ENDOMETRIOSIS AND THE PROCESS OF INVALIDATION

By

JoEllen Schoblom, R.N., B.S.N.

A Masters Research Project
Presented to

Oregon Health Sciences University
School of Nursing
in partial fulfillment of
the requirements for the degree of
Master of Science
June 1, 1992

APPROVED:

[redacted]

Margaret A. Imle, R.N., Ph.D.. Associate Professor,

Department of Family Nursing

Research Advisor

[redacted]

Jane Harrison-Hohner, R.N., M.S.N., WHCNP, Instructor,

Department of Family Nursing

First Reader

[redacted]

Barbara Limandri, R.N., DNSc., Associate Professor,

Department of Mental Health Nursing

Second Reader

[redacted]

Sheila Kodadek, Ph.D., R.N., Associate Professor and

Chairperson, Department of Family Nursing

This study was supported in part by funds from the Professional Nurse Traineeship Program, a Public Health Service Grant.

Grant numbers: 2 All NUO0250-15 (1990-91)
2 All NUO0250-16 (1991-92)

ACKNOWLEDGEMENTS

The following people are acknowledged with sincere gratitude:

The research participants for their willingness to share their personal stories with me.

Margaret Imle for her encouragement, support and willingness to go the extra mile for the sake of research and women's health.

Jane Harrison-Hohner for her encouragement, interest and shared concerns regarding women's health, research and endometriosis.

Barbara Limandri for her insights and editorial comments.

Ann Marie Monahan for convincing me I should persist with the project.

Eric Schoblom, my husband, for his unwavering support and encouragement.

Abstract

This qualitative study was done to examine the concept of invalidation within the endometriosis experience of four women. The concept of invalidation, wherein women's perceptions of their symptoms of endometriosis are not accepted or recognized, was supported by the data. The concept of invalidation was found was to be only one aspect of a larger process that women with endometriosis experience. This process includes three stages during which women; initially accept their symptoms as 'a woman's lot', later seek diagnosis, and finally examine the impact of the disease on their lives in order to cope with a chronic disease. A core variable, called 'conspiracy of silence', was identified as the underlying factor responsible for explaining the major variance in the conceptual categories of the endometriosis experience. Implications for nursing include the need for assessing women for symptoms suggestive of endometriosis, adequate follow-up on reported symptoms, information, support, and understanding the importance of viewing endometriosis as a chronic disease. Developing appropriate means of providing education and information to the women, their families, peers and physicians is an area for future research.

TABLE OF CONTENTS

CHAPTER PAGE

I INTRODUCTION.................................... 1

CLINICAL EXPERIENCE............................. 4

II REVIEW OF THE LITERATURE....................... 6

LAY LITERATURE............................. 7

MEDICAL AND NURSING LITERATURE............ 8

RELATED CONCEPTS.............................. 10

CHRONIC ILLNESS............................ 10

CHRONIC ILLNESS AND GRIEF................. 14

INVALIDATION AND ILLNESS EXPERIENCE....... 15

CHRONIC ILLNESS: DIAGNOSIS AND TREATMENT.. 16

SUMMARY OF LITERATURE......................... 18

CONCEPTUAL FRAMEWORK.......................... 19

III METHODS.. 22

RATIONALE FOR STUDY DESIGN.................... 22

DESIGN.................................... 23

INTERVIEW QUESTIONS....................... 24

HUMAN SUBJECTS............................ 25

PARTICIPANTS.............................. 25

DATA GENERATION AND DATA ANALYSIS............. 27

IV FINDINGS....................................... 29

CATEGORIES.................................... 31

GRIN AND BEAR IT.......................... 31

INCREASING FEAR AND ANXIETY............... 32

FAMILY COMMUNICATION PATTERNS............. 33

DISBELIEF BY PEERS........................ 34

PROVIDER DENIAL........................... 34

ATTRIBUTION OF SYMPTOMS................... 35

LACK OF KNOWLEDGE......................... 36

IMPACT ON LIFE............................ 37

V INTERPRETATION OF FINDINGS..................... 38

PROCESS OF INVALIDATION........................ 38

GRIN AND BEAR IT.......................... 38

INCREASING FEAR AND ANXIETY............... 41

FAMILY COMMUNICATION PATTERNS............. 42

DISBELIEF BY PEERS........................ 43

PROVIDER DENIAL........................... 44

ATTRIBUTION OF SYMPTOMS................... 46

LACK OF KNOWLEDGE......................... 47

IMPACT ON LIFE............................ 49

View of disease as chronic........... 49

CORE VARIABLE.................................. 53

TENTATIVE CONCEPTUAL STRUCTURE................. 54

DISCUSSION..................................... 56

COMPARISONS WITH THE LITERATURE........... 60

IMPLICATIONS FOR NURSING RESEARCH.............. 63

IMPLICATIONS FOR HEALTH CARE PROVIDERS.... 67

SUMMARY.. 70

REFERENCES.. 73

APPENDICES.. 76

A. INTERVIEW QUESTIONS...................... 77

B. PERMISSION TO RECRUIT HUMAN SUBJECTS...... 79
C. CONSENT FORM.............................. 81

Chapter I

Endometriosis is a puzzling disease affecting women in their reproductive years. Endometriosis can seriously interfere with a woman's sense of well-being and compromise her ability to carry out daily activities and life plans and goals. It is by definition the presence of endometrial tissue outside of the endometrium (Lichtman & Papera, 1990). Although a number of hypotheses have been examined, the etiology remains poorly understood. Symptoms and sequela of endometriosis result from pathophysiologic changes including bleeding from the lesions, the presence of cysts, adhesions and/or anatomic distortions and obstructions (Lichtman & Papera, 1990). Endometriosis can present as dysmenorrhea, dyspareunia, chronic pelvic pain, abnormal vaginal bleeding, infertility and miscarriage. Less well-defined symptoms associated with the disease include fatigue, headache, nausea, vomiting, diarrhea, constipation and rectal bleeding. Definitive diagnosis is made by laparoscopy. Because of the progressive nature of the disease, early treatment is recommended. However most women have symptoms for years before obtaining diagnosis. In studies conducted by the Endometriosis Association (EA), 1,179 women obtained diagnosis 10 to 15 years after onset of symptoms (EA, 1990). It is estimated that over 15% of the female population suffers from endometriosis. Of the 10 million women with the disease approximately 5 million remain untreated (Weinstein, 1987). A variety of medical and surgical treatment options are available. Although a number of researchers have attempted to evaluate the efficacy of each, conclusions are varied and results must be considered tentative and not representing a definitive cure.

Women experiencing the disease of endometriosis face many unique challenges in managing their lives and their health care. Endometriosis is a chronic disease which impacts and disrupts lives on a physical, emotional, social and financial level. This situation is compounded by the length of time it takes to arrive at a diagnosis. For many women the process of arriving at a diagnosis is not handled with respect, understanding or belief in the women's awareness of her own body signals.

As a chronic disease, endometriosis shares some commonalities with other less visible chronic diseases wherein patients may experience invalidation of symptoms by care providers; denial by oneself that anything is wrong; and during the process of diagnosis, loss of self-esteem and control (Werner-Beland, 1980). Therefore, it may be useful to explore whether patients with endometriosis experience the feeling of having their symptoms invalidated. Validation of symptoms would involve establishing them as true or genuine. Invalidation of symptoms indicates they are denied or not responded to as genuine, thus, having the effect of putting an end to reports about the symptoms. Invalidation appears to be a key aspect of the endometriosis diagnostic problem because often the magnitude of a woman's symptoms is denied, minimized or attributed to psychogenic origins.

The purpose of this study is to examine the impact endometriosis has on a patient's life. Specifically, this study will be done to identify and describe what appears to be a concept of invalidation by exploring women's experience of endometriosis and the process of getting diagnosis and treatment.

The large numbers of women experiencing this disease means that nurses working in family practice, Obstetrics and Gynecology, family planning clinics, mental health, women's health care, and medical-surgical units in hospitals are likely to come in contact with this population of patients. Nurses with an understanding of the disease and its impact on patients' lives will be able to assist them in coping and can facilitate their return to health.

Dossey, Keegan, Guzzetta and Kolkmeier (1988) described the role of the nurse healer as "one who facilitates another person's growth and life process toward wholeness (body-mind-spirit connections) or who assists with recovery from illness or transition to peaceful death" (p. 6). She expands this concept with a philosophy of "holism" that views everything in terms of "patterns of organization, relationships, interactions, and processes that combine to form a "whole" (p. 15). Wholeness can be present when one has high levels of wellness and also when one has known disease or disability. She further states that "in order to maximize our potential, it is important to assess where we are in each aspect of our being: physical, mental, emotions, spirit, relationships and choices" (p.16).

Clinical Experiences

This researcher has talked with women with endometriosis and has experienced the disease personally. The feelings suggestive of invalidation had occurred at some point for each woman. Most of the patients had consulted four or five physicians before beginning to find answers or recognition that a disease process was indeed occurring. Many treatment options were tried in an attempt to find relief from the symptoms. For many patients the struggle with the disease consumed all their energy. As life plans were delayed, finances depleted, relationships strained or lost, a sense of losing control of one's life emerged, and patients began to experience a loss of self-esteem. Not having one's body messages believed by care providers contributed additional negative stress to already symptomatic women, leading to a sense of loss of control and contributing to anger, frustration, self-doubt and eventually, depression (Halstead, Pepping & Dmowski, 1989). The consistent association of physiologic and psychosocial problems indicates the clinical importance of exploring the women's diagnostic experiences. Additionally, how the diagnostic experience influences coping needs to be understood.

An interesting aspect of coping with endometriosis on a daily basis was addressed during a conversation with Dr. Redwine, a surgeon who serves as an Endometriosis Association Advisor, (personal communication, April, 1988). He described the phenomenon of women continually adjusting and readjusting their activity levels and tolerances to pain in order to live with the disease. Dr. Redwine believes this occurs to such an extent that eventually the woman's ability to judge accurately how severely her life is compromised is lost. He said he sees patients who tel him "they are doing O.K." but on closer investigation he discovers these patients are really "on their knees." This researcher questions whether there may be a relationship between the invalidations most endometriosis patients have experienced prior to diagnosis and this phenomenon of denial of body cues in daily life with the disease.

Chapter II

Review of the Literature

Aside from the controversy about what constitutes a diagnosis and the various treatment options available, there appear to be gaps in the medical and nursing literature about endometriosis. This researcher could find only one published study which examined the psychosocial consequences of the disease and no studies that addressed the difficulty of arriving at a diagnosis. Endometriosis is by definition a chronic illness, yet there are no studies that explore this aspect. In fact most descriptive medical literature and research tends to view endometriosis as an acute medical situation. Furthermore, medical studies address diagnosis and treatment rather than the patient's response. Understanding the dimensions of chronic illness and grief are also important when exploring the endometriosis experience and will be examined as well.

