DOCTORS!!!! They are the worst!” Jenna said. “I seriously cannot express to you the anger I feel for each doctor who looks at me funny when I say I’m in pain!”

As well, some women found their former acquaintances (ex-boyfriends, ex-spouses, etc.) did not help them deal with endometriosis at all:

“My ex-husband made it very difficult to cope...he started blaming me. Like I was doing something to myself to cause the pain,” said Monica.

It was not only acquaintances who could create strains: family members were also sometimes considered unsupportive:

“Some family - they just don’t understand,” said Ingrid.

“My parents have been the least helpful - even my boyfriend’s family has done more for me than my own,” said Susan.

“My family at times with the expected “Grin and bear it”...” said Dawn.

Question 10. Endo: It’s not Just about Babies.

Women were offered a chance to add to their comments, and their last chance for comments revealed that their feelings and fears did indeed extend beyond fertility concerns.

“My life has always in a sense revolved around the effects of endo,” Anna said. “I would plan my trips according to my cycle, accept/refuse party, dinner invitations...It’s really overwhelming how endo rules (or how I let endo rule) my life...everywhere I go, the first thing I do is locate a washroom or a safe, private area. I hate it. I know I have

missed out on a lot of things in my life...I'm 24, and I have a lot of living to do. I just hope I won't have to battle endo and its painful effects for the rest of my life."

Charlotte said,

"I often wonder WHY ME??? I have always been so healthy...I just get so frustrated, especially because it has even affected my face. Since the endo has become worse, these large...cysts have been forming on my face and they leave such horrible scars...My self esteem has dropped, I am scared to leave my apartment at times, and I have no idea what I have in store for myself in the future."

"Living with endo has affected every part of my life. It takes a toll on your mental health as it robs you of your physical health....even after all these years with medical treatment for this disease I still wonder what's really wrong with me...If I hear "You're too young to have all these problems" one more time..." said Susan.

On the positive side, some women drew strength from their experience.

"In some way, I believe that my experience of living with endo has, in some part, been beneficial. I now understand what true pain is like and have more understanding and compassion for others who are suffering," said Meg.

"Learning that I have endo has empowered me a great deal,...and I feel an enormous load has been taken off my shoulders - I have to deal with knowing I have endo now, but I think it will be much easier than being in the dark," Anna said.

"Being diagnosed with Endo has answered a lot of questions for me," said Shirley.

"It is very depressing to consider what the rest of my life might be like as I continue to deal with endo," said Karen. "However,...you are quickly reminded (with the disease) of what is important in life and what isn't...You have to rejoice in the days that you have a pain-free (or pain-reduced) day."

“I feel having endo has made me a stronger person and given me the ability to deal with almost anything that comes my way,” said Monica.

Summary

The interview results reveal striking similarities in experiences of living with endometriosis, despite the varied backgrounds and other experiences (i.e., pain levels, time since diagnosis, and treatment methods) of these women. For many of these women, a pattern emerged of misdiagnosis, followed by relief at diagnosis, and then uncertainty and/ or confusion, followed by anger. Not a single one of these women was indifferent to diagnosis. Confusion appears to be a short-term emotion, felt at the initial diagnosis and then for a short time afterward. Women in the questionnaire component who were fairly newly diagnosed sometimes mentioned not really knowing what having endometriosis meant, whereas this emotion was not expressed by any women who had either a) been diagnosed more one year ago (at the time of the study) or b) had more than two surgeries. Anger, however, is a more lasting emotion, and some women speak of frustration in their last comments (e.g., see Charlotte’s comment of “Why me” in question ten, or Brittany’s “I didn’t ask for endo, it’s not my fault.” in question 3); time since diagnosis does not appear to abate this emotion.

As well, these findings suggest that single women with endometriosis do worry about a lot more than just their family career expectations, though this area still ranked as a major concern for all these women; even those who were seemingly indifferent and nonchalant at one point would mention fears of infertility, or fears for a relationship - if not for their own sakes, then for the sake of a potential spouse. Indeed, relationships and role-taking abilities often featured predominantly in concerns and fears expressed by

these women (whether that role be as a mother, spouse, friend, daughter, employee, student, etc.).

For most of these women, every area of life they were asked to talk about appears to have been affected by living with this disease; only two women fairly consistently felt that they were doing well, that their goals and lives had not been severely disrupted. But even they occasionally qualified their remarks, suggesting that they might feel differently when the time came to actually deal with certain issues (e.g., infertility).

For the most part, these women spoke about endometriosis in general, and not about specific aspects of the disease. However, they did frequently mention pain interference with various areas of their social lives (e.g., sexual relations, activities, work, schooling aspirations); several also wished for a better method of diagnosis, testament to the difficulties they had experienced. Treatment methods were occasionally mentioned as well, especially regarding their effects on relationships with significant others, and their effects on feelings of self-worth, adequacy, and moodiness.

Chapter V

Discussion

In this chapter, the major findings regarding the research problems and the varied experiences of living with endometriosis will be discussed. Implications for future research are addressed in Chapter 6.

Endometriosis and life course careers

In general, the results of both the questionnaire and interview components indicate that single young women with endometriosis do indeed feel the disease affects their family, occupational, and educational careers; both expected events and current and/or past events in these areas have been affected for many women. As mentioned, over two-thirds of the women in this study (69%, $n = 50$) stated that they had rearranged their life goals, usually in the areas of family planning, and occupational goals. To a lesser extent, educational expectations were also affected: seventeen of the 43 women (40%) who were not attending school felt that endometriosis (symptoms and/or treatment) played a role in keeping them from attending, and the comments made by women in the interview component also reveal the difficulties the disease has created for them.

Family careers are particularly affected by this disease, which is unsurprising given that the fear of infertility was prominent in many of these women's responses (both in the questionnaire and the interview components). One-third of these women ($n = 24$) had rearranged family goals, either by marrying earlier than previously planned, by starting a family earlier than previously expected, or by placing a greater emphasis on achieving family goals. As well, dating and marriage expectations also emerge in the

interview component as major concerns. Occupational expectations are also affected: fourteen percent of the women in the questionnaire component of the study had changed their career goals.

