

An Exploratory Look at the Experiences of Women with Endometriosis in China

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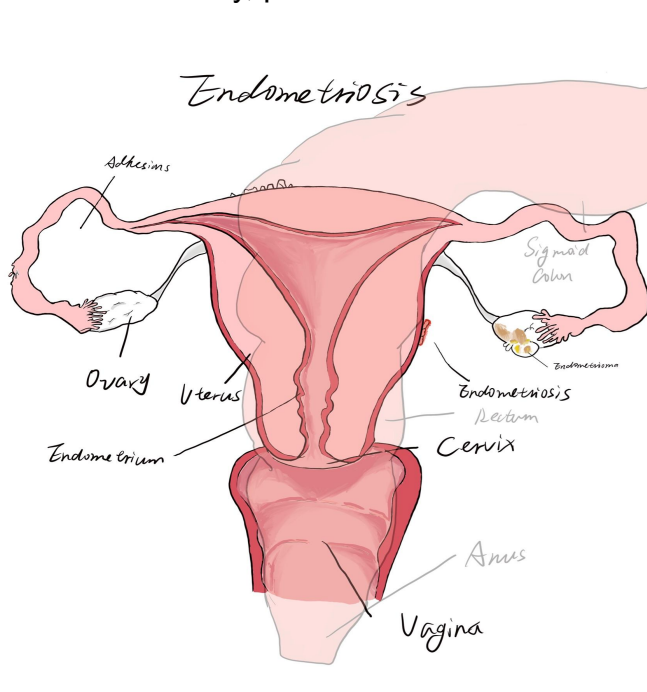
Overview

The article focuses on the experiences of Chinese endometriosis patients that live in China to understand the relationship between their cultural identity and the disease. The paper is composed of two parts: the first part is a synthesis of the medical research that provides the most current understanding of the disease, and the second part is an analysis of a survey conducted in a sample of 53 Chinese patients who are currently living in China that are diagnosed with endometriosis. The author's main motivation for conducting this research is his experience with his mother, who has been diagnosed with endometriosis for 5 years.

The online questionnaire revealed in this sample that surgery, particularly chocolate cyst removal, is the most common type of treatment. When being asked suggestions from their experiences, the majority of the patients encourage early treatment and warn not to normalize pain. They strive to speak against Chinese traditional culture, which encourages women to endure pain such as dysmenorrhea and childbirth as the natural part of womanhood.

I. What is endometriosis?

Endometriosis is a hormone-related gynecological disorder in which the inner lining of the uterus — endometrium — develops outside of the uterus, causing inflammation and adhesions in regions such as the ovaries, fallopian tube, pelvic lining and even parts of the colon. Common symptoms of endometriosis are moderate to severe lower abdominal and pelvic pain, irregular menstruation activity, painful intercourse and infertility.





There are more than 190 million women suffering from endometriosis globally, with approximately 10%-15% of them are of reproductive age (15-49 years). The disease appears to be more common in Asian women, with roughly 15% of the population suffering from the disease. Western and European women have a comparatively lower percentage, about 5-10%.

Unfortunately, modern research has yet to find the pathology behind endometriosis, leaving the cause of the disease unknown. There are certain theories indicating some worth mentioning potential causes of the disease, but they are yet to be proven. According to Mayo Clinic, certain causes are listed as follows:

- 1) Scar tissue. In cases such as hysterectomy and C-section, scar tissue left may cause adhesions within the endometrial area;
- 2) Immunity disruption that misidentifies the endometrial tissue outside the uterus, causing it unable to destroy misplaced tissue effectively;
- 3) Surgical adhesion caused by hysterectomy and C-section, causing the incision area to adhere with the endometrial cells;
- 4) Retrograde menstruation which causes backwards bleeding back to the abdominal cavity to the fallopian tube, carrying endometrial cells with the blood flow, causing endometriosis to develop.

Although the current cause of the disorder remains uncertain, there are certain risk factors that should be taken into consideration: never giving birth, early start of period and late start of menopause, short menstrual cycle and heavy menstrual loads, having family members with endometriosis, having a history of reproductive diseases, high level of estrogen exposure, and low body mass index.

