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Bridging the Gap Between Medical Science and Communication:
An Interpretive Analysis of Messages Portrayed on Endometriosis Websites

A thesis
presented to
the faculty of the Department of Communication
East Tennessee State University

In partial fulfillment
of the requirements for the degree
Master of Arts in Professional Communication

by
LaKesha Nichole Anderson
May 2004

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Keywords: Women's Health, Endometriosis, Internet Use, Physician-Patient
Communication, Qualitative Methodology, Lived Experience

ABSTRACT

Bridging the Gap Between Medical Science and Communication: An Interpretive Analysis of Messages Portrayed on Endometriosis Websites

by

LaKeshia Nichole Anderson

This study examined women's health messages found on ten endometriosis websites. Qualitative research methods were used to investigate messages available via Internet media about causes and treatments of endometriosis, particularly as they relate to the suggestion that hysterectomy and pregnancy are effective treatments. Messages about infertility, physician-patient communication, and accessibility were also examined. Findings indicate that the websites provided similar messages regarding the symptoms, causes, and treatments of endometriosis; results pertaining to infertility were mixed. Little information was available on methods of improving physician-patient communication. Most websites provided additional low-cost information while requiring minimal technological competency or additional software of site patrons. The results of this study have implications for future research in medical science and communication and reflect the importance of research on women's health communication. A detailed discussion of findings and suggestions for further research are offered. The author's own experiences with endometriosis are incorporated into the analysis.

DEDICATION PAGE

I dedicate the development of this thesis to my husband, Jerrad Anderson, for his never-ending support, dedication, encouragement, and love, and for his willingness to share details of our very personal struggles with my audience. The completion of this work would not have been possible without him. My thanks will never be said enough.

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CONTENTS

	Page
ABSTRACT	2
DEDICATION	3
ACKNOWLEDGEMENTS	4
Chapter	
1. PERSONAL NARRATIVE	8
2. INTRODUCTION	18
Advocating for Equality	20
The Mystery of Endometriosis	22
Health Communication: A New Medium Gains Prominence	23
Importance of this Study	24
Overview of this Study	25
3. LITERATURE REVIEW	27
Taking Back Our Bodies: The Women’s Health Movement	27
Defining Obstacles to the Women’s Health Movement	29
Physician-Patient Dynamics	30
Socioeconomic Disparities to Health Care	32
Endometriosis: Examining a Medical Mystery	36
Unraveling a Mystery: Endometriosis Explained	37
The Misdiagnosis of Endometriosis: Issues and Attitudes	40
The Internet: Breaking New Ground in Health Communication.....	43
The Internet: Health Care Redefined	44
A New Group of Internet Users	45
Literature Review Summary	50

Research Questions	51
4. METHODS	55
Description of Sample	55
Qualitative Methodologies	57
Interpretive Analysis	61
Methods Summary	63
5. FINDINGS AND DISCUSSION	65
Messages about Causes and Treatments	66
Themes	66
Many Symptoms, One Diagnosis	66
Unknown Cause, Many Theories	68
No Cure, Myriad Treatments	69
Endometriosis Affects Everyone	70
Discussion	70
Author Comments	72
Messages about Infertility	75
Themes	75
Infertility Ambiguity	75
Discussion	76
Author Comments	77
Physician-Patient Communication	78
Themes	78
Communicating about Endometriosis	78
Discussion	80
Author Comments	81
Information Accessibility	83
Themes	84

Support for Sufferers	84
Abundant Information	85
Technology and Cost Requirements	86
Discussion	87
Author Comments	88
Findings Summary	89
Discussion Summary	91
6. CONCLUSION	93
Summary	93
Connections to Literature Review.....	96
Limitations of this Study	99
Suggesctions for Further Research	100
Concluding Thoughts	102
REFERENCES.....	105
VITA	115

CHAPTER 1

PERSONAL NARRATIVE

I was what they call an “early bloomer.” I was barely 11 when I experienced my first menstrual period, a time I had both dreaded and eagerly anticipated. At that age, I did not understand what a “normal” period was and, as a result, I ignored the intense pain I felt each month. I experimented with a host of over-the-counter drugs: Tylenol, Midol, Motrin, etc., but no form of medication seemed to halt the pain. By the time I was 14 the pain was unmanageable; I cried in agony during my period as I felt the steady, stabbing pain pulse through my small abdomen. My mother, having experienced a variety of reproductive problems herself, made me several appointments with a gynecologist. One such physician claimed she had discovered the root of my pain. I simply had a tilted uterus, a normal part of being female, she assured me. When I asked how my condition would affect me in the future, she explained that it would probably correct itself with time. A couple of years later, another physician ordered an ultrasound, after which he informed me that my uterus was fine; my pain was a result of ovarian cysts, yet another normal part of being female, he said. I did not question his diagnosis as my mother had suffered with cysts for years. I assumed I had just inherited this condition from previous generations. Unfortunately, I was given nothing to help manage the pain and my monthly suffering continued. Another year passed and with each period, I grew ever more impatient. I wanted a name for my problem and a physician who was willing to listen.

I made an appointment with my family physician, a wonderful man who is always ready to listen and does not subscribe to 15-minute office visits. Before I went to his office, I did my homework on the Internet. I came across a disease called endometriosis and it described my symptoms perfectly. I showed the online information to my mother who agreed that endometriosis was certainly a primary suspect.

On the day of my appointment, I explained my symptoms: intense aching, heaviness in my pelvic area, bloating, and gastrointestinal problems that seemed to get worse with my period. I also had a history of allergies and yeast infections. It took only seconds for my doctor to confirm my suspicions. He suggested a follow-up with my gynecologist, a new doctor whom I had seen once before for a routine appointment. My doctor also explained to me that if I did in fact have endometriosis, I might never have children. The physician made a referral to my gynecologist in an effort to speed up the appointment time. I left the office that day with an appointment card and a tinge of sadness, but I was content knowing that, for the first time, my symptoms had a name. After being misdiagnosed twice before and wondering if the intense pain was simply a normal part of my development, I was reassured by my doctor's preliminary diagnosis. For the first time someone told me that my pain was not normal and that it could possibly be managed. I no longer felt like a constant complainer; I felt like I had a justification for my pain.

A month later, I walked into my gynecologist's office not knowing what to expect. Would he shrug my symptoms off as "normal" or would he be willing to help? During my first appointment, I had decided I liked this doctor. He was young and friendly and he listened to my concerns. I had told him about my previous diagnoses and we were in the "wait and see" phase of contraceptive management when I came in for my referral appointment. He listened to my symptoms and did an exam. During the bimanual exam, my doctor touched a part of my cul-du-sac, a common place to find endometrial growths. I squirmed and groaned in pain. He then explained that without a laparoscopy, he could not definitively rule out other diseases, but he was very confident that I was suffering from endometriosis. He asked if I wanted children, I replied "One day." My answer ruled out radical surgery, as I would need my ovaries to conceive a child. I had several options: I could undergo laparoscopic surgery to eliminate all visible endometriosis lesions; I could start a series of shots designed to reduce the size of the

endometriosis; or I could continue with contraceptive management. Hysterectomy, a more definitive solution to the problem, was eliminated due to my desire to have children. I opted to continue the “wait and see” phase of contraceptive management. I was too afraid of surgery and did not want to subject myself to monthly doses of hormones about which I knew nothing.

Years passed and my condition only worsened. Throughout my undergraduate education, my doctor tried unsuccessfully to convince me to have laparoscopic surgery. I resisted out of fright; I have always been terribly afraid of anesthesia. My doctor put me on a range of birth control pills. I gained weight, battled depression, and endured frequent migraine headaches while trying to find the perfect combination of estrogen and progesterone. It seemed that if a pill helped the endometriosis, it created another problem. I began to wonder if anything would help manage my pain.

While I charged on, searching for the practical, non-surgical remedy to an incurable ailment, friends and family members offered advice and coping strategies. A frequent theme emerged from these offerings: pregnancy cures endometriosis. Even if it were true, I was in no hurry to get married or have children. Eventually, I stopped listening to this well-intended but misinformed advice and listened only to my doctor. I also relied on information I obtained on endometriosis-related websites to help me make decisions about treatment options and ways to chart my symptoms.

I got married only a few weeks after graduating from college. My husband knew about my disease and understood that having children naturally may be impossible. During the beginning of our marriage, my endometriosis symptoms were the same as usual. However, six months into our nuptials, I began suffering indescribable pain and I could no longer engage in sexual intercourse. I was scared, embarrassed, and ashamed. I also felt like a bad wife, particularly with so many people joking that the first year of marriage was spent having sex. For my next appointment, I arrived with a list of complaints. I was concerned that something other than endometriosis was causing me

this new pain. At this point, my doctor began to get real serious about the need for surgery. He explained that laparoscopy was the only way to rule out another disease and confirm endometriosis. Only after a confirmation could he determine what the best course of treatment would be. I said I would consider the surgery. Again, I decided against the procedure opting to try home remedies like lubricants and relaxation instead. I even went to therapy to see if something were psychologically wrong with me. After two rounds of biofeedback and no satisfactory results, I was so frustrated that I stopped therapy.

Two years into my marriage, I was finishing up my first year of graduate school and seriously contemplating becoming a mother. I knew that my husband desperately wanted a child but I also knew he would never mention it to me. In the spring of that year, I had what I refer to as my nervous breakdown. I was at work one day and became so consumed with thoughts that my pain may be attributed to some underlying, undetected disease that I started sobbing hysterically. I felt diseased; I wondered if I might have another serious condition like pelvic inflammatory disease, a sexually transmitted disease, even AIDS. I wondered if I was going to die before I could get treatment. My racing thoughts overwhelmed me and I telephoned my husband, then my mother, then a friend. On their advice, I left work and went in for blood work with my family physician who assured me everything was fine. As I returned to my office after my blood work, I reflected on my conversations with my gynecologist. When I returned to work, I left him a frantic voice mail. Later, he left me a voice mail along with his home telephone number and suggested that I call him there. I had prepared a list of questions, covering topics from diagnoses to surgery to childbirth. I glanced over the questions as I dialed his number. By this point in our relationship, my physician and I had established a great rapport. Still, my hands trembled and my body shook as I carefully took notes during our conversation. Although I was terrified by my decision, I chose to go through with the surgery. No longer could I withstand the physical or

emotional pain, especially now that my disease was affecting my husband and our visions for our future.

In the month leading up to surgery, I conducted extensive online searches for information on laparoscopy. Most sites iterated what my doctor had said: surgery will provide a definitive diagnosis, allow him to destroy visible endometriosis, and create a window of opportunity for pregnancy. Websites also provided helpful “what to bring to the hospital” lists and tips for a quick recovery, some even listed ways to cope with nervousness about the surgery. In addition, the hospital where the procedure occurred provided online information about laparoscopy and endometriosis. Though I was nervous about the anesthesia and what my doctor would find, I also felt prepared and informed. The day of the surgery, I was amazingly calm, in part because of my trust in my doctor and the support of my husband and mother, who stood by my side until they wheeled me into the operating room, and in part because of the information I had obtained online. The online information had really helped me cope with my fears and come to understand the need for the surgery.

Surgery went wonderfully except for the excruciating pain I experienced trying to use the bathroom after being catheterized. My doctor was able to confirm my endometriosis diagnosis. He also explained that my fallopian tubes had not been blocked by the endometriosis and I could probably still have children, though it may take more time than usual. At my follow-up appointment, however, he suggested that I begin monthly injections of Lupron, a gonadotropin-agonist, to shrink the endometriosis that could not be removed during surgery. Basically, Lupron works by telling the pituitary gland to stop estrogen production thereby causing the patient to enter menopause, complete with hot flashes, night sweats, mood swings, and bone loss. His office manager had already approved the injection with my insurance company; however, I was not comfortable committing to hormonal therapy without more information. I explained that I needed more time to make a decision. My doctor sent me

away with information and I began an extensive Internet search for information about Lupron.

The web search netted me mixed results. The most credible sites were the least informative while the most informative were the least reliable. I took what information I could gather and phoned two neighborhood pharmacists. Unfortunately, they could provide little information on the long-term effects of the drug because of its newness on the market. For two days I gathered information and discussed it with my husband. On the third day, I phoned my physician and scheduled my first injection. Although my doctor said I could have children, I needed to be able to engage in intercourse before that could become a reality. Furthermore, I was afraid that long-term sexual dysfunction would eventually create problems in my marriage. I saw Lupron as my last chance at a normal life.

I endured the normal six-month treatment (standard when used for endometriosis) of Lupron. The first few months I was plagued by menopausal symptoms, especially hot flashes and memory loss. However, in the third month the side effects were diminished and I could see an improvement in my pain. For the first time in two years, I could engage in intercourse without pain, I could urinate without pain, and I rarely experienced gastrointestinal problems. It was as if I had been given a new body. However, my happiness was only temporary; by the end of the sixth month, I was no longer pain free. Indeed, I was back to my "old self," battling sexual dysfunction and growing concerns over my reproductive health.

I completed Lupron therapy in the fall of 2003. The injection did provide me some pain relief though most of my symptoms are still present. I dread having to use the restroom because of the pain of urination; I have to watch what I eat during my period because it may upset my stomach; I cannot engage in intercourse without pain; and I am filled with constant worry that I may never have children, a concern that as a married 24-year-old means much more to me than it did as a 17-year-old college

freshman. Although I am grateful to my family, and especially my husband, for their continued support and thankful for my physician, I know that no one in my immediate social network understands the pain I feel. They cannot understand the never-ending worrying or experience the same constant feelings of failure. I find solace in online support groups and narrative literature, places where I can relate to other women who understand my physical and emotional suffering.

Recently, I spoke with my doctor about the reoccurrence of my endometriosis-related problems. He feels that it is time I see an endometriosis specialist who can better understand my problems and provide a more effective treatment, if one is available. He feels that my vaginal muscles tightened in response to pain and that I may need both physical and psychological therapy. Although I want to have a child, I chose to go back to contraceptive management in an effort to relieve the pain. While I looked forward to the “window of opportunity” that was supposed to be available for childbirth once my six-months of Lupron therapy were finished, I am now beginning to come to terms with my illness. I desperately want children; yet, unfortunately to combat the pain of endometriosis I must rely on contraceptives or medications that prohibit pregnancy during their use. Having moved over 400 miles away from my doctor, I am looking for a reproductive endocrinologist on my own and searching the Internet for information on in-vitro fertilization. Though I feel defeated and I am scared that I will never be “normal,” and I dread the thought of seeing another physician, I hold onto a glimmer of hope that someday, some way, I will beat this disease. Until then, I rely on the support of family, friends, and the thousands of women whose stories I read online and in books. The Internet has become my medium of choice; when I chat with women who are experiencing the same problems, I feel less afraid, less strange, and more hopeful. I have never met anyone in-person who shares my pain and feelings of shame and guilt. I have come to believe strongly that the Internet is an important tool for helping women with endometriosis maintain some sense of balance in their lives. I

know from experience the physical and emotional pain that endometriosis inflicts upon its victims. I also know that while there may not be a cure, or in my case a helpful treatment, for the physical pain, I do not have to endure the emotional struggle. While it is hard constantly battling the guilt and anger, I have decided that with the encouragement of my peers, increased funding for research, and the efforts of feminist health activists, I will achieve my goals; I will not let this disease defeat me.

Throughout my college career, my endometriosis has grown increasingly worse. Also during that time, I have developed as a researcher. I have learned to define what it means for me to be an endometriosis patient and, as a result, I can now provide a voice for the many women who suffer in silence. While my experiences certainly do not represent those of every endometriosis sufferer, one can assume that our experiences may be very similar.

I have often complained about the absence of quality of research available on physician-patient communication, particularly where it concerns female patients. More recently, I have become increasingly concerned about the quality of messages being received by endometriosis patients concerning causes, symptoms, and treatments of the disease. My growing concern stems from a conversation with a middle-aged woman who offered her support about hearing about my ongoing “battle with cancer,” one she had fought for years only to have it render her infertile. I have found that many women with endometriosis have been told they have cancer and that infertility is a direct result of their disease. Many of the patients I know opted for hysterectomy at a young age, preventing them from ever having children naturally. Some women may find it easier to accept this fate, particularly if their pain is reduced after hysterectomy. Yet, there are others, like me, who will never make the decision to have radical surgery because their desire to have children is stronger than their desire to alleviate the pain. Thankfully, I live in an information age where point-and-click Internet technology provides instant access to a host of websites designed to refute the plethora of myths surrounding many

diseases, including endometriosis, a commonly misdiagnosed women's illness. I am also thankful to have found a wonderful physician who provides helpful information at liberty. His willingness to share his knowledge with me is important to me as a woman who was misdiagnosed several times and faces uncertainty about a particular disease. Unfortunately, many women have suffered under the care of misinformed and undereducated physicians, and continue to do so today. Despite this fact, I realize that extensive knowledge-sharing can have negative effects for the patient, such as information overload.

* * * * *

The purpose of this study is to examine the messages present on endometriosis websites. As I discuss in later chapters, the Internet is becoming a commonly used channel of health communication and increasing numbers of women are using the Internet. Unfortunately, perhaps due to health communication being a relatively new discipline of communication study, the field has been slow to progress because medical science has not kept abreast of advances in communication. This study is an attempt to merge the two fields, bridging medical science and communication studies to examine health messages found on endometriosis websites. By exploring the messages on Internet websites, medical and communication scholars will be able to provide more accurate and easily accessible information. This study looks at not only the messages but barriers to access including technology and costs requirements which may prevent some populations (for example, those who are economically disadvantaged, uneducated, or live in rural areas) from accessing free Internet information. This study also investigates the relationship between gender discrimination, women's health, and Internet communication. While this study will not instantly change the state of women's health in America, improve endometriosis care, or increase the accuracy or accessibility of media messages on the disease, it is a start. It is my hope that through research such as mine, other endometriosis sufferers will come forward with their stories and

conduct research of their own. Together we can make a difference; we can be the pioneers of our time, sparking changes in women's health care – if not for our generation, for the one that follows.