Endometriosis: The Effect of Time

Previous literature suggests that time since diagnosis might be a key variable in explaining differential experiences with endometriosis. Family Development Theory posits that the likelihood of any given role transition decreases after a certain time (White, 1991). Untested hypotheses by Matthews and Matthews (1986) also implicitly suggest that over time, people redefine their situation to reconcile their abilities with their goals. And Schmitz, Saile, and Nilges (1996) also stated that a person living with a chronic condition changes coping techniques over time.

As the results of Research Problem indicate, time since diagnosis does not appear to have a significant effect on the experience of having endometriosis for this sample. Neither did time since symptoms, or the difference between these two variables. In the event that the relationship was a curvilinear one, the duration variables were squared; no significant findings emerged. Women diagnosed recently are no more or less likely to experience role strain or to be more optimistic about their prognosis than women diagnosed earlier. In the interview component, no significant differences in coping techniques were found; women mentioned similar coping "helps", regardless of how long they had been living with endometriosis. In fact, the one variable of time which was related to any of the experiences of having endometriosis (as defined in Chapter 2) was a perceptual one: perceived delay in diagnosis.

Why did duration not have a greater effect? This sample may have been too small to have enough variation in duration differences to see anything of significance: 44% of the sample had been living with the diagnosis of endometriosis for two or more years, while the majority were diagnosed during the year prior to this study. In other words, there was not a lot of variety in duration since diagnosis in this sample. Again, this was not surprising; young women are more likely to have been newly diagnosed because they are less likely to be diagnosed in general: a recent study of 4,000 women with endometriosis states that women experience an average of 9.28 years delay in diagnosis because most of them experience symptoms before they are 25, and are often misdiagnosed (EA, 1998).

Schmitz, Saile, and Nilges (1996) hypothesised that assimilative coping (i.e., not rearranging goals)

“might play an important role chiefly at the beginning of chronic pain, when sufficient actional resources are available and the afflicted person feels capable of solving pain-related problems through active efforts. With increasing chronicity, however, the failure...may make accommodative forms of coping more relevant for maintaining psychological well-being.”

(p. 49)

Their study supported the hypothesis that the longer a person has had chronic pain, the more likely that person would be to rearrange goals. The current study did not support this hypothesis. An analysis of some of the comments made by women in the questionnaire component reveals that women recently diagnosed did not seem any more or less likely to indicate that they had not reanalysed or rearranged goals than women diagnosed earlier (see Table 9). The interview component supports this: several different women commented at various times that they were not changing certain goals (e.g.,

Shirley's comment regarding her occupational expectations: "I always knew I wanted a research career and that hasn't changed"). It may be that these two studies are not comparable. For instance, Schmitz, Saile, and Nilges (1996) do not state which diseases their subjects suffered from, and it is not clear whether or not they equate chronicity with degree of pain. That is to say that the presence and/or severity of pain might be a more important variable for women with endometriosis than the length of time they have been dealing with that pain.

It is possible too that measures of perceived duration variables are more effective when investigating chronic conditions. Perceived delay in diagnosis was significantly positively correlated with goal rearranging, though it was not with goal reanalysis (see Table 9). So it would appear that if these women felt they had experienced a delay (whether it be of eight months duration, or 8 years), they were more likely to rearrange their goals than if they felt diagnosis had come with very little waiting time.

And what of the actual diagnosis of endometriosis, as opposed to the suspicion of having the disease? Time since symptoms was measured as well, with the expectation that a longer wait in diagnosis may occasion some women to reanalyse, or rearrange, goals because of symptoms preventing them from achieving things, and not because of the actual diagnosis.

But time since symptoms appears to have no effect (see Table 9). For example, Anna, who was newly diagnosed a few months before the study, mentioned that she had suffered from symptoms for over 12 years; though she was "new" to the disease, she did say her life had always been affected by it in some way. The diagnosis, however, seems to have been what triggered her thoughts on fertility and relationships; the previous

symptoms did not appear to occasion reflection. This result was also found with other women who participated in the interview component: no-one mentioned their pre-diagnostic experiences as including any kind of thoughts on their life goals.

This finding supports some previous research. Peveler et al (1996) found in comparing social dysfunction of women with endometriosis to women with unexplained pain that the former reported a higher level of disruption and dysfunction. Low et al. (1993) had hypothesised that longer pain duration might make women more anxious, depressed, etc. However, they found no evidence to support this effect of duration in their study. In fact, women who received a diagnosis (versus women who had unexplained pain, and therefore a continued duration of pain without discernible cause) experienced more anxiety and depression. These studies suggest that duration since symptoms is not a key variable; the knowledge of the disease appears to have a greater effect than pain symptoms.

Women who participated in the interview component of the study were asked to talk about their experiences waiting for a diagnosis and the feelings they experienced; no-one mentioned reanalysis of life goals, or rearranging goals prior to diagnosis (due to pain symptoms, for example); although this finding also suggests that diagnosis is more important than time since symptoms, the statement can only be made with caution as these women were not directly asked to comment on what they did prior to diagnosis.

Another variable which may have proved useful is that of perceived control. Schmitz, Saile, and Nilges (1996) found that not only did time living with a chronic condition aid in finding accommodative coping (i.e., flexible goal adjustment), but perceived control over the situation affected which coping strategies were used.

Perceived control was not assessed in this study, but this finding of Schmitz, Saile, and Nilges (1996) is worth noting; several women did mention educating themselves about endometriosis and/or working on it among their coping techniques.

Endometriosis and Expectations: The Effect of Pain

Almost all of the women in this study experienced some degree of pain due to their disease. Only two participants did not. This makes sense, since young single women are more likely to be seeking medical help for pain symptoms - i.e., manifest symptoms - than for infertility, a symptom that is more or less undetectable unless one is actually trying to get pregnant. Pain appeared to play a role in influencing women's expectations.

As mentioned in the results section, pattern of pain (cyclical versus constant) appears to affect expectations for normative and nonnormative sequencing of events (asynchrony) (see Table 10). The majority of women expecting asynchronous sequencing of events experience constant pain, regardless of the degree of that pain. Pattern of pain also seems to have a greater impact than degree of pain. No previous studies on the effect of endometriosis-related pain on various aspects of life (e.g., social functioning, life satisfaction) have looked at pattern of pain, and so this area obviously needs more attention. Most research has concentrated on degree of pain and some studies don't even do this; Peveler et al.'s (1996) study on quality of life and ability to perform various roles compared the experiences of women with endometriosis to those with unexplained pain in general.