Treatment decisions are made based on the symptoms, physical conditions, and age of the patients. Some choose to receive pain medication that reduces menstrual cramping, while others seek fertility professionals for assistance with conceiving. One of the most common treatments is hormone replacement therapy (HRT). There are several types of therapy that utilize the effects of estrogen which serves various purposes. More detail on treatments can be seen in the graph below.

Types of Hormone Therapy	How it Works
Hormonal contraceptives	Patients are given birth control pills, patches and vaginal rings (one of the most common ones is IUD), to reduce pain. Such medications simulate the hormonal conditions during pregnancy, which prevents regular periods, thus reducing the pain.
Gonadotropin-releasing hormone (Gn-RH)	Blocks the production of ovarian hormones that is related to menstrual pain and simulates menopause, which causes shrinking in endometrial tissues. Potential side effects are also menopause-related, such as lower bone density, hot flashes, and

	vaginal dryness. However fertility is not affected and can be restored once the medication is discontinued.
Progestin therapy	Progestin prevents the release of the egg from the ovaries, which interrupts the menstrual cycle. This can be given as pills, injections or contraceptives. However this treatment increases the risk of blood clots, especially for patients over 40.
Aromatase inhibitors	Instead of adding supplemental estrogen, aromatase inhibits estrogen. It is usually combined with progestin and hormonal contraceptives for treatment.

There are situations where a patient may not be a good match for medication, such as when the patient wants to have children in the future. In this case, conservative surgery is usually the treatment.. A manifestation of endometriosis is the development of non-cancerous, dark colored liquid-filled cysts in the ovary, commonly known as chocolate cysts. To remove these cysts surgical measures are taken.. Other common types of surgery include presacral neurectomy and hysterectomy (removal of parts or the entire uterus) to reduce extensive bleeding and pain. In cases of hysterectomy, even if the ovaries are kept, which is the majority of the cases,, it will still function normally, meaning hormone and pain management is still needed. However, considering the ovaries are critical estrogen providers, doctors tend to favor treatments that would preserve the ovaries, therefore hysterectomy is relatively less frequently chosen. These treatments generally have a 50% to 80% chance of success, thus are not guaranteed to be completely effective. Furthermore, in cases in which only the cysts are surgically removed or the ovaries are kept, there is still a chance of recurrence, especially for women who have not entered menopause, due to the effects of self-produced estrogen. Therefore, patients who have gone through chocolate cysts removal are required to take birth control pills or use and replace IUDs to inhibit the overproduction of estrogen.

Though these treatments are considered the most substantiated and effective ones, they have numerous side effects. Hormonal contraceptives limit the production of estrogen, an essential part of hormonal regulation. Due to the lack of estrogen produced, patients may experience side effects such as headache, mood swings, irregular bleeding and even perimenopause for older patients. Surgeries that involve removal of the diseased tissue or even sometimes parts of the uterus are invasive and can be potentially damaging to the reproductive system.

Diagnosis of endometriosis is done through a combination of a series of exams and checking of the medical history of the patient. Gynecologists do physicals to feel tenderness on the abdomen to identify certain fixtures, ligaments, or growing masses.

Due to the complicated nature of the disease, endometriosis remains one of the most commonly misdiagnosed gynecological disorders. Since the common signs of the disease often

involve abdominal pain and menstrual disruption, physicians usually misinterpret them as dysmenorrhea (pain during period) and inflammatory bowel disease.

