

# “The Social and Psychological Impact of Endometriosis on Women’s Lives: A Critical Narrative Review” (2013), by Lorraine Culley, Caroline Law, Nicky Hudson, Elaine Denny, Helene Mitchell, Miriam Baumgarten, and Nicholas Raine-Fenning

In “The Social and Psychological Impact of Endometriosis on Women’s Lives: A Critical Narrative Review,” hereafter “Social and Psychological Impact of Endometriosis,” authors Lorraine Culley, Caroline Law, Nicky Hudson, Elaine Denny, Helene Mitchell, Miriam Baumgarten, and Nicholas Raine-Fenning review the extent at which endometriosis results in a negative quality of life for affected women. Endometriosis is a condition characterized by the growth of cells similar to that of the endometrium, or the tissue that lines the uterus, outside of the uterus, and can cause heavy menstrual periods, pain, and infertility. Such symptoms can impact how women balance romantic or sexual relationships, due to the fact that endometriosis can cause chronic pelvic pain and pain during sexual intercourse. The authors found that women living with endometriosis are more likely to experience depression or anxiety, and conclude that the lack of both overall academic research and factual information given to women at diagnosis results in negative effects on their psychological wellbeing.

“Social and Psychological Impact of Endometriosis” is a review article, meaning it summarizes the available information that existed at the time of the article’s publication that was pertinent to the research team’s question. The research team was composed of researchers and professors who worked at De Montfort University in Leicester, United Kingdom. Culley, a professor of social science and health at De Montfort University, served as the principal investigator of the research team. Prior to the article’s publication, Culley had conducted research into socioeconomic effects on chronic conditions such as endometriosis. Law, a research fellow, compiled a list of relevant scientific articles from various databases, then organized and analyzed the data collected during the research process. Law specialized in public policy and reproductive health.

Alongside Law, Mitchell, a senior lecturer at De Montfort University, helped with the compilation of literature. Mitchell’s research interests included the psychological effects of chronic conditions like endometriosis. Hudson, a research fellow, compiled the final list of literature used for the research. Hudson specialized in the sociology of chronic conditions, and she served as the leader of the Center of Reproductive Research at De Montfort University. Additionally, Denny, a professor at Birmingham City University in Birmingham, United Kingdom, helped determine the quality of each article used for the purposes of the research. Denny’s research was primarily concerned with women’s experiences in healthcare settings. Both Baumgarten and Raine-Fenning applied their training and expertise as gynecologists to the research. Baumgarten focused her work on pregnancy loss and male infertility, while Raine-Fenning focused his research on assisted reproduction and pregnancy imaging techniques.

Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning divided “Social and Psychological Impact of Endometriosis” into eight sections. First, the authors describe the extent at which endometriosis affects the lives of women and include data that details how endometriosis can reduce fertility and increase pain and bleeding during menstruation, at the financial expense of women who must seek medical care for symptom management. Then, Culley and colleagues explain the methods they used in their research, which includes a literature review of the existing

information regarding the social and psychological impacts of endometriosis, such as how women balance symptoms and long-term effects with romantic relationships and pain management. Next, the authors detail similarities between the articles that they had assessed, which included specifics regarding the women sampled in each article, the impact of endometriosis on their quality of life, and the medical management of endometriosis. Then, the authors discuss the importance of the social and psychological impacts of endometriosis and how each impact affects the overall health of women and girls with the condition. Lastly, Culley and colleagues offer suggestions as to how factors such as geographical location may further impact the social and psychological impacts of endometriosis. The team guides their overall research question toward answering the question of how endometriosis affects women's lives and how researchers have studied those effects.

