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“YEAH, BUT CAN IT KILL YOU?”

UNDERSTANDING ENDOMETRIOSIS IN THE ATLANTA AREA

by

AMANDA DAY

Under the Direction of Cassandra White

ABSTRACT

This paper contributes to a growing body of literature on women with endometriosis, a gynecological condition in which tissue similar to the endometrium, or lining of the uterus which is shed during menses, grows elsewhere in the body. Despite a growing understanding of the disease in medical literature, it is still not well known by the general population or fully understood by the medical community. The paper incorporates a biomedical understanding with Emma Whelan’s idea of these women as an epistemological community, autoethnography, and narratives of sufferers in order to understand how women discuss, experience, and form communities around it. It draws upon individual interviews, a focus group, and readings of medical and social science literature and found that women of dissimilar socioeconomic backgrounds approached and discussed the disease distinctively from one another with three phases of coping with the illness: the discovery, quest, and revelation.

INDEX WORDS: Endometriosis, Medical anthropology, Inequality, Feminism, Structural violence, Autoethnography, Women’s health

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by

AMANDA DAY

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2012

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2012

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UNDERSTANDING ENDOMETRIOSIS IN THE ATLANTA AREA

by

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College of Arts and Sciences

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December 2012

DEDICATION

For all of my endosisters and their loved ones!

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A great many thanks to all of the women who were in this study, I couldn't have done it without you! You know who you are and all of you are my heroines. Also, this study would not have been possible without the support and guidance of my wonderful committee: Dr. Cassandra White, who encouraged me to continue my work, not only because it is important, but because I personally learned and grew while pursuing it; Dr. Emanuela Guano, who has been such a wonderful guide and support throughout this process; Dr. Steven Black, who had some great ideas and encouragement to give during the hard times, always given with a smile of course; and finally to Dr. Kathryn Kozaitis, who may not have been on my committee, but who along with Dr. Guano, introduced me to the tools of autoethnography that changed my life forever! A great deal of thanks goes out to the entire department, which has felt like home for many years, I will miss you all very much!

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1 INTRODUCTION

1.1 Endometriosis, a Personal Journey

Think back to the worst pain you have ever felt in your life. Was it, childbirth, kidney stones, maybe migraines or perhaps something else altogether? Now, if you would, imagine that it happens nearly every day of your life and that you do not know why it is happening or what to call it. Now, picture seeing doctor after doctor, who perform test after test, with all of them telling you the same thing, which is that they cannot find anything wrong with you. Also, imagine the people around you, both the medical professionals and your loved ones, are telling you that it is exaggerated, or worse that it is all in your head. The pain often becomes so intense that it leaves you curled up in the fetal position on the bathroom floor unable to function normally for days, weeks, or months at a time. This was my life from the age of nine, when I began menses, until my diagnosis with a disease known as endometriosis when I was twenty-one. Endometriosis is a gynecological condition in which tissue similar to the endometrium, the lining of the uterus which is shed during menses, grows elsewhere in the body and may correlate with serious symptoms, such as depression, chronic pain, anxiety, and infertility.

1.1.1 The Beginning of a Journey

I began my period when I was nine, which is not uncommon now, but was much less so back in 1993. The first few years the pain was only associated with my periods and was not debilitating, but it began to worsen when I was eleven. That was when my mother took me to the

gynecologist for the first time. I had passed a clot and was bleeding so heavily that the school nurse thought I might be hemorrhaging somewhere internally.

The gynecologist my mother took me to was an older, Southern man, who sounded as though he had come from Mayberry, and was the doctor that many members of my family had gone to for their yearly exams since I could remember. He began the appointment by asking my mother a few questions and then proceeded to examine me, which was excruciatingly painful. His conclusion was that I, like my mother and grandmother, simply had what he called "hard periods" and that I would probably need to have a hysterectomy someday, as my grandmother had. This continued for a couple of years; he practically ignoring me during my visits, until I was fourteen and demanded to be taken to another doctor for a second opinion. I refused to believe that what I was going through was part of the normal female experience of periods; what I had heard from girls at school and other women in my family was that they were an unpleasant reality that did not tend to interfere in daily life, as mine did. Between the ages of fourteen and twenty I went to over a dozen doctors ---gynecologists, gastroenterologists, internists, and even a couple of psychologists--- who agreed that there did not seem to be anything physically wrong with me. Many of them thought that I was exaggerating the pain that perhaps it was psychosomatic, or, in the case of one doctor when he found out how many siblings I had (seven sisters), that I simply wanted attention and was completely fabricating the pain.

1.1.2 Finally Some Answers

Finally, in 2005 while in a desperate state, my significant other, at the time, found a holistic practitioner who worked with rape survivors outside of Grady Medical Center, in downtown

Atlanta. She was the first doctor who did not give me a barrage of tests, but rather asked me to explain what was going on with my body and how I felt about it. After hours of answering her questions, over at least two sessions, she gave me a pamphlet on endometriosis and told me to go home and research it online. I searched for it and almost everything I found was bleak. I discovered that most women with the illness had to wait many years for a diagnosis, like myself, and that I was not officially diagnosed because the only way to be was via a laparoscopic surgery. This was also when I told my mother about my possible illness. I explained what it was, how it worked and told her that I believed that I had it. Her reaction is now the title of this thesis.

I brought all of this up to the doctor and she told me that she did not do surgeries, but that she was certain that this was the illness that I had been struggling with for many years. Her plan of action was to change my diet to an all organic one and to cleanse my system, but due to the many allergies that I have, this dietary change made me even sicker. Eventrually, we changed the approach and I began to feel better, for a time. I stayed with this doctor for a few months, until I lost my job due to my illness and subsequently lost my health insurance as well. At the time I was not able to purchase insurance because of other preexisting conditions, like chronic bronchitis and sciatica.

1.1.3 Surgeries and Beyond

Shortly after losing the health insurance, I began to see another doctor who would allow me to see her despite my lack of insurance. It was costly, nearly $17,000 in total, and it took convincing for her to believe that I had the illness, but in 2006, after over a year of seeing this particular doctor, she conducted my diagnostic surgery. She cauterized the areas where she saw

that the disease was growing, removed cysts from each of my ovaries, and diagnosed me with stage three of the illness; staging and how it functions is discussed in depth later in the paper. After the surgery I began feeling much better and was even able to start another job; however, six months later my symptoms came back with a vengeance. This time I began to have significant medical problems with my GI tract as well as frequent bladder infections, neither of which I had experienced before. When I asked my doctor what was going on she said that sometimes with these types of surgeries, the disease grows back, and she said that another surgery is usually conducted, but that only one is ever done per year, in order to prevent adhesions. I refused another surgery primarily due to the cost of it all for such a little possible benefit, but also because I was beginning my senior year in school and planning a wedding at the same time.

After graduation I moved to South Carolina with my husband because he was getting his Master's degree and had gotten a teaching job as well which allowed for me to be on his insurance through the school. While there I continued to seek treatments and tried "everything under the sun," similar to my informant Laura who said this during the focus group. I was put on multiple types of treatments, including from oral contraceptives, hormonal shots, combinations of the two, and even another diet which was more restrictive than the first one I had tried. After my divorce, when it came time for me to decide what I wanted to do for graduate school, I knew that I had to do something with endometriosis. I moved back home, to Georgia, and began the journey that led me to this paper. I searched for support groups because I knew I needed help getting through the tough days and I found a wonderful group of women who introduced me to yet another doctor. This particular doctor was an expert in endometriosis and preformed an excision surgery on me on May 1, 2012. All of the medical photos found throughout this paper are from that surgery. Many of the same women who introduced me to the doctor are also participants in

the study and are now friends.

1.2 Purpose of the Study

This project is focused on women with endometriosis in Atlanta and the surrounding metropolitan area. Endometriosis is one of the most common gynecological diseases diagnosed, yet many people, including healthcare professionals, do not understand the disease or the impact that it can have on a woman's life (Redwine 2009). The aims of this project were to research endometriosis awareness, to learn more about communities that form around the disease, to explore the treatment options for those with it, and to document how endometriosis affects the lives of women who have it. I also examined how women's health beyond illness plays a role in endometriosis care. There are many diseases, especially those that are nonfatal, which are often understudied by medical science and misunderstood/misrepresented in the media, which means that the majority of the public does not understand them well either; this is especially true when those diseases occur primarily in women or marginalized populations (Einstein & Shildrick 2009; Strausz 2001; Steege *et al*. 1998; Tang & Anderson 1999; Verdonk *et al*. 2007).

1.3 Participant Information

Endometriosis is an understudied and often overlooked illness that has a major impact on the lives of the women with it. As someone with the disease, I can attest to how endometriosis can affect the lives of those who have it, but I wanted more understanding beyond simply my own personal experiences with the illness. I belong to many endometriosis support groups

online, as well as one in person support group that was started on Meetup.com, but which no longer uses that service. The majority of my informants came from the in-person, meetup group and I knew them for over a year before research began. Another group of informants consisted of a woman I had worked with at a local supermarket and her children. Table 1.1 gives a demographic break down of the informants who participated in the study. The ages of participants ranged from thirteen years old to around forty. Many participants chose their own pseudonyms and for those who did not I assigned one.

Table 1.1 Endometriosis Specific Details:

Detail	Number of Participants	Detail	Number of Participants
Stage of Endometriosis		***Hysterectomy***	
Stage I (Minimal)	0	Partial	0**
Stage II (Mild)	6	Full	5
Stage III (Moderate)	2	Has not had one	9*
Stage IV (Severe)	1		
Unknown	5*		
Motherhood Status		***Miscarriages***	
Does not have children	10*	Has never had one	6*
Has Biological children	2*	One	3
Adopted children	2	Multiple	5
Total # of Participants	**14**	**Total # of Minors**	**3**

** Indicates Minors are Present in this group.*
*** Many women had Partial Hysterectomies, but later had Full*

Table 1.2 Demographic Information:

Demographic	Number of Participants	Demographic	Number of Participants
Race/Ethnicity		***Languages Spoken***	
African American	0	English	14*
Asian	0	French	2
Hispanic/Latina	4*	German	1
White	7*	Italian	1
Other	3**	Spanish	6*
Highest Education Level		***Socio-economic Class***	
Some Middle School	1*	Upper Middle	1
Some High School	2*	Middle	5
Graduated High School	2*	Working	4*
Some College	3	Fluid/Changes	4***
Graduated College	6		
Relationship Status			
Single/Less than 1 year	4*		
Married/Greater than 1 year	7		
Divorced	1		
Minors (not allowed to date)	2*		
Total # of Participants	**14**	**Total # of Minors**	**3**

** Indicates Minors are Present in this group.*
*** One identifies as Italian American, one as mixed, and the last as Human (she did not want her race known)*
**** These women have seen themselves as both Middle and Working Class at one point or another, it often changes, and it is related to their illness.*

1.4 Problems for this Type of Research

1.4.1 Funding

Within biomedicine is not fully understood what endometriosis is, where it comes from, or how to treat it efficiently without expensive surgeries with which most doctors and patients are unfamiliar, but at the same time it is not a life threatening illness either. This becomes a problem when dealing with medical research because most funding goes to diseases with high mortality rates or that are drastically life altering, which is not how most people view endometriosis. Diseases such as various cancers or highly virulent, communicable diseases like malaria or AIDS are most likely to get funding, particularly in countries that are steeped in the biomedical model, because they cause the loss of millions of lives every year (Lock and Nguyen 2010; Hahn and Inhorn 2008; Sobo 2009). Another sizable portion of diseases that are more likely to be funded are those which are life altering to the point of complete loss of mobility or those that cause issues like dementia. Illnesses such as Parkinson's disease or Alzheimer's fall under this category. These diseases in and of themselves need to be funded so that we can better understand them and possibly eradicate them someday, but other diseases which are also life altering, such as endometriosis, fibromyalgia, and many other chronic pain diseases, need to receive funding as well, yet often do not (Redwine 2009; Morris 2006; Tulandi and Redwine 2004; Diamond and Osteen 1997). In order to achieve more funding for the study of these chronic pain illnesses, the biomedical field, as well as the patients being treated for them, must stop treating these diseases as though they are merely the one symptom: pain (Steege *et al.* 1998). There are other limiting factors to take into account as well, predominantly those of public

and medical opinions, interpreting pain scales, and racism/classism in diagnosis of the disease which will all be discussed throughout this paper.

1.4.2 Public Opinion

Public opinion and medical practice are especially interconnected matters in Western biomedical practice. It is a common occurrence for many women with endometriosis to come across people, often other women, who believe that they are simply exaggerating their periods when it comes to symptoms of the disease (Whelan 2007; Morris 2006; Redwine 2009). There are movements for many diseases, such as breast cancer or autism, which have high public outreach and involvement. They may not be fully understood by the public at large, but are nonetheless seen as important illnesses to combat, in part, because they are so easily identified as something that is wrong or malfunctioning while endometriosis is not so easily recognized. Medical personnel are not immune to these same judgments and it affects the quality of care that many patients receive and can delay diagnosis or treatment or may even lead to an incorrect diagnosis (EFA 2011; Whelan 2007; Morris 2006; Roberts 1997). As you will see later, this is an issue that many dealing with female healthcare are familiar with because of pervasive stereotypes about the "hysteric woman" and the accepted practice of the female body being somehow fundamentally different from the male body and therefore othered (Cook 2009; de Beauvoir 1949; Einstein & Shildrick 2009; Green 2008; Huntington & Gilmour 2004; Lagro-Janssen 2007; Mansdotter *et al*. 2006; Morris 2006; Roberts 1997; Strausz 2001; Verdonk 2005; 2007; Whelan 2007). Dorothy Roberts and Monica Green look at the histories of women dealing with the healthcare system in the United States. Roberts (1997) focuses on the black body and

discusses women throughout the text while Green's (2008) primary concern is the gendered healthcare system in general and why it has turned out to be what it is today. Those who specifically discuss these issues with regard to endometriosis include Emma Whelan (2007), who discusses it from a social science perspective; Kerry-Ann Morris (2006), who discusses it from a survivors perspective; and finally, Ivan Strausz (2001) as well as Annette Huntington and Jean Gilmour (2004) who discuss endometriosis from a more medical perspective.

Another problem I faced in my research has to do with the ethics of working with a vulnerable group of people who may not be fully comfortable sharing their medical histories. One way to overcome this particular issue is to explain that I have a personal history with this illness and that I plan to use autoethnography to share my story as well. This lead to many women being more inclined to share, since I am seen as one of the group, being a fellow patient (Jones 1988; Whelan 2007). This in and of itself can prove to be problematic though, I had to take extra precautions not to become overly present in my work and to let the voices of the women I interviewed come through. One such precaution was that I shared my notes with the participants after their interview and plan to share the final paper with them as well. Finally, an ethical issue that I face in my research is the fact that as an applied, medical anthropologist I push for change in the current way that the healthcare system is set up, particularly involving women. In doing this I must remain vigilant of my biases and work hard to make sure that I am not simply pushing my personal agenda. Rather I need to make sure that it is one that is informed by the women that I have spoken with about this topic as well as the healthcare professionals who are already aiding in treatment for this disease.

2 METHODOLOGY

2.1 Stages of Research

The first stage of research revolved around the women of Atlanta and their experiences with endometriosis while the second stage made inquiries into the research being done by bio-medicine to understand and treat the disease; finally the last stage of the research was a look at organizations and movements on local, regional, and global scales to better understand how they approach dealing with endometriosis.

