



# "Anyone else have this experience?": Sharing the Emotional Labor of Tracking Data About Me

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Self-tracking technologies, ranging from digital thermometers to wearable fitness trackers, allow users to use personal data accumulated from their everyday activities. But, to use these data, people have to make sense of how these numbers and figures are relevant to their lives in some way in order to make decisions and gain new insight. This process is impacted by people's emotional reactions to their data. While seeking support from others can be an effective strategy for overcoming these emotional challenges, self-trackers face unique barriers in sharing their personal data. Our study investigates 1) how users seek out support online for emotional barriers elicited by their self-tracking data and 2) what self-described impact this sharing has on their self-tracking practices. To investigate these topics, we analyzed discussions in two online communities on Reddit.com centered around infertility and trying to conceive that consistently describe self-tracking experiences. We found that community members described three distinct driving emotional tensions with their self-tracking data. In seeking community input, users were focused on support for understanding and acting upon their feelings and emotions. Even when data was uncertain, frustrating, or viewed as inaccurate, comparing and learning with others benefited users through feelings of connection, control, and humor this collective sense-making provided. Additionally, we found that users taking breaks from self-tracking in whole or part appeared to support their emotional well-being and long-term motivation to track. Based on these findings, we conclude that self-tracking data has social and emotional value beyond perceived accuracy and individual treatment goals.

CCS Concepts: • **Applied computing** → Health informatics; • **Information systems** → *Collaborative and social computing systems and tools*; • **Human-centered computing** → **Empirical studies in HCI**; *Collaborative and social computing systems and tools*; **Empirical studies in collaborative and social computing**; **Social content sharing**; **Computer supported cooperative work**; *Social media*.

Additional Key Words and Phrases: personal informatics; self-tracking; emotion; sense-making; infertility; Reddit; online communities

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## 1 INTRODUCTION

Internet-connected and sensor-based wearables (i.e. FitBit, Apple Watch) are tools centered around recording personal information to support individual goals, ranging from fitness to skill development. People often use these devices to record things they do (like going for a run, injecting insulin, or watching a movie). They also use them to record bodily states (such as blood pressure or heart rate) and their psycho-physiological experience of the world (such as mood or ideas). These self-tracking technologies are increasingly popular. A 2019 survey found that about one in five Americans use a wearable device to track their behavior and other information about their body [70] with that number expected to grow as self-tracking becomes more integrated and accessible.

But, this proliferation of personal technology has not fundamentally changed why people want to self track [29, 52, 61]. Rather, what these technologies have changed is the *scale*, *scope*, and *ease* of collecting self tracking data. The automatized, integrated nature of these self-tracking platforms allows for hundreds of different factors to be recorded and quantified during individuals' existing everyday routines [73]. Predictions generated from these aggregated data can illuminate trends across place and time [20, 28, 55]. As a result, these platforms have made comprehensively quantifying "friendships, interests, casual conversations, information searches, expressions of tastes, emotional responses" (pg.198) [66] and other complex, individualized experiences possible. Though tools for tracking your life may seem more effective and easier to use than ever before, these tools and the data they generate also create new challenges for the people they reflect.

Self-trackers face barriers to sharing their data that consistently relate to the emotional reactions that data provokes. Data can spark happiness and sadness, hope and despair, confusion and clarity, whether that goal is weight loss [23] or beating cancer [47]. Positive or negative emotional reactions to data can influence an individual's likelihood to continue tracking [85] and potential benefits and outcomes of tracking [12, 47]. Rather than navigating these emotional experiences with data alone, sharing them with others can elicit support and empathy, helping to ease emotional burdens and supporting people to move forward with their personal goals related to tracking [20, 21, 58].

Despite users generally wanting to share their self-tracking data with others, hurdles to accessing social support for self-tracking data include the fact that many people don't use self-tracking technology for more than a few weeks or months [3, 89], which limits the amount and scope of material for sharing. Additionally, disappointing results can discourage users and make them feel less confident in sharing their data with others [20, 22]. Existing design approaches have been critiqued for their focus on context-devoid output factors with little or no support for the emotional experience of data [7, 34]. As a result, though self-tracking data can open new opportunities for detailed reflection and improved communication outcomes, it can also make it more challenging to sort through rich reservoirs of personal data and cultivate common ground with supporting social ties while also emphasizing one's particular situation.

One explanation for these barriers with data interpretation and sharing is that many self-tracking technologies, such as phone apps and digital diaries where users can input their self-tracking information, offer little or no support for the emotional sense-making of that data. The collected data is typically presented without the inclusion of emotional context and do not offer tools for processing the feelings that can arise from disappointing, promising, or otherwise emotionally evocative data [49]. In other words, while automatized self-tracking can create more accurate and useful data logs, individuals still have to "make sense" [60] of how these complex data actually reflect their life and what use it has, if any, for them going forward. When engaging with self-tracking data, people rely on their past experiences [16], sharing and connecting with others [93], sources of domain expertise [38] their own feelings [35] and "gut instincts" [4] to answer the questions

*What do these numbers say about me?* and *What should I do about it?*. This includes dealing with the emotions that these data create.

While self-tracking technology for emotions *as part of the data being explicitly recorded* are becoming increasingly common (for example, mood disorders, see: [47]), emotional management of reactions to the data itself have received less attention. Work in CSCW suggests that people reach out for support while still dealing with emotional reactions to their data and deciding how they should move forward [21, 22, 58]. In particular, collaborating with other people to make new, meaningful connections from personal data, or collective sense-making [30, 81], is common.

Considering the unique, personal qualities of self-tracking data, it's plausible that social sense-making regarding that data and emotional responses to it is even more important than generalized support seeking. Rather than just being *about* them, self-tracking data can be viewed as a reflection of self-worth or personal success [79], thus inextricably weaving self-tracking practices and reactions within social and cultural pressures [54]. As a result of these pressures, engaging with self-tracking data in productive ways may be especially benefited by sharing with others about it.

In light of the highly personalized, intimate qualities of self-tracking data we argue that self-tracking technologies can produce amplified emotional challenges for everyday users. Dealing with these emotional responses is necessary to integrate data as personally relevant and useful or otherwise able to be discarded [30]. Further, we argue that this emotional work can be accomplished in part by sharing the process with others. We argue that **online social spaces can support the unique challenges of emotional reactions to personal tracking data and in turn influence how users describe their self tracking behaviors and the value they gain from their data.**

To investigate how self-trackers choose to share and reap benefits from their self tracking data, we analyzed discussion in two pregnancy and conception oriented communities on Reddit.com, [r/TryingForABaby](#) and [r/infertility](#). While definitions of infertility vary across cultural and medical contexts [88, 92], the term is often used to refer to a medical condition described as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” [59]. Infertility as a topic was selected due to the importance of individual self-tracking. Unlike many other chronic conditions that have been evidenced to benefit from self-tracking, such as diabetes [56] or cancer [35] management, many people seeking medical treatment related to infertility have a clear end goal, having a child, with an unclear path to attain it. Upwards of hundreds of consequential biological and other factors have been implicated in infertility diagnoses, and so-called “unexplained infertility” is widespread [14]. As a result, tracking individual symptoms plays an important role in self-knowledge, individual treatment plan development, and coordination with medical professionals [8, 51, 84]. We also selected the infertility context as a case study due to its prevalence worldwide, with approximately 15% of heterosexual couples worldwide being classified as experiencing infertility within their lifetime [60]. Our goal with this approach was not to reduce the complexities of infertility to one definition, one context, or certain kinds of experiences. Rather, focusing on the pervasive, diverse, and emotionally-laden experiences captured across infertility-related contexts served as a valuable case study to deeply examine the emotional entanglements of self-tracking and sense-making with social ties in real world contexts.

