Described as “a riddle wrapped in a mystery inside an enigma” (Ballweg 1995, 275; Wilson 1987, 1), endometriosis is defined by the presence of endometrial-like tissue found in the extra-uterine environment (Johnson and Hummelshoj for the World Endometriosis Society Montpellier Consortium 2013). The disease elicits a sustained inflammatory response accompanied by angiogenesis, adhesions, fibrosis, scarring, and neuronal infiltration (Giudice 2010). The gold standard for confirmation of diagnosis is laparoscopy (D’Hooghe et al. 2019).

Characterized by marked distortion of pelvic anatomy (Kennedy et al. 2005), development of endometriomas and high association with
comorbidities (Parazzini et al. 2017), endometriosis can result in significantly reduced quality of life. Although considered ‘benign,’ the disease may also be associated with higher risks of certain malignancies and shared characteristics with the neoplastic process (Matalliotakis et al. 2018; He et al. 2018).

Endometriosis is estimated to affect nearly 176 million individuals globally (Adamson, Kennedy, and Hummelshoj 2010), and ranks high among the most frequent causes of chronic pelvic pain (van Aken et al. 2017). A leading contributor to infertility, gynecologic hospitalization, and hysterectomy (Yeung et al. 2011; McLeod and Retzloff 2010; Ozkan et al. 2008), systemic influences of the disease can significantly impair physical, mental, emotional, and social health (Marinho et al. 2018). Definitive cause remains elusive, as does universal cure or prevention, and much of the discourse surrounding etiology and treatments remains ardently debated. Endometriosis imposes a staggering healthcare burden on society, with associated costs soaring into the billions (Soliman, Coyne, et al. 2017).

The complexities of this multidimensional condition remain poorly elucidated in current scientific works and little progress has been made toward deciphering endometriosis. Although research seems omnipresent, much of it is redundant in nature and the few qualitative studies conducted on the realities of living with the disease lack rigor (Moradi et al. 2014).

Though classically viewed as a ‘disease of menstruation,’ a uterus and routine menses are not de rigueur to diagnosis. The condition has been documented in post-hysterectomy/postmenopausal individuals (Ozyurek, Yoldemir, and Kalkan 2018; Soliman, Du, et al. 2017), rare cis males (Makiyan 2017, et al.), gender diverse people (Cook and Hopton 2017; Yergens 2016) and the human fetus (Schuster and Mackeen 2015; Signorile et al. 2010, 2012). Nevertheless, many continue to link the condition to simply ‘painful periods’ despite its profound impact far and apart from menses.

Comprehensive review of treatments for endometriosis, and the ensuing debates encompassing each, is outside the scope of this writing. However, timely diagnosis and multidisciplinary, integrative treatment are necessary to

Much of what is communicated about endometriosis, particularly in the scientific literature and media, reflects a stagnant belief system that perpetually confounds the diagnostic and treatment processes. Whilst medical knowledge, clinical experience and therapies are ever-evolving, the condition remains fundamentally mired in outdated assumptions that invariably lead to poor health outcomes. If we are to achieve real progress, we must strive towards an ideology which is truly reflective of modern concepts in order to elevate the condition to the priority public health platform it well deserves. To that end, though not intended as exhaustive or all-encompassing, the author has endeavored to incorporate the most current, authoritative facts about endometriosis herein—some of which run contrary to public doctrine.
effectively manage the condition—yet universal access to quality care remains limited in many settings, due in large part to dismissal of symptomology. 

**In brief:**

Laparoscopic excision is one of the most effective therapeutic options (Donnellan, Fulcher, and Rindos 2018; Franck et al. 2018; Pundir et al. 2017), affording biopsy-proven diagnosis and subsequent removal of lesions at the time of the surgical encounter. However, accuracy of diagnosis and treatment depends on ability of the surgeon to adequately identify the tissue in all affected areas.

Secondary to surgery are medical therapies. No drugs for endometriosis are curative; all have potential side effects (Rafique and Decherney 2017) and similar clinical efficacy in temporary reduction of pain. Menstrual suppression—which does not treat endometriosis, only symptoms—further supports the perception that menstruation is ‘unhealthy’ and requires pharmaceutical intervention.