The lay literature presents a broader picture of the disease process, the difficulty of arriving at a diagnosis, and the impact this has on a patient's life and well-being. Because a more holistic perspective can be obtained by combining types of literature, this study will include both lay literature on endometriosis and medical and nursing literature on chronic disease.

Lay Literature

Kate Weinstein's (1987) book summarizes the state of scientific research and inquiry into the disease of endometriosis. The one fact that emerges is that endometriosis is a poorly understood disease with conventional wisdom derived in large part from clinical observations and impressions handed down from decade to decade without benefit of rigorous scientific scrutiny. The lack of consensus on the part of physicians and researchers contributes to women's confusion and complicates decision making when seeking diagnosis and information about treatment options. The following quotation clearly illustrates the dilemma.

> Women with the disease must recognize the controversies and the gaping holes in the research, and realize that there is no unified viewpoint from which to comprehend the disease. To prepare themselves for the uncertainties and challenges that endometriosis may pose, women need to understand that their decisions may have to be based on possibility and probability, the half-known and the unknown. There will not always be satisfactory answers to their questions (Weinstein, 1987, p. xii).

When discussing the emotional consequences of the disease, Weinstein (1987) examined the following concepts of patient reactions: disbelief, fear, denial, coping, stress, withdrawal, isolation, and self-esteem. This author's treatment of these issues is one of the most extensive found in the lay literature on endometriosis.

Medical and Nursing Literature

A review of the medical literature documents the controversy that exists regarding etiology, diagnosis and treatment. While Dmowski, Braun and Gebel (1990) prepared a conference paper investigating the role of genetics and immunology as a new explanation for the etiology of this disease, other physicians and researchers continue to support the cell transplantation theory (Jenkins, Olive, & Haney, 1986); and yet others believe cell transformation is the answer (Redwine, 1987).

While it has been accepted that laparoscopy offers the definitive diagnosis, what is found at laparoscopy still remains controversial. The arguments include questions of appearance of the disease (Redwine, 1987) and the possible existence of microscopic implants invisible to laparoscopic procedures (Murphy, Green, Bobbie, Cruz & Rock, 1986; Redwine, 1990).

Treatment options range from hormonal to conservative surgical procedures which attempt to preserve the reproductive organs or to the radical surgical procedure of hysterectomy and bilateral oophorectomy. All of these treatments have substantial risks, side effects and consequences and none offers a definitive cure. This outcome is not always clearly presented to patients (EA, 1989; Lichtman & Papera, 1990).

The lack of nursing literature reflects perhaps the largest gap in the literature. This researcher was able to find only one research study on endometriosis which was an exploratory study by Halstead, et al. (1989) describing help-seeking behaviors of twenty-five women with endometriosis and reported responses of family, caregivers, and the patient to symptoms and diagnosis. Women who had been diagnosed with endometriosis were interviewed by using open-ended questions about their experience. All of the women had experienced symptoms for 2 to 10 years before obtaining diagnosis. Eleven of the 25 women had seen four or more physicians prior to diagnosis. Family and friends responded to the women's complaints of symptoms with a lack of sympathy while caregivers minimized complaints and frequently told the women they were overreacting to pain and would just have to learn to live with it. Upon obtaining a diagnosis, several feelings emerged for the study participants: relief that something was wrong and could be done, vindication or proof that their pain was physiologic and not psychogenic in origin, fear and devastation about what was the disease meant, and anger or a sense of betrayal from having previously been lied to by care providers. Interestingly, this study reported that family and friends continued to be unsympathetic and surprised that the women's symptoms were physiologically based. The respondent's current feelings about having endometriosis included anger, frustration, loss of self-esteem, sadness, grief, fear and uncertainty about the future. The researchers concluded that women with endometriosis "experience significant delays in diagnosis and treatment and suffer considerable disruption of their life" (Halstead, et al, 1989, p. 5).

The results obtained by the Halstead et al study have significance for this research project. It verified that diagnosis is difficult to obtain, that participants lives were disrupted by the disease and process of obtaining diagnosis and that emotional responses of fear, anger, uncertainty and grief emerged in response to this illness. Although the sample size was small, (25 women), the Halstead et al study addressed the same questions this researcher is asking. If responses consistent with the Halstead study emerge from this research as well, the understanding of the impact of endometriosis on a life, with particular emphasis on defining the concept of invalidation, may be further clarified.

Related Concepts

Chronic Illness

Chronic illness can be defined as the experience of one or more long term illnesses that are not curable or have residual features that impose limitations on an individual's functioning and require special adaptation in coping (Dimond

& Jones, 1983). The course of the illness may be relatively stable or marked by exacerbations and remissions or treatment failures and recurrences. Both the course of the illness and the response to the illness vary with each individual (Woods, Yates, & Primomo, 1989).

Several studies that examined the dimensions and demands of chronic illness concluded that psychological reactions to illness include anxiety, anger helplessness, uncertainty, depression and fear of increasing disability or recurrence (Stuifbergen, 1990; Viney & Westbrook, 1982; Woods, Yates, & Primomo, 1989). Additionally, chronic illness has been viewed as a multidimensional experience that disrupts lives by causing increased dependence, functional limitations, decreased participation in the work force and loss of income, decreased sexual activity and ability to fulfill nurturing roles, and restrictions in leisure and recreation activities. Keller (1988) stated, "a person with chronic illness not only experiences the disease but the accompanying medical, social, and economic costs" (p.98).

Other researchers have focused on the adaption process and coping skills needed to deal with the stress of living with a chronic illness. Cornwell and Schmitt (1990) studied women with rheumatoid arthritis and systemic lupus erythematosus and the relationship of perceived health status, self-esteem and body image. These two illnesses share some similarity to endometriosis in that both pain and fatigue are symptoms and there is frequently difficulty with diagnosis in the early stages of the disease. Additionally, individuals must cope with uncertainty, chronicity and lack of successful treatment regimens. These authors found that a patient's emotional response to her illness was determined by how severely the patient felt the illness handicapped her. Marital relationships, employment status, and leisure activities were most frequently affected.

These authors and several others, (Foote, Piazza, Holcombe, Paul, & Daffin, 1990; Primomo, Yates, & Woods, 1990; and Viney & Westbrook, 1982) also explored the concepts of coping and social support in relation to adjustment to illness. The basic premise that underlies these studies is that diagnosis has occurred and in fact must occur before the patient can begin to assess and cope with the life changes caused by chronic illness. Viney and Westbrook (1982) suggest some coping strategies may facilitate adjustment better than others and that patients need to be aware of their own capacities or of the need to develop new coping strategies. Keller (1988) explored coping models of illness to explain the differences in styles of adaptation patients use. She concluded that patients whose illnesses were unmanageable by themselves or medical efforts used emotionally based coping strategies such as denial or wishful thinking. Problem-solving strategies were used most frequently by those capable of controlling their illnesses.

Primomo et al (1990) suggest family, friends, and other members of the social network play a significant role in how well the individual adapts to chronic illness. While they stress that literature supports the notion that social support plays an important part in well-being, they hypothesize that if illnesses are not clearly defined or are misperceived, support may be inappropriate or inadequate. Additionally they discovered that social support tends to diminish and may become inadequate as a greater period of time since diagnosis passes.

The impact of support received from health professionals was also examined. These authors found that women confided about their illness first to their partners, but confided in their health professionals more than their friends. This has implications for women's expectations about sources of support needed and perhaps about types of support they hoped for. They found, as well, that failure of a health care provider to give anticipated informational support was detrimental to health. Another study (Woods et al 1989), discovered that information and advice were most helpful if they came from health professionals. However emotional support provided by the health professional was equally important, and professionals who helped patients manage the emotional distress of illness by developing strong therapeutic relationships contributed to their patients' sense of well-being. Conversely, lack of emotional support from the health professional seemed conspicuous when absent and was evaluated as unhelpful. For example, a consistent characteristic of cancer patients who chose to attend support groups, was a negative experience with the medical community (Woods, et al 1989).

Chronic Illness and Grief

The impact of endometriosis may be studied by examining chronic illness and the effect it has on a life, a relationship explored by Werner-Beland (1980) in a book dealing with grief responses to long-term illness. This author contends the idea of grief and mourning should be of interest to nurses and other health providers who work with individuals who have long-term illnesses. All illnesses create a grief response, however Werner-Beland (1980) states, "this response takes on even greater significance with those individuals who continue to liver under less than ideal physical conditions for extended periods" (p. 3). Chronic illness creates a state of chronic grieving not unlike grief reactions that occur following the loss of a significant other. However, because the loss is a part of one's self (loss of health) and because there is no immediate end to the situation that produces the grief, there is no foreseeable closure or resolution.

Werner-Beland (1980) contends that when evaluating the meaning and significance of chronic illness, the nurse should take into consideration the intrapsychic, interpersonal, socioeconomic, vocational and avocational meaning of the loss. The author notes that there is a lack of data on the grief response occurring with chronic illness which suggests this area needs more study.

Invalidation and Illness Experience

Sanford and Donovan (1985) in their exploration of women and medicine describe an issue which speaks strongly to the woman with endometriosis and expresses the concept of invalidation.

> Beyond the embarrassments and indignities modern medicine visits on the patient, modern scientific medicine has a detrimental effect on our self-esteem in other important ways. First, modern medicine undercuts our trust in ourselves and our powers of perception. It does this by requiring that we place our trust in doctors to tell us what's wrong, and that we further place our trust in machines or lab tests. Fundamental to the practice of medicine today is the assumption that regardless of what a patient feels, she is only ill if a doctor and his technological testing tools can verify it. Instead of trusting what our bodies tell us, we are to trust what doctors and their machines and their tests tell us. Since the doctor and his tests

> tell the truth it follows that if we feel pain even when the physician tells us 'nothing is wrong,' we must be crazy. The problem with this is that doctors and their tests are not omniscient diagnosticians. In fact they often make mistakes. Before a patient discovers a mistake has been made, her trust in herself is eroded and she begins to doubt her sanity (p. 252).

The clinical consequences of disbelief in one's body messages as it relates to endometriosis were clearly described early in this paper by comments made by Dr. Redwine. He describes his patient's inability to realize how severely limited their lives had become.

