Title
Data Work and Data Tracking Technologies in Fertility Care: A Holistic Approach

Author
Costa Figueiredo, Mayara

Publication Date
2021

UNIVERSITY OF CALIFORNIA,
IRVINE

Data Work and Data Tracking Technologies in Fertility Care: A Holistic Approach

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Informatics

by

Mayara Costa Figueiredo

Dissertation Committee:
Associate Professor Yunan Chen, Chair
Professor Kai Zheng
Associate Professor Melissa Mazmanian
Assistant Professor Daniel A. Epstein
Associate Professor Stephen M. Schueller

2021

DEDICATION

To family, love, and friendship, from near and afar

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

Page

ACKNOWLEDGEMENTS

The work described in this dissertation would not be possible without the support of many people to whom I would like to express my deepest gratitude.

I would like to primarily thank my advisor, Dr. Yunan Chen, for all the guidance, feedback, and support throughout the years. Thank you for working with me, for inspiring my work, for helping me in organizing my ideas when I felt confused, and for helping me in navigating graduate school as an international student. A special thanks for all the support in the last year, during the COVID-19 pandemic which coincided with my final and most intense year.

I am also grateful to the other members of my committee, who have been working with me since the early stages of my studies: Dr. Kai Zheng, Dr. Melissa Mazmanian, Dr. Daniel A. Epstein, and Dr. Stephen M. Schueller. Thank you for your guidance through the years and particularly during the milestones of the program. Our discussions were fundamental for building this work and my research trajectory as a whole.

I am extremely grateful to Dr. H. Irene Su, for all the fundamental support in recruiting participants, conducting the studies, reviewing results, and navigating the medical side of my research.

I must also thank other faculty members in the departments of Informatics, Computer Science, and Education at UCI with whom I had the pleasure to learn from in classes and other interactions. Thank you, Dr. Geoffrey Bowker, Dr. Paul Dourish, Dr. Shanyce L. Campbell, Dr. Kylie Peppler, Dr. Constance Steinkuehler, Dr. Rebecca Black, and Dr. Sameer Singh for insightful class discussions and feedback on materials that contributed to this dissertation and my growth as a researcher. Your lessons have stayed with me and guide my research. I also would like to dedicate a special thanks to Dr. Neha Kumar and Dr. Cleidson de Souza, who have been mentors and inspirations in multiple moments of my trajectory.

I would like to extend my sincere thanks to Archana Sheth, Juancho Banaag, Marty Beach, Suzie Barrows, Julio Rodriguez, Adriana Avina and all other UCI staff members who helped me deal with paperwork pertaining to graduate school and navigate the administrative challenges of being an international graduate student in the U.S.

I'm also deeply indebted to my supportive colleagues and lab mates that passed through the HAI and PIE labs through these years: Dr. Clara Caldeira, Dr Xinning Gui, Dr. Yu Chen, Dr. Elizabeth Eikey, Mustafa I. Hussain, Tera L Reynolds, Lu He, Zhaoyuan Su, Brian Tran, Lucas de Melo Silva, Xi Lu, Elizabeth A. Ankrah, Zhaoxian Hu, Alessandro Ghigi. and Mohammad Eletriby. Thank you for sharing this journey with me.

I am also grateful for all the undergraduate students that worked with me and greatly contributed to my studies. Thank you, Thu Anh Huynh, Edward Wu, Marawin Chheang, Anna Takei, Donggun Lee, Joonyoung Park, Ye Lin Jeong, and Sean Victory.

This work was made possible thanks to the financial support I received from different agencies and institutions (NSF, NIH, UCI, and the school of ICS) and the research fellowships and scholarships I received throughout my Ph.D.: the Roberta Ellen Lamb Memorial Fellowship, the Miguel Velez Scholarship for Latin-American students, and the Microsoft Dissertation Grant. Thank you for your generous support. Thank you also to Universidade Federal do Pará for greatly contributing in different and fundamental ways to my Ph.D.

Although I cannot name them, I would like to deeply thank each of my research participants who confided me their intimate fertility experiences and other anonymous individuals who have made this work possible. Through the years I have deeply shared your experiences and I sincerely hope this research contribute to improving the many challenges related to infertility trajectories.

Last and most important, I would like to thank my family, love, and friends. You are everything to me and the *only* reason I was able to do this. I miss you, I love you, and I thank you above everything else.

VITA

Mayara Costa Figueiredo

2016-2021 Ph.D in Informatics
University of California, Irvine

2009-2011 M.S. in Computer Science
Universidade Federal do Pará, Brazil

2004-2008 B.S. in Computer Science
Universidade Federal do Pará, Brazil

FIELD OF STUDY

Human-Computer Interaction, Computer-Supported Cooperative Work, Health Informatics, Personal Informatics

PUBLICATIONS

Journal Articles

[J10] Eikey, E. V., Caldeira, C. M., Costa Figueiredo, M., Chen, Y., Borelli, J. L., Mazmanian, M., & Zheng, K. (2021). Beyond self-reflection: introducing the concept of rumination in personal informatics. Personal and Ubiquitous Computing, 1-16.

[J9] Costa Figueiredo, M., Huynh, T., Takei, A., Epstein, D. A., Chen, Y. 2021. Goals, Life Events, and Transitions: Examining Fertility Apps for Holistic Health Tracking. The Open Journal of the American Medical Informatics Association (JAMIA Open).

[J8] Caldeira, C. M., Costa Figueiredo, M., Dodakian, L., de Souza, C. R. B., Cramer, S. C., Chen, Y. 2021. Towards Supporting Data-Driven Practices in Stroke Telerehabilitation Technology. Proc. ACM Hum.-Comput. Interact., CSCW. [forthcoming]

[J7] Epstein, D. A., Caldeira, C. M., Costa Figueiredo, M., Silva, L. M., Lu, X., Williams, L., Lee, J. H., Li, Q., Ahuja, S., Chen, Q., Hilby, C., Sultana, S., Yari, P. D., Eikey, E. V., Chen, Y. 2020. Mapping and Taking Stock of the Personal Informatics Literature. ACM Interactive, Mobile, Wearable and Ubiquitous Technologies.

[J6] Costa Figueiredo, M., Su, H. I., Chen, Y. 2020. Using Data to Approach the Unknown: Patients' and Healthcare Providers' Data Practices in Fertility Challenges. Proc. ACM Hum.-Comput. Interact., CSCW. Honorable Mention Award – top 5% papers (1000 papers total).

[J5] Hussain, M. I., Costa Figueiredo, M., Tran, B. D., Su, Z., Molldrem, S., Eikey, E. V., Chen, Y. 2020. A Scoping Review of Qualitative Research in JAMIA: Past Contributions and Opportunities for Future Work. Journal of the American Medical Informatics Association (JAMIA).

[J4] Costa Figueiredo, M., Chen, Y. 2020. Patient- Generated Health Data: Dimensions, Challenges, and Open Questions. Foundations and Trends® in Human–Computer Interaction: Vol. 13, No. 3, pp 165–298. DOI: 10.1561/1100000080

[J3] Costa Figueiredo, M, Caldeira, C. M., Eikey, E. V., Mazmanian, M., Chen, Y. 2018. Engaging with Health Data: The Interplay Between Self-Tracking Activities and Emotions in Fertility Struggles. Proc. ACM Hum.-Comput. Interact. 2, CSCW, Article 40 (November 2018), 20 pages. (acceptance rate: 26%) DOI:https://doi.org/10.1145/3274309

[J2] Costa Figueiredo, M., Caldeira, C. M., Reynolds, T. L., Victory, S., Zheng, K., Chen, Y. 2017. Self-Tracking for Fertility Care: Collaborative Support for a Highly Personalized Problem. Proc. ACM Hum.-Comput. Interact. 1, CSCW, Article 36 (November 2017), 21 pages. (acceptance rate: 27%) DOI:https://doi.org/10.1145/3134671

[J1] Costa Figueiredo, M., de Souza, C. R. B., Pereira, M. Z., Prikladnicki, R., Audy, J. L. N. 2014. Knowledge Transfer, Translation and Transformation in the Work of Information Technology Architects. Information and Software Technology, 56(10), 1233-1252. DOI: https://doi.org/10.1016/j.infsof.2014.04.001

Conference Proceedings

[C7] Costa Figueiredo, M., Chen, Y. 2021. Health Data in Fertility Care: An Ecological Perspective. In the 2021 CHI Conference on Human Factors in Computing Systems. Honorable Mention Award – top 5% papers.

[C6] Su, Z., Costa Figueiredo, M., Jo, J., Zheng, K., Chen, Y. 2020. Analyzing Description, User Understanding and Expectations of AI in Mobile Health Applications. American Medical Informatics Association Annual Symposium.

[C5] Costa Figueiredo, M., Caldeira, C. M.*, Chen, Y., Zheng, K.. 2017. Routine Self-Tracking of Health: Reasons, Facilitating Factors, and the Potential Impact on Health Management Practices. American Medical Informatics Association Annual Symposium. 3rd place in the AMIA Student Competition (68 submissions total).

*Mayara Costa Figueiredo and Clara Caldeira are co-first authors

[C4] Costa Figueiredo, M., de Souza, C. R. B., Pereira, M. Z., Prikladnicki, R., Audy, J. L. N. 2012. On the Role of Information Technology Systems Architects. 18th Americas Conference on Information Systems, 2012, Seattle.

[C3] Pereira, M. Z., Audy, J. L. N., Prikladnicki, R., Costa Figueiredo, M., de Souza, C. R. B.. 2011. SOA Practices and Patterns Applied in Global Software Development. In: International Conference on Enterprise Information Systems, Beijing, China.

[C2] Costa Figueiredo, M., de Souza, C. R. B. 2009. Supporting Impact Analysis Activities in Distributed Software Development. XXXV Latin-American Conference on Informatics, Pelotas, Brazil.

[C1] Oeiras, J. Y. Y., Bentolila, D. L. M., Costa Figueiredo, M. 2008. Heva: A Support Tool for Heuristic Evaluation for Web Systems. In Proceedings of the VIII Brazilian Symposium on Human Factors in Computing Systems (IHC '08). Sociedade Brasileira de Computação, BRA, 136–145.

Extended Abstracts and Workshop Publications

[P6] Costa Figueiredo, M., Su, H. I., Chen, Y. 2020. An Evaluation of Commercial Fertility Apps: Algorithmic Predictions and Users' Perceptions. In: American Society for Reproductive Medicine Scientific Congress. Late Breaking Abstract Poster.

[P5] Costa Figueiredo, M., Hussain, M. I., Ankrah, E. A., Chen, Y. 2019. Powered by AI: Analyzing the Influence of Artificial Intelligence Claims in Fertility Self-Tracking. Workshop: Identifying Challenges and Opportunities in Human–AI Collaboration in Healthcare. In CSCW 2019.

[P4] de Souza, C. R. B., Costa Figueiredo, M., Ferreira, M. N. M., Pantoja, F. L. 2013. An Experience in Integrating Design Thinking and Agile Methodologies for Software Development. Forum in Education in Software Engineering, Brasília, Brazil.

[P3] Costa Figueiredo, M., de Souza, C. R. B. 2012. Wolf: Supporting Impact Analysis Activities in Distributed Software Development. Proceedings of the 5th International Workshop on Co-operative and Human Aspects of Software Engineering (CHASE'12). In ICSE 2012.

[P2] Costa Figueiredo, M., de Souza, C. R. B. 2010. An Empirical Study About Software Architects. Workshop of Theses and Dissertations of the VII Brazilian Symposium on Collaborative Systems, 2010, Belo Horizonte, Brazil.

[P1] Leal, M., Costa Figueiredo, M., de Souza, C. R. B. 2008. A Semi-Automatic Approach to Maintaining Traceability Links. Workshop on Requirements Engineering, 2008, Barcelona, Spain.

Doctoral Consortiums

[D2] Costa Figueiredo, M. 2020. Self-Tracking for Fertility Care: A Holistic Approach. In Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems (CHI EA '20). Association for Computing Machinery, New York, NY, USA, 1–9. DOI:https://doi.org/10.1145/3334480.3375029

[D1] Costa Figueiredo, M. 2019. Engaging with Health Data: A Holistic Analysis of Patients, Doctors, and Technology Perspectives in the Context of Fertility Self-Tracking. Doctoral Consortium, the 7th IEEE International Conference on Healthcare Informatics, Xi'an, China.

ABSTRACT OF THE DISSERTATION

Data Work and Data Tracking Technologies for Fertility Care: A Holistic Approach
by
Mayara Costa Figueiredo
Doctor of Philosophy in Informatics
University of California, Irvine, 2021
Associate Professor Yunan Chen, Chair

The uptake of self-tracking technologies made it possible for health consumers to gather and interact with a variety of types of personal data. However, individuals often encounter difficulties in understanding and using their tracked health data. In my dissertation, I explore the data work individuals perform when self-tracking for health and the challenges of interpreting and using personal health data within their daily routines, interpersonal and institutional interactions, and life goals. I investigate these issues through the context of fertility, which is a data intensive, sensitive, and complex case of self-tracking that has recently drawn significant attention in the consumer health technology market. To examine this challenging context, in this dissertation I adopt a holistic approach comprising three studies to address multiple perspectives: (i) through the analysis of an online health community I explain the individual challenges of fertility data work and individuals' emotional engagement with their health data, (ii) through a mobile app review study I investigate how individuals' data work is mediated, supported, and shaped by technology, and (iii) through an interview study with individuals facing fertility challenges and healthcare professionals specializing in infertility care I discuss how fertility data influence and are influenced by broader ecologies of care. These studies show how individuals' data work for health is strongly entangled with their emotional experiences and technology often falls short of adequately supporting people's diverse data needs and changing life goals. They also highlight how individuals' data and self-tracking activities do not exist in isolation and their data work is shaped by interpersonal, organizational, and societal influences. Drawing from these findings, I discuss specific characteristics of the data work performed by individuals that should be considered when researching and designing technologies to support individual data work for health, explaining how societal pressures are transmitted to the individual through technology and drawing implications for design and for practices beyond the individual.

CHAPTER 1. INTRODUCTION

1.1. Overview

Personal or self- tracking (i.e., the practice of collecting personal data for self-reflection (Li et al., 2010)) have always been practiced by individuals (Rettberg, 2014). With the uptake of mobile and sensor devices, these practices have become increasingly digitized and pervasive. People use technologies to track step counts, diet, productivity, financial habits, sleep hours, social interactions, emotional states, time on social media, etc., producing and interacting with these extensive tracked data in their daily lives. Data are not always numeric, but range from *"facts, numbers, letters, and symbols that describe an object, idea, condition, situation, or other factors"* (Bossen, Pine, et al., 2019). A large portion of these data tracked by individuals about themselves focus on or are related to their health (Epstein et al., 2020). Through data tracking, our health (and an array of related activities and experiences) is being increasingly recorded, analyzed, understood, and shaped by personal data, the work individuals perform with data, and the technologies that mediate these data-oriented activities.

Individuals are collecting and using personal data for a wide range of health issues, from general wellbeing (Rooksby et al., 2014) to managing health conditions such as diabetes (Katz et al., 2018) and cancer (M. L. Jacobs et al., 2015). These data can be called patient-generated health data (PGHD), which can be roughly defined as health data collected and used by patients outside of clinical settings (Costa Figueiredo & Chen, 2020). Extensive research has described possible benefits of PGHD and self-tracking for health, especially concerning patient empowerment (Ayobi et al., 2017; Grönvall & Verdezoto, 2013a) and self-knowledge and self-awareness of one's own health (Li et al., 2011). These data and practices are also connected with an increased sense of control, especially in the context of complex or poorly understood health conditions (Ayobi et al., 2017; Grönvall & Verdezoto, 2013a; Mamykina et al., 2008).

However, having data does not equal to understanding (Kaziunas et al., 2017; Lomborg et al., 2020). Individuals face a variety of challenges when self-tracking their own health, from difficulties to identify appropriated goals (Li et al., 2011) and collect data (Ancker et al., 2015), to being overwhelmed by data (Lomborg et al., 2020) and facing challenges in making sense of data (Katz et al., 2018). Studies in different health contexts have reported that individuals often feel confused about their data, not being able to derive actionable insights (Li et al., 2011; Mamykina et al., 2016) or struggling to uncover or understand associations between different types of data (G. Mitchell et al., 2021; Karkar et al., 2017a). Moreover, recent studies have reported series of negative effects related to self-tracking, such as feelings of guilt, failure, and stress (Ancker et al., 2015; Cordeiro et al., 2015; Eikey & Reddy, 2017; Katz et al., 2018), and questioned if the promises of control can become *"a burden disguised as empowerment"* (Neff & Nafus, 2016). These studies suggest that exposure to health data may have adverse or problematic effects, and people may experience not only positive but also negative consequences when tracking for health. In summary, self-tracking activities, particularly in the health domain, are not *"dispassionate"* analysis of one's own body (Rooksby et al., 2014). Instead, these practices are deeply embedded in individuals' emotional experiences, illness trajectories, and life goals. They are also entangled with individuals' relationships with other people, institutions, and society.

Although self-tracking and personal data have typically been seen as individual-driven or self-oriented, these practices influence and are influenced by the embedded social context, impacting and being impacted by many other people beyond the individuals themselves (Neff & Nafus, 2016). A growing body of research has been investigating self-tracking beyond the self, examining aspects such as individuals' relationships with others including partners (Homewood, Boer, et al., 2020; Mishra et al., 2019), caregivers (L. S. Liu et al., 2011), and healthcare providers (Sanger et al., 2016; Schroeder et al., 2017), infrastructures that influence tracking activities (Saksono et al., 2018), and societal factors that shape these practices (Lupton, 2013; Spiel et al., 2018). And all these pieces (i.e., individual challenges, interpersonal relationships, interactions with institutions, and societal influences) are increasingly influenced, supported, mediated, and shaped by data tracking technologies. These studies suggest that data tracking technologies are socio-technical systems embedded in and entangled with complex social relations.

All these challenges of using data and managing entangled relationships are far away from being effortless and require considerable work.. Bossen, Pine, et al. (2019) define data work as *"any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data."* Previous research on health data tracking have described how collecting and using data felt like additional work for patients (Ancker et al., 2015), who already have to deal with the illness and everyday life work (Corbin & Strauss, 1985) related to and impacted by their health condition. Data work adds another layer of responsibility for individuals to deal with while they manage their health and go about their daily lives. Gitelman et al. (2013) discusses that in the context of scientific research *"the work of producing, preserving, and sharing data reshapes the organizational, technological, and* *cultural worlds around them"* (Gitelman et al., 2013). By extension, individuals' health data work has the potential to reshape, by influencing and being influenced by, multiple aspects of individuals' lives, including their interpersonal relationships, daily activities, and institutional interactions.

In this dissertation, I adopt the concept of data work to explore individuals' holistic experiences that investigate not only the challenges of data collection and analysis, but also the emotional aspects of interacting with data, the benefits and constraints of data-tracking technologies, and how all these activities are embedded in the broader ecologies of care. In addition, my work offers unique contribution to understand non-professionals' engagement with data work, since most past work centered on the data work performed by healthcare providers in healthcare organizations due to the exponential digitization of healthcare systems. In this context, previous research has discussed challenges related to decision making (Even Chorev, 2019), interoperability (Pine, 2019), reliability (Cabitza et al., 2019), and veracity of data (Mønsted, 2019). Patients (or individuals, the term I use in this dissertation) are often accounted for as data producers or *"prosumers"* (Langstrup, 2019) and the analysis focus more on their interactions with healthcare providers than on their own specific challenges in interacting with their own data. However, with the increased use of self-tracking technologies by health consumers, the data work performed by individuals themselves has also grown exponentially, and these individuals are often not experts in healthcare nor in technology, which may increase the often invisible work and challenges they face. Therefore, it is unclear how this potentially extensive data work and personal monitoring may affect individuals' health experiences and how data tracking technologies influence and shape such activities within their broader ecologies of care.

My research focuses on the data work individuals perform when self-tracking for health. The main motivations for this work are: first, to understand, characterize, and explain health data work from the perspective of non-expert individuals, highlighting how data work influences their lives and the entanglement of these activities with individuals' emotional experiences. Second, to investigate the role data tracking technology plays in supporting, shaping, and limiting individuals' data work. Third, to position this data work within broader ecologies of care, emphasizing how data work and data tracking technologies influence and are influenced by interpersonal and institutional relationships and societal factors. And finally, to provide insights and inform the design of self-tracking technologies so they can better support the broadness of individuals' data work for health. To concretely explore these issues, in this dissertation I investigate individuals' data work through the lens of a very specific health context: fertility.

1.2. The Case of Fertility Data Work

This dissertation's main focus is on a specific fertility-related goal: trying to conceive. More precisely, the data work individuals perform when they are trying but facing challenges to conceive. Although literature suggests "fertility" is a broader term that covers different aspects of individuals' reproductive cycles and health (Gambier-Ross et al., 2018; Speroff & Fritz, 2005), throughout this dissertation I use the term "fertility tracking" for three main reasons: (i) though I focus on individuals facing challenges to conceive, many of them do not consider themselves infertile. In fact, some do conceive. To respect them I use fertility tracking instead of infertility, which some individuals consider a stigmatized word. (ii) Part of my studies also include other fertility goals and life stages with data needs that intersect with those of trying to conceive (and not necessarily with infertility). (iii) Infertility is defined as a *"failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse"* (*WHO | Infertility Definitions and Terminology*, n.d.)(WHO | Infertility Definitions and Terminology, n.d.), which does not mean that the individual will not conceive. Also, my studies included individuals trying to conceive for varied lengths of time, shorter and longer than a year. In some studies, I was able control this variable, in others the nature of the data collection did not allow that. Therefore, it is more appropriated for this dissertation to use the broader term fertility.

Fertility is an ideal case to study the aspects previously discussed for various reasons. First, female fertility is uncertain and complex (Speroff & Fritz, 2005), still understudied, and intrinsically connected to various aspects of the health and life quality of individuals who menstruate (since not all people who menstruate are women and not all women menstruate, I adopt this term and variations to be inclusive to non-binary people, trans people, and women who menstruate), such as premenstrual syndrome (Office on Women's Health, U.S. Department of Health and Human Services, 2017; Steiner, 2000), menopause, and other health conditions that have been reported to be induced, exacerbated, or influenced by fertility (Case & Reid, 1998; IHS Classification, n.d.). These health issues are often enigmatic (McKillop et al., 2018), stigmatized, and entangled with taboos. As a result, people may not receive proper treatment and care (Almeida, Comber, & Balaam, 2016; Case & Reid, 1998; Johnston-Robledo & Chrisler, 2013; Symul et al., 2019). Therefore, fertility form a context that is important to be investigated per se.

Second, fertility is strongly entangled with many individuals' life goals (e.g., to have children or not), the biography they envision for themselves (e.g., specific parenthood and family goals) (Corbin & Strauss, 1985), and their own sense of self (e.g., what it means to be a woman and who are considered women). Because of these factors, fertility is often entangled with emotional experiences, particularly when individuals desire but face challenges to conceive. This emotional context, although often considered very intimate and private, is impacted and shaped by different social factors, such as interpersonal relationships (e.g., partners, families, healthcare providers), gender norms, family ideals, and one's own role in society. These broader social aspects of fertility directly influence data work performed by individuals, calling for a deeper investigation of the intertwined relationship among social factors, technology design and individuals' health experiences.

Third, fertility has a long history of data tracking that precedes technology use (S. E. Fox et al., 2020; Klaus, 1982). Tracking for menstrual cycles, which is one factor in fertility, is common among individuals who menstruate. Fertility is also potentially data intensive: individuals track and review diverse and possibly large amounts of personal health-related data potentially associated with their fertility cycles and attempt to make sense of them (Costa Figueiredo et al., 2017), performing intense data work for their various health needs. For individuals facing challenges to conceive, this data work often assumes more extreme characteristics than for other fertility-related goals (and other health conditions or interests) because of all the increased emotional load of tracking fertility to achieve a much desired but very uncertain goal.

Fourth, recently, fertility self-tracking has drawn significant attention in the consumer health technology market, particularly mobile applications (apps for short), which, as of 2016, were downloaded around 200 million times worldwide (Eschler et al., 2019). This prominence of fertility tracking tools suggests that fertility-related experiences are being more recognized and approached. However, it also adds another strong layer of influence on individuals' data work: market pressures and the interests of the data industry (Neff & Nafus, 2016), which may not always align with individuals' personal interests.

These reasons make fertility an extreme case for self-tracking and data work and, as previous research highlight (Choe et al., 2014; Pine & Liboiron, 2015), such overt cases are useful to make issues that may be invisible in common cases more explicit and provide insights for other conditions and situations that share similar characteristics but are less extreme. Therefore, my dissertation research on fertility self-tracking not only provides valuable contributions to the specific and important context of fertility but also to derive insights for individuals' data work for health and related data tracking technologies more broadly.

1.3. Research Approach

This dissertation uses a holistic approach to investigate individuals' data work focusing on three interconnected aspects: (i) the specific data work practices of non-expert individuals and their entanglement with their daily lives, emotional experiences, and fertility trajectories, (ii) the support and breakdowns of consuming-facing fertility technology and how they shape individuals data work, and (iii) the relationship of the first two aspects with individuals' broader ecologies of care, investigating how data work and data tracking technologies influence and are influenced by interpersonal and institutional relationships and societal factors. And based on the analysis if these complimentary aspects, this dissertation derives insights to data work research and the design of self-tracking technologies to better support individuals' data work for health.

The holistic approach I adopted in this dissertation combines different methods (i.e., online health community analysis, app evaluation, interviews) to investigate multiple perspectives (i.e., patients, anonymous forum users, mobile app users, partners, healthcare providers). A holistic approach is especially important due to the complexity of the fertility context, which includes specific and diverse challenges entangled with different and personalized expectations. Such an approach can provide a more comprehensive understanding of data work in fertility and other health contexts, aiming to provide insights for research and the design of technologies so they can better support different people with different needs, experiences, and interactions. In summary, this work investigates the following research questions:

RQ1. How do people facing fertility challenges collect, make sense of, and use their personal health data? How does individuals' data work impact their emotional well-being?

RQ2. How does fertility tracking technology support users' goals and data needs and influence the ways individuals use personal data?

RQ3. How do individuals engage in data work throughout their fertility trajectory? How does individuals' data work involve their partners? How does healthcare providers assess the increasing use of fertility self-tracked data?

RQ4. What opportunities exist for designing fertility tracking technologies to facilitate individuals' data work and mitigate interpersonal, institutional, and societal challenges?

To answer these questions, I conducted three main studies (I refer to them as study 1, 2, and 3) that make the core of this dissertation. Table 1.1. provides an overview of these studies. Each of them approaches a different perspective of data work in fertility care, using different methods that complement each other.

Table 1.1. Overview of the three studies with references to the publications derived from them

Characteristic	**Study 1**	**Study 2**	**Study 3**
Focus	Individual practices and challenges of fertility data work	Technology support for fertility data work	Social influences on and from fertility data work
Motivation	Little was known about fertility self-tracking specific practices and challenges. As an extreme case for self-tracking, fertility can provide insights for other conditions	Inspired by Study 1, to investigate technology support and influence on individuals' data work	Inspired by Study 1, to investigate the interpersonal, institutional, and societal influences on fertility data work
Methods	Analysis of online health community data focused on infertility	Mobile app review analyzing app store pages, features, user reviews, and auditing app predictions	Narrative and semi-structure interviews with individuals, partners, and healthcare providers
Participants	3,527 threads with 15,944 replies, from 2006 to 2016	31 most popular (2019) fertility apps and 3,433 user reviews	19 individuals, 2 partners, 5 infertility specialists
Publications from the study	(Costa Figueiredo et al., 2017, 2018)	(Costa Figueiredo et al., 2020; Costa Figueiredo, Huynh, et al., 2021)	(Costa Figueiredo, Su, et al., 2021; Costa Figueiredo & Chen, 2021)

The first study focused on investigating fertility self-tracking to provide the initial understanding of individuals' data work and related emotional engagement that guided my research. In Study 1, an exploratory study using data from an online health community, I examine the individual experiences of self-tracking, providing a description of the data work involved in fertility with the goal of conception. I highlight how such data work is different from other types of self-tracking, describing the many challenges individuals face and how the complexity of fertility contributes to pressure and emotional burden, pushing individuals to turn self-tracking into a collaborative activity of making sense of personal data. Then, I focus on the emotional impact of such data work, describing how self-tracking activities are entangled with emotions and how individuals develop different relationships with data, from positive to more negative ones. Study 1 provided the baseline for the following studies of this dissertation research.

Considering the impacts of technology on individuals' data work and building on Study 1, in Study 2 I conducted an in-depth analysis of commercial fertility apps, examining app-store descriptions, features, user reviews, and simulating data entry to analyze the feedback from predictions. The features and reviews' analyses show that most apps offer extensive data collection options, but fewer options for feedback, and many app users want to use fertility apps for holistic analyses, including changing goals, life-events, life-stages, and transitions between them. The simulated data revealed inconsistencies in fertility predictions and that few types of data tracked by users influenced them. This lack of clear description of what data are used in making predictions can cause potential tracking burden, distrust of fertility technologies, or over-trust in predictions that may not be accurate. In summary, these findings suggest that apps support normative single-goal oriented fertility trajectories, using technological jargons to suggest accurate and personalized predictions. However, people's practices and life experiences are broader than what apps currently support, and technological claims present in apps promotion materials and interfaces do not translate into personalization for users. This difference can impose restrictions on individuals' data work and reinforce negative societal expectations related to fertility.

To complement these previous studies, Study 3 focused on the broader ecologies of care involved in fertility data work. In this study I used narrative and semi-structured interviews with individuals, partners, and healthcare providers to investigate individuals' lived experiences with fertility data, including their long-term experiences with fertility self-tracking, how tracking involves their partners, how it impacts their daily lives and emotional experiences, and how healthcare providers assess the increasing use of fertility self-tracked data in their work. I leverage the Ecological Systems Theory (Bronfenbrenner, 1977, 1992) to investigate how individuals' data work influences and is influenced by their relationship with others, the institutional and technological spaces they are part of, and the broader societal context. I then discuss how these multiple layers of influence, allied with the complexity of fertility, are translated into intense invisible data work imposed on the individual in the center of this ecology.

Together, these studies show that self-tracking is hardly individual even in contexts as private as fertility, instead, it is much more heterogeneous and dynamic than the single-goal and linear trajectories self-tracking technologies support, and it can create intense, invisible, and emotional data work for individuals. In summary, this dissertation:

- Approaches data work from the non-expert individual perspective, focusing on (i) individuals and their work in interacting with healthcare providers and institutions, (ii) how data require or impose invisible work on individuals, (iii) how this data work unfolds in their daily lives, and (iv) how it is often entangled with individuals' emotions and aspirations. This investigation complements current data work research focused on healthcare workers and organizations;

- Explores how individuals engage differently with their health data, focusing on their emotional and lived experiences. Such exploration allows for furthering the discussion on how to support positive interactions with health data, so users can enjoy its potential benefits, and avoid negative experiences and influences;
- Positions self-tracking and PGHD in larger ecologies of care and overarching societal contexts to analyze how broader interpersonal, technological, and institutional aspects impact and are impacted by individuals' data work. By doing that, it shows that although data are often seen as private and restricted to the individual level, individuals' data work is embedded and entangled with organizational and social forces, highlighting the role technology plays in reinforcing societal norms by defining, supporting, and imposing data work on individuals; and
- Provides insights to improve self-tracking technology design to better support individuals' data work more broadly and explore opportunities to use technology and data to influence the broader ecologies of care involved in fertility data work. Such insights can also be helpful for supporting individuals' data work in other similarly complicated and uncertain health journeys.

1.4. Contributions

The study of data work in fertility care contributes to the fields of Human Computer Interaction (HCI), Computer-Supported Cooperative Work (CSCW), and Personal and Health Informatics in the following ways.

First, this dissertation broadens our understanding of data work for health, conceptualizing the main characteristics of the data work of individuals and explaining this data work in a very sensitive and holistic way. It reveals that individuals' data work is emotional and burdensome, heterogeneous, social, and dynamic. It also provides insights on health data in general and into the design of technologies that can better support these multifaceted aspects of data work. Individuals' data and data work are a central piece for healthcare relations and processes since patients' health is the reason for healthcare practices. Therefore, this dissertation also provides empirical contributions to the development of a more complete theoretical understanding of data work in the health domain.

Second, this dissertation examined a specific health domain and offered in-depth understanding about individuals' experiences with data in the context of a stigmatized and personalized health condition. It is one of the first to study such issues and their intersection with data. By doing so, it contributes to Health Informatics in general and specifically to the fertility domain and fertility care practices by providing empirical explanations of how individuals engage with their data and how this engagement is complex and intrinsically entangled with their personalized fertility trajectories. The findings help us to understand the private yet social aspect of fertility struggles and provide profound insights into designing health technology for fertility and other aspects of the health of individuals who menstruate. Considering that individuals with fertility concerns are increasingly using data to help them conceive and bringing extensive data to clinical appointments, this contribution provides insights for clinical practices, supporting the development of future guidelines on how to address patients' engagement with data within providers' protocol and workflows.

Third, through this dissertation I propose that research on data work for health consider individuals invisible work outside clinical settings more deeply, and that self-tracking research and design adopt a wider lens to analyze and produce the technologies individuals use for tracking their own health. That encompasses studying technology support for individual data collection and analysis, but also its interactions with social ecologies that always influence and shape this data work even when the context and practices are considered individual, intimate, and private. My dissertation intentionally focuses on these different parts, providing insights on how they are interconnected and influence each other and, consequently, positioning data tracking technologies and individuals' data work in the health domain within broader ecologies of care. These perspectives will become even more important as our daily lives, our health, and our relationships and interactions are more and more entangled with data. A broader lens such this allows for more complete understandings of this entanglement, which contribute to both HCI and CSCW work that intersect with data work research.

Fourth, this dissertation contributes to CSCW and HCI by explaining how societal influences trickle down to the individual level through technology characteristics that support single-goal oriented, linear, and normative health experiences and trajectories. More specifically, it provides an empirical understanding of how specific self-tracking technology features and jargons are used to convey accuracy and objectivity that contribute to unbalanced expectations in highly emotional domains, such as healthcare. It also demonstrates how even highly private data influence, mediate, and shape interpersonal relationships and interactions with institutions, characterizing the sociality of data that is especially relevant to CSCW, and explaining how technology often falls short in supporting nuanced and dynamic interactions through data. Based on these aspects, my dissertation calls for an increased focus on designing (i) for algorithm understanding, not only for experts, but for lay people, (ii) for the entanglement between data and emotions, (iii) for learning experiences and advocacy to help in counter influencing societal forces, and (iv) for different attitudes toward the body that go beyond efficiency in data collection and analysis and consider individuals' experiences as a whole.

1.5. Dissertation Structure

This dissertation document has 6 chapters:

After this introduction in Chapter 1, Chapter 2 provides an overview of the research context and literature of this dissertation work, including terminology and related studies in the areas of data work, self-tracking, and fertility.

Chapters 3 to 5 provide in-depth descriptions of the three studies, including related literature, methods, findings, and discussion. Chapter 3 focuses on the individual data work of fertility self-tracking and the entanglement between data work and individuals' emotional experiences. In Chapter 4, I explore the technology support for fertility data work, presenting an extensive analysis of commercial fertility apps. Chapter 5 presents a social ecology approach to fertility data work, broadening the lens with which I analyze data work for fertility care.

Finally, Chapter 6 builds on the empirical findings of Chapters 3 to 5 to provide an integrated discussion, drawing on the findings of the fertility context to describe general characteristics of individuals' data work for health, provide insights for technology and research, and highlight critical aspects of data work that this intense context turned visible, discussing topics related to data objectivity in an emotional context, and the sociality of private data. This chapter ends translating these findings in implications beyond the individual.

CHAPTER 2. Research Context and Literature

This chapter presents a review of literature related to the main terminology underpinning this dissertation: patient-generated health data, self-tracking, and data work. After providing this terminology note, the chapter moves to present fertility, the context in which I approach such themes.

2.1. Patient-Generated Health Data

Medical practices are essentially data oriented. The decisions involved in medical work are largely based on patients' data: data reported by patients during medical consultations, data generated from various clinical tests, and data produced from patients reactions to treatment plans (Loos & Davidson, 2016; Schroeder et al., 2017). Diagnosis and treatment processes largely rely on data, both clinically generated, and patient reported (normally in the verbal format). Lately, with the increased datafication of health (Ruckenstein & Schüll, 2017), the rapid development of technologies that facilitate data collection and use (e.g., mobile phones, sensors, and connectivity), and an increased culture of biomedicalization (Neff & Nafus, 2016), the use of PGHD has been encouraged in medical decision making and to assist patients in self-managing their conditions outside of clinical encounters.

Because of its interdisciplinary nature and the varied terms that refer to similar or overlapping data (e.g., Patient Reported Outcomes, Observations of Daily Living), there is not one unified definition for PGHD (Costa Figueiredo & Chen, 2020; Piras, 2019). The following definition was proposed by the Office of the National Coordinator for Health Information

Technology of the U.S. Department of Health and Human Services in a white paper aiming to explore PGHD opportunities and challenges (Shapiro et al., 2012):

> *"PGHD are health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees [...] to help address a health concern. PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways. First, patients, not providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or dis- tributing of these data to health care providers and other stakeholders. In these ways, PGHD complement provider- directed capture and flow of health-related data across the health care system."*

As this definition suggests, PGHD is a broad and loosely defined term that encompasses a wide spectrum of data from different types, including physiological indicators measured by patients (e.g., temperature, weight), symptoms of medical conditions (e.g., tremors), lifestyle data (e.g., exercise, diet), quality of life data (e.g., mood, sleep quality), contextual data that can be related to health (e.g., weather), treatment history, or any other information that can be associated with the observed health issue (Costa Figueiredo & Chen, 2020; Shapiro et al., 2012; Slevin & Caulfield, 2018).

These data are envisioned to promote diverse benefits to healthcare for both patients and providers, such as to support personalized care (Cortez et al., 2018; Loos & Davidson, 2016; Slevin & Caulfield, 2018; Zhu et al., 2016), lead to new insights for patients' diagnosis and treatment (Chung et al., 2019, 2016; Slevin & Caulfield, 2018; Zhu et al., 2016), encourage and support patient empowerment (Ayobi et al., 2017; Slevin & Caulfield, 2018), support patient-provider communication and foster shared decision-making (K. G. Cheng et al., 2015; Chung et al., 2019, 2016; Slevin & Caulfield, 2018), help to identify associations or triggers of health events (Karkar et al., 2015; Pina et al., 2017), and reveal unexpected side effects (Cortez et al., 2018; Nundy et al., 2014; Slevin & Caulfield, 2018), among others. However, several studies have pointed to challenges in achieving these benefits. Some of these challenges include conflicting expectations from patients and providers on how these data should be used (Chung et al., 2016; Raj et al., 2017; Sanger et al., 2016; Slevin & Caulfield, 2018; Zhu et al., 2016), the risk of information overload for providers (Chung et al., 2019; Loos & Davidson, 2016; Slevin & Caulfield, 2018), the lack of financial incentive for providers to use these data (R. B. Kumar et al., 2016; Sanger et al., 2016), and the countless barriers to integrate these data into electronic health record systems and into healthcare providers workflow (R. B. Kumar et al., 2016; Sanger et al., 2016; Slevin & Caulfield, 2018).

While the views of PGHD and the related infrastructure have not yet been realized, individuals are increasingly collecting and using these data, supported by the uptake of commercial self-tracking technologies, particularly mobile apps and wearables. This increased use creates new practices and challenges for individuals, especially when healthcare providers are not involved. Individuals, who are not health specialists, are progressively interacting with these data and making health decisions based on them. As these practices become prevalent in our increasingly datafied daily lives, it is critical to understand how they can influence individuals' life experiences and impact their relationships.

In this dissertation, I adopt a simplified definition for PGHD: health data collected and used by patients outside of traditional clinical settings (Costa Figueiredo & Chen, 2020). This definition encompasses a variety of data potentially related to health collected by patients themselves in their everyday lives. Although the origins of the term imply the data is used by healthcare providers (Piras, 2019; Shapiro et al., 2012), I follow more recent uses of PGHD that highlight that sharing data is patients' or individuals' decision (Costa Figueiredo & Chen, 2020). Therefore, in this dissertation I consider that PGHD can but are not necessarily shared with healthcare providers. In addition, self-tracking is currently the main way for individuals to access their personal health data. Thus, in this work, I use the term self-tracking to refer to the practices of collecting and using PGHD, as described in the next section.

2.2. Self-Tracking or Personal Informatics

Collecting and using individuals' personal health data are not new practices (Cortez et al., 2018) and people have been recording data about themselves for hundreds of years (Rettberg, 2014), often with specific self-management goals (Neff & Nafus, 2016). In HCI, systems have historically focused on supporting people to gather and use data about themselves. For example, early systems have focused on encouraging physical activity habits, including providing users personal (Consolvo et al., 2008) and shared visualizations (Lin et al., 2006) of their data.

Building on previous research on different fields such as lifelogging, personal information management, casual information visualization, and slow technology, and on previous technologies that supported collecting and reflecting on one's own data (e.g., UbiFit (Consolvo et al., 2008) and Fish'n'Steps (Lin et al., 2006)), Li et al. (2010) defined Personal

Informatics as the systems and practices of collecting and reflecting on one's personal data to acquire self-knowledge or achieve a goal (Li et al., 2010, 2011). They also proposed a stage-based model for analyzing the use and problems of personal informatics systems comprised of 5 stages: preparation, collection, integration, reflection, and action (more on this model in Chapter 3).

Personal Informatics, also called self-tracking (Li et al., 2010), has become an important research topic in the HCI community. Initial work on self-tracking focused specifically on technologies to support behavior change (Li et al., 2010, 2011), but following research highlighted how tracking data is embedded in people's lives, who may have more diverse goals to perform these activities (Epstein et al., 2015; Rooksby et al., 2014). Within the context of health and wellness, past research investigated the use of self-tracking for managing chronic conditions (Mamykina et al., 2008; Schroeder et al., 2018) and promoting preventive activities, such as improving exercise and sleep habits (Choe et al., 2015; Miller & Mynatt, 2014). In general, people may self-track to: be more aware of the state of their health or condition (Epstein et al., 2017), work on a goal (e.g., quit smoking (Paay et al., 2015)) (Li et al., 2010; Rooksby et al., 2014), monitor progress towards a goal (Ancker et al., 2015), find associations or causality in health events (e.g., identify the trigger of an allergic reaction) (Karkar et al., 2015, 2017b), take actions (e.g., change diet based on glucose levels) (Ancker et al., 2015), share information with healthcare providers (Ancker et al., 2015), document ones' activities without aiming to change them (Epstein et al., 2015; Rooksby et al., 2014), or feed their curiosity (Epstein et al., 2015).

Several studies have reported the potential benefits of self-tracking practices and technologies. The most common ones are related to supporting self-knowledge and self-awareness of one's own health (Li et al., 2011), helping in managing chronic diseases (Mamykina et al., 2008), and contributing to a sense of control and agency (Ayobi et al., 2017). In addition, different studies suggest that PGHD activities and technologies can support visibility, social recognition, and self-validation for people living with complex conditions (Felipe et al., 2015; MacLeod et al., 2015; Park & Chen, 2015). More recent studies have described negative consequences of self-tracking, such as feelings of failure, guilt, and stress, that can lead to abandonment (Ancker et al., 2015; Ayobi et al., 2017; Cordeiro et al., 2015; Costa Figueiredo et al., 2017; Eikey & Reddy, 2017; Epstein et al., 2016; Katz et al., 2018). These studies reinforce that data, particularly health data, are never neutral, are emotionally loaded, and can impact individuals' experiences. All these studies suggest that people likely have both positive and negative experiences when engaging with their data in interactions that require intense data work.

2.3. Data Work

With healthcare becoming increasingly digitized, there has been a *"drastic increase in volume, velocity, variety, exhaustiveness, resolution, flexibility, and relationality of data"* (Bossen, Pine, et al., 2019) related to health available and expected to be used by a variety of stakeholders. These data are expected to, for example, enable more precise diagnoses, improve care, reduce costs, increase accountability, and support clinical decision-making (Bossen et al., 2016; Bossen, Pine, et al., 2019; Islind et al., 2019; Mønsted, 2019; Raghupathi & Raghupathi, 2014). However, in order to gather value out of these ever-expanding, extensive, and heterogeneous data, individuals have to invest extensive efforts to understand such data. These efforts can be called data work. Bossen, Pine, et al. (2019) define data work as "*any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data.*"

Most research on data work for health has investigated healthcare institutions and the data work performed by healthcare providers. These studies focus on how organizations are struggling under the pressure to deliver "data-driven" care, addressing issues such as the effortful work of data production (Pine, 2019; Pine & Liboiron, 2015), the difficulty in generating meaningful conclusions, particularly concerning secondary use of data (Pine et al., 2016), the multiplicity of data (Cabitza et al., 2019), issues around compensation (Bossen et al., 2016), the emergence of new roles (Bossen, Chen, et al., 2019), and the reconfiguration of healthcare work (Bossen et al., 2016) among many others. Some of these studies include patients as *"'prosumers' who produce valuable data in the process of consuming digital health services"* (Langstrup, 2019).

Piras (2019) argue that patient data work, as a synonym of personal health information management (PHIM), refers to the "*unfinished business of personal health management and the tinkering to accommodate one's personal life and providers' recommendations.*" These concepts (PHIM and patient data work) emphasize the increasing burden of data work on patients, who need to perform as *"prosumers,"* and how these health and wellbeing management activities fit in their daily mundane lives (Piras, 2019). With the increase datafication of self-care (Ruckenstein & Schüll, 2017) and the widespread use of self-tracking tools, patients not only produce data to be used in the health services they consume, but they also consume large amounts of health-related data they produce, even without engaging in clinical encounters with healthcare providers. Similar to what happens in clinical contexts, data and data interpretation do not exist spontaneously; they require extensive data work from individuals who are often not health nor data experts. Furthermore, Bossen, Pine et al. (2019) highlight that data are created through diverse forms of situated work that require encounters between people, technologies, and data. Therefore, individuals' data work, besides challenging per se, is also highly influenced and shaped by these encounters. Self-tracking activities and PGHD do not exist in isolation and they often involve managing data amidst individuals' daily lives and interacting and coordinating with different stakeholders, technologies, and institutions (Piras, 2019). As a result, individuals often encounter difficulties in generating meaningful conclusions, and experience invisible and emotional work that is often not recognized much less compensated (Kaziunas et al., 2017; Langstrup, 2019).

This dissertation draws on previous research on PGHD, self-tracking, and data work to specifically investigate the data work performed by individuals themselves, including an analysis of (i) their relationships with healthcare providers and other stakeholders, (ii) the technologies they use and how they shape their data work, and (iii) how data and related data work may influence, change, and affect their daily lives, relationships, and experiences. In this dissertation, I approach these issues through the specific context of fertility; a complex and potentially extreme use of self-tracking and PGHD.

2.4. Fertility

In this section I first present basic fertility background, starting with the fertility cycle and how it is connected to different aspects of female reproductive cycles. I then introduce fertility with the goal of conception, the main focus of this dissertation, describing the social context that motivates this work and the main fertility treatments and trajectories experienced by people trying to conceive, followed by how fertility self-tracking technologies are used in this context. This section ends with a summary of current fertility research in HCI, highlighting how this dissertation builds on this body of work.

2.4.1. The Fertility Cycle

The menstrual or fertility cycle is one of the most important aspects of female reproductive systems. It comprises intricate cyclic processes involving multiple organs (e.g., brain, ovaries, and uterus), hormone changes, and physiological mechanisms centered around ovulation (i.e., the release of the egg from the ovaries into the fallopian tube). These processes are not completely scientifically understood, and most of the current knowledge is recent (Speroff & Fritz, 2005).

The fertility cycle starts in the first day of menstruation and ends when the following period begins, with ovulation happening approximately in its mid-point. It can be divided in three phases: the follicular phase, the ovulation, and the luteal phase, as represented in Figure 2.1. In the follicular phase the pituitary gland in the brain produces the Follicle Stimulating Hormone (FSH) to stimulate the ovaries to prepare an egg to be released. Thirty-four to 36 hours before ovulation the body increases the production of the Luteinizing Hormone (LH), which peaks 10-12 hours before ovulation. This spike in the LH hormone causes the follicle containing the egg to burst, releasing the egg from the ovaries into the fallopian tube, i.e., ovulation. After ovulation, the luteal phase starts. In this phase the ovaries produce hormones (progesterone and estrogen) to support a potential pregnancy. If the egg is not fertilized, the ovary structure that produces such hormones (*corpus luteum*) starts to rapidly decline after 9-11 days post ovulation (Speroff & Fritz, 2005).

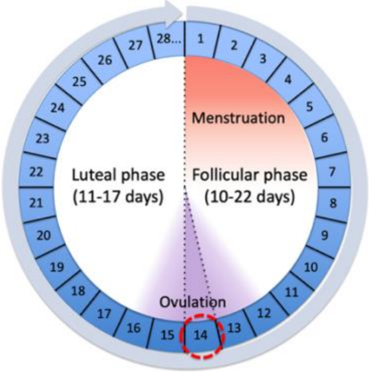


Figure 2.1. Phases of the fertility cycle

This intricate timeline of hormones and physiological mechanisms defines the length of each fertility cycle, which varies from person to person and from cycle to cycle for the same person. The main determinant of cycle length is the duration of the follicular phase and the time required for follicular growth and maturation (Speroff & Fritz, 2005). It can last proximately from 10 to 22 days. Ovulation usually happens from 13 to 15 days before the next menstruation. The length of the luteal phase is less variable, because once it starts to decline, the *corpus luteum* degenerates very fast in processes that are still unknown. In cycles considered regular, the luteal phase usually lasts 14 days, but lengths from 11 to 17 days *"can be considered normal"* (Speroff & Fritz, 2005). Generally, so-called regular cycles are considered to last around 28 days, with ovulation happening mid-cycle, around day 14. However, although it is still the most common length, studies show that overall, only 15% of reproductive age cycles last 28 days (Speroff & Fritz, 2005).

Based on these phases of the fertility cycle, we can generate four phases as experienced by individuals: menstruation, pre-ovulation, fertile days (or fertile window), and post-ovulation (Figure 2.2). Menstruation, pre-ovulation, and post-ovulation periods are typically infertile. The fertile window typically goes from 4 days before to 1 day after ovulation; therefore, there is only, on average, 6 days per month when conception is possible. Extreme cases included intervals between 6 days before and 3 days after ovulation, but most pregnancies occur when intercourse or fertility treatments happen in the 3 days before ovulation (Speroff & Fritz, 2005).

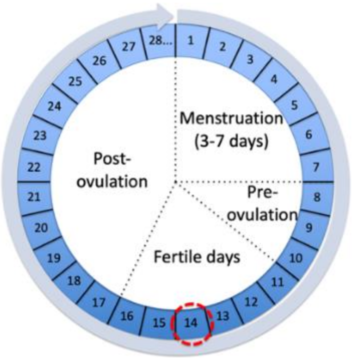


Figure 2.2. Fertility cycle phases as experienced by individuals

The changes in hormones and internal processes that happen in these phases often lead to cyclical external symptoms and physical changes, such as menstruation or the symptoms commonly associated with pre-menstrual syndrome (PMS). Knowing when such symptoms should occur is useful for individuals to, for example, prepare the necessary provisions (e.g., from menstrual supplies to pain medication), adapt plans, and be aware of their bodies. The fertility cycle phases also define the period in the cycle when pregnancy is possible (i.e., the fertile window), information useful for individuals avoiding and trying to conceive.

2.4.2. Trying to Conceive and Fertility Treatments

Over the last 50-60 years, changes in the political and economic climate, and important scientific and technological advances, have contributed to radical social transformations in many, largely high-income, countries around the world. One of the most significant has been shifts in gender roles and family dynamics. Busy lifestyles, career priorities, and safe, effective, and inexpensive methods of contraception contributed to a trend in delaying parenthood (Gregory, 2012). However, conception chances for individuals who menstruate tend to decrease after 30 years old (CDC, 2021). The combination of these factors increases the pressure to conceive within a relatively narrow window, before pregnancy becomes biologically impossible (*WHO | Mother or Nothing*, n.d.).

Infertility is defined by the World Health Organization (WHO) as a *"failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse"* (*WHO | Infertility Definitions and Terminology*, n.d.). According to the 2017 National Survey of Family Growth, 13% of U.S. women of age 15-49 face fertility challenges (CDC, 2017) and studies have reported that, as of 2012, 48.5 million couples faced infertility worldwide (Mascarenhas et al., 2012; WHO, 2012). In addition, the WHO considers infertility to be a global public health issue and indicates that many challenges of individuals and couples trying to conceive are not being sufficiently addressed (e.g., restricted knowledge and lack of access to fertility treatments) (*WHO | Infertility Is a Global Public Health Issue*, n.d.). Although infertility is not uncommon, it is still largely invisible: individuals often are not aware of how common it is, the burden of struggling with infertility is underestimated (*WHO | Infertility Is a Global Public Health Issue*, n.d.), and the various loss associate with it (i.e., not only a pregnancy but an entire envisioned life stage—parenthood) are not recognized (McBain & Reeves, 2019). It is also entangled with varied social expectations and taboos, particularly related to gender (Almeida, Comber, & Balaam, 2016; Johnston-Robledo & Chrisler, 2013).

