

THE SOCIAL SUPPORT EXPERIENCES OF WOMEN WITH ENDOMETRIOSIS

by

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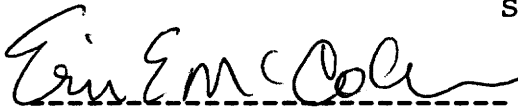
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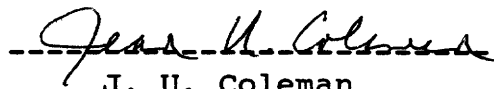
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(ABSTRACT)

Approximately one in seven women have endometriosis, a disease that may cause pain and/or infertility. Therefore, many women experience the stress of this disease in their life and yet little is known about how they cope with this stress. This study focuses on the coping resource of social support.

The social support experiences of forty-six women, who participate in an endometriosis support group on the Internet, were examined. A questionnaire was designed to explore the social support experiences of these women in four relationship categories: spouse/partner, friends/extended family, others with endometriosis, and health care providers. In written responses, these women shared many poignant and compelling stories about their struggles with the disease and their experiences with social support relative to the disease.

The participants' responses were analyzed for themes. Overall themes that emerged from the analysis include: the participants wanted to be listened to and believed, they wanted their support network to be knowledgeable about endometriosis, they wanted others to understand the symptoms of the disease, and they wanted their support system to share information about the disease.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION 1

 Statement of the Problem 3

 Medical Overview 4

 Objectives 8

 Rationale for this study 9

 Organization of the Study 11

CHAPTER TWO: LITERATURE REVIEW 12

 Introduction 12

 Theoretical Framework 12

 Psychosocial Phenomena Associated with Endometriosis
 20

 Associations with Psychopathology 21

 Associations with Childhood Abuse 25

 Summary 27

 Coping with Infertility 27

 Coping with a Chronic Illness 30

 Summary 33

CHAPTER THREE: METHODS 35

 Introduction 35

 Theoretical Sensitivity 35

 Design 36

Instruments	37
Participants	39
Procedures	44
Analysis	45
CHAPTER FOUR: RESULTS	47
Introduction	47
Context of the Social Support	48
Struggles	48
Emotional Impact	56
Overview of Experiences with Social Support	62
Support by Listening and Believing	63
Support by being Knowledgeable	64
Support by Understanding	66
Support by Sharing Information	67
Spouse or Partner	69
Support by Listening, Believing and Understanding	71
Support with Knowledge	72
Support by Committing, Being Patient and Caring	74
Support by Asking, Comforting, and Helping	75
Support by Expressing Feelings	77
Support by not Fixing	77
Support by not Judging or Blaming	78

Impact on Sexual Relationship	79
Friends and Extended Family	81
Support by Listening and Believing	86
Support with Knowledge	88
Support by Understanding	89
Support by Sympathy or Empathy	90
Support with Disease Struggles	91
Support by not Blaming, Minimizing or Worrying	93
Overall Support Advice for Friends and Family Members	96
Others with Endometriosis	96
Value of Networking	100
Support with Commiseration	103
Support with Information	105
Support by not Focusing on Misery	107
Support by Recognition of Individual	108
Health Care Providers	111
Support by Listening and Believing	115
Support by Being Knowledgeable	120
Support with Information	122
Support without Condescension	125
Support by Recognizing Individual	126
Comments about Psychotherapists	129
Work Place	130

Support with Understanding	130
Support with Flexibility and Practical Help	132
Support with Struggles	133
Summary	135
CHAPTER FIVE: DISCUSSION	140
Introduction	140
Social Context	142
Cultural Issues	142
Gender Issues	143
Limitations	145
General Limitations	145
Question Limitations	147
Implications for Psychotherapeutic Intervention .	158
Implications for Future Research	161
REFERENCES	165
APPENDICES	171
Appendix A	172
Appendix B	179
Appendix C	181
Appendix D	183
Appendix E	185

Appendix F	187
VITA	190
TABLES	
Education Profile	42
Income Profile	43
Years of Symptoms and Diagnosis	50
Rating of Infertility and Pain	54
Level of Spouse/Partner Support	70
Level of Support from Friends/Extended Family	82
Friends and Extended Family Members Spoken With	84
Level of Support from Others with Endometriosis	98
Health Care Providers Spoken With	112
Level of Support from Health Care Providers	114

The Social Support Experiences of Women with Endometriosis

CHAPTER ONE: INTRODUCTION

Historically female problems related to the menstrual cycle have been ignored, belittled, made fun of, dismissed as psychogenic and in general not taken seriously. In fact the root of the word, hysteria, which involves physical impairment without an underlying organic cause (Sue, Sue, & Sue, 1990), is hyster, meaning uterus (Smith & Davis, 1972). Hysteria was originally perceived as a problem of women only. Hippocrates believed movement of the uterus, because of its "desire" for a child, caused the physical impairment (Sue, Sue, & Sue, 1990). With the women's movement and the increase in female physicians, the problems related to menses are being taken more seriously. A female physician laments,

"Women's complaints have long been both baffling and frustrating for the medical profession. Traditionally, most physicians have been male and have no personal experience from which to draw. Past research has produced little hard data on pathophysiology, and even current technology has only started to explain the physical and emotional changes associated with basically normal hormonal function" (Yankauskas, 1990, p. 295).

Problems surrounding the menstrual period are just

recently beginning to be researched and documented. For example, one study in the late 1980s examined menstrual cycle symptoms in nursing students who had a mean age of 25. Results showed that 18% reported acute perimenstrual symptoms, the highest level of severity, and an additional 44% reported strong perimenstrual symptoms, the next highest level of severity. Symptoms were rated from a list of forty-seven and included water retention, negative affect and pain. Similar results for menstrual-only symptoms indicated that 13.3% reported acute symptoms and an additional 36.7% reported strong symptoms (Busch, Costa, Whitehead, & Heller, 1988). Another study of 594 nurses aged 21 to 50 found that 55% reported having cramps either frequently or every month (Lee & Rittenhouse, 1991). Nurses in both of these studies reported uncomfortable symptoms, including pain, associated with their menses.

Painful periods have been discounted by physicians for years. "For centuries, women were told that their complaint of menstrual cramps was psychosomatic" (Yankauskas, 1990, p.295). One of the primary symptoms of endometriosis is dysmenorrhea or painful periods (Webster's, 1989).

Endometriosis is one problem that tends to surround and be affected by the menstrual period. Symptoms of endometriosis include pelvic pain, pelvic mass, alterations of menses and infertility (Merck, 1992). Although

endometriosis is most prevalent among women in their thirties and forties (Shephard & Shephard, 1990), it has also been detected in teenagers (Merck, 1992). While reported incidence varies, ten to fifteen percent of women between the ages of twenty-five and forty-four who are actively menstruating have been found to have endometriosis (Merck, 1992).

"Endometriosis can be, from the patient's point of view, a nightmare of misinformation, myths, taboos, lack of diagnosis, and problematic hit-and-miss treatments overlaid on a painful, chronic, stubborn disease" (Ballweg, 1992, p. 750). The purpose of this research was to better understand the social support women use to cope with this disease and provide guidance to partners, family, friends and professionals in being more supportive.

Statement of the Problem

As many as one in seven women have endometriosis. With the number of people in these women's support networks added to that number, the disease directly or indirectly touches many people. The disease is chronic and typically progressive, so the social support needed is often ongoing for many years.

In addition to the chronic nature of endometriosis, there are other reasons that social support may be difficult for these women to obtain or maintain. Endometriosis is

difficult to diagnose, often leaving women not knowing a reason for their problems and placing a strain on relationships with health care providers. Health care providers and others may suggest that the problems are psychogenic, adding further strain. Furthermore, symptoms of the disease are private and difficult to discuss. It is therefore not surprising that anecdotal evidence indicates that women may actually feel worse after interacting with others.

Given the prevalence and nature of endometriosis, it would be helpful to have information on what women want in the way of social support. With this information, her network can be more supportive. This study begins to paint that picture.

Medical Overview

Endometriosis is a medical condition in which endometrial tissue, or tissue that normally lines the uterus, is present outside the uterus, usually in the pelvic area (Merck, 1992). These endometrial cells are responsive to the same hormonal influences as those found in the uterus (Shephard & Shephard, 1990), therefore symptoms are often cyclical. Like endometrial cells in the uterus, it is expected that the endometrial implants, outside the uterus, also bleed during menstruation. However, instead of being eliminated from the body cyclically as is the normal

endometrial tissue lining the uterus, this abnormal bleeding in other parts of the body can lead to an inflammatory process and additional problems (Merck, 1992).

Endometriosis is a chronic, typically progressive disease (Shephard & Shephard, 1990) without a cure (Merck, 1992). Clinical symptoms include pelvic pain, pelvic mass, alterations of menses, and infertility (Merck, 1992). Pain complaints encompass: dyspareunia or painful intercourse (Webster's, 1989), dysuria or painful urination (Webster's, 1989), painful defecation, and low backache (Yankauskas, 1990). Infertility is present in about 30% of endometriosis patients (Shephard & Shephard, 1990). These symptoms are usually considered private and are often difficult or taboo to talk about.

The only definitive procedure to diagnose endometriosis is exploratory surgery (Yankauskas, 1990). The lesions need to be directly observed and/or biopsied, usually by laparoscopy (Merck, 1992). Laparoscopy is the insertion of a narrow tube into the abdomen through which the pelvic organs can be viewed (Laparoscopy, 1985). Because a definitive diagnosis requires a surgical procedure, endometriosis often goes undiagnosed. Physicians repeatedly take a wait and see attitude, implying that the disease is not that serious (Ballweg, 1992). Undiagnosed pain and a laissez-faire attitude by physicians can be

devastating for the patient with endometriosis, as this patient comments:

"The chronicity of the illness is devastating, especially if no one is able to tell you that what you feel indeed does exist. It is incredibly miserable when you start to believe that they are right, and you are wrong. It affects every waking moment, and you think, 'Oh no, this can't be happening, not again.' Your family tries to help, but they, too, cannot bear it. With the diagnosis, at least you can wake up and say, 'I hurt, but there's a reason. I'm not nuts.' After 5 years of hell, I am just beginning to see a light at the end of the darkest medical tunnel, filled with self-doubt and frustration. For me it is only the beginning of knowing. I am not sure if the disease or the medical community has caused me more despair" (Ballweg, 1992, p.759).

Treatment is individualized based on the patient's age, symptoms, desire for pregnancy, and extent of disease. Treatment typically consists of surgery, medication or a combination of the two. Frequently, the prescribed medications suppress ovarian function to slow or stop the growth and activity of endometrial tissue implants. Common medications are danazol or gonadotropin-releasing hormone (GnRH) agonists which include nafarelin and leuprolide

(Merck, 1992). These medications are expensive, potentially adding a great financial strain. A thirty day treatment with danazol costs about \$190, whereas the more recent and promising drug, leuprolide depot, is about \$440 for a thirty day treatment (Peoples, 1993). Both medications have significant side effects, including emotional instability.

Surgical treatment can be either conservative or radical. Conservative surgery removes as many endometrial growths as possible. Total hysterectomy, removal of the uterus, and frequently the ovaries and fallopian tubes, is a more radical surgical approach (Merck, 1992). Neither prescribed drugs nor conservative surgery cures endometriosis and recurrence after treatment is common (Merck, 1992).

Pelvic pain is a common complaint. Stout and colleagues (1991) studied 102 women undergoing laparoscopic surgery. Pain was measured based on self-report questionnaires prior to surgery. Of this group of women, 88% indicated that they experienced pelvic pain. As a result of surgery, the endometriosis and adhesions were rated by the surgeons as to severity based on the American Fertility Society scoring system. The surgeon's total scores classifying endometriosis and adhesions were significantly related to the patient's self-placement in the

pain or no pain group. However, the surgeon's rating for the extent of disease was not significantly correlated with pain levels reported by the patients (Stout, Steege, Dodson, & Hughes, 1991).

Infertility is another devastating symptom of endometriosis. Abbey and colleagues studied 185 infertile couples. Their research found that higher treatment cost was associated with more stress for both women and men. Also, increased perceived personal control was significantly related to decreased stress in men and women. In addition, their study found that greater social support satisfaction in women was significantly correlated with lower problem stress surrounding fertility (Abbey, Halman, Andrews, 1992).

Endometriosis often means pain, may mean infertility, is progressive, and is incurable. "The uncertainties surrounding the diagnosis and management of endometriosis often leave the patient in pain, feeling confused by the limited information provided by her doctor and with a mixed bag of emotions: fear, grief, anger and self-guilt prominent among them" (Kennedy, 1991, p. 8).

Objectives

The purpose of this study was to explore the perceived social support of women who are adapting to endometriosis. The type and dynamics of social support that were utilized and available to these women and the meaning they attached

to that social support were examined. Research questions include: Whom do women with endometriosis interact with about their endometriosis? How supportive do women find their interactions with friends, family, others with endometriosis, and health care providers? What is supportive and not supportive about these interactions? What advice do these women have so that friends, family, others with endometriosis, and providers can be more supportive? These questions probe the social support experiences of women with endometriosis.

Rationale for this study

As many as one in seven women are affected by endometriosis (Merck, 1992) and research related to how these women cope with the pain and infertility is limited. Social support was an appropriate place to focus research attention for several reasons. Topics surrounding the symptoms of endometriosis, such as painful intercourse, are forbidden or difficult to talk about. Friends, family and health care personnel all too often are likely to reinforce not speaking of the forbidden or difficult topics, rather than listening. They may even go further and suggest that the problems are psychogenic. A nurse relates that "it would spare many women's self-esteem if their doctors would admit they don't know what's wrong, rather than suggesting psychological causes for physical symptoms" (Ballweg, 1992, p. 759). In

addition to the difficulty of discussing symptoms, anecdotal evidence demonstrates that women may actually feel worse after encounters with others. This could indicate that other people may not know how to be helpful. Social support research can help family, friends, and professionals associated with these women to be more supportive. Another reason to examine social support, is the difficulty of diagnosis. Diagnosis can only be confirmed with a surgical procedure, so there is often a lack of validation for what the woman is experiencing.

A few studies have been done on the psychosocial phenomena surrounding endometriosis. These few focused on psycho-pathology and produced conflicting results. No studies were found that examined how women adapted to and coped with the pain or infertility associated with endometriosis. This area is wide open for future research. This study begins to fill that void by focusing on the social support experiences of women with endometriosis.

The resources that are available to the woman with endometriosis include psychological, social, interpersonal, and material attributes of the individual, her family or community. This study will begin to describe the social support accessed by these women, and their level of satisfaction with the support. This study was limited to exploring social support, which is only one part of the

available and accessible resources within an interactive system.

Organization of the Study

Chapter one is an introduction to the experience of endometriosis for women. It includes a medical overview, a rationale for this research, study objectives and this section on organization. Chapter two is a review of the literature and includes the topics of an appropriate theoretical framework, psychosocial phenomena associated with endometriosis, and coping with related chronic illness. Chapter three outlines the methods and encompasses: design, instruments, participants, procedures, and analysis. Chapter four describes the results and chapter five summarizes and discusses the results.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The literature was reviewed to develop a knowledge base and context for this research. An appropriate theoretical framework was selected and reviewed. The psychosocial phenomena associated with endometriosis, and coping with related medical conditions, was also examined and outlined here to provide a backdrop for this study.

Theoretical Framework

In order to study coping and adaptation to endometriosis, a combined theoretical framework of a stress and coping model and symbolic interactionism was used. Folkman and Lazarus (1988) define coping as: "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.310). When coping, there is a high degree of variability among and within persons and coping is a multidimensional process (Folkman & Lazarus, 1988). To understand coping and evaluate its effectiveness, it is necessary to view it in the context of the problems people are experiencing and the potential emotional impact of those problems (Pearlin & Schooler, 1978).

Pearlin and Schooler (1978) describe three major types of coping distinguished by the function each serves. The first type involves responses that change the situation

which would cause strain. The second involves responses that control the meaning attached to a life-strain before stress occurs. The final type consists of responses that manage stress once it occurs.

Pearlin and Schooler (1978) observe that in life-strain situations in which a person has little direct control, evidence indicates that psychological characteristics or resources, such as mastery and self-esteem, are helpful. Whereas with problems in which a person has more control, more personal influence, it is the things one does that make the most difference. They also find that "the sheer richness and variety of responses and resources that one can bring to bear in coping with life-strains may be more important in shielding one's self from emotional stress than the nature and content of any single coping element" (p. 15).

This research was based on the McCubbin and Patterson double ABCX model of stress and coping (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983). This model involves three units of analysis: the individual family member, the family unit and the community. As depicted in Figure 1, the aA factor represents the pile-up of demands, bB reflects the resources, cC refers to the perception of the stressor and xX depicts the adaptation to the stressor.

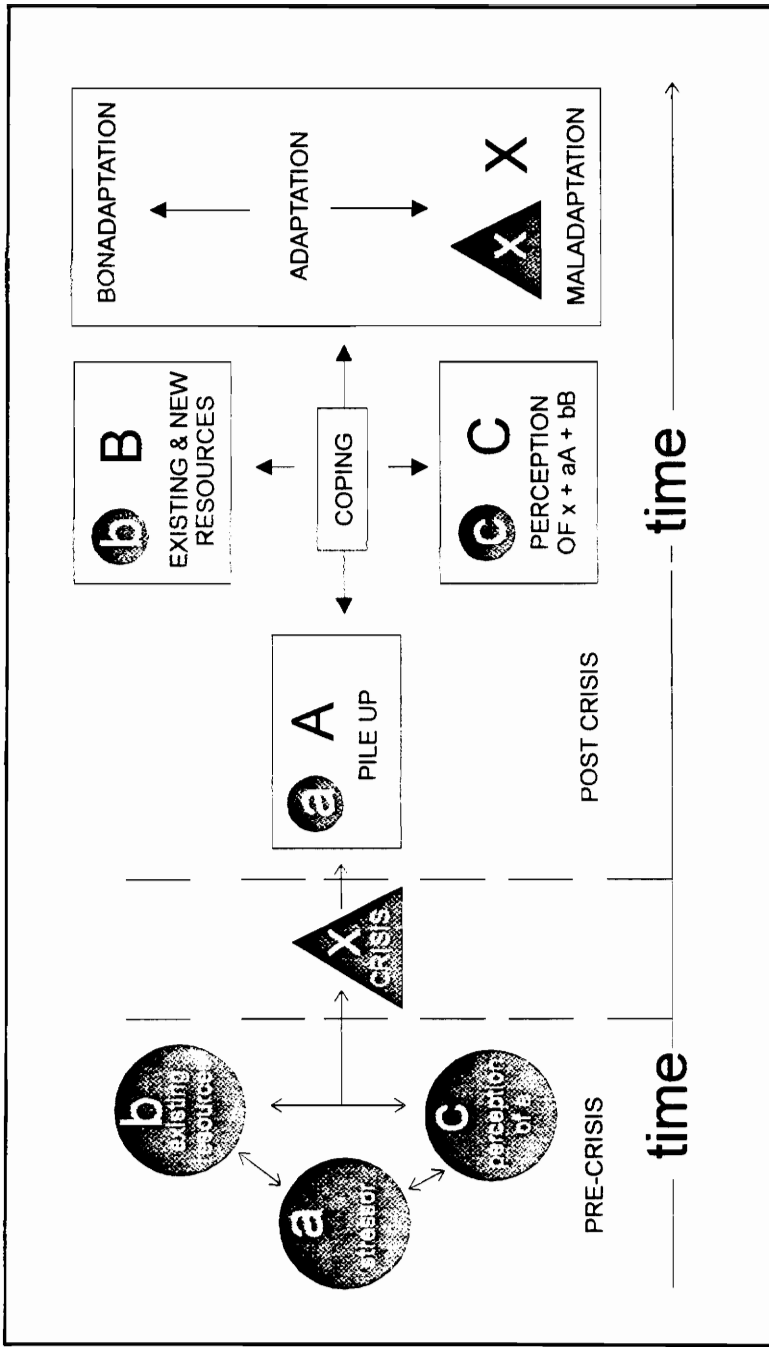


Figure 1
 Double ABCX Model of Stress and Coping
 Figure is adapted from McCubbin and Patterson (1983) and Patterson and McCubbin (1983).

These factors are interactive and represent family attempts, before and after a crisis, to recover and achieve a new balance. Coping is the process delineating these efforts to adapt and achieve a new organization or balance in the system. Coping arises, after a pile-up of demands, from an interaction of resources, perception, and behavioral responses. This study focused on the resource (bB) aspect of coping, looking at the social support of the individual with endometriosis.

The aA factor represents the pile-up of demands on the family including the chronic illness, normative changes, the ambiguity surrounding the illness, and other hardships. In the case of chronic illness such as endometriosis, the initial a factor depicts the onset of symptoms. Patterson and McCubbin (1983) discuss hardships or sources of stress on the family when a child has a chronic illness, and the following might also be expected to apply to the family when an adult female is ill: strained family relationships, modifications in family activities and goals, burden of increased tasks and time commitments, increased financial burden, need for housing adaptation, social isolation, medical concerns, and grieving.

As looked at slightly differently, by Zarski and colleagues (Zarski, DePompei, West, & Hall, 1988), pileup is the result of the interaction of the patient's symptoms,

stresses outside the family, family system characteristics (rules, boundaries, and flexibility) and mediating mechanisms (physiological, biochemical, and psychological). "Important stressors include family rules, power structure, ability to deal with loss and separation, developmental stage, finances, communication patterns, flexibility, and premorbid level of patient and family functioning" (Zarski, DePompei, West, & Hall, 1988, p. 146).