2.1.1 Stage One

The first stage consisted of speaking with many women in the Atlanta area. I had participants who were between 13 and early 40s in age so as to have a range of all ages of women who might have the disease or who are still dealing with it during early menopause. In speaking with these women I relied heavily on semi-structured interviews and taking their illness narratives, especially pertaining to the role endometriosis has played in their lives as well as the beliefs and practices surrounding the disease, themselves, and their quality of life. The semi-structured interviews revolved around a predetermined set of fifteen questions for every participant modified for age appropriateness, comfort level, and the participant's own answer to previous questions. An example of this modification was leaving out questions dealing with sexuality when speaking with minors or those not comfortable with the subject. Another example of necessary adjustments were the follow up questions asked while listening to the illness narratives in order to better understand what the informant was trying to communicate.

I chose to do the first stage of my research in Atlanta primarily because it is an area that I am already familiar with including having contact with many women in the region who have endometriosis. Also, there are a growing number of support groups in the area, of which I participate in two. Another contributing factor was that the city has the Center for Endometriosis Care, which is one of a handful of endometriosis specialists in the United States and one of only a tiny fraction of those that specifically treat women with this disease (EFA 2011). Most of the other centers specialize in patients who have various other gynecological disorders such as infertility (which women with endometriosis often have) uterine fibroids, and poly-cystic ovarian syndrome. This leaves endometriosis as a secondary or even tertiary understanding for many of these clinicians.

2.1.2 Stage Two

The second stage was a more in-depth review of the medical literature dealing with endometriosis. This stage was done mainly in the library and on the internet via medical articles, books, and journals with some supplemental medical anthropology/sociology texts where available. This area of research focused on literature by: endocrinologists (hormone imbalance), gynecologists (female reproductive system), immunologists (immune system), medical geneticists (genetic traits), obstetricians/perinatologists (pregnancy/extremely high risk pregnancy), rheumatologists (autoimmune diseases) psychologists and psychiatrists (mental and emotional effects of the disease) as well as social scientists such as Arthur Kleinman and his fellow researchers (1978, 1988), Emily Martin (1994), Michel Foucault (1973), Elisa Sobo (2009), Stacy Langwick (1992), Robert Hahn and Marcia Inhorn (2009), and Margret Lock and Vinh-Kim Nguyen

(2010). People in the medical professions listed above are all involved in endometriosis research at this time and are of the utmost importance to search out when discussing the medical literature on the subject (EFA 2011; Diamond & Osteen 1997; Huntington & Gilmour 2004; Jones 1988; Morris 2006; Steege *et al*. 1998; Tulandi & Redwine 2004). All of the social scientists listed above deal with medical theories and ideas within their works. Foucault (1973) and Martin (1994) take historical approaches to the matter of healthcare and explain how its ideas and concepts change over time while the other authors take a more hands-on, applied approach to medical anthropology. This data was collected and added to the interviews done with the participants in the first stage of research and has a primary focus on the theories on causation, treatment options, and best practices for patient interaction. These two stages combined will assist in building a better dialogue between endometriosis patients and those in various biomedical fields. Stage two of research was the primary focus of the Background section of this paper.

2.1.3 Stage Three

The third and final stage of the research was to look at the endometriosis healthcare movements and organizations on local, regional, and global scales. This stage consisted of looking at the visual representations portrayed by the media of this disease and, combined with the first stage, has helped determine how it is perceived by the public and how these images might be used to educate the public further about the illness. This may also be applied to the medical field and their understanding and research on the disease as well. The main reason for this aspect of research is to understand how these campaigns have grown over time and how they may continue to grow and become well accepted and recognized in the public sphere. This stage

of research has primarily been conducted via the internet and library. I have also made visits to local organizations such as EndoHope and The Center for Endometriosis Care, also known as the CEC. EndoHope is a new organization that is just starting and is in the process of applying for nonprofit status. The group wants to raise money to assist with the payment of surgery for those who cannot afford it on their own. They want to pay for these women to come to the Center for Endometriosis Care in Atlanta, where most of the participants who have had excisions went, including me. The CEC is the base of operations for two local endometriosis specialists, two of only a handful to be found in the United States.

Like the interviews in my second stage of research, the third is too ambitious to try and fully accomplish in my short time at Georgia State, but I have at least begin to research these avenues since they are so numerous in the area. The result of combining interviews with women affected by endometriosis in Atlanta, understanding what biomedicine has to say about the disease and considering how education movements handle obstacles is important to create a more holistic understanding of the disease that is endometriosis and all that goes along with it.

2.2 Autoethnography

What I ultimately want to understand is the following: how do women, particularly those in Metropolitan Atlanta, understand, conceptualize, and cope with endometriosis in their daily lives, and what can bringing this information into conversation with biomedical understanding of the disease as well as feminist and healthcare movement ideologies accomplish? Anthropological, sociological, feminist, psychological, and public health theories all have something to offer in addressing this complicated research question.

First and foremost, my research would not be possible without an understanding of ethnographic styles and methods. Understanding that ethnography is more a methodological topic, I will discuss how my methods are informed by theory. Autoethnography is a primary methodological tool used in this project. This type of ethnography has highly influenced my writing ever since I was introduced to it in my Theory and Praxis class with Dr. Emanuela Guano at Georgia State University. Because I, like the women I study, have endometriosis, I find autoethnography to be an invaluable theoretical tool in my work. This style is briefly touched on in Karen O'Reilly's book *Ethnographic Methods* (2005), but is understood mostly as autobiographical in nature and many others see it as little more than anecdotes; however, as Anderson (2006) and Narayan (1993) show in their work it can be a wonderful analytical instrument. There are numerous forms of autoethnography represented in the literature. The most common are “analytic” and “evocative”, according to Anderson (2006: 374). Evocative types of autoethnography, which are more literary, poetic, and artistic in nature, have a place in the literature and can be very powerful and helpful tools; however, this particular type of autoethnography is not one which I feel especially capable of practicing effectively, though there is an attempt at the end of this section (Anderson 2006: 374). I do find the more theoretical, analytical type much more relevant to my work (Anderson 2006: 375).

Anderson says that there are five components that make up analytic autoethnography: complete member researcher status (CMR), analytic reflexivity, narrative visibility of the researcher’s self, dialogue with informants beyond the self, and commitment to theoretical analysis (2006:378). Anderson uses Adler and Adler's breakdown of the two types of CMR, the opportunistic and the convert--explaining that the opportunistic CMR is the more prevalent and can be understood as one who was thrust into their situation by birth, illness, or other

circumstances beyond ones control while the convert is one who might be understood as having "gone native" or choosing to remain with their research group indefinitely (Anderson 2006:379). The second component, analytic reflexivity, is found in most ethnography and "involves an awareness of reciprocal influence between ethnographers and their settings and informants. It entails self-conscious introspection guided by a desire to better understand both self and others through examining one's actions and perceptions in reference to and dialogue with those of others" (Anderson 2006:382). Anderson's third requirement is a "Visible and Active Researcher in the Text" and can be summarized as an ethnographer who actively shares their own experiences and feelings with a self-reflexive understanding that it is valid and belongs in the text (2006:383-384).

Fourth is the idea that there must be informants besides the researcher themselves, which is fairly self-evident when one realizes that ethnography is supposed to be about groups of people, but I suppose it should be stated when one tries to explain an often misunderstood methodological practice, such as autoethnography. Anderson (2006) approaches autoethnography differently from others, such as Carolyn Ellis, a popular autoethnographer (Ellis 2008). Ellis (2008) often speaks about her informants as though they are secondary in a story about herself while Anderson's (2006) approach has the ethnographer as an informant of sorts. Lastly, Anderson says that there should be a "Commitment to an Analytic Agenda [where] [t]he purpose of analytic ethnography is not simply to document personal experience, to provide an 'insider's perspective,' or to evoke emotional resonance with the reader. Rather, the defining characteristic of analytic social science is to use empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves" (2006:386-387). These criteria that Anderson sets forth are a wonderful way of approaching autoethnography, but that is not to say

that all of these components are useful in every context. I for one do not use all of the criteria the way that they are set out above. The idea of the CMR can be fairly problematic. The CMR is, according to Anderson (2006), someone who belongs to the group that they study and it is especially the idea of them as being opportunistic in their group. The reason that this is problematic can be understood by looking at its contradiction with Narayan's (1993) idea that even those who might be understood to be "native" may not be recognized as such either by themselves or by the community in which they study. Within my work the way to explain this is that while I belong to the group of women who have endometriosis, I do not propose to represent them. Also, simply because I have the illness does not mean that I understand what a woman who is African-American, Latina, from a different socio-economic class, or of a different age from myself may have had to go through in order to be diagnosed, if she even has been.

2.2.1 Killing Endometriosis, an Example of Evocative Autoethnography

On one of the endometriosis support groups that I belong to online a woman asked the question, "If you could kill endometriosis, how would you do it?" Most of the women agreed that they would stab it, shoot it, drown it, or in some other way give it the physical pain that they had felt over the years. One of my favorites was a woman who said that she would tar and feather the disease, parade it around town for all to see, then she would put it in the stocks and let others who had suffered with it throw rotten vegetables at it before finally taking it to be drawn and quartered in town square. I thought about it for a few days before I responded and my response was a bit different. I decided that because we were assuming that the disease was somehow sentient now that it was too easy to simply kill it.

My response was as follows: I would not kill it; I would make it suffer as it has made me suffer. To start, I would make it live in agonizing pain that nobody believed it had for nearly a decade. During this time it would miss work and school and end up questioning its own worth for doing so, then, I would make it watch as its life passed it by, having to frequently apologize to family, friends, and lovers for canceling plans, yet again. Next, I would make it sit there and listen to every single person who ever asked me what was wrong with me or why I could not do something, and explain to them why I had to do the above for so many years. I would make it love and adore children and then take away any hope of having its own. No, I would not kill endometriosis; I would make it live the life that it made me live for so long. Oh no, I would not kill it; I would make it want to kill itself, like it has done to me and so many other women, but then give it so much to live for that killing itself would not even be an option.

3 BACKGROUND & THEORY

The stages of research are out of order here because one must know the background and history from stage two of the research in order to fully appreciate the results from stages one and three. A literature review for works dealing specifically with endometriosis mainly consist of biomedical texts with very little social science literature existing on the subject. So in this review I have looked at other gynecological disorders and diseases, pregnancy, infertility, menopause, other predominantly female illnesses, as well as chronic pain conditions. This portion of the paper is about the ins and outs of endometriosis and biomedicine: the history, theorized causality, methods of diagnosis, and practiced treatments. After this I will proceed with discussing the social science and lay literatures about endometriosis specifically. Later, I will discuss other ill-

nesses and how the biomedical field and social science discuss and approach them as well as looking at reproductive health throughout a woman's lifetime.

3.1 A Brief History of Endometriosis and Biomedicine

Googling Endometriosis: The Lost Centuries is a book by Dr. David Redwine (2012) where he explains that the disease has been discussed under many names before in various points in time from Ancient Egypt and China to the middle ages and the Renaissance. He begins the book by explaining that the illness was first discussed as far back as 1825 BCE in Ancient Egypt where they describe what they called *tiAw-pain* of the womb and give examples of the pain as well as treatments for it (Redwine 2012:1-9). This book ends in 1899 when what we understand as medical literature took over. Later, endometriosis began being discussed as a gynecological disorder in the late 1890, but during this period only some of the larger more easily seen lesions were considered part of the disease (Tulandi & Redwine 2004). Following its official medical discovery research on the disease increased for a time, but it was mostly done as an afterthought while other surgical issues were being dealt with or during autopsy (Tulandi & Redwine 2004; Osteen 1997). Since the introduction of endoscopy in the 1960's interest in the disease and the study of it have been growing wildly again, which is likely because of the fact that it is recognized as one of the most common gynecological disorders with estimates that 1 in 10 women have the disease (Tulandi & Redwine 2004; Strausz 2001; EFA 2011; Redwine 2012; Whelan 2003). Despite this fact it is defined differently by various organizations and medical practitioners, there is still little understanding as to how the disease functions, and there are still many differing theories within biomedicine about causation and appropriate treatments. The simplest and

most common biomedical definition is that it is an autoimmune disease where the growth of a tissue similar to the endometrial tissue (which lines the uterus and is expelled during menses) in, on, and around other parts of the body (including, but not limited to, the ovaries, fallopian tubes, cervix, vagina, implanted into outer uterine walls, rectum, intestines, bodily organs, and walls of the pelvic cavity; rarely cases have been seen on the diaphragm, lungs, brain and even the eye) and that these lesions may cause hormonal issues as well as pain, infertility, and other symptoms (EFA 2011; Tulandi & Redwine 2004; Strausz 2001; Osteen 1997; Morris 2006; Redwine 2009).

3.1.1 Causation & Stages

Causation is still unclear; however, there are many theories as to what causes the disease with three that are the most accepted within the biomedical community. The first, and oldest, is Sampson's Retrograde Menstruation Theory which explains that the reason endometrial tissue can be found outside of the uterus is because it flows the wrong direction in the body and rather than being expelled from the body during menses it instead flows out of the fallopian tubes and implants elsewhere (EFA 2011; Tulandi & Redwine 2004; Strausz 2001; Osteen 1997; Morris 2006). This particular theory “holds that progression of endometriosis, once established, is unavoidable... [and] considers endometriosis as normal endometrial cells behaving abnormally in an abnormal environment”; the main problems with this theory are that it cannot explain why only some women have endometrial implants while others do not and it cannot explain why infant females and males may sometimes develop the illness as well (Tulandi & Redwine 2004; Redwine 2009).

The second major theory regarding this disease is Endometriotic Disease Theory (EDT) that builds off of the Retrograde Menstruation Theory. EDT considers retrograde activity to be normal and that attachment and implantation of these cells occurs in all women, but that in most women the body's defense mechanisms prevent it from becoming full blown endometriosis (Tulandi & Redwine 2004). This theory also takes it a step further explaining that endometriosis is caused by a cellular mutation in the women who have it. It also says that this is most likely due to a genetic component because it often runs in families, but how this component relates to other aspects of the disease is still unknown (Tulandi & Redwine 2004). The final and most recent theory is that of Dr. David Redwine (2009); he postulates that endometriosis is actually a disease that begins during the embryonic stages of development and becomes active when estrogen (which has been correlated to the illness in many studies) is introduced to the body during puberty. This latest theory also explains why young prepubescent, females, who may produce small amounts of estrogen before puberty, and some males (all reported cases of males with the illness are those who have been treated with estrogen drugs) can develop the disease (Redwine 2009).

The increasing rate of patients being diagnosed with endometriosis since the 1960's has led some to believe that there are also environmental factors which may have an effect on the disease (Morris 2006; EFA 2011; Redwine 2009). There are those who say that this is in fact not the case and that a better understanding of the illness has just led to more accurate rates of diagnosis than were previously available, much like can been seen in the Autism debate (EFA 2011; Morris 2006; Redwine 2009, 2012). The reason for this increase in diagnosis is most likely because when endometriosis was first named it was only what would now be considered stage IV that was called endometriosis. In Tulandi and Redwine (2004), Koninckx explains that in the

1960's black-puckered lesions were added to the diagnosis followed by non-pigmented endometriosis in the 1980's and infiltrating endometriosis in the 1990's.

At this point one can begin to see how the four stages of endometriosis began to form. Though the stages are arbitrary and are subject to change depending on how a doctor assess them. The amount of pain that a patient suffers has nothing to do with the stage of endometriosis that her doctor assigns. This system of staging is primarily based on how the endometriosis will affect a woman’s chances of fertility. For example, a patient with State I may have much more pain than a patient with Stage IV; however, the patient with Stage IV is less likely to bear children so is therefore diagnosed with a more severe form of the disease (Tulandi and Redwine 2004; Strausz 2001; Morris 2006). Many medical professionals disagree with this type of staging, but few have given an acceptable alternative (Redwine 2009).