While examining the role of social and emotional support in online communities for infertility experiences is not new [33, 51, 69, 80] we expand upon existing approaches by focusing our inquiry on self-described emotions related to self-tracking and the impact of these experiences on community support. To this end, we analyzed 120 individual forum threads, each consisting of a handful to upwards of hundreds of individual comments, in which users discussed how using self tracking technology influenced their experiences with infertility. We found that three central tensions, each associated with distinct self-tracking scenarios and contextual influences, drove

users to share their self tracking data with others in the community. Rather than solely seeking authoritative facts or information resources, participants in this community predominantly sought input from others to satisfy the *emotional challenges* they were facing rather than just learning new things. The driver of user activity in the community was to learn from others how to situate their own emotional reactions, positive or negative, in the context of their own data and general “*infertility journeys*”. We use these findings to argue the value of outlining the unique emotional challenges that are amplified by self-tracking technologies. To this end, we expand upon previously identified design recommendations to suggest ways to more effectively support the emotional experiences of self tracking data.

## 2 RELATED WORK

### 2.1 What is Self-Tracking?

People record information about their thoughts, feelings, and day-to-day activities to reflect on their own experiences, learn, and work towards improving their lives in the future. These activities often take place using recording technologies, ranging from pen and paper to digital diaries and mobile phone applications. What is considered “self-tracking” [54, 56] data is diverse. In interviews with self-identified “quantified selfers”, a community of self-tracking technology enthusiasts, reveals 57 distinct types of possible data [20]. These data included heart rate, GPS location, body fat, number of movies watched, skin condition, posture, snoring rates and many other factors [20].

Though recording personal information over time for future reflection is often referred to by a variety of context-specific terms, including datafication [29, 55], self-monitoring [23], personal informatics [17, 53], and lived informatics [32], these concepts are unified by the fact that they all concern data that is related to an individual person which has been intentionally collected. In this vein, Li et al. define personal informatics as technologies “that help people collect personally relevant information for the purpose of self-reflection and gaining self-knowledge” [52]. Choe et al.’s definition describes self-tracking as “a class of systems or practices that help people collect and reflect on personal information” [20]. Based on these definitions, in the remainder of this discussion, **self-tracking** will be used exclusively to refer **any intentional recording of personal data** unless otherwise stated. Unpacking other contexts for personal data recording, such as the rapidly expanding industry of big data, data aggregation and surveillance [50], including the important ethical concerns therein [68], is beyond the scope of this discussion.

### 2.2 Why Do People Track?

Just as the type of data collected varies widely, people are motivated to use self-tracking technologies for diverse and numerous reasons. Natural curiosity [52] and a desire to understand more about one’s own body are commonly described [61]. Wanting to change behavior is another typical driving motivation [44, 62]. In one study of people who used personal fitness trackers, users were motivated to reflect on the past to learn how their behavior may have changed and identify opportunities to be more physically active in the future [28].

In understanding if these goals for self-improvement are actually made more attainable by the use of these technologies, the empirical evidence is generally positive. Figueiredo et al.’s examination of self-reported fitness tracker use found that consistent, habitual use of tracking technology improved longitudinal health outcomes and health literacy [34]. In the area of mental health, use of a self-tracking system designed to target a variety of behavioral and health predictors resulted in more positive treatment outcomes for patients diagnosed with bipolar disorder [9]. Similar positive results have been found in the context of health and disease management [31], athletics [73], food consumption [62], mood and mental states [9], and learning new skills [91].

But, barriers to these positive outcomes are common, including reduced motivation to continue tracking [47, 55, 89] and challenges with using the technological interfaces [29]. These challenges are often centered around emotional experiences emerging from collecting, interpreting, and sharing self-tracking data [29, 47, 63]. Users repeatedly face social, technological, and personal barriers to effectively engaging with the emotions that arise from reflecting on their self-tracking data; barriers to engaging in collective sense-making include making highly individualized data make sense to other people [22], social pressures to quantify the self in idealized ways [51, 54], and confusing or frustrating technological interfaces [10, 29, 57]. These barriers are unified by the fact that they all suggest that way data makes users *feel* impacts how they engage with their data, the technology, and other people.

### 2.3 Emotion and Self-Tracking

How self-tracking data makes people *feel* has been shown as important in the overall experience of self-tracking, including impacts and barriers to success. For example, self-tracking made it more challenging for some participants to move past mistakes and short-comings reflected by the data, leading to increased emotional distress and decreased motivation to track [48]. Negative data can be interpreted by users as a poor reflection on them personally, resulting in sadness, distress, and other negative feelings [12].

Though emotion is a complex, fuzzy concept, examining how emotion has been defined and operationalized offers a useful starting point for understanding emotion's significance in self-tracking. Many scholars agree on several core components of emotion, as follows:

- 1) Emotion is part of how people perceive and respond to situations [64]. For example, feeling stress in response to a challenging upcoming exam [66].
- 2) Emotion includes a physiological component. Among other factors, heart rate and skin temperature have been evidenced as predictive of emotional arousal [74].
- 3) Emotion is a subjective, internal experience [64]. Many scholars recognize archetypes of emotion, based on patterns of cognition and psychological arousal, such as Plutchik's typology of emotion which argues that humans can experience eight different primary emotions: joy, trust, surprise, anticipation, fear, sadness, anger, and disgust [72]. Others argue that emotion is so individual that it could present itself in infinite ways [6].
- 4) Emotion can motivate behavior. In studying the role of self-tracking in patients with multiple sclerosis, patients were motivated to track because of the stress, anxiety, and exhaustion resulting from managing their health [7].
- 5) Emotion is related to patterns of motor activity, including facial expressions and body position [63].

Inspired by this summary, in our approach we define **emotion** as **the thoughts, feelings, and internal sensations that play a role in individuals' reactions to their self-tracking data**. We focus our concept of emotion on **what self-trackers actually describe** - the reactions that they describe as arising while collecting and thinking about personal data.

In the context of self-tracking specifically, emotion is an emerging area of attention. Li et al.'s Staged-Based Model of Personal Informatics model has been challenged for not explicitly considering the role of emotion in self-tracking. For example, Figueiredo et al.'s investigation of infertility self-tracking in online communities [34] found that emotions played an integral role to how users moved between different kinds of self-reflection. They also noted that Li et al.'s proposed 5 stages often occurred for self-trackers simultaneously rather than sequentially. This suggests that emotions influence self-tracking outcomes across the lifespan of people's engagement with their data, from initial recording to sharing with others.

These more holistic and contextualized approaches to user experiences with their data have been broadly referred to as lived informatics, grounded in the metaphor of sense-making [30]. Sense-making is an empirical framework in which cognition, emotions, and values serve as “bridges” between the situation a person is facing (such as a problem or a question) and some outcome, whether that’s taking action or seeking out more support [26]. Baumer summarized this process as reflective sense-making, which describes sense-making as occurring in three stages: defied expectations that trigger a cognitive response; inquiry about the surprising data (alone or with others); and a final transformed thought and/or action [10]. An example of reflexive sense-making in action was demonstrated by Kaziunas’s examination of parent-child dyads’ use of the Nightscout diabetes monitoring platform [46]. Parents and children had to learn how to navigate their responses to the often confusing, surprising recorded data in a way that respected one another’s emotions while simultaneously maintaining the child’s safety. These dynamics led to emotional tensions, including guilt, isolation, and anger surrounding tracking practices [46].

## 2.4 Challenges of Navigating Emotional Reactions to Self-Tracking Data

First, the *design* of self-tracking technologies can unintentionally create barriers and hardship for users. One examination of menstrual tracking technology use found that some users experienced feelings of exclusion and isolation sparked by the user interface [29]. For example, the application’s integration with the user’s Google Calendar made them feel embarrassed about indirectly sharing that information with everyone else using those calendars. Further, some users felt that the inability to remove notifications about ovulation and other factors related to conception were emotionally painful, triggering, or annoying.