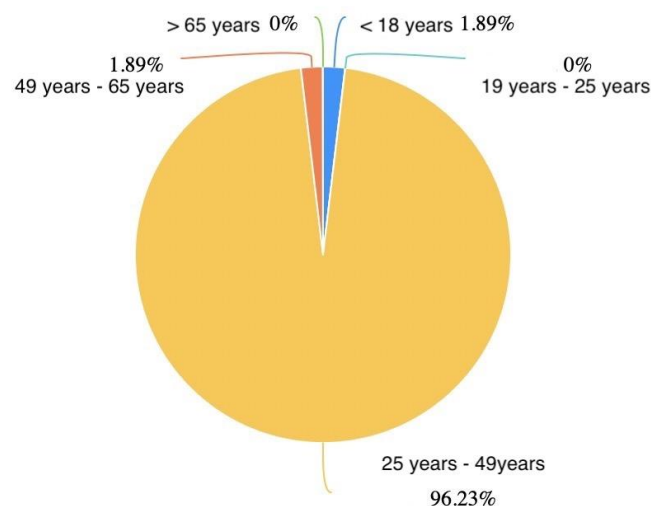
A disease that shares many features with endometriosis is adenomyosis, This can make diagnosis challenging. A key distinction is where abnormal tissue is located. Whereas in endometriosis, the endometrial tissue develops around the lining of the uterus, in adenomyosis, the tissue grows inside the muscular walls of the uterus, making it harder to diagnose and treat.

Apart from the pathological aspect of the disease, there has been a lack of patient education, causing misconceptions and stigmas about the illness. One of the most concerning stigmas is around possible infertility caused by the obstruction of the fallopian tubes. Patients that are still in the reproductive age are usually the ones that are most concerned with this misconception. A key element of the survey development was to explore if this misconception is prevalent in Chinese culture.

II. Survey Study

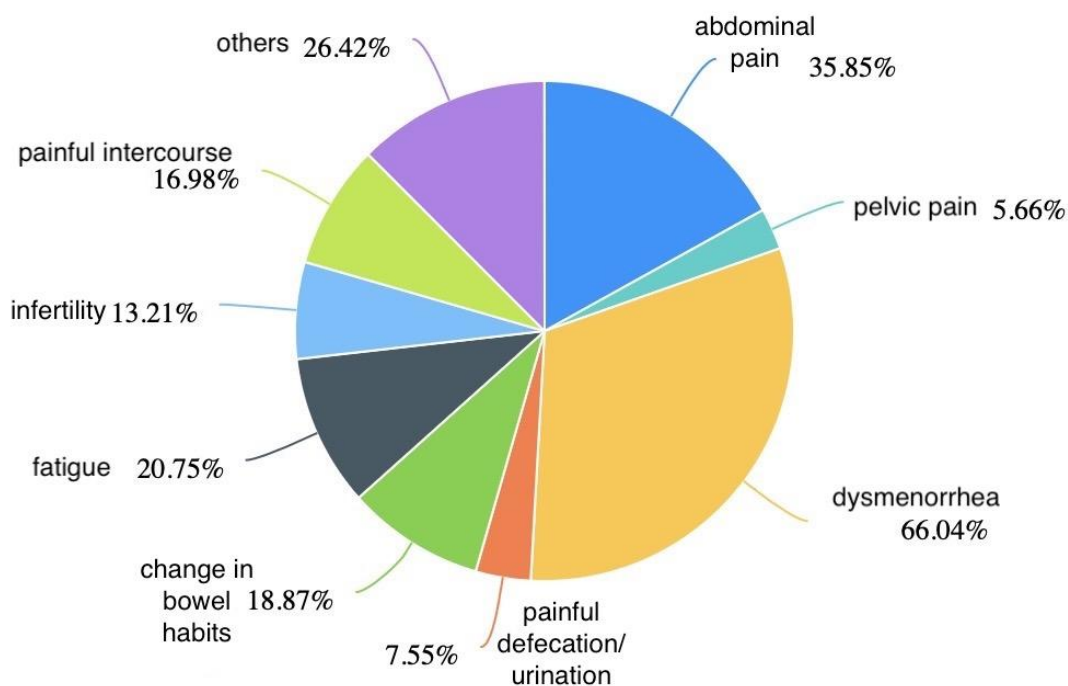
Research and studies have been not only focusing on the medical aspect of endometriosis, but also the psychological experiences of patients with the disease. An anonymous, voluntary, self-report survey of Chinese women with endometriosis in China was conducted online in January 2023. There were 53 responses that met the inclusion criteria. The survey was composed of questions collecting basic demographic information, women's experience with diagnosis and treatment, and their perspectives on the emotional aspect of the disease.