Despite over 100,000 hysterectomies being performed annually as of this writing for a primary diagnosis of endometriosis and approximately 12% of individuals with the disease eventually undergoing hysterectomy as ‘treatment,’ there is an approximate 15% probability of persistent pain after hysterectomy, which may be due to incomplete disease removal, and a 3–5% risk of worsening pain or new symptom development (Rizk et al. 2014). Nor is menopause protective, with an estimated 2–4% of the endometriosis population being postmenopausal (Suchońska et al. 2018). In fact, postmenopausal endometriosis has demonstrated a predisposition to malignant change, greater tendency for extrapelvic spread, and development into constrictive and/or obstructive lesions (Tan and Almaria 2018).

Derived from the misogynist, antediluvian belief that painful menstruation was ‘ordained by nature as punishment for failing to conceive’ (Strange 2000, 616), pregnancy has long been suggested as a treatment or even cure for endometriosis. Nonetheless, pregnancy is not a ‘treatment’ option in any current clinical guidelines (Young, Fisher, and Kirkman 2016), nor does it prevent or defer progression of endometriosis (Setúbal et al. 2014). Moreover, the disease is linked to infertility, miscarriage, and potential complications in obstetric outcomes (Shmueli et al. 2017) and ectopic pregnancy (Jacob, Kalder, and Kostev 2017).

Finally, adjuncts like pain management and pelvic physical therapy are also often recommended post-surgically to address secondary pain generators common with endometriosis that is, pelvic floor dysfunction. Other alternative and complementary measures may also be considered.

**Defying Dogma: ‘Killer Cramps’ Are Not Normal**

Classic presentations of endometriosis include but are not limited to abdominopelvic pain, infertility, dyschezia, dyspareunia, dysuria, physiologic dysfunction, and significantly reduced quality of life. Extrapelvic disease, while less common
(Chamié et al. 2018), may manifest in a variety of ways for example, catamenial pneumothorax. Among the most widely recognized of endometriosis symptoms is incapacitating menstrual cramping (‘dysmenorrhea’).

Indeed, menstrual pain without pelvic abnormality (“primary dysmenorrhea”) is among the most common of gynecological disorders. Though accurate prevalence of dysmenorrhea is difficult to establish, it is estimated to impact up to 93% of adolescents (De Sanctis et al. 2015) and between 45 and 95% of all people with periods. When interviewed by Writer Olivia Goldhill (2016) for her heralded Quartz article on the lack of research into dysmenorrhea, Professor John Guillebaud went on record stating “period cramping can be almost as bad as having a heart attack.” Though some have questioned the notion that any degree of menstrual pain is “normal” (Dusenbery 2018, 221), primary dysmenorrhea generally maintains a good prognosis.

Conversely, severe pain failing to respond to intervention (“secondary dysmenorrhea”) is typically associated with conditions like endometriosis and warrants timely intervention (Bernardi et al. 2017). Moreover, a link between dysmenorrhea and the future development of chronic pelvic pain has been suggested (Hardi, Evans, and Craigie 2014), though symptoms are routinely misdiagnosed or otherwise dismissed (Bullo 2018). As a result, those suffering may be disparaged as ‘menstrual moaners’ or portrayed as simply unable to ‘cope with normal pain’ (Ballard, Lowton, and Wright 2006)—yet nearly 70% of adolescents with intractable dysmenorrhea or pelvic pain that fails to respond to initial therapy will later be diagnosed with endometriosis (Highfield et al. 2006).

Delays in the diagnosis of causative gynepathologies persist at the individual and medical level. To that end, healthcare professionals must engage patients in conversations which remain sensitive to cultural context, perceptions, and attitudes, yet draw out possible menstrual issues early so individuals are treated in timely and effective ways that harmonize with their specific needs.

**Embodyed Experience**

A widespread lack of public education about pelvic pain and menstrual-related disorders persists. As a result, endometriosis remains under-diagnosed, inadequately treated and frequently marginalized. Inappropriate diagnostic tests, poor history taking, provision of temporary analgesics or hormonal suppression to merely treat symptoms—but not the disease itself—creates confusion in diagnosis, postponement in diagnostic confirmation and mismanagement (Riazi et al. 2014). Only a minority of studies adds to the contextual information required to understand what it means to actually struggle with endometriosis.