Chronic Illness: Diagnosis and Treatment

Patients with endometriosis frequently experience an extended time period (up to 10 years on average) of living with symptoms of illness, but without being able to obtain a diagnosis. This time period also frequently includes denial of body messages by the health provider prior to definitive diagnosis and by the patient during subsequent exacerbations of illness or perhaps in instances of new illness symptoms. In order to clearly understand the impact endometriosis has on a life, the effects of the denial of body messages by the care provider, and subsequently perhaps by the patient, need examining. An extensive search of the literature for information about the process of diagnosis in chronic illness or the problems patients encounter when unable to find a diagnosis revealed that the research literature is practically non-existent. Stephens (1986), in a paper presented at the Academy of Psychosomatic Medicine addresses this problem from a medical practitioner's perspective by using the example of patients who do not fit the standard classifications of diseases. While patients with endometriosis do indeed have a clear disease, the state of medical and personal confusion encountered before they arrive at diagnosis bears great similarity to patients described by Stephens. He describes patients with "multiple spells of acute illnesses; multiple and chronic complaints; much health seeking behavior; and overall ineffectiveness of medical and surgical interventions" (p. 466). The questions he asks of medicine are important.

> How are we to understand, explain, and treat such patients? How do they appear in our medical records, and how do they impact on research in health-care delivery and epidemiology that is based on medical records? (p. 466-67).

Though Stephens' raises important issues, his questions do not address the perspective of the patient. It is this researcher's belief that the patient's perspective is one that needs understanding.

The disagreement among members of the medical community about the diagnosis and management of endometriosis stems in part from the inability to obtain good results with current treatment regimens. When good results are not obtained, care providers feel frustrated. This frustration may be manifested in the therapeutic relationship as lack of emotional support for the patient and denial of her body messages. Other relationships are impacted as well. Family and friends are confused and worn out by the length and extent of the illness. The patient's ability to perform at work is compromised by the high number of sick days needed, and financial resources are compromised by the on-going medical interventions. The patient must learn to cope with pain and fatigue on a daily basis and accept the limitations this imposes on life plans and goals (EA, 1989).

Summary of Literature

The literature reviewed demonstrates that endometriosis has characteristics of a chronic disease, yet because of the ongoing conflict regarding etiology, diagnosis and treatment, this has not been clearly presented to patients. The ongoing conflict is reflected by the gaps in the medical and nursing literature where no exploration of endometriosis as a chronic illness has occurred. Clinical examples and the lay literature have described an experience of invalidation of a patient's symptoms. However, this researcher was unable to find any research literature that defined the concept of invalidation or addressed the possible relationship between endometriosis as a chronic illness, the process of invalidation and the impact this may have on a woman's life and well-being. With this knowledge deficit there may be a lack of basis for appropriate understanding and interventions by health care providers when dealing with the patient with endometriosis.

Conceptual Framework

Until a person experiences illness, health and wellness may be taken for granted. Good health provides the energy to perform one's daily activities including work, play and relationship involvements. The literature recognizes that chronic illness engenders a grief response (Werner-Beland, 1980) and imposes limitations in one's life (Keller, 1988). The research on the concepts of grief in chronic illness and a patient's ability to cope with and adapt to illness are important areas of study. Chronic illness causes disruption in one's life. A patient does not prepare for illness but must learn to cope and adjust to illness on many levels.

The patient experiencing the disease of endometriosis faces unique challenges. The length of time to reach a diagnosis, the fact that a definitive diagnosis can only be reached by the invasive procedure of laparoscopy and the controversy over treatment options and results presents the patient with additional problems. The lack of answers for the patient with endometriosis presents the patient with the need to cope with a chronic illness without having the support provided by a definitive diagnosis validating that illness indeed exists. Endometriosis patients are often told by friends or employers that they do not look ill, therefore nothing much can be wrong. Social support is often lacking and many women have had the experience of physicians attributing their symptoms to psychogenic origins (EA, 1990). The lack of social and professional validation of the illness for a patient experiencing endometriosis apparently affects coping, one's sense of self and sense of well-being. Whether the grief response is due to the chronic illness itself or the process of invalidation is not known.

Due to the considerable life disruption a patient with endometriosis experiences, this researcher believes the concepts of nurse healer and holism need to be understood before one can facilitate a patient's healing. Assessment of all of the aspects noted previously by Dossey et al (1988) must be taken into consideration as an important role of nursing involves helping a patient maximize their well-being, either within the context of continuing illness or at it's resolution. As Dr. Anne Brooks says, "I believe there's a difference between healing and curing. Curing is getting rid of the disease, but healing is the balance, the interaction with the environment" (Clancy, 1990, p. 217).

If patients are to maximize their well-being when having a chronic illness, the nurse must understand issues related to chronic illness. The concept of grief as an outcome of chronic illness has been examined; however grief as a response to endometriosis has not been systematically documented in the research literature. If women with endometriosis experience invalidation and if a consequent grief response and difficulty in adapting to illness can be documented, nurses will have a greater understanding of endometriosis as a chronic disease and can intervene with a holistic response.

This researcher questions the patient's ability to maximize well-being or return to health and the nurse's ability to facilitate that process if important issues such as invalidation, grief, and self-esteem are not understood and taken into consideration. The conceptual perspective for this study involves exploration of the concept of invalidation within the experience of endometriosis. The question this study seeks to answer is; do patients with endometriosis experience a process of invalidation and what are the meaning and consequences of invalidation to the patient.

Chapter III

Methods

Rationale for Study Design

The focus of a conference sponsored by the National Center for Health Services Research addressed research issues in the area of women's health. An important point was made by Olesen (1977) with the statement that "research about women must be grounded in women's views, definitions, and concerns lest health care research continue to render inaccurate and biased views of those worlds based on the inappropriate categories generated at second hand by persons not a part of those worlds" (p. 2). Women who experience endometriosis share a common, but uncommon, course of illness and health. Controversy about the diagnosis, treatment, results and most importantly, about the woman's perceptions of her body's message abound for the women coping with the disease. Unless the impact of that controversy is examined and addressed, the process of healing may be delayed indefinitely.

McBride and McBride (1981) proposed a theoretical framework for considerations of women's health, the central premise of which is that women's health means taking women's lived experience as the starting point for all health efforts. The authors also suggest this model implies a rejection of the traditional (patriarchal) medical model in favor of one concerned with "attaining, retaining and regaining health" (McBride and McBride, 1981, p. 41). In addition they emphasize that health promotion, specific protection, early diagnosis and prompt treatment, disability limitation, and rehabilitation-all of these levels of preventive measures are concerns of women's health, and not just the situation of a person in acute distress or the needs that health care professionals may assume clients have. Moreover, physical and psychological well-being are always presumed to be intertwined, as well as determined by the context (interpersonal), socio-economic, political, environmental, etc.) in which the individual operates.

Design

Because a gap in the literature exists, the design of the study was a descriptive, exploratory one. The purpose of the design was factor isolating. As little was known about the concept of invalidation, this study was undertaken to explore this phenomenon for women with endometriosis. They lay literature documents that invalidation does occur; however it does not explore what happens when a women's body messages are invalidated. Therefore the research problem was concerned with "understanding the meaning and pattern of human responses in conditions of biopsychosocial health or illness" (Woods & Catanzaro 1988, p. 134). A descriptive approach to the phenomenon was used. Grounded theory analysis was used with the data to produce conceptual descriptions and interrelationships. The sample will be purposive in that the investigator will select cases from the sample available from the Oregon Health Sciences University Menstrual Disorders Clinic. The selection criteria will be: a) diagnosis must have been made from direct pelvic visualization, by either laparoscopy or laparotomy; b) length of time since onset of symptoms will be one to fifteen years; and c) participants primary presentation to their health care providers was due to the symptoms of endometriosis and not for other medical reasons, e.g. infertility. As this is an exploratory study, sample size will be limited. Five participants from the sample population will be interviewed.

Interview Questions

Interviews were conducted in the participants homes to provide as natural a setting as possible. The interview began with a broad, opening question and continued with follow-up probing questions. Interviews lasted approximately one hour and were guided with the use of open-ended questions. Each participant was asked the same opening question, with essentially the same phrasing. Choice of open-ended questions was guided by the nature of the study which was an exploratory descriptive study seeking to understand a process. Open-ended questions allowed participants to answer fully from their personal experience. The principal investigator conducted all of the interviews. (See Appendix A).

Human Subjects

The confidentiality of the participants was protected by maintaining anonymity. Only the researcher and the Menstrual Disorders Clinic manager (a research committee member), knew the identity of the participants. Tapes were identified by numbers and names used in the recordings were changed during transcription. Anyone who assisted with data analysis used the altered, numbered transcriptions. Each participant read and expressed verbally their understanding of an informed consent. The researcher debriefed participants following the interviews. No issues were uncovered with which the subjects needed assistance in coping. Participants had the right to withdraw from the study without prejudice, at any time. The researcher was prepared to stop the interview if it appeared too stressful for the subject.

Participants

Four women participated in this research project. All of the women gave written informed consent to participate in the study. Participants were drawn from patients who had a definitive diagnosis of endometriosis made by direct pelvic visualization. Three participants were selected from Oregon Health Sciences University's Menstrual Disorders Clinic. These participants were approached initially by the nurse practitioner clinic manager and asked if they would like to participate in a research study on endometriosis. The fourth participant was Canadian and had received all of her health care in Canada. This participant was referred to the researcher by another student after expressing interest in participating in the study. Three of the women were Caucasian, one was African American. Two women were high school graduates, two had advanced college degrees. The ages of the women ranged from 37 to 50. One participant had a hysterectomy, the other three participants had conservative surgeries that preserved their reproductive organs. Two participants had one term birth and two had not had any pregnancies. The names used in this paper are not the women's real names. To help the reader understand the dimensions of the disease and the impact on the women's lives, a brief explanation of each woman's history is given.

Sarah was 40 years old and had experienced symptoms of the disease since she began menstruating. She did not seek help until she was 35 years old and clearly indicated how living with the disease of endometriosis had impacted her entire life. She was able to find help with the first physician she saw for the pain. She had laparoscopic surgery followed by laparotomy. Five years prior to this, she had laparoscopic surgery for a tubal ligation and did not at that time mention the pain and symptoms, nor did anyone note any pathology. She has experienced good pain relief, although still has some episodes of pain each month.

Rose was 50 years old. She also began to experience symptoms when she started menstruating and also did not seek help for many years. Her first attempts to find help when she was in her early twenties were unsuccessful and she did not try again until her mid-thirties. She had a hysterectomy and bilateral oophorectomy and has experienced good results.

Alison was 37 and also began experiencing pain and symptoms when she started menstruating. She began looking for help in her early twenties and did not find answers until her early thirties. She has had a laparoscopy and a laparotomy. She experienced good pain relief for two years, however, her pain has returned to same level it was prior to surgery. She has been advised to have a hysterectomy.