To continue with the double ABCX model, the bB factor depicts the resources including psychological, social, interpersonal, and material attributes of the individual in the family, the family system and the community. An individual's personal resources include finances, health, psychological well-being, and education. Cohesion and adaptability are included in the family's resources. Community resources would include available medical services and support groups. For the scenario of chronic illness, the b factor represents the resources available and accessible at the time symptoms are first appearing. The B factor, for a woman with endometriosis, might portray newly found resources such as a support group or more qualified physician. (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983). This study focused on the social support perceived by the individual with endometriosis, which is part of the bB factor.

The cC factor is the individual and/or family definition and meaning, their perception, of the stressor. In illness, the c factor is the meaning attributed to the stressor believed to have caused the illness. The C factor is how over time individuals and/or families constructively manage the stressor and redefine their situation, thereby restoring balance to the system (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983). Since this study focused on the social support experiences of women, it is their perception of that social support, that is the focus of the study and so the cC factor is involved.

And lastly, the x factor refers to the initial crisis and the xX factor represents the family's adaptation. Adaptation is the outcome of family efforts to achieve a new balance after a family crisis and includes the balance between the individual and the unit and the unit and the community (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983). The xX factor therefore reflects adaptation to endometriosis.

To further explain how the double ABCX model applies to a woman with endometriosis, the hypothetical examples of Mary and Sue are presented to show two different ways in which the model applies. When Mary was 23, she began to have severe pain with menstruation. This onset of symptoms is the a factor. Mary had recently graduated from college

and was working as an accountant. Her resources (b factor) included a reasonable income and a supportive family nearby. Her perception (c factor) of the pain was one of powerlessness and anger. Mary's crisis (x factor) came when she had to go home from work because her over-the-counter pain medication was not adequate for her to function. Pile up (aA factor) occurred as the sequelae of the disease manifested. Mary began acquiring some new resources (B factor). She changed physicians to one who listened to her and was knowledgeable about endometriosis. After the new physician confirmed a diagnosis of endometriosis with surgery, Mary joined a local support group for women with endometriosis and a national group that helped her stay informed about the disease. After Mary had a definitive diagnosis and was more knowledgeable about the disease, the meaning (C factor) she attached to it changed. She felt more in control. Mary began coping better, and overall she adapted (X factor) to having endometriosis.

The double ABCX model can also be applied on a different time scale, coinciding with the menstrual cycle. The hypothetical case of Sue will be presented to demonstrate this. Sue was 35 years old and she had been trying to get pregnant for 4 years. Each month she has the same stressor (a factor) of not being pregnant. There have been months that she has tried a new medical treatment (B

factor) only to have the stressor (a factor) reappear. Month after month of this has caused a pile up (aA factor). Initially (b factor) her financial resources had been good, but each cycle an expensive medical treatment further dwindles that resource (B factor). Sue's perception at the beginning of her cycle (c factor) is different from at the end of her cycle (C factor) as she becomes hopeful and then has those hopes dashed. Because the symptoms of endometriosis tend to coincide with the menstrual cycle, there is a shorter term process overlaid on the longer term process of disease progression. The double ABCX model applies to both processes.

To the double ABCX model, the framework of symbolic interactionism was added to begin to understand some of the complexities in the life of a woman with endometriosis. This additional framework will add to the focus on meaning of the bB and cC factors of the double ABCX model. Symbolic interactionism highlights the "symbolic meanings of situations and behaviors" (Noller & Fitzpatrick, 1993, p. 45). Focus is on the subjective world of the individual and the need to understand this in order to understand the individual's behavior. It is a theory about individual perceptions and interpretations as well as the shared meanings and understandings that are worked out in social interactions (Noller & Fitzpatrick, 1993).

Symbolic interactionists assume that symbols are important to the understanding of human behavior (Burr, Leigh, Day & Constantine, 1979). From this assumption it follows that "humans decide what to do and not to do primarily on the basis of the symbols they have learned in interaction with others and their beliefs about the importance of these meanings" (Burr, Leigh, Day & Constantine, 1979, p. 47). When trying to understand humans, symbolic interactionists believe that the most productive area of research is the "beliefs and values that individuals get from interacting with others" (Burr, Leigh, Day & Constantine, 1979, p. 47). This leads to an emphasis on qualitative research (Burr, Leigh, Day & Constantine, 1979). For example, knowing that a woman has a friend to talk to about her endometriosis indicates that she has a resource. By knowing the value, beliefs and meaning she attaches to this resource, a much richer and deeper understanding is acquired.

This study examined the different experiences of women with endometriosis from the perception of the woman. The perceived social support experiences of woman with endometriosis have not previously been studied and this study begins to fill that void.

Psychosocial Phenomena Associated with Endometriosis

Even though, no previous research has examined the

social support of women with endometriosis, some research has been conducted that has studied associated psychosocial phenomena. Conflicting and primarily exploratory studies, attempted to link pelvic pain and endometriosis with psychological problems and abuse in childhood.

Associations with Psychopathology

Several studies have attempted to link endometriosis or other pelvic pain with various psychological problems. Rosenthal and colleagues (Rosenthal, Ling, Rosenthal, & McNeeley, 1984) studied 60 patients with chronic pelvic pain. The Minnesota Multiphasic Personality Inventory (MMPI) was administered to the women prior to laparoscopy. Of those studied, 75% had pelvic abnormalities, and 17%(10) of the total had endometriosis. They found that the presence of abnormal MMPI results did not predict pelvic pathology.

Renaer and colleagues (Renaer, Vertommen, Nijs, Wagemans, & Van Hemelrijck, 1979) also looked at pelvic pain and results of the MMPI. They compared three groups of female patients: one with chronic pelvic pain but no clear organic cause(n=15), the second had chronic pain and diagnosis of endometriosis(n=22), and the third had no complaints of pain(n=23). In contrast to Rosenthal and colleagues, Renaer and colleagues found that while the two groups with pelvic pain were not significantly different on

clinical scales of the MMPI, their scores were higher than the other patient group and the MMPI standardization group for hypochondriasis, depression, and hysteria, overall indicating neurotic behavior. They also found that the patient control group showed a higher neurotic tendency than the standardization group. They postulated that this was due to the uncertainty surrounding contact with the medical community.

Two other studies looked at endometriosis patients for possible DSM III diagnosis. Lewis and colleagues (Lewis, Comite, Mallouh, Zadunaisky, Hutchinson-Williams, Cherksey, & Yeager, 1987) studied 16 women being treated for endometriosis. They failed to mention if the treatment consisted of medication that might have emotional instability as a side effect. They found that twelve (75%) of the women with endometriosis met the criteria for mood disorder. Seven were diagnosed by the research team as bipolar, mixed; three were diagnosed as bipolar, manic; and two were diagnosed with major depression. The research team also found that two had symptoms of mood disorder that were insufficient for diagnosis, and two had no evidence of mood disorder. Even though their research did not include a control group, the sample size was very small, and medication was not discussed, results of this study suggest a possible association between mood disorders and

endometriosis.

In contrast to the study by Lewis and colleagues, Walker Katon, Jones, and Russo (1989) did use a control group and found no significant psychiatric differences between women with endometriosis (n=14) and women who did not have endometriosis (n=55). None of the women with endometriosis had bipolar disorder, compared to 5% of the women who did not have endometriosis. Fourteen percent of the endometriosis subjects were currently diagnosed with major depression, while 22% of the non-endometriosis group were similarly diagnosed. Thirty-six percent of the endometriosis group had a lifetime episode of major depression while 40% of the non-endometriosis group did.

Another research group looked at major depression and compared groups with (n=25) and without pelvic pain (n=30). Sixty-four percent of the pelvic pain group had experienced a lifetime episode of major depression and twenty-eight percent currently were having an episode of major depression. This was significantly higher than the control group of 16% and 3% respectively (Harrop-Griffiths, Katon, Walker, Holm, Russo, & Hickok, 1988). It would be erroneous to assume that either the depression caused the pain or the pain caused the depression.

Low, Edelman and Sutton (1993) also investigated the possible association of a specific psychological profile

with endometriosis. They compared two groups of women with pelvic pain; one group of 40 was diagnosed with endometriosis and the second group of 41 had other specific diagnoses. In comparison, the endometriosis group was significantly younger, more introverted and scored higher on state and trait anxiety scales. Although within the normal range, scores for psychotic symptoms were also higher than the other pelvic pain group. No significant differences were found with depression scores.

Because of conflicting and limited studies on endometriosis, no consensus exists as to whether there is an associated psychological profile or whether that profile is positively or negatively related to endometriosis. Also, any cause and effect relationship a profile may have with the endometriosis can not be determined. Did the endometriosis cause the anxiety or did the anxiety cause the endometriosis? There is no clear evidence to answer this question.

Despite inconclusive research findings, many physicians continue to view a woman's problems as psychological. By focusing on psychological pathology and not thoroughly following up on the medical pathology, a physician could cause a patient unnecessary pain. Crenshaw (1985) writes a case study of Jane, who was 24 years old and married. Jane began to have pain with intercourse which became

progressively worse. "Jane's gynecologist could find nothing wrong. The last time she saw him, he suggested that she visit a psychiatrist, stating that her problem must be of emotional origin" (p. 21). Because of the problem, Jane and her husband separated. Jane then did become depressed. After intensive psychiatric treatment, including hospitalization, Jane several years later consulted another clinic. During laparoscopy, she was diagnosed with endometriosis and her lesions were cauterized. Jane remains free of discomfort during intercourse and has reconciled with her husband. This case study demonstrates the importance of listening to and believing the patient. In this case an erroneous assumption was made that the pain was psychogenic, and therefore medical interventions were suspended for several years, resulting in unnecessary pain. Endometriosis was associated with psychiatric problems in this case, but in fact the medical community could have exacerbated, if not caused, the psychiatric problems. Jane suffered unnecessary discomfort, while research attempting to link psychological problems with endometriosis is contradictory and limited.

Associations with Childhood Abuse

Another area of research that looks for a relationship between psychological problems and endometriosis focuses on childhood abuse. There is disagreement as to whether there

is an association. Walker and colleagues (Walker, Katon, Jones, & Russo, 1989) found no significant difference in child abuse history between a group of women with endometriosis and a group of women without endometriosis. This was the only study found that expressly studied endometriosis in relation to childhood abuse. Rapkin and colleagues (Rapkin, Kames, Darke, Stamper, & Naliboff, 1990) did not study endometriosis specifically, but studied chronic pelvic pain in relation to a history of child abuse and compared the chronic pelvic pain group with a group that had pain other than pelvic pain and a third group without pain as a control. Sixty-five percent of their pelvic pain sample had detectable pathology, about two-thirds of which was endometriosis. Although reported sexual abuse was highest in the pelvic pain group (9%), this was not significantly different from either the other pain group or the control group. However, 39% of subjects with pelvic pain (n=31) reported childhood physical abuse, which was significantly more than either the other pain group (18%, n=142) or control group (9%, n=32).

Harrop-Griffiths and colleagues (Harrop-Griffiths, Katon, Walker, Holm, Russo, & Hickok, 1988) compared women with (n=25) and without pelvic pain (n=30). They found no significant difference in the amount of disease found by laparoscopy between the control and pelvic pain group.

Abnormalities in both groups were typically either endometriosis or adhesions. Sixty-four percent of subjects with pelvic pain reported a history of childhood sexual abuse, which was significantly higher than the control group reporting only 23%. There is no consensus among studies that attempt to link endometriosis with childhood sexual abuse.

Summary

The current research does not definitively associate any psychosocial phenomena with endometriosis. Research has attempted to connect various psychological profiles, psychopathological categories, and childhood sexual abuse with pelvic pathology. No psychosocial phenomena, however, has been conclusively connected to endometriosis.

Coping with Related Medical Conditions

There is a paucity of studies to examine how women cope with endometriosis. However, studies have investigated how women cope with other medical problems. Social support appears to be an important factor in this coping process.

Coping with Infertility

Infertility is a possible consequence of endometriosis. Social support associated with the stress of infertility was studied by Abbey, Andrews, and Halman (1991,1992). In this study of 157 white middle class couples with primary infertility, the researchers found that the participants'

assessment of supportive and conflictual behavior provided to spouses was highly related to the amount of supportive and conflictual behavior they reported receiving from their spouse. In the same study, both sexes reported receiving an equal amount of social support from each other, but women reported that they provided more than men did. The men reported both providing and receiving more interpersonal conflictual behavior than women. For men and women both, spousal social support related positively to well-being, and spouse interpersonal conflict related negatively to well-being. Overall, the levels of received spousal support were high, and levels of received spouse conflict were low (Abbey, Andrews, & Halman, 1991).

In this same study, 96% of females and 88% of males had discussed their fertility situation with a friend or family member in the last 12 months (Abbey, Andrews, & Halman, 1991). Both males and females reported feeling somewhat better after talking with friends and family. However, wives were more likely than husbands to mention both positive and negative effects of talking with friends and family, while husbands were more likely than wives to report that they were not influenced by what other people said (Abbey, Andrews, & Halman, 1991).

They also examined interactions with others who have a similar problem. Seventy-three percent of females and 53%

of males reported talking to someone with a fertility problem in the previous 12 months. In this study, wives were more likely than husbands to describe positive aspects of talking with similar others, and husbands were more likely than wives to state that they were not influenced by others. These participants were less likely to have talked with similar others than friends and family members, even though the exchanges with similar others were viewed as more helpful (Abbey, Andrews, & Halman, 1991).

In a related study, Abbey, Halman, and Andrews (1992) examined 170 couples with primary infertility. For the women, attitudes about infertility treatments involving surrogates and donors were significantly negatively related to fertility problem stress; the more important children were to them, the greater the fertility problem stress. The greater the social support satisfaction, the lower the fertility problem stress. Finally, the importance of children and the number of tests received were significant positive predictors of stress (Abbey, Halman, & Andrews, 1992).

Since infertility is a possible sequelae of endometriosis, and social support was found to be important to coping with infertility. It would follow that social support might also be important for coping with endometriosis.

Coping with a Chronic Illness

Additional studies have looked at ways women cope with a chronic illness other than endometriosis. Warren and Baker (1992) studied premenstrual syndrome (PMS) and coping resources in 54 women. To measure coping resources, they used the Coping Resources Inventory for Stress (CRIS). They found a statistically significant positive relationship between the severity of PMS and both self-disclosure and stress monitoring. CRIS defines self-disclosure as "a measure of the tendency to disclose freely one's feelings, troubles, thoughts, and opinions" (Matheny, Aycock, Curlette & Junker, 1993, p. 817). Therefore, in general, this research showed that the more severe the PMS, the more one reveals oneself intimately. This group also found a statistically significant inverse relationship between both severity of PMS and social support. Social support is defined by CRIS as measuring the "availability and use of a network of caring others (usually family members and friends), which acts as a buffer against stressful life events" (Matheny, Aycock, Curlette & Junker, 1993, p. 817). So, according to this study, the more one has and uses a network of caring others, the less the severity of PMS.

Primono and colleagues (Primono, Yates, & Woods, 1990) took a more in-depth look at social support than Warren and Baker (1992) in the previous study. Primono and colleagues

studied the social support of 125 women with chronic illness. These women had either breast cancer, fibrocystic breast disease or diabetes. Amounts of the following types of support were measured: affective support, affirmation, tangible aid, likelihood to be confided in about the illness, and chance of reciprocity. In all three groups, the woman's partner was identified as providing the major amount of support, for all types of support measured. In addition, the higher the woman's perception of affect and affirmation from her partner and family members, the higher her self-reported marital quality and family functioning and the lower her illness demands and depression. Another finding was that as time since diagnosis increased, women confided less in friends about their illness.

Instead of looking at three different chronic conditions, the following two studies focused on the chronic illness of rheumatic arthritis. Rheumatoid arthritis (RA) in women (n=61) and men (n=31) was studied by Affleck and colleagues (Affleck, Tennen, Pfeiffer, & Fifield, 1987). As reflected in the sample, RA affects mostly women. Like endometriosis, RA is incurable, chronic, progressive, and painful. Their study found that RA patients reporting higher personal control over medical care and treatment also reported more positive mood and were rated as showing increased positive adjustment to their illness. Goodenow,

Reisine, and Grady (1990) studied 194 female patients with RA. They found that the perceived quality of social support was an important determinant in deterring social and psychological dysfunction.

Social support was also an important variable in the next study which focused on the chronic illness of diabetes. White, Richter and Fry (1992) studied coping, social support and adaptation to chronic illness in 158 women with diabetes mellitus. The construct variable of social support included areas of intimacy, social integration, nurturance, worth, and assistance. Their results showed that the higher the perceived social support the better the psychosocial adjustment to illness. Also, it was demonstrated that with lower levels of perceived social support, health was poorer. They found social support to be a significant factor in explaining psychosocial adjustment to illness and health outcomes.

Perceived social support was again found to be an important variable when researching chronic pain. Five hundred and twenty-one chronic pain patients were studied for the influence of family support by Jamison and Virts (1990). In this study, patients, who described their families as supportive, reported having less pain intensity, less interference from pain, less reliance on medication and greater activity levels, than patients who described their

families as non-supportive. These researchers found that perceived family support was an important consideration in the rehabilitation of these chronic pain patients.

In summary, studies have examined coping with medical conditions other than endometriosis. Social support was found to be an important factor in coping with infertility, PMS, diabetes, fibrocystic breast disease, breast cancer arthritis, and chronic pain. However, there is a void of research exploring social support of women with endometriosis.

Summary

The literature on a theoretical framework, psychosocial phenomena associated with endometriosis and coping with other medical conditions was reviewed. The double ABCX model of stress and coping along with symbolic interactionism was outlined and served as a theoretical framework for this research. The current literature available on the psychosocial phenomena associated with endometriosis was limited. The limited research in this area has attempted to link endometriosis with either psychopathology or childhood abuse. No definitive link has been established. Since there was no literature available on coping with endometriosis, coping with infertility and chronic illness was reviewed. Social support was found to be an important factor in coping with chronic conditions other than endometriosis.

CHAPTER THREE: METHODS

Introduction

To begin to explore the social support experiences of women with endometriosis, a primarily qualitative study was developed. Theoretical sensitivity, design, instruments, participants, analysis, and procedures are outlined in this chapter.

Theoretical Sensitivity

In developing and conducting this study, theoretical sensitivity was an important factor. "Theoretical sensitivity is the ability to recognize what is important in data and to give it meaning" (Strauss & Corbin, 1990, p.46). Two basic sources of theoretical sensitivity exist in qualitative research. One source involves the background of the researcher and includes the literature reviewed, professional experience, and personal experience (Strauss & Corbin, 1990). Familiarity with the literature gave this researcher a backdrop from which to explore social support experiences. As a beginning family therapist, this researcher has observed how chronic illness influences the family and the individual within the family. As a woman with endometriosis, the researcher has experienced the phenomena being researched, and over the last ten years, through contact lists and support groups, she has spoken with many other women with endometriosis. This researcher

has a background that made her more sensitive to the nuances in the data.

The second source of theoretical sensitivity is the receptiveness developed during the analytic process (Strauss & Corbin, 1990). By intensely interacting with the data, during the analytic process, insight and understanding increase. Awareness in the subtleties of meaning and relationships in the data increased with repeated analysis. The researcher's background and the analytic process used, contribute to the theoretical sensitivity in this study.

Design

Based on the theoretical sensitivity available to the researcher, a primarily qualitative study was developed. The research was designed to be exploratory and descriptive. The methodology is primarily qualitative, and secondarily quantitative. There is very little information on the psychosocial phenomena associated with women who have endometriosis, and the available research focuses on psychopathology. No research can be located on coping and adaptation by women with endometriosis. Therefore basic description is needed to begin a foundation for further research.

A quantitative format is used to obtain general descriptive information about the participants, who they received social support from, and their perception of the

level of support that they received. Answers to these questions can be linked with the answers to the open-ended questions to obtain a deeper understanding of the social support experiences of these women.

A qualitative design was used to ask open-ended questions about least and most supportive experiences and obtain advice about how others can be more supportive. The qualitative researcher "attempts to describe and understand the perceptions of the research participant, with a particular emphasis on the context in which the behaviors occur" (Heppner, Kivlighan, & Wampold, 1992, p. 196). This is a particularly relevant approach for describing and understanding the social support of women with endometriosis and assimilating their advice. The interactive dynamics of these social encounters are important to better understand the complex process of how these women cope. By using both qualitative and quantitative methods instead of only a quantitative approach, answers to the research questions have more depth.

Instruments

Data was collected by means of a survey questionnaire. This self-report questionnaire consists of basically three parts. A copy of the questionnaire is found in Appendix A.

The first section assesses current problems the participant may be experiencing that are related to

endometriosis. The first question inquires about how much infertility is currently a problem and the second question asks the same about pain. Responses to both questions are answered on a one through five likert scale from "not at all a problem" to "an overwhelming problem".

The second part of the questionnaire was developed to ascertain the social support accessed by women with endometriosis, their perceived level of support, a description of what was perceived as least and most supportive, and advice to those with whom these women interacted. Most of these questions were patterned after questions from a study of couples with infertility by Abbey, Andrews and Halman (1991). They asked if participants had talked about their fertility problem with (1) either friends or family and (2) other infertile people. If participants reported they had such discussions, then they were asked to rate how the interaction made them feel. As shown in Appendix A, the questions developed for the current study are similar and ask the participants, if in the last twelve months they talked about their endometriosis to any of the following people: spouse/partner, extended family/friends, others with endometriosis, or health care providers. If they had, participants are asked to rate the level of support of the response and describe the least and most supportive response. If the participant did not talk about

endometriosis, they are asked to explain. The participants were then asked to give advice on how others can be more supportive. A final general question asks about other sources of support.