CHAPTER 2

INTRODUCTION

It has only been in the past 25 years that health communication has come to be recognized by researchers as a legitimate field of communication study (Rogers, 1994). In fact, Nussbaum (1989) credits the 1980s as the arrival of health communication as a respected subject. Yet, despite the recent surge of interest in women's health care, medical research is largely dominated by findings on male patients. It has only been since the mid-1990s that women have become relevant in health studies, having been excluded from previous medical training and clinical trials ("How Far We've Come," 1999; Sargent & Brettell, 1996). The recent interest in women's health studies stems from the work of feminist scholars and health professionals dedicated to empowering women to take a more active and informed role in their health care. This re-emerging interest in women's health coincided with the availability of a new form of mass media, the Internet, to the public. According to Parrott and Condit (1996), traditional media (television, radio, and books) have historically ignored women's health or reported only breaking or outdated news on the topic. Additionally, Parrott and Condit (1996) claim that traditional media are limited in what information they can provide women seeking health care information. For instance, newspapers often report only new and sensational information; magazines tend to focus on the dramatic and timely; and books tend to be quickly outdated (Parrott & Condit, 1996). Therefore, the Internet, with its ability to report both current and archival information, is a new form of mass media deserving attention by researchers. By gaining a better understanding of Internet trends in health care, mass media scholars can begin closing the knowledge gap that exists for women using mass media to seek health-related information.

The Internet has changed the way in which consumers seek information. While used for nearly 20 years in the private sector (prior to its availability to the public in the 1990s), the Internet sparked a demand for personal computers and made once

inaccessible information available to numbers of people throughout America (Edworthy, 1999). With information so easily accessible, it is important that scholars study how online messages are being conveyed and interpreted by the target audience. This paper will investigate the relationship between women's health and the Internet, exploring the content of websites dedicated to endometriosis and attempting to determine what messages are available to women about the disease.

Although it is an incurable, often misdiagnosed disease affecting over five million women in the United States alone, little research is available on the causes and treatments of endometriosis. However, in an effort to gain accurate, unbiased access to health care information, women are no longer relying solely on medical science for health advice. As I discuss later, women are seeking information from other sources and becoming empowered to take health care back into their own hands. This perhaps contributes to a recent increase in the number of women using the Internet to acquire health information. Unfortunately, women's efforts may be limited by traditional media's propensity to provide outdated or biased information. Rather than provide continuous coverage of women's health issues, many media are reporting only sensational or archival data (Parrott & Condit, 1996). Nevertheless, women are increasingly relying on the Internet to gain health care information. Because of the surge in Internet reliance and the limits of traditional media to providing updated and continual information, it is important to study the content of messages women receive from endometriosis websites. Currently, little research has focused on the messages being sent about many diseases such as endometriosis. Research on the messages women may be receiving about this disease will provide medical scholars with the ability to address false information found on the Internet and serve as a means for facilitating discussion with patients about the disease. Additionally, this research will provide media professionals with information on the gaps in online endometriosis information. Perhaps more importantly, research into online health care messages can help provide women

with a voice by which to express their need and desire for factual, easily accessible information on women's health issues. As illustrated in my narrative, the Internet can often provide women with the information they need to make decisions regarding their health care, providing them with the knowledge to take on a more active role in their treatment plan. Though the Internet does provide quick access to many accurate health care sources, there are consequences of using the Internet that must be mentioned. For example, while websites do provide instant access to a plethora of expert opinions and recommendations, it is not always possible to determine the accuracy of such claims, thus making it possible for site users to obtain false or misleading information. The easy accessibility and unreliability of online information are primary criticisms of Internet research. In addition, security issues pose a greater threat to consumers seeking any type of online information.

This study also explores reasons why women may be turning to the Internet for health-related information and the importance of studying online health care messages. Once scholars, media practitioners, and medical professionals begin to understand the reasons women use the Internet and how online information is used, they can begin to provide women with the information they need to become more educated and more vocal health care participants.

Advocating for Equality

The exclusion of women from clinical trials has resulted in an absence of information about ways to prevent and treat many illnesses. This omission of women in medical studies has also led to substandard medical care (Schur & Nicolette, 1997). During the 1960s, feminists and women's health advocates noticed this gender bias in medicine and urged scholars across the nation to "expand attention and information about health care for women" (Parrott & Condit, 1996, p. 2), thus initiating the women's health movement.

Inspired by women's health activists, many of whom had formed and managed women's health clinics and written successful women's health publications, women across the country began forming organizations dedicated to advancing women's health care in America (Morgen, 2002; Null & Seaman, 1999). In 1974, the National Women's Health Network, the first lobbying organization dedicated solely to progressing women's health care, was founded (Morgen, 2002). Since then, a host of organizations including the Society for the Advancement of Women's Health Research and the Office of Research on Women's Health have formed ("Advances in Women's Health," 1999). These groups have been instrumental in furthering the mission of the women's health movement which gained a significant victory with the abolishment of federal policies preventing women from participating in clinical studies (Sargent & Brettell, 1996). However, many obstacles still exist for the women's health movement; this issue will be further explored in Chapter 3.

One problem women face when accessing medical care is a lack of physician knowledge resulting from the years of exclusion from medical research ("Advances in Women's Health," 1999). Another difficulty women face, discussed in later chapters, is physicians' dismissal of women's health care concerns. Women face further barriers to adequate health care because of not only gender but also class and race discrimination (Williams & Collins, 1995; Morgen, 2002). Therefore, while the women's health movement has made great strides in bringing gender equality to health care, there are still many problems facing women of all backgrounds. Though women are now being included more often in health care research, it is important to identify gaps in research about women's health as well as gaps in the messages provided by media about women's health (Parrott & Condit, 1996), particularly given that women's reliance on the Internet for health information is increasing. Additionally, it is pertinent that women's health concerns be studied in a woman-centered framework (Parrott & Condit, 1996)

and that attention is given to researching diseases specifically affecting women, such as endometriosis.

The Mystery of Endometriosis

Endometriosis is a common disease affecting approximately 5.5 million females in their reproductive years in the United States and Canada alone (Taylor, 2003). The disease is defined by the presence of endometrial tissue outside of the uterus (Shah, Tager, & Feller, 1995) and is characterized by a variety of physical and emotional problems. Despite having very specific symptoms, physicians often find endometriosis difficult to diagnose. Many women are told that the often debilitating pain associated with endometriosis is either all in their head, normal, or exaggerated (Taylor, 2003). This is particularly disturbing considering endometriosis is a disease for which there is no known cause and no available cure. Women often suffer months or years, believing their pain to be normal, only to find out that they have endometriosis. Ignored or untreated, endometriosis can lead to infertility by blocking the woman's fallopian tubes. Physicians commonly overlook endometriosis, especially in adolescents (Jancin, 2003), because the symptoms of the disease so closely resemble those of other reproductive and gastrointestinal ailments. Therefore, it is important that women have access to medical information outside the physician's office. The availability of such resources can encourage women to seek a second medical opinion, articulate their own experiences, formulate questions regarding their symptoms and treatment options, and have informed discussions about options for pain management (Ziguras, 2000). Hines (2001) points out that most patients do not seek a second opinion for fear of insulting their physician. Thus, it is important that patients are provided access to alternative methods of information-gathering that will allow them to seek additional information and advice from the privacy of their own homes. In short, women can better become more active participants in their own health care. As women's health activists call for higher

quality, unbiased health information and the Internet increases in popularity, this newest form of mass media is quickly becoming one of the primary tools used by patients to acquire health-related information.

Health Communication: A New Medium Gains Prominence

Much of the research on women's health communication has focused on the interpersonal relationships that exist between patients and their physicians, friends, and family members. Additionally, there is a wealth of research devoted to the analysis of the mass media messages women receive from popular books, magazines, television shows, and films (Parrott & Condit, 1996). Until the 1990s, most of the information women received about their health came from these sources; however, the advances of modern technology have redefined the way individuals seek information (Wilkins, 1999). A recent study found that health information was the third most frequently researched topic by Internet users (Fox & Fallows, 2003). According to Fox and Rainie (2002), Americans are witnessing the formative stages of a "transition to an Informative Age in health care" (p. 14).

Patients are taking more active roles in their health care and are seeking medical advice outside the examining room, particularly on the Internet which hosts more than 17,000 websites dedicated to health care information (Milio, 2001). Physicians claim that nearly 60% of patients bring Internet printouts to medical visits (Milio, 2001). Women appear to be utilizing the Internet for health-related reasons far more than men. Of those who report using the Internet to obtain information on health care, 72% are female (Fox & Rainie, 2002). These numbers will almost certainly rise as the number of individuals using the Internet continues to increase. In 1997, Internet usage increased more than 100% from the figures reported in 1996 and it is estimated that by 2005 as many as 200 million people will be online (Wilkins, 1999).

The accessibility of previously hard-to-obtain information has had empowering effects for patients (Ziguras, 2000). The Internet provides patients with the ability to shop for medical advice, review literature about treatment plans, and discuss health-related issues with other physicians and disease sufferers. This equal dissemination of health information allows patients to take more active roles in their diagnosis and subsequent treatment (Ziguras, 2000). However, society's growing dependence on the Internet has some scholars and physicians concerned that web-based information lacks in quality, reliability, and security (Kerwin, 2002). Because the information obtained on websites can often be conflicting, it may be difficult for users to evaluate the accuracy of health-related websites. Despite researcher's concern over the quality of online information, many of which are discussed in Chapter 3, studies show that most patients use the material only as a supplement to information obtained from their primary physician. In fact, a study conducted by Fox and Rainie (2002) found that only one in five patients use information obtained online as a replacement for expert medical advice. In addition, physicians report that patients most often benefit from health care information received on the Internet thereby leading some Internet researchers to claim that the risks associated with online health information are exaggerated (Potts & Wyatt, 2002).

Importance of this Study

Regardless of how accurate scholars perceive the Internet to be in providing health care information to patients, it is obvious that female patients are seeking health care information outside the examining room. As the number of women using the Internet increases, it is important to determine what web-based health-related messages are being sent to women and how those messages can impact their decision-making processes. Many factors may lead women to use the Internet to obtain information about endometriosis including the fact that endometriosis is often

overlooked or misdiagnosed by physicians. Additional factors may include a lack of available information on the disease and patient's communication apprehension, which often results in patients not discussing the disease with physicians. Communication apprehension can be the result of a variety of factors including feeling subordinate to physicians, uncertainty about the disease, and fear of discussing sexual orientation. Because women are so often told that their pain is normal or exaggerated, it is important to examine the messages women may receive about the disease, such as how to assess symptoms and how to facilitate discussion about endometriosis with physicians. By providing accurate information to women seeking information on this puzzling disease, websites can empower women to take a more active and informed role in managing endometriosis. Analyzing the content of endometriosis websites can help to determine the extent to which these sites function as empowering. As this study examines only the messages being sent to women, it is pertinent that future studies focus on determining the messages women are actually receiving from these websites. Specifically, researchers can begin to determine how these messages impact a woman's quality of life, overall health and well-being, and satisfaction with her physician. Studies such as the current one provide scholars, physicians, and media professionals with insight into how to best serve the growing number of females who are using the Internet for health information. While face-to-face interactions with an empathic physician cannot be replaced by web-based advice, it is important that researchers and health care professionals understand the reasons women are turning to the Internet for health information and the implications of such messages on the future of women's health.

Overview of this Study

This study focuses on the messages displayed on endometriosis websites and the implications of these messages on the future of women's health care. In Chapter 3,

I provide a review of literature regarding germane topics associated with this study. I also discuss the history of the women's health movement and the rise of feminism in health care practices as well as the role of media in women's health information-seeking. I describe endometriosis as well as the difficulty in diagnosing the disease and the impact that lack of physician knowledge and misdiagnoses can have on women afflicted with the illness. Finally, I discuss the increase in Internet technology use, especially among women, along with reasons why women may be going online to obtain health-related information. The review of literature leads to four research questions, also outlined in Chapter 3. I outline the qualitative methods used to answer these questions in Chapter 4. The findings of this study and a discussion of those findings are then presented in Chapter 5. I chose to incorporate the findings and discussion into one chapter to be consistent with the proceeding chapters' emphasis on my voice. Finally, in Chapter 6, I provide a discussion of the limitations of this study as well as recommendations for future research.

CHAPTER 3

LITERATURE REVIEW

This chapter serves as a summary of literature about the relationship between women's health, particularly endometriosis, and Internet use. First, it explores the history of the women's health movement and the rise of feminism in women's health care practices. It also details the importance and evolution of mass media in progressing the women's health movement and creating awareness for women's health issues. Second, endometriosis is examined and linked to a need for additional women's health resources. Third, this literature investigates the relationship between the increased use of Internet technology and women's health. Finally, the chapter concludes with a brief summary of the literature and the current study emerging from it, and a preview of subsequent chapters.

Taking Back Our Bodies: The Women's Health Movement

American society is largely male-oriented; the woman's "way of knowing, her perceived realities, and her intellectual models for understanding the world and its numerous activities have been dwarfed by the male perspective" (Gary, Sigsby, & Campbell, 1997, p. 141). Historically, women have been misrepresented or even dismissed in research studies. However, women are questioning in new ways the traditional roles ascribed to them by American society (Gary et al., 1997). In the past, women were viewed primarily as the caretakers of men; yet, once women began to understand that gender was a product of societal, rather than biological, definition, new models of thinking emerged (Gary et al., 1997, p. 140). This revolution resulted in the birth of the women's health movement, which focused on providing women with equal access to health care rights in America.

Feminism is often seen as the framework for the women's health movement, which coincided with the second wave of feminism during the 1960s (Scott, 1999). A

feminist approach to health care takes into account the actual experiences of women. More specifically, feminist activism “accounts for and eliminates the disparities in health status experienced among groups and communities in this society” (United States Department of Health and Human Services, 1995 as cited in Gary et al., 1997, p. 141). Additionally, a feminist approach to health care “stimulates change in the social, political, educational, and health structures for a healthier and safer society” (Hooyman & Gonyea, 1995 as cited as Gary et al., 1997, p. 142). Parrott and Condit (1996) explain that it is important to view women’s health issues within a framework of their own experiences: “When people feel they can take part in decisions and do something to ameliorate problems, it gives them a feeling of autonomy” (p. 5).

According to Evans (2002), “a right to health is one of a range of socioeconomic rights for which states accept an obligation under the law.” However, the right to health has not always been given the same consideration as civil and political rights (Evans, 2002, p. 197), especially for women. In fact, gender barriers to health care often prevent women from accessing resources (Sargent & Brettell, 1996). Before 1990, women were largely absent from medical studies (“How Far We’ve Come,” 1999; Sargent & Brettell, 1996). Efforts to alleviate this problem started in 1969 when a few women banded together with the common goal of reforming women’s health care in America (Morgen, 2002). Re-emerging from the Civil Rights Movement, the women’s liberation movement spawned a nationwide debate over abortion and prompted several women to form discussion groups to facilitate dialogue and change in abortion laws (Morgen, 2002). Collectively, these women vowed to learn more about their bodies and to teach other women how to take control of their bodies. From these discussions, Jane, the organization that helped women secure safe, but illegal, abortions, was formed (Morgen, 2002; Null & Seaman, 1999). Furthering the women’s health movement were the teachings of a few controversial women’s health activists, namely Carol Downer, Lorraine Rothman, Barbara Seaman, and Belita Cowan. Together with

The Boston Women's Health Book Collective, publishers of the revolutionary book entitled *Our Bodies, Ourselves*, these women helped create the women's health movement that has transformed the way in which society views women and how women access health care (Morgen, 2002).

Defining Obstacles to the Women's Health Movement

One primary obstacle for the women's health movement is that it is deeply rooted in reproductive rights. In fact, the pioneering research of the movement involved reproductive issues such as abortion, self-examination, and birth-control. During the first half of the twentieth century, most all research in women's health care pertained to issues related to reproduction (Rosser, 1988; "Advances in Women's Health," 1999). Mostly, these issues are reproductive, physiological, or psychological in nature (Rosser, 1988). While many of these problems are centered on reproduction, the emphasis on reproductive rights has overshadowed the need for additional research on non-reproductive health issues such as osteoporosis and heart disease and, as Kinser (1997) explains, places more attention on the development of a fetus than the health of the woman. Yet, in her 1988 book *Feminism Within The Science & Health Care Professions: Overcoming Resistance*, Rosser explains how scientists are attempting to reform women's health care despite encountering resistance from the male-dominated health care profession and gender-biased society. In 1989, these scientists became forever linked to the movement, founding the Society for the Advancement of Women's Health Research. This group helped bring about an investigation of the General Accounting Office which found that women had indeed been overlooked in medical research. Soon after, the National Institutes of Health formed the Office of Research on Women's Health. Since then, various government agencies including the Food and Drug Administration have abolished federal policies that prevented research on women in their reproductive years ("Advances in Women's Health," 1999b). These changes in

federal policy were due in part to the women's health movement and also in part to women's employment in higher positions within media and political organizations (Sargent & Brettell, 1996), perhaps a direct effect of the coinciding feminist movement which advocated for equal opportunity employment and compensation.

