The Womb Wanders Not: Enhancing Endometriosis Education in a Culture of Menstrual Misinformation

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THE ENDOMETRIOSIS ENIGMA

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

The vernacular of endometriosis is rooted in classic scholarship and the topic of menstruation itself is often cited as an example of biological reductionism: the medicalization of women and standardization of bodies (Rodríguez and Gallardo 2017). Hence, the author acknowledges that the terms “women” and “women’s health” are enforcers of hetero-cisnormativity, gender binarism and gender essentialism. For the purposes of this chapter, incorporation of such terms is intended only as a theoretical framework, inclusive of all bodies who struggle with endometriosis and have suffered from the bias, negligence, misdiagnosis and medical misogyny which so often characterize the disease; such use is not intended to trivialize, equate or otherwise limit the scope of the condition to only lived experiences of those essentialized categories of “females.” Furthermore, although often associated with the disease, “menstruation” is not synonymous with “endometriosis.”

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 Retzliff 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 obstetrical 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.

EMBODIED 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 (*pitthos*) 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 gynepathologies 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 off-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 gynecopathologies, 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.

REFERENCES

- Adamson, D., S. Kennedy, and L. Hummelshoj. 2010. "Creating Solutions in Endometriosis: Global Collaboration Through the World Endometriosis Research Foundation." *Journal of Endometriosis and Pelvic Pain Disorders* 2 (1): 3–6.
- Ahn, S. H., K. Khalaj, S. L. Young, B. A. Lessey, M. Koti, and C. Tayade. 2016. "Immune-Inflammation Gene Signatures in Endometriosis Patients." *Fertility and Sterility* 106, no. 6 (November): 1420–1431.e7.de.

- Ahn, S. H., S. P. Monsanto, C. Miller, S. S. Singh, R. Thomas, and C. Tayade. 2015. "Pathophysiology and Immune Dysfunction in Endometriosis." *BioMed Research International* 2015: 1–12. Article ID 795976. <https://doi.org/10.1155/2015/795976>.
- van Aken, M. A. W., J. M. Oosterman, C. M. van Rijn, M. A. Ferdek, G. S. F. Ruigt, B. W. M. M. Peeters, D. D. M. Braat, and A. W. Nap. 2017. "Pain Cognition Versus Pain Intensity in Patients with Endometriosis: Toward Personalized Treatment." *Fertility and Sterility* 108, no. 4 (October): 679–86.
- Ayoola, A. B., G. L. Zandee, and Y. J. Adams. 2016. "Women's Knowledge of Ovulation, the Menstrual Cycle, and Its Associated Reproductive Changes." *Birth* 43 (3): 255–62.
- Ballard, K., K. Lowton, and J. Wright. 2006. "What's the Delay? A Qualitative Study of Women's Experiences of Reaching a Diagnosis of Endometriosis." *Fertility and Sterility* 86, no. 5 (November): 1296–301.
- Ballweg, M. L. 1995. "The Puzzle of Endometriosis." In *Endometriosis*, edited by C. R. Nezhat, G. S. Berger, F. R. Nezhat, V. C. Buttram, and C. H. Nezhat. New York, NY: Springer.
- Bernardi, M., L. Lazzeri, F. Perelli, F. M. Reis, and F. Petraglia. 2017. "Dysmenorrhea and Related Disorders." *F1000Research* 7 (6): 1645.
- Bloski, T., and R. Pierson. 2008. "Endometriosis and Chronic Pelvic Pain: Unraveling the Mystery Behind This Complex Condition." *Nursing for Women's Health* 12 (5): 382–95.
- Bobel, C., and E. Arveda Kissling. 2011. "Menstruation Matters: Introduction to Representations of the Menstrual Cycle." *Women's Studies* 40 (2): 121–26.
- Bullo, S. 2018. "Exploring Disempowerment in Women's Accounts of Endometriosis Experiences." *Discourse & Communication* 12 (6): 569–86.
- . 2019. "I Feel Like I'm Being Stabbed by a Thousand Tiny Men": The Challenges of Communicating Endometriosis Pain." *Health* (London). February 19: 1363459318817943. <https://doi.org/10.1177/1363459318817943>.
- Burney, R. O., and L. C. Giudice. 2012. "Pathogenesis and Pathophysiology of Endometriosis." *Fertility and Sterility* 98 (3): 511–19.
- Bush, D., E. Brick, M. C. East, and N. Johnson. 2017. "Endometriosis Education in Schools: A New Zealand Model Examining the Impact of an Education Program in Schools on Early Recognition of Symptoms Suggesting Endometriosis." *The Australian and New Zealand Journal of Obstetrics and Gynaecology* 57, no. 4 (August): 452–57.
- Chamié, L. P., D. M. F. R. Ribeiro, D. A. Tiferes, A. C. Macedo Neto, and P. C. Serafini. 2018. "Atypical Sites of Deeply Infiltrative Endometriosis: Clinical Characteristics and Imaging Findings." *Radiographics* 38, no. 1 (January–February): 309–28.
- Chandra-Mouli, V., and S. V. Patel. 2017. "Mapping the Knowledge and Understanding of Menarche, Menstrual Hygiene and Menstrual Health among Adolescent Girls in Low-and Middle-Income Countries." *Reproductive Health* 14: 30.
- Chrisler, J. C., M. L. Marván, J. A. Gorman, and M. Rossini. 2015. "Body Appreciation and Attitudes toward Menstruation." *Body Image* 12 (January): 78–81.
- Clark, M. 2012. "Experiences of Women with Endometriosis: An Interpretative Phenomenological Analysis." Doctoral Thesis, Queen Margaret University, Edinburgh. Accessed January 2, 2018. <http://etheses.qmu.ac.uk/1812>.

