Chronic Illness as Trauma:
The Case of Endometriosis, an Adlerian Perspective

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Abstract
When confronted by the diagnosis of endometriosis, many women experience psychological distress. Some are initially told by medical professionals that their symptoms are somatic. However, additional study reveals that, when determining the etiology of these women’s emotional distress, their psychological state is a response to verifiable physical discomfort and chronic pain. Telling women experiencing autoimmune disorders that their symptoms are somatic frequently results in a deepening of their distress and despair. From the emerging field of trauma research, this experience is not only distressing; it can cause Post Traumatic Stress Disorder. From an Adlerian perspective, this thesis explores ways in which psychologists can help support a woman with endometriosis. Recommendations are offered concerning appropriate treatment and future research.
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Introduction

Endometriosis is a gynecological condition that is often characterized by chronic pain, blood loss, growth of ovarian cysts, formation of scar tissue, and interference with other normal bodily functions (Simon, 2005). For many women with endometriosis the emotional side effects can devastate many other areas of their lives leading them to report conditions such as anxiety, depression, irritability and hopelessness (Simon, 2005).

Many studies of endometriosis find various reasons for the correlation between well being and chronic pelvic pain in particular, as pain is the most prevalent side effect of the disease. The etiology of emotional side effects has been debated in much of the research.

Historically, some researchers hypothesize that women’s emotional instability caused chronic pain (Gomibuchi et al., 1993). Some studies try to ascertain the direction of correlation between pain and psychological distress (Lorencatto, Petta, Navarro, Bahamondes, & Matos, 2006; Low, Edelmann, & Sutton, 1993; Renaer, Vertommen, Nijs, Wagemans, & Van Hemelrijck, 1979). More recently, studies have investigated the reasons behind the psychological distress women feel while living with diagnosis of endometriosis (Ballard, Lowton, & Wright, 2006). The research offers many varied opinions.

However, there is no debate that endometriosis has a significant impact on women’s emotional well being. From a trauma perspective, this impact can cause symptoms of Post Traumatic Stress Disorder. From an Adlerian perspective, this thesis explores ways in which psychologists can help support a woman with endometriosis. Recommendations are offered concerning appropriate treatment and future research.
Literature Review

There are very few studies of endometriosis during the last few decades. This is a relatively new area of research in both the medical and psychological community. This paper begins by looking at the research and knowledge base that is currently available.

The Effect of Endometriosis on Women’s Emotional Well Being

Many studies have confirmed a lessened quality of health for women living with endometriosis (Ballard et al., 2006). In fact, according to Christian (1993), up to 10% of all women with endometriosis experience a significant reduction in the overall quality of their lives. Frequently women go years without being properly diagnosed. Consequently, their level of uncertainty in addition to their level of chronic pelvic pain lessens their already poor quality of life (Ballard et al., 2006).

Living with the unknown can be far more stressful than living with a chronic medical condition. Instead of asking more questions and searching for a cause behind the pain, many medical professionals tell women to just “deal with it,” as pain during monthly cycles is a normal part of being female. Many women report that by far the worst experience during the course of their disease is the way in which some health care professionals trivialize their struggles (Cox, Henderson, Anderson, Caglierini, & Ski, 2003).

And a struggle it is; from the qualitative research interviews done with women living with endometriosis we have reports about the effect this illness has on their everyday lives (Cox et al., 2003; Denny, 2004; G. Jones, Jenkinson, Taylor, Mills, & Kennedy, 2006). Women report that they lose jobs due to employers not understanding the chronic nature of their disease and therefore defining them as unfit workers when they use up all or most of their sick time. Some women lose friendships when over the course of their illness other women do not believe them
about the severity of their symptoms. The stress of monthly chronic pain causes a rift in some marriages that ends with the dissolution of the marriage. Infertility, which is also a common side effect of endometriosis, adds yet another layer of frustration and despair to many already tenuous relationships (Christian, 1993).

During the struggle with their physical disease, many women also suffer from depression and anxiety (Cox et al., 2003). Many report that their depression worsens after each experience of disbelief in the reality and severity of their symptoms, and that continually being compared with others who were able to manage their monthly periods and its resulting pain leave them feeling distraught and hopeless (Cox et al., 2003). The continual search for someone to believe their pain is physical and not emotional leaves women exhausted and wary of being judged yet again. Many women try to find medical specialists whom they believe can help them get an accurate picture of what is happening to their bodies, but in many cases this too fails and they feel judged yet again (Cox et al., 2003).

Some researchers hypothesize that endometriosis has a very specific effect on women’s emotional well being, such as lower self esteem as measured by the Rosenberg Self Esteem Scale (Christian, 1993). However, while data from their research did not support the conclusion that women with endometriosis have lower self esteem, they did observe that endometriosis interferes significantly with women’s quality of life (Christian, 1993).

Similarly, Low et. al. (1993) compared two groups of women who both had surgical procedures to determine the etiology of their chronic pelvic pain. He hypothesizes that women with endometriosis will have elevated levels of anxiety and depression when compared with women with chronic pelvic pain unrelated to endometriosis. While he was able to say that
chronic pain is correlated to anxiety, he was not able to ascertain the directionality of the correlation (Low et al., 1993).

Some researchers study whether there is a link between known mood disorders and endometriosis. (Lewis, Comite, Mallouh, & Zadunaisky, 1987) used a sample size that was relatively small and therefore their results could not be generalized across populations. Within that small sample (16 women), they did find a relatively high number of women also diagnosed with mood disorders. Many of the symptoms they used to diagnosis the women with mood disorders (Lewis et al., 1987) are also characteristic of women with pelvic pain issues. Their study did look at first degree relatives and a possible genetic component to the mood disorders, but did not investigate the possible genetic component to endometriosis.

Many investigators discuss the long time interval between symptoms and an actual diagnosis of endometriosis. This long delay in diagnosis is problematic for many women not only in medical and physical costs, but also in emotional costs. Interviewing women living with endometriosis, the time delay in getting an actual diagnosis was raised time and again as a factor that led to more overall trauma during the course of their disease (Cox et al., 2003).