Communicating data to other people also has inherent challenges. Not receiving positive support or receiving negative support can be harmful. In one study, Parkinson’s disease patients were provided with FitBit devices to use for one month before a follow-up visit with their doctor [63]. In this follow-up visit, the doctor was focused on data “anomalies”, referring to days where the average steps walked was a high or low outlier. The doctor wanted to work on strategies to target the behavior that lead to these outliers. However, the participants were frustrated by this approach. They viewed these data points not as surprises linked to one specific day, but as resulting from situations that were persistently present in their lives every day. For example, when questioned about a low step count day, one patient explained that they experience chronic pain in their legs, something they faced everyday [63]. This disconnect between the patient’s view of a chronic problem versus the clinician’s focus on anomalies led to the patient feeling ignored and disenfranchised in communicating their own experience.

These challenges also reveal how seeking support from others can be a powerful tool to overcome these emotional hurdles, particularly when this support is lacking in other aspects of life. In one study of an online community centered on a poorly understood chronic pain condition, participants cited a lack of information resources to learn about symptomology, treatment, diagnosis, and other aspects of the condition [91]. In response to these uncertainties, users described persistent feelings of anxiety, depression, and other negative emotions. As a result, these community members worked together to accomplish highly detailed symptom-tracking work that they viewed existing self-tracking technologies, such as virtual pain diaries, as being inadequate to achieve. Developing their own tracking techniques helped them seek interpretive support from others which helped them feel better. When people don’t receive support or otherwise struggle to deal with the emotions surrounding data, there are often adverse consequences for their self-tracking outcomes, such as decreased motivation to track [47] and feelings of isolation and exclusion [51].



## 2.5 Infertility as a Self-Tracking Case Study

Relying on social support for the emotional experiences of infertility, including infertility self-tracking, is not new. Figueiredo's examination of how participants in an infertility online community described their emotional relationships to their personal data revealed a reciprocal relationship between emotion and data interpretation [34]. In other words, how users felt about their data influenced how they interacted with others in the community and chose to share their data.

Additionally, it has also been evidenced that these online spaces can be positive for users to get through the emotional challenges of their situation, especially for those facing stigmatized experiences such as infertility. Patel's examination of men who participated in infertility online communities found that these communities were particularly valuable in the face of perceived in-person stigmatization; the community helped them recognize their common bonds with others and learn to accept the challenges of their situation with renewed optimism [69].

Our inquiry builds upon this existing work in several innovative ways. First, we intentionally focused our inquiry on moments of sense-making rather than just emotions and tracking broadly. In other words, our analytical criteria centered on identifying discussions in which users were talking back-and-forth and building off of one another together to better understand and respond to personal data. This approach offers further insight into the explicit role of social support in emotional processing and data sense-making. Our approach also allows this process to be examined at multiple stages over time rather than in the context of just a single comment. This allows us to discuss the process of data sense-making we found in these communities. Additionally, our inquiry is innovative in that it focuses on collective sense-making not just in the context of positive emotions and ideal circumstances, but also when facing breakdown, technical problems, negative emotions, and potentially unhealthy data practices. Finally, we further expand upon Figueiredo's work [33, 34] in particular by examining how feelings of control and self-autonomy may have implications for the emotions of self-tracking in the context of infertility and potentially in other self-tracking contexts.

## 3 METHOD

To examine the role of emotion in self-tracking, we studied two online communities, [r/infertility](#) and [r/TryingForABaby](#), on Reddit.com. This inquiry developed from our interest in understanding what role online social spaces may play in how people *learn about*, *describe using*, and *form beliefs* about self-monitoring technologies. Reddit.com was selected because it is the seventh-most popularly searched website in the United States and seventeenth worldwide [2]. In addition to its popularity, Reddit is divided into thousands of subreddits, smaller internal forums centered on specific topics, which allowed us to focus our inquiry on a case study of self-tracking practices about a particular topic. On Reddit, anonymity is the norm as compared to many other social platforms, which may be appealing to users facing challenging, often stigmatized situations such as those related to infertility [45, 50].

Prior to the main study, the first author spent approximately ten hours, inspired by topics from existing self-tracking literature in HCI, exploring Reddit communities that discussed self-tracking, including [r/infertility](#) and [r/TryingForABaby](#). These communities in particular were selected as the specific field sites for the main study due to their popularity; at the time of this writing, these two communities had the most registered users and regular postings out of all the communities on Reddit.com related to maternal health. We elected to examine two topically similar online spaces to determine if our findings were reflected across multiple contexts, which they all were for both [r/infertility](#) and [r/TryingForABaby](#).

In considering our approach and our contribution, it's important to consider our position as authors. None of us have been personally impacted by the experience of infertility as community members describe. Considering how not having this lived experience may influence our orientation towards our participants and the data is valuable. To this end, we incorporated Berger's three suggestions for considering reflexivity and potential researcher biases (keeping a detailed analysis log; reviewing the data repeatedly; and discussing the research with others) [13] into our analysis, as described in detail below.

### 3.1 Data

We collected postings on [r/infertility](#) and [r/TryingForABaby](#) by using the Reddit API to download all new threads and comments once per hour. Each thread was re-downloaded three days after it was initially posted in order to evaluate additional discussion. Based on our observations, virtually no comments were contributed past 72 hours. We started the scraper in August 2019 and collected data through February 2020. All the activity in our data corpus took place during this time span.

We filtered through all the scraped threads and eliminated those with no comments. At the time of this writing, we also removed any threads that had been deleted by a community moderator or the original contributor from our analysis. We refined our data corpus to the daily discussion threads, which are general discussion threads programmed by the community moderators to be automatically posted several times per day. These threads were selected because the vast majority of all community discussion is concentrated in them. [r/infertility](#) had a total of four automated discussion threads posted daily while [r/TryingForABaby](#) had two. In random sampling, the fact that [r/infertility](#) had twice as many daily discussion threads was managed so that the study sample breakdown reflected the quantity of data produced. As a result, 70% of our corpus originated in [r/infertility](#), while 30% was from [r/TryingForABaby](#). As a result, the entire corpus of relevant threads was approximately  $n = 1,000$ . Our analysis of these data took place over three stages: pilot analysis, codebook testing, and finally analysis with the revised codebook.

### 3.2 Analysis

Our qualitative content analysis used grounded-theory inspired approaches based on Timonen et al.'s distillation of core principles of grounded theory across qualitative methodologies [83]. First, we defined action and practice in terms of how it actually impacts the community of study. To this end, our takeaways focus on what community members actually said and how others reacted while avoiding external assumptions. Next, we practiced theoretical sampling, a process in which new explanations and theories are continuously generated from the data, which was accomplished during our weekly team research meetings. This process included returning to the data to develop or critique our analysis approaches and sampling more threads weekly to further develop our emerging findings. These meetings were focused on generating creative, critical discussion of new possible explanations sparking from each new set of data. Finally, across all stages of the analysis, the authors also engaged in constant comparison, in which we continuously returned to the data with our nascent findings to evaluate if our interpretations truly "emerge from the actual data" [83].

Our approach also draws methodology from abductive analysis. Abductive analysis critiques grounded theory to argue that abductive reasoning, focused on generating possible explanations within and beyond the realm of established theories when faced with surprising data to develop new theoretical insights [82]. To this end, during all stages of analysis we continuously examined literature on self-tracking technology, personal data, and emotion to critique and expand on our emergent explanations. This back-and-forth between the data and theory, practiced alongside during our weekly analysis meetings, allowed us to "identify changed circumstances, additional



dimensions, or misguided preconceptions” [82] in our findings. Based on these approaches, our iterative analysis occurred over three stages defined based on their primary research goal: 1) initial immersion in the field, 2) data analysis, and 3) methodological techniques to validate the trustworthiness of our findings.

In **Stage 1** of our analysis, the first author became immersed in the community, a qualitative technique for capturing rich, process-oriented data in a naturalistic setting [83]. During this immersion, she followed [r/infertility](#) and [r/TryingForABaby](#) for several weeks. This included reading through the daily threads and familiarizing herself with the acronyms and slang used by community members. During this time, she also conducted a literature review to understand historical, medical, and cultural approaches to infertility experiences. Over the course of this initial inquiry, she open-coded phrases, topics of discussion, and other emerging patterns that occurred across interactions in 18 threads randomly selected from the data corpus.