- Cook, A., and E. Hopton. 2017. "Endometriosis Presenting in a Transgender Male." *Journal of Minimally Invasive Gynecology* 24 (7): S126.
- Cooper, S. C., and P. Barthalow Koch. 2007. "'Nobody Told Me Nothin': Communication About Menstruation among Low-Income African-American Women." *Women & Health* 46 (1): 57–78.
- Culley, L., C. Law, N. Hudson, E. Denny, H. Mitchell, M. Baumgarten, and N. Raine-Fenning. 2013. "The Social and Psychological Impact of Endometriosis on Women's Lives: A Critical Narrative Review." *Human Reproduction Update* 19, no. 6 (November–December): 625–39.
- Delbandi, A. A., M. Mahmoudi, A. Shervin, E. Akbari, M. Jeddi-Tehrani, M. Sankian, S. Kazemnejad, and A. H. Zarnani. 2013. "Eutopic and Ectopic Stromal Cells from Patients with Endometriosis Exhibit Differential Invasive, Adhesive, and Proliferative Behavior." *Fertility and Sterility* 100, no. 3 (September): 761–69.
- D'Hooghe, T. M., A. Fassbender, F. O. Dorien, and A. Vanhie. 2019. "Endometriosis Biomarkers: Will Co-Development in Academia-Industry Partnerships Result in New and Robust Noninvasive Diagnostic Tests?" *Biology of Reproduction*. February 1. <https://doi.org/10.1093/biolre/iox016>.
- Donnellan, N. M., I. R. Fulcher, and N. B. Rindos. 2018. "Self-Reported Pain and Quality of Life Following Laparoscopic Excision of Endometriosis as Measured Using the Endometriosis Health Profile-30: A 5 Year Follow-Up Study." *Journal of Minimally Invasive Gynecology* 25 (7): S54.do.
- Dusenbery, M. 2018. *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*. New York: HarperOne, pp. 221.
- Franck, C., M. H., Poulsen, G. Karampas, A. Giralidi, and M. Rudnicki. 2018. "Questionnaire-Based Evaluation of Sexual Life After Laparoscopic Surgery for Endometriosis: A Systematic Review of Prospective Studies." *Acta Obstetrica et Gynecologica Scandinavica* 97: 1091–104.
- Giudice, L. C. 2010. "Clinical Practice: Endometriosis." *The New England Journal of Medicine* 362 (25): 2389–98.
- Gogacz, M., M. Sarzyński, R. Napierała, J. Sierocińska-Sawa, and A. Semczuk. 2012. "Ovarian Endometrioma in an 11-Year-Old Girl Before Menarche: A Case Study with Literature Review." *Journal of Pediatric and Adolescent Gynecology* 25, no. 1 (February): e5–e7. <https://doi.org/10.1016/j.jpbg.2011.09.009>.
- Goldhill, O. 2016. "Period Pain Can Be 'Almost as Bad as a Heart Attack.' Why Aren't We Researching How to Treat It?" *Quartz Media*. Accessed October 15, 2017. <https://qz.com/611774/period-pain-can-be-as-bad-as-a-heart-attack-so-why-arent-we-researching-how-to-treat-it>.
- Grundström, H., S. Alehagen, P. Kjølhed, and C. Berterö. 2018. "The Double-Edged Experience of Healthcare Encounters among Women with Endometriosis: A Qualitative Study." *Journal of Clinical Nursing* 27, nos. 1–2 (January): 205–11.
- Hardi, G., S. Evans, and M. Craigie. 2014. "A Possible Link between Dysmenorrhoea and the Development of Chronic Pelvic Pain." *Australian and New Zealand Journal of Obstetrics and Gynaecology* 54, no. 6 (December): 593–96.
- Harlow, S. D., and S. A. Ephross. 1995. "Epidemiology of Menstruation and Its Relevance to Women's Health." *Epidemiologic Reviews* 17 (2): 265–86.

