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

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

1 INTRODUCTION

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, especially as women moved from primarily unpaid work in the home to the paid workforce. Busy lifestyles, career priorities, and safe, effective, and inexpensive methods of contraception contributed to a trend in delaying parenthood [20]. However, chances of conception tend to decrease after 30 years old [42]. The combination of these factors increases the pressure to conceive within a relatively narrow window, before pregnancy becomes biologically impossible [43].

Infertility is defined as a "failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse" [44]. According to the 2013 National Survey of Family Growth, 7.5 million U.S. women face fertility challenges, and 6.9 million have used some sort of infertility services [8]. In addition, the World Health Organization (WHO) considers infertility to be a global public health issue and indicates that many challenges of couples trying to conceive are not being sufficiently addressed (e.g., restricted knowledge and lack of access to fertility treatments) [45].

These couples face significant emotional and knowledge challenges, including those related to perceived time and/or social pressures and taboos in fertility care. There are taboos related to women's intimate care (e.g., women's body is often considered a private issue) that can contribute to the "invisibility" of fertility issues, often resulting in women feeling isolated, and that other people do not know or understand what they are going through. Finally, while both men and women can have medical conditions that affect the couple's ability to conceive, women tend to bear more of the social burden [46], e.g., prejudice and the responsibility for not having a child. This burden can cause severe emotional consequences, including guilt, self-blame, depression, possibly even violence against women, and suicide [14]. Considering this, the remainder of this paper focuses on women, and on the area called "women's health."

Most fertility treatments include self-tracking health indicators. Before seeking professional treatment, most women go through a period of self-care, where fertility self-tracking, i.e., tracking fertility health indicators to estimate the time of ovulation (the period when the woman is able to conceive [21]), is their main activity. But even when women seek healthcare providers' guidance, fertility self-tracking is still an important part of most treatments. These self-tracking activities can help women plan their conception efforts (e.g., intercourse), and give them their best chances of success. Despite being relatively common, and with or without the support of technology (i.e., websites or smartphones' applications), challenges often arise during self-tracking, and tend to be particularly problematic. Thus, there is a crucial need to better support women's fertility self-tracking, especially in terms of addressing the knowledge challenges that they face.

These challenges may be due to the paucity of research on the process of fertility tracking in general. While many studies have investigated self-tracking for health management, few have focused on fertility self-tracking. The majority of prior self-tracking literature focuses on chronic conditions, such as diabetes [32], and it is unclear how this work can be applied to fertility self-tracking, as there are critical differences between these conditions in the processes, available support, and social perceptions. Specifically, managing chronic conditions is a fundamentally different process – it is continuous over a long period (often for the rest of the patient's life). In contrast, with fertility self-tracking, there is a singular discrete goal: to get pregnant, and it occurs for a relatively shorter time window. In addition, there is often clearer guidance on how, when, etc. to track chronic conditions. This is not true for fertility self-tracking. Finally, most chronic conditions are not as affected by social taboos. Therefore, there is also an imperative need to better understand the process of fertility self-tracking, and the specific challenges that arise, so that more effective, evidence-based tracking tools can be designed.

Our research addresses this need, and aims to understand (1) the process of fertility self-tracking, and the specific challenges that arise; (2) the process of sensemaking; and (3) the relationship between self-tracking practices and collaboration in the sensemaking process. To achieve these aims, we qualitatively analyzed 400 threads from a fertility community in one popular U.S. online health forum. We used the Personal Informatics Model [26] as a conceptual framework to examine the fertility self-tracking process. This model describes self-tracking as a 5-stage process and analyzes the main barriers individuals face in each of them. We found that women transition twice through the stages of the Personal Informatics Model during a single

fertility cycle, and face different challenges in each stage. Based on our findings, we discuss the practice of self-tracking in a knowledge-intensive context, how women use online collaboration to create personalized solutions, and the emotional toll of fertility self-tracking. This study contributes to the existing literature on self-tracking for health management by providing insights into self-tracking practices for very individual, yet highly contextualized conditions. These insights can be used to inform the design of technologies to support self-tracking for these conditions. These insights can also be used to rethink some aspects of Personal Informatics, such as the intrinsic social activities performed within self-tracking.

2   RELATED WORK

This study is informed by previous research in technology for women's health, self-tracking, and collaborative sensemaking.

2.1 Women's Health

Women's health is defined by the HCI community as health issues that affect women exclusively, or are more common or severe in this population. It is comprised of topics such as menstruation, pregnancy, menopause, and breast cancer [2]. Most HCI studies related to women's health focus on maternal care [2], for example on the prevention of gestational excessive weight gain [35] and the experience of public breastfeeding [5]. Studies focusing on other aspects of women's health are rare, and Almeida et al. suggest that this gap is in part due to the taboos historically connected to women's bodies and intimate care [2]. Some exceptions are studies approaching menstrual tracking [16], urinary incontinence in women [2], menopause [25], and the contraceptive pill [40]. However, fertility issues and related practices remain understudied in the field of HCI. This lack of attention motivates studies concerning fertility care and fertility self-tracking.

2.1.1 Fertility Care. Fertility care encompasses different methods and treatments aimed at conceiving a child or simply getting acquainted with one's own fertility cycle. Fertility awareness methods are the least complex and expensive fertility care methods, and therefore usually the first option [6,21]. These methods focus on analyzing cycle length and physical indicators of ovulation to identify the fertile days in a woman's cycle (i.e., the days when conception is possible) [21]. If these methods do not work, the next steps consist of medication to stimulate ovulation, intrauterine insemination (IUI), and in vitro fertilization (IVF) [47]. Fig. 1 represents the most common fertility care methods and treatments and the possible transitions between them.
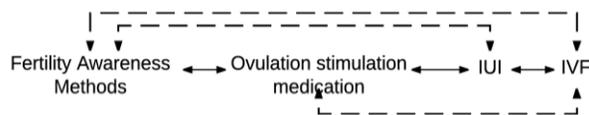
Fig. 1. Fertility care methods and treatments.