In the interview component, several women listed pain as one of the things that made coping difficult, making them reconsider what they could accomplish in life; others talked about pain with intercourse and how it made them want to avoid relationships,

affecting their expectations for marriage. Pain also appeared to affect expectations outside of the three realms of family, education, and career. Several women in the interview component talked about how they tried to do more on their "pain-reduced" days because they didn't expect to do much on the days they were in pain. Others mentioned giving up activities like figure skating and dancing because of pain symptoms, and not expecting to pursue them. When one considers that pain serves as a constant (or at least cyclical) reminder of a chronic condition, it is not surprising that it had some effect for most of these women. However, women were not explicitly asked in the questionnaire or interview components to state to what degree pain had affected various aspects of life (e.g., the ability to be a mother); women were asked how endometriosis itself had affected these areas. Some women directly referred to pain preventing them from pursuing educational or career goals, while others spoke in less specific terms about endometriosis in general. Pain appears as an important concern for most women, and, more tellingly, it is also listed in the top three concerns of 75% of the 72 women (n = 54).

Alternatives to the "Norm": Substitute Roles

The mother role appears to be a salient one for most of the women in this study. Only four percent (n = 3) of these women expect to never be mothers, naturally or otherwise. The percentage of women planning to adopt at some point seemed quite high. Previous research has suggested that adoption is not only a decreasing route to parenthood (Sobol & Daly, 1994), but that it is also not a desirable route. One might argue that infertile or subfertile women are more likely to view the option more positively, all limitations considered. However, Halman and Abbey (1992) surveyed 185 infertile couples and some presumed fertile couples concerning their attitudes toward

various interventions for infertility (e.g., in vitro, adoption). The one option which was not viewed as favourably as the others, regardless of fertility status, was adoption. This suggests there is a stigma associated with adoption, and several studies support this (e.g., Kressierer & Bryant, 1996).

The women in this study clearly value the mother role, no matter what route they may have to take. Many of the women in the interview component talked about reconciling themselves to an alternate route, a process which echoes Matthews and Matthews' (1986) hypothesis 3 (role strain leading to redefinition of the situation so that desired goals become more congruent with the range of alternatives available). These women's comments, and the high percentage of women expecting to adopt both support the notion of "finding alternate paths".

Treatment Methods and Expectations

Surprisingly, treatment methods did not appear to play a major role in expected life events. Although women who have undergone a variety of treatments make up the majority of women who expect some form of nonnormative sequencing, these women also make up the majority of the sample. Four women in this study have had hysterectomies; two of them never expect to have children (i.e., never to adopt). Because many of the treatment categories developed had been experienced by only a few respondents, it was not expected that significant results would be found. But collapsing categories and ranking them proved a daunting task. Only these women themselves could truly state that they found medical treatments to be more traumatic and interfering than surgeries, for instance. And placing a single young woman who has undergone pregnancy

as a treatment in the same category as a woman who has changed her diet is obviously inappropriate.

Women in the interview component did talk about treatment methods, although they were not asked to comment specifically on the effect of treatment methods. When women mentioned them, it was usually in negative terms. As detailed in the results section, treatments were often held responsible for ruining relationships (typically by causing mood/personality changes). Drugs and surgeries seem to take their toll on relationships for women; does this have a lasting effect? As women were not asked directly in either the interviews or the questionnaires about treatment methods, this limitation precludes making any statements about the influence of this variable. However, treatment methods were listed in the top three concerns of 53% of the 72 women ($n = 38$), suggesting that future research should ask specific questions about the effect of treatment methods.

Perhaps the more interesting finding here was the number of women who had undergone so many diverse treatments, given the range in ages and time since diagnosis. Is this common for women with endometriosis? The Endometriosis Association (1998) found that 75% of their sample of 4,000 women had taken birth control pills or painkillers; alternative treatments were also popular, with around 35% of the sample trying a variety of treatments. Seventeen percent of women in that study had had a hysterectomy; nineteen percent had had their ovaries removed. The study does not differentiate between women who initially had hysterectomies and then had their ovaries removed and women who had either one or the other. As well, basic demographic variables were not available as of this writing. We do not know the ages of these women,

or when they were diagnosed. Without this information, it is impossible to draw conclusions on the similarities in treatment methods between these two studies. No other detailed studies currently exist on treatment methods undergone for endometriosis.

Expectations: Asynchrony, Timing, and Sequencing

As mentioned, 40% of the sample in this study expect to deviate from normative sequencing patterns. Despite this, the modal category for these women was still marriage then a child. No matter what endometriosis might put these women through, they still want to have "normal" lives. The rate of nonnormative expectations cannot readily be compared with rates in the general population; there are undoubtedly undiagnosed women in the general population, and the current sample is not a random one; drawing comparisons between the two groups would not therefore prove.

Expected timing of events does appear to be affected by endometriosis; many women in both the interviews and questionnaires talked of "speeding things up" while they could. This is in distinct contradiction with a supposition from Peveler et al (1996) that women with endometriosis may start families relatively later in life and therefore encounter various difficulties. However, the differences in timing of events are not large, and could be accounted for by mere chance.

Why is there not more deviance? Most of these women clearly do not appear to be following the advice to "get pregnant as soon as possible". According to Family Development Theory, there are social norms governing social behaviour, and sanctions against those who deviate (White, 1991). Do these women perceive social sanctions against choosing non-normative paths? The fact that most women want to follow the normative sequence of marriage then child, and a relatively normative timing of those

events suggests that they are aware of social norms, whether they recognise them as such or not. This contradicts some previous research; some researchers suggest that social norms do not even really exist. Buchman (1989) argues that there is increasing diversity in the timing of transitions to marriage and parenthood, suggesting that such deviance that there is needs to be distinguished from mere normative variation. Settersten and Hagestad (1996) went further, and asked people if they perceived deadlines for various transitions and the reason why that deadline existed, and consequences there might be for missing one. The authors conclude that sequencing may matter more than timing of events, but that there are no strong informal norms in existence for family transitions, and no informal mechanism of social control. Why then do the women in this study want to have a relatively normative sequencing and timing of life events?