The third part of the instrument elicits demographic data to obtain a general description of the sampled population. Included in this section were questions about age, income, ethnicity, education, time since diagnosis of endometriosis and time since the appearance of endometriosis symptoms. Finally space was allocated for additional comments.

The questionnaire was pilot tested on women with endometriosis and revised only minimally based on responses. The time that these respondents took to complete the questionnaire ranged from ten to 60 minutes. They commented on two errors with directions which were later corrected. Directions were modified and a question inquiring into ethnicity was added before the questionnaire was sent to other participants.

Participants

The subject pool chosen was the subscribers to the Internet list, WITSEND0. WITSEND0 is a forum to discuss endometriosis, with an emphasis on coping with the disease and its treatment. This list has 337 subscribers. Only subscribers who are eighteen or more years of age and who

are diagnosed with endometriosis were invited to participate.

Prior to the questionnaire being widely disseminated to subscribers to WITSEND0, a few volunteers from this group were sought for a pilot study. The announcement asking for volunteers is in Appendix B. Eight people volunteered from the sample population and seven completed the questionnaire.

After the questionnaire was revised, an announcement asking for study participants was sent as found in Appendix C. Fifty-one additional people volunteered and were sent a letter as found in Appendix D and a survey questionnaire. Forty-one additional participants completed the questionnaire. Therefore between the pilot and final questionnaires, fifty-nine were sent and forty-eight were returned, for an overall return rate of 81%.

Description of the Participants

Since endometriosis only affects females, all participants were female. In general, they were from the United States, white, in their thirties, well educated and affluent. Thirty-five (78%) of the participants were United States citizens, seven were Canadian citizens, two were citizens of the United Kingdom and one, an Irish citizen. The United States citizens resided in twenty-one different states: Arizona (1), California (6), Connecticut (1), Colorado (2), District of Columbia (1), Florida (2),

Georgia (1), Hawaii (1), Illinois (1), Massachusetts (3), Maine (1), Michigan (1), Missouri (1), North Carolina (1), New York (2), Oregon (1), Texas (5), Virginia (1), Washington (1), Wisconsin (1), and West Virginia (1). Ninety-two percent, n=34, of the participants indicated their ethnic origin as White, while only one each indicated Hispanic, American Indian/Alaskan Native or Asian/Pacific Islander. The mean age of participants was 34 years and the median was 33. Ages ranged from twenty-two to fifty-one.

The sample of participants was very well educated as indicated in Table 1. As shown, all responding participants had some college education, with thirty-five percent possessing a graduate degree.

The number and percentage of respondents in each income category is outlined in Table 2. As Table 2 shows, the vast majority of participants (81.4%) have estimated annual family incomes of \$30,000 or greater with 44% of those at \$60,000 or greater.

In summary, the profile of responding participants included affluent, highly educated, white, and United States citizens.

Table 1
Education Profile

Highest Level of Education	Count	Percent
High School not yet completed	0	0
High School Graduation or Equivalent	0	0
Some College	11	25.6
Bachelor's Degree	13	30.2
Graduate Studies	4	9.3
Graduate Degree	15	34.9

Table 2
Income Profile

Estimated Annual Family Income	Count	Percent
less than \$14,999	4	9.3
\$15,000 - 29,999	4	9.3
\$30,000 - 44,999	7	16.3
\$45,000 - 59,999	9	20.9
\$60,000 or greater	19	44.2

Procedures

First, an announcement, as found in Appendix B, was placed on the WITSENDO mailing list to ask for participants to test the questionnaire. The first eight subscribers to respond were selected. The questionnaire was then slightly modified based on these responses.

Next, participants from WITSENDO were solicited for the study with an announcement, as found in Appendix C. Volunteers in response to that announcement were sent a uniquely numbered questionnaire over the Internet, along with the letter, found in Appendix D. The letter explains that voluntary consent to participate is implied. Questionnaires were numbered for tracking responses and coding. One master list connecting names and numbers was kept confidential and locked in a filing cabinet. Follow-up reminders were mailed weekly until forty-six questionnaires were received. A typical reminder is found in Appendix E.

As the questionnaires were returned, the researcher downloaded the responses from the electronic mail on the mainframe computer into a data file on a personal computer. Responses that were sent through the postal service were typed in and added to this file. Any identifying data, such as respondent name or electronic mail address, was deleted.

A preliminary analysis of the data was made and these

early results were sent back to the sample to receive feedback. A copy of this message is in Appendix F. Sixteen women responded with comments.

Analysis

Responses to the questionnaire were moved from the mainframe computer to a personal computer. The quantitative and qualitative questions were analyzed separately. For the quantitative data, statistical means or frequencies were calculated.

The qualitative data was evaluated for themes. Completed questionnaires were compiled in text files for each respondent and in a master file for all respondents. The data was also arranged by question for each of the open-ended questions in the four relationship categories.

By comparing these responses and asking questions as the text is reviewed, concepts emerged (Strauss & Corbin., 1990). The researcher reviewed responses multiple times to evaluate for recurring themes. Each completed questionnaire was reviewed five times and the responses arranged by question were reviewed an additional two times. Searches and counts for specific words were also performed.

To obtain another perspective, an experienced colleague without endometriosis also reviewed the data. She reviewed half of the completed questionnaires and all of the data arranged by question. While reading the data, she searched

for missing themes. This provided a second opinion that helped to assure that the women's voices were accurately portrayed.

CHAPTER FOUR: RESULTS

Introduction

This research study was undertaken to develop an in-depth understanding of social support experienced by women with endometriosis. It focused on the support these women received and wanted from spouses or partners, friends and family, others with endometriosis, and medical personnel.

Forty-six women with endometriosis shared their experiences. Each woman's experience was unique, yet there were many common themes which echoed throughout the experiences of all of these women. This chapter presents results of an analysis of themes which emerged from the women's own experiences. The participants' own words are used in an effort to build a compelling story that captures the complexity of how these women experienced and dealt with endometriosis and its impact on their lives. Even though data was collected through electronic mail, the researcher was struck by the intensity and power which came through in the women's stories.

The major organization of this chapter is based on the questions asked; that is, the chapter is organized according to social support experienced with spouses/partners, friends/family, others with endometriosis, and health care providers. However, as the data were read and re-read, it became evident that in order to appreciate these women's

experiences with social support, an understanding of the backdrop of the disease they coped with every day must be provided.

Context of the Social Support

It became clear from the participants' stories that they wanted people in their support network to recognize and understand the backdrop of the disease that they experience every day. Since this study focused on social support, it did not specifically ask much about the disease. However participants clearly felt their struggles with endometriosis, and its emotional impact and stress, influenced their social support network. For example, one participant wrote, "a woman with endometriosis often feels her life is a battleground: she must fight with pain simply to meet her obligations each day, fight to maintain her dignity in the work place despite numerous absences and sick leaves, constantly fight with physicians who are uninformed, etc."

Struggles

While each woman's experiences were unique, they each wrote poignantly about their struggles with endometriosis. These women often refer to endometriosis as "endo." The participants identified multiple struggles that included the following: the difficulties associated with diagnosis and prognosis, the pain, and the possibility or certainty of

infertility.

Struggles of diagnosis and prognosis.

Many participants described struggles of being diagnosed, and then once diagnosed facing a disease with no cure, a chronic nature, and an uncertain progression. Many of the participants indicated a difficulty obtaining a diagnosis; as this woman states, "my biggest problem was getting it diagnosed in the first place." Similarly, another woman wrote that she went to several doctors "who were unable to make the correct diagnosis."

Participants were asked "how long have you had the symptoms of endometriosis? (years)" and "how long have you had a diagnosis of endometriosis? (years)." Table 3 displays the mean, median, minimum, and maximum values.

Table 3
Years of Symptoms and Diagnosis

	Mean	Median	Minimum	Maximum
Years of Symptoms	11.5	10	1	35
Years of Diagnosis	4.5	3	0.2	16
Difference in Years between Onset of Symptoms and Diagnosis	7	4.2	0	29

As indicated by table 3, the women on average indicated seven years between the onset of the symptoms of endometriosis and a formal diagnosis. One participant stated that the most supportive response a physician had was that "he (physician) was able to tell me what the problem was and why I had been feeling the way I had been for so long." In a similar vein, another participant wrote that "I saw my doctor for the first time in May 1994, after 18 months of trying to get a diagnosis and treatment from another doctor ... For the first time I was told it was all in my abdomen, not my head! Just getting the facts straight has been an immense help." Another woman also wrote of the implication of psychogenic causes, "a major symptom of my endo was pain with intercourse. Because of the significant delay in my diagnosis, I was told (and believed, as my husband did) that it was all in my head." Another participant summarizes the difficulty by stating that "endo is an UNSOLVED problem and that women today are still being misdiagnosed and suffering from horrible and ineffective treatments."

During and after the struggle of obtaining a diagnosis, these participants still face a disease with no cure. One woman emphatically states that "I feel victimized by the physicians -- which is not helpful given all that the disease has put me through. I don't feel it should be my job

to convince them that endo is never cured, to justify my pain in order to "earn" their assistance!" Another woman who did not talk with a health care provider during the last twelve months wrote that "I have found that it doesn't make any difference--no one has a cure, and I already know what the treatments are."

Endometriosis has no cure and an uncertain progression, and this comes out in these women's stories. One example of dealing with the uncertainty of the disease progression and how it affects social support is from one participant who states that "I think my doctor was as supportive as she could be, but ... it was hard for her to be positive about long term results." Similarly another states that "having never had endo, my mother could not understand completely how it feels to live in the shadow of the threat of this disease returning with a vengeance." Another expresses concern for her future, "I just don't want to envision myself with chronic problems in the future."

The chronic nature of endometriosis is part of these women's struggles. Many participants wanted their support network to be aware of this, as demonstrated by one woman when she stated, "try to keep in mind that endo is a chronic disease that we deal with every day, not just a one time pain." Because of the chronic nature of the disease, certain responses were not found to be supportive by these

women. Typical non-supportive statements regarding this were "forgetting about the chronic nature of this disease" and "the assumption that if I wasn't complaining then everything was OK." Another woman laments the ongoing nature of the disease and how it affects her support when she states that "they also found it hard to believe that I could have so many symptoms and such intense pain on a regular basis ... in my case several years." Many participants wanted others to "to realize that coping with chronic pain is exhausting." One offered this advice to others on how they can be more supportive, "remind her that a chronic disease is draining, and that she should give herself credit for having so many good days." Another participant wants others to "accept that this is a chronic condition and that I have very little control over its progress. Don't place the burden of curing myself on me."

Struggles with infertility and pain.

In addition to the struggles with diagnosis and prognosis of endometriosis, participants struggled with the symptoms of pain and infertility. Each participant was asked to rate on a scale of one to five how much infertility and pain were a problem for them at this time. A one on the scale represented "not at all a problem" and five corresponded to an "overwhelming problem". Table 4 shows the results of those two questions.

Table 4
Rating of Infertility and Pain

Rating	Infertility		Pain	
	Count	Percent	Count	Percent
1	27	59	7	15
2	9	20	12	26
3	2	4	14	31
4	1	2	8	17
5	7	15	5	11

Even though the participants overall rated infertility as "not at all a problem" and pain as a moderate problem, many of their stories indicate that either is a problem.

Some women wrote of the devastating effects of infertility on their lives and social support networks. One participant wrote that "finding the endo was just another blow to my inability to conceive, and another item for me to have to deal with emotionally." Another found that "the most difficult part is probably the typical difficulties that come up in the context of infertility (insensitive questions, heart-touching situations)." One stated, "my husband knew how disappointed I was that the doctor had indicated it was extremely unlikely, given my situation, that we would be able to have children." Another participant indicated how it affected the support she received from her grandfather, "so he's too concerned to really be supportive. He wants grandchildren from me and is very worried that I cannot now have them."

Other women wrote about how the uncertainty of infertility was a difficulty. One woman stated that "not all endo causes infertility, and there really isn't a way to figure out whether or not you are infertile until you try. Many of my relatives figure that since I am 'barren,' they shouldn't discuss their children or their pregnancies with me." Another woman wrote about her deep concerns, "even

though I'm not trying to get pregnant, I feel a great fear and sadness that I will never be able to conceive." These participants have shared how infertility is part of the backdrop with which they live and how it affects their current lives and their futures.

Other women's stories reflect another symptom of endometriosis, the struggle with pain. One woman laments that she has "had to cancel get-togethers at the last moment because of endo pain." One participant wrote that "women dealing only with the infertility aspect of the disease cannot understand the extent to which the pain can affect a life or a family." Another participant implores others to "believe she is telling the truth about the pain and the symptoms. Offer your support to her because it is so debilitating at times that it's difficult for even the simplest of tasks to be accomplished." Endometriosis is hidden inside and this participant asks partners to "understand that some days your partner may look great on the outside but still be gritting her teeth through the endo pain." Coping with endometriosis is an ongoing struggle as expressed by the participants.

Emotional Impact

Facing the chronic struggles of endometriosis, such as the pain, the infertility, the difficulties of diagnosis and treatment, and the uncertainty of prognosis, takes an

emotional toll. Several themes were repeated that relate to the emotional impact and stress caused by the disease. These themes included: stress, emotional volatility, bitchiness, anger, frustration, fear, failure, guilt, disappointment, loss, sadness and depression. The emotional impact and stress that this disease had on participants' lives was powerful. Many of the participants noted the emotional impact of the disease with comments such as the following: "in fact, I have found coping with the emotional aspects of endo/chronic pain the worst part of it"; "the emotional pain of having this 'invisible'crippler is almost as bad as the physical pain it can bring"; "maybe some of that is my own discomfort, as if my womanhood has been damaged or something sad"; "he believes my pain is unbearable & he knows how emotionally crippling it is"; and "I think it could be easy to ignore the emotional turmoil and stress coming from the disease."

Stress.

The theme of stress included general stress and relationship stress. Comments relating to the stress of the disease were numerous. For example, several participants recognized the stress on relationships, one found it helpful when someone "understands the disease itself and how it can place stress on a relationship"; another participant noted "I wasn't able to be very attentive to his needs ... It was

stressful for me"; and another noted that "I find it stressful that my mother worries so much about me." Others indirectly recognized the stress by wanting other stresses removed, "give them time and space to deal with the pain by taking away the stresses of everyday chores and obligations."

Emotional Volatility and Bitchiness.

The theme of emotional volatility was also noted by several participants. For example, emotional volatility was noticed as a stress in the work place when one participant stated that "I have been unemployed for the last 3 years, unable to keep a job longer than a menstrual cycle, because people are unable or unwilling to make allowances for the emotional volatility and physical constraints that endo has given me." Another participant notices that "having endo can raise erratic emotions and frustrating experiences."

In addition to emotional volatility, being "bitchy" was another theme mentioned by several women. These participants typically noted that "she becomes bitchy, depressed or antisocial"; and she is "bitchy when she's in pain." Also, often noted was that "we don't WANT to be bitches or whiners."

Anger and Frustration.

The themes of anger and more frequently frustration were also noted by the participants. Examples of comments

about anger include: "I was insulted, angry and hurt"; and "he used to make me so angry, because" of the assumptions he made.

Anger was only mentioned by several women but frustration was mentioned numerous times. Even though general frustration was expressed, themes of frustration were mostly concerned with either the disease or the medical profession. Typical comments regarding the frustration relating to the disease were, "it is incredibly frustrating to have a disease that can't be cured"; "even with the renewed frustration of having breakthrough symptoms, of overcoming my treatment"; and "I was frustrated by the pain." Representative comments of the frustration with the medical community include: "experiencing the same frustration with the medical profession"; and "the frustration of going from doctor to doctor seeking treatment." Many of the participants found the experience of having endometriosis to be frustrating.

Fear.

In addition to the theme of frustration, the theme of fear was prevalent. Fear was expressed by participants regarding infertility. Examples of this include: "as infertility is an unknown if you've never tried to conceive but will want to in future. I am greatly worried about it- but this may be an unfounded fear"; and "he won't even

discuss my fears about infertility (we haven't started trying yet)." As noted by this participant, there is the fear of surgery, "she was really in tune with my fears about surgery, about feeling like I had no choice but to have this surgery if I wanted to escape the pain." Other fears include: "my fears about losing this job too"; and "that seems to open the door for me to talk in safety, without fear of appearing to be seeking sympathy."

In addition, fears were noted regarding the possible loss of an important relationship as with these examples: "she may be fearful that you will no longer care for her because the disease makes her less fun to be with when she is in pain and fatigued"; and "she may fear you will leave her if she can't bear children." The participants noted general fear, fear of infertility, fear of surgery and fear of losing an important relationship.

Self-Esteem and Guilt.

Another theme of the emotional impact was a sense of failure or a difficulty with self-esteem noted by several women. Related comments include: "I feel very much a failure"; "she may take questions about children as a sign that she is a failure if she can't produce"; concerns expressed about "what endo is doing to my life (what impact it's having on my relationship, my job, my self-esteem, my peace of mind)"; and "we're harder on ourselves than anyone

else could ever be."

In addition, guilt was an occasional theme in these women's stories. Examples of this include: "I still feel a lot of guilt dealing with my female factor infertility"; and some women "may be feeling guilty for burdening those close to her with her problems."

Disappointment, Loss and Depression.

Disappointment was also an occasional theme as noted by these participants, "my husband knew how disappointed I was that the doctor had indicated it was extremely unlikely, given my situation, that we would be able to have children"; and "he shares the disappointment of not being able to have a child."

Also, the theme of loss emerged from the stories of several participants. Pertaining to this theme are these comments, "hear her when she needs to express the sense of loss she is experiencing>"; "she is concerned about how I feel about what's happening to me, about the sense of loss"; "they understood the awful loss of control over your life and your relationships with other people"; and "I was still in the state of "mourning" for my own lost children."

The final theme, that is perhaps related to a sense of loss, is one of sadness and depression. A number of the participants wrote of the sadness and depression they experienced with the endometriosis. Thoughts of infertility

often evoked expressions of sadness as with these participants, "I feel a great fear and sadness that I will never be able to conceive"; "my husband tries to understand how sad I get about infertility." The following two responses demonstrate the theme of depression: "the disease can be pretty debilitating, and feeling bad day after day can become quite depressing" and "I'm thinking about going to see a counselor soon about the depression I feel with this disease." The next quote indicates how serious the depression can become and the importance of social support; "I know that I get very suicidal sometimes, from frustration and despair, and if I didn't have the amount of support I do, I would probably have ended my problem long ago."

In summary, themes of emotional impact included: stress, emotional volatility, bitchiness, anger, frustration, fear, failure, guilt, disappointment, loss, sadness and depression. The social support of these participants takes place in the context of endometriosis and the related struggles with infertility, pain, difficulties with diagnosis and treatment, and disease progression; all overlaid with the emotional impact of the disease.

Overview of Experiences with Social Support

Within the context of endometriosis, women stated what they found supportive and did not find supportive. The survey divided social support into four categories: spouse

or partner, friends and family, others with endometriosis, and health care providers. Some of the themes are more prevalent in one category, but there are some very strong overarching themes present in all four categories. For example, the participants, in general, wanted their social support network to really listen to them and believe that their symptoms are real, to be knowledgeable about the disease, to understand the context of the disease, and to share information about the disease.

Support by Listening and Believing

These women expressed a strong desire to have people listen to them. This desire was expressed in all four categories of relationships. In fact the word "listen" or some form appeared 86 times in the data. As one woman wrote, "merely taking the time to be a 'listening ear' is helpful in itself." Other typical comments that indicate what the participants found to be most supportive follow: "she knew when to just listen"; "listen to them and believe what they are telling you"; and "it was the listening and accepting primarily." The "just listen" part seems particularly important as this woman related, "just listen and don't try to give any 'quickie' answers or any type of quick solutions because there aren't any, and if there were don't you think that we would have found them and would be using them, if they worked."

Even though these women emphasize the listening, participants also indicated that the listener's responses were important. They wanted to be believed and accepted as stated by this participant, "listen without diminishing the experience of the woman (e.g. with 'gee, so-and-so had it worse because ...'). Understand that each woman's experience is real and valid, that you need to be careful to listen without being judgmental."

The participants found it to be supportive when they felt believed and not supportive when they did not feel believed. They wanted others to recognize that the symptoms they experience are real. One woman commented that "I find it very aggravating to deal with women who have never experienced painful periods and therefore don't believe those of us who do could possibly be in as much pain as we say we are." Other representative comments follow: "reassure the sufferer that you know her pain and other symptoms are real"; "believe she is telling the truth about the pain and the symptoms"; "recognize that the symptoms are real, and that they affect the quality of life"; and "reassure her that you know the disease is real, and not just in her mind."

Support by being Knowledgeable

In addition to wanting people to listen and believe, the participants wanted their listeners to be well informed

about the disease. This theme was the strongest for health care providers. One woman writes that "many doctors are not yet sufficiently informed about the symptoms, causes, and treatment of endometriosis." Another states that "I had to go through 'several' physicians over the years that had no knowledge of what my problem was."

These women also wanted spouses or partners, and friends and family to be knowledgeable about endometriosis. As one participant advises, "learn about endo and the anatomy/hormones of a woman's system. It's hard to talk about a specific problem when you have to keep explaining basic anatomy." Related responses follow: "learn how it differs from normal menstruation"; "read up on the disease and understand it"; "learn more about endo"; "read as much information as possible and try to offer helpful suggestions on treatment, methods of coping, etc"; and "learn as much about the disease as possible as soon as possible."