Pat, who is 41, also began to experience symptoms at the onset of menstruation, however did not feel they were a problem until her early thirties. She has sought help from many care providers and had two laparoscopic surgeries with moderate relief. She continues to struggle with symptoms of the disease.

Data Generation and Data Analysis

Data were gathered by interviewing four women who had endometriosis determined by pelvic surgery. Data were obtained from audiotaped interviews which were transcribed and coded. Interviews were coded to identify potential concepts. As concepts emerged, further data was collected through the process of theoretical sampling, until theoretical saturation occurred. As needed, additional review of the literature occurred to clarify concepts.

The first phase of the analysis involved coding the transcribed interviews. The principal investigator and the research advisor coded the first two interviews separately and then compared analysis as a means of establishing intercoder reliability. The principal investigator coded the remaining two interviews with the research advisor reviewing the coding scheme.

After the interviews were coded by using comparative analysis of the data, codes were grouped into categories. Further analysis reduced the categories into mutually exclusive groupings. Theoretical notes were written to provide interpretation and conceptualization of the data. After analysis of the first three interviews was completed, the process the women had experienced when dealing with endometriosis emerged. Questions were developed based on this process and a fourth interview was conducted in order to verify the data analysis. This interview generated data consistent with the first three and data collection was ended.

Chapter IV

Findings

This study was conducted to discover if women who have endometriosis experience a process that is similar as they seek a diagnosis and treatment. Specifically the research question asked about a process of invalidation of the women's symptoms. As a pattern suggestive of a process emerged, the research inquiry was expanded to include what the meaning and the consequences of this process were to the women. The initial research question was focused on the experience of seeking a diagnosis for their symptoms. The data which resulted enlarged the research question to include the effects the disease had on the women's lives and whether or not the effects bore resemblance to literature descriptions of chronic disease effects. Thus the initially sought process of invalidation became expanded to the process of living with endometriosis, a process which included invalidation.

The data from this study suggest that a process of invalidation of the women's symptoms does occur. However a surprising finding emerged from the data. The process of invalidation did not occur only in the context of the women's attempts to obtain a diagnosis for the disease of endometriosis. It appears that the invalidation process was a result of the context within which women live and are provided health care. This finding emerged from the women's responses to the initial interview question requesting a description of the process of obtaining a diagnosis. All of the women began their story by spontaneously describing their initial menstrual history and their early years of living with the pain with the attitude that it was normal to have pain. This aspect of the process involved an extended time period during which the women had symptoms but were not actively seeking a diagnosis. For three participants these symptoms occurred at onset of menstruation. For the fourth participant, although minor symptoms occurred at onset of menstruation, these symptoms became most troublesome during her third decade. The women all experienced severe menstrual pain; however, they attributed it to the fact of 'just being a woman' and felt they should accept the pain as normal. During this initial part of the process the women did not think the pain was something that might have needed medical attention. This time period of living with the pain, which averaged sixteen years, was longer than the time period they spent actively seeking diagnosis, which averaged seven years.

After the large number of symptomatic years had passed, the increasing severity of symptoms moved the women toward seeking help. By then the women were unable to maintain the belief that the pain was normal. Each woman began to experience fear and anxiety that something indeed must be wrong. It was during this period of increasing fear and anxiety that the women began to actively seek a diagnosis.

The women also clearly described the effects they felt the disease had on their lives. The effects described emerged from all aspects of the process, both the time when they believed the symptoms were normal and the time when they were seeking diagnosis and obtaining treatment. The women felt these effects continued even into the present time.

Categories

Several categories emerged from the data of each woman that seemed to define and explain the process for all the women. In the following section, each of the categories is defined and illustrated with example data.

Grin and Bear It

'Grin and Bear It' is a category that represents the behavior the women used in an attempt to normalize their symptoms by attributing the pain to the fact of being female. The women lacked the knowledge to distinguish normal from abnormal body function and they assumed that accepting and enduring the pain was a 'woman's lot'. This behavior appears to be recalled as the earliest aspect in the process of invalidation. The 'grin and bear it' behavior was also used throughout the process whenever the women felt they had no options or control. For this reason, the behavior also appeared to represent a coping strategy.

Rose, who lived with the symptoms for over twenty years before seeking any help, sums up the process of accepting and handling the pain as a normal experience that must be endured.

> This is what you bear being a woman...you know, you're just going to be in pain.... And, I really, I guess at first, or for many years, I just thought, oh, it's kind of a woman's lot in life to...to feel kind of painful in her abdomen, you know. I don't know, I think it was, that was the time period that I thought, well, you gotta grin and bear it...it's pain that you just go through. (Rose)

Increasing Fear and Anxiety

'Increasing Fear and Anxiety' is a category describing another aspect of the women's process. It also represents the collapsing of the coping strategy defined in 'grin and bear it.' When symptoms escalated to severe levels the women experienced increasing fear and anxiety. The women were no longer able to maintain the 'grin and bear it' facade that the pain was normal. The women began to fear something was wrong and the increasing anxiety caused them to make attempts to find help and answers. This category of 'increasing fear and anxiety' recurs throughout the process as the women encountered changes in their disease course.

Rose reached a point where she decided she could not endure the symptoms anymore and began to question if indeed there was something wrong with her and that perhaps she should try to find out.

> And I would have these severe pains and not know what they were and they would be severe enough I thought I was dying.....And then I thought, I guess, after years of ...I guess I just got fed up and kind of was at the point of saying, oh, okay, there's something wrong, and I don't know what it is, but I'm going to try and find out. (Rose)

Family Communication Patterns

'Family Communication Patterns' is a category containing two factors that represent communication patterns families developed for talking about menstrual matters. These patterns of communication resulted in a certain silence about gynecological matters. First is passing on family misinformation and second is the openness with which female matters were discussed.

The first communication pattern is what is passed down from symptomatic mothers to daughters about coping with menstrual life. Two of the participants' mothers had also experienced severe menstrual pain. Because of this, they passed on the erroneous view that menstrual pain was normal. They had 'socialized' their daughters to think the pain was normal and not to be complained about. This pattern is illustrated by the way Sarah's mother dealt with Sarah's menstrual pain.

> So it was part of being a woman. "I've always suffered (her mother is saying about herself), so this is the way it is, and are you sure you're not just making more out of it"....so right from the beginning I (Sarah) was socialized to believe that I couldn't trust my own reactions...by my mother. (Sarah).

The second factor is developed from the embarrassment that existed about discussing 'female matters' in the family. Sarah's communication with her mother reflects the embarrassment about menstrual issues which led to avoidance of the subject.

> I started menstruating quite young, I think it was just before my 11th birthday. And the whole thing was extremely embarrassing, my mother was very embarrassed telling me about it. And my mother was the type of person... that if you hide your head in the sand, it goes away. (Sarah).

Disbelief by Peers

'Disbelief by Peers' is a category representing women's experiences of co-workers and friends inability to acknowledge the magnitude or existence of their symptoms. The disbelief was due to the lack of visible signs of disease which peers could see. This category includes the perceived lack of empathy women received from others when they attempted to discuss their symptoms.

The following data illustrates the lack of empathy one of the participants received from co-workers.

> I was in a great deal of pain, my supervisor didn't think I should take time off for anything. You know, and um they just thought it was like, you know, "get over this, or we're going to fire you." (Pat)

Provider Denial

'Provider Denial' represents the women's experience of response from health care providers. It contains three responses the women encountered in their dealings with health care providers. The first aspect of provider denial occurred when the women attempted to discuss their symptoms and the provider did not accept them as real or minimized them. A second aspect of denial occurred when the symptoms were elicited by the provider but then were not explored or investigated. However, if investigations were made and initially did not produce answers, the women again experienced provider denial. Provider denial occurred in a third way when physicians made no attempt to inquire at any time whether the women had symptoms.

Alison and Rose expressed the feeling of frustration about the lack of an adequate response and lack of belief their complaints received.

> But looking back when I, at first, they would write it down, but there was never any issue of let's see what this could be, like maybe it could be endometriosis. I mean it was like "oh yes, so you say you have hard, you know your periods are painful"...and that was the end of the conversation. (Alison)

> Something wrong is going on in there and I could tell people till I was blue in the face, you know, you think about it, I could tell the doctor this, but what are they going to do? There's nothing they're going to find, they never find a thing--there's nothing they're going to find. So, it's just end of discussion. (Rose)

Attribution of Symptoms

'Attribution of Symptoms' is a category that refers to the process of assigning causes other than physical disease to the symptoms the women were experiencing. The most frequent attribution was to psychological causes.

Physicians, family, friends and co-workers participated in attribution of symptoms.

Alison, after reaching the point where she could not deal with the pain anymore, sought answers from a physician. She had her symptoms attributed to emotional origins.

> The symptoms got to where I couldn't deal with them in college and uh let's see the initial diagnosis was based on mental stress. I was told by a campus physician that thought it was based on just the stress of college and my graduate program and really not to worry about them. Then like it was as if it was modern day passivity. That it was very much of just an emotional behavior that I was going through other than looking at it as something that was documented or something that was scientific or something that was of some substance, that might be critical. (Alison)

Lack of Knowledge

'Lack of Knowledge' is a category used to describe the informational base not available for the women and others. This category included lack of information about normal and abnormal reproductive functioning. The women, their families, peers and some of the health care providers all lacked knowledge about endometriosis. This lack of knowledge created a void which made it difficult to identify problems, ask questions and find solutions.

Alison, when asked what she thought would be helpful for other women experiencing symptoms of endometriosis to know, indicated the importance of knowledge about their own bodies.

> ...I think it's important that you understand what's going on in your body. I mean as women,

> you have the right to know what's going on in our bodies. But by the same token, I think we don't know the proper questions to ask. (Alison).

Impact on Life

'Impact on Life' is a category used to describe the effects the disease of endometriosis had on the women's lives. This category contained data from all realms of life. The women described effects to their lives in the following areas: relationships, work, finances, education, social, leisure activities and emotional well-being.

The inability to work consistently because of the number of 'bad' days caused Rose economic problems.

> And every time I'd go to work, I would end up having to be an employee in like lower echelon jobs that weren't real meaningful to our society. It was real difficult doing any of the jobs, because you don't have good days all of the time. You don't just go and have you know, the worse thing happen to you during the month is your period. I mean, no, sometimes you just wake up and you think you're going to die. (Rose)

Chapter V

Interpretation of Findings

The Process of Invalidation

The data will be interpreted by discussing the previously defined categories. Of the categories identified below, each contributes to the process of invalidation. Additional data will be used to illustrate the women's process of going through the endometriosis experience in their own words. Then, a core variable will be defined.