Settersten and Hagestad (1996) failed to delve into their questions. Though they conclude that norms and sanctions do not truly matter, that others aren't aware of them, they merely asked "By what age should a woman ...(be married, etc.)?" and "Why should a woman be ...(married, etc.) by that age?". Assessing perceived consequences for divergence might be better accomplished by asking those people who are contemplating such a divergence; the issue is likely to be more salient for them than for anyone in general.

In the current study, however, it was clear that women had changed expectations in comparison with their own previously held goals. A high percentage (69%) had rearranged their own plans because of endometriosis, and many spoke in the interviews of having to consider things before they really wanted to, and of having to change expectations for what they could realistically achieve out of life. Women's own life goals

were therefore affected by this disease regardless of whether changing goals made women "nonnormative" or not. Asynchrony with prior expectations emerged as a theme in both the interview component and the responses to open-ended questions in the questionnaire component.

The Role of Role Strain

The one other variable that must be discussed is role strain. Role strain appeared to be a significant factor in relation to depression (unsurprisingly), life satisfaction (again, unsurprisingly) and rearranging goals (see Table 9). Some might argue that rearranging goals increases role strain because the change was not necessarily desired, creating stress. For the most part, these women spoke of *anticipated* rearranging; that is, they had not yet acted on the changes they had made. This could be considered anticipatory role strain. However, it is also possible that anticipated *role strain* (or blocking) leads to rearranging. According to untested hypotheses of Matthews and Matthews (1986), it is the experience of role strain (in the form of role blocking) that leads most people to redefine and realign goals with abilities in an effort to ease or eliminate the strain experienced. Schmitz et al (1996) suggest that accommodative forms of coping are healthier, and rearranging goals should indeed be considered a form of coping. Schmitz et al (1996) also state that pain-related coping strategies lead to a reduction in disability experienced *only* when accompanied by a high degree of flexible goal adjustment (i.e., accommodative coping). This suggests that rearranging (anticipated or not) occurs to reduce role strain, and that role strain is not experienced in anticipation of rearranging.

However, research on expected stressful events (e.g., Joselevich, 1988; Pittman, 1988) suggests that anticipated role strain can also be experienced. Expectable crises,

such as the birth of a child, or other family transition, typically involve stress and strain (Joselevich, 1988); anticipated changes can be prepared for, and role strain should therefore not be as high as it would with unexpected events. Are the women in this study experiencing anticipated role strain? It is unlikely, because role strain was measured in such a way to assess "role blocking" (i.e., the questions were meant to measure the strain experienced due to endometriosis' "blocking" of various roles).

Endometriosis is not predictable in its career (i.e., there is no standard progression of the disease), and as an unexpected event is more likely to create a higher level of stress and strain (especially if it is blocking a woman from a highly desired role). A possible sequence may be that role salience and perceived role blocking feed off of one another, the role blocking strain leads to rearranging goals, and in turn, there may indeed be further anticipated role strain (not role blocking) based on the rearranging of goals. This area definitely merits further research.

Chapter VI

Conclusions, Limitations, and Implications

The purpose of this exploratory study was to investigate the effects of having endometriosis on single young women's expectations for family, occupational, and educational careers.

Limitations

There were several limitations to this study that must be noted. The first is the volunteer sample: not only was this a volunteer sample, these women learned about the study through support group meeting places on the internet. These women are actively seeking support in dealing with endometriosis; they would not have learned of this study otherwise. Perhaps this similarity in needs outweighs any differences in other areas, such as time since diagnosis. Because this study was exploratory in nature, the most important goal was to find an adequate sample, regardless of generalizability. However, these women, as mentioned, are, regardless of any other differences, similar in that they participate in support groups. They are also volunteers, and may be quite different from women who do not volunteer.

As well, the sample was composed of a highly educated group of women, all computer literate. Many women also held professional or semi-professional jobs. Many other studies on endometriosis have found that a large proportion of women in their samples were from higher socio-economic groups (e.g., Christian, 1992; Peveler et al, 1996).

Along the same lines, there were also no questions about ethnicity in this study. This might also play a role in differential experiences with endometriosis, since previous

literature has indicated that white women are more likely to be diagnosed earlier when compared to black women, for example (Ballweg, 1995). Although no women offered information on ethnic background which might account for some of their decisions and expectations (e.g., "Coming from a large Portuguese family, I feel I should have children", etc.), the findings still cannot therefore be easily generalised to other women living with this disease. As well, this exploratory study does not purport to address issues relevant to married women with this disease, or older single women with endometriosis (though these two groups deserve their own research as well).

Finally, many of the questions used in this study, tailored to be appropriate for women living with endometriosis, were previously untested. Due to a lack of available measures, this was understandable and unavoidable. However, it bears mentioning as a limitation; variables may have to be redesigned for future research. In particular, perhaps the measure of time since diagnosis must be revisited. Although current age was controlled for, it is possible that age at time of diagnosis might play a role in affecting experiences. As well, questions were more broad in scope, and this may have failed to yield more significant results (e.g., women were not asked to comment specifically on any one aspect of endometriosis). In an exploratory study, this broad approach is useful, as too narrow a scope imposes pre-supposed and essentially unfounded assumptions, and thereby risks limiting the potential to uncover significant results.

Conclusions

Although there is still so much to be researched in this area, a few comments can be made based on the results of this exploratory study.

First, living with endometriosis clearly affects expectations for many single young women. In interviews, women spoke of trying to get things done while they could, of wondering if relationships with partners could last, or even be developed with endometriosis present, and especially of what this disease did to views on having children. In the questionnaires, women indicated giving up roles, some small, some large, because of endometriosis. When asked to what degree this disease played a role in rearranging goals, almost every woman ranked it at the highest degree.

Pain symptoms from endometriosis also clearly affect women's life goals. Previous research on endometriosis often found level of pain to be significant in some way, even when it was not always the main focus of the study (e.g., Christian, 1992). Although fear of infertility was a major concern for many women, it was more a concern about future fertility (i.e., the majority of these women were not actively trying to conceive); pain symptoms had a current impact on relationships, and work, social, and recreational activities, and on expectations and aspirations as well. Moreover, pattern of pain seems to have a greater impact than degree of pain (see Table 10). Indeed, women in the interviews who experienced constant pain commented on its interference more often than women who suffered cyclical pain, regardless of the severity of pain symptoms.