All fertility care methods and treatments require tracking relevant health indicators, i.e., fertility self-tracking. The tracking responsibilities shift from the woman to her healthcare provider as the care becomes more medically complex. For example, the woman usually completes almost all of the tracking activities for fertility awareness methods, while the healthcare provider performs most of the monitoring in IVF [48].

2.2 Self-tracking

In managing health conditions, especially chronic illnesses, individuals often engage in self-tracking: the practice of collecting and reflecting on one's personal data to acquire self-knowledge or achieve a goal [26]. Self-tracking, also called Personal Informatics, has recently gained attention in the HCI community due to the popularity of mobile technology and its ability to facilitate recording health information. Within the

context of health and wellness, past research investigated its use for managing chronic conditions and promoting preventive activities, such as improving exercise and sleep habits [9,38]. People may self-track to: be more aware of the state of their health or condition, work on a goal (e.g., quit smoking), monitor progress towards a goal, find associations or causality in health events (e.g., identify the trigger of an allergic reaction), take actions (e.g., change diet based on glucose levels), and share information with healthcare providers [3,37].

In the context of women's health, a recent study investigated menstrual cycle tracking and the reasons leading women to perform these practices [16]. Nevertheless, even with increasing research on health and wellness self-tracking, no studies have focused on fertility self-tracking. Therefore, little is known about this process and the challenges women face. Women encounter many knowledge challenges as they perform the knowledge-intensive work that commonly accompanies fertility issues. This work has a steep learning curve, involving complex, interrelated processes such as (i) researching (e.g., searching for educational information online), (ii) gathering data (key health indicators, e.g., basal body temperature), (iii) learning (e.g., medical terminology and concepts), (iv) monitoring (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.

2.3 Sensemaking

Sensemaking, as described by Dervin [15], refers to how individuals "construct sense of their worlds," that is, how a person uses her, and other people's, observations to understand her reality, overcome gaps, and guide her own behavior. It has been studied in many different domains, such as organizational sciences [24]. In HCI, it has been used to investigate how people collect, organize, and develop mental representations of complex information in order to understand a problem [28,34].

Studies have also examined sensemaking in the context of health and healthcare. Previous studies focusing on healthcare providers highlighted the importance of collaboration in the sensemaking process toward achieving a shared goal [34]. In the personal health area, sensemaking has been used 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 [28]. Existing research offers some insights into collaboration in the sensemaking process in online health forums. These environments are one important place for people, particularly patients, to discuss health-related topics. In one such study, they found that diabetes patients build shared meanings through discussions, perspective negotiation, and conflict resolution [27]. There is also evidence that online groups can support the development of individualized solutions [23]. These forums are also used by patients as a mechanism to validate experiences and determine if their experiences are "normal" [33]. Finally, research suggests that, in some cases, such as eating disorders and cancer [41], people prefer to interact and ask questions online rather than discuss these issues with family and friends [49], since members of these communities might be more knowledgeable about the condition, or have had a similar experience.

In the context of women's health, 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 [19,31]. Another study found that breast cancer patients asked for and received advice, especially through sharing personal experiences, on an online forum [39]. However, to the best of our knowledge, the collaborative sensemaking process that many women engage in while facing fertility issues has not been previously studied, especially in terms of fertility self-tracking.

These previous studies have motivated this exploratory research focused on understanding the process of sensemaking through online forums for fertility care. We are specifically interested in the relationship between self-tracking practices and the process of collaborative sensemaking in these forums. Our study builds upon this prior work by applying concepts of self-tracking and sensemaking to the challenges related to fertility care. The goal of this study is to shed light on how to support women engaged in this work. More specifically, we 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 them to overcome the

burden and invisibility related to infertility. The results of this study draw attention to how complex self-tracking and sensemaking can be in the context of more individual, invisible, and less known health conditions.

3 STAGE-BASED MODEL OF PERSONAL INFORMATICS

Li et al. have proposed a stage-based model of personal informatics systems (Fig. 2), and identified the main barriers individuals face in each stage [26]. 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. Later studies expanded or proposed adaptations of this model [10,17]. For example, Epstein et al. [17] expanded the model to encompass people's motivations and lapses when self-tracking. We chose to use the original model in our analysis because of its discussion of barriers, which is most suitable to our goal of identifying and understanding the challenges women face when performing fertility self-tracking.
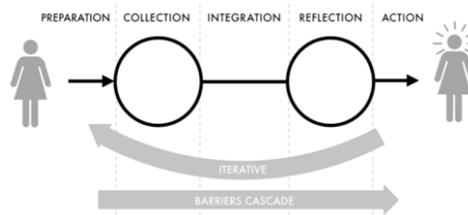
Fig. 2. Personal Informatics Model [26].

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, or subjective or relying on subjective and 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). Also, barriers sometimes prevent 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) [26].

We analyzed the data using this model as our conceptual framework. The next section includes details of the methods employed in this research.

4 METHODS

In this exploratory research, we used an online health forum to collect data. Online health forums are a source of information for patients' concerns and questions. They provide a platform for users to ask questions and receive answers and support (usually from peer patients). Additionally, many women who are using fertility awareness methods are not monitored by physicians, making it difficult to recruit them through medical visits. Moreover, many women consider fertility challenges to be sensitive, so they tend not to share their concerns with people in their offline social circles, but may feel comfortable sharing their concerns and questions anonymously online [49]. Therefore, the health forum is an ideal site allowing us to approach the concerns of women using different fertility methods and treatments, with or without the assistance of healthcare providers. In this study, we use the gendered terms "woman" and "women"

following the general use of "women's health" in the HCI community [16] to refer to individuals who self-track indicators specific to female biological sex for fertility care.