Grin and Bear It

'Grin and bear it' was the category used to describe the behavior the women assumed as almost an automatic response to the pain they experienced when they first began to have symptoms. In this part of the process, the pain was accepted as normal because it was viewed as part of being a woman. The women perceived the pain as something that had to be borne. The women decided they could handle it and found an acceptable image to project while they endured it. They use the phrase "grin and bear it" to describe this behavior and their acceptance of the pain. The 'grin and bear it' behavior is considered by the researcher to be one part of the process of dealing with endometriosis. As it is a behavior adapted in response to symptoms; it can also be considered a coping strategy.

Sarah clearly accepted the pain as part of a normal experience for a woman. Her family had a history of female problems and when Sarah also began to experience severe pain with her menstrual periods, it was accepted as part of the normal experience of her family.

> So it was part of being a woman, "I've always suffered, (her mother told her) so this is the way it is, and are you sure you're not just making more out of it." (Sarah)

Pat also experienced the feeling that the pain had to be accepted and endured and so developed the attitude that it was bearable.

> But that was it, (the pain), and it was bearable, You know it was bearable. (Pat)

Alison also acknowledged that the acceptance of the pain as a normal female experience kept her from seeking help for her symptoms.

> But I mean I knew nothing about endometriosis or that it was very common. So back then, that was the way I dealt with it for many years, (grin and bear it). (Alison)

While humans generally are conditioned to react to pain as a signal that something is wrong, both Sarah and Rose, while admitting that the pain existed, accepted the pain as a normal part of being female and initially did not question whether it was abnormal. Because of this acceptance, they also did not seek an explanation for the pain or look for intervention.

> And the intense pain...and I don't think I was ever seen by a doctor, like it wasn't considered that this was something that would need to...(be looked into)...(Sarah)

> That was ten years of real discomfort, with medical problems, you know, we never spent a great deal of money or researched things that could be going on, I just guess well probably because of culturally growing up...thinking this is just the way it's supposed to be. I'm supposed to be in pain. I don't know why, I guess I just never researched it. (Rose)

The women also seemed to be saying that the combination effect from lack of knowledge about their own bodies and their mother's silence and acceptance of their pain as normal led the women to develop the 'grin and bear it' behavior. For each woman, moving from the 'grin and bear it behavior into the process of finding help in the form of an accurate diagnosis and treatment took more than one attempt. In many ways, as the data will illustrate, 'lack of knowledge' was a factor that contributed to the maintenance of the 'grin and bear it' behavior.

Of interest is the fact that Alison, who continues to experience severe pain despite surgical intervention, seems to be relying on the process again, by using 'grin and bear it' as a way of coping with the pain. The fact that Alison would return to the 'grin and bear it' behavior after finding answers in the form of a diagnosis, but experiencing a poor outcome after intervention, led the researcher to consider 'grin and bear it' as a coping behavior used when there were no apparent alternatives available.

> And that's been, that's how I've treated it, I just grin and bear it. I still go to work. (Alison)

Additionally, Alison is quite clear that 'grin and bear it' is indeed a mask, a facade used to cope with pain that cannot be alleviated. The mask is used as a means to maintain the 'grin and bear it' behavior. It is a projection that everything is normal and all right.

> And you can say "Yeah, I mean you know we all wear a mask." (Alison)

Increasing Fear and Anxiety

The 'grin and bear it' behavior is maintained until the pain and symptoms escalated to the point where the women found they could not bear the pain anymore and began to wonder if they might have something wrong with them. They began to think perhaps the pain was something more than just "a woman's lot." As symptoms increased, so did the women's fear and anxiety; and their ability to maintain the 'grin and bear it' behavior began to falter.

At this point, for each of the women, another aspect of the process emerged. The inability to deal with the pain and the subsequent fear and anxiety brought with it the admission that indeed there must be something wrong. With the acceptance of something being wrong came the desire to find answers.

Alison reached a point where it became clear she could not endure the pain and accept it as normal anymore.

> I dealt with it for many years, until 5-6 years ago when the symptoms were becoming so severe and debilitating. I've always had painful periods, ever since I started to menstruate, but to the

> point where I couldn't, I would say, not deal with it anymore was in college. (Alison)

Pat endured the pain until symptoms began to escalate to the point where it became difficult to maintain the 'grin and bear it' mask.

> I always had cramps with my periods but you know I wasn't really bad...and then in March or April '85 I remember saying 'I can't understand this, I'm just feeling awful for two weeks (each month). When is this going to be over. (Pat)

It was essentially the women's inability to 'bear' the symptoms any longer that forced them to admit something might be wrong and to begin the process of finding answers.

Family Communication Patterns

One antecedent to the 'grin and bear it' behavior was the fact that in many of the women's families gynecological problems were viewed as closet diseases, not to be openly discussed. This view seemed to be perpetuated in the family by the mothers' unwillingness to discuss female problems or female matters with their daughters. The family communication patterns can be viewed as both a result of and a contributing factor to the 'lack of knowledge.'

Rose clearly shows how the communication patterns in the family contributed to the 'grin and bear it' behavior and 'lack of knowledge.'

> I don't think people talked about it then, and I don't think that's good, because I didn't know what was wrong with me, and I think that I might have looked back at my mother, thinking, well, or maybe it didn't even go through my mind; maybe

> thinking that well, since we don't talk about these things. (Rose)

Rose also expresses regret and longing for the communication that would have informed her about her body and perhaps led her to seek help for an abnormal condition earlier rather than living with it for twenty years.

> Wouldn't it be smart if people just kind of found out from their, (family) I mean, I think that's totally wrong not to educate and inform your children. I mean, making gravy I can do without learning, "tell me about my bodily parts." More education. (Rose)

Family communication about dealing with menses had an effect on the women's views as well. Sarah considers she was socialized to accept the symptoms as a normal event for the women in her family, herself included.

> I was kind of always just socialized with, well, all the women in this family have that kind of trouble, so you're just another woman in this family, so you have this trouble. (Sarah)

Disbelief by Peers

Other people in the women's lives, such as friends and coworkers contributed to the invalidation process by minimizing or disbelieving the women's complaints. Because the women did not have visible signs of illness it was suggested that they must be really alright.

Rose found that people would not believe her because she did not look sick.

> That was always (their response) that "you look fine. You're not doubled over in pain, you're not throwing up, and you're not white as a ghost, so

> not much can be wrong,"...yet you feel like crap. (Rose)

Alison considered the response of others as difficult to deal with as was the pain.

> And the other women who don't, who think that this is all a fallacy, that I'm making this all up, that I'm not going through this pain. "How can a period be that bad." When I try to describe it...it would be like going into labor and they go "oh come on, it can't be that bad." But the frustration of having to deal with it mentally you know and having to deal with how other people are responding to you. (Alison)

Co-workers and Pat's supervisor did not acknowledge the magnitude of her symptoms. In addition to not receiving empathy from her peers, Pat faced the threat of losing her job if she continued to experience problems with her health. The experience of receiving threats of loss of employment and the disbelief from others, encouraged the women to be silent about their symptoms. This disbelief from others also served to perpetuate the 'lack of knowledge.' Since no one was discussing the situation with anyone, how could information and support be exchanged.

Provider Denial

Health care providers also contributed to the process of invalidation. By this time, the women had moved well beyond 'grin and bear it' and were actively seeking help or an explanation for what could possibly be wrong.

Physicians either did not ask questions to determine if the women were symptomatic, did not listen to, or minimized the women's symptoms when they tried to tell about their symptoms. Another response of the physicians was to not explore or investigate possible causes for the reported symptoms. If physicians did investigate but did not find causes, they suggested to the women that there could not be a problem. Denial by others, including health care providers, caused them to feel frustrated and have feelings of self-doubt. The provider denial also helped maintain the lack of knowledge because the women did not receive answers or information about their condition. It is also possible that lack of knowledge about endometriosis on the part of the physicians contributed to their response to the women. All of these experiences made it difficult for the women to keep telling others about their symptoms.

Pat had struggled with the impact of the denial from health care providers which made it difficult for her to tell others what was wrong and to receive some support from them. When symptoms returned for the second time, several years after her first surgery, she sought help from a specialist in endometriosis. He reluctantly performed surgery and, after the surgery, told her:

> "Oh, you probably didn't have any, but we'll look at the path reports anyhow." (Pat)

It turned out that Pat did indeed have endometriosis again and she expressed how she felt about the provider's denial.

> So, they sent me the path report, I called my family up and said, "See, I was right! The doctor was wrong." (Pat)

Attribution of Symptoms

Another aspect of the invalidation process the women experienced was attribution of symptoms to causes other than physical disease. Attribution of symptoms to other causes occurred with physicians, family members and peers. This aspect also had the effect of maintaining the lack of knowledge and made it difficult for the women to seek answers.

The first physician Sarah saw reinforced the belief that her body was perfectly normal, therefore if something was wrong it was not physical, but rather a psychological problem.

> It was your nerves, "it has to be your nerves. There's no reason for you....you have big hips and you know there's no reason for anything in the female organs to be malfunctioning. It would have to be emotional" (the physician told her.) Sarah.

Sarah had made this one attempt to find answers soon after she had married, but the response of the physician caused her to continue to endure the pain for many years. Attributing her symptoms to emotional reasons caused her to loose self-esteem and eroded her trust in doctors. It was many years before she sought help again.

> It took me two doctor changes...and a very bad incident with my son before I finally smartened up and then changed to this other doctor, and really liked him, and then after awhile, of going to him with my son, was able to trust him with you know, what I had been going through....And finally I got help and subsequently had a hysterectomy. But before then, I was so programmed that it was all

> in my head, I wasn't going to take the risk of hearing that one more time. (Sarah)

Pat's coworkers and supervisor also attributed her symptoms to emotional causes.

> They just thought it was in my head. You know, it was like ... I was very emotional at the time, I was in a great deal of pain.

The attribution of the women's symptoms to psychogenic origins, as well as making it difficult for them to continue pursuing help, made it difficult to share their problem with others and get support.

<u>Lack of Knowledge</u>

'Lack of Knowledge' emerged throughout the data as a major contributor to the process the women experienced when dealing with endometriosis and attempting to find answers and solutions. The lack of knowledge appears to be pervasive in that all the people the women encountered lacked knowledge to some degree.

'Lack of knowledge' appeared to be a major factor in the length of time it took each woman to first, admit she might have a disease and second, to find answers once she started looking. A basic lack of knowledge about their own bodies and what was normal or abnormal menstrual functioning seemed to be a major contributing factor to the women's experiences.

Physicians frequently lacked knowledge about endometriosis as they did not consider endometriosis a diagnostic possibility when the women presented their symptoms. Nor did the physicians apparently understand the importance of soliciting information about the women's menstrual histories as a means of helping the women report symptoms.

