

1 SOCIAL NETWORKS AND INFLUENCERS AS THE MAIN SOURCE OF “SCIENTIFIC”  
2 INFORMATION ON ENDOMETRIOSIS: A MEDICAL CLASS HARAKIRI?

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4 Sir,

5 Thurnherr and colleagues (2024) are to be commended for their informative and useful report  
6 describing the results of an online survey on hormonal therapies for endometriosis conducted on a  
7 large international sample of patients. The authors conclude that “*endocrine endometriosis*  
8 *therapies are associated with negative mental images and emotions and there seems to be a pre-*  
9 *therapeutic information deficit on the part of physicians*”.

10 In our opinion, it cannot be excluded that the reported findings are partly due to the ominous  
11 combination of limited awareness and knowledge of the condition among physicians on the one  
12 hand (Ballard *et al.*, 2006), and the long-standing scientific polarisation between advocates of  
13 medical versus surgical treatments **on the other** (Vercellini *et al.*, 2018), **resulting in potentially**  
14 contradictory information from experts.

15 In particular, the adverse effects on mental health associated with the use of oestrogen-  
16 progestogen combinations and progestogen monotherapies are the subject of an ongoing debate,  
17 given the inconsistencies of the available evidence. The risk of depression is generally concentrated  
18 in specific subpopulations, such as adolescents and patients with a previous diagnosis of psychiatric  
19 disorders (McCloskey *et al.*, 2021; Kraft *et al.*, 2023). Therefore, the issue of past or current  
20 depression should be systematically **investigated** when taking history and before prescribing  
21 hormonal treatments (Martell *et al.*, 2023).

22 More in general, the impact of first-line endocrine therapies for endometriosis should be  
23 addressed within the context of the management of a chronic inflammatory disorder with potential  
24 severe consequences. Thus, the overall balance between benefits and harms **may be** different  
25 compared with that in healthy women “merely” seeking contraception. This should also be made  
26 clear to patients. Moreover, the information provided during counselling should take into account

27 not only the risk of side effects affecting mental health but also the possibility that mental health  
28 and sexual functioning may improve as a consequence of pain reduction and of ameliorated overall  
29 quality of life associated with endocrine therapies (Barbàra *et al.*, 2021).

30 Finally, we wonder whether the participants in this survey (Thurnherr *et al.*, 2024) could  
31 have effectively discriminated between different classes of endocrine treatments, since side effects'  
32 frequency and severity vary considerably among medications. Throwing all drugs into one big pot  
33 may have led to an overestimation of potential adverse events (e.g., the popular concept of  
34 “pharmacologically-induced menopause” when using GnRH analogues).

35 The potential misinterpretation of this excellent article by enthusiastic surgeons to further  
36 discourage patients from using medical treatments would be a bad service to women and public  
37 health systems. We should all focus, together with nation-based patient associations, on  
38 disseminating complete and impartial evidence-based information on what is currently the only  
39 medical modality to control endometriosis and prevent its progression or its post-excisional  
40 recurrences. Shared decision-making and patient-centred medicine are incompatible with  
41 disinformation. Empowering women also implies that the medical class should be responsible for  
42 preventing its complete replacement by social networks and influencers as the main source of  
43 information (Lee *et al.*, 2022; Wu *et al.*, 2023; Adler *et al.*, 2024; Isaac *et al.*, 2024). Only by  
44 dedicating time to the medical encounter, giving voice to patients' fears and expectations,  
45 respecting their priorities and preferences, and adhering to international guidelines and  
46 recommendations (e.g., Becker *et al.*, 2022) could this be obtained (Cappella and Street, 2024).  
47 Well-informed clinicians have a moral duty to explain to patients that, when correctly prescribed in  
48 individuals without major contraindications, first-line hormonal medications are safe, effective and  
49 inexpensive. This allows equitable access to care, which is particularly important in middle- and  
50 low-income countries. As the authors have pointed out, non-hormonal treatments are a long way  
51 off. In the meantime, we plead for more research on tolerability and customisation of available  
52 therapies.

53 **Conflict of interests:**

54 P.V. is a member of the Editorial Board of the Journal of Obstetrics and Gynaecology Canada and  
55 of the International Editorial Board of Acta Obstetrica et Gynecologica Scandinavica; has received  
56 royalties from Wolters Kluwer for chapters on endometriosis management in the clinical decision  
57 support resource UpToDate; and maintains both a public and private gynaecological practice.

58 All other authors declare no conflict of interest.

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