- He, J., W. Chang, C. Feng, M. Cui, and T. Xu. 2018. "Endometriosis Malignant Transformation: Epigenetics as a Probable Mechanism in Ovarian Tumorigenesis." *International Journal of Genomics* 27 (March): 1465348.
- Herbert, A. C., A. M. Ramirez, G. Lee, S. J. North, M. S. Askari, R. L. West, and M. Sommer. 2017. "Puberty Experiences of Low-Income Girls in the United States: A Systematic Review of Qualitative Literature from 2000 to 2014." *Journal of Adolescent Health* 60, no. 4 (April): 363–79.
- Highfield, E. S., M. R. Laufer, R. N. Schnyer, C. E. Kerr, P. Thomas, P. M. Wayne. 2006. "Adolescent Endometriosis-Related Pelvic Pain Treated with Acupuncture: Two Case Reports." *Journal of Alternative and Complementary Medicine* 12, no. 3 (April): 317–22.
- Houston, D. 1984. "Evidence for the Risk of Pelvic Endometriosis by Age, Race and Socioeconomic Status." *Epidemiologic Reviews* 6 (1): 167–91.
- Jacob, L., M. Kalder, and K. Kostev. 2017. "Risk Factors for Ectopic Pregnancy in Germany: A Retrospective Study of 100,197 Patients." *German Medical Science* 19, no. 15 (December): Doc. 19.
- Johnson, N.P., and L. Hummelshoj for the World Endometriosis Society Montpellier Consortium. 2013. "Consensus on Current Management of Endometriosis." *Human Reproduction* 28 (6): 1552–68.
- Jones, C. 2015. "Wandering Wombs and 'Female Troubles': The Hysterical Origins, Symptoms, and Treatments of Endometriosis." *Women's Studies* 44 (8): 1083–113.
- Kennedy, S., A. Bergqvist, and C. Chapron et al. 2005. "ESHRE Guideline for the Diagnosis and Treatment of Endometriosis." *Human Reproduction* 20 (10): 2698–704.
- Khazali, S. 2018. "The BSGE Meets...David Redwine." *BSGE Newsletter/The Scope*. Issue 10, Autumn, p. 25.
- King, H. 1998. *'Hippocrates Woman': Reading the Female Body in Ancient Greece*. London: Routledge, pp. 2, 47–48, 58, 227, 237.
- Klein, S., T. D'Hooghe, C. Meuleman, C. Dirksen, G. Dunselman, and S. Simoons. 2014. "What Is the Societal Burden of Endometriosis-Associated Symptoms? A Prospective Belgian Study." *Reproductive BioMedicine Online* 28, no. 1 (January): 116–24.
- Makiyan, Z. 2017. "Endometriosis Origin from Primordial Germ Cells." *Organogenesis* 3; 13, no. 3 (July): 95–102.
- Marinho, M. C. P., T. F. Magalhaes, L. F. C. Fernandes, K. L. Augusto, A. V. M. Brilhante, and L. R. P. S. Bezerra. 2018. "Quality of Life in Women with Endometriosis: An Integrative Review." *Journal of Women's Health* 27, no. 3 (March): 399–408.
- Marsh, E. E., and M. R. Laufer. 2005. "Endometriosis in Premenarcheal Girls Who Do Not Have an Associated Obstructive Anomaly." *Fertility and Sterility* 83, no. 3 (March): 758–60.
- Marván, M. L., R. Vázquez-Toboada, and J. C. Chrisler. 2014. "Ambivalent Sexism, Attitudes towards Menstruation and Menstrual Cycle-Related Symptoms." *International Journal of Psychology* 49, no. 4 (August): 280–87.
- Matalliotakis, M., C. Matalliotaki, G. N. Goulielmos, E. Patelarou, M. Tzardi, D. A. Spandidos, A. Arici, and I. Matalliotakis. 2018. "Association between Ovarian Cancer and Advanced Endometriosis." *Oncology Letters* 15 (5): 7689–92.
- McCartney, P. 2016. "Nursing Practice with Menstrual and Fertility Mobile Apps." *The American Journal of Maternal/Child Nursing* 41 (1): 61.