Family members also often lacked information as demonstrated by acceptance of pain as a normal female condition. Peers demonstrated their lack of knowledge about the disease in that not only was the possibility of an organic illness not even considered by them, but their lack of empathetic response to the women's complaints may illustrate how little knowledge the general public has about the disease. Further, even when the condition was diagnosed, there was no knowledge base from which family and peers could respond appropriately. Pat's frustration at not receiving recognition or support for endometriosis and her subsequent views about the need for breaking through the silence with open discussion are stated in the following remarks.

> I'm working on this lately...I'm taking it more out of the closet and talking about it. Because in an ideal world, more people would understand how this happens and there would be more support. (Pat).

The idea that endometriosis is unmentionable because it is a gynecological disease was also apparent in the interview with Pat.

> It's hard to deal with it in some ways because it's um, it's a closet disease. It's a gynecological closet disease. (Pat)

Impact on Life

The effect of dealing with the disease emerged from the data. Each woman expressed the fact that the disease had affected her life in a major way. This disease was not viewed as an episode that occurred occasionally, but rather as an illness that permeated each women's everyday life. It influenced decisions and nearly every aspect of their lives, from relationships to work, and education to social/leisure activities. Most of the women considered endometriosis to be a chronic disease and felt they had to contend with all the aspects of what a chronic disease meant. However the prevailing 'lack of knowledge' and difficulties they had when trying to discuss the illness made coping with a condition, which they viewed as chronic, even more difficult. In their initial experiences there was belief in normality and therefore no diagnosis, meaning there was not even a name for the symptoms they had experienced for 10-20 years. After they had a diagnosis, there was still a lack of support from health care providers, peers and family, for both the magnitude of the symptoms and the impact on their lives.

View of disease as chronic.

Sarah sums up the feeling and frustration most clearly when she describes how the disease affected her life and how the extent of the impact caused her to view it as a chronic condition. One of the consequences of living with a chronic disease is the impact on self-esteem.

> And it really affects your whole self-esteem, your whole picture of yourself, you know, it's very much affected when it's a chronic disease. It's not just something that is part of that's an aberration of a normal cycle, it's a chronic disease..... A period wasn't just a period that happened in the genital area, it was your whole body, your thinking, your whole functioning, because you had this pain, and it just became...it was always going on...it was never just a distinct four or five day period. And it affected my life. I'll say I lived it. It was my life...it was a terrible way to live. (Sarah)

Sarah also expressed how coping with the disease affected her social activities.

> I got so bad, that I wouldn't even have company, I wouldn't even plan company, or anything in the last ten days of the month. (Sarah)

Sarah's marriage was in the process of ending as she provided data for the study. She felt that all of the problems, both physical and emotional, that resulted from living with endometriosis have played a major role in this marital relationship.

Relationships were impacted for Rose also. Rose's first marriage ended in divorce and she felt that living with endometriosis contributed to the problems in that relationship.

> Well, I think it probably affected it a great a lot. Probably...yeah, affected it a great deal, because everything having to do with my reproductive organs seemed to like...seemed to

> kind of come to a cataclysmic head during that relationship. (Rose)

Rose expressed a sense of regret at the loss of the choices she felt she had because of the interference of the disease in her life.

> There's a lot lost. I feel really angry sometimes because I feel really cheated. I feel like I've spent a great majority of time in pain. I think I would have made different career choices, I would have made difference choices educationally. (Rose)

In addition to career and educational losses, Rose also expressed how the disease impacted her social life and leisure activities.

> There were a lot of activities that I couldn't do because, you know, after awhile, you just kind of stop doing things because you just don't feel well. It's like you have zero energy. And you have to get like motivated from the bottom all the way up and it's really hard to be that way when you feel awful all the time. And you physically feel awful. (Rose)

Rose also expressed how coping with endometriosis affected her view of her own behavior.

> ...there are a lot of things associated with it too, because finally, the thing I didn't like about it was it affected my behavior. I would hear myself saying the way I felt, physically and it sounded like complaining. (Rose)

Alison, who continued to have pain at the level she did prior to her surgical intervention, believed there were behavioral consequences to dealing with pain. These consequences once again were influenced by the prevailing 'lack of knowledge' and the difficulty in discussing the disease. She said it would have been helpful to have had some information about the psychological components of the disease, in particular, how to deal with the pain. She expressed concern that pain changed her behavior and that there were consequences to that.

> Pain tends to bring out a lot of personality traits that I don't care to have. And I also get depressed and testy you know, when I feel it's coming.

She expressed concern for the consequences of this behavior.

> And I would, things would happen at work, and it would, there were consequences to some of these actions I had. But now I try to alleviate the stresses in my life and I just kind of fade into the woodwork for that week. (Alison)

Alison had developed a strategy of "fading into the woodwork" which may be viewed as both a consequence and a maintenance of the 'lack of knowledge' and the silence that exists about gynecological problems. As she explained earlier, her attempts to describe to co-workers the severity of the pain met with disbelief. Because others could not understand the severity of the symptoms, it was difficult for them to accept the behavior changes. "Fading into the woodwork" was then a coping strategy that allowed Alison to maintain relationships at work, but did not allow her to gain validation or support for her disease.

Pat also addressed the consequences of symptoms affecting work and work relationships when she discussed the threats of firing, described earlier, if she could not pull herself together. Pat's frustration at not receiving support for her chronic illness comes out in the following statement.

> ..... in an ideal world, more people would understand how this happens and there would be more support. Like the second time I had it, I was having a nervous breakdown. I had no way to leave my job. I needed to leave my job to be well. And if society realized this was a chronic, disabling condition, there would have been some way that I could have, you know, gotten some kind of financial support. (Pat)

Core Variable

A core variable represents the central theme of a process (Glaser and Strauss, 1967). As a pattern reflecting the process women experience while living with endometriosis emerged from the data, the identification of a core variable became apparent. The core variable identified for this study is called 'conspiracy of silence.' 'Conspiracy of silence' has been identified as the core variable because it appears to be the common underlying factor that influenced every step of the process of living with endometriosis.

'Conspiracy of Silence' means that for various reasons, the information and validation the women needed to have in order to understand what was happening in their bodies was not available. This occurred not only concerning the undiagnosed condition of endometriosis but also occurred for the availability of information about women's bodies and reproductive functions. Many people contributed to the silence. All aspects of the disease experience have been influenced by the 'conspiracy of silence' the women seemed to encounter from the earliest days of living with endometriosis. The categories form the many dimensions of the core variable 'conspiracy of silence.' Some of these are antecedents and others are consequences of the core variable.

The endometriosis experience can be described as an attempt by the women to understand and cope with what was happening in their bodies. It includes their attempts to acknowledge and seek validation of the symptoms, find answers and solutions to the symptoms, find acceptance of the disease by other people in their lives and cope with a disease that has consequences resembling those of a chronic illness. This process includes the following conceptual categories as defined earlier: a) grin and bear it; b) increasing fear and anxiety; c) family communication patterns; d) disbelief by peers; e) provider denial; f) attribution of symptoms; g) lack of knowledge and h) impact on life.

Tentative Conceptual Structure

The process of living with endometriosis appears to have three distinct stages. The conceptual categories previously identified and defined, are associated with one or more of the stages in the process of living with endometriosis. The first stage in 'living with endometriosis' is 'accepting a woman's lot.' This is a stage when the women experience onset of pain and symptoms but believe these have to be accepted as a woman's lot in life. Coping during this stage is 'grin and bear it.' Each participant clearly endured the symptoms for nine to twenty-five years by engaging in 'grin and bear it' behavior. While most women had mentioned their pain to someone early in their menstrual life, they had not experienced any validation or encouragement to seek help. Rather, family communication patterns initiated and supported the women's process of accepting pain as normal. The inability of the women's families to discuss menstrual issues maintained the silence. The result of these factors was that their symptoms were not acknowledged as such and they stopped asking or talking about them. Thus the core variable, 'conspiracy of silence' was the reason they were each willing to endure and accept as normal a condition that was in fact abnormal and needed intervention.

Each participant reached a stage, called the 'help seeking stage,' when she sought diagnosis. This occurred when escalating symptoms prevented her from maintaining 'grin and bear it' behavior and started her on the process of seeking help. During this time she experienced 'increasing fear and anxiety' in reaction to the escalating symptoms. The core variable 'conspiracy of silence' had a pervasive effect during the help seeking stage when the women experienced denial by health care providers, attribution to other causes and disbelief by peers and others. These experiences affected women's efforts to get help. After a period to time which averaged seven years had elapsed, all the women obtained a diagnosis of endometriosis and received treatment. It appears that only after the diagnosis was obtained and the women had a name for their symptoms could they move to a third stage, that of 'coping with a chronic disease.' This stage involved realizing the impact the disease had on their lives. The women continue to struggle with this stage and the data suggests the 'conspiracy of silence' continues to contribute to the women's experience when there is lack of acceptance by others that endometriosis is a chronic disease. These three stages take place within the context of 'lack of knowledge' and family communication patterns.'

Discussion

The question this research project attempted to study was, "do women with endometriosis experience a sense of having their symptoms invalidated as they work through the process of arriving at a diagnosis?" The results of this study address that question in a partial manner. A definite process that each of the women seemed to experience was identified, one which had many components that contributed to women's feelings of invalidation. Perhaps the most interesting aspect of the invalidation process was the fact that the women themselves invalidated their symptoms for many years. This invalidation was a feeling women experienced related to their attempts to get help in an atmosphere of silence.

During the first stage of the endometriosis experience, women lived with what were often disabling symptoms for an average of sixteen years before looking for answers and help. Components of this experience were reflected in the 'grin and bear it' behavior that occurred because of the women's lack of knowledge about their bodies and reproductive functioning and family communication patterns which reinforced the silence.

Even when help was sought, invalidation continued in numerous ways. The second stage of the endometriosis experience involved getting a diagnosis and treatment, successful or not. However, obtaining a diagnosis did not stop peer disbelief. This disbelief contributed to the ongoing process of invalidation. There were many reasons why the invalidation occurred, as was outlined by the antecedents and consequences of the key variable 'conspiracy of silence,' These antecedents and consequences formed a constellation of events that maintained and perpetuated the belief that symptoms experienced by the women were part of a normal female experience. Physicians attribution of symptoms to psychogenic causes, physicians lack of listening to and exploration of the women's symptoms and friends and co-workers disbelief were components of the second stage.

All of these components contributed to the 'conspiracy of silence' creating a situation where the women have no where to turn for the information, support and help they needed. Thus they use emotion-based coping patterns.