Stage I, often called typical endometriosis, is defined by the easily seen black puckered lesions with superficial and filmy adhesions that are minimally present in the pelvic area. Stage II is a more mild form of the disease with superficial as well as deeper endometriosis beginning to form; it is often called subtle endometriosis, and has more of the non-pigmented lesions. Stage II of the illness is what I was diagnosed with in 2012. Stage III of the disease consists of most of the same criteria as stage II, but has more severe symptoms. Stage IV is the most severe of the cases and is defined as having deep endometriosis adhesions in multiple parts of the pelvic cavity along with endometriosis being present outside of the pelvic area, and may include large cysts on the ovaries (called chocolate cysts because of their coloration); this is the stage of the disease that I was diagnosed with in 2006 (EFA 2011; Morris 2006; Tulandi & Redwine 2004; Osteen 1997). As one can see even by my own experience, the staging is not always consistent and different doctors will diagnose different patients according to their own standards. Since staging is often

inconsistent from doctor to doctor and since the various symptoms do not always present similarly in stages, many doctors choose not to incorporate this system into their diagnosis. Many women with Stage I of the illness will be in far greater pain than women who present with Stage IV, for example. Other women may not even know that they have the illness at all until they are infertile and must see a doctor for those reasons.

The doctor who conducted my first surgery used the standards set by the American College of Obstetrics and Gynecology, which I could not find a chart for while Figure 2.1 shows how the doctor who performed my 2012 surgery approaches staging. His practice uses the American Society for Reproductive Medicine's guidelines. The chart below shows that the staging here consists of a point system, as most endometriosis staging systems do. Stage I, Minimal, is from 1-5 points; Stage II, Mild, is from 6-15; Stage III, Moderate, is from 16-40; and Stage IV (Severe) is anything above 40 points. The chart also shows how many points to assign depending on the depth and location of the lesions and/or adhesions. They run from one point for superficial lesions on the ovary and/or peritoneum to 20 for deep ones found in the same locations. In the case of adhesions, it runs from one point for filmy, superficial adhesions on the fallopian tubes and/or ovary to 16 for dense in the same areas. Also taken into consideration is how large the particular lesion or adhesion is; the greater the size the great the points added. So, a lesion found deep on the ovary that is one centimeter or less in diameter is only 2 point while one, like mine, that is larger than 3 centimeters is worth 6 points. The problem with this particular chart is that it does not account for endometriosis outside of these areas, for example in my case it does not give a point assignment for the disease being found on my appendix. Finally, this particular chart gives an area for the doctor to illustrate what they saw while preforming surgery but does not give guidelines for how to draw it or even include all the areas where the disease is found.

AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE
REVISED CLASSIFICATION OF ENDOMETRIOSIS

Patient's Name Amanda Day Date 5-1-12

Stage I (Minimal) - 1-5
Stage II (Mild) - 6-15
Stage III (Moderate) - 16-40
Stage IV (Severe) - >40
Total 10 II

Laparoscopy Laparotomy Photography
Recommended Treatment
Prognosis

PERITONEUM	ENDOMETRIOSIS	<1cm	1-3cm	>3cm
	Superficial	1	2	4
	Deep	2	4	6
OVARY	R Superficial	1	2	4
	Deep	4	16	20
	L Superficial	1	2	4
	Deep	4	16	20

	Partial	Complete
POSTERIOR CULDESAC OBLITERATION	4	40

OVARY	ADHESIONS	<1/3 Enclosure	1/3-2/3 Enclosure	>2/3 Enclosure
	R Filmy	1	2	4
	Dense	4	8	16
	L Filmy	1	2	4
	Dense	4	8	16
TUBE	R Filmy	1	2	4
	Dense	4*	8*	16
	L Filmy	1	2	4
	Dense	4*	8*	16

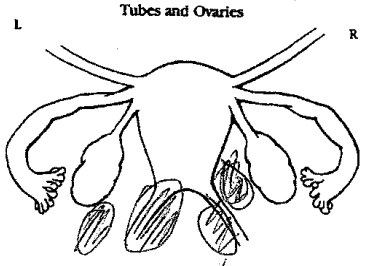
*If the fimbriated end of the fallopian tube is completely enclosed, change the point assignment to 16.

Denote appearance of superficial implant types as red [(R), red, red-pink, flamelike, vesicular blobs, clear vesicles], white [(W), opacifications, peritoneal defects, yellow-brown], or black [(B) black, hemosiderin deposits, blue]. Denote percent of total described as R___%, W___% and B___%. Total should equal 100%.

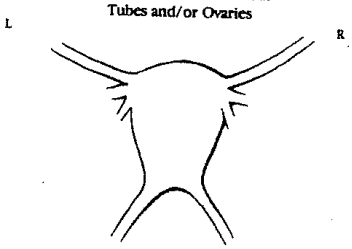
Additional Endometriosis:

Associated Pathology:

To Be Used with Normal Tubes and Ovaries



To Be Used with Abnormal Tubes and/or Ovaries



Vol. 67, No. 5, May 1997 American Society for Reproductive Medicine *Revised ASRM classification: 1996*

Figure 2.1 Endometriosis Staging Chart

3.1.2 Diagnosis and Treatment

According to the biomedical model, the only way to diagnose endometriosis in a patient is via surgery with the currently preferred method being laparoscopy (EFA 2011; Morris 2006; Tulandi & Redwine 2004; Strausz 2001). This procedure allows doctors to see inside the pelvic area by inserting a laparoscope (a long, thin, and flexible interment with a light at the end) into the abdomen via small incisions through the navel, just above the pubic region, on the sides of the abdomen just above the pelvis, and/or, without incision, through the vagina (EFA 2011). The patient is then filled with a gas, usually carbon dioxide, to make the abdominal region easier to explore and the organs more distinguishable from one another (Morris 2006; Redwine 2009). The surgery can then take many forms depending on the patient, physician, and diagnosis. After finding implants or adhesion during the exploratory part of the surgery doctors will often remove them via cutting, burning, or scraping and then send them off to be tested for any signs of cancer or other disease (Morris 2006; Redwine 2009). Figure 2.2, from my first surgery, shows the most common incisions done during the procedure while Figure 2.3, from the Washington Center for Reproductive Medicine, shows the most common set up for a basic laparoscopic procedure.

Figure 2.2 Most Common Locations of Laparoscopic Incisions

Figure 2.3 Laparoscopic Procedure

Hormonal and surgical therapies are the most common ways to treat endometriosis. Multiple surgeries, including laparoscopic and hysterectomy, are one treatment frequently suggested by doctors to patients, but they require long recovery periods, and can cause scaring which can make the disease more painful, not to mention the fact that they may not ease the pain associated with it (Strausz 2001). Also, many young women are told that if they have a baby that this could possibly help in their treatment process by drastically changing their hormonal systems, this treatment option has fallen out of favor, but was often the prescription in the 1960's and 70's (Morris 2006; Redwine 2012). Since surgery is a rather expensive option many women will go without an official diagnosis for many years, instead trying the most popular treatments, which are hormonal (EFA 2011; Osteen 1997; Steege *et al*. 1998; Morris 2006; Whelan 2007). These hormone therapies consist of things such as birth control pills, contraception shots, intra uterine

devices (IUDs) and replacement therapies (Morris 2006; EFA 2011). Many women take issue with these therapies because they inhibit procreation and with a disease that already makes one vulnerable to infertility it is a frightening prospect (Inhorn & Balen 2002; Morris 2006). Also, many of these treatments can cause serious and unpleasant side effects in women with endometriosis (Morris 2006; EFA 2011; Whelan 2007; Redwine 2009).

3.2 Medical Anthropology and Endometriosis

In my literature search, I found that most biomedical texts contained only a scientific analysis of endometriosis; a few, however, seemed to incorporate a medical anthropological approach, such as Strausz (2001), Steege *et al*. (1998), and Redwine (2009, 2012). All of these books are written by physicians, but are supplemented by the voice of the patients and while the first two are not specifically about endometriosis they both have chapters dedicated to discussing it. These types of texts are important for medical anthropologists to look at because it gives us insight into what doctors and medical professionals are already doing to support patients more than just dealing with their conditions and where we might be able to assist them in these endeavors. While these are not strictly social science texts they do use aspects of social science in ways that are more approachable to the medical field. As Koninckx mentions there are hundreds of studies on endometriosis published in medical journals every year, but they are always filtered through a biomedical lens that does not always see the value of social scientific analysis (Tulandi & Redwine 2004:1).

3.2.1 Medical Anthropology

Medical anthropology has many of its own sub-schools of thought. One of the most prominent is critical medical anthropology which problematizes many of the ideas that biomedicine and public health take for granted. Authors such as Hahn and Inhorn (2009), Langwick, (2011), Lock and Nguyen (2010), Kleinman *et al*. (1978), and Sobo (2009) all discuss such matters in their works where they use critical medical anthropology approaches to point out some of the issues they have come across in the field. In the 1970's and 1980's, Arthur Kleinman, an anthropologist as well as psychiatrist, was one of the first to understand that psychological and biomedical ideas were not universal and should be discussed in accordance with cultural beliefs from which they originated. His research took place in China where he noticed that many of the psychological conditions that Americans suffered from were not considered to be as problematic there and vice versa (Kleinman 1978, 1988). He also pioneered the idea of the illness narrative where he encouraged medical professionals to be more attentive caretakers and to listen to the patients more often rather than do things "to" or "for" them (Kleinman 1988).

Piggybacking off of Kleinman's ideas that approaches to biomedicine are culturally constructed, Sobo (2009), Langwick (2011), and Lock and Nguyen (2010) show that they are often conceived of differently within the larger culture as well. In her book, *Bodies, Politics, and African Healing: The Matter of Maladies in Tanzania*, Stacey Langwick shows that even within a community where the people are often times considered homogeneous, such as a Tanzanian village, there are, in fact, great differences amongst the people, especially in the ways in which they approach biomedicine (2011). I wanted to see how women in Atlanta approach biomedicine

when it comes to their disease while also looking at how women as well as the disease itself are conceptualized within biomedicine. Also, I want to compare the ways in which it is approached by different groups applying Kleinman and Langwick's understanding that different groups of people, even within the same community, approach disease from many varied angles.

Critical medical anthropological ideas are helpful and informative, but if they are not expressed in a sustainable manner in the biomedical field then as anthropologists we must ask what we can do differently to enact positive change. Authors such as Hemmings (2005), Manderson (2010), Pfeiffer (2008), and Singer (1995) explain that medical anthropology needs this critical component, but they also argue that it is not enough for the field to simply critique healthcare policy and practices. Many of these authors, as well as myself, call for the addition of applied anthropological knowledge to this critical approach as one way of making a difference. Some see applied medical anthropology as simply the next logical step when dealing with critical medical anthropology (Manderson 2010; Pfeiffer 2008). Combining these two approaches can be difficult due to the fact that anthropology and healthcare often hold contrary ideas about what is important and how to help patients.

Many anthropologists have discussed the importance of understanding personal histories and illness narratives in order to study people; they are especially useful in a globalizing world. Kleinman (1978) was one of the first to do so in his work. He (1976) and Wolf (2010) also take a more holistic approach to most subjects, preferring to show how different theories, histories, powers, and other ideas intersect with one another rather than simply focusing on a single subject. This is the type of anthropological inquiry I would like to use in my own work in order to better understand how to apply changes which will help the quality of lives of many of the women who suffer from endometriosis. Understanding these narratives one may also better

understand how women with this illness view and conceptualize their disease. Looking at explanatory models and how they embody their disease is of the utmost importance when discussing it because it will help them feel that their voice is being heard and can inform their relationships with doctors as well as the disease itself (Einstein 2009; Huntington 2004; Lock 1993; Mamo 2009; Ross 2002).

3.2.2 Applied Anthropology

Medical professionals often do not see the qualitative work of ethnography as useful in their setting because what they are after is often more empirical, quantitative, or statistical data (Hemmings 2005; Manderson 2010; Pfeiffer 2008; and Singer 1995; Sobo 2009). Ervin's (2000) book, *Applied Anthropology: Tools and Perspectives for Contemporary Practice*, does not focus specifically on medical anthropology, but it does give some insight into how to deal with people and groups who do not traditionally value the work of anthropologists. One of the foci of the second edition is the use of rapid assessment which can be highly valuable in applied medical anthropology because it does not take as much time or funding as full on ethnographic endeavors, but also shows the value of having an anthropological point of view present (Ervin 2000).

Both Ervin (2000) and Bennett (2010) give a similar history of applied anthropology, with minor differences, saying that when it was started in the 1960's and 1970's it was looked down upon because it was not the way that the majority of social scientists were doing things. To this day applied anthropology has not fully recovered from a past where it was used by colonial

and other powers to assist in the maltreatment of participants; Ervin suggests that during the latter part of the 19th and early part of the 20th century that applied anthropology could be seen as the "handmaiden of imperialism" particularly with regard to the British colonies in Africa and the United States' Bureau of Indian Affairs (200:17). Bennett points out that the "applied side of academic fields in the human sciences is often viewed by scholars with ambivalence or even contempt" (2010:S23). Ervin (2000) brings up a similar point as well in his works, but says that as time has gone by it has become more acceptable and is considered anthropology's "fifth sub-discipline". Using Eric Wolf's (2010) ideas to try and understand the history of how political powers and the movements act as a pendulum to one another is important in figuring out what the next step is in possible actions to be taken within trying to understand women's healthcare. This is where applied anthropological theory is helpful to the medical aspect and may be put to good use.

3.2.3 Social Science, Endometriosis, and Trends

Sarah Jones' (1988) Ph.D. dissertation, *Body Image and Anxiety in women with Endometriosis,* could be argued to further explore areas between medical establishment and social science. The text has aspects of autoethnography and critical medical psychology (similar to Kleinman's (1978) original work that helped contribute to the development of critical medial anthropology) scattered throughout a text that is for all intents and purposes a psychological work on a disease. It is highly medicalized with charts, graphs and statistics throughout, but the subject matter, body image and anxiety, as well as the sociocultural components suggests the influence of social science. Of note in Jones' dissertation is the fact that in her appendix she shows The

American Fertility Society (now called the American Society of Reproductive Medicine) Revised Classification of Endometriosis chart for staging the disease and it is the same chart that was used by my second doctor to diagnose me with Stage II. Jones' dissertation was finished in March of 1988 and I was diagnosed with the exact same classifications in May of 2012; with all of the advances made in studying this illness in those 24 years and two months it is surprising that the same chart would continue to be used with simply a name change at the top of the form.

Jones is not the only person to have endometriosis and to discuss it in a sociocultural context. Emma Whelan, a sociologist, (2003, 2007) also discusses it in her work. Whelan focuses on chronic pain conditions in her work and how doctors and patients interact with one another. Whelan's 2003 article, "Putting pain to paper: endometriosis and the documentation of suffering," integrates her academic interest in chronic pain and her status as a woman with endometriosis. She states that "[w]e attempt to defy pain's privacy by defining it, measuring it, theorizing about it and analysing the accounts of the one in pain. But representations of pain – definitions, measurement, body language, theories – are not equivalent to pain itself" (Whelan 2003:464). She further discusses the use of pain scales and how they are often another hindrance between doctors and patients. She also explains that there are currently two widely used pain scales specifically dealing with endometriosis. The first is from the American Fertility Society and focuses on pain scales similar to those found elsewhere, focused on numbers, while the other is by a woman who has endometriosis, Andrea Mankoski (Whelan 2003). The Mankoski pain scale focuses on a three column system which explains pain with a number system similar to those regularly used, but also gives parameters to measure functional ability and how the pain responds to various medications (Whelan 2003). Figure 3.1 shows the scale which is read from left to right with each row correlating with one another, for example, 0 indicates that an individual is pain

free and does not need medication while the number 5 shows that the pain cannot be ignored for prolonged periods of time and that mild pain killers will work temporarily. Many groups both support groups for chronic pain and doctors themselves have adopted this pain scale because it is more informative than simply telling the doctor a number (Whelan 2003).