- McLeod, B. S., and M. G. Retzliff. 2010. "Epidemiology of Endometriosis: An Assessment of Risk Factors." *Clinical Obstetrics and Gynecology* 53, no. 2 (June): 389–96.
- McMillan, C., and A. Jenkins. 2016. "A Magical Little Pill That Will Relieve You of Your Womanly Issues': What Young Women Say About Menstrual Suppression." *International Journal of Qualitative Studies on Health and Well-Being* 23, no. 11 (November): 32932.
- Moradi, M., M. Parker, A. Sneddon, V. Lopez, and D. Ellwood. 2014. "Impact of Endometriosis on Women's Lives: A Qualitative Study." *BMC Women's Health* 14: 123.
- Nezhat, C., F. Nezhat, and C. Nezhat. 2012. "Endometriosis: Ancient Disease, Ancient Treatments." *Fertility and Sterility* 98 (6): S1.
- Oni, T. H., and T. G. Tshitangano. 2015. "Prevalence of Menstrual Disorders and Its Academic Impact amongst Tshivenda Speaking Teenagers in Rural South Africa." *Journal of Human Ecology* 51 (12): 214–19.
- Ozkan, S., W. Murk, and A. Arici. 2008. "Endometriosis & Infertility: Epidemiology and Evidence-based Treatments." *Annals of the New York Academy of Sciences* 1127: 92–100. Assessment of Human Reproductive Function.
- Ozyurek, E. S., T. Yoldemir, and U. Kalkan. 2018. "Surgical Challenges in the Treatment of Perimenopausal and Postmenopausal Endometriosis." *Climacteric* 21, no. 4 (August): 385–90.
- Parazzini, F., G. Esposito, L. Tozzi, S. Noli, and S. Bianchi. 2017. "Epidemiology of Endometriosis and Its Comorbidities." *European Journal of Obstetrics & Gynecology and Reproductive Biology* 209 (February): 3–7.
- Pope, C., V. Sharma, S. Sharma, and D. Mazmanian. 2015. "A Systematic Review of the Association between Psychiatric Disturbances and Endometriosis." *Journal of Obstetrics & Gynaecology Canada* 37 (11): 1006–15.
- Pundir, J., K. Omanwa, E. Kovoov, V. Pundir, G. Lancaster, and P. Barton-Smith. 2017. "Laparoscopic Excision Versus Ablation for Endometriosis-Associated Pain: An Updated Systematic Review and Meta-Analysis." *Journal of Minimally Invasive Gynecology* 24 (5) (July–August): 747–56.
- Rafique, S., and A. H. Decherney. 2017. "Medical Management of Endometriosis." *Clinical Obstetrics and Gynecology* 60, no. 3 (September): 485–96.
- Redwine, D. B. Mulleriosis. 1988. "The Single Best Fit Model of the Origin of Endometriosis." *Reproductive Medicine* 33 (11): 915–20.
- Rei, C., T. Williams, and M. Feloney. 2018. "Endometriosis in a Man as a Rare Source of Abdominal Pain: A Case Report and Review of the Literature." *Case Reports in Obstetrics and Gynecology* 2008 (January 31): 2083121.
- Riazi, H., N. Tehranian, S. Ziacy, E. Mohammadi, E. Hajizadeh, and A. Montazeri. 2014. "Patients' and Physicians' Descriptions of Occurrence and Diagnosis of Endometriosis: A Qualitative Study from Iran." *BMC Women's Health* 14: 103.
- Rizk, B., A. S. Fischer, H. A. Lotfy, R. Turki, H. A. Zahed, R. Malik, C. P. Holliday, A. Glass, H. Fishel, M. Y. Soliman, and D. Herrera. 2014. "Recurrence of Endometriosis After Hysterectomy." *Facts, Views and Vision in Obstetrics and Gynaecology* 6 (4): 219–27.
- Rodríguez, M. B., and E. B. Gallardo. 2017. "Contributions to a Feminist Anthropology of Health: The Study of the Menstrual Cycle." *Salud Colect* 13, no. 2 (April–June): 253–65.

