Management of Endometriosis: Toward Value-Based, Cost-Effective, Affordable Care

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Abstract

Endometriosis management seems to be influenced by outcome-independent biomedical, pharmacological, and technological developments. The propensity towards doing more affects several aspects of care, sometimes translating into proposals that are not based on sound epidemiological principles and robust evidence. Different stakeholders share the interest for doing more testing and using novel and costly drugs or devices in patients with endometriosis. Although some women may benefit from such an approach, the majority do not, and some may be harmed. Moreover, an uncontrolled increase in expenditures for endometriosis management without demonstrated and proportional health benefits would waste the finite resources of national health care services and would risk cost-related non-adherence. Cost-effectiveness analyses should be systematically pre-planned in future trials on endometriosis, and the concept of "value" of medical interventions should guide investigators and health care policymakers. Reducing low-value care, financial toxicity, and the burden of treatment is respectful not only of endometriosis patients, but also of the entire society. Whenever possible, long-term therapeutic strategies should be tailored to each woman's needs, and high-value tests and treatments should be chosen based on her priorities and preferences. Moreover, listening to patients, understanding their concerns, avoiding disease labelling, explaining plainly what is known and what is unknown, and giving constant reassurance and encouragement may be exceedingly important for the successful management of endometriosis and may change the patient's perception of her clinical condition. Physician empathy has no untoward effects, does not cause harms, and may determine whether a woman successfully copes or desperately struggles with her disease during reproductive life.

Key Words: Endometriosis, medical treatment, surgery, value of care, comparative cost-effectiveness research, burden of treatment

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Résumé

La prise en charge de l'endométriose semble être influencée par des avancées biomédicales, pharmacologiques et technologiques, indépendamment des issues cliniques. La tendance à multiplier les interventions affecte plusieurs aspects des soins et entraîne parfois des propositions ne reposant pas sur des principes épidémiologiques ni sur des données probantes solides. Différents intervenants peuvent avoir intérêt à recourir à de nombreuses analyses et à proposer de nouveaux médicaments et appareils coûteux pour traiter les patientes atteintes d'endométriose. Si certaines femmes peuvent être avantagées par une approche de ce type, ce n'est pas le cas pour la majorité : d'autres peuvent même subir des préjudices. De plus, une hausse non contrôlée des dépenses liées à la prise en charge de l'endométriose en l'absence de bienfaits proportionnels et démontrés pour la santé viendrait gruger les ressources limitées des systèmes nationaux de soins de santé et pourrait entraîner une non-observance des traitements en raison de leurs coûts. Des analyses de coût-efficacité devraient automatiquement être intégrées à la planification des futurs essais sur l'endométriose, et le concept de « valeur » des interventions médicales devrait orienter les chercheurs et les responsables des politiques dans le domaine des soins de santé. La réduction de la prestation de soins de faible valeur, de la toxicité financière et du fardeau associé aux traitements profiterait non seulement aux patientes atteintes d'endométriose, mais aussi à l'ensemble de la société. Dans la mesure du possible, les stratégies de traitement à long terme devraient être adaptées pour répondre aux besoins de chaque femme. Il faudrait également choisir les examens et les traitements de grande valeur en fonction des priorités et des préférences des patientes. Qui plus est, le fait d'écouter les patientes, de comprendre leurs préoccupations, d'éviter de mettre une étiquette sur leur maladie, d'expliquer le plus simplement possible les éléments connus et inconnus et de leur fournir constamment réconfort et encouragement peut être l'aspect le plus important d'une prise en charge efficace de l'endométriose et peut changer la perception des patientes à l'égard de leur état. La compassion démontrée par le médecin n'a aucun effet fâcheux, ne cause aucun dommage et peut aider une femme à bien gérer sa maladie durant sa vie génésique au lieu d'éprouver de grandes difficultés.