The participants often made a connection between possessing knowledge about endometriosis and the supporters' ability to understand. These comments reflect that connection, "friends who are uninformed about the disease DEFINITELY do not understand what you are going through"; "I gave both of them some information from the Endometriosis Association, and after they had read it they were much more understanding"; and "being more informed about the disease

helps to be more understanding towards the people suffering from the pain (physical and/or emotional) of endometriosis."

Support by Understanding

These women felt supported when they were understood. Being understood was important in the personal relationships with their spouse or partner, friends and family and others with endometriosis and only minimally important in the professional relationships with health care providers. The participants wanted others to understand what they were going through as reflected by this response, "this disease is chronic and a woman goes through a lot emotionally and physically." The participants wanted others to "understand that the pain is real, that it is tough to live with"; and to "understand that LOTS of stuff hurts... and lots of stuff just doesn't feel good." Another states that they want others to "understand that it is incredibly frustrating to have a disease that can't be cured, where you can't predict how you will feel one day to the next, and whose treatments are often as problematic as the disease".

It follows that the participants did not feel supported when they did not feel understood. Some representative comments include: "some co-workers (not necessarily 'friends') don't understand why I've had to leave work with this strange 'illness' so often"; "not really understanding the extent of my fatigue after my menses. The pain seems to

wear me out completely"; "a few people had trouble understanding why, at the height of my illness, I wasn't willing to spend any of my 'free' time with them. I was so wiped out at the end of the day that I needed all the time I has just to recuperate from the workday"; and "applies to friends: did not understand the difference between endo and regular menstrual cramps and continue to equate the two." Two women offered this advice: "listen and be understanding when pain/medical tests, etc. get in the way of social events, etc."; and "a little understanding goes a long way."

The participants clearly wanted to be understood. One woman emphasizes the value to her of an understanding person when she states, "understanding and caring are the two most important gifts any person can give us."

Support by Sharing Information

In addition to being listened to, believed and understood, the participants not only wanted their support network to be informed but they also wanted them to pass information on to them. This is reflected by the following comments: "keep your feelers out for information on endo and any helpful hints and pass those on"; and "they can be on the lookout for articles or news information about endo and be able to call up precisely how & where WE can get the info, if they can't clip or videotape it." Another woman makes the same point when she writes appreciatively about

those who "were very supportive, going to the extent of searching out information for me, and contacting other women they knew who had endometriosis to get advice from them for me."

This theme was especially strong in the relationship categories of health care provider and others with endometriosis. In writing about their health care providers, one woman states, "again, I think information is the key. Doctors need to explain WHY they are recommending or not recommending treatments of various kinds"; and another states they should "provide literature in their offices to educate women about the disease." In writing about other women with endometriosis, a typical response was that "I also appreciated the additional support in the form of concrete information about the illness and feedback from others with endometriosis."

The participants intensely believed in keeping themselves informed about endometriosis. One participant believes that "no one can ever know too much about a disease they are suffering with." Others stated the following: "I also make frequent reference to material from the endo assoc. and to books"; "I think it is most important to educate yourself. Therefore, going to the library and reading all you can is a good thing"; and "reading the Endometriosis Association newsletter has helped me to become

better educated about the disease and has given me more insight into my symptoms."

In general the women in this study found it supportive to be listened to, believed, and understood. They also wanted their support network to be knowledgeable about endometriosis and to share information with them.

Spouse or Partner

When writing about their spouses or partners the participants shared many poignant and compelling stories. Every participant who had a spouse or partner (n=42) talked with that person in the last twelve months about her endometriosis. In general spouses or partners responses were supportive. Responses were rated on a five point scale from one, "not supportive", to five, "extremely supportive". The level of support from responses is shown in table 5. As indicated, 40.5% of the participants with a spouse or partner rated their partner as being extremely supportive and 73.8% rated them in the top two categories.

Table 5
Level of Spouse/Partner Support

Rating	Count	Percent
1	0	0
2	2	4.8
3	9	21.4
4	14	33.3
5	17	40.5

A number of themes emerged from the participants' stories indicating what women wanted and did not want in the way of support. One quote that represents many of those themes follows: "he (my husband) reassured me that he loves me and that my having endo doesn't change his feelings for me. He stayed with me in the hospital, feeding me ice chips and holding my hand after a very difficult surgery. He runs interference for me, and is my 'second self' when dealing with doctors, family etc. He knows the information and asks the questions right along with me. He has been immensely understanding and patient with my limitations, and tries to be gentle with sex, which is painful for me." What these women wanted and did not want in the way of support reflects the overall themes of listening, believing, understanding, being knowledgeable and sharing knowledge; and the additional themes of committing, being patient, caring, asking, comforting, helping, expressing feelings, not fixing, and not judging or blaming. Themes associated with the impact of pain with intercourse on a relationship are also discussed.

Support by Listening, Believing and Understanding

The listening, believing and understanding that the participants wanted from spouses or partners fits the pattern described in the overview. Comments reflective of this pattern include: "understand that some days your

partner may look great on the outside but still be gritting her teeth through the endo pain"; and "accept that the illness is real and a serious issue, and not something that is imagined or of little import." Another participant writes about what she found to be most supportive about her spouse or partner, "he listens and accepts. While it's difficult for him to understand sometimes, he makes the attempt and does his best. He always goes to appointments with me if I ask him to. He's my rock of support."

Support with Knowledge

In order to participate in discussions and understand endometriosis, women repeatedly stressed that a supportive spouse or partner is knowledgeable about the disease. This comment reflects the importance of knowledge in helping with decision making, "find out about the disease. You need to know as much about it as she does. Read the pamphlets and books she has. If she doesn't have any information about it, buy a book on endo and give it to her. Contact the Endometriosis Association and find out about support groups and literature. When your partner is going through treatments and making decisions about what to do, you may be the one she turns to to help her decide the right course. You need to understand what is going on and what the various options are."

Other quotes from the participants that reflect the

importance of an informed spouse or partner follow: "the most important support a spouse can provide is to educate himself about the disease"; "I guess I would encourage partners to learn all they can about endo, so they can really understand what it is we are dealing with"; "he tries to dig up as much information (through libraries, Internet, various other sources) as possible regarding endometriosis and treatments and anything else which might apply to our particular situation"; "find out about the disease. You need to know as much about it as she does." These women did not find it supportive when "he doesn't seem to be interested in helping research the issues"; or "his seeming disinterest in learning much about the disease. (reading the many books, etc, lying around the house!)."

One value of knowledge as mentioned by several participants was the ability to participate in discussions. These participants found it supportive when the spouse or partner was available to discuss her treatment options. For example, two participants noted the following as being supportive: "I ended up needing a hysterectomy for the endo. My husband talked me through the decision-making process"; and "understand that the pain is real, that it is tough to live with, and any decision on dealing with the disease helps to be talked out with the significant other."

Support by Committing, Being Patient and Caring

Many participants wrote eloquently about the commitment her spouse or partner had towards her, that he loved her and would be there for her. Participants found commitment to be very supportive. Comments representative of that commitment follow: "my spouse helps me by reminding me that he married 'a packaged deal.' Problems and all, and that 'in sickness and in health' is just as real to him now as it was ... when we married"; "he (my husband) reassured me that he loves me and that my having endo doesn't change his feelings for me"; "I didn't feel abandoned/alone trying to deal with it (it's your problem, you deal with it)"; "he assures me he didn't marry me to make babies. He tries to be supportive by being here for me"; and "whatever I needed to do, he would have been there for me." To summarize, this participant advises spouses or partners, "BE THERE FOR THEM!!! There is nothing worse than feeling like hell and then having no support at all from the one you love."

Endometriosis is chronic so the commitment needs to be long term. Because of this, several participants recognized the value of patience in their spouse or partner, as reflected in these comments, "my husband is very patient"; and "my husband has been very patient with the length of time the medical process has taken." Two participants advise that spouses and partners "be patient without

patronizing" and "be patient when I am bad tempered. Realize I hate me being bad tempered just as much as he does."

Also related to commitment, the participants found concern and caring to be supportive. Comments reflective of this follow: "the genuine concern that he shows even though he can't take away the pain is very comforting because it shows he cares about me and my future"; "he is very understanding and caring about how I'm feeling"; "he was, and still is, very concerned and understanding" "his concern & desire to do whatever he could to help"; and "he is very tender with me and careful of my feelings."

Support by Asking, Comforting, and Helping

The participants liked to be asked what they wanted, to be comforted and helped. A number of women noted that it was supportive when their spouse or partner asked her what she wanted. Examples of this follow: "ask if there is anything they can do to help"; "ask me if I need advil!"; "go to see the physician with your partner--if she doesn't offer, ask"; "The best thing to do is listen and then ask what you can do to make life easier or more comfortable;" and "ask her if there is anything you can do for her."

In addition to being asked what they wanted, these women found it supportive when their spouses or partners helped them to be more comfortable as reflected in these comments, "make your partner as comfortable during those

painful times"; and "find a way that you can contribute to their emotional and physical comfort." The following are examples of comforting behavior from spouses or partners: "he knew and could sense when I was in terrible pain ... he would be very gentle with me rubbing my back, getting me hot tea and pillows, running a tub of water"; "babys me when I am dealing with painful periods, medical tests, etc."; "get the heating pad, a cup of tea, some pillows, fix dinner, look after the kids, whatever you think will make her feel better or will take her mind off her pain."

One form of comfort is touching. A number of women found it to be supportive to be touched in a caring way. Holding and hugging was important behavior as reported by these participants, "He does a lot of just holding/hugging me"; "loads of hugs!"; and "he just sits and holds me or rubs my back." Back rubs was another supportive form of touching as noted by these women, "he'll rub my back when I get pain and get the heating pad for me--as well as the Motrin"; "he rubs my back and legs for me when I request it."

In addition to being comfortable, the participants wanted practical help. Participants emphasized that it is important "to realize that coping with chronic pain is exhausting and help out more with kids"; and "my spouse's response is in his actions rather than his words ... He does

the cooking, shopping and cleaning when I am not able to. He rearranges or cancels social engagements if I am not able to participate due to pain. (This includes giving up tickets to see the Phoenix Suns, which are his favorite)."

Support by Expressing Feelings

Several women found it supportive to have their spouses or partners express their feelings about the endometriosis. Women especially mentioned the feeling of frustration and outrage. For example, two participants' comments, who wanted their spouses to be outraged, follow; "my spouse is deeply involved in my medical care, attending appointments with physicians, assisting me in every way. During the last discussion, he was primarily concerned with my feelings surrounding an interview with a physician who blamed my endometriosis on being on a 'career gal'. My spouse expressed his personal outrage that I had to endure this"; and "I sometimes want my husband to be as outraged as I am that so many women are in pain and that the medical community hasn't done a thing to advance the understanding and treatment of this debilitating disease--nor has it done anything to educate physicians about how "real" it is." Two others wanted the sharing of frustrations, "share your own feelings and frustrations"; and "share your frustration at the lack of knowledge."

Support by not Fixing

Several women noted that they did not expect their spouse or partner to fix their problems or find a solution and did not find it supportive when they tried.

Representative comments follow: "It's OK not to fix things! Men (in my experience and in what I've read) love to fix things and sometimes get frustrated when they can't be Mr. Fix-It. Even though they can't fix it, don't give up - just being there, listening and being supportive is a big help"; "Do not pressure your partner to seek 'solutions' - try to understand that this is an ongoing problem not something that one can just see a doctor about and get a quick fix"; and it is not supportive "anytime he starts making suggestions about my care, my treatment, how I handle my interactions with my doctors. I don't want suggestions, I just want him to listen."

Support by not Judging or Blaming

The participants did not find it supportive to be blamed, accused or judged and they found it supportive when those behaviors were missing. For example, these two women relate how supportive it was for them to not be judged, "he doesn't judge, he just accepts"; and "all without judging my own emotional & physical response to the endo."

Representative comments concerning blaming follow: "I didn't feel blamed or accused (what's wrong with you anyway)"; "he's very frustrated by the lack of concrete answers and

sometimes seems to think they are out there but I'm just not asking the right questions to the right people. I keep explaining that I don't know why I suddenly have pain and that probably no one else does either. He also suggests that some of my symptoms are brought on by letting myself get too stressed which essentially puts the 'blame' on me"; and "at the least, the partner needs to avoid 'blaming' the endo patient for their difficulty in having kids."

Impact on Sexual Relationship

Even though the survey did not specifically ask about sexual intercourse, many women noted with poignancy how associated pain affected their relationship and the spousal/partner support. One participant writes about the strain on her marriage that pain with intercourse and a delayed diagnosis of endometriosis caused, "a major symptom of my endo was pain with intercourse. Because of the significant delay in my diagnosis, I was told (and believed, as my husband did) that it was all in my head. Residual effects from this symptom strained our marriage because I did not have the libido I once had (who would after enduring that much pain?) even after my laparoscopy."

Other participants wrote about the limitations that painful intercourse places on the sexual relationship, as follows, "our sex life has been limited because of the endo (I have a very tender cervix.) At times I know he is

dissatisfied with our sexual situation, especially because he has to be so careful. While he doesn't pressure me about sex, its hard knowing that he is not fully satisfied with our sex life"; "also... I find the whole concept of sex when I'm having symptoms really alien. Very private parts of me hurt in odd and very personal ways... and he wants to touch them???? Sex is nice when it doesn't hurt, but it's almost unimaginable when it hurts... and my mental attitude about not wanting to be touched lingers after the real pain has gone. Partners have to understand and be VERY careful."

Many participants wanted partners to be understanding about their sexual limitations. These participants found it supportive that "when I told him that sex was painful, he was very understanding and undemanding"; "I suppose the most supportive response was being "okay" with not having sex with me"; "he was just there for me, and still is...he doesn't get mad at me if I don't feel good or when it hurts to have intercourse"; and it was not supportive when "he didn't agree to any ... relationship changes (e.g. no sex during extremely painful times)". Other related comments included: "I wish that partners (including my husband) would consider that fact that a partial sex life is better than no sex life at all"; and "do not make your partner feel inadequate w.r.t. [with regards to] frequency of sex."

The disease symptom of pain with intercourse has

affected the lives of these women in profound ways. For many, this pain limits sexual relationships with a husband or partner. How the spouse or partner responds to this limitation can be supportive or non-supportive. In general, these women want spouses or partners to be understanding and to accept this limitation.

Friends and Extended Family

The participants shared their experiences with support from friends and extended family. Forty-five participants out of forty-six had spoken with friends or family in the last year about their endometriosis. One participant did not and she explained that "I don't have pain like I used to, and the pain I have is pretty much controlled by medication. I find that support from my husband goes a long way and that my family lives too far away to do anything for me (though I believe they would if I was living with them, for example, and needed for them to help me)."

The forty-five women that spoke with a friend or extended family member about their endometriosis rated the level of support of that person's response. In general friends and family members' responses were fairly supportive but less supportive than spouses. Responses were rated on a five point scale from one, "not supportive", to five, "extremely supportive." The level of support for responses is shown in Table 6.

Table 6
Level of Support from Friends/Extended Family

Rating	Count	Percent
1	0	0
2	5	11.1
3	13	28.9
4	16	35.6
5	11	24.4

As table 6 indicates, 35.6% of the respondents rated support relatively highly, with the vast majority of respondents (93.9%) rating the level of support moderately to extremely supportive.

Participants were also asked with whom they had talked about their endometriosis in the last twelve months. Table 7 outlines with whom among friends and extended family members the participants spoke. As Table 7 shows, forty of the forty-six participants spoke with a female friend. Respondents talked with female friends and mothers the most frequently, and talked with male friends, sisters and fathers the next most frequently. In general, participants talked more with other females.

Table 7
Friends and Extended Family Members Spoken With

Friend or Family Member	Count
Female Friend	40
Male Friend	20
Mother	36
Father	19
Brother	12
Sister	20
Female Cousin	9
Male Cousin	1
Aunt	8
Uncle	1
Other*	17

(*Other includes: grandmother, grandfather, mother-in-law, husband's step father, boyfriend's mother, sister-in-law, brother-in-law, co-worker, boss, niece, and nephew.)

A few participants noted that depending on the phase of disease and treatment, their amount of speaking about the disease to friends and family changes, accordingly. Examples of this include: "My mother, friends, and a cousin have all been aware of my experiences with painful periods, etc., so it's pretty much just a topic that I bring up if anything's happening in particular"; and "My experiences with endo during 1994 were "quieter" than during 1993, when I was diagnosed and had surgery. During 1994, I talked much less about the endo since I was into a "wait and see" phase for fertility questions."

From the shared experiences with support from friends and family, a number of themes emerged. Several participants noted a similarity between what they wanted from partners or spouses and what they wanted from friends and extended family. When asked about support from friends and family, one participant stated "almost the same answer I give for partners"; and others wrote "same as husband, depending on degree of 'friendship'"; and "same ... although I'd expect more from my partner in terms of the reading." As was true with support from spouses, responses in the category of friends and family shared the common themes of listening, believing, being informed, sharing information and understanding; and additional themes of sympathy or empathy, support with disease struggles, and not blaming,

minimizing or worrying.

Support by Listening and Believing

The participants expressed a strong desire for friends and extended family to listen to them. This theme was quite prevalent. One woman states that, "in all relationships I think the ability just to talk out what you're feeling and feeling that someone is listening is the best because no one really knows what to say and sometimes that is best..." Another woman wrote, "listening! That is the best gift my friends have given me. (Who must be so sick of hearing about this, but you wouldn't know it by their responses)." Similarly, another participant describes the value of a good listener, "in general, my friends have been quite tolerant of my ranting about endo, and have provided me with a great outlet for blowing off steam."

The emphasis was on listening but the participants indicated that the responses of the listeners were also important. One woman describes what several women noted, that an important part of listening is a willingness to hear unpleasant details, "All the people I talked to were quite supportive in that they listened to me and wanted to know the details and didn't act all grossed out." Another woman gives this advice to friends and family that is representative of the advice offered by many of the participants, "Don't assume that the cramps you have or your

period are anything like hers. Also don't assume that you have any idea of what the pain is like. If you can do that, then you will be a better listener."

Another identified important response from listeners was to not give advice, "Listen, don't offer advice unless asked for it. Most of the women I know with endo are much better informed about the disease than their physicians -- the last thing they need is unschooled advice on how to cope;" "If she just needs to talk it over - which is often the case - listen, ask questions, but don't give medical advice unless you are sure she wants it."

The participants did not just want to be listened to, they wanted to be believed. They wanted listeners to believe that their symptoms were real; as stated by these participants, it was supportive when "they all believe me, something I've had problems with (i.e., work supervisor's, drs.); and it is important that listeners "not question whether pain was real."

Others noted that it was not supportive when the implication was that her symptoms were not believed and might be psychogenic. For example, it was not supportive when "the real health nuts cannot be dissuaded from their belief that my pain is at least in part in my head or the result of stress." Another participant notes that only one of her female friends "has been doubtful, questioning

whether "it's psychological", even in the face of watching me having a period." In this theme, representative advice to friends and family was "Believe someone if they say it's a problem! -Don't say "You need to see a psychologist."

Support with Knowledge

In addition to wanting to be listened to and believed, many of the participants discussed the value of having friends and extended family members who were knowledgeable and shared information about the disease. For example, one participant advises friends and family to "learn how it [endometriosis] differs from normal menstruation." Often it was not supportive, when friends or family members were not well informed, as in this example, "My mother is the least supportive person I have spoken to. I have tried everything to get her to read literature, to seeing a tape on endo, etc."

In general the participants not only wanted friends and family to be well informed, but they found it supportive when the information was obtained and shared. The following participants write about their supportive experiences: "I have gone into the gory details the most with my mom; she has been very supportive, interested to hear my stories, and has found literature for me, and has asked friends in the medical profession for input"; and "Both my mother and mother-in-law were very supportive, going to the extent of

searching out information for me, and contacting other women they knew who had endometriosis to get advice from them for me"; "My mother has actively sought out information for me and discussed options with me without pressuring me to act in any particularly way"; "I also appreciated the additional support in the form of concrete information about the illness"; "(Female) friends have searched medical databases for me."

Support by Understanding

Participants often made a connection between knowledgeable friends and extended family members and their ability to understand. As an example of this, one woman wrote that "being more informed about the disease helps to be more understanding towards the people suffering from the pain (physical and/or emotional) of endometriosis." Another participant wrote about how more knowledge increased understanding, "My mother-in-law was under the mistaken impression that pregnancy "cures" endo, and encouraged me to have a baby. I gave both of them some information from the Endometriosis Association, and after they had read it they were much more understanding."

Many participants felt supported when they felt understood. Participants noted that "the only person I found 100% supportive was/is my sister ... She also has endo so she clearly understood my pain and symptoms"; and a

mother was supportive because she was "very curious, anxious to understand."

Many participants appreciated it when friends and family members understood the need to change plans because of the endometriosis, as discussed in the following quotes from participants: "My friends often let me off the hook when we've planned to do stuff together, but I'm too sick to go. I really appreciate their understanding"; and "I've had to cancel get-togethers at the last moment because of endo pain." One participant advises friends and family to "listen and be understanding when pain/medical tests, etc. get in the way of social events, etc." Another participant notes that friends and family were supportive because "they were as understanding and patient with me as they could be. They volunteered to help whenever and how ever they could."

Conversely, participants often did not find it supportive when friends or family members were not understanding. One woman wrote "some friends were less understanding than others. A few people had trouble understanding why, at the height of my illness, I wasn't willing to spend any of my 'free' time with them. I was so wiped out at the end of the day that I needed all the time I had just to recuperate from the workday."