Numeric Pain Intensity Scale

The typical numeric scale to gauge pain is from 0 to 10, with 0 being no pain, and 10 being very severe, intolerable level of pain. The scale below explains the numbers.

Mankoski Pain Scale

	0	Pain Free	No medication needed
	1	Very minor annoyance-occasional minor twinges	No medication needed
	2	Minor annoyance-occasional strong twinges	No medication needed
	3	Annoying enough to be distracting	Mild painkillers are effective. (Aspirin, Ibuprofen)
A "good day"	4	Can be ignored if you are really involved in your work, but still distracting	Mild painkillers relieve pain for 3 to 4 hours
	5	Can't be ignored for more than 30 minutes	Mild painkillers reduce pain for 3 to 4 hours
Average Pain level somewhere around here	6	Can't be ignored for any length of time, but you can still go to work and participate in social activities	Stronger painkillers (Codeine, Vicodin) reduce pain for 3 to 4 hours
	7	Makes it difficult to concentrate, interferes with sleep. You can still function with effort.	Stronger painkillers are only partially effective. Strongest painkillers relieve pain (Oxycontin, Morphine)
Frequent spikes up to here	8	Physical activity severely limited. You can read and converse with effort. Nausea and dizziness set in as factors of pain.	Stronger painkillers are minimally effective. Strongest painkillers reduce pain for 3 to 4 hours.
	9	Unable to speak. Crying out or moaning uncontrollably - near delirium.	Strongest painkillers are only partially effective
	10	Unconscious. Pain makes you pass out.	Strongest painkillers are only partially effective.

Source: www.valis.com/landi/painscale

Figure 3.1 Mankoski Pain Scale

In Whelan's 2007 article on endometriosis, "'No one agrees except for those of us who have it': endometriosis patients as an epistemological community," she postulates that the women in her study are an epistemological community as defined by Lynn Hankinson Nelson (Nelson 1993 cited in Whelan 2007), who are disenfranchised with biomedical care for various reasons

and form a community of their own in order to assist and support one another. Some of the women in Whelan's (2003, 2007) study had taken years to receive a diagnosis while others had tried many hormonal treatments that did not work for them. Also, she points out that these communities are not simply about "griping… or sharing experiences," especially and increasingly since they have moved online (Whelan 2007:977). She further explains the ways in which these women began to build their epistemological:

> "First, women *use medical sources to evaluate the validity of clinicians' statements…*Secondly, women with endometriosis often *use the claims of medical science to evaluate each other's assertions*, which again demonstrates the extent to which they take on medical epistemological standards…Thirdly, *one's own experience and the experience of other women with endometriosis are used to evaluate medical claims*…Fourthly, some women use both medical information and the experiential accounts of other women to interpret their own experience, especially their state of mind and physical sensations…" (Whelan 2007: 968-971).

Both Whelan (2003, 2007) and Jones (1988) do give bibliographies that list many sources which deal with endometriosis; however, they were primarily biomedical in nature. There are many books written about endometriosis in lay literature. The most prominent and highly recommended is often Morris' (2006) *Living Well With Endometriosis: What Your Doctor Doesn't Tell You... That You Need to Know*, which has been referenced in this paper many times, because it has a comprehensive medical section mixed with stories and suggestions from other women with the disease. This particular book reads similar to autoethnography with the exception that the author does not talk about herself except in the introduction to the book (Morris 2006). Other books that I read after my diagnosis included *Endometriosis for Dummies* (Krotec & Perkins 2006) and *100 Q&A About Endometriosis* (Redwine 2008), which has also been referenced in this paper, these all pretty much acted as survival guides in dealing with the disease. There is a current trend in self-help books dealing with a so called "endometriosis diet" and still others dis-

cussing a detox regimen, but I have not read any of these works and the EFA (2011) as well as many doctor suggest being weary of them. These books often suggest that one can cure themselves of the disease or, less drastically, minimize their symptoms by omitting foods, such as dairy, gluten, and/or meats, from their diet; many doctors, such as my own, do suggest minimizing the intake of foods, like meats that have been injected with artificial hormones, those that have caffeine or other foods that can cause inflammation since these can often make the pain worse (EFA 2001; Morris 2006; Redwine 2009). In *Flexible Bodies: the role of immunity in American culture from the days of Polio to the age of AIDS,* Martin (1994) points out that this is not an uncommon phenomenon. She discusses how healthy Americans have historically been encouraged by the media to view themselves as empowered and having control over their bodies while the ill are blamed for being unsuccessful at curing themselves (Martin 1994).

3.3 Women's Health beyond Illness

3.3.1 Hysteria, Mental Illness, or Attention

Taking a look at the history of endometriosis one sees that the healthcare of women under the biomedical model has indeed changed over the years, but perhaps not as much as we would like. Western biomedicine has moved from a time when everything wrong with a woman was blamed on "hysterical moods" to the present where she might instead be looked upon as having a personal problem with depression or anxiety rather than a larger scale social or in this case medical, issue; women with endometriosis often face this dilemma. The idea of hysteria is illustrated best in Charlotte Perkins Gilman's partially autobiographical work, *The Yellow Wallpaper,* where

she talks about being kept in a single room and having her husband and a physician tell her that if she does not give up her passion for “intellectual labors” that she will not become well again (1892:172). Luckily for herself and feminism, she refused and became one of the major names in first wave feminism. She wrote extensively on feminist ideals and eventually lived to see women get many of the rights that she sought for them. Sadly, healthcare equality was not one of those things accomplished by early feminists. Even forty years after achieving the right to vote, women were not equally treated as citizens, and their healthcare suffered for it. Betty Friedan (1963) illustrates in her work, *The Problem That Has No Name*, how the mental health of women was all but ignored in America during the 1950's. They made up the majority of a psychologist's patients, but when they went to their doctors for explanations about why they were not happy, they were often still told that they should be happy and it was explained that their problems were being exaggerated (Friedan 1963:364).

3.3.2 Health is NOT Simply about Disease

One must also understand health beyond looking at diseases alone. The human body is immensely complex on its own without the worry of disease. If you believe the pervasive public and medical opinions, women's bodies are even more complex and difficult to understand than those of men (Cook 2009; Einstein *et al*. 2009; Green 2008; Hahn 1987; Lagro-Janssen 2007; Lock & Nguyen 2010; Simonds *et al*. 2007; Verdonk *et al*. 2005, 2007). Menses, pregnancy, birth, infertility, menopause and noncancerous breast health are all important when trying to get a holistic picture of women's health and care, not to mention all of the other organs an systems that help to make it up. Biomedicine often looks at these aspects of a woman's life as though they

are abnormal in and of themselves. They are treated as though they need medical attention and treatment and so have moved out of the realm of natural bodily functions to a medicalized area where they can be observed and controlled, especially aspects of procreation and menopause (Simonds *et al*. 2007; Lock 1997, 2010; Cook 2009; Einstein *et al*. 2009; Green 2008; Hahn 1987; Lagro-Janssen 2007; Lock & Nguyen 2010; Simonds *et al*. 2007; Verdonk *et al*. 2005, 2007). In *Laboring On: Birth in Transition in the United States,* Simonds *et al*. (2007) discuss the medicalization of pregnancy and birth while Lock (1997, 2010) discusses this over medicalization in other aspects of women's lives such as puberty and menopause, from a cross-cultural perspective. Many authors call for a fundamental restructuring of the biomedical system and the ways in which it deals with female bodies, particularly the ways in which it deals with diseases that predominantly affect women and the over medicalization of nondisease related healthcare (Simonds *et al*. 2007; Lock 1997, 2010; Cook 2009; Einstein *et al*. 2009; Green 2008; Hahn 1987; Lagro-Janssen 2007; Lock & Nguyen 2010; Verdonk *et al*. 2005, 2007). Many of those who participate in the biomedical system, such as doctors, nurses, and duals are also calling for similar changes with the desire to help women in all aspects of their healthcare (EFA 2011; Tulandi & Redwine 2004; Strausz 2001; Osteen 1997; Morris 2006; Simonds *et al*. 2007).

3.3.3 Patient Activism (Part I)

At this point one must also understand that this is an area where some of the patients are also activists, volunteers, and, in my case, even the native researcher. In order to fully understand these individuals Sherry Ortner’s (2006) discussion of agency is useful. Agency in this case can be understood as an individual's ability to affect their cultural surroundings and act to change

their current situation (Ortner 2006). As she states, “[a]s truly and inescapably social beings, they [in this case, patient-volunteers] can only work within the many webs of relations that make up their social worlds” (Ortner 2006:252). Many women with endometriosis have a complex role to play being a patient, volunteer, researcher, amongst other roles and they must approach these roles differently, while at the same time understanding that they are most definitely intertwined. As one who takes on many of these roles, I understand and empathize with the women who wear multiple hats within the endometriosis community. Unlike many of them, I can use my knowledge of applied anthropological knowledge, agency, critical medical anthropology, and other awareness to assist in these changes. Ultimately social science theories that relate to women and the body and to historical processes that shape them in a coherent way to effect change on local as well as global situations when it comes to women's healthcare.

4 RESULTS

4.1 Phases of Endometriosis

Endometriosis, like a woman’s life and body, goes through many phases and cycles. Many societies, the ancient Celtics, Greek, and Romans as well as many Pagan groups today, have myths where there is a triple goddess or three phase goddess, usually represented by the phases of the moon; these are generally called the maiden, the mother, and the crone and correlate with the waxing, full, and waning moon respectively (Christ and Plaskow 1979, 1989; Davis 2005). In these beliefs, woman’s individual body also goes through these cycles when she is pre-

pubescent, goes through puberty, and finally reaches menopause (Christ and Plaskow 1979, 1989). These stages do not correlate to endometriosis; however, endometriosis itself does have phases that may not be as well defined as those of a woman's life, but they can still be seen in all of the stories from the women that I have spoken with for this research and should be understood and discussed.

The first phase of endometriosis is the shortest and often the scariest; it is what I refer to as the discovery phase. This phase happens when the girl or woman discovers that her body does not work the same way as those of the other females around her. Each of the women that I interviewed had their own discovery story. Anna's discovery occurred when she realized that none of the other girls in her class had to bring a change of clothes to school because they did not bleed through theirs as she did. Laura's was when she realized that after her third child that she would never have a "normal" period again and most likely would not have any more children (she had four miscarriages after the birth of Harmony). Mine was when I realized that the pain that I was feeling during my periods was not the same as the other girls around me; I could take the same medications that they did, Pamprin, Mydol and the like, and feel worse than I had before (I discovered later that this could be caused by caffeine which can be found in many of these pills). For Penny this phase occurred later when she discovered that she could not have children.

The second phase is the quest phase which can often be the longest and most trying phase of the three. This phase is after the woman accepts that her body is different and begins the journey of asking why that is the case. For many women this phase can take years or even decades, such as in my story. Women go through various doctors; must deal with incorrect or inaccurate diagnoses; and miss vast quantities of school, work, and life events during their quest. Some women will get diagnosed with as many as four incorrect or not fully explained illnesses before

reaching the conclusion that she has or also has endometriosis; the misdiagnosis can include everything from PID, IBS, ulcers, stress, anxiety, domestic/sexual violence, and more.

The third, and final, phase is the revelation phase. This is the phase where the quest is fulfilled and a diagnosis is achieved; however, diagnosis is not the end of the journey. Often the revelation that women with endometriosis have is that they are not alone on her quest for answers. Also, the quest phase and the revelation phase may significantly overlap with one another, especially when these women realize that their quest for answers does not simply end with a diagnosis of endometriosis. Since treatment for the illness is not standardized and often left to the discretion of a woman's insurance company there can be a quest for pain relief and a cure even after the revelation of diagnosis (Morris 2006, Redwine 2009; Diamond & Osteen 1997; Strausz 2001). Many women such as Becca, Penny, and Rose had multiple quests and revelations when they had to go through hysterectomies even after their excision surgeries.

4.2 Individual versus Illness

Whelan explains the ways in which individuals with endometriosis view themselves beautifully when she says:

> The way that women in the endometriosis community conceptualize their bodies is complex… Sometimes, the body is equivalent to the self ('I'm sick'). At other times , the ill body is depicted as alien to—and a burden to—the self 'Someday hopefully I will like my body again and there will be a cure' (W8) At still others, the disease of endometriosis is the alien, and the body is burdened with it. For these women, their bodies are a fundamental source of self, understanding, critique, puzzlement, and misery all at once (Whelan 2007:972-973).

This is often how the women that I spoke with also discussed themselves in relation to the illness. During interviews with the adults some variation on all of three cases

came up in each interview, usually it was the second “my body is doing this to me” scenario with instances of the others scattered throughout. The first was usually mentioned in past tense saying that they were sick, before the diagnosis when they were unsure of what was wrong with them. Often the women would discuss the endometriosis as alien situation when the topic of having children was brought up. The reason for this is most likely so that the blame of infertility and/or miscarriage(s) was not placed on the self, but rather on the alien residing inside their womb. Many of the women, including myself, Rose, Laura, Becca, and Heather all had feelings of guilt and anger towards ourselves and bodies after our miscarriages, but as Heather (who has not been officially diagnosed) said during the focus group, “If I can’t have kids because of this disease, then it isn’t my fault, it’s the disease’s and I shouldn’t feel like I did something wrong.”

In the case of the minors, none of whom had been officially diagnosed, the reactions tended overwhelmingly toward the first, “I’m Sick” scenario, with no instances of the third and only one of the second. One of the minors that I spoke with, Harmony, was not sick and shows no signs of the illness, but was present when her family participated in the focus group and so was allowed to as well. That being said, she discussed the illness similarly to the first scenario when talking about her mother and sisters. She frequently said things such as, “They’re always sick” or “I guess I don’t get it because I’m not sick” equating her family members to the illness. There are multiple reasons that this may be so prevalent in the younger participants, Heather, who is not a minor but is still close in age at 19, said many of the same things. First, these girls are not yet fully socially self-aware and have not had a chance to develop the self-awareness that is so common in adults. Secondly, and I would argue more likely, is because they have not been diagnosed

with the illness so they do not have anything to blame but themselves at this point. They are still in the discovering phase or possibly the early quest phase of their illness, which many of the older women discussed in the same manner when reflecting back on it.

Most of the women would agree that the transition from discovering to quest phase is one of the most isolating and difficult times. Rose discussed it at length because hers happened more recently than most of the other women's. She did not begin to show signs of endometriosis until her thirties, after multiple miscarriages. She became very depressed, felt isolated and lonely, much as the other women describe during this time in their narratives. Since most of the participants began to show signs of this in their teens it is simple to see how these girls who have not yet been diagnosed might internalize it even more since they do not yet know for certain if they are sick with endometriosis.

4.2.1 Racial & Socioeconomic Differences

There are many diseases that are predominantly found in women that have been looked at through a social science lens including: breast and cervical cancers, uterine fibroids, and pelvic inflammatory disease (PID). Lende and Lachiondo (2009) discuss breast cancer in African American women while Modiano (1995) discusses breast and cervical cancer in Hispanic women; both studies focus on the embodiment of the diseases and how the women conceptualize having it and deal with it emotionally. These studies were conducted in a manner similar to Whelan's. Roberts (1997) briefly discusses PID in her book, *Killing the Black Body: Race Reproduction and the Meaning of Liberty*, and explains how many women of color are incorrectly diagnosed with pelvic inflammatory disease, or PID, instead of endometriosis

because of perceptions of them as having more sexually transmitted illnesses and a general uncleanliness associated with them. It has long been understood that women of color have taken longer to get diagnosed with illnesses than white women of similar socioeconomic means (Tulandi & Redwine 2004; Lende & Lachiondo 2009; Modiano 1995; Roberts 1997; Morris 2006).