Misinformation about the disease remains ubiquitous, saturating the healthcare and public sectors. Affected individuals may delay seeking care for
their symptoms, believing them to be a part of ‘normal’ menstruation, and healthcare workers may in turn dismiss their pain as “imaginary” (Bloski and Pierson 2008). To that end, healthcare encounters have been expressed as double-edged, both destructive and constructive; affecting not only the perception of the individual’s physical condition, but her self-esteem, body, and sexuality (Grundström et al. 2018) as well. As a result, those with the condition must often become ‘expert’ or ‘lead’ patients; that is, those who are proactive with respect to their health and possess knowledge of their disease and symptoms in order to effectively direct and manage their own care.

Individuals with the endometriosis from all backgrounds have long described journeys characterized by ignorance, disbelief, and lack of knowledge on the part of their doctors and the public. Encountering attitudes that they ‘exaggerated or imagined their symptoms or [have] low pain thresholds’ and further insinuation that “psychological factors or former abuse enhanced the symptoms” (Grundström et al. 2018, 8) may compound feelings of vulnerability and anxiety. Many “feel angry and frustrated when they [have] experiences with doctors who misdiagnosed, did not diagnose, delayed diagnosis of endometriosis, or just generally did not listen to their concerns, symptoms, and experiences” (Moradi et al. 2014). Not surprisingly, some people with endometriosis may resort to maladaptive coping strategies as a result (Zarbo et al. 2018).

Clark (2012, 83) has described the impact endometriosis may have on a woman’s sense of identity: “self-doubt plagued many . . . where they questioned their perception of the severity of the symptoms and ultimately their own sanity; mainly due to not being believed by medical practitioners and other lay people.” Yet as Culley et al. demonstrated (2013), the distress so commonly experienced by those with endometriosis is in fact related in large part to dissatisfaction with care for the disease. The authors correctly suggest the negative social and psychological impacts of the condition could be improved by a number of strategies; not least of which include practitioner education efforts and raising awareness via education through schools and support groups.

Pandora’s Jar: The Impact of The Wandering Womb and Hysteria on Endometriosis

From Greek *hysterikos* (‘of the womb’), assumptions on the ‘wandering’ uterus have long influenced attitudes about women’s health. Since the genesis of gynecology arose from the mythical first woman, Pandora, the womb was believed to have ‘no natural home.’ Identification of Pandora’s jar (*pithos*) as a uterus has been widely represented in Hippocratic gynecology and Western art; its subsequent opening brought forth ‘a range of evils including disease’ (King 1998, 2, 47–48, 58).
Anxiety, sense of suffocation, tremors, convulsions, or paralysis and more have been attributed to the ‘migratory uterus’ (Tasca et al. 2012). Hippocrates remains largely credited for grouping such issues under the single designation of “hysteria,” though King (1998) challenges such ascription (227, 237). Nonetheless, early physicians suggested that ‘hysteria’ could be counted among the ‘... symptoms of menstruation.’ Some advised that women who frequently displayed nervous or hysterical symptoms in relation to menses ‘ought to be incarcerated for their own safety and the good of society’ (Strange 2000, 616); a tenuous correlation might even be drawn to today’s menstrual huts.

Nezhat, Nezhat, and Nezhat (2012) further suggest there is irrefutable evidence that “hysteria, the now discredited mystery disorder presumed for centuries to be psychological in origin, was most likely endometriosis in the majority of cases ...” and as Jones (2015) proposes, discourse about the disease is “at least related to if not influenced by the social forces that shaped a diagnosis of hysteria” (1084).

Though ‘hysteria’ has been largely abandoned in modern nomenclature, the legacy of its impact persists. Today, symptoms of endometriosis may dismissed not as hysteria but ‘somatization’ (Pope et al. 2015). Women’s pain is routinely under-treated, labeled inappropriately as having a sexually transmitted infection, told their symptoms are ‘in their head’ (Whelan 2007) or too often, simply not heard (Moradi et al. 2014).