The forum we chose is one of the most popular health forums in the U.S., offering peer support, information, and tools (e.g., temperature charts). It has communities containing thousands of questions, and their threaded replies (e.g., answers) about many different conditions and health issues. One such community is the Fertility/Infertility/IVF, which contained 52,017 threads in April 2017. We selected this health forum because of its popularity, and because it has a specific community focused on infertility. We have considered other health forums, 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). We chose the Fertility/Infertility/IVF community on this specific health forum since it is directed towards infertile women (i.e., those who have been trying to conceive for a year or longer) in different stages of fertility care, ranging from fertility awareness methods to IVF. We received the ethical approval from the Institute Review Board where the researchers are affiliated prior to data collection and analysis, and only used information that were publicly available in the forum (the community does not require subscription or login to access the threads).

4.1 Data Collection

We collected data by downloading all threads (until September 2016) from the forum to a database. We selected relevant threads by using a query to retrieve information from the database. We first created a list of keywords by analyzing a set of threads in the Fertility/Infertility/IVF community. Since we were interested in the threads specifically discussing self-tracking activities when trying to conceive, we used keywords matching this activity, e.g., "fertility tracking," "ovulation tracking," "cycle patterns."

After developing an initial query, one researcher analyzed the first 50 threads to check the results and improve the query. We then generated the final query, which 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 fertility, ovulation, cycle, temperature, temp, CM (Cervical Mucus), period, and BBT (Basal Body Temperature). Group 2 consisted of tracking, monitoring, pattern, and chart. The result must present one word from each group, regardless of the order, place (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 women discuss the subject in the health forum. We specifically adopted this approach to cover different combinations of terms. The second part of the query searched for specific terms that were not covered by the first part: opk, ovulation kit, conception kit, ovulation prediction kit, and prediction kit. We excluded IVF treatments from our search because, in these cases, healthcare providers perform most of the monitoring, which is outside of the scope of this study. The query resulted in 3,527 threads with 15,944 replies, from 2006 to 2016.

4.2 Data Analysis

After defining the set of threads relevant to the study, we performed a two-stage qualitative analysis. First, to gain initial understanding of the infertility issues women raised in the forum, two researchers independently coded the 100 most recent posts and their 377 replies using an open coding technique to identify the main topics present in the data [12]. At this stage, we found that, while women 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. The researchers then discussed their results, and chose to use Li et al.'s stage-based Personal Informatics Model [26] as a conceptual framework to recognize and compare the challenges women face with the barriers described by the model. Our 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 women experience the stages of the Personal Informatics Model. Based on this model, we defined the initial codebook to be used in the

next stage. Relevant new information found in the second stage of analysis was incorporated into the coding scheme. Any disagreements were resolved through discussion among the researchers.

In the second stage, we selected a random sample of 500 threads between 2006 and 2016. We elected this dataset because we believe 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 three researchers using the initial codebook. The codebook was continuously modified whenever new themes emerged from the data until theoretical saturation [12] was reached. 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 responses, before achieving theoretical saturation.

5 RESULTS

We found that women utilize self-tracking extensively throughout the cycle, and face barriers in every stage, from Preparation to Action. This section presents the results of the study. First, we describe the characteristics of self-tracking for fertility care, the fertility cycle, the reasons for using self-tracking in this scenario, and the measures women usually track. Then, we present the application of the Personal Informatics Model to fertility self-tracking and the main issues women face in each stage.

5.1 Self-tracking for Fertility Care

5.1.1 The fertility cycle. Fertility care treatments are centered on the model of a regular fertility cycle, which starts on the first day of menstruation and lasts 28 days. The cycle can be divided into 4 phases: menstruation, pre-ovulation, fertile days, and post-ovulation (Fig. 3). Menstruation, pre-ovulation, and post-ovulation periods are typically infertile. The ovulation usually occurs around the 14th cycle day. The fertile window typically goes from 4 days before to 1 day after ovulation; therefore, women have, on average, 6 days per month where conception is possible.
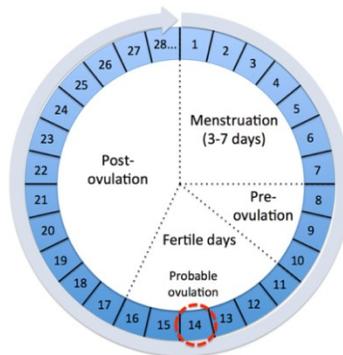
Fig. 3. A regular fertility cycle.

However, we found that women suffering from fertility issues often do not experience the "regular" fertility cycle. The length of each phase and of the whole fertile cycle, as well as the ovulation day, vary from woman to woman and may change every month (variability represented by the dashed lines in Fig. 3). This variability plays an important role in the development and outcomes of fertility treatments and is one of the main reasons why self-tracking is used in fertility care.

5.1.2 Why self-tracking. When trying to conceive naturally or using any of the methods prior to IVF in Fig. 1, the main common goal is to identify the ovulation period, i.e., the days when women are fertile during the fertility cycle to maximize the chances of conceiving. Self-tracking can help women in understanding 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.

Self-tracking is the basis of fertility awareness methods and we found that many women adopt it without medical supervision for several reasons, including (a) to understand their cycles, (b) to see how their bodies respond to treatments, (c) to communicate with providers more effectively, and (d) to try a more affordable option before resorting to more complex treatments. The following excerpts exemplify some of these reasons. In the first quote, the woman explains why self-tracking is important to improve the chances of conceiving:

> "you CAN NOT get pregnant at anytime. You only have about 3 to 4 days out of each cycle to get pregnant. [...] Those ovulating kits are the best thing to tell you when to try otherwise you're going it blind."

In the next excerpt, the woman highlights the economic reasons for self-tracking, recommending learning about one's own cycle to maximize the chances of conception without resorting to expensive treatments.

> "I recommend getting as smart on the subject [understanding her cycle] as you can. Especially since you have limited insurance coverage."