**Stage 2** centered on testing and developing the codebook in addition to the main analysis. The first three authors coded 102 additional randomly selected threads, approximately 10% of the total corpus, using the codebook over several months. The authors met weekly to discuss their coding, compare memos, and discuss patterns of interest for further analysis. Based on these discussions, the codebook went through several rounds of second-order coding to identify emerging patterns with more precision and detail related to our topics of interest. This iterative process of independent qualitative coding coupled with team analysis was used as a tool to capture and critique emerging findings that sparked from the data itself. We randomly selected two to twelve threads to add to our corpus each week until we all agreed that we reached theoretical saturation; we defined data saturation [53, 75] as 1) when new patterns did not emerge from further analysis and 2) how well our data informed details and descriptions of emotional self-tracking. This occurred after analyzing the 18 pilot threads and 102 other threads.

From this team analysis, we developed a codebook that captured the following: 1) self-described practices related to self-tracking technologies use and infertility experiences 2) how participants seek out and give support to people in the community about their self-tracking data challenges and 3) the ways in which emotions, feelings, and intuition play a role in these social sense-making efforts. The final codebook contained 31 unique items, and served as an analytical tool to organize and critique our findings rather than as an output in and of itself.

Finally, in **Stage 3**, the first author used this final codebook to assess the validity of the findings across all 120 threads from the pilot and main study. She re-examined the data to determine if the findings, quotes from participants, and concepts were accurate representations of what was in the data. She also employed Onwuegbuzie and Leech’s principles for validating qualitative data analysis, including checking for negative or disconfirming cases, checking the representative-ness of findings across the data, and practicing rich, thick description [65]. She determined that our findings reflect the data and there were no cases that varied significantly from our understanding.

### 3.3 Ethical Issues

People often seek out online spaces, such as the communities we studied, to intentionally avoid scrutiny and social pressure from other people. We did not directly interact with any community discussants; our analysis was based entirely on text-based discussions that occurred spontaneously. Our Institutional Review Board ruled this study does not necessitate human subjects approval due to the public nature of the data, but for the privacy and safety of community participants, several ethical concerns are relevant.

Though our data was publicly available, discussions in these communities centered on personal, evocative topics. It was the norm for community members to share intimate details of their day-to-day activities, thoughts, and feelings about their infertility-related experiences and the impact it

had on their life. Existing evidence suggests that online community participants have expectations for who will be looking at the information they share [32, 40]. In other words, despite the content being freely available for any Internet user to find, people expect that others going through similar situations who care about what they are going through are the ones interacting with their content [40]. Additionally, it has been evidenced in the context of Twitter that users care about how their content is represented by researchers (such as portraying them in a positive or negative way) [32].

In consideration of user privacy and the concerns users have about the use of their online material, we took several steps to protect user privacy. First, we did *not* collect any information about users beyond the comments they posted, such as older comments, activity on other subreddits, or information on their Reddit.com user profile. We also anonymized participant usernames by assigning a number to each thread in our data corpus and a letter to each username based on the order they appear in the paper. Additionally, we paraphrased participants' comments so they would not be easily searched online. In an effort to maintain the original content and cadence of the original quote, we focused this paraphrasing on spelling errors, punctuation, and other small changes. The second author searched the paraphrased quotes on Google's web search engine and verified that the paraphrased quotes are not easily or obviously traceable to Reddit.com; nor are the paraphrased quotes traceable to the original comment when searching within the subreddits themselves. To this end, we also omitted any potentially identifiable information from their quotes, including the so-called signatures many users connected to their posts. These signatures included information such as age, gender, diagnosis, and location. Though we did choose to identify Reddit.com and the two subreddits, this was an intentional choice to provide context for the reader, as past work online communities work has done [67, 77, 78].

## 4 FINDINGS

We found that [r/infertility](#) and [r/TryingForABaby](#) users frequently discuss the self-tracking devices they use during their day-to-day infertility treatment activities. This includes discussions of what technologies they use, how they use them, and what they have learned from their accumulated data. Many of these discussions are centered predominantly on the feelings and emotions that self-tracking evokes. Throughout this discussion, community members frequently use slang and abbreviations. Table 1 in Appendix 1 provides definitions some of the most commonly used terms.

We found that community discussions centered around three core *emotional tensions* that consistently and repeatedly arose across our sample. To understand how these emotional tensions drive discussion on [r/infertility](#) and [r/TryingForABaby](#), we begin with a brief examination of how users describe their initial motivation to seek out support online.

### 4.1 The Value of Online Communities for Empathy and Accessing Support

The value of online communities for social support from other people living through the same experiences has been widely demonstrated across many different topics [24, 43, 87, 93]. We identified two motivations identified by community participants seeking out online support for their infertility experiences: empathy and a lack of face-to-face support. [r/infertility](#) and [r/TryingForABaby](#) community members repeatedly describe the benefits of finding a lot of people experiencing the same things all together in one place.

As described by community members, the online community has particular value because it offers expertise that they cannot find anywhere else: the day-to-day experiences of those living with infertility. Members of the community describe feeling at least somewhat equipped to find resources about infertility via more traditional information-seeking, like research articles or talking with their doctor, but feeling less equipped to deal with the everyday heartbreaks and disappointments of infertility treatment. These participants describe how the ambiguity of their own bodily sensations

coupled with the high stakes of treatment results combine to create complex emotional experiences that are difficult to describe to people who have not lived through it, too. **User 61a**'s comment demonstrates the power that this empathy and emotional connection has:

**User 61a:** *"I deal with those feelings constantly. I cry on the couch a lot. But I always post here when I'm feeling negative and there's always SOMEONE here who has experienced what I have. I have forced myself to be open and transparent and now I have a wonderful online support system ..."* (r/TryingForABaby)

**User 61a** was responding to another user who shared that their struggles to conceive were making them feel deeply depressed. They began their comment from a position of empathy: *"I deal with those feelings constantly"*. As is typical in these communities, after establishing their shared perspective, they flesh out their shared experiences with rich, contextual details of their emotional reactions to their infertility experience: *"I cry on my couch a lot"*. **User 61a** goes on to share how when they are *"feeling negative"* they have found that, in this online community, *"there's always SOMEONE who has experienced what I have"*.

In addition to the power of knowing they are not alone, community participants describe being ostracized, misunderstood, or otherwise treated poorly by friends, family, medical professionals, and other people in their face-to-face social networks. These are people that they trust and generally go to for advice, but in the case of infertility, they cannot offer effective support. Often, these issues are related to what is perceived as a fundamental ignorance of infertility because they have not lived through it themselves. Even well-intentioned family and friends can create more harm and stress for community participants. **User 13a** demonstrates a typical example of these social tensions when describing a situation they are facing with their spouse:

**User 13a:** *"... It's only my second cycle so I'm trying not to get frustrated with him but I've also tried explaining with stats and facts that hitting 1 day is not great for our odds... I can feel that we're gonna have to have a talk ... and it probably won't be pleasant."* (r/TryingForABaby)

**User 13a** is frustrated with their spouse because of their unwillingness to adhere to the timed intercourse schedule that the **User 13a** developed from self-tracking. **User 13a** believes that *"hitting 1 day"* is not as good for their conception chances as having intercourse on multiple days. But, as this user describes, their attempts to convince their spouse of their plan have failed so far. **User 13a** describes their anxiety in figuring out how to talk to their spouse about this. Frustrations about their spouse's perceived lack of engagement and willingness to put in effort drive these described feelings of isolation and the desire to connect to community members.

