

Endometriosis affects women during their “prime” and most productive years

Endometriosis affects an estimated 176 million women worldwide between the ages of 15-49¹. While endometriosis is a disease that sometimes causes symptoms before and after the reproductive years, it most commonly impacts significantly on the general physical, social and mental wellbeing of women during their prime and most productive decades².

It is important to understand that endometriosis is not a “life-style” disease. Also, even though endometriosis cannot be prevented, many of its symptoms can be ameliorated through early diagnosis and effective treatment.

The first global studies investigating the impact and cost of endometriosis, across ten countries on five continents, were performed by the World Endometriosis Research Foundation (WERF)^{3,4} and found that:

- 65% of women with endometriosis presented with pain, a third of whom also reported infertility;
- 14% of women with endometriosis presented with infertility and no pain; and 14% had no symptoms;
- The pain symptoms of endometriosis significantly reduce all aspects of quality of life; the main impact is on physical, rather than mental, health;
- 47% of women experienced pain with intercourse and, as a consequence, 64% of these women have to interrupt intercourse and 73% avoid intercourse altogether;
- Women with endometriosis report a 38% greater loss of work productivity than those without endometriosis – mainly explained by a greater severity of pain symptoms among women with the disease;
- Reduced effectiveness at work accounts for more loss of work productivity than time missed from work, and accounts for two-thirds of the annual costs associated with the disease (ie. twice that of the direct cost of treatments);
- Non-work related activities, such as housework, exercising, studying, shopping, and childcare were also significantly impaired by the painful symptoms of endometriosis.

One of the biggest problems with endometriosis is that there is a significant delay of 7-11 years before the average woman with the disease is diagnosed, depending on health care setting.

Women see an average of seven health care professionals before they are referred to a specialist and treatment is commenced³. This delay is due partly to a lack of awareness of endometriosis in adolescents, social taboos shrouding the disease, and the fact that many women don’t know what is normal – and what isn’t – when it comes to menstrual health⁵.

However, the delay is also due to a general lack of awareness among primary care providers about the high prevalence of endometriosis, resulting in symptoms suggestive of the disease often being overlooked or dismissed.

It is worth noting that approximately 70% of adolescents, who at some time complain of and are treated for menstrual pain, eventually are diagnosed with endometriosis^{6,7}.

Hit and miss treatments with poor reimbursement

Awareness of endometriosis as a disease with substantial morbidity, and even co-morbidity, is essential for its proper management. However, it is also important to acknowledge that there is no known cure for endometriosis. Various hormonal treatments may keep symptoms associated with endometriosis under control for a while, but most are not suitable for long-term use due to side-effects². Also, in some states, it is increasingly difficult for women to fill prescriptions for hormonal treatments such as the oral contraceptive “Pill” or the IUD – both of which are commonly used to keep symptoms suppressed.

Surgery can be effective for the removal of lesions but, as with cancer treatment, is highly dependent on the skill of the surgeon. Yet these specialist surgeons who treat endometriosis are currently not reimbursed commensurate with other specialities. In most cases six hours of meticulous removal of endometriosis disease is reimbursed at the same rate as a 30-minute superficial surgical procedure – or not covered at all. Surgeries in which the endometriosis lesions and scarring are only superficially treated adds to the risk of acute inflammation and more scarring on top of the endometriosis-generated chronic inflammation. Consequently, women with endometriosis may have to endure multiple surgeries that increase their risk of morbidity and mortality – as well as increasing personal and societal cost.

Endometriosis is associated with infertility in 30-40% of sufferers^{3,8}. Earlier detection and management of the disease might be able to improve fertility in some of these women. Delayed diagnosis and treatment risk progression of the disease and possibly increases the risk of infertility, both of which can increase the long-term cost of treatment. Furthermore, long-term endometriosis is associated with poorer pregnancy outcomes⁹.

Inadequate treatment options for endometriosis leads to too many women having hysterectomies during what should be their child-bearing years. Not only does a hysterectomy not “cure” endometriosis unless the actual disease is surgically excised at the same time (which almost always requires specialist endometriosis surgeons) but surgical menopause before the age of 45 also carries an increased risk of early cardiovascular mortality and other morbidities¹⁰.

The cost of endometriosis is comparable to Crohn’s disease, diabetes, and rheumatoid arthritis

Annual healthcare costs of endometriosis are estimated at \$70-95billion in the United States alone⁴. This cost is comparable to other chronic diseases. However, two-thirds of these costs are attributed to loss of productivity at work rather than direct health care costs because untreated pain is so debilitating. How can we continue to justify this personal and societal cost?

What’s more, state and federal investment in endometriosis research is not comparable to other chronic diseases. National Institutes of Health (NIH) funding in excess of \$1bn is now being proposed, yet “endometriosis” is not listed as one of the diseases entitled to any of this funding.

An estimated 7.5 million American women are affected by endometriosis. Timely and effective treatments would see these women back – productively – in the work force. But it is going to take investment in improved understanding, diagnosis, and treatment to make this happen!

And, money aside, wouldn’t it be wonderful if these millions of women were to suffer less pain and fewer fertility problems during the years when they should be finishing an education, starting and maintaining healthy relationships, having a career, and creating a family?

A call for action: what needs to be done?

1. EDUCATION

Young women, the general population, and primary care providers need to be educated about what is and isn't normal when it comes to menstrual pain.

If pain prevents a girl from going to school or a woman being productive at work it is not normal and she needs treatment.

→ Local, state-wide, and/or national-wide education campaigns are needed.

2. SPECIALIST CARE WITH APPROPRIATE REIMBURSEMENT

Treatment for endometriosis needs to be specialised and access to this treatment made available to everyone who needs it.

Insurance companies and payers have to acknowledge that surgery for endometriosis requires highly trained and specialised surgeons and that such specialised surgery must be reimbursed appropriately. If this does not occur then this treatment modality will gradually disappear all together, which will further compromise millions of women's lives.

→ A dialogue must be entered into with insurance companies and payers to change status quo.

3. RESEARCH INTO DISEASE MECHANISMS

Endometriosis, affecting one-in-ten women during their most productive years, should become a research priority in line with other life-altering, yet non-fatal, diseases.

Until we understand the pathogenesis and underlying mechanisms of this disease, that affects so many women in so many different ways, it will be impossible to develop more effective and safe treatments.

→ Funding allocated for research on pain mechanisms and infertility in women with endometriosis is urgently needed to prevent this devastating and debilitating disease in the next generation.

REFERENCES:

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