Towards Precision Medicine for Endometriosis: Dynamic Disease Characterization Through Temporal Tracking of Patient Reported Outcomes

Objective: Endometriosis remains a mysterious disease. In particular, there exists a gap between physicians' mental model of the disease and the patient experience of endometriosis. We aim to bridge this gap through an observational study of patient reported outcomes relevant to the patients' experience through time, as collected through a novel smartphone app.
Design: Focus groups, Surveys, User-centered and Participatory Design, Observational Study
Materials and Methods: Five focus groups (27 women), two surveys (1246 respondents), and one-on-one interviews (20 alpha testers), all women with official or doctor-suspected diagnosis informed the design of the app. The app is now collecting patient-reported data from endometriosis patients, creating the first dataset of patient experience of endometriosis tracked by patients themselves through time.
Results: Given the dynamic nature (both within menstrual cycle and over time) of endometriosis signs and symptoms, the app is a promising method to collect patient-reported outcomes, providing a complement to more standardized questionnaires like the World Endometriosis Research Foundation Endometriosis Phenome and Biobanking Harmonisation Project questionnaires. Collection of this type of data provides a comprehensive and rich dataset for the research community. Preliminary results indicate that there are a wide range of signs and symptoms experienced by patients, but some commonalities exist that help to create a cohesive and more nuanced depiction of the disease. Identifying potential clusters of patients from their signs and symptoms, and comorbidities furthers what is known about disease subtypes and is a good first step toward precision medicine for endometriosis.
Conclusion: Characterizing endometriosis through temporal tracking of patient reported outcomes using a novel smartphone app is both feasible and proves useful for better understanding that disease. Data collected through the app indicates its potential for identifying disease subtypes, moving us closer to precision medicine for endometriosis.
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