As these examples demonstrate, 1) dealing with social support perceived as insufficient and 2) recognizing the unique, irreplaceable value of learning from others who have lived through similar things are the two main experiences that users again and again describe as driving their participation in these online communities. While these two motivators are not novel in and of themselves, they reveal that users enter these communities with the expectation of receiving a certain kind of embodied, sensory expertise (living with infertility too) that they haven't been successful in finding elsewhere. Participants describe the community as a trusting, understanding place where they can share their authentic, uncensored thoughts and feelings and openly reach out for the input of community members. Against this established backdrop of trust, user discussions of their self-tracking challenges reveal the complex and context-sensitive strategies they use to manage the emotions that arise when reflecting upon their data.

## 4.2 Tension 1: Constructing Meaning From Surprising Data

The first major tension evidenced in this community is rooted in the inherent ambiguity of self-tracking data. Data in general is always one of many tools used to make a prediction or decision; its meaning is always situated within the lens of past experiences, culture, and other factors.

Connecting records of past behavior, bodily measurements, and potentially hundreds of other variables to medical outcomes is challenging. Further, unlike other complex medical conditions that have been the subject of more research and institutional support, such as diabetes [57] or certain cancers [35], the path to success when facing infertility is highly diverse. As community participants describe, what's viewed as a sign of success for one person may not apply to another. Community members describe being unified and motivated by the desire to become pregnant above all else, with self-tracking data becoming an accessible, controllable tool to work towards that goal.

As a result, users frequently describe their data as surprising, confusing, worrisome, or otherwise not what they expected. Surprise results from contradiction [15]. In this context, users often face apparent inconsistencies between their self-tracking results and their own recollections; examples of this include physical symptoms that are atypical from what the user expected or inconsistencies between the output of two different measuring devices. The negative emotions resulting from this surprise can become a roadblock to individuals' ability to connect their data to their everyday experiences, a core element of sense-making.

When users get results that are surprising, they reach out to the community for alternative plausible explanations. This sparks the process of collective sense-making, in which community members work together to support interpreting and acting upon individual's data. We found that in these communities, collective sense-making when faced with tensions surrounding data ambiguity occurs over three distinct, ordered stages: *initiating connection*; *identifying similar narratives*; and *generating and refining multiple plausible explanations*.

The first stage, *initiating connection*, is when users first present their surprising, frustrating, uncertain, or otherwise unexpected and distressing data to the community. **User 64a**'s request for advice exemplifies this first stage of the collective sense-making process. Here, **User 64a** is describing buying a new thermometer and attempting to explain a discrepancy between the results of this one as compared to their old thermometer:

**User 64a:** *"Got my temp drop [FitBit style wearable that measures body temperature] yesterday and used it! It had my temp at a whole degree lower than my previous temping. I know everything says to wait to change methods until your next cycle ... Anyone else have this experience?" (r/TryingForABaby)*

**User 64a** begins with explaining the situation that surprised them: their new Tempdrop device read one degree lower than their previous temping device. As is common in the community, even a seemingly straightforward self-measurement like body temperature can produce surprise, distress, concern, and a variety of other emotions. **User 64a**'s description is followed by framing the surprise within the details of their individual experience, including their explanation as to why they acted the way they did. Here, they're wondering if going against what *"everything says"* by starting with the new temping device in the middle of an ovulation cycle could explain this discrepancy. They initiate connection with others by explaining the situation and why is surprised them.

The language used in this quote, *"Anyone else have this experience?"* represents a pattern across these initial requests: that users don't only seek out any potentially relevant advice, resources, or conclusive answers. They want not only others' numbers, but their whole story and a recounting of the context surrounding their explanation. Starting from a place of lived experiences allows users to find empathetic support before diving into the details.

Next, community members begin to respond to the original commenter's story with their own. This begins stage 2 of the sense-making process for tensions surrounding surprise: *identifying similar narratives*. Users offer support for the emotional challenges presented by other self-trackers through sharing their own experiences. This sharing also typically centers on *identifying* and *justifying* the outcomes they experienced. Here, in typical fashion, **User 64b** replies to **User 64a**'s request:

**User 64b:** *"I started using my Tempdrop during the middle of my cycle, but I am still taking my temperature orally too until the algorithm kicks in."* (r/TryingForABaby)

**User 64b** starts with explaining why their situation is similar, and thus potentially useful to **User 64a**; **User 64b** also started using their Tempdrop device in the middle of a cycle. They focus on sharing what they did when using this self-tracking technology. They describe their response to possible differences between their regular thermometer and the Tempdrop: choosing to continue taking their temperature with the old thermometer as well *"until the algorithm kicks in"*.

While **User 64b** does not describe what this point of when *"the algorithm kicks in"* will actually look like, they are offering a possible explanation of **User 64a**'s issue. Many user comments, including this one, center on the *why* of others' experience with data; they offer their interpretation and explanation of why they did what they did and what happened as a result. **User 64b**'s comment is then further probed by **User 64a** for more contextual details, another common practice. This third and final stage of dealing with surprising data encompasses discussants' efforts to *probe respondents for more details about their data in order to generate more plausible explanations for their own situation*. **User 64a**'s responds to **User 64b**:

**User 64a:** *"Do your temps come out similar or the same? I'm just confused as to why mine would fluctuate so greatly. Maybe I'm doing it wrong but I wake up, slip the thermometer in and record it at the same time everyday no matter what."* (r/TryingForABaby)

Using the information that **User 64b** shared about using both the thermometer and Tempdrop, **User 64a** asks if this users' temperatures *"come out similar or the same"* between the two. They further offer another possible explanation for why their own results *"would fluctuate so greatly"* and cause their confusion: their own behavior. They wonder if they're *"doing something wrong"*. These back and forth discussions allow users to consider multiple explanations to understand and use their own surprising or contradictory experiences.

**User 64a**'s exchange with **User 64b** exemplify how users work together to point out and connect potential causal factors. Demonstrating this, **User 64a**'s final reply in this conversation reveals, based on this input, what they are going to do moving forward:

**User 64a:** *"... I'm tracking with both until my next cycle so I'm going to confirm that they follow the same pattern."* (r/TryingForABaby)

Comparing this plan with **User 64a**'s initial description, this path forward does not actually sound that different from their initial approach in which they described using both technologies. But, using the reflections shared by the community, they have a larger base of possible explanations to draw upon as they continue to track and compare their data going forward. Based on this input, they further describe feeling comfortable moving forward with this plan of action. If the results of the continued dual tracking go as expected or offer new surprises, they will be able to better interpret and justify those results based on the first-hand explanations they have closely considered with other community members. These findings demonstrate how users rely on the experiences of others in similar, even if not identical, situations to ground their interpretation of their own data when that data surprises them.



Self-tracking discussions about surprising data were not limited to information gathered using personal technology like thermometers; users also seek support for data accumulated from their own memory and experience. They approach the logic of their own bodies similarly to that of self-tracking technologies, as **User 114a**'s request for advice understanding their body demonstrates:

**User 114a:** *"That time when you just know AF is coming but it hasn't come yet. Argh. Just come already so I can move on. Feeling irritable and crampy and just done with this. Anyone else get bad PMS [Pre-Menstrual Syndrome]? I assume if I was preg the bad PMS wouldn't be there? Just wondering so I know what to look out for."* (r/TryingForABaby)

As **User 114a** is asking if their physical sensations, "*Feeling irritable and crampy*", signify PMS or if they should anticipate it to indicate something more. They are seeking out experiences from the community to confirm or discredit their theory that PMS, or possibly pregnancy, would not be associated with these symptoms based on their past experiences. They want to rely on the experiences of others so "*I [they] know what to look out for*" and are able to respond to data that seems surprising or uncertain. As is typical, users seek out a variety of alternative possible explanations based on the experiences of others. In other words, they are looking to accumulate relevant data scenarios to be able to navigate the uncertainty of their self-data in a more critical, informed way. **User 114b** replies with a description of their own internal sensations:

**User 114b:** *"I get this very light, almost ethereal twinging (Can't even call it cramps) that lets me know when it's all about to happen. I'm never wrong, even when it seems too early ..."* (r/TryingForABaby)

Like **User 114a**, **User 114b** shares their internal experience in descriptive, highly personal terms. These signs "*just lets me [them] know it's all about to happen*" and claim they are "*never wrong*" in predicting this. This causal connection between feelings and outcomes is unique to this discussant's experience of the world. But, it appears useful to **User 114a** because it offers a potential narrative for sense-making that they can connect bits and pieces of to their own emotional experience. Most of **User 114a**'s frustrations derive from their symptom ambiguity rather than the actual outcome they predict. Again, learning more about others' experiences allowed them to imagine more certain possibilities and be less frustrated.