For many people, conceiving seems a natural part of their life journeys (Corbin & Strauss, 1985) and facing challenges to conceive often becomes a great disruption to their lives (Gay Becker, 1994). Couples often start their fertility trajectory (i.e., their journeys towards conception) trying to conceive without medical assistance for 6 to 12 months (Speroff & Fritz, 2005). When conception does not happen, they may seek help from medical professionals, from family doctors, to gynecologists, and eventually Reproductive Endocrinology and Infertility specialists (REIs). These professionals will use their medical expertise to identify any underlying cause and define the appropriate treatment. However, even with medical specialists' assistance, it is estimated that between 15% to 30% of couples are diagnosed with unexplained infertility because their infertility evaluation tests fail to reveal any biological or physical problem (Quaas & Dokras, 2008). In these cases, healthcare providers have to treat infertility without knowing the cause. The most common fertility treatments are medications to induce ovulation or superovulation with intrauterine insemination (IUI) and *in vitro* fertilization (IVF) (Quaas & Dokras, 2008). It is indicated to try the least complex treatment first and increase complexity when simpler treatments do not result in pregnancy. Figure 2.3 summarizes these fertility care methods and treatments in order of medical complexity.

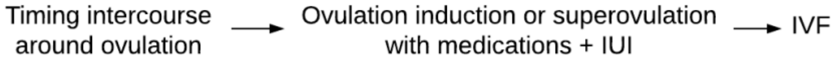


Figure 2.3. Fertility care methods and treatments

PGHD are critical for both individuals trying to conceive on their own and patients working with healthcare providers since all methods in Figure 2.3 require timing intercourse or treatment procedures with individuals' cycle. Figure 2.3 transition of treatments may look a reasonably straightforward process, but people's lived experiences are often much more complicated. This complex relationship between individuals, data, interpersonal and institutional relationships, and social expectations makes fertility a suitable case to analyze data work in an uncertain and emotional context, where the final goal (i.e., conceiving) may not be achievable.

2.4.3. Fertility Tracking Technology and Fertility Data

Although fertility processes are internal, they often lead to cyclical physical changes and symptoms that can be directly recognized by the individuals. Fertility awareness-based methods (FAMs) have historically focused on observing and recording these changes in bodily indicators (or fertility biomarkers (Duane et al., 2016)) to help individuals in identifying their fertile days and support family planning. Such methods include counting days between periods, tracking basal body temperature, analyzing changes in cervical mucus characteristics and cervix position, or some combination of these, possibly alongside tracking other fertility-related health indicators such as ovulation pain, breast tenderness, and other symptoms (S. E. Fox et al., 2020; Klaus, 1982). These methods are specifically focused on avoiding or seeking conception (couples should have or avoid having vaginal-penile intercourse during the fertile days), although menstrual cycles are related to many other experiences of individuals who menstruate. These methods are also the core of current fertility tracking technology.

The variability in the length of each cycle phase and, consequently, in the patterns of ovulation, symptoms, and bodily experiences makes fertility very personalized and it is one of the main reasons why self-tracking is used in fertility care. Although previously ignored (Duhaime-Ross, 2014; Eveleth, 2014), recently female fertility has drawn increasing attention in the consumer health technologies market. Around 28,000 mobile health applications (apps for short) available in app stores as of 2018 were classified in the *"female healthcare and pregnancy"* category (Dabbs, 2018). A large share of these apps focuses on fertility self-tracking. Figure 2.4 provides a few examples of fertility apps.

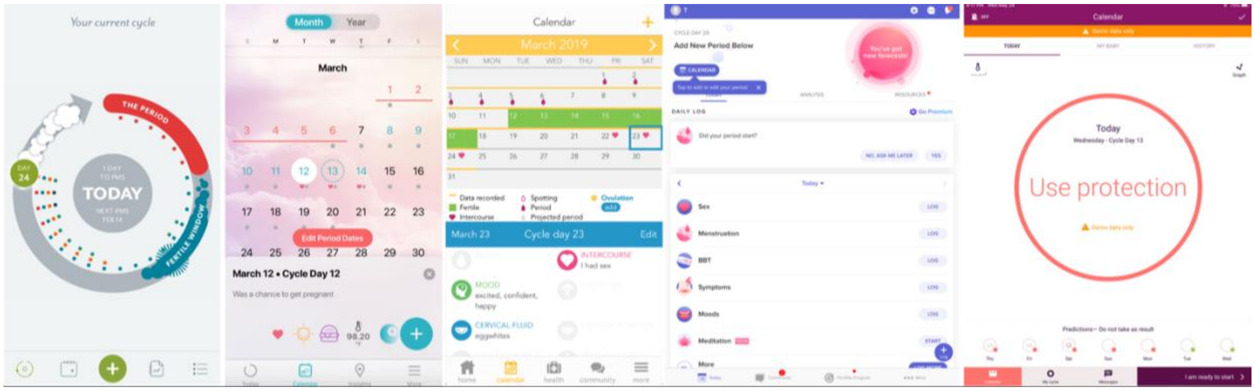


Figure 2.4. Examples of fertility apps

These mobile apps and often their associated wearables are currently the most popular self-tracking technologies for fertility. Like other self-tracking systems they are used to logging data (Li et al., 2010), in this case varied health-related data potentially associated with female fertility cycles. Apps in which users manually input their bodily information are more common and widespread, but recently sensor-based devices (always connected with a mobile app) have been used to automatize data collection, such as smart thermometers that store and automatically send temperature data to apps (Kindara, 2021), smartwatches that measure temperature and other bodily signals (Ava Science Inc., 2021), and even intimate devices that measure internal temperature and other indicators (Fertility Focus Inc., n.d.).

Fertility apps allow users to track the health indicators commonly used in FAMs (e.g., period days, temperature, cervical mucus), but also include a varied list of other bodily measures and symptoms. They also allow users to track the results of hormonal tests: recent advances in fertility scientific research allowed the development of reasonably low-cost home tests that can identify rises in the hormones associated with the fertility cycle. In particular, ovulation predictor kits (OPKs) measure the rise in the LH hormone and are currently considered the most reliable indication of ovulation (Klaus, 1982; Speroff & Fritz, 2005). Tests that measure the human chorionic gonadotropin (HCG) hormone, or pregnancy tests, are also commonly possible to track within fertility apps.

Besides allowing individuals to collect and store data, apps also provide feedback to the users based on these data. This feedback is often through visualizations that plot the data tracked by users or reminders for specific phases of the cycle (e.g., reminding users that the menstruation is about to start). Another type of feedback, which often comes within the visualizations, are predictions for future periods, ovulation, and fertile windows. More recently, with the increased use of self-tracking technologies (and consequently the increase in available data) and the rise of data analytics, fertility tracking tools have started to adopt predictive models that aim to generate more accurate fertility predictions based on individuals' personal data and the accumulated data of all their users (S. E. Fox et al., 2020).

With this recent popularity and the proliferation of mobile and sensor devices, individuals are using fertility self-tracking technologies for a variety of goals (Epstein et al., 2017), including to understand the specificities of their cycles, to identify their fertile days, and to recognize potential cyclic patterns of symptoms or experiences. This dissertation, however, focuses on the most expected, supported, and potentially extreme use of these tools: trying to conceive.

Fertility tracking with the goal of conceiving is data intensive (Costa Figueiredo et al., 2017): individuals may track a wide variety of health-related data to identify ovulation and time intercourse with the fertile window. However, these data can be very complex to analyze since none of them can precisely pinpoint ovulation (Costa Figueiredo et al., 2017). As a result, many individuals engage in intense self-tracking, increasingly supported by technology (e.g., mobile apps), to compare and make sense of different types of health-related data. These self-tracking practices are expected to directly impact the outcomes of their fertility trajectories. Because of this, people facing fertility challenges may perform extensive tracking and face extreme experiences, representing a population that needs more support. Some of them may represent *"extreme"* users, whose perspectives may provide insights that contribute to the support of a more general population because they have used and experienced many of the available practices and tools (Choe et al., 2014).

Finally, fertility data are often seen as private and individual. However, although fertility is considered a private matter, it is not isolated from the influences and interactions with other stakeholders. Partners and healthcare providers are often directly involved in individuals' fertility trajectories. Others, such as family and friends, are also important relationships that can positively (e.g., supporting) or negatively (e.g., pressuring) affect individuals' fertility experiences. However, it is still unclear how intense data work affects individuals' lives and how all these relationships influence and are influenced by the data work individuals engage in when facing fertility challenges.

2.4.4. HCI Studies on Fertility, Fertility Data, and Fertility Tracking

Recently, female fertility has received increased attention in HCI, with a growing body of research focusing on health issues and experiences of individuals who menstruate. Although pregnancy has been historically studied, with research on issues such as excessive gestational weight (Peyton et al., 2014) and information seeking behavior (Gui et al., 2017;

Kraschnewski et al., 2014; N. Kumar & Anderson, 2015), stages pre- and post-pregnancy have been less investigated. Many people face challenges to conceive, and this dissertation focuses specifically on this population and technology aimed to support them. Recent studies have investigated **the experiences of individuals facing challenges to conceive**, exploring how they use data to try to overcome conception challenges (Costa Figueiredo et al., 2017; Costa Figueiredo, Su, et al., 2021; Homewood, Boer, et al., 2020) and online forums for support (Costa Figueiredo et al., 2018; Patel et al., 2019), especially when living painful related events, such as pregnancy losses (Andalibi, 2020; Andalibi & Forte, 2018). These studies highlight the challenges of collecting and understanding personal fertility-related data, the emotional experiences of having a major life plan suddenly disrupted, and the related invisibility and lack of support. All these aspects are central to this dissertation research that builds on these studies to provide a comprehensive view of the data work performed by individuals trying to conceive.

More generally, because of the gaps in knowledge related to the natural complexity of fertility (Speroff & Fritz, 2005) and the taboos related to the female body (Almeida, Comber, & Balaam, 2016; Johnston-Robledo & Chrisler, 2013), several studies have focused on technology to support **menstrual education** (e.g., (Jain & Yammiyavar, 2015; Tuli et al., 2018, 2019)) and how people use online spaces to find information, support, and make sense of their experiences in varied fertility-related contexts, such as menopause (Lazar et al., 2019), infertility (Costa Figueiredo et al., 2017, 2018), endometriosis (McKillop et al., 2018), and vulvodynia (Young & Miller, 2019). These studies highlight how individuals who menstruate have generally low access to information about their bodies, how they often use technology to try to meet these needs, how technology can potentially be used to fill this education gap, and how this general lack of knowledge is entangled with different social taboos. Although many of these studies focus on other needs apart from conception, fertility knowledge and education are topics strongly entangled with infertility invisibility.

With the increasing availability of **fertility tracking apps**, other studies have turned to analyze the support offered by these technologies and individuals' related experiences. Studies evaluating fertility tracking apps have primarily used different methods to evaluate the accuracy of apps' predictions for ovulation (Duane et al., 2016; Freis et al., 2018; S. Johnson et al., 2018; Moglia et al., 2016). These studies report that most apps do not explain how they calculate predictions, do not cite scientific literature, and their accuracy varies significantly. In a different approach, Fox et al. (2019) analyzed fertility apps' terms of use, privacy policies, and data practices, raising privacy concerns about how companies may use personal data, and how data collection practices *"may subject the menstruating body to undue surveillance."* In another approach, Eschler et al. (2019) analyzed apps focusing on menstrual literacy, reporting on the insufficient support they offer. Finally, a few studies focused on understanding users' experiences with fertility apps, analyzing individuals' goals and challenges of using such tools (Epstein et al., 2017; Gambier-Ross et al., 2018; Levy & Romo-Avilés, 2019), users' opinions concerning apps' accuracy (Epstein et al., 2017; Gambier-Ross et al., 2018), alternative designs to communicate uncertainty related to fertility predictions (Schneider et al., 2019), and normative stereotypes of female bodies reinforced by such technologies (Epstein et al., 2017; S. E. Fox et al., 2019). This dissertation builds directly on these studies to analyze the support offered by fertility tracking tools, how predictions are affected by data entry, and users' perceptions of such support and predictions.

Another line of work has focused on challenging the taboos associated with fertility by using critical approaches and speculative or alternative designs (e.g., (Almeida, Comber, & Balaam, 2016; Bardzell et al., 2019; Campo Woytuk et al., 2019, 2020; Flemings et al., 2018; Homewood et al., 2019; Lupton, 2015)). For example, Homewood et al. (2019) explored designs of fertility self-tracking tools that go beyond utility, efficacy, and accuracy. They developed a prototype device to be used by couples trying to conceive aimed to support experiences that are *"DIY* [do-it-yourself]*, shared, and domestic rather than expert-led individual, and clinical"* (Homewood, Boer, et al., 2020). On another example, Fox et al. (2019) used speculative design fiction to create a catalogue of speculative menstrual tracking technologies that invite critical analysis of how intimate technologies data practices, particularly data sharing, may affect users *"across social, economic, and legal contexts"* (S. E. Fox et al., 2019). These studies highlight **normative views of gender, sexuality, and health** that are reproduced by fertility-related technologies, challenge current mainstream design, and invite readers to reimagine these technologies to better support people. Therefore, these studies provide critical inputs for the analysis of individuals' data work developed in this dissertation to provide contributions that engage with current available fertility tracking technologies and practices beyond technological utopian views of individuals' fertility experiences.

Finally, another stream of work has analyzed **infrastructural aspects beyond the body** that influence individuals' fertility experiences. For example, studies centering the parent post pregnancy have analyzed issues such as finding places to breastfeed (Balaam et al., 2015), pumping experiences (D'Ignazio et al., 2016), and the struggles of dealing with fragmented healthcare systems (Gui et al., 2018; Gui & Chen, 2019). Similarly, studies focusing on menstruation have used feminist approaches to question the design of public infrastructures and related technologies and how they can directly influence the lives of individuals who menstruate (S. E. Fox et al., 2018) specifically because they menstruate, even when such infrastructures are not directly related to menstruation (Tuli et al., 2020). Although these studies are not focused on fertility challenges, they highlight the lack of support individuals face independent of conception and even after conceiving. Many of these challenges are present in similar forms in the fertility context investigated in this dissertation as well.

In summary, all these studies suggest that fertility-related issues involve aspects beyond the bodies of people who menstruate, including challenges entangled with broader aspects of their lives, such as education, stigma, socio-cultural taboos, infrastructure breakdowns, and lack of support. This dissertation approaches self-tracking for the goal of conceiving, a fertility-related issue that involves all these challenges, is very data intensive, hardly individual, and increasingly targeted by self-tracking technologies. As fertility self-tracking technologies become increasingly entangled with our activities, bodies, and lives (Costa Figueiredo et al., 2018; Homewood, Karlsson, et al., 2020), it becomes critical to holistically analyze not only individual challenges of collecting and visualizing data, but also individuals' emotional engagement with these data and practices, the broader interpersonal, institutional, and societal aspects that influence and are influenced by this data work, and the role of technology in shaping individuals' experiences and intermediating their relationships. As an extreme case of self-tracking, analyzing experiences in the fertility context can also provide insights for other contexts that may face similar challenges.

CHAPTER 3. The individual Data Work of Fertility Self-Tracking

This chapter presents Study 1, which focuses on practices and challenges of fertility data work at the individual level. This exploratory study uses data from an online health community to address particularly the first research question of this dissertation: how do people facing fertility challenges collect, make sense of, and use their personal health data and how does individuals' data work impact their emotional well-being? In this chapter I first describe the motivation for this work and a summary of the related literature it builds on. Then I present the study, including methods, results, and discussion. This study highlights how fertility data work is complex, describing the many challenges individuals face, how the complexity of fertility contributes to pressure and emotional burden, how individuals develop different relationships with their data, and how these challenges push individuals to turn self-tracking into a collaborative activity of making sense of personal data. These findings and discussion provide the baseline for the following studies of this dissertation research and were previously published in (Costa Figueiredo et al., 2017, 2018).

3.1. Motivation

This study focuses on investigating fertility self-tracking to provide the initial understanding of individuals' data work and related emotional engagement with data. Prior to this study, few studies have investigated individuals' experiences with fertility self-tracking (e.g., (Epstein et al., 2017)), and most often they did not focus on challenges to conceive. Little was known about the practices individuals trying to conceive engage, the problems they face, and how they approach such problems, particularly when facing challenges for a long time.

With the uptake of fertility tracking technologies, individuals are collecting and using extensive and varied personal data potentially related to their fertility. Data work literature have described different challenges healthcare professionals and organizations encounter when dealing and using extensive health related data, highlighting that solely having data does not guarantee the promised benefits (Bossen, Chen, et al., 2019; Bossen, Pine, et al., 2019; Pine, 2019). Similar issues can happen in the individual or patient context, with the aggravation that these individuals are most often not health experts nor technology experts, and they may encounter multiple challenges when trying to interpret and use their now extensive personal data. However, less is known about how individuals engage in this data work and what may be the impact of these activities. Fertility is a particularly suitable context to explore these data work challenges faced by individuals because it is an extreme case where there is a singular discrete goal (i.e., to get pregnant) that occurs for a relatively shorter time window, there is a significant level of personalization and a lack of information and guidance regarding data work, and there is a strong influence of social taboos, particularly related to gender and sexuality. Therefore, this study focuses on investigating how individuals engage in this data work, the challenges they encounter, and how they deal with them as an initial understanding for the remaining studies included in this dissertation.

In summary, this first study aims to understand (i) the process of fertility self-tracking and its specific challenges; (ii) the process of sensemaking involved in understanding one's own fertility data; and (iii) the relationship between self-tracking practices and collaboration in the sensemaking process. Finally, inspired by previous work on the emotional consequences of self-tracking, and because trying to conceive is a complex and emotional goal in which individuals have low control of the outcomes, this study also included an investigation of the interplay between self-tracking practices and emotions. The results of this study draw attention to how complex self-tracking, sensemaking, and related data work can be in the context of more individual, invisible, emotional, goal-oriented, and less known health conditions.

3.2. Related Work: Understanding One's Own Data

To investigate how people use self-tracking and make sense of their data in the fertility context, I draw from literature on sensemaking, emphasizing the challenges of understanding one's own health. To analyze the emotional context involved in individuals' data work, I build on previous related work that has reported the emotional load of data and its impacts on individuals. This section presents literature regarding these two critical aspects to provide a theoretical background to the findings of this study.

3.2.1. Sensemaking

Sensemaking, as described by Dervin (1983), refers to how individuals *"construct sense of their worlds,"* that is, how a person uses their and other people's observations to understand their own reality, overcome gaps, and guide their behavior. It has been studied in many different domains, such as organizational sciences (Karunakaran et al., 2013; Weick, 1995) and education (Warren et al., 2001). In HCI, sensemaking has historically focused on how people organize and encode complex information to answer task-specific questions in information-rich domains, often within the fields of intelligent systems and information retrieval (Klein et al., 2006; Russell et al., 1993). In general, sensemaking is intrinsically associated with finding, understanding, and using information to fill a gap in understanding (Dervin, 1983; Mamykina, Smaldone, et al., 2015; Paul & Reddy, 2010; Weick, 1995).

In the health domain, sensemaking has been used to investigate how people collect, organize, and develop mental representations of complex information to understand a problem (Mamykina, Smaldone, et al., 2015; Paul & Reddy, 2010). Mamykina, Smaldone et al. (2015) have used sensemaking as a lens for analyzing self-management of chronic diseases, since patients need to reexamine daily activities to adjust to the demands of their health condition. They proposed a sensemaking framework for the self-management of chronic conditions, particularly diabetes. This framework describes how individuals perform self-management activities in two modes: the habitual mode and the sensemaking mode. In the first, individuals use their existing knowledge and mental models to understand new information. In these cases, new information, although new, do not lead to a gap in understanding. The opposite happens in the sensemaking mode: individuals need to explicitly engage with a new situation analytically and create new explanations that can support their actions because this situation does not fit their pre-existing mental models. Once this new situation is understood and a mental model is created or adapted, individuals can return to the habitual mode (Mamykina, Smaldone, et al., 2015). This framework highlights that besides supporting individuals to change health behaviors, it is also critical to help them make sense and understand their conditions and their own data and experiences.

Although initially viewed as a mostly individual activity, several studies have focused on sensemaking within collaborative environments, or collaborative sensemaking. Previous studies focusing on healthcare providers highlighted the importance of collaboration in the sensemaking process toward achieving a shared goal (Paul & Reddy, 2010). Recent studies have focused on the role of online forums in supporting sensemaking, since they have been an important and popular place for people to discuss health-related topics. For example, Mamykina, Nakikj, et al. (2015) found that diabetes patients build shared meanings through discussions, perspective negotiation, and conflict resolution in the online forum they analyzed (Mamykina, Nakikj, et al., 2015). Other studies have provided evidence that online groups can support the development of individualized solutions (Huh & Ackerman, 2012). These forums are also used by patients as a mechanism to validate experiences and determine if their experiences are "normal" (O'Kane et al., 2016). Finally, research suggests that, in some cases such as eating disorders and cancer (Sullivan, 2003), people prefer to interact and ask questions online rather than discuss these issues with family and friends (Walther & Boyd, 2002), because members of these communities might be more knowledgeable about the condition, or have had a similar experience. In the context of fertility, past research investigated how these environments are used by pregnant women and early mothers to understand if their symptoms and experiences are "normal," and to look for support and information (Fourney et al., 2015; Morris, 2014).

These previous studies have motivated this exploratory research focused on understanding the process of sensemaking through online forums for fertility care. This study focused specifically on the relationship between self-tracking practices and the process of collaborative sensemaking in these forums. It builds upon this prior work by applying concepts of self-tracking and sensemaking to the challenges related to fertility care. More specifically, I used the personal informatics model to analyze the challenges and barriers to fertility self-tracking, and how online forum collaboration supports these activities and helps individuals to overcome the burden and invisibility related to facing challenges to conceive. In this analysis, I also investigated the emotional load of self-tracking, and how individuals' emotional experiences influence their tracking activities.

3.2.2. Emotional Load of Self-Tracking

Initial work on self-tracking focused on the use of these activities and technologies with the specific goal of changing behavior (Li et al., 2010, 2011). Subsequent research emphasized that data are used in individuals' daily lives, highlighting how their experiences with data are embedded in their lived experiences (Epstein et al., 2015; Rooksby et al., 2014). Rooksby et al. (2014) described how people reported on their tracking activities in terms of *"lives, worries, hopes, interests, careers and so on,"* calling attention to the emotionality of tracking.

Several studies have reported the potential benefits of self-tracking practices and technologies, particularly related to inspiring reflection (Bentley et al., 2013; Li et al., 2010) and positive behavior change. Besides encouraging self-knowledge and self-awareness of one's own health (Li et al., 2011), self-tracking has been reported to provide a sense of control, especially in complex or poorly understood conditions (Ayobi et al., 2017; Grönvall & Verdezoto, 2013a; Mamykina et al., 2008), giving individuals a plan that they can follow (Kragh-Furbo et al., 2016). For example, Ayobi et al. (2017) described how the use of self-tracking by patients with multiple sclerosis helped some individuals to recover a sense of control when adapting to the complex, unpredictable, and degenerative characteristics of their disease. Additionally, different studies suggest that PGHD and self-tracking activities and technologies can improve visibility, social recognition, and self-validation for people living with complex conditions (Felipe et al., 2015; MacLeod et al., 2015; Park & Chen, 2015).

In contrast with these benefits, other studies have reported potential negative effects related to self-tracking, particularly concerning the emotional load of data and its impacts. For example, Ancker et al. (2015) explained that personal data can be charged with strong moral and emotional implications and data can carry moral values that lead patients to judge themselves as "good" or "bad" based on their results. Similarly, Cordeiro et al. (2015) described how some individuals experience guilt and shame when tracking food data, feeling unhealthy and judged. Eikey and Reddy (2017) call attention to the possibility of developing dependence on logging and obsessive tracking, and how self-tracking tools may promote potentially unhealthy habits especially for at-risk populations (e.g., individuals with eating disorders). Other studies have reported individuals experiencing similar negative feelings, such as vulnerability, failure (Katz et al., 2018), hopelessness (Ayobi et al., 2017), and feeling constantly reminded of their diseases and all related negative aspects (Ancker et al., 2015).

All these studies suggest that people likely have both positive and negative experiences and emotions when collecting and making sense of their data, which indicates that people interact with and are impacted by their data in different ways. Understanding the positive and negative emotional aspects around engaging with self-tracking data and activities is critical in the health context because, besides impacting individuals' commitment to self-tracking practices and outcomes (Clawson et al., 2015; Costa Figueiredo et al., 2017; Epstein et al., 2016), users' emotional experiences may directly affect their mental and physical health. Inspired by this previous work on the emotional consequences of self-tracking, this first study also directly explored the interplay between self-tracking and emotions. Fertility is an especially suitable context for this investigation, since it is very emotionally loaded, directly connected with individuals' life plans, and entangled with social expectations and taboos. Besides being critical to better support this population, understanding individuals' emotional engagement with data in such an extreme case may provide useful insights for other self-tracking contexts as well. The next sections describe the theoretical framework and detail the methods employed in this research.

3.3. Theoretical Framework: Stage-Based Model of Personal Informatics

Li et al. (2010) have proposed a stage-based model of personal informatics systems (Figure 3.1) and identified the main barriers individuals face in each stage. The model separates the self-tracking process into five stages: (1) *Preparation*, involving planning and preparing; (2) *Collection*, comprising gathering data; (3) *Integration*, encompassing formatting and combining data from different sources; (4) *Reflection*, encompassing reflecting on the data; and (5), *Action*, comprising acting based on the reflection.

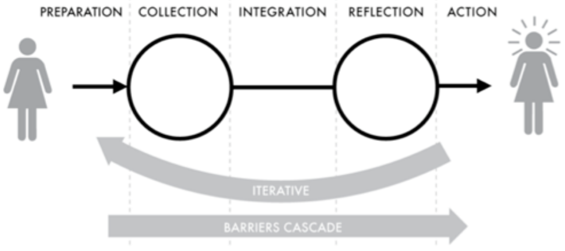


Figure 3.1. Personal Informatics Model (Li et al., 2010)

Later studies expanded or proposed adaptations of this model (Choe et al., 2014), such as including people's motivations and lapses when self-tracking (Epstein et al., 2015). I chose to use the original model as conceptual framework in my analysis because of its discussion of barriers, which was most suitable to my goal of identifying and understanding the challenges individuals face when performing fertility self-tracking. Barriers in the *Preparation* stage are related to deciding what and how to track, while in the *Collection* stage they can be related to the tool (for being inadequate or difficult to use), to the user (lack of time, motivation, or forgetting to collect), or to the data (hard to collect, subjective, or relying on non-standard ratings). Barriers in the *Integration* stage concern problems in combining data from multiple sources or differences in data format. In the *Reflection* stage, barriers prevent users from understanding their information, which can happen in both short and long-term reflection. Finally, in the *Action* stage, barriers arise from lack of suggestions or information on what to do next. In addition, these barriers cascade, as a problem in one stage can affect later stages and may escalate along the way (e.g., collecting data in incompatible formats increases challenges in Integration, which may prevent Reflection), even preventing users from advancing from one stage to another (e.g., if individuals cannot understand their data in Reflection, they may not be able to advance to the Action stage) (Li et al., 2010).

3.4. Methods

In this exploratory research, I used an online health community (OHC) to collect data. OHCs are a common source of information for patients' or individuals' concerns and questions. They provide a platform for users to ask questions and receive answers and support (usually from peers) for many different types of conditions. Such forums were particularly suitable for this study's analysis because many individuals who are trying to conceive through fertility awareness methods are not monitored by physicians, so they cannot necessarily be identified through medical visits. They also provide in-situ data of people reaching out while living that emotional experience. Moreover, individuals may consider fertility challenges to be sensitive, feeling more comfortable to share their concerns and questions anonymously online (Walther & Boyd, 2002). Therefore, an OHC is a suitable site for investigating the concerns of individuals using different fertility methods and treatments, with or without the assistance of healthcare providers.

The OHC selected for this study was chosen because of its popularity, and because it offers a community specifically focused on fertility. It is one of the most popular OHCs in the U.S., offering peer support, information, and tools (e.g., temperature charts). It has communities containing thousands of questions and threaded replies (e.g., answers) about many health conditions and issues. The specific community I analyzed was a popular forum (it contained 52,017 threads in April 2017) dedicated to fertility and infertility and specifically directed to individuals who have been trying to conceive for a year or longer in different stages of fertility care, ranging from fertility awareness methods to IVF. I considered other OHCs, but their discussion groups were either too broad (e.g., not focusing on infertility, but on conception in general) or too narrow (e.g., separating the groups per treatment type).

Ethical and privacy issues were considered in using data from OHCs. Since the OHC used in this study is public (i.e., the community does not require subscription or login to access the threads) and the terms of service allow the use of data for research, the data can be considered “publicly available.” However, because it comprises conversations about a sensitive topic, and users of OHC may have the expectation that their information will not be identifiable outside the community, I took measures to assure OHC users’ anonymity. The OHC name is not revealed in this dissertation or in any paper published based on the data. All potentially identifiable information (e.g., usernames) were removed. Quotes used in this dissertation and on publications were paraphrased to ensure de-identification. Final quotes were searched for online to ensure the original posts are not easily identifiable, and edited to ensure they were not a top search engine hit.

3.4.1. Data Collection

All threads (until September 2016) from the OHC were downloaded to a database. Relevant threads were selected by using a query to retrieve information from the database. To do that, I first analyzed a few threads to create a list of keywords. Since I was interested in the threads specifically discussing self-tracking activities when trying to conceive (using or not technological tools), in this stage I used specific terms such as "fertility tracking," "ovulation tracking," "cycle patterns." I did not restrict the query to technology use because self-tracking may or not be performed using technological solutions. However, the act of self-tracking in general can inform technological tools, which was part of the goal of this study.

After developing an initial query, I analyzed the first 50 threads to check the results and improve the query. I iteratively developed the query by analyzing the relevance of sets of threads and improving the search criteria. The final query included words related to health indicators tracked in fertility treatments, the activity of tracking, and tools used for tracking. It was composed of two parts. The first part searched for a combination of words from two groups. Group 1 consisted of words related to health indicators tracked in fertility treatments: "fertility," "ovulation," "cycle," "temperature," "temp," "CM" (Cervical Mucus), "period," and "BBT" (Basal Body Temperature). Terms in Group 2 were related to the activity of tracking: "tracking," "monitoring," "pattern," and "chart." The result must present one word from each group, regardless of the order, place (i.e., title, question, or answers), and the number of words in between. These terms are related to the main tracking aspects of fertility care and were selected after analyzing the content of significant threads to understand how individuals discuss the subject in the OHC. I specifically adopted this approach to cover different combinations of terms. The second part of the query searched for specific terms related to tools used for tracking that were not covered by the first part: "opk," "ovulation kit," "conception kit," "ovulation prediction kit," and "prediction kit." I excluded IVF treatments from the search because, in these cases, healthcare providers perform most of the monitoring. Since this study focuses on self-tracking experiences on the individual level, threads involving IVF treatments were outside of the scope of this study. The query resulted in 3,527 threads with 15,944 replies, from 2006 to 2016.

3.4.2. Data Analysis

After defining the set of threads relevant to the study, I performed a three-stage qualitative analysis. First, to gain initial understanding of the fertility issues individuals raised in the OHC, I and another researcher independently coded the 100 most recent threads and their 377 replies (from 2013 to 2016) using an open coding technique to identify the main topics present in the data (Corbin & Strauss, 2014). At this stage, we found that, while individuals still perform most of the self-tracking activities in IUI treatments, in some specific cases, healthcare providers perform most of the monitoring. We decided to exclude such cases for the same reason that we excluded IVF-related threads.

After discussing our results, I chose to use Li et al. (2010)'s stage-based Personal Informatics Model (PIM) as a conceptual framework to recognize and compare the challenges individuals face with the barriers described by the model. My intent was not to extend the model, but to use it as a framework to understand the process of self-tracking in fertility care and how individuals experience the stages of the PIM. Based on this model, I defined the initial codebook to be used in the next stage.

In the second stage, which happened in the beginning of 2017, I selected a random sample of 500 threads between 2006 and 2016. Such dataset was selected because it would be a more representative sample, since self-tracking practices might have changed over the past 10 years (e.g., digital devices and mobile apps have become more common recently, generating different issues and challenges). This time frame covers the period since the first smartphone was introduced (iPhone, 2007), so the sample reflects changes in technology that might have influenced self-tracking activities. The questions and answers were analyzed by me, the same previous researcher, and a third one using the initial codebook. The codebook was continuously modified whenever new themes emerged from the data until theoretical saturation (Corbin & Strauss, 2014) was reached. Any disagreements between the three researchers were resolved through discussion. In total, from the 100 most recent and the 500 randomized threads, we reviewed 400 threads (300 randomized + 100 most recent), a total of 1963 posts including replies, before achieving theoretical saturation.

The first two stages of data analysis revealed that emotional aspects are critical in fertility self-tracking, so the third stage explicitly focused on the emotional component of tracking. In this stage, I recoded all the reviewed threads, analyzing the emotional aspects previously identified in the data, in two steps. First, I categorized the feelings and emotions expressed in the quotes (e.g., anxiety, hope, frustration, happiness, anger, depression). At this step, I identified differences in the emotional relationship with self-tracking data and activities. These differences seemed to configure different levels of emotional intensity, from positive engagement with self-tracking activities and data to a point where individuals were so overwhelmed by negative feelings that they could not do it anymore. Then, in the second step, based on these feelings and their relationship with tracking activities, I categorized the quotes into five different types of engagement, which represent different levels of intensity with which individuals engage with their data: positive, burdened, obsessive, trapped, and abandoning. The next sections present the limitations and the results of these analyses.

3.4.3. Limitations

Many of the limitations of this study are related to using data from an OHC. First, these data may be biased towards individuals that want to share their experiences online. This bias may impact the representativeness of the population, since many individuals who face infertility may not use this type of channel, may use it without contributing, or may not have access to the health forum due to social, economic, language, or technological barriers. Further, the majority of users of the analyzed forum are from the U.S. In sum, these users may not represent the broad spectrum of individuals who face fertility issues that have different social and cultural values, ethnicities, genders, or sexual orientation.

Second, although some studies affirm that increased stress can be detrimental to fertility (Boivin & Schmidt, 2005), I make no claims concerning the association between any of the types of engagement with self-tracking and the results of fertility treatments, neither positively nor negatively. Fertility is a complex topic, and this study did not focus on what can or cannot increase the success of trying to conceive. My focus was on analyzing how self-tracking may impact individuals' lives when they are dealing with such a complex and emotionally-laden situation.

Finally, since I analyzed individual posts and answers from different individuals, my data show only the experiences of tracking with each of the described types of engagement, and different ways with which people relate with their own data and self-tracking activities. I did not trace back the posts of each individual. Thus, this study's data may suggest, but do not directly show the progress of the engagement (i.e., how an individual's engagement may change over time, transitioning between different types of engagement).

3.5. Results

In the following sections I first detail the characteristics of fertility self-tracking with the goal of conceiving, including why and what to track, followed by the application of the Personal Informatics Model and the main issues individuals face in each stage, showing that individuals utilize self-tracking extensively throughout the cycle, and face barriers in every stage. After that, I report how these experiences involve different and intense emotional responses, describing each type of emotional engagement with data identified in the OHC.

3.5.1. Why Self-Tracking

When trying to conceive naturally or using any of the methods prior to IVF, the main common goal is to identify ovulation and the fertile window to maximize the chances of conceiving. Self-tracking can help individuals to understand the specificities of their cycles and to identify their fertile days. Estimations based on their own measurements increase the chances of identifying patterns that can be useful to any fertility treatment.

Within the goal of identifying ovulation, individuals use self-tracking for several reasons, with or without the support of healthcare providers, including (i) to understand their cycles, (ii) to see how their bodies respond to treatments, (iii) to communicate with providers more effectively, and (iv) to try a more affordable option before resorting to more complex and expensive treatments (e.g., "*I suggest you to get as smart on the matter [understanding the cycle] as you can. Especially because you have limited insurance coverage*").

Although most individuals in the OHC suggested they were tracking on their own, physicians can also recommend and support self-tracking, as the next quote suggests: "*My OB/GYN wants me to try tracking temperature and use an ovulation predictor kit this month. Can anyone suggest a kit that worked for you in the past and hopefully was not so expensive?*" In this case, the healthcare provider recommended the individual to track but the person still turned to the OHC to seek more information, including brands and prices.

Treatments involving medication to stimulate ovulation (with or without IUI) also require tracking to identify the fertile period. In these cases, the tracking is still mainly in patients' hands, but healthcare providers play a role in these activities: healthcare providers may suggest tracking (e.g., "*I have very irregular cycles…I do not ovulate at all except when I was taking the Clomid [medication to stimulate ovulation]. My physician still advised me to measure and keep track of my temp*"), or individuals may use self-tracking to understand their treatments and to communicate with their healthcare providers better, particularly when they feel they did not receive enough information. For example, the user of the following quote describes their healthcare provider did not explain how medication would impact the results of OPKs. This person turned to the OHC and intended to use what they learned there and their tracking data to ask questions to the healthcare provider in the next appointment: *"I have another question related to OPK's…I think I usually ovulate close to CD [cycle day] 14 but I read Clomid can change that…This is the first month I use any type of fertility medication and my doctor did not tell me much about any of it...but, man, I will have so many questions for him on this weeks' appointment!"*

Individuals undergoing IUI also benefit from tracking, but in these cases, physicians perform more of the monitoring. The next quote shows that although the person was monitored by the healthcare provider, they still used OPKs to track ovulation and these tracking results have influenced the treatment:

> *"I took letrozole [medication to stimulate ovulation] on days 4 to 8. I'm scheduled for ultrasound on day 12, which is tomorrow. My ovulation kit came positive today. When I called my doctor's office, they scheduled the IUI tomorrow instead of the ultrasound. In my last cycle I had to take a trigger shot [before the IUI, to ovulate]. Is it possible that I have ovulated without a trigger shot?"*

These quotes illustrate the reasons individuals use self-tracking in different treatment scenarios within the main goal of identifying ovulation to match intercourse or treatments. They also provide examples of the multiple health indicators individuals can track, which is the topic of the following section.

3.5.2. What to Track

The main goal of self-tracking for conception is to identify ovulation. Different measures can estimate the ovulation day through self-tracking, but all of them have limited precision and no unique measure can precisely identify when individuals ovulate. Instead, individuals often collect, integrate, and reflect on multiple measures to estimate the probable time of their ovulation. Table 3.1 briefly summarizes the main health indicators individuals trying to conceive use as we identified in OHC data.

Besides identifying ovulation, individuals also use self-tracking to find out if they conceived. In this case, the most common tracked indicators are symptoms or the results of home pregnancy tests, as suggested in the following quote: *"Very bloated [possible early pregnancy symptom] since 4 days post ovulation and getting worse! Temperature is over 98 since 1 day after ovulation. Eating all junk food...Peeing a lot and having twingy cramps in lower abdomen. Please give opinions, do you think I'm pregnant?"*

Table 3.1. Main health indicators used in fertility self-tracking

Indicator	**Description**
Cycle day (CD)	Fertility cycle day
Ovulation Predictor Kit (OPK) or Monitor	Home test that measures a rise in the Luteinizing Hormone (LH). A positive result indicates that ovulation will occur in 12-36 hours. It is considered the most reliable way to identify ovulation
Basal Body Temperature (BBT)	Lowest body temperature. In the day after ovulation, it rises by 0.5-1F, and remains high if pregnancy occurs
Cervical Mucus (CM)	Vaginal discharge. Indicates ovulation when similar to egg whites in color and texture (EWCM: egg white CM)
Cervical Position (CP)	Cervix position: it should be soft, high, open, and wet in the fertile days
Home Pregnancy Tests (HPT)	Home test that detects the HCG hormone. Usually used 2 weeks after ovulation, in case of a late period
Symptoms	Emotional and physical symptoms can be interpreted as indicators of ovulation or pregnancy

These data exemplify how the OHC is an important source of information and support to data interpretation. The OHC is an important resource for all the challenges individuals face when self-tracking their fertility, as described next.

3.5.3. Stages of Fertility Tracking

When applying the PIM to understand the fertility cycle, I found that, unlike personal tracking in other illness situations, within one fertility cycle, individuals transition twice through the model stages, and the stages overlap (e.g., individuals may start the Action stage while still collecting, integrating, and reflecting on data). Figure 3.2 shows the application of the model to the fertility cycle and is used to uncover and understand the barriers individuals experience. The dashed lines represent the variance intrinsic to fertility self-tracking.

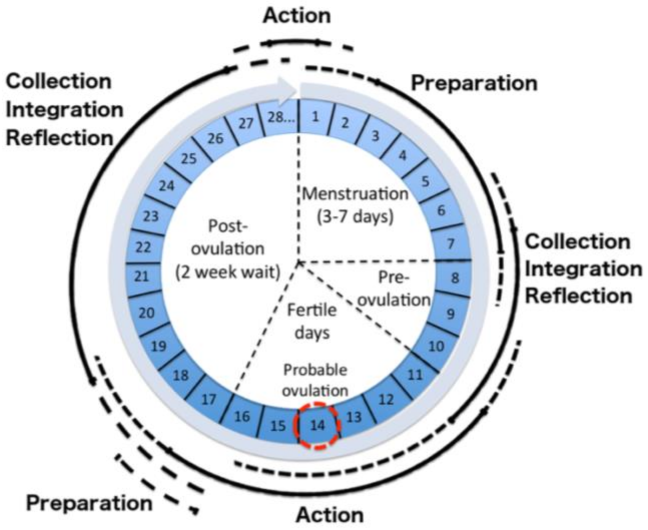


Figure 3.2. Personal Informatics Model Applied to the Fertility Cycle

The process of fertility self-tracking for conception begins on the first day of the menstrual phase. This phase is primarily used for preparation activities, since individuals are typically not fertile, and the menstrual flow makes it harder to collect measures such as cervical mucus. Measures such as temperature can be collected throughout the whole cycle, but collection, integration, and reflection usually start after the end of menstruation. It is suggested to start using OPKs near the expected ovulation date, around cycle day 11. However, since fertility cycles can vary, some individuals start using them earlier, especially when they expect to ovulate early in the cycle. The action stage mainly consists of having intercourse or treatment to attempt to conceive after identifying the possible ovulation day. Since the ovulation day varies, and individuals often want to maximize their chances, this stage may be much longer than the 6 fertile days and often overlaps with other stages.

After the fertile phase, there is what individuals call the two-week wait: the time until the next cycle is expected to begin. Individuals are usually instructed to wait until their next menstrual period is late to test for pregnancy, since pregnancy tests are not able to detect conception earlier. However, many individuals engage in collection, integration, and reflection activities during this time to try to identify early signs of pregnancy (e.g., collecting temperature and home pregnancy test results). These activities may be preceded by, or even happen alongside, a new preparation stage. This new preparation would be focused on detecting a possible pregnancy by, for example, choosing the pregnancy test, identifying which symptoms to observe, and planning when to start such tasks. The cycle ends either when they have a positive pregnancy test, or when the menstruation phase starts. Around this time, they may engage in a new action stage, in which they stop tracking for fertility care and focus on pregnancy care or stop the treatment for any other reason (e.g., interval between treatments). The next sections describe the main challenges faced in each stage.

Preparation

The main challenges regarding preparation are related to learning how to start tracking, and how to collect data. In this stage, individuals need to decide which indicators they will track, and how. They decide whether to use paper or website charts, the type of OPK, and the frequency of data collection. People turn to the OHC to ask information on how to start tracking (e.g., "*How should I track my ovulation, so I know exactly when I should have* *intercourse?*") and often other users offer detailed information that is valuable for their learning process, and critical for the preparation stage. For example, in the following quote, an individual explains, with an impressive level of detail, to a newer user how to calculate the appropriate day in the cycle to start using OPKs:

> *"You can test at any time of day, but you should test approximately at the same time every day. You should reduce your liquid intake 2 hours before testing. To find out when to begin testing, find the length of your normal cycle. Your cycle length is from the beginning of one period to the beginning of the next one. Count the first day of bleeding or spotting as day 1. If your cycle length is irregular (i.e., if it varies by more than a few days a month), you should take the average number of days for the last 3 months. Use the graph below [image provided by the user] to find the day you should start testing. The day you start testing is listed opposite to the number of days of your cycle. If the cycle length is 28, you begin testing at cycle day 11"*

This information seeking behavior also occurs in subsequent cycles, when individuals use the OHC to discuss whether to change their approach in their next fertility cycle, even when they might receive guidance from a healthcare provider. For example, in the following quote, the individual explains they discussed tracking activities with their healthcare provider, but after a few cycles without tracking, the individual is considering trying it, despite their healthcare provider advising against it: "*I asked my doctor before I start clomid if I should track BBT, but because I have always had REALLY irregular cycles, he said it really would not be worth the effort...I have been thinking about tracking it next cycle just to see what happens, though.*"

Individuals select measures and how to track them in this stage. Choosing an inadequate or incomplete set of indicators to track (e.g., measures affected by a treatment or failing to track a critical indicator) or choosing an inappropriate tracking tool generate problems that may impact further stages in the fertility cycle. For example, a user turned to the OHC to confirm, based on the experiences of others, if their symptoms (severe abdominal pain) could be related to ovulation, despite the negative ovulation tests. In the answers, another user asked if they were tracking cervical mucus (CM) and cervical position (CP): *"I am just tracking temperature at the moment. I am not used to all these things yet, so I'm just getting to know my body. What is cm and cp? I have been noting down everything else, like moods, etc."* Through this conversation, this user learned that CM and CP can offer information that could help answering their questions. Since the user missed tracking these measurements, even if they start collecting now, they will only be able to make sense of them in the next cycle, possibly delaying their understanding of their symptoms.

Regarding problems related to choosing an inadequate tracking tool, the following user realized the OPK they chose may not be suitable for them only later in the cycle, also possibly delaying their understanding or generating inaccurate results:

> *"I have started to use the clear blue monitor [OPK type] and I am currently on my first cycle using it. Now…I realized that there is a possibility that it may not be appropriate for me. My period is irregular, and the length of my cycle can range from 26 to 44 days. I'm aware the monitor is only suitable for cycles up to 42 days."*

The choices made in the preparation stage are fundamental for the following stages, and the problems created by inadequate choices impact and add complexity to the other stages' challenges.

Collection

The main issues identified in the collection stage were related to OPKs and their results. Although these tools provide a critical measure in fertility care and are considered the most accurate way to identify ovulation, OPKs can be misleading, and reading their results can be subjective. OPKs measure the LH surge that precedes ovulation by 12-36 hours and peaks 10-12 hours before ovulation. It is possible that the surge happens between two subsequent measurements. In this scenario, the tests might fail to detect ovulation. The individual in the following quote explains this to another user and suggests testing twice daily instead of once (which increases the expense): "*Technically the test line should be as dark or darker than the control line, but you might have just missed it [ovulation]. Some people just have a shorter surge. For some time, I actually tested twice each day to make sure I would not miss it*."

This quote also approaches the other main problem related to OPKs: the result (i.e., identifying a line darker than the control line) can be ambiguous or difficult to interpret. The next user used the OHC to overcome this difficulty by comparing their results with the ones from others and found out that, apparently, they have been misreading their OPKs:

> *"I am really beginning to think I was totally wrong about my positive OPk. I looked the opk result of another girl that was positive in here [OHC], and I used the same brand, and hers is definitely positive (the test line is clearly darker than the control*

> *line). Mine was kind of weird. It was like: half of the line was the same color as the control line, but the other half was lighter."*

Because of this difficulty in comparing the line colors, many individuals decide to use digital tests, which are more expensive, but have a clearer presentation of results: *"I had trouble with the 2 lines, so I only use the Clearblue Easy [digital OPK] with the happy face or empty circle. That way there's no guesswork!*"

Besides these issues in interpreting OPK results, other measures individuals track can also be subjective or potentially impacted by multiple factors. Temperature is a particularly burdensome indicator to track: it needs to be collected every day at the same time, early in the morning, before getting out of bed. Besides, temperature increases are small, and the values can be affected by many factors, such as the time of measurement, the number of hours slept, the quality of sleep (e.g., quietly or moving a lot), alcohol intake, getting up to go to the bathroom during the night, and health conditions such as fever: *"I had a mild fever a few days. I believe my coverline [in the chart] may be off because of this 2-week illness."*

In another example of measure difficult to collect, cervical mucus is based on visually identifying the characteristics of the mucus, which is subjective. Besides, not all individuals get enough or any mucus to analyze, and not all individuals that get it are able to recognize the expected characteristics in a meaningful pattern, as this user comments: *"I don't ever get the kind of CM they say you should have."* Finally, symptoms are always subjective indicators.

Considering all this, users often turn to the OHC for help in understanding how to collect or identify their individual indicators and to share how to use tracking tools with others, especially if their results are not exactly as expected.

Integration and Reflection

In the two periods where collection, integration, and reflection happen in Figure 3.2, individuals daily collect, integrate, and reflect on the measures they decided to track. Collection has its own challenges, but the challenges in integration and reflection are intertwined, and the two stages constantly overlap. The main issues in these stages are related to the characteristics of the measures, the need to integrate different indicators, and the emotional factors involved in fertility self-tracking.

First, the measures themselves are difficult to understand. For example, OPKs can give false positives since it is possible to have a LH surge and not ovulate (Marik & Hulka, 1978). Furthermore, conditions such as polycystic ovary syndrome (PCOS—a hormonal disorder that may impact fertility) may affect OPK results, causing an incorrect interpretation: "*I know a symptom of PCOS can be elevated LH levels, which can lead to multiple positive OPKs. If this is one of your symptoms, you might want to talk with your doctor about the best way to track.*"

Because cycles vary from person to person, individuals have to determine their own process of tracking and making sense of their data individually. Even when they become knowledgeable about their patterns, the results can vary every cycle for the same person. For example, one user asked about the possibility of having a LH surge without ovulating *("Does a positive LH surge really mean that I'm ovulating, or could I have a surge but no egg?"*). In the exchanges of that thread, this user explained they used self-tracking to conceive their first child, but were having difficulties in conceiving again, even after following the same steps and having intercourse when all their measures pointed to ovulation.

Second, the need to integrate data from multiple sources is intrinsic to fertility self-tracking since it increases the chances of accurately identifying ovulation or pregnancy. However, integration can be complex, and the measures can lead to contradictory or inconclusive results, creating a barrier for reflection: *"I just wanted to see if anyone had a similar experience. I'm currently tracking my temperature, measuring cm, and using opks. I'm on cycle day 24 (my cycles are extremely irregular) and I have not seen my temperature increase at all. I have had seven positive opks, but no egg-white cm, just sticky. Any ideas?"* In this example, OPK results indicate ovulation, but temperature and cervical mucus readings do not. Similarly, in the following quote OPK and symptoms indicate ovulation, but the temperature results are not conclusive. Besides, the user is also worried the fertility medication they are using can also impact in the measures: "*I felt the pains the day of the positive OPK and after. I don't even know if I ovulated because my temperature measures are very goofy this month. I heard the clomid can mess your temperature up, is that correct?*" As these examples show, individuals find it difficult to integrate and interpret these data and ask other OHC members for help.

Third, individuals' expectations can also influence reflection. For example, it is recommended to wait until having a late period to start testing for pregnancy; however, OHC users often use different measures during the two-week wait, hoping to identify conception earlier, even repurposing some measures (e.g., OPK) or looking for an "implantation dip" – a reduction in the temperature that supposedly happens when a fertilized egg attaches to the uterine wall (in the next day the temperature would return to the prior value): *"Has anyone tracking BBT had an implantation dip in their graphs? My temperatures have been steadily going down…Is there a chance it is an implantation dip?"* However, there is no concrete evidence that these measures can detect pregnancy. At this stage, emotional status can affect reflection, increasing pressure and frustration (more on this aspect in section 3.5.4).

Action

The first action stage in the fertility cycle (Figure 3.2) focuses on having intercourse or IUI. In the second, the main possible actions are to continue using any fertility treatment in the next cycle, to stop it for some time or indefinitely, or to stop it due to pregnancy.

First Action Stage. As soon as they identify ovulation, individuals try to conceive. They calculate the best dates to have intercourse within the fertile window to maximize their chances. This calculation is based on positive OPK results and on how long egg and sperm can live in the body. They also often consider sperm count, discussing if having intercourse multiple times in a short period may or not reduce concentration, which could lower the chances of conceiving, especially in the case of existing male fertility issues (e.g., low sperm count). In the next quote, the OHC user disagreed with their healthcare provider's suggestions on when to have intercourse. The user then turned to the OHC to discuss and seek for advice on deciding if they should follow the doctor's recommendations.

> *"[My Reproductive Endocrinologist] said to have intercourse tomorrow night, the following morning, and the following night. Does it sound good to you guys? I'm wondering if we should start tonight because I seem to be starting or almost starting my surge. I know the little guys can live for some time in there, so it seems like it would not hurt, but I worry about 'diluting the pool'. When I asked the doctor if we should do it tonight, he said no."*

Second Action Stage. Often when individuals get a negative pregnancy test, they do not know what they can do in the next cycle to improve their chances. They turn to the OHC to get information and guidance, engaging in collaborative sensemaking and communicating their decisions for the next steps: "*I'm using opk and temperature tracking to predict and confirm ovulation for the last 6 months with no result…What should be my next step?*"

Negative emotions also affect their decisions for the next stage. Many individuals use the OHC to vent their frustration, especially when combining these feelings with the social pressure surrounding pregnancy: "*I am on drugs [fertility medication], visiting a hospital every other day, and handling the sadness and the fear that come whenever my period arrives. I know as well as they do that I am getting older.*" Isolation is a common feeling, since they often do not know people facing similar challenges outside the OHC: "*The hardest part of the journey for me, is the isolation from everyone else around me. No one relates*." Individuals facing challenges, particularly for a longer time, find support in the OHC, and develop ways to overcome these issues and decide their next steps based on advice and similar stories from other OHC members, as the next excerpt illustrates:

> *"You are feeling like many of us in this forum who have been trying to conceive for years with no success. The first thing you need is a game plan: it will make you feel better and as you are doing something instead of waiting every month to see if that is your month, and living in 2-week increments...First you should visit your OB/GYN and get some preliminary tests…it is a time consuming process, but being proactive helps…You may also want to contact your insurance to see what infertility coverage*

> *you may have, in case you may need to do IUI or IVF. This forum helps because it is a great support group, and you feel like you are not alone."*

Finally, in the second action stage, after reflecting on their data and on the whole process they have been through, individuals can also decide to interrupt tracking even without pregnancy. It can be a temporary interruption in-between treatments, especially after using medication for some cycles, or a spontaneous pause, as in this quote: "*I'm not sure if I will ovulate this weekend, but I will try 1 more month. After that, I'll take a break, and let it naturally happens on its own*." The interruption can also be definitive, especially when they have tried to conceive for many years and exhausted all treatment options.