Results for the main research problems also suggest that endometriosis in general, and pain in particular, influence life course expectations for single young women. Although no significant results were found for duration variables (see Table 9, p. 71), results for research problem 2 reveal that pattern of pain (i.e., cyclical or constant) appears to have an effect on women's expectations (Table 10, p. 74). In particular, most women expecting a normative sequence of events did not experience constant pain. Most

women with constant pain, regardless of severity, indicated they did not know when to expect events in their lives. Although treatment methods did not appear to have any influence on expectations (see Table 11), findings in the interview component suggest that the area is worth investigating.

Findings also suggest that women do search for other routes to motherhood, or at least the experience of being a mother. The high percentage of women expecting to adopt (78%), and responses to open-ended questions reveal that these women try to reconcile their goals with the limitations they feel endometriosis has placed upon them.

Results for research problem 5 suggest that women try to reconcile their goals with the limitations of this disease in several ways. The two most common ways are: a compression of timing of events (witnessed, for example, in the anticipation of marriage at an earlier age than North American societal averages); or rearranging goals (changing priorities, changing career goals or having a child before marriage, for example). Although most of these women (60%) expected a normative sequencing of events (i.e., education, then marriage, then children), the majority (69%) also felt they had compromised previously held expectations for their life paths.

This exploratory study contributes to previous literature on endometriosis by suggesting that analysing the biological and/or psychological components of this disease, though admirable and important foci, do not completely capture the experience of living with endometriosis. Indeed, previous research on psychological functioning of women with endometriosis found that women with endometriosis were no more or less likely to have psychological problems than women in general (e.g., Low et al, 1993; Peveler et al, 1996). And although fear of infertility ranked as the number one concern for women in

the questionnaire component, their comments on open-ended questions and the responses of women in the interviews suggest that biology is not all that matters, especially when a woman is not actively trying to conceive. For many of these women, goals for fertility (among other areas such as career) lagged in importance behind goals for basic good health, or even a “good” day.

Implications for future research

There has been so little previous research on the non-biological (i.e., non-pathology) aspects of living with endometriosis that implications of this study for future research could easily fill up several pages. However, only a few key areas will be discussed here.

Although one of the limitations of this study was the use of e-mail as the data collection method, this usage also proved helpful, particularly with regards to the interview component.

Women’s emphasis on words (through the use of italics, uppercase letters, bold letters, icons such as smiling faces or frowns, etc.) was clear, not easily leaving room for misinterpretation. One intriguing finding was the way in which women referred to the disease. Some women called it “the endo”, some always capitalised it, no matter where the word appeared in a sentence (e.g., “since being diagnosed with Endo...”). Others referred to it as “my endo”. The meaning of this disease to women might therefore be a worthwhile avenue of research to pursue. Previous literature on chronic pain suggests that a person’s perception of their disease, and their beliefs about their coping capabilities influences adjustment (e.g., Jensen, Turner, & Romano, 1991; Williams & Keefe, 1991). Williams and Keefe (1991) found that a pain patient’s beliefs about their pain (e.g.,

understandable versus mysterious; long-term versus short-term) influenced not only the coping strategies used, but also the perceived effectiveness of those strategies. Where other variables had no significance (e.g., time since diagnosis, prognosis of disease), this perceptual one might. Perhaps the notion of perceived control mentioned earlier comes into play here (e.g., “my endo”; is this a sense of ownership, or more control?).

The issue of perceived control, mentioned previously in chapter five, is an area that deserves closer attention. Previous literature on managing chronic pain and/or illness suggests that a perceived internal locus of control aids in coping (e.g., Brandtstaedter, Rothermund, and Schmitz, 1998; Spinhoven, Moniek ter-Kuile, Linssen, & Gazendum, 1989; Weinstein, 1987). Another facet of perceived control that can potentially affect coping and the experience of having endometriosis is that of a woman’s level of involvement in her disease. Self-education was mentioned by several women in the interview component as a particularly helpful way of coping with their disease. These comments support previous research findings that a person’s active role in managing a disease (e.g., through involvement in treatment decisions, finding positive aspects of having the disease, or through self-education) is conducive with healthy adjustment (e.g., Affleck & Tennen, 1996; Davis, 1992; Felton, Revenson, & Hinrichsen, 1984; Jensen et al, 1991; McCracken, Goetsch, & Semenchuk, 1998). Women were not asked to comment on this particular area; future research might do well to utilise such measures as the Chronic Pain Coping Inventory (CPCI; Jensen, Turner, Romano, & Strom, 1995) to further explore the relationship between coping with endometriosis and expectations.

The family experience of living with endometriosis was only lightly examined in the current study; the interview component in particular reveals that family dynamics

might also affect coping behaviours and abilities, which in turn could affect expectations. Previous research by Dunn-Grier, McGrath, Byron-Rourke, and Latter (1986) examined the effect of family interactions, particularly mother-child interactions, on adolescents' coping abilities in handling chronic pain. Findings suggested that healthy coping is influenced by these interactions. Hepworth (1987) also discusses the relationship between family dynamics and a person's ability to cope with chronic pain, as do Greene-Bush and Pargament (1997); their research illustrates the importance of assessing family dynamics and the role they play in coping behaviours.

There is no current research on coping with endometriosis. This area merits further attention, as Schmitz, Sailes, and Nigles (1996) posited that coping styles and goals are indeed interrelated, and coping research therefore has the potential to assist in understanding the role coping plays in forming life expectations.

As well, previous research noted the need to analyse life events and endometriosis (e.g., Christian, 1992; Damario & Rock, 1995; Peveler et al, 1996). This exploratory study has made an effort to do so; future research should also consider assessing not only expectations, but also actual behaviour.

This study also illustrated the importance of role strain (and in particular, role blocking, a form of role strain). As this variable was not a main focus of the study, its full potential as an explanatory factor has not been utilised. Future research should explore the effect role strain has on differential experiences of living with endometriosis, and greater attention should be paid to the conceptualisation of the variable (in this exploratory study, it was impossible to determine to what extent women perceived the disease to increase or decrease the salience of a role, for example).

As well, the role of pain (versus the disease itself) is well worth investigating further. Because this was an exploratory study, the scope was relatively broad, and women were asked about the effect of the disease, not pain. However, pain and its impact emerge as major issues for most of these women: pain symptoms were a hindrance to coping, and a great concern for women (second only to the fear of infertility); these findings suggest that research explicitly meant to capture the effect of pain (versus endometriosis) is worthwhile. What little research exists on endometriosis and chronic pain has largely focused on psychological functioning (e.g., Low et al, 1993; Waller & Shaw, 1995); future research should further investigate the role of pain in affecting expectations for life goals.

