The Enigma of Endometriosis

Years of Misunderstanding
Endometriosis:
Ancient Disease
Ancient Treatments

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FREUD WAS WRONG; THE PAIN WAS REAL

A 4000-year survey chronicling the travails of women with endometriosis
Treatment of Endometriosis

- Historical Perspectives of Pelvic Pain
- Discovery of Endometriosis
- Treatment options through the ages
- The Empire of Medical Mythology:
  - Chronic Indifference to Women with Pelvic Pain
  - Freud was wrong; the pain was real
Historical Perspectives of Pelvic Pain: Suffocation of the Womb

- 13th century medical textbook: an image of a woman who has doubled over in pain.

- Experts believe this depicts one of the most commonly diagnosed gynecological disorders of medieval times: Suffocation of the Womb.
Suffocation of the Womb, Hysterical Uterus

- Centuries later traces of these concepts can be seen in the Hippocratic Corpus and other Greco-Roman works of Classical Antiquity.

- The basic concept was that the uterus was not a regular organ, but rather a live animal, hungry for motherhood.

- If a woman did not become pregnant, it was believed that her uterus would become agitated and begin wandering about – the famous wandering womb – and thereby cause illness.
“Disease of Virgins”

- Indeed, with young, unmarried women appearing to be afflicted more often, the Hippocratic texts named the disorder as one of the “diseases of virgins.”
Other Symptoms of Suffocation of the Womb: Extremest Anguish

Circa 375 BC, Plato mentioned that women with uterine suffocation suffered “extremest anguish”
Other Symptoms of Suffocation of the Womb:
Nausea & vomiting in relation to menstruation
Other Symptoms of Suffocation of the Womb:

Pliny the Elder reported women were falling unconscious.
Other Symptoms of Suffocation of the Womb: Violent Pain

• Soranus (ca. 98-138 AD) suggested violent contractions of the uterus were causing the symptoms
• Galen, Celsus, and Aretaeus also described violent “fits” of pelvic pain and convulsing and collapsing in agony during menstruation.
Ancient Treatments for Suffocation of the Womb

In addition to prescriptions for pregnancy, other treatments included:

- medicants to restore balance
- opiate-like herbs to relieve pain
Ancient Treatments for Suffocation of the Womb

- Some forms of treatment were a little bit curious: hanging women upside down and shaking them up and down so that their “wandering” womb would return to its correct place.
Ancient Treatments for Suffocation of the Womb

Medicinal substances were sometimes less than delectable, such as those that called for:

- the urine of bulls
- the brains of hares
- boiled beetles
Medieval Medicine

Despite the achievements of the ancients, unfortunately, by the time of Medieval Europe, women’s medicine had taken several backward steps:

Disorders viewed as gynecologic for thousands of years were now being defined as *psychological*.

And, gynecological Illnesses began to be viewed as the consequence of immorality or bad behavior.
The Curse of Eve
Illness as indicator of immoral behavior

- With certain gynecological illnesses now perceived as indicators of immoral behavior, this meant that women were sometimes blamed for their suffering. Or called it the Curse of Eve, karmic payback for the incident with the apple
Medicine from Medieval times to the Victorian Era

Or stricken with lovesickness
Medieval Medicine
Or depraved nymphomaniacs
Medieval Medicine
Or weak & complaining hypochondriacs:
“It is all in their heads”
Medieval Medicine

Or hysterical
Medieval Medicine

• Accusations of being demonically possessed or witches engaged in witchcraft.

• During a witch hunt craze of this era, women who seemed ill were sometimes described as appearing “possessed.”

• These portraits depict women described as suffering from hysteria-like symptoms. They are being thrown off the bridge into the river, cold water being the only known cure.
Medieval Medicine

- Accusations of witchcraft in particular could lead to execution by burning at the stake.
Medieval Medicine

- Or torture such as being sent to the pillory.
By the 17th century, physicians continued to notice a correlation with menstruation dysfunction causing pain & infertility which appeared to be curable with pregnancy.