In summary, this analysis shows that individuals who use fertility self-tracking to try to conceive face several challenges in each stage of self-tracking. These challenges are caused by the complex nature of self-tracking for fertility, as its many elements make it difficult for individuals to decide what to track, to interpret their data, and to solve problems when they face unexpected results. Because pregnancy is often an important part of these individuals' life plan, these challenges are faced in a very emotional context. These emotions become entangled with self-tracking and shape the way people engage with their health data.

3.5.4. Emotional Engagement with Data

In coding the emotional aspects related to the self-tracking activities, I characterized the quotes into five types of engagement with data, describing the varying, and emotionally laden, relationships with data that individuals exhibited in the OHC. Fertility can be an emotionally loaded context, so many of the emotions I describe could be experienced without tracking. However, this section describes how these emotions impact tracking activities, and how tracking may not necessarily cause but influence, reinforce, or exacerbate the described emotions. The following subsections describe each type of engagement, including their main emotional characteristics and tracking activities.

Positive Engagement: Excited with Data

In the positive engagement, individuals have a positive attitude towards self-tracking and data. Often occurring at the beginning of a fertility process, individuals within this type express positive experiences learning the measures and practices associated with tracking. Individuals often express excitement upon seeing data and trying to understand what the data mean. For example, a OHC user described being excited to see their *"darkest line"* on an OPK: still not darker than the control line, but the darkest they have had so far. Although it is not a positive result, it gives them a feeling of progress, which encourages them to continue tracking, as illustrated in the quote: "*Do you think I should test again tomorrow and the following 2 days? This is exciting!*"

When individuals are in a state of excitement, self-tracking can foster a feeling of control about the fertility process. Tracking data provides a structure that enables them to make plans about how to deal with their fertility challenges. Further, tracking is expected to guide behavior in a manner that increases the chance of pregnancy. For instance, in the next quote the user describes their current practices and preparations for the next year: *"I had a similar experience last month, so it is not bothering me yet. I keep having sex every other day and measuring my temperature too. I even bought a year membership in [a fertility tracking website] in order to use all available tools. I am ready for the long journey!"*

These quotes exemplify a positive engagement with tracked data, in which individuals are tracking their data, feeling that they can make sense of these data, and having a sense that if they use these data, they will be able to achieve their goal. Although stress and anxiety are present in any kind of engagement, individuals who enjoy positive engagement generally orient to data with hope and excitement.

Burdened Engagement: Concerned with Data

In the second form of engagement with data, individuals express a higher degree of stress and anxiety with tracking practices. For these users, tracking can be more emotionally demanding. For example, the user in the following quote describes how they feel pressured to get positive results (i.e., anxiety):

> *"I feel somewhat silly, but I wonder if there is any other woman who experienced anxiety when first started charting your ovulation and cycle? My cycle was absolutely predictable until the DAY before we began discussing about starting to use OPKs to figure out ovulation and etc. Now my cycle seems to be completely over the place. With my partner's previous child, they had to pass through fertility treatments, so now he wants to be more relaxed and to look for patterns before trying to get pregnant. It is almost as I am getting stressed because I want to show that my cycle is predictable."*

Individuals who experience a more burdened engagement with data use language that suggests a more intense focus on tracking practices and concern with regards to tracking behavior. Often these users describe wanting to understand their measures better, so they can track and reach a more precise understanding of their cycle. So, they may start to collect, check, and re-check measurements frequently. For example, the first user in the following dialog excerpt is trying to understand how the basal body temperature works and how much it oscillates so they can identify the changes with more confidence, while the second one explains all the experiments they have made in order to better understand their patterns:

> *"A: Has anyone tried to take temperature later in the day to see how much higher it gets after walking, living, etc? Do you think it should be close to the temperature when you wake up? I know it is important to measure it before leaving bed because it rises, but I wonder if anybody knows or tested how much it usually rises?*
>
> *B: My temperature is very sensitive to the moment I measure it and to the temperature of the place I am in. I discovered that if I measure it some few hours later than I normally do, or if I stand up before measuring it, it can be around 0.5° higher. Other activities also seem to make a relevant difference, e.g. eating, talking, and drinking. This makes it harder to have an accurate temperature after leaving bed. Many times, my temperature was more than 0.5 lower during the evening than in the morning. I think these differences must be due to changes in my mouth temperature after drinking or eating."*

Here we see an example of how the act of tracking data can become burdensome, particularly as individuals attempt to understand with a high degree of specificity measurements that are variable and often unpredictable. In this state, users express the desire to increase the amount of tracking in the attempt to get more precise results. However, although such activities may increase the chances of conception, achieving such precision is not straightforward. The user of the following quote has decided to include cervical mucus in her tracking, but she is not sure how to interpret their data: *"I am trying to understand everything I can about cervical mucus, so I can track it, but my body is not consistent with the data. My menstruation ended 4 days ago. Since that, I am having a lot of watery mucus. Shouldn't the mucus be dry (based on all I read)?"*

My data suggest that some individuals experiencing burdened engagement with tracking have been tracking for some amount of time without conceiving and have typically sought other measures to complement what they have been doing. As another example, a user explains the patterns they identified after tracking for two years, which demonstrates that they understand their cycles. Yet, they have not conceived. So, the user is trying to find answers, even considering menopause, which is not common for a person of their age:

> *"I am tracking my cycles for around two years. I have noticed a pattern: I have one 55-days cycle followed by a 45-days one. I'm ovulating typically between cycle day 23 and cycle day 33. My luteal phase lasts around 13 to 14 days every cycle. I have intercourse when the ovulation predictor kit is positive…I have read somewhere that it could be menopause, but I am only 23 now. Any ideas?"*

Regardless of time, not achieving the goal can increase anxiety (after months for some, years for others). Further, the anxiety becomes a central part of the experience of tracking. Individuals describe planning their schedules around tracking and getting upset when things do not go as expected – thus increasing stress. This cycle is apparent in the following excerpt, in which the user described being anxious because they have not been able to keep to a precise tracking schedule: *"I measure my temperature at 5:30 in the morning. The past 2 days*

I have been totally exhausted, and I overslept. Yesterday, I did not measure my temperature until 6:30 and today I did it only at 6:50. Do you think I screwed up my temperature chart?"

Despite expressions of frustration, anxiety, and stress, individuals in the burdened engagement maintain a generally positive orientation to tracking, as illustrated by the advice provided by the next user: "*Try to just enjoy the journey. Avoid overthinking and stressing. Tracking is awesome but sometimes it makes you think and stress so much about tracking that you do not even notice you are adding stress to your body. Just enjoy!*" These individuals have hope and feel that tracking will eventually enable them to get pregnant, as the next quote exemplifies: *"I am trying not to stress now that I am already trying for 7 months. Everybody tells me it will not happen if I keep trying [so hard]. And I think: what the hell! So, I suppose we cannot control it for real, but we can try to increase our chances as much as possible."*

Obsessive Engagement: Consumed with Data

When individuals are in a state of obsessive engagement, they are consumed with self-tracking activities and data. Users in this state express frustration, anxiety, stress, and begin to feel hopeless, as exemplified in the case of the following quote.

> *"My doctor did not find anything wrong in my blood tests. I thought I did everything right: timing, OPKs, intercourse on the right days. Please can somebody tell me how can I get pregnant? Does clomid [medication to stimulate ovulation] truly work? If the doctor says my levels of progesterone are fine, should I try to make him make me a prescription anyway for extra precaution? I also tested my vitamins B and they are normal. What can I do next? Please someone help me, it is so heartbreaking to try month after month with no success."*

As this quote illustrates, the measures become the focus of attention in this state of engagement with data. Individuals track multiple things and select the ones they will deposit their hopes in case the others give discouraging results. They also start seeing any symptom as a possible measure to track. Since fertility is uncertain and there is no definitive measure to use, individuals are continually looking for other measures that can give them hope. This behavior is seen more often when individuals track to find out if they are pregnant, as exemplified in the next quote: *"I understand that most people do not have symptoms until the menstruation is due. I want a positive result so badly that I am searching for any little pain or irregularity to give me hope. You understand how it works! I will test tomorrow."*

Along with obsessing, over-tracking, and searching for new ways to track, are examples of users attempting to repurpose existing tests in the hopes of getting a hopeful answer. In the next excerpt, the user is using an OPK to test for pregnancy, assuming that it would show a positive result in this case too (an activity performed by other users in the OHC as well). This attempt is based on similarities between the hormones OPK and home pregnancy tests detect (LH and hCG) (Choi & Smitz, 2014). However, the OPK was created to identify an increase in the LH, not the presence of hCG. So, any result it can give is not confident concerning pregnancy, since it is more likely that it is identifying changes in the LH levels.

> *"I had this crazy thought: can I be pregnant? My menstruation lasted only 2 days last cycle. There is NO WAY I could be pregnant, so I believe I am officially crazy. I am tempted to get a cheap pregnancy test just to stop thinking about it. But that is so dumb! I used an OPK last night and the result was negative. It would be positive*

> *if I was pregnant, correct? I guess that when you want something SO BADLY, your mind will find a way to go to this crazy space. I am so tired of the waiting..."*

Finally, in obsessive engagement with tracking, we see individuals start to interpret symptoms in their bodies as signs that they might have conceived. There is a condition known as false pregnancy in which the individual feels pregnancy symptoms although they are not pregnant. In such a scenario, which can occur completely separated from tracking activities, tracking may be used to reinforce these feelings. For example, the user may focus on trusting the symptoms they are feeling as indicators of pregnancy, ignoring, for example, the pregnancy test results. In this sense, they may play with the uncertainty of fertility to find reasons that support their feelings and give them hope:

> *"I swear I have made myself feel pregnancy symptoms before. My menstruation was late for 4 days, my breasts were swollen, I was very tired. I was having negative results in pregnancy tests, but I convinced myself that I was pregnant. I read that you can do this type of thing with your mind and then your body follows the symptoms, but you are not pregnant. The mind is a really powerful crazy thing."*

Individuals in this state are consumed with their data in a manner that is emotionally draining. They express frustration, anxiety, and eventually even despair. However, they have not entirely given up hope. In fact, these individuals keep trying to find reasons to have hope – even if such hope is coming through a paradoxical relationship with the data. The following user makes sense of "bad" temperature charts through a lens of disheartened hope – if prior good charts did not lead to achievement of the goal perhaps bad charts will?

> *"Today is the 15th day after ovulation. My temperature chart looks really bad, it is the worst I ever had. But…I had a bunch of beautiful charts that turned into negative results. I cannot believe I handled this long without my beloved pee sticks. I am 99% sure it will be another negative result. But, there is that lone 1% provoking me."*

These individuals are consumed with data, finding new forms of data and of interpreting these data. They have not given up on the power of self-tracking to help them achieve their goal.

Trapped Engagement: Ensnared within Data

While the prior form of engagement is the most tracking-intense, trapped engagement is the most emotionally intense relationship with self-tracking and data. These individuals have generally tried to conceive for some time, explored different measures and activities, to no avail. Often, they express a mixture of guilt and despair – as if something is wrong with them. The next quote shows an example of this state of mind:

> *"I need any sincere advice, because I feel I am getting more depressed with time…I am formally tracking my temperature, using OPKs and everything else since the beginning of this year…I am sure I am ovulating, my cervix is high, I have a lot of mucus, and I have positive OPK results. I have sex every day, every month, during the fertile period, and 2 to 3 times a week in the remaining of the month. We are doing all things right. What is wrong with myself?…I feel I am losing my mind. I am crying all the time. People in my circles are getting pregnant with no problems, and I am here, every month, with one more disappointment. Please someone give me an advice, tell me any detail that can help me figure out what is wrong with myself."*

Individuals in a trapped relationship with self-tracking often express a desire to stop tracking, but they feel as they cannot. They are dependent on these activities. They are tracking everything they can and not conceiving. They feel emotionally overwhelmed and depressed. Yet, they persist in tracking: *"I want to stop trying so badly, but I just do not think I can forget about all this. I seriously do not believe I can refrain my brain from thinking 'today is the 10th day of my cycle, I should have sex, and so on'."*

This engagement is extremely emotionally loaded. These users regularly use a language of depression, and some describe avoiding contact with other people. The pressure to stop tracking appears to intensify the inability to get out of a relationship of ensnarement with their data. These negative feelings are illustrated in the following excerpt:

> *"We have been trying to conceive for the last 2 years without any luck. I have become depressed and obsessed with all that…We finally look for a specialist in IVF and did multiple types of test only to be diagnosed with unexplained infertility. That did not help me at all…Everybody say that as soon as I relax and stop thinking about it I will get pregnant. It is easy when you already achieved what you desire. Some days it is so hard to me to even leave the bed, because I am really sad about all this."*

Although these feelings are likely to exist without the presence of tracking, self-tracking may reinforce them. The health indicators in fertility are only proxies to achieve the goal, having "good" data does not guarantee conceiving. In this sense, seeing and interacting with the data may make the difficulty or inability to conceive more visible, increasing the sense of failure and despair, as well as reinforcing the feeling of not being "normal."

Abandoning Engagement: Rejection of Data

The final type of engagement is a stopping point: tracking has become so onerous and the emotional costs of a new frustration month after month so devastating that individuals declare that they will stop tracking and trying to conceive. This may be a temporary decision, as in the case of the following quote.

> *"I tested twice this morning, once with a test from the internet and once with the Clear Blue Easy digital. Both negative. Apparently, my temperatures are dropping again…I am very sure my period is coming. Everything looked so right and on time on my graph. Thank you all for the support, but I am stopping this for a while. I cannot handle the obsession and the stress anymore, so I am not trying for at least 3 or 4 months."*

However, for many individuals who have come to the point where they need to abandon their engagement with self-tracking, the break is indeterminate or permanent. These quotes are often phrased as coda; outlining an emotional journey and saying goodbye: *"After 3 medication cycles I feel sad to say that I was not able to conceive. I have been trying for 8 years but no luck. I BELIEVED clomid would be my 'magic solution' but after all the stress, constant worrying, tracking temperature, having intercourse on time, visits to doctors, blood tests, and medications I just decided I needed a break."*

Here we see individuals describing how they end their relationship with data and self-tracking. Through this break, they can explore other ways to achieve their goal. The next quote shows an example of this emancipation from such a negative relationship with data: *"I tried to conceive for 7 years and my last failed IUI was a month ago. After this one more* *heartbreak me and my partner decided to adopt. I am feeling a bit better now that I know I will be a mother through this other path. I will miss the experience of pregnancy, but I think I will fill this empty place when I have a child."*

In many of these cases, abandoning data tracking seems to be intertwined with abandoning trying to conceive (i.e., their goal). This highlights the complicated relationship between tracking activities, the goal, and the emotional experience in a context where the link between these issues is problematic (i.e., the goal may not be achieved, tracking may reinforce negative behaviors, and the experience is very emotionally-loaded).

The Components of Engagement: Actions and Emotions

These five distinct forms of engagement with self-tracking data and activities revealed different orientations to data and the concomitant emotional experience of tracking. Our analysis suggests that each type of engagement has two components: actions related to tracking and the emotional experience of tracking and reflecting, as outlined in Table 3.2.

Table 3.2. The different components of engagement with data

	Positive	**Burdened**	**Obsessive**	**Trapped**	**Abandoning**
Emotion	-Excited about tracking -Hope, plan, agency	-Some stress, anxiety -Frustration -Increased focus -Some impact in relationship -Still mostly positive	-Obsession -Full and selective trust in measures or blind hope	- Guilt: What is wrong with me? -Reclusion -Depression	-Cannot handle it anymore
Action	-Learning to track -Seeing data -Becoming competent in understanding data	-Increase tracking -Strict tracking schedules -Wants to try different measures -Wants to try different treatments	-Obsessed with data -Data manipulation -Measures take over other feelings	-Dependent on tracking and data	-Stop or take a break

These actions and emotions are intertwined and mutually dependent: they progress together and influence each other. Individuals tracking for fertility with the positive and burdened types of engagement can experience adverse effects, but their relationship with data is still mostly positive. They are learning to track, seeing the data for the first cycles or getting competence on reading them, trying different measures, and trying to understand how to navigate such a personalized condition. These activities are performed within and reinforced by positive emotions, such as hope and the feeling of agency. However, the three final forms of engagement (obsessive, trapped, and abandoning) present a more delicate or negative relationship with data.

The obsessive engagement is very tracking-intense, and the measures and tracking activities dominate the emotional response. Some individuals may obsessively track even more measures trying to increase their chances, getting so deep in the tracking activities that they become their primary focus. This is a relationship that may not be sustainable. The intensity of the components is then flipped in the trapped and abandoning types: the emotional component is more extreme and dominates the tracking activities. Within the trapped engagement, many individuals feel desolated for having repeated frustrations every month, but they keep tracking. In this scenario, pregnancy is seen as the only success possible, everything else is seen as a “failure.” Through the quotes, we can see that some individuals internalize the “failures,” believing that something is wrong with them or their bodies or that they did not do everything they could. Finally, the last type of engagement is as reaching a stopping point: this engagement is so negatively loaded that it becomes unsustainable to them and stopping, unlike often in the other types of engagement, becomes a more concrete option. While there are different types of abandonment (Epstein et al., 2016), our findings highlight abandonment that results from negative feelings.

These data suggest that stress and anxiety are generally present in all types of engagement. However, individuals experience these emotions with varying intensity and with more or less hope and excitement. Fertility struggles are inherently emotional and stressful, whether or not an individual chooses to engage in self-tracking. That said, these data suggest that tracking can add complexity and even intensify stress.

3.6. Discussion

Self-tracking is an important part of individuals' data work and encompasses the activities of data collection and analysis necessary to make use of data. Since this study focused on the individual challenges of data work and many of these challenges are connected to data collection and analysis, the next sections focus on three important aspects of self-tracking in the extreme case of fertility: (i) the challenges of tracking in a knowledge intensive context, (ii) the use of collaboration to create personalized solutions, and (iii) the interplay between tracking and emotions.

3.6.1. Self-Tracking in a Knowledge-Intensive Context

This study's results highlight that self-tracking for fertility is an extremely complex issue. Fertility self-tracking comprises specialized complex knowledge that lay-people do not commonly possess. To improve their chances of conception, individuals trying to conceive need to obtain information to understand the health indicators they need to track. Most people are unfamiliar with several indicators (e.g., basal body temperature and cervical mucus) before using fertility methods and treatments (Hampton et al., 2013). This lack of knowledge may be in part attributed to taboos historically related to female bodies, since these measures are concerned with intimate care (Almeida, Comber, & Balaam, 2016).

Another complication arises from the natural uncertainties of fertility. Ovulation is fundamental for conceiving, but many individuals who menstruate have biological difficulties in producing healthy eggs. Many factors can influence fertility, and some of them are unexplained. Health indicators in this context are also not exact; they might give contradictory or ambiguous results. Further, these challenges are increased by the subjective nature of measurements, such as cervical mucus, which makes them difficult to interpret.

These complex aspects make fertility self-tracking an exceptional case in comparison to other reasons for health self-tracking. But besides that, the self-tracking process is fundamentally different. Self-tracking for self-knowledge, behavior change (Li et al., 2010), and monitoring chronic conditions (Caldeira et al., 2016) may be more straightforward because interpreting data such as step counts tends to be simpler. Further, fertility tracking does not fit in any of these three goals of self-tracking. Instead, it is used repeatedly to estimate the best timing to pursue a concrete goal that can only be achieved fully or not, as opposed to gradual goals where past progress might provide motivation (e.g., weight loss). Additionally, studies on self-tracking often describe the burden in data collection (Almalki et al., 2016). For instance, Ancker et al. (2015) found that patients with multiple chronic conditions describe tracking as effortful and time-consuming. In the self-tracking literature, each health indicator usually has its own meaning, for example, number of steps measures the quantity of steps a person took in a specific period of time. In this context, collection requires most of the work and thus may generate most of the burden. In contrast, in fertility self-tracking individuals collect multiple health indicators but their isolated results do not give them the information they want. Instead, individuals integrate all these measures to estimate a single discrete outcome: the ovulation day. Therefore, the burden is also increased in the preparation and reflection stages, due to the complex nature of estimating fertility. In addition, in fertility self-tracking the PIM stages tend to overlap with individuals performing activities from different stages at the same time. For example, they might reflect on the data from previous cycles (reflection) while preparing for the next one (preparation). Or they may learn about a different indicator to be collected (preparation) while collecting the ones they previously chose (collection). As a result, models might need to acknowledge that stages can co-occur in order to support these simultaneous activities.

Previous studies in HCI approached other complex and personalized conditions. For example, O'Kane et al. (2016) discussed the idiosyncrasies of diabetes and migraines and how patients use different resources to deal with them, while Ayobi et al. (2017) studied multiple sclerosis, describing patients' experiences of lack of control when facing this unpredictable and degenerative disease. Fertility self-tracking shares many characteristics with the conditions described in these studies: it is complex and needs specialized knowledge (Ayobi et al., 2017; O'Kane et al., 2016); it is idiosyncratic and personalized like migraines and diabetes (O'Kane et al., 2016); and there is no primary indicator that can be controlled through self-care like multiple sclerosis (Ayobi et al., 2017). However, fertility self-tracking also has its own complexities. Unlike diabetes and migraines, the expected goals are not gradual, i.e., they do not grow towards an expected result. In fertility self-tracking, the results in one month may not influence the next cycle. Also, the interpretation of the health indicators tends to be more complex, especially because individuals need to integrate many different indicators. Self-tracking for fertility is similar to multiple sclerosis in its complexity, but because it restarts in each menstrual cycle the dynamics and time constraints are different and may add to its complexity.

These differences suggest that more research on the data work individuals perform when self-tracking for health is desired, especially to meet the needs of complex, knowledge-intensive, and highly personalized health conditions, such as fertility. Investigating complexity in self-tracking is important and calls for more emphasis to offer better support for patients facing such conditions and the data work they perform.

3.6.2. Creating Personalized Solutions Through Collaboration

Individuals encounter many knowledge challenges as they perform the knowledge-intensive self-tracking part of fertility data work. This data work has a steep learning curve, involving complex, interrelated processes such as (i) researching (e.g., searching for educational information online), (ii) gathering data (e.g., key health indicators such as basal body temperature), (iii) learning (e.g., medical terminology and concepts), (iv) tracking (e.g., changes in health indicators over time), (v) reflecting (e.g., after making a change or trying something new), and (vi) making decisions (e.g., selecting a treatment option). These challenges demand a complex process of sensemaking.

Fertility tracking is highly individual. Similar to the idiosyncrasies of migraines and diabetes (O'Kane et al., 2016), an approach that works for one person may not work for another. However, the idiosyncratic (or personalized) characteristic of fertility self-tracking can be more complex, since symptoms and indicators for the same person can vary greatly in different cycles. Individuals then need to "solve a puzzle" constantly to create their personalized solution. This study indicates that individuals attempt to overcome the complexity of their condition by engaging in collaborative sensemaking to reflect and reach conclusions based on their tracked data and on the experiences of others.

Sensemaking refers to how people perform self-management activities by trying to organize experiences, identify patterns and connections, and make choices based on these insights. As previously described, these self-management activities can be performed in two modes: (i) sensemaking, when individuals need to engage with the situation analytically, examining its properties and creating explanations, and (ii) habitual, when experiences do not cause barriers to understanding (Mamykina, Smaldone, et al., 2015). For individuals with fertility problems, especially those dealing with them for a long time, the complexity and individuality of the process require them to spend most of the time working on sensemaking. They need to examine the situation constantly, compare it to their current knowledge and to the knowledge obtained from others, and create a mental model that can guide future action.

In this scenario, collaboration is useful to create personalized solutions. Although self-tracking may seem to be an individual activity, it is often a social one (Rooksby et al., 2014). Individuals using the OHC while trying to conceive collaborate with each other throughout the whole fertility self-tracking process to make sense of their data. Since clinical appointments are often months apart, users often turn to the OHC to try to resolve time-sensitive concerns. They also rely on the community to prepare for their medical visits, and to seek a second opinion or more information about what was discussed with their healthcare providers. These findings are aligned with the role of online communities in augmenting traditional healthcare (Huh, 2015). Through the OHC, individuals trying to conceive collect different pieces of information, and try to apply them to their own situations to make sense of their problems and to plan the next steps. During the whole fertility cycle, they try to overcome the complexity and lack of precise information through building personalized self-knowledge based on collective experiences.

Paul and Reddy (2010) describe the importance of collaborative sensemaking to build the shared understanding needed to achieve a collective goal. In fertility self-tracking, and in many personal health scenarios, people engage in collaborative sensemaking as well, but the goal is usually individual—to manage one's own health. Huh and Ackerman (2012) discuss how collaborative sensemaking can inform and support chronic disease management. They argue that one of the main challenges involved in this process is to (re)contextualize information shared by others in order to apply it to one's specific situation. This challenge becomes more complicated when patients achieve a higher knowledge level and face unexpected problems specific to their case (Huh & Ackerman, 2012). Within the fertility context, often there is no regular situation or explanation, and individuals have to base their actions largely on (re)contextualization from other people's experiences.

This extensive collaboration is another difference from the traditional description of self-tracking as an individual activity (e.g., (Choe et al., 2014; Li et al., 2010)). Many studies approach personal informatics as only one person collecting and reflecting on their own data. Self-tracking for fertility is different in two aspects: (i) the stage, and (ii) the triggers for sharing. Concerning the stage, most models, such as the PIM, usually place social aspects only in the action stage, when people receive feedback or encouragement (e.g., from healthcare providers, family, or in social networks) (Li et al., 2010). Health indicators that are relatively simple to interpret may fit better within this model. In the fertility context, individuals in the OHC collaborate through all the stages in order to make sense of their data and create their own personalized solution.

More recent studies have explored collaboration in other stages of self-tracking (e.g., (Chung et al., 2016; Pina et al., 2017)). However, fertility self-tracking also holds differences concerning the triggers for collaboration. For instance, Rooksby et al. (2014) have stated that tracking is often social and collaborative—people usually track among friends, families, and coworkers, by preparing, collecting, analyzing, and sharing and comparing results together. In this study, I found a similar behavior, but with a different trigger: the unique challenges related to the complex context forced individuals to turn self-tracking into a collaborative activity of sensemaking. This is an important aspect that needs to be taken into account when developing tools to support fertility self-tracking and, more broadly, when approaching self-tracking for complex and highly personalized conditions. It also points to the need to consider social aspects when analyzing individuals' data work, once even their individual and personalized challenges of data collection and analysis involve or lead to collaboration with different stakeholders (e.g., healthcare providers and peers).

3.6.3. The Interplay Between Tracking and Emotions

As identified in this study, another aspect very influential in individuals' data work is their emotional engagement with data, which is characterized by the interplay between individuals' fertility tracking activities and emotional experiences. This interplay is reciprocal, as the emotional response and the tracking activity influence one another. Literature has found that self-tracking contributes to a feeling of agency, especially for people facing complex conditions (Ayobi et al., 2017; Neff & Nafus, 2016). This study identified similar results in fertility, especially in the context of the two first kinds of engagement (positive and burdened). However, fertility is complex and uncertain, one cannot control its health indicators, and it is not possible to guarantee the desired outcome.

These characteristics impact and limit this sense of agency. When individuals experience uncertainty and a lack of agency, tracking can enhance or reinforce strenuous and unhealthy relationships with data, and individuals can experience emotional distress.

The negative emotions described here (e.g., stress, anxiety, obsession, depression) are likely not caused by tracking. These negative emotions and behaviors likely commonly appear when people cannot reach emotionally-loaded goals, regardless of whether using self-tracking or not. However, in the scenario of this study, self-tracking is potentially contributing to the aggravation of such feelings. The characteristics of self-tracking data for fertility can contribute to this aggravation. First, fertility indicators are not direct measurements of ovulation. For example, OPKs detect an increase in the LH hormone that happens *before* ovulation while temperature slightly increases *after* ovulation. Second, it is not possible to directly control such measures (i.e., there is not much one can do to control ovulation, particularly without medication). Third, such measures are not exact. The data can give contradictory or ambiguous results, particularly given the subjective nature of some measures (e.g., symptoms and characteristics of cervical mucus). Further, aligned with Ancker et al. (2015) discussion regarding the moral load of glucose results, this study shows that data are not neutral and can have strong moral and emotional implications in sensitive contexts. Based on their data, individuals asked if they were “normal” or “what was wrong” with them because “good” data did not lead to the expected results.

Katz et al. (2018) described how seeing data that suggest a “failure” can generate stress. Similarly, this study found that tracking without achieving a positive result contributed to anxiety and stress. These findings suggest that the nature of the goal, in this case pregnancy, is related to intense forms of engagement with self-tracking and the emotional reactions to not reaching the goal. Li et al. (2011) suggested that personal informatics should be used to set and achieve program-level goals: specific and concrete activities that can be performed through a sequence of actions. However, for many individuals, conception may not be achievable through tracking or at all. As individuals get frustrated with their tracking activities not leading to the goal, they are pushed into more intense and negative relationships with tracking and fertility. This study's data suggest a feedback loop between one's perceived ability to achieve a goal (or to move towards it) and the subjective experience of self-reflection around data.

These findings suggest that this interplay between emotions and tracking is an important piece, influencing individuals' experiences and actions. In this context, in addition to sensemaking, the OHC allowed individuals to express emotional struggles and garner emotional support, which is essential for them given the emotional burden involved. However, this support is often missing in self-tracking tools. Without the context of their emotional experience, tracked data is not enough to observe their pattern of engagement with data, including how their emotions affect their tracking and vice-versa. Thus, this research emphasizes a need to support social and emotional aspects that are inherent to many health contexts (especially emotionally laden ones like fertility) in which people self-track and are an influential part of individuals' data work.

CHAPTER 4. Technology Support for Fertility Data Work

As the data work literature describes, technology directly influence data work. Considering this relationship, and building on the challenges of data collection and analysis identified in Study 1, Study 2 analyzed the support offered by current available commercial fertility tracking apps, addressing the following research question: how does fertility tracking technology support users' goals and data needs and influence the ways individuals use personal data? This chapter describes Study 2, beginning with the motivation for this work and a summary of the related literature it builds on. I proceed to detail the methods, including how each app was selected and the 4 different data collection sources (i.e., app store pages, features, user reviews, and app predictions), the results of all these analyzes, and the discussion. Findings describe the support offered by the apps and discuss how people's practices are broader than what apps support, how this difference can impose restrictions on individuals' data work, and how these conflicts influence individuals' experiences. Findings presented in this chapter were previously published in (Costa Figueiredo et al., 2020; Costa Figueiredo, Huynh, et al., 2021).

4.1. Motivation

Building on the results of the first study and considering that technology largely influences and shapes individuals data work (Bossen, Pine, et al., 2019), Study 2 focused on obtaining an extensive view of the support offered by commercial fertility self-tracking technologies, investigating how design influences individuals' data work. Mobile health applications focused on fertility tracking (fertility apps for short) are a very popular means of collecting, analyzing, and using personal fertility-related data (Eschler et al., 2019). Their design may influence people's data work by suggesting what, how, and how often to track, and emphasizing certain data through their feedback. They also influence fertility data work through the activities they do not support, reflecting societal views and helping to shape what is fertility and its needs.

When the first Apple Health was launched, in 2014, it came with the promise of allowing users to manage *"all of your metrics that you're most interested in"* (Duhaime-Ross, 2014). However, it did not include menstrual tracking, an important "metric" for approximately half of the population, which was added months later after backlash for the oversight (Perez, 2015). Despite being initially ignored by the mobile apps industry (Duhaime-Ross, 2014; Eveleth, 2014), recently female fertility has drawn increasing attention in the consumer health technologies market. The term *"Femtech"* has been used to denote *"software, diagnostics, products, and services that use technology to improve women's (sic) health"* (Frost & Sullivan, 2018). Mobile apps are a large portion of this market: as of 2018, there were around 28,000 apps for *"female healthcare and pregnancy"* in the Google Play and Apple App stores (Dabbs, 2018). The interest is so large that this industry has been estimated to reach a market value of $50 billion by 2025 (Frost & Sullivan, 2018). Therefore, it is a powerful industry with important economic interests beyond users' needs, and it is capable of shaping fertility data work through its tools, the activities they support, the needs they may ignore, and the interests they advance.

More recently, with the popularity of data driven algorithms and the increased availability of sensors that can automatically collect bodily data, fertility tracking apps are progressively including predictive models that use wearable and manually tracked data to generate fertility predictions, particularly for periods, ovulation, and fertile window (S. E. Fox et al., 2020). Currently, many fertility apps are claimed to use 'artificial intelligence,' 'smart algorithms,' or 'machine learning.' Millions of people currently use such apps (e.g., 2016 estimates point to around 200 million downloads (Dreaper, 2016)) and trust their predictions for varied fertility-related goals, including to achieve or avoid pregnancy—goals that can be very emotionally-loaded (Costa Figueiredo et al., 2018) and potentially life-changing. Besides, many of these individuals have only low to intermediate knowledge about fertility (Ayoola et al., 2016; Bunting et al., 2013; Hampton et al., 2013; Lundsberg et al., 2014), and are not data nor health experts. These claims of accuracy may directly influence individuals' data work experiences, potentially impacting their expectations, influencing them to track data, and playing a role in how much they trust such tools. Furthermore, media reports have also increasingly point to negative practices or aspects related to such apps. From privacy issues, such as the app sharing data with insurance companies or employers (Harwell, 2019), to reports of unintended pregnancies (Sudjic, 2018) and questions concerning the interests being reproduced or hidden in such apps (e.g., the case of an anti-abortion group secretly funding a fertility app (Glenza, 2019)), to even claim that such technologies are ultimately not built *"for women (sic)"* (Tiffany, 2018). These aspects suggests that these tools may influence individuals' experiences practically (i.e., the activities they perform) and emotionally, but it is still unclear how these influences take place, how features can be mapped to challenges, and how technology interests may shape individuals' experiences, particularly when facing fertility challenges.

These aspects make commercial fertility tracking apps a critical perspective to be included in the study of individuals' fertility data work. Therefore, in this study, I conducted an extensive analysis of 31 popular fertility apps, collecting and analyzing data from the content of apps' app store pages, their features, and user reviews, and simulating four months of data entry to analyze apps' predictions and visualizations. The results of this study draw attention to how fertility tracking apps, through their data collection and feedback features, can shape potentially narrow views of fertility data work, how the claims of objectivity play in practice, and how individuals interact with such aspects.

4.2. Related Work: Studies of Fertility Apps

Mobile apps are currently the most popular self-tracking technologies for fertility, allowing users to collect data potentially related to fertility, such as period dates and other physical and emotional data, and providing feedback through visualizations, including predicting future periods, ovulation, and fertility windows. Studies analyzing fertility apps have focused on (i) analyzing their accuracy, (ii) using their databases to do other analysis, and (iii) analyzing individuals' experiences using these technologies. The next subsections describe these three strains of related work.

4.2.1. Analyzing Apps' Accuracy

Studies analyzing fertility apps in medical-related areas have primarily focused on the accuracy of predictions. Many of these studies focus on developing scoring systems to evaluate available apps. For example, Moglia et al. (2016) considered an app accurate if period predictions were based on the average of at least three past cycles, ovulation predictions when provided were in between the 13th and 15th cycle day, and the application did not contain misinformation (Moglia et al., 2016). They used these criteria to select the apps (n=20) and evaluate them with a scoring system based on the presence or absence of common features (e.g., password protection, internet connectivity, social media, possibility of tracking menstrual flow, symptoms, and intercourse, presence of alerts). On another study, Duane et al. (2016) defined *"evidence-based apps"* the ones that *"use evidence-based fertility awareness-based methods"* (Duane et al., 2016). Focusing on contraception, the authors developed a rating tool to evaluate apps predictions (n=40) in comparison with predictions generated using fertility awareness methods for seven cycles of standardized data. Freis et al. (2018) criticized these two studies stating that averages do not account for physiological variation and that only few fertility awareness methods are considered highly effective. Instead, Freis et al. (2018) developed a scoring system considering cervical mucus as the most meaningful measure, analyzing if there were any published studies about the app or underlying method, and if the app offered any counseling service. Focused on conception, they evaluated the predictions for fertile window of 12 apps using this system, indicating that the results point apps that are good candidates for trials to evaluate their efficacy (Freis et al., 2018). Finally, Johnson et al. (2018) analyzed apps predictions for ovulation by comparing apps' results (n=73) with the probabilities of ovulation based on data from volunteers trying to conceive who provided urine samples (used to detect the LH surge) for an entire menstrual cycle. They found that the maximal probability of apps' predictions for ovulation day being correct was 21% (S. Johnson et al., 2018).

All these studies found that most apps do not publish or describe their methods to calculate ovulation and fertile window, do not cite scientific literature and even provide *"erroneous medical information"* (Moglia et al., 2016), and have varying accuracy (Duane et al., 2016; Freis et al., 2018; S. Johnson et al., 2018; Moglia et al., 2016; Zwingerman et al., 2019). In addition, Zwingerman et al. (2019), who analyzed 140 iPhone fertility apps for the presence or absence of several features (e.g., privacy policy, data export, cycle tracker, temperature tracker, intercourse tracker, appointment tracker, medication tracker, ovulation predictor, fertile window predictor, etc.), highlight that few of them address the needs of individuals facing challenges to conceive.

This study builds on this previous literature by focusing not on apps' accuracy, but users' perceptions of accuracy, investigating what data generate visible changes in apps visualizations and feedback, trying to audit what data was used by the algorithms from the user perspective, and analyzing user reviews that discuss experiences of accuracy.

4.2.2. Using Fertility Apps' Data

Another line of research focuses on using the massive amounts of data accumulated by fertility apps to analyze possible correlations of different health aspects with the menstrual cycle. With the popularity of fertility apps and their ever-increasing amounts of data, apps are partnering with researchers, providing them data for different analyses. For instance, Sohda et al. (2017) used data from a menstrual app (Luna Luna) to investigate the relationships between the lengths of the menstrual cycle, follicular phase, and luteal phase and explore the possibility of predicting future cycles based on app users' data. Their analysis used only the first day of menstruation to predict the next fertile window, finding better results than some calendar-based methods. The authors suggest that these correlations *"would be the best option for couples during the early stages of their attempt to have a baby or for those who want to avoid the cost associated with other methods"* (Sohda et al., 2017).

Similarly, Liu et al. (2019) used large-scale data from another fertility app (Clue) to analyze the feasibility of predicting pregnancy from self-tracking data. In contrast with Sohda et al. (2017)'s study, Liu et al. (2019) used 112 different health indicators as input for their model, including period bleeding, mood, birth control, basal body temperature, resting heart rate, and body weight. Although multiple indicators were analyzed, the study unsurprisingly found that the indicator most strongly associated with positive pregnancy tests was unprotected sex and, conversely, the one most strongly associated with negative pregnancy tests was protected sex. Similar to previous studies (Pierson et al., 2018), the authors highlight the challenges missing data and tracking variability (i.e., what each user chooses to track) present for building these models (B. Liu et al., 2019).

With a different focus, Alvergne et al. (2018) analyzed longitudinal cycle data from users of a fertility app (Clue) to investigate if sexually transmitted infections (STIs) were correlated with premenstrual syndrome (PMS) symptoms. They analyzed users' menstrual bleeding patterns (i.e., cycle length, period length), pain, emotions, and hormonal contraceptive use from users who answered yes to an in-app short survey asking if they previously had STIs. The study found that some possible PMS symptoms (e.g., cramps, headaches, sensitive emotions, and sadness) were aggravated by the presence of an undiagnosed STI within users not on hormonal contraceptives. However, the authors caution these results because, besides the data being self-reported, there was also no information about inflammatory levels and the fertility app is biased towards negative symptoms associated with western cultural views of PMS as pathological (Alvergne et al., 2018). In fact, they discuss that headaches and emotions may be associated with worries and negative experiences related to the STI symptoms pre-diagnosis.

In another example, the Citizen Endo project (Elhadad et al., 2016) uses an observational smartphone app that allows individuals with endometriosis to track symptoms, treatments, and self-management practices, and creates a citizen science community to support research through individuals' personal data. When using the app, individuals can consent to have their data used for endometriosis research. Through different studies, the researchers developed the Phendo Research App and used it to combine self-tracked data with gold standard measures and EHR data to profile and gain a deeper understanding of the disease (Ensari et al., 2020; Ensari & Elhadad, 2021; McKillop et al., 2016, 2018; Urteaga et al., 2020). Among the results, the project identified four distinct types of phenotypes of endometriosis symptoms according to their severity based on self-tracked data. These results were aligned with previous endometriosis literature but also suggested novel correlations, such as the association of some symptoms (e.g., menstrual irregularity, painful sex) with specific groups of patients indicating a subtype of the disease (Urteaga et al., 2020).

These studies focus on leveraging the massive amount of self-tracked data stored by fertility-related apps to apply machine learning algorithms and discover potential associations between symptoms and improve disease understanding. In contrast, instead of focusing on secondary uses of available data, the study described in this chapter analyzes how patients themselves want to use these data, what uses and correlations commercially available fertility apps allow them to pursue and investigate, where these tools fall short, and where they offer adequate support.

4.2.3. Analyzing Users’ Experiences and App Support

In a more user-oriented approach, recent studies have evaluated how apps may impact people’s lives by investigating how individuals use these tools and aspects of apps’ support that influence this use. In this context, different studies have examined why individuals track their menstrual cycles, finding a varied of goals, including to be aware, to understand their cycle’ stages and verify menstrual experiences, to be prepared, to inform interactions with healthcare providers and treatments, to conceive, and to avoid conception (Epstein et al., 2017; Gambier-Ross et al., 2018; Levy & Romo-Avilés, 2019).

Studies focused on users’ experiences also call attention to users’ concerns regarding accuracy and transparency (Epstein et al., 2017; Eschler et al., 2019; Gambier-Ross et al., 2018). For instance, Gambier-Ross et al. (2018) report that individuals would like to know how their apps generate the predictions to see if they are personalized to their cycles or generic. On a different but related approach, Schneider et al. (2019) investigated how to communicate uncertainty in fertility predictions. They discuss how challenging it can be to display uncertainty in fertility prognosis for non-expert users and how design decisions can influence individuals’ emotional experiences (Schneider et al., 2019).

Fertility education is another topic approached by these studies. Gambier-Ross et al. (2018) and Levy and Romo-Avilés (2019) highlight that individuals believe fertility apps helped them in getting more educated about their bodies. However, Eschler et al. (2019) analyzed 17 menstrual tracking apps focusing on menstrual literacy, reporting on the insufficient support they offer, particularly for the teenage and perimenopausal life stages, and the lack of evidence-based information present in these tools. Similarly, Starling et al.

(2018) discuss that future interventions focused on educating individuals specifically about fertility apps are necessary, particularly with the growing interest in using these tools for contraception.

Different studies also highlighted how apps can reproduce societal problems, such as normative stereotypes that exclude gender and sexual minorities, and fail to support different life stages of people who menstruate (Epstein et al., 2017; Eschler et al., 2019; Gambier-Ross et al., 2018). Similarly, Lupton (2015) describes sexual and reproductive self-tracking apps (which include what this dissertation calls fertility apps) portray women (sic) as *"reproductive subjects,"* reinforcing societal gender stereotypes and emphasizing medicalization. Aligned with Lupton (2015), Levy and Romo-Avilés (2019) and Schneider et al. (2019) also cautioned for the risk of apps to reinforce overmedicalized views of individuals' bodies, associating common irregularities with pathologies. With this increased scrutiny over the bodies of individuals who menstruate, privacy is another aspect commonly mentioned, although not directly approached in most studies (Gambier-Ross et al., 2018; Levy & Romo-Avilés, 2019). In contrast, Fox et al. (2019) directly analyzed fertility apps' terms of use, privacy policies, and data practices, raising privacy concerns about how companies may use personal data, and how collection practices *"may subject the menstruating body to undue surveillance"* (S. E. Fox et al., 2019).

The study described in this chapter is inspired by and builds on this literature to analyze the features offered by these apps and the possible uses (or data work) they support and limit, focusing on aspects related to data collection, feedback through visualizations, algorithmic feedback through predictions, and support for changing goals.

4.3. Methods

In this study, I analyzed 31 currently available (in 2019) and popular commercial fertility apps. The following subsections describe the process of app selection, data collection, and data analysis.

4.3.1. App Selection

To select the apps, I first used "fertility" as a keyword to identify apps from the Apple App Store and Google Play Store, currently the two most popular app stores. Although fertility overlaps with menstruation, literature suggests fertility is a broader term that covers different aspects of individuals' reproductive cycles and health (Gambier-Ross et al., 2018; Speroff & Fritz, 2005). For this reason, this study considers menstrual tracking a subset of fertility tracking, and "fertility" was the keyword used to search for relevant apps in the two app stores. This search returned 524 apps in February 2019, as illustrated in Figure 4.1.

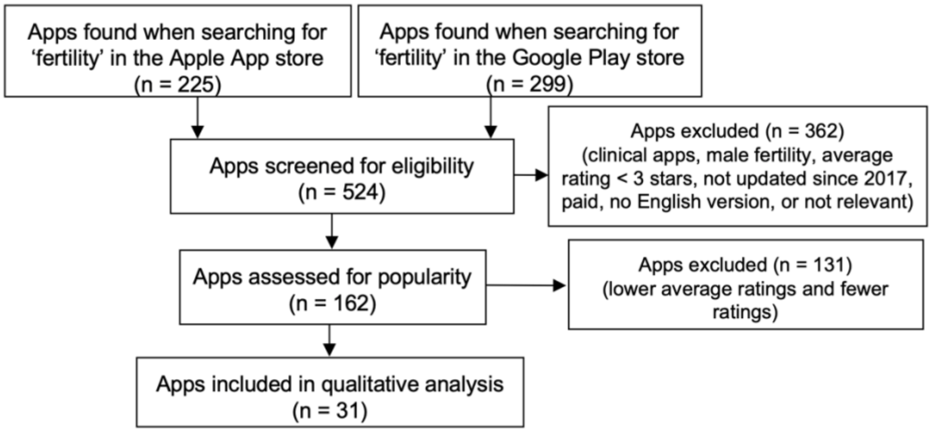


Figure 4.1. App selection process

To identify current, accessible, and widely used apps among this initial list, I draw on previous app studies (Caldeira et al., 2018) and applied the following eligibility criteria: the app needed to (i) focus on female fertility, (ii) have an average rating >= 3 stars, (iii) have had at least one update since 2017, (iv) be free, and (v) have an English version. Since the focus was on consumer-driven apps used in everyday life, apps for clinical use were excluded (e.g., apps to support IVF treatments). After applying these initial metrics, I used star rating averages and number of ratings to assess app popularity and generate a ranked list for each app store. The 15 best and most rated apps were selected from this list (Table 4.1). Poorly rated and paid apps (excluded based on the eligibility criteria) were double checked, but all had fewer reviews in comparison with the final list. For example, among the 94 Apple apps with less than 3 stars, 86 had 0 stars and 0 ratings. This suggests that the eligibility criteria were appropriate and did not exclude significant apps for the goal of this study.

Table 4.1. Analyzed apps by platform, as of February 2019 – name (average stars, number of ratings)

Apple App Store	**Google Play Store**
Flo (4.8, 365K)	Period Calendar (4.8, 4M)
Glow (4.7, 29K)	Flo (4.9, 795K)
Life (4.8, 27K)	Clue (4.8, 627K)
Clue (4.8, 24K)	Period Tracker (GP) (4.5, 334K)
Ovia (4.8, 12K)	My Calendar (4.7, 185K)
Cycles (4.5, 7K)	Maya (4.7, 173K)
Period Tracker Health Calendar (4.5, 4K)	Pepapp (4.7, 155K)
Kindara (4.6, 3K)	Petal (4.8, 140K)
Natural Cycles (4.8, 3K)	Lilly (4.5, 140K)
My Calendar (4.8, 2K)	WomanLog (4.5, 123K)
Ferdy (4.5, 2K)	Period Tracker (Amila) (4.9, 119K)
Dot (4.7, 1.7K)	Woman Diary (4.6, 94K)
Femometer (4.8, 1.6K)	My Days (4.5, 93K)
My Cycles (4.6, 1.4K)	Period Tracker (Leap Fitness) (4.9, 83K)
Premom (4.7, 1.3K)	Ladytimer (4.5, 72K)
Monthly Cycles (4.6, 1.2K)	

Three apps appeared in the list of 15 best and most rated in both app stores. These apps were analyzed individually because features may vary by platform. Though Natural Cycles appeared among the 15 most popular Apple apps, its free version offered very limited features. To make a fair comparison, I have replaced it with another app (Monthly Cycles, the 16th app in the final list of Apple apps) from Apple. Natural Cycles' free version was still analyzed to the extent it was possible because it has received increased attention due to its recent FDA approval for birth control (Altman, 2018; FDA, 2019). With these inclusion criteria, I analyzed in total 16 apps from Apple and 15 from Google app stores (Table 4.1).

Finally, after getting the final list, to guarantee "fertility" was an appropriate keyword, I searched both app stores using other search terms such as period or menstrual tracking and applied the same inclusion and exclusion criteria to compare the results, finding a considerable overlap in retrieval: there were only two differences in the original 31 apps retrieved, suggesting "fertility" was an appropriated term for the goals of this study.

4.3.2. Data Collection

This study included data from four different sources: (i) **content of app store pages** to understand how apps are promoted, (ii) **app features** to identify the types of data work they suggest, support, and limit, and the types of feedback they offer, (iii) the results of four months of **simulated data entry** to investigate how apps produce predictions for ovulation and fertile window (algorithmic feedback), and (iv) **users' reviews** to explore users' perceptions and challenges.

First, the content of each app's app store page was copied to a file for analysis. For the feature analysis, all 31 apps were downloaded by two researchers who entered test data for all features and available health indicators, including common variations (e.g., regular and irregular cycle length), and observed app output.

For the prediction analysis, two researchers entered four months of fertility data (a time frame used in previous fertility studies (J. Lee & Kim, 2019; Moglia et al., 2016)) simulating a regular cycle to investigate algorithmic feedback by observing apps' predictions for ovulation and fertile window. We first entered period dates and annotated the dates predicted for ovulation and fertile window. Then we annotated the changes in predictions generated by data entry for a set of variations and indicators commonly used in fertility tracking for conception (i.e., temperature, ovulation or OPK results, and cervical mucus) (Costa Figueiredo et al., 2017). Table 4.2 summarizes this data collection process.

Table 4.2. Simulated data used to test algorithmic feedback

Initial Values	**Variations**			
	Period Dates	**Temperature**	**Ovulation or OPK**	**Cervical Mucus**
Cycle length: 28 days Period length: 6 days 1st period: 12/07 – 12/12 2nd period: 01/04 – 01/09 3rd period: 02/01 – 02/06 4th period: 03/01 – 03/06	Changed period dates of 4th and 3rd cycles individually annotating any change in predictions	Added temperature data for the 4th cycle (~97.5F until 3 days before ovulation, followed by ~98.2F) annotating if temperature data changed initial predictions	Added ovulation data (positive ovulation 3 days before predicted) annotating if ovulation data changed initial predictions	Added cervical mucus data (3 days of egg-white CM 2 days before predicted ovulation) annotating if cervical mucus data changed initial predictions
	Changed period dates for all 4 cycles cumulatively, annotating any change in predictions	Added temperature data for all 4 cycles cumulatively, annotating any change in predictions	Added ovulation data for all 4 cycles cumulatively, annotating any change in predictions	Added cervical mucus data for all 4 cycles cumulatively, annotating any change in predictions

For user reviews, a complete user review history was downloaded for each app at the Google store, but Apple's store policy only allowed accessing the 500 most recent reviews. In total, 70,685 reviews were collected (6,313 from Apple and 64,372 from Google) between April and July 2019. I considered ethical and privacy issues in using user reviews for research. Since user reviews are intended to be seen by anyone who accesses app stores, it is reasonable to assume that reviewers expect their reviews to be public. Nevertheless, I took extra measures to assure reviewer anonymity by removing reviewer and app names when using review quotes and rephrasing or paraphrasing quotes used in publications to ensure de-identification. Final quotes were searched for online to ensure the original reviews are not easily identifiable and edited to ensure they were not a top search engine hit.

4.3.3. Data Analysis

I first scanned app store page content, app features, and review data to understand what fertility apps claim to support, how they are designed, and users' attitudes and perceptions. Although my focus was on experiences of individuals facing challenges to conceive, this initial exploration revealed challenges that spanned users' needs beyond conception, and that often are entangled with it. For this reason, this study broadened the focus encompassing an analysis of app support for different goals, including conception. In summary, this initial exploration highlighted issues related to (i) app features offered and requested by users, (ii) apps' feedback, (iii) users' perceptions of predictions, and (iv) users' goals and life stages, which then guided the analysis of the four datasets.