Endometriosis also remains tethered to psychological profiling, with those suffering routinely described as high risk for anxiety, depressive symptoms, and other psychiatric disorders. In fact, however, it has been demonstrated that the presence of pain—versus endometriosis per se—is associated with such psychological and emotional distress (Vitale et al. 2017). Whelan (2007) further asserts what those with the endometriosis well know: “[c]ertainly, medical experts’ ways of representing endometriosis often undermine the credibility of patient accounts . . . patients have often been represented in the medical literature as nervous, irrational women who exaggerate their symptoms” (958). Indeed, endometriosis is very much a corporeal condition with no regard for race, religious, sexual, socioeconomic, or mental health status.

**SAMPSON AND THE ITINERANT UTERINE TISSUE**

Reminiscent of the migrating womb, much of the dogma guiding endometriosis treatment and research today is rooted in the archaic supposition that the disease is caused by normal endometrium that has ‘roamed’ to distant sites. Just as the uterus does not wander, however, nor do fragments of entirely normal uterine tissue simply meander idly hither and yon resulting in endometriosis.

The premise of the condition arising from wholly normal albeit peripatetic endometrium sustains a century-old concept based on the works
of Dr. John Sampson (1927). Essentially, he considered endometriosis lesions to be comprised of ordinary endometrial cells; in fact, while somewhat resembling native endometrium, they are not identical (Ahn et al. 2016)—an important distinction. An abundance of differential invasive, adhesive, and proliferative behaviors have been demonstrated in the eutopic and ectopic counterparts of endometrial stromal cells in patients with the disease (Delbandi et al. 2013), and the tissue is functionally dissimilar (Zanatta et al. 2010).

Contrary to Sampson’s Theory, there is also evidence of endometriosis in cis males (Rei, Williams, and Feloney 2018, et al.), the human fetus (Signorile et al. 2009, 2010, 2012), females who have never menstruated (Suginami 1991; Houston 1984), and premenarcheal girls (Gogac et al. 2012; Marsh and Laufer 2005). The premise of ‘retrograde periods’ also fails to account for extrapelvic endometriosis in most cases. Moreover, though reflux menses is very common among people with periods, not all develop endometriosis; the incidence of disease is small compared to the occurrence of backflow experienced by most menstruators (Ahn et al. 2015). Similarly, as Redwine (1988) confirmed decades ago, endometriosis lacks the characteristics of an autotransplant (Khazali 2018).

Undeniably, pathogenesis remains rife with contention. Differing theories on varied mechanisms abound; stem cells, genetic polymorphisms, dysfunctional immune response, and an aberrant peritoneal environment have all been suggested in the establishment of endometriosis (Sourial, Tempest, and Hapangama 2014). The evidence also favors embryologic origins, with additional cellular and molecular mechanisms involved (Signorile et al. 2009, 2010, 2012; Redwine 1988). Nevertheless, no unifying theory to date accounts for all of described manifestations of endometriosis (Burney and Giudice 2012).

**Unremitting Misinformation, Menstrual Taboos, and Diagnostic Delay**

Much of society’s derogatory view of menstruating individuals, including within the political sphere (‘blood coming out of her wherever …’), remains virtually unchanged, and the very normal physiological process of menstruation remains linked to unfavorable attitudes in all cultures (Chrisler et al. 2015). Periods are still considered taboo in many parts of the world, with persistent knowledge gaps resulting in part from poor puberty guidance (Chandra-Mouli and Patel 2017). Research on menstrual cycle-related risk factors is lacking (Harlow and Ephross 1995), and the media continues to reinforce misconceptions around social captivity, restrictions, professional inefficiency, physical, and mental discomfort (Yagnik 2012) related to menses. Menstrual bleeding continues to be portrayed as “messy, inconvenient, and [an] unnecessary phenomenon to be controlled or possibly eliminated” (McMillan and
Jenkins 2016, 1). Yet, with a nod to Bobel and Kissling (2011): “menstruation matters:” menstrual history is a key component in a comprehensive women’s health assessment and an increasingly important variable in disease research (McCartney 2016).