For those definitively diagnosed with endometriosis, the sad truth remains that there is no known cure for this disease. This means treatment is focused entirely on reduction of symptoms (Lemaire, 2004). The need for research on the causes, treatment and impact of this disease is great, including the need to discover better chronic pain management strategies. Although endometriosis is not life threatening, the other physical and psychological side effects associated with the disease, such as infertility and chronic pelvic pain, mean that women must deal with these complications over a long period of their lives. This period is generally considered to be one of the most productive periods in a person’s life (young adulthood) (Marques, Bahamondes,
Aldrighi, & Petta, 2004). For this reason, one must consider these problems as multi-disciplinary issues to be considered by the culture at large.

In addition to medical and psychological issues, women with endometriosis also impact society from an economic point of view. These women are not as able to be productive because of their inability to get an accurate diagnosis quickly. Consequently they are missing more time at work going to doctor’s appointments, only to be told there is nothing wrong with them. This long delay also means more time lost at work due to the pain they continue to experience while remaining improperly diagnosed.

*Chronic pain.*

By far the most debilitating side effect women identify in all studies on endometriosis is their experience of chronic pelvic pain (Denny, 2004; Huntington & Gilmour, 2005; G. Jones, Jenkinson, & Kennedy, 2004; Marques et al., 2004). This pain often leads to other physical difficulties including nausea, dizziness, fainting, vomiting, and fatigue (Denny, 2004). Pain is not just confined to the time around women’s menstrual cycles. Pain is also reported around ovulation, copulation, urination, defecation, and gynecological exams (G. Jones et al., 2004). It is important to note that this type of chronic and repeated pain is different from situational pain in that it is more frequently associated with decreased emotional well being (Lemaire, 2004).

Chronic pain does have more side effects because of the repetitive nature of the experience. Each new episode drains a bit more energy from those affected by the pain. Their reserves are weakened, and often they are then susceptible to other illnesses. There is research linking endometriosis to other chronic immune system disorders such as lupus, chronic fatigue syndrome, fibromyalgia, and multiple sclerosis (Simon, 2005). Many women suffer not just with endometriosis and its side effects but the long term side effects of a weakened immune system.
In qualitative studies, the women interviewed were able to specifically describe their pain and the many effects it had on their lives (Ballard, 2006). Women were very familiar with their pain history and all that they had done in an attempt to find a name for their pain and someone to believe them about the severity of their suffering. Many women reported relief upon first finding out that their pain was not somatic but had a real name and possible treatment protocols.

Once diagnosed, many women were then faced by the frustrating lack of available means to adequately control their now namable pain. Many tried almost everything available both in western medicine and alternative medicine, yet found no relief from the unrelenting nature of chronic pain (Huntington & Gilmour, 2005). Many reported that they just marked their calendars knowing that they would be unable to perform their daily tasks during a certain number of days each month, due to the lack of adequate pain control mechanisms.

Many women spoke about the whole of their lives being affected by endometriosis and pain. They slept, ate, played, worked, entertained and related to others less during episodes of pain compared to pain free times (G. Jones et al., 2004). Fatigue was a factor described by many women, as well as their lessened emotional well being while dealing with endometriosis and pain. Overall, many women described symptoms of moodiness and some even went so far as to define feeling violent (G. Jones et al., 2004). Their concerns for themselves often led to a heightened concern for others with this disease, especially their own daughters given the genetic component of endometriosis.

Directionality.

Some studies seek to understand the directionality of the link between pain and psychological distress. Gomibuchi et al. (1993) hypothesized that one’s psychological personality profile may in fact affect one’s perception of pain. They concluded that although
their research suggests areas for future study, they could not conclusively clarify the correlation between pain and personality.

The women interviewed by Jones (2006) were quite frank in revealing that, in their opinion, the pain came before their psychological distress. Many felt worry only after being dismissed by the medical community or after undergoing unsuccessful treatment (G. Jones et al., 2004). Many were frustrated by the lack of knowledge about endometriosis readily available to both doctors and lay people. Many reported that they felt socially isolated by their disease and this isolation had a major effect on their overall wellbeing (G. Jones et al., 2004).

There is a subset of research being conducted on the correlation between chronic pelvic pain, endometriosis, and the hypothesis that sexual abuse in early childhood may have somehow either caused increased sensitivity to pain or actually caused the pain itself (Thomas, Moss-Morris, & Faquhar, 2006; Walker et al., 1988). Women with endometriosis studied by Leserman (2006) were not found to have any significantly higher level of early sexual trauma in comparison other pain groups. In their study, patients with diffuse abdominal pain issues were more likely to have suffered early abuse than those diagnosed with endometriosis (Leserman, Zolnoun, Meltzer-Brody, Lamvu, & Steege, 2006). Walker (1988) found that a statistically significant number of women with chronic pelvic pain had experienced some type of sexual abuse. However, their sample size was relatively small and much debate has ensued about the “blame the victim” nature of this line of research.

In another study, Lorencatto (2006) hypothesized women with diagnosed personality disorders may have a lower threshold for pain tolerance to begin with and therefore will be more adversely affected by pain. They found that depression was linked to chronic pain, but they could not conclusively decide which came first, pain or depression. They noted that their study
did not take into account the length of time the women had suffered from pain prior to the
diagnosis of endometriosis and that this may account for some of the depression (Lorencatto et
al., 2006). They did report that in previous studies when depression was found in people with a
chronic physical ailment the depression was generally believed to come after the physical illness
(Lorencatto et al., 2006).