Support by Sympathy or Empathy

Related to the desire to be understood, some

participants wanted sympathy and/or empathy from friends and/or extended family. For example, one participant wrote the following: "Listen and try to understand or at least express sorrow and support." Other participants had the following related comments about what was supportive:

"Sister-in-law said that she felt bad for me that I had to deal with such a bad disease"; "My sister supports me by not offering sympathy, but empathy. She is concerned about how I feel about what's happening to me, about the sense of loss. She does not allow the conversations to drift into "hopelessness" but rather listens and empathizes by saying she would react in a similar manner etc."; and that "listening to my complaints, and sympathizing with them helps me so much." One woman gave this advice: "Basically, just listen and sympathize."

In contrast, one participant emphatically stated that sympathy was not what she wanted, "The discussion was about the disease: I wasn't looking for|discussing support ... sympathy/support has never been something I've searched for."

Support with Disease Struggles

The participants wrote poignantly about their struggles with endometriosis. Examples of what they found supportive from friends and extended family follow: "One of my friends continually reminds me whenever I'm not feeling well that

it's the endo... not me. Especially around the issue of fatigue... I tend to start thinking I'm lazy, and it's REALLY helpful to have friend remind me that IT'S THE ENDO"; "My dad has chronic arthritis so he was good to talk to on the patience that you need to try different mixtures of treatments until something works for you." Examples of what participants did not find supportive follow: "Mother--has heard about endo so long that it seems she's lost interest"; "Having never had endo, my mother could not understand completely how it feels to live in the shadow of the threat of this disease returning with a vengeance"; "I don't find it supportive when fertile friends tell me to just adopt or that it will happen when I'm not trying to get pregnant anymore"; and "The thing I found/find most difficult to deal with is people asking 'How are you?' It feels to me as if there is an expectation that the answer is going to be "Great!" and most of the time I don't."

Participants offered the following advice to friends and family on how they can be more supportive with the struggles of endometriosis: "Be careful about asking "How are you?" If you do ask, be prepared to listen to a long list of aches, pains and problems. Don't ask too often - I don't want to dwell on all my problems all the time, sometimes I want to just forget about the bad things"; "Let her know you still need her by sharing your problems etc.

with her, just like with any other friend. She may be feeling guilty for burdening those close to her with her problems. Knowing that she is still helpful to others and isn't always the needy one really helps"; "Accept that this is a chronic condition and that I have very little control over its progress. Don't place the burden of curing myself on me. Ask how I am- but when I respond that things are worse do not say 'but I thought that last (drug, treatment, surgery, test) would help'"; "Remind her that a chronic disease is draining, and that she should give herself credit for having so many good days"; "Don't respond to the announcement [of diagnosis of endometriosis] with: 'So you can't have children?' Not all endo causes infertility, and there really isn't a way to figure out whether or not you are infertile until you try"; and "Don't look embarrassed if someone brings up the disease in conversation. Because it is a disease of the female reproductive organs, discussions of it run sidelong into discussions of sex--and that makes people feel uncomfortable. It is a disease, pure and simple. There's no need to feel 'dirty' when discussing it."

Support by not Blaming, Minimizing or Worrying

The participants did not feel supported when friends or extended family members blamed them for the disease, minimized their symptoms or worried about them. Several

participants noted that it was not supportive when friends and family responded in a way that could be perceived as blaming. One woman wrote that "I did not talk to my in-laws because they tend to regard medical problems as a failure on the part of the sufferer." Another participant writes of an example when she felt blamed, "My parents believe they are being supportive, but they tend to focus on going to yet another physician -- which it feels like they believe I personally am not doing enough to solve the problem, not standing up for myself etc. I know they don't mean it that way, but that's how I hear it, as though somehow the level of suffering I'm experiencing is my fault."

Participants did not find it supportive to feel blamed, nor did they find it supportive when friends and family minimized their experience of the disease. Many women noted that it was not supportive when their experience was minimized, as noted in these examples: "Only casual acquaintances appear unsupportive, speculating that I must be either imagining it, exaggerating or a wimp"; "One or two friends have made comments like, 'you should just live with the pain during intercourse, it can't be that bad'. But that hasn't happened very often"; and "I get the subtle implication that I am a hypochondriac for letting a little thing like menstrual problems get me down, especially when it is ongoing despite surgery and other treatments."

Many participants advised friends and family to not minimize their experience of the disease, as demonstrated in these examples: "Listen without diminishing the experience of the woman (e.g. with 'gee, so-and-so had it worse because ...'). Understand that each woman's experience is real and valid, that you need to be careful to listen without being judgmental"; "Do not suggest that any of the patients' symptoms are exaggerated"; "Also, avoiding comments about how that pain can't be that bad, or that you should just 'tough it out'"; "Don't discount what you don't have. They often say 'Yes, I have cramps , too.' -- almost defensively. I'll trade places"; "Again, recognize that the pain of this disorder and its secondary symptoms is very real. Do not treat these women as though they are exaggerating or making up symptoms. Realize that the threat of the disease never goes away."

A few of the participants wrote about how difficult it was when others, mothers in particular, worry or become distressed about the endometriosis. These examples relate how it is not supportive when friends or family worry or become distressed: "I find it stressful that my mother worries so much about me. She is frustrated by the inability to 'fix' this problem for me, even though I am an adult and do not expect her to feel so directly involved"; "My mother is the least supportive. She is so distressed by

my pain (and feels guilty because she cannot stop it), that I rarely share any of my endo/infertility related stories with her."

Overall Support Advice for Friends and Family Members

One participant eloquently summarized what she found to be supportive and not supportive from friends and extended family. Her comments also summarize what many participants related: "Good help can be: 'I know a doctor who specializes in that, maybe you should call her.' or, 'I have a friend who has that, would you like me to introduce you?' or, 'If you need someone to talk to, I'll listen. You aren't upsetting me by talking about it, and it isn't too gross for me.', or, 'Let's go for a walk and get some hot cocoa.' or, 'I'm going to the store, would you like me to bring you something?' Bad help is: 'I think my cousin had that, she's been perfectly healthy ever since she had the twins.' or, 'My boss had that surgery - she almost died and she was in the hospital for 8 weeks because the doctor screwed up!' or, 'What you need is wheat grass juice enemas!' or, 'You should talk to my psychiatrist to try to find out what it is about you that makes you cling to pain.' (Yes, I've really heard people say these things! Can you believe it?!?)"

Others with Endometriosis

The participants, in general, wrote in glowing terms about their experiences with other women with endometriosis.

Since the sample was obtained from WITSEND0, a group on the Internet of women with endometriosis, all but three participants indicated that they had contact with or talked with someone else with endometriosis. The three participants who indicated no contact with others with endometriosis, had not considered the WITSEND0 list to be this contact and had the following comments: "Don't know anybody who has it (other than the WITSEND0 list)"; "I joined the listserv to see if I could learn from others - and I have learned an incredible amount from reading the letters posted to the list. However, my endometriosis didn't seem to be in the same category as that of the women active on the listserv. In ways, it made me feel more apart rather than included"; "Before my surgery I thought I was about the only one in the world with endo. Since then, I sure know better because I now read and investigate because my daughter has endo."

Of the forty-three participants indicating contact with others with endometriosis, the vast majority rated the responses of others with endometriosis as "extremely supportive." This category of relationships, others with endometriosis, had the highest rating for level of support of all the categories in this study. Table 8 outlines how respondents rated the level of support, with 1 representing "not supportive" and 5 representing "extremely supportive."

Table 8
Level of Support from Others with Endometriosis

Rating	Count	Percent
1	0	0
2	1	2.3
3	3	7
4	6	14
5	33	76.7

Many of the participants' comments backed the high rating of support, as follows: "Female friends, especially with the WITSEND0 listserve group who actually share the condition, are the most helpful"; "My female friend on the WITSEND0 list is the most supportive. She doesn't simply focus on the medical/pain issues but is equally concerned about how I feel about what endo is doing to my life (what impact it's having on my relationship, my job, my self-esteem, my peace of mind). This is the single most valuable relationship I have right now. The pain itself no one can 'support' me through. But the 'impact' of the disease is what I need to feel supported about"; and "The fact knowing that there are other people with the same problems as you is really one of the best support available because you don't feel alone. Most of the women that I knew never heard of endo. so when I heard that there were women who not only heard of it but were dealing and living with it and leading 'normal' lives that was the best news that I had for the past 7 years."

A number of themes emerged from the participants' stories indicating what they did and did not perceive as supportive from others with endometriosis. The vast majority of comments reflected how these other women had been supportive. Pervasive themes included: the value of networking, commiseration, sharing information, not focusing

on misery, and recognizing the individual.

Value of Networking

The participants found it helpful to seek out other women with endometriosis and interact with them. As one woman stated, "I recently went to a meeting of the endo. association, a local chapter. They are very supportive and it's good to exchange information"; while another stated that responses from others with endometriosis contained "unending, lively, empathetic support that doesn't focus solely on illness but on 'life' -- can't beat that."

Many of the participants found it difficult to identify anything that was not supportive, as indicated by these comments: "I've never had a discussion with another sufferer about endo that was not incredibly supportive and helpful"; "Others I've met with endometriosis have always been very supportive"; and "There wasn't anything that wasn't supportive. No one bad mouths you and no one judges you. They just want to help you and help you realize that you're not alone and that anytime you feel alone just remember that you're not fighting this problem alone." Another participant does not know how her support from others with endometriosis could be improved, "I cannot think of any way to improve the support I have received from our group. Just keep on being empathic, encouraging, caring, listening, sharing and humble!"

Some of the participants encouraged involvement with other women with endometriosis, as noted by these participants, "Network. Join the WITSENDO list, or the Endometriosis Association or local support groups. Other women need you Be involved and share"; and "GET INVOLVED!!! I talk now to 'anyone' that suspects they may have endo. I have talked several into seeking treatment. I want people to recognize it as a disease but know there's some treatment and they're not crazy or alone."

After contact with other women with endometriosis and hearing about their struggles, a few participants recognized how fortunate they were. In comparison to other women with endometriosis these participants recognized their good fortune, "for now the contact has made me realize how extremely lucky I am compared to many women with the disease. That has helped me concentrate on my blessings rather than my problems"; and "to be honest, relief that I wasn't the WORST, that there were people out there who had more problems than I did!"

A few participants observed that they found it helpful to be helpful to others with endometriosis. Examples of how participants themselves felt supported by providing support to others follow: "Empathy and information. I also find it therapeutic to provide the same in return"; "Other women need you (and that's a good thing, it makes you realize that

you are still a vital and important person)."

Participants repeatedly noted two different support networks that have world-wide access, The Endometriosis Association and the WITSEND0 listserv on the Internet. One woman wrote "I am on the WITSEND0 line, and it is great. I've gotten so much sympathy and information (especially with the Lupron shots). It is so nice to feel like you are not the only person in the world with a problem!" Another participant observed, "I receive a lot of support from other endo patients via my computer Endometriosis can be a very lonely disease. So it's sometimes hard to find other people who have it. (Although there are millions of us!) The computer links many of us together." Where as someone else recognizes that "e-mail lists are somewhat impersonal by nature, so there's not much of the 'warm fuzzy' feeling one gets by sharing experiences face-to-face."

Other participants wrote about the importance of the support received from the Endometriosis Association, "I can't imagine life without that organization. After my hysterectomy I went about educating myself (I had not been diagnosed until I was on the operating table so I knew nothing about the disease). The resources they provided and the links with other women have simply been invaluable. No one can ever know too much about a disease they are suffering with and the Endometriosis Association removes the

isolation factor by sharing information, stories and research directions"; and "The Endometriosis Association helped me find literature, my doctor, and a support group."

Support with Commiseration

As one participant noted, "commiseration- pure & simple" is the most supportive response from others with endometriosis and as another participants wrote, "It's nice to have someone to commiserate with. :-)" Commiseration was a potent theme for the participants. As one woman stated, "They KNOW and UNDERSTAND! It is SO wonderful to have someone to talk to who knows EXACTLY what is going on with you and who both gives you support and needs support from you. I don't feel guilty blathering on about my treatment and frustrations, because I know that at the next turn I'll be the listener and my friend with endo will be the one describing her barium enema in gory detail Women who have had a diagnosis longer than I gave me good advice about what to expect from various treatments. And I don't feel so alone facing this monster."

In commiseration, many of the participants described a certain camaraderie, almost a strength in sisterhood, when interacting with other women with endometriosis. The following comments were typical: "The feeling of not being alone, not being the only one, of there being someone who really could understand what I was going through"; "I have

found that just knowing other women are in the same boat as I am (many on the list are, in fact, much worse off than I am) and are experiencing the same frustration with the medical profession that I feel has been reassuring. I am not alone"; "knowing that I wasn't the only one out there having difficulty functioning and looking for ways to cope with the pain or alleviate it to some extent"; "In what they said, I heard my 'past' and was able to see my 'future' because they had already been through it before me. It validated what I believed my problem was and was a relief because I could see some hope down at the end of the tunnel"; "We must all support each other, and that means sharing our successes, even if those methods didn't work for another woman. We must also acknowledge the failures and lend ears to another woman's tale of woe. We should feel as free to bitch about how its affecting our lives, as we are to talk about our symptoms (no matter how 'gross')"; and "No woman should feel that she's alone: There ARE other women who are walking that same path and they've tripped over the same pitfalls."

Through commiseration, the participants felt understood by others with the same disease, as demonstrated by these comments: "Others with the same problems know where you are coming from, what you are feeling, and have an idea on how to help you cope with your symptoms"; "No assumption about

my pain, just understanding that it was bad for me"; "They've been there and really understand"; "They understood the awful loss of control over your life and your relationships with other people - getting mad with your colleagues and friends for no reason, sex life ruined due to pain during sex, problems with concentration and memory loss at work"; "They've been there and really understand."

Support with Information

Another very strong theme was the level of support participants found from the shared information from other women with endometriosis. One woman summarized, "The best support I feel I've got from others with endometriosis is information" and another added "I've been more educated by other women with the disorder, than by any medical person." Another woman advised women with endometriosis to "share any and all information that you get your hands on. This in particular, is what has been so wonderful about the WITSENDO list in my opinion. Various things that people mention have caused me to look into other things that I would not have otherwise thought about."

Many participants wrote about the value of exchanging information. For example, participants wrote: "Most importantly, the endo group on the Internet has been the best support because it connects me with so many women who are experiencing this disease and we are all able to share

information"; "The help from being able to compare notes with others in the same medical boat has been invaluable"; "It's wonderful to communicate with other women who are suffering from the same disease. We share practical info (doctors, drugs, diet, etc) as well as emotional support"; "Suggestions about lifestyle. Suggestions for pain relief"; "We can support one another. We have ears and eyes in many directions, so can share widely differing experiences and discoveries." Another participant notes that women with endometriosis "are interested in the ins and out of the disease and treatment which understandably bore others."

Many participants found it supportive to share experiences with symptoms and treatments. For example, participants wrote: "Especially helpful are comparisons of symptoms (especially weird, subtle ones); information on what some treatments feel like/do to the body; discussions about alternative coping strategies"; "The fact that we all share with each other our experiences of what happened when we went through this test or that test, what we had to do etc. Someone will sometimes share some trick or hint that helps them cope with the pain, or someone will share a book that offers good advice on diet and exercise"; "It's nice to hear about other's experiences with surgeries and specific treatment plans (e.g. 'How did Lupron work for you? Did you have hot flashes? If so, how bad were they? Did you find

it to be useful in stalling the spread of endometriosis?')"; and "Getting specific is really helpful. Some of the most useful discussions have been about rather embarrassing subjects such as constipation and sexual positions."

Participants offered the following advice on how women with endometriosis can be more supportive of other women with endometriosis by sharing information: "Exchange as much information as possible. Be realistic with one another but do not be overly negative"; "Be willing to compare symptoms... share information on what hurts... be specific; Share information on treatments"; and "Keep in contact, share information on journal articles and books about endometriosis, share helpful advice about living with pain."

Support by not Focusing on Misery

Information sharing had its limits, since several of the participants did not find it supportive when they became overwhelmed with other women's stories of misery in coping with endometriosis. Examples of this include: "When I hear these people talking of their experiences, some of which is much worse than mine, (e.g. multiple surgeries, no children yet, etc..), I sometimes don't want to associate myself with them. I can sympathize and hope the best for them, but I would like to hear more positive things... I just don't want to envision myself with chronic problems in the future"; "The outlook was occasionally a little gloomy. I found,

with most of my friends with endo, that it usually comes back fairly quickly after surgery. This can be very discouraging when you're suffering daily with it & hope surgery will offer a 'cure'; and "Some women with endo I find are so damned depressing and DON'T want to be cheered up, they just want to feel sorry for themselves and drag others down with them."

To avoid being mired in the trap of misery, participants offered this advice when interacting with others with endometriosis: "Keeping in mind the variety of endo experiences and the fact that comparison of endo symptoms is not a contest for who-hurts-worse or whose-problems-are-most -serious"; and "Try to be upbeat and avoid horror stories when talking to a woman who is facing surgery or a new drug regimen. Do share stories of treatments or lifestyle changes that have helped you. By all means spread the word if you find an especially good (or especially bad) doctor."

Support by Recognition of Individual

A number of participants found it more supportive when others with endometriosis recognized, acknowledged and accepted that each woman with endometriosis is an individual with personal choices and issues. Some participants did not find it supportive when "sometimes there is an attitude of -this worked for me therefore it should work for you";

"Some assume that you should be undergoing the same treatment as they are. Even if you don't want to take a drug, or have already taken it with no effect"; and "Assumptions that my life goals are the same as theirs."

Participants offer the following advice to recognize the individual: "Share your experiences. Also, realize that other's experiences may not turn out the same as yours (e.g. reactions to drugs)"; "Realize that there are a variety of symptoms (including pain and/or infertility) and that everyone affected by the disease may weight the importance of these symptoms differently depending on what they are experiencing, the varied successes of their treatments, their level of support received, etc."; and "It MUST be remembered that the disease produces erratic symptoms -- one woman will be incapacitated while another feels nothing. It produces a wide variety of symptoms and concerns, none of which duplicate in any two women. ANY woman with ANY amount of endo is going to be suffering somehow, whether its occasional bouts of IBS [Irritable Bowel Syndrome], repeated miscarriage, or debilitating pain. We might all be in different parts of the boat, but *its the same boat nonetheless*."

Some participants believed that advice could be a problem because of individual differences, as noted in the following example: "Some women with endo are very

opinionated about their care. They can take it too far. (Like saying you should never have a hysterectomy; never have a laparotomy; never take certain drugs, etc.)." Others offer that it would be helpful to "Respect the decisions of others. Offer advice in a non-challenging way"; "Listen to others. Don't be too quick with advice"; and "Sometimes, and we can all be guilty of this, we try to give advice to others with Endo, because we know. WE forget to shut up and LISTEN."

Because of individual differences, a few participants noted that it was difficult to feel supported by others with endometriosis who had different symptoms. Examples of this include: "I find that much of the discussion focuses on fertility issues. I sometimes feel irrelevant as it was never the issue to me"; "Women dealing only with the infertility aspect of the disease cannot understand the extent to which the pain can affect a life or a family"; and "As the youngest person in the support group, I couldn't relate to much of the infertility problems people had. I didn't find it useful when people told me to go have a baby now."

From participants' stories, a number of themes emerged describing what they did and did not perceive as supportive from others with endometriosis. In general, participants revealed a value in networking, commiserating, sharing

information, not focusing on misery, and recognizing the individual.

Health Care Providers

Participants shared many poignant and compelling stories about their experiences with health care providers. All of the responding participants except two had spoken with a health care provider in the last twelve months. The two that had not spoken with a health care provider in the last twelve months had the following explanations: "I have no health insurance"; and "I have found that it doesn't make any difference--no one has a cure, and I already know what the treatments are. I have taken several of them, as a matter of fact. In addition, I find that it is worse for me to talk to someone (responses from physicians are unbelievable) and get an insensitive, stupid, condescending remark than to get nothing at all. I keep up on what information is 'out there' and will go to someone if I already know they can help me via a specific treatment."

The participants spoke with a variety of health care providers in the last twelve months about their endometriosis, as shown in Table 9. Nearly all of the respondents spoke with a physician in the last twelve months and about one-fourth spoke with a nurse and/or nurse practitioner.

Table 9
Health Care Providers Spoken With

Health Care Provider	Count
Physician	42
Nurse	12
Nurse Practitioner or Midwife	12
Health Educator	2
Nutritionist	1
Chiropractor	4
Acupuncturist	4
Homeopath	0
Counselor or Psychotherapist	8
Massage Therapist	2
Physiotherapist	1

Forty-two of the participants rated the level of support of the health care providers' response with 1 representing "not supportive" and 5 representing "extremely supportive". Table 10 outlines how respondents rated the level of support from health care providers: As shown in table 10, respondents rated health care providers all along the scale, with the largest group rating support as moderate. Health care providers received the lowest rating for support among the four designated categories of relationships in this study, spouse/partner, friends/family, others with endometriosis and health care providers. A number of participants revealed some distressing experiences with health care providers, only some of which took place during the last year, as noted by this participant whose level of support from health care providers has improved in the last year, "I've been to so many doctors that I lost count long ago. I've only had two positive experiences with health care providers and both individuals came into my life just this year." On average participants have had symptoms of endometriosis for twelve years, and so have had many years to experience different health care providers and search for a better one.