- Sampson, J. A. 1927. "Metastatic or Embolic Endometriosis, Due to the Menstrual Dissemination of Endometrial Tissue into the Venous Circulation." *The American Journal of Pathology* 3 (2): 93–110.43.a
- De Sanctis, V., A. Soliman, S. Bernasconi, L. Bianchin, G. Bona, M. Bozzola, F. Buzi, C. De Sanctis, F. Tonini G, Rigon, and E. Perissinotto. 2015. "Primary Dysmenorrhea in Adolescents: Prevalence, Impact and Recent Knowledge." *Pediatric Endocrinology Reviews* 13, no. 2 (December): 512–20.
- Schuster, M., and D. A. Mackeen. 2015. "Fetal Endometriosis: A Case Report." *Fertility and Sterility* 103, no. 1 (January): 160–62.
- Seear, K. 2009. "The Etiquette of Endometriosis: Stigmatisation, Menstrual Concealment and the Diagnostic Delay." *Social Science & Medicine* 69, no. 8 (October): 1220–27.
- Setúbal, A., Z. Sidiropoulou, M. Torgal, E. Casal, C. Lourenço, and P. Koninckx. 2014. "Bowel Complications of Deep Endometriosis During Pregnancy or In Vitro Fertilization." *Fertility and Sterility* 101, no. 2 (February): 442–46.
- Shmueli, L., L. Salman, L. Hirsch, E. Ashwal, E. Hadar, A. Wiznitzer, Y. Yogev, and A. Aviram. 2017. "Obstetrical and Neonatal Outcomes of Pregnancies Complicated by Endometriosis." *Journal of Maternal-Fetal and Neonatal Medicine* 29 (October): 1–6.
- Signorile, P. G., F. Baldi, R. Bussani, et al. 2010. "New Evidence of the Presence of Endometriosis in the Human Fetus." *Reproductive BioMedicine Online* 21 (1): 142–47.
- Signorile, P. G., F. Baldi, R. Bussani, M. D'Armiento, M. De Falco, and A. Baldi. 2009. "Ectopic Endometrium in Human Foetuses is a Common Event and Sustains the Theory of Müllerianosis In the Pathogenesis of Endometriosis, a Disease That Predisposes to Cancer." *Journal of Experimental and Clinical Cancer Research* 28 (1), article 49.
- Signorile, P. G., F. Baldi, R. Bussani, R. Viceconte, P. Bulzomi, M. D'Armiento, A. D'Avino, and A. Baldi. 2012. "Embryologic Origin of Endometriosis: Analysis of 101 Human Female Fetuses." *Journal of Cellular Physiology* 227 (4): 1653–56.
- Soliman, A. M., E. X. Du, H. Yang, E. Q. Wu, and J. C. Haley. 2017. "Retreatment Rates among Endometriosis Patients Undergoing Hysterectomy or Laparoscopy." *Journal of Women's Health* 26, no. 6 (June): 644–54.
- Soliman, A. M., K. S. Coyne, K. S. Gries, J. Castelli-Haley, M. Snabes, and E. Surrey. 2017. "The Effect of Endometriosis Symptoms on Absenteeism and Presenteeism in the Workplace and at Home." *Journal of Managed Care & Specialty Pharmacy* 7: 745–54.
- Sommer, M., P. A. Phillips-Howard, T. Mahon, S. Zients, M. Jones, and B. A. Caruso. 2017. "Beyond Menstrual Hygiene: Addressing Vaginal Bleeding Throughout the Life Course in Low and Middle-Income Countries." *BMJ Global Health* 2: e000405.
- Sourial, S., N. Tempest, and D. K. Hapangama. 2014. "Theories on the Pathogenesis of Endometriosis." *International Journal of Reproductive Medicine* 2014: 179515.
- Strange, J. M. 2000. "Menstrual Fictions: Languages of Medicine and Menstruation, c. 1850–1930." *Women's History Review* 9 (3): 607–28.
- Subasinghe, A. K., L. Hapoo, Y. L. Jayasinghe, S. M. Garland, A. Gorelik, and J. D. Wark. 2016. "Prevalence and Severity of Dysmenorrhoea, and Management Options Reported by Young Australian Women." *Australian Family Physician* 45, no. 11 (November): 829–34.