Methodology

Many studies of endometriosis have used qualitative research methods. Because the
research into this topic area is still very young, there are not many quantitative studies published.
The qualitative studies mostly consist of interviews with women living with endometriosis in
order to find the common denominators influencing their lives and their emotional well being.
These qualitative studies have used a thematic approach to sifting through the hours of interview
tapes and sorting out what ideas mattered most to participants (Ballard et al., 2006; Denny, 2004;
Huntington & Gilmour, 2005; G. Jones et al., 2004). Some studies demonstrated scientific rigor
by being very precise about reliably reporting the exact words that the women used in describing
their own experience (Denny, 2004). Some researchers (Cox et al., 2003) subsequently used
their qualitative survey responses to go further and use quantitative methods to explore
additional hypotheses. Jones (2004) used the initial qualitative results to build a comprehensive
quality of life questionnaire to be used in additional research on endometriosis.

Huntington and Gilmore (2005) specifically mentioned using feminist research methods
in their work, including the use of qualitative research. This is not only an important part of their
methodology, but also an important part of their philosophy. Listening to women’s stories,
believing their experiences, and learning from their personal histories is all part of feminist
methodology.
Quantitative studies used many already established paper and pencil tests to study the symptoms of women’s emotional well being. The Beck Depression Inventory, Mishel Uncertainty in Illness Scale, Health Opinion Survey Information Scale, Visual Analogue Scale, Pressure Pain Threshold, Rand 12-Item Health Survey and Short Form 36 are a few of the more popular scales used to study women’s emotional well being.

Endometriosis is a worldwide problem and all women, regardless of race, social status, or religion, get diagnosed at equal rates consequently, research is not limited to the United States. Studies have been conducted in Brazil, England, New Zealand, Australia, Denmark, and Japan. The findings do not vary across cultures or continents. Results are similar for every culture. Women’s reports of endometriosis’ effects on their emotional well being are concurrent across the globe.

Limitations in Current Research

Research in this area is still relatively new. The oldest published studies are from Lewis et al. in 1987. For a medical condition, 20 years of research represents research at the very initial phase. Therefore, many studies had confounding variables and method problems which hopefully can be corrected in the next generation of research.

Confounding variables.

One of the most common confounding variables in all research on endometriosis is the very complicated matter of specifically diagnosing this condition. Many of the traditionally less-invasive ways of diagnosing other gynecological disorders are not options for diagnosing endometriosis. For instance, transvaginal ultrasounds, frequently show both false positives and false negatives for endometriosis (Ballard et al., 2006) and therefore cannot be used for diagnosis. The most commonly used gold standard is a surgical procedure called laparoscopy.
However, there are difficulties with this standard as well, as many doctors are not trained thoroughly enough to detect some of the small lesions that may be present and account for substantial amounts of pain (Denny, 2004; Huntington & Gilmour, 2005). In fact, several recent surgical investigations question the sensitivity of the laparoscopy to define pelvic pain accurately (Reiter, Shakerin, Gambone, & Milburn, 1991).

Studies that attempted to group women by those diagnosed with endometriosis versus those who had chronic pelvic pain but not endometriosis may have had a confounding variable in their study because their patients may not have been accurately diagnosed. Similarly, the relationship between pain and the degree of endometriosis present during surgical examination is not highly correlated (Reiter et al., 1991). Given the length of delays many women experience in being diagnosed with endometriosis, it is not only likely but almost a certainty that these confounding factors hamper the validity of the research results.

Many of the subjects in these studies came from convenience samples of women attending either conferences, pain clinics, or doctor’s offices. In many of these studies, this resulted in a very homogenous sample group. A majority of the subjects in the self-esteem study (Christian, 1993) were white, middle-class women who were either employed or financially secure.

In Jones’ (2006) analysis, all the women had already been referred to a secondary clinic because of their pain, so it is very likely that these women already represented a different cohort from those who were not yet referred to another level of medical expertise. Jones (2006) intends to continue testing the quality of life questionnaire with more samples of women with endometriosis to make sure that they are asking the right questions to measure information about women’s quality of life while living with this disease.
In the qualitative research, interviews often relied on women’s recall of their own
medical history, events, and treatments. As is well documented by other psychological research,
recall in reporting can be less than accurate. Therefore, some researchers have suggested
utilizing a longitudinal study to follow women over time using a daily journal to obtain accurate
details regarding pain, treatment, and psychological functioning across their life span (Denny,
2004)

For Lemaire (2004), the sample came from a conference to which women had to travel. This led to participants being only those well off physically and financially to travel. By their
own account, this sample is quite limited and therefore their results could not be generalized to
the population at large.

Another confounding variable was that some of the medical treatments designed to help
with endometriosis also have the medical side effect of inducing depression in women with no
previous history of clinical depression (Waller & Shaw, 1995). This confounding variable was
accounted for in some but not all of the research. Hormonal treatments are so well known to have
the side effect of symptoms mimicking clinical depression that a literature review could be done
just on this topic alone (Metzger, 1997) but is outside the parameters of this paper.

In Leserman’s (2004) study of chronic pelvic pain and trauma, the methods were open to
effects in judgment by the researchers given that defining abuse was left up to a ranking system
which left open the definition of severe trauma. In all the studies of childhood trauma, the issue
of faulty memories as well as increasing or decreasing the severity based on personal judgment
remains a problem for researchers. There can be no outside verification of the amount or type of
abuse experienced by the subjects.

_Etiology of the Effects_
Particularly in the studies of pain and personality, serious questions were raised about the etiology of which effect was experienced first. Women in pain who have not yet experienced someone who believes their story and can help direct them to possible treatments may well feel their pain more acutely and more personally, as they have no language with which to name their discomfort (Cox et al., 2003). It is also interesting to note that some women with endometriosis experience very little pain, while others with very little scar tissue visually identifiable via laparoscopy experience severe pain. However, many medical texts do expound upon the many and variable ways that endometriosis can present itself as a disease, including effects on the personality. This includes depression, anger, and moodiness (Simon, 2005).

Some researchers investigated questions about the personality of pain (Gomibuchi et al., 1993). Others hypothesized that women with a greater degree of pain sensitivity would also have a higher degree of impairment in their quality of life (Laursen, Bajaj, Olesen, Delmar, & Arendt-Nielsen, 2005). They were able to find a correlation between pain and quality of life, but were unable to prove that those who were more sensitive to pain were different in any statistically significant ways from those who were not (Laursen et al., 2005). This is an important finding because it leads to the conclusion that pain in and of itself lowers the emotional well being of those experiencing it. It is not the sensitivity to pain or a predetermined personality factor making one more susceptible to pain, but rather the pain itself that lowers quality of life.