Regardless of how the women's health care movement has advanced, it has survived many obstacles throughout its history and remains strong in the new millennium. Surviving bureaucratic hostility, physician resistance, and political backlash (Morgen, 2002), the women's health movement made great strides in the 1990s, helping to establish a multitude of government-funded studies on women's health issues including human immunodeficiency virus and acquired immune deficiency syndrome, breast cancer, colon cancer, osteoporosis, and menopause ("Advances in Women's Health," 1999). Despite these advancements, Morgen (2002) declares that many obstacles still exist for the women's health movement such as:

the increasing impoverishment of women in all countries; welfare reform in the United States; the growing income gap between the nations of the North and the South and between the wealthy and the middle and working classes in the United States; the continuing problem of violence; the effective denial of reproductive rights to poor women who cannot afford to pay for them; the specter of a Supreme Court that might overturn *Roe vs. Wade*; enduring racism resulting in racial and ethnic disparities in health status and access to primary health care (p. 237).

Physician-Patient Dynamics

Another challenge facing women's health care involves the physician-female patient relationship and can be affected, in part, by the historical exclusion of women from medical studies. The omission of women in health studies and clinical trials hampers the development of the physician-female patient relationship. Physicians,

even those who want to better serve female patients, often cannot provide answers to many of their questions. This is likely due to the greater availability of information on diseases affecting men as opposed to those affecting women (“Advances in Women’s Health,” 1999) but can also be impacted by one’s inability to access additional information or the patient’s failure to manage information resulting in overload. Lack of information is a problem even for diseases that present only in women, which frequently affect the reproductive system.

The physician-female patient relationship can be further complicated when the physician dismisses the concerns of the patient (Bradford, 2002; Nolan, 2003). One example of this is found in *Partnership for Health: Building Relationships Between Women and Health Caregivers*, when author Christine Beck (1997) recounts a painful experience in which her new obstetrician questioned her desire for what he deemed unnecessary testing and medication. Rather than standing firm in her belief that such tests and supplements were needed, Beck followed her physician’s orders and eight weeks into her pregnancy suffered a miscarriage. While she reports that she partly blames the physician for the miscarriage, Beck also reports that she blames herself for not standing up for her rights and the treatment she requested. This is only one example of how even the most educated women’s health advocate can fall victim to gender oppression in the examination room.

Fortunately, interpersonal communication skills training programs have been implemented in various medical schools across the country. Aimed at alleviating situations such as the one described by Beck, interpersonal skills training for physicians can improve patient satisfaction, patient compliance, and medical outcomes (Cline & Cardosi, 1983). Cline and Cardosi (1983) claim that interpersonal communication skills training is needed to address two primary problems affecting physician and patient satisfaction: relationship-based problems and information-based problems.

Relationship-based problems begin when the patients’ needs and emotions are not

considered while problems with information result when the quantity or quality of the information received by the patient is insufficient. Despite the obvious need for interpersonal communication skills training for physicians, it has been only in the last 30 years that programs teaching these skills have been implemented in medical schools (Fine & Therrien, 1977). With the success of earlier programs, interpersonal communication skills training is becoming more accepted by the medical community that once downplayed the need for such training. Programs such as these provide a starting point for which physicians can begin to eliminate the problems that hinder physician-patient communication.

While it is important to the success of the women's health movement that women are now being included in scientific health research, it is equally important to understand the obstacles facing the movement in the United States in order for researchers and medical professionals to begin eliminating gender discrimination in health care practices. The long history and remarkable accomplishments of the women's health movement should be recognized. Even so, women and health professionals must realize that it may be years before clinical studies can provide the information needed to gain a clearer understanding of how diseases manifest in women. Although the women's health movement has empowered many women with the resources and information they need to stand up for their rights and demand equal access to health care, there are women who are nevertheless denied these basic rights because of class, race, and/or gender oppression. According to Williams and Collins (1995), "racial and socioeconomic inequality in health is arguably the single most important public health issue in the United States" (p. 380-381).

Socioeconomic Disparities to Health Care

Although gender oppression is a common critique among white women, race and class oppression are not. American health systems are largely focused on the

health care issues facing the majority population (Green, 2003). In fact, most health care systems and organizations reflect a white, middle-class perspective to health care, an attitude that resulted in many minority populations forming their own women's health alliances, encouraging white women to confront the link between health care and race and class discrimination (Morgen, 2002). Gary et al. (1997) claim that access to adequate health care depends on a multitude of factors including "economics, access, levels of acculturation and assimilation, education, language competency, and the level at which cultural diversity is acknowledged and respected" (p. 145). Unfortunately, minority populations are more socioeconomically disadvantaged and more likely to live in poverty, work in more hazardous jobs, live in more polluted areas, have lower educational levels, and are less likely to have insurance coverage than white populations (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; Talsma, 2002; Stone & Dula, 2002; Pappas, 1994; Nickens, 1991; Williams & Collins, 1995; Bobinski, 2003).

Many scholars have addressed health care disparities, most often focusing on those facing African-American (Lurie, 2002) and Latino populations (Balsa, Seiler, McGuire, & Bloche, 2003). Unfortunately, it is all too common that nonwhite populations experience racism and sexism in the examining room. In fact, physician prejudice is one of the most frequently cited explanations for disparities in health care (Bobinski, 2003; Balsa et al, 2003).

African-Americans are particularly likely to receive less satisfactory care than whites (Bobinski, 2003). Members of this racial group are less likely to receive high-technological procedures despite being the most effective means of managing many illnesses (Shelton, 2000). Shelton (2000) claims that African-Americans are also less likely than whites to have access to surgical procedures, be hospitalized, and have routine tests conducted, such as having blood drawn. Scholars claim African-American's decreased access to medical research and technology is only one of the

many problems hindering the advancement of minority health care. There is a long history of racial discrimination in medicine toward African-Americans (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Boulware et al. (2003) claim that this history is one of the reasons why many African Americans distrust the medical system. In fact, some studies suggest that African-American's knowledge of the Tuskegee incident specifically impacts their trust in medical research and may cause them to refuse participation in medical studies (Shavers, Lynch, & Burmeister, 2000; Shavers et al., 2001).

According to Balsa et al. (2003), even unbiased physicians may unintentionally revoke patients of their right to receive adequate medial care. Those physicians who "communicate less well" with minority patients may increase both their uncertainty and the patients uncertainty about their illness (Balsa et al., 2003, p. 203). Also, language barriers and cultural differences may cause some physicians to make decisions about treatment that they would make differently for white patients (Balsa et al., 2003).

Unfortunately, researchers have not fully explored the link between racial and ethnic attitudes and access to health care (Boulware et al., 2003; Balsa et al, 2003). One such project that is focused on addressing this topic is the Racial and Ethnic Approaches to Community Health demonstration project, being facilitated by the US Department of Health and Human Services in response to the Federal Race Initiative (Ma'at et al., 2001). Called REACH 2010, the project seeks to eliminate health disparities faced by various racial and ethnic groups. The project focuses on reducing barriers to six particular health issues: infant mortality, breast and cancer screenings, cardiovascular diseases, diabetes, HIV and AIDS, and immunizations (Ma'at et al., 2001). Despite this much-needed effort to reduce disparities to health care for minority populations, much more attention is needed before racial and ethnic disparities to health care can be properly understood and addressed.

As Williams and Collins (1995) point out, it may be difficult to measure the level of health disparity in many populations because they are excluded from research. For instance, married women are typically associated with the economic stature of their husbands while single women are often affiliated with the status of their fathers, regardless of whether the women are employed (Williams & Collins, 1995). Additionally, medical communities largely assume that patients are heterosexual; therefore, lesbian women may avoid the health care system because they dread discussing sexual orientation with physicians or because they fear discrimination (Endometriosis Research Center, 2003). Moreover, physicians may neglect to recognize the differing attitudes of multi-cultural patients. Physicians often treat non-American females who access health care in the United States the same as they would an American female patient, which can create problems if women are not active participants in their health care because of culturally-imposed standards regarding the roles of women (Kielich & Miller, 1996) as compliant and submissive.

Barriers to adequate health care exist for all socioeconomically disadvantaged populations. However, health care organizations rarely act as change agents and many majority class members deny discrimination as being a problem (Stone & Dula, 2002). Therefore, scholars and medical professionals must continue to address these issues, advocating for the acceptance of diversity in health care. Until women are provided access to quality health care information that specifically meets the needs of women, it is crucial that women's health advocates continue providing relevant information and support to women of all backgrounds through traditional and emerging media, as media act as "translators" for women, determining what is important, credible, and valuable (Parrott & Condit, 1996, p. 7). While each form of media has both strengths and weaknesses, according to Parrott and Condit (1996), each form of mass media should be supplemented with another. Therefore, it is important to study the women's health from a feminist perspective as it emerges in all media. Because much work has

focused on the messages women receive in traditional media such as newspaper, television, radio, and books, it is important to study the health messages being sent by new forms of mass media, particularly the Internet. It is also important that researchers continue to study women's reproductive health issues, focusing on the woman rather than exclusively the fetus she may or may not be carrying and on diseases that specifically affect women as opposed to those dominated by findings on male patients.

Endometriosis: Examining a Medical Mystery

Chronic pelvic pain is a common complaint expressed by female patients (Smith, 1997). In fact, chronic pelvic pain accounts for as many as 10% of gynecologic referrals and is the reason for an estimated 10 to 15% of hysterectomies and 40% of laparoscopic surgeries performed each year in America (Fowler, Milburn, Reiter, & Robinson, 1994; "Women Report Chronic Pelvic Pain," 2002). Chronic pelvic pain is defined as the presence of cyclic abdominal pain for a period of six months or longer; however, many women may suffer for years before seeking the advice of a physician for their pain (Fowler et al., 1994). Most often, chronic pelvic pain occurs in women between the ages of 20 and 35 and is typically characterized by sexual dysfunction, reduced physical activity, job absenteeism, and an inability to work or maintain relationships (Fowler et al., 1994; Smith, 1997). The cause of chronic pelvic pain is usually difficult to diagnose; though a survey conducted by the Endometriosis Association found that 89 percent of chronic pelvic pain sufferers could attribute their pain to endometriosis while nearly 40 percent reported having post-surgical scar tissue formation, commonly known as adhesions ("Women Report Chronic Pelvic Pain," 2002). Adhesions are defined as abnormal deposits of scar tissue found in a woman's abdomen after pelvic surgery ("Women Report Chronic Pelvic Pain," 2002). While endometriosis can cause pelvic adhesions to form, the disease is one that continues to

perplex physicians and baffle medical science. Words that commonly associated with endometriosis in the literature include “mysterious”, “unidentified”, and “misdiagnosed.”

Unraveling a Mystery: Endometriosis Explained

Endometriosis is a condition related most directly to menstruation. An estimated 5.5 million women and girls are affected by endometriosis, accounting for between 7 and 15% of the female population in the United States (Taylor, 2003; “Women Report Chronic Pelvic Pain,” 2002; Null & Seaman, 1999). The disease becomes present when the glands and tissues of the uterus, referred to as the endometrium, grow in locations outside of the uterine cavity (Null & Seaman, 1999; Parrott & Condit, 1996; “Women Report Chronic Pelvic Pain,” 2002; Shah et al., 1995; Taylor, 2003; Endometriosis Research Center, 2003). As a woman’s body prepares for menstruation, the lining of the endometrium thickens and, unless fertilized, sheds cells through what is known as the menstrual flow. For patients with endometriosis, however, not only does the normally placed endometrial tissue thicken and shed, the abnormally located tissues found outside the uterine wall also shed (Null & Seaman, 1999) resulting in intense pain and discomfort. Endometriosis is usually manifest in locations that may include the cul-du-sac (also known as the Pouch of Douglas), fallopian tubes, ovaries, bladder, colon, bowels, intestines, gallbladder, kidneys, appendix, and in some cases the lungs, chest, and thighs (Parrott & Condit, 1996; Endometriosis Research Center, 2003). Symptoms of endometriosis include irregular and/or painful menstruation (dysmenorrhea), sexual dysfunction (dyspareunia), lower back and abdominal pain, gastrointestinal problems (including diarrhea, painful bowel movements, and bloating), chronic fatigue, aggravated premenstrual syndrome (PMS), and persistent bladder infections (Parrott & Condit, 1996; Taylor, 2003; Null & Seaman, 1999). Additionally, women with endometriosis are at greater risk for developing allergies, chemical sensitivities, yeast infections, endometrial cancer, ovarian cancer, breast cancer, and lymphoma

(Endometriosis Association, 2003; Taylor, 2003). Endometriosis is typically diagnosed in white women in their late twenties and early thirties who have delayed childbearing; however, research has shown that women in their forties (Shah et al., 1995) as well as teenagers (Jancin, 2003) can be affected. As previously discussed, however, women of color face barriers to health care not usually experienced by white women. Therefore, while the disease is most often diagnosed in white women, it may as common in racial minorities who are being misdiagnosed or who are unable to seek treatment. The Endometriosis Research Center points out that endometriosis “affects women of all backgrounds, races, ethnicities, socioeconomic status and sexual orientation” (2003, p. 1) and has been found in infants and menopausal women.

The exact cause of endometriosis is not known though myriad theories attempt to explain the origin of disease. Among the most popular are retrograde menstruation theory and genetic theory. Retrograde menstruation theory, or transtubal migration theory, suggests that during menstruation tissue backs up into the abdomen through the fallopian tubes and grows (Endometriosis Association, 2003). Genetic theory holds that certain families may pass along predisposing genes to female members of their family (Endometriosis Association, 2003). Other less accepted theories suggest that tissue remains in the body from the time a woman is an embryo and later develops into endometriosis and that endometrial tissue is distributed throughout the body via the lymphatic system (Endometriosis Association, 2003). A study conducted by the Endometriosis Association (2003), the first organization created solely for the purposes of endometriosis research and education, found a positive correlation to exist between exposure to dioxin (a chemical byproduct) and development of endometriosis. A link was also found between the length of exposure to this chemical and severity of the disease. The Oxford Endometriosis Gene (OXYGENE) Study is currently conducting the world’s largest endometriosis research experiment to date. The goals of the study are to advance research into the causes of endometriosis, new ways of diagnosing the

disease, and effective treatment options (Oxford Endometriosis Gene Study, 2003; Jancin, 2003).

Just as there is no known cause for endometriosis, there is also no known cure for the often debilitating illness. The primary goal of endometriosis patient care is pain management (Blair, 1986). Once diagnosed through laparoscopy, endometriosis can be treated through laser surgery (which can be performed during the diagnostic laparoscopy) or hormone therapy (Fowler et al., 1994; Blair, 1986; Taylor, 2003, Parrott & Condit, 1996; Null & Seaman, 1999). Hormone therapy can include continual use of birth control pills (where menstruation is avoided by maintaining a continuous supply of hormones in the body), gonadotropin-releasing hormone antagonists (which disable the pituitary gland from producing endometriosis-stimulating hormones such as estrogen), and progestins (that halt ovulation and limit implantation growth) (Taylor, 2003). While these treatments may be temporarily effective, many physicians claim that the only way to permanently alleviate the pain associated with endometriosis is through hysterectomy or surgical removal of the uterus (Blair, 1986; Angier, 1999). In fact, “endometriosis is the second most common reason hysterectomies are performed in the United States” (Parrott & Condit, 1996, p. 359). This dependence on hysterectomies to eliminate chronic pelvic pain, including the pain caused by endometriosis, accounts for up to 80,000 procedures being performed each year in America (Fowler et al., 1994). Ironically, up to 90% of the women who undergo surgery to treat endometriosis will develop adhesions, a common cause of severe pelvic pain (“Women Report Chronic Pelvic Pain,” 2002). However, as Parrott and Condit (1996) point out, hysterectomy is a radical surgery that is often overused. This may be due to a number of reasons including physician’s propensity to perform the procedures in which they specialize, medical schools’ continued teachings that hysterectomy is a remedy for many female ailments, and physician’s lack of interest in non life-threatening reproductive illnesses (Parrott & Condit, 1996). Therefore, women must be prepared to

propose a consideration of alternative approaches to treatment and be assertive in their request to receive them. While there are physicians that will offer less radical pain management solutions, many women will have to conduct their own research “to empower [themselves] in this regard” (Parrott & Condit, 1996, p. 283).

The Misdiagnoses of Endometriosis: Issues and Attitudes

Confounding the problems associated with identifying a cause and cure for endometriosis is its diagnostic difficulty. At an early age women become accustomed, or are told to get accustomed, to menstrual pain. The disease often goes undiagnosed for years as a result (Taylor, 2003). Results from a 1998 study by the Endometriosis Association found that most women suffer with endometriosis an average of nine years before seeking medical attention. Many women do not understand that their symptoms are abnormal while others experience little, if any, pain with endometriosis (Taylor, 2003). Women with mild to moderate endometriosis can experience pain far greater than those with severe cases making it a difficult disease to characterize (Blair, 1986). Often infertility must be present before endometriosis is suspected though, interestingly, women suffering with severe forms of the disease may have less trouble becoming pregnant than those women with a mild form of the illness (Taylor, 2003). Physicians may also mistakenly diagnose patients with other conditions such as irritable bowel syndrome, appendicitis, and even Chron’s disease (Shah et al., 1995) as the symptoms associated with these illnesses are similar to those representative of endometriosis. Additionally, endometriosis may go undetected because women are frequently told that their pain is exaggerated or normal. Another study conducted by the Endometriosis Association found that 40 percent of women suffering from endometriosis or adhesions have been told they exaggerate their pain, with over half of these remarks made by their physicians. Another 60% were told their pain is normal; 56 % heard this from their physician (“Women Report Chronic Pelvic Pain,” 2002). As

Taylor (2003) states, when the “physician is not listening to the patient’s concerns, the disease very easily could go undetected” (p. 298). Physician attitudes, and patient perceptions of those attitudes, are a determining factor in whether or not a woman seeks medical care (Fowler et al., 1994). Physicians who undermine the significance of menstrual pain may lead women to discontinue medical care and accept their pain as a normal part of womanhood.