This first set of findings, all surrounding tensions related to how people deal with the thoughts and feelings brought on by surprising, uncertain, and ambiguous personal data, reveal important information about the processes these community members undertake to share their data with others. It is important to note that none of these reflections on **User 64a** and **User 114a**'s issues entirely solved, or even attempted to solve, these users' confusion over their symptoms. Rather, other community members sharing their personal experiences offered both new perspectives to consider for explaining this kind of self-data. In this context, users intentionally sought out support for multiple plausible expectations grounded in lived experiences rather than information separate from who lived through it.

These practices also opened a point of interpersonal connection over this uncertainty, one of many challenges everybody in the community faces when making sense of their data during their infertility journeys. This kind of sharing over three stages (making a connection, identifying complimentary narratives, and working together to generate multiple explanations) in the context of data collected by both personal tracking technology and users' own personal recollections was present across numerous discussions.

Further, the support sought for all the different data contexts evidenced in the community were centered around the *emotions* the data evoked, whether that be the frustration of using a new piece of technology to track or the discomfort arising from wondering if their body sensations are typical.



They approach both their physical body and technical tools through the lens of what they should be feeling about their data. These findings support existing calls for self-tracking technology design to incorporate emotional context in their data collection [7, 34] and also suggest potential value in a technical infrastructure for capturing even difficult to describe, “*ethereal*” sensations that others could reference in the future.

Examining tensions surrounding surprising data offers community members a starting point for empathy and support for emotional challenges. They recognize that, even with their similarities, no other person’s experience and outcomes will be identical to theirs. But, accumulating lots of different experiences and perspectives offers its own certainty, of multiple possible explanations that could make sense. This trend of seeking out lived experiences to model their own expectations after serves as the starting point for the next two emotional tensions we identified. While **Tension 1** centered around dealing with surprise and figuring out how to connect data to outcomes in a way that makes sense, the second tension we found that drove discussion in the community related to users’ dilemmas regarding whether data warrants feeling hopeful or not.

### 4.3 Tension 2: Learning How to Invest Your Hope

Hope drives infertility experiences in these communities. As users repeatedly describe, the time, effort, and resources they continuously invest in their treatment is ultimately working towards their family planning goals. Their tracking efforts, doctors’ appointments, and other efforts are all for a chance to glimpse the possibility of having a child. Feeling hopeful drives these self-trackers’ persistence and determination, in addition to serving as an important lens through which their self-tracking data becomes meaningful. Hope is described in this community as sparking positive feelings, like joy and comfort.

However, hope is also dangerous. While it can be a source of strength for community members, they simultaneously explain feeling hopeful as opening themselves to greater disappointment and heartbreak. This paradox results from the fact that the stakes of self-tracking data are especially high for this community; beyond curiosity or learning more about themselves, self-tracking data in an infertility context offers access to future family planning goals and success. How data is interpreted is imagined to make or break the possibility of having a child.

As result, members of these communities often discuss the “*emotional rollercoaster*”, the soaring highs and crushing lows of self-trackers’ reactions to their data. As these users describe, hope is always fragile. Data that seems like cause for hope is always at risk of turning negative as time passes and more information is accumulated. In one example, **User 61b** recounts how repeated self-tracking with just one tool, home pregnancy tests, led to them experiencing a range of emotions when making sense of their data.

**User 61b:** “TW: Loss

*Still new to all this TTC [Trying To Conceive] stuff, but I never anticipated I’d be as sad as I am about going through a CP [Chemical Pregnancy]. Sure, it was only positive for a few days, but the sheer \*desperation\* of holding and testing, holding and testing, just to watch that pink line fade and eventually disappear.... I didn’t tell DH [Dear Husband] about the positive tests bc his birthday is soon and it would have been such a sweet gift. So I had to just tell him that they were positive, and now they’re not ... this is a major disappointment.” (r/TryingForABaby)*

Here, **User 61b** is describing how they came to find out that they experienced a chemical pregnancy (a pregnancy that ends in very early miscarriage and is only detectable through hormone levels, like those shown on home pregnancy tests). Initially, **User 61b** was excited and hopeful about their home testing results. But, they describe “*the sheer \*desperation\**” of repeatedly using

home pregnancy tests over time with each one being a less positive result than the prior. As they describe, this loss is particularly upsetting because they were initially hopeful and optimistic. They “*never anticipated*” feeling this upset about misleading positive results. Additionally, they are especially upset because of how they anticipate these results influencing their spouse’s emotions.

As is standard for respondents, **User 61c** recognizes the emotional intensity of this situation for people in these communities:

**User 61c:** “*So sorry for your loss. Once that line shows up our world changes. It doesn’t matter how long that line stays. I totally understand.*” (r/TryingForABaby)

**User 61c**’s reply captures the sentiment that part of the challenge comes not just from signs of failure or success, but that having a beacon of hope, “*that little pink line*”, and then losing it is even more devastating than negative results alone. As **User 61c** describe, “*Once that second line shows up, our world changes, doesn’t matter how long that line stays*”. **User 61c** shares the wider community’s experiences with the highs and lows of self-tracking during infertility to support what **User 61b** is going through.

As **User 61b** and **User 61c**’s discussion demonstrates, hope is risky. Users invest considerable emotional energy for glimmers of positive results. When these are followed by negative results, the letdown can feel worse than disappointment by itself. Self-tracking data can be frustrating and feel unhelpful. Despite this, users repeatedly describe cycles of re-engaging with self-tracking and feeling hopeful again, even with repeated disappointments. In this example, **User 13b** describes how the pressures they feel to continue using their self-tracking data, and the hope it provides, can also be emotionally harmful:

**User 13b:** “*11dpo and a bfn [Big Fat Negative]. Troll [chart](https://www.fertilityfriend.com/home/...) my chart had me feeling hopeful after I temped this morning, then a whitest of white FRER [home pregnancy test] made it all feel like a cruel joke. ... I was so excited to fully throw myself back into tracking and move forward ... I had hoped to be pregnant again by the time my would-have-been due date rolls around in October...I never really thought that I wouldn’t be, to be honest. But now I’m afraid there will be a double sting of loss while still doing TTC when that day comes.*” (r/TryingForABaby)

As is common in these communities, **User 13b** is sharing how their self-tracking made them feel, with an emphasis on their negative feelings and doubts. **User 13b** described their initial hopefulness being dashed by the “*whitest of white*” negative result from their home pregnancy test. Further, they acknowledge that paying close attention to every potentially meaningful sensation (which they commonly refer to as “*symptom spotting*”) does not always reduce their uncertainty. As they remark, “*everything can be explained away with another reason*”, but they still feel a small sense of control and certainty just by tracking and knowing, even if the results are disappointing. They conclude their sentiment with a reference to the fear of intensified negative feelings after being initially hopeful, the “*double sting of loss*”.

Users repeatedly describe how self-tracking can often amplify negative emotions and make them feel worse, while simultaneously feeling pressured to continue because of the degree of verification and control it offers them. In **User 13b**’s case, this highly involved tracking, even when recognized as unhelpful, is used as a verification metric that the data was actually meaningless. In other words, as is described here, losing can feel “*like a cruel joke*” when expectations are dashed.

In balancing this desire for control, certainty, and justified hopefulness with the inherent unpredictability underlying attempts to conceive, users rely on the input and emotional reassurance of respondents to determine what aspects of their self-data are *worth* being hopeful about. During

this collective sense-making and emotional management work, users repeatedly use the phrase “*hope fortress*” to describe the cycles of hope that dominate their infertility experiences.