In previous research, Reiter (1991) tried to find correlations between sexual abuse and chronic pelvic pain, the implied hypothesis that sexual trauma was experienced first and then the pain followed. However, evidence has not been found to substantiate this theory. In fact, the most significant difference researchers found was that those with a past history of abuse had a
younger age of first intercourse and a higher number of partners, but history did not have a link to somatic complaints at all (Reiter et al., 1991).

Clinical symptoms of depression and anxiety were more often observed in women with chronic pelvic pain (Lorencatto et al., 2006). In this study, researchers did not ask when the depression and anxiety began. Therefore, the question of which came first is a confounding variable for their results. Women with pain were more often experiencing depression than those without pain, regardless of their gynecological diagnosis (Lorencatto et al., 2006). These results give credence to the conclusion that it is the pain which comes first, although their reading of the literature still left the researchers questioning which came first (Lorencatto et al., 2006).

The women interviewed by Jones (2006) were emphatic that their quality of life was directly affected by endometriosis and the consequences it had in their daily lives. The impact of even non pain-related symptoms, such as infertility, had long-lasting effects on the women’s emotional well being. The social isolation many women felt from being unable to discuss their symptoms openly with others for fear of judgment had a negative impact on their overall quality of lives.

Etiology is difficult to ascertain under the most controlled circumstances. But for women living with endometriosis, a common thread is living with large amounts of uncertainty (Lemaire, 2004), not just about whether or not they had endometriosis, but about what effect it would have on their lives. Questions about whether or not they would be able to have children, about what each day’s level of pain would allow them to accomplish, and about what treatments would work were subjects that these women lived with on a daily basis. This uncertainty is frequently coupled with a lack of control over their personal medical situation. All these issues
lead to stress which affects women’s overall emotional well being. Providing accurate and timely information can lead to less uncertainty and, consequently, less stress (Lemaire, 2004).

The Problem from a Personal Perspective

The Story of EB: Case History

The story of EB (name changed to protect confidentiality) begins before she is diagnosed with endometriosis. Like most women in the research studies mentioned in the literature review, EB began having symptoms many years before she was diagnosed. She had numerous mysterious abdominal aches that nobody could figure out, and also bowel disruptions, headaches, and bladder symptoms.

Her early recollections of being sick include “being told it was all in my head and I couldn't possibly be hurting and getting in trouble for using up all the baby aspirin and Pepto Bismol” E.B. (personal communication, January 2007).

No one believed EB, not doctors, parents, friends, or other relatives. No one believed her until her eventual diagnosis at age 29. No one believed it could be ‘female issues’ as it started about a year before puberty. Everyone who knew EB blamed her parent's divorce, her hatred of school, boyfriend troubles, and all sorts of other psychological roots instead of looking for a medical cause. “I was always referred to psychiatrists and psychologists rather than being treated for my very real physical illness” E.B. (personal communication, January 2007).

EB felt depressed because she was sick and no one believed that her physical symptoms were not somatic. Her symptoms included pain, bowel disturbance, chronic yeast infections, chronic bladder infections, insomnia, daily crying, and despair. Everyone thought EB was exaggerating her symptoms. No one believed her physical symptoms preceded her emotional distress. Everyone believed that her psychological symptoms were at the root of her ‘imagined pain.’
Her earliest memory of pain began when she started menstruating at age 12 and the pain became much worse. In EB’s, experiencing the physical pain lead directly to the emotional pain, “without a doubt.”

She describes it like this, “Being in chronic pain is depressing, plain and simple. It sucks to hurt all the time. It sucks even worse when nobody believes you. I still have a hard time, even after having a diagnosis, with people not understanding, not realizing how much it hurts, and with doctors not wanting to prescribe anything for my pain. Inadequate medication for the pain is the number one contributor to my depression. I've had several different doctors pressure me to take antidepressants, telling me it would help with the pain. When I did take the antidepressant meds, the pain was still there and so was the depression, I was simply unable to cry anymore while on them so it made those people around me feel better. Deep down inside, I still wanted to cry, I just couldn't” E.B. (personal communication, January 2007).

One very memorable story for EB came late in high school. She was certain her pain was gynecological and believed if she could just get an appointment with a female gynecologist she would get to the root of her pain. She convinced her mother to drive 4 hours roundtrip to the nearest female gynecologist. This physician spent exactly 5 minutes in the office with EB and told her to “buck up and deal with the pain, every woman goes through this” E.B. (personal communication, January 2007). EB spent the entire trip home crying, feeling her last hope was gone.

At age 29, EB was finally definitively diagnosed with endometriosis; 17 years after her journey with pain began. She describes the diagnosis this way, “After my lap, when they discovered I had stage IV endo, I was almost relieved. Now my family knew it was something
‘real.’ They were so used to talking about my ‘hypochondria’ that, even today, I still have to defend myself from time to time” E.B. (personal communication, January 2007).

EB’s history is very similar to many women who live with endometriosis. The lengthy wait for a diagnosis leads to decreased emotional well being. Those who are closest even suspect that the person is not actually in physical pain but rather psychological pain. The toll of years of that is incalculable in terms of lost productivity, strained relationships, damaged self-esteem, and the trauma experienced.

An Historical Perspective from Alfred Adler

Adler’s Individual Psychology gave insight into the phenomenon of trauma and physical illness many years before the modern discussions of PTSD and EMDR. An exploration of Adler’s viewpoint can lend greater insight into the discussion of chronic illness as trauma.

Belonging

In Adler’s view, all human beings are social creatures who are yearning to belong, to fit into a group, to be loved (Ansbacher & Ansbacher, 1956). As in EB’s story, many women with endometriosis do not feel they belong anywhere. Society at large, and doctors in particular, have given them the message that somehow they are different from other women. This message given enough times by numerous people eventually leads a person to question his or her belonging. In Adler’s view, this in and of itself would be traumatic.