Physicians may disregard the concerns of patients with endometriosis, questioning whether their pain is real or imagined. Additionally, Fowler et al. (1994) suggests that many women’s physicians are failing in their attempts to provide information to their patients with endometriosis. As a result, patients likely perceive these physicians as insensitive or unconcerned. Patients can therefore become anxious, angry, or frustrated with the physician’s inability to determine a definitive cause or effective plan for treating their pain (Fowler et al., 1994), which can cause them to shun treatment or embark on a personal search for information. These doctor-female patient problems can be attributed, at some level, to the historical exclusion of women from clinical trials which has resulted in a lack of information on women’s health care issues (Schur & Nicolette, 1997; Parrott & Condit, 1996; Null & Seaman, 1999; Sargent & Brettel, 1996). Other possible reasons why women seek outside information could be communication apprehension, barriers to access, and gender discrimination. Such problems lend credence to the idea that women suffering from endometriosis seek additional resources that enable them to assess their symptoms and inquire about their condition in communities where information is openly provided and their concern is reciprocated. For many women, these communities consist of their social networks, including their interpersonal relationships with friends and family. Additionally, research shows that women increasingly rely on mass media to gather information about women’s health issues (Okamura, Bernstein, & Fidler, 2002; Pandey, Hart, & Tiwary, 2003).

According to Fox and Fallows (2003), most Americans consider health a family affair. Many individuals report that family, friends, and co-workers are most influential when making health-related decisions (Fox & Fallows, 2003; Epstein, Campbell, Cohen-Cole, McWhinney, & Smilkstein, 1993). Wilkins (1999) reports that most people view family and friends as the trustworthiest disseminators of health-information. However, health information is rapidly increasing in the mass media in response to changes in the communication and production of self-help information (Ziguras, 2000). Women's health is being discussed more often in mass media; breast cancer, menopause, and infertility are only a few of the women's health issues being addressed in the news. Unfortunately, however, much of what is being discussed in the media is breaking news concentrated on specific diseases.

In sum, despite the remarkable efforts of the women's health movement, there is still much to be done in the way of achieving gender equity in medical care. Throughout the 1990s, increased attention was given to providing interpersonal communication skills training to medical students (Ratzan, Stearns, Payne, Amato, Liebergott, & Madoff, 1994; Epstein et al., 1993). Today, while several university medical programs require their students to enroll in communication courses, little research has explored the benefits of such programs (Cegala & Broz, 2002; Humphris & Kaney, 2001; Brown, Boles, Mullooly, & Levinson, 1999). Research suggests that physicians who have never received such training may have increased incidences of malpractice claims and their patients may report low levels of satisfaction and compliance (Cline & Cardosi, 1983). Ballweg (1995) notes that physician communication skills are discussed repeatedly in letters received by the Endometriosis Association. Because less research exists on women's health care issues, female patients may experience higher levels of uncertainty regarding health care issues. Therefore, it is important that physicians are empathic and able to effectively communicate with patient's about their concerns. However, in order to alleviate uncertainty and acquire additional information, women

may seek other resources to satisfy their need for health information. Many women rely on family and friends to gain pertinent information about health issues. However, perhaps due to concerns regarding privacy, reliability of information, and gender inequality, and the aforementioned limitations of traditional media, women are increasingly utilizing the Internet to gather important health-related information.

The Internet: Breaking New Ground in Health Communication

The fastest growing form of mass media is the Internet, an independent public network that enables users from around the world to communicate and access information (Kerwin, 2002; Waldo, 1998; Flaherty, Pearce, & Rubin, 1998). Originally developed in the late 1970s as a mode of communication for United States military (Comer, 1999), there are currently more than 93 million Americans regularly using the Internet (Fox & Fallows, 2003). Attracting a larger audience in a quicker amount of time than any form of mass media to date, the Internet, home to over one billion websites, serves as a popular means of entertainment and information for millions of people across America (Edworthy, 1999; Jackson, Ervin, Gardner, & Schmitt, 2001; Pandey et al., 2003). Contributing to the popularity of Internet technology is that it is accessible 24 hours a day, offers information on a broad range of topics, and provides a plethora of search options to facilitate ease in usage (Wilkins, 1999; Perse & Ferguson, 2000). Additionally, advancements in computer technology have diminished the need for individuals to acquire technical skills in order to access web-based information (Edworthy, 1999). Despite the fact that Internet usage continues to rise, little research has investigated the reasons for this phenomenon. Hines (2001), however, suggests that the availability of health information on the Internet has resulted in patients seeking information at increased rates. Supporting this idea is a study conducted by Fox and Fallows (2003) which found that 80% of adult Internet users have sought health-related information online, making health-information seeking the third most popular online

activity, after email at 93% and product research at 83%. Milio (2001) cites health information as being the most explored news topic by Internet users. Interestingly, public users comprise the majority of journal users registered on the American Medical Association website (Milio, 2001).

The Internet: Health Care Redefined

According to Kerwin (2002), the Internet has the potential to greatly enhance the way people seek health-related information and in turn improve the overall quality of user's health care. Additionally, Waldo (1998) claims that the Internet is an effective tool for enhancing health care marketing, education, and communication. The Internet is "a vehicle by which health care organizations can broaden the accessibility of applications by users, facilitate exchanges of information, reduce costs, enhance revenue, and provide better delivery and quality of care to patients" (Kerwin, 2002, p. 226). Additionally, the Internet serves as a method of empowering patients by providing increased access to continually updated health care information (Waldo, 1998; Crandall, Zitzelberger, Rosenberg, Winner, & Holaday, 2001). Milio (2001) claims that up to 60% of patients come to physicians with information they found on the Internet and request additional treatment or information. This Internet information serves, therefore, as a starting point for informative and potentially more satisfying physician-patient interactions. Of those using the Internet for health-related information, 70% say the knowledge they gain influences their medical decisions (Hawkins, 2001). Physicians appear to be receptive to the idea that patients are browsing the Internet in an effort to take on more active roles in their health care. Physicians report that patients gain mostly beneficial health care information from Internet research while patients report physicians as being interested in the online research brought to the examining room (Potts & Wyatt, 2002; Fox & Rainie, 2002).

As the average length of the medical visit decreases (Beck, 1997; Kerwin, 2002), patient autonomy increases (Elwyn, Edwards, & Britten, 2003), and doctors focus more on illness and research rather than the patient (“Doctor, the Patient Needs Urgent Help,” 2004), consumers are seeking alternative sources of information. An immense amount of health-related information is available online; educational literature, health databases, and interactive tools are easily accessible to web users (Brooks, 2001). Meanwhile, many independent and group physicians are hiring web programmers and software developers to design websites that provide information to the general public and allow patients to access medical records (Brooks, 2001; Deye, Kahn, Jimison, Renner, Wenner, & Gabello, 1997). As a result, health care information is quickly becoming democratized, empowering patients to take an equal part in their medical interactions with physicians (Ziguras, 2000, p. 37). Fox and Fallows (2003) provide a list of the 16 health topics of most interest to consumers. The report claims that 63% of consumers are using the Internet to research specific diseases (making it the most sought after health information) while six percent search for information on smoking cessation (making it the least researched health topic). As physicians, patients, and health organizations throughout the nation flock to the Internet, Fox and Rainie (2002) claim that America is experiencing a transition into an Information Age in health care. As discussed in the next section, however, increased use of the Internet for health-related information does have potentially serious drawbacks.

A New Group of Internet Users

According to Fox and Fallows (2003), females are the most frequent seekers of health-related information on the Internet. In fact, the report claims that 85% of female Internet users have sought health-information compared to 75% of male Internet users. In addition, more girls go online for health information than boys (Fox & Rainie, 2002). The Boston Women’s Health Book Collective (1998) has even published a new edition

of *Our Bodies, Ourselves* entitled *Our Bodies, Ourselves for the New Century* that provides information on Internet health resources for women, tips on how to gain access to and maneuver the Internet, and a listing of feminist health organizations (Scott, 1999).

Although many Internet users are searching for health information, most users do not engage in frequent health-related searches. In fact, the Pew Internet & American Life Project (Fox & Fallows, 2003) shows that individuals conduct health searches only once every few months and most do not search for information related to personal illness. Rather, these information-seekers are searching for information about loved ones, typically spouses, children, parents, and friends. This could explain the reason behind the growing numbers of female Internet users as women are most often seen as caretakers (Gersch, 1998; Vogel, Wester, Heesacker, & Madon, 2003; The Boston Women's Health Book Collective, 1998). Communication apprehension may also result in women turning to the Internet. Booth-Butterfield, Chory, and Beynon (1997) report that women who suffer from communication apprehension tend to avoid open discussions about health issues and, as a result, receive inadequate medical care. Past research indicates that as a woman's communication apprehension increases with her gynecologist, her willingness to engage in candid dialogue about gynecological problems decrease (Booth-Butterfield et al., 1997). Less assertive women may also turn to the Internet for information. According to Ballweg (1995), more assertive women are able to ask for additional information whereas passive women are less likely to request supplementary information from their physician. Women may find the Internet offers a community that encourages discourse and satisfies their interpersonal needs while allowing them to briefly transcend power structures (Jackson et al., 2001; Gersch, 1998) and socioeconomic discrimination (The Boston Women's Health Book Collective, 1998) though this may not be true for women with significant barriers to access. Lesbian women may be particularly more reliant on alternative forms of information as

physician homophobia can result in mistreatment or misdiagnoses (Endometriosis Research Center, 2003). Additionally, women may turn to the Internet due to the lack of women's health literature and women's bookstores. Most women's media are produced by aging volunteers (who may be less educated on ways to reach out to today's technology-dependent society) and are supported by foundations, contributing to a decline in printed information and an increase in Internet development (Gibbons, 2003). Since 2000, *Ms. magazine*, *Sojourner: The Women's Forum*, *Women's International Network News*, and *Feminist Bookstore News* have all ceased publications though an electronic version of *Sojourner* is available and the producer of *Women's International Network News* is exploring the option of moving online. Additionally, the presence of women's bookstores has declined dramatically; in 2001 the Feminist Bookstore Network reported 74 women's bookstores in the United States and Canada, a 61% decline in the total reported in 1997 (Gibbons, 2003). According to Pandey, Hart, and Tiwary (2003) women are using the Internet to supplement information received from physicians in an effort to improve the quality of their health. Researchers Fox and Fallows cite one individual who claims that having access to the Internet would have prevented her from following a physician's poor advice, "If I had the resources of the Internet then I would have not had the surgery knowing that this doctor was not telling me the truth about the after-effects and outcomes of hysterectomy" (as quoted in Fox & Fallows, 2003, p. 10) Regardless of the reasons, the Internet is quickly becoming the primary source for women's health information (Gibbons, 2003; Okamura et al., 2002).

While most researchers agree that the Internet provides people with increased access to information, some question the confidentiality, quality, and reliability of these resources (Edworthy, 1999; Okamura et al., 2002; Haddow, 2003; Kerwin, 2002; Waldo, 1998; Brooks, 2001; Hawkins, 2001). In fact, Lueg, Moore, and Warkentin (2003) report that although there are potential benefits to patients, using the Internet to acquire health research has not been as successful as was expected. Waldo (1998)

claims that the public is concerned about the accessibility and security of the Internet. Low-income and unemployed individuals, as well as those who suffer with neurological disorders, may be unable to access the Internet (Edworthy, 1999) while rural and less affluent populations may be less likely to have access to reliable and secure Internet service (Milio, 2001). Kerwin (2002) suggests patients may be wary of using the Internet to gather health information because of concerns about quality and that physicians may feel a greater danger for malpractice claims when corresponding via email or online discussion. Although she believes that Internet users understand that not all websites contain scholarly material, Haddow (2003) suggests that it is particularly important to produce quality health information because of the potential for misinformation to cause serious harm to the user. Haddow (2003) expresses concern that the lack of accountability on the World Wide Web may foster the production of unreliable information by non-experts. This potential for misinformation is very dangerous to Internet users (Lueg et al., 2003), particularly those who use the information as a replacement for physician advice (Brooks, 2001). Further, Okamura et al. (2002) propose that because Internet material is not subject to review, health information disseminators should take on the responsibility of ensuring the quality of the information presented on websites. Fox and Rainie, directors of research for the Pew Internet & American Life Project (2002), found that although people are using the Internet to access health-related information, users often find it difficult to locate the desired material. They also claim that higher education leads to increased experience with the Internet thereby making it easier for individuals to seek medical advice on the web. Therefore, while the Internet certainly has advantages for information seekers, there are undeniable drawbacks to using this medium as a source of health-related information. Despite the concerns raised by many scholars, Fox and Rainie (2002) claim that most Internet users turn away from information that does not clearly identify the source of material presented. Lueg et al. (2003) challenge this claim, citing a study

by Eysenbach and Kohler which says most health information-seekers do not check the source of the health information and are largely unable to recall which sites they visit. Additionally, bringing Internet research to an office visit can impact the physician-patient relationship, either positively or negatively, depending on the physician's response to the information (Lueg et al., 2003). It is evident that Internet information has its limitations and should never be used as a replacement for the advice of an actual physician.

Fox and Rainie (2002) found that the typical Internet user is likely to verify web-based health information with their doctor before making a final decision regarding treatment. In their research for the Pew Internet & American Life Project, Fox and Rainie learned that 73% of all health information-seeking Internet users have rejected one or more websites for a variety of reasons. Of those 73% who have turned away from information presented on health-related websites, 47% deemed the website too commercial; another 42% rejected the website because they could not determine the source of the information; and an additional 37% could not tell when information was last updated (Fox & Rainie, 2002). Moreover, Fox and Rainie found that only a small percentage of Internet users substituted online information for the advice of their physician. Brooks (2001) claims that while there are legitimate concerns about information quality, there are also guidelines to help Internet users evaluate health websites thereby providing users with a way to measure the credibility of a particular source. Deye et al. (1997) maintain that although the Internet is a source of misinformation, it also provides physicians and patients with a valuable resource tool. They also point out that malpractice insurers are increasingly interested in the benefits of using technology to supply patients with access to relevant health information, even providing physicians with free patient education software (Deye et al., 1997).

The Internet is the fastest-growing form of mass media, yet little research has been conducted on motives for Internet usage. Researchers claim online health

information is an empowering tool for consumers, enabling them to take a more active role in their health care. However, questions concerning the quality of Internet information abound. Physicians, though, claim that patients typically benefit from information found online. Fox and Fallows (2003) report that 63% of consumers search for information regarding specific diseases. In addition, Hawkins (2001) reports that 70% of patients claim Internet information directly impacts their medical decisions. These factors are among the plethora of reasons why it is important that researchers examine the content of websites dedicated to female conditions.

Literature Review Summary

Women have been largely ignored in previous medical research; however, the women's health movement has made much progress in advocating the importance of women's health care issues in America. In spite of the accomplishments of women's health advocates and feminist health organizations, research indicates that obstacles remain for women desiring information on many health care issues, particularly reproductive problems. Endometriosis continues to baffle medical science; it is a commonly misdiagnosed disease affecting millions of women of all classes, ages, and races. Mistreatment or oversight of endometriosis can have devastating physical and social outcomes such as infertility, lack of activity, autoimmune deficiency, loss of employment due to inability to work, irritability, and trouble maintaining personal and professional relationships (Endometriosis Research Center, 2003; Fowler et al., 1994; Smith, 1997). These problems can lead to a host of emotional issues including severe depression (Fowler et al., 1994) and low self-esteem (Ballweg, 1995). Unfortunately, due to lack of physician education, endometriosis is often viewed as a part of normal female embodiment and patients are left feeling upset, frustrated, and confused. Perhaps in an attempt to offset the lack of information provided by medical professionals, women are increasingly using the Internet for health information. In fact,

health information is one of the most researched online topics and women are the primary seekers of health-related information, perhaps due to their roles as primary caretakers or because of a lack of additional resources or because the Internet provides an effective, cost-efficient method of obtaining information and interacting with women suffering with similar issues. While this phenomenon is attributed to multiple factors, it can be assumed that women are using the Internet to compensate for the lack of information provided by physicians. It can also be assumed that women are using the Internet to learn important information about endometriosis.

Despite the increased research produced on women's health issues, there is still much to be learned about how media are portraying these issues. Internet use by women continues to increase, women are relying increasingly on the Internet to obtain health-related information (as evidenced by a 2003 study directed by Fox and Fallows which found health-related information-seeking to be among the three most popular uses of the Internet), and feminist literature is becoming scarce or moving online to offset the high costs of production. As a result of this developing interest in Internet usage, many scholars have questioned the quality of Internet information. Therefore, it is important to study the messages being received by women health information-seekers.

This literature review establishes a basis for the research questions outlined below. These research questions call for an exploration of the messages found on ten of the most popular endometriosis websites. Methods for examining these research questions are detailed in Chapter 4.

Research Questions

The areas of focus for this study are the availability of endometriosis-related Internet sites, the messages Internet users receive about endometriosis, its causes, symptoms, and treatments, the messages Internet users receive about infertility, and

the availability of additional resources. Research questions emerged from the literature review as well as from personal experience; questions one and two are specifically addressed in my Chapter 1 narrative. The research questions for this study are:

1. What messages are endometriosis websites sending to women about the disease and its causes and treatments?

- a. Is endometriosis linked to a specific cause?
- b. To what extent do these websites promote hysterectomy as the only certain cure for endometriosis?
- c. Are these messages representative of those I have received from a physician or my online research?

2. How do endometriosis websites portray infertility?

- a. Do websites propose that infertility is a definitive long-term effect of the disease or a probable effect?
- b. Do websites provide information on when to seek medical attention for infertility?
- c. Are these messages similar to those I have received from my physician and online research about endometriosis-related infertility?

3. What information, if any, is provided on endometriosis websites about communicating with physicians about the disease?

4. How available is additional information regarding endometriosis to women visiting endometriosis websites in terms of cost and retrieval methods?