Table 10
Level of Support from Health Care Providers

Rating	Count	Percent
1	6	14.3
2	3	7.1
3	13	31
4	11	26.2
5	9	21.4

A number of themes evolved from the stories women related about their experiences with health care providers. Most but not all of the comments related to physicians. The following quote demonstrates some of those themes that the participants found supportive: "My GYN [gynecologist] has been very sympathetic and has never questioned whether my pain really exists or not. He has given me articles from med. journals and has answered all my questions. He has treated me like an intelligent person and has told me what he can do, and what he CAN'T do. Being kept informed about my condition has given me a feeling of some control over this problem." Another participant advises health care professionals to "1. LISTEN, 2. BELIEVE, 3. Educate themselves about endo." Themes that emerged from the analysis include: the overall themes of listening, believing, being knowledgeable and sharing knowledge, as well as the themes of not acting condescending and recognizing the patient as an individual. Comments will also be shared about participants' experiences with psychotherapists or counselors.

Support by Listening and Believing

The participants noted that it was supportive when health care providers listened to them and believed what they said. One woman wrote glowingly about "one marvelous doctor who actually put away his pen and chart and LISTENED,

and kept on listening and asking if there was anything else until I felt that I was 'talked out'." Another participant wrote that she "found one doctor out of 10 who was willing to listen to me and find the best methods to help me out. I would recommend him to anyone with endo."

The participants wanted health care providers to believe that the symptoms are real and something to be taken seriously. Many participants found it supportive when their symptoms were believed as in the following examples: "OB/GYN ... She never doubted me for one minute when I told her about my pain and symptoms. She listened intently and was very patient with me because I cried throughout the whole visit once I realized I had finally found someone who not only believed me but was actually going to help me"; "Acknowledgement that the pain is REAL and that no matter how serious the disease may LOOK from a physical standpoint (inside), the look of the disease can not judge the amount of pain"; "My GYN has been very sympathetic and has never questioned whether my pain really exists or not." Similarly, participants advised medical personnel to believe them, as in the following examples: "Believe what your patient is telling you and treat them accordingly. Express the willingness to try whatever it takes to take care of the problem"; "And don't question whether or not the patient feels pain - she knows her body better than anyone

else"; "Listen to all symptoms- take them seriously. Believe in us."

Believe Symptoms Require Medication.

A few participants wanted health care providers to believe that the pain was real and provide appropriate medication. One woman wrote that "getting adequate pain medication was a blessing"; and another advises health care providers to "give women the medicine they need to get through the pain. Through my orthopedic surgery, I learned that 1 or 2 tablets of tylenol 3 with codeine a month makes a huge difference in my ability to cope with endo."

Do Not Believe Psychogenic.

The participants wanted health care providers to believe that they had a medical problem that was not psychogenic. Participants noticed that it was supportive when the following happened: "For the first time I was told it was all in my abdomen, not my head! Just getting the facts straight has been an immense help"; "The fact that she didn't tell me it was all in my head or make me feel like I was just being a 'crybaby' or a hypochondriac" and "All my doctors recognize that endometriosis is a real disorder, and that I am not merely a hypochondriac. That in and of itself is reassuring." It was not supportive: when physicians order "humiliating tests that come back normal and then want to say it's all in the patient's head or they become

dismissive so that a further search for a doctor then must begin if we want any help." One participant offers this advice to health care providers: "Never tell the patient it is 'all in her head' or that she is 'frigid,' if you believe that to be the case. The repercussions of being told this linger and are more painful (at least in my case) than the endo itself."

Believe by Taking Seriously.

The participants not only want their medical symptoms recognized as "real" but they also want them taken seriously and not minimized. Many participants wrote about how it was not supportive when they were not taken seriously or their symptoms were minimized, as follows: "I feel victimized by the physicians -- which is not helpful given all that the disease has put me through. I don't feel it should be my job to convince them that endo is never cured, to justify my pain in order to 'earn' their assistance!"; "The urologist asserted that only 'career gals who put off having their babies' get endo -- I was insulted, angry and hurt"; "I've gone to the doctor's wondering if they've written 'hypochondriac' into my file because they seemed so unconcerned with my pain. I've only had one nurse practitioner after seeing ~20 doctors take me seriously"; "Yet while I lay on the exam table white-knuckled with tears streaming down my face, the nurse assisting with the

procedure told me, 'relax, I'm sure its not that bad'; and "The doctors I went to, kind of brushed off my menstrual pains, like they weren't a serious problem. I think doctors need to realize that if periods are incapacitating, there is a problem, and tests should be performed, and pain relief offered." On the other hand, participants found it supportive when they were taken seriously, as in the following examples: "They [health care providers] took me seriously (which is more than they did years ago)"; and "My RE [reproductive endocrinologist] takes my disease and my symptoms very seriously - which in itself can be tremendously supportive when so many health care professionals don't acknowledge the disease's impact."

The participants advise health care providers to take them seriously and not minimize their symptoms, as in the following examples: "Don't ever ignore it all as just 'female problems.' Take it seriously! Do a lap! Educate yourself on endo like you would any serious disease"; "Don't tell a woman with severe pain that 'a glass of wine' might help"; "Never dismiss any symptom reported by the patient. if the patient is reporting the symptom then it is important to them"; "Take their symptoms seriously. This is not a disease that is in their heads"; "Don't minimize their problem and/or feelings"; and "When a woman comes to you complaining of severe menstrual pain, don't tell her it's

stress. Most women aren't going to complain unless it's really bad because we've all grown up believing that pain during menstruation is 'normal'."

Support by Being Knowledgeable

In addition to listening and believing, the theme of knowledgeable health care providers as being supportive was overwhelmingly strong. Many of the participants wrote about how supportive it was to have a well-informed health care provider, as follows: "My GYN. seems to know what he is doing (he specializes in fertility cases, which means he treats and performs surgery for a lot of women with endometriosis), which I find comforting. He doesn't have a great bedside manner, but is always willing to stay and answer all my questions if I make a mental list ahead of time, and he seems knowledgeable"; and "Fortunately, I have a very good gyn. and nurse practitioner both of whom are knowledgeable and supportive in general, but especially when it comes to endo."

Some of the most compelling stories were of health care providers who were not knowledgeable and added to these women's struggles. Examples of nonsupportive responses, because of a lack of knowledge, from health care providers are as follows: "He [physician] also made some astoundingly inaccurate medical statements about the disease which made me furious that I had read more medical journals than he

had. I felt as though I had to 'educate' him and yet he has the 'power' to help me or not"; "I had to go through 'several' physicians over the years that had no knowledge of what my problem was"; and in the "gynecology department, where a kindly older doctor suggested I try getting pregnant to cure it. He put me on birth control pills 3 times a day which is not only outmoded therapy, but considering the extent of my disease was never going to help anyway."

The participants offer the following advice to health care providers on how to be more supportive of women with endometriosis by being knowledgeable: "I want them to do their reading, keep up with journals, go to conferences, and stop blaming patients for diseases which as yet are idiopathic"; "Be willing to discuss it, stay abreast of the latest treatments, and combine their medicine with nutrition and holistic attempts to manage the disorder"; "Stay as current as possible with the information available on the disease"; "If you haven't read up on endometriosis much in the last 5-10 years, now's the time to get some education. Know what advances there are in treating the disease. Don't let your patient know more about treating endometriosis (or any other disease, for that matter) than you do unless she is a doctor herself and therefore is reading all the same medical journals etc. that *you* should be reading. Many

patients with chronic illnesses can be very knowledgeable about their disease, its etiology, prognosis, treatment options, etc."

Some of the participants wanted health care providers to recognize their limits of knowledge and refer elsewhere when those limits are reached. The following quotes of participants illustrate that: "Also admit that you don't know much about it if you don't and refer her to a specialist. You shouldn't be treating women for a disease that you don't know much about!"; "If they don't know enough about this disease, either learn about it or refer the patient elsewhere. Not only is pain a huge issue but so is fertility. Women should not WASTE time with doctors who don't know or care enough about this problem"; "Refer them to an expert if you feel you do not have the expertise or personality to deal with them."

Support with Information

The participants wanted their health care providers to be knowledgeable and to share that knowledge with them. The sharing of information was another strong theme. The following participants wrote about how supportive it was to be kept informed: "He has given me articles from med. journals and has answered all my questions. He has treated me like an intelligent person and has told me what he can do, and what he CAN'T do. Being kept informed about my

condition has given me a feeling of some control over this problem"; The doctor and nurse "encouraged me to call - were unfailingly cheerful in answering all my questions & complaints"; "He did draw me a diagram and explained briefly what the disease entailed to help me understand the situation a little better"; "The medical practitioners have all been very accepting of my need to be informed about both the disease and about the treatments"; "He did things like finding me articles on endo. because he knows I like information, and posting them to me. He didn't have to do that."

It follows that the participants did not find it supportive when health care providers did not keep them informed, as noted by the following participants: "I hate the feeling that I don't have all the information that she does... I want to be fully informed so that I can discuss my treatment choices as an equal"; "The physician & nurse practitioner did not explain very much about Endo or the side effects of Lupron"; "My consultant gynaecologist is very overworked. I think he is a good doctor, but I think I got a raw deal so far in terms of his time explaining what was wrong and what the options were. I asked for more information I did not get it"; "My doctors that I mentioned it to, all recommended a hysterectomy. After the 3rd recommendation for it, I gave in, because of the pain. I

would have liked more info going into the operation."

In regards to information, the participants had the following advice for health care providers: "I think information is the key. Doctors need to explain WHY they are recommending or not recommending treatments of various kinds. I think many health care professionals feel that the patient does not have the necessary background to understand all the issues and err on the part of not giving the patient credit for understanding and having input into decisions made which directly (and intimately) concern her health"; Health care providers need to "Provide literature in their offices to educate women about the disease"; "Remember that this is an intelligent adult who wants to be informed about her condition and options. Explain what you know, what you are doing, and what you don't know"; "Encourage your patient to educate herself and others about the disease. Give her information about the 'Endometriosis Association'"; and "Help them [patients] to come to clear decisions by keeping reference material on endo or lists of associations, books etc."

Information to Work Together.

The women in the study wanted to be informed and to work with the health care provider as a participant in their own health care. Being an active participant and decision-maker in her health care was another important theme to many

of the study respondents. Examples of this theme follow: One research participant wanted "some education on the disease, and some discussion of therapies"; For another participant, "it took me 10 doctors and more nurses until I found one who was willing to help me find the solution to all the pain"; Others wrote that "I think it is crucial that physicians let women have a say in the care they are given. Give them the options, tell them the pros and cons (and for crying out loud be HONEST about it!) and let them decide which option is best for them"; "Doctors should share treatment plans more completely (first we try this, then this, and if this happens, we do this). Make me a partner in the process... I want to know EVERYTHING"; "Offer options. Don't get irked when we want a second opinion. Encourage us to ask questions & learn as much as possible. Be honest. Explain procedures & medications clearly."

One participant found it supportive when "he [physician] allows me to make my own decisions, like when I refuse to take certain drugs. He supports me in that"; and another found that her physician's "unwillingness to accept that the final decision about treatment is mine" as not being supportive. As an active participant in their health care, the women in this study did not want to be looked down on.

Support without Condescension

Another theme observed in a number of participants was that a condescending or patronizing attitude on the part of the health care provider was not supportive. Quotations from participants that demonstrate this theme follow: "My previous gynecologist, a woman, was very patronizing and insisted that I should get pregnant and quit whining"; "When they finally did decide it might be endo, my primary doctor sent me off to the gynecology department, where a kindly older doctor patted me on the hand and said basically, 'there there, dear'." Participants give this advice to health care providers: "Don't talk down to them [patients]"; and "LEARN about the disease! Don't hide your ignorance behind a condescending attitude."

Support by Recognizing Individual

The participants not only wanted to be an informed decision-maker and treated like a partner without condescension, they wanted health care providers to recognize that they are unique with unique bodies and values. The concept of being treated as an individual by health care providers was noted by many participants with comments such as "Don't treat them [women with endometriosis] with a 'cookie-cutter' response, as a formula that is used on each patient without taking individual into consideration"; and "Treat each patient as an individual, listen to what they want/expect."

The following participant wrote about her physician who did not consider her uniqueness or acknowledge her as an individual, "My OBGYN cares nothing about providing me with good health care or easing the pain I suffer with this disease. At my last visit she prescribed Synarel without any examination (I had not seen her for 4 years) and the only information she gave me was a copy of the manufacturer's info sheet written in medical jargon. She prescribed twice the recommended dose and when I queried her on it she said that she didn't want me getting pregnant (SHE did a hysterectomy on me 5 yrs ago). She also told me that if it didn't work - then she would know to look for 'something else.' She did not even close the door during my appointment (all of 5 min) and spent half the time with her head out the door."

Another participant wrote about not being respected or acknowledged as an individual, "Where to start?!!! The doctor who gave zero empathy and the roughest pelvic exam I've ever suffered? who, after an hour's drive and a longer wait asked one question "did the pills help" and when I said no, gave me a different prescription, and kicked me out? A different doctor who wanted to put me on drug treatment for depression when it turned out I had insomnia as a reaction to codeine? The 'educator' who knew it all and had all the answers and blithely disregarded any other experience?!"

Several participants wrote about being respected as an individual. One woman noted that "they have all apologized in advance for hurting me during pelvic exams. I don't know why that makes such a difference, but it does."

Participants also wrote about health care providers not taking the entire individual into account. Examples follow: "All my doctors have a tendency to focus only on that small part of me which they themselves are treating, without (in my opinion) sufficient concern about how their treatments will affect my other conditions"; "Listen to the patient, consider her feelings, do not forget that she is a *whole* person and that the functioning of other subsystems in her body affects the functioning of her reproductive system, and hence her endo."

A few participants wanted health care providers to acknowledge their unique beliefs and value systems, as noted by this participant, "I'd also suggest that health care providers avoid any value judgements associated with fertility issues (e.g. avoid pressuring the patient to have children soon, avoid suggesting that if they had had children their endometriosis would be alleviated, etc.)."

In summary, participants found it supportive when health care providers listened to them, believed them, were knowledgeable, shared information, did not look down on them and viewed the participant as a unique individual. One

participant wrote that her health care providers were supportive because "they take me seriously and know what I am talking about. They have good suggestions for management of endo and are up to date on the latest in the literature. (I guess I just lucked into a good set of Drs.!!)"

Comments about Psychotherapists

Eight participants had spoken with a psychotherapist or counselor in the last year. In general, these participants' comments indicated that the psychotherapist/counselor was supportive, as evidenced in the following: for one participant, the "(Psych.) Listened- help me to understand my emotional tangle"; Another participant's counselor was supportive by helping her realize "I needed to find supportive doctors"; Another participant revealed, "My therapist has been incredibly supportive... always asks about it... and always responds sympathetically to my reports of pain"; and another participant wrote "A few years ago I saw a therapist who was terrific. I saw her because I was, in part, at the end of my rope over pain from endometriosis and thought that I hadn't tried therapy to relieve the pain--and that maybe it would help."

One woman did not find her psychotherapist/counselor supportive because "the psychiatrist my husband and I saw did not spend much time on this problem. She didn't seem to offer many methods for coping with the problems that endo

causes."

Work Place

Although experiences with employment were not asked about specifically by the survey, many participants commented on their employment. They valued having an employer's support and recognized how difficult it was without that support. A few participants commented on co-workers and what was and was not supportive. Some participants also wrote about their struggles in the work place because of endometriosis. Themes which emerged included understanding, flexibility, practical help, and support with struggles.

Support with Understanding

A number of participants wrote about the value of having an understanding employer and co-workers. The following quotes demonstrate the value of an understanding employer: "When I was first diagnosed with endo I had a boss who immediately understood my situation since his wife was also dealing with endometriosis. He was extremely understanding of the fact that I was absent from work a great deal due to the pain and later recovering from surgery. He never questioned my time off from work and suggested I speak with his wife regarding the disease"; "Well, my boss actually qualifies as a male (and very supportive) friend. But I think it is important that a

woman be able to talk to her employer (if she is able to work). There are lots of sick times, lots of just "pain days" that need to be acknowledged as a real thing. My boss happens to have a science background, and so he's interested in what Endo is and how it affects me. He's also just a very kind man who cares when I am in pain. Again, I've been pretty blessed. Understanding and caring are the two most important gifts any person can give us."

These respondents did not feel supported when their employers and co-workers lacked understanding of their illness: There was "no support from employers who dismiss the symptoms and problems associated with endo as 'women problems' at 'that time of the month'"; "I guess the least supportive response has been from people who don't want to know what it's all about. Some co-workers (not necessarily "friends") don't understand why I've had to leave work with this strange "illness" so often. I feel a subtle disdain, like I'm not doing my job. Mostly from the males."

Since health insurance is often an employee benefit, problems with it may be associated with employment issues. As in this case, the employer may be understanding, but there are still struggles with health insurance. "Health insurance is a big headache for any chronic problem like endo. Even where employers are understanding and sympathetic, as mine is, their hands are tied by what the

insurance companies dictate! The whole health care system is set up to handle acute problems and fails abysmally to cope with chronic problems."

Support with Flexibility and Practical Help

In addition to wanting understanding, several participants commented on how they felt supported when employers were flexible and provided practical help.

Examples of employer support with flexibility are:

"Employment is affected strongly when you must be seen frequently at the doctor's office, have surgery, etc. That means taking time off from work. In my office, I was lucky to be able to utilize flex time to allow me time for medical treatment"; "My employer was very understanding and gave as much leeway as possible during the worst of my illness (e.g. I worked at home quite a bit pre- and post-surgery)"; "My boss was fantastic- (male)- he helped to rearrange my work schedule & location."

Some respondents received support when their employers provided assistance with the practical aspects of struggling with endometriosis: "My employer made coping with endo. *much* easier. My boss was very understanding about being out a day or two a month due to pain. When I had a hysterectomy, my boss arranged for medical leave-pool money for me, so that my paycheck wasn't extremely smaller than usual during the 8-week recovery time. One co-worker

transferred some of his unused sick time to me, again so that my paycheck wasn't too small"; "My boss even made sure I had an office with a cooling unit so I could deal with the Lupron-induced hot flashes! I've been pretty open with every one about my endo - and people have been great."

Support with Struggles

A few participants wrote about their struggles with endometriosis and the difficulties that causes in the work place. One participant wrote: "The work place is VERY important, because it is here where women often get their most unsupportive people. I have been unemployed for the last 3 years, unable to keep a job longer than a menstrual cycle, because people are unable or unwilling to make allowances for the emotional volatility and physical constraints that endo has given me. I am not alone in this boat. A supportive employer is VERY important, as important as a supportive life partner: I have a part time job, 8 hrs/week, with moderate physical labour. About 4 hrs into it, I conk out -- I get nauseated and sick, too dizzy to stand, hips won't support weight, etc. After this, I cannot work. I feel very much a failure, unable even to work 4 simple hours without getting ill. My boss, however, sees me in a different light: She's never seen anyone pack more work into 4 hours, and thinks I'm more valuable in my 4 workable hours than her last crew of completely able-bodied people.

This is slowly assuaging my fears about losing this job too."

Another participant wrote: "The employer issue is one that I can relate to. For about 2 years prior to my lap. in May 1994, I was using at least a day of sick time per month on average due to my severe cramps and bleeding. As a result, by the time I was diagnosed, had my lap. and was then out of work for a month (because of an ovarian cyst that was discovered during the procedure and then burst), I had used all of my available sick time and was forced to use short-term disability benefits (75% of regular pay) for the last week or so of my time out of work. Of course, now I'm feeling better, but have zero sick time remaining until my anniversary date in March 1995. So now even getting a cold means having to either take a day without pay or use vacation time. Bottom line here is that while direct supervisor (a woman) is very understanding, she has little control over the general sick time policies that govern where I work. She has cut me a little slack during this period of having no available sick time, but it's been minimal. For example, I'm in work today with a horrible cold when I should be home in bed!, but I don't want to use my vacation time or go without pay. This may sound minor in the big picture, but has actually been a source of anxiety for me personally."

One participant summarized the positive and negative aspects of the job world: "Employers can make endo especially harrowing. I am fortunate to have as a boss a fifty-something woman who had an endo-related hysterectomy some twenty years ago, so she understands why I sometimes miss work during my periods. Other sufferers are not nearly so fortunate, especially those whose bosses are men. I would expect that many sufferers have similar problems with co-workers."

Summary

Forty-six women shared their experiences with endometriosis. They communicated their stories in writing on a survey, designed to develop an in-depth understanding of their experiences with social support. The survey focused on what these women wanted and received from four categories of relationships: spouses/partners, friends/extended family, others with endometriosis, and health care providers. Almost everyone spoke with someone in each of these categories in the last year about their endometriosis. As the data were analyzed, the context of the disease with which these women were struggling emerged. It became evident that this context was important to appreciate the participants' experiences with social support. Even though not specifically part of the survey, many participants commented on the relationship with an

employer. The chapter was therefore organized with the following sections: context, overview, spouse or partner, friends or extended family, others with endometriosis, health care providers, and the work place.

Each woman's experience was unique, yet there were many common themes that echoed throughout the experiences of all participants. These themes emerged from the stories of these women's experiences as the data were read and re-read. In relating the themes, the participants' own words were used in an attempt to capture the intensity behind their stories and the complexity of their experiences.

The participants poignantly described the context in which they received social support. They described their struggles with endometriosis and its emotional impact. Included in their struggles were problems with diagnosis, prognosis, infertility, and pain. The emotional impact of the disease was powerful and involved stress, emotional volatility, bitchiness, anger, frustration, fear, self-esteem, guilt, disappointment, loss, and depression.

Some themes were very strong across all of the relationship categories in this study. These were discussed in the overview section and included the importance of listening, believing, being knowledgeable, understanding, and sharing information.