One’s ability to function in society and be an active member of the world leads to that sense of intrinsic belonging that Adler proposed. In the case of women with endometriosis, their disease, which occurs at the height of their productive career years, takes away that ability to be a functioning member of society. Many women interviewed (Jones, 2006) discussed their
inability to keep appointments, make commitments, and in some cases even hold down a job due to their level of incapacity when dealing with their chronic pain.

Many women interviewed (Jones, 2006) discussed their relationships with family, friends, co-workers, and loved ones broken due to their disease. Many felt isolated and alone, particularly during the years when their illness remained undiagnosed. The hope and the connection that some women feel when actually given a diagnosis also give credence to the hypothesis that this sense of belonging is so very important.

Once women find that their illness has a name, they can begin to reintroduce that sense of belonging into their lives. They can find other women with this disease on the Internet, in their doctor’s office, or in their family tree. They can and do find support groups for women with endometriosis. This is frequently cited as one of the most beneficial interventions for their emotional well being.

All of this anecdotal and qualitative data found by many of the researchers discussed in the literature review reinforce this very key concept of Adler’s: belonging. If women can find a sense of belonging sooner, their emotional well being will be more fully supported. This very basic need of all human beings must be recognized in the journey of those with a chronic illness. In concrete terms, this would mean (a) working to find a provisional diagnosis sooner, (b) getting women connected with other women experiencing the same symptoms more quickly, and (c) acknowledging the loneliness that accompanies any journey involving a chronic health condition.

Wholism

Adler’s viewpoint on a person’s life was that a psychologist must take into account the entire pattern of the life, the “lifestyle” versus just a part of the life (Ansbacher & Ansbacher, 1956). For women with endometriosis, this is particularly important.
Very often, women with endometriosis are told just to live with their monthly pain, because it is “just monthly.” However, that point of view does not take into consideration all the other aspects of life that this disease effects. Not only is it about menstrual pain, but also pain accompanying urination, defecation, copulation, and the pain is frequently accompanied by other symptoms like migraine headaches, recurrent bladder infections, and irritable bowel syndrome.

Taking Adler’s wholism into account, one must do an assessment of the entire pattern of the person’s life, not just the symptom that brought him or her into the medical system in the first place. According to Adler, much more must be taken into consideration, including family atmosphere, family values, guiding lines, family constellation, birth order, and early recollections (Ansbacher & Ansbacher, 1956).

**Acting “As If”**

Adler’s writing often discussed the interaction between the mind and the body (Adler, 1931). This is a topic that is frequently debated to this day. In Adler’s view, the topic was not an either/or discussion, but rather parts of a whole. This was discussed in the previous section. Adler (1931) stated that the body and the mind strive for unity and for a common goal.

However, it is not always possible and stress occurs when in striving for the unified goal, the body and the mind cannot find agreement. The mind must break the tie, so to speak, and make a choice. In so doing, the mind is making a decision about the direction of movement. Then the mind must also chose what meaning to give the direction it chose to take.

Here Adler (1931) is clear. Human beings are in essence meaning makers. We choose the meaning to put on any particular event based on the choices we made to get to that moment in time. Therefore, Adler also proposes that we can then choose a different meaning.
This is called “acting as if” (Ansbacher & Ansbacher, 1956). This concept acknowledges that we are the creator of our own realities and can choose the meaning we make of any particular event or moment in time. We can, therefore, reframe that choice and create a new meaning for our life, possibly a more psychologically healthy meaning.

In the case of women with endometriosis, they could be encouraged to “act as if” they know that their disease has a name and is real, way before they are officially diagnosed by a medical doctor. Then how would their lives be different if they knew that their disease had a name and was an actual disease not just “all in their heads?” Their support system could give them permission to empower themselves by knowing that their disease has a name and has a treatment protocol, it is just not known yet. In so doing, their support system may be able to lessen the traumatic impact from those around them saying that their endometriosis symptoms are simply somatic and not in fact real.

They could “act as if” they will find a doctor who can and will be able to help them. The hope that this movement would give them may very well empower them to seek out others who have been in a similar situation and were able to find help from one medical group or clinic in their area.

Anything Can Also Be Different

This hope would then lead to another of Adler’s core principles; anything can also be different (Ansbacher & Ansbacher, 1956). If women with endometriosis are living with chronic pain and uncertainty, they can find hope in the understanding that life will not always be this way.
Again, knowing that all life is movement, we can see that movement away from the current place of unknowing and misunderstanding could lead to a place of knowledge and understanding, a place desperately sought by those living with an unknown disorder.

As psychologists and Adlerians, hope can be found in the idea that people are not “stuck” in any one particular thought pattern. People are the creators of their own reality. Therefore, people can imagine a life where things are different than they are now.

**Organ Inferiority**

One of Adler’s passions was the investigation of what allowed some people with physical disadvantages to thrive while others became unable to function at all (Adler, 1917). Adler defined conditions of biological origin as “organ inferiority” (Adler, 1917).

Adler (1931) specifically noted that those with organ inferiorities can and do make choices that are socially interested and community minded. He advanced the idea that a choice made on a cognitive level can change the direction of the pathology. Not that one could cure a disease with the mind, but rather that they could choose the attitude with which they face the disease.

This choice will be definitive in how they are able to cope with chronic pain and illness. If women are not given the full support of their community, their family, their friends, and most of all of their medical team; we find that chronic illness leads to trauma.

**A New Perspective from Trauma Research**

**Chronic Illness Defined as Trauma**

Recent research based on the work of neuropsychology, neuroimmunology, and neurobiology introduces a new way of thinking about the intrinsic reasons for the emotional discord experienced by women with endometriosis. Research confirms what is already
suspected; that trauma affects the physical body in very profound ways and disruptions in physical health can cause trauma-induced psychological symptoms.