- Suchońska, B., M. Gajewska, A. Zyguła, and M. Wielgoś. 2018. "Endometriosis Resembling Endometrial Cancer in a Postmenopausal Patient." *Climacteric* 21, no. 1 (February): 88–91.
- Suginami, H. 1991. "A Reappraisal of the Coelomic Metaplasia Theory by Reviewing Endometriosis Occurring in Unusual Sites and Instances." *American Journal of Obstetrics and Gynecology* 165, no. 1 (July): 214–18.
- Tan, D. A., and M. J. G. Almaria. 2018. "Postmenopausal Endometriosis: Drawing a Clearer Clinical Picture." *Climacteric* 21, no. 3 (June): 249–55.
- Tasca, C., M. Rapetti, M.G. Carta, and B. Fadda. 2012. "Women and Hysteria in the History of Mental Health." *Clinical Practice & Epidemiology in Mental Health* 8: 110–19.
- Vitale, S. G., V. L. La Rosa, A. M. Rapisarda, and A. S. Laganà. 2017. Comment on: "Impact of Endometriosis on Quality of Life and Mental Health: Pelvic Pain Makes the Difference." *Journal of Psychosomatic Obstetrics & Gynecology* 38, no. 1 (March): 81–82.
- Whelan, E. 2007. "No One Agrees Except for Those of Us Who Have It": Endometriosis Patients as an Epistemological Community." *Sociology of Health and Illness* 29, no. 7 (November): 957–82.
- Wilson, E. A. 1987. *Endometriosis*. New York, NY: Alan R. Liss.
- Wong, L. P. 2011. "Attitudes towards Dysmenorrhoea, Impact and Treatment Seeking among Adolescent Girls: A Rural School-Based Survey." *Australian Journal of Rural Health* 19, no. 4 (August): 218–23.
- Yagnik, A. S. 2012. "Construction of Negative Images of Menstruation in Indian TV Commercials." *Health Care for Women International* 33 (8): 756–71.
- Yergens, A. R. T. 2016. "Endometriosis and Gender Nonconformity." *Huffington Post*, June 9. Accessed September 1, 2018. https://www.huffingtonpost.com/ashley-rt-yergens/pumpkin-spice-lattes-endo_b_10265178.html.
- Yeung, P. Jr., K. Sinervo, W. Winer, and R. B. Jr. Albee. 2011. "Complete Laparoscopic Excision of Endometriosis in Teenagers: Is Postoperative Hormonal Suppression Necessary?" *Fertility and Sterility* 95, no. 6 (May): 1909–12, 1912.e1.
- Young, K., J. Fisher, and M. Kirkman. 2016. "Endometriosis and Fertility: Women's Accounts of Healthcare." *Human Reproduction* 31, no. 3 (March): 554–62.
- Zanatta, A., A. M. Rocha, F. Carvalho, R. Pereira, H. S. Taylor, E. Motta, E. Baracat, and P. Serafini. 2010. "The Role of the Hoxa10/HOXA10 Gene in the Etiology of Endometriosis and Its Related Infertility: A Review." *Journal of Assisted Reproduction and Genetics* 27 (12): 701–10.
- Zarbo, C., A. Brugnera, L. Frigerio, C. Malandrino, M. Rabboni, E. Bondi, and A. Compare. 2018. "Behavioral, Cognitive, and Emotional Coping Strategies of Women with Endometriosis: A Critical Narrative Review." *Archives of Women's Mental Health* 21, no. 1 (February): 1–13.

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