- a. Are women provided access to online support groups?
- b. Are additional printed materials available via postal mail or email?
- c. Do websites require patrons to have particular software in order to access additional information?
- d. Do websites require users to have a high technological competency in order to retrieve additional online information?

e. Are there are costs associated with accessing additional information?

These questions represent those that are not clearly answered by researchers, scholars, or medical professionals. Additionally, these questions seek to provide answers to women suffering from endometriosis who are given incomplete or misguided information from their physician, friends, family, or an online endometriosis website. For instance, a subpart of question one asks if endometriosis is linked to a specific cause. From personal experience I know that some women believe endometriosis to be caused by cancer and is a myth commonly discussed on the Internet sites I researched. Hysterectomy is also often promoted as a cure for endometriosis, as discussed in the literature review and alluded to in my narrative. Having a proper understanding of a disease is key to making decisions about one's course of treatment. A woman who believes she has cancer may spend her time looking at information about cancer treatment plans rather than literature about endometriosis. A woman who wishes to have children but is misinformed about the use of hysterectomy in treating endometriosis may decide to have the procedure done thereby destroying any chance of having a child naturally. Having a clear understanding of these issues is important not only to the physical health of the endometriosis patient, but to her emotional health as well.

Linking phenomenological research with a hermeneutic analysis of online endometriosis websites, this research has many purposes. This study serves as a learning tool, teaching medical and media professionals how to provide more accurate, comprehensive information to a rising population of female Internet users. This research also acts as a guide for women searching for endometriosis-related information on the Internet. Overall, this study seeks to enhance the reader's knowledge and understanding of endometriosis, the shortcomings of traditional media in promoting the disease (as well as other women's health issues), and the emergence of the Internet as a viable source for endometriosis-related information.

In Chapter 4, I describe the methods used to conduct this study. Then, in Chapter 5, I provide the findings of this study and offer a discussion of the implications of these findings. Finally, in Chapter 6, I detail the limitations of this study and offer directions for future research.

CHAPTER 4

METHODS

In this chapter, I explain the research methods used to answer the questions posed in Chapter 3 of this study. For this study, I focused on identifying the messages produced by websites dedicated to providing women with information about endometriosis. Qualitative research methods, particularly phenomenology and hermeneutics, were used to compare the themes found in the literature review and my personal narrative with those found on the ten analyzed websites. Qualitative research methods are particularly helpful when attempting to understand experiences, such as those of a person suffering with a chronic disease, because these methods allow the researcher to go into the “field” and examine actions and thought processes (Strauss & Corbin, 1998, p. 11). In addition, qualitative methodologies can manage the existence of multiple realities more so than quantitative methods and allows for the humanness of the researcher to emerge as opposed to more positivist studies which largely ignore human-as-instrument research (Lincoln & Guba, 1985, p. 27). In the following sections I explain how the sample websites were selected and how qualitative methodology was implemented in this study. For this study, I investigated those websites most accessible to the average Internet user.

Description of Sample

For this study, I analyzed 10 websites dedicated specifically to providing information on endometriosis. A listing of major search engines and directories was retrieved from Search Engine Watch (<http://www.searchenginewatch.com>), a major source for search engine marketing. Search engine giant Google, found at <http://www.google.com>, was listed as the top choice for obtaining information on the Internet. Additionally, the directory cites Google as providing the most comprehensive, quality information to Internet users. Fox and Rainie (2002) claim that most health-

information seeking individuals start their search with a search engine rather than a medical site. Therefore, I conducted a Google search to obtain the listing of the 10 endometriosis websites to be analyzed for this study. To ensure that these sites were the ones most accessible to the average consumer, I did a follow-up search using the second, third, and fourth ranked search engines, AllTheWeb.com, Yahoo!, and MSN Search. These search engines produced the same results as number one ranked Google.

I eliminated six sites from the study. One site was eliminated from the study because it is no longer functional (meaning it could not be displayed); four were excluded because they were repeats of already selected websites; another was barred from analysis because it was not a professional health website, rather it was a personal site providing information about online endometriosis resources. I excluded personal websites from this study as research indicates that women tend to draw more heavily from professional websites. Eliminating these sites from the study produced the following ten websites, ranked by Google in order of highest quality and greatest relevance. I conducted this search and selected websites on October 13, 2003.

1. The Endometriosis Association (<http://www.endometriosisassn.org>)
2. Endometriosis.Org (<http://www.endometriosis.org>)
3. Endometriosis Research Center (<http://www.endocenter.org>)
4. National Endometriosis Society (<http://www.endo.org/uk/>)
5. Center for Endometriosis Care (<http://www.centerforendo.com>)
6. Endometriosis Zones (<http://www.endozone.org>)
7. MEDLINEplus (<http://www.nlm.nih.gov/medlineplus/endometriosis.html>)
8. Endometriosis Awareness & Information (hcgresources.com/endoindex.html)
9. Endometriosis Institute (<http://www.endometriosisinstitute.com>)

10. Oxford Endometriosis Gene Study (OXEGENE)

(<http://www.medicine.ox.ac.uk/ndog/oxegene/oxegene.htm>)

Qualitative Methodologies

Qualitative methods enable a researcher to observe data from a variety of perspectives and interpret the meaning of the findings by taking a naturalistic approach to “studying phenomena in natural settings often referred to as the field” (Mann & Stewart, 2000, p. 195). All qualitative research studies are notably subjective in nature; interpretive research methods are used in order to understand the significance of the themes found in one’s lived experiences and/or environment (Keyton, 2001; Strauss & Corbin, 1998). For the purpose of this study, I relied upon phenomenological research methods, which assume the pertinence my personal experiences as a person struggling with endometriosis and my consequent perceptions and ideas about the information being provided by these websites. In addition to writing from my own experience, I explored emergent themes in both the literature review and my personal narrative. Then, I conducted a hermeneutic analysis of online content to determine which of the emergent themes were also prevalent in the website content. Specifically, themes emerged through unitizing and categorizing data. Unitizing is defining the pieces of information that are interpretable without the presence of additional text. Categorizing is the process of organizing the unitized data into inferential information, a process called constant comparison by Lincoln and Guba (1985, p. 203). The methodologies used in this study were aimed at identifying and relating commonly occurring concepts based on my experiences with endometriosis and the findings of a review of literature specifically conducted for this project.

Phenomenology and hermeneutics methodologies are particularly important to feminist-oriented research (Morawski, 1997) as scholars are constantly seeking to define the most effective form of feminist methodology (Fielding, 1999). Through

narration, and other forms of writing, women become subjects with their own voices, able to speak out in a society where a white male authority dominates experience (Coffey, Holbrook, & Atkinson, 1996). I used my own voice as a person with endometriosis in an effort to bring the disease to life – to give endometriosis suffering a voice – and as a means of comparing the information I have received throughout my 10-year battle with the information provided by today’s endometriosis websites, many of which I have relied on for information in the past. This concept of interweaving personal experience and linguistic meaning was discussed in detail by Ricoeur, who claimed that when used together, experience and meaning allow one to interpret his/her world for the audience. By doing so, the audience becomes involved in the world lived by the writer, thereby creating for the audience an understanding and appreciation of that world (Hoogland, 2003; Ricoeur, 1991). Used together, phenomenology and hermeneutics are qualitative research methods used to develop and heighten understanding (Byrne, 2001) by researching lived experience and analyzing the textual representations of those experiences.

In his book, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, van Manen notes that “a true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance” (1990, p. 32). He notes that phenomenological research provides a voice for findings that already exist. Boeree (n.d., online) simply defines phenomenology as a description of someone’s experiences, whether they are those of the researcher or an observed participant. Phenomenology is based on the thesis that subjects are given meaning only when they are experienced (Ochs & Capps, 1996). This study is grounded in my lived experiences as a woman with endometriosis and while these experiences are certainly not the only ones had by endometriosis sufferers, van Manen points out that “the phenomenologist knows that one’s own experiences are also the possible experiences of others” (1990, p. 54). Lincoln and Guba (1985) argue

the importance of using personal experience to develop the audiences understanding of a phenomenon. They claim that it is possible that no single generalization will emerge from a qualitative account of experience, but that many others will emerge to represent “naturalistic generalizations” made by the audience to assist in developing their understanding of the subject (p. 120). According to Strauss and Corbin (1998), qualitative researchers who have the same general perspectives, rely on relatively similar methods of data collection and analysis, and perform their work under similar circumstances will often arrive at the same conclusions though each researcher may emphasize different points. Discrepancies, claim Strauss and Corbin (1998), can often be cleared up by reexamining the data and identifying possible alternatives. This is particularly true of research on chronic health conditions; researchers often arrive at the same conclusions yet emphasize different points of significance (Strauss & Corbin, 1998, p. 267). Strauss and Corbin (1998) encourage qualitative researchers to describe their experiences, realizing the importance of these experiences in comparing and discovering the properties of a phenomenon (p. 5).

A narrative is a “constructed intelligence that filters the relationships between authors, depicted events, and readers” (Lindlof & Taylor, 2002, p. 284); it is a “version of reality” (Ochs & Capps, 1996). My narrative, which appears in Chapter 1, represents the lived experience by which I constructed the perceptions and ideas that were used to interpret results from a hermeneutic, or thematic, analysis of the content of the aforementioned websites. Peshkin refers to these perceptions and ideas as the “incipient field of study” (2000, p. 5). According to Berger and Luckmann (1966), lived experiences provide individuals with a future frame of reference. Based on that frame of reference I attempted to uncover the themes and topics present in both my review of literature and narrative. I then sought to determine if those same themes were present in the studied websites (noting any additional themes as they emerged), a method of interpretive analysis loosely discussed by Denzin (as cited in Ellis & Flaherty, 1992) and

Lindlof and Taylor (2002), and defined as constant comparison by Lincoln and Guba (1985). Lincoln and Guba (1985) claim that this type of reflexive work records information about the self much like traditional methods used in the more conventional, quantitative studies record information about other data sets(p. 327).

Interpretive analysis, also known as hermeneutics, provides a way for the researcher to identify with the subject, using knowledge gained from past experiences to present a better understanding of the phenomena studied (Peshkin, 2000). Hermeneutics is defined as textual interpretation (Byrne, 2001; Smith, 1999; Josselson, 1995) aimed at providing readers with a deeper understanding of the phenomena being studied (Byrne, 2001; Smith, 1999). According to Gadamer, hermeneutics defines the textual meaning of the author's intentions by exploring his/her worldview. By understanding the thoughts and ideas that motivate the author, greater reader understanding is then made possible (Mallery, Hurwitz, & Duffy, 1987; Gadamer, 1975). Josselson (1995) maintains that these interpretations lack objective or neutral perspective and are, therefore, subject to the personal biases of the researcher and readers. Some researchers argue that researcher prejudice should be eliminated; however, others believe that "in order to understand each other, we cannot shed our past experiences, and that these experiences actually enhance our understanding" (Byrne, 2001, p. 969). For this study, my personal experiences are the cornerstone of my interpretation of the content studied. As a woman and as a woman with endometriosis, my experiences are very different from the medical experiences of a man or of a woman without the disease. The same is true of a man suffering with impotency or a woman with breast cancer. Without a representative voice, the experiences of endometriosis sufferers remain unnoticed. By honoring my experiences with the disease in my narrative, I was able to define the most common themes in my narrative and sought to determine whether those same themes were also present in the literature reviewed for this project. A theme, such as "endometriosis causes infertility,"

which appeared in both the literature review and narrative were then compared to the messages presented on the studied websites. This process of finding patterns or themes is described by Smith (1999) as one of the most creative steps of the hermeneutic analysis process. Themes help the researcher to communicate findings and link them to the subject being studied (Byrne, 2001).

Interpretive Analysis

This qualitative analysis focused on the textual content of my Chapter 1 narrative, an extensive review of literature, and ten endometriosis websites. Specifically, I used my personal narrative to articulate my story and experiences as a woman with endometriosis. After comparing the most dominant themes of my narrative to those found in the literature review, I established organized themes. Then, I compared the themes to the online messages being sent to online users. On these websites, I identified the most dominant themes, which can be defined as “an element (motif, formula, or device) which occurs frequently in the text” (van Manen, 1990, p. 78). Content was defined for this study as textual messages. Banners and advertisements were eliminated from this analysis due to the rapidly changing nature of these media on websites. Images were also excluded from this analysis. Analysis of the selected websites occurred from November 24 - 27, 2003.

While analyzing endometriosis websites, I looked for recurring themes in the literature and in my personal narrative that reflected the research questions detailed in the Chapter 3. While I identified themes by analyzing the content of each website, I expected, based on the literature review and my narrative, certain themes to emerge. The following themes are common ones referred to in endometriosis-related literature as well as themes that appeared in my narrative. I used these themes merely as a guide when analyzing the sample. If additional themes emerged during the analysis, they were recorded, as only predominant themes were reported. The themes that

emerged during interpretive analysis are largely unpredictable; therefore, while I expected certain themes would be more salient, the overall research design emerged during the process of writing (additional discussion on this topic is provided by Lincoln and Guba, 1985).

To determine which themes would guide my research, I looked for those most common in the literature review and my narrative. Regarding the messages women are receiving about endometriosis, its causes, and available treatments (research question one), I expected the following topics would emerge in my research:

- 1: Pelvic pain is a normal characteristic of womanhood
- 2: Use the “wait and see” approach to pelvic pain management (defined by the assumption that the problem may subside with time)
- 3: Have a baby/do not postpone pregnancy (defined by the assumption that becoming pregnant will cure endometriosis and the longer one waits, the worse the disease becomes)
- 4: Have a hysterectomy (based on the incorrect, but reinforced idea that having a hysterectomy is the only permanent cure for endometriosis)
- 5: Rely on contraceptive management to alleviate the symptoms of endometriosis (typically this requires the women to commit to taking daily birth-control pills)

Concerning infertility (research question two), both the review of literature and my narrative suggest the following criteria for analysis:

- 1: Infertility is a definitive result of endometriosis (rather than a possible result)
- 2: Infertility can be alleviated through surgery (based on the assumption that once a woman has laparoscopic surgery for endometriosis, she will have a window of opportunity to become pregnant)

3: Infertility can be managed by medication used to shrink endometriosis (incorrectly, physicians often claim that medications prescribed to manage endometriosis can be used to treat infertility)

Research question three, information about physician-patient communication, was analyzed according to the following criterion:

1: Question-asking and clarification facilitate effective and assertive communication (literature suggests that repeating information for clarification and asking questions promote effective communication while literature claims assertive women more frequently request information).

Finally, research question four, regarding the accessibility of endometriosis-related information, was analyzed using the following criteria:

- 1: To what extent are support groups available to site visitors?
- 2: How accessible is additional information provided on the website?
3. What particular software programs, if any, are needed to view the website? If software programs are required, are these software programs available online or must they be acquired by the user?
4. What level of technological competency is needed in order to maneuver the website?
5. What costs are associated with receiving additional information or accessing particular parts of the site, such as online support groups?

Methods Summary

By conducting an interpretive analysis of endometriosis website content and my personal narrative, I was able to determine the common themes that emerged from these websites. I was then able to consider the impact these messages may have on women and their relationships with physicians and management of their disease by comparing it with my own relationships and decisions regarding disease management. By relying on multiple research methods, phenomenology and hermeneutics, I was able

to identify and decipher themes relying on information gained from a review of literature and my first-hand knowledge as a woman with endometriosis. These methods allow the reader to gain a better understanding of the significance of the phenomena being studied and provide the researcher and readers with a means of exploring the reflexive nature of this study. In Chapter 5, I detail the findings of this analysis and offer a discussion of the findings of this study, organizing the chapter by the dominant themes presented on the endometriosis websites. Lastly, Chapter 6 provides a summary of the main points as well as a discussion of the limitations of this study and directions for further research.

CHAPTER 5

FINDINGS AND DISCUSSION

This chapter represents the findings of a qualitative analysis of content found on 10 endometriosis websites. This chapter is organized into five sections: Messages about Causes and Treatments, Messages about Infertility, Physician-Patient Communication, Information Accessibility, and Technology and Cost Requirements. Each of these sections is organized by results, discussion, and author comments. Though it is common in research reports to present the findings and discussion in separate chapters, I chose to combine them in an effort to honor the personal nature of this study. In doing so, this chapter remains consistent with the preceding chapters' emphasis on my voice and personal experiences. Further, it assists the reader in linking findings to discussion, literature, and my comments. Excerpts from my narrative, literature review, and analyzed websites were placed at the beginnings of many sections. These excerpts are offered as a means of relating the findings back to the literature review or to my personal narrative and as a method of linking the findings to information provided on endometriosis websites. The chapter concludes with summaries of both the findings and discussion sections.

Analyzing my Chapter 1 narrative and review of literature, I expected to find similar themes on the websites. Indeed, most websites reflected themes about treatment with the exception of the use of hysterectomy and the role of pregnancy in treating endometriosis. Findings regarding the messages portrayed about infertility were mixed. While no website cited infertility as a definitive result of endometriosis, most sites listed infertility as a symptom of the disease and some recommended surgery and hormonal therapy as possible treatments for infertility. Overall, little information was available on these websites for women interested in learning how to communicate more effectively with physicians. In fact, only five websites provided any information on physician-patient relations and only limited information was available.

The majority of websites provided additional information to site patrons. Mail, email, and downloadable materials were readily available on each website. Links to online support groups were largely absent from the sites. My interactions with these websites also indicate that even less experienced users do not need a high technology competency to maneuver these websites and the only additional software needed was Adobe Acrobat Reader and Real Player, both of which are available for free download on the Internet.

Messages about Causes and Treatments

Research question one asked what messages are endometriosis websites sending to users about the disease, its causes, and treatments. Of particular importance to this question was whether endometriosis was linked to a specific cause and to what extent websites promoted hysterectomy as the only certain cure for endometriosis.