Being undiagnosed and having many intervening years prior to actual diagnosis of endometriosis is a very real trauma. This trauma compounds the psychological symptoms of distress felt by women with endometriosis.

For women with endometriosis, those intervening years in which they are undiagnosed constitutes trauma. The trauma inevitably means no flow can happen and the woman remains “overwhelmed by the event, defeated, and terrified” (Levine, 1997). This incomplete cycle means that they are stuck in the unknown, unable to move either forward or back. In the language of trauma, they cannot flee or fight, they are simply frozen. Levine’s (1997) theory is that if the body can not complete the fight or flight cycle it starts, then a person remains stuck in the moment of the trauma, no movement or flow happens away from that stress filled moment and the trauma response is continually triggered by current events.

This can leave women with endometriosis feeling as though they have failed. Levine (1997) stated that women are much more likely to heal if they have a positive framework surrounding them during the healing. They are more likely to heal if they can have a ‘felt sense’ that they will overcome the trauma, versus the ‘felt sense’ that they are failing.

Gendlin (as cited in Levine, 1997) defines this ‘felt sense’ as a “whole body awareness of the situation, person, or event.” People experience life through all of the senses at once, not just one or another. This very real experience gives people a broader picture of the world than just how it tastes, smells, looks, sounds or feels. It is a fully embodied experience of every moment they live. Consequently the ‘felt sense’ of pain and chronic pain is not just a feeling in the physical body but rather an entire experience encompassing all the senses.
With this perspective in mind, it is apparent why someone living with chronic pain that remains undiagnosed for a decade or more might be traumatized. While this trauma goes unrecognized, the treatment of the person experiencing this reality is inadequate.

Levine (1997) describes events that are continuously experienced as a threat as the greatest challenge to treat. Indeed, the cycle of pain experienced by a woman with endometriosis is one that is continuously threatening. Women who remained undiagnosed are often given the untenable choice of either having a hysterectomy at an early age or being committed to a mental hospital (Ballweg, 1997). EB reports that she was offered a hysterectomy at age 13 to alleviate her symptoms and distress. Luckily, her mother refused and EB went on to become a mother at 33 years old, after 4 years of endometriosis induced infertility. E.B. (personal communication, January 2007).

Ballweg (1997) reports that many doctors attempt to convince their patients that their pain is somatic. This only succeeds in lowered self-esteem and reduced confidence in the medical system as a whole. Ballweg (1997) reports that 70% of the women who contact the Endometriosis Association have been told at least once that their symptoms are psychological and not physical in origin.

PTSD and Undiagnosed Illness

Levine (1997) illustrates a medical trauma by discussing the case of a person dealing with an undiagnosed condition for a long period of time. He explains the lasting effects of going through many medical procedures in order to diagnosis the daily pain experienced by women with endometriosis. It should be noted that the only way to definitively diagnosis endometriosis is surgical and one of the most used symptom reduction techniques is also surgical. Consequently,
women like EB will have had two to five surgeries in a short time span to diagnosis, alleviate
pain, and decrease infertility.

Levine (1997) found the following:

The traumatic after effects from … especially surgeries are often long lasting and severe. On
a cellular level the body perceives that it has sustained a wound serious enough to place it in
mortal danger. This biological fact is a primary reason why surgery will often produce a post-
traumatic reaction. (p. 54)

Levine (1997) is emphatic that one overlooked source of trauma can be a serious illness
which necessitates medical procedures like surgery and other interventions. These medical
traumas have psychological consequences that mimic the symptoms of anxiety and depression
(Levine, 1997). Traumatized people remain overwhelmed by the traumatic event itself, not to
even mention the physical symptoms of pain.

Van Der Kolk’s (2006) work also recognizes the need to define chronic medical problems as
traumatic. He explains that if a person cannot define what is wrong with his or her physical body
in terms of needs, he or she is then incapable of caring for themselves appropriately. This creates
a situation in which the person experiences a type of learned helplessness in which he or she feel
as though there is no hope and no end to the chronic pain. Indeed, if we revisit the story of EB,
we see a young woman who was lost in the chronic cycle of asking for help only to be told it was
“all in her head.”

If illness does not form a concise and coherent story in a woman’s mind, and she is left with
more questions than answers, the future is left in question and the woman is left with a sense of
shame at having an undiagnosed illness (Penn, 2001). As can be seen with EB, this shame leads
to a diagnosis of depression and anxiety. This does not accurately reflect the symptoms and etiology of her disease.

Van Der Kolk (2006) suggests that the integration of western and non-western techniques (like Yoga, Tai Chi, and massage) can help to heal the wounds of the psychological traumas experienced by those who are misdiagnosed or not diagnosed at all.

Van Der Kolk (2006) found that:

Trauma victims tend to have a negative body imagine – as far as they are concerned, the less attention paid to their bodies, and thereby, their internal sensations, the better. Yet, one cannot learn to take care of oneself without being in touch with the demands and requirements of one’s physical self. (p. 287)

In the case of a woman with endometriosis, Van Der Kolk’s (2006) suggestion to work with the stress of the medical trauma by becoming mindful seems to apply only after the appropriate diagnosis has been given. While a woman is still in the cycle of chronic pelvic pain without an answer as to why she is experiencing this pain, mindfulness and/or a more increased “felt sense” could lead to further traumatization.

Recent psychoendocrinological studies have revealed a prevalence of stress related symptoms caused by traumatic life events (Helm, 1997). Growing evidence suggests that the stress of a chronic illness over a life span can indeed lead to Post Traumatic Stress Disorder (PTSD) (Alonzo, 2000). Alonzo agrees with Levine’s (1997) premise that medical and surgical events can cause trauma and trauma-like symptoms.