In other words, by the 17th century, 4 patterns of illness similar to modern understandings had been observed by multiple authorities for a period of nearly 3300 years.
17th Century

- By this time hysteria, nymphomania and lovesickness had been introduced as other names to describe suffocation of the womb or hysterical uterus.
17th Century

- though nymphomania now suggested immoral behavior.
Young women continued to be seen as especially susceptible, as these 17th century paintings on the subjects show.
The Curse of Eve

Illness as indicator of immoral behavior

- With certain illnesses now perceived as indicators of immoral behavior, this meant that women were sometimes blamed for their suffering.
Ad from 1934 for relief from “Frazzled Nerves”

- These medical myths actually ended up negatively impacting women with endometriosis in the 20th century.
Few cases of endometriosis appear to have been cited.

Daniel Schröen’s 1690 work, cited by Vincent Knapp and confirmed by our independent translation describes symptoms and lesions that may have been those of endometriosis.
We also found another 17th century investigator named Frederik Ruysch who had been identified - not by Knapp – but by several early to mid 19th century physicians as identifying an endometriosis-like disorder.
The only treatments were vaginal injections of various materials, including ground up goat gonads, broiled brains, bull’s urine, and opium and alcohol for the pain.
Early 19th Century Surgical Milestones

- 1809: American surgeon, Ephraim McDowell, performed the world’s first successful oophorectomy
19th Century
Carl Rokitansky

- 1860: Dr Rokitansky was the first to microscopically identify endometrial glands in these growths
Freud was Wrong; The Pain was Real
Freud was Wrong; Hysteria: Most Colossal Mass Misdiagnoses in History

- However, even with clear evidence of an organic, gynecological disorder, women continued to be diagnosed as hysterical

- Such a diagnosis could have devastating consequences, as it implied that the woman was mentally unstable or faking her symptoms
19th Century Treatment Options

- Other treatments included:
  - caustic acids
  - bloodletting
  - clawing out with fingernails
19th Century Treatment Options

- With the introduction of anesthesia by about mid-century, either vaginal or abdominal puncturing of the cysts was also done. Mortality rates were reportedly as high as 70%.
19th Century Treatment Options

- 1850s-1870s increased intervention. One surgeon described as clawing out with his fingernails.

- In 1874, Dr James Marion Sims used this technique on a patient who ended up dying. This is one of the earliest accounts of a patient with endometriosis dying as a result of surgical intervention.
In 1887 Franz Winckel became one of the first to note that women with endometriosis suffered violent pain but that, when the nodules were too small for most to notice, they were unfortunately described as “hysterical’ instead.
Suicide & Endometriosis

- 19th century medical reports also demonstrate that women with endometriosis were considering suicide rather than suffer another moment with so much pain.
By the early 20th century, there were dozens reporting on cases of endometriosis. However, the work of Thomas Cullen stood out.
John Sampson of Albany, NY helped our understanding

- He published several articles starting in 1921, but it was his 1927 article that was most influential
  - He re-introduced the reflux theory from 236 years earlier
  - He introduced the term endometriosis
  - He confirmed that many disorders were all actually the same disease: endometriosis.

1921 - John A. Sampson
1950s: Introduction of Gynecological Endoscopy

- The new field of gynecological laparoscopy also briefly shined, with Kelly, Orndoff, Bernheim, Palmer, Frangenheim, and a few others, performing dozens of very minor therapeutic and diagnostic laparoscopies by the 1950s.

http://archsurg.ama-assn.org/cgi/content/full/139/10/1110
In the 1970s we introduced operative video laparoscopy.

Prior to this, even mild cases of endometriosis were being treated by laparotomy.
1980s – Basic Science and Medical Treatments

- GnRH agonists and prostaglandin inhibitors were introduced, while in 1990, the FDA approved Depot Lupron and later, studies on CA-125 emerged.
Throughout the 1990s and 2000s, breakthroughs in basic science research continued to be achieved by numerous investigators such as Drs Guidice, Taylor, Abrao, Berga D’Hooghe, Fazleabas, Goldenberg, Nisolle, Stratton, Surrey, and Tabibzadeh.
How far have we come?

Has our understanding of pain in women truly changed since our early history?

Looking back at how far we’ve come, though extraordinary progress has been made, it is amazing that it seems we still have the same problem of pelvic pain and advocate the same treatments - that was advocated 4000 years ago.
Thank you

The Nezhat Family