Finally, more qualitative research should be considered. Surprisingly, no previous qualitative research exists on this disease, though it has been recommended (e.g., Christian, 1992). This is actually not so surprising if we bear in mind the fact that previous research tended to focus on issues that lent themselves well to quantitative measures (e.g., pain, depression, self-esteem). Salient topics such as the importance of various roles such as mother and wife, as well as career woman, were areas that appeared to be affected, and merit further exploration.

Implications for Practitioners

This study also had implications for health care professionals and support groups for women with endometriosis (including family and friends).

One common reaction to diagnosis was confusion; in interviews, many women spoke of not realising the true nature of the disease. Another common reaction was relief, especially that the disease was not “all in the head”. The fact that women still feel the

need for validation of the disease, and did not always find it from their doctors, suggests that health practitioners should be more aware of what is actually known about endometriosis (i.e., it is not a psychological disease; it is not caused by delaying childbirth, etc.).

And doctors were sometimes deemed the least helpful of people, in both the interview and questionnaire components. When asked to list people with whom they felt most comfortable talking about endometriosis, most women mentioned family and/or friends; very few mentioned doctors or support groups (14% and 7% listed these people, respectively). Many women in the interviews talked of needing more support, whether from doctors, family, or support groups. The importance of support groups and others who empathise was illustrated by the fact that many women considered these people to be the greatest “coping helps”. At the same time, well-intentioned support (from doctors, support groups, family, and friends) was not always appreciated, particularly when assumptions were made regarding what mattered to these women.

Single young women living with endometriosis appear to grapple with issues that extend beyond whether the AFS classifies them as having Stage 1 endo or Stage 4, or whether or not fertility is compromised. This exploratory study has illustrated the importance of studying this disease and its effects, for its social consequences as well as its biological ones.

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Appendix A

Letter of Introduction

Hello! My name is Lisa Mason, and I am a Master's student at the University of British Columbia. For my thesis research, I am doing a study entitled "Single young women with endometriosis and their life course expectations", and looking for participants.

The purpose of this study is to explore how this disease affects the life goals of single women. I myself was diagnosed at the age of twenty, and feel that this area is under-researched.

I am looking for women who are: currently single (cohabiting or engaged included!), 28 years old or younger, and surgically diagnosed with endometriosis.

If you fit these criteria and would like to participate, e-mail me privately at: lkmason@unixg.ubc.ca with the words "Endo Study" as the subject.

I will then send you out a questionnaire, via e-mail. It should take about 30 minutes to complete. All information collected from this research will be strictly confidential. No participants will be identified by name in the completed study. Return of a completed questionnaire to me constitutes your consent to participate. However, you may withdraw from this study at any time, with no consequences for your membership in this support group.

If you have any questions about this, please feel free to e-mail me privately, or contact Dr. Jim White, my supervisor, at blanco@unixg.ubc.ca. You can also contact Dr. Richard Spratley, Director of Research Services at the University of British Columbia ((604) 822-8598).

Thanks!

Lisa K. Mason, Investigator
UBC

Appendix B

Questionnaire

If you have any questions regarding this study, please e-mail Lisa K. Mason (lkmason@unixg.ubc.ca) or her supervisor, Dr. Jim White (blanco@unixg.ubc.ca, (604) 822-4683). All information collected from this data will be kept confidential. Participants will not be identified in any way in the final study. The purpose of this study is to explore how endometriosis affects the life goals of single young women. This questionnaire should take 30 - 45 minutes to complete. **Please answer every question. If a question does not apply to you, please indicate this by writing "N/A" as your response.**

Return of this completed questionnaire (9 pages long) to Lisa K. Mason at the e-mail address above constitutes consent to participate in this portion of the above study. However, you are free to withdraw from this study at any time, with no consequences for your membership in this support group. If you have any concerns about your treatment or rights as a research subject, you may contact Dr. Richard Spratley, Director of Research Services at the University of British Columbia (822- 8598).

I'd like to first ask you to answer some basic questions about yourself and your family background.

1. Do you reside in Canada _____
 USA _____
 Elsewhere (please specify) _____
2. How old are you? Age:
 Birth date: _____
3. What is your current occupation? (Please be as specific as possible; e.g., if you are a student, state whether you are a high school student, a college student, etc.)
4. What are the occupations of your parents?
 Father:
 Mother:
5. What is your marital status?
 _____ single, never married
 _____ separated
 _____ divorced
 _____ widowed
 _____ cohabiting - when did you begin current cohabitation? (date) _____
 _____ engaged - since when (date) _____
6. What is your highest level of education attained as of this date?

- completion of a master's degree/doctorate
- completion of a bachelor's degree/ undergraduate
- completion of a diploma program/ vocational program
- completion of high school
- completion of Grade 10
- completion of Grade 7

7. In the household you currently reside in, do you share with (check all that are applicable):

- (a) parent(s)
- living alone
- living with a female non-relative companion
- living with a male non-relative companion
- living with (a) female roommate(s)
- living with (a) male roommate(s)

8. What is your personal income bracket for the past year?

- \$0 - \$5,000
- \$5,001 - \$11,000
- \$11,001 - \$20,000
- \$20,001 - \$40,000
- \$40,001 - \$80,000
- \$80,000 +

9. Did you receive financial support from a parent in the past year?

Yes No

If Yes, how much money did you receive?

- \$0 - \$11,000
- \$11,001 - \$30,000
- \$30,001 - \$50,000
- \$50,001 +

I would now like to ask you some questions about endometriosis.