Culley and colleagues provide background information regarding endometriosis in the introductory section. Although endometriosis is a difficult condition to diagnose, the authors state that overall, researchers estimate that endometriosis affects two to seventeen percent of women around the world. For a doctor to diagnose a woman with endometriosis, they must perform a laparoscopic surgery to look for endometrial lesions in the woman's body, typically in her pelvis. Moreover, approximately forty-seven percent of infertile women experience endometriosis. The most common symptoms of endometriosis include pelvic pain as well as heavy and irregular menstrual bleeding. The authors indicate that endometriosis cannot be cured, but those painful symptoms may be temporarily relieved through various types of treatments and therapies such as hormonal birth control and surgery. Furthermore, women may find that endometriosis is expensive to manage, since as of 2020 the condition cannot be cured and therefore must continuously be treated. So, as endometriosis is a condition often associated with painful symptoms and is capable of causing infertility, the authors indicate that they were motivated to examine the social and psychological impacts that the condition has on the lives of women.

In their methodology section, Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning discuss how they conducted their research. Specifically, Culley and colleagues collectively produced a systematic way to extract data from articles that fulfilled their selection criteria. Separately, Law and Mitchell examined the titles, abstracts, and keywords of each of the articles to determine each article's relevance to the team's research question of how endometriosis affects women's lives and how researchers have studied those effects. Then, Culley, Denny, and Law performed quality assessments for each article to determine the best articles to use for their study. The researchers considered an article as high-quality if it included information most relevant to the team's research question. Finally, Hudson compiled the final list of articles that the authors included in their review.

Next in the methodology section of the article, the team details how they used particular data collection and analysis processes to collect, organize, and analyze their data. After they collected the articles, the authors further screened the full text of each article. The authors selected text fragments within the articles that pertain to the research question. After each article was coded, Law categorized all of the open codes into seven themes, including diagnostic delay and uncertainty in diagnosing the condition, quality of life and everyday activities, intimate relationships, planning for and having children, education and work, mental health and emotional wellbeing, and medical management and self-management. For example, Law organized all text fragments including words such as stress, depression, and anxiety into a broader theme titled mental health and emotional wellbeing.

Then, Culley and colleagues discuss the commonalities of the examined articles in the section titled, "Characteristics of Papers." The authors conclude that there had been a recent interest among women's health activists and public health officials in the social and psychological impact of endometriosis on women's lives. They quantify the recent interest based on there being more than half of the articles published between 2005 and 2010, relative to the 2013 publication date of "Social and Psychological Impact of Endometriosis."

Furthermore, Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning further discuss the specifics of each of the seven themes organized by the authors in the section titled, "Findings on the Social and Psychological Impact of Endometriosis." First, the authors indicate that twenty-one articles included information on the diagnostic delay and uncertainty surrounding en-

dometriosis. In short, the authors found that there is a diagnostic delay in cases of endometriosis, and such a delay is found to be correlated to a lower quality of life. Factors at the patient- and medical-levels may influence the diagnostic delay of endometriosis. Women wait approximately four years between experiencing endometriosis-like symptoms for the first time and seeking medical attention, because the authors assert that it is difficult for women to distinguish between normal and abnormal menstrual cycles. Then, on average, women may wait an additional four to six years before receiving a final diagnosis. According to the authors, health professionals often dismiss women in clinical settings, as they view their symptoms as normal, which the authors state reflects a lack of knowledge among health professionals surrounding endometriosis. Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning found that many women often reported feeling relieved after receiving a concrete diagnosis, while other women reported feeling disappointed with the delay in receiving a diagnosis.

Next, the authors discuss how endometriosis affects a woman's quality of life and daily activities. Specifically, the authors found and analyzed seventeen articles related to quality of life and everyday activities. Based on the articles, the authors conclude that endometriosis-induced pain tends to negatively impact a woman's quality of life. For example, Culley and colleagues state that women reported not being able to complete daily activities due to endometriosis, as painful symptoms oftentimes result in women having low energy. The authors found that such painful symptoms often lead to stress and anger, which may negatively impact a woman's relationship with family members, friends, and intimate partners. Similarly, Culley and colleagues found twelve articles related to the theme of intimate relationships. Specifically, the authors conclude that one of the most common complaints was painful sexual intercourse due to endometriosis. Because pain may last days after sexual intercourse, the authors found that women with the condition often avoid sexual intercourse. Also, Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning mention that many women are hesitant or embarrassed to address painful sexual intercourse with their doctors, enabling their condition to persist or worsen over time. In general, women reported that painful symptoms oftentimes led to relationship problems. However, other women stated that their partners helped them cope with endometriosis.