The people who filled out the form are divided into five age groups: 18 years or younger, 19 to 25 years, 25-49 years, 49 to 65 years, and 65 years or older. 96.23% of the participants are in their reproductive age: 25 to 49 years. Only two participants fall out of this range, with one of them being younger than 18, and the other one ages between 49 and 65 years. According to the data, the age of the surveyed sample mostly lies within the reproductive age, thus corresponding to the phenomenon of a high percentage of middle-aged women being diagnosed. However, it is also possible that the survey is biased towards access to the internet, considering it is an online questionnaire. Graph 1 below illustrates the sample breakdown by age.



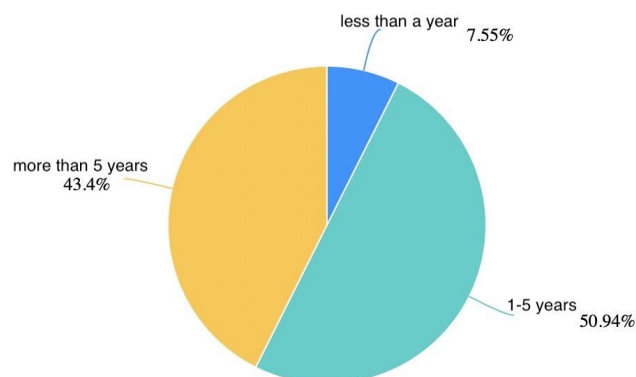
(Graph 1)

Then participants were asked about the most common symptoms they experience. 66% of participants responded that they suffer from dysmenorrhea. Other respondents shared they experience atypical symptoms such as change in bowel habits. One of the participants, who suffers from bowel endometriosis, a variation of the disease that affects the colon and is often misdiagnosed with appendicitis and irritable bowel syndrome, says that she experiences anal pain every time after period. Interestingly, there are 6 patients who experience no symptoms at all. They didn't find out they had endometriosis until their annual physical. Graph 2 demonstrates common symptoms below.



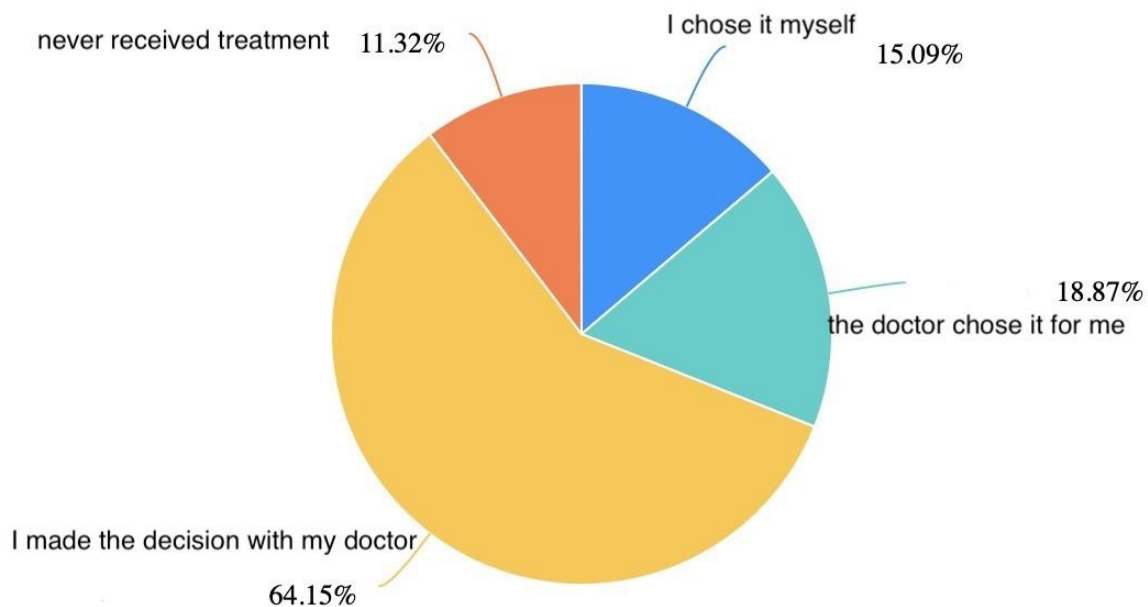
(Graph 2)