Every participant who had a spouse or partner talked

with that person in the last year about their endometriosis. A number of themes evolved from the compelling stories, shared by these women about their experiences with their spouse or partner. The participants found the following to be supportive from their spouses or partners: listening, believing, understanding, being knowledgeable, committing, being patient, caring, asking, comforting, helping, expressing feelings, not fixing and not judging or blaming. Participants also described the impact of endometriosis on their sexual relationship and the importance of an understanding and accepting partner.

Some participants noted a similarity between the support they wanted from partners and from friends or extended family, with perhaps more expected from spouses/partners. The participants spoke with a wide variety of friends and family. From the shared experiences with support from friends and family, a number of themes emerged. As was true with support from spouses/partners, responses in the category of friends and extended family shared the common themes of listening, believing, being informed, sharing information and understanding; and additional themes of sympathy or empathy, support with disease struggles, and not blaming, minimizing or worrying.

Of the four major relationship categories studied, participants rated the category of others with endometriosis

as providing the highest level of support. The vast majority of comments reflected how these other women had been supportive. Pervasive themes included: the value of networking, commiseration, sharing information, not focusing on misery, and recognizing the individual.

In contrast to the category of others with endometriosis, the relationship category of health care providers received the lowest rating among the four major groups of relationships. The participants had spoken with a wide assortment of health care providers but the majority of comments focused on physicians. Themes discussed included: the overall themes of listening, believing, being knowledgeable and sharing knowledge, as well as the themes of not acting condescending and recognizing the patient as an individual. Comments were also shared about participants' generally supportive experiences with psychotherapists or counselors.

A number of participants commented on their social support experiences in the work place. They valued having an employer's support and recognized how difficult it was without that support. Themes discussed were understanding, flexibility, practical help, and support with struggles.

The participants related many very compelling and intense stories surrounding their endometriosis. The researcher was struck by the power projected through their

written words. They eloquently related what they did and did not want from their support network. Although each woman's experience was unique, many common themes reverberated throughout the experiences of these forty-six women.

CHAPTER FIVE: DISCUSSION

Introduction

As many as one in seven women are affected by endometriosis (Merck, 1992) and research related to how these women cope with the pain and infertility caused by the disease is limited. This study begins to fill that void by describing the social support experiences of the study participants and their level of satisfaction with the support. Forty-six women with endometriosis participated in this study. They shared their struggles with the illness and their stories of social support.

This study used a combined theoretical framework of a stress and coping model and symbolic interactionism. The McCubbin and Patterson double ABCX model of stress and coping fit because the bB factor depicted resources, and social support was definitely a resource that the participants utilized. The participants utilized this resource and gave meaning to it. The social support experiences of these women, as portrayed and perceived by these women, were studied. The cC factor in the double ABCX model and symbolic interactionism provide a framework that focuses on the meaning of the participants' experiences. This study explored the resource of social support as perceived by the participants.

A written questionnaire was designed to research the

social support experiences of women with endometriosis. The questionnaire asked about support with spouses/partners, friends/extended family, others with endometriosis and health care providers. Volunteers were sought from the WITSEND0 listserv on the Internet. Forty-six women with endometriosis shared their experiences. The participants took the time and effort to share many poignant and compelling stories.

Many common themes echoed throughout these women's stories. Some of the themes are more prevalent in one category of relationship, while others were strong across categories. In general, participants wanted their social support network to be knowledgeable about the disease, to understand the context of the disease, to share information about the disease, to really listen to them, and to believe that their symptoms are real.

Other research studies (Abbey, Halman & Andrews, 1992; Abbey, Andrews, & Halman, 1991; Goodenow, Reisine, Grady, 1990; Jamison & Virts, 1990; Primono, Yates, & Woods, 1990; Warren & Baker, 1992; White, Richter, & Fry, 1992) have found social support to be an important factor in coping with medical conditions other than endometriosis. As with the other studies, the participants with endometriosis in this study clearly valued their support network.

Abbey, Halman and Andrews (1991, 1992) studied the

stress of infertility. Since infertility was one struggle of some of the women in this study, a similarity in results was anticipated. Similarly to this study, Abbey, Andrews and Halman (1991) found the levels of spousal support to be high. Also like this study, exchanges with similar others were viewed as being more helpful than exchanges with friends and family members (Abbey, Andrews & Halman, 1991).

Social Context

The social context in which women with endometriosis live, impacts their coping. Culture and gender issues influence the social support these women receive.

Cultural Issues

The socio-cultural context in which the participants live impacts their struggles with endometriosis and their social support system. This study included participants from four different countries with differing attitudes. One participant from the British Isles noted that in her country, "there are additional problems due to women being embarrassed to talk about problems with sex and reproduction, and due to poor general knowledge about endometriosis among general practitioners."

In addition to cultural differences in medical practice and acceptable topics of conversation, availability of health insurance or health care may be an issue. The four different countries represented by the sample have different

health care systems with differing availability and accessibility. One citizen of the United States reported that "health insurance is a big headache for any chronic problem like endo. Even where employers are understanding and sympathetic, as mine is, their hands are tied by what the insurance companies dictate! The whole health care system is set up to handle acute problems and fails abysmally to cope with chronic problems." Another participant did not see a health care provider in the last year because of "no health insurance." The culture in which the participants live influences their experience with endometriosis.

Gender Issues

Participants noted some gender differences in their experiences of social support. Interestingly, the differences were not consistent. Some women found men more supportive and others found women more supportive. The following responses indicate that men are more supportive: "I've found men to be more supportive than women (who don't have endo). Women who haven't had endo seem to think that I'm just a whiner. :) [smiling face symbol] They take the 'it's all part of being a woman' attitude. Men, I think, are a bit overwhelmed by the topic of a woman's reproductive system. They're more curious and empathize more"; "Male vs. Female acquaintances: Men are more understanding; women

seem to think 'it's not so bad for me, she must be exaggerating or a wimp'; "Men acquaintances are more accepting and understanding than women, and show more interest in learning about the disease"; and "the majority of men I talked to were willing to listen and often told me they knew other women who were experiencing the same thing"; "Male friends: Overwhelmingly supportive, even to staying up all night to keep me company online, if I'm having a period. Most are very interested in learning about the hormonal complexities involved, and how the physical symptoms and mental symptoms relate. Most 'file it away', in case they have a wife or g.f. [girl friend] with endo."

In contrast, the following comments reflect that women tend to be more supportive than men: "Male friends (to which I go into much less detail) seem very grossed out by the very idea of endometriosis once they hear what it is; I find this kind of irritating"; "Being male and never having experienced menstruation, he could not empathize with my discomfort or begin to imagine how I felt physically"; "My male friends.... well, they are pretty uncomfortable with the topic"; "I guess the least supportive response has been from people who don't want to know what it's all about ... Mostly from the males"; whereas "my female friends, by and large, have been overwhelmingly supportive and loving. There seems to be an understanding there, a real caring";

and "my mother was more able to deal with the details than my brother or father." In referring specifically to health care providers, one participant reflected, "in general, I would say that most of the male health care providers I've seen (but not all!) were insensitive, uncaring, and mistrustful about the amount of pain I told them I was in. Most (but not all!) of the female health care providers were more sympathetic, and didn't just toss pain pills at me." Another participant, in writing about her gynecologist and nurse practitioner, wrote "mostly, it helps if they are ... women." Gender differences in social support noted by respondents were inconsistent.

Limitations

General Limitations

This study focused on the social support of women with endometriosis. The sample was limited to a group on the Internet, so women with endometriosis who do not have access to the Internet are not represented. There is currently no data to indicate how female users of the Internet differ from women who do not use the Internet, but it is possible that these computer literate women differ in important ways from the general population of women. The participants were unique, highly educated consumers of health care, and in general, had the financial resources to access the health care of their choice. This study was not expected to be

generalizable to all women with endometriosis. It did however attempt to develop an understanding of the experiences and advice of the women who participated.

Other factors, not explored in this study, interact and influence the factors in the study therefore limiting the interpretation of the data. The woman with endometriosis could have other stressors and resources not explored in this study. For example, other factors such as family and individual financial resources or individual and family characteristics could interact with and influence social support.

Also, the process of adaptation is interactive. For example, pain can influence adaptation but adaptation can also influence pain. Roth and Robinson (1992), in describing rheumatoid arthritis, state that "it is important to recognize the virtual impossibility of separating psychological from physical variables. The two are wed in an interactive cycle, pain leading to negative affect and stress, negative affect and stress exacerbating pain, and so on" (p.61). It was, therefore, limiting to look at only social support in a linear fashion without considering other variables.

This study used a self-report, written questionnaire to collect the data. By using this design instead of an interview, feedback was severely limited. In an interview,

additional questions could have been asked about the meaning of a response that were not feasible with this design.

As well as being an asset, the researcher's diagnosis of endometriosis may also be a limitation. Some themes resonated more and some less based on the researcher's experience with social support. Therefore, some themes, with less resonance with the researcher, might be overlooked. To reduce this possibility, a colleague reviewed the data for missing themes.

Question Limitations

Infertility Question.

Question number one asked "How much is infertility from endometriosis a problem for you at this time?". Of forty-six participants, twenty-seven answered with "1", representing "not at all". The researcher asked participants for feedback to help in understanding this result. This answer does not indicate how many participants have ever had a problem or might in the future. One participant, in providing feedback about this question, noted that "I think that the qualifier 'at this time' almost certainly had an effect on results. For example, at this time in my life, I don't think I should have children. A few years ago I really would have wanted one, therefore at this time infertility doesn't bother me."

Several participants, without being asked, wrote that

they have had a hysterectomy. Comments about this included: " Re: question #1: infertility is not a problem due to total hysterectomy five years ago. (Therefore, it is a problem and it isn't, (as pregnancy is not now an option)"; and "Infertility from endo is not a problem for me at this time, since I'm infertile from the hysterectomy and not the endo. I ranked Infertility a '1'."

Other participants provided feedback indicating that they just did not know about their fertility. Reflective of this is the following comment: "The infertility issue for me 'at this moment' is not really a valid question as I do not know how difficult it will be to conceive--I have not tried." Because of these issues, conclusions from question one need to be interpreted carefully.

Pain Question.

Question two inquired, "How much is pain from endometriosis a problem for you at this time?" Of forty-six respondents, fourteen answered three and twelve answered two, with answer one representing "not at all a problem" and answer five representing "overwhelming problem." Pain was rated lower than anticipated. To understand these results, the researcher sent a note to participants asking for their help in interpreting why the results did not indicate more severe pain. Like the infertility question, the "at this time" part of the question may have restricted

some answers, as suggested in the feedback from these participants: "Your 'at this time' questions really restricted the level of answers"; and "To me, that implies 'how are you feeling *now*, today,' as opposed to 'how do you typically feel with endometriosis'."

A couple of participants did provide feedback that indeed pain was not a problem for them. Their comments follow: "For me, I have never experienced any pain with the endo. From what I know this is not the norm, as the main reason for diagnosis via a lap is either because the pain is so severe that the doctor wants to see or that there is a problem with infertility. I underwent a lap due to a huge ovarian cyst that proved to be endo, and am now being monitored for reoccurrence of cysts on the remaining ovary. I still do not experience any pain (the bcp [birth control pill] I am taking makes me feel a bit off but no pain that an advil cannot kill)"; "In My case pain with endo was not an issue. If I was not looking for help with infertility and fibroid removal, I wouldn't have discovered that I had endo in the first place I don't consider the endo a 'painful' issue now, because it was removed during my surgery, and supposedly that corrected the infertility problem. Should I develop painful periods in my future, then I will consider the endo an issue at that time."

One participant shared feedback that she rated her pain

lower because of the qualifier, "overwhelming", related to the highest rating. She wrote, "I think I answered a 4 out of 5 about how much of a problem pain from endometriosis is for me. I avoided the 5 mainly because the word overwhelming seemed to suggest I had lost the battle or given up on coping with it. If the scale had been 1= minimal and 5= severe I would have selected 5."

Other participants noted that because of treatment, they were feeling less pain at the time of the survey. Examples of these comments include: "As for pain, the responses may reflect the number of respondents who have had treatment/intervention. In my case, for example, prior to the hysterectomy the pain was the single most important issue in my life (which is why I am a member of Witsendo and the Endo Association -- it could/has come back, although to a much lesser degree of intensity)"; "In response to your pain issue.....I just had a hysterectomy...so NO I don't have any pain, but it WAS so bad that I couldn't cope any longer I'm 33 and tried for 6 years to have children - without any luck... Perhaps there are others like me who also have no pain now....but DO have quality of life again...."; "In response to your question about the rating of pain in the survey. When I answered that question I felt I had to weigh the degree of pain I have now with what I had in the beginning. 4 years ago I missed work and school on a

monthly basis. I took pain killers hand over fist. The Doctor was trying to find the best medicine for me, a process that took 5 tries and 11 months. My quality of life was dismal, I was anemic, in pain, attached to my heating pad, and my brain was too fuzzy to do school work. By comparison, now I have completed a Master's degree. I work a 40 hr week on my feet. I don't call in sick for endo. I can't say that I don't have pain or take meds [medications] anymore, I do. I have some truly awful days, but I am able to continue with my normal daily activities, that is work. My social life and housekeeping sometimes slide by the wayside due to pain. I rated pain less than 5 because it used to exceed 5"; "In my case, I had had surgery just prior to answering the questions. Unless the question specifically asked for a general response, I was answering them based on how I felt at the moment"; "Over my history with the disease, pain is very definitely an overriding factor, but at the time I filled out the questionnaire, I was still responding (for the most part) to my treatment and pain was not a limiting factor in my life. Now, however, things have changed and pain is once again overwhelmingly important."

Other participants provided feedback suggesting that women with chronic pain rate pain lower than those who do not have chronic pain. Some representative feedback

follows: "Regarding the pain issue..... my sense is that we get inured to the level of pain that we cope with. I bet if I were no longer in pain I'd finally realize just how bad it's been. Since pain is what I am used to, I have no real baseline to measure it against! If someone were magically transported into my body for a moment, someone who did not live with pain, they might report a very high level of pain in comparison"; "I've heard from other endo sufferers and in my own case the pain is so intense that our tolerance for pain may be higher than most people. I used to get up and go to work in a level of pain that would floor most people -- could it be that people who live with chronic pain view it differently (in terms of rating it on a scale) than others would?"

Additional participants compared their pain to the descriptions of pain from others with endometriosis and decided that their pain was less severe. One woman who rated her pain as three on the scale related that "I have never had the problems with adhesional pain that some women have described which is why I rated my pain level low. During the week before my period and the first 2 days of my period I would rank it as very high. I miss an average of 2 days a month due to endo and would miss more if I felt I could without screwing up my job." Another participant noted that "my pain only recently has become severe (again)

so at the time of your survey, I may have been doing better. And rating myself against many other women on the list who have pain all month or pain during intercourse, I consider myself lucky to only be brought to my knees once a month. So maybe I rated my pain lower based on that." Included in the reasons that pain was rated lower than expected are the following: pain was not a problem, the qualifier "overwhelming" was thought different from "severe", pain was less because of treatment, chronic pain sufferers may rate pain lower and participants thought their pain was less when compared with others with endometriosis.

Another participant recognized that issues addressed in the survey were complex and difficult to correspond with a number. She wrote, "I suspect part of the problem with your results being different than expected was because of using a numbering system to evaluate complex issues like pain and support from health care providers. Also maybe some of it was due to averaging."

Rating of Support.

Averaging by participants was definitely a difficulty in interpreting responses about support from friends/extended family and health care providers. Support was rated on a five point scale, with one representing not supportive and five representing extremely supportive. One question asked, "How supportive was your friends' or

extended family's response?" This one question referred to any friends or extended family contacted in the last year, which often included many different people. It is an overall rating and not specific to any one person. As one participant noted, "responses differed for different people 3 is an average."

Similar difficulties occurred with the question, "How supportive was your health care providers' response?" One participants noted that "this is an average - I found the nutritionist very supportive, but the doctors, nurses and educators only slightly supportive." Another wrote that "NOTE: Since we are talking about multiple and very different health care providers, allowing only one answer for this question is giving you an inaccurate answer for all of them."

Based on the distressful stories about health care in this study and others, the rating for the level of support in health care providers' responses was higher than expected. Health Care Providers did receive the lowest rating for support in the different relationship categories in this study, although three was the most chosen response, which is still moderately supportive.

In addition to difficulties in interpretation of results, one possible reason for the higher than expected rating is that the study participants have had disease

symptoms for an average of twelve years. Twelve years may be time enough to find a supportive health care provider. One participant gave this feedback: "I suspect that if the average woman has been having symptoms for 12 years, she has been to a whole series of doctors, most of whom haven't understood a thing she was saying to them, and she has by this point finally found someone who can help her, or at least be sympathetic."

The question asking about level of support followed a question about health care providers contacted in the last twelve months. This, combined with the twelve years of symptoms, could explain the higher than expected rating. Examples of related feedback from participants follow: "I've been to so many doctors that I lost count long ago. I've only had two positive experiences with health care providers and both individuals came into my life just this year"; "The first year of my treatment was adequate, and would have been better if I had asked more questions and insisted on getting explanations. I was young and unsure of myself, so kept my mouth shut. After that, I changed doctors (different insurance) and had absolute jerks as doctors for several years. They just said that painful periods were something that women have to just live with, and gave me codeine, darvocet, percocet, etc. It has only been in the past few years that I have had wonderful treatment, and that from a

nurse practitioner at a holistic clinic rather than a regular MD"; "Also, as far as care providers, during the last 12 months I have been more satisfied with care (although I'd rate it a 2.5 or so) than previously, whereby I would rate my care as 1"; "I think again, the specification for recent experience might affect the results. The gynecologist who's been treating me for the past year and a half has been very supportive, understanding and active in my care, but the gyms I've had previous to him (both male and female, and I've found the female gyms to be the more sexist and offensive), as well as alternative health care practitioners (Chinese herbalists, chiropractors, etc), have all been very offensive, sexist, patronizing and inclined to either write me off as a malingerer, blame me for eating the wrong diet, or tell me to go off and have babies like a good little wife. The last 12 months have been the *only* time, in the history of my pain, that I've felt satisfied with the care I was being given."

Several participants suggested another possible explanation for the higher than expected rating, and that is the specific characteristics of the sample. One participant provided the following feedback: "There is a common element among the women who are on your Internet base...for the most part there are a few assumptions you can make. These women

are: very educated about endo, willing to talk and ask questions, willing to do research in order to find ways to feel better, have lived with this disease for a long time, have probably butted heads with primary doctors years ago, and have moved on to other physicians if they were NOT feeling better or being taken care of."

Another participant mentioned the education and ability to talk about the disease, "As you can tell, I'm very verbal. And I am not a medical victim if I can help it. I rarely go into a medical appointment without a written list of questions that I expect answers to. I am also responsible for the medical care of 3 of my elderly family members, so after that walloping experience you lose your timidity and become quite Up-front in your dealings with doctors. I also consider my doctor a partner in my health care, rather than his being 'god'. I give him room to make blunders and leave stuff out a little bit....and I make myself responsible for researching my medical conditions. And being as educated about my health as possible. My doctor and I can almost discuss my medical conditions as 'colleagues', because I know the vocabulary, and the symptoms and the drugs, etc. It could very well be that the folks who elected to fill out your survey, are not patients who walk in and swallow pills on command...and thus, do have better relationships with their physicians. In my case, if

I had a doctor that would not treat me like a partner, he would not be my doctor for very long."

Another example of how a well-informed sample might influence health care follows: "I suspect that we have all encountered health care providers who are bad, but if you read this list [WITSEND0], you realize that there are supportive doctors out there - you just need to find them. I suspect someone who is willing to find and read a news group would also be willing to act on these suggestions and find a caring, supportive doctor."

Possible explanations for the higher than expected rating for health care provider support could include: difficulties in interpreting data, the sample on average has been coping with disease symptoms for many years, health care providers' response in the last year was specified and the sample had specific and possibly unique characteristics.

When interpreting the data in this study, it is important to be aware of possible limiting factors. Some limitations, such as the sample selection, interactive factors not explored and the survey design affect the study in general. Other limitations, such as the wording of a specific question affect only responses to that question.

Implications for Psychotherapeutic Intervention

This study has implications for psychotherapeutic treatment of women with endometriosis which may extend to

other chronic illnesses. Participants noted the importance of family, especially spouses when coping with endometriosis. This implies that it is important to involve the family in therapy and not just the woman with endometriosis.

It is also clear from these womens' struggles with the disease that there is an impact on the family. This impact can be direct or indirect. Because the women in this study often want their family to be interested in the disease and concerned for them, the family is indirectly impacted. A symptom of infertility not only directly impacts the couple, but concerns about childlessness reverberate throughout the family. Another example of a direct impact to the couple is the possibility of pain with intercourse. The family of a woman with endometriosis will likely feel the impact. It is important for the therapist to recognize and address these issues.

The women in this research study rated other women with endometriosis as being the most supportive, of the four relationship categories studied. One therapeutic intervention may be to encourage contact with these other women through support groups, meetings, newsletters or hot lines. Membership in the international Endometriosis Association is one place to start.

Since the research participants did not feel listened

to or believed, it follows that an important piece of therapy would be to provide a place where they are listened to and believed. One common struggle is obtaining a diagnosis, therefore it is important to believe that the symptoms are real even when there is no definitive diagnosis.

There might be occasions when the therapist may consider a referral elsewhere. The therapist may not be knowledgeable about endometriosis and may be more comfortable referring clients to someone with the expertise. In addition to being knowledgeable about endometriosis, the therapist needs to be comfortable discussing sexual concerns and again may prefer to refer elsewhere.