Physicians can also recommend and support self-tracking, as the next quote suggests. In this case, the healthcare provider directly recommended the woman to use ovulation predictor kits and track her temperature, so she turned to the health forum to seek information about brands and prices:

> "My ob [OB/GYN] wants me to try temp charting and use an ovulation prediction kit this month. Can anyone suggest a kit that has worked for you in the past and hopefully wasn't too expensive?"

Treatments involving medication to stimulate ovulation also require tracking to identify the fertile period. In these cases, the tracking is still mainly in women's hands, but physician support is also present, as the following quote illustrates. In the excerpt, the woman describes how her healthcare provider recommended tracking her temperature, when taking medication to ovulate, even considering her irregular cycles and polycystic ovary syndrome (PCOS), which may impact temperature measures.

> "I have really irregular cycles (they are anywhere from 22 days to 56+ days long). I was also diagnosed with PCOS. I don't ovulate at all except for when I was taking Clomid. My doctor still advised me to take my temp and keep track of it."

On the other hand, women also use self-tracking to understand their treatments and to better communicate with their healthcare providers. As the following shows, a woman mentioned that her healthcare provider did not explain how medication would impact the ovulation predictor kits results. Consequently, she intended to use her tracking data, and what she learned in the health forum, to ask her healthcare provider questions during her next appointment.

> "Ok so I have another question about OPK's. [...] I think I usually O [ovulate] closer to CD [cycle day] 14 but I have read that Clomid [medication to stimulate ovulation] can change that. [...] This is my first month using any type of fertility drugs and my dr didn't say much about any of it...but boy will I have lots of questions for him on Thursday!!"

Women using IUI also benefit from tracking, but in these cases physicians perform more monitoring. The next quote shows that although a woman was monitored by her healthcare provider, she still used ovulation predictor kits (OPK) to track ovulation. The tracking results have influenced her treatment.

> "I took letrozole [medication to stimulate ovulation] on day 4-8 [of my menstrual cycle]. I am scheduled for ultrasound on day 12 tomorrow. My clearblue ovulation kit turned positive today. When I called my doctors office, they have scheduled for IUI tomorrow instead of ultrasound. My last cycle I had to take a trigger shot. Is it possible that I have ovulated without triggershot?"

Together, these quotes exemplify the reasons women use self-tracking in different treatment scenarios. They also show that the health forum is an important source of information that can shape how women use self-tracking during their treatments, and how they interpret their data.

5.1.3 What to track. Our analysis shows that the main goal of self-tracking for conception is to identify ovulation. Different measures that can estimate ovulation through self-tracking, but all of them have limited precision and cannot alone pinpoint ovulation precisely. Instead, women often collect, integrate, and reflect on multiple measures to estimate the time of their ovulation. The following quote show some of the many health indicators women can track, and Table 1 briefly summarizes the indicators we identified in the data.

> "I am currently taking my **temps** [temperatures], measuring **cm** [cervical mucus], and using **opks** [ovulation predictor kits]. I am on **cycle day** 24"

Women also use self-tracking to find out if they conceived. In this case, the indicator/tool tracked are symptoms or home pregnancy tests, as suggested in the following quote:

> "Very bloated [possible early pregnancy symptom] since 4dpo [days post ovulation] and getting worse!! Temp has been over 98 since 1 day after ovulation. Eating all junk food in site and sending for more when its gone. Peeing a lot and twingy cramps in lower abdomen. Please give your opinions. Think I'm pregnant??"

Table 1. Main health indicators measured in fertility care

Indicator	Description
Cycle day (CD)	Fertility cycle day (Fig. 3).
Ovulation Predictor Kit (OPK) or Monitor	Home test that measures the Luteinizing Hormone (LH). A positive result indicates that ovulation will occur in 12-36 hours.
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 similar to egg whites in color and texture (EWCM: egg white CM).
Cervical Position (CP)	Cervix position. In the fertile days it should be soft, high, open, and wet.
Home Pregnancy Tests (HPT)	Home test that detects the HCG hormone. Usually used 2 weeks after ovulation, in case of late period.
Symptoms	Emotional and physical symptoms can be interpreted as indicators of ovulation or pregnancy.

5.2 Stages of Fertility Tracking

When applying the Personal Informatics Model to understand the fertility cycle, we found that, unlike personal tracking in other illness situations, within one fertility cycle, women transition twice through the stages, and the stages overlap (e.g., women may start the Action stage while they are still collecting, integrating, and reflecting on data). Fig. 4 illustrates the application of the model to the fertility cycle. Fig. 4 is used to understand and uncover the barriers women experience during the fertility cycle. The dashed lines represent the variance intrinsic to fertility self-tracking.
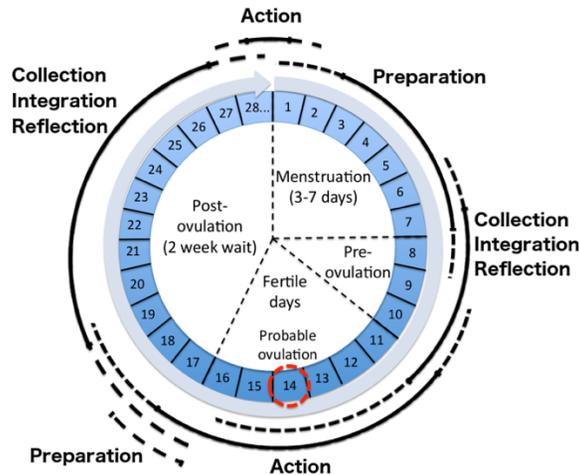
Fig. 4. Fertility cycle and the Personal Informatics Model.

The process of self-tracking for fertility care begins on the first day of the menstrual phase. This phase is primarily used for preparation activities, since women are typically not fertile and the menstrual flow makes it harder to collect measures such as CM. 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 OPK use near the expected ovulation date, around cycle day 11. However, since fertility cycles can vary, women tend to start using them earlier, especially when they expect to ovulate early in the cycle. The Action stage mainly consists of having intercourse or IUI to attempt to conceive after identifying the possible ovulation day. Since the ovulation day varies, and women 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 the two week wait (i.e., the time until the next cycle is expected to begin). Women are usually instructed to wait until their next menstrual period is late to test for pregnancy, since pregnancy tests are not able to detect a successful conception earlier. However, many women engage in Collection, Integration, and Reflection activities during this time, 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, e.g., choosing the pregnancy test and planning when to start using it. 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.