The majority of the research participants are experienced patients that have been aware of their condition for years. 50.84% of the participants have been diagnosed for 1 to 5 years, 43.4% of them are diagnosed for more than 5 years, and only 7.55% of the participants have been diagnosed for less than a year. (See Graph 3)



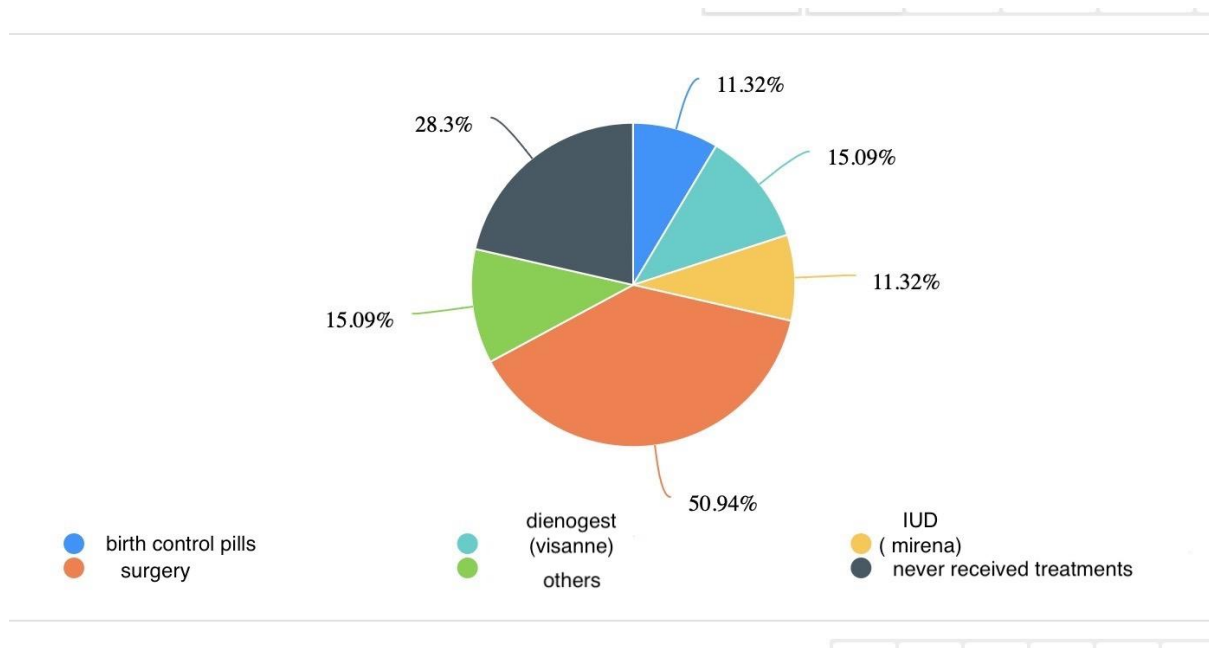
(Graph 3)

When it comes to choosing the best treatment for a patient, the right to make decisions plays a major role in treatment selection. 64.15% of survey respondents make the final decision with their doctor, 18.87% let their doctor make the decision for them, 15.09% of the participants decided solely for themselves, and 11.32% of the participants have never received any treatment. See graph 4 below.



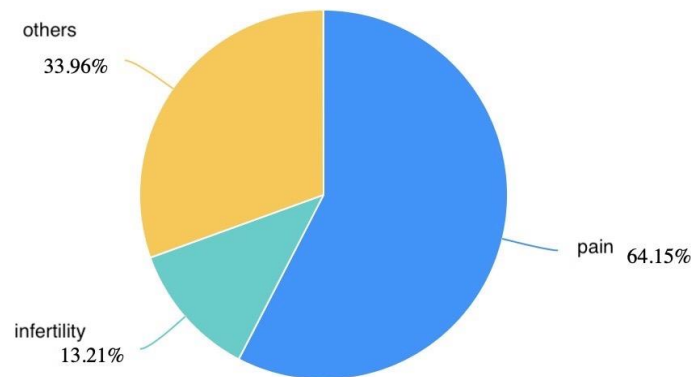
(Graph 4)