One has to wonder if the years of coping with the 'grin and bear it' behavior and constantly wearing a mask as each woman did, contributed to the response they received from others when they began the second stage, that of seeking answers and validation of their pain. Perhaps they had become so skilled at "carrying on" against all odds that they continued to fool others. Dr. Redwine has referred to this phenomenon when he sees women who are clinically not well but describe themselves as "fine." The only change for the women between the first and second stages apparently was the change in their thinking. In stage two the woman had begun to realize something was wrong, that there might be more to the symptoms than simply the fact of being a woman. However, because of the responses they had always gotten from others, they had learned to create and maintain a facade that everything was alright. As Sarah expressed, cited earlier, her family's response was that all the women had this problem and if you couldn't cope you were in a sense "wimping out." This made the help seeking stage one of ambivalence.

It starts to become clear from reviewing the steps of the process that the women found it very difficult to get the answers they needed. A considerable length of time passed for each woman, on average sixteen years, before she accepted that there was something wrong and began to seek answers. Finding the answers also was a process involving time, with seven years being the average. Throughout this process, due to the experience of invalidation resulting from the 'conspiracy of silence', it was difficult for the women to learn to listen, trust, and interpret their body cues and symptoms. Even once the women arrived at the point where they could no longer deny the existence of an abnormal condition, maintaining belief in themselves continued to be challenged by the responses of others to their symptoms and problems.

When looking at the impact on life for the women, it became clear to the investigator that endometriosis affected all areas of their lives. It seemed that the women could look at the impact on their lives only after they had obtained a diagnosis and had a name to give their symptoms. The process of coping with the disease has been identified as the third stage of the endometriosis experience. The core variable, 'conspiracy of silence' continued to play a role as the underlying theme. By listening to the women describe the complexities of coping with the disease, it became clear that in almost all areas of their lives, had there been validation and support for the fact that they were dealing with a chronic, disabling disease, different choices might have been possible. One result of the 'conspiracy of silence' is the sense of isolation the women seemed to experience both prior to and after diagnosis.

Comparisons with the Literature Review

This qualitative study exploring four women's process of obtaining diagnosis and treatment for endometriosis has results which correspond with those of previous studies. An Endometriosis Association study (1990), showed that on average it took women 10-15 years after the onset of symptoms to obtain a diagnosis. The average length of time for the women in this study to begin to look for a diagnosis was 16 years. It took an average of seven more years before diagnosis was obtained.

This study clearly identified the chronic nature of the disease as demonstrated by the major disruption and impact on life. The women interviewed discussed impacts to all areas of their lives including work, finances, education, social and leisure activities, relationships and emotional and psychological consequences. Studies cited earlier in the review of the literature, reported the multidimensional experience of chronic illness. Keller (1988) suggested that a person with chronic illness experiences medical, social and economic costs. Woods et al. (1989) suggest chronic illness disrupts lives by causing increased dependence, functional limitations, decreased participation in the work force, loss of income, decreased sexual activity and restrictions in leisure and recreation activities. The participants in this study clearly corroborated the extent of the disruption to their lives caused by living with endometriosis. This disruption suggests endometriosis might be viewed as a chronic illness.

An interesting finding from this study was discovery of the initial stage of adaptation to symptoms which both the women and the researcher have called 'grin and bear it'. This behavior was adopted due to the 'conspiracy of silence' by which the participants were surrounded when the women first began to experience symptoms. Symptoms were normalized and the 'grin and bear it' behavior was developed and maintained. Keller (1988) explored coping models of illness and discovered differences in styles of adaptation that patients use. She concluded that patients whose illnesses were unmanageable by themselves or medical efforts used emotionally based coping strategies such as denial or wishful thinking. Problem-solving strategies were used most frequently by those patients capable of controlling their illnesses. 'Grin and bear it' could be viewed as an emotionally based coping model incorporating denial (a women's lot to feel pain) and wishful thinking (it will be better next month). This response suggests that even without the validation of illness that a diagnosis would have provided, the women where reacting to a chronic illness by adopting coping behaviors that reflected their sense of helplessness.

Also of significant interest is the role of social support in chronic illness. Primomo et al. (1990) suggest family, friends and other members of the social network play a significant role in how the individual adapts to chronic illness. These authors note that social support plays an important part in well-being. They hypothesize that if illnesses are not clearly defined or are misperceived, social support may be inadequate or inappropriate. These authors also noted that patients had expectations of emotional and informational support from their health care providers. Emotional support from the health professional seemed conspicuous by its absence and was an event that the women evaluated as unhelpful. Failure to give anticipated informational support was detrimental to health. It is clear from the data that both the emotional and informational support received from all others in the participants lives was inadequate.

This study's findings are similar to those of Halstead et al. (1989) wherein 1) family and friends responded to the women's complaints of symptoms with a lack of sympathy and 2) providers minimized complaints and frequently told the women they were overreacting to the pain and would just have to learn to live with it. This study supports the conclusion of the Halstead study which suggested that women experience significant delays in diagnosis and treatment and suffer considerable disruption to their lives.

Although the sample size for this study was small, the corroboration with results of other studies as outlined above provides the findings with significance. These findings support the conceptual framework of viewing endometriosis as a chronic illness rather that an acute episode that is amenable to early intervention and positive treatment outcomes.

Implications for Nursing Research

Nursing has a role to play in the realm of research on the illness experience. Very few nursing studies have been conducted about endometriosis. None have explored the concept of viewing endometriosis as a chronic disease. What are the needs of this patient, who must cope with pain on a daily basis for many years.

While the categories reported reflect the conceptual areas where saturation occurred, there were several other interesting factors that emerged from the interviews. The data in these areas were not saturated but do contain some relevance for future nursing research studies. The women expressed the need for consideration of the following points: what they would have liked to have experienced from others; their need to have information in order to seek help earlier and more efficiently; and what they believed other women living with endometriosis need to know. These areas are in a sense, an overview of what the women would like to have had in their lives had the 'conspiracy of silence' not been present. These are areas which might be considered for future study.

Perhaps the view that captures the feeling all the women expressed the most frequently is the need for empathy, both from the health care providers and from others.

> I guess emotionally being able to find a real compassionate, uh, health professional, you know, who will listen to you. And that's the key. Just emphasizing as much as you can. Active listening, plus hearing the little side nuances of what's being told. (Alison)
>
> I have this great empathy for anyone who's had to go through this and who has it. I know what they are going through and I let people know right off the bat, I know exactly what it is like. And I know if anything, it's a lonely road. (Alison)
>
> Because, I think talk...sometimes just to find out if someone else has been there. (Sarah)

Finding a health care provider who was willing to listen and take the women's symptoms seriously was important and obviously the first step to finding help and answers. Once an empathetic provider had been found, there was a need for information.

It was the lack of information the women had about their bodies that made it impossible for them to distinguish an abnormal condition from a normal one. This lack of knowledge was both the antecedent and the consequence of the 'conspiracy of silence.' Rose explains how the lack of information from a provider hindered her ability to understand and take charge of her health.

> Before I met the nurse practitioner I didn't know that all of those things weren't normal. Now, that's really old. Forty years. I mean, even when I had my surgery and had my endometriosis taken care of, my gynecologist and I didn't have the conversation that the nurse practitioner and I had and he didn't educate me because I didn't know the questions to ask. But, boy, a big difference. Keep educating people. (Rose)

Even though Rose recognizes that the provider is the one with the information she needs, she stills feels that in some way it might have been her responsibility to know the right questions to ask. Alison also expresses a similar thought in terms of assuming responsibility for educating oneself and also needing information from the providers. The following quote shows how she educated herself about endometriosis once she had a diagnosis.

> I read up on it. I read everything I could on it and but when I was in the doctor's office, I asked her questions and as much as my mind could absorb. And it would at least bring to mind the issue. (Alison)

When asked what would be helpful for providers to know about patient's needs, Alison had this to say.

> I think you could be part of an educating team. I think there are times, uh that as patients, we want to ask questions but maybe there's a twinge of intimidation to ask the physician. But I think what really impressed me is if the practitioner or doctor will initiate information right off the bat. Say "do you know anything about endometriosis" you know and that just kind of opens the door in explaining to them what it is and how it has come about. (Alison)

Pat also expressed the need for education and information for women. She felt the information needed to be presented in such a way the patient could absorb it without feeling overwhelmed.

> Because I think one of the things, getting back to your question about what a practitioner should do is like when a person is faced with this, in some ways the patient can only take so much information or try so many things at a time...there's only so much you can absorb at a time. (Pat)

The conclusion the women all had was that there was a need for education about their bodies and endometriosis early in life. They felt the consequence of living with endometriosis for so long was due to the 'lack of knowledge' brought about by the 'conspiracy of silence.'

> Well, educating people would definitely be a must, I think if you start real young; I think my first experience was with Planned Parenthood---becoming aware of reproductive things. (Rose)

> If there was a flood of information out on the market,...if there were articles, even in magazines, like all kinds of magazines that touch women's lives, that would really help. (Rose)

> I just hope that more information will come about you know. That research is continued...especially if there are other medical ways of dealing with it. Or just understanding why do we get it (endometriosis), (Alison)

Sarah incorporated all the needs in one quote; the need for mothers to talk to their daughters, the need for education and the need for providers to respond empathetically to patients.

> I think that women are now much more open with their daughters, and much more aware themselves,

> so they know when their daughter is experiencing something. The on-going education in the medical---I still don't think a lot of the doctors are as educated as they could be. Or as aware...I guess what I'm getting at is that the consciousness needs to be raised with medical health professionals that don't...even if a woman is acting hysterical and neurotic and all the rest of it, don't brand her that way, because maybe her experience is making her look...look beyond that. We're so quick to brand the behavior without looking at what causes it. (Sarah)

Implications for Health Care Providers

These findings have important implications for health professionals providing care to these women. It seems clear from identification of the core variable of 'conspiracy of silence' that the most important step health professionals might take is in the area of assessment. Women, and in particular, young women need to have a thorough menstrual history taken at their first visit following onset of menses. A method for eliciting the symptoms of endometriosis could be developed by incorporating into the initial intake form a questionnaire directed at these symptoms.

One of the problems the women experienced was a lack of investigation on the part of the health care provider after asking questions about the women's symptoms. So, in addition to assessing for symptoms there needs to be adequate follow-up. The role of the nurse in both of these areas is important. Nurses could be responsible for reviewing the intake questionnaires of all patients and further evaluating those whose responses indicate they may be at risk for endometriosis. With thorough screening a woman at risk for endometriosis would be identified. Early intervention is obviously necessary if disruption to women's lives is to be avoided.