5.2.1 Preparation. The main challenges regarding Preparation are related to learning how to start tracking, and how to collect data. Problems originating in this stage impact subsequent ones.

In this stage, women need to decide which indicators they will track, and how. They decide whether to use paper or website charts, OPK type, and frequency of data collection. They might receive guidance from

an OB/GYN or Reproductive Endocrinologist, but still seek information on the health forum. The next excerpts illustrate how women turn to the health forum to look for suggestions on how to start tracking:

> "I am extremely irregular due to pcos [polycystic ovary syndrome] [...]. My husband and I have been trying since May with no luck conceiving. Wanted to try ovulation tests. What does everyone recommend?"

> "How should I be tracking my ovulation so I know exactly when to have intercourse???"

This information seeking behavior also occurs in subsequent cycles, when women use the health forum to discuss whether to change their approach in the next fertility cycle. In the following quote, the woman relates that she discussed tracking activities with her healthcare provider before starting the treatment. After a few cycles without tracking, she is considering trying it, despite her healthcare provider advising against it:

> "I had asked my doctor before starting the clomid if i should do BBT [Basal Body Temperature] charting, but I have always had VERY irregular cycles, and he said it really wouldn't be worth the effort so no, I haven't been. I have been thinking about doing it my next cycle just to see what happens though."

The health forum is a source for them to gather useful information in the preparation process. For example, in the following quote, a woman explains to a newer user how to use OPKs:

> "You may test at any time of day, but you should test approximately the same time each day. Reduce your liquid intake for 2 hours before testing. To find out when to begin testing, determine the length of your normal cycle. The length of your cycle is from the beginning of one period to the beginning of the next. Count the first day of bleeding or spotting as day 1. If your cycle length is irregular, that is, if it varies by more than a few days each month, take the average number of days for the last 3 months. Use the chart below [image provided by the user] to figure out the day you should begin testing. The day you begin testing is listed opposite the number of days in your cycle. Cycle length 28 start testing on cycle day 11"

Women 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, the woman in the following quote turned to the health forum to confirm, based on the experiences of others, if her symptoms (severe abdominal pain) could be related to ovulation, despite her negative ovulation tests. She explains that she wants *"reassurance because the docs don't seem to have a clue and I don't see specialist for 2 weeks so wanted to ask for other people experiences to help me."* In the answers, another user asked if she was charting her cervical mucus (CM) and cervical position (CP). She answered, *"Im just charting my temperature at moment I'm not used to all this kind of thing yet so just getting to know my body. whats cp and cm? I've been noting down everything else like moods etc."* She then learned in the health forum that CM and CP offer important information to pinpoint ovulation, which could help to answer her question. Since she missed critical measurements, even if she starts collecting now, she will only be able to make sense of them in the next cycle, possibly delaying her understanding of her symptoms.

The next quotes, on the other hand, exemplify problems related to choosing an inadequate tracking tool. The women realized the tracking tool may not be suitable for them only later in the cycle.

> "I have just started using the clear blue monitor and I am currently on my first cycle of using it. Now when I started to use this item I did realize that there was a possibility that it may not be suitable for me. My af [period] has been irregular and my cycle length can range between 26 days and 44 days. I am aware that the monitor is only suitable for cycles of up to 42 days."

"After a lot of research I think my 10 positive opks with no peak was from the test I was using and my clomid [medication to stimulate ovulation] not doing well together so now I'm just gonna try the ovulation test strips"

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.

5.2.2 *Collection.* The main issues in the Collection stage are caused by the use of ovulation predictor kits and their results. Although they provide a critical measure in fertility care, OPKs can be misleading, and their results can be subjective. OPKs measure a LH surge, which precedes ovulation by 12-36 hours. It is possible that the LH surge happens between two subsequent measurements. In this scenario, the tests might fail to detect ovulation. The woman 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 a while there, I actually tested twice a day to make sure I didn't miss it"

The previous quote also approaches the other problem related to OPKs – the result can be ambiguous, and difficult to interpret, as described in the following excerpts:

"I'm really starting to think I was completely wrong about my +OPk. I looked at another girls opk that was positive on here [in the forum], and I used the same kind and hers is definitely positive (test line clearly darker than the control line). Mine was weird. It was like half of the test line was the same color as the control line, but the other half was lighter."

"I am the type that has such a hard time with the ones [OPKs] with the lines, because I can never tell when it is actually +"

For this reason, many of them decide to use digital tests, which are more expensive, but have a clearer presentation of results:

"I had trouble with the two lines, so I only use the Clearblue Easy [digital OPK] with the happy face/empty circle. That way there's no guesswork!"

Other measures can also be subjective: temperature increases are small and can be affected by the time of measurement and by conditions such as fever: *"I had a midgrade fever a couple of days. I believe my coverline [in the chart] may be off due to this 2 week illness."* CM is based on visually identifying the characteristics of the mucus and not all women are able to recognize it: *"I don't ever get the kind of CM they say you should have."* Symptoms are always subjective indicators. Women turn to the health forum to understand and share how to use tracking tools, especially if their results are not exactly as expected.

5.2.3 *Integration and Reflection.* In fertility care, Integration and Reflection are directly connected and can happen simultaneously. In the two periods where Collection, Integration, and Reflection happen in Fig. 4, women 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 [29]. Furthermore, conditions such as polycystic ovary syndrome (PCOS) may affect OPK results, causing an incorrect interpretation.

"I know with PCOS, a symptom can be elevated LH levels, which can result in multiple positive OPK's. If that's one of your symptoms, you might want to talk with your doctor about the best way to track for you."