Treatments vary for each patient, but certain treatments are more common than others, which can be inferred from the question about treatments received. According to the survey, conservative surgery is the most common type of treatment, with 50.94% of the participants receiving this treatment. 28.3% of the participants have never received any treatment. 15.09% of the participants have used progesterone treatment. IUD and birth control both have 11.32% of the participants using them as treatment. (See Graph 5)



(Graph 5)

Participants were asked about the effects of the disease on their life. 64.15% of the participants responded that they are mostly disturbed by the pain accompanied with the condition, while only 13.21% of them responded that infertility has the most effect. 33.96% of the participants consider something else and some of them give varying answers. (See Graph 6)



(Graph 6)

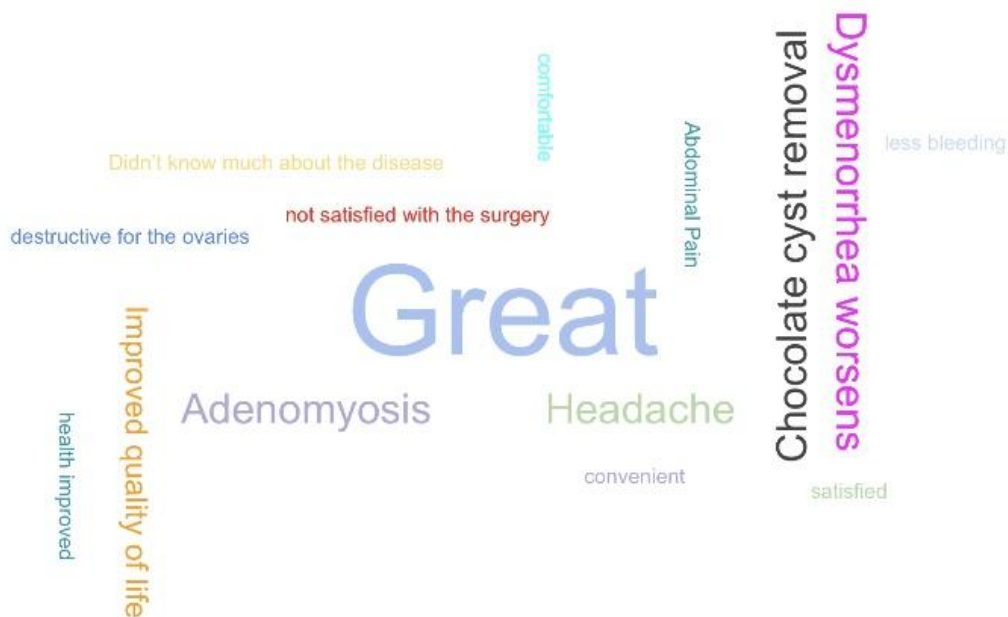


Survey participants were asked to share their feelings about the treatment they received in an open-ended format. These responses were translated from Chinese to English by the researcher. The most common responses are displayed in a word cloud format to highlight the frequency of response. The larger the text, the more frequently it was mentioned.

From the graph it is apparent that the most frequently stated word is “Great,” along with some less mentioned but similar words like “satisfied” and “Improved quality of life.” These responses show that the majority of the participants who have received treatments are mostly satisfied with the results. One of the patients shared that she was struggling with losing weight before treatment due to edema caused by inflammation, but now, several years post surgery, she feels her quality of life has improved significantly and much healthier than before. Another noticeable term is “chocolate cyst removal”, highlighting this procedure as the most common procedure among the participants.

However there are other terms that highlight negative experiences such as “Dysmenorrhea worsens” and “Headache.” Certain responses reflect participants’ regret of certain treatments and their lack of understanding prior to the treatment, indicating that not all treatments are perfect.