Alonzo (2000) also finds a very real connection between chronic illness and PTSD:

Similarities are: 1) sudden onset 2) lack of preparation 3) threat to life and traumatic loss 4) collapse of the structure of the self 5) hindrance to continuous autonomous functioning
6) loss of wholeness, integrity or way of life 7) inability to integrate the experience into the self structure. (p. 1477)

Alonzo continues the list of researchers who are now concluding that uncontrollable pain and chronic illness while waiting for a proper diagnosis can cause PTSD symptomatology. Seng (2006) also recognizes the need to properly treat women’s health issues in order to side step the devastating additional side effects of dealing with PTSD. He sees the compounded effects of PTSD and chronic illness as a combination that may create serious life consequences for the sufferer (Seng, 2006).

Clinical Implications

**EMDR and Chronic Pain**

Eye Movement Desensitization and Reprocessing (EMDR) was developed by Shapiro in the late 1980’s. Since then, much research has been done on the validity of this method in working with trauma victims (Grant, 2001). Since July 2007, there is an academic journal, *Journal of EMDR Practice and Research*, covering the research done using EMDR as a treatment protocol.

Grant (2001) wrote a book on the effective use of EMDR in working with people suffering from chronic pain. He outlines a specific protocol for working with the psychological effects of chronic pain. Although the exact mechanisms of how EMDR work are not fully known, Grant (2001) describes a particular process for working with those experiencing chronic pain:

Since chronic pain involves numerous neurological similarities to trauma, including disruption of REM sleep, EMDR ought to work with pain. Just as EMDR is thought to ‘push-start’ REM-type information processing of traumatic feelings, it is also thought
to facilitate reprocessing of distressing sensations and thoughts associated with chronic pain. (p. 101)

PTSD has been found to respond robustly to EMDR. As such, the traumatic effects of living with a chronic disease may find some relief with this procedure. The prevalence of PTSD in the U.S. population is thought to be 12.3% over the lifetime (Seng, 2006)

Grant’s (2001) observations uphold earlier research hypotheses that trauma precedes pain. However, as this field develops, more research is needed to verify the hypothesis presented by this thesis that the pain in and of itself is the trauma.

*Psychological Treatment for Women with Endometriosis*

Metaphors, narratives, and stories are also found to be profoundly helpful in working with women with chronic pain and endometriosis (Penn, 2001). The stories women tell their therapists, their support groups, their doctors, and themselves can help them make sense of the suffering and bring meaning to an indescribably lonely situation.

Penn (2001) describes the process of bringing a new voice to the situation. This does not replace the story of pain, but lives along side of the story. This new voice can co-exist with and can help the woman with endometriosis remember that there are other parts to her life besides the pain. This takes out of the black and white thinking of “either I am completely sick or completely healed.” There can be an in-between.

“The biopsychosocial model proposes that a person can only be adequately understood if the therapist considers all levels of a patient’s functioning” (Sperry, 1999, p. 234). Sperry (1999) suggests that in order to treat a person with chronic pain, one must look at all parts of their lives in order to adequately treat them. A collaborative effort by all members of the person’s care team will create a better outcome for the woman with endometriosis.
(Sperry, 1999) suggests that the approach be patient-centered. In this model, one’s doctor, support group leader, therapist and massage therapist all communicate in order to provide the most effective treatment to the person.

This dovetails nicely with Adler’s ideal of treating the patient from a perspective of wholism (Ansbacher & Ansbacher, 1956). Adler believed that if the therapist looked at the person in his or her totality versus just a part of his or her lives, therapists could do a much better job of treating their patients.

Other research agrees that increased levels of support from the system as well as from family, friends, support groups, and coworkers leads to a more positive outcome for the sufferer of chronic pain (Lutgendorf et al., 2005). Pain management requires that the system be involved, not just the patient herself (Metzger, 1997). Endometriosis requires a long term approach integrating medical care, education, nutrition, physical activity, therapy, support groups, and medication management (Reiter, 1998).

This is not a disease that is experienced in a vacuum. The family, friends, and loved ones of the woman with endometriosis also suffer. Many support group models invite the woman’s circle of support to attend group with her in order to help others understand what the woman with endometriosis is experiencing.

For the women themselves, support groups can be a self-esteem builder after the long time waiting to find out what was wrong with them. Being able to meet with women who have walked in their shoes is an excellent experience (Hirsh, Ladipo, Bhal, & Shaw, 2001). These groups not only provide support, but also education, resources, and information (K. J. Jones, 1988). Prior to a diagnosis, these are three things that were desperately sought by women with endometriosis.
Gathering relevant information, hearing the stories of other women, finding community resources, and discovering strength for a “can do” attitude all are positive outcomes of attending support groups and being treated in this collaborative manner (ONeill & Morrow, 2001). Women with endometriosis need to have their stories heard. More than anything, they need to be taken seriously (Denny, 2004). Listening to and truly hearing the stories of these women’s lives is critical to ending their psychological suffering (Stratton, 2006).

_Treatment Implications_

Many women experience significant delays in obtaining an accurate diagnosis of endometriosis, ranging from months to 10 years. This delay has a detrimental effect on women’s emotional well being (Ballard et al., 2006). If one uses a model where it is assumed that chronic pain in and of itself is the reason for someone to start using psychological interventions to improve his or her life, this delay need not cause as much havoc in women’s emotional lives.

If women were given a provisional diagnosis (Ballard et al., 2006), they could start confirming or denying this conclusion based on their own life experiences. They would have a tool with which to empower themselves. This provisional diagnosis could provide them with more emotional stability than they previously had with no name for their chronic pain. The relief in giving their pain a name often leads to hope, something many of these women have lived without for a very long time (Ballard et al, 2006).

However, this relief may be short lived when women are faced with the prospect that endometriosis is incurable (Denny, 2004). Once they get past the initial optimism of knowing their disease has a name and there are treatment options, women come to realize that in most cases the recurrence rate is very high (Cox et al., 2003). This knowledge leads some women to feel more pessimistic about their futures. This pessimism might be misjudged as depression in
some diagnostic interviews or on some objective scales. For the most part, the interviewees did not seem to view their pessimism as depression, but rather as gathering their strength for the next storm (Denny, 2004).