The process of discussing support may help clients realize the kinds of support they desire. It might help clients know what they want just by beginning the discussion. One participant noted that responding to the questionnaire helped her to clarify her own thoughts. She wrote: "Thank you for this opportunity to contribute to your study, and to clarify my own thoughts on the impact endometriosis has had on my life. Getting it down on paper has helped me to see more clearly what I want from my caregivers and 'support staff'."

Participants in this study experienced difficulty in relationships with health care providers. Another important

piece of therapy may be to empower the woman to get the appropriate health care from an appropriate provider. Gaining control in the medical system may be a struggle in which the therapist can assist with interventions such as discussion or role play.

Implications for Future Research

It was evident from the articulate and well thought out responses, that the participants spent a lot of time and energy completing the questionnaire. This is one indication that they viewed the research as important. Another indication is the many participants who added comments thanking the researcher for studying this topic. These comments included: "Thanks for doing the research and good luck"; "Thank you for taking this on as a research project"; and "Thanks for doing this important work." This is also an indication that these women want their "voices" heard.

In addition to being heard, many participants wanted to know what other women voiced, since they requested the research results. Requests for the research results also demonstrates the importance of the study to the participants. Examples of this include: "Thanks for doing this! I hope one day I will be able to read your findings"; and "I am very interested to find out the results of your research. Thank you and I hope you get lots of responses!" From these womens' strong desire for their "voice" to be

heard and the value they placed on this study, the implication is that more research would be welcomed.

The sample in this study was limited to women on the WITSEND0 listserv. The same questionnaire could be used with other groups of women with endometriosis, such as women in face-to-face support groups, women in physicians offices, or a sample of women from the general population. By sampling other women with endometriosis, a different perspective might be gleaned. Also, social support concerns of women with endometriosis could be compared to social support concerns of women without endometriosis.

In this study the responses were written, but the same questions could be used in an interview format. There are probably advantages and disadvantages to each format. One possible advantage of the written format is that the anonymity of a written response allowed participants to be more open about very personal issues, such as pain with sexual intercourse. Whereas one advantage of an interview format could be the capability of the researcher to probe more deeply into the meaning of responses. Using a different format would gain a new perspective.

The social support experiences of women with endometriosis were examined. Participants' relationships with spouse/partner, friends/extended family, others with endometriosis and health care providers were considered.

Another study could examine the experiences of the support network in supporting the woman with endometriosis. For example, the spouse or partner could be interviewed to determine his/her experience of the support.

Health care providers could also be questioned about their experiences of how they support women with endometriosis. Those responses could be analyzed for differences in length of time out of training and place of training. Also, experiences could be examined by type of provider.

Research is also needed into the interactions and influences of other factors in the coping process. Examples of other factors in the double ABCX model of stress and coping would include: normative changes, family characteristics, financial resources, and community resources.

Adaptation and coping with endometriosis would be expected to change over time influencing the experience of social support. The process of coping during different phases of diagnosis, treatment, and illness progression could be studied. A related study could focus on the differences between having symptoms but no diagnosis and having a confirmed diagnosis.

This study is just one drop in a large empty bucket of research on coping with endometriosis. It focused on social

support. Many more studies are needed to research social support, and many beyond that needed to research other aspects of the coping process.

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APPENDICES

Appendix A
Questionnaire for use on the Internet

Number

Coping with Endometriosis

The purpose of this research is to obtain information about the support of women with endometriosis. Filling out this questionnaire implies your permission of consent to participate in this research. Thank you for taking the time and effort to complete the entire survey. This survey is designed so that you may edit the file on screen and send the edited version back to me over the Internet. If you prefer, you have the option of printing it and mailing it through the postal service. Please return by NOVEMBER 21, 1994 to Martha Whitney at:

MWHITNEY@VTVM1.CC.VT.EDU

OR

Virginia Tech, Department of Family and Child
Development

2990 Telestar Court
Falls Church, VA 22042

This first section asks about problems relating to endometriosis that you might currently be experiencing. Rate how much the following are a problem for you on a scale from 1 to 5, with 1 representing not at all a problem, and 5, an overwhelming problem. Please PLACE THE NUMBER that best corresponds to how much it is a problem for you IMMEDIATELY TO THE RIGHT OF THE "#".

not at all					overwhelming problem
	1	2	3	4	5

1. How much is infertility from endometriosis a problem for you at this time? 01#

2. How much is pain from endometriosis a problem for you at this time? 02#

Second, I would like to know with whom you have talked about your endometriosis and the level of support you received with that response. This section asks about four categories of relationships: spouse/partner, extended family/friends, others with endometriosis and health care providers. Your explanations are extremely important to understanding how women cope.

SPOUSE OR PARTNER:

3. During the last 12 months, have you talked about your

endometriosis with your spouse or partner? INDICATE CHOICE IMMEDIATELY TO THE RIGHT OF "03#".

1=YES, indicate and proceed to items 4-6, 8

2=NO, indicate and proceed to item 7

3=NOT APPLICABLE, indicate and proceed to item 9

03#

IF YES,

4. How supportive was your spouse or partner's response? (Rate your level of support on a scale from 1 to 5, with 1 representing not supportive, and 5, extremely supportive. Please indicate the number that best corresponds to the level of support immediately to the right of the "04#".)04#

5. What did you find the most supportive about the response? (Type in answer.)

6. What did you find the least supportive about the response? (Type in answer.)

7. IF NO, you did not talk with your spouse or partner, please explain. (Type in answer.)

8. What advice would you give to spouses or partners on how they can be more supportive of women with endometriosis? (Type in answer.)

FRIENDS AND/OR EXTENDED FAMILY:

9. During the last 12 months, have you talked about your endometriosis with your friends or extended family (for example: parents, sisters, brothers, aunts, uncles, cousins, grandparents)? INDICATE CHOICE IMMEDIATELY TO THE RIGHT OF "09#" 1=YES, indicate and proceed to items 10-12, 14 2=NO, indicate and proceed to item 13

09#

IF YES,

10. With whom among your friends or extended family did you talk in the last 12 months? (INDICATE ALL CORRESPONDING NUMBERS, WITH ONE SPACE BETWEEN, THAT APPLY, IMMEDIATELY TO THE RIGHT OF THE "10#") 1=female friend 2=male friend 3=mother 4=father 5=brother 6=sister 7=female cousin 8=male cousin 9=aunt 10=uncle 11=grandmother 12=grandfather 13=other (specify, by typing in who):

11. How supportive was your friends' or extended family's response? (Rate your level of support on a scale from 1 to 5, with 1 representing not supportive, and 5, extremely supportive. Please indicate the number that best corresponds to the level of support immediately to the right of the "11#".) 11#

12. What did you find the most supportive about the response?

(Type in answer; If you talked with more than one person in this category of friends or extended family, please identify the relationship to which your comments are referring.)

13. What did you find the least supportive about the response? (Type in answer; If you talked with more than one person in this category of friends or extended family, please identify the relationship to which your comments are referring.)

14. IF NO, you did not talk with your friends or extended family, please explain. (Type in answer.)

15. What advice would you give to friends or extended family on how they can be more supportive of women with endometriosis? (Type in answer.)

OTHERS WITH ENDOMETRIOSIS:

16. During the last 12 months, have you talked or had contact, about your endometriosis, with others with endometriosis? INDICATE CHOICE IMMEDIATELY TO THE RIGHT OF "16#".

1=YES, indicate and proceed to items 17-19, 21

2=NO, indicate and proceed to item 20

16#

IF YES,

17. How supportive were the responses of others with endometriosis? (Rate your level of support on a scale from 1 to 5, with 1 representing not supportive, and 5, extremely supportive. Please indicate the number that best corresponds

to the level of support immediately to the right of the "17#".)

17#

18. What did you find the most supportive about the responses? (Type in answer.)

19. What did you find the least supportive about the responses? (Type in answer.)

20. IF NO, you did not talk with others with endometriosis, please explain. (Type in answer.)

21. What advice would you give to others with endometriosis on how they can be more supportive of women with endometriosis? (Type in answer.)

HEALTH CARE PROVIDERS:

22. During the last 12 months, have you talked about your endometriosis with a health care provider, such as a physician, nurse, health educator, nutritionist, chiropractor, acupuncturist, homeopath, OR counselor or psychotherapist? INDICATE CHOICE IMMEDIATELY TO THE RIGHT OF "22#"

1=YES, indicate and proceed to items 23-26, 28

2=NO, indicate and proceed to item 27

22#

IF YES,

23. With which health care providers have you talked during the last 12 months? (INDICATE ALL CORRESPONDING NUMBERS, WITH ONE SPACE BETWEEN, THAT APPLY, IMMEDIATELY TO THE RIGHT OF THE "23#".)

1=physician 2=nurse 3=nurse practitioner or midwife

4=health educator 5=nutritionist 6=chiropractor

7=acupuncturist 8=homeopath 9=counselor or

psychotherapist

10=other (specify by typing in who):

23#

24. How supportive was your health care providers' response?

(Rate your level of support on a scale from 1 to 5, with 1 representing not supportive, and 5, extremely supportive. Please indicate the number that best corresponds to the level of support immediately to the right of the "24#".)24#

25. What did you find the most supportive about the response?
(Type in answer; If you consulted more than one health care provider, please identify to which provider your comments are referring.)

26. What did you find the least supportive about the response? (Type in answer; If you consulted more than one health care provider, please identify to which provider your comments are referring.)

27. IF NO, you did not talk with a health care provider, please explain. (Type in answer.)

28. What advice would you give to health care providers on how they can be more supportive of women with endometriosis? (Type in answer.)

29. I have surely omitted many other potential sources of support which have either helped you cope with endometriosis or made coping more difficult. Please comment on these additional sources such as employers, acquaintances, or support groups. Include important sources you have encountered at any time while coping with this disease. (Type in answer.)

Finally, a few general questions to better describe the population of participants. PLEASE INDICATE NUMBERED ANSWER IMMEDIATELY TO THE RIGHT OF THE "#".

30. What is your present age?(years) 30#

31. What is your current estimated annual family income?

- 1) less than \$14,999
- 2) \$15,000 - 29,999
- 3) \$30,000 - 44,999
- 4) \$45, 000 - 59,999
- 5) \$60,000 or greater

31#

32. What is your highest educational level?

- 1) High school not yet completed
- 2) High school graduation or GED
- 3) Some college
- 4) Bachelor's degree
- 5) Graduate studies
- 6) Graduate degree

32#

33. How do you describe your ethnic origin?

- 1) White
- 2) Black
- 3) Hispanic
- 4) American Indian/Alaskan Native
- 5) Asian/Pacific Islander

33#

34. How long have you had the symptoms of endometriosis?
(years)

34#

35. How long have you had a diagnosis of endometriosis?
(years)

35#

36. In what country is your citizenship? Country:

1=USA 2=Canada
3=Other (specify by typing):

36#

37. If USA, in what state do you now live:(specify by
typing)

Additional Comments (Type in answer):

Appendix B
Announcement Requesting Pilot Study Participants

Subject: Pilot Study

After being diagnosed with endometriosis about eight years ago, I became intrigued with how women coped with this chronic disease. As a master's candidate in Marriage and Family Therapy, I am now studying that issue for my thesis.

At the moment, I need to pilot test my survey to see if it is understandable and will give me the information I need. For now, I am looking for a few women who are 18 years and older and have been formally diagnosed with endometriosis to help me test my questionnaire. I am on a tight schedule and would like volunteers who could return responses to me within a week. If you are interested, I can send you a copy to your e-mail address. The questionnaire is designed so that it can be answered on your computer screen and sent back to me.

When I have revised this survey, based on input from the pilot test, I will be looking for additional participants for my research. I will keep you posted.

I really appreciate your help. I am working to add to the understanding of this complex disease and how women cope with it. Thank you for helping. If you have any questions, please write me at MWHITNEY.VTVM.CC.VT.EDU OR call and leave a message for me at (703) 698-6033.

Appendix C
Announcement Requesting Participants

Subject: Research on Support

After being diagnosed with endometriosis about eight years ago, I became intrigued with how women coped with this chronic disease. As a master's candidate in Marriage and Family Therapy, I am now researching that issue for my thesis. I am exploring the support of women like you and me.

Based on my own experiences with endometriosis, I know the difficulties frequently encountered in finding and keeping supportive relationships with friends, family and health care professionals. Through my study, I want to learn how other women find support and what kind of support is useful to them. With this information I want to help make a difference by educating health care providers with the knowledge of what women, like us, find supportive.

If you are a woman who has been formally diagnosed with endometriosis and are 18 years or older, I invite you to participate. If you meet these criteria and are willing to participate, please contact me at MWHITNEY@VTVM1.CC.VT.EDU with your Internet address and I will gladly mail you a questionnaire. The survey takes about 30 minutes to complete and is designed so that it can be answered on your computer screen and sent back to me. If you have any questions, I would be quite willing to answer them.

Thank you for considering to participate. I want to add to the understanding of this complex disease and how women cope with it. I plan to post an abstract of my results to the this list.

Appendix D
Letter to Women with Endometriosis

October 31, 1995
Department of Family and Child Development
Virginia Tech
2990 Telestar Court
Falls Church, VA 22042

Dear Fellow Woman with Endometriosis:

After being diagnosed with endometriosis about eight years ago, I became intrigued with how women coped with this chronic disease. As a master's candidate in Marriage and Family Therapy, I am now researching that issue for my thesis. I am exploring the social support of women like you and me.

Based on my experiences with the disease, I know the difficulties frequently encountered in finding and keeping supportive relationships with friends, family and health care professionals. Through my study, I want to learn how other women find support and what kind of support is useful to them. With this information I want to help make a difference by educating health care providers with the knowledge of what women, like us, find supportive.

If you are a woman who has been formally diagnosed with endometriosis and are 18 years or older, please take the time to fill out the attached questionnaire and return it to me by November 15. I want to hear from as many of you as possible to obtain the best overall understanding of this issue.

I assure you that your confidentiality will be protected. I will delete from the questionnaire any identifying data such as your name or Internet address. One master list linking questionnaire numbers and names will be kept only until after my thesis has been defended. In the meantime, this list will be kept in a locked filing cabinet. By filling out the questionnaire and returning it to me, you are implying your permission for me to use and report the information I receive. If you have any concerns or questions about the research, please contact me at MWHITNEY@VTVM1.CC.VT.EDU or (703) 698-6033, or Sandra Stith, Ph.D., my faculty advisor, at SANDI@VTVM1.CC.VT.EDU OR (703) 698-6035. For other questions about the research or its conduct, you may call Ernest Stout, Chairman Institutional Review Board, Virginia Tech University, (703) 231-6077.

Thank you for adding to the understanding of this complex disease and how women cope with it. I appreciate your thoughtfulness and expect this information to ultimately make a difference in how we are treated.

Sincerely,

Martha L. Whitney

Appendix E
Follow-up Reminders

Subject: Research Reminder

I mailed a survey to you and have not yet heard back. Did you receive it? Do you have any questions for me? I look forward to receiving your input before NOVEMBER 15.

Appendix F
Preliminary Results Message

To Research Participants:

I am just beginning to analyze your responses to my research on coping with endometriosis and have some *preliminary* results. In general participants reported pain to be slightly more of a problem than infertility. On a scale of 1 to 5 with 1 representing no problem at all and 5 representing an overwhelming problem, respondents rated infertility, 2, on average and pain, 3, on average. Almost everybody who had a spouse or partner talked to them in the last 12 months. On average spouse/partner responses to this were highly supportive. On average these responses were rated as 4 out of a possible 5, with 5 being extremely supportive. Again, almost everybody spoke with friends or family about their endometriosis. Responses of friends or family were also very supportive and were rated on average 4 out of 5. Most of you had interacted with someone else with endometriosis. Responses from others with endometriosis were rated the highest with an average of 5 out of 5. Again most of you spoke with a health care provider in the last 12 months. Health care provider responses were the least supportive and were rated 3 out of 5, on average. Participants had symptoms of endometriosis on an average of 12 years and a diagnosis for an average of 5 years for a difference on average of *7* years between the onset of symptoms and a definitive diagnosis. Thorough analysis of your comments will take me longer to complete. However, one common theme that is already apparent is that women with endometriosis want to be listened to and believed.

These are only preliminary results but I am curious about some of the outcome. I am wondering about endometriosis being rated only a slight or moderate problem for pain or infertility. Can you help me explain this? Are you doing unusually well? In the pain and infertility questions I included the phrase "at this time", does that have some bearing? Are you in extreme pain during your period but did not fill out the questionnaire during your period and so rated it low? Please if you have any thoughts about this, let me know what they are.

Also, even though health care providers were rated the lowest for supportive response, I expected it to be even lower, based on what I read on WITSENDO and women I have talked with. Have you had particularly good experiences as a group or because on average you have been having symptoms for 12 years you have found supportive providers? This question did specify "during the last 12 months" and also asked about an overall response from all health care providers. Does that explain the amount of support? Can you help me explain the average of 3 out of 5 for rating for

health care providers?

If you have any thoughts or comments on these very preliminary results, please pass them on to me.

Thanks again for your help with this research.

Martha Whitney

VITA

MARTHA L. WHITNEY

SKILLS

Research in Marriage and Family Therapy and Education

- Researched topics such as chronic illness in the family, juvenile delinquents, adolescent sex offenders, domestic violence, dating violence and the psychosocial factors associated with hysterectomy, infertility, and endometriosis.
- Interviewed children participants in a qualitative study to assess their experiences in family therapy.
- Interviewed children as part of a national study in early childhood education.

Therapy, Psycho-education and Support

- Worked with families and individuals as a therapist intern. Assessed and managed cases.
- Co-facilitated a support group for single parents.
- Trained to co-facilitate a group of men who have a history of abusive behavior. The purpose of this group is to teach and support non-violent anger management.

New Business Planning and Development - Part of a team developing and implementing a new Individual Practice Association component to the existing staff model Health Maintenance Organization.

- Marketed new program to community physicians including preparation of plan, creation of marketing materials and coordination of sales presentations.
- Coordinated preparation of a major proposal adopted by the Board of Trustees, to add a new component to the existing staff model structure.
- Analyzed the private practitioners in the metropolitan Washington, D.C. area to identify target physician groups.

Management Information Systems Development

- Created program evaluation tool for recreational events.
- Synthesized information to create and implement a prototype productivity reporting system for over 325 clinical support staff Full Time Equivalents.
- Initiated, designed and produced clinical Full Time Equivalent Control System to facilitate staffing decisions, control overtime, on-call and agency staff and set staffing standards.
- Developed reporting system to monitor member access and trained staff in use of system.
- Analyzed access for over 148,000 members to appointments in nine clinical centers and 19 departments.

Financial Planning and Monitoring

- Prepared departmental budget of \$300,000 and monitored expenses.
- Initiated and implemented system to track payroll hours, purchase orders and honorarium reimbursement.

Needs Assessment/Analysis

- Analyzed fair visitor survey responses.
- Researched and assessed pertinent data in targeted geographic locations to determine need for inpatient psychiatric facilities.
- Interfaced with state regulatory agencies.

Operational Systems Development

- Improved member access by modifying department procedures and patient scheduling.
- Worked with nursing staff at a 22,000 member multi-specialty center to improve provider and support staff scheduling. Improvements included: better member access, smoother scheduling of providers, and more even support staff coverage.
- Worked collaboratively with managers of a 22,000 member medical center to improve the telephone advice system. Changed work flow patterns and staff behavior to increase member satisfaction, improve access to nursing advice, and increase efficiency.

Training and Development

- Presented progress reports to Board of Trustee committees.
- Trained and motivated 250 employees in customer relations skills.
- Developed and created educational materials to promote better member/staff interactions.
- Educated clinical management in production and interpretation of reports.

EMPLOYMENT EXPERIENCE

The Family Tree, Alexandria, VA
Therapist Intern, 1995- Present

Center for Family Services, Falls Church, VA
Therapist Intern, 1993- Present

Messiah Methodist Church, Springfield, VA
Support Group Co-facilitator, 1993-1994

Virginia Tech, Early Childhood Transition Project,
Falls Church, VA
Fiscal Controller, 1993-1994

Virginia Tech, Department of Family and Child Development,
Falls Church, VA
Graduate Research Assistant, 1992-1993

Northwest Center for Community Mental Health, Reston, VA
Volunteer, 1992

Fairfax County Park Authority, Fairfax, VA
Intern, 1990-1991

Group Health Association, Washington, DC
Project Manager, 1987-1989
Special Assistant to the Director of the Medical
Group Management Office, 1986-1987
Management Intern, 1985-1986
Psychiatric Institutes of America, Washington, DC
Research Analyst, 1984
The Central Intelligence Agency, Washington, DC
Medical Technologist, 1982-1983
The National Institutes of Health, Bethesda, MD
Medical Technologist, 1979-1982
The Veterans Administration Medical Center, Washington, DC
Medical Technologist, 1977-1979

EDUCATION

Candidate for Master of Science in Marriage and Family
Therapy, Virginia Tech, Falls Church, VA
Master of Health Services Administration, The George
Washington University, Washington, DC, 1985
Medical Technology Certificate, The Fairfax Hospital,
Falls Church, VA, 1977
Bachelor of Arts, Chemistry, Virginia Polytechnic
Institute and State University, Blacksburg, VA,
1976

PUBLICATION

Bischof, G., Stith, S., & Whitney, M. Family
environments of adolescent sex offenders and other
juvenile delinquents. Adolescence, 30 (117), 157-
170.

MEMBERSHIP IN PROFESSIONAL ORGANIZATION

Student member, American Association of Marriage and Family
Therapy