The second area that has importance for nursing care is communication of the appropriate information. Had the women had knowledge about normal and abnormal body functioning, they would not have accepted their symptoms as normal. With additional knowledge they could have approached health care providers with pertinent questions and perhaps received appropriate intervention years earlier. Also, with appropriate information, they could have sought out a physician with expertise in endometriosis. For two of the participants, help did not come until they had gathered enough information to identify their condition themselves and then sought help from an appropriate physician. The third participant found help with the first gynecologist she saw, however she had suffered for 25 years after accepting the silence about her symptoms that her family communicated to her. The fourth participant sought help several times, persisting until finding a physician who listened. The physician then had to find a gynecologist to establish the diagnosis since the first physician did not know the cause of symptoms.

There are two more areas where nurses have a significant role to play in endometriosis. Nurses can serve a role by providing the much needed emotional and informational support the women indicated they needed. The other one involves care for patients who have been coping with the chronic disease of endometriosis for many years. As the data has shown, endometriosis can be viewed as a chronic disease.

As described earlier, chronic illness is viewed as a multi-dimensional experience. Early identification may lead to early intervention and better health even within the context of chronic disease. As this study shows, all of the participants continued to cope with some aspect of illness in their lives and none had regained complete health. Nurses can provide support for the chronic nature of the disease. Nurses can help the family to understand the implications by validating the symptoms, explaining how the symptoms impact lives and supporting healthy coping methods.

Most importantly for women's health, what happens to these patient's ability to trust and believe in body cues and communicate these to health professionals. What are the effects on self-esteem for patients who have had to cope in silence with a major illness or who have had to deny their own body signals for years, or who have received invalidation from those to whom they turned for help.

Summary

This qualitative study was done to examine the concept of invalidation within the endometriosis experience of four women. Data were collected by the use of open-ended interviews and analyzed by constant comparison of data excerpts from the coded interviews. Coded data were grouped into categories and concepts were developed and defined.

The concept of invalidation was supported by the data; however, this concept was found to be only one aspect of a larger process that women with endometriosis experience. This process includes three stages wherein the women; initially accept their symptoms as 'a woman's lot', later seek diagnosis, and finally examine the impact of the disease on their lives in order to cope with a chronic disease. A core variable, called 'conspiracy of silence', was identified as the underlying factor responsible for explaining the major variance in the conceptual categories of the endometriosis experience. 'Conspiracy of silence' affects each of the defined categories: a) 'grin and bear it,' b) 'increasing fear and anxiety,' c) 'family communication patterns,' d) 'provider denial,' e) 'attribution of symptoms,' f) 'disbelief by peers,' g) 'lack of knowledge' and h) 'impact on life.' The 'conspiracy of silence' is the underlying theme of all the stages of the process the women experience.

Although the sample size was small and caution must be taken when considering the findings, similarities to findings in other endometriosis literature did emerge in this study. The descriptions of the impact on the women's lives bear similarities to the literature descriptions of chronic illness, thus suggesting that endometriosis may be viewed as a chronic disease. The participants acknowledged major disruptions to their lives in the areas of work, finances, education, relationships, social and leisure activities and emotional consequences. The women offered suggestions about how family, friends and physicians might have assisted them in more positive ways to minimize the impact to their lives. Early diagnosis and intervention would have been the most beneficial assistance. Receiving empathy from others during the entire process was what each women would have liked. The need for young women to have knowledge about their bodies was considered essential if the problems this women had experienced were to be avoided for younger women.

Implications for nursing included the need for assessing women for symptoms suggestive of endometriosis, adequate follow-up on reported symptoms, information, support and understanding the importance of viewing endometriosis as a chronic disease. Considerations for future research include a) implications of women's health care seeking behavior and b) understanding coping strategies of patients with endometriosis. Developing appropriate means of providing education and information to the women, their families, peers and physicians is another area for research.

References

Clancy, F. (1990). Healing the delta. American Health, 9, 43-51.

Cornwell, C., & Schmitt, M. (1990). Perceived health status, self-esteem and body image in women with rheumatoid arthritis or systemic lupus erythematosus. Research in Nursing and Health, 13, 99-107.

Dimond, M., & Jones, S.L. (1983). Chronic illness across the life- span. Norwalk, Conn: Appleton-Century-Crofts.

Dmowski, P.W., Braun, D., & Gebel, H. (1990). Endometriosis: Genetic and immunologic aspects. D.R. Chadha, & V. C. Buttram (Eds), Current concepts in endometriosis (pp.99-122). N.Y.: Alan R. Liss, Inc.

Dossey, B., Keegan, L., Guzzetta, C., & Kolkmeier, L. (1988). Holistic nursing. Hagerstown, Maryland: Aspen.

Staff. (1989). Endometriosis Association Newsletter, 10 (5), 1-6.

Staff. (1990). Endometriosis Association Newsletter, 11 (3), 1-8

Foote, A.W., Piazza, D., Holcombe, J., Paul, P., & Daffin, P. (1990). Hope, self-esteem and social support in persons with multiple sclerosis. Journal of Neuroscience Nursing, 22, 155-159.

Glaser, B., & Strauss, A.L. (1967). The discovery of grounded theory. Hawthorn, N.Y.: Aldine.

Halstead, L., Pepping, P., & Dmowski, W.P. (1989). The woman with endometriosis: Ignored, dismissed and devalued. Endometriosis Association Newsletter, 10, (5), 1-5.

Jenkins, S., Olive, D.L., & Haney, A.F. (1986). Endometriosis: Pathogenic implications of the anatomic distribution. Obstetrics and Gynecology, 67, 335.

Keller, C. (1988). Psychological and physical variables as predictors of coping strategies. Perceptual and Motor Skills, 67, 95-100.

Lichtman, R., & Papera, W. (1990). Gynecology: Well-woman care. Norwalk, Conn: Appleton & Lang, Pub.

McBride, A., & McBride, W.L. (1981). Theoretical underpinnings for women's health. Women & Health, 6, 37-58.

Murphy, A., Green, R.W., Bobbie, D., Cruz, A.C., & Rock, J.A. (1986). Unsuspected endometriosis documented by scanning electron microscopy in visually normal peritoneum. Fertility and Sterility, 46, 522-524.

Olesen, V. (Ed.) (1977). Women and their health: Research implications for a new era (DHEW Publication No. 77-3138). Springfield, Virginia: U.S. Government Printing Office.

Primomo, J., Yates, B.C., & Woods, N.F. (1990). Social Support for women during chronic illness: The relationship among sources and types of adjustment. Research in Nursing and Health, 13, 153-161.

Redwine, D.B. (1990). Is "microscopic" peritoneal endometriosis invisible? Fertility and Sterility, 50, 665-666.

Redwine, D.B. (1987). Distribution of endometriosis in the pelvis by age groups and fertility. Fertility and Sterility, 47, 173-175.

Sanford, L.T., & Donovan, M.E. (1985). Women and self-esteem. New York, N.Y.: Penguin Books.

Stephens, G.G. (1986). Careers of illness: Problems in the diagnosis of chronic illness. Perspectives in Biology and Medicine, 29, 464-474.

Stuifbergen, A.K. (1987). The impact of chronic illness on families. Advances in Nursing Sciences, 3, 45-50.

Viney, L.L., & Westbrook, M.T. (1982). Coping with Chronic illness: The mediating role of biographic and illness-related factors. Journal of Psychosomatic Research, 26, 595-605.

Weinstein, K. (1987). Living with endometriosis. Redding, Ma.: Addison-Wesley Publishing Co.

Werner-Beland, J.A. (1980). Grief responses to long-term illness and disability. Reston, Virginia: Reston Publishing Company, Inc.

Woods, N.F., & Catanzaro, M. (1988). _Nursing research_. Washington, D.C.: The C.V. Mosby Company.

Woods, N.F., Yates, B.C., & Primomo, J. (1989). Supporting families during chronic illness. _Image: Journal of Nursing Scholarship_, _21_, 46-50.

APPENDICES

APPENDIX A

Interview Questions

What concerned you most about how you were treated in the process of being diagnosed with endometriosis?

(If necessary these questions to follow-up)
If someone you cared about had beginning symptoms of endometriosis, what would you tell them about getting care?
How many people did you go to with your problem?
Did they all agree?
Disagree?
Confirm that you had a problem?
Were you referred to other health care professionals?
Who were you referred to?

(At the conclusion of the interview:)
Since this information will help nurses care for women in a more sensitive way, is there anything else I should have asked?
Is there anything else you would like to tell me?

APPENDIX B

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787
Institutional Review Board/Committee on Human Research

DATE: October 18, 1991

TO: Jo Ellen Schoblom, RN EJSN
Margaret Imle, PhD

FROM: Nancy White, Admin. Asst. N. WHITE / fw
Committee on Human Research

SUBJECT: Project Title: Endometriosis and the Process of Invalidation.

The above-entitled study falls under category #2 of the federal regulations (45 CFR Part 46.101 (b)) and is considered to be exempt from review by the Committee on Human Research.

This study has been put into our exempt files, and you will receive no further communication from the Committee concerning this study. However, if the involvement of human subjects in this study changes, you must contact the Committee on Human Research to find out whether or not these changes should be reviewed. If possible, please notify the Committee when this project has been completed.

Thank you for your cooperation.

APPENDIX C

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form

TITLE
Endometriosis and the Process of Invalidation.

PRINCIPLE INVESTIGATOR
JoEllen Schoblom, RN, BSN, Master's student.
Phone: (503) 452-8762.

PURPOSE
JoEllen Schoblom, a master's student in the School of Nursing, is doing a research project designed to understand and examine the impact endometriosis has on a patient's life by exploring women's experience of endometriosis and their process of diagnosis and treatment.

PROCEDURE
If I agree to participate in the study, JoEllen will interview me in my home. The interview will last from 45 minutes to 2 hours. I may stop the interview at any time. JoEllen may contact me at a later date to clarify responses made during the interview. If I want to, I will have the opportunity to meet with the other study participants and JoEllen at the end of the project to comment on the research conclusions.

RISKS AND DISCOMFORTS
Information shared in the interview will be used in the study, however my identity will be protected. I may stop the interview and withdraw from the study at any time. Some women may find that recalling events causes them to feel some emotional distress.

BENEFITS
Participating in this study gives me an opportunity to share my experience of living with endometriosis. While I may not benefit directly, my information may help other women who have endometriosis.

CONFIDENTIALITY
Neither my name or my identity will be on the tapes or transcription. In the research report or publication, no single person can be identified.

COSTS
There are no monetary costs involved for me as a participant. There will be no payment for participating in this study.

LIABILITY
The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please call Dr. Michael Baird at (503) 494-8014.

JoEllen has agreed to answer any questions I may have. I may refuse to participate in this study or withdraw at any time without affecting my relationship with Oregon Health Sciences University. I will be given a copy of this consent form. My signature below indicates that I have read the foregoing and agree to participate in this study.

------------------------------ ----------------------

Participant's Name Date Witness' Name Date