All text on app store pages was open coded focusing on how apps promotion materials approach these issues (Saldaña, 2015). Example of codes included: list of indicators, contraception, conception, period tracking, pregnancy, support for pattern visualization, interfaces. The main themes identified on app store pages were fertility goals, available health indicators, types of feedback, and claims of control.

A codebook was derived from the initial exploration to analyze user reviews focusing on goals, app interaction, perceptions of predictions, and fertility experiences described in prior literature (Andalibi & Forte, 2018; D'Ignazio et al., 2016; Epstein et al., 2017; Eschler et al., 2019; Lazar et al., 2019; McKillop et al., 2018; Tuli et al., 2019). Specifically, codes for goals included conceiving, avoiding conception, period tracking, pregnancy, changing goals, and goal mismatches. App interaction codes encompassed tracked indicators, offered feedback, reactions to indicators, reactions to feedback, reactions to predictions. Other fertility experiences codes included adolescence, menopause, miscarriage, breastfeeding, and endometriosis.

Since most app reviews focused only on general app experience (e.g., *"Easy for use. I love it"*), I specifically searched for reviews covering 12 fertility-related terms (e.g., "fertility," "conception", "TTC," "miscarriage", "menopause," "endometriosis," "pcos," "breastfeeding," "pregnancy," and variants of these terms), that identified 3,433 relevant reviews (1,075 from Apple and 2,358 from Google). These reviews were iteratively coded by two researchers using the codebook. First, we coded the same 500 reviews and compared results, resolving disagreements through discussion. Then we split the remainder reviews and coded them separately, meeting frequently to discuss the analysis. A point of data saturation (Strauss & Corbin, 1998) was reached around 2,000 reviews, but all 3,433 reviews were coded.

For the feature analysis, two researchers annotated the offered features, including what and how data are entered in the app, what visualizations are available, what data are shown in the visualizations, what (if any) are the options for setting and changing goals. These data were then consolidated in a spreadsheet and used to provide quantitative summaries of data collection and visualization features of the apps. Similarly, the data annotated for the simulation test were consolidated in a spreadsheet and analyzed using descriptive statistics. These data were then triangulated with the analysis of app store pages and user reviews to identify possible mismatches between apps' supported data collection and feedback, and needs and challenges reported by users.

4.3.4. Limitations

Leveraging user reviews to investigate people's needs and challenges has inherent limitations: first, it provides only snippets from people's experiences. Second, reviews are biased toward people who want to share their experiences through this channel, being less representative, and usually includes extreme experiences, either positive or negative. This method was used to assess user experiences at a scale and provide enough description of how the app landscape supports them. It was a practical way to capture these experiences in ways other methods may not. Future lab or field studies of peoples' experiences with these apps can provide deeper understanding of people's lived experiences with app use under the specific circumstances they are experiencing. Finally, although the keyword "fertility" is suitable to this study, other keywords produced similar results. However, I did not analyze the two extra apps listed by the new searches. I was also interested in general fertility apps, so I did not search for apps focusing on specific issues such as menopause or endometriosis.

4.4. Results

4.4.1. App Store Pages: Fertility Apps Aim to be Comprehensive

App store pages offer insights of industry's perspective and beliefs about user needs and the benefits that apps can provide. This study's results show that fertility apps aim to be comprehensive, which their app store pages reflect by focusing on four main aspects: (i) support for different fertility goals, (ii) available health indicators to track, (iii) types of feedback offered, and (iv) app-enabled *"control over the body."*

Most app store pages (26 out of 31) claim their apps support multiple fertility goals, with descriptions such as *“whether you are concerned about conceiving, birth control and contraception, or regularity of period cycles”* [A3] or “[the app] *predicts menstrual cycles, helping women to get pregnant or avoid pregnancy”* [A21]. The most common goals described in these pages are period tracking (PT–29 apps), trying to conceive (TTC–21), trying to avoid conception (TTA–9), and pregnancy tracking (PgT–7). According to apps’ pages, these different goals can be supported through tracking multiple health indicators.

All app pages but two emphasize they support tracking several different health indicators (e.g., *“Our tracker is easy to use and offers everything you need”* [A3], *“Track over 30 health categories and start to see the patterns in your health”* [A22]), often highlighting *“Comprehensive Health Tracking”* [A1]. Only two apps in this study’s list emphasized a limited list of indicators, describing there is *“no need for extensive charting”* [A14] and users only need to track period dates. In both cases, being able to collect personal health data is the main focus in the promotion materials for all the apps.

Besides tracking, apps provide feedback to users, including predictions for next periods, ovulation, and the fertile window. Besides common reminders, this feedback is often provided through visualizations of tracked data. App store pages frequently say it will be easier for people *to “see fertile days and variations in your cycle”* [A5] and visualize *“vital information at a glance”* [A17] through apps’ visualizations, particularly the calendar.

Finally, app store pages often underscore that any person (e.g., *“even for those with irregular cycles”* [A7]) can use their tools to recognize health patterns, understand their bodies, and even to *“take full control of your health with the app”* [A11]. Expressions such as *"take control"* are not uncommon (suggested by at least 10 apps), claiming that using fertility apps can help people understand or control their *"cycle," "fertility," "reproductive health,"* or even their overall *"health."*

These descriptions suggest that apps support multiple goals by providing data tracking features and feedback based on data, particularly predictions. App descriptions suggest that taken together, these activities can support people who menstruate to improve their control over their bodies. The following sections report results on aspects intended to support control: goals offered by the apps, data tracking features, and typical forms of feedback, including algorithmic feedback.

4.4.2. Intended and Supported Fertility Goals

Goals for using fertility apps are mostly visible in three places: app store pages, apps' onboarding process, and settings (for changes within the app) as summarized in Figure 4.2.

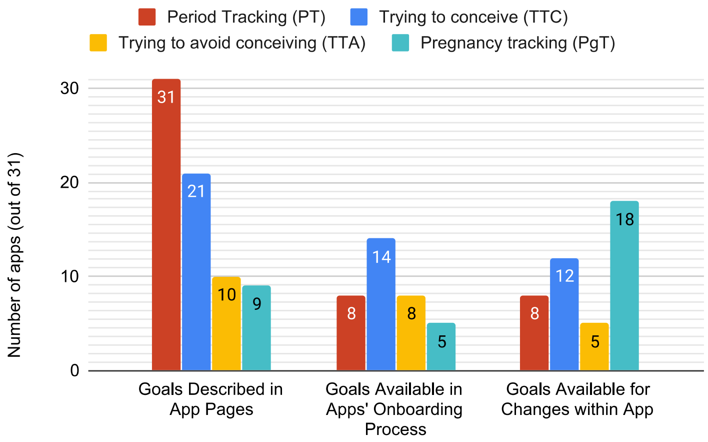


Figure 4.2. Goals within apps

Among the 31 apps analyzed, 18 include an onboarding process (i.e., the initial set of screens that ask information from users to set app's parameters and initialize features). However, only 14 of them ask users' goals during this process (Figure 4.3), with all 14 including the goal of trying to conceive (TTC). Although period tracking (PT) was referenced on all 31 app store pages, only eight apps include it as a goal in the onboarding process. Only two apps include all four goals of TTC, PT, trying to avoid conception (TTA) and pregnancy tracking (PgT) in the onboarding process.

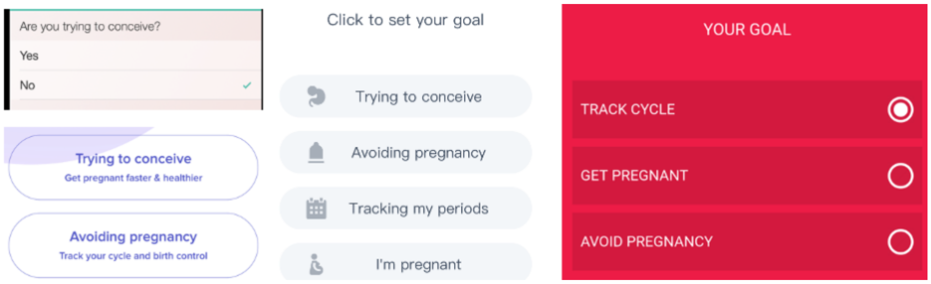


Figure 4.3. Examples of goals' question in the onboarding process

These results suggest that apps primarily focus on conception, which is reflected in user reviews. Reviews for apps mentioning conception are generally favorable. Users often indicate they achieved their goal while using the app. Some report abandoning it once conception was successful (e.g., *"I have been using [A6] for more than a year to TTC and now I feel very funny to delete the app since I am pregnant!"*), potentially resuming app use when TTC a second child (e.g., *"I used this app when we were TTC our son some years ago, and today I am using it again while we try for a second child"* [A1]).

Although many people use apps only for TTC, others use apps continuously to support multiple goals: *"I used this app for five years. In the beginning I successfully avoided pregnancy, and now I am on my second pregnancy"* [A8]. Nineteen apps supported a few transitions by allowing users to change their goals in settings within the apps. Six of these apps do not ask goals in the onboarding process but allow users to change to a pregnancy-specific mode within the app later (the only transition available). Most apps do not offer transitions for all four main identified fertility goals.

Users appreciate when apps tailor aspects of the interface and features according to their goal, especially when their goal is not TTC. For example, an app review written by a mother described tracking the menstrual cycles of a disabled daughter. She is satisfied with the current app (A30) because it allows her to focus on what she needs: "*Love this app, I use it to keep track of my disabled daughter's periods. No pregnancy planning if you don't want it, no complex charts, just a calendar charting her periods.*" In fact, users often complain when apps are not adaptable to their non-TTC needs:

> *"I really wish this tracker would be geared toward what you want to track. For instance: I selected 'I am not trying to conceive yet' as my goal. I only want to track my periods to avoid getting pregnant. It does not seem to matter although I defined it as my goal. The app still encourages conception and gives me tips and motivation to 'keep trying.' This creates anxiety when we do not want to conceive yet" [A1].*

As this quote suggests, besides selecting and changing a goal selection, apps' support for users' goals need to be translated in the data collection and feedback features they offer, otherwise users experience breakdowns.

4.4.3. Data Collection: Comprehensive and Long-Term Driven

This section reports apps' support for and users' reactions to data collection – a main feature that enables the many promises of fertility apps.

Apps Support Extensive Tracking

Most apps offer a vast list of health indicators to track including those directly related to fertility, such as period dates, as well as broader ones, such as diet and exercise. I identified 62 unique types of indicators apps offer to track (mostly manually), ranging from two to 34 per app (mean=13.93, median=14). The most common ones are period dates (31), intercourse days (30), symptoms (26), mood (26), and basal body temperature (26). Most health indicators are tracked manually or at least offer manual tracking. Other input modes include synchronizing (sync) with other devices (e.g., smart thermometers) and computer vision to capture the result of an ovulation predictor kit (OPK) or a pregnancy test. Table 4.3 lists these indicators, with numbers of apps, input mode, and frequency of data input.

Table 4.3. Health indicators offered by the apps

Indicator	# Apps	Input mode	Implied periodicity
Period	31	Manual	Monthly
Intercourse	30	Manual	By occurrence
Symptoms	26	Manual	By occurrence
Mood	26	Manual	By occurrence
Temperature	26	Manual (23) / Manual + sync (3)	Daily
Notes	26	Manual	Vary
Cervical mucus	22	Manual	Daily
Weight	21	Manual	Vary
Flow	21	Manual	Monthly (3-7 days)
Ovulation	21 (19 OPK, 9 selection)	Manual (18) / Manual + computer vision (3)	Monthly (10-20 days)
Intercourse protection	20	Manual	By occurrence
Contraceptive	17	Manual	By occurrence
Medication	15	Manual	Vary
Pregnancy test	15	Manual (12) / Manual + computer vision (3)	Vary
Cervical observations	12	Manual	Daily
Sleep	11	Manual (9) / Manual + sync (2)	Daily
Exercise	10	Manual	Daily
Others	Alcohol (8), disease (7), water (6), pregnancy (5), blood pressure (5), custom indicator (5), spotting (5), meditation (4), diet (4), orgasm (4), insemination (3), smoking (3), pain (3), stress (3), doctor appointment (2), location (2), sex position (2), fern test (2), collection method (2), craving (2), digestion (2), hair (2), skin (2), stool (2), energy (2), mental (2), motivation (2), social (2), party (2), travel (2), lochia (2), fertility, caffeine, vaginal sensation, treatments, events, progesterone test, lab results, waist, chest, hips, pulse, breasts, habit, headache.		

Besides period dates (necessary for app functions), each person can choose which indicators to track and how often to track them. However, some indicators may suggest specific frequencies of tracking. For example, temperature is expected to be measured daily and periods are naturally tracked once per cycle, which can mean roughly once a month. Other indicators are expected to be tracked every time the "event" or symptom is experienced (e.g., intercourse, mood), based on each person's experience.

The health indicators in fertility apps often support multiple phases of a regular fertility cycle (e.g., menstruation, pre-ovulation, fertile days, post-ovulation), but most indicators focus on fertility or pregnancy. Of the 17 indicators present in 10 or more apps, 7 relate primarily to fertile days and conception (temperature, cervical mucus, ovulation, intercourse, cervical observations, pregnancy test), while two are closely related to menstruation (period dates and flow), and other two relate to avoiding pregnancy (intercourse protection, contraceptive). However, although apps tend to prioritize TTC-related indicators, few of them offer data collection related to infertility treatments (beyond pregnancy tests and ovulation-related indicators): only 3 apps offer the possibility to track insemination, two support tracking medical appointments, while treatments, laboratory tests, and progesterone levels are supported by 1 app each. Besides, only 10 apps out 31 ask users year of birth during the onboarding process or at all.

Besides these indicators directly related to the main goals suggested by fertility apps, three indicators present in 10 or more apps are primarily associated with general health (weight, sleep, exercise), while four flexibly relate to fertility or general health depending on the context (medication, notes, symptoms, mood). For example, people could use mood indicators to monitor premenstrual impacts, but also as a more general indication of their health. Individuals can track all these indicators across the fertility cycle.

Users' reviews express desiring a similarly vast and varied list of indicators. Many users highlight how they enjoy *"how extensive tracking is"* [A1]. Surprisingly, even with the already extensive manual tracking features, some reviewers request the ability to track more, frequently asking for additional indicators. Requested indicators are often associated with periods or general symptoms (e.g., *"I wish I could track other things such as headaches, hunger, mood, cramps, and etc. I currently use another app to capture these other data"* [A31]). However, people's health circumstances often lead to other suggested indicators that apps do not commonly associated with fertility. For example, a user with diabetes and TTC wished to also track insulin levels to avoid complications around her glucose level (NIH National Institute of Diabetes and Digestive and Kidney Disease, 2017): *"the app should include the option to track sugar levels for woman with diabetes and TTC. We should be allowed to track our insulin level within the app"* [A1]. Another user who is pumping wished to track how aspects of her menstrual cycle influence milk production: *"I know that moms who are solely pumping are a minority, but [if] things like milk production in ounces…appeared as a line in the fertility graph, I would be able see how ovulation and menstruation actually affect my milk output"* [A1]. These reviews suggest that users want extensive, but also individualized tracking that allows them to know more about themselves.

Data Storage and Problems over Long-Term Tracking

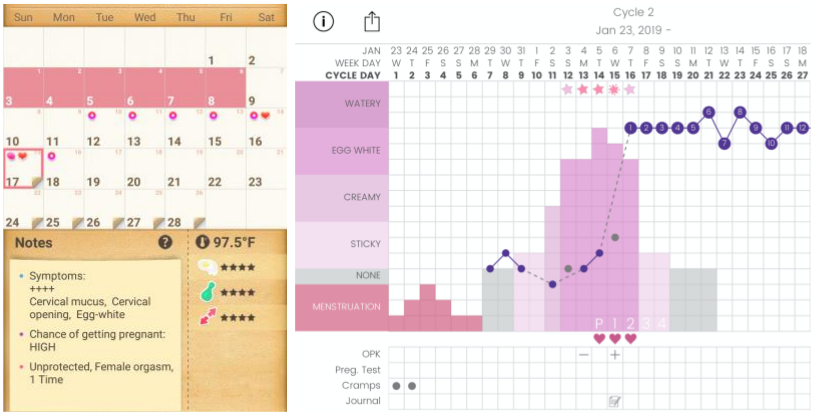
Reviews revealed that many people use fertility apps as data storage tools, so they can *"have all my information in one spot so I can look back on"* [A6]. Keeping all the data they want to track in one place allows them "*to stay organized*" [A8], especially when analyzing patterns for TTC. For example, users like the feature of uploading pictures of OPKs because *"the app saves the strips' photos, so you are not holding them for weeks!"* [A15]. Additionally, some users felt that storing long-term data could be useful to prepare for goal changes: *"I believe that when I am ready to have a child, it will be easy to switch the goal and see my most fertile days because I have logged so much data already"* [A31].

Given the value of storing long-term data, many users complain about data loss. For example, one user dealt with unexpected loss of long-term data from different stages of life: *"After six years of using this app, I now have lost everything! I tried to import my data to my new phone, but it is all gone. I lost all my notes of my miraculous pregnancy, my unpredictable periods information, and the lovely chats I had in the groups. I am upset because I need to start over again! Off to get a new app"* [A21].

In summary, most apps offer extensive tracking, often including long lists of health indicators. Users enjoy all the options, but they are also interested in flexible indicators that allow them to personalize the app to their needs. This often includes maintaining long-term data, either because goals can take longer to be achieved or because data can be used for multiple goals. In fact, data is often the main reason to either change or remain using an app.

4.4.4. Main Feedback: Visualizing Tracked Data

Apps most commonly provide feedback to users through calendars (31) and temperature graphs (21), although some apps include other forms of feedback (e.g., reminders, raw data lists, or line and bar graphs). Calendar and temperature graphs (Figure 4.4) emphasize dates and ovulation. Although many users comment how they like being able to see their data through these visualizations, user reviews highlight that they do not fully support individuals' fertility goals.



- Symptoms:
  ++++
  Cervical mucus, Cervical opening, Egg-white
- Chance of getting pregnant: HIGH
- Unprotected, Female orgasm, 1 Time

Figure 4.4. Calendar and temperature graph visualizations

Calendar View: Assessing Data through Clicking on Days

Calendar views emulate paper calendars by aligning menstrual cycles to months and days. This visualization displays predictions for periods, ovulation day, and fertile window in calendar cells. It is often possible to see more tracked indicators by clicking on each day's cell. Calendars are either part of the main screen of the apps or easily accessed through it. App users enjoyed how predictions on calendars helped them see their fertile window *"at a glance"* [A22], as the app pages advertise (e.g., *"I really like the calendar feature – it makes it easy to track sex and my cycle…and any changes in my body: from mood to fatigue and acne. It is helpful to identify patterns"* [A6]). However, the monthly calendar is not a cycle view: a cycle may span over different months, demanding users to navigate back and forth to visualize it. Limiting the visualization to calendar months limits full cycle analysis. Many users, as the one of the next quote, want to compare data between cycles to identify patterns, which the calendar visualization does not easily support: *"now you have to scroll month by month [to analyze the visualization], and it can get burdensome when you have some years of* *data in between pregnancies"* [A8]. A similar problem happens when users want to input historical data in their apps, creating situations that can be especially complicated for individuals TTC and TTA:

> *"support to import data previously collected is a great need, since I had sixteen years of previous information that I could not transfer to the app, even when I tried to enter it manually. You can scroll to the past, select a past date, and add data for it. But when you finish entering that data you are taken immediately back to the current day again and have to do the scrolling all the way back. This is really unhelpful when you are inputting five days of period in sequence to the cycle that happened three months ago" [A31].*

Temperature Graph: Centered on Ovulation

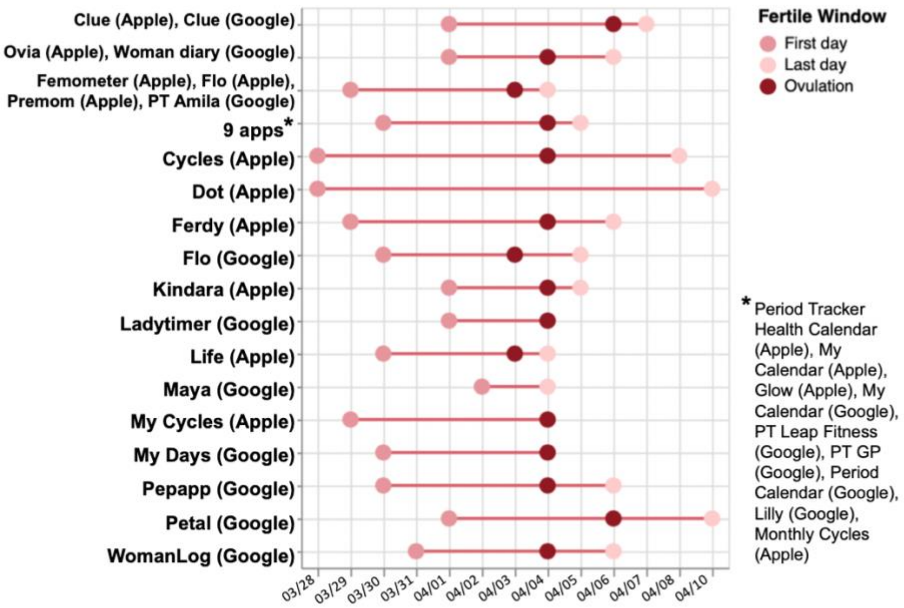
The second most common visualization present in fertility apps are temperature graphs, which are used to identify ovulation by visualizing days (x-axis) against a person's basal body temperature (y-axis) (Figure 4.4). Unlike calendars, they usually do not offer predictions into the future; instead, they display current and past cycles.

Temperature graphs allow users to see multiple days of data at once. However, these graphs often only show health indicators directly related to conception such as temperature (21 apps), period days (19), intercourse (13), cervical mucus (9), OPK results (6), and pregnancy test results (3). Therefore, temperature graphs primarily help support goals of TTC or TTA because the patterns displayed mainly help identify fertile days. Consequently, most of the positive reviews on temperature graphs are from users either TTC (e.g., *"I got pregnant! It helped me in understanding my body! From things such as cervical mucus, cervical* *changes, to tracking basal temperature. The graphs are easy to understand"* [A8]) or TTA (e.g., *"we do not want to conceive so soon…Observing my temperature values increase and decrease really helps me"* [A31]). Temperature graphs have limited or no use if users do not track temperature and as they tend to only show a limited set of indicators, users often cannot rely on them to analyze other aspects of their fertility cycles, particularly symptoms and mood, as described by the following user: *"The app allows us to add other symptoms and observations, but it does not display them on the graph, making it a useless feature" [A9]*.

Algorithmic Feedback

Fertility apps have been increasingly used to predict ovulation and fertile window, but it is unclear how these predictions are made (e.g., what indicators are used, how cycles are calculated) and how users perceive and trust them. In my analysis of apps' algorithmic feedback and users' experiences I found that predictions vary across apps, only few health indicators visibly affect predictions, and users consider this variance and lack of perceived influence important when they notice them.

In the test using simulated data, predictions varied considerably among apps. The first day of the fertile window varied by five days, with 13 apps predicting the same start day (03/30). Ovulation day varied by five days, with 19 apps predicting the same day (04/04) and 2 apps not providing predictions. Length of fertile window ranged from 3 to 14 days (mean=7.167, sd=2.036). Figure 4.5 shows all these results. I excluded Natural Cycles from this analysis because its free version limited the features I could use in this simulated test.



* Period Tracker Health Calendar (Apple), My Calendar (Apple), Glow (Apple), My Calendar (Google), PT Leap Fitness (Google), PT GP (Google), Period Calendar (Google), Lilly (Google), Monthly Cycles (Apple)

Figure 4.5. Predictions for ovulation and fertile window

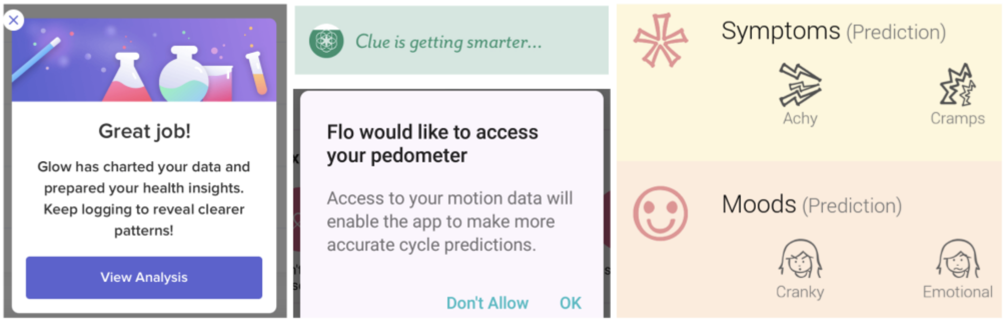
Changes in the first day of last period affected predictions in 29 out of 30 apps (96.66%), while changes in previous periods dates affected predictions in 18 out of 30 apps (60%). Among the 30 apps, 20 provided ovulation tracking features but entering ovulation data only changed the prediction in 13 of them (65%). Similarly, temperature and cervical mucus tracking were present in 25 and 22 apps but entering temperature and mucus data affected predictions in only 6 (24%) and 1 app (4.54%) respectively.

Comparing these data with user reviews, I found that users have mixed reactions towards apps' algorithmic feedback. Some users trust algorithmic predictions and describe being impressed on how accurate it is. Positive comments from people who were trying to conceive and got pregnant while using the app are very common (e.g., *"I used this app for my first pregnancy and I am happy to say that I am starting my second today!...Everything I ever tracked was period dates, mucus consistency, and pre-natal vitamins. The app 'learned' my cycle and was spot-on with my ovulation timing"* [A8]*).* However, although many users describe good experiences regarding accuracy, comments concerning inaccurate predictions are also frequent, often times for the same app (e.g., "*This app tells you exactly when you are ovulating and your chances of pregnancy on each day…For any woman trying to conceive, this is the app"* and *"I do not recommend this app, because it is not accurate at all. I have been trying to conceive for 9 months with this app, with no luck"* both for A6).

Many individuals who experience inaccurate predictions compare their predictions with other ways they measure their cycle, such as the results of OPKs, and get surprised and disappointed with the inconsistencies they find, as illustrated in the following review: *"After trying to conceive for some months, I started using OPKs and found that my fertile window started earlier than the app predicted...I have been missing my fertile window all this time"* [A15]. Users get especially frustrated when predictions do not change following the data they enter, which is aligned with the results of my test with simulated data. For example, the following user complains that the app gives the impression it uses their data, but it does not: *"it always acts like it's improving cycle predictions but no matter what you put for cervical mucus or temperatures it does not change"* [A11]. In another example, the following user noted that even positive results of OPKs, considered the most reliable indicator of ovulation (Speroff & Fritz, 2005), do not lead to changes in predictions of ovulation: *"This app always gets my ovulation wrong. It uses the length of your period as the first way to calculate the ovulation day. And I feel it barely uses your temperature information at all!...And even when I enter my ovulation test information, it completely ignores it most times"* [A9].

Many of these users wish they could customize their predictions so the app could learn with them. The following user was frustrated about the lack of customization possibilities in their app and emphasized that due to the natural variability of fertility, such features should be of primary consideration: *"By locking you to their algorithm they neglect the basic truth that not all women are wired the same. I did not find any way to update the app and put my correct ovulation day"* [A14].

While some users develop a more balanced trust in apps predictions (e.g., "*people complain that it does not always predict the exact day of ovulation, but the app is just one tool among many to help you predict the best time for conception*" [A6]), apps promoted materials and characteristics can reinforce beliefs of accuracy and personalization. App store pages and in-app messages often emphasize how much users can track and commonly suggest (or the simple existence of the indicators may suggest) that these tracked data will make predictions more accurate. Figure 4.6 shows examples of in-app messages that may reinforce this belief. Such messages can contribute to these expectations of accuracy and personalization (e.g., *"I decided that if I enter more data, such as temperature and ovulation kits, it will have more information to adjust appropriately.. Nope"* [A1]) that, as my analysis with simulated data suggests, are not commonly the case.



Great job!

Glow has charted your data and prepared your health insights. Keep logging to reveal clearer patterns!

Clue is getting smarter...

Flo would like to access your pedometer

Access to your motion data will enable the app to make more accurate cycle predictions.

Figure 4.6. In-app messages suggesting the use of tracked data

Extreme beliefs in apps' accuracy can contribute to negative emotions, such as disappointment and guilt. For instance, the following user believes the app works if you track diligently, and that they will confirm its accuracy if they conceive in this cycle: *"I think it* *works amazingly as long as you track daily. I still do not know how accurate it is, but if it is accurate, I should be pregnant this week"* [A28]. This mental model is complicated because (i) it assumes the app will always be accurate if the user inputs data and (ii) even if the app is accurate, a person will not necessarily get pregnant with the first attempt. Chances of conception for a couple without underlying conditions and having intercourse on the fertile window are only 20% at each cycle (depending on the age of the female partner) (American Society for Reproductive Medicine, 2021).

Putting this amount of faith in apps can contribute to increased frustrations with negative results, as illustrated by the following user trying to conceive: *"It gave me false hope. I am extremely upset and down. I was using the app to track my fertility. It not only got my fertile and ovulation days wrong; it also got my period days wrong. I was super excited cause I missed a period, so I thought I conceived. It was incredibly hard to accept that I'm not pregnant again!"* [A6]. It also opens room for guilt or (self-)blaming, as suggested by the next quote from a user who got pregnant while trying to avoid conception even though they tracked very diligently: *"My partner and I used this app to avoid pregnancy until I could finish graduate school, but it did not work. I know everybody will assume we just did not correctly follow the app, but we took absolutely zero risks, and we did exactly what the app told us to, and yet here we are!"* [A31].

In summary, my analysis of algorithmic feedback reveals inconsistencies in fertility predictions among the popular reviewed apps. Many users consider these inconsistencies important to their goals and describe they can influence their emotional state. Besides, other than period dates, most data tracked by users do not lead to changes in predictions, which suggests that indicators that may require daily and disciplined work are not used. This lack of transparency can reinforce complicated accuracy beliefs that can lead to disappointments and even life-changing consequences. These results show that the lack of clear description of what data are used in making fertility predictions can cause potential tracking burden, distrust of fertility technologies, or over-trust in predictions that may not be accurate.

Feedback Beyond Dates and Ovulation

App descriptions often suggest that people can collect different types of data to compare their fertility cycles and see "*variations in your cycle*" [A5] or *"patterns in your health"* [A7]. User reviews indicate users generally have these goals (e.g., *"I am terrible in memorizing patterns of symptoms from one month to the other and this app does it for you"* [A1]). However, calendars and temperature graphs, apps' most common visualizations, offer limited support for such goals.

Understanding symptoms and mood is not particularly well-supported by fertility apps. Although 26 out of 31 apps present these indicators (only period and intercourse appear more often) only five apps included visualizations that enable seeing how they and other non-TTC indicators relate to cycle days, periods, ovulation, and fertile days (examples in Figure 4.7). In contrast, users suggest wanting to compare their mood and symptoms by cycle: *"It could include a better way to monitor monthly mood and symptoms on a graph, so you could see whether the same moods appear at the same time in the cycle, and not just days"* [A23]. Despite apps' focus on conception, even some users who are TTC complain they do not support identifying and understanding patterns of symptoms throughout the cycle: *"If you are trying to get pregnant, this app is very plain. I use this and several other apps and while* *this one has a few features to track symptoms, it does not explain how they correlate to your cycle"* [A29].

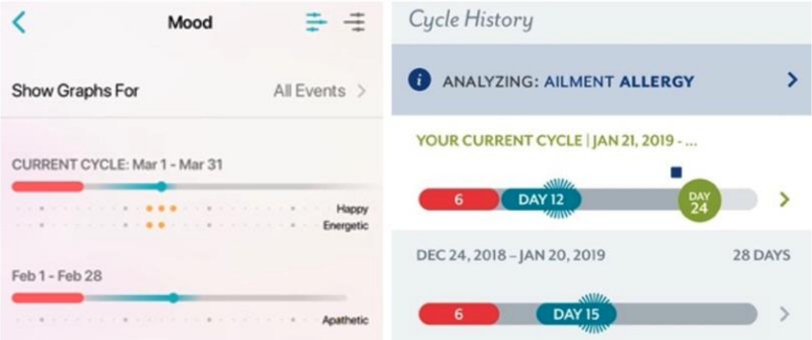


Figure 4.7. Visualizations comparing other indicators with the cycle

Besides this lack of visualizations comparing other indicators with the cycle, all app visualizations analyzed were pre-defined and not customizable, so users cannot choose which indicators they want plotted, analyzed, or correlated within a cycle. Only two apps allow users to partially define what indicators appear within the calendar days. Graphs are not customizable and pattern analysis features (Figure 4.7) are uncommon and show only one indicator at a time.

Overall, although users manage to find patterns in how other health indicators vary throughout their cycle, current visualizations are not entirely supportive for identifying patterns and insights for indicators not directly related to conception. This analysis suggest that extensive tracking does not translate to extensive feedback. Reviews show that users are interested in comprehensive long-term tracking. However, they also want flexible data collection and visualizations that provide feedback related to the data they choose to collect. Moreover, they want feedback connected to their current goals and needs that are beyond conception, even when they do want to conceive.

4.4.5. Users' Experiences Using Fertility Apps

Fertility spans the life of people who menstruate, being key to multiple life stages and events. However, this study revealed that apps generally do not adequately support users apart from their reproductive years, during which apps often presume people have conception goals. However, even with this focus on conception, apps often lack support for many related health events and individuals' needs, as described in the following subsections.

Support for Conception-Related Events

Many user reviews complain about how apps support pregnancy, miscarriage, and breastfeeding, events that are directly related with conceiving. Eighteen out of 31 apps allow users to indicate pregnancy in the app and often offer a pregnancy tracking mode, which was positively reviewed by the users (e.g., *"I love this app's pregnancy mode. It was my 1st pregnancy and it guided me through it"* [A16]). However, similar to previous literature reports (Epstein et al., 2017), many users also note that although they enter in the app that they were pregnant, some apps kept warning them their period was late (e.g., *"It would be good if you could tell the app you are pregnant. I keep receiving these almost panicked notifications about how late my period is"* [A17]) or even changed predictions as the person was having a very long cycle, as happened to the following user: *"I do not believe I can continue using this app without reinstalling it and losing my data, because now my average period length will be very off"* [A7].

Moreover, not all pregnancies come to full term: 20% of all pregnancies are estimated to end in miscarriage (Savitz et al., 2002). Only 5 apps among the 31 offer some level of support after a miscarriage, for example by allowing registration of a miscarriage, providing articles and supportive messages, providing guidance for tracking after a miscarriage, and resetting or stopping predictions and emails. Some users comment that apps, even ones that offer support for TTC, do not offer an option to input a miscarriage (e.g., *"I lost two pregnancies and I cannot track that in the app, which completely messes up cycle predictions. No app, I did not have a sixty days cycle. I had a miscarriage!"* [A15]), or even impact predictions in unexpected and potentially irreversible ways when a miscarriage is tracked, as described by the following user: *"after having an early miscarriage, the app changed not only the future, but also the data for past months! So now I do not know whether my period is late or not. Thank you so much for that"* [A2]. Additionally, apps' pregnancy messages, if not configurable, could serve as a reminder of miscarriages, as highlighted by the next user, whose app fortunately had the appropriate feature: *"I lost my baby and I became severely depressed. I reported my miscarriage in the app in order to stop the daily e-mails, which served as a daily reminder of my baby's death"* [A1].

Finally, even when pregnancy comes to term, other events can interfere with app use and fertility cycles. For instance, some users expressed that apps did not support their needs while breastfeeding, as described in the following quote: *"I really like this app to plan for pregnancy, but now that I am using it after conceiving, it keeps saying it cannot track because my periods are irregular. I want to tell the app that I know! I had a child and then I breastfed for two years. Now I need the app's help until I get regular again"* [A14].

Support for Other Life Stages

Individuals' fertility needs change considerably in different life stages. Three fertility-related stages are especially important because nearly every person with periods will live them: adolescence, when people start having periods and need to learn and deal with initial irregularities; reproductive years, that may involve different goals such as trying or avoiding pregnancy; and menopause, when fertility cycles become irregular again until they stop. However, in general, apps do not adequately support users beyond the reproductive years.

For adolescence, aligned with prior findings (Epstein et al., 2017), some teenage users found it inappropriate when apps focused on conception (e.g., *"The app always asks 'did you have sex? It is the perfect time to make love with you partner today'…I am still a teenager and I am still not thinking to have sex"* [A4]). In fact, only 10 apps ask user age during the onboarding process, even though this information can also help towards conception goals.

Most reviews concerning menopause are positive, with people benefiting from tracking their cycles when their periods became irregular (e.g., *"I am going through pre-menopause, so this app has been a blessing!"* [A12]). However, users recognize that the apps were not developed for menopause (e.g., *"I wish there were more symptoms specific to my condition, but I know this app is not for people in the peri-menopause stage"* [A2]) and try to adapt them to support their needs. Menopause users also describe lack of support to their specific needs, such as not being able to track missed periods (e.g., "*When I missed a period, I was not able to add this to the tracker"* [A13]), the intensity of symptoms (e.g., *"I am looking for something that allows me to distinguish levels, such as spotting, light, and heavy, because I track pre-menopause"* [A18]), or symptoms more directly related to the menopause experience (e.g., *"I would like additions for tracking night sweats, sleeplessness, hot flashes"* [A18]).

These results suggest that apps focus on the stage of life in which periods tend to be more stable, lacking support for more transitional moments. However, these are the moments in which people may need more support to understand the changes happening in their bodies.

Conflating Reproductive Years with Conception

While fertility apps are praised for supporting the goal of TTC, many users were disappointed by this limited focus: *"I wish they would allow us to customize more since not every woman wants to be a mother, but every woman has to deal with that period of the month"* [A29]. As this user describes, many people do not have conception goals during reproductive years.

Although periods are often more regular during reproductive years, people with periods often have "irregular" experiences. People may face temporary changes in their cycle, and tracking can help identifying them, as described by this user: *"I began to use this app to track my moods alongside my cycle…I discovered that my moods were difficult to control during ovulation. I told my doctor and he made me a prescription of a medication that I have been using for a year so far, and the things are much better now"* [A12]. In addition, reviews suggest people want to use fertility apps to monitor their cycle regularity and *"to track inconsistencies"* [A30]. To other people, "irregularities" may be part of their regular experience, such as people facing fertility issues, PCOS, and endometriosis. Apps can support identifying and managing these issues by recording data useful for diagnosis, as was the case of the following user: *"when I was not getting pregnant, I looked for a doctor and I was able to tell exactly what my body was doing and I was then diagnosed with PCOS"* [A1]. However, apps can also normalize particular experiences and ignore others, as highlighted by the next review *"I would give this app more stars if it mentioned adenomyosis and endometriosis with* *the description of how painful periods are NOT normal. Millions of women worldwide suffer from unexplained pelvic pain. It took me 15 years to be diagnosed!"* [A26].

Fertility apps also often make heteronormative assumptions about users' genders or sexuality (Epstein et al., 2017). Participants who did not fit these assumptions noted that their data needs were not well-supported: *"I personally track my ovulation to deal with mittelschmerz pain, but I do not ever need to track cervical mucus or basal body temperature because me and my partner are not capable of conceiving. So, please give me a way to turn these things off!"* [A13]. Another user facing a similar challenge concludes that *"even though these [gender and sexuality] aspects may not have a direct effect on our cycles, I believe this app is about accurate data, but there are data that I cannot input"* [A11].

4.5. Discussion

This study revealed that fertility apps are generally supportive of single goal uses, particularly TTC. This aligns with traditional uses of self-tracking technology (Li et al., 2010). However, this study also found that the support offered is mostly limited to traditional conception trajectories, which often do not translate to peoples' lived experiences. Besides, results show that people also want to use these apps more broadly than apps data collection and feedback support. The next sections discuss these issues, first focusing on fertility support and then broadening the focus to holistic tracking.

4.5.1. Supporting Fertility Experiences

Although fertility apps have a strong focus on supporting conception efforts, this study shows that the data work supported by the apps is limited to traditional conception trajectories. Such trajectories exclude individuals that face challenges to conceive, pass through infertility treatments, or have miscarriage experiences.

Aligned with previous work (Zwingerman et al., 2019), I found a lack of options for tracking aspects related to infertility or fertility treatments, such as insemination procedures, *in vitro* fertilization, medications, or doctor appointments. These are data that individuals cannot track in the apps. These treatments usually require intense coordination, including medications and procedures that need to be taken on specific moments and timed with the cycle. Therefore, this significant data work involved in fertility care is ignored by popular fertility tracking technologies.

Apps are also less supportive for people who face challenges for longer periods: most of the positive comments of individuals who conceived mention that they did it in a few months after starting using the app. As study 1 suggested, individuals who face challenges to conceive tend to try to integrate more data to get a more precise and personalized estimation of ovulation. Although many current commercial apps describe using AI to personalize predictions, that is not the experience of many users, which was also reflected in the test using simulated data: from the user point of view, apps seem to not take most of their data into account, which generates frustration and distrust. Starling et al. (2018) suggest that app developers may be using scientific terminology in apps' promotion materials to improve consumer confidence the same way such jargons were used for beauty products in the past. Our study suggests that something similar may be happening with the use of "artificial intelligence," "data driven," and other technological jargon: these terms may be used to inspire increased technological precision and accuracy, encouraging users' confidence in predictions. And such claims may reinforce unbalanced expectations or false hope, which can contribute to the negative engagements with data described in study 1, including feelings of disappointment, frustration, and despair.

Besides, although I excluded apps focused on IVF from the analysis, the general fertility apps analyzed are largely used by people facing challenges to conceive. The absence of features and information focused on infertility in such apps can also suggest that all that is necessary for conceiving is timing intercourse with the fertile window (Zwingerman et al., 2019). While there are many possible underlying causes for infertility, such suggestion can reinforce feelings of guilt, giving users the impression that the only reason they did not conceive is because they did not try hard enough.

Andalibi (2021) draws on Winner's notion of artifacts' politics (Winner, 1980) and builds on theories developed by feminist scholars (Gerbner & Gross, 1976; Tuchman, 2000) to propose the concept of symbolic annihilation through design: *"how technology design reinforces stereotypes about humans or phenomena and sustains social inequities like marginalization and stigmatization"* (Andalibi, 2021). Focusing on pregnancy loss experiences, Andalibi (2021) analyzed pregnancy and fertility apps concluding that the lack of information and support for such experiences is a symbolic annihilation that *"portrays a linear, normative, and unrealistic narrative of pregnancy that fails to account for a common complication."* As Lupton (2015) describes, apps are sociocultural products able to shape human bodily experiences and notions of self, creating or reinforcing practices and knowledges. This study reinforces these aspects: infertility is another common trajectory that is not represented in the common narrative reinforced and propagated by fertility apps.

As a result, these experiences can become even more marginalized, increasing feelings of isolation and disenfranchised grief (McBain & Reeves, 2019).

These aspects emphasize the contrast between apps promotion materials and the data needs of individuals who use them, highlighting how experiences and data work for fertility and menstruation are much broader than the few goal-oriented uses apps focus (S. E. Fox et al., 2020). As this study shows, if apps poorly support the data work involved in conception trajectories that fall out of the idealized, linear, and normative experience of pregnancy, other goals are even less supported. This indicates that apps should broaden their focus and support the data work for more holistic experiences of fertility tracking.

4.5.2. Supporting Data Work for Holistic Needs

Although fertility apps support a few specific (often linear and normative) goals, and many people who have these goals enjoy using these technologies, this study shows that some individuals also want to use these apps in a more holistic way: to support multiple goals, different life stages and events, and transitions between them. For example, the most common scenario is to use a fertility app as a family planning tool, transitioning from avoiding pregnancy to trying to conceive, and then to early parenthood with breastfeeding and other activities, ideally without deleting the app or losing data. Previous research highlight that the lack of support for transitions between goals is a common problem of self-tracking tools (Epstein et al., 2017). However, fertility represents a more complex case.

First, although apps typically support data work for a subset of possible fertility-related goals (e.g., TTC or PT), people often use fertility apps to track data on other health factors influenced by fertility, such as moods, glucose, and pumping. Second, fertility spans over most of the life of individuals who menstruate, including intrinsic transitions. Fertility inherently encompasses three important life stages: adolescence, reproductive years, and menopause. Aligned with previous literature (Eschler et al., 2019), this study also found some of these life stages (i.e., adolescence and menopause) are largely missing in the current fertility app design, which primarily focuses on conception. Therefore, apps tend to not support data work for these important life stages, although they usually include experiences of cycle variability and changes that could benefit from tracking. Furthermore, as discussed in the previous section, even conception itself is entangled with multiple life transitions (e.g., from TTA to TTC, being pregnant, miscarriage, and breastfeeding). These transitions are entangled with broader changes in peoples' lives requiring users to collect and analyze their data (and other data work activities) across different stages and events holistically. Some transitions can be planned (avoiding or trying to conceive), some can be expected (from teenage to reproductive years to menopause), others just happen (e.g., miscarriage). Finally, the reproductive years are not constant nor homogenous: it is typically the longest fertility stage of the lives of individuals who menstruate, so it is unreasonable to assume fertility will be constant during this time (e.g., changes in birth control methods can impact the menstrual cycle). It is also unreasonable to assume that every individual who menstruate will have the same experiences. People have different genders and sexualities, have health conditions affecting fertility (e.g., PCOS, endometriosis), and use different conception methods (e.g., IVF, egg or sperm donation), and more.

These differences suggest that, although other self-tracking domains also strongly benefit from holistic tracking, fertility may intrinsically require it. For example, food tracking often includes different goals such as to manage weight (Cordeiro et al., 2015), understand

IBS symptoms (Karkar et al., 2017b), and recover from eating disorders (Eikey & Reddy, 2017). However, it is less likely for a person to experience all of these food tracking goals and related data work throughout their lifetime, while people typically pass through many goals, life-stages, and events when tracking for fertility. Biological changes do alter people's food goals, such as changing metabolism, but common biologically-influenced changes in fertility goals can be more drastic and happen in a shorter time (e.g., from TTA to TTC, to breastfeeding, to TTA again potentially in a relatively short time). Thus, fertility app users may need a holistic approach because their goals and situations change more frequently in response to factors inside and outside of their control. These changes make their data work intrinsically dynamic, while apps tend to offer static support. Different goals, life-stages, and events, including the ones related to infertility, can all benefit from the same self-tracked data, but as this analysis shows apps are still focused on goal-directed uses, particularly the ones society still associates with individuals who menstruate (i.e., conceiving).

Designing for Holistic Tracking

Ideally, holistic tracking should include long-term, extensive, but flexible data tracking. This study's results indicate people value the capability of storing long-term data, but they typically do not want to track all available health indicators at once. Instead, they prefer personalized tracking for their current and individualized needs. Currently, users have limited control over data collection: they can choose what to track but only within the possibilities offered by the apps. Beyond offering extensive lists of indicators, app developers could learn from flexible tracking configuration tools (Kim et al., 2017) offering people the possibility of creating their own fields and defining how they will track them (e.g., selection, quantities, text). This type of customization would give more power to the users and support more varied data work. However, because such extensive customization may be burdensome to some users, app developers should keep offering default data collection options for users who do not wish to configure their tracking, and examine how to make such options as inclusive as possible.

In general, people often have limited control over their own personal data generated through interactions with digital infrastructure: *"data about me"* is different from *"my data"* (Crabtree & Mortier, 2015). Similarly, fertility apps enable people to generate extensive data about themselves but tend not to give people enough control over these data or how to visualize them. Individuals usually cannot manipulate these data the way they want or choose how to analyze, compare, and visualize data at different levels of detail. The feedback they receive is pre-defined and often generic. This is another important aspect of data work that apps do not adequately support.

Tracking feedback might be provided in two more ways to better support holistic tracking. First, tracking tools should provide a full view of the cycle (besides the current monthly view) and cycle-to-cycle comparisons to allow people to compare their cycle length, symptoms, mood, and other indicators across cycles. Second, people should be able to reconfigure feedback to their specific goals. For example, the frequently-included temperature graph assumes that people will measure temperature daily and input the data. However, the burden of doing so may make it only worthwhile for those TTC or TTA. Customizable graphs can provide more support for the data work of users with a variety of goals, supporting pattern recognition by allowing users decide the type of graph and plotted indicators. Fertility apps can draw inspiration from information visualization studies focused on democratizing visualization tools (Huron et al., 2014; Pousman et al., 2007) and self-experimentation research aiming to support users' exploration of personal data (Bentley et al., 2013; Karkar et al., 2017b). Both can provide insights for visualizations that allow users to experiment (Karkar et al., 2015, 2017b) and make sense of their *"personally meaningful data"* (Pousman et al., 2007). For example, customizable graphs can be built from building blocks (Huron et al., 2014) provided to users so they can generate their own visualizations and associations of health-related events, indicators, symptoms, or contextual information. However, to avoid over medicalization of menstrual cycles or wrong conclusions, as suggested by Levy and Romo-Avilés (2019), fertility apps should also include instructions to their users emphasizing that some factors or symptoms, although influenced, are not necessarily caused by individuals' fertility cycles and that possible correlations or patterns can be normal and not a sign of pathology.

Finally, apps should enable people to further customize their interfaces to better match their different goals and transitions between them. For example, apps could confirm a person's current goal when they do not track periods for some time (which might indicate pregnancy, for example). Apps could allow users to indicate a miscarriage and halt references to the lost pregnancy, and also allow resetting predictions. To do so, apps could leverage data from before the pregnancy, taking care to avoid interpreting the miscarriage as a very long cycle. Apps could also provide ways for users to configure predictions (e.g., people TTA may want more conservative predictions, while people TTC may need more accurate ones (Epstein et al., 2017)) and allow users to hide and add indicators and visualizations to match their needs.

CHAPTER 5. A Social Ecology Approach to Fertility Data Work

This chapter describes Study 3, which focused on analyzing people's relationships with data, aiming to understand how individuals experience fertility self-tracking for fertility in the long term, and investigating how their data work is situated and shaped by their interpersonal relationships, institutional interactions, and societal influences. Therefore, this study addressed the following research questions:

RQ3. How do individuals engage in data work throughout their fertility trajectory? How does individuals' data work involve their partners? How does healthcare providers assess the increasing use of fertility self-tracked data?

RQ4. What opportunities exist for designing fertility tracking technologies to facilitate individuals' data work and mitigate interpersonal, institutional, and societal challenges?

The chapter starts detailing the motivation for this study and providing a summary of the related literature it builds on. After describing the methods, I describe two examples of fertility trajectories to provide context for the other results. Using the Ecological Systems Theory (Bronfenbrenner, 1977, 1992) as a lens to present and understand the results, this study uncovers the broader ecologies of care involved in participants' fertility data work, showing that although fertility data are often considered private, they influence and are influenced by interpersonal, technological, institutional, and societal factors. Technology plays a significant role in this ecology of care by supporting, shaping, limiting, and defining fertility data work, often reinforcing societal pressures and market interests. The chapter ends, however, by discussing how data can potentially be used to influence individuals' ecologies of care from the inside out. Findings presented in this chapter were previously published in (Costa Figueiredo, Su, et al., 2021; Costa Figueiredo & Chen, 2021).

5.1. Motivation

The engagement with personal health data has typically been seen as individual-driven or self-oriented. However, recent studies show that self-care is highly collaborative (Nunes & Fitzpatrick, 2015) and self-tracked data influence and are influenced by individuals' relationships and the contexts where the self-tracking activities are situated (Murnane et al., 2018). A growing body of research has focused on the collective aspects of health data, investigating topics such as using data to support patient-provider collaboration (Sanger et al., 2016; Schroeder et al., 2017), caregivers' experiences of tracking those being cared (L. S. Liu et al., 2011), and collaborative data tracking in families (Pina et al., 2017; Saksono et al., 2019). These studies cover a wide range of stakeholders who directly interact with individuals and can be directly impacted by their self-tracking practices.

Beyond direct relationships and interactions, other social environments and contexts may influence the ways individuals use personal data. For example, perceived neighborhood characteristics (e.g., presence of parks or incidence of crime) may impact individuals' ability to perform physical activity, thus, influencing their self-tracked exercise data (Saksono et al., 2018). Other studies have discussed how self-tracked data are shaped by the broader social, cultural, and political institutions and ideologies in which individuals are embedded (Lupton, 2013b; Spiel et al., 2018). These studies call attention to the different forms of social and environmental contexts involved in individuals' self-tracking activities and data.

Inspired by this body of research, and building on the collaboration aspects uncovered in study 1, in this study I approach the ecologies of care involved in the experiences of individuals facing fertility challenges. Fertility data are often seen as private and individual. However, although fertility is considered a private matter, it is not isolated from the influences and interactions with other stakeholders, as discussed in Chapter 3. Partners and healthcare providers are often directly involved in individuals' fertility trajectories. Others, such as family and friends, are also important relationships that can positively (e.g., supporting) or negatively (e.g., pressuring) affect individuals' experiences. Furthermore, fertility care is clearly influenced by organizations such as healthcare institutions and societal taboos related to the female body (Almeida, Comber, & Balaam, 2016). However, it is still unclear how these relationships, institutional interactions, and societal pressures are influenced by the intense data work individuals engage in when trying to conceive.