As we can see there is a presence of racism that can be found in the diagnosis of endometriosis. African American women, as well as other minority women are often misdiagnosed as having diseases other than endometriosis such as PID (Robters 1997; Morris 2006). PID has many of the same symptoms as endometriosis such as pelvic pain, scar tissue formation, and/or irregular periods, but it is often associated with venereal diseases or uncleanliness. (Roberts 1997). Since there were no African-American women in my study and none of the Latinas had seen a doctor regarding diagnosis I cannot attest to how women of color were treated by the Atlanta doctors. However, while conducting this research I discovered that this tendency towards misdiagnosis not only holds true for women of color, but also for white women of lower, or perceived lower, socioeconomic class such as Kate, Laura, Tiffany, and myself.

The four of us all originated in families that were at or below the poverty line and visited doctors in the metro-Atlanta area who worked at discounted or free clinics because we did not have health insurance. We all encountered many of the same misdiagnosis that women of color faced when dealing with endometriosis in other studies. For example, doctors suggested that our symptoms may have originated with PID, complications due to previous abortions (none of us had gotten one), overuse of hormonal birth control, and/or domestic/sexual violence. This might suggest that at least some Atlanta area doctors have the notion that women of a lower

socioeconomic background are more promiscuous than middle class women since none of the middle class women admitted to being asked about these possibilities. The fact is that two of us were virgins when we went to the clinics and the other two were in long term committed relationships with their only partner at the time. These misdiagnoses are hugely problematic and stem not from the patients themselves but from the medical practitioners preconceived notions of who does and does not have endometriosis, if the doctors knew what it was at all.

There were also other differences in how the women of various socioeconomic classes dealt with the disease. The greatest discrepancy was in how each group approached working and schooling. For those in the middle class, school was a priority even if they were unable to attend classes all the time. On the other hand, work was important for those in the laboring class with attendance being of the utmost importance. Laura would frequently go to work at a local grocery store while sick and in pain then have to physically lean on a counter in order to not fall over from pain. When we worked together at this store, she and I would often cover for one another when the other became ill. Interestingly enough, we had the same illness but did not know it until many years later after we were both diagnosed. Also, we had coworkers who would frequently explain to me that I should not cover for Laura because she was a hypochondriac who was just making up excuses to not have to work. I am not sure if they said the same about me to her and did not ask.

4.2.2 Doctor-Patient Relationships

Doctors and patients often do not see eye-to-eye on many subjects, especially if that patient is a woman and/or a chronic illness sufferer (Steege et al 1998; Strausz 2001; Manderson

2010). This is particularly true for the pain that is often associated with chronic conditions. Many women told me of being treated as addicts or drug seekers. Kate and I discussed, via Facebook, how she had been accused of being a drug seeker at the ER:

> *Kate*: "I went to the ER because I didn't have a script [prescription], it ran out, and they treated me like all I wanted was a good fix."
>
> *Amanda*: "How so?"
>
> *Kate*: "They ignored the pain, thought I was making it up just to get meds, but I was in real pain, ya know? They just would NOT give me meds that I knew would work. They kept wanting to give me ones that had stopped working a long time ago. When I told them that those didn't work anymore they thought it was proof that I was looking for drugs [seeking]."
>
> *Amanda*: "Yeah, I know. You're not the only one to tell me a story like this, but it happened more than once, right?"
>
> *Kate*: "It happened in the hospital near me a couple times and then it happened when I was on vacation to Florida. I left the bag with all of my meds and things at home. Dumb! That time was way worse because it was a weekend and they couldn't get ahold of my doctor to verify that I had a script."

Earlier, I discussed Whelan's work on understanding pain and how it is interpreted which is of great importance when discussing illnesses like endometriosis; however, pain is often thought of as a symptom that can easily be taken care of with medications. She further discusses endometriosis and pain interpretation when she explains that people, especially doctors, "attempt

to defy pain's privacy by defining it, measuring it, theorizing about it and analyzing the accounts of the one in pain. But representations of pain – definitions, measurement, body language, theories – are not equivalent to pain itself" (2003:464).

In their book, *Chronic Pelvic Pain: An Integrated Approach*, Steege *et al*. discuss just this dilemma; they explain how pain is different for every patient, and that pain scales often do not fully allow for accurate interpretations by medical professionals (1998). Most pain scales in the United States are based on a numerical system from 1 to 10 and do not take into account information such as personal history, a patient's pain tolerance levels, or the fact that pain, as well as reactions to it, are sociocultural constructs (Steege *et al*. 1998; Morris 2006). This sort of thing is rectified in the Mankoski Pain Scale, but These complications of understanding pain are important issues when discussing endometriosis due to its classification as a chronic pain disease, but without a better comprehension of how to talk about or interpret pain dealing with illnesses like this one there cannot be progression in treatments and a patient's quality of life of suffers.

Pain and perceived drug seeking behaviors are not the only reasons why doctors and endometriosis patients do not always agree. Again, Whelan (2007) says it best when she describes how doctors feel about endometriosis:

> … literature describes many serious problems for women with endometriosis, such as delayed diagnosis, underfunded research, widespread physician ignorance, physicians' unwillingness to share what they do know about the disease, and medical minimization of the distress it causes; and it suggests that medical professionals do not take endometriosis seriously, probably because its suffers are women" (Whelan 2007: 958). "It seems clear that we cannot understand conflicts between physicians and patients and the challenge to biomedical authority in the present day simply as the result of patient demands for *more* or *better* medical information *from physicians*. What *counts* as good health information, and *whose* information is best, are at issue. The challenge of embodied health movements is not merely political; it needs to be addressed at the much deeper level of epistemological strategy and principle (Whelan 2007:979).

"[I]t suggests that medical professionals do not take endometriosis seriously…" I quote that again because it is important to understand that, as both myself and Whelan have pointed out, many of the women suffering from endometriosis view themselves as inherently linked to this disease. When the disease is not taken seriously, neither is the patient. Each participant who went through a quest phase discussed how it made her anxious and nervous to go to yet another doctor who she felt would not believe that she was really sick. All of the women had a major distrust of doctors, including the girls most likely either because the women in their families had been treated poorly by the medical establishment or because those in the lower socioeconomic class, which all of the minors were, tend towards this reaction when dealing with doctors (Mulder and Lambert 2005).

4.2.3 Insurance, the "Frienemy"

A frienemy is defined by UrbanDictionary.com as "an enemy disguised as a friend." Many authors both of medical and lay works discuss insurance companies in this way. Frequently insurance companies will only allow for select treatments of endometriosis and in most cases certain types of surgery, such as cauterization or exploratory, are only partially covered while excision is not usually covered at all (Redwine 2009; Morris 2006; Tulandi and Redwine 2004; Strausz 2001; Steege et al 1998). Drug treatments, particularly the hormonal shots, such as Lupron and Depo Provera, are often covered, but not for the entire duration of recommended treatment (Redwine 2009; Morris 2006). These also have side effects that can be devastating for many women. I spoke with participants who discussed Lupron as a treatment option they were given and all of them regretted taking it, including myself. The side effects that many of these

women brought up were weight gain, depression, anxiety, and loss of sexual drive or ability, not helping with or changing the pain, hair loss, acne, and mood swings. One of the women said that Lupron had such negative effects on her that she even went as far as to blame it for her divorce.

Many women had to file multiple appeals in order for insurance to cover things that are used in basic endometriosis care, such as birth control pills. The reason for this is because insurance would only cover twelve pill packs per year and usually only one per month; however, doctors often prescribe birth control pills continually for endometriosis in order to prevent menses, since this is the time when symptoms of the illness are the worst for most women. In taking the pills continuously, they skip the last week of placebo pills every month and continue a new pack earlier than they would have regularly. This makes it where they must purchase, most often times completely out of pocket, another pill pack in order to take their medication the way in which it was prescribed to them by their doctor.

4.3 The Atlanta Endometriosis Community

Most of the time when the endometriosis community is discussed it is from an outsiders perspective with information that they accumulated via online resource, at least in the medical literature (Redwine 2009; Tulandi and Redwine 2004; Strausz 2001; EFA 2011). The Meetup group, according to Rose, who founded it and paid for an online account for the group for over a year, consisted of about thirty members with only ten or so active members who came to most events. Rose explained that she began the group because she did not like how the online groups had been set up. She described the women on the forums as too whiney and said that she wanted

to move past the self-pity and negativity that she had felt for so long. She started the group in order to move away from discussing pain, both emotional and physical.

The group did discuss issues such as infertility, pain, loneliness, and the like, from time to time, mainly when someone was changing medications or doctors. The primary focus of the group was always on being active and making sure you did not become a shut in, as tends to happen with many chronic illness patients (Manderson 2010; Steege et all 1998). Meetups consisted of everything from meals together, to meeting at people's homes to watch movies/television events, to pool parties, hikes, and many other activities. The focus was always on the community, catching up with one another, talking about boyfriends and husbands, who got a cute haircut and the like without major focus on the illness itself. As Penny shared during an outting,"[w]e deal with this disease every day; we don't want to bring it into the fun of the meetups!"

Whelan's participants were from a similar in person group; however the initial focus of her study was to understand how these women discussed the drugs that had become the standard for endometriosis care at the time, not to understand these women as a group. Why did so many women join this group while others did not? While it was not in my initial questions for this project, I began to ask this question especially once I saw that different groups of women reacted differently towards such things. For example, most of the women who were part of the group had at least some college education with most of them having graduated or gone on to post-secondary education while those who did not seemed to shy away from the groups, including those online but to a lesser extent. This could be another part of the reason that endometriosis is seen as a "working woman's," understood in this context to be middle class, disease (Morris 2006). Joining the group requires the ability to participate in various events, or meetups as the

group calls them. This participation requires transportation, money, and time which not all of the participants were willing or able to dedicate to an endometriosis group. The main reason that I found for not participating in the group was that if one was unable to go to a meetup then there is not much point in joining. Also, of interest is that the women within this group had almost all had excision surgery with a local endometriosis specialist at the Center for Endometriosis Care while the women outside of the group had seen other OB/GYNs.

4.3.1 Patient Activism (Part II)

There are individuals who belong to the meetup group, but were unable to participate in the study who work for various endometriosis organizations. Both of these women are in other states, like Elizabeth now is, and participate in the group primarily online. One of these women, Heather Roppolo-Guidone, currently works for the CEC and is known as "one of the loudest voices in endometriosis" (CEC 2012). She is a women's health educator and endometriosis activist currently residing in New York. The last time she was in Atlanta she participated in a meetup where we all went to dinner. It is a dinner I will never forget. It was October of 2011 and Breast Cancer Awareness Month was in full swing, a couple of young women came to our table and asked for a donation. Heather stopped them in the middle of their spiel and said that we would give them money if they could tell her what endometriosis was; neither of them could and so did not get money from our table. This is not a story of activism itself, but of the fact that endometriosis needs more activists, like Heather, to educate people about what the illness is. She does this all the time when she gives speeches, presents at conferences, and even when she speaks at the Endometriosis Walk. During the opening speeches for the walk Roppolo-Guidone's "Survivor

Letter" was read on the steps of the Lincoln Memorial in Washington DC (2012). The entirety of the letter can be found in the appendix section and has been used to help explain what women deal with when they have endometriosis to family, friends, doctors, coworkers, and more.

Another important activist who is also a patient is Nancy Petersen, who Roppolo-Guidone admits to wanting to be just like when she grows up. Petersen was one of the first women to begin advocating for endometriosis patients. She has worked closely with and often advises many endometriosis specialists including the doctor who performed my surgery and Dr. David Redwine, who has been sited multiple times in this paper. Petersen works as a nurse and activist on the West coast.

Over time many of the women in the meetup group realized that there were other women, less fortunate than themselves, who were unable to seek the best treatments. This is when Elizabeth brought up the idea to begin EndoHope, a nonprofit group to help women pay for excision surgery, in order to help them. The idea was discussed at a meetup where everyone was going out to lunch and then going for a hike. I was unable to attend this event, but Rose discussed it in her interview when she said that Elizabeth "lit up" when discussing the possibility of helping do something of this magnitude. Ultimately, the goal of the new group was to pay for excision surgery via the CEC for women who could not afford it for whatever reason.

4.3.2 When Epistemological Communities "Split"

The new group actually caused a rift within the meetup group. From my understanding, initially EndoHope was supposed to be an offshoot of the meetup group that women did not have

to join unless they felt compelled; however, controversy came into the picture when Jody, amongst others, adamantly opposed the affiliation. EndoHope then became its own organization with many crossover members still involved in the meetup group. Since this time many situations have arisen which have caused a decline in the meetup group's attendance and the number of scheduled meetups: Rose has resigned as leader of the group, Elizabeth has moved to another state, and Kate and Jody have moved to more rural areas of Georgia. This is in no way suggesting that EndoHope was the cause for the breaking up of the meetup group, but if Whelan's (2007) assumptions about the epistemological community are correct, a drastic shift in ideology or the discovery that the group is not as cohesive in their thoughts as they once were may cause the group to disconnect from one another. This disconnection is evident when looking at the groups Facebook page where the last entry was one I posted about my thesis in early November and the last post before that was in mid-October. That post was not about a meetup, but rather about surgery advice.

5 CONCLUSIONS

I began this paper with my own journey through endometriosis and I have defined the phases of endometriosis consciousness that patients often go through when dealing with this disease. First there is the discovery phase where the patient realizes that her body and experiences are different from the women around her. Second is the questing phase where she seeks answers as to why the body and experiences are so different from the norm. Thirdly, but not always finally, is the revelation phase; in this phase the woman may visit the other two phases frequently, especially phase two. In the third phase the woman has gotten her diagnosis of endometriosis, but must

face new challenges such as the health care system not having standards for the care of endometriosis, difficulties with insurance companies, and even more surprisingly the fact that people will still criticize her after her diagnosis because it deals with her reproductive system.

I have shown that women in the Atlanta endometriosis community, though divided along many facets such as age, socioeconomic background, beliefs about activism and so on, all tend to agree on major key points. First and foremost, they agree that endometriosis must be taken more seriously by medical professionals. Next, the fact that doctors do not take them seriously about their pain extends into the rest of the world because the lay person often does not take them seriously either. Our society has many historical precedents for this type of behavior as illustrated in this paper, but these women still have the hope that it will change. Participants also agreed that this is not something that a woman should ever have to endure alone. While many of the women turned to support groups, either in person or online, others turned to family and friends who they trusted to help them through their illness. Only one of the women, Jody, ever suggested that her doctor was present in her support system.

5.1 Future Research & Goals

Future research must be conducted on this topic because it is one of the most prevalent human diseases with ten percent of the female population possibly having it, yet rarely individuals know what it is (Redwine 2009; Morris 2006; EFA 2012). Aspects that still need further examination from a biomedical standpoint include, but are not limited to: doctor-patient relationships, causation, consensus on treatments, and the simplest way of distributing the existing knowledge to more doctors as well as lay people. From a social science aspect much more can be

studied and learned by examining this disease and the women who have it. We must examine the community around the illness, women's experiences with it, how the media and biomedical field approach it, doctor-patient relationships, activism surrounding the disease, and much more.