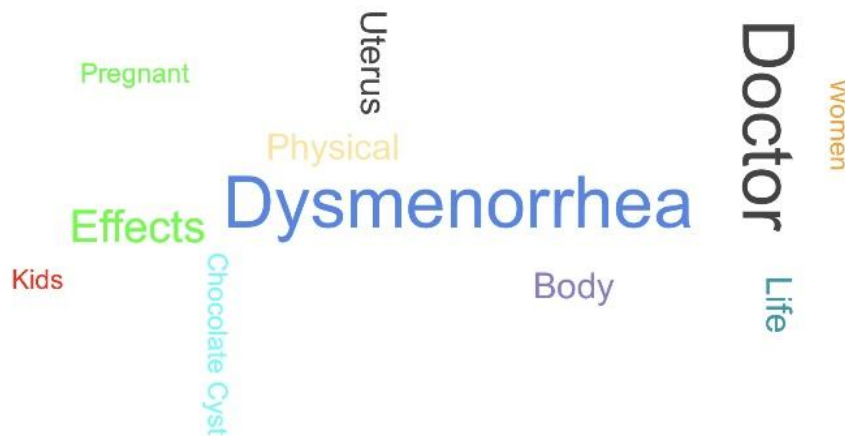
One patient describes her experience as a decision that was not made with caution. She did not know about treatments other than surgeries and received surgery without consideration, causing irreversible damage to her ovaries, yet she still suffered from a relapse. She shared in her response that she regretted the treatment and wished to choose alternatives if given another chance.



The final survey question asked the participants to share what they would want people without endometriosis to know about the disease. The word cloud below shows multiple responses including]“dysmenorrhea” and “doctor.” In context of the responses, participants

wanted people to know that dysmenorrhea is one of the most common symptoms of endometriosis, and that doctors were considered the most reliable source for help.

Another interesting observation seen in the survey results is not as clearly shown in the word cloud due to the variations in the individuals' replies. A surprisingly high number of respondents cautioned younger girls not to endure the pain as a natural part of being a woman and strongly encouraged them to seek professional help.



III. Discussion

According to the data, the age of the surveyed sample mostly lies within the reproductive age, thus corresponding to the phenomenon of a high percentage of middle-aged women being diagnosed. However, it is also possible that the survey is biased towards access to the internet, considering it is an online questionnaire.

In Chinese culture, women are commonly defined by their role as the birth giver. With this context, in Chinese women, losing the ability to become pregnant is may be seen as demeaning. Women who suffer from this disease experience various levels of stress, anxiety, and depression caused by hormone-related mood swings caused by the treatments and pain and discomfort. In Chinese culture, gynecological symptoms and side effects such as abdominal pain, dysmenorrhea, and infertility are considered a natural part of womanhood and therefore believed they must be endured. Medications and procedures such as ibuprofen, assisted reproductive technology, and even epidurals are stigmatized as and seen as detrimental to their health, as they "disrupt" the natural cycle of being a woman.

According to *A Study of Sociocultural Factors On Depression in Chinese Infertile Women in Hunan Province* (Hunan is known for being one of the most conservative provinces in China), in a study involving 211 infertile Chinese women, 88.15% of the patients have felt any reproductive stress, with the majority of the stress coming from themselves (71.51%), their parents-in-laws



(70.43%), and their husbands (65.59%). And over half of the participants (50.71%) are classified as depressed.

It is very likely that the long rooted Chinese traditional culture is the main contributor to stresses and controversies surrounding infertility, as the article states “In China, the ideas of Confucianism are still strongly rooted, whereby the maintenance of the family line has maximum priority.” (Li H;Lei J;Xu F;Yan C 16). Confucianism also advocates establishment of a patriarchal society which emphasizes the importance of order and authority. The idea demands absolute obedience from the people considered as subordinate or inferior to the authority: women obey to men, children obey to parents, and peasants obey to the emperor. This structure places the pressure of infertility on women, considering them as the one responsible for her inability to provide a complete family and continue the bloodline.

This study suggests that this cultural perspective is shifting. Study participants were not as concerned about infertility as the study researcher predicted. Participants were more concerned about pain rather than infertility and wanted to share more knowledge of their experiences with younger generations. This suggests a more progressive mindset developing among Chinese women in mainland China. Future research should explore education programs for young people about reproductive health, which helps enforce more progressive understanding of women’s reproductive health.

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