To approach this context, in this study, I conducted narrative and semi-structured interviews with individuals facing fertility challenges, partners, and healthcare providers specialized in infertility to understand individuals' experiences and their engagement with personal health data. Leveraging the Ecological Systems Theory (EST), I explore fertility larger ecologies of care, and how data influence and are influenced by different stakeholders, institutional spaces, and sociocultural factors present in the context of the participants (i.e., mostly U.S. and western environments). The chapter ends with a discussion about the importance of uncertainty in fertility struggles, how it plays a role in individuals' interpersonal, institutional, and societal interactions, and how these interactions influence the individual, highlighting how these influences translate into intense and invisible data work and opportunities for using data to influence from inside out.

5.2. Related Work: Self-Tracked Data Beyond the Self

Although the name suggests an individual activity, self-tracking is often not exclusively personal, especially in the health domain. Various aspects of health affect and are affected by multiple relationships (Barbarin et al., 2016; Pina et al., 2017) and several studies have explored how individuals' self-tracking activities influence or are influenced by such relationships. For instance, patient-provider relationships have been largely explored in HCI (Ding et al., 2019; Street Jr et al., 2014), with many studies focusing on how self-tracked data influence clinical encounters. PGHD are expected to support patient-provider interaction by facilitating their collaboration and fostering shared-decision making (Chung et al., 2016; Schroeder et al., 2017), by combining providers' medical expertise with patients' knowledge about their illness experiences (Schroeder et al., 2017). However, past studies have described different conflicts around PGHD use between patients and providers, particularly when patients start tracking data on their own (Chung et al., 2016; Costa Figueiredo & Chen, 2020; M. L. Jacobs et al., 2015; Schroeder et al., 2017). Often patients and providers have different needs and expect data to be used in different ways, which can lead to dissatisfaction in both sides (Chung et al., 2016; Raj et al., 2017; Schroeder et al., 2017).

Other relationships that have been studied include partners, family, and caregivers. Studies analyzing the influence of self-tracking in the family have discussed aspects of motivation (Katule et al., 2016), privacy (Hong et al., 2016; Pina et al., 2017), division of labor (Ancker et al., 2015), and burden of caregiving, particularly when caregivers track the individual (Kaziunas et al., 2017). For example, Mishra et al. (2019) describe individuals with Parkinson's disease appreciate their partners' help in tracking symptoms they cannot perceive (e.g., sleep) but tensions arise with conflicting interpretations of ambiguous symptoms. In the fertility context, Homewood, Boer, et al. (2020) developed a self-tracking device to support shared use by couples, but despite their intention, tracking was still mostly centered in the partner who would carry the child. Other studies describe how individuals use data to make an invisible condition visible to others from both close (e.g., family) and extended networks (e.g., work colleagues) (Felipe et al., 2015; MacLeod et al., 2015).

Most of these studies focus on one type of relationship (e.g., family), but a growing body of research has considered the role of technology within ecologies of care, approaching multiple relationships at once. For example, Evans et al. (2020) examined the care ecologies of veterans with PTSD, analyzing how relationships with clinicians, trusted others, and non-human intermediaries (e.g., technology systems) support the veteran. Other studies have included not only relationships, but infrastructure and social aspects as important forces shaping individuals' self-tracking activities. Parker et al. (2012) argue that health cannot be reduced to an individual effort of changing behaviors and health interventions need to engage with broader community and socio-cultural forces that shape individuals' living conditions (Parker et al., 2012). Peyton et al. (2014) investigated social, demographic, cultural, and economic factors that influence the gestational weight of pregnant lower-income American women. Finally, Murnane et al. (2018) analyzed self-tracking as a collective endeavor embedded in multiple social structures. They used the EST (Bronfenbrenner, 1977, 1992) to propose an ecological model that includes an informatics layer to account for the mediation role data play in the social ecology of serious mental illness.

This work builds directly on this previous research that highlight the importance of taking an ecological perspective that considers the multiple stakeholders involved in health and illness contexts (N. Kumar et al., 2020; Murnane et al., 2018). This study is particularly inspired by Murnane et al. (2018) use of the EST, since self-tracked data play an important role in fertility experiences (Costa Figueiredo et al., 2017, 2018), influencing and being influenced by different stakeholders, institutional contexts, and sociocultural factors. Thus, I leverage the EST to investigate how these multiple influences manifest during the fertility trajectories of individuals' facing challenges to conceive. This study's results suggest that the influence of data is more structured and intense in the fertility context, in which individuals are expected to take responsibility to directly influence the outcomes of their fertility trajectories through personal actions based on their data (M. Lee, 2017; Lupton, 2015). Self-tracking is then seen as a possible way to directly control individuals' fertility trajectories (Costa Figueiredo et al., 2018), a belief that is largely influenced by societal views of healthcare (e.g., one needs to take responsibility for their health) and expectations about gender (e.g., "women" are responsible for conceiving).

5.3. Theoretical Framework: The Ecological Systems Theory

First introduced for early children development, the Ecological Systems Theory describes how individuals are influenced by different types of environmental systems that interact with and influence each other (Bronfenbrenner, 1992). As Figure 5.1 illustrates, the EST model is composed of five nested layers or systems that form the ecology of human development: the microsystem encompasses the immediate settings and relationships that surround the individual, usually including family, friends, and peers. The mesosystem represents the interrelations between the microsystem entities (therefore sometimes it is omitted from graphical representations (Murnane et al., 2018)). The exosystem comprises other settings and or organizations that surround the individual, such as workplace, government agencies, and healthcare systems. Last, the macrosystem encompasses broader socio-cultural patterns, such as educational, political, social, and economical systems that are manifested in the other systems (Bronfenbrenner, 1977, 1992). Besides these main layers, the EST also includes a chronosystem (Bronfenbrenner, 1992), which encompasses the dimension of time and accounts for changes in environments during life transitions and throughout the individual's life course.

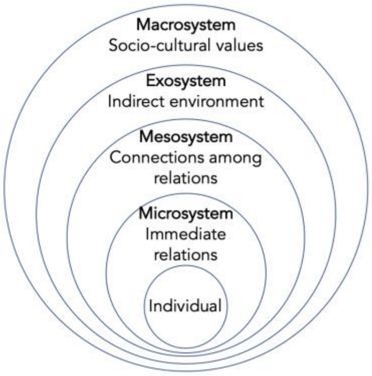


Figure 5.1. Representation of the Bronfenbrenner's ecological model (Bronfenbrenner, 1977, 1992)

Since its creation, the EST has been widely used as a theoretical framework in a variety of areas to explain and explore human relationships with the surrounding environments, including studies that explore computational support for autism (Arriaga, 2017), substance use disorders (Yarosh et al., 2019), serious mental illness (Murnane et al., 2018), and asthma (Jeong & Arriaga, 2009). Similarly, this study uses the EST to investigate how individuals' fertility data work is influenced by these multi-layer environmental systems and to explore ways to better support individuals' fertility trajectories through an ecological perspective.

5.4. Methods

To investigate individuals' fertility experiences and their ecologies of care, I conducted an interview study with people who have faced or were facing challenges to conceive for at least 6 months and with medical specialists who directly work with infertility. I use the ecological model from the perspectives of the individual with female fertility who is trying to conceive (the “individual” in the center of the model) to show how their fertility experiences are situated in their complex relationships with others. The interviews with partners and healthcare providers were used to understand their interactions with individuals, focusing on individuals’ experiences. I did not interview stakeholders from outer layers of the model but addressed these relationships through individuals’ accounts of their interactions with different roles, organizations, institutions, and broader social systems.

5.4.1. Recruitment

I recruited participants in three ways: I and two collaborators (i) used snowball sampling, (ii) partnered with a fertility clinic located in the west coast of the U.S. to distribute the research flyer, and (iii) posted the flyer in an online health community (OHC) focused on trying to conceive (TTC). These recruitment methods allowed me to obtain participants with rich and varied experiences, from the ones managing fertility on their own to those who have gone to extensive clinical treatments. In total, I recruited 19 individuals, 2 partners (hereafter represented by P1 to P21), and 5 Reproductive Endocrinology and Infertility Specialists (REIs – D1 to D5). I will not disclose the name and location of the clinic nor the name of the OHC to protect participants’ anonymity. To further protect healthcare providers’ identity, I use a neutral pronoun to refer to them to avoid possible identification based on their gender. All participants verbally consented to participate and received compensation for their participation. This study was approved by the Institute Review Board prior to recruitment and data collection.

Most of the individual participants were recruited through snowball sampling (10) or from the OHC (6), having no connections to the fertility clinic. Although many patients from the clinic were interested in the research, only three contacted me and completed the study. Partners were recruited through snowball sampling: I asked each individual if they were willing to refer their partners, if there was one, but only two partners agreed in participating (P5 and P20, partners of P4 and P19 respectively). Sixteen individual participants were located in the U.S. The others were located in Brazil (3), Portugal (1), and the U.K. (1). All five REIs were recruited from the same U.S. fertility clinic we partnered with. Interviews lasted from 23 minutes to 1 hour 21 minutes. Two interviews were conducted in person, while the other 24 were online or via phone calls. Each interview generated rich descriptions of participants lived experiences, data work and self-tracking practices, and the main relationships of their ecologies of care.

5.4.2. Data Collection

Individuals and Partners

Using the terms participants used in the interviews, Table 5.1 summarizes the characteristics of individuals and partners and the main aspects that influence their fertility experiences: their demographics (i.e., age by the time of the interview, gender, ethnicity, highest degree, marital status, and profession), age when they faced fertility challenges (Age TTC), how long these challenges lasted or are lasting (Time), main diagnoses and fertility-related events (Diagnosis and events), treatments and activities (e.g., tracking) they tried (Actions and treatments), number of healthcare providers they consulted with (HP), and if they conceived any child (Conceived). Since several participants faced challenges conceiving more than one child, I use "/" to separate information for their first child / second child.

Table 5.1. Participants' demographic information and fertility trajectory characteristics

P#	Age	Time	Gender	Ethnicity	Highest degree	Marital status	Profession	Age TTC	Diagnosis and events	Actions and treatments	HP	Conceived
P1	43	4y 6m / 1y	Female	Philippine, Italian	BA	Divorced, Married	Transcriptionist	25 / 37	Endometriosis	Tracking, endometriosis surgery, procedure for cervix obstruction / Tracking	7 / 1	Yes / Yes
P2	43	7y	Female	White	BA	Married	Beauty industry	36	-	Tracking	3	Yes
P3	35	1y / 6m	Female	White	MS	Married	Pre-school teacher	29 / 33	Low motility (partner), 1 miscarriage	Tracking, regular exams / Tracking, regular exams	2 / 1	Yes / Yes
P4	35	2y / 3y+	Female [b]	Hispanic	College	Married	Stay at home mom	29 / 32	Unexplained infertility, 1 miscarriage	Tracking, 1 IUI / Tracking, 6 IUIs, 1 Mini IVF	2 / 5	Yes / No
P5	30	2y / 3y+	Male [b]	Caucasian	PhD in progress	Married	PhD student	24 / 27	Same as P4	Same as P4	2 / 5	Yes / No
P6	32	4y+	Female	White	Bachelors	Married	Teacher	28	3 ectopic pregnancies	Holistic treatment, tracking, IVF	3	No
P7	40	1y+	Female	White, Ashkenazi Jew	MS	Married	Speech therapist	39 [a]	Insulin resistance, PCO	Tracking, homeopathic treatment, progesterone treatment	3	No
P8	34	4y+	Female	Asian Korean, Hmong	-	Married	Math and Science instructor	30	Fibroid	Tracking, fibroid surgery, 3 IUIs	1	No
P9	40	10y	Female	Asian Chinese	MS	Married	Accountant	30	3 miscarriages, partial mole	Tracking, ovulation stimulation, 3 IUIs, traditional Chinese medicine	3	Yes
P10	34	1y / 5m+	Female	Hispanic	Bachelors	Married	Medical field representative	32 / 34	PCOS, dermoid cyst	Tracking, birth control to have periods, cyst surgery, IUI / Tracking, IUI	1 / 1	Yes / No
P11	39	2y	Female	White European	PhD	Divorced, Married	Professor	24	PCOS, 1 miscarriage	Tracking, progesterone treatment, ovulation stimulation	1	Yes

P#	Age	Time	Gender	Ethnicity	Highest degree	Marital status	Profession	Age TTC	Diagnosis and events	Actions and treatments	HP	Conceived
P12	31	1y 6m	Female	Brazilian white	PhD	Married	Professor	29	Endometriosis	Abortion, tracking, endometriosis surgery, endometriosis medication	3	No
P13	28	2y 8m	Female	Caucasian white	BS	Married	Software engineer	23	PCOS, MODY diabetes, unexplained male infertility	Tracking, ovulation stimulation, IVF	5	Yes
P14	49	6y / 1m	Female	Caucasian	BA	Married	Non-profit worker	28 / 37	Unexplained infertility, 1 miscarriage	Ovulation stimulation, IVF / Tracking	1 / 0	Yes / Yes
P15	31	3y+	Female	Caucasian Hispanic	PhD	Married	Post-doc fellow	29	Endometriosis	Tracking, ovulation stimulation (endometriosis surgery and IVF postponed due to the pandemic)	4	No
P16	33	4+	Female	Brazilian	MS in progress	Married	Physician	30	PCOS, male factors	Tracking, starting IVF	4	No
P17	30	2y 2m+	Female	Caucasian	JD	Married	Attorney	28	PCOS, anovulatory	Tracking, medication for PCOS	4	No
P18	31	3y 6m+	Female	Caucasian	Some college	Married	Concierge	28	PCOS	Tracking, ovulation stimulation, 1 IVF, starting 2nd IVF	2	No
P19	34	2y	Female [c]	Latina white	College	Married	Program manager	30	Endometriosis, tube problem, 1 miscarriage, blood clotting disorder	Tracking, laparoscopy, endometriosis removal and birth control, ovulation stimulation, 1 IVF	2	Yes
P20	41	2y	Male [c]	Brazilian white	PhD	Married	Professor	37	Same as P19	Same as P19	2	Yes
P21	41	2y+	Female	White	MS	Married	Researcher	38	Fibroids, 2 miscarriages	Tracking (fibroids surgery cancelled due to the pandemic)	2 teams	No

The average age of participants when they first faced fertility challenges was 29.85. The average time TTC was 33.48 months (approximately 2 years and 9 months) and the average number of healthcare providers they worked with was 2.59 (both these averages consider first and second child attempts). The time to conceive the first child was between 1 and 10 years, while the time to conceive the second was between 1 month and 1 year. Both these times consider only the length of fertility trajectories of participants who conceived. These numbers can then increase since 11 participants were still TTC when I interviewed them.

Interviews with individuals and partners followed a narrative approach (Elliott, 2020; Jovchelovitch & Bauer, 2000) to solicit their lived experiences and situated life events during their fertility trajectory. Narrative interviews support the investigation of ecologies of care because they foreground the context of people's experiences and their own explanations about them (Elliott, 2020; Jovchelovitch & Bauer, 2000). The interviews happened as follows (Jovchelovitch & Bauer, 2000): first, I explained the project (initiation phase) and used *"a generative narrative question"* (Riemann & Schütze, 1991) (i.e., can you tell me about your experience trying to conceive?) to invite participants to share their personal experiences (main narration), signaling attentive listening to encourage the participant and taking notes when necessary. After the participant clearly signaled ending the narrative, I asked clarifying questions (questioning phase), to guarantee a clear understanding of their fertility trajectories, and follow-up questions when certain aspects were not described sufficiently.

Healthcare Providers

I used semi-structured interviews with the five healthcare providers because such method allows for openness of responses and for ensuring all aspects of interest were covered. Because the focus of this study was on individuals' experiences and the influences on them, my focus with providers' interviews was on their interactions with patients, not on their own work experiences or the factors that affect their work experiences. Therefore, semi-structured interviews were more appropriated for this case. I developed the interview protocol based on previous literature review and an initial meeting with the clinic. The interviews focused on (i) healthcare providers' experiences conducting fertility treatments, (ii) their attitudes towards self-tracking technologies and data, and (iii) their views of patients' fertility experiences.

5.4.3. Data Analysis

All interviews were recorded and transcribed. I and a collaborator used a mix of inductive and deductive approaches to data analysis (Creswell, 2007) in two different stages. First, we read a subset of interviews to discuss themes and identify ways of coding the data. In this stage, one main theme emerged from the interviews: *"the unknown"* generated by the uncertainties related to fertility and how participants use data to understand this *"unknown."* Following this main theme, I then conducted two coding stages.

First Coding Stage

Individuals' and Partners' interviews: based on the initial analysis and discussion, I analyzed individuals' data using the illness trajectory concept proposed by Strauss et al. (1985) as a lens. This concept "*refers not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization*" (p.8). Later, Riemann and Schütze (1991) generalized the concept of trajectory into a "*central category denoting disorderly social* *processes and processes of suffering*" (p.337) which are structured by events that feel out of one's control. I used this concept to analyze patient participants' narratives because I believe their data work is intrinsically connected with their trajectories. I call these trajectories as fertility trajectories to better reflect the experiences of the participants.

I then reconstructed each participant's fertility trajectory based on their narratives. Patients' narratives tend to highlight the aspects people consider more important because those are the ones they more easily recall, particularly when they are recollecting facts that happened in the past, as it is the case for many participants of this study. After discussing a few reconstructed trajectories, my collaborator and I identified three main aspects highlighted by patients in their recollections: participants' data tracking activities, their interactions with healthcare providers during treatment processes, and the fertility-related events participants encountered throughout their trajectories and the consequences of such events. Each individual trajectory was then plotted into a timeline, following these three aspects participants self-reported in their narratives (see Figure 5.2 in results for examples).

Providers' interviews: the initial analysis and discussion prompted to further analysis of providers' interviews using open coding (Charmaz & Belgrave, 2012) and focusing on their work practices, their interactions with patients, and their assessment, attitudes, and usages of patients' self-tracked data.

After analyzing the data from individuals and partners and from healthcare providers separately, I coded the whole dataset together in an inductive manner, focusing on patients' and providers' data practices, and their relation to *"the unknown."* Relationships (individual-partner, individual-providers, individual-others), data interactions (individual-data, partner-data, provider-data, others-data), infrastructure, misconceptions, learning, and emotional experiences, are examples of codes that emerged from this analysis. At this point, I identified the influence of multiple stakeholders and the different levels of environmental systems involved in participants fertility trajectories specific to this data corpus. I then decided to leverage the EST (Bronfenbrenner, 1977, 1992) as a theoretical framework to reanalyze the interviews and explore the ecologies of care involved in fertility trajectories and better explore the different relationships described by the participants, the role data plays, and how data influence their experiences.

Second Coding Stage

In the second stage of analysis, I re-analyzed the whole dataset one more time using a deductive approach, conducting open and focused coding (Saldaña, 2015) focusing on the layers of the ecological model, individuals' main relationships with others and institutions, the relations among them, and how this whole ecology influences individuals' fertility trajectories and related data work. Throughout the whole coding process, I met regularly with my collaborator to discuss data analysis.

5.4.4. Limitations

This study has limitations that reflect the challenging nature of this population and the nature of the model. First, because fertility is sensitive, invisible, and stigmatized, recruitment is generally difficult. This is reflected in the low diversity of participants, who were all heterosexual cis people, from medium to high socio-economic status, not representing diverse experiences and critical challenges faced by other individuals who menstruate. Participants also did not include Indigenous, Black, and other minoritized individuals who may experience diverse influences particularly in the exo and macrolevel. Second, most participants (16) live in the U.S., therefore, as many of the factors emphasized by the ecological model are culturally and institutionally shaped, the findings can only speak to the U.S. or western contexts. Third, although the EST model includes various stakeholders and different institutional and social factors, it is challenging and near impossible to study all the involved entities as many of them are unknown and invisible to me (e.g., the designer of fertility app, the insurance representative). Thus, I opted to focus on individuals and to unpack the relationships through their lived experiences. I attempted to recruit partners, but due to the sensitivity of fertility, I was not able to recruit many of them. Also, my study focuses on female fertility, therefore, male experiences with infertility are not discussed in this dissertation (I refer to Patel et al. (2019) for a discussion on the theme). Finally, the five healthcare providers I interviewed were all REIs and worked in the same clinic. However, individuals facing fertility challenges often work with multiple providers from different specialties. It is likely that the practices the REI participants described are not generalizable to the practices of every healthcare provider from every specialty. I addressed this limitation by getting patients' accounts of their interactions with other healthcare providers, however, it would be useful to conduct further interviews with a more varied group of providers.

5.5. Results

In this section, first I provide a rich description of how fertility trajectories are complex and involve different challenges, explaining how they are entangled with what my participants referred to as *"the unknown."* I then describe the application of the EST to the fertility context, reporting data use in each layer, including how data mediate relationships and support treatments, how different personal and institutional spaces need to be coordinated with data, and how broader socio-cultural patterns influence individuals' fertility experiences and data work.

5.5.1. A Plurality of Fertility Trajectories

Individuals' lived fertility trajectories are distinct, full of "alternative paths," and unexpected challenges. In this section, I present two examples of fertility trajectories from my participants to illustrate the complicated processes and factors that might influence them. All names are pseudonyms.

Claire (P9) – 10 years of western and eastern medicine: Claire was 28 when she conceived and had her first miscarriage. After that, she and her partner started actively trying to conceive, but she *"didn't get pregnant for quite a few years… I just feel that maybe I was too skinny, or I was too stressful. My work is giving me too much pressure. So I was trying to find the reasons that I can probably change…to help the process*." She used a fertility app and a digital spreadsheet, tracked period dates, intercourse, temperature, and monitored her lifestyle measures (e.g., diet), mood, and symptoms (e.g., stress). She conceived again but had another miscarriage. She and her partner then looked for a specialist that did several tests *"but unfortunately, they didn't find anything wrong. You know, we were hoping that they could find anything wrong so that there is something to fix."* They kept trying on their own, also using OPKs, until an exam indicated the presence of a partial mole (a tumor generated by problems during egg fertilization (Cavaliere et al., 2009)). Because of the risk of turning into cancer, the specialist suggested to stop trying to conceive for a year to monitor Claire's health. *"It turned out that it was totally benign, there was nothing, and they weren't even sure if that really existed."* After that year, Claire and her partner conceived again, facing another miscarriage. They changed their insurance to see "*more prestigious infertility doctors*." They did three IUI cycles *"along with a lot of tracking, like doing ultrasound every couple of days…to basically monitor the whole ovulation process."* None of the IUIs led to pregnancy so Claire ended up "*kinda like giving up on the western medicine*" and decided to try traditional Chinese medicine (TCM). She spent three years taking herbal medications (*"the herbs, and you boil it and you just take it. You don't know if that helps, but just pray that it's gonna help"*), doing acupuncture, and monitoring blood pressure, pulse, and hormones. Eventually she stopped seeing the TCM doctor and conceived after almost giving up completely.

Anna (P11) – obsessing after a miscarriage: Anna was 24 and in graduate school when she started trying to conceive. She stopped taking birth control, but she did not get a period for many months. She then started a progesterone treatment prescribed by her midwife, got a fertility book, and started tracking temperature using a digital spreadsheet, *"just kinda lightly tracking stuff…I wasn't super committed to it."* She conceived but had a miscarriage, which was a very difficult experience: *"I had just not even thought that that could happen, and it was a huge shock. For me, it was a super hard loss, and I had a big depression afterwards."* She became afraid she would not be able to conceive again: *"who knows where these thoughts were coming from, but it was just a lot of fear."* At some point, she had to return to birth control because she had recurrent bleeding, *"which was really frustrating to me because I was like, 'no, I'm trying to get pregnant. I don't wanna be on birth control pills.'"* The miscarriage experience led her to track more, trying to understand the causes and avoid other miscarriages: *"that's when that [tracking] really, really intensified, and I started to use the software. I was tracking all of my symptoms. I was tracking my temperature every day. I was tracking my periods and intercourse and everything."* She also tracked cervical mucus, cervical position, symptoms, OPK results, and medication. *"I was using that [software] for months. I had months and months of data; I got really obsessed with it."* She also started a treatment with medications to stimulate ovulation, prescribed and led by her midwife. She did five cycles of ovulation stimulation alongside tracking, until she finally conceived: *"it was interesting because…the cycle that I got pregnant…it didn't seem like I ovulated…I never ovulated, according to the software. But I still got pregnant."*

Figure 5.2 summarizes Claire's and Anna's fertility trajectories. These two participants were young when they first started having fertility challenges, younger than the age fertility is typically expected to decline (CDC, 2021; Quaas & Dokras, 2008). Their trajectories have different lengths; while Anna conceived in two years, it took 10 years for Claire to conceive. Figure 5.2 also highlights the different healthcare providers they worked with (REIs, TCM doctor, midwife), the different treatments they tried (IUI, ovulation stimulation, TCM), the various fertility-related events they experienced (miscarriages, partial mole), and the intense tracking activities they performed.

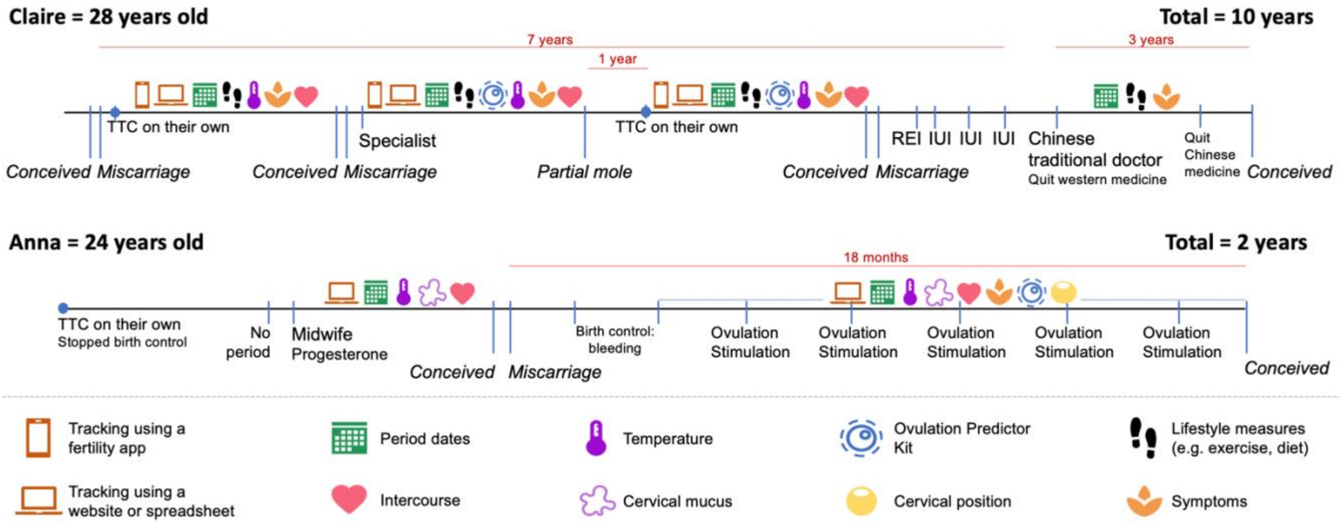


Figure 5.2. Claire's and Anna's fertility trajectories

Claire's and Anna's cases are not common or typical: every fertility trajectory is different with unique experiences and challenges. For example, P1 visited five different healthcare providers who dismissed her painful periods until being diagnosed with endometriosis. P2 had to rent a car to see an infertility specialist in a different city, but conceived one month before treatment. P3 did not know anything about tracking until her OBGYN told her to track OPKs and temperature, which she used to conceive three times, with one miscarriage in between pregnancies. P6 engaged in intensive tracking and worked with different healthcare providers to try to conceive *"naturally,"* but after 3 ectopic pregnancies she decided to move to IVF. After having the first child without difficulties, P7 engaged in intensive tracking, using up to 5 fertility apps at once, to try to conceive her second child. P8 tried initially on her own using tracking, then she did three cycles of IUI alongside tracking, which did not result in pregnancy. P14 had her first child through IVF after 4 cycles of ovulation stimulation and 6 years of trying. She had a bad experience with the IVF treatment and turned to tracking to conceive her second child, which happened in the first month. P17 was diagnosed with PCOS after trying for a year and started to track multiple health indicators using several pieces of technology. She had her first sign of ovulation by the time of our interview. P19 discovered her painful periods were due to endometriosis only when she was diagnosed with infertility. After two years of intense tracking and trying ovulation stimulation, she conceived through IVF and plans to do another one to conceive the second child. P15 and P21 had their different surgeries (endometriosis and fibroid) cancelled or postponed due to the COVID-19 pandemic, while P16 moved to a different country and had to restart her trajectory after settling down. All three keep tracking some measures during these interruptions in clinical treatments.

A common aspect of these experiences is the presence of tracking: all participants performed some level of tracking and engaged with their data. Data tracking, either by apps or by other means, plays an important role in individuals' fertility journeys. As illustrated by Claire's and Anna's trajectories summarized in Figure 5.2, participants use a variety of tools to track a variety of health indicators, starting, changing, intensifying, or reducing tracking in different moments of their journeys. Claire's and Anna's cases also illustrate how individuals' data work is directly connected to the complexity and uncertainty of the fertility context. Claire used tracking throughout the years to try to identify the reasons why she was not getting pregnant. Anna intensified her tracking to understand the reasons and try to avoid another miscarriage. In both cases, the end goal (i.e., pregnancy) was uncertain, no matter how hard they tried. All participants faced similar uncertainties, leading them to *"resort to these [data practices], kinda trying to make sense out of… nothing because there's just such little information"* [P11]. Individuals used their data practices to deal with what some of them called *"the unknown"* every step of the way.

To understand how this unknown influences data work in the individual level and how it influences and is influenced by individuals' broader ecologies of care, I adopted an ecological perspective, using the EST to consider the multiple stakeholders, institutional, and societal aspects involved in fertility data work. The next sections describe the application of the EST to the fertility context, highlighting how individuals use data to approach *"the unknown,"* and reporting the most important relationships and the associated data use identified in each layer, how data mediate relationships and support treatments, how different personal and institutional spaces need to be coordinated with data, and how broader socio-cultural patterns influence individuals' fertility experiences and data work.

5.5.2. Individual Level: Using Data to Approach the Unknown

Fertility is extremely complex, involving intricate hormonal processes not completely understood scientifically (Speroff & Fritz, 2005). Struggles in fertility trajectories are also per se unexpected, since people commonly do not anticipate they will face challenges to conceive. Besides, pregnancy is often central to many individuals' life plan. This combination of complexity, invisibility, and life goals creates stress and stigma for individuals facing challenges to conceive (e.g., "*you feel alone, and you feel defective*" [P14]), commonly leading them to experience a feeling of groping in the dark and lack of control.

As uncovered in study 1, the uncertainty of fertility comes from many factors related to its idiosyncratic nature, personal variability, and indicators that are uncertain, subjective, or difficult to interpret and cannot precisely pinpoint ovulation. All these factors add to the clinical uncertainties of fertility and make the whole experience very complex and uncertain. Amidst all these uncertainties, many participants explained that the biggest challenge of their fertility trajectories is dealing with *"the unknown of everything"* [P3], which is generated by the uncertainty of not knowing what is wrong or if treatments will work. P9 summarized the general feeling of facing fertility struggles for over many years:

> *"Just the unknown. Like you never know what's the end result because nobody can give you an answer, or give you like a plan, and you just follow this plan and it's gonna happen. Or it's all gonna be fine after how long. Nobody can give you a clear explanation or a definitive answer. So basically, you are just going but not knowing the direction or the light. You don't know where is the light. Yeah. So, it's just unknown."*

The unknown resulting from this uncertainty is often the hardest part of patients' fertility trajectories. Hence, individuals turn to data tracking in the hope of increasing their chances of pregnancy and sense of control. Tracking then becomes a way to explore the unknown: participants use data in an exploratory way, tracking new measures and lifestyle practices over time, trying to triangulate the data to increase their chances of conceiving amidst the uncertainty of fertility. P7 described a clear example of using data to explore the unknown, explaining she was *"slowly adding stuff. It was more like every month that ticked by, I kinda needed a greater sense of control, so I was the one that was like, 'Okay, I'm gonna take my body temperature, and I'm gonna buy something else to help me feel like I can control this, I can be in charge of this."* She even used multiple apps at the same time (5) to store and analyze her data, and to compare the different feedback they provided: *"I was like, 'I'm gonna cover all the bases.' Do you know what I mean? What's lining up?"* [P7].

Amidst all the uncertainty of fertility, tracking becomes a way to find *"some information and some kind of hope"* [P13], to get *"some sense of structure"* and avoid the feeling of *"roaming aimlessly"* [P10], and to cope with the emotional toll of dealing with the unknown: *"but because of the way…I deal with uncertainty through information-seeking, I actually think it was a way that I was able to stay calm and maintain some sense of control, even though it was sort of a difficult time"* [P11]. Tracked data can help individuals learn about their bodies, which they describe as being *"really fascinating"* [P1], and set appropriate fertility expectations: *"it [app]…tells you…how much of an outlier that cycle is…I found that very useful, especially when nothing was happening"* [P15]. In summary, seeing and interacting with data increased participants' sense of control because it gave them a feeling of acting to turn the unknown into known.

However, fertility data are often not easy to understand. As P3 highlights tracking *"is really quite fascinating but they're also kind of tricky."* Data interpretation was not as straightforward as some participants expected; especially considering these data work is immersed in their daily lives. For example, some measures require strict steps to be collected, which are hard to fit in a person's routine: *"I have an infant who doesn't wake up at the same time every morning. And if I had to sit here for two minutes, listening to her cry while I take this stupid temperature reading, you've gotta give me a break. That doesn't work with our lifestyle, right?"* [P7]). To some participants, these demanding requirements to collect data created *"all these variables that were just like user error"* [P7] and the complicated process required to collect data creates noise that hinders data analysis: *"It always has some noise, so to speak, so when you wake up one morning, maybe you ate too much the night before, and your body temperature will be affected. So, there is a lot of noise in your data. It's not easy sometimes because, you know, the temperature doesn't show the pattern anymore"* [P9].

As these examples show, tracking activities directly impact people's daily lives. In another example, data collection and interpretation challenges can also impact individuals' sexual experiences: P12 described that for some time, the data became so important to her that her sexual activity was focused on them. She explained that she *"tried to have intercourse in that period [fertile window]. And sometimes I finished it [intercourse] and then I went to the app to make notes, so it was not good."* Living with data often turns to be confusing and complicated: the data are often imperfect, take too much effort to collect, are difficult to understand, impact individuals' routines and activities, and do not tell them why they cannot conceive even if they track everything they can. Therefore, having data does not mean understanding, especially in a context so naturally uncertain and largely still unexplained as fertility. P4 explained this interaction between data and hope using the analogy of a rollercoaster: "*It's [an] emotional challenge of being on a rollercoaster of uncertainty. So, it's an emotional rollercoaster, really. For the first two weeks, you work really hard. You're excited. You're going to do it. And then, for the last two, you really don't know. And then comes the result. So – oh, that uncertainty – it's huge. It's a big challenge*" [P4]. More so, data may even intensify this rollercoaster experience, as explained by P12 who would compulsively check her data while her hopes got high and down during the cycle: *"You did your job, you got a good probability of being pregnant, and you are in the middle of 2 periods. And your period should come in the day 2 and then it doesn't come. And it is day 5. Then I start to check [the fertility app] almost compulsively and when my period comes it makes me feel sad, makes me feel nervous, makes me feel stressed. It wasn't very good for me"* [P12].

As Chapter 3 explained, individuals' data work and their emotional experiences are entangled and mutually dependent. Some participants experience undesirable fertility-related events (e.g., miscarriages, partial mole) that negatively impact their emotional experiences and data work, as exemplified by P11 in the next quote. Such events increase individuals' emotional toll, affecting their data work and their relationships with data.

> *"I think my tracking probably would have been much more just in sort of, 'this is fun and interesting,' if I hadn't had the miscarriage first. I think that having a miscarriage really – that was such a difficult event for me. I grieved a lot and I became really depressed about the loss. I think that then sometimes the tracking became one way of kind of obsessing about that. You know what I mean? Like, 'will it happen again?' I was really scared about that" [P11]*

Together, the disappointed, unexpected, unpredictable, and undesirable experiences most participants lived also remind them that, even after intensive tracking, the unknown remains unknown. And these experiences spread to individuals' whole lives as explained by P11:

> *"It takes over your whole life. It's something where, even getting up and going to work when you were dealing with recurrent pregnancy loss for three years or something like that and you're supposed to be a productive worker is – that's so hard. I feel like we need support on all levels, like social support, institutional support, emotional support, medical support because I think it's just, we don't recognize the physical and emotional burden" [P11].*

As this quote suggests, although these fertility activities and data may be personal and private in nature, they are situated in broader contexts. They are influenced by diverse factors and stakeholders in the whole ecosystem, including partners, healthcare providers, peers, healthcare institutions, social expectations. The next sections describe and explain the relationships between the individual and the main entities identified in each layer of the EST, highlighting how they influence and are influenced by individuals' fertility data and data work in the uncertain context of fertility.

5.5.3. Microlayer: Data and Immediate Relationships

The microlayer encompasses individuals' closer ties which in this study included partners, healthcare providers, family & friends, and peers. These relationships are largely influenced by the uncertainties of fertility. Below I summarize how data is extensively used and shared across this layer, in different formats and amounts, and at different moments.

Partners: Involved in Fertility Process but not in Data Tracking

Partners are often individuals' closer relationship in their fertility trajectory. Since all participants who carried or would carry the child were cis women in heterosexual relationships, this section refers to male partners. Trying to conceive is often a couple's shared trajectory that is discussed and agreed by both parts. However, aligned with previous studies' (Homewood, Boer, et al., 2020), tracking tends to be individual.

Tracking Male and Female Bodies

Unlike for the female body, there are currently not many health indicators directly related to male fertility that could be self-tracked at home (e.g., sperm quality can only be analyzed in laboratory), as highlighted by P5: "*we've been doing things like basal body temperature and tracking cycle…I'm not actually even aware of anything that is useful to track for men…Most of it is for – it's just for her.*" Mostly, the only indicators that can be tracked by male partners to improve their fertility and the couple's chances to conceive are lifestyle measures, such as exercise and diet, and medications or vitamins. However, it is often the female partner who track and manage these data, often by memory, which may involve memorizing different and even opposed schedules, as explained by P13 in the following quote. This work adds to the tracking of their own measures.

> *"For male fertility they suggest pumpkins seeds, a quarter cup a day, a multivitamin that has magnesium and zinc, drinking at least a gallon of water a day, no soda. You want to have lower fat…My husband and I were drinking different types of milk. I think he was supposed to have lower fat and I was supposed to have higher fat milk. Whatever it was, we had different milks in the fridge…And then, the amount of fat in your diet was slightly different…I guess that was me [who managed the different*

> *diets]. I just tried to keep track of everything and kept a little schedule going on…Most of it was just me trying to meal plan and snack plan appropriately" [P13].*

P7's partner was the only partner from my sample that became very involved in tracking. As P7 described, he tracks her data with her. She collects the data, and he stores them using a manual system. Then they look for patterns together: "*So, with the mucus, he tracks it every night. Like, he physically writes it down, and there's some code that he does, some sticker system. I don't know. It's his job. I just report out what I'm experiencing, and his job is to record it, which is really nice, like so nice…that's his job. And my job is just to relay the information. But we're looking for patterns*" [P7].

In contrast with P7's experience, tracking female fertility data is often a task for the individual only and most partners do not directly track or interact with data. According to my participants' descriptions, all the other partners did not or do not directly participate in their self-tracking activities. By far the most common attitude is to defer to the female partner, because it is her body. Thus, the predominant dynamics is the female partner taking the initiative of tracking and bringing the decisions to be discussed by the couple: *"my perception is that he thinks it's my life, it's my body, I have the right to decide when and what to do. We discuss but I never felt that he imposed something or really manifested something. It's on myself. I decide everything basically"* [P12]. Although this a respectful support, an unintended consequence is the risk to letting the female partner alone in dealing with the unknown.

Although partners may not directly track, they are influenced by tracked data. For instance, P20 and P5 reported being very aware of their partners' tracking activities, describing them in detail and as a joint experience (e.g., "*We ended up dropping that [temperature tracking] after a while because we felt we were getting a good enough idea of the window anyway*" [P5]). Partners also participate in medical procedures when couples look for more specialized infertility treatments, as described by P8: "*So, my reproductive endocrinologist nurse…also showed my husband…how to use it to inject me [the medication to stimulate ovulation] and what to expect*" [P8]. This participation offers a great support to the individual, positively influencing their emotional experience with the unknown. Moreover, partners need to act upon data results: having intercourse in the fertile window, often being as affected by the consequences of data work challenges as the individual. For example, P10 faced problems with OPK, getting 15 days of high fertility but no peak for multiple months, which was confusing and exhausting for her and her partner:

> *"That blinky smiley face [high fertility indication] was 15 days long and I never got an ovulation day… And I never got pregnant for those 3 months. And based upon the length of my cycles, it honestly got very frustrating. We were just like, 'Okay, we must've gotten the window,' and it was like we got sexual fatigue. Even my husband was like, 'Can we take a break?' I was like, 'Yes, we can totally take a break'" [P10].*

Finally, partners also have to adapt their schedules and work to accommodate various needs in the fertility process and support their partners through every cycle whatever the results are, as illustrated by P14's quote "*I was more invested, I guess, than he was. Emotionally invested and he was there for me, and with me, and wanted children too, but it wasn't the same kind of emotional investment. So, he was mostly as my support. And a willing and engaged participant.*"

Conflicting Views of Tracking

In this shared context, it is natural that conflicting views of tracking may arise. Besides P7, the only other example of partner directly tracking female fertility in this study's dataset was described by P14. When trying to conceive their first child, P14's partner tracked her cycle days by memory, but he actually did not believe in any other tracking activities or tools:

> *"My husband is a math guy, and he kept track of the cycle for me, just, in his head. Because it was a numbers thing. So, that was the only information we had…Although, I do remember a conversation with my sister-in-law. She was like, 'Have you tried an ovulation kit?' And my husband scoffed and said, 'You mean an egg timer?' So, you know, we didn't think it was necessary" [P14].*

Despite that, to conceive their second child, after a bad experience with IVF in her first pregnancy, P14 used a wearable to track temperature.

Some partners actually dislike tracking. For example, P20 described he did not believe or like tracking in the beginning: "*She [P19] would show everything to me. And she was very enthusiastic. And somehow, I think I didn't like it very much because it's mechanical...So, I didn't deal with that very well…She even tried me to have the apps in my phone, too, but I wasn't very good with them.*" As he suggests, these differences can create conflicts, which was echoed by his partner, P19: "*He wasn't interested at all in my charts and in my fertility data. It was actually like a turn-off for him. He didn't wanna know. And I on the other hand, it was the only thing I wanted to talk about.*" But even not liking tracking, partners try to support individuals the best they can. P19 explained they managed to balance their different engagements with data, and she felt supported by P20: "*his support was very important to me. And he did support me. He felt different, and it's okay*" [P19]. Later, P20's opinions concerning tracking changed:

> *"Well, I think it's good that we can have an education. I don't think they are 100% reliable. At first, I would have some doubts…We're having troubles having the baby, so I would not trust the data too much. But after many, many months where she could show me the trends and it would repeat every month. So, I was like, oh, maybe this is really something interesting and helpful. So, even though we didn't have much success, I ended up thinking that it was very good to have those tools" [P20].*

Managing Each Other's Emotions

As P19 and P20 example illustrates, partners often take the role of emotional support, trying to be stronger for the partner who experiences most of the physical and emotional struggles of fertility tracking and treatments: *"I always tried to be strong for her, so she wouldn't have both of us down*" [P20]. In another example, P9 explained how her partner's support was critical when she faced the scary partial mole diagnosis:

> *"He always encouraged me, and he would make sure that I didn't feel pressured. And he would do a lot of research on his side, and he would kinda summarize and let me know what he thinks about it, especially during the time when we were suspect to have the partial mole. We were doing a lot of blood tests and all kinds of tests during that year because that's a lot of uncertainty…So he was doing a lot of research because I was so scared. I didn't want to even look at those researches because sometimes those researches can sentence you to death. You know what I mean?… So yeah, so he carried a lot of burdens for me." [P9]*

Although the female partner usually takes more of the impact of infertility, it also impacts the male partner, who has their own needs and experiences. Even not tracking, the male partner can be as emotionally impacted by tracking results as the female partner, as exemplified by P20: "*when it doesn't work, it just makes you feel really down because you have done everything you could, and you have timed it. And then, the period comes. And then, you keep doing that over and over again, it's discouraging*" [P20].

In this shared journey, dealing and managing each other's emotions is a constant sentimental work (Strauss et al., 1985), which evolves with time during individuals fertility trajectories. P7 provides an interesting example of the evolution in the relationship between her, her partner, and data:

> *"One thing I'd say is hard about my husband is he's very sweet, and he's trying to be sensitive…every night we check in: 'How was your mucus? How was your period?' …the days I had to tell him 'Oh, I got my period' there's typically this response…he does this thing…'Oh, really? Oh, no.' Like that kind of thing, right? And I had to tell him, 'Honey, I really appreciate you trying to sympathize with me, but I'm actually okay. I think there was a time where I was there, and I'm actually not there anymore when I get my period.' So, now, when I hear it, I'm like, 'Oh, no. You're disappointed.' And I don't want it to get to the point where it's like, 'Oh, I let you down.' Right? Because I haven't. I know I haven't. So, I just told him, 'This is what comes up. I'm actually okay…My emotions have shifted a little bit around this situation'." [P7]*

In summary, these examples show that partners need to balance respect and involvement in order to support the individual. This balance is another delicate and idiosyncratic aspect of fertility that involves one's body autonomy and relationship styles that need to be negotiated amidst the unknown. They also show that this negotiation is highly impacted by data and individuals' and partners attitudes towards data, which are intrinsically related to their emotional experiences with the uncertainties of fertility.

Healthcare Providers: Sharing Specific Data to Facilitate Treatments

The second closer relationship in the microlayer is often with healthcare providers, which can vary greatly. My participants described working with OBGYNs, OB nurses, midwives, urologists, REIs, endometriosis surgeons, traditional Chinese medicine doctors, geneticists, holistic doctors, fertility acupuncturists, homeopathic specialists, and metabolism specialists. As described in Chapter 2, people with fertility challenges often go through a long and complex treatment process from the regular family doctor to specialists such as REIs and going through different treatments. Thus, healthcare providers are an important entity in the microlayer. They also directly receive patients' data and use them in their own way to approach the uncertainties of the fertility context.

Dealing with Fertility Uncertainty

Fertility is not uncertain only for individuals: uncertainty is also part of healthcare providers' work. The main uncertainty for them comes from the fact that the mechanisms of fertility and the causes of infertility are not completely clinically understood. The field of Reproductive Endocrinology and Infertility is still considerably new, and many of the current medical tools and processes are recent. For example, D4 explained that OPKs are a recent development: *"it's really just been my generation—the last 30 years I would imagine—that we had a kit [OPK] to detect it [ovulation]."* Besides, the diagnosis process naturally involves uncertainty. For example, as D1 exemplified, even OPKs may not be 100% accurate: *"so* *particularly in patients that have polycystic ovary syndrome, there is a risk of false positive ovulation predictor kits. But we don't know – that doesn't happen in everyone that has PCOS."*

Additionally, it is not uncommon that physicians, including REIs, cannot identify the cause of infertility. All REI participants in this study described seeing patients with unexplained infertility in their daily work. D3 explained that these patients are especially difficult to treat because the cause of their infertility may be due to factors that our current medical knowledge cannot recognize: *"the patients who are more difficult are the unexplained patients, because they may have some type of implantation factor [a factor impacting the attachment of the egg to the uterus] or something that we don't have the means to test for yet"* [D3]. If the patient has unexplained infertility, healthcare providers need to define treatments to achieve pregnancy without solving its underlying causes.

Data Valued by Providers

In this context, providers largely use PGHD. Patients' menstrual history is critical information for providers and they generally value patients' tracking data for this matter. These data provide a source of cycle information that allows treatment to begin sooner, as explained by D1:

> *"I think they [fertility apps] are actually really helpful for that main intake of history, because if we have someone coming in for an evaluation for infertility and they don't have any of that information, it sort of delays their evaluation a bit, or makes their evaluation more difficult, because without tracking, they can't really answer that question about their menstrual cycle. And I think that's one of the most*

> *important starting points in evaluating someone who's trying to conceive. So, it's really helpful"* [D1]

Besides the initial history, REIs also need PGHD to identify ovulation patterns, a necessary step to proceed with their evaluation and treatment decision. As the previous quote suggests, if patients already have tracked data that indicate ovulation, it may save them months. In cases where patients have never tracked ovulation before, or in cases where they have irregular cycles, it is common for REIs to ask patients to track for a few cycles, as explained by D2: *"so, patients who cannot recall menstrual pattern or who seem to have long menstrual patterns, we ask them to track…the beginning and the stop dates of their menstrual period. And if they do use LH kits [OPKs], to track the results."*

However, as this quote indicates, REIs consider and ask for only a few types of data, mainly period dates and OPK results. They combine these data with radiology and laboratory tests they conduct, which are often used to confirm what patients reported and to explore possible factors for infertility, as explained by D1: *"then other helpful things after I know that [menstrual history] are to do an ultrasound, to look at the ovaries and the uterus, because that can give me more details to explain why their menstrual periods are occurring the way that they've described."* Other data tracked by patients are often not viewed as useful from REIs' perspective. For instance, while many individuals interviewed in this study attempted to precisely measure and understand their temperature data, these data were often considered controversial by the REIs because it does not work for everybody (which is aligned with the challenges individuals described): *"it doesn't work for everybody, just like the ovulation predictor kits don't work for everybody, but I pay attention to that…But if they were able to* *track their temperature and they have a clear spike in the temperature, that's useful information"* [D5]. Similarly, cervical mucus, another type of data valued by many individuals, is considered *"nonspecific"* [D2], *"not reliable"* [D1], or *"subjective"* [D3], by the REIs I interviewed, and they do not use it. D4 explained that these measures were probably more useful when more precise data and tools were not available, describing it is still good to know that patients identify fertile characteristics (color and consistency) in their mucus, but they do not use these data: *"I think in the past when we didn't have the ovulation predictor kits, it [temperature and mucus] was more helpful. And certainly, knowing that they [patients] get the egg yolk, thickening cervical mucus, it's good things to hear. But I already know from other information whether they're ovulating or not"* [D4]. These examples suggest that providers emphasize controlled and objective data, which are expected to have better quality and reliability.

Dealing with Patients' Engagement with Data

Data also create the need for healthcare providers to deal with patients' engagement with data, dealing with their expectations and anxieties. For instance, some individuals take their apps or data spreadsheets to providers. The REI participants reported that a smaller portion of their patients *("probably 15%"* [D4]) seem to get obsessed with data tracking, collecting several months of data for multiple health indicators, as explained by D4:

> *"I've had several patients come, and they have literally an Excel sheet of data. And they'll say, 'this is the length of my menses this cycle. This is the number of days that I've bled.' And they've tracked the last 12 months. And, 'this is the consistency of the bleeding. This is my basal body temperature. This is my cervical mucus. This is my*

> *ovulation predictor kit. This is my days of intercourse.' I mean, so they literally come in with this Excel data sheet" [D4].*

However, this level of detail is not helpful for REIs. The data they need is more defined and summarized, which is often better captured through a conversation than checking months of data points, as exemplified by D1: *"Some people also track…the number of days that they bleed…For people that have irregular bleeding for some reason, like intermenstrual spotting, the number of days of bleeding can kind of be helpful, but in general, that's not more helpful than someone just saying, 'I bleed between periods,' or 'I have heavy periods.'"* [D1].

Similarly, D3 also highlighted that collecting and analyzing months' worth of temperature data is difficult for them and for patients: *"I think it's harder for me to interpret that data when they come in and they have their temperature logged for a whole month… Also, I discourage using that method [temperature] because I think it's a lot of work for the patients. I don't think it's necessary and I think there's other easier ways."* As these quotes show, healthcare providers face challenges when patients bring extensive data to them because although they do not use them, they need to respond to patients' requests.

Although patients have various experiences with providers not checking their data, the REIs I interviewed all mentioned they try their best to look at patients' data, even if just skimming through them to get the information they need. They also acknowledged that patients' data work are a *"powerful way for us to feel like we're taking control of our life, and we don't feel powerless"* [D4]. So, despite not needing these extensive records, all REIs I interviewed tried to check and help their patients interpret such data:

> *"There's a lot of science behind all of these things that is not common knowledge. And I think without understanding this, it leads to a lot of anxiety…I try to positively affirm them and then talk with them about what all this [extensive data] means. A lot of what we do is reassurance that this is occurring. Then I talk with them about healthy lifestyle choices, healthy mental habits to protect their mental health" [D4].*

As D4 indicated, since REIs work almost exclusively with fertility issues, they have a deeper understanding about fertility data and the emotional struggles patients may face. The data brought in by patients thus serve as a basis for them to understand patients' past trajectories. By understanding what caused patients' extensive (and potentially obsessive) data tracking behaviors, providers can then suggest ways to support their mental health, direct them to other forms of support, and provide enough structure and the clearer and most objective information so there will be less room for patients feeling out of control:

> *"We talk with patients about finding whatever it is that helps relieve stress for them, so whether that's mild exercise, meditation, yoga, spending time with family – we try to help them focus on those things too. And then also, just trying to make things as clear as possible so that things go according to plan and patients aren't meeting a lot of unexpected challenges, because I think that adds more stress" [D1].*

When providers do not engage in data interpretation with patients, they may feel discouraged and disengaged. P1, P7, P17, and P21 complained that providers they have seen focused on their age (P1 was too young to face challenges; P7 and P21 too old), or weight (P17), but overlooked their individual experiences that can be demonstrated through their data. Some individuals then use data to try to show providers that there may be other factors they could address: "*at my age I don't necessarily believe that doctors will take the specifics of my case seriously…The apps…help me to demonstrate to them that these aspects of my cycle the apps can track are still viable and I'm still worth taking seriously as a fertility case*" [P21].