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TOWARDS AFFORDABLE ENDOMETRIOSIS CARE

After a PubMed search for "endometriosis AND review," 1219 articles published in the last 5 years were identified through May 29, 2017. The available reviews covered all aspects related to endometriosis, from epidemiology to pathogenesis and management. Most reviews were narrative, but many were systematic and several included meta-analyses.[1] Some reviews were methodologically adequate; very well written; updated, informative, and balanced; and could be of great benefit for patients, physicians, and medical decision makers when choosing among different therapeutic alternatives, writing guidelines, and defining health care policies.

Thus, we did not perform another comprehensive overview of the published data regarding diagnosis and treatment of endometriosis. Instead, here we have tried to offer a critical analysis of still open issues encountered in everyday practice, evaluating available data also from the perspective of health care systems and policy makers in addition to that of the individual patient-physician dyad. We believe that, especially in a period of global shrinkage of health care resources, the endometriosis scientific community should begin to systematically consider the cost-effectiveness of tests and treatments because the economic burden of any therapeutic choice may affect the welfare of individual families and national health systems.[2]

The effectiveness of any strategy for long-term treatments of chronic disorders is based primarily on its affordability. Affordability of new medicines also has been described in terms of "value" of a product within the context of health care system budgets. The value of a medical intervention has been defined as the health outcomes achieved per dollar spent or the balance between potential benefits, potential harms, and costs.[3] The implementation of the concept of value of medical interventions also has been suggested in endometriosis management.[4]

Restrictions on the use of efficacious therapies can result from affordability concerns.[5] The cost of health care may act as a barrier for people with different chronic conditions who eventually forgo care because of out-of-pocket expenditures.[6,7] Approximately one third of Canadians' prescription medical costs are paid directly out of pocket,[8] and about one in 10 to 12 Canadians who received a prescription reported cost-related non-adherence.[9] According to a recent cross-sectional study assessing the effects of costs on access to medicines in 11 developed countries offering different levels of prescription drug coverage for their populations, Canada had the second-highest national prevalence of cost-related non-adherence.[10] Thus, reducing low-value care and financial toxicity in endometriosis care are measures that are respectful not only of patients, but also of the entire society. Providing the best possible care, while at the same time limiting harms and costs, protects women and preserves precious resources for all patients and for the medical community at large.

Along this line, the advent and spread of intellectual, pivotal movements, such as the "Choosing Wisely" initiative[11–13] are shifting the attention from technical innovation to value of health care and sustainability. Similar campaigns also have been published in general medical journals (e.g., "Less is More" in *JAMA Internal Medicine*[14]; "Too Much Medicine" in *BMJ*[15]; Choosing Wisely Canada in CMAJ[16]), with the objective of limiting over-medicalization, with its inherent potential harms to patients in the absence of demonstrated improvements in outcomes. A series of international conferences are dedicated to this aspect of medicine.[17]

Health care systems are striving to evolve from an unsustainably expensive fee-for-service, high-volume care regulatory environment that encourages wasteful use of high-cost tests and procedures to an evidence-based, high-value care model.[18] The endometriosis scientific community should not escape this common effort.[4]

The attitude towards careful selection of tests and treatments in women with endometriosis should not be viewed as a mere attempt at curtailing expenditures, but as a challenge aimed at investing resources in medical interventions that have been demonstrated to be of sufficient benefit to patients to justify the associated risks and costs. Avoiding excessive emphasis on the purported absolute effects of some measures may also prevent harms. Gynaecologists caring for women with endometriosis should assess treatments not only in terms of efficacy (i.e., whether an intervention works within the context of a formal trial conducted on selected participants) but also in terms of effectiveness (i.e., whether an intervention works in the entire population of women with endometriosis in everyday practice).[19,20]

ABBREVIATIONS

ART	assisted reproductive techniques
COI	conflict of interest
HRT	hormonal replacement therapy
NETA	norethindrone acetate
OC	oral contraceptive
QALY	quality-adjusted life-year
US	ultrasonography