Themes

In answering this question, the following four themes emerged concerning the causes of endometriosis: Many symptoms, one diagnosis; Unknown cause, many theories; No cure, myriad treatments; and Endometriosis affects everyone.

On the day of my appointment, I explained my symptoms: intense aching, heaviness in my pelvic area, bloating, and gastrointestinal problems that seemed to get worse with my period. I also had a history of allergies and yeast infections (personal narrative: Chapter 1, para. 2).

Many Symptoms, One Diagnoses. Women visiting these websites for information regarding symptoms of endometriosis will find the same answers on all

sites. Each site listed nearly the same information, stating that the primary symptoms of endometriosis include pain with menstruation and sexual intercourse; pain with urination and bowel movements; infertility, fatigue, and gastrointestinal upset. The Endometriosis Association also included non-reproductive symptoms common among many endometriosis sufferers, citing allergies, chemical sensitivities, and frequent yeast infections as symptoms which endometriosis patients may also suffer. The Endometriosis Research Center also included a statement addressing the stereotypes associated with endometriosis symptoms, saying many symptoms have “long been stigmatized as painful periods” or “killer cramps.” Additionally, 8 of the 10 sites stated that endometriosis could not be diagnosed properly until a laparoscopy was performed. The Endometriosis Institute only briefly mentioned laparoscopy but not as a diagnostic tool while Endometriosis Zone made confusing claims regarding use of diagnostic laparoscopy. The site claimed there to be “clinical reasons to review the place of traditional laparoscopy in the diagnosis of endometriosis,” citing high costs, invasiveness, and impracticality as factors that negate the need for laparoscopy in diagnosing endometriosis. However, the Endometriosis Zone also said “most doctors agree that laparoscopic surgery is the only definitive way to diagnose endometriosis.”

Three sites (Endometriosis Research Center, Endometriosis Awareness & Information, and the National Endometriosis Society) claimed that most women suffer with endometriosis for seven to nine years and visit between 5 and 10 physicians before a proper diagnosis is obtained. In fact, the Endometriosis Awareness & Information site stated that “endometriosis takes an average of nine years to be diagnosed, and it [is] usually only after a woman has seen anywhere from five to ten doctors for the same complaints.” Additionally, both The Endometriosis Association and Endometriosis Research Center defined endometriosis symptoms as “life altering.”

The cause of endometriosis is not known. A number of theories have been advanced, but no one of them seems to account for all cases (literature: Ballweg, 1995, p. 11).

Unknown Cause, Many Theories. While all sites stated that the cause of endometriosis is unknown, each site provided nearly the same information regarding the theoretical causes of endometriosis. Retrograde menstruation theory, genetic link theory, embryonic, lymphatic and surgical transplantation theories, and environmental theory were each listed as possible causes of endometriosis; however, it was clearly mentioned on all websites that these theories are unproven and are merely speculation on behalf of the medical community. Endometriosis Zone, however, did claim that endometriosis is only in rare cases caused by genetics. Because many studies, such as the Oxford Endometriosis Gene Study, are focused on understanding the link between heredity and endometriosis, this assertion may be premature. The Medline website links to the Mayo Clinic, a partner website that explains the many symptoms and treatments of endometriosis. On the site, Mayo Clinic claims that “a woman whose mother, sister or daughter has endometriosis is 10 times more likely to have endometriosis than a woman without an affected relative.” Overall, endometriosis was not linked to any specific cause. On the other hand, the National Endometriosis Society, Endometriosis.Org, and Medline provided lists of what *does not* cause endometriosis, which included infection, cancer, and sexually transmitted diseases.

I had several options: I could undergo laparoscopic surgery to eliminate all visible endometriosis lesions; I could start a series of shots designed to reduce the size of the endometriosis; or I could continue with contraceptive management (personal narrative: Chapter 1, para. 3).

No Cure, Myriad Treatments. Women searching for a cure for endometriosis will not find one listed on the pages of these 10 websites. Each site clearly stated that there is no current cure for endometriosis; however, a plethora of treatment options are listed. Hormonal therapy, surgery, and alternative treatments were among the most popular treatments listed on these websites. Interestingly, while each site mentioned that other treatment options should be explored before radical surgery, only four sites stated that hysterectomy is not a cure for endometriosis, with one (Medline) claiming that hysterectomy is “usually needed” for endometriosis. Comparatively, five sites stated that pregnancy is not an effective or safe cure for the disease. One site, the Endometriosis Research Center, claimed that “alternative medicine, acupuncture, herbal therapy, massage techniques, and dietary measures” may decrease the pain associated with endometriosis and stated that “exercise (as indicated and advised under the guidance of a trained professional who is familiar with your condition), good nutrition, and adopting a generally healthy lifestyle may significantly improve symptoms” of endometriosis.

Of particular interest are statements made on three sites. The Endometriosis Association website, while claiming that there is no known cure for endometriosis, defined association members as being “those who have or had endometriosis,” possibly indicating that the disease can be cured. Two sites, the Center for Endometriosis Care and Endometriosis Zone, listed no cure for endometriosis; however, the sites touted the “wait and see” method as a possible form of treatment for endometriosis patients. Specifically, Endometriosis Zone stated “sometimes a wait and see approach is advised” while the Center for Endometriosis Care recommended patients to partake in a “watchful, wait and see period” before beginning aggressive treatment.

Although it used to be taught that endometriosis was a disease of white, affluent, childless, educated, older women, we know now that it can affect any woman, regardless of age, race, and economic or childbearing status (online source: Center for Endometriosis Care, 2003).

Endometriosis Affects Everyone. Four out of 10 sites actively refuted the stereotypical image of an endometriosis sufferer (white, mid-30s, educated females who have delayed childbearing). The Endometriosis Research Center, National Endometriosis Society, Medline, and Center for Endometriosis Care each claim that endometriosis can affect women of any age, race, and class, whether they have children or not. The quote above by the Center for Endometriosis Care alludes to the historical misrepresentation of the endometriosis patient. The Endometriosis Research Center also provided a quote addressing this issue, claiming “Endometriosis knows no racial or socioeconomic boundaries. Women of all ages, including teens, and post-menopausal women, can suffer from endometriosis.”

Discussion. Each of the 10 endometriosis websites analyzed for this study provided nearly the same information regarding disease symptoms and treatment options. The symptoms reported on these websites are congruent with those reported in many medical reports about endometriosis. Using the Internet, women are able to match their symptoms with those reported on the website; therefore, as discussed by Ziguras (2000), the consistency of these websites in providing information on endometriosis symptoms allows women to more accurately self-diagnose and/or discuss their symptoms with a physician. Eight of the 10 websites explained that a diagnostic laparoscopy is the only certain way to obtain a definitive diagnosis; this finding supports that found by Ballweg (1995). This consistency may encourage women to obtain a second opinion or undergo laparoscopic surgery before agreeing to

hormonal therapy or more radical surgery. Websites also mentioned the problems women face when attempting to obtain a diagnosis for their symptoms. Supporting a 1998 Endometriosis Association study, some sites reported that it has taken women up to nine years to obtain a definitive diagnosis. This reflects, in part, a lack of physician knowledge about endometriosis and the propensity of physicians to ignore women's reproductive problems or shrug them off as "normal."

Information on treatment plans is also pertinent to women seeking endometriosis-related information, as radical surgery is reportedly overused in endometriosis treatment. Hysterectomy was mentioned only four times as being an incorrect treatment for endometriosis, despite the fact that literature suggests hysterectomy is commonly overused (Parrott & Condit, 1996), particularly for treatment of endometriosis (Blair, 1986). Pregnancy, however, was mentioned five times as being an improper treatment of endometriosis. It is important for women to have access to such information as it may prevent women from speeding up childbearing or agreeing to radical surgery in an effort to cure endometriosis.

Another important element of information provided by these websites addresses the stereotypical image of the endometriosis patient. Endometriosis affects over 5.5 million women and girls in the United States and Canada (Taylor, 2003); it is erroneous to assume most are white, mid-30's, educated professionals who have delayed childbearing. Before research on endometriosis can advance, science must acknowledge that endometriosis does not only affect one group; rather, it is a disease with no socioeconomic or racial boundaries (Endometriosis Research Center, 2003). Perhaps websites such as these that clearly refute the stereotype will empower women of lower socioeconomic class and different racial backgrounds to speak up about their symptoms and demand treatment.

Though most information presented on these websites is factual and helpful, the language used by the Endometriosis Association, Center for Endometriosis Care, and

Endometriosis Zone warrants examination. By defining a member as one “who has or had endometriosis,” the association contradicts statements made on their website that claim there is no cure for endometriosis. Even long-time sufferers may wonder what is meant by that statement and may give newly diagnosed patients a false hope that a cure is available. Additionally, the Center for Endometriosis Care’s promotion of the “wait and see” method is particularly disturbing. When diagnosed with an incurable disease such as endometriosis, there is little reason to avoid treatment. With no further explanation of the intent of that message, it is hard to know exactly what is meant; however, encouraging women to “wait and see” may discourage women from seeking treatment. According to Ballweg, a physician who uses the “wait and see” method “ is doing a “disservice to the woman with endometriosis” (1995, p. 356).

Author Comments. I did my homework on the Internet before I went to the doctor. At my appointment, my physician confirmed that I had endometriosis and iterated the information I had found online. However, for many women it is reversed: they turn to the Internet to supplement information provided to them by their physicians. For me, having my doctor confirm my diagnosis and online research validated the use of the Internet in obtaining health-related information. After that, I began relying on the Internet to learn about the disease, laparoscopy, and treatment options (particularly Lupron). Some sites helped me formulate questions for my doctor, some provided guidelines on how to prepare for surgery. Others offered tips on how to facilitate better physician-patient communication by keeping a journal, and still others listed the benefits and consequences of hormone therapy. These sites certainly proved helpful to me during my initial diagnosis phase as I tried to understand the disease and figure out how I had acquired the illness. They have proved even more useful to me in the years since, as technology and endometriosis websites have advanced. Though now I have a

better understanding of my disease, I rely on the opinions of researchers and other sufferers when determining the next step in my battle with the disease.

I was astonished to find out that the average length of time to obtain a definitive diagnosis is nine years. This finding supports the need for additional endometriosis research and the need for increased physician knowledge. It also furthers the importance of the women's health movement in obtaining funding for women's health problems and raising awareness for the treatment of women in the health care industry.

I also found it odd that hysterectomy was so infrequently mentioned as an improper treatment of endometriosis. My story reveals that many women I know have been told that a hysterectomy is the only way to cure endometriosis, only to discover that their physicians were wrong. I have been told that a hysterectomy is in my best interest; I have been told that expediting the childbearing process is in my best interest, as a hysterectomy is needed before I reach 30 years of age. Although my physician has not told me that hysterectomy will cure my disease, I have heard from many women that it will. The decision to undergo radical surgery is a personal choice to be made when and if the time arrives for such a decision to be made.

I was surprised and disappointed to find that pregnancy was not more often mentioned as an ineffective treatment for endometriosis. As a woman with endometriosis who is experiencing fertility problems, it is particularly difficult to listen to people ask me, "Why haven't you had children?" and "Why don't you just get pregnant and get rid of your endometriosis?" While I know that pregnancy does not treat endometriosis, it is hard to convince others that this common "cure" is simply a myth.

I was also appalled at the language chosen by the Endometriosis Association, Center for Endometriosis Care, and Endometriosis Zone. Endometriosis can go into a "remission" phase, where symptoms are briefly alleviated after surgery or hormonal therapy, but there is no cure for the disease. I hope that this is simply an oversight by the association, as it typically provides some of the most accurate and detailed

information about endometriosis on the Internet. A “wait and see” approach to endometriosis care may encourage women to “wait to seek.” That is, those who suspect endometriosis may opt to wait and see before seeking treatment.

Unfortunately, a wait and see period coupled with the average length of obtaining a diagnosis may prove problematic in the long term. This is especially true in adolescence where early detection and treatment of endometriosis can lead to better quality of life and increase one’s chance of pregnancy in the adult years.

Lastly, I applaud the efforts of the websites that are actively refuting the stereotypical image of the endometriosis patient. I am often told that being a successful student and professional is not nearly as important or fulfilling as being a mother. While I do want to be a mother, I find this statement to be insulting. I certainly did not acquire endometriosis because I chose to delay pregnancy or because I am ambitious, educated, professional, middle-class, or white. I share this problem with many women; together we represent a multitude of races, ages, socioeconomic and education backgrounds, and professional industries. I hope more websites follow the lead of these four sites in placing the focus on the actual and diverse women who have endometriosis, rather than the stereotypical white woman who has endometriosis because she delayed childbirth because of her selfish desire to be educated and successful. Findings such as these indicate a possible shift in the way women are being portrayed in medical research and in society. Continuing to promote a new image of the endometriosis sufferer allows women who choose not to have children, or are unable to become pregnant, to be proud of their successes as individuals rather than guilty for choosing to establish their careers. Taking the emphasis off the fetus or pregnable woman also is a victory in the ongoing struggle to get medical science to see women as individuals rather than fragile, fertile individuals.

Messages about Infertility

Research question two asked how endometriosis websites portray infertility. More specifically, I questioned whether infertility was portrayed as a definitive long-term effect of endometriosis and whether websites provide women with information on when to seek medical attention for infertility.

Themes

One theme emerged when analyzing online content for messages concerning infertility: Infertility Ambiguity.

While I looked forward to the “window of opportunity” that was supposed to be available for childbirth once my six-months of Lupron therapy were finished, I am now beginning to come to terms with my illness. I desperately want children; yet, unfortunately to combat the pain of endometriosis I must rely on contraceptives or medications that prohibit pregnancy during their use (personal narrative: Chapter 1, para. 13).

Infertility Ambiguity. Endometriosis sufferers visiting these websites will find mixed messages regarding the topic of infertility. Eight of the analyzed websites listed infertility as a symptom of the disease and claimed that endometriosis is to blame for many cases of infertility. Five sites claimed that endometriosis results in infertility in 30-40% of all endometriosis patients. However, the Center for Endometriosis Care and Endometriosis Awareness & Information websites claimed that most patients will conceive, yet the sites also claimed that surgery followed by drug therapy opens a window of opportunity for which a woman can more easily become pregnant. The Endometriosis Awareness & Information website cited studies that “proved that the best time to conceive or maintain a pregnancy for a woman with endometriosis is within the

six month window following a laparoscopy.” These findings support information provided by my physician and literature provided to me on laparoscopy. The Endometriosis Research Center, Medline, and Endometriosis Awareness & Information websites maintained that given the proper treatment and medical professional, a woman is likely to bear children. The Endometriosis Research Center also claimed, however, that 35% of women with endometriosis will be unable to become pregnant. Endometriosis.Org maintains that endometriosis results in infertility only when left untreated. Like Blair (1986) and Ballweg (1995), The National Endometriosis Society asserts that while infertility may result from endometriosis, it is not a certain diagnosis. No site in this sample provided information on when to seek medical attention for infertility.

Discussion. The websites produced mixed results regarding infertility and endometriosis, which may lead to ambiguity for information-seekers. According to Okamura et al. (2002), it is not uncommon to find confusing results concerning infertility on the Internet. While multiple sites claim endometriosis is responsible for a rather high percentage of infertility, others claim that with proper treatment, infertility is preventable. Websites, however, that tout the “window of opportunity” theme may be providing unrealistic information to endometriosis patients. Surgery and hormonal therapy may indeed shrink endometriosis implants, but no medication has been proven to assist in endometriosis-related infertility (Ballweg, 1995). Messages such as these should be discussed with a physician and additional sources of information should be sought before making the decision to undergo surgical procedure or hormonal therapy in hopes of sparing fertility.

It is also interesting to note that no website provided information on when to seek medical attention for infertility. According to Ballweg, it is very important that women understand exactly who is considered infertile and when they should seek

treatment (1995, p. 239). According to my physician, couples are usually labeled infertile after one year of actively trying to conceive; however, women without this information may be unaware that their disease is affecting their ability to become pregnant. The media are an increasingly important tool for bringing to light information about infertility. If a woman hopes to bear children, she may be wary of visiting a physician, as contraceptives are often the standard treatment for endometriosis. In addition, as one in three endometriosis sufferers are deemed infertile (Ballweg, 1995), it is important that women are provided information on when and where to seek medical treatment as well as information on treatment plans and alternatives to natural conception.

Author Comments. The vagueness of the information presented in this section is incredible; however, this ambiguity is not limited only to information provided by websites. I have been told that I would be able to have children and that I would not be able to have children. I have also been told that I would only be able to have children if I did it in a timely manner, meaning before or during my mid-20s. What I have found is that I can have children but only when my pain during intercourse can be managed. With the contrasting information on infertility and the treatment options touted (such as surgery and hormonal therapy), it is wise for women to seek physician input before making a decision regarding when she should attempt pregnancy.

It is unfortunate that websites do not provide more information on when to obtain treatment for infertility. I have been told by my physician that infertility is suspected (and treatment therefore necessary) in the endometriosis patient after six months of unsuccessful fertilization or inability to maintain a pregnancy. No website analyzed provided any information on this topic, which may cause some women to continue to try to become pregnant without needed assistance from a fertility specialist. Knowing when to seek treatment may mean the difference between successfully achieving natural

pregnancy and indefinite infertility. It is also unfortunate that alternative forms of pregnancy such as in-vitro fertilization are not discussed on these websites. Alternative methods of pregnancy and the costs associated with such procedures need to be discussed more often. In my experience, alternative methods are not discussed until the woman is actively trying to conceive. However, learning more about other methods of fertilization may help ease the minds of women who are experiencing trouble becoming pregnant and prepare them for the costs of alternative treatment methods. Knowing when to seek treatment may also allow couples to avoid problems in their relationships. I have read many stories of couples whose infertility problems led to breakdown of the marital relationship. Given the consequences of not seeking treatment at the correct time, it is pertinent that media begin sending the correct messages about infertility.

