

Qualitative Assessment of Women's Attitudes Towards a Tracking App for Phenotyping Endometriosis

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Introduction

Endometriosis— a chronic disease of the female reproductive system in which the uterine lining grows outside of the uterus— is associated with significant morbidity, a reduced quality of life (0.809 quality-adjusted life years per woman) and substantial health care costs and productivity loss [1,2]. It is estimated to affect 1 in 10 women in their reproductive years [3]. Despite its impact and prevalence, little is still known about the disease, and diagnosis is often delayed by several years because of the lack of phenotypic knowledge about it. Our long-term goal is to phenotype endometriosis. A first step is to elucidate the catalogue of signs and symptoms of the disease and their manifestations throughout a patient's menstrual cycles. Creating such a catalogue is important for identifying clusters of symptoms and their interactions throughout a cycle that could in turn indicate potential subtypes of the disease. While there exist research surveys to collect endometriosis patients' experiences, they assume a static set of symptoms. In contrast, we aim to engage patients in becoming active participants in disease phenotyping through the development of a mobile app called Phendo. Phendo will allow patients to track their endometriosis symptoms as they occur throughout their menstrual cycle, and allow its users to contribute tracking custom/individualized symptoms. To assess the need and elucidate functionalities for Phendo, we conducted a series of focus groups to explore patients' attitudes towards a tracking mobile application for the sake of disease phenotyping.

Methods

A series of 5 focus groups were conducted with a total of 27 women from the New York metropolitan area over a period of three weeks. Women were recruited through emails to endometriosis patient advocacy groups and flyers posted on the Columbia University campus and through Twitter. Eligibility included official endometriosis diagnosis through laparoscopic surgery. Each focus group lasted approximately 90 minutes and a semi-structured focus group guide was used to direct the conversation. Each focus group was audio recorded and transcribed verbatim. Thematic analysis was carried out to identify major themes related to tracking and endometriosis.

Results and Discussion

Overall, focus group participants felt positive towards tracking, although some women worried that tracking would lead to being reminded that “nothing helps”. Most participants used some sort of tracking for one or more aspects of their endometriosis (e.g., pain, diet and GI issues, exercise, emotions), but they felt that existing tracking apps (e.g., period trackers, fitness, diet trackers) were not appropriate for the range of symptoms and granularity of symptoms they wanted to track. Several participants reported having created their own customized tracking system.

Women expressed a range of motivations to track: to better understand their own experience of the disease (i.e., discover and reflect on potential patterns of symptoms throughout their cycle); to explore strategies for symptom management (“what works and what doesn't”); to help manage their work and personal schedule based on their past tracked data and forecasted flares; and to communicate better with their doctors. Participants expressed a strong altruistic will to contribute their data for the sake of research and helping other patients, in particular women struggling to make sense of their symptoms and who had not yet arrived at an official diagnosis.

Our findings indicate that patients would welcome an app for phenotyping endometriosis that captures the wide range of endometriosis symptoms. The discovered themes also help elucidate different strategies to engage patients in tracking, which we are currently exploring in the design of Phendo.

References

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