Because women have different cycles, they have to determine their own process of tracking and making sense of the data individually. Even when they become knowledgeable about their patterns, the results can vary every cycle. For example, one woman asked about the possibility of having a LH surge without ovulating (*"Does a positive LH surge really mean that I am ovulating, or could I have an LH surge but no egg?"*). She had used fertility awareness methods to conceive her first child, but was having trouble conceiving again, even after following the same steps and having intercourse when all her 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 correctly identifying ovulation or pregnancy. However, integration can be complex, and the measures can lead to contradictory or inconclusive results, creating a barrier for reflection:

> "So was just going to see if anyone had a similar experience. I am currently taking my temps, measuring cm, and using opks. I am on cycle day 24 (my cycles are extremely irregular) and haven't seen my temp go up at all. I have had 7 positive opks, but no ewcm.. Just sticky. Any ideas?"

> "I got the pains the day of the ++ OPK and the next day. I don't even know if I ovulated b/c [because] my temps are so goofy this month. I heard the clomid [medication to stimulate ovulation] can mess up your temps, is that correct?"

In these examples, OPK results indicate ovulation, but temperature and CM readings do not. Women find it difficult to interpret these data, and ask other members of the health forum for help.

Third, women's expectations and biases can influence reflection. It is recommended to wait until having a late period to start testing for pregnancy; however, they often use different measures during the two week wait, hoping to identify conception earlier.

> "I know most women don't have any symptoms until after AF [period] is due. I just want a BFP [positive pregnancy test result] so badly that I am looking for any little pain/abnormality to give me hope. You know how it is!"

A few of them try to interpret different data to predict pregnancy, e.g., using OPKs: *"would an opk stay positive if I was pregnant?"*; 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 who is doing BBT had an implantation dip in their charting? My temps have been steadily going down [...]. Is there a chance this is an implantation dip?"* However, there is no concrete evidence that these measures are able to detect pregnancy. At this stage, emotional status can affect reflection, increasing pressure and frustration.

5.2.4 Action. The first Action stage in the fertility cycle focuses on trying to conceive by 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, women 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 (indicates ovulation by 12-36 hours), and on how long egg and sperm can live in the body. They also consider sperm count, because having intercourse multiple times in a short period reduces concentration, and might lower the chances of conceiving, especially in the case of male fertility issues (e.g., low sperm count). In the next quote, the woman disagreed with her healthcare provider's suggestions on when to have intercourse. She turned to the health forum to discuss and seek advice on deciding if she should follow the recommendation.

> "[My Reproductive Endocrinologist] said to BD [have intercourse] tomorrow night, the following morning, then the following night. Does this sound good to you guys? I am wondering if we should start tonight since I seem to be starting or almost starting my surge. I know the little guys can live for a while in there, so it seems like it wouldn't hurt,

but I worry about "diluting" the pool so to speak. When I asked the doc if we should do tonight, he said no."

Second Action Stage. Often when women get a negative pregnancy test, they do not know what they can do in the next cycle to improve their chances. To get information and guidance, they turn to the health forum, engaging in collaborative sensemaking and communicating their decisions for the next steps:

"I am using opk and bbt chart method to predict and confirm ovulation from last 6 month but no result.[…] What should be my next step?"

"If it doesn't happen this month I'll probably switch from Femara to Clomid, or maybe injectables, and IUI. I had been hoping to have as little medical intervention as possible, but I'm also sick of waiting!"

Negative emotions also affect their decisions for the next stage. Many women use the health forum to vent their frustration, especially when combining these feelings with the social pressure surrounding pregnancy:

"The hardest part of the journey for me, is the isolation from everyone else around me. No one relates"

"I'm on drugs [fertility medication], visiting a hospital every other day and handling the sadness, the fear that comes whenever my period arrives. I know just as well as they do that I'm getting older"

"I feel like an emotional wreck this week. And I just want to hide away. I have no intention to socialize with our friends (who ALL have children). I am feeling very isolated. [...] I also get annoyed at how inconsiderate people can be. We are continually asked when we are going to have kids"

They find support in the health forum, develop ways to overcome these issues, and decide their next steps based on advice and similar stories from other forum members; for example:

"You are feeling like many of us on this board that have been trying to conceive for years without success. The first thing you need is a game plan - it will make you feel better and like you're doing something instead of waiting every month to see if that is your month and living in 2 week increments... First you should see your OBGYN and get some preliminary testing done. […] it's a time consuming process but being proactive will help[…]. You also may want to call your insurance and see what infertility coverage you may have, in the event that you may need to do IUI or IVF. This board helps because it's a great support group and you feel like you're not alone."

Finally, in the second Action stage, after reflecting on their data and on the whole process they have been through, women 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 described in this quote: *"Not sure if I will ovulate during weekend or not, but will try one more month. After that, I will take a break and naturally let it happens on it owns."* The interruption can also be definitive, especially when they have tried conceiving for many years and exhausted all treatment options. The woman in the next excerpt explained that she could not further bear the emotional burden, and decided to try adoption:

"I tried for 7 years and my last unsuccessful IUI was in July. After the last heartbreak, my husband and I have decided to go for adoption. I am feeling a little bit better about life now since I know I will be a mother one way or another."

Our analysis has shown that women 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 women to decide what to track, to interpret their data, and to solve problems when they face unexpected results.

6   DISCUSSION

Our analysis revealed three main themes in self-tracking for fertility care. First, self-tracking in a knowledge-intensive context can be a complex and frustrating experience, requiring comprehensive information about different aspects of the fertility cycle, and tools that can be used for tracking. Second, it is often necessary to create personalized solutions, and our analysis has shown that this often happens through collaborative sensemaking. Third, engaging in fertility tracking can have an emotional toll caused by repeated frustration and societal pressure. In this section, we discuss implications for each of these aspects.