**4.3.1 The Hope Fortress Metaphor.** Users in these communities use the phrase “*hope fortress*” to describe the self-tracking data they have accumulated that supports (or weakens) their ability to feel hopeful about their treatment outcomes, and summarize all the intersecting factors influencing how they feel about their current treatment status. Hope fortresses are described almost exclusively in the possessive first person, such as “*my hope fortress*”.

To this end, users typically discuss their personal, individual hope fortresses in terms of *how strong* they are and *why* they are strong or not. A strong, sturdy, or resilient hope fortress is one in which the owner has a lot of reasons to feel optimistic about their conception odds, such as self-tracking results that indicate pregnancy or positive feedback from their healthcare professional. Meanwhile, a weak hope fortress is one that is being damaged by unfavorable evidence, such as self-tracking data that suggests low chances of conceiving.

Expanding on these discussions of strength, it is also common to describe the hope fortress using characteristics of actual buildings or fortresses. For example, their ability to protect their hope from invaders (in this case, the invaders being disappointing self-tracking data). Sometimes, when community members share disappointing results, they will change “*fortress*” to another, weaker kind of structure, for instance, a “*hope tent*” and a “*hope lean-to*” to emphasize their fragility and transience as disconfirming evidence accumulates.

The hope fortress metaphor is valuable because it serves as a reflection of how community members experience hope during their day-to-day conception efforts. Like hope itself, community members recognize that their hope fortresses are temporary. While they are built piece by piece through interpreting self-tracking data as encouraging and other positive outcomes, every failed treatment cycle leads to a leveling and rebuilding of their hope fortress. The emotional highs and lows of hopefulness are understood and shared through describing hope fortresses as being built up or collapsing. Community members build up their hope fortress at the intersection of their personal data and the support they receive from the community about how to feel about it, as the following exchange between **User 120a** and **User 120b** shows:

**User 120a:** “10DPO[days post ovulation] (<https://fertilityfriend.com/home/...>), and I have declared my hope fortress as my permanent address.” (r/TryingForABaby)

**User 120b:** “Wow, your temp rise is so much more solid than mine! That is a really great chart you have got there!” (r/TryingForABaby)

Here, **User 120a** is sharing their Fertility Friend chart. Fertility Friend is a popular online tool commonly referenced by community members that allows users to input their self-tracking data, which the system then uses to generate potentially useful predictions for ovulation dates and other relevant metrics of success. **User 120a** indicated that the results are promising and would like to make their hope fortress their “*permanent address*”. Discussions of hope fortresses often directly or indirectly acknowledge that being in a hopeful place is fickle and can be taken away at any moment, when new, contradictory data is discovered or collected. This comment captures the community recognition that hope is desirable, but also temporary and often painful in the long run; as a result, they want to permanently inhabit this brief time period of optimism.

**User 120b** replies to compliment their chart. **User 120b** also interprets that chart as meriting feeling hopeful, thus supporting **User 120a**’s hope fortress. Characteristic of these affirmations, this reply also compares the data in the chart to their own data by saying that their “*temp rise is so much more solid*” than theirs. As their dialogue continues, **User 120a** again directly highlights how inhabiting a hope fortress can be a double-edged sword:

**User 120a:** *"Thanks! I'm considering framing it. It's the prettiest chart I've ever had. I'm letting it mess with my head waaaaay too much."* (r/infertility)

**User 120b:** *"Haha, frame it! Later your can embarrass your child by pointing at the line and saying: look, that's you!"* (r/infertility)

**User 120b** is encouraging **User 120a**, despite their fear and uncertainty, to frame their FF chart like they had playfully suggested so they can show it to their future child. Here, **User 120b** is literally translating **User 120a**'s data into their hopes for the future, a future where they would have a child and could look back on this data and say: *"look, that's you!"* Without discounting the risks and uncertainties of being hopeful, **User 120b** reminds **User 120a** to not be afraid to focus on the success every member of the community is working towards.

As this example demonstrates, much of the value of this social support comes from the fact that, in this community, hope is also a thing to be feared. But, support is virtually always encouraging and optimistic, even if the person seeking advice has doubts. **User 120b**'s responses reaffirm why, even though self-tracking can open oneself to disappointment, in the long run its worth it due to the positive future it allows those in treatment to hang on to.

These findings demonstrate that, just like body rhythms, community members describe rapt, dedicated attention to their emotional cycles' ebb and flow. The input they receive is diverse and centers on features of the body, test results, or personal experience, and serves to tweak the individual's emotional barometer of hopefulness because it draws their attention to certain data and perspectives to consider.

The "hope fortress" metaphor also captures the community recognition that hope is not just an emotion that appears; it is something that is cultivated piece by piece, data point by data point. Even when the actual data indicators themselves have not changed, what helps users get through is that they don't have to reassemble these hope fortresses by themselves. In these communities, the interpretative, supportive work done by other users serves as both a remedy for emotional struggles and a point of connection, empathy, and commonality. Despite the implications of hope for this community, they do not hesitate to critically engage with what their self-tracking data actually means, and how it could be having negative impacts on their infertility experience.

#### 4.4 Tension 3: Doubt, Guilt and Stopping Tracking

The third and final tension that drives discussion in these communities centers around individuals' decisions to persist with self-tracking. Due to the highly detailed and time sensitive nature of infertility self-tracking, users have to continuously make decisions about how much they want to track, what variables or metrics they choose to record, what technologies or tools they will use, and many other decisions. This work of self-tracking is impacted by users' emotional experiences with the data they have already gathered.

Repeatedly investing time and energy into tracking only to not reach their desired outcome, often after numerous attempts and years of trying, can lead to frustration, depression, and feelings of hopelessness. This is likely intensified by the reality that self-tracking in the infertility context involves a particularly high level of commitment. Community members describe tracking as a lot of work on top of the day-to-day demands of living with infertility<sup>1</sup>.

<sup>1</sup>It's important to note that tracking is one strategy towards success among many described by members of these communities. Other activities include interactions with medical institutions and receiving medical treatment, other lifestyle activities such as joining a support group, and seeking advice and support from social ties (like in these online communities). All of these activities are intended to work towards the same over-arching goal: conception, and making the journey towards that goal easier or possible at all. The main goal of community members experiencing infertility is not to create the most accurate database from their tracking; rather, tracking is useful insofar as it supports their overall infertility journey

As a result, when users face emotional and other challenges with their data, it raises the question *Is all this time and effort spent tracking really worth it?* For tensions surrounding quitting or reducing tracking, guilt, doubt, and other negative emotions drive users to seek support. This support seeking typically focuses on emotional hurdles with the practices that make tracking possible, issues with tracking technologies, and the emotions resulting from potentially malfunctioning or poorly functioning data analysis tool.

Community member **User 12a** shares their experience with these challenges while reaching out for support from the community for their new distaste for self-tracking:

**User 12a:** *"I seem to have developed an aversion to temping. It's right next to my bed, it's alarm is going off every morning and I just don't want to... I just don't want to get back into the TTC mental zone... My last cycle was incredibly difficult emotionally and that made me realise a lot about how I see myself and my value in the world. I think that my brain just doesn't want to go back there right now. ... ." (r/TryingForABaby)*

**User 12a** describes feeling apprehensive and discouraged about continuing to self-track this menstrual cycle. As they describe here, they were hoping to pick up the same tracking routine as their previous cycles. However, they were surprised to see that even though their usual *"alarm is going off every morning"* for taking their temperature, they *"just don't want to"*. They attribute this new reaction to how emotionally challenging their last cycle was. They describe how their last cycle was *"incredibly difficult emotionally"* and seems to have had a lasting impact on how they *"myself and my value in the world"*. They are attributing their apprehension to *"my brain just doesn't want to go back there"*. This comment exemplifies the anxiety and hardships users repeatedly share across these online communities. Users overwhelmingly share how, even more so than the amount of time or other resources involved with the necessary degree of self-tracking, the negative emotions they experienced during past cycles sparked desires to not track.