Physician-Patient Communication

Research question three asked what information, if any, is provided on endometriosis websites about communicating with physicians. The results of research question three are found in the following section.

Themes

Regarding research question three, the following theme emerged from website content. A discussion of this theme and author comments are also provided in the following sections.

Communicating about Endometriosis. Only 5 of the 10 websites discussed physician-patient communication; however, four sites produced only brief statements or offered products that teach women how to communicate about the disease. The Endometriosis Association mentioned nothing about communication other than in the

online product catalog, where a diagnostic kit is sold that teaches women how to tell if symptoms are related to endometriosis, how to keep track of symptoms, and how to discuss symptoms with their physician. Similarly, the Endometriosis Zone provided a listing of questions physicians may ask of patients at each visit. The site included a brief, five-sentence paragraph explaining the need for women, particularly teenagers, to be honest about their symptoms and precise when explaining their condition to the doctor. Endometriosis.Org made brief statements concerning physician-patient relations, encouraging women to seek additional resources outside their physician's office in order to learn all the available options for treatment. Additionally, the site claims that if physicians do not begin to educate themselves, patients will educate them. The Endometriosis Research Center promoted the formation of a partnership between women and their physicians in which they make joint decisions regarding endometriosis care. The site also encouraged women to provide physicians with information on the disease. Neither the Center for Endometriosis Care nor the National Endometriosis Society discussed communication. The Endometriosis Awareness and Information website offered patients the most extensive information on improving physician-patient communication. The site details ways to increase communication effectiveness, encouraging women to seek and get to know the capabilities of a physician specializing in endometriosis (such as a reproductive endocrinologist). The website also explained that keeping a journal of symptoms and providing copies of previous medical reports enables physicians to have a more precise record of your condition thereby increasing the level of care possible. Additionally, the site provides tips on how to talk to physicians about the disease, telling women that "by working together to treat your case the best way possible, you can reach a successful level of management of your endometriosis."

Discussion. Significantly less medical research is available on women's health care issues (Merton, 1993; "Advances in Women's Health," 1999); therefore, female patients may experience higher levels of uncertainty about particular health care issues. As a result, it is important that physicians are able to effectively and empathically communicate with patients about their medical concerns. Ballweg (1995) alludes to the importance of physician communication skills in her book, *The Endometriosis Sourcebook*, where she explains that physician communication skills are regularly mentioned in letters received by the Endometriosis Association. In more recent years, medical schools have offered physicians communication skills training to medical students in an effort to improve physician-patient interactions (Ratzan et al., 1994). However, studies on the effectiveness of these programs are inconclusive (Brown et al., 1999; Cegala & Broz, 2002, Humphris & Kaney, 2001). Recent studies also point to the importance of the physician-patient relationship, claiming that patients rank their physicians second to their families in relational importance (Iles, 2003; Pincock, 2003) and trust physicians more than even their pastors (Iles, 2003).

Despite this emphasis on effective communication skills, websites provided little information on ways to talk to physicians about endometriosis. In fact, only three websites mentioned physician-patient communication specifically, while two others made brief statements about physician education and communication. By not including information on patient-physician communication, a woman may assume that physicians have all the right answers thereby reinforcing the idea that physicians are in control of the medical visit. Also, by failing to include information on improving physician-patient interactions, these websites are doing little to counteract the power status often afforded male physicians or to negate the idea surfacing in federal legislation, such as welfare reform, that women do not control their lives or bodies. By providing women with information on endometriosis but no information on ways of communicating knowledge or confusion or both, women may be unable to discuss their symptoms with

their doctor, regardless of his/her willingness to listen to the patient. While providing opportunities for women to increase their knowledge of the disease may be empowering, if women are unable to communicate their concerns or desires, the experience loses its empowering effects.

Women have historically been excluded from medical research (Gary et al., 1997; "How Far We've Come," 1999; Sargent & Brettell, 1996) and physicians continue to dismiss female patients' concerns (Beck, 1997). Therefore, it is important that websites begin providing women with information that empowers women to take control of their health, not only in the privacy of their own home, but in the examining room as well. Once the medical community begins to address gender discrimination in health care, women can begin to reap the rewards associated with empowerment through knowledge and action. Furthermore, it is important that women of lower socioeconomic status, nonwhite racial backgrounds, and homosexual populations be provided information on how to address medical concerns. Research shows that disparities in health care exist for individuals of these populations (Balsa et al., 2003; Betancourt et al., 2003; Bobinski, 2003; Boulware et al., 2003; Gary et al, 1997; Green, 2003; Morgen, 2002; Nickens, 1991; Pappas, 1994; Stone & Dula, 2002; Talsma, 2002; Williams & Collins, 1995); however, women in these groups are particularly vulnerable to experiencing discrimination because of their gender. Therefore, it is pertinent that websites, as well as traditional forms of mass media, begin to address physician-patient communication and educate both women and physicians about ways to eliminate discrimination in the examining room.

Author Comments. The lack of information on communicating with physicians may be reflective of the traditional power dynamics of the physician-female patient relationship. If so, these websites, which represent the highest quality endometriosis research online, are doing an injustice to women with the disease. Further, it can be

assumed that if endometriosis websites are not providing information on physician-female patient communication, other women's health sites may not be providing information either. Whether gender dynamics are to blame for this lack of information, these findings speak volumes about the need for the women's health movement and point to a need for physician communication education.

Despite having done extensive research on endometriosis and laparoscopic surgery, I was unable to discuss my fears of having the surgery with my doctor for many years. As I mention in my narrative, it took a "nervous breakdown" before I could talk to him about my fears and make the decision to move forward with the surgery. I had the information I needed but I had no way of communicating my fears or my needs. I knew what I needed to be satisfied, I knew what I wanted to result from the surgery; yet, when I talked with my physician the words were lost. Although I had known him for years and held him in high regard, I feared he would tell me what I needed to hear in order to get me to "go along" with the surgery. Because I was so afraid of the consequences of the surgery and unable to discuss my fears with my physician, I began to think that my physician was motivated by external factors. I thought he was pushing surgery and hormonal therapy for money; I went as far as to create a scenario in my mind that he was being paid a stipend by the pharmaceutical company for each patient he could get to take Lupron. All of these concerns built up and eventually I found my voice, but only out of necessity. I wish I had been given information on how to talk to my physician, how to express my fears without dreading that he would reject me or dismiss my concerns, and if he did, how to deal with that. As I mention above, having the information may be empowering but being unable to communicate about it negates any empowering effects that may be created. Since finding my voice and learning how to best communicate with my physician, my confusion about the disease and treatment options has decreased dramatically. However, as I begin treatment with a specialist, I am concerned that the same fear and inability to speak will prevent me from

maximizing my care. Luckily, as a student of communication, I have access to scholarly research and other materials on physician-patient communication. Hopefully, I will be able to use this information and the knowledge gained from this study to my benefit. Unfortunately, many women cannot access such materials and may continue to experience problems with physician-patient communication, perhaps until, like me, they experience a culmination of fear and concern that forces the words to surface.

Disparities to health care are not addressed by these websites. In many rural areas where specialists are rare and transportation problems often limit access to health care, online research is sometimes used in lieu of physician information. Additionally, women of lower economic and educational status, nonwhite backgrounds, and homosexual populations experience greater disparities to health care, are more widely discriminated against in the health care setting, and often have limited health coverage. These individuals may therefore rely more heavily on media generated information about health care or information provided by friends and family. As a result, media are in a position that requires them to be morally responsible to a group people. However, it does not appear as though Internet media are taking that responsibility seriously by continuing to remain silent about physician-patient communication and failing to address the problems created by health care disparities in the American medical community.

Information Accessibility

Research question four questioned the accessibility of additional information regarding endometriosis to women visiting websites in terms of cost and retrieval methods. Of particular importance to question four was whether or not women were provided access to online support groups and additional printed materials via postal mails or email; whether users had to have particular software in order to access

additional information; the level of technological competency required to access information; and the costs associated with accessing additional information.

Themes

The results of research question four are answered in three sections: Support for Sufferers, Abundant Information, and Technology and Cost Requirements.

Support for Sufferers. “While society at large may not be discussing [endometriosis], the online community is busting with conversations and publications about it. Women are talking, and together we will find the answers,” exclaims the Endometriosis Awareness & Information website. Despite the bustle reported on the site, the presence of online support groups was uncommon among the websites analyzed. Neither the Center for Endometriosis Care, Endometriosis Institute, Medline, nor the Oxford Endometriosis Gene Study websites provided access to support groups for site visitors. The Endometriosis Association and Endometriosis Zone provided only a listing of local, live support groups. Endometriosis.Org and the National Endometriosis Society listed only in-person support groups. Endometriosis.Org also provides a free listserv available to all site visitors while the National Endometriosis Society provide both a free chat room and message board for site patrons. The Endometriosis Research Center provides perhaps the most additional resources to visitors. Users can sign up for a free listserv, take advantage of a free mentoring program, join programs such as legislative, writing, yellow ribbon, adopt-a-physician, and general awareness. These awareness programs provide women with the opportunity to take part in lobbying activities, contact media who release incorrect endometriosis information, distribute yellow endometriosis awareness ribbons, and provide information about the disease to a selected physician. In addition, the Endometriosis Research Center dedicated a section to clinical research and releases

contact information for clinical trials throughout the country. The Endometriosis Awareness & Information site provided a link to the Endometriosis Research Center listserv site and access to GirlTalk, a Yahoo! Chat group for endometriosis patients ages 25 and under.

Abundant Information. Most of the 10 websites analyzed provide a vast amount of information for members and non-members alike. The Endometriosis Association provides free brochures in 21 languages by mail as well as online, access to news articles, and information on breaking news stories. A product catalog, membership form, volunteer form, and donation form can also be found online. The association provides members with a newsletter, chapter and support group information, correspondence networks, crisis hotlines, prescription drug plans, and literature discounts for an annual fee. The Center for Endometriosis Care provides free literature and newsletters to site visitors as well as a list of endometriosis-related links, an email address for question and answer, and a listing of endometriosis sufferers and their published email addresses. Endometriosis.Org provides access to free research articles, narratives and stories about endometriosis, press releases, and tips for endometriosis surgery. The Endometriosis Research Center provides a toll free telephone number, free membership, and free information packets, fact sheets, articles, reviews, and media kits. The National Endometriosis Society provides a free help line, newsletter, publications, fact sheets, information packets, and links to endometriosis-related websites. The Endometriosis Awareness & Information website offers free access to a database of articles dated from 1996 which covers endometriosis and a host of related conditions. The site also includes a news section, glossary, and links to over 50 additional endometriosis sites. The Oxford Endometriosis Gene Study site provides a toll free information line (available only to residents of the United Kingdom), over 10 years of articles on endometriosis, and links to a plethora of online

endometriosis resources (which include four sites analyzed in this study). The Medline website presents information on how to become involved in clinical trials as well as contact information for the National Institute of Health (which provides a 12-page endometriosis-education package on the Medline website). In addition, Medline provides site visitors access to a free directory of physicians compiled by the American College of Obstetricians and Gynecologists. The Endometriosis Zone sends site users monthly updates from Endometriosis Zone as well as OBGYN.net. Site users can also sign up to receive daily headline news from OBGYN.net. The site provides free access to articles, information on congressional hearings and legislative activities around the world, and a glossary. The site also provides links to a host of endometriosis-related websites, including sites dedicated to infertility, laparoscopy, and professional associations. Lastly, the Endometriosis Institute website provides the least amount of information, providing site users with only information on how to participate in one of the organization's clinical trials or studies on infertility.

Technology and Cost Requirements. In addition to providing a wide range of additional information, no site required users to have a high technological competency and half (5 out of 10 websites) did not require additional software. In addition, most information was provided for free or at a minimal cost to users. The Endometriosis Association requires the use of Adobe Acrobat Reader, available for free download on the Internet, to view the online catalog and brochures. Books, ranging in price from \$11.95 to \$16.95 were available as was a physician registry at \$2. The most expensive item listed in the product category was conference videos at \$55. Membership into the association provides additional services and is available at \$35 annually. The Endometriosis Research Center offers free membership and fact sheets, articles, and reviews at a cost of \$1 to \$2 each.

The Endometriosis Research Center, Oxford Endometriosis Gene Study, Medline, and Endometriosis Zone also required Adobe software to download articles. The Endometriosis Zone also required the use of Real Player to listen to interviews with medical professionals. Other than Adobe Acrobat and Real Player, software installed on most public computers and available for download at no cost on the Internet, no other technology was needed to view these sites.

Books were also available for purchase, the most expensive being \$14.95. The Endometriosis.Org site allows users to purchase nine books at various prices. A video, produced by the organization, is also available for approximately \$30. The Endometriosis Awareness & Information site advertised two books, citing the cost of one at \$11. Neither the Center for Endometriosis Care, National Endometriosis Society, nor the Endometriosis Institute offered products for sale. Additionally, these three sites did not require the use of additional software.

Discussion. Findings indicate that most websites provide users access to additional information, via mail, email, and instant downloads. These sites provided a large amount of literature, such as articles, research, narratives, and stories. Information on support group locations, toll free help lines, chat rooms, and message boards were provided by many sites. Special information was provided for teenagers and pre-teens interested in learning more about endometriosis, particularly important due to the difficulty in diagnosing endometriosis in adolescents (Jancin, 2003). Additionally, some sites provided limited materials for non-English speaking users.

No website required the use of special knowledge about the Internet or computers. In fact, most information was available by clicking on descriptive links. Five sites required the use of additional software: Adobe Acrobat Reader and Real Player. Fortunately, both Adobe Acrobat Reader and Real Player are available at no cost on

the Internet and many libraries and public access computers have a version of these software packages installed.

In addition to providing a wealth of additional resources to users, most information was accessible for a minimal fee. Articles and fact sheets could be purchased from some sites for as low as \$1 while other products were significantly more expensive. However, most general information about endometriosis was available at a low cost to consumers. Some sites provided free information while others provided extra materials for members.

These findings are important as lower-income individuals and teens may be unable to purchase high-priced materials. Because endometriosis is not a disease limited to the affluent populations (Endometriosis Research Center, 2003), it is important that additional resources are made available to individuals who may be unable to access medical care due to lack of insurance (Balsa et al., 2003) or transportation. At times, economically disadvantaged individuals must rely on health information obtained from social workers, family and friends, and libraries. Due to this unfortunate conundrum, it is important that websites continue providing affordable, easily accessible information on endometriosis. The Endometriosis Association waives membership fees for endometriosis sufferers who cannot afford the payment. Gestures such as this provide individuals who would otherwise be unable to access information with the opportunity to gain valuable information that could help them to better understand their condition and seek alternative methods of pain relief.

Author Comments. My narrative alludes to my heavy dependency on the Internet for endometriosis related information. For 10 years I have searched online for information about the causes, symptoms, and treatments my disease as well as ways to more effectively manage pain and preserve my fertility. However, it was only recently that I began requesting additional information in the form of brochures or pamphlets. In

fact, I requested a large amount of the additional information available on these sites as I conducted the analysis portion of this project. The information requested via mail arrived quickly and discreetly in my mailbox and was very informative, even to a veteran endometriosis researcher and experienced patient.

I was surprised that so much additional information was available on endometriosis. Also, because most websites were those of American organizations, I was surprised that such a vast amount of information was available to so many people. Many sites provided materials in a variety of languages, catering more so to the English and Spanish speaking populations. A few sites provided information specifically for teenagers, which is encouraging given that endometriosis is often misdiagnosed in teenagers due to its very different presentation in adolescent and adult bodies. I was also delighted to find that most information was available at a low cost to users or site members, and some materials were available for free. So often, particularly when attempting to access scholarly literature, it seems as though nothing is available for free. However, these sites provided abundant access to articles, brochures, and pamphlets at no cost. I was surprised, though, to find very few support groups, as research indicates that many people, particularly women, rely heavily on social support networks for medical advice. Online support groups can provide women with a community in which to discuss their disease with women who share their experiences and can provide information on different treatment options and tips on how to manage the disease.

Findings Summary

Findings show that each of the 10 analyzed websites provided similar messages regarding the symptoms, causes, and treatments of endometriosis. All sites included nearly the same information on symptoms, describing endometriosis as a disease causing immense pain during sexual intercourse, menstruation, urination, and bowel

movements, as well as fatigue, gastrointestinal upset, and infertility. Half (5 out of 10) of the sites declared that pregnancy is often incorrectly prescribed as a cure for endometriosis. However, only four sites mentioned hysterectomy as being an incorrect form of endometriosis treatment. Overall, the websites claimed there is no known cause or cure for the disease and all but two emphasized the need for diagnostic laparoscopy. It is interesting, though, to note the language used by the Endometriosis Association (which defined members as “those who have or had endometriosis”) and the treatment options offered by the Center for Endometriosis Care and Endometriosis Zone, which supported the “wait and see” method to endometriosis care. It is also of importance to note that 4 of the 10 websites actively refuted the image of the stereotypical endometriosis sufferer. These sites asserted that endometriosis is not a discriminatory disease but rather one affecting women of all ages and sexual orientations as well as all racial and socioeconomic backgrounds.

Analysis produced mixed results on the messages women receive about infertility. Most sites listed it as a symptom; however, the “window of opportunity” theme also appeared regarding infertility, surgery, and hormonal therapy (which includes contraceptive management and gonadotropin-agonists such as Lupron, a drug referred to in my narrative that is designed to shrink endometriosis). No information is provided to women about when medical attention for infertility should be sought.