6.1   Self-tracking in a knowledge-intensive context

Our results highlight that self-tracking for fertility care is an extremely complex issue. Fertility care comprises specialized complex knowledge that lay-people do not commonly possess. To improve their chances of conception, women need to obtain information to understand the health indicators that they need to track. Most women are unfamiliar with several indicators (e.g., basal body temperature and cervical mucus) before using fertility methods and treatments [21]. This lack of knowledge may be in part attributed to taboos historically related to women's bodies, since these measures are concerned with intimate care [2].

Another complication arises from the natural uncertainties concerning fertility care. Ovulation is fundamental for conceiving, but many women have biological difficulties in producing healthy eggs. Many factors can influence fertility, and some of them are unexplained. Health indicators in fertility care are 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.

Fertility self-tracking is an exceptional case in comparison to other reasons for health self-tracking because of these complex aspects, and because the process is fundamentally different. Self-tracking for promoting self-knowledge, behavior change [26], and monitoring chronic conditions [7] is often relatively straightforward, because interpreting data such as glucose reading and step counts tends to be simpler. Further, fertility tracking does not fit in any of these three known 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, as discussed by Almalki et al., most studies on self-tracking describe the burden in data collection [1]. For instance, Ancker et al. found that patients with multiple chronic conditions describe tracking as effortful and time-consuming [3]. In the self-tracking literature, each health indicator usually has its own meaning, e.g., glucose level is a precise measure that indicates the level of sugar in the blood, while number of steps measures the amount of exercise a person performs 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 women collect multiple health indicators (OPK results, temperature, cervical mucus, cervical position, and symptoms) to estimate a single 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 stages of the Personal Informatics model tend to overlap – women may perform activities from different stages at the same time. For example, they might reflect on the data (Reflection) from previous cycles while preparing for the next one (Preparation). Or they may learn about a different indicator to be collected (Preparation) while collecting the ones that 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 the HCI field approached other complex and personalized conditions. For example, O'kane et al. discussed the idiosyncrasies of diabetes and migraine and how patients use different resources to deal with them [33]. Ayobi et al. studied multiple sclerosis, an unpredictable and degenerative disease, and found that patients experience a sense of lack of control [4]. Fertility self-tracking shares many characteristics with the conditions described in these studies: it is complex and needs specialized knowledge [4,33]; it is idiosyncratic and personalized like migraine and diabetes [33]; and there is no primary indicator that can be controlled through self-care like multiple sclerosis [4]. However, fertility self-tracking also has its own complexities. Unlike diabetes and migraine, 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 is more complex, especially because women 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 self-tracking is desired, especially to meet the needs of complex, knowledge-intensive, and highly personalized health conditions, such as fertility care. Investigating complexity in self-tracking is important, and calls for more emphasis to offer better support for patients facing such conditions.

6.1.1 Implications. In order to support women in this knowledge-intensive context, it is necessary to offer technological support to address the common challenges that women currently face in the preparation phase by supporting learning, accounting for exceptions, and facilitating medical guidance. Specifically, new tracking devices and tools should support learning by offering clear information about fertility, especially in the first few cycles, to help users better understand the fertility self-tracking process. It is essential to provide basic knowledge at the beginning, but also enable users to explore and deepen their knowledge discovery when desired (e.g., for conditions such as PCOS). In addition, it is also important to account for exceptions: systems should not provide results and information focusing only on a "regular" 28-day fertility cycle, because it is a simplification of a very individual, highly contextualized, and "irregular" process.

Finally, medical guidance could also mitigate many of the challenges women experience in the preparation phase. Systems' features that enable interaction with different healthcare providers would allow women to ask questions, and receive evidence-based answers. For example, features for exporting a summary of a woman's journey –from patient portals, other types of personal health records, or even from personal tracking tools and applications that women could print and/or send providers– would facilitate transitions, making it easier for the provider to understand the case, interact with the patient, and together decide on the best course of action.

6.2   Creating personalized solutions through collaboration

Fertility tracking is highly individual. An approach that works for one person may not work for another. This is similar to the context described by O'kane et al. concerning the idiosyncrasies of migraine and diabetes [33]. 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 fertility cycles. In such case, women need constantly to "solve a puzzle" to create their personalized solution to fertility care.

Our findings indicate that women attempt to overcome the complexity of their condition by engaging in collaborative sensemaking to reflect and reach conclusions based on their tracked data. 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. 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 [28]. For women with fertility problems, especially those dealing with it 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. Women collaborate with each other throughout the whole fertility self-tracking process to make sense of their data. Since clinical appointments are often months apart, women often turn to the health forum 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, which may be due, at least in part, to the limited time of medical consultations. These findings are aligned with the role of online communities in augmenting traditional healthcare discussed by Huh [22]. Through the health forum, women 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 [34] describe in their study with healthcare providers 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. In this context, Huh and Ackerman discuss how collaborative sensemaking can inform and support chronic disease management [23]. 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. Within the context of fertility self-tracking, often there is no regular situation or explanation, and women 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., [10,26]). Many studies approach Personal Informatics as only one person collecting and reflecting on her own data. Self-tracking for fertility is different in two aspects: 1) the stage, and 2) the triggers for sharing. Concerning the stage, most models usually place social aspects only in the action stage, when people receive feedback or encouragement. In fact, the Personal Informatics Model describes data sharing (e.g., with healthcare providers, family, or in social networks) as an activity of the Action stage, after reflection [26]. Health indicators that are relatively simple to interpret may fit better within this model. In fertility self-tracking, women collaborate through all the stages in order to make sense of their data and create their own personalized solution.

More recent studies have approached collaboration in other stages of self-tracking (e.g., [11,36]). However, fertility self-tracking also holds differences concerning the triggers for collaboration. For instance, Rooksby et al. 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 [37]. In our study, we found a similar behavior, but with a different trigger: the unique challenges related to the complex context forced women 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 [11] and, more broadly, when approaching self-tracking for complex and highly personalized conditions.

