

Self-Tracking for Fertility Care: Collaborative Support for a Highly-Personalized Problem

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Abstract

This research highlight presents our recent publication “Self-Tracking for Fertility Care: Collaborative Support for a Highly-Personalized Problem”, which was accepted for the Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW 2018).

Original Abstract

Infertility is a global health concern that affects countless couples trying to conceive a child. Effective fertility treatment requires continuous monitoring of a wide range of health indicators through self-tracking. The process of collecting and interpreting data and information about fertility is complex, and much of the burden falls on women. In this study, we analyzed patient-generated content in a popular online health community dedicated to fertility issues. The objective was to understand the process in which women engage in tracking relevant information, and the challenges they face. Leveraging the Personal Informatics Model, we describe women’s self-tracking experiences during their fertility cycles. We discuss how a complex and highly personalized context leads to responsibility, pressure, and emotional burden on women performing self-tracking activities, as well as the role of collaboration in creating individualized solutions. Finally, we provide implications for technologies aiming to support women with fertility care needs.

Relevance to WISH

The World Health Organization (WHO) considers infertility to be a global public health issue that affects many couples worldwide¹. While both men and women can have medical conditions that affect the couple’s ability to conceive, women tend to bear more of the social burden². They usually engage in many tracking intensive activities, since most of the treatments for infertility include self-tracking several health indicators. Despite being relatively common, and with or without the support of existing technology (i.e., websites or smartphones’ applications), challenges often arise during self-tracking, and tend to be particularly problematic. However, to the extent of our knowledge, there is a lack of studies in the HCI community focusing on fertility care. Thus, there is a crucial need to better support women’s fertility self-tracking, especially in terms of addressing the knowledge challenges that they face.

Our study investigates the use of self-tracking for fertility care. Leveraging the Personal Informatics Model, we qualitatively analyzed threads from a fertility community in one popular U.S. online health forum. We used the model as a conceptual framework to examine the fertility self-tracking process aiming to understand (a) the process of fertility self-tracking, and the specific challenges that arise; (b) the process of sensemaking; and (c) the relationship between self-tracking practices and collaboration in the sensemaking process. Based on our findings, we discuss how self-tracking in a knowledge-intensive context can be a complex and frustrating experience, requiring comprehensive information about different aspects of the fertility cycle, and tools that can be used for tracking. We also discuss that women often need to create personalized solutions, which they often do through collaborative sensemaking. Finally, we analyze the emotional toll of fertility self-tracking, caused by repeated frustration and societal pressure. We also present implications of these aspects for the design of systems aiming to support fertility self-tracking.

We believe our paper is a good fit for this year’s theme (“Citizen Science: Leveraging interactive systems to connect to our data, our families, and our communities”) since it approaches self-tracking practices and challenges, emphasizing the collaboration aspects around data (how women collaborate using their personal data with each other to understand their situation and define their actions). We look forward participating in the WISH workshop to discuss the challenges of self-tracking for personalized and knowledge-intensive conditions, such as fertility care, and the consequences these practices bring to people’s lives. We also hope to engage in discussions about the consequences of self-tracking and the responsibility of design to avoid negative emotional impact. The WISH community seems a perfect fit for these discussions and for developing new insights on how better support people self-tracking for fertility care or for other complex and personalized health condition.

Statement of Non-Conflict with Policies

This WISH submission does not conflict with the policies of CSCW, where the work was originally published.

References

1. WHO | Infertility is a global public health issue [Internet]. WHO. [cited 2017 Jun 6]. Available from: <http://www.who.int/reproductivehealth/topics/infertility/perspective/en/>
2. WHO | Infertility [Internet]. WHO. [cited 2017 March 15]. Available from: <http://www.who.int/reproductivehealth/topics/infertility/keyissues/en/>