For many, persistent taboos and perpetuation of ‘period shaming’ come at a high price: menstrual pain specifically, such as that often accompanying endometriosis, is routinely dismissed. Hence, the path to diagnosis is largely dependant upon the individual’s own “knowledge and experience of painful menstruation and other symptoms and whether they know other people who have been diagnosed” (Clark 2012, 85).

Delayed diagnosis serves as a high source of stress responsible for an important psychological impact on individuals with endometriosis. Average diagnostic delays worldwide hover around 7.5 years (Bullo 2019) or even longer, with continued resistance to timely intervention and referrals. Indeed, several clinicians consider themselves inadequately trained to understand and provide psychosocial care for patients with the disease (Zarbo et al. 2018). Conversely, earlier diagnosis and efficient intervention decreases productivity loss, quality of life impairment, and healthcare consumption, consequently reducing total costs to patients and society alike (Klein et al. 2014).

Studies reveal a relationship between ambivalent sexism and more negative attitudes toward menstruation, which may also lead to reticence to report menstrual cycle-related symptoms (Marván, Vázquez-Toboada, and Chrisler 2014). Others may deliberately conceal concerns for fear of stigmatization, further leading to diagnostic delay (Riazi et al. 2014). Still others may seek to reduce stigma associated with menstruation through ‘menstrual etiquette’ (Seear 2009), perpetuating social rules and normative expectations of menstruating persons and fearing that disclosure would result in embarrassment or perception that they are ‘weak’ (Culley et al. 2013). The literature further suggests some patients may simply fail to seek timely medical help due to their own inability to identify symptoms as ‘abnormal’—a failing of our menstrual education system.

To navigate the experiences of menstruation, endometriosis, and other episodes related to pain or vaginal bleeding, individuals “require factual and supportive information that enables them to differentiate between healthy and abnormal bleeding, to understand and take care of their bodies or those of dependents who may require assisted care, and to seek health advice appropriately” (Sommer et al. 2017, 2). Yet, menstrual teachings remain hampered by deficient cycles of misinformation. Education and perception are primarily communicated by mothers, sisters, or friends who themselves may lack accurate understanding (Cooper and Barthalow 2007), with resulting poor body literacy regarding reproductive anatomy, female hormones and their functions, effect of hormones on the menstrual cycle, ovulation, and conception (Ayoola, Zandee, and Adams 2016).
Likewise, menstrual health education programs in school and community settings remain deficient, particularly in low income settings, with many girls viewing school education about menstruation as “inaccurate, negative, and late” (Herbert et al. 2017, 14).

Conquering the Prevailing Ethos of Menstrual Shaming to Effect Positive Change

The perpetuation of menstrual shaming (for example, ‘The Curse’) has led to a prevailing ethos of generational taboos and lack of body literacy. There are consequences for such persistent bias, poor information systems, and practices; the resulting lack of education leads to delayed diagnosis and quality treatment of endometriosis and other gynecopathologies with subsequent impact on fertility, loss of libido and pleasurable sex, chronic pain, diminished quality of life, loss of sense of self, body-negative thoughts, and more.

While disease knowledge has evolved, the deeply entrenched cultural norms surrounding both endometriosis and menstruation must continue to be challenged. Existing gaps must be bridged in order to eliminate the enduring barriers that persist. How and when girls learn about menses and its associated changes can impact response to the menstrual event and is critical to their knowledge, autonomy, and empowerment. Hence, it is necessary to overcome persistent myths, increase authoritative awareness of endometriosis, and articulate effective strategies to develop more robust literacy on the condition than presently exists.

Cooper and Barthalow (2007) previously established the need for menstrual education in schools, with the topic being offered even before menarche in order to better prepare girls for the experience and continuing throughout their educational career so that students can build upon their basic knowledge of the many themes involved with menstrual health. A three-pronged approach has been suggested (Subasinghe et al. 2016) to better inform individuals about dysmenorrhea specifically: having the school nurse provide educational leaflets to increase familiarity with the condition; encouraging health professionals to be more proactive in asking patients about the topic so that young menstruators with dysmenorrhea may be more likely to disclose their pain and symptoms; and finally, joint promotion by health professionals and schools of reliable, authoritative websites, and resources for additional guidance.