6.2.1 Implications. Facilitating collaboration and peer support could help women to work together in sensemaking. Facilitating collaboration among users with similar problems and experiences might support creating personalized solutions for them. This could be done using profile information that users fill in their own tracking tool, as well as the tracking data they decide to share. For example, matching women with PCOS could facilitate sharing strategies and success stories of similar cases, thus stimulating collaboration. However, it is important to warn users that a solution that worked for one person may not work for another, even if they have similar experiences, due to the individualized nature of fertility.

Systems directed at supporting fertility self-tracking also could facilitate reflection by suggesting possible interpretations of the results as women record their data. This could help in creating personalized solutions

and better interpreting the information acquired through collaboration. For predicting ovulation, a key challenge is to understand what different indicators mean when combined, especially when they show contradictory results. A feature that analyzes these results and proposes possible explanations day-by-day would help to expand women's knowledge about the process and their specific cycle. The feature could also propose actions accordingly, addressing the challenges in both the Reflection (what the results mean) and Preparation (what to do in the next cycle) stages. When suggesting more complex treatments, tracking tools could show practical information such as insurance coverage (or how to find this information), fertility clinics, price ranges, and possibly (after agreement) users with similar experiences who have tried clinics/treatments in the region.

These approaches would help women understand different possible explanations and the individuality of each case, so they can inform their own practices and balance their expectations. However, it can also trigger negative feelings, since women can repeatedly try different suggestions without achieving pregnancy or building a plausible explanation for this result. For this reason, any tracking tool aiming to support women facing fertility issues needs to consider the emotional burden involved in fertility care seriously.

6.3 Emotional impact

When women face fertility problems, their burden is increased by social pressures to have children. They usually feel isolated and with no support from friends and family, especially when the reasons for their infertility are unknown or unexplained. Many women turned to the health forum to vent or unburden, especially when they felt that everyone else in their personal circle was getting pregnant. They also felt worse when their frustration prevented them from feeling happy for their pregnant friends. The invisibility of the condition adds to these struggles, since infertility numbers are generally underestimated [50], and those facing infertility usually do not talk about it publicly.

Prior research described negative aspects of self-tracking, such as constantly reminding the person about her illness [3]. We observed similar aspects in fertility self-tracking. When women have been trying to conceive for a long time, self-tracking may become frustrating and burdensome, especially when they cannot find an explanation for not being able to get pregnant. Additionally, personal data may be embedded in strong emotional implications. Ancker et al. describe how patients with multiple chronic illnesses would experience frustration when their data does not reflect what they expect [3]. Women performing fertility self-tracking experience similar feelings, since they cannot control many of the health indicators they track. Frustration can also trigger compulsive tracking and generate stress, as found by Cordeiro et al. in their study on self-tracking of calorie consumption [13]. In fertility self-tracking these behaviors and the stress they carry can even affect health indicators, e.g., changing menstruation patterns. Ayobi et al. suggest that self-tracking should also consider mental wellbeing [4], instead of overly focusing on symptoms. They suggest that self-tracking tools should stimulate alternative viewpoints and parallel thinking. The same suggestion fits in the fertility self-tracking context. As found in our study, focusing excessively on health indicators results, without offering alternative possibilities and emotional support, may trigger negative feelings, such as frustration, stress, and depression.

Further, because fertility care is considered a sensitive topic affected by social pressure and taboos, women may not discuss it with family and friends. In this scenario, online help becomes crucial. As discussed in previous research on areas such as sexual abuse [18] and eating disorders [30], people going through sensitive conditions benefit from the anonymity and from interacting with people with similar experiences in these environments.

6.3.1 Implications. These aspects suggest that self-tracking technology should also account for the emotional issues related to the condition they aim to support, especially when it is complex, unpredictable, and highly personalized. Any tracking system or device aiming to support fertility self-tracking must consider the emotional burden and avoid reinforcing it. How the information is presented needs to be carefully crafted. The interface should not present pregnancy as the only success and all other possibilities as failure. Small design decisions, such as color scheme, can reinforce the emotional toll taken by its users.

The language needs to be carefully analyzed to avoid judgmental or condescending undertones that may reinforce the emotional burden.

Further, intentionally facilitating emotionally supportive activities among users, such as comforting and encouraging one another, could reduce feelings of distress among the women who use these systems, helping them to overcome feelings of invisibility and isolation throughout the process of trying to conceive. These activities already take place organically in the discussion forum we analyzed; however, the intentional design of features for this purpose could lead to more engagement and a larger impact on users.

7 LIMITATIONS AND FUTURE WORK

This research presents some limitations that should be addressed in the subsequent studies. First, since we collected our data from an online health community, the sample consisted mainly of women that want to share their experiences with others online. This population might not be representative, as many women may not feel comfortable sharing their experiences online, or may not have access to these online communities due to social, economic, and technological barriers. Women who have access to the health forum but do not post their concerns are also not represented in our sample. Further, the majority of users of the online health forum we analyzed are from the U.S. These users may not represent the broad spectrum of women who face infertility issues that have different social and cultural values as well as different ethnicities. In addition, analyzing online posts may miss certain issues, emotional concerns, or social taboos women face in their daily lives. Thus, future studies using methods such as interviews are necessary to address these issues by sampling from fertility clinics, hospitals, and community clinics in diverse communities, and try to reach women that use self-tracking practices before seeking professional fertility care.

8 CONCLUSIONS

This is a preliminary study investigating the use of self-tracking for fertility care. It contributes to the current literature by describing how women use self-tracking in fertility care and the main challenges they face in these activities. Based on these results, we recommend that tracking tools support the learning process and collaboration, and facilitate the process of identifying similar cases to help generate personalized solutions. Tracking tools also need to account for the variability of the conditions and the different possible responses to treatments. Finally, tracking systems should carefully consider the impact of design choices and avoid reinforcing the negative emotional burden on women. Future work will include interviews with patients and providers and an evaluation of the tools that are currently available.

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