10. At what age do you feel you first experienced symptoms of endometriosis?

Age:

Date (mm/yy):

11. When were you surgically diagnosed?

Date (mm/yy):

12. Did you experience a delay in diagnosis due to (please check)
being waitlisted for surgery

lack of adequate health coverage ____
 waitlisting to see a specialist ____
 lack of specialists in area ____
 other (please specify) _____
 I did not experience delays ____

13. Does anyone else in your family have this disease?

____ Yes ____ No

If YES, please give person(s)'s relationship to you _____

I would now like to ask you some questions about pain symptoms related to endometriosis

14. What statement best describes your pain associated with endometriosis?

- my pain is constant and mild
 my pain is cyclical (with ovulation and menses only) and mild
 my pain is constant and moderate
 my pain is cyclical and moderate
 my pain is constant and severe
 my pain is cyclical and severe
 I do not experience pain

15. The following words represent pain of increasing intensity:

0	1	2	3	4	5
no pain	mild	discomforting	distressing	horrible	excruciating

Choose the number of the word which best describes:

- Your pain right now (related to endometriosis)
 Your pain at its worst (related to endometriosis)
 Your pain at its least (related to endometriosis)
 The worst toothache you ever had
 The worst headache you ever had
 The worst stomach-ache you ever had

16. Pain and Sleep:

always sometimes never

Trouble falling asleep:

Medication needed

to fall asleep:

Awakened by pain:

17. What are the greatest concerns for you with this disease? Please rank three of them from 1 - 3, 1 being the greatest concern.

- | | |
|---|---|
| <input type="checkbox"/> infertility | <input type="checkbox"/> surgery in general |
| <input type="checkbox"/> chronic pain | <input type="checkbox"/> medical side effects |
| <input type="checkbox"/> painful sex | <input type="checkbox"/> hysterectomy |
| <input type="checkbox"/> cancer | <input type="checkbox"/> other (please specify) _____ |
| <input type="checkbox"/> lack of support | _____ |
| <input type="checkbox"/> uncertainty of prognosis | _____ |

18. Below is a list of possible treatments for this disease. If you have had one, please place the year in which you did. If two or more treatments occurred in the same year, please indicate the approximate month for each one. If you have not, place a 0 next to it. If you expect to undergo a specific treatment in the next 5 years, place a projected time beside it.

- none (currently)
- dietary changes
- yoga
- acupuncture
- therapy/counseling
- birth control pill
- diagnostic laparoscopy
- subsequent laparoscopy (if +1, place the year for each)
- laparotomy (if +1, give year for each one)
- danazol (if more than once, give year for each)
- pregnancy
- colectomy
- pain mapping
- GnRH agonists (Synarel, Zoladex, Lupron) (if more than once, give year for each)
- removal of an ovary
- removal of a fallopian tube
- hysterectomy
- definitive hysterectomy (includes removal of both ovaries)

19. Below is a list of ways you might have behaved or felt during the past week. Please respond on a scale from 0 to 7 days (0 being none, 7 being every day of the week)

On how many days during the past week did you:

- a) Feel bothered by things that usually don't bother you? ____
- b) Not feel like eating; your appetite was poor? ____
- c) Feel that you could not shake off the blues even with help from your family or friends? ____
- d) Have trouble keeping your mind on what you were doing? ____
- e) Feel depressed? ____
- f) Feel that everything you did was an effort? ____
- g) Feel fearful? ____

- h) Sleep restlessly for no apparent physical reason? ____
 i) Talk less than usual? ____
 j) Feel lonely? ____
 k) Feel sad? ____
 l) Feel you could not get going? ____

20. Are you currently taking

- Danazol? ____ Yes ____ No
 Lupron? ____ Yes ____ No
 Synarel? ____ Yes ____ No
 Zoladex? ____ Yes ____ No
 birth control pills? ____ Yes ____ No
 provera (or other progesterone)? ____ Yes ____ No

21. How important are the following roles to you?

List them on a scale of 1 to 5, with 5 being extremely important, 1 being not important at all. Please note that all of these roles can be extremely important, or not important at all (e.g., both the mother role and the wife role can be 5s). Answer each one, even if you are not currently a mother, wife, etc.:

- being a mother ____
 being a wife ____
 being a daughter ____
 being a friend ____
 being a student ____
 being a girlfriend ____
 being an employee ____ (please specify what occupation: _____)

22. Please answer each one below, even if you are not currently a mother, wife, etc.,. On a scale of 1 to 10 (10 being the highest degree, 1 being not at all), please indicate:

To what degree do you feel endometriosis has affected your ability to perform as

- a mother ____
 a wife ____
 a daughter ____
 a friend ____
 a student ____
 a girlfriend ____
 an employee (in the same occupation specified above) ____

23. What are your feelings about your future with this disease?

Optimistic _____

Depressed _____

Neutral _____

Could you briefly [e.g., two sentences] describe why you feel this way?

24. Since your diagnosis, have you reanalyzed life goals (e.g., goals for a job, or a family)?

Yes No

Could you briefly [2 sentences] describe this to me?

25. Have you *rearranged* goals since diagnosis?

Yes No

Could you briefly describe this to me?

If No, please proceed to question 28.

26. Are there things you wanted to do or be (e.g., mother, athlete) that you feel endometriosis has stopped you from doing?

Yes No

If No, please skip to question 27.

If Yes, what were the things

you wanted to do or be?:

What are you doing instead?:

27. On a scale of 1 to 10, where 10 is the highest degree, and 1 is not at all, to what extent do you feel endometriosis played a role in rearranging goals? ____

28. The following is a list of life events.

Starting from today's date, in the next 5 years, which of these events do you ***realistically*** expect to experience and when?

Put the year in which you expect the event to occur beside the event.

If you don't expect to experience it in the ***next 5 years***, place a ? beside the event.

If you never expect to experience an event, place a 0 next to it.

If you have already experienced an event, place the year beside it. If you experienced two or more events in the same year, please give an approximate month for each event.

high school graduation

marriage

divorce

completion of highest degree

birth of first child

- birth of second child
 birth of third child
 adoption
 start of cohabitation
 separation
 entrance into a full-time occupation

I would now like to ask some questions about various areas of your life, and your experiences with endometriosis within these areas.

29. Have you ever been in a relationship?

Yes No

If No, skip to question 35

30. Are you currently in a relationship?

Yes No

If YES, since when? (approximate date)

If NO, skip to question 32

31. Does your partner know of your disease?

Yes No

If YES, when did you tell? (date)

32. When was your last relationship? (date)

33. When did it end? (date)

34. Do you feel endometriosis play a part in its ending?

Yes No

35. If not in a relationship, do you feel that endometriosis has played a role in this (symptoms or treatment)?

Yes No

36. Who are the three people you feel most comfortable talking with about your disease?

Name, relation _____

Name, relation _____

Name, relation _____

37. Did you have difficulties convincing others (family and/or friends) of the seriousness of this disease?

Yes No

38. Are you currently attending school?

Yes No

If YES, year/level

If NO, if you did not have endometriosis, would you attend school?