Oni and Tshitangano (2015) previously proposed that school health teams may also consider screening students for menstrual disorders in order to help diagnose underlying pathological causes and attend such issues accordingly. Similar findings on the need for adolescent education on the effective management of dysmenorrhea suggest that extending the educational program to parents and school leaders is beneficial as well (Wong 2011).
Evidence demonstrates that consistent delivery of a menstrual health education program in schools specifically increases awareness of endometriosis (Bush et al. 2017). Two successful examples of such programs are already underway:

The Endo What? Documentary team School Nurse Initiative (https://www.endowhat.com/school-nurse-initiative), founded by Shannon Cohn, is a collaborative effort to provide endometriosis education and awareness among school nurses and their students and
The New Zealand model and the first of its kind in the world, developed over two decades ago by Deborah Bush, MNZM, QSM, Dip Tchg. LSB, Chief Executive of Endometriosis New Zealand (http://www.nzendo.org.nz/how-we-help/all-about-me). Both efforts have served to educate countless individuals.

Building on the examples above, clinicians and the public alike will benefit from better understanding of endometriosis, thereby improving patient experiences and leading to improved outcomes. We must incorporate correct disease information along with ethical, social, cultural, economic, and diversity perspectives in emerging menstrual education curriculum.

In order to ensure appropriate intervention and reduce costly, unproven protocols, like-minded collaborators from practitioner, allied and mental health and others need to engage in associated efforts. There must be an emphasis placed on optimal pathways, evaluation of modern concepts, and cross-collaborative strategies. It is imperative that all individuals know when, where and how to obtain help when symptoms of menstrual-related disorders first arise, and it is vital that the public, including but not limited to, legislators, hospital administrators, gynecologists, and subspecialists become involved in these efforts.

Moreover, in that mothers often traditionally teach their daughters, we must rectify misperceptions and offer instruction on menstrual practices and disorders like endometriosis by providing compulsory education at school, in clinics, and kinship settings in order to encourage story-telling narratives and break the legacy of silence, misinformation, and fear. We must better elucidate the parameters of normal versus abnormal bleeding, pain, and related symptomology in order to recognize disorder and pain signaling throughout the cycle.

To address difficulties faced by low resource and medically underserved communities, use of participatory/community-based efforts, integrated messaging during clinic visits, and use of Information Technology (IT) and digital health tools where applicable can improve access to healthcare services and information in ways that enhance patient knowledge and self-management, thereby positively impacting health outcomes.
Through stakeholder partnerships, we can foster new menstrual educational programs to produce high-quality educational materials and afford better outcomes for all. A strong public health agenda for menstrual/endometriosis education must include a collaborative interface among public health, community and non-healthcare sectors.

**Summary**

Endometriosis has the propensity to take away so many of an affected individual’s choices: when and whether to engage in sex, when or if to pursue fertility, whether or not to undergo invasive procedures or to choose oft-ineffective menstrual suppressives that alter her cycle and more. We must strive toward early recognition and diagnosis, better understanding of pathophysiology and pain mechanisms, increased translational research and dissemination of authoritative facts on a widespread basis, starting with menstrual education among youth.

The current deficiency in quality menstrual education leads to confusion, inaccurate beliefs about and negative views on menstruation and related conditions. Though steps forward have been made, many individuals lack understanding of what constitutes menstrual dysfunction and *when, where and how* to seek care. It is imperative that patients and health professionals alike become better educated on the clinical characteristics of endometriosis, not least general practitioners and school nurses, who play crucial roles in early diagnosis. This is achievable through menstrual education programs that incorporate the disease as a leading cause of pain. Outlining optimal care pathways, encouraging timely recognition, improving research priorities, accepting modern concepts and emphasizing appropriate, cross-collaborative strategies to optimize outcomes can transform endometriosis care and reduce the role of ‘menstrual silence’ in its diagnosis and treatment.

Embarking on robust educational programs which begin in the primary setting and are shared across varied resources will enhance literacy on painful menstruation and gynepathologies, thereby affording access to better, earlier care and improving the lives of the millions suffering. By revitalizing menstrual communication and key conversations, we can put an end to the secrecy, silence, shame, and pain.

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