Following the general "illness" protocol, it is less likely that young people with regular periods will have fertility issues (CDC, 2021; Quaas & Dokras, 2008). However, the average age of my participants when they first faced fertility challenges is 29.85, and five of them (P1, P4, P6, P8, P19) explicitly mentioned they always had regular periods. These examples suggest that engaging more with patients' specific data may be helpful to recognize their individual struggles that do not follow the standard decision rationale. P11 provided a good example on how patients and providers different data work can work together. She explained that, although her midwife would not deeply analyze her data, she would listen to her descriptions and consider her information. In this case, the patient talked through her data to the provider, who identified that the patient needed an increased dose of medication to ovulate:

> *"when we did Clomid, I think the first dose I didn't really ovulate. And so then, I was showing her the [temperature] chart or I was describing the data I was collecting [temperature, OPK, cervical mucus, cervical position, and symptoms] to her, and she increased the dose. So, it was that kinda thing. It's not like we were sitting at my computer looking at stuff together. I think I took my laptop to the office a couple times. She'd be like, 'oh okay. Well, just tell me what does it say.' And she was and is really good about listening to me" [P11].*

Providers can also help patients engage with their own self-tracked data differently. For instance, D2 described trying to help patients that track too much data to figure out what are the best data to use depending on *"what you are using that for,"* such as when patients use multiple types of data to predict ovulation: *"and then when you have multiple ways of tracking, it's also possible for us to help them by looking at which of those ways is best…in helping you to predict ovulation"* [D2]. Similarly, D3 commented they do not analyze their patients' self-tracked data in detail, but use the data to educate their patients:

> *"I look at it [data], I see if it's reasonable and then I tell them, 'okay, now based on this app, do you know why it's telling you to have sex during this day, at this time?' And a lot of them, most of them can explain to me why but if not, I say, 'it's not day 14 for everyone,' and explain the physiology behind that…And I think a lot of patients don't know that, so I make sure that their app is coinciding with that" [D3].*

Patients appreciate this use of their data, since it can help guide them not only through the protocol, but also through the sea of fertility information available for consumption, as described by P11: *"There's still so much we don't know about what causes fertility. But I feel like she [midwife] did a good job of helping me deal with ambiguous information and with the unknowns while giving me information that was more concrete, you know what I mean, about the things that I can do."* Such practices also foreground how much is known about fertility, which helps in avoiding creating expectations that cannot be met and supports patients in building the structure and plan they need. Finally, data can play a great role in educating individuals about fertility, which may support effective patient-provider collaboration, as described by D5: *"It's good to have well-informed patients who understand their body and who* *are in touch with their physiology. So, I think that these apps can help educate patients very well and they can be very helpful"* [D5]. Therefore, data are critical and commonly shared with healthcare providers. Although often patients and providers have different data needs and use data in different ways, their practices complement each other through data and are directly entangled with fertility uncertainties, or the unknown.

Family & Friends: Sharing (Partial) Experiences Over Time

The next role in the microlayer is family & friends, who interact with individuals closely and influence particularly their emotional experiences, both positively (e.g., supporting) and negatively (e.g., pressuring, asking insensitive questions). Despite this closeness and potential to influence, family & friends most often do not have access to data, partially because of the sensitivity of the data and stigma. Individuals most often share only experiences, summaries, and high-level issues with them, and this sharing evolves with time.

At first, individuals often do not even mention they are trying to conceive and avoid answering questions regarding having children. Some of them consider fertility something very personal that other people do not need to know. With time, when their challenges last longer, individuals often feel the need to tell some people, particularly their families. They tend to share their situations with a few close family and friends without any data. For example, P15 and her partner did not to tell their families when they started trying to conceive because they *"didn't want to get anybody's hopes up"* [P15] because of her endometriosis (diagnosed years before). But over time, they felt they should let them know to avoid questions and comments that could be negative to their personal experience: *"when we found out that it really wasn't working, we told both our families…once they knew, at least* *they were more careful about the kind of questions they asked, which made it a little easier. Now, I can call her [mother] to complain about the prices of IVF. It's better now, but that first conversation…you could see in their face they don't even know what to say"* [P15]. Individuals' relationship with their family evolves alongside their fertility trajectory, with information being shared gradually in different formats. In addition, P5 (P4's partner) explains that sharing is affected by many factors, including couple's dynamics, their relationship with others, and the fertility experiences of those they share data with:

> *"I've left the decision of whom to share with more in her hands because I feel like emotionally the judging that we would receive – she feels it more keenly… As she has felt, with individual people in the family, or some at church, or with friends, she could share, she has done so…there's just a handful in our family or others we've shared some things with. And to differing extents. Some just, in general, that we have been trying, haven't been able to. Some know that we've tried IVF. And there are some, usually family members who themselves have gone through IVF, with whom we've discussed the entire process and everything that we've gone through" [P5]*

In summary, family & friends are important relationships in individuals' lives that can influence their emotional experiences in both positive and negative ways. However, because infertility is so invisible and uncertain, sharing can become another burden to individuals, especially due to expectations and social pressure.

Peers: Sharing Detailed Data and Experiences

Peers are the last microlevel entity identified in this study's data, representing people who face similar challenges, with whom individuals are more open to share. Peers can be "real life" relationships, as in P5's experience described before, or peers from online health communities (OHC) where individuals have no prior relationships. Peers are a central source of information and support and are important for avoiding feelings of isolation. They are people who also faced the unknown, so these relationships are important to normalize individuals' experiences and to identify possible solutions that can be adapted to their specific cases, as discussed in Chapter 3. However, because fertility is invisible and entangled with taboos, it is common that individuals do not know other people experiencing fertility difficulties among their real-life relationships, as described by P11: *"I don't think most people really understood what I was going through when I went through it. I had a hard time finding any people with that experience"* [P11]. Others know a few peers in person, but because fertility challenges vary a lot, some feel more comfortable turning to online spaces, such as OHCs, where they can find people with similar infertility experiences more easily.

Individuals exchange detailed experiences with peers and data are often intensely shared in OHCs, especially when participants use the same tracking app and befriend each other in the app, being able to access each other's data, and send personalized messages based on these data. P19, a moderator in one of these OHCs, explains these interactions:

> *"When you can see another person's chart, you know where they are in their cycle. And the days right before we got our period were days that we were really anxious… By looking at each other's charts, we knew 'oh, this person is in the second week of the two-week wait. So, she's probably trying not to pee on a test'…If it was on those sensitive days, we would not say anything like 'oh, are you just dying to take a test.'*

> *And after someone got a negative or their period that would be also in the chart. So, we could go and say, 'Oh, I'm sorry you got your period again. This sucks'" [P19].*

Some OHCs even organize "buddy systems," pairing people in similar situations and facing similar challenges, so they can share experiences, such as personal feelings during treatments: *"because a lot of the women found it a little alienating…they [OHC] had a survey saying put how old you were, how long you've been trying, what kind of issues you were facing, and they would try to pair you with somebody who was very close to you"* [P15]. These examples show that OHCs can be a source both of information and support. In fact, people usually start using these spaces to find information, including information about tracking, but the ones who stay longer and interact more often, keep using them because of the sense of community: "*after a few months, you just know what to do. And you just stay because of the sense of community. And you stay because you wanna talk about it. I wanted to talk about it. It was the only thing I wanted to talk about, even in real life*" [P19].

Although some of our participants found real value in these OHCs (e.g., *"I'm on them all the time. It's really helpful"* [P18]), not every person experiencing fertility struggles uses them and among the ones that do, some do not post or interact with others much. Others may not like these spaces at all, as P20 described: *"I just think that's very depressing because people just say, oh, I lost it, I lost it again. I'm like, I can't be part of a group like that"* [P20]. P17 echoed this feeling, describing she likes but reduced her use of OHCs in part due to the burnout of "*…just constantly seeing other people's disappointments, feeling their disappointments that are so similar to mine. And then, also people having successes, which is great, but then if I'm not having a success that month, that can be a little disappointing to see*" [P17].

These examples suggest that sharing tracked data can be an important way for individuals to obtain support and information amidst fertility uncertainties; and sharing data with people who also faced the unknown and can understand their experiences is critical for their fertility trajectories.

5.5.4. Exolayer: Aligning Data and Organizational Spaces

Individuals' fertility trajectories do not exist in isolation; they are embedded in social and institutional spaces. In this section I identify three main spaces entangled with fertility trajectories: healthcare, work and life, and technology. Although personal data are not directly shared with the exolayer spaces, the exolayer must be aligned and coordinated with individuals' needs and data work. These external spaces surround the work of dealing with fertility uncertainties, influencing individuals' trajectory work, affecting individuals' emotional experience, and adding various coordination tasks.

Healthcare Space: Financial Cost and Infrastructural Fragmentation

Healthcare (particularly in the U.S.) is perhaps one of the most important yet fragmented spaces in the exolayer, which poses significant financial burden and requires extensive coordination and management work that needs to be aligned with individuals' data work, which, as explained in the previous sections, are deeply embedded in uncertainty.

Insurance and Financial Cost

Fertility treatments can impose a huge financial burden on individuals. Generally, the more complex the treatment, the more expensive it is, since the treatment may not be covered by insurance or the healthcare system. Many people simply cannot go for clinical treatment because they cannot afford it. D5 explained that the U.S. context of insurance and cost creates *“a demographic gap in access to infertility care…Not all insurances cover fertility services and that’s a problem. So, we end up selectively seeing the patients who can afford to see us, who are well informed enough to realize that there’s a problem and to…make an appointment”* [D5]. Echoing D5, P1 described her fears when she had financial hardships in her trajectory: *“my first reaction was ‘there are no programs for people with low income… because they don’t want people with low income to have children.’”* Even when insurance or the healthcare system covers the procedures, it can take longer than individuals are willing to (and sometimes can) wait. Facing this reality, those who have financial resources may opt for paying treatments out of pocket because of the time pressure (e.g., P16).

The financial burden is so high that participants often described it as a major challenge in their trajectories: *“the emotional part…is exacerbated when it's also a big financial sacrifice…because you have this extra big stake…because if it doesn't [work], it has bigger implications, or consequences, for the rest of our family life because of our investment in it”* [P5]. This financial burden adds pressure to an already complex context. It also adds financial insecurity to the uncertainties of individuals’ fertility trajectories: as P5 explained, it is an extra stake with no guarantees and that can have consequences for their future.

Finally, the financial burden also opens room for the increased use of self-tracking as a cheaper and more accessible alternative. However, although self-tracking can be a cheaper option when comparing with fertility treatments, (i) it cannot solve all fertility problems and (ii) it can also be costly: *“I have spent a good amount of money just on the process of becoming pregnant. I’m really privileged and glad I can do that. I know that a lot of other people can’t buy several different pieces of wearable technology for this process”* [P17]. These factors may also feed into complicated emotional engagements with data described in Chapter 3, considering that individuals may increasingly track if they feel that it is their best chance.

Coordinating and Aligning Multiple Healthcare Facilities

Because of the temporal structure of fertility, all treatments have to be aligned with individuals' menstrual cycles (and thus with individuals' data), otherwise individuals may miss their fertile window and have to wait for the next cycle. For example, P18 described the intense work she had to do to carefully coordinate the multiple steps of her IVF treatment, medical appointments, insurance, and the pharmacy with her fertility cycle:

> *"Honestly, just communication between the clinic's staff, the pharmacy, and my insurance company, and my job is certainly – Juggling is stressful…Making sure that the medications would be here on time, because the whole process moves very quickly...They're pretty much like 'Okay, well, you're gonna start birth control, you're gonna be off of it this day, you need to start your medication by this time.' And that's a matter of weeks. Sometimes you don't get your calendar for all the appointments until a week before they start. So, you have to call the pharmacy like, 'Hey, just found out I need XYZ medicine.' And they ship it to you, but somebody has to be home to sign for it…And then trying to manage that quick turnaround with my job…So, just the quick turnaround is probably the most stressful part" [P18]*

Another extreme example of aligning different fragmented healthcare institutions with personal data comes from P4 and P5. After 6 IUIs that did not lead to full term pregnancy, the couple's best option was IVF. However, they could not afford the costs in the U.S. After intensive online research, they decided to do an IVF in Mexico. The coordination work increased since they needed to manage and time different healthcare institutions in different countries with P4's cycle:

> *"We couldn't buy the plane tickets very far in advance to get cheaper prices because they depended on a test that is done towards the beginning of the cycle. We could only get them a week or two in advance. Or, if we wanted to get them more in advance…that would cost more because we would need to pay for a hotel there for longer and I would miss more school…But we just bit the bullet and did the test here, got the plane tickets when we had an idea of when she would be ovulating [based on personal data]…But we were in for a bit of surprise because there were some irregularities with my wife's cycle, which hadn't happened before for a long time. But it made it so that the timing of things wasn't going to work...so, we had to lose our plane tickets. And ended up not working out that cycle. We had to come home and make plans to come back the next cycle and do the same tests over again…And we had my mother come [to their city], and she took care of our son while we went there initially for the first cycle. And then, on the second cycle, we took him with us. But yeah, it ended up being much more complicated" [P5].*

Finally, unexpected events can disrupt people's carefully made plans, and require extra management and coordination. This is the case of the COVID-19 pandemic: four out of the seven participants I interviewed during the pandemic described it impacted their fertility plans. For instance, P15 had planned to do an IVF in a low-cost clinic in New York, far from where she lives. But New York was one of the places most impacted by COVID-19, and P15 does not know if she will be able to travel there, which increases her stress, as she explains:

> *"Now it's even more stressful because I was really worried about the first endo surgery…and then, it was canceled [due to COVID]. Now, I also have to think about the additional risk of catching the virus. My husband has asthma and lung issues, so I have to be really careful, and now, I just feel like I'm getting older. I know that these things have a time limit and I'm kicking myself for dragging my feet before the virus" [P15].*

As these examples show, the healthcare space shapes people's experiences, requiring careful and constant coordination that involves personal data (i.e., timing with the cycle) and their relationships in the microlayer (e.g., their partners, families, and healthcare providers).

Work and Life Spaces: Managing Life Amidst Fertility Challenges

Fertility treatments also involve tremendous resources that go beyond financial costs and distract individuals from their normal life and work, as explained by D4: "*it's a significant investment of a couple's resources and the resources of time, energy, emotions, financial, work – away from work, all these different things*" [D4]. As this quote surfaces, individuals need to coordinate their fertility cycles with theirs and their partners' work, and with their other activities. For example, when using data to time intercourse, individuals and partners need to act upon the tracking results. P1 told her partner that whenever she gets a positive OPK they would have to find a way to meet: "*I just told my then husband that…if he is really ready, that we would have to take the opportunity the next time that little symbol comes up. He was at [the University], and I said you will have to bike home, and I'll meet you from the office, and we will just gonna have to do it*" [P1]. Other aspects of people's lives also influence and are influenced by their fertility trajectory and data work. For example, P16, who closely monitored hers and her partner's lifestyle measures, explained that they had to change their lifestyles to be *"healthier"* and save money, avoiding social events, entertainment, and unnecessary expenses: "*we have to have a very strict way of life to be the healthiest that we can…and to not waste money*" [P16].

More complex treatments may interfere with individuals' work and life spaces more since they have to accommodate multiple medical appointments and procedures. P18 managed to coordinate her work by having extremely early appointments when possible to have the minimum possible impact on her schedule: "*I'm lucky in that my clinic offers appointments extremely early in the morning at 6:30 AM and I have to be at work at 7:30. So, the majority of the time I can go to my doctor and be back at work. But some of them are a little bit later than that, so I have to push my schedule a little bit*" [P18]. Other life decisions are also entangled in this context. Four participants faced the decision of moving countries while trying to conceive, where they would be forced to figure out a new healthcare system under time pressure. P19 and P20 decided to do the IVF before moving from Brazil to the U.S. to use P19's prior "*very nice health benefits*" [P19], P16 decided to delay the procedure until they settled in the new country (Portugal), and P20 considered returning to the U.S. from the U.K. but decided not to do it in part because of the COVID-19 pandemic.

The work and life space impacts how fertility trajectories are planned and carried out, and individuals had to carefully make time in their work and life context and consider other stakeholders' work and life to accommodate the rather intensive fertility treatments that need to be timed with their cycles.

Technology Space: The Data Industry

With the wide use of fertility technologies, individuals' experiences are increasingly shaped by the data industry, particularly through mobile apps and wearable devices, as well as the media surrounding them. Unlike the other spaces in the exolayer, this space directly connects to personal data tracking. However, in this case data are not shared by the individual or used by the individual to coordinate healthcare, work, and life: technology companies define how individuals track their data through their products, store their data, and thus affect their fertility trajectories through such influence.

Technology define which health indicators individuals are expected to monitor, as illustrated by P18: "*I just…picked the two [apps] that seemed the most highly rated, and whatever they had in there to track, I tracked.*" So, if something was not available in the app, P18 did not track it, which can include not tracking measures that could be important to her or over tracking measures that may not be relevant to her case (and that can stimulate overmedicalization of the body (Levy & Romo-Avilés, 2019)). Technologies also define who can track and access the data. For example, P21 argued that even if her partner desired to analyze her data, he would not be able to: *"the app on the phone, it's not something that he can get too into because he can't just be curious and then go see it because it's not posted anywhere"* [P21]. The only partner that was actively involved in data tracking did it manually*: "he physically writes it down, and there's some code that he does"* [P7].

As discussed in Chapter 4, technology also adds limitations on how fertility data can be analyzed. P9, P11, P17, and P21 described they had to manually copy data from wearables or apps to spreadsheets, so they could do different analysis that the original device did not allow, or to other apps, so they could combine data from different apps to do more analyses and comparisons. However, such efforts were not easy because “*it’s not transferable, the data in the app. You cannot get the conclusion from the app, but it’s not easy to export the data to any other software*” [P9]. As these examples show, the design of tracking technologies can impose more burden on individuals and even influence them to track more.

In addition to shaping how individuals collect and analyze their personal data, fertility tracking technologies also aggregate data in ways that can reinforce certain standards back to individual users: “*they have some models based on…data from many users…they have points that they'll give you out of 100, of pregnancy indicators which are based on your own indicators and other people's indicators*” [P21]. As P21 experienced, such features may help users to better understand their data that can be difficult to interpret on their own (she particularly likes such features). However, as approached in Chapter 4, often there is not enough information to show how these calculations are made and how valid they are, which can potentially contribute to more stress and anxiety.

All these influences are entangled with technology companies’ economic interests. Such companies often offer paid versions of their apps or other integrated products such as OPK strips that work with the app (e.g., *“[app] sells its own strips*” [P17]) or secondary apps (e.g., “*they push you into some sort of pregnancy version of their app*” [P21]). Also, some participants (P7, P13, P17) described finding out about the tracking technologies they acquired through advertisements in television shows or in social media, such as Facebook, Instagram, and Pinterest, as described by P17: “*a Facebook ad. And that was the first thing that really introduced me to the world of tracking*” [P17]. Similarly, P7 reported an experience of discovering a fertility-related product through the recommendation feature of a major shopping platform: "*I ordered something for my labor…and Amazon was like, 'based on your purchase of this, you may wanna also buy this.' And it was a spray bottle for the bathroom. No one had told me that after delivery, I wasn't gonna be able to wipe myself…Like, of course, that makes perfect sense. But why is Amazon telling me this? Why didn't anybody in the class tell me?*" [P7]. It is not necessarily P7's case, but this quote suggests that lack of knowledge about fertility may influence individuals to purchase products following companies' economic interests, which may not be aligned with individuals' experiences of even health guidelines.

Finally, as discussed in Chapter 4, the marketing of tracking technologies may imply that tracking increases pregnancy chances and that if individuals act on the fertile window predicted by the app, pregnancy is guaranteed. Such misperception can lead to increased disappointment when people do not conceive: "*People think that the chance of conception if you have sex during the fertile window…is 100%. So, if it's not happening for them, something's wrong…that's where the apps come in…In the beginning I think it reduces anxiety, because it makes them feel in control. But then it becomes, actually, an anxiety in and of itself and an obsession. And I see that quite a lot*" [D4].

In summary, the pervasive use of fertility tracking technology makes it a unique space that influences, defines, and dictates how fertility data are used and fertility data work and related activities are performed. The influences of individuals' data work in the exolayer in general are profound and can further reshape people's daily activities, their interactions with others, and their engagement with institutional spaces.

5.5.5. Macrolayer: Broader Societal Influences

The macrolayer refers to overarching societal contexts, such as ideological, cultural, economic, and political systems, that affect and are manifested in all the other layers. Due to the demographics of the participants, my data speaks about cis heterosexual women mostly in the U.S. or western contexts. Our study found many societal forces influencing individuals' fertility trajectories. The main ones are knowledge about female fertility, and social expectations of gender. These forces shape the context in which individuals use self-tracking and their personal data.

Knowledge about Female Fertility

Fertility education and knowledge about the female body were discussed by most participants (individuals, partners, and healthcare providers). The lack of knowledge about female fertility leads people to look for other sources of information, particularly online. Although such spaces can be a great source of fertility information and support, misinformation is a common risk (e.g., "*people were claiming that a gel helped the sperm to survive better and move quicker. I almost bought it, but I talked to a doctor and he said, '...we have to be careful, because sometimes those gels...can actually damage and kill more sperm than help*'" [P4]). Some participants also mentioned "*it was just a little bit of information overload*" [P17] when they looked for fertility information online.

Misconceptions about fertility also influence treatments. D2 explained that people largely overestimate the likelihood of pregnancy, and this increases their frustration when treatments results are not as expected: *"people overestimate the likelihood that women become pregnant every month...There are [also] misconceptions on the probability of success* *with different fertility treatments. Meaning I think it's overestimated"* [D2]. D4 also highlighted how media plays a role in spreading misinformation and reinforcing these misconceptions:

> *"People have seen movie stars get pregnant at 45, 50 years old...Conscientious public figures will say 'this was done with a donor egg.' Or, 'this was done with eggs I had frozen in my early 30s.' But oftentimes the public figure is not conscientious like that, and she says, 'I got pregnant with my own eggs at 45 or 48.' And so, couples come in thinking, 'well, I'm 48. Let's get pregnant with my own eggs.' And that's just not possible" [D4].*

Such misconceptions influence individuals' emotional connection with the goal (i.e., conceiving), making it difficult to balance expectations even when patients understand treatments probabilities, as D1 explained: *"I think once you tell people that, they understand it, but it's still hard to change the emotional connection they have to that belief, so that's one thing that's sort of difficult"* [D1]. And these beliefs influence their attitudes when using fertility self-tracking technologies, potentially contributing to their engagement with data.

Many participants reported that the lack of knowledge of how common infertility and fertility-related events (e.g., miscarriages) are increases their feelings of isolation and inadequacy. For instance, P7 uses herself as an example of how even highly educated women do not know enough about their bodies: "*All this information really could have been taught to me much younger, and it would have been much less confusing…Women specifically are not taught enough about their bodies…Why didn't anyone teach me about my mucus? All these years, you're like, 'What's in my underwear? I don't know. Whatever. Is it an infection? Whatever'"* [P7]. P19 described a similar but more severe experience: her extremely painful periods were only taken seriously when she was diagnosed with infertility, suggesting that female bodies and experiences may be more easily neglected when the complaints are not directly related to pregnancy:

> *"I was the textbook case for endometriosis since my first period when I was 12…My cycles were 8 days long. I had really awful pain…[that] didn't get better with medicine, even though every time I went to an OBGYN they would say 'you just have to take this one'… After I was sexually active, I had pain during intercourse. I had everything…And it wasn't until I was diagnosed with infertility that someone took me seriously like – she is really in pain. After a while, I just started believing that it was all in my head and that I was just weak. Because people, even doctors, kept telling me 'no, your pain is normal. Every woman goes through that. It's just what it is.' And now I know that it's not the normal way…But I was just neglected for almost 20 years" [P19].*

Although our participants think knowledge about the female body should be more widespread ("*I think it's a public health concern that should be taught more, even in school*" [P19]), many of them believe that the use of tracking technologies and personal data is an opportunity to learn more about their bodies, a thought also echoed by the healthcare providers I interviewed. P13 builds on this thought and adds that tracking technologies can help in normalizing fertility experiences: "*as the [tracking] technology continues to improve and becomes more mainstream, I think people will just inherently understand more about how everything goes as has happened kind of in other areas. And then, it will be an easier topic to talk about because more people will be knowledgeable*" [P13].

This lack of knowledge about female fertility and bodies is connected with historical taboos (Almeida, Comber, & Balaam, 2016), reinforces such taboos, and plays a role in existing social expectations of gender, as described next.

Social Expectations of Gender

Conception is strongly entangled with social expectations of gender. Pregnancy and motherhood are still seen as women's role and strongly entangled with what it means to be a woman. Many women internalize these beliefs and, as D4 argues: "*much of their self-identity is wrapped up in this idea that women are fertile, and providing a baby, and having that ideal family*" [D4]. In fact, many participants stated that facing challenges to conceive made them feel "*defective*" [P14], "*incomplete*" [P12], or not "*working right*" [P1]. Such negative feelings are internalized oppressions (Keyes et al., 2020) commonly fed or reinforced by media, as well as by other people's expectations.

Because such expectations are so widespread and infertility is still so stigmatized, people reproduce these beliefs in such a way that put the blame on the person having challenges, as described by P14: "*I was frustrated with family members who didn't understand and thought we were doing it wrong or something*" [P14]. And although "*infertility is a couple's disease*" [D4], this pressure is often placed mostly on women. D5 even commented that although male factors for infertility are not uncommon, sociocultural beliefs about gender can interfere in treatments: "*in some cultures the males think that it's always the female's fault and they might even refuse to even get a semen analysis and they might say, 'Oh, this is not my problem'*" [D5]. Although our participants did not experience conflicts as serious as these with their partners, they were still the ones responsible for all the self-tracking activities, including managing their partners' lifestyle measures.

Although our sample was not significantly diverse, individuals from different cultural backgrounds described similar cultural expectations on pregnancy. Such similar expectations were described in the context of Hispanic ("*Hispanic families…in my family, in my culture, it's very normal. I'm very old [33 years old] for my culture for not having a kid yet*" [P15]), Chinese ("*my in-laws, definitely, they can't accept that [not having kids] – for Chinese parents, that's very normal*" [P9]), and U.S. mid-western cultures ("*I'm from the Midwest where people tend to get married and have families younger…It seemed to make sense in my neatly laid-out Midwestern plan*" [P11]). Although these are very different cultures, they revealed similar expectations towards pregnancy (i.e., essential, early) which indicates that some ideologies are bigger than specific cultural influences and may be related to gender expectations in general.

Finally, conception expectations are also entangled with education, work, and other life decisions. Many individuals are delaying pregnancy to pursue education and a career, but the plan (and the pressure) of conceiving remains. D4 explained that this sociocultural context increases the pressure for conceiving in a short window of time, which may not be currently possible: "*The [childbearing] age in the U.S. has been pushed back by 4 years…And that's to pursue careers, pursue education, find the ideal partner, what have you. So, that by the time they're ready to conceive…there's already this sense of stress that they know they're older. They know they've waited. And so, it has to happen right now. And it doesn't work that way*" [D4]. The shorter the window of time the more important access to fertility treatments may become. However, as described in the exolayer section, such treatments are often very expensive and not covered by healthcare insurances, opening space for increased use of self-tracking technologies (and for the influence of the data industry) to fill this gap.

These aspects of the macrolayer influence data and data work through internalized socio-cultural values and biases that can influence how individuals interact with technologies or even be reproduced in technology design. In summary, as the results show, individuals' fertility trajectories are entangled with fertility uncertainties and are bounded and shaped by their relationship with others, the institutional and technological spaces they are part of, and the broader societal context. These factors generate additional work for individuals who track data and manage the painful experience of struggling to conceive.

5.6. Discussion

Based on these findings, I first describe the specificities of the application of the ecological model to the fertility context related to data and temporalities. I then discuss how these unique characteristics, combined with the influence from outer layers, make this a challenging context for the individual in the center of this ecology. Such context demands individuals to perform intense data work across multiple layers in the model with the constant pressure of time. Finally, I discuss opportunities to influence broader layers through personal data collected by individuals.

5.6.1. An Ecological Model of Fertility Data Work

Figure 5.3 presents a model of EST applied to this study's participants data work. This ecological perspective is suitable and critical for the fertility context for multiple reasons. First, it highlights the relations between the individual whose body is primarily tracked, their partners, healthcare providers, peers, and family & friends, and how data and data work influence and are influenced by these relationships. Second, it recognizes the work of managing different organizations that need to be coordinated with individuals' fertility cycles and, thus, with their data. It also highlights the influence of the technology industry in defining, supporting, and limiting people's data work. Finally, this perspective surfaces how these layers are influenced by the larger societal contexts in which individuals' experiences and related data work are situated.

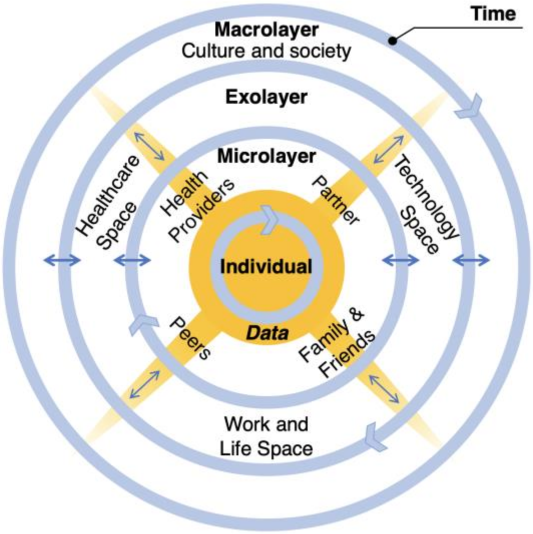


Figure 5.3. Bronfenbrenner ecological model (Bronfenbrenner, 1977, 1992) applied to fertility

Previous research using EST have explored how technology can support different relationships (Arriaga, 2017; Jeong & Arriaga, 2009; Yarosh et al., 2019), but most of them did not directly approach technology and data as mediators of these interactions. Inspired by Murnane et al. (2018), we use the EST model to analyze the influence of personal self-tracked data. Our findings suggest that the influence of data is much more structured and intense in the fertility context when compared to other ecologies of care contexts (Evans et al., 2020; Kaziunas et al., 2019; Murnane et al., 2018). This is partially due to the expectation of action present in fertility (M. Lee, 2017; Lupton, 2015), which creates a context in which data are seen as a way to directly control the results of individuals' trajectories. Thus, individuals engage in intense self-tracking activities that influence and guide their interactions with stakeholders in the microlayer and institutions in the exolayer.

Another unique influential factor in the ecological model applied to fertility is time. Prior research using the EST often describe time as an overarching layer representing changes in time or life transitions that impact individuals (Bronfenbrenner, 1992; Murnane et al., 2018). While my study identifies this influence as well, time plays more direct and diverse roles in fertility, working both as a structure and as a pressure: it structures all the activities individuals need to perform (e.g., all layers need to be timed with menstrual cycles' temporalities), under the pressure of time, since pregnancy chances reduce over time and with age (Speroff & Fritz, 2005). For this reason, I represented time as multiple temporal circles surrounding the original EST layers, symbolizing the multiple temporalities involved in fertility trajectories and how they relate to and influence each layer, including cycle temporalities (e.g., length of the cycle, ovulation, and fertile window) and the pressure of time surrounding the individual, the differences in data tracking and sharing through time surrounding the microlayer, the influence of time on individuals' interactions with different institutions that need to be coordinated with their cycle surrounding the exolayer, and the transitions and changes in sociohistorical conditions that influence individuals' lives surrounding the macrolayer.

Adopting this broader perspective to self-tracking data allows us to investigate how data influence individuals' lives beyond the individual level. Such view is important because data work does not exist in isolation. The EST helps mapping major influences that may not be immediately recognized by technology developers, identifying breakdowns and potential negative consequences. Future studies can use the model to explore the breakdowns identified in this study (and others that were not represented in the experiences of this study's population) and propose support (technological or not), improve processes, and advocate for change. It is also important to analyze how these different entities interact (e.g., the interactions of the mesolayer were not sufficiently detailed in the data from my interviews). And how all these aspects generate intense and invisible data work.

5.6.2. Microlayer and the Unknown

The microlayer is the layer where the data influence is more visible. Individuals are constantly dealing with *"the unknown"* and that influences their relationships. This is particularly visible in the interactions between individuals and healthcare providers, who use data to approach the unknown, between individuals and partners, who experience the unknown together but in different ways, and between individuals and peers, who support each other when facing the unknown, as described next.

Healthcare providers and individuals need to collaborate to face the unknown and work together towards pregnancy. Individuals' data work is much more exploratory, embedded in their lived experiences, and driven by their emotions, while providers' data work is more objective, supported by the rationality commonly applied in medical decision-making. As the findings show, individuals' and providers' data work are not only different, but they also serve different purposes. The inherent differences suggest that there are unique benefits in each form of data work, and they should be approached cautiously. On the one hand, although providers' data work can overlook important aspect of patients' idiosyncratic trajectories, their practices are useful to define the best, most viable, and affordable treatment course, investigating aspects of the body that patients are not able to access by themselves. It is not feasible to expect providers to analyze months of self-tracked fertility data, which could potentially delay treatment; and time is an important factor in the fertility context. Also, providers' protocol is based on current medical knowledge, which aims to benefit majority of cases (Timmermans & Almeling, 2009). Imposing high levels of personalization may impact cases that would be easily supported by the current protocol. On the other hand, although patients' data work does not lead them to understand the unknown, their practices help them in learning about their bodies, which is beneficial not only for them, but for providers as well. Patients' data work also serves as a way to make them feel that they are in control and empowered amidst the uncertainty of their fertility trajectories. These feelings give patients the structure they need to cope with the disruptive experience of infertility. Although applying the rationality of providers' data work to individuals' data work may be useful, aiming to completely change individuals' practices to mimic providers' practices could hinder the benefits related to their coping mechanisms and feelings of agency. It would also hide the personalized aspects of their trajectory that can point to exceptions to the protocol. Similar to previous analysis of infertility treatments and experiences (A. Greil, 1997), focusing on adjusting individuals' data work solely to fit providers' protocol can shift our attention from how to adjust infertility treatments for better supporting people to how people facing fertility challenges should be adjusted to fit processes that may be "imperfect" to their reality.

Partners are individuals' closest relationships in their shared fertility trajectories. Individuals' data work directly affect partners: they often follow individuals directions on lifestyle measures, they need to act on data results, they are as emotionally impacted by negative results as the individuals, and conceiving is also part of their life plan, thus their fertility trajectories also impact their biographical work (Corbin & Strauss, 1985). However, despite living this unknown with individuals, partners often do not engage in data exploration. The most common attitude is to support and defer to individuals' decisions. This is a delicate situation because it entangles one's own body's autonomy and shared biographical goals. If partners want to more actively participate in individuals' data work, they need to respect their autonomy, which is complicated when tracking somebody else's body. Research in family tracking and tracking by caregivers discuss many challenges that can arise in such situations, such as privacy (Hong et al., 2016; Pina et al., 2017), burden (Kaziunas et al., 2017), and tensions over conflicting interpretations (Mishra et al., 2019). These challenges are even increased in the fertility context, where many of the used health indicators are directly involved with individuals' intimacy.

However, extending previous studies' results (Homewood, Boer, et al., 2020), this study's findings also show that the other tracking direction happens much more often: I found that although conceiving is a shared goal, individuals were not only responsible for all female tracking activities, they were also often responsible for managing their partners' lifestyle data and guide couples' main decisions. Lifestyle measures are considered much less intimate than ovulation, cervical mucus, or cervix position, to cite some. However, it seems much more common to accept the female partner role of managing the couples' fertility data then to find ways for the partner to share such tasks. This is also reinforced by technology, since most of these tools do not allow or make it difficult for individuals to share their data. This study did not analyze if there is any difference in the data work when the couple has only male infertility factors and future studies could verify if tracking is used (as mentioned before, there are not many direct indicators currently available to track male fertility at home) and, if so, by whom.

Obviously, data tracking is only one component of individuals' experiences in dealing with the unknown and partners' support encompasses (or should encompass) many other critical aspects in individuals' fertility trajectories, such as emotional support, research, and dealing with infrastructure breakdowns. All these aspects are critical for individuals to deal with the unknown of fertility. Besides, partners do not participate in data tracking for varied reasons (e.g., not believing in tracking, having negative emotions triggered by these activities, not wanting to restrict their partners' body autonomy, believing it's not their job), including individuals not wanting their partners to take that role. Individuals may feel more comfortable in have these discussions with people who face similar experiences. This gap in support is often filled by peers, especially for individuals who engage in OHCs focused on fertility challenges. As described in Chapter 3, individuals use these communities to create personalized solutions based on collective knowledge, turning self-tracking into a collaborative effort of making sense of personal data. These interactions help individuals in normalizing their experiences and learning about their bodies, supporting the development of a sense of control that is very useful when facing the unknown of the fertility context.

In summary, the findings show that the relationships between the entities of the microlayer and the individual are very influenced by the unknown and individuals' data work to try to deal with fertility uncertainties. The relationships between the individuals and the entities in the microlayer are often intermediated through data and relationships are even created to fill a gap in support for data work (e.g., peers).

5.6.3. The Influence from Outer Layers on Individuals' Data Work

Although data work in fertility is individual oriented and fertility data are often not shared and used beyond the microlayer, there are profound influences from the outer macrolayer on individual's data work at the center. The macrolayer influences the other layers through cultural and societal ideologies that are embedded in institutions, technologies, relationships, and practices that produce, use, and influence data. Such connection may be subtle, but it has much lasting influences and takes time to change.

As described in the findings, the social forces in the macrolayer directly and indirectly influence the experiences of the individual in the center of the fertility model. They shape and influence both the knowledge about the body (which deepens the feeling that fertility is private and a social taboo) and the expectations of gender (which dictates that females are expected to reproduce). Because of these historically formed societal influences, this study's findings show that many individuals had to learn about fertility knowledge and fertility technologies through advertisements they encountered on social media or recommendation systems in shopping websites. Without appropriate knowledge about fertility, individuals may be more vulnerable to market influences, and more likely to be affected by misinformation about fertility.

Technologies and media may also reinforce unrealistic and idealized fertility goals and experiences, reproducing and reinforcing societal values and biases. When these goals are not achieved, individuals may experience increased stress and disappointment. Some may further question their identity (in this case as women) and keep working with data in a trapped engagement hoping that something will work. Lupton (2015) describes sexual and reproductive self-tracking apps portray women as *"reproductive subjects"* (Lupton, 2015) reinforcing gender stereotypes as the ones I encountered in this study. Similarly, Epstein et al. (2017) describe how menstrual apps assume the gender and sexuality of individuals and their partners. These are a few examples on how these technologies may limit individuals' experiences, their data collection and analysis possibilities, and even turn invisible the experiences of many individuals who menstruate or face challenges to conceive, contributing to symbolic annihilation through design (Andalibi, 2021), as discussed in Chapter 4. Thus, societal influences may be brought into design of technologies and then influence individual's data work through these technologies.

Societal influence, including the political and economic policies and ideologies, also shapes the healthcare system in the exolayer and how individuals are expected to deal with their own health. Countries like the U.S. (where most participants were located) do not have universal healthcare coverage, and among the ones that do, many do not cover infertility treatments (e.g., U.K.). This lack of support adds to neoliberal views of healthcare that promote a high level of individualization of health and put the responsibility to be "healthy" on the individuals instead of providing institutional support to them (Fotopoulou & O'Riordan, 2017; Gui & Chen, 2019; Ruckenstein & Schüll, 2017; Sacramento & Wanick, 2017). Under such views, persistent action is praised while doing "nothing" is seen as a failure (Gay Becker & Nachtigall, 1994). Self-tracking technologies and data arise in this context, often embedded in *"techno-utopian discourses"* (Lupton, 2013b) that emphasize the potential benefits of technology for patient empowerment. Individuals then have the moral responsibility to engage in data work and act towards their health goals, in this case towards conception. The narratives of self-responsibility and the belief that persistent action ultimately leads to individuals' goals (i.e., conceiving) directly influence individuals to engage in more data work (Gay Becker & Nachtigall, 1994; Costa Figueiredo et al., 2018). Such narratives may also reinforce feelings of guilt, leading individuals to double down on tracking or to blame themselves for not conceiving. As Homewood, Karlsson et al. (2020) describe, internalized socio-cultural values and biases also play out on how individuals interact with technologies. So, technologies not only reproduce societal influences, but the ways with which individuals use and engage with them also reflect the cultural and societal context in which individuals are embedded (Homewood, Karlsson, et al., 2020). Therefore, the macrolayer societal factors exert their influences through the infrastructure of healthcare systems and through leading to increased data work by individuals.

Other societal influences were not very apparent in this study's data due to the representativeness of the participants, which did not include individuals from some minoritized populations, such as Black, Indigenous, and LGBTQ+ people. While this study shows clear influence of gender stereotypes, such influences may be different and interconnected with other social dimensions for individuals from these populations (Crenshaw, 1997; Inhorn et al., 2009). For instance, infertility studies (A. Greil et al., 2011; Inhorn et al., 2009) show that the isolation and loneliness African-American women experience during their fertility trajectories have strong racial and cultural components: they are reinforced by stereotypes about their sexuality and the public image of infertile couples as white. People with low social-economic status often do not have access to infertility treatments (as explained by D5) and may be more often directed towards contraception than to assisted reproduction (as lived by P1), reproducing negative stereotypes of hyper-fertility and sexual irresponsibility (A. Greil et al., 2011). Technology and data can reinforce such stereotypes as well (S. E. Fox et al., 2020; Hogle, 2016; Ruckenstein & Schüll, 2017) and even increase health disparities (Veinot et al., 2018).

5.6.4. The Data Work of Individuals

One aspect that was clear in the studies described in this dissertation is the intense and multifaceted work individuals do during their fertility trajectories in the individual level and across multiple layers of the ecological model. Previous research has discussed different types of patient work, such as illness trajectory work, everyday life work, and biographical work (Corbin & Strauss, 1985), uncertainty abatement work (Wiener & Dodd, 1993), sentimental work (Strauss et al., 1985), and infrastructuring work (Gui & Chen, 2019). I found evidence of individuals performing all these types of work in their trajectories. I also found that data work influences, merges, entangles, and shapes many of these activities.

As described in Chapter 1, Bossen, Pine, et al. (2019) define data work as "*any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data.*" This study's findings show that individuals conduct intense data work in two main ways: their direct work with data and their work influenced by data. First, individuals use data individually to understand their own fertility cycles, particularly their temporalities (e.g., ovulation day, fertile window, two-week wait time). Data work is also present in their relationships and interactions with others, particularly with partners, who have to act upon tracking results, healthcare providers, who need some of individuals' data to inform their own work (Costa Figueiredo, Su, et al., 2021), peers, who can provide support in making sense of the data and family & friends to whom individuals need to summarize their experiences that involve data (but without sharing data) to gather support or avoid negative interactions. It can be an intense daily work, which is often shaped by the technologies individuals use (Bossen, Pine, et al., 2019; Homewood, Boer, et al., 2020).

Individuals' fertility data work is often facilitated and structured by technology, particularly mobile apps and wearables, which support and impose what to do, when, and in which order (Bossen, Pine, et al., 2019). In fact, what is considered fertility data is almost (re)defined by technology: technology defines what bodily measures can be tracked, which data can be stored, what data analysis can be done (S. E. Fox et al., 2020). However, when their needs are not fully supported, individuals in my study had to manually copy data from apps to do more analysis or to cross examine data from multiple devices. In addition, how data can be shared is most often not individuals' choice but defined by the fertility technology. When the data cannot be easily shared (e.g., the partner is not a default user of a fertility app), often times individuals have to copy the tracked data out of the technologies, curate the data to an appropriate format, then share them to the stakeholders they wish to benefit from the data. These are added data work imposed by technology.

The second form of data work plays out through the coordination activities centered in fertility data. As my findings show, individuals need to coordinate multiple organizations, overcoming different breakdowns and allocating their time, effort, energy, financial, and emotional resources to maintain a balance between different aspects of their lives and the demands of their fertility treatments (Corbin & Strauss, 1985). All these activities need to be coordinated with the temporalities of individuals' cycles and, consequently, with their data (i.e., it is often through their data work that they identify their cycle phases). As the findings show, everything needs to be carefully aligned and mapped out following the cycle timeline, which creates a significant amount of work that is influenced by and related to fertility data.

Unlike the direct data work that can be assisted fully or partially by technology, the second form of indirect data work is seldom supported by technologies. Coordinating, aligning, anticipating, and allocating work is often referred to as articulation work in CSCW (Suchman, 1995). Such work is characterized as complex, burdensome, invisible, and difficult to be automatized. For instance, fertility apps do not help individuals to coordinate their cycle time, work schedule, life commitments, and treatment time. Even if they did, it would still be individuals' task to pull and put the different times into the apps. As such, this work is often imposed on individuals as a form of invisible work (Star & Strauss, 1999) that contributes to the underestimation of individuals' burden (WHO, n.d.) and to infertility's double invisibility: the invisibility of the condition and of its painful consequences, reinforcing feelings of disenfranchised grief (McBain & Reeves, 2019).

In summary, these data work and work around data can be intense and are often enforced on individuals through the multiple layers of influences I identified in the ecological model. This work is also often performed by individuals alone, imposing significant physical and emotional burden that adds on the existing stress of infertility.

5.6.5. The Data Influence from Inside Out

The ecological analysis shows clear influences and impacts from the outside layers to the individual data work inside. Although it may seem that individuals have to obey the societal norms, face the institutional constraints, follow the guidance of technology design, in this study, I also found cases that suggest that the data and data work from the center of the model can act inside out to influence the outside layers. First of all, all participants (individuals, partners, and healthcare providers) appreciated the positive aspects of data tracking. None of them described tracking and technologies as inherently negative. This study shows that data and technology enable individuals to learn about their bodies and gain more fertility knowledge, make the internal fertility processes "visible" (Ruckenstein & Schüll, 2017), and provide individuals a sense of control over their bodies and fertility experiences (Ayobi et al., 2017; Bussone et al., 2016; Costa Figueiredo et al., 2018). Similar to previous studies in rare and invisible conditions (Davies et al., 2019; Felipe et al., 2015; MacLeod et al., 2015), my participants also described occasions where they used data as advocacy to raise fertility awareness to the public. Besides, although technology and data have the power to define what is fertility data and how such data should be tracked, individuals do not simply comply with technology suggestions or impositions (S. E. Fox et al., 2020; Gross et al., 2017; Ruckenstein & Schüll, 2017). For example, some participants circumvented the limitations of fertility technologies by actively copying data from one technology to others to perform comparisons and further analysis. Therefore, as represented in the model, data can also be used to influence the outer layers. Below I discuss a few open suggestions on bringing the data influence inside out through technology design.

On the individual and microlayer: technology could support data ownership and multiple personal (S. E. Fox et al., 2020) and shared (Felipe et al., 2015; MacLeod et al., 2015) uses of data. It could allow different and evolving relationships with data, both for the individual facing challenges (supporting the different fertility temporalities, such as life stages and treatment) and for the other stakeholders they need to interact with in their fertility trajectories. For example, designers and researchers could explore designs that go beyond utility, efficacy, and accuracy (e.g., Ovum (Homewood, Boer, et al., 2020; Homewood et al., 2019)) and investigate how to reduce the burden these activities may impose on individuals. Fertility tracking technologies could also engage more with partners, not only allowing individuals to share data (if they desire), but also supporting partners in playing a more active role in the fertility trajectory, by, for instance, offering information about their own fertility, allowing tracking their own lifestyle data, and supporting partners in managing exolayer influences and helping to coordinate the interactions with different healthcare institutions. Partners' inclusion, particularly male partners, can also tackle the broader societal pressures, such as expectations about gender, and relieve some of the burden of data work on individuals. Different levels of disclosure (Felipe et al., 2015) that are personalizable, modifiable (Luo et al., 2019; Murnane et al., 2018), and that support a *"slow discovery process"* (MacLeod et al., 2015) (allow others to slowly transition from gaining awareness to understanding how to be helpful) could help in expanding individuals' care network and potentially reducing their burden. Sharing data could also help individuals to find peers to gain support and ease the emotional burden, especially for those who are not currently on online communities. My participants described enjoying the "cycle buddies" programs in the OHC, so fertility tracking technologies could replicate these experiences. These interactions with peers, family, and friends can also indirectly influence macrolayer aspects such as the lack of knowledge about fertility (Almeida, Comber, Wood, et al., 2016). Finally, technology could better bridge patients' and providers' different data practices, supporting providers to identify the information they need and supporting patients to emphasize the personalized aspects of their fertility trajectories that may need deeper attention from providers (Costa Figueiredo, Su, et al., 2021).

On the exo and macrolayer: data can be a powerful tool to influence organizational design and cultural perceptions. First, data from individuals can act up to reveal the prevalence of infertility cases, the struggles individuals experience, the challenges they encounter in seeking health services, and the various burden they face. As a highly stigmatized health issue, individuals may not be comfortable of individually sharing their experiences, but their accumulated fertility data can be valuable and powerful to influence health policy (e.g., (Ng et al., 2020)) and organizational design that direct impact people's fertility experiences. As Ruckenstein and Schüll (2017) suggest, self-tracking data can have social and political impacts if used to showcase health inequalities, by for example, showing that negative experiences are tied to societal norms and pressures and not to individual characteristics and personal actions. For instance, initiatives such as data feminism (D'Ignazio & Klein, 2020) and Data for Black Lives (*Data 4 Black Lives*, n.d.) have proposed the use of data science to challenge power inequalities and benefit marginalized populations. Other initiatives like the Citizen Endo (Elhadad et al., 2016) create a citizen science community to support research through individuals' personal data, which can help in identifying symptoms and experiences related to endometriosis (McKillop et al., 2018). Such data-driven initiatives can exert the influence from inside out. In addition, although many participants described tracking as a means to learn about their bodies, most current fertility tracking tools are not designed with the goal of educating their users (Eschler et al., 2019). Fertility tracking technologies could explore ways of using personal data to foster learning experiences. Promoting fertility education on a large scale can make infertility experiences more visible to the public and lead to more structural changes in the outer layers. Fertility education can also include learning about the complicated social relationships involved in fertility experiences. As suggested by my participants, their interactions with others and their work across layers would be easier if more people were knowledgeable about infertility experiences. Finally, changes on the outside layers take time, as the sociocultural perceptions are formed historically, but data may help in this process. Frameworks such as the EST can be useful in self-tracking and HCI research to identify breakdowns that can be tackled by technology and aspects that technology cannot (or should not) approach (e.g., imposing more "self-responsibility" and work on the individual).

CHAPTER 6. Discussion

As defined by Bossen, Pine, et al. (2019), data work refers to *"any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data."* A large portion of the literature on data work in healthcare focus on healthcare professionals and organizations (Cabitza et al., 2019; Even Chorev, 2019; Mønsted, 2019; Pine, 2019) or on their interactions with patients (Grisot et al., 2019; Islind et al., 2019; Vallo Hult et al., 2019). However, as Islind et al. (2019) describe, introducing PGHD to healthcare distributes the data work to patients outside the clinics, where individuals perform these activities in their everyday lives and data influence and are influenced by their larger ecologies of care. Focused on this specific type of data work, this dissertation presented three studies that investigated different and interconnected aspects of individuals' data work in the fertility context. Chapter 3 described data work in the individual level, emphasizing how it is complex, intense, and emotional. Chapter 4 focused on technology support, discussing how current available tools shape individuals' fertility data work although they are most often single-goal oriented and do not adequately support the varied and holistic aspects of individuals' data needs. Finally, Chapter 5 positioned individuals' data work and technology in broader ecologies of care, mapping the interpersonal, institutional, and societal aspects that influence participants' fertility trajectories.

The findings and discussion presented in Chapters 3-5 refer to the fertility context, emphasizing the sensitive, challenging, and intense nature of data work. Though these studies are situated in this single and often extreme health context, as Pine and Liboiron (2015) describe, overt cases are important to make issues that can be less explicit in common cases more visible (Pine & Liboiron, 2015). Considering this, this chapter is dedicated to discussing the general insights that can be learned through studying fertility data tracking. First, I use the case of fertility to discuss important characteristics of individuals' data work in contrast to the data work of health professionals and organizations, highlighting technology breakdowns, providing insights for researching and designing technologies to support individual data work for health, and emphasizing the importance of adopting a wide lens when researching and designing for individuals' data work. Building on that, I discuss two critical aspects that this dissertation turns visible through its holistic analysis of individuals' data work in an extreme health context, which exemplify how macrolevel influences trickle down to the individual level through technology: (i) the claims of objectivity in a highly emotional context and (ii) the sociality of highly private data. Finally, I end this chapter with implications for related fields.

6.1. The Data Work of Individuals in the Health Domain

The data work performed within healthcare institutions (by healthcare providers and other roles) and the data work performed by patients or individuals share some similarities but also hold unique differences. By focusing on an extreme case of individuals' data work this dissertation shed light on characteristics that can apply to the data work of individuals in the health context in general.