My eventual professional, as well as personal, goal is to see this research bring patients, their doctors, those who study the disease, social scientists, and activists for women's health issues into conversation with one another to help find better treatment options, inform biomedical research, create a public that is knowledgeable of the disease, and to foster community for those who already live with it. My greatest wish is to somehow be involved in aiding to find preventative measures and/or a cure for endometriosis through my research. More practically, I would like to be involved in the endometriosis healthcare movement throughout my career.

5.2 Recommendations

- Healthcare providers, doctors, especially OB/GYNs and pain specialists, must be educated about the illness: theories of causation, treatment options (both hormonal and surgical), its relationship to depression and anxiety as well as other illnesses, and finally, how to discuss these things with patients in terms which they can understand.
- Doctors should also be familiar with the Mankoski Pain Scale as it is a superior tool for discussing pain, especially chronic illnesses such as endometriosis.
- Doctors and pharmacists should implement more understanding and sympathy when dealing with patients who have a chronic condition as they are the most likely to consider a woman a "drug seeker."
- Patients must also be educated about the illness. Ideally this would come from their

healthcare provider rather than the internet or a support group.

- Support groups should be more focused on the aspects of wellbeing, activity, and advice rather than as simply a place to vent frustrations.
- Insurance companies should not have a choice but to provide patients with the care that is considered appropriate by themselves and their doctor, be it surgery, medication, or any other treatments.
- Books discussing the disease, especially the dietary aspects, should be reviewed for quality and rated for accuracy.

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APPENDICES

Glossary of Terms

- *Adenomyosis*: Was known as endometriosis interna for many decades, but was later found to be a separate disease. It is found inside the muscle tissue of the uterus and may also cause many of the same symptoms as endometriosis, such as infertility, pelvic pain, sexual issues, as well as difficulties with their bladder and bowels. Adenomyosis and endometriosis will occur together in many women.
- *Adhesions*: Internal scaring that connects tissues that are not usually connected
- *Autoethnography (as I use it):* There are multiple ways to conduct autoethnography, but the way I chose to follow was Leon Anderson's idea of Analytic Autoethnography with a few minor changes. He defines it using five steps which culminate in a paper or project which uses the authors' native status as a form of information which is as analyzed and interpreted as those of any informant. I add to this Narayan's concept that there is no such thing as a native anthropologist.
- *Cul-de-sac (aka Recto-uterine pouch or Pouch of Douglas)*: The region in the pelvic area where the pelvic cavity, rectum, and uterus meet.
- *Endo*: The standard abbreviation of endometriosis
- *Endometriosis*: a gynecological disease where tissue similar to the endometrium is found elsewhere in the body. Usually, it is found on the outside of the uterus, in the pelvic cavity, in the cul-de-sac and can sometimes be found on the bladder, rectum, vaginal walls, diaphragm, appendix, lungs and brain, with the last four being very rare.
- *Endometrium*: the lining of the uterus that is shed during menses

- *Endosister*: A fellow woman with endometriosis. Most of the women that I spoke with used this term for anyone with the illness, not just those found within the groups. It is frequently found online and in books that discuss the topic.
- *Excision*: Surgical removal by cutting, in this case endometriosis lesions
- *Hysterectomy*: When part or all of the female organs are removed from the body, may happen laparoscopically or via traditional surgery.

  Multiple types:

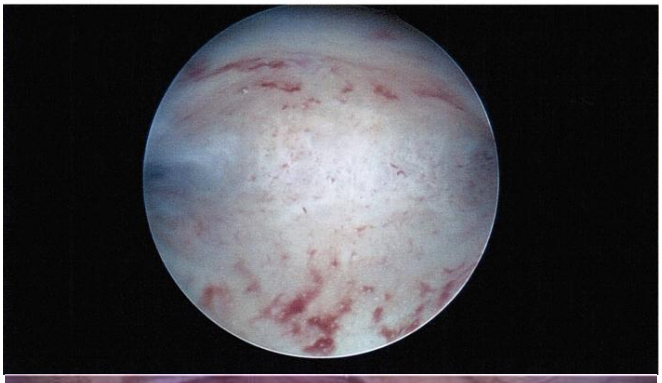
  Full: indicates all of the female organs including the ovaries, uterus, and fallopian tubes were removed. May also indicate that even parts of the cervix and vagina were removed, but not in most cases. *Most often given to women with endometriosis*

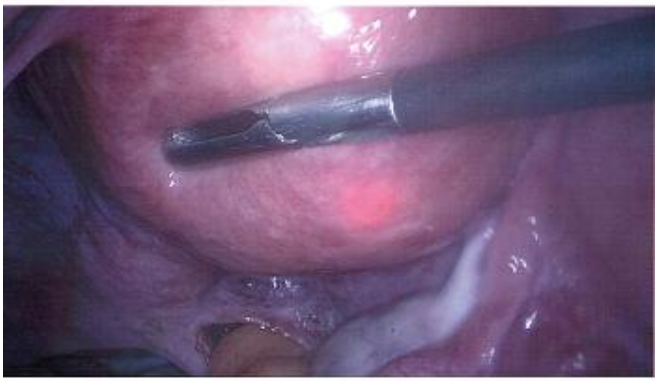
  Partial: indicates that only some organs mentioned above were removed while others remain, usually does not involved the cervix or vagina.
- *In vitro fertilization (IVF)*: When a woman's eggs are removed, fertilized, and then placed inside of a uterus (either hers or a surrogate's).
- *Inter-uterine deceive (aka IUD): Method of birth control which is implanted directly into the uterine wall to prevent implantation. Has been used in women with endometriosis as a way to keep the endometrium from growing. The idea being that if the lining is thin then shedding it will be less painful with fewer clots.*
- *Lupron*: Hormonal drug that is often prescribed to women with endometriosis. It can have undesirable side effects, such as worse pain, mood swings, hair growth/loss (usually to different parts of the body, example growth on the face/arms/breasts and loss on the top of the head or pubic area at the same time),

weight gain/loss (usually gain), menopausal symptoms such as hot flashes, night sweats, and dry mouth/vagina.

- *Med(s)*: Short for medication(s)
- *Menarche*: A girl's first period
- *Menses (aka period or "that time of the month"*: When the endometrium is shed and the woman bleeds after not fertilizing an egg during her cycle.
- *OB/GYN*: Obstetrics and gynecology
- *OTC*: Stands for Over the Counter, these are drugs that can be purchased from local drug stores or supermarkets without a prescription from a doctor.
- *Pelvic Inflammatory Disease (PID)*: is a vague term and can refer to viral, fungal, parasitic, though most often they are bacterial infections which lead to inflammation and scar tissue leading to adhesions in the pelvic area. Often women with endometriosis, especially those of lower socioeconomic classes or women of color, are misdiagnosed with this illness.
- *Polycystic Ovarian Syndrome (aka PCOS or PolOsy)*: An gynecological disorder where the ovaries produce multiple cysts and can cause infertility, pain, and irregular periods. PCOS and endometriosis will often occur together in women.
- *Sciatica:* Refers to pain, weakness, numbness, and/or tingling in the leg. It is caused by injury to or pressure on the sciatic nerve.
- *Script(s):* Short for prescription(s)

Amanda's Surgery Photos





Endometriosis Organizations

Endometriosis Foundation of American

Headquarters: Milwaukie, WI

Mission Statement:

The Endometriosis Foundation of America is a 501(c)3 non-profit organization focused on fighting against the devastating effects of a painful disease affecting 176 million women and adolescent girls around the globe. Through increased awareness, education, research, and legislative advocacy, the EFA is committed to improving lives through early detection and treatment

Website: endofound.org

Other Information:

- The organization was founded by Padma Lakshmi and the physician who diagnosed her with the illness.
- They conduct a scientific and medical conference every year
- They have an annual gala known as the Blossom Ball after the conference

Endometriosis Association

Headquarters: Milwaukie, WI

Mission Statement:

The Ulitmate goal of the Endometriosis Association is to find a cure and prevention for endometriosis while at the same time providing education, support, and research to those accepted. We are an international nonprofit organization that provides information about endometriosis in numerous languages.

Website: endometriosisassn.org

Other Information:

- First organization for endometriosis, founded in 1980
- The only multinational endometriosis organization

Endometriosis Research Center

Headquarters: Delray Beach, FL

Mission Statement: Educate, Support, Empower. It is the ERC's goal to make a positive difference in the lives of the millions suffering from this disease.

Website: endocenter.org

Other Information:

- The largest free resource for people interested in endometriosis

- Began as a resource for doctors who wanted to learn more about the illness
- Still one of the largest funders of research into the disease

“Survivor Letter”

Dear Parents, Partners, Friends, Families, Employers & Doctors:

We have spent the last years of our lives apologizing for being stricken with a disease we did nothing to contract, and we can do it no longer. We are asking - again - for your understanding. We are not responsible for failing to live up to your expectations, the way you think we should. What you seem to fail to realize, is that you are just as much a part of the cycle of the disease as we are, because you are not getting the whole of our person and our capabilities.

We are not "lazy," we are not "whiners," we do not make the pain up "in our heads."

We have endometriosis.

We know that we look healthy on the outside, and that is sometimes harder to accept than if we exhibited the disease in our every day appearance. What you don't see is what our organs look like on the inside, and you don't see what living with it has done to our emotional well-being.

When we call in sick, it's not because we need a mental health day or to "go shopping." It's because we can't get out of bed from the pain. Do you think we like letting our careers suffer? Would it be easier for you to understand if we said we had cancer and looked the part?

When we get emotional and cry at the seemingly silliest things, or get angry for even less reason, it's not because we are "flaky women." It is because we are taking drug therapies to stall this incurable disease, or perhaps it's because we have come close to the breaking point after dealing day in and day out with the pain for which there is no defined cause or absolute cure.

When we can't have intimate relations with our partners, it is not because we don't love you or want to. It's because we can't. It hurts too much. And we aren't feeling real attractive right now.

When you, our parents, can't understand that since you are healthy, we should be too, but aren't - try harder. We don't understand it either. We need your support more than anyone's.

When we can't go to family gatherings or accept social invitations, it's not because we don't wish to share in your fun. It's because we feel like pariahs. You are all having such a nice time with your children and loved ones - we can't remember the last time we had a nice time, or the last time we were pain-free. We can't have a nice time with our children (some of us); because we were robbed of that chance before we were old enough to even care about having them in the first place. Do you think we need to be reminded of our battle with infertility by watching you and your babies? Or for those of us who were blessed enough to be able to conceive, do you think we want a constant reminder that we never feel well enough to spend enough quality time with our children, or worse - that we might have passed this disease down through our genetics onto our daughters?

When you married us, you didn't know that we meant the "in sickness and in health" part literally, did you? We bet you were counting on at least a 50/50 split of that combination, rather than the 90/10 ratio you got. You are our caretakers, the ones who drive us to and from our doctors, countless surgeries, and emergency room visits. You are the ones who hear us crying in the night and see us break down during the day. You are the ones who wait on us hand and foot after surgery. You are the ones that go for months on end without sharing our beds with us. You are the ones that deal with our infertility right along with us. We strike out at you when we are hurting and angry, and you take it in stride. You are perhaps bigger victims of endometriosis than even we are. You are appreciated more than words can ever say.

Don't give up on us now.

As a medical professional, we are coming to you for help. We are asking you to do the job you were trained to do and ease our suffering. We do not need you to tell us that we are imagining the excruciating pain we live in, or worse yet, that it is "normal for a woman to hurt." Keep up with your research, find the cause of this disease and better yet, find a cure! Stop taking the easy way out and drugging us into oblivion so that we will quiet down. We want answers and it is your job to provide them. You were the ones that took the oath to heal - why do we have to try to do your job? Do you understand what it means when we tell you that we literally can no longer live a normal life and care for ourselves and our families? We're not drug seeking; we're answer seeking.

Are you not up to the challenge to find the answers?

To those we have called friends all our lives, why have you deserted us when we needed your compassion and understanding the most? Do you see the selfishness of your actions? When we can't get together with you, it's not because we don't like you or we don't care - it's because we are no longer capable of enjoying healthy leisure time. Our minds are consumed with our next doctor's appointments, what surgery we are going to have next, and why we feel so sick all the time. This is not about you - it never was and it never will be. It is about us. Please try to remember what the term "friend" means.

Try to walk one minute in our shoes. We have fought a war for the better part of our years. We are faced daily with physical pains we can't understand and mental anguish we can barely cope with some days. We face a society daily that doesn't even know the word "endome-

triosis," much less the ramifications of living with the disease. We have to face uneducated and unsympathetic doctors who tell us "it's all in your head", and "have a hysterectomy, it will cure you", or "get pregnant, it will cure you", when we know that it won't and have been dealing with infertility for the last however many years. Can't you see that?

We have to fight to get medical treatment that insurance companies don't deem necessary, or worse, we deplete our savings because aren't able to obtain proper care unless we pay for it ourselves and travel thousands of miles to the rare specialists that are few and far between. We have to have surgery after surgery and subject ourselves to horrific medications just to be able to get out of bed in the morning. This is not a conscious choice we made, it was the hand we were dealt. It is enough of a war we wage just to try and live with some modicum of normalcy - don't make it harder on us by not seeing the reasons why.

Endometriosis is a disease that affects all of us.

Take the time to learn about it and understand. If you can do that, and you can join us in the battle for a cure, then we can one day return to our old selves and live a normal, pain-free life. We can have healthy relationships with our loved ones. We can stop taking the painkillers that numb our suffering to a degree and become part of the living again.

Please don't judge us and declare that we are all the things we are not - until you have lived with this disease ravaging your mind and body, you cannot speak on it.

Whatever doesn't kill us makes us stronger, someone once said. While endometriosis may not kill our physical body, it tries like hell to kill our spirit. It tries to kill every hope and dream we ever had of doing the things that make us happy. All of us are out here searching for a cure to put an end to the disease...and we are holding our heads high in spite of endometriosis and fighting it every single day.

We are asking you to take part in that battle and work with us beating it. Wouldn't it be nice to have back the daughter, wife, friend or loved one you once knew?

Think about it.

~The Sentiments of Millions of Endometriosis Survivors Around the World~

Interview Questions

1. At what age did you begin your period?
2. What sorts of things did you learn about periods before you got it? What were some of the things that you learned after getting it?
3. Have you been diagnosed with endometriosis?

    * If yes, at what age? What stage is it?

    * If not, do you/your family/your doctor(s) believe that you have it? Why?
4. Did you ever hear about endometriosis before it was brought up as a possible diagnosis? How did you know about it & what did you know?
5. What symptoms do you have? When did you start showing symptoms? Have your symptoms changed over time? How so?
6. Can you explain what it feels like physically? Emotionally?
7. How do other people react when you tell them you (might) have it?
8. Do you know other women who have it?

    * If so who? Do you often talk about it with them? What do you discuss?
9. What kinds of treatments do you use, if any? Why did you choose these specifically? What would you like to see out of endometriosis treatments that you do not see available now?
10. Describe your surgery experience. How many have you had? What kinds? All the same doctor? What were the results? Surgeries in the future?
11. Do you have any other illnesses?

* If so, are they related to your endometriosis? How?

12. What kind of support system do you have in dealing with this disease? (ex. Doctors, friends, family, support groups: online or off)
13. Has endometriosis caused problems for you in your daily life? (ex. Ability to do basic chores, ability to perform your duties at work/school, ability to function normally in social situations)
14. Has endometriosis caused any sort of issue in your romantic relationships? (ex. Ability to have/enjoy sex, fertility, and so on)
15. Have you had any children?

    * If so, how many? Was it difficult for you to conceive? Explain the process.