A minimal amount of information was available on ways to improve communication between endometriosis patients and physicians. There is, however, a large amount of information available to patients on these websites, with the exception of online support groups, which are largely absent from these sites. Websites, particularly the Endometriosis Research Center site, provided many ways for users to get involved in endometriosis-related activities such as lobbying for federal funding and providing physicians with endometriosis information. Additionally, users do not need to have a high level of technological competence to access or maneuver these sites and

only five sites require the use of additional software to view material. The additional software required, Adobe Acrobat Reader and Real Player, are available at no cost on the Internet. Most information is offered at a minimal price to site patrons and in some cases information is provided free of charge.

Discussion Summary

The findings of this study lend support to previously cited research that claims that endometriosis is a disease affecting a vast number of women and teens of every racial background, sexual orientation, and socioeconomic status (Shah et al., 1995; Jancin, 2003; Endometriosis Research Center, 2003). Results of this study indicate that some endometriosis websites are acknowledging this issue and are working to erase the stereotypical image of the average endometriosis sufferer. Websites are not, however, doing their part to change the socially accepted standard of what role the female patient plays in the examining room. The lack of information provided on physician-patient communication speaks volumes about the role of women in health care. By continuing to downplay the importance of communication in physician-female patient relationships, websites are perpetuating the idea that women should be compliant and non-assertive in the examining room. By continuing to cultivate this image of the female patient, media are hindering the women's health movement's actions to transcend gender discrimination in health care. Media, especially the Internet with its increasing number of female users, are in the position to assist in breaking through the barriers that prevent women from obtaining unbiased medical care; however, media do not appear to take this responsibility seriously.

The websites presented in this study provide similar information to the literature on the symptoms, causes, and treatments of endometriosis. By encouraging women to seek additional resources and providing women with information on the disease, these sites are providing women with the knowledge they need to begin to take control of their

health care. However, information on infertility is very often ambiguous, as has been reported in research by Okamura et al. (2002), and women interested in learning more about endometriosis and infertility should consult additional forms of media as well as a qualified physician.

CHAPTER 6

CONCLUSION

In this concluding chapter, I further examine the critical findings of this study in the Summary section. I then connect these findings to the literature review. Finally, I provide a discussion of the limitations of this study and make suggestions for further research.

Summary

The review of literature provided a brief history of the women's health movement and indicated the importance of mass media in assisting health-information seekers in accessing relevant and factual information. Research shows that Internet use is far more popular amongst women than men. This could be for a variety of reasons including lack of physician knowledge (due in part to the exclusion of women from medical studies); physician's continued dismissal of women's health concerns as "normal;" absence of feminist health literature; class, race, and homosexual discrimination; need for privacy; and the desire to access additional information about specific diseases or conditions. It could also be because certain women's disease, like endometriosis, are very difficult to diagnose or a patient's eagerness to learn more about their condition or the condition of a family member or friend. Whatever the reason, women have spurred an increase in health-related Internet browsing; searching for health-related information is currently the third most frequent use of the Internet. While women face many obstacles to accessing unbiased health care, the Internet can have empowering effects for women, encouraging them to seek second opinions, be more assertive in the examining room, and take an overall more active role in their health and treatment plans.

One such reason women may turn to the Internet is to acquire information on endometriosis, the source of chronic pelvic pain for over five million women and girls in

America. Many endometriosis sufferers are told that their pain is exaggerated or simply a normal part of being female. The disease has been linked to a host of physical and emotional problems such as high work absenteeism, inability to maintain relationships, depression, and anxiety. Hysterectomy is reported as an often overused treatment for endometriosis. Often women are misinformed that hysterectomy is a cure for endometriosis. Because of these reasons, it is important that women be provided access to additional information, particularly as physician knowledge about the disease is lacking.

Hosts of endometriosis websites are available on the Internet. Google, a leading search engine, which ranks websites in relevance to search terms, selected the 10 sites chosen for this study. Analysis of these sites produced interesting results.

Overall, the websites studied provided information congruent with medical reports about endometriosis symptoms and available treatments. Most sites explained the importance of obtaining a definitive diagnosis through laparoscopic surgery. Messages such as these allow women to compare information, generate questions, and become more knowledgeable about the disease.

Websites did not provide as clear information on the topic of infertility. Websites revealed different opinions about the likelihood that an endometriosis patient will conceive and conflicting information was also found on ways to treat infertility. Interestingly, no information was provided on when to seek treatment for infertility. In addition, no information was offered on alternative methods to natural conception. However, this could be due in part to a lack of research on the topic.

Very little information was provided on physician-patient communication. In fact, the website that discussed this issue most did not provide any free tips or information on increasing effective communication. Rather, a diagnostic kit was offered for purchase that explained, among other issues, how to better communicate with physicians about the disease. It is unfortunate that information on physician-patient

communication is not easily accessible given the importance of effective communication skills in all interpersonal relationships, especially between female patients and male physicians, where power issues abound.

It is important to note that each website offered additional information to site patrons. Also, most information was free or offered at a very low price, making it more accessible for members of economically disadvantaged populations. No special technological skills were required to view the sites and the only additional software required was available for free download on the Internet. Because low-income and geographically isolated populations often rely on health information obtained from social networks and media, it is important that websites such as these continue to offer factual, affordable information that is easily accessible through libraries and other public access channels.

Another interesting finding is that most websites are encouraging women to refute the stereotypical image of the endometriosis sufferer. Many medical studies promote the image of a white, mid-30s, affluent woman who has delayed children as the representative endometriosis patient. However, endometriosis is not a disease relegated to white, upper-class populations. Because of lack of insurance and unreliable transportation, lower-income individuals may go undiagnosed, suffering in silence. Lesbian women as well as women of minority racial backgrounds are regularly discriminated against in the health care industry. By promoting a better understanding of the disease, rather than the image of the typical sufferer, websites may empower more women to seek treatment than in years past.

Overall, it can be assumed that women are receiving empowering messages from these endometriosis websites. Sites provide information about endometriosis, its symptoms, and treatments; encourage women to seek second opinions and access additional information outside the examining room; and actively refute the stereotypical image of the endometriosis patient. These messages can be empowering for women,

as women face a variety of obstacles to achieving equality in health care. At the same time, these websites are continuing to cultivate the belief that women should be quiet, submissive, and compliant by being silent about physician-patient communication. Lack of information regarding this topic could lead women to assume physicians have the right answers and prevent women from asking questions that could positively impact their treatment.

Connections to Literature Review

The findings presented in this study support the work of a plethora of scholars interested in women's health care, endometriosis, and Internet use, particularly the increase in online research amongst the female population. The Pew Internet and American Life Project (Fox & Fallows, 2003) found that more women use the Internet to search for health-related information than men. While this could be for a variety of reasons, it is important to note the significance of this finding as it brings attention not only to the growing incidence of female technology users but serves as a starting point for additional research into the causes of these searches and the use of online material.

Multiple scholars have written on the absence of women from medical studies and the advancement of women's health care in America (Morgen, 2002; Null & Seaman, 1999; Parrott & Condit, 1996). This is important to the continued success of the women's health movement and reflects a continued interest in the subject. It is important to note, as many have, the significant changes that have occurred in women's health care, particularly throughout the 1990s. It is also important, however, that researchers continue to draw attention to the need for clinical studies which include women and to the need for additional research into women's diseases.

The literature review points to an interest in debunking the myths that surround endometriosis research. Taylor (2003), Jancin (2003), Blair (1986), Ballweg (1995), and

Shah et al. (1995) have each written on the difficulty of diagnosing endometriosis and the physical and emotional stress patients face while attempting to find a proper diagnosis and treatment. I know, from my own experiences, the difficulty women face when struggling to manage the physical agony and feelings of guilt, anger, and defeat that are typical of the endometriosis patient. As with any disease, there should be continued efforts to make the medical community more aware of the severity and symptoms of the disease. Helping physicians to understand the importance of good communication skills and physician-patient relations can help patients better manage the tension felt by those coping with illness uncertainty, confusion about their fertility, and lack of treatment options. As research points out, many medical schools are making it mandatory for students to enroll in communication skills training courses. Though, according to Iles (2003) and Pincock (2003), little research has been done of the effects of such programs, it is important that physicians are receiving this training and equally important that studies address the impact of these programs on the physician-patient relationship.

An extensive review of relevant literature produced themes which also emerged in my Chapter 1 narrative. Therefore, much of what is reported in the literature was also reported by my physician or encountered by me during my diagnosis and treatment. My struggle to find a definitive diagnosis and physician who did not diminish the importance of my pain is on course with the literature that claims endometriosis is difficult to diagnose and that female patients are often told to get accustomed to chronic pelvic pain. My experience also supports the idea that further research is needed on the effects of physician communication skills training and the biased treatment of women in health care settings. The literature also supports my use of Internet information and claims that many more women are seeking online health information as well. As previously discussed, there are both benefits and potential consequences to using the Internet to obtain health care information. The literature fairly explains both the benefits

and risks of seeking health information online; however, few studies have looked at the way this information is being used. Therefore, the potential for benefits and risks can only be assumed.

The results of this study also largely support the literature. Most websites mentioned the same causes and treatments for endometriosis as were discussed in the literature. Infertility ambiguity, a common finding on the analyzed websites, was also detailed in the literature, particularly by Okamura et al. (2002). The need for improved physician-patient communication was documented in the literature though mentioned by only a few of the websites. Information was also found to be mostly accessible by site patrons with many organizations offering free material or free access to online chat groups or listings for live support groups in their region. Neither a high technological competency nor additional software was needed to view the websites. In fact, the software needed to view these sites is available for free download on the Internet and is readily available for use on many public computers. These findings are important as literature suggests that not all groups, especially minority and rural populations, have access to additional materials or even the Internet due to low incomes, rural geography, and low educational levels.

Though an extensive review of literature was conducted, there are many more researchers and scholars who are dedicated to the important topics addressed by this study. However, the literature reviewed for this study shed light on the many victories and struggles faced by all women as they attempt to gain access to a fair and unbiased medical system. The themes emerging from my personal narrative are also supported by the literature and the findings of this study indicate that the issues being addressed in the literature are the ones important to women seeking health care in America.

Limitations of this Study

While I made extensive efforts to keep limitations to a minimum, some did emerge. One such limitation is sample size. For this study, I conducted a qualitative analysis of 10 websites. However, Google (the search engine used to select the sample) lists approximately 505,000 endometriosis websites, a quantity well beyond the scope of this study. In addition, a variety of women's health websites are available for study. While they do not focus entirely on endometriosis, they are a source of information for many women using the Internet for health-related information. Furthermore, I only investigated professional endometriosis websites. Many sites exist that were created by endometriosis sufferers which provide accurate information on the disease and often include personal narratives and access to online diaries detailing these women's struggles with the disease and with physicians. It can be assumed that endometriosis sufferers obtain information from sites other than ten studied for this project.

Another limitation of this study is that it is unknown the exact reasons why women browse the selected sites. It can be assumed that they are researching endometriosis, but it not known if they are looking for specific information, perhaps symptoms, treatment, or fertility rates. Additionally, it is unknown whom the user is seeking information for; an Internet user is not limited to researching information only for herself. In fact, as the Pew Internet & American Life Project (Fox & Fallows, 2003) points out, many Internet users seek to obtain health-related information for a family or friend rather than themselves.

Despite the limitations of this study, results warrant additional analysis of website content. Findings show that endometriosis websites are promoting varying messages on topics germane to endometriosis research. Women receive empowering messages regarding endometriosis information (particularly symptoms and treatment options),

ambiguous messages about infertility, and stereotypical messages concerning the role of women in the health care industry.

Suggestions for Further Research

Although previous literature has focused on the role of media in providing messages about women's health care, few studies have focused on the messages women receive from Internet health websites. This is due, perhaps, to the newness of the Internet and the recent increases in women's Internet use. Yet, the limitations of the current research highlight multiple opportunities for future study.

One additional area of research could focus on a different unit of analysis. It would be interesting to study images, particularly as websites appear to be promoting a new image of the endometriosis patient, one that includes all races, ages, and socioeconomic classes. It would also be interesting to examine the presence of diagrams that show where endometriosis pain is located in the body, as endometriosis can affect areas as removed from the pelvic region as the brain. It would also be interesting to investigate site sponsors for each of these websites. Websites may promote certain treatments, regardless of their effectiveness, due to agreements made with corporate sponsors such as pharmaceutical companies. It would also be interesting to examine the Internet messages received by women. This study only investigated those sent by endometriosis websites; however, future studies could explore the messages women received from these websites and how the information was used.

Another important area of additional research involves the use of human subjects. Qualitative analyses (particularly thematic analyses) of women's journals, published narratives, interviews, website content, chat room conversations, or personal conversations is of particular importance to this topic. By analyzing lived experience, researchers will likely obtain a better understanding of why women with endometriosis

are using the Internet. Information on physician-patient communication can also be obtained without the restrictions imposed by conducting large surveys in physician's waiting rooms. Women who may be less likely to access the Internet, such as rural and minority populations, should also be studied as they may often be excluded from research on Internet use and endometriosis care.

Future studies should also compare Internet information to that found in more traditional forms of textual media, such as books and magazines. While it is noted that media have historically misrepresented women's health issues, it is important to analyze the accuracy of Internet messages, particularly due to its increasing popularity among women. Additionally, studies should attempt to uncover why women do or do not use certain websites to obtain endometriosis-related information.

This study serves as a starting point for future research on the messages women receive about endometriosis from the Internet. As women continue to use the Internet to obtain health-related information, it is important that researchers examine the motives behind such behavior as well as the messages being received from this newest form of mass media. A lack of research on this topic provides many opportunities for additional research. Undeniably, the rise of the Internet as the fastest-growing form of mass media warrants further investigation itself. However, for the women's health movement to progress, researchers must begin to understand the reasons behind women's information-seeking behaviors. Additionally, future research should focus on providing physicians and women with information on how to eliminate gender, class, and racial oppression in the examining room. Media are in the unique position to help women, especially lesbians and women of nonwhite racial backgrounds and lower-income status, to gain equal access to health care in America. Unfortunately, continuing to cultivate the stereotypical image of women as passive and compliant patients negates the empowering effects available by many media, including endometriosis websites.

Concluding Thoughts

Throughout the process of developing this thesis, I have grown both as a person and a researcher. I have learned to “think outside the box” and embrace new types of methodologies. I have strengthened my skills as a researcher and I feel confident in my abilities to look at an issue from multiple perspectives. For instance, before beginning this process, I never really considered the role of race in endometriosis research. However, now I have a deeper appreciation for the impact of socioeconomic factors on health care and the role of these factors in gaining access to adequate health care.

Personally, I have grown as well. With the exception of my gynecologist, I generally had a low opinion of physicians. Though I knew good physicians were available, I was skeptical about every doctor I saw, regardless of the specialty. I went to office visits with the expectation that any problem I described would be dismissed as a normal female problem or an exaggeration of the truth. In writing this thesis, I have realized that misdiagnosis is not always the fault of the examining physician; endometriosis is a particularly difficult disease to diagnose, especially in adolescents. This could explain why it took so many physicians and so many years for me to obtain an accurate diagnosis. Also, there exists a great deal of conflicting information about treatment options. Some websites promote hysterectomy, others promote pregnancy, and still others promote birth control and/or other hormonal therapies. When I first began looking for information about Lupron, I was disappointed. Though I trusted my physician would give me the information I needed, I wanted a second opinion before I chose to receive monthly injections of hormones. Unfortunately, websites provided mixed results, with some praising the drug and others threatening lawsuits against the manufacturer. Pharmacists could provide little information due to the newness of the drug and the fact that few researchers have studied the long-term effects of the drug. After learning more about the lack of medical research being conducted on endometriosis and other diseases affecting women, I know that a lack of knowledge is

not always the physician's fault. Through this process, I have certainly become more objective and understanding of physicians. I cannot forget what made me skeptical but I have made great strides in improving my physician-patient interactions by attempting to understand the physician's difficulty in identifying and treating diseases, especially ones like endometriosis that often masquerade as other common illnesses.

My hope is that my study will be a springboard for additional research on endometriosis and encourage other sufferers to come forward with their stories. Additional research and narrative literature serve as advertisements for the endometriosis awareness campaign. As a community of sufferers, endometriosis patients can work together to bring attention and resources to research efforts in hopes that one day a cause and cure will be found. Until then, these stories give voice to experience of suffering, the human element often missing from medical studies. This research also focuses on the actual, diverse woman as opposed to the white woman or woman who is or may become pregnant. It is also important for interpretive researchers to focus on other women's health issues, such as breast cancer, or other less discussed illnesses like uterine cancer or fibromyalgia. As humans, I hope studies such as this one will teach readers the importance of understanding suffering. I hope readers develop a deeper understanding of the disease and what it means to be a woman with endometriosis. I also hope that as researchers we are compelled by the strength of these stories, encouraged to produce more research on women's health, endometriosis, and online messages.

As the nation becomes more and more dependent upon technology, it is pertinent that we begin to understand the messages being sent via the Internet. These messages are available to such a wide audience and while research reports a plethora of benefits, there are many serious drawbacks to using technology as a source of health care information. If I had made decisions about my treatment based solely on the information I received online, I would have had a hysterectomy. Thankfully, I was

able to access additional information and make my treatment decisions based on the advice of a physician and my personal desire to experience natural childbirth. Many women, though, are denied this opportunity because they do not seek additional information. Unfortunately, Internet messages can be a “double-edged sword.” Therefore, it is important to continue studying this newest form of media messages.

In sum, conducting this research project has strengthened my abilities as a researcher and helped me develop certain ideas and thoughts while causing me to reconsider others. I hope that this study causes other women to relate their personal struggles to the worlds of communication and medicine. I hope that these studies raise awareness for the disease, the struggle of the endometriosis sufferer, and the obstacles women, particularly minority women, face in gaining access to adequate health care. By continuing to produce studies like this one, I believe we are taking the first steps toward bridging the gap between communication and medical science, a step I see as beneficial to the health of all people, particularly women.

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