First, as evidenced by my findings, data work for health in the individual level is complex, diverse, and entangled with individuals' emotions. This combination of factors turns data work into an **emotional and burdensome** activity that in the health domain is often performed in the context of sensitive and potentially disruptive experiences, as in the fertility case. To experience illness or the discovery of a health-related condition often impacts individuals lives in multiple different ways, requiring them to make sense of their new situation, adapt their routines, and often rework their biography and the plans they had to their lives, temporarily or permanently (Corbin & Strauss, 1985; Mamykina, Smaldone, et al., 2015; Riemann & Schütze, 1991). So, in the individual level, health data work may add burden to an emotionally-loaded context: individuals need to learn to perform this work, understand the varied technologies that support it, translate their experiences into data, analyze, interpret, curate, and share data, and coordinate their multiple relationships and institutional interactions with data that are intrinsically connected with their hopes, biography, and sense of self. As discussed in Chapter 3, this data work, with its complexities, ambivalence, and challenges, becomes entangled with the hopes, doubts, and anxieties related to the health condition (Lomborg et al., 2020) in a feedback loop that reinforce each other. In this context, it is difficult to disentangle burden from individuals' emotional experiences, because one influences the other. This is a fundamental difference in comparison to the data work performed by professionals in the organizational context of healthcare.

In the exo and macrolevel, as PGHD becomes more widespread, data work is becoming an extensive part of patient work, adding complexity and, as discussed in Chapter 5, influencing, merging, and shaping many of the other types of work patients need to perform. The individual performing this complex data work is most often not health nor technology expert and needs to deal with institutional, market, and hidden social pressures imposed on themselves. Although individuals' data work is often personally initiated, there are many forces, particularly socio-cultural factors, that influence and lead individuals to perform data work. In this context, power imbalances play a more incisive role that is often not accounted for and may be hidden behind a *"logic of choice,"* which as discussed by Mol (2008) *"can lead to poor care"* (Mol, 2008). As discussed throughout this dissertation, technology can also reproduce societal stereotypes and taboos or reinforce logics that conflate patients' production of data with patient empowerment (Langstrup, 2019; Neff & Nafus, 2016), as if the production of data was enough to engage patients in their care and that this type of engagement would ultimately lead to better care. Such views tend to ignore or consider positive the burden indirectly imposed on patients and how this burden is entangled with their emotional experiences during their illness trajectory. This invisibility of the burden of data work and its consequences increases the emotional toll of individuals' data work, by suggesting that their health outcomes are entirely in their hands. This aspect and the entanglement between data tracking technology and individuals' emotional trajectories will be further discussed in section 6.2.

Second, individuals' data work related to health is **individualized and heterogeneous**. Similar to infrastructuring work, Chapter 5 discussed that individuals' data work encompasses multiple types of work, which *"involves connecting with heterogeneous resources, people, and organizations"* (Gui, 2019). Building on that, my studies show that, even within a very specific domain (e.g., self-tracking fertility for conception), individuals' trajectories can still vary (e.g., including miscarriages, IVF treatments, diabetes) and include influences from heterogeneous ecologies of care. This combination of heterogeneous types of work, varied illness trajectories, and diverse ecologies of care creates a complex context for technology support, which, as Chapter 4 reported, tends to be pre-defined and not customizable, often focusing on unique goals of a linear and normative health experiences.

Kaziunas et al. (2017) argue that *"there are many unexpected and deeply human narratives about data still emerging and that these stories offer an alternative way of living with data."* In all my studies I described individuals engaging with data in varied ways in their unique fertility trajectories. Instead of trying to make individuals' data work completely rationalized, summarized, and objective, technologies and research could explore how self-tracking tools and PGHD can carry the uniqueness of each individuals' trajectory. Besides investigating the possible variance in the specific health context being studied, technology and research focused on individuals' data work for health should account for different contexts, personality traits, and types of engagement. In this sense, customization, flexibility, and adaptive systems (such as the holistic tracking discussed in Chapter 4) configure important options to be explored and developed to better support the diverse data work of individuals in a specific health domain.

Additionally, this individualized and heterogeneous characteristic of individuals' data work, combined with the emotional and burdensome characteristics described before, emphasize the need to explore how to design for negative experiences. For example, my dissertation described how unexpected health events, such as miscarriages, negative outcomes of fertility procedures, and the discovery of infertility factors, are not uncommon in the fertility context. These unexpected and often negative and invisible experiences are valid and commonly exist in individuals' illness trajectories in general. However, technology often focus on positive and linear health experiences (Andalibi, 2021; Søndergaard, 2017). In order to better account for these valid negative experiences, the whole technology development process (e.g., product conception, requirements, user testing) should be informed by the possibility of seeing undesired data and dealing with negative types of engagement (Costa Figueiredo et al., 2018; Katz et al., 2018), investigating how to design for unexpected health events and contexts that can be considered taboo and complex (Søndergaard, 2017).

Third, individuals' data work is highly **social but invisible.** Since *"encounters between people, technologies, and data"* are necessary to make data useful (Bossen, Pine, et al., 2019), individuals' data work requires collaboration. Collaboration involves intense translation and transformation of data, which need to cross different knowledge boundaries (Bødker, 2016; C. P. Lee, 2007). While some studies cover this work during clinical appointments and consultations (Islind et al., 2019) or between different health providers and other roles in healthcare organizations (Bonde et al., 2019), patients' or individuals' translation and transformation beyond the clinics tend to be more invisible. Individuals must directly translate and transform their data in different ways to share them or information based on them to their microlayer. Each interpersonal relationship in the microlayer constitutes a boundary through which data do not pass directly and need to be translated, transformed, and often negotiated. In addition, while data work in the organizational level changes roles and can (or should) lead to the creation of new ones (Bossen, Chen, et al., 2019; Vallo Hult et al., 2019), in individuals' cases, beyond changing roles in patient-provider collaboration, data work can lead to new relationships that can be intensely mediated through data, particularly with peers. Similar translation and transformation data work also happens between the individual and the spaces of the exolayer, which the individual needs to coordinate with their data, often performing intense articulation and infrastructuring work, as discussed in Chapter 5. Individuals then need to "*create, collect, manage, curate, analyze, interpret, and communicate data"* to manage their relationships, get support, coordinate heterogeneous institutions, and work towards their goal in invisible intense data work that happens in a daily basis while facing disruptive health experiences.

Despite all these social aspects, technology often do not support sharing, nor the other types of work related to institutions, such as articulation and infrastructuring work. To approach this gap, technology could support multiple personal (S. E. Fox et al., 2020) and shared (Felipe et al., 2015; MacLeod et al., 2015) uses of data. Data work technologies could also engage more with the important interpersonal relationships of the microlayer, as discussed in Chapter 5 through the relationships with partners, family and friends, and peers. Identifying influential interpersonal relationships and their impact in individuals' data work allows us to understand if and how these relationships can be leveraged to reduce the burden on the individual. They also allow us to identify the differences in data work and needs of these different relationships and analyze the best strategy to support different data work practices that need to interact (e.g., merge the practices vs. keep them different but bridged (Costa Figueiredo, Su, et al., 2021)), as in the case of patients' and providers' different practices identified in Chapter 5.

As discussed in Chapter 5, some implications of emphasizing the social aspects of data work in technology design include offering more nuanced sharing, with different and modifiable levels of disclosure (Felipe et al., 2015; Luo et al., 2019; Murnane et al., 2018). Technology and research could also focus on the strategies of support that organically emerge from peers' relationships, such as the "cycle buddies" programs in online health communities, to understand what factors drive the positive experience my participants described. However, it is also important to analyze and compare these strategies with the negative experiences other individuals have faced in similar environments. For example, in study 2 many user reviews commented about bad interactions in apps' communities that were described as *"toxic,"* a similar experience described in other fertility-related studies (L. S. Liu & Siek, 2017). Therefore, a potential focus of research would be to investigate if there is anything in these platforms that could reinforce or promote these opposite experiences aiming to better support the positive ones.

Fourth, individuals' data work is also **evolving and influenced by time**. Study 1 showed that individuals engage with their data differently, with different intensities, and suggested that this engagement is not constant. Study 3 builds on that explaining that this engagement changes based on individuals' experiences and evolves with time. For example, Anna's (P11) fertility trajectory described in Chapter 5 clearly shows she intensified her tracking after a miscarriage. Another participant, P7, also explained how she would add more health indicators in her tracking list every month, intensifying her data work. Later, she mentioned she stopped tracking some indicators (e.g., temperature) after having a clearer diagnosis. As these and other examples of Chapter 5 show, in the individual level, concerning their tracking activities, individuals get more and less focused on their data: they add more measures and drop some, they stop or start tracking some measures after interacting with providers, etc. In parallel, their emotional experience also changes throughout their trajectories: they get more obsessed towards their data or reduce their investment in data tracking, they see similar data with hope or with frustration, etc. Different factors may play a role in these changes, including learning experiences, diagnosis, treatments, emotional exhaustion, and positive results. But the fact is that individuals' engagement with data changes with time.

The influence of time is also clear in the other layers of individuals' data work. Individuals' interpersonal relationships and related data sharing practices also change with time, becoming more or less intense depending on the stage and experiences they face in their trajectories. The work of coordinating different institutions and services in the exolayer with their cycles (including all the necessary translation and transformation of data) is also dynamic, changing following their treatments and events of their trajectories. Their relationships with technology aimed to support data work also change: they adopt more apps, acquire wearables and devices, but also abandon some. Finally, socio-cultural factors may change, but much less often. It is more likely that individuals' reactions towards these factors change, particularly when they realize the invisible pressures they exercise in their experiences—some of them, as some participants in study 3, then engage in advocacy efforts.

In summary, the time component was extreme in the fertility context, but it can be expanded to other domains because individuals' health experiences are not constant, they are part of a trajectory (Corbin & Strauss, 1985). Consequently, their data work is also dynamic. However, technology tends to be static and not support changing goals and the evolution of engagements with data. Holistic tracking as described in Chapter 4, with support for changes in engagement with data that reinforce positive relationships, and the nuanced and modifiable sharing practices previously discussed could improve technology support in that realm as well.

Finally, as each of the described characteristics (i.e., emotional and burdensome, individualized and heterogeneous, social but invisible, and evolving and influenced by time) suggest, research and technology for individuals' data work for health should engage more with the broader ecological aspects involved in these activities. It is also necessary to clearly situate technology in these broader ecologies of care, including the role of designers and researchers in shaping individuals' experiences (Helms, 2019; Lomborg et al., 2020). Data work by definition calls for broader perspectives of data use, beyond data collection and visualizations. This is even more visible and critical in the case of data work of individuals. Without taking this wide lens we can develop inadequate or even harmful technologies, hide negative consequences, reinforce societal pressures, and degrade care. My dissertation took a holistic approach to purposefully explore these ecological factors and how technology is entangled with them in an extreme context. By doing so it was able to shed light on two critical aspects that map how macrolayer influences are manifested in technology to directly influence the individual and shape their data work, which are discussed in the next sections.

6.2. Claims of Objectivity in a Highly Emotional Context

Aligned with previous literature (Lupton, 2015, 2013b; Neff & Nafus, 2016), my studies show that self-tracking technologies and the discourse around them are often based on a belief of objectivity. However, these technologies are usually limited and not transparent, providing very little information of how their algorithms work and what and how data are used to generate the predictions (as discussed in Chapter 4). People face multiple challenges when trying to use these technologies, developing different relationships with their data (Chapter 3), which are intermediated by technology design that reflects industry interests (Chapter 5). In this section I discuss the problems of making claims of objectivity in a context that is highly uncertain (or *"unknown"*) and emotionally loaded.

As deeply discussed in Chapters 3 and 5, fertility is a very uncertain context. Self-tracking rises as a possible solution for this uncertainty. By collecting, integrating, (often) quantifying, and plotting bodily data, self-tacking technologies offer support for individuals to deal with the uncertainty of their conditions. With these tools, individuals now have means to analyze their data and find a *"sense of control in a space of uncertainty"* (Pink et al., 2018). As Lomborg et al. (2020) describe, many individuals choose how to interpret the data, often in ways that reinforce their beliefs and hopes. These interpretations can be beneficial when the validity of the data is not as important, and individuals' data collection and use is more playful than serious (Lomborg et al., 2020). However, health contexts are high stakes and directly tied to individuals' lives and identities, which increases the likelihood of rumination patterns (Martin & Tesser, 1996). Individuals invest their hopes in the premise that with data accumulation they will be able to reflect and manage their health (Baumer et al., 2014; Lomborg et al., 2020). However, this is a fragile premise (Lomborg et al., 2020) influenced by two important factors: (i) the quantification process and its consequences, and (ii) individuals' emotional experiences, which are situated in broader societal contexts.

First, the discourse around self-tracking technologies often reinforces a culture of quantification that conflates quantified data with objectivity. Extensive literature have emphasized the issues of quantification, such as data authority, loss of meaning, reduction, and classification (Espeland & Stevens, 2008; Lupton, 2013; Verran, 2011). These issues are particularly relevant to the fertility context because of its variability, which is simplified (and it needs to be simplified) to create the measures that make tracking possible (e.g., cycle length, temperature values, amount and quality of mucus). However, quantifying a bodily phenomenon will always be a reduction, a partial representation of a person or observation in data, not the whole person or observation (Nafus, 2016). Despite that, after the creation of these measures, they and their combination are associated with objectivity and rationality and may acquire an authoritative role, being seen as the exact representation of reality and the self (Espeland & Stevens, 2008). Despite the real limitations of quantifying aspects of the body and that quantitative calculation always involve qualitative judgment (Pine & Liboiron, 2015), bodily data are often viewed as objective, neutral, scientific, and separate from uncertainties.

The increased use of AI in fertility apps brings a new layer to this discourse. As discussed in Chapter 4, technological jargon such as “artificial intelligence,” “data driven,” “machine learning” and other similar terms may be used to inspire technological precision and accuracy, encouraging users’ confidence and trust in prediction (Starling et al., 2018). Apps’ promoted materials, in-app messages, and even the simple presence of features without further information about them can reinforce beliefs of accuracy and personalization, suggesting that the more the user track data the more accurate the predictions will be. Similar to what has been discussed in the context of intimate platforms (Olgado et al., 2020) and to the experiences of participants of study 3, fertility apps’ logics can resonate with users, potentially leading them to adopt uses that are in line with the interests of the data industry. Fertility, a very uncertain context, is then viewed and evaluated through these numbers (Lupton, 2015) and the algorithms that produce them, which are often proprietary and not well explained. Apps’ claims and design then play a role in the entanglement between tracking and emotions and may reinforce unbalanced expectations, which can contribute to the negative engagements with data described in Chapter 3.

Second, as Rooksby et al. (2014) emphasized, personal tracking is not a *"dispassionate"* data analysis endeavor. It is instead deeply embedded in emotional aspects of people's lives. Building on this perspective, this dissertation calls attention to the emotional component that is part of the self-tracking process and is entangled and mutually dependent with the tracking activities. Fertility is directly connected to individuals' life goals and the life plan they envisioned for themselves, aspects that require intense and painful biographical work to change (Corbin & Strauss, 1985). The experiences of infertility have been previously described as a *"roller coaster of raised hopes followed by tragic disappointment"* (A. Greil, 1997), an expression that was echoed by the participants in study 3, by the forum users in study 1, and in user reviews in study 2. In order to persistently manage their trajectory, individuals need to project a future and visualize ways to get there, which involves hope and commitment (Corbin & Strauss, 1985). Data then become a way for individuals to act towards their projected future, so they can feel like they have some control over the unknown.

These emotional data experiences happen in the context of broader socio-cultural influences and the technologies that mediate them participate in the shaping (and reshaping) of human bodies and selves (Lupton, 2015). The emotional component is especially important when the engagement with data seems to reinforce or exacerbate cultural pressures and standards, such as the ones around gender roles, motherhood, and the ability to conceive that are influential in the fertility context (Costa Figueiredo & Chen, 2021; Daar & Merali, 2002; *WHO | Infertility*, n.d.). In combination with these pressures, the fertility context also reflects a culture of persistence in which "*doing 'nothing' is equated with the failure to take responsible action, whereas doing 'something' is viewed as leading to the* *betterment of a given situation"* (G. Becker & Nachtigall, 1994). In this sense, not just action but *persistent* action is the dominant and often celebrated narrative, reinforced by a *"cultural faith"* that this persistence will ultimately pay off (i.e., lead to the conception) (G. Becker & Nachtigall, 1994; M. Lee, 2017). This belief may be reinforced by self-tracking tools and technologies that emphasize the role of consistent tracking in goal achievement.

Tracking more indicators for more extended periods of time fits into this cultural notion of persistence. Individuals want to believe in fertility algorithms, which they see as a chance to achieve their goal (and due to the cost of fertility treatments, potentially their only chance). Self-tracking then is a way of "doing something" and persisting. Similar to intimate platforms, fertility apps are also situated in an ideological and political context based on market logics, which presupposes rationality, autonomy, and choice (Olgado et al., 2020). However, fertility (as well as many other health issues) is incredibly emotional. In this context, data would function as an illusion of certainty (Gay Becker & Kaufman, 1995): individuals' data work aim to bring objectivity to their experiences (Neff & Nafus, 2016), but individuals' trajectories are so emotionally embedded in their lives that having access to extensive data does not make their experiences less challenging (Kaziunas et al., 2017).

In summary, although self-tracking is often embedded in a discourse of objectivity and quantified data are conflated with objective and true data, subjectivity is inherent of health contexts, particularly in emotionally intense ones. Technology can be very helpful in supporting a sense of control and help individuals learn about their bodies (which is important to counter influence some societal taboos in the health domain), but most of these tools lack transparency and support for balanced expectations and learning experiences. The increased use of AI in the self-tracking deepens this problem, not only for fertility but for varied health contexts (Su et al., 2020). Here, fertility works as an example of an extreme or overt case that can point to problems and potential solutions to other contexts, shedding light on issues or politics that may be less visible in more common and less loaded situations (Pine & Liboiron, 2015). By doing so, this dissertation calls attention to the need to design (i) for algorithm understanding, not only for experts, but for lay people, and (ii) for the entanglement between data and emotions and the feedback loop in which one feeds the other. Chapters 3 and 4 suggest that it is possible to minimize negative engagements with data by increasing transparency. Particularly with the growth of AI use in consumer-focused technology, it is necessary to make it clear for users how these tools generate their predictions and what these predictions mean. That includes making the simplification and uncertainty involved in the process of quantifying a bodily phenomenon more visible and designing for algorithm transparency to support users in understanding that variability is part of the process, especially in health. That will demand deeper analysis of visualizations that strongly consider aspects such as numeracy and health literacy.

Claims of objectivity in highly emotional contexts can directly and deeply impact individuals' lives. By changing processes of knowing and defining what "normalcy" is (Espeland & Stevens, 2008; S. E. Fox et al., 2020), technologies based on such claims may reinforce or increase harm, particularly for marginalized populations. Such embedded societal influences are harder to change. However, as Helms (2019) explains, supporting individuals in understanding what their data mean and how apps' algorithms work can also help in counteracting such power structures and societal pressures.

6.3. The Sociality of Highly Private Data

Self-tracked data is often seen as personal and private, however, these data, no matter the context, are embedded in broader social environments and influence individuals' interactions with interpersonal relationships and institutions. Fertility can work again as an extreme example to discuss the contrast between private data and social interactions: fertility data configure a type of data that are much often considered very private or intimate, but even these data are socially generated and used. In this session I discuss this sociality of data and how it happens in two ways, one practical and one implicit.

The practical sociality of fertility data refers to how these data are directly and indirectly shared, even though they are considered highly private and intimate. Previous HCI research on intimate care has defined it as *"those care tasks associated with personal hygiene, bodily functions and bodily products, which demand direct or indirect contact with or exposure of the sexual parts of the body as defined culturally by the individual"* (Almeida et al., 2014). Intimate care thus encompasses care work involving parts of the body that are considered private, associated with sexuality, or that breaks the boundary of the body (e.g., oral care) (Almeida, Comber, & Balaam, 2016). According to Almeida et. al (2014) these characteristics often turn intimate care invisible. Fertility challenges turn these invisible tasks visible for the individuals involved in them, their partners and other relationships, and the institutions they must interact with. Suddenly internal characteristics (e.g., cervical mucus, basal body temperature), processes (e.g., ovulation), and related practices (e.g., intercourse, IUI, IVF) are tracked, analyzed, discussed, and acted on by a group of people in different levels, pointing to social consequences of intimate highly private data.

Kwon et al. (2018) discuss that *"intimate data is not intimate per se, nor is intimacy a property of the data, but is an interactional outcome. Thus, judgements whether the data is too sensitive, private, or intimate to share are contingent on situated sense-making"* emphasizing that data becomes intimate depending on *"what can be read form the data, by whom, and for what potential purposes"* (Kwon et al., 2018). The fertility context supports that, emphasizing that who receives the data is a critical part of this process. For example, many individuals that actively use fertility online forums have no problems in sharing detailed data, including graphs generated by fertility technologies that clearly describe where they are in their fertility cycles, their symptoms, their emotions, and other aspects that allow others to derive diverse private information from them (e.g., when they have sex with their partners, their contraceptive habits, how their mental health is affected by their cycles, when they are more emotionally vulnerable, etc.). They share this information with individuals that access the same forums and face similar challenges, but they do not share that level of detail with their families, for example. The type of interaction individuals expect from sharing is also an important factor: sharing is also dependent on the type of support individuals envision to receive. As Chapter 3 showed, in OHCs individuals expect to get support in understanding their data and advice from their peers who face similar experiences. With families and friends who did not face such challenges they expect understanding and appropriate interactions (e.g., do not ask insensitive questions), so detailed data are not necessary.

Whose data are involved (i.e., the subject of data collection) is another important aspect. In Kwon et al. (2018) work, shower data are analyzed by both partners, and the authors discuss how such data can generate accountability (e.g., spending too much water) and how remote monitoring threats individuals' personal privacy (which can be used for harm in the context of abusive relationships (Freed et al., 2017)). But couples discussing their data during the study was even described as a humorous exercise. These descriptions contrast with my findings and those of Homewood, Boer, et al. (2020) concerning fertility data. In particular, Homewood, Boer, et al. (2020) created a fertility tracking device that was intended to be social and experienced by couples together, but they found that the tracking activities still fell on the female partner. While shower data include data from both partners, in the fertility context most data are usually about only one partner (the one who would carry the child). Discussing such data as a couple involves stronger negotiations around body and personal boundaries.

In summary, fertility is an extreme context in which there is a goal and a rush, the data are often about only one person, connected to a life plan, and as previously discussed, incredibly emotional. This context makes explicit how sharing personal data is not a constant (Van De Garde-Perik et al., 2008) and makes the different factors that influence these processes visible. As the fertility context shows, sharing intimate data is a function of who receives these data, the level of detail that is shared (which is related to what information others can get from the data), the support the individual expects to receive from the sharing interaction, and the stakes the others have on that interaction. These different factors for sharing highlight not only that intimate data is situated but that sharing is important and granular. Data that are considered very personal and intimate can be directly shared, guide individuals' interactions, serve as rapport means, and initiate empathic interactions. Therefore, as Cabtree and Mortier (2015) discuss, instead of being solely a *"thing-in-itself"* (i.e. *"a distinctive phenomenon worthy of treatment in its own right"*), data are a *"thing-embedded-in-human-relationships"* (Crabtree & Mortier, 2015) and should be treated as such.

However, self-tracking technologies do not offer support for these different levels of interaction. Self-tracking apps such as the ones focused on fertility usually offer only one way of sharing, which is often the less nuanced one and potentially the most exploitative (i.e., that gathers more data to be used by the company). Aligned with previous discussions (Bhat & Kumar, 2020; Ekbia, 2015; Lomborg et al., 2020; Olgado et al., 2020), my findings suggest that self-tracking technologies and the discourse around them often obliterate the complex support structure surrounding the individual and their health, particularly the critical role that other individuals play in care.

This practical sociality is also influenced by the implicit sociality of intimate data, which concerns how intimate data are socially constructed. Intimate data reflect socio-cultural norms; and society, particularly in the western and US contexts approached in this dissertation, says female bodies and its parts and processes (e.g., the vagina, menstruation) are private, often shameful, and that their aspects should not be discussed (Almeida, Comber, Wood, et al., 2016; Johnston-Robledo & Chrisler, 2013). In this context, menstruation is socialized to be invisible, but individuals are expected to conceive. Although these two things are dealt with as they were not connected, the invisibility of the first contributes to the lack of knowledge about fertility (as discussed in Chapter 5) which directly influence individuals' experiences when trying to conceive (as described in Chapter 3). As Almeida, Comber, Wood, et al. (2016) discuss, it is significant that it is necessary a life disruption (e.g., urinary incontinence or infertility) for individuals who menstruate to develop body literacy.

Self-tracking technologies often also align more with data industry interests than with individuals' needs. Fertility apps are designed more to accumulate data than to support individuals' data analysis and data sharing, as Chapters 4 and 5 show. This data accumulation follows an extractive market logic (Olgado et al., 2020) and is interesting to the technology industry that can generate value out of big datasets of varied and extensive data about a large number of users (Neff & Nafus, 2016).

The implicit sociality of intimate data is then characterized by the strong socio-cultural pressures to keep fertility invisible and the influential market pressures to accumulate data, combined with the macrolayer influences described in Chapter 5 (i.e., knowledge about female fertility, social expectations about gender). So, although the practical sociality defines that what is intimate depends on situated use, the implicit sociality says that anything that is related to sexuality (Kannabiran et al., 2011) and particularly connected to female bodies is intimate. The implicit sociality puts pressure to make data intimate despite how individuals may want to use them. Amidst these conflicting characteristics of intimate data, technology often sides with the macrolayer influences, by not supporting the nuances of the practical sociality and hiding the influence of the implicit one.

As Lupton (2015) describe, self-tracking apps are *"sociocultural products located within pre-established circuits of discourse and meaning"* and participate in the shaping of individuals bodies and selves. However, the original focus on "personal" or the "self" in the self-tracking domain obfuscates these socio-cultural influences and how health and self-care are inherently collaborative and embedded in larger ecological factors (Bhat & Kumar, 2020; Nunes & Fitzpatrick, 2015). The different characteristics of data sociality should not be ignored because of the negative consequences this avoidance can generate and because, as Almeida, Comber, Wood, et al. (2016) describe, *"health and wellbeing can benefit from* *intimate knowledge of the body, interpersonal communication within communities, and advancements in technology,"* aspects investigated and discussed in the different studies that form this dissertation. These studies show that an important part of individuals' data work is related to education, for themselves and for others, and the pressures that come with the lack of knowledge. So, supporting learning experiences and advocacy efforts are critical to counterinfluence the powerful macrolayer entities that greatly influence and shape individuals' experiences. As hypothesized by Søndergaard (2017), intimate technologies are inherently political and it is necessary to consider and question political and cultural issues by design. Doing that involves negotiating societal norms and assumptions (Homewood, Boer, et al., 2020), challenging the false private/public binary (D'Ignazio et al., 2020; Wright, 2012), and surpassing the common extractive market logic to support different interactions, such as supporting feminist consciousness raising (D'Ignazio et al., 2020) and social learning (Almeida, Comber, Wood, et al., 2016).

6.4. Implications Beyond Individuals

Finally, based on this dissertation's findings and discussion, it is possible to derive implications for different areas and professionals that are involved in the data work of individuals:

For healthcare providers: My findings show that even when healthcare providers do not need extensive data, they are increasingly having to deal with patients' engagements with these data, and conflicts may arise when patients do not understand providers' own data work (Costa Figueiredo, Su, et al., 2021). Therefore, my dissertation suggests that healthcare providers should aim to provide patients with explanations of their clinical reasoning and how PGHD fits in this process (e.g., what data and tests they need and how their results take them to the treatment). Making the clinical rationale, including data use, transparent to patients can help them understand providers' decision-making process and how it is supported by data. If patients understand the protocol providers follow and its underlying reasoning, they can be prepared to provide the necessary data to support them. In addition, making providers' data practices accessible to patients may help reduce uncertainty (Gay Becker & Kaufman, 1995; Mishel, 1988) and influence patients' own engagement with data, proposing a more rationalized data use without limiting the benefits of their own existing data practices (Costa Figueiredo, Su, et al., 2021).

Providers are often not able to ease the complex emotional context involved in patients' illness trajectories and its relationship with data. However, the existence of such relationship impacts their practices. Addressing patients' emotional needs is as critical for improving care as it is to treat their physical needs (Mullaney et al., 2012). Providing reassurance, as described by the REIs I interviewed, is a subtle way to address the complex emotional context of patients' health conditions and a good way to normalize patients' experiences. Patients also described positive interactions when providers let them talk through their data. These examples suggest that healthcare providers are already developing practices to deal with patients' engagements with data even when they do not use the data. My dissertation calls for such activities to be more directly defined and integrated with providers' protocol. Having procedures to deal with patients' relationship with data in sensible ways can support providers in addressing patients' emotional needs. It may even help providers in understanding the underlying causes that account for such emotions or recognize patterns of negative experiences, and direct patients to appropriate care.

For data work researchers: as this discussion stated, providers' and patients' data work for health differ significantly. While the data work performed within healthcare institutions has been increasingly examined, the other point of healthcare data work (i.e., patients) deserves more attention. It is fundamental for data work researchers to consider the characteristics of individuals' data work to not underestimate how much this work can influence people's lives, how much it is entangled with their emotional experience, and how much burden this work generates on individuals who are not experts and are passing through difficult or even life-threatening health events. This impact of data work needs to be investigated in different levels, focusing on breakdowns and gaps in different layers, examining more than data collection and visualization, and analyzing other types of work that are entangled with data work, such as infrastructuring, articulation, emotional, illness, and biographical work. Moreover, it is necessary to investigate the ecology of data work within ecologies of care, such as how individuals' data work interacts with providers' data work and how macrolevel influences trickle down to the individual level, often through technology, leading to more work and burden on the individual and, potentially, degrading care (Mol, 2008).

My dissertation also calls attention to reverse influences from data work: how individuals' data and data work can impact outerlayers. Examples include how individuals use data for advocacy, how data is used to mediate relationships and interactions, and how data work support learning experiences, which can directly influence societal forces. So, data work research should engage more with these and other similar practices to leverage data and data work to support changing negative stereotypes and pressures that influence health and health behavior. As previously discussed, self-tracking data can have social and political impacts if used to showcase health inequalities, such as revealing that negative experiences are consequences of societal norms and not individuals' personal behavior (Ruckenstein & Schüll, 2017). Data work research could then align with data science to explore these opportunities, situating patients, their experiences, and work in broader ecologies of care with a specific focus on education, advocacy, and justice. That includes considering who will have access to and who will be (positively and negatively) affected by the technology by (i) analyzing whether it can increase social disparities or reinforce social bias, (ii) targeting structural and environmental aspects, and (iii) dedicating effort to develop equity-focused interventions and technologies (Veinot et al., 2018). Data work research seeking these goals could include for example feminist approaches to data science (D'Ignazio & Klein, 2020), explore social learning (Almeida, Comber, Wood, et al., 2016), examine and support community forms of care (Kaziunas et al., 2019), incorporate design justice principles (Costanza-Chock, 2020), and promote feminist consciousness raising (D'Ignazio et al., 2020).

For technology designers: my dissertation intentionally adopted a wide lens to explore how self-tracking technologies for health are embedded in individuals' lives and influence and are influenced by interpersonal relationships, institutional interactions, and societal forces. Technology design should consider and adopt similar wide lenses more often to position data-driven technologies for health in broader ecologies of care and have a clearer understanding of the influences from and on these technologies. That includes first broadening their view on users to offer support to more than normative single-goal oriented trajectories. In this sense, it is critical to carefully consider who the users are – not only the "ideal" or target user but also unexpected ones that may use the system. Exploring means to support holistic tracking, offering customization and personalization, and offering a default version that is the most inclusive possible while the least overwhelming possible are examples of ways to broaden support to more varied and real health experiences and trajectories.

Data tracking technologies also need to clearly present their real capabilities. For example, algorithmic predictions should be explained in terms easy to understand, fast to get, and easy to find, making the results and their interpretations clear for lay people and avoiding “technoutopian” descriptions and jargons. Showing scales, average values, and standard measures based on a population that is more similar to the user, showcasing the inherent variability of health indicator values and predictions, and displaying uncertainty can improve users’ recognition and support balanced expectations concerning their own results. It is also fundamental to account for exceptions, making it clear to the user that their results may be different from the expected. There is a growing body of research on AI explainability (e.g., (Bansal et al., 2021; Biran & Cotton, 2017; H.-F. Cheng et al., 2019; M. Jacobs et al., 2021; Samek et al., 2017)) and a long research tradition on visualizations (e.g., (Huang et al., 2014; Huron et al., 2014; B. Lee et al., 2020; Pousman et al., 2007)) from which consumer focused data tracking technologies can draw on to better display data and support users’ data work. It is also necessary to consider aspects of literacy, numeracy, health literacy, and now AI literacy when developing data-driven technologies directed to health consumers, and to avoid overestimating the burden of data work on them, their lives, and relationships.

Finally, technology designers should aim to avoid reinforcing limited definitions of health through PGHD (Eikey & Reddy, 2017; Purpura et al., 2011) and consider the larger sociocultural contexts where technologies are embedded. Social norms can be intractable, but may be possible to consider, embrace, or co-adapt in design (Gross et al., 2017). In this context, we, as designers, need to be critical about different aspects and dimensions of PGHD (Costa Figueiredo & Chen, 2020) and the characteristics of individuals' health data work, aim to support everyday lives as whole, and remember the limits of technological solutions, which can potentially improve, but cannot fully address systemic challenges and infrastructural breakdowns (Kaziunas et al., 2019).

For policy and regulations: with the widespread use of self-tracking technologies and the growth in direct-to-consumer AI, consumer-technologies are getting closer to the medical field and there has been increasing discussions about regulation. The fertility context again offers insights to what may happen in other areas: recently two fertility apps have received FDA approval as digital birth control devices, the second one (Clue) being approved for being *"substantially equivalent"* to the first one (Natural Cycles) (FDA, 2019, 2019, 2020; Wetsman, 2021). The decision created controversies because Natural Cycles affirms that, although the apps have the same function and in principle work in the same way (i.e., use individuals' data to predict fertile windows), their algorithms are different and even the data used to make the predictions are different (e.g., Natural Cycles uses temperature, Clue does not). Additionally, as my dissertation described, many health apps are currently using AI algorithms and using AI and technological jargons to convey objectivity and accuracy. However, many of these claims are not backed up by studies such as the ones necessary to get FDA approval. So, this context, alongside the FDA decision concerning birth control apps, raises questions on how parameters such as *"substantially equivalent"* can be defined and evaluated in regard to algorithms and what happens if an app changes the algorithm after the approval.

Looking to the broader ecologies of care where these technologies are embedded also point to other implications for IT policies, consumer health, and policy makers. It is the case, for example, of incentivized PGHD-based health programs promoted by health insurance companies and their effect on the healthcare of (and associated cost for) people who may not be able to participate, such as programs based on step count and disabled individuals. In such cases, policies are often necessary to avoid discrimination and the increase of health disparities (Zulman et al., 2013). These relationships between data, technology companies, and insurers and employers also raise important privacy questions that may benefit from policy interventions. In the fertility context, the practices of the data industry have already generated controversies, with reports of apps sharing data with employers or insurance companies (Harwell, 2019) and marketing services like Facebook (Lomas, 2021), this last one leading to a complaint and settlement with the U.S. Federal Trade Commission (FTC) (Federal Trade Commission, 2021).

Moreover, if healthcare institutions adopt PGHD technologies such as mobile apps more intensely, questions arise regarding how to maintain the same level of care for patients who use and who do not use these data tracking technologies (R. L. Johnson et al., 2004; Loos & Davidson, 2016; Veinot et al., 2018), if care will be contingent to app use, how to evaluate quality of care with mixed technology use, and if this evaluation will consider the unpaid work and burden potentially transmitted to patients. All these aspects could benefit from a policy-oriented analysis, with a focus on both the data and data tracking technologies used and the consequences of this use. In summary, self-tracking and other data-driven technologies are here to stay and are increasingly entangled with multiple aspects of our lives, directly and indirectly. As this relationship intensifies, policies will have to evolve to support and protect individuals in multiple levels, regulating healthcare practices related to data, and avoiding degradation of services.

CONCLUSION

With the recent uptake of self-tracking technologies, it became easier for individuals who are not technology nor health experts to access and use extensive data potentially related to their health. Such data can be classified as patient-generated health data and are commonly associated with varied potential benefits. However, individuals often face challenges in making sense of this data and such activities demand a lot of effort from them in what can be called data work: *"any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data"* (Bossen, Pine, et al., 2019). Data work literature most often focuses on the data work performed by healthcare professionals within healthcare organizations, but this data work performed by individuals outside clinical settings has growing exponentially requiring further attention.

This dissertation investigated the data work individuals perform when self-tracking for health through the fertility context. Fertility is a complex, sensitive, and data intensive context that can be considered as an extreme example and as such can turn visible aspects that are less explicit in other cases. Through three different studies, I explored this context holistically, analyzing the perspectives of (i) individuals and the challenges they face with data collection and analysis, (ii) technology and its influence on supporting, limiting, and shaping individuals' data work, and (iii) broader ecologies of care, including healthcare professionals and partners, focusing on how individuals' data and data work influence and are influenced by interpersonal relationships and institutional and societal factors.

Through these studies I explain how, from the individual perspective, fertility uncertainties make it a complex context for self-tracking, posing varied challenges of data collection and interpretation that are entangled with individuals' emotional experiences and fertility trajectories, which vary greatly. From the technology perspective, my studies show that while fertility self-tracking are often single-goal oriented and have a specific focus on conception, individuals' fertility trajectories are dynamic and much more varied than the support apps offer. By providing similar data collection and visualization options, these tools can shape individuals' data work, posing limitations for those whose needs do not fit in the idealized, linear, and normative experience of fertility and pregnancy. Recent claims of artificial intelligence add a new layer to this context, by aiming to inspire technological precision and accuracy, encouraging users' confidence and trust in predictions, potentially suggesting that all that is necessary for conceiving is timing intercourse with the fertile window with apps' help, giving users the impression that the only reason they did not conceive is because they did not try hard enough. Finally, the ecological perspective positions these two first in the context of larger ecologies of care, emphasizing that those activities are not limited to the individual level nor to the personal interactions between individual and technology. Individuals perform data work and face all these challenges while living their daily lives, dealing with infertility, and interacting with others and with institutions, all of it under the influence of societal norms and pressures. Their data work needs to be analyzed within this context to avoid reductionist solutions.

Based on these findings, I used the context of fertility to identify the main characteristics of individuals' data work for health, contrasting them with the data work performed by healthcare providers and institutions and providing insights for research and design for individuals' data work. Finally, I argue that data work in general, and individuals' data work in particular, require the adoption of wide lenses when designing and analyzing the impacts of self-tracking technologies, providing two examples of broader analysis coming from the specific and extreme context of fertility that were developed because this dissertation took a holistic approach. First, I discuss the role of claims of objectivity in a highly emotional context, emphasizing that subjectivity is inherent of health contexts, particularly in emotionally intense ones. These claims are often hidden in technology design and may shape not only individuals' data work but also their interactions with the technology and their emotional engagement with data. Then I discuss the sociality of highly private data, arguing that even fertility data, which are often considered intimate, are intrinsically social in two different ways: one practical, referring to how much such data is directly shared, and one implicit, which refers to how these data's intimacy is socially constructed and carries varied social influences. I then highlight that self-tracking technologies do not offer the nuanced sharing features the practical sociality needs, and often hide the influence of the implicit sociality in shaping individuals' data work. These types of analyzes are useful to rethink the ways we research and design for health tracking, challenge common hidden extractive logics, and aim to support a different project of health and body.

REFERENCES

Almalki, M., Gray, K., & Martin-Sanchez, F. (2016). Activity Theory as a Theoretical Framework for Health Self-Quantification: A Systematic Review of Empirical Studies. *Journal of Medical Internet Research*, *18*(5). https://doi.org/10.2196/jmir.5000

Almeida, T., Comber, R., & Balaam, M. (2016). HCI and Intimate Care As an Agenda for Change in Women's Health. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 2599–2611. https://doi.org/10.1145/2858036.2858187

Almeida, T., Comber, R., Olivier, P., & Balaam, M. (2014). Intimate care: Exploring eTextiles for teaching female pelvic fitness. In *Proceedings of the 2014 companion publication on Designing Interactive Systems* (pp. 5–8).

Almeida, T., Comber, R., Wood, G., Saraf, D., & Balaam, M. (2016). On Looking at the Vagina through Labella. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 1810–1821. https://doi.org/10.1145/2858036.2858119

Altman, A. (2018, October 2). The Unlikely Politics of a Digital Contraceptive. *The New Yorker*. https://www.newyorker.com/tech/annals-of-technology/the-unlikely-politics-of-a-digital-contraceptive

Alvergne, A., Vlajic Wheeler, M., & Högqvist Tabor, V. (2018). Do sexually transmitted infections exacerbate negative premenstrual symptoms? Insights from digital health. *Evolution, Medicine, and Public Health*, *2018*(1), 138–150.

American Society for Reproductive Medicine. (2021). *Waiting To Have A Baby?* https://www.asrm.org/resources/patient-resources/google-adwords-landing-pages/waiting-to-have-a-baby/

Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van de Graaf, M., & Wei, E. (2015). "You Get Reminded You're a Sick Person": Personal Data Tracking and Patients With Multiple Chronic Conditions. *Journal of Medical Internet Research*, *17*(8), e202. https://doi.org/10.2196/jmir.4209

Andalibi, N. (2020). Disclosure, Privacy, and Stigma on Social Media: Examining Non-Disclosure of Distressing Experiences. *ACM Transactions on Computer-Human Interaction (TOCHI)*, *27*(3), 1–43.

Andalibi, N. (2021). Symbolic annihilation through design: Pregnancy loss in pregnancy-related mobile apps. *New Media & Society*, 1461444820984473.

Andalibi, N., & Forte, A. (2018). Announcing Pregnancy Loss on Facebook: A Decision-Making Framework for Stigmatized Disclosures on Identified Social Network Sites. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, 158:1-158:14. https://doi.org/10.1145/3173574.3173732

Arriaga, R. I. (2017). Using an ecological systems approach to target technology. *Autism Imaging and Devices*, 419.

Ava Science Inc. (2021). *Ava: A Fertility Tracking Bracelet Unlike Anything Else*. Ava. https://www.avawomen.com/order/

Ayobi, A., Marshall, P., Cox, A. L., & Chen, Y. (2017). Quantifying the Body and Caring for the Mind: Self-Tracking in Multiple Sclerosis. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 6889–6901. https://doi.org/10.1145/3025453.3025869

Ayoola, A. B., Zandee, G. L., & Adams, Y. J. (2016). Women's Knowledge of Ovulation, the Menstrual Cycle, and Its Associated Reproductive Changes. *Birth*, *43*(3), 255–262. https://doi.org/10.1111/birt.12237

Balaam, M., Comber, R., Jenkins, E., Sutton, S., & Garbett, A. (2015). FeedFinder: A Location-Mapping Mobile Application for Breastfeeding Women. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 1709–1718. https://doi.org/10.1145/2702123.2702328

Bansal, G., Wu, T., Zhou, J., Fok, R., Nushi, B., Kamar, E., Ribeiro, M. T., & Weld, D. (2021). *Does the whole exceed its parts? The effect of ai explanations on complementary team performance*. 1–16.

Barbarin, A. M., Klasnja, P., & Veinot, T. C. (2016). Good or bad, ups and downs, and getting better: Use of personal health data for temporal reflection in chronic illness. *International Journal of Medical Informatics*, *94*, 237–245. https://doi.org/10.1016/j.ijmedinf.2016.06.011

Bardzell, J., Bardzell, S., Lazar, A., & Su, N. M. (2019). (Re-)Framing Menopause Experiences for HCI and Design. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 115:1-115:13. https://doi.org/10.1145/3290605.3300345

Baumer, E. P. S., Khovanskaya, V., Matthews, M., Reynolds, L., Schwanda Sosik, V., & Gay, G. (2014). Reviewing Reflection: On the Use of Reflection in Interactive System Design. *Proceedings of the 2014 Conference on Designing Interactive Systems*, 93–102. https://doi.org/10.1145/2598510.2598598

Becker, G., & Nachtigall, R. (1994). "Born to be a mother": Cultural Construction of Risk in Treatment in the U.S. *"Born to Be a Mother": Cultural Construction of Risk in Treatment in the U.S.*, *39*(4), 507–518. https://doi.org/0277-9536(93)E0097-X

Becker, Gay. (1994). Metaphors in Disrupted Lives: Infertility and Cultural Constructions of Continuity. *Medical Anthropology Quarterly*, *8*(4), 383–410. https://doi.org/10.1525/maq.1994.8.4.02a00040

Becker, Gay, & Kaufman, S. R. (1995). Managing an uncertain illness trajectory in old age: Patients' and physicians' views of stroke. *Medical Anthropology Quarterly*, *9*(2), 165–187.

Becker, Gay, & Nachtigall, R. D. (1994). 'Born to be a mother': The cultural construction of risk in infertility treatment in the U.S. *Social Science & Medicine*, *39*(4), 507-IN2. https://doi.org/10.1016/0277-9536(94)90093-0

Bentley, F., Tollmar, K., Stephenson, P., Levy, L., Jones, B., Robertson, S., Price, E., Catrambone, R., & Wilson, J. (2013). Health Mashups: Presenting Statistical Patterns Between Wellbeing Data and Context in Natural Language to Promote Behavior Change. *ACM Trans. Comput.-Hum. Interact.*, *20*(5), 30:1-30:27. https://doi.org/10.1145/2503823

Bhat, K. S., & Kumar, N. (2020). Sociocultural Dimensions of Tracking Health and Taking Care. *Proceedings of the ACM on Human-Computer Interaction*, *4*(CSCW2), 1–24.

Biran, O., & Cotton, C. (2017). *Explanation and justification in machine learning: A survey*. *8*(1), 8–13.

Bødker, S. (2016). Rethinking technology on the boundaries of life and work. *Personal and Ubiquitous Computing*, *20*(4), 533–544.

Boivin, J., & Schmidt, L. (2005). Infertility-related stress in men and women predicts treatment outcome 1 year later. *Fertility and Sterility*, *83*(6), 1745–1752. https://doi.org/10.1016/j.fertnstert.2004.12.039

Bonde, M., Bossen, C., & Danholt, P. (2019). Data-work and friction: Investigating the practices of repurposing healthcare data. *Health Informatics Journal*, *25*(3), 558–566.

Bossen, C., Chen, Y., & Pine, K. H. (2019). The emergence of new data work occupations in healthcare: The case of medical scribes. *International Journal of Medical Informatics*, *123*, 76–83.

Bossen, C., Pine, K., Ellingsen, G., & Cabitza, F. (2016). *Data-work in healthcare: The new work ecologies of healthcare infrastructures*. 509–514.

Bossen, C., Pine, K. H., Cabitza, F., Ellingsen, G., & Piras, E. M. (2019). *Data work in healthcare: An Introduction*.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513.

Bronfenbrenner, U. (1992). *Ecological systems theory.* Jessica Kingsley Publishers.

Bunting, L., Tsibulsky, I., & Boivin, J. (2013). Fertility knowledge and beliefs about fertility treatment: Findings from the International Fertility Decision-making Study. *Human Reproduction*, *28*(2), 385–397. https://doi.org/10.1093/humrep/des402

Bussone, A., Stumpf, S., & Buchanan, G. (2016). It Feels Like I'm Managing Myself: HIV+ People Tracking Their Personal Health Information. *Proceedings of the 9th Nordic Conference on Human-Computer Interaction*, 1–10. https://doi.org/10.1145/2971485.2971542

Cabitza, F., Locoro, A., Alderighi, C., Rasoini, R., Compagnone, D., & Berjano, P. (2019). The elephant in the record: On the multiplicity of data recording work. *Health Informatics Journal*, *25*(3), 475–490.

Caldeira, C., Bietz, M., & Chen, Y. (2016). Looking for the Unusual: How Older Adults Utilize Self-tracking Techniques for Health Management. *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*, 227–230. http://dl.acm.org/citation.cfm?id=3021319.3021354

Caldeira, C., Chen, Y., Chan, L., Pham, V., Chen, Y., & Zheng, K. (2018). Mobile apps for mood tracking: An analysis of features and user reviews. *AMIA Annual Symposium Proceedings*, *2017*, 495–504.

Campo Woytuk, N., Nilsson, L., & Liu, M. (2019). Your Period Rules: Design Implications for Period-Positive Technologies. *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, LBW0137:1-LBW0137:6. https://doi.org/10.1145/3290607.3312888

Campo Woytuk, N., Søndergaard, M. L. J., Ciolfi Felice, M., & Balaam, M. (2020). *Touching and Being in Touch with the Menstruating Body*. 1–14.

Case, A. M., & Reid, R. L. (1998). Effects of the Menstrual Cycle on Medical Disorders. *Archives of Internal Medicine*, *158*(13), 1405–1412. https://doi.org/10.1001/archinte.158.13.1405

Cavaliere, A., Ermito, S., Dinatale, A., & Pedata, R. (2009). Management of molar pregnancy. *Journal of Prenatal Medicine*, *3*(1), 15–17.

CDC. (2017). *NSFG - Listing I - Key Statistics from the National Survey of Family Growth*. https://www.cdc.gov/nchs/nsfg/key_statistics/i.htm

CDC. (2021). *Infertility FAQs*. https://www.cdc.gov/reproductivehealth/infertility/index.htm

Charmaz, K., & Belgrave, L. (2012). Qualitative interviewing and grounded theory analysis. *The SAGE Handbook of Interview Research: The Complexity of the Craft*, *2*, 347–365.

Cheng, H.-F., Wang, R., Zhang, Z., O'Connell, F., Gray, T., Harper, F. M., & Zhu, H. (2019). Explaining Decision-Making Algorithms through UI: Strategies to Help Non-Expert Stakeholders. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–12. https://doi.org/10.1145/3290605.3300789

Cheng, K. G., Hayes, G. R., Hirano, S. H., Nagel, M. S., & Baker, D. (2015). Challenges of integrating patient-centered data into clinical workflow for care of high-risk infants. *Personal and Ubiquitous Computing*, *19*(1), 45–57. https://doi.org/10.1007/s00779-014-0807-y

Choe, E. K., Lee, B., Kay, M., Pratt, W., & Kientz, J. A. (2015). SleepTight: Low-burden, Self-monitoring Technology for Capturing and Reflecting on Sleep Behaviors. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 121–132. https://doi.org/10.1145/2750858.2804266

Choe, E. K., Lee, N. B., Lee, B., Pratt, W., & Kientz, J. A. (2014). Understanding Quantified-selfers' Practices in Collecting and Exploring Personal Data. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 1143–1152. https://doi.org/10.1145/2556288.2557372

Choi, J., & Smitz, J. (2014). Luteinizing hormone and human chorionic gonadotropin: Origins of difference. *Molecular and Cellular Endocrinology*, *383*(1–2), 203–213. https://doi.org/10.1016/j.mce.2013.12.009

Chung, C.-F., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J. A., & Munson, S. A. (2016). Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*, 770–786. https://doi.org/10.1145/2818048.2819926

Chung, C.-F., Wang, Q., Schroeder, J., Cole, A., Zia, J., Fogarty, J., & Munson, S. A. (2019). Identifying and Planning for Individualized Change: Patient-Provider Collaboration Using Lightweight Food Diaries in Healthy Eating and Irritable Bowel Syndrome. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, *3*(1), 7:1-7:27. https://doi.org/10.1145/3314394

Clawson, J., Pater, J. A., Miller, A. D., Mynatt, E. D., & Mamykina, L. (2015). No Longer Wearing: Investigating the Abandonment of Personal Health-tracking Technologies on Craigslist. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 647–658. https://doi.org/10.1145/2750858.2807554

Consolvo, S., McDonald, D. W., Toscos, T., Chen, M. Y., Froehlich, J., Harrison, B., Klasnja, P., LaMarca, A., LeGrand, L., Libby, R., Smith, I., & Landay, J. A. (2008). Activity sensing in the wild: A field trial of ubifit garden. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 1797–1806. https://doi.org/10.1145/1357054.1357335

Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, *8*(3), 224–247.

Corbin, J., & Strauss, A. (2014). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. SAGE Publications.

Cordeiro, F., Epstein, D. A., Thomaz, E., Bales, E., Jagannathan, A. K., Abowd, G. D., & Fogarty, J. (2015). Barriers and Negative Nudges: Exploring Challenges in Food Journaling. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems CHI Conference*, *2015*, 1159–1162. https://doi.org/10.1145/2702123.2702155

Cortez, A., Hsii, P., Mitchell, E., Riehl, V., & Smith, P. (2018). *Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024 (White Paper).* Office of the National Coordinator for Health Information Technology. https://www.healthit.gov/sites/default/files/onc_pghd_final_white_paper.pdf

Costa Figueiredo, M., Caldeira, C., Chen, Y., & Zheng, K. (2017). Routine self-tracking of health: Reasons, facilitating factors, and the potential impact on health management practices. *AMIA ... Annual Symposium Proceedings. AMIA Symposium*, *2017*, 706–714.

Costa Figueiredo, M., Caldeira, C., Eikey, E. V., Mazmanian, M., & Chen, Y. (2018, November). Engaging with Health Data: The Interplay Between Self-Tracking Activities and Emotions in Fertility Struggles. *Proc. ACM Hum.-Comput. Interact.* CSCW. https://doi.org/10.1145/3274309

Costa Figueiredo, M., Caldeira, C., Reynolds, T. L., Victory, S., Zheng, K., & Chen, Y. (2017). Self-Tracking for Fertility Care: Collaborative Support for a Highly Personalized Problem. *Proc. ACM Hum.-Comput. Interact.*, *1*(CSCW), 36:1-36:21. https://doi.org/10.1145/3134671

Costa Figueiredo, M., & Chen, Y. (2020). Patient-Generated Health Data: Dimensions, Challenges, and Open Questions. *Foundations and Trends® in Human-Computer Interaction*, *13*(3), 165–297.