    * If not, do you want children? Can you have them if you do want them in the future?

Interview Highlights

This section will highlight the interviews (mainly the researcher's notes with some direct quotes which will be in quotation marks) of each participant, explain how they came to be part of the study, their relationships with one another as well as the researcher, and give any other important information that was found out during the interview, focus group, or by other means. Many parts of the interviews, such a follow up questions and focus groups, were not added to the following.

Amanda:

Age: 28

Self Identifies: Mixed, Native American/White, Fluid Socio-economic Class

Relationship Status: Divorced, Engaged again

Speaks: English, Spanish

School: Graduated College

Occupation: Student, Teaching Assistant

Children/Pregnancies/Miscarriages: 0/2/2

Diagnosed Officially: Yes

1) 9

2) a. Grew up with mother, aunt and two older sisters living in the same house, so I knew what to expect

b. that it can be way worse than people describe

3) Yes, Stage II & State III

4) No

5) a. fatigue, anxiety, depression, pelvic pain, back pain, joint pain, bowel and bladder problems, anemia when on period, and headaches

b. 11 was when they got bad

c. Yes, they progressively got worse over time. After the first surgery they got better and then began to get worse again after six months. After the second surgery they have stayed better for the most part.

6) a. It hurts so bad sometimes you can’t move because of the pain, stabbing, needles, and aches everywhere.

b. Very lonely, isolated, confused, angry

7) Confused, offer advice, tell you to get over it

8) now, yes, but not growing up. I know the meetup group, women from various jobs, and women I've met online.

9) a. Birth control pills, hormonal shots (Lupron and Depo Provera), surgery, OTC and prescription pain medications

b. I wanted to stop the pain and they were suggested

c. Faster diagnosis

10) a. 2 surgeries with 2 different doctors. The first was cauterization surgery and the second was excision by a specialist.

b. The results after the first surgery were less than ideal because of a complication which caused gas to become trapped in the left shoulder. So far, so good with the second surgery. No more surgeries if I can help it.

11) seasonal allergies, allergies to citric acid, tarragon, sulfa/sulfur drugs, arthritis, scoliosis, sciatica, anxiety, depression, dyslexia, and chronic bronchitis

12) Meetup group, online community, fiancé and friends

13) Yes, issues with school and work (especially physically demanding jobs), problems doing house work, difficulties keeping appointments due to pain

14) Has caused a great deal of pain during sex, freaks out partners that I can bleed that much, I have problems accepting help and have been lucky to have partners who are patient and understanding.

15) No, I had a miscarriage in the very early stages of pregnancy, but have never tried to conceive since

Other Important Information: Knows everyone involved in the research, set up the research, and is related to Anna.

Anna:

Age: 13

Self Identifies: White

Researcher Identifies: Working Class

Relationship Status: Not allowed to date

Speaks: English

School: Some middle school

Occupation: N/A

Children/Pregnancies/Miscarriages: 0/0/0

Diagnosed Officially: No

1) 10

2) a. the basics from a video at school

b. "that you can bleed irregular" meaning a cycle that is more or less than 28 days

3) a. No

b. "Yeah, 'cause I'm like you when it [her period] happens"

4) "Yeah, I knew. You got it and I might have, but uuuhhh… not sure what it is. I just know it hurts a lot on my periods and I bleed through stuff. What is it really?" [we discuss it for a while]

5) a. debilitating pelvic and back pain, heavy periods with clotting, severe headaches associated with periods

b. pelvic, back and head pains began before menarche, always a heavy/irregular bleeder, PMS, severe mood swings, anxiety

c. "They got more… worse when I got older"

6) a. “Like someone is punchin me in the guts or hittin me witha baseball bat, ya know? Sometimes like sombodys stabbin me right here” [points to her lower back].

b. “I don’t like thinkin ‘bout it.”

7) *Anna*: “Like I said, I don’t talk about it. It might freak ‘em out, like I’m sick or somethin.”

Amanda: “What if you are sick with it, like me?”

Anna: “Then I’ll take medicine; get better from it, like you.”

Amanda: “It isn’t something you can ‘get better’ from. If you have it, then you always have it. Kinda like, ya know, how Daddy has Diabetes [*Anna*: “Yeah”] even though he has medicine for it?

Anna: “That’s not right.”

Amanda: “No, it’s not fair, but that’s why people like me are researching it.”

8) a. Yes

b. Amanda [her sister]

c. not often, usually discuss the pain. Researcher suggests new ways to cope with the excessive bleeding.

9) a. heating pad, OTC drugs like Midol or Pamprin, exercise

b. different ones help different things, for example exercise helps take the mind off of the pain while Midol helps with the head/body aches and heating pad helps with the cramps.

c. “I don’t always want it, like you said, so a medicine that can make it go away.”

10) “I don’t want surgery again. Doctors already opened me up and did stuff to my heart… [*Amanda*: I remember, you were a baby”] I don’t want ‘em doin it to me there

too" [implicating her pelvic area].

11) a. anxiety, allergies [seasonal, aloe, aloe extract/fragrance, eucalyptus]

b. Did not understand the question

12) Family mainly her mother, father and her sisters. She has spoken to the school nurse about it before and goes there if she is having a rough day.

13) Cannot function normally while on period. Misses school/classes

14) N/A

15) N/A

Other Important Information: Anna is the researcher's younger sister. Amanda asked her to be in the study and permission was granted by their father. She has never met any of the other participants in this study, does not go to support groups, and has never been to a gynecologist.

Becca:

Age: Did not share (early 30's)

Self Identifies: White, Middle class

Relationship Status: Long term relationship

Speaks: English, French

School: Graduated College

Occupation: Tech Studies

Children/Pregnancies/Miscarriage: 0/1/1

Diagnosed Officially: Yes

1) Doesn't remember, in middle school

2) a. “I got the birds and the bees talk”

b. It can be debilitating

3) a. Yes, mid-twenties, she thinks 26

b. Stage III

4) a. Yes, from a co-worker whose sister had it.

b. He told her that it sounded like what she had, that there was pain and infertility

5) a. “Now, none. Maybe some fatigue.”

b. around 18, when she started college

c. Yes, but does not have any of these symptoms since her hysterectomy. pelvic pain, back problems, PMS, and migraines. Still has these symptoms: painful sex, anxiety, depression, infertility [now due to hysterectomy].

6) a. “Like being run over by a Mack truck, from the inside!”

b. “Lonely, very lonely.”

7) “Most people have never heard of it. If they have it’s because they are like my ex-co-worker and have a relative with it.”

8) a. Yes, the meetup girls

b. Yes, discuss things like going to dinner or a fair. Try not to focus on the illness

9) Excision, full hysterectomy,

10) a. 3

b. 1st diagnostic, doctor did not remove the illness, 2nd hysterectomy, 3rd excision

c. The first two were by the same doctor, the last was by someone else

d. “I’m supposedly cured, I guess. I don’t have that kind of pain all the time anymore if that’s what they mean by ‘cured’.”

e. “Not if I can help it!”

11) a. Yes: adenomyosis, anxiety, depression, seasonal allergies, food allergies to many spices (garlic especially), sciatica, and arthritis.

12) “I’ve got my endosisters from the meetup group and online, my mom tries too, but she doesn’t really understand. She has kids, ya know?” Often uses online support networks, calls for meetup group sessions, helped form EndoHope, talks to her excision surgeon frequently.

13) Yes, had difficulty in doing regular chores, could not maintain relationships [especially sexual ones], work and school were difficult. Now things are easier since she doesn’t have the constant pain, but she still feels like sexual relationships are difficult.

14) “And how! It has been an issue with every single guy I have ever dated. My boyfriend now has three kids, so he doesn’t care that I can’t, but others did. I broke up with my fiancé about a year after my hysterectomy. He wanted kids, but I couldn’t have them anymore. He didn’t SAY that, but I knew. With Eric [pseudonym given to the man she is currently seeing] though it is all because I can’t enjoy sex so I don’t want it often… it’s an ordeal just to try! We do though and I guess we get by”

15) *Becca*: “No, Eric’s kids are all I need. They are beautiful and wonderful. I like having them in my life. We have been together for four years so I’ve seen them grow and they are like mine now, but I can send them back to their mom too!” [Starts to tear up]

Amanda: “What’s the matter?”

Becca: “Thinking about having my own…[pause] makes me this way sometimes.”

Amanda: “I think about it too, what it might be like…”

Becca: “You still can, right?”

Amanda: “I’m not sure, but I still have all the ‘parts’ for it. I’m not sure if I want to though, especially daughters. What if I gave them this?”

Becca: “Then they’d have a mom who knew what to do.”

Other Important Information: Becca is very driven and has gone to multiple colleges including Georgia State, UGA, and Georgia Southern. She has her master’s degree and is a consultant. Other Important Information: One of the founding members of the Meetup group and EndoHope. She has met all of the participants who were recruited through these groups and distributed the flyer to them via e-mail and facebook. She did not participate in the focus group.

Elizabeth:

Age: 29

Self Identifies: Italian American

Researcher Identifies: Middle class

Relationship Status: Long term relationship

Speaks: English, Italian

School: Some College

Occupation: Life Guard

Children/Pregnancies/Miscarriages: 0/0/0

Diagnosed Officially: Yes

1) 11

2)

3)

4)

5)

6)

7)

8)

9)

10)

11)

12)

13)

14)

15)

Other Important Information:

Elyse:

Age: 25

Self Identifies: White, Middle class

Relationship Status: Long term relationship

Speaks: English, Spanish

School: Graduated College

Occupation: Social Worker

Children/Pregnancies/Miscarriages: 0/0/0

Diagnosed Officially: Yes

1) 12, began at the local movie theater

2) The basic information from mom, including that it would hurt and that it was something that could make her uncomfortable.

3) Yes, Stage II

4) Yes, her aunt had it & she knew it could cause infertility and pain

5) back pain, pelvic pain, fatigue, bowel and bladder symptoms, painful sex, anemia and anxiety

6) a. like being kicked in the stomach, a stabbing pain in the side

b. isolation, lonely, confused, alone, like losing womanhood

7) "They usually don't know what it is and if they do they always tell you who they know who has it."

8) a. Yes: aunt, women from the meetup group, maybe a cousin

b. Aunt taught her about it when she was younger and started showing signs of having it. Meetup group women: discuss other things, but sometimes endo comes up as a topic, compare symptoms, discuss possible kids and how they talk to others, mainly doctors, about it.

9) Many types of treatments like birth control pills, shots (Lupron), holistic approach (change in diet and exercise), and acupuncture. Started Lupron at 18, wouldn't recommend it to anyone because it caused so many problems including weight gain, worse sexual discomfort including vaginal dryness. Chose it because the doctor presented it as the only option after the first surgery.

10) 4 surgeries by three doctors. The first two surgeries were performed by the same gynecologist around age 18. The first one was a diagnostic surgery where nothing else

was done. A few months later the second surgery was performed by the same doctor to remove the disease. The third surgery was conducted by an excision specialist that missed some growths so a fourth surgery was needed, but was conducted by a fourth doctor who was the associate of the third.

11) a. Allergies to cats and dogs, IBS, ADHD, and bipolar disorder

b. "Probably, but I'm not sure how. I believe that everything is related, like in a holistic way and that they are somehow intertwined. Like what you eat, how you feel, sickness, all that."

12) Talks to friends and aunt about it mainly, some are online, but most are off

13) Yes: missed work, missed school, don't want to do anything. Brush people off when feeling bad so she doesn't have to explain it again.

14) "Relationships! HA!" They've never been easy for her and she is not currently in one.

15) No: doesn't want them because she doesn't think she could take care of them right now, but maybe someday.

Other Important Information: Youngest founding member of the meetup group is 25. Knows all of the women from Meetup and EndoHope. Has a degree in social work from Georgia State.

Hailey:

Age: 17

Self Identifies: Mixed, Latina/White

Researcher Identifies: Working Class

Relationship Status: Broken up, Single

Speaks: English, Spanish

School: Graduated High School

Occupation: Cashier

Children/Pregnancies/Miscarriages: 1/1/0

Diagnosed Officially: No

1) 14 started showing signs at 15

2) a. “Got the basics from Mom & Heather”

b. That you can never really be ready for it

3) No, might have it. Has had cysts, heavy flow, painful intercourse, and clots

4) Yes, mother has illness, sister may. Knew that it was painful and could lead to infertility

5) pelvic pain, back pain, heavy bleeding, clots, ovarian cysts, period “comes when it wants,” fatigue, bloating, PMS, mood swings

6) a. “Pain everywhere, like being stabbed. You don’t wanna move!”

b. “Don’t wanna deal with this.” Something is wrong

7) “I don’t talk about it. People don’t care.”

8) “Mom, you, and my freshman bio teacher. She had a hysterectomy, like mom, and she told us why. I didn’t really talk to her about it though.”

9) OTCs namely Midol, lay down with compression and heat. Can’t use hormones because of Protein S deficiency.

10) Has not had surgery, but is willing to someday

11) a. Protein S Deficiency, allergic to tomatoes, seasonal allergies, chronic kidney infections, anxiety with panic attacks

b. Believes so, but is not sure how

12) Mom and sisters, no support groups because “family is enough”

13) “If that is what I have, then yeah!” Has caused problems at school (took online classes & graduated early because she missed so much school), issues with work (missing and being sick), When on period cannot perform basic tasks.

14) Painful sex and not wanting it often added to the trouble that lead her to breakup with the child’s father

15) Has a daughter, not difficult to conceive, happened the second time she ever had sex. She is afraid that her daughter might end up with the illness, but is willing to help her through it.

Other Important Information: Daughter of Laura and sister to Harmony and Heather. Has not met anyone else from the study and participated in the focus group.

Harmony:

Age: 15

Self Identifies: Mixed, Latina/White

Researcher Identifies: Working Class

Relationship Status: Not allowed to date

Speaks: English, Spanish

School: Some High School

Occupation: N/A

Children/Pregnancies/Miscarriages: 0/0/0

Diagnosed Officially: No

1) 10

2) a. What a period was from mom and older sisters

b. That she doesn't have a period like her mom & sisters, she counts herself lucky

3) No, doesn't think she has it

4) Yes, her mother has it and her older sisters may

5) none

6) Has not gone through it so does not want to assume

7) When she tells them her mom has it they don't know what it is and don't like to hear about it when they find out it involved periods.

8) Mom, researcher, maybe sisters

9) N/A

10) N/A

11) Protein S Deficiency

12) Does not need one for endo, but her mother and sisters are good for

13) Yes, mom and sisters cannot function normally so she has to pick up the slack.

14) N/A

15) N/A

Other Important Information: Daughter of Laura, sister of Heather and Hailey. Does not seem to have endometriosis, but was present for the focus group, so she participated and gave insight into what it is like to live with women who have the illness.

Heather:

Age: 20

Self Identifies: Mixed, Latina/White

Researcher Identifies: Working Class

Relationship Status: Dating someone, less than one year

Speaks: English, Spanish

School: Graduated High School

Occupation: Customer Service Rep

Children/Pregnancies/Miscarriages: 0/1/1

Diagnosed Officially: No, but has seen a doctor about it

1) 12, was with an aunt in AL. Aunt freaked out and called mom

2) a. "Mom gave us the basics… it hurts, blood, babies… that sort of thing."

b. "Tampons hurt!"

3) No, but she looks to have it

4) a. Has never been to the doctor about it

b. Mother has it, researcher has it.

c. Knew that it was painful and that it may be difficult to have children

5) clotting (got worse after miscarriage, she was 18), pelvic pain, heavy flow, back pain, headaches, mood swings, anxiety, and bowel issues

6) a. "Like someone is ripping my insides out, cramps."

b. "All I can think is that I want chocolate and sleep."