After reviewing the first theme, quality of life, the authors review the theme of planning for and having children. Culley and colleagues found ten articles related to that theme, and those articles suggested that approximately half of all women studied experienced problems with becoming pregnant. Many women expressed symptoms of anxiety and depression regarding problems becoming pregnant and potential infertility.

Furthermore, the authors discuss how symptoms of endometriosis may affect a woman's attendance at school and work. On average, women miss about nineteen days of work per year due to endometriosis-related symptoms. The researchers also found that many women reported a decrease in the quality of their work performance due to endometriosis. Additionally, many women reported avoiding mentioning their endometriosis diagnosis to their employers.

Continuing in "Social and Psychological Impact of Endometriosis," Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning discuss the negative impacts of endometriosis on mental health and emotional wellbeing. In some of the articles they surveyed, the authors found that women living with endometriosis tend to have higher levels of anxiety and emotional distress than the normal population. However, Culley and colleagues determine that anxiety and emotional distress are more strongly correlated with the painful symptoms of endometriosis rather than the condition itself. Instead of attributing mental health implications directly to the condition, the authors instead attribute it to the secondary effects of chronic pain. Also, the authors determine that emotional distress is a prevalent theme throughout most of the articles. For example, some women reported feeling short-tempered when endometriosis-related pain seemed to be unmanageable.

Continuing in the article, Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning then explain the medical management of endometriosis and potential self-management options. For example, the authors describe that treatments for endometriosis, such as surgery, oftentimes are associated with short-term relief from painful symptoms of the condition. However, the researchers state that women often experience a return of symptoms and pain after the surgery, and that surgery is not a cure for the condition. They then mention that women sometimes express anger to their

healthcare providers about the lack of long-term solutions for endometriosis. For self-management techniques, the authors found that many women attempt to treat their endometriosis symptoms through dietary changes and exercise in conjunction with medical management. They state that although those changes may contribute to short-term relief, they do not provide long-term alleviation of symptoms.

In the discussion section of the article, Culley and colleagues consider the implications of their major findings and how social and psychological impacts of endometriosis may contribute to the overall health of women. According to the authors, they found that diagnostic delay was one of the most prevalent themes across all articles. The authors also indicate that many other researchers had previously published literature concerning the diagnostic delay of endometriosis. However, Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning claim that no efforts had been made to decrease the amount of time women endure between experiencing endometriosis-like symptoms and receiving a final diagnosis. Also, Culley and colleagues found that endometriosis tends to have a significantly negative impact on a woman's quality of life. Furthermore, the authors express surprise to learn that limited literature regarding the relationship between endometriosis and infertility exists, as the authors found that as many as half of all infertile women were diagnosed with the condition. The authors suggest certain policies to protect women with endometriosis in the workplace, such as paid sick leave. Additionally, they conclude that there is a correlation between endometriosis, anxiety, and emotional distress.

In the last section, Culley, Law, Hudson, Denny, Mitchell, Baumgarten, and Raine-Fenning offer suggestions as to how factors like a woman's geographical location or age may further impact the social and psychological impacts of endometriosis. Since endometriosis is correlated with anxiety and emotional distress, the researchers assert that it may be valuable to know how such feelings impact girls that experience symptoms from endometriosis in their teenage years. Also, geographical location may impact the management of endometriosis, as some countries may not have the capacity to provide access to healthcare facilities or staff able to treat women with endometriosis.

Following publication of the article, Culley and colleagues partnered with Endometriosis UK, an advocacy group for endometriosis in the United Kingdom, to create the ENDOPART 2 Project in 2017. That project aims to further research and awareness on how endometriosis affects women's quality of life and specifically, their intimate relationships. Also, after the article's publication, Endometriosis UK began holding support group sessions for couples affected by endometriosis by providing counseling on how to manage the negative impacts that endometriosis may have on intimate relationships. Furthermore, in 2017, one of the article's authors, Hudson, talked about the research team's findings as well as the ENDOPART 2 Project on the British Broadcasting Channel Radio 4 Women's Hour.

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