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Title:

Proposal for a new ICD-11 coding classification system for endometriosis

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TEXT:

Dear Editor,

We report on work from our international taskforce established to improve the documentation of endometriosis in the upcoming 11th edition of the International Classification of Diseases (ICD-11). Our taskforce comprised representation from the World Endometriosis Society, World Endometriosis Research Foundation, European Society of Human Reproduction and Embryology, American Society for Reproductive Medicine, Society for Endometriosis and Uterine Disorders, European Society for Gynaecological Endoscopy, and British Society for Gynaecological Endoscopy.

The goal of ICD is to leverage information collected through health care systems to better understand predictors of clinical outcomes, implement data-driven strategies to improve outcomes and cost-effectiveness, and evaluate the changing impact of these strategies as health care evolves. Although new methodologies have been developed, and computing power has grown exponentially, the fundamental ingredient required for these analyses is high quality data, of which ICD coding remains a key component. For women with endometriosis, systematic ICD coding is clearly crucial to advance clinical care: it is a condition that has a high prevalence and is associated with a considerable diagnostic delay, high societal/personal burden, and no known cure.

Our taskforce noted the urgent need for improvement in the mechanics/focus of the coding process and in the structure/content of the codes for endometriosis. Classification systems for endometriosis exist including the revised American Society for Reproductive Medicine (r-ASRM) classification [1] and the Enzian classification [2,3]. There is also one validated outcomes prediction tool – the Endometriosis Fertility Index [4]. At present, no one single classification system has fully encompassed anatomic distribution and disease phenotypes nor a staging system that predicts or directs clinical outcomes such as symptom management, response to therapy, lesion and symptom recurrence, association with other disorders, or quality of life.

The nature of ICD coding lends itself to anatomical classification but even within this scope there were significant limitations with the ICD-10 classification. First and foremost, endometriosis was coded within 'noninflammatory disorders of female genital tract', which is entirely inconsistent with its current categorisation [5]. There was no clear distinction between superficial or deep disease, and there was an absence of further descriptors of location of peritoneal lesions such as the Pouch of Douglas, uterosacral ligaments, and the pelvic side wall. Peritoneal pockets were not included, nor disease affecting the bladder or ureters. Ovarian disease was not subclassified into endometrioma or superficial disease overlying the ovarian cortex, and there was no facility to reflect unilateral or bilateral disease. Furthermore, there was no specific classification for more unusual presentations, such as thoracic endometriosis and endometriosis lesions within the CNS, making estimates of prevalence challenging.

Following a consensus meeting held on 14 March 2018, we have worked closely together, following rigorous pre- and post-meeting processes, and have developed a proposal for a new ICD systematic classification of endometriosis (see Supplementary file). We believe that our proposal is both logical, inclusive of all phenotypes, and allows accurate description of anatomical distribution, within the confines of the ICD coding system. It includes specific classification of superficial and deep disease, and extended options for describing distribution. In addition, it offers structured classification of extra-abdominal lesions, particularly within the thorax, abdominal wall, central/peripheral nervous systems. ICD coding does not facilitate further description with respect to size of lesions or extent of adhesions, and so this system may have some limitations with regard to linking fertility outcomes with endometrioma size, nor can it be used to calculate Enzian or r-ASRM scores.

We submitted our proposal to WHO in June 2018 and believe that our proposed ICD classification system will facilitate the diagnostic process and lead to improved tailoring of treatments and more accurate epidemiological data.

References

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Disclosure of interests

Andrew Horne has received research support from the MRC, NIHR, CSO, Wellbeing of Women, Roche Diagnostics, Astra Zeneca and Ferring, and has served as a consultant for AbbVie, Roche Diagnostics, Ferring and Nordic Pharma. Lone Hummelshoj has served as a consultant for AbbVie. Ertan Saridogan received honoraria from Olympus UK, Gedeon Richter and Hologic. Stacey Missmer has received research support from the NIH, AbbVie and the Marriott Family Foundations, and has served as a consultant for AbbVie and Celmatix. Lucy Whitaker, Lone Hummelshoj, Lucky Saraswat, Dominic Byrne and Carla Tomassetti have nothing to declare.

Contribution to Authorship

The project was coordinated by Lucy Whitaker. All other authors contributed equally to the project and the correspondence.