7) "I don't really talk about it with anyone but maybe mom."

8) "You, mom, maybe her [points to sister], and my eighth grade chorus teacher… she had to have eye surgery 'cause they found it up there somewhere…" (did not know any more about the chorus teacher or how she faired)

9) “I don’t want surgery! I won’t have what mom had! That messed her up bad. I can’t take the hormone stuff anyways because of the Protein S.”

10) N/A

11) Protein S deficiency, anxiety/panic attacks, seasonal allergies

12) “Mommy” and her sisters, also talks to boyfriend about it, but “he doesn’t really get it”

13) “Same as Mommy & Hailey. Work is hard and school was too. I can’t always to laundry or stuff at home.”

14) Painful sex, break up due to aftermath of the miscarriage

15) No, but wants them someday. Is afraid that a daughter might have endo too.

Other Important Information: Sister of Harmony and Hailey, daughter of Laura. Participated in focus group. Worked with the researcher at a local grocery store. Has never met any of the other women in the study and does not belong to any support groups.

Jody:

Age: 36

Self Identifies: Human

Relationship Status: Long term relationship

Researcher Identifies: Middle class

Speaks: English, German

School: Graduated College, PhD.

Occupation: Sociology Professor, also studies endometriosis

Children/Pregnancies/Miscarriages: 0/1/1

Diagnosed Officially: Yes

1) 13

2) a. Not much, nothing in school. Mostly got info from Mom and friends

b. Pain!

3) 34 Stage II

4) Yes, knew that it was associated with infertility and pain

5) a. long, heavy period, pelvic pain, back pain, stomach issues, fatigue, painful sex

b. Started before the period included stomach issues and fatigue

c. More pain

6) a. stabbing pains, bloated, and exhausting

b. “Gotta smile through the pain and pretend that everything is okay.”

7) They don’t know what it is, assume infertility, and/or suggest hysterectomy as cure

8) a. Endo gals, maybe mother

b. Talk on facebook mostly because of time & distance. Talk about the pain, set up meetings, discuss inability to have children.

9) a. cold packs, OTC and prescription pain killers, IUD, birth control pills, Meraina for four months, excision surgery, dietary changes and exercise

b. Chose these because doctors and fellow endo patients suggested them

c. It should be detected earlier; women shouldn’t have to live a decade in pain. Excision surgery should be the first line of defense and not something women should have to fight to get Birth control is not the end all be all of women’s health, so don’t prescribe it for everything.

10) a. 4 different doctors performed surgeries:1995, cyst ruptured and had to have emergency surgery diagnosed with PCOS; September 2010, laparoscopic procedure for endo, December 2010, had excision from specialist and was diagnosed with adenomyosis; May 2011, partial hyst due to adenomyosis; May 2012 another excision and removal of the rest of the female organs including most of the cervix

b. "NO MORE!" Results varied and there is still pain, but it could be due to other medical conditions

11) a. Back problems, hypothyroidism, hyper tension, cholesterol problems, blood pressure issues, panic attacks, migraines, anxiety, and many allergies

b. Panic attacks and hypothyroidism have been related to endo statistically, unsure as to how they are related

12) boyfriend, family, and online support groups

13) rarely able to eat out due to dietary restrictions, "After surgery bad [pain] days are fewer and far between. Before surgery they were all day every day."

14) "It's been a journey." Current boyfriend is patient and willing to work on pain/lubrication issues.

15) No, does not want children

Other Important Information: PhD in medical sociology, studies the social implications of endometriosis from a sociological perspective (might work together in the future), member of the meetup group

Kate:

Age: 29

Self Identifies: White, Fluid socio-economic class

Relationship Status: Not seeing anyone, broken up, used to be engaged

Speaks: English

School: Some College

Occupation: Unemployed

Children/Pregnancies/Miscarriages: 0/0/0

Diagnosed Officially: Yes

1) Unsure, believes 12

2) The basics

3) Yes at 26, different diagnosis from different doctors

4) At 19, a co-worker told her about his wife having it. She knew that it could cause pain, infertility and painful sex

5) 15 when it began during periods and 22 when it began occurring on a regular basis, fatigue, pelvic pain, lower back pain, sciatica, painful ovulation, stomach problems (nausea, vomiting, & diarrhea), painful intercourse, anxiety, and depression.

6) a. "That horrible cramp that you get when you have diarrhea, right before you 'go.' Where it hurts so severely and your back feels like it will break in half, but then you have the relief of expelling the source of pain." But that relief never comes.

b. Depressed, lonely, misunderstood, untrusting, afraid, alone, anxious

7) "'Endo what?' Is the most common. Next is, 'Oh I knew somebody with that one time." And of course the always pleasant, 'so, can you have kids?'"

8) "I have found support and discussion forums online that make me feel as if I 'know' these women." They discuss the illness, helping one another with symptoms and other

questions, assist one another in finding doctors/pharmacies.

9) a. Birth control pills, OTC and prescription pain killers, Nuva Ring, Depo Provera, as well as diet and exercise changes.

b. “I would like to see that women are treated with more respect when going through something so painful.” She was treated as a drug seeker in the hospital many times for asking for different medications.

10) Diagnostic lap in 2008, another surgery by the same doctor in 2009, a second doctor did excision in 2011 and in 2012 because they were unable to excise it all in 2011.

11) Intersistal Cystitis, Osteoarthritis, Fibromyalgia, Depression, Degenerative Disc Disease, Bulging Disc, IBS, and Anxiety

12) “This is difficult to answer. At times I feel that I have the support of my friends and family, but at others I do not. When I was diagnosed I found a ‘Letter from Endometriosis Survivors’ published years before by Heather Guidone. I printed it and gave it to all my friends and family to read so that hopefully they could understand what I was dealing with a little better.”

13) difficult to do daily activities, work, and has had difficulty staying in school.

14) Yes, it ended at least two relationships. One because of the painful sex and another because of the fatigue and pain

15) “No, I have always wanted children, almost desperately. I am fortunate to be fertile. However, after… spending the majority of my adult life in nothing less than agony, I do not know if I could be so selfish as to bring a child into this world. I do not know how well I would be able to care for them with my illness. I certainly do not want to pass this on genetically.”

Other Important Information: Her mother died the day of Amanda's surgery in 2012. She knows a hand full of the women from the meetup group, but was mainly active online. Does not belong to EndoHope because she believes that it is a bad idea and that not-for-profit organizations do not actually help those they are set up to assist.

Laura:

Age: 42

Self Identifies: White

Researcher Identifies: Working

Relationship Status: Married

Speaks: English, Spanish

School: Some high school

Occupation: Accounting and Customer Service Red

Children/Pregnancies/Miscarriages: 3/7/4

Diagnosed Officially: Yes

1) 12

2) a. "We didn't talk about it at home, a little at school though."

b. "It hurts, honey!"

3) Yes, at 32 but does not know the stage

4) Never heard of it until a doctor said it was a possibility when he saw a cyst

5) a. cysts, lower abdominal pain, clots, heavy flow, irregular cycles, fatigue, anxiety, depression, back pain, headaches

b. "Yeah, it changed. It got worse after my kids. Everybody said it would get

better, but it didn't it got worse after the girls were born."

6) a. "Labor times ten!" a vice grip, "a nut cracker on my [back] bones"

b. Misunderstood, lonely, crazy

7) "They don't know what it is… I try to explain, but don't get too in depth. People always say ewww or TMI, If you had it I bet you'd wanna know!"

8) "Nobody really, except you and maybe my girls"

9) a. Lupron "Wouldn't recommend it. It fucked me up real bad! Excuse my language.", Anaprox, heat pads, OTC and prescription pain meds

b. chose them because doctor suggested them as the only options

c. "A cure that doesn't involve a hyst that doctors know about!"

10) a. A hysterectomy in 2004, bad experience, didn't get all the disease, still had pain

b. "No more surgery! I can live with it now, no excision either. I know that's what you had, but just I can't do another surgery!"

11) a. Protein S deficiency, incompetent cervix (could not hold any pregnancies to term, all the children were early), anxiety/panic attacks, depression, hip/back problems, sciatica, IBS, PCOS, possible adenomyosis

b. Probably, but doesn't know how except for the adenomyosis and incompetent cervix which can be explained by the adhesions

12) "The doctors sucked! I mostly kept to myself, I talked to you some, so I knew I wasn't all alone. The girls have more options and if I'd've known about them I'd've used them, like the internet. I hope they use 'em."

13) Missed a lot of school

Laura: "Oh, all over the place! Mainly work… I lean on the counters to hold myself up.

You can't miss work for some pain so I go and lean on the counters. Couldn't do what you did and just leave… I've got family!" [refers to when I quit my job by walking out when a boss was insensitive due to the illness]

Amanda: "I was dying, remember? I couldn't stand up without almost passing out. Besides, you could take meds. They always made me sick to my stomach."

Laura: "I wish I coulda just done what you did. The meds helped deal with it, but they didn't make it go away."

14) "Not really, bothered me during my cycle some. The bleeding and cyst was there and it made everything feel shoved up there. Didn't really hurt though."

15) a. Yes, 3 girls and multiple miscarriages

b. "No problem conceiving, most issues [endometriosis related problems such as pain] started after the girls were born. The Youngest was already in school when issues started."; "It was hard to stay pregnant though… I had the miscarriages, Hailey was supposed to be twins, but because of the incompetent cervix I lost one, then they put me on bed rest."

Other Important Information: Mother of Hailey, Harmony, and Heather. Does not know any of the other women in the study. Knew the researcher from working together before research began and they are friends on Facebook, volunteered herself and her daughters that way.

Penny:

Age: Did not share (early 40s)

Self Identifies: White

Researcher Identifies: Upper Middle class

Relationship Status: Divorced, not seeing anyone

Speaks: English

School: Graduated College

Occupation: Public Relations in a local cancer center

Children/Pregnancies/Miscarriages: 0/3/3

Diagnosed Officially: Yes

1) Ninth grade year

2) the basics

3) Yes, mid-thirties different stages by different doctors

4) "Yes and no, a co-worker thought I had it and so I looked it up and asked my doctor about it. I guess you can say I self-diagnosed."

5) "Pain, lots of pain." Back pain, pelvic pain, headaches, anxiety, and stomach problems around period (vomiting and diarrhea). They began after the last miscarriage.

6) a. stabbing, burning, death

b. lonely, isolating

7) "Most people are unaware of it, so I advocate for people knowing about it, especially at work."

8) Women in the endo groups

9) Had a hysterectomy and excision surgery

10) First surgery: diagnostic surgery for endo with removal of cysts, diagnosed as stage III with possible adenomyosis

Second surgery: Confirmed adenomyosis, excision of endometriosis on appendix,

bladder, bowel, and cul-du-sac. Concluded that a hysterectomy was needed because adenomyosis was causing uterus to collapse.

11) “Skin cancer, but they’re not related… I spent too much time tanning when I was younger, it was the 80’s.”

12) Family, friends, co-workers, endosisters (meetup group and online)

13) “Not in many years, but it did cause me to miss work.”

14) First husband left after hysterectomy, no sexual issues except during periods where it didn’t hurt, but felt bloated and full

15) No, tried in vitro many times but was unable to carry pregnancies beyond the first trimester. Adopted second husband’s son from previous marriage.

Other Important Information: One of the founding members of the meetup group. Knew all of the women from that group and from EndoHope. Has a job working with a large cancer group in Georgia and is on the committee for others.

Rose:

Age: 40

Self Identifies: White, Fluid Socio-economic Class

Relationship Status: Married, was engaged to someone else before but broke up

Speaks: English, French

School: Graduated College

Occupation: Part-time life coach

Children/Pregnancies/Miscarriages: 0/2/2

Diagnosed Officially: Yes

1) 12

2) a. Biological stuff from mom

b. not the same for everyone, tampons usage (mom couldn't use them)

3) a. diagnosed at 30 with Stage II

4) No, did not come up as a possibility until a doctor suggested an experimental lap and found it while performing the surgery

5) GI symptoms, bloating, pain, sneezing/wheezing (was on diaphragm), abdominal pains, fatigue, anxiety

6) a. "Not like myself; excoriating/intense pain that is both sharp and dull at the same time. It's exhausting, but you get used to it."

b. "You've got to be tough, you just go into survival mode."

7) Most people don't know, range of emotions from supportive to just "glazed over"

8) Yes, began the Meetup.com group, Founded group because she wanted to get away from the "victim mentality" found in the online support groups. She wanted to start a more positive, empowering group to show that "we are greater than the disease. Get out and live your life!"

9) a. None currently, took prescription pain meds and one round of Lupron, but had to stop because of side effects. Finally had excision surgery and hyst due to adenomyosis

b. tried them because doctors suggested it

10) 4 surgeries with two different doctors. First was the exploratory lap which discovered the disease. Next, excision surgery with a professional which diagnosed adenomyosis. Third was partial hyst with removal of the uterus. Fourth was the removal of both ovaries after endo had come back.

11) “I was constantly sick as a baby and young child with respiratory problems. I had to get shots til I was 6 years old.” Seasonal allergies, asthma

12) Doesn’t need the support system anymore, but likes to be there for the other women in the support groups to answer their questions

13) No physical endurance, hired house keeper for a while to do daily chores, “Gotta keep moving, stay active”

14) Separated from husband for a time due to illness, but working hard to keep it together

15) No children. The disease “changed me as a woman. The loss of the babies [miscarriages] was the loss of family. I took for granted that I’d get that someday. I was never like OMG I’ve gotta be a mom, but it devastated me when the chance was gone.”

Other Important Information: Founder of the in person Meetup.com group in early 2011. Group has 25-30 members with 10 or so that show up with consistency. She is slowing leaving the community because she feels that she has facilitated all that she can for it and is no longer needed since she does not really suffer from the disease anymore. Rose knows all of the women in that group. She helped facilitate EndoHope because Elizabeth “lit up” when she was talking about starting it. Did not know, and is disappointed, that EndoHope would begin to break apart the Meetup group.

Tiffany:

Age: 28

Self Identifies: White, Fluid Socio-economic Class

Speaks: English

Relationship Status: Engaged, was engaged to someone else before but broke up

School: Some College, still attending

Occupation: Unemployed

Children/Pregnancies/Miscarriages: Currently 0/2/2

Diagnosed Officially: Yes

1) 14

2) Health class basics

3) Yes at 19, mild to moderate, not sure of stage

4) Aunt had it, but still wasn't sure what it was

5) "18, the pelvic and back pain were the biggest symptoms. And I also have chocolate cysts."

6) Physically, it feels like being stabbed in the ovary with a sharp rusty knife, repeatedly. Emotionally, it's extremely tiring. I want to just not hurt, I wish every month to have "normal" cramps, I hate calling out of work due to the pain, I hate cancelling plans, I hate not feeling like myself.

7) "Sympathetic, but I feel no one really understands what it means to have endo."

8) "Yes, My aunt and a coworker. They've both had hysts and don't talk about it."

9) Diet changes, exercise, and birth control pills, but they had bad side effects

10) "I've had 2 DNC's – neither of which helped at all. Both performed by the same doctor. I've opted not to have any more DNC's; my doctor knows how much having children means to me so it's been decided that I won't have any more surgeries until after trying to conceive unless absolutely necessary."

11) Could not think of any

12) "My family is a great support system!"

13) Misses work, cannot do daily chores sometimes, cancels plans due to pain

14) “The week before and the week of my period sex is excruciating!”

15) No, the doctor says wait and see

Other Important Information: Tiffany and Amanda went to high school with one another and have been facebook friends ever since. She does not belong to any groups dealing with endometriosis and often feels that they foster self-pitty.