Yes
 No

39. Are you attending school full time?

Yes No

If NO, do you feel endometriosis has played a role in this?

Yes (symptoms)
 Yes (treatments)
 No

40. Are you currently working (paid employment)?

Yes No

If Yes, skip to 42

41. If you are not currently working, if you didn't have this disease, would you be working?

Yes No

42. What is the longest length of time you have been in a job? _____

43. How many hours a week do you work? _____

If this is not full-time (40 hours/week), would you be working full-time if you didn't have this disease?

Yes No

44. Since diagnosis, has endometriosis caused changes in:

a) # of hours/wk Yes No

b) type of duties Yes No

c) satisfaction

with work Yes No

d) efficiency

at work Yes No

e) absenteeism Yes No

45. If endometriosis has caused changes, are these changes due to symptoms Yes No

treatment Yes No

46. Does your employer know of your disease? Yes No

47. Do your colleagues know of your disease? Yes No

For the questions below, answer on a scale from 1 to 7 as follows:

1 = extremely satisfied

2 = satisfied

3 = somewhat satisfied

- 4 = neutral
- 5 = somewhat dissatisfied
- 6 = dissatisfied
- 7 = extremely dissatisfied

- 48. How satisfied are you with your family life? ____
- 49. How satisfied are you with your social relationships? ____
- 50. How satisfied are you with your recreational activities? ____
- 51. How satisfied are you with your educational development? ____
- 52. How satisfied are you with your work activities? ____

Thank you for your participation.

Would you like to receive a summary of the results of this study? If you would, please indicate your preferred method of receipt:

e-mail address:

regular address:

Appendix C

Interview Guide

Thank you for your interest in participating in this study. You might want to know what this interview will involve, and its purpose. I'm going to ask you some questions about your experiences living with endometriosis, and what effect you feel it has had in your life. The purpose of this interview is to give you a chance to tell me in your own words what your experiences have been. This interview should take an hour and a half to two hours to complete. Return of interview questions to me, Lisa Mason, at lkason@unixg.ubc.ca constitutes consent to participate in this portion of the study. You can withdraw at any time, or refuse to answer any questions to which you do not wish to respond. A list of the themes that emerged from these interviews will be provided to you, and you are invited to comment on this list.

All information provided is strictly confidential, and your name will not be identified with any reports of the findings. Excerpts of interviews may be used in the final report, but no names will be included.

If you have any questions concerning this study, you can contact Lisa Mason (lkason@unixg.ubc.ca) or her supervisor, Dr. Jim White (blanco@unixg.ubc.ca; 604 822-4683).

1. Tell me a bit about your experience of waiting for a diagnosis of endometriosis. How did you feel when you received this diagnosis?

2. Has endo changed your outlook on life? If it has, in what ways? If it hasn't, why do you feel it hasn't?

3. [If in relationship] Has endo changed your relationship with your partner, and in what ways?

If in no relationship, and said "yes" to endo as a reason:

What are your feelings about discussing this disease with potential partners?

4. If answered "Yes" to endo as reason for break-up (check Q. 34)

You mentioned that you feel endo played a role in ending your last relationship. Could you tell me how?

If No, or N/A, proceed to Q.5

5. How do you feel endo has affected your views on dating and/or marriage? On sexual relations? On having children?

6. Has endo changed your relationship with family members, and how? [if no family members listed as a person you feel comfortable with - check Q. 36. - probe here for why (I notice you didn't list any family members as people with whom you feel comfortable talking about endo; could you explain why you don't include family?).]

7. Has endo changed your outlook on working? On education? (if applicable - check Q. 38, 39) Have you changed personal ambitions or career goals (no matter how small or big!)? Where and why?

8. I'd like you to talk a bit about your expectations for life events, and how endo has affected them.

[If had 0s : could you tell me a bit about those life events you never expect to experience <list them>]? Probe: E.g.s: Do you have expectations now that you didn't before? Why? has nothing changed, and why not?

9. Finally, I'd like to ask you what and who has helped you cope. What and who has made it difficult to cope?

10. Is there anything else you'd like to add about your experiences living with endo?

11. Are there any questions you'd like to ask me?

Thank you so much for participating in my study. I wish you good health!

Would you like a summary of these findings? If you would, please indicate your preferred method of receipt:

e-mail address:

regular address:

Appendix D

Auditor's Report

Audit Report of Lisa Mason

I have followed Lisa's qualitative research with interest for several important reasons. Her choice of grounded theory reflects a symbolic interactionist perspective that I find to be an interesting and important approach to research. My interest has been heightened by my own experience as a woman who has endometriosis. Finally, my interest has partially been sustained by my commitment to serve as auditor for Lisa's research.

An audit of the qualitative component of Lisa's research on women's experiences with endometriosis reveals a rigorous and credible investigation. This was facilitated by her careful attention to the details of procedure and to self-awareness as a researcher.

Lisa committed herself persistently to detailed recordings of her thoughts and ideas as they developed. Throughout the process of each interview and repeated readings of each, she consistently recorded her own reactions and ideas about emerging themes. In addition, Lisa compulsively recorded decisions and changes regarding adjustments to the instruments (questions) and changes in her thinking about emerging themes as they occurred. This helped to insure that her perceptions, decisions and ideas were not altered by the passage of time.

Lisa's self-awareness as a researcher contributes to the credibility of her investigation. As a woman who has been diagnosed with endometriosis, she was constantly aware of the bias with which she approached her research. This awareness allowed her to use her knowledge of the disease to more openly explore the experiences of other women rather than using her experience as a base line for all women's experiences.

The sensitive and emotionally draining nature of this type of research may potentially take its toll on the overall quality of the study. Lisa was aware of this possibility and guarded herself and the integrity of her work. Lisa has an established network of supportive and understanding people who enjoy listening to her ideas and experiences with research. On long commutes to and from university we had extended conversations regarding her experiences as a researcher. In addition, she often sorted through emerging and changing ideas about themes of the interviews after she had recorded them. These conversations with others and myself seemed to serve as a catharsis for the sensitive and emotionally draining effect of the research.

I wish to use this audit report as an occasion to congratulate Lisa on her rigorous and credible investigation.

Sharon Aller