Costa Figueiredo, M., & Chen, Y. (2021). *Health Data in Fertility Care: An Ecological Perspective*. 1–17.

Costa Figueiredo, M., Huynh, T., Takei, A., Epstein, D. A., & Chen, Y. (2021). Goals, Life Events, and Transitions: Examining Fertility Apps for Holistic Health Tracking. *The Open Journal of the American Medical Informatics Association*.

Costa Figueiredo, M., Su, H. I., & Chen, Y. (2020). *An Evaluation of Commercial Fertility Apps: Algorithmic Predictions and Users' Perceptions*. Late Breaking Abstract Poster in the American Society for Reproductive Medicine Scientific Congress.

Costa Figueiredo, M., Su, H. I., & Chen, Y. (2021). Using Data to Approach the Unknown: Patients' and Healthcare Providers' Data Practices in Fertility Challenges. *Proceedings of the ACM on Human-Computer Interaction*, *4*(CSCW3), 227:1-227:35. https://doi.org/10.1145/3432926

Costanza-Chock, S. (2020). *Design justice: Community-led practices to build the worlds we need*. MIT Press.

Crabtree, A., & Mortier, R. (2015). Human Data Interaction: Historical Lessons from Social Studies and CSCW. In *ECSCW 2015: Proceedings of the 14th European Conference on Computer Supported Cooperative Work, 19-23 September 2015, Oslo, Norway* (pp. 3–21). Springer, Cham. https://doi.org/10.1007/978-3-319-20499-4_1

Crenshaw, K. (1997). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *The Legal Response to Violence against Women*, *5*, 91.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches, 2nd ed*. Sage Publications, Inc.

Daar, A. S., & Merali, Z. (2002). *Infertility and social suffering: The case of ART in developing countries.*

Dabbs, M. (2018, November 2). *Does Your Mobile Medical App Need FDA Approval? | Reinvently*. Reinvently | Mobile App Design and Development. https://reinvently.com/blog/mobile-medical-application-approval-fda/

Data 4 Black Lives. (n.d.). Retrieved September 15, 2020, from https://d4bl.org/

Davies, T., Jones, S. L., & Kelly, R. M. (2019). Patient Perspectives on Self-Management Technologies for Chronic Fatigue Syndrome. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–13. https://doi.org/10.1145/3290605.3300452

Dervin, B. (1983). An Overview of Sense-making Research: Concepts, Methods, and Results to Date. *Paper Presented at the Annual Meeting of the International Communication Association. Originally in: Http://Communication.Sbs.Ohio-State.Edu/Sense-Making/Art/Artdervin83.Html*. http://faculty.washington.edu/wpratt/MEBI598/Methods/An%20Overview%20of%20Sense-Making%20Research%201983a.htm

D'Ignazio, C., Hope, A., Michelson, B., Churchill, R., & Zuckerman, E. (2016). A Feminist HCI Approach to Designing Postpartum Technologies: "When I First Saw a Breast Pump I Was Wondering if It Was a Joke." *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 2612–2622. https://doi.org/10.1145/2858036.2858460

D'Ignazio, C., & Klein, L. F. (2020). *Data feminism*. MIT Press.

D'Ignazio, C., Michelson, R., Hope, A., Hoy, J., Roberts, J., & Krontiris, K. (2020). " The Personal is Political" Hackathons as Feminist Consciousness Raising. *Proceedings of the ACM on Human-Computer Interaction*, *4*(CSCW2), 1–23.

Ding, X., Chen, Y., Ding, Z., & Xu, Y. (2019). Boundary Negotiation for Patient-Provider Communication via WeChat in China. *Proceedings of the ACM on Human-Computer Interaction*, *3*(CSCW), 1–24.

Dreaper, J. (2016, August 11). Women warned about booming market in period tracker apps. *BBC News*. https://www.bbc.com/news/health-37013217

Duane, M., Contreras, A., Jensen, E. T., & White, A. (2016). The Performance of Fertility Awareness-based Method Apps Marketed to Avoid Pregnancy. *Journal of the American Board of Family Medicine: JABFM*, *29*(4), 508–511. https://doi.org/10.3122/jabfm.2016.04.160022

Duhaime-Ross, A. (2014, September 25). *Apple promised an expansive health app, so why can't I track menstruation?* The Verge. https://www.theverge.com/2014/9/25/6844021/apple-promised-an-expansive-health-app-so-why-cant-i-track

Eikey, E. V., & Reddy, M. C. (2017). "It's Definitely Been a Journey": A Qualitative Study on How Women with Eating Disorders Use Weight Loss Apps. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 642–654. https://doi.org/10.1145/3025453.3025591

Ekbia, H. R. (2015). Heteronomous humans and autonomous agents: Toward artificial relational intelligence. In *Beyond Artificial Intelligence* (pp. 63–77). Springer.

Elhadad, N., Pichon, A., Gorman, S., & Horan, E. (2016). *Welcome to Citizen Endo*. http://citizenendo.org/

Elliott, J. (2020). *Using Narrative in Social Research* (By pages 17-35). SAGE Publications Ltd. https://doi.org/10.4135/9780857020246

Ensari, I., & Elhadad, N. (2021). mHealth for research: Participatory research applications to gain disease insights. In *Digital Health* (pp. 79–102). Elsevier.

Ensari, I., Pichon, A., Lipsky-Gorman, S., Bakken, S., & Elhadad, N. (2020). Augmenting the Clinical Data Sources for Enigmatic Diseases: A Cross-Sectional Study of Self-Tracking Data and Clinical Documentation in Endometriosis. *Applied Clinical Informatics*, *11*(05), 769–784.

Epstein, D. A., Caldeira, C., Costa Figueiredo, M., Lu, X., Silva, L. M., Williams, L., Lee, J. H., Li, Q., Ahuja, S., Chen, Q., Dowlatyari, P., Hilby, C., Sultana, S., Eikey, E. V., & Chen, Y. (2020). Mapping and Taking Stock of the Personal Informatics Literature. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, *4*(4), 1–38.

Epstein, D. A., Caraway, M., Johnston, C., Ping, A., Fogarty, J., & Munson, S. A. (2016). Beyond Abandonment to Next Steps: Understanding and Designing for Life after Personal Informatics Tool Use. *Proceedings of the CHI Conference on Human Factors in Computing Systems*, 1109–1113. https://doi.org/10.1145/2858036.2858045

Epstein, D. A., Lee, N. B., Kang, J. H., Agapie, E., Schroeder, J., Pina, L. R., Fogarty, J., Kientz, J. A., & Munson, S. (2017). Examining Menstrual Tracking to Inform the Design of Personal Informatics Tools. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 6876–6888. https://doi.org/10.1145/3025453.3025635

Epstein, D. A., Ping, A., Fogarty, J., & Munson, S. A. (2015). A Lived Informatics Model of Personal Informatics. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 731–742. https://doi.org/10.1145/2750858.2804250

Eschler, J., Menking, A., Fox, S. E., & Backonja, U. (2019). Defining Menstrual Literacy With the Aim of Evaluating Mobile Menstrual Tracking Applications. *Computers, Informatics, Nursing: CIN*. https://doi.org/10.1097/CIN.0000000000000559

Espeland, W. N., & Stevens, M. L. (2008). A Sociology of Quantification. *European Journal of Sociology / Archives Européennes de Sociologie*, *49*(3), 401–436. https://doi.org/10.1017/S0003975609000150

Evans, H., Lakshmi, U., Watson, H., Ismail, A., Sherrill, A. M., Kumar, N., & Arriaga, R. I. (2020). *Understanding the Care Ecologies of Veterans with PTSD*. 1–15.

Eveleth, R. (2014, December 15). *How Self-Tracking Apps Exclude Women*. The Atlantic. https://www.theatlantic.com/technology/archive/2014/12/how-self-tracking-apps-exclude-women/383673/

Even Chorev, N. (2019). Data ambiguity and clinical decision making: A qualitative case study of the use of predictive information technologies in a personalized cancer clinical trial. *Health Informatics Journal*, *25*(3), 500–510.

FDA. (2019, September 11). *FDA allows marketing of first direct-to-consumer app for contraceptive use to prevent pregnancy*. FDA News Release. http://www.fda.gov/news-events/press-announcements/fda-allows-marketing-first-direct-consumer-app-contraceptive-use-prevent-pregnancy

FDA. (2020, September 9). *Device Software Functions Including Mobile Medical Applications*. FDA; FDA. https://www.fda.gov/medical-devices/digital-health-center-excellence/device-software-functions-including-mobile-medical-applications

Federal Trade Commission. (2021, January 12). *Developer of Popular Women's Fertility-Tracking App Settles FTC Allegations that It Misled Consumers About the Disclosure of their Health Data*. Federal Trade Commission. https://www.ftc.gov/news-events/press-releases/2021/01/developer-popular-womens-fertility-tracking-app-settles-ftc

Felipe, S., Singh, A., Bradley, C., Williams, A. C., & Bianchi-Berthouze, N. (2015). Roles for Personal Informatics in Chronic Pain. *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare*, 161–168. http://dl.acm.org/citation.cfm?id=2826165.2826189

Fertility Focus Inc. (n.d.). *OvuSense Fertility Monitors & Ovulation Trackers—99% Accuracy*. Retrieved March 13, 2021, from https://www.ovusense.com/us/

Flemings, M., Kazmi, S., Pak, R., & Shaer, O. (2018). Crimson Wave: Shedding Light on Menstrual Health. *Proceedings of the Twelfth International Conference on Tangible, Embedded, and Embodied Interaction*, 343–348. https://doi.org/10.1145/3173225.3173292

Fotopoulou, A., & O'Riordan, K. (2017). Training to self-care: Fitness tracking, biopedagogy and the healthy consumer. *Health Sociology Review*, *26*(1), 54–68.

Fourney, A., White, R. W., & Horvitz, E. (2015). Exploring Time-Dependent Concerns About Pregnancy and Childbirth from Search Logs. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 737–746. https://doi.org/10.1145/2702123.2702427

Fox, S. E., Howell, N., Wong, R., & Spektor, F. (2019). Vivewell: Speculating Near-Future Menstrual Tracking Through Current Data Practices. *Proceedings of the 2019 on Designing Interactive Systems Conference*, 541–552. https://doi.org/10.1145/3322276.3323695

Fox, S. E., Menking, A., Eschler, J., & Backonja, U. (2020). Multiples Over Models: Interrogating the Past and Collectively Reimagining the Future of Menstrual Sensemaking. *ACM Transactions on Computer-Human Interaction*, *27*(4), 22:1-22:24. https://doi.org/10.1145/3397178

Fox, S. E., Silva, R. M. L., & Rosner, D. K. (2018). Beyond the Prototype: Maintenance, Collective Responsibility, and Public IoT. *Proceedings of the 2018 Designing Interactive Systems Conference*, 21–32. https://doi.org/10.1145/3196709.3196710

Freed, D., Palmer, J., Minchala, D. E., Levy, K., Ristenpart, T., & Dell, N. (2017). Digital technologies and intimate partner violence: A qualitative analysis with multiple stakeholders. *Proceedings of the ACM on Human-Computer Interaction*, *1*(CSCW), 1–22.

Freis, A., Freundl-Schütt, T., Wallwiener, L.-M., Baur, S., Strowitzki, T., Freundl, G., & Frank-Herrmann, P. (2018). Plausibility of Menstrual Cycle Apps Claiming to Support Conception. *Frontiers in Public Health*, *6*. https://doi.org/10.3389/fpubh.2018.00098

Frost & Sullivan. (2018, January 31). Femtech—Time for a Digital Revolution in the Women's Health Market. *Frost & Sullivan*. https://ww2.frost.com/frost-perspectives/femtechtime-digital-revolution-womens-health-market/

G. Mitchell, E., M. Heitkemper, E., Burgermaster, M., E. Levine, M., Miao, Y., L. Hwang, M., M. Desai, P., Cassells, A., N. Tobin, J., & G. Tabak, E. (2021). *From Reflection to Action: Combining Machine Learning with Expert Knowledge for Nutrition Goal Recommendations*. 1–17.

Gambier-Ross, K., McLernon, D. J., & Morgan, H. M. (2018). A mixed methods exploratory study of women's relationships with and uses of fertility tracking apps. *DIGITAL HEALTH*, *4*, 2055207618785077. https://doi.org/10.1177/2055207618785077

Gerbner, G., & Gross, L. (1976). Living with television: The violence profile. *Journal of Communication*, *26*(2), 172–199.

Gitelman, L., Jackson, V., Rosenberg, D., Williams, T. D., Brine, K. R., Poovey, M., Stanley, M., Garvey, E. G., Krajewski, M., & Raley, R. (2013). *Data bite man: The work of sustaining a long-term study*.

Glenza, J. (2019, May 30). Revealed: Women's fertility app is funded by anti-abortion campaigners. *The Guardian*. https://www.theguardian.com/world/2019/may/30/revealed-womens-fertility-app-is-funded-by-anti-abortion-campaigners

Gregory, E. (2012). *Ready: Why Women Are Embracing the New Later Motherhood*. Basic Books.

Greil, A. (1997). Infertility and psychological distress: A critical review of the literature. *Social Science & Medicine*, *45*(11), 1679–1704. https://doi.org/10.1016/S0277-9536(97)00102-0

Greil, A., McQuillan, J., & Slauson-Blevins, K. (2011). The social construction of infertility. *Sociology Compass*, *5*(8), 736–746.

Grisot, M., Moltubakk Kempton, A., Hagen, L., & Aanestad, M. (2019). Data-work for personalized care: Examining nurses' practices in remote monitoring of chronic patients. *Health Informatics Journal*, *25*(3), 608–616.

Grönvall, E., & Verdezoto, N. (2013a). Beyond Self-monitoring: Understanding Non-functional Aspects of Home-based Healthcare Technology. *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 587–596. https://doi.org/10.1145/2493432.2493495

Gross, S., Bardzell, J., Bardzell, S., & Stallings, M. (2017). Persuasive Anxiety: Designing and Deploying Material and Formal Explorations of Personal Tracking Devices. *Hum.-Comput. Interact.*, *32*(5–6), 297–334. https://doi.org/10.1080/07370024.2017.1287570

Gui, X. (2019). *Navigating the Healthcare Service "Black Box": Individual Healthcare Consumers' Practices and Design Opportunities*.

Gui, X., & Chen, Y. (2019). Making Healthcare Infrastructure Work: Unpacking the Infrastructuring Work of Individuals. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 458:1-458:14. https://doi.org/10.1145/3290605.3300688

Gui, X., Chen, Y., Kou, Y., Pine, K., & Chen, Y. (2017). Investigating Support Seeking from Peers for Pregnancy in Online Health Communities. *Proc. ACM Hum.-Comput. Interact.*, *1*(CSCW), 50:1-50:19. https://doi.org/10.1145/3134685

Gui, X., Chen, Y., & Pine, K. H. (2018). Navigating the Healthcare Service "Black Box": Individual Competence and Fragmented System. *Proc. ACM Hum.-Comput. Interact.*, *2*(CSCW), 61:1-61:26. https://doi.org/10.1145/3274330

Hampton, K. D., Mazza, D., & Newton, J. M. (2013). Fertility-awareness knowledge, attitudes, and practices of women seeking fertility assistance. *Journal of Advanced Nursing*, *69*(5), 1076–1084. https://doi.org/10.1111/j.1365-2648.2012.06095.x

Harwell, D. (2019, April 10). Is your pregnancy app sharing your intimate data with your boss? *Washington Post*. https://www.washingtonpost.com/technology/2019/04/10/tracking-your-pregnancy-an-app-may-be-more-public-than-you-think/

Helms, K. (2019). *Do you have to pee? A design space for intimate and somatic data*. 1209–1222.

Hogle, L. F. (2016). Data-intensive resourcing in healthcare. *BioSocieties*, *11*(3), 372–393. https://doi.org/10.1057/s41292-016-0004-5

Homewood, S., Bewley, H., & Boer, L. (2019). *Ovum: Designing for Fertility Tracking as a Shared and Domestic Experience*. 553–565.

Homewood, S., Boer, L., & Vallgårda, A. (2020). Designers in White Coats: Deploying Ovum, a Fertility Tracking Device. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–13.

Homewood, S., Karlsson, A., & Vallgårda, A. (2020). *Removal as a Method: A Fourth Wave HCI Approach to Understanding the Experience of Self-Tracking*. 1779–1791.

Hong, M. K., Wilcox, L., Machado, D., Olson, T. A., & Simoneaux, S. F. (2016). Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems . CHI Conference*, *2016*, 5337–5349. https://doi.org/10.1145/2858036.2858508

Huang, D., Tory, M., Aseniero, B. A., Bartram, L., Bateman, S., Carpendale, S., Tang, A., & Woodbury, R. (2014). Personal visualization and personal visual analytics. *IEEE Transactions on Visualization and Computer Graphics*, *21*(3), 420–433.

Huh, J. (2015). Clinical Questions in Online Health Communities: The Case of "See your doctor" Threads. *CSCW: Proceedings of the Conference on Computer-Supported Cooperative Work. Conference on Computer-Supported Cooperative Work*, *2015*, 1488–1499. https://doi.org/10.1145/2675133.2675259

Huh, J., & Ackerman, M. S. (2012). Collaborative Help in Chronic Disease Management: Supporting Individualized Problems. *CSCW : Proceedings of the Conference on Computer-Supported Cooperative Work. Conference on Computer-Supported Cooperative Work*, *2012*, 853–862. https://doi.org/10.1145/2145204.2145331

Huron, S., Carpendale, S., Thudt, A., Tang, A., & Mauerer, M. (2014). Constructive Visualization. *Proceedings of the 2014 Conference on Designing Interactive Systems*, 433–442. https://doi.org/10.1145/2598510.2598566

IHS Classification. (n.d.). *Migraine without aura*. ICHD-3 The International Classification of Headache Disorders 3rd Edition. Retrieved September 10, 2019, from https://ichd-3.org/1-migraine/1-1-migraine-without-aura/

Inhorn, M. C., Ceballo, R., & Nachtigall, R. (2009). Marginalized, invisible, and unwanted: American minority struggles with infertility and assisted conception. *Marginalized Reproduction: Ethnicity, Infertility and Reproductive Technologies*, *11*, 181–197.

Islind, A. S., Lindroth, T., Lundin, J., & Steineck, G. (2019). Shift in translations: Data work with patient-generated health data in clinical practice. *Health Informatics Journal*, *25*(3), 577–586.

Jacobs, M., He, J., F. Pradier, M., Lam, B., Ahn, A. C., McCoy, T. H., Perlis, R. H., Doshi-Velez, F., & Gajos, K. Z. (2021). *Designing AI for Trust and Collaboration in Time-Constrained Medical Decisions: A Sociotechnical Lens*. 1–14.

Jacobs, M. L., Clawson, J., & Mynatt, E. D. (2015). Comparing Health Information Sharing Preferences of Cancer Patients, Doctors, and Navigators. *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*, 808–818. https://doi.org/10.1145/2675133.2675252

Jain, M., & Yammiyavar, P. (2015). Game Based Learning Tool Seeking Peer Support for Empowering Adolescent Girls in Rural Assam. *Proceedings of the 14th International Conference on Interaction Design and Children*, 275–278. https://doi.org/10.1145/2771839.2771895

Jeong, H. Y., & Arriaga, R. I. (2009). *Using an ecological framework to design mobile technologies for pediatric asthma management*. 1–4.

Johnson, R. L., Roter, D., Powe, N. R., & Cooper, L. A. (2004). Patient race/ethnicity and quality of patient–physician communication during medical visits. *American Journal of Public Health*, *94*(12), 2084–2090.

Johnson, S., Marriott, L., & Zinaman, M. (2018). Can apps and calendar methods predict ovulation with accuracy? *Current Medical Research and Opinion*, *34*(9), 1587–1594. https://doi.org/10.1080/03007995.2018.1475348

Johnston-Robledo, I., & Chrisler, J. C. (2013). The Menstrual Mark: Menstruation as Social Stigma. *Sex Roles*, *68*(1), 9–18. https://doi.org/10.1007/s11199-011-0052-z

Jovchelovitch, S., & Bauer, M. W. (2000). Narrative interviewing. *Qualitative Researching with Text, Image and Sound*, 57–74.

Kannabiran, G., Bardzell, J., & Bardzell, S. (2011). *How HCI talks about sexuality: Discursive strategies, blind spots, and opportunities for future research*. 695–704.

Karkar, R., Schroeder, J., Epstein, D. A., Pina, L. R., Scofield, J., Fogarty, J., Kientz, J. A., Munson, S. A., Vilardaga, R., & Zia, J. (2017a). TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 6850–6863. https://doi.org/10.1145/3025453.3025480

Karkar, R., Schroeder, J., Epstein, D. A., Pina, L. R., Scofield, J., Fogarty, J., Kientz, J. A., Munson, S. A., Vilardaga, R., & Zia, J. (2017b). TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 6850–6863. https://doi.org/10.1145/3025453.3025480

Karkar, R., Zia, J., Vilardaga, R., Mishra, S. R., Fogarty, J., Munson, S. A., & Kientz, J. A. (2015). A framework for self-experimentation in personalized health. *Journal of the American Medical Informatics Association: JAMIA*, *23*(3), 440–448. https://doi.org/10.1093/jamia/ocv150

Karunakaran, A., Reddy, M. C., & Spence, P. R. (2013). Toward a model of collaborative information behavior in organizations. *Journal of the American Society for Information Science and Technology*, *64*(12), 2437–2451. https://doi.org/10.1002/asi.22943

Katule, N., Densmore, M., & Rivett, U. (2016). Leveraging Intermediated Interactions to Support Utilization of Persuasive Personal Health Informatics. *Proceedings of the*

Eighth International Conference on Information and Communication Technologies and Development, 19:1-19:11. https://doi.org/10.1145/2909609.2909664

Katz, D., Price, B., Holland, S., & Dalton, N. (2018, February 1). *Data, Data Everywhere, and Still Too Hard to Link: Insights from User Interactions with Diabetes Apps*. CHI 2018 - 2018 ACM Conference on Human Factors in Computing Systems, Montréal, Canada. http://nrl.northumbria.ac.uk/33422/

Kaziunas, E., Ackerman, M. S., Lindtner, S., & Lee, J. M. (2017). *Caring through Data: Attending to the Social and Emotional Experiences of Health Datafication*. 2260–2272. https://doi.org/10.1145/2998181.2998303

Kaziunas, E., Klinkman, M. S., & Ackerman, M. S. (2019). Precarious Interventions: Designing for Ecologies of Care. *Proceedings of the ACM on Human-Computer Interaction*, *3*(CSCW), 113:1-113:27. https://doi.org/10.1145/3359215

Keyes, O., Peil, B., Williams, R. M., & Spiel, K. (2020). Reimagining (Women's) Health: HCI, Gender and Essentialised Embodiment. *ACM Transactions on Computer-Human Interaction*, *27*(4), 25:1-25:42. https://doi.org/10.1145/3404218

Kim, Y.-H., Jeon, J. H., Lee, B., Choe, E. K., & Seo, J. (2017). OmniTrack: A Flexible Self-Tracking Approach Leveraging Semi-Automated Tracking. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.*, *1*(3), 67:1-67:28. https://doi.org/10.1145/3130930

Kindara. (2021). *Bluetooth Basal Body Temperature Thermometer | Kindara*. https://www.kindara.com/products/wink

Klaus, H. (1982). Natural family planning: A review. *Obstetrical & Gynecological Survey*, *37*(2), 128.

Klein, G., Moon, B., & Hoffman, R. R. (2006). Making sense of sensemaking 1: Alternative perspectives. *IEEE Intelligent Systems*, *21*(4), 70–73.

Kragh-Furbo, M., Mackenzie, A., Mort, M., & Roberts, C. (2016). Do Biosensors Biomedicalize? Sites of Negotiation in DNA-Based Biosensing Data Practices. In *Quantified:Biosensing Technologies in Everyday Life* (pp. 280-). MIT Press. http://ieeexplore.ieee.org/xpl/articleDetails.jsp?arnumber=7580219

Kraschnewski, J. L., Chuang, C. H., Poole, E. S., Peyton, T., Blubaugh, I., Pauli, J., Feher, A., & Reddy, M. (2014). Paging "Dr. Google": Does technology fill the gap created by the prenatal care visit structure? Qualitative focus group study with pregnant women. *Journal of Medical Internet Research*, *16*(6), e147. https://doi.org/10.2196/jmir.3385

Kumar, N., & Anderson, R. J. (2015). Mobile Phones for Maternal Health in Rural India. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 427–436. https://doi.org/10.1145/2702123.2702258

Kumar, N., Karusala, N., Ismail, A., & Tuli, A. (2020). Taking the Long, Holistic, and Intersectional View to Women's Wellbeing. *ACM Transactions on Computer-Human Interaction (TOCHI)*, *27*(4), 1–32.

Kumar, R. B., Goren, N. D., Stark, D. E., Wall, D. P., & Longhurst, C. A. (2016). Automated integration of continuous glucose monitor data in the electronic health record using consumer technology. *Journal of the American Medical Informatics Association: JAMIA*, *23*(3), 532–537. https://doi.org/10.1093/jamia/ocv206

Kwon, H., Fischer, J. E., Flintham, M., & Colley, J. (2018). The connected shower: Studying intimate data in everyday life. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, *2*(4), 1–22.

Langstrup, H. (2019). Patient-reported data and the politics of meaningful data work. *Health Informatics Journal*, *25*(3), 567–576.

Lazar, A., Su, N. M., Bardzell, J., & Bardzell, S. (2019). Parting the Red Sea: Sociotechnical Systems and Lived Experiences of Menopause. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 480:1-480:16. https://doi.org/10.1145/3290605.3300710

Lee, B., Choe, E. K., Isenberg, P., Marriott, K., & Stasko, J. (2020). Reaching broader audiences with data visualization. *IEEE Computer Graphics and Applications*, *40*(2), 82–90.

Lee, C. P. (2007). Boundary negotiating artifacts: Unbinding the routine of boundary objects and embracing chaos in collaborative work. *Computer Supported Cooperative Work (CSCW)*, *16*(3), 307–339.

Lee, J., & Kim, J. (2019). Can menstrual health apps selected based on users' needs change health-related factors? A double-blind randomized controlled trial. *Journal of the American Medical Informatics Association: JAMIA*, *26*(7), 655–666. https://doi.org/10.1093/jamia/ocz019

Lee, M. (2017). Don't Give Up! A Cyber-ethnography and Discourse Analysis of an Online Infertility Patient Forum. *Culture, Medicine and Psychiatry*, *41*(3), 341–367. https://doi.org/10.1007/s11013-016-9515-6

Levy, J., & Romo-Avilés, N. (2019). "A good little tool to get to know yourself a bit better": A qualitative study on users' experiences of app-supported menstrual tracking in Europe. *BMC Public Health*, *19*(1), 1213. https://doi.org/10.1186/s12889-019-7549-8

Li, I., Dey, A., & Forlizzi, J. (2010). A Stage-based Model of Personal Informatics Systems. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 557–566. https://doi.org/10.1145/1753326.1753409

Li, I., Dey, A. K., & Forlizzi, J. (2011). Understanding My Data, Myself: Supporting Self-reflection with Ubicomp Technologies. *Proceedings of the 13th International Conference on Ubiquitous Computing*, 405–414. https://doi.org/10.1145/2030112.2030166

Lin, J. J., Mamykina, L., Lindtner, S., Delajoux, G., & Strub, H. B. (2006). Fish'N'Steps: Encouraging Physical Activity with an Interactive Computer Game. *Proceedings of the 8th International Conference on Ubiquitous Computing*, 261–278. https://doi.org/10.1007/11853565_16

Liu, B., Shi, S., Wu, Y., Thomas, D., Symul, L., Pierson, E., & Leskovec, J. (2019). *Predicting pregnancy using large-scale data from a women's health tracking mobile application*. 2999–3005.

Liu, L. S., Hirano, S. H., Tentori, M., Cheng, K. G., George, S., Park, S. Y., & Hayes, G. R. (2011). Improving Communication and Social Support for Caregivers of High-risk Infants Through Mobile Technologies. *Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work*, 475–484. https://doi.org/10.1145/1958824.1958897

Liu, L. S., & Siek, K. A. (2017). *Sticky Baby Dust After Baby Dancing: Guilt and Judgment in "Trying to Conceive" Communities on YouTube*. Workshop on Interactive Systems in Healthcare CHI 2017, Denver.

Lomas, N. (2021). Flo gets FTC slap for sharing user data when it promised privacy. *TechCrunch*. https://social.techcrunch.com/2021/01/13/flo-gets-ftc-slap-for-sharing-user-data-when-it-promised-privacy/

Lomborg, S., Langstrup, H., & Andersen, T. O. (2020). Interpretation as luxury: Heart patients living with data doubt, hope, and anxiety. *Big Data & Society*, *7*(1), 2053951720924436.

Loos, J. R., & Davidson, E. J. (2016). Wearable Health Monitors and Physician-Patient Communication: The Physician's Perspective. *2016 49th Hawaii International Conference on System Sciences (HICSS)*, 3389–3399. https://doi.org/10.1109/HICSS.2016.422

Lundsberg, L. S., Pal, L., Gariepy, A. M., Xu, X., Chu, M. C., & Illuzzi, J. L. (2014). Knowledge, attitudes, and practices regarding conception and fertility: A population-based survey among reproductive-age United States women. *Fertility and Sterility*, *101*(3), 767–774. https://doi.org/10.1016/j.fertnstert.2013.12.006

Luo, Y., Liu, P., & Choe, E. K. (2019). Co-Designing Food Trackers with Dietitians: Identifying Design Opportunities for Food Tracker Customization. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–13. https://doi.org/10.1145/3290605.3300822

Lupton, D. (2013). Quantifying the body: Monitoring and measuring health in the age of mHealth technologies. *Critical Public Health*, *23*(4), 393–403. https://doi.org/10.1080/09581596.2013.794931

Lupton, D. (2015). Quantified sex: A critical analysis of sexual and reproductive self-tracking using apps. *Culture, Health & Sexuality*, *17*(4), 440–453. https://doi.org/10.1080/13691058.2014.920528

Lupton, D. (2013b). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health*, *11*(3), 256–270.

MacLeod, H., Oakes, K., Geisler, D., Connelly, K., & Siek, K. (2015). Rare World: Towards Technology for Rare Diseases. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 1145–1154. https://doi.org/10.1145/2702123.2702494

Mamykina, L., Levine, M. E., Davidson, P. G., Smaldone, A. M., Elhadad, N., & Albers, D. J. (2016). Data-driven health management: Reasoning about personally generated data in diabetes with information technologies. *Journal of the American Medical Informatics Association*, *23*(3), 526–531.

Mamykina, L., Mynatt, E., Davidson, P., & Greenblatt, D. (2008). MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 477–486. https://doi.org/10.1145/1357054.1357131

Mamykina, L., Nakikj, D., & Elhadad, N. (2015). Collective Sensemaking in Online Health Forums. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 3217–3226. https://doi.org/10.1145/2702123.2702566

Mamykina, L., Smaldone, A. M., & Bakken, S. R. (2015). Adopting the sensemaking perspective for chronic disease self-management. *Journal of Biomedical Informatics*, *56*, 406–417. https://doi.org/10.1016/j.jbi.2015.06.006

Marik, J., & Hulka, J. (1978). Luteinized Unruptured Follicle Syndrome: A Subtle Cause of Infertility*. *Fertility and Sterility*, *29*(3), 270–274. https://doi.org/10.1016/S0015-0282(16)43151-1

Martin, L. L., & Tesser, A. (1996). Some ruminative thoughts. *Advances in Social Cognition*, *9*, 1–47.

Mascarenhas, M. N., Flaxman, S. R., Boerma, T., Vanderpoel, S., & Stevens, G. A. (2012). National, Regional, and Global Trends in Infertility Prevalence Since 1990: A Systematic Analysis of 277 Health Surveys. *PLOS Medicine*, *9*(12), e1001356. https://doi.org/10.1371/journal.pmed.1001356

McBain, T. D., & Reeves, P. (2019). Women's Experience of Infertility and Disenfranchised Grief: *The Family Journal*. https://doi.org/10.1177/1066480719833418

McKillop, M., Mamykina, L., & Elhadad, N. (2018). Designing in the Dark: Eliciting Self-tracking Dimensions for Understanding Enigmatic Disease. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, 565:1-565:15. https://doi.org/10.1145/3173574.3174139

McKillop, M., Voigt, N., Schnall, R., & Elhadad, N. (2016). Exploring self-tracking as a participatory research activity among women with endometriosis. *J Participat Med*, *8*, e17.

Miller, A. D., & Mynatt, E. D. (2014). StepStream: A School-based Pervasive Social Fitness System for Everyday Adolescent Health. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 2823–2832. https://doi.org/10.1145/2556288.2557190

Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, *20*(4), 225–232.

Mishra, S. R., Klasnja, P., MacDuffie Woodburn, J., Hekler, E. B., Omberg, L., Kellen, M., & Mangravite, L. (2019). Supporting Coping with Parkinson's Disease Through Self Tracking. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–16. https://doi.org/10.1145/3290605.3300337

Moglia, M. L., Nguyen, H. V., Chyjek, K., Chen, K. T., & Castaño, P. M. (2016). Evaluation of Smartphone Menstrual Cycle Tracking Applications Using an Adapted APPLICATIONS Scoring System. *Obstetrics and Gynecology*, *127*(6), 1153–1160. https://doi.org/10.1097/AOG.0000000000001444

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.

Mønsted, T. (2019). Achieving veracity: A study of the development and use of an information system for data analysis in preventive healthcare. *Health Informatics Journal*, *25*(3), 491–499.

Morris, M. R. (2014). Social Networking Site Use by Mothers of Young Children. *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing*, 1272–1282. https://doi.org/10.1145/2531602.2531603

Mullaney, T., Pettersson, H., Nyholm, T., & Stolterman, E. (2012). Thinking beyond the cure: A case for human-centered design in cancer care. *International Journal of Design*, *6*(3).

Murnane, E. L., Walker, T. G., Tench, B., Voida, S., & Snyder, J. (2018). Personal Informatics in Interpersonal Contexts: Towards the Design of Technology That Supports the Social Ecologies of Long-Term Mental Health Management. *Proc. ACM Hum.-Comput. Interact.*, *2*(CSCW), 127:1-127:27. https://doi.org/10.1145/3274396

Nafus, D. (2016). *Quantified: Biosensing Technologies in Everyday Life*. MIT Press.

Neff, G., & Nafus, D. (2016). *Self-Tracking*. MIT Press.

Ng, S., Bardzell, S., & Bardzell, J. (2020). The Menstruating Entrepreneur Kickstarting a New Politics of Women's Health. *ACM Transactions on Computer-Human Interaction*, *27*(4), 21:1-21:25. https://doi.org/10.1145/3397158

NIH National Institute of Diabetes and Digestive and Kidney Disease. (2017). *Pregnancy if You Have Diabetes | NIDDK*. https://www.niddk.nih.gov/health-information/diabetes/diabetes-pregnancy

Nundy, S., Lu, C.-Y. E., Hogan, P., Mishra, A., & Peek, M. E. (2014). Using Patient-Generated Health Data From Mobile Technologies for Diabetes Self-Management Support: Provider Perspectives From an Academic Medical Center. *Journal of Diabetes Science and Technology*, *8*(1), 74–82. https://doi.org/10.1177/1932296813511727

Nunes, F., & Fitzpatrick, G. (2015). Self-Care Technologies and Collaboration. *International Journal of Human–Computer Interaction*, *31*(12), 869–881. https://doi.org/10.1080/10447318.2015.1067498

Office on Women's Health, U.S. Department of Health and Human Services. (2017, July 12). *Premenstrual syndrome (PMS)*. Womenshealth.Gov. https://www.womenshealth.gov/menstrual-cycle/premenstrual-syndrome

O'Kane, A. A., Park, S. Y., Mentis, H., Blandford, A., & Chen, Y. (2016). Turning to Peers: Integrating Understanding of the Self, the Condition, and Others' Experiences in Making Sense of Complex Chronic Conditions. *Computer Supported Cooperative Work (CSCW)*, *25*(6), 477–501. https://doi.org/10.1007/s10606-016-9260-y

Olgado, B. S., Pei, L., & Crooks, R. (2020). *Determining the Extractive Casting Mold of Intimate Platforms through Document Theory*. 1–10.

Paay, J., Kjeldskov, J., Skov, M. B., Lichon, L., & Rasmussen, S. (2015). Understanding Individual Differences for Tailored Smoking Cessation Apps. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 1699–1708. https://doi.org/10.1145/2702123.2702321

Park, S. Y., & Chen, Y. (2015). Individual and Social Recognition: Challenges and Opportunities in Migraine Management. *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*, 1540–1551. https://doi.org/10.1145/2675133.2675248

Parker, A., Kantroo, V., Lee, H. R., Osornio, M., Sharma, M., & Grinter, R. (2012). Health promotion as activism: Building community capacity to effect social change. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 99–108. https://doi.org/10.1145/2207676.2207692

Patel, D., Blandford, A., Warner, M., Shawe, J., & Stephenson, J. (2019). "I feel like only half a man" Online Forums as a Resource for Finding a" New Normal" for Men Experiencing Fertility Issues. *Proceedings of the ACM on Human-Computer Interaction*, *3*(CSCW), 1–20.

Paul, S. A., & Reddy, M. C. (2010). Understanding Together: Sensemaking in Collaborative Information Seeking. *Proceedings of the 2010 ACM Conference on Computer Supported Cooperative Work*, 321–330. https://doi.org/10.1145/1718918.1718976

Perez, S. (2015). Apple Stops Ignoring Women's Health With iOS 9 HealthKit Update, Now Featuring Period Tracking. *TechCrunch*.

https://social.techcrunch.com/2015/06/09/apple-stops-ignoring-womens-health-with-ios-9-healthkit-update-now-featuring-period-tracking/

Peyton, T., Poole, E., Reddy, M., Kraschnewski, J., & Chuang, C. (2014). “Every Pregnancy is Different”: Designing mHealth for the Pregnancy Ecology. *Proceedings of the 2014 Conference on Designing Interactive Systems*, 577–586. https://doi.org/10.1145/2598510.2598572

Pierson, E., Althoff, T., & Leskovec, J. (2018). *Modeling individual cyclic variation in human behavior*. 107–116.

Pina, L. R., Sien, S.-W., Ward, T., Yip, J. C., Munson, S. A., Fogarty, J., & Kientz, J. A. (2017). From Personal Informatics to Family Informatics: Understanding Family Practices Around Health Monitoring. *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, 2300–2315. https://doi.org/10.1145/2998181.2998362

Pine, K. H. (2019). The qualculative dimension of healthcare data interoperability. *Health Informatics Journal*, *25*(3), 536–548.

Pine, K. H., & Liboiron, M. (2015). The Politics of Measurement and Action. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 3147–3156. https://doi.org/10.1145/2702123.2702298

Pine, K. H., Wolf, C., & Mazmanian, M. (2016). The work of reuse: Birth certificate data and healthcare accountability measurements. *IConference 2016 Proceedings*.

Pink, S., Lanzeni, D., & Horst, H. (2018). Data anxieties: Finding trust in everyday digital mess. *Big Data & Society*, *5*(1), 2053951718756685.

Piras, E. M. (2019). Beyond self-tracking: Exploring and unpacking four emerging labels of patient data work. *Health Informatics Journal*, *25*(3), 598–607.

Pousman, Z., Stasko, J., & Mateas, M. (2007). Casual Information Visualization: Depictions of Data in Everyday Life. *IEEE Transactions on Visualization and Computer Graphics*, *13*(6), 1145–1152. https://doi.org/10.1109/TVCG.2007.70541

Purpura, S., Schwanda, V., Williams, K., Stubler, W., & Sengers, P. (2011). Fit4Life: The Design of a Persuasive Technology Promoting Healthy Behavior and Ideal Weight. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 423–432. https://doi.org/10.1145/1978942.1979003

Quaas, A., & Dokras, A. (2008). Diagnosis and treatment of unexplained infertility. *Reviews in Obstetrics and Gynecology*, *1*(2), 69.

Raghupathi, W., & Raghupathi, V. (2014). Big data analytics in healthcare: Promise and potential. *Health Information Science and Systems*, *2*(1), 1–10.

Raj, S., Newman, M. W., Lee, J. M., & Ackerman, M. S. (2017). Understanding Individual and Collaborative Problem-Solving with Patient-Generated Data: Challenges and Opportunities. *Proc. ACM Hum.-Comput. Interact.*, *1*(CSCW), 88:1-88:18. https://doi.org/10.1145/3134723

Rettberg, J. W. (2014). *Seeing Ourselves Through Technology: How We Use Selfies, Blogs and Wearable Devices to See and Shape Ourselves*. Springer.

Riemann, G., & Schütze, F. (1991). Trajectory as a basic theoretical concept for analyzing suffering and disorderly social processes. *Social Organization and Social Process. Essays in Honor of Anselm Strauss*, 333–357.

Rooksby, J., Rost, M., Morrison, A., & Chalmers, M. C. (2014). Personal Tracking As Lived Informatics. *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems*, 1163–1172. https://doi.org/10.1145/2556288.2557039

Ruckenstein, M., & Schüll, N. D. (2017). The Datafication of Health. *Annual Review of Anthropology*, *46*(1), 261–278. https://doi.org/10.1146/annurev-anthro-102116-041244

Russell, D. M., Stefik, M. J., Pirolli, P., & Card, S. K. (1993). *The cost structure of sensemaking*. 269–276.

Sacramento, I., & Wanick, V. (2017). mHealth and the Digital Cyborg Body: The Running Apps in a Society of Control. In *Mobile e-Health* (pp. 39–70). Springer.

Saksono, H., Castaneda-Sceppa, C., Hoffman, J., Seif El-Nasr, M., Morris, V., & Parker, A. G. (2018). *Family health promotion in low-SES neighborhoods: A two-month study of wearable activity tracking*. 1–13.

Saksono, H., Castaneda-Sceppa, C., Hoffman, J., Seif El-Nasr, M., Morris, V., & Parker, A. G. (2019). *Social reflections on fitness tracking data: A study with families in low-SES neighborhoods*. 1–14.

Saldaña, J. (2015). *The coding manual for qualitative researchers*. Sage.

Samek, W., Wiegand, T., & Müller, K.-R. (2017). Explainable artificial intelligence: Understanding, visualizing and interpreting deep learning models. *ArXiv Preprint ArXiv:1708.08296*.

Sanger, P., Hartzler, A., Lordon, R. J., Armstrong, C. A., Lober, W. B., Evans, H. L., & Pratt, W. (2016). A patient-centered system in a provider-centered world: Challenges of incorporating post-discharge wound data into practice. *Journal of the American Medical Informatics Association: JAMIA*, *23*(3), 514–525. https://doi.org/10.1093/jamia/ocv183

Savitz, D. A., Hertz-Picciotto, I., Poole, C., & Olshan, A. F. (2002). Epidemiologic measures of the course and outcome of pregnancy. *Epidemiologic Reviews*, *24*(2), 91–101. https://doi.org/10.1093/epirev/mxf006

Schneider, H., Wayrauther, J., Hassib, M., & Butz, A. (2019). Communicating Uncertainty in Fertility Prognosis. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 161:1-161:11. https://doi.org/10.1145/3290605.3300391

Schroeder, J., Chung, C.-F., Epstein, D. A., Karkar, R., Parsons, A., Murinova, N., Fogarty, J., & Munson, S. A. (2018). Examining Self-Tracking by People with Migraine: Goals, Needs, and Opportunities in a Chronic Health Condition. *Proceedings of the 2018 Designing Interactive Systems Conference*, 135–148. https://doi.org/10.1145/3196709.3196738

Schroeder, J., Hoffswell, J., Chung, C.-F., Fogarty, J., Munson, S., & Zia, J. (2017). Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food and Symptom Journals. *CSCW: Proceedings of the Conference on Computer-Supported Cooperative Work. Conference on Computer-Supported Cooperative Work*, *2017*, 1726–1739. https://doi.org/10.1145/2998181.2998276

Shapiro, M., Johnston, D., Wald, J., & Mon, D. (2012). *Patient-generated health data (White paper)*. Office of Policy and Planning Office of the National Coordinator for Health Information Technology.

Slevin, P., & Caulfield, B. (2018). Patient-Generated Health Data: Looking Toward Future Health Care. *Wearable Technology in Medicine and Health Care*, *261*.

Sohda, S., Suzuki, K., & Igari, I. (2017). Relationship Between the Menstrual Cycle and Timing of Ovulation Revealed by New Protocols: Analysis of Data from a Self-Tracking Health App. *Journal of Medical Internet Research*, *19*(11), e391. https://doi.org/10.2196/jmir.7468

Søndergaard, M. L. J. (2017). *Intimate Design: Designing Intimacy As a Critical-Feminist Practice*. 320–325.

Speroff, L., & Fritz, M. A. (2005). *Clinical Gynecologic Endocrinology and Infertility*. Lippincott Williams & Wilkins.

Spiel, K., Kayali, F., Horvath, L., Penkler, M., Harrer, S., Sicart, M., & Hammer, J. (2018). Fitter, Happier, More Productive? The Normative Ontology of Fitness Trackers. *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems*, 1–10. https://doi.org/10.1145/3170427.3188401

Star, S. L., & Strauss, A. (1999). Layers of silence, arenas of voice: The ecology of visible and invisible work. *Computer Supported Cooperative Work (CSCW)*, *8*(1–2), 9–30.

Starling, M. S., Kandel, Z., Haile, L., & Simmons, R. G. (2018). User profile and preferences in fertility apps for preventing pregnancy: An exploratory pilot study. *Mhealth*, *4*.

Steiner, M. (2000). Premenstrual syndrome and premenstrual dysphoric disorder: Guidelines for management. *Journal of Psychiatry and Neuroscience*, *25*(5), 459–468.

Strauss, A., & Corbin, J. M. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. SAGE Publications.

Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1985). *Social organization of medical work* (pp. xii, 310). University of Chicago Press.

Street Jr, R. L., Liu, L., Farber, N. J., Chen, Y., Calvitti, A., Zuest, D., Gabuzda, M. T., Bell, K., Gray, B., & Rick, S. (2014). Provider interaction with the electronic health record: The effects on patient-centered communication in medical encounters. *Patient Education and Counseling*, *96*(3), 315–319.

Su, Z., Costa Figueiredo, M., Jo, J., Zheng, K., & Chen, Y. (2020). *Analyzing description, user understanding and expectations of AI in mobile health applications*. American Medical Informatics Association Annual Symposium.

Suchman, L. (1995). Supporting articulation work. In *Computerization and controversy (2nd ed.): Value conflicts and social choices* (pp. 407–423). Academic Press, Inc.

Sudjic, O. (2018, July 21). *'I felt colossally naive': The backlash against the birth control app*. The Guardian. http://www.theguardian.com/society/2018/jul/21/colossally-naive-backlash-birth-control-app

Sullivan, C. F. (2003). Gendered cybersupport: A thematic analysis of two online cancer support groups. *Journal of Health Psychology*, *8*(1), 83–104. https://doi.org/10.1177/1359105303008001446

Symul, L., Wac, K., Hillard, P., & Salathé, M. (2019). Assessment of menstrual health status and evolution through mobile apps for fertility awareness. *NPJ Digital Medicine*, *2*, 64. https://doi.org/10.1038/s41746-019-0139-4

Tiffany, K. (2018, November 13). *Who are period-tracking apps really built for?* Vox. https://www.vox.com/the-goods/2018/11/13/18079458/menstrual-tracking-surveillance-glow-clue-apple-health

Timmermans, S., & Almeling, R. (2009). Objectification, standardization, and commodification in health care: A conceptual readjustment. *Social Science & Medicine (1982)*, *69*(1), 21–27. https://doi.org/10.1016/j.socscimed.2009.04.020

Tuchman, G. (2000). The symbolic annihilation of women by the mass media. In *Culture and politics* (pp. 150–174). Springer.

Tuli, A., Chopra, S., Kumar, N., & Singh, P. (2018). Learning from and with Menstrupedia: Towards Menstrual Health Education in India. *Proc. ACM Hum.-Comput. Interact.*, *2*(CSCW), 174:1-174:20. https://doi.org/10.1145/3274443

Tuli, A., Chopra, S., Singh, P., & Kumar, N. (2020). Menstrual (Im)Mobilities and Safe Spaces. *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–15. https://doi.org/10.1145/3313831.3376653

Tuli, A., Dalvi, S., Kumar, N., & Singh, P. (2019). “It’s a Girl Thing”: Examining Challenges and Opportunities Around Menstrual Health Education in India. *ACM Trans. Comput.-Hum. Interact.*, *26*(5), 29:1-29:24. https://doi.org/10.1145/3325282

Urteaga, I., McKillop, M., & Elhadad, N. (2020). Learning endometriosis phenotypes from patient-generated data. *NPJ Digital Medicine*, *3*(1), 1–14.

Vallo Hult, H., Hansson, A., Svensson, L., & Gellerstedt, M. (2019). Flipped healthcare for better or worse. *Health Informatics Journal*, *25*(3), 587–597.

Van De Garde-Perik, E., Markopoulos, P., De Ruyter, B., Eggen, B., & Ijsselsteijn, W. (2008). Investigating privacy attitudes and behavior in relation to personalization. *Social Science Computer Review*, *26*(1), 20–43.

Veinot, T. C., Mitchell, H., & Ancker, J. S. (2018). Good intentions are not enough: How informatics interventions can worsen inequality. *Journal of the American Medical Informatics Association*, *25*(8), 1080–1088.

Verran, H. (2011). Number as Generative Device: Ordering and Valuing our Relations with Nature. In *Inventive Methods: The Happening of the Social (Hardback)—Routledge*. https://www.routledge.com/Inventive-Methods-The-Happening-of-the-Social/Lury-Wakeford/p/book/9780415574815

Walther, J. B., & Boyd, S. (2002). Attraction to computer-mediated social support. *Communication Technology and Society: Audience Adoption and Uses*, *153188*, 50–88.

Warren, B., Ballenger, C., Ogonowski, M., Rosebery, A. S., & Hudicourt-Barnes, J. (2001). Rethinking diversity in learning science: The logic of everyday sense-making. *Journal of Research in Science Teaching: The Official Journal of the National Association for Research in Science Teaching*, *38*(5), 529–552.

Weick, K. E. (1995). *Sensemaking in organizations* (Vol. 3). Sage.

Wetsman, N. (2021, March 17). *Birth control apps show the contradictions in FDA device oversight*. The Verge. https://www.theverge.com/22335858/birth-control-app-clue-natural-cycles-fda

WHO. (n.d.). *WHO | Infertility is a global public health issue*. WHO; World Health Organization. Retrieved September 10, 2020, from http://www.who.int/reproductivehealth/topics/infertility/perspective/en/

WHO. (2012). *WHO | Global prevalence of infertility, infecundity and childlessness*. WHO; World Health Organization. https://www.who.int/reproductivehealth/topics/infertility/burden/en/

WHO | Infertility. (n.d.). WHO. Retrieved June 5, 2017, from http://www.who.int/reproductivehealth/topics/infertility/keyissues/en/

WHO | Infertility definitions and terminology. (n.d.). WHO. Retrieved March 15, 2017, from http://www.who.int/reproductivehealth/topics/infertility/definitions/en/

WHO | Infertility is a global public health issue. (n.d.). WHO. Retrieved March 15, 2017, from http://www.who.int/reproductivehealth/topics/infertility/perspective/en/

WHO | Mother or nothing: The agony of infertility. (n.d.). WHO. Retrieved March 21, 2017, from http://www.who.int/bulletin/volumes/88/12/10-011210/en/

Wiener, C. L., & Dodd, M. J. (1993). Coping amid uncertainty: An illness trajectory perspective. *Scholarly Inquiry for Nursing Practice*, *7*, 17–17.

Winner, L. (1980). Do artifacts have politics? *Daedalus*, 121–136.

Wright, D. C. (2012). Theorizing history: Separate spheres, the public/private binary and a new analytic for family law history. *Private Binary and a New Analytic for Family Law History*.

Yarosh, L., Bakken, S., Borning, A., De Choudhury, M., Lampe, C., Mynatt, E., Schueller, S., & Veinot, T. (2019). *Computational Support for Substance Use Disorder Prevention, Detection, Treatment, and Recovery*. Computing Community Consortium. https://cra.org/ccc/events/mental-health-and-addiction/

Young, A. L., & Miller, A. D. (2019). "This Girl is on Fire": Sensemaking in an Online Health Community for Vulvodynia. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 129:1-129:13. https://doi.org/10.1145/3290605.3300359

Zhu, H., Colgan, J., Reddy, M., & Choe, E. K. (2016). Sharing Patient-Generated Data in Clinical Practices: An Interview Study. *AMIA ... Annual Symposium Proceedings. AMIA Symposium*, *2016*, 1303–1312.

Zulman, D. M., Damschroder, L. J., Smith, R. G., Resnick, P. J., Sen, A., Krupka, E. L., & Richardson, C. R. (2013). Implementation and evaluation of an incentivized Internet-mediated walking program for obese adults. *Translational Behavioral Medicine*, *3*(4), 357–369. https://doi.org/10.1007/s13142-013-0211-6

Zwingerman, R., Chaikof, M., & Jones, C. (2019). A Critical Appraisal of Fertility and Menstrual Tracking Apps for the iPhone. *Journal of Obstetrics and Gynaecology Canada: JOGC = Journal d'obstetrique et Gynecologie Du Canada: JOGC*. https://doi.org/10.1016/j.jogc.2019.09.023