

Response to ‘Endometriosis’ – JAMA Patient Page

This response is not to criticize attempt by the authors of ‘Endometriosis’⁽¹⁾ to provide a simplified overview; indeed, I commend their action to bring focus to the disease. However, the accuracy of content is of concern. The disappointment is with the healthcare information system itself. Unfortunately, the majority of endometriosis literature continues to perpetuate outdated information. Disease knowledge has significantly evolved, yet accuracy remains lacking in many publications and derived information found on most health information websites.

Endometriosis is defined as “the presence of endometrial-like tissue outside the uterus which induces a chronic inflammatory reaction.”⁽²⁾ It is not merely “endometrium present outside the usual location.” Progressive thought leaders recognize the latter definition as outdated and maintain that “...stroma and glands...represent only a minor component of lesions...and are often absent in some disease forms.”⁽²⁾

Similarly, endometriosis is not exclusive to menstruators during the reproductive years. Symptoms may onset pre-menarche⁽³⁾ and persist after natural menopause or hysterectomy, with/without oophorectomy.⁽⁴⁾ Endometriosis has also been found in female fetuses, females with uterus agenesis and rare males.⁽⁵⁾ Retrograde Menstruation is simply unable to account for these presentations.

Conversations about endometriosis frequently revolve around the mistaken belief that the disease ‘ends’ with menopause. This has been proven false, for many, endometriosis remains active.⁽⁴⁾ Lesions have the capacity for self-sustaining levels of hormone synthesis, translating to active symptoms.⁽⁶⁾ Moreover, though once considered a disease of the female reproductive system, identification of body-wide endometriosis has led to greater awareness and reported frequency of extrapelvic forms. Disease has been documented among all (11) major body systems and up to 47% of those with the endometriosis have extrapelvic disease.⁽⁷⁾

The stepwise management approach outlined in ‘Endometriosis’, while in accordance with popular doctrine, lends to diagnostic (surgical) delay and inadequate treatment. As outlined in “The Case for Surgery for Endometriosis”,⁽⁸⁾ timely laparoscopic excision validates a diagnosis and is strongly associated with symptomatic improvement.

There is an opportunity to build a framework for accurate portrayal of endometriosis. It is time to embrace a new chapter on the disease and stop the perpetual recycling of outdated information.

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