Another clear clinical implication of this research is the need to educate not just the person on the street, but also the whole medical community about what is a normal amount of pain to cope with before seeking medical intervention. Many women in Ballard’s (2006) study reported that often their mothers, friends, nurses, doctors, and even specialists told them they were unlucky to have such pain but did not explain that it may be a medical condition. It was often presented to women like a game of chance-- some women have pain with their periods and others do not-- versus presenting it as a symptom of a possible chronic disease for which women could be tested and treated.

Women themselves questioned their own reports, as many have suffered with severe chronic pelvic pain since their first menstrual experience (Ballard et al., 2006). Because many of these women had chronic pelvic pain since they began menstruating, they had no comparison with which to accurately gauge what was normal. On top of questioning themselves, having their experiences dismissed by friends and family was yet another blow to their emotional well being. To then experience having their pain dismissed by the medical community as psychosomatic was identified as a key moment in the histories of many of the women interviewed.

If the medical caregivers (including psychologists) have a holistic understanding of what living with chronic pain entails, women living with this pain may have a very different experience within the medical system (Cox et al., 2003). This is an area that could be addressed
with education on a community level, support systems for women living with chronic pain, and advanced training for medical professionals.

The relief of finding someone who understands these women’s medical plight cannot be overemphasized. Support groups could network with gynecological offices so that all women know they have options versus just believing they are unlucky to have severe pain with their periods. Advocacy groups could give out informational handouts at every doctor’s office. Educational seminars could be held free of charge around the community. In order for endometriosis patients to take control of their medical care, it is necessary to train more specialists in the disease so that is not so difficult to find a compassionate, knowledgeable doctor (Cox et al., 2003).

Women need to be taken seriously and not have their pain dismissed by anyone (Denny, 2004). Many women are never referred to appropriate specialists to get an adequate diagnosis (Cox et al., 2003). After years of being told their symptoms did not have merit, women find significant relief in knowing that what they are experiencing has a name, endometriosis, and that it is not a malignant condition (Ballard et al., 2006). That relief and the decision-making following the diagnosis can be a very fruitful area of exploration for women in psychotherapy. Having a new language with which to describe their problem to friends, family, and even employers can empower women to make decisions based on their newfound knowledge (Ballard et al., 2006).

Frequently the damage caused by living for years with a chronic unnamable condition leaves a mark on women’s emotional lives. This is another area in which psychologists can help to reverse some of the damage caused from living with an undiagnosed disorder. Setting goals, becoming assertive, and sharing their knowledge with others (Cox et al., 2003) were all
directions that women in the many of the research studies believed would begin to repair the
damage of living with chronic pain. The themes found in their interviews led them to be able to
conclude that pain management is an essential component to any treatment program (Huntington
& Gilmour, 2005).

Waller (1995) concluded that having a psychologist work directly with the gynecologist who works with women with endometriosis can be productive in some cases. This recommendation was posited nearly a decade ago and the current evidence suggests that this is still not being done (Huntington & Gilmour, 2005).

Evidence is widespread that access to support groups of women who are also dealing with the side effects of endometriosis can have an impact on women’s overall emotional well being (Huntington & Gilmour, 2005). Emotional support in any form is highly recommended for women living with endometriosis (Lorencatto et al., 2006). There were many general themes raised by the qualitative research. If those themes could be structured into a support or therapy group or even into individual therapy, it may have a positive effect on women’s overall quality of life.

**Future Research**

The common theme of many of the research studies examined in this thesis was the need for additional education for the medical community and the impact this would have on the quality of life for women with endometriosis. The other common theme was the effect that structured and well informed support and therapy groups would have on women’s well being.

Quantitative studies can be constructed to explore the effects of both conditions on the overall quality of life for women. To find support for these goals, quantitative studies can
examine the quality of life of women participating in support groups versus women not participating.

Studies might also be constructed to look at the well being of women seeing doctors educated in the treatments for endometriosis versus those women seeing general gynecologists. This research could evaluate the conclusion that there is a need for continued support and education for both women and doctors alike.

Marques (2004) found that exercise was strongly correlated with higher levels of well being and reduced amounts of anxiety. Additional studies are needed to define what other lifestyle changes might help women lessen the detrimental side effects of living with chronic pain.

One of the questions left hanging by the research is the idea of which came first, pain or psychological distress. Because of the genetic component of endometriosis, it may be possible to construct a longitudinal study looking at the personality of daughters of women with confirmed endometriosis prior to the onset of their menstrual cycle and after their first bout with pelvic pain. However, assuming this cohort would have at least a basic understanding of endometriosis based on the knowledge that their mothers provide them; this too would be a confounding variable. This would not reliably answer the question of which comes first, pain or psychopathology.

The emerging field of trauma research and the *Journal of EMDR Practice and Research* could play a major role in researching the directionality of pain and trauma. The research remains divided about which came first. But the woman living with endometriosis, like EB, remain absolute in their conviction that the pain came first and the trauma came from disbelief and misdiagnosis.
This is the direction that this writer believes will be the most productive for answers to the questions asked by the women interviewed in the qualitative studies and the women seen in pain and psychological clinics all over the world.

**Conclusion**

In the end, we know decidedly that women with endometriosis have a lowered quality of life and emotional well being. Whether or not this comes from the pain caused by the disease or the disease itself is still an unanswered question. However, regardless of the etiology of the depression and decreased sense of well being, much of the research suggests a direction for improving the lives of the millions of women living with endometriosis on a daily basis.

Support groups, education of medical caregivers, provisional diagnoses, and more information given to the women as a whole were suggestions the majority of the researchers found to be solidly supported by their studies. Regardless of which comes first the studies are clear. Information can lead to less stress and, therefore, fewer traumas in women’s overall emotional well being.

As psychologists, we can contribute to the increase in women’s well being by being part of the support system that allows women to discuss their pain, explore their options, and openly question the medical establishment when their concerns are not being heard. Our role as holistic practitioners who listen, provide information, and also advise women to continue to fight for a definitive diagnosis can help women living with endometriosis experience less stress in the long run. Reduced stress can then allow these women an overall higher quality of life.
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