As **User 12a's** comment demonstrates, questioning the validity of tracking is common for community members. Reaching out for help with the thought *Should I not track anymore?* usually focuses on one of two driving concerns. The first concern is users describing feelings of guilt and regret when they consider stopping tracking or tracking less. The second concern is focused on the accuracy and usefulness of self-tracking technologies; perceived problems with the data itself can amplify the doubts raised from negative emotional experiences.

While guilt related infertility treatment goals have been found in other communities [51], the beliefs expressed in this community are more complicated. Commenters on [r/infertility](#) and [r/TryingForABaby](#), in addition to espousing the necessity and benefits from highly involved self-tracking, openly validate the emotional challenges individuals face with testing. Despite the pervasive narrative on the subreddits extolling the value of persistent testing, users in these communities actively encourage users to take breaks from testing as a panacea for their mental and emotional health, allowing them to return to their tracking and other efforts with new energy.

In the previously discussed quote, **User 12a** attributed their apprehension to start their daily routine of testing due to how emotionally difficult their testing experience was during their last cycle. When individuals like **User 12a** highlight the emotional barriers that make them want to stop testing completely, other users jump in to offer support for taking a break, such as **12d**:

**User 12d:** *"Sometimes it's nice to take a bit of a mental break or downtime. TTC is much more exhausting than it is made out to be sometimes." (r/TryingForABaby)*

**User 12d** is replying to **User 12a's** dilemma. They are suggesting that **User 12a** *"take a bit of a mental break or downtime"*. Here, **User 12d** is specifically acknowledging that attempts to conceive are often *"much more exhausting"* than initially anticipated. They are supporting **User**



**12a**'s discouragement by explicitly recognizing how the continuous cycles of tracking and other efforts take a toll.

**User 12d**'s reply demonstrates the tendency of community members to support taking a break from self-tracking in an effort to improve mental health and recover from how tiresome efforts to conceive are. Giving users explicit permission to take these breaks validates others' challenges and has been described as incredibly valuable by the community members receiving support; they remark that trying again after a rejuvenating break as being more positive experiences as compared to forcing themselves to keep going without rest.

This exchange also suggests a seemingly paradoxical effect of this type of support: social support to not always self-track supports self-tracking in the long run. In other words, getting support from other users, motivated by guilt about not participating in every possible potential tracking mechanism, helps people come to terms with the fact that it's okay to take a break sometimes. These breaks appear to help their stamina and emotional resilience to keep going in the future. These findings demonstrate that sustained use is possible even with breaks and that the social support of others supports these intermittent tracking plans.

But, despite this community support for taking breaks, the pressure and guilt to continue tracking still permeate community member's experiences. Individuals sharing their feelings about tracking acknowledge repeatedly going back-and-forth between the recognition that tracking less or not at all is okay, and the desire to feel informed and in control of their treatment progress. In dealing with these tensions, users often share their thought processes with the community in an exaggerated, humorous way. **User 12e**'s discussion of their struggle with reducing their amount of tracking practices demonstrates this tension:

**User 12e:** *"...I had told myself I'd take a month off from OPKs and temping ... so I could let my brain chill the fuck out. If I'm only peeing on ONE stick per day, that's way more chill, right??"* (r/TryingForABaby)

Here, **User 12e** is describing the promise they made to themselves and shared with the community about taking a break from close self-tracking and planning so their *"brain [could] chill the fuck out"*. Often, when community members decide to reduce their tracking activities in this manner, they will announce it to the community beforehand to support their self accountability. **User 12e** ends their comment by elaborating on the new tracking plan they've been trying: *"only peeing on ONE stick per day"* which they remark is *"way more chill"*. Comments about *"peeing on sticks"* refers to one of the most ubiquitous tracking activities, using home pregnancy tests. Users navigating the self-tracking journeys often describe having to resist the temptation to repeatedly use pregnancy tests, even when they recognize that it's too early or otherwise not particularly useful to use them at that point in time. They openly identify this tension as silly but a point of connection across many users in the community. User replies to this comment empathize with the tension by jokingly agreeing with the *"way more chill"* sentiment and sharing their own tracking dilemmas and struggles with trying to *"chill the fuck out"*.

The second factor that drives emotional challenges of self-tracking is when tracking technology produces data visualizations and/or predictions that don't align with people's own bodily experiences or existing knowledge. Even when community members are confident in their own internal experiences and conclusions, the aggregation work of self-tracking technologies can make them doubt themselves and send them into an emotional tailspin. In one example, **User 120c** describes the online tracking tool Fertility Friend as producing confusing, illogical *"crosshairs"*, slang for their predicted date of ovulation:

**User 120c:** *"I think FF is drunk and should go home. (<https://www.fertilityfriend.com/home/...>) I seriously thought that I ovulated early ... but then FF wasn't giving me crosshairs all*



*week. And now it thinks my cycle will be 28 days?? Sorry, FF, but my cycle hasn't been that long in ages. Am I the crazy one or is FF just going with what little information I have put in for this cycle?"* (r/TryingForABaby)

**User 120c** begins their comment with an immediate critique of Fertility Friend's logic and accuracy, describing the platform as "*drunk*". Then, they bring up how FF has made them doubt their own experience. **User 120c** remarks that they "*seriously thought*" they had already ovulated. But, FF contradicted this by not giving them "*crosshairs*" for this week, which they thought it should have if they had actually ovulated. This user expresses further doubt in FF by remarking how the software is predicting that their cycle will be 28 days, despite in their experience, it not having "*been that long in ages*".

Despite this evidence they have accumulated to justify their doubt in FF's predictions, they are still unsure whether they are "*the crazy one*" or if FF is inaccurate because they did not self-track as much this cycle. This disconnect created distress and uncertainty for this user. As this example demonstrates, when technology creates doubt between lived experiences and anticipated treatment outcomes, users seek out the support of the community.

These findings demonstrate the tension between the benefits of using self-tracking tools and the feelings of doubt, guilt, and stress they can amplify for users. But even when users doubt the accuracy of self-tracking tools, they recognize other ways they can be useful, such as a verification mechanism or as a way to share their general frustrations with empathetic community members. When data predictions appear confusing or illogical, community members work together to make sense of them. These findings demonstrate that even when users explicitly recognize information as not reflecting reality accurately or completely, it does not necessarily suggest that they'll stop tracking altogether. Rather, they reorient their tracking goals towards creating new explanations and finding emotional support.

**4.4.1 Limitations.** One limitation of our approach is that we cannot draw conclusions about actual behavior. Our data consists entirely of text-based discussion. As a result, our conclusions must be grounded in what we can infer from these discussions. We cannot draw any conclusions about actual behavior; however, we can use the processes outlined in these discussions to spark future work about potentially influential factors in other self-tracking contexts and face-to-face encounters.

Another limitation of our inquiry is the influence of moderation on these online discussions. Subreddits on Reddit.com have volunteer moderators, often passionate and highly active community members themselves, who create, revise, and enforce forum rules. Existing evidence suggests this moderation influences the social norms of communities including what users post about [18, 42]. While it is difficult to say what effect these overarching influences may have on what people post are difficult to determine, we did actively consider the role of moderation in our analysis by coding for moderation activity, such as deleted text labelled as deleted by moderator. In the entire course of analysis, we did not come across any explicit example of moderator influence the course of community discussions.

## 5 DISCUSSION

Self-tracking technologies are one tool among many that can support individuals' goals. It is important to recognize that the core, driving motivator of these community members is probably not to create self-tracking data; rather, that self-tracking data becomes a stepping stone towards becoming pregnant. In other words, self-tracking is a starting point for r/infertility and r/TryingForABaby members to communicate about the highly personal, individual emotional experiences that accompany their infertility experiences. Even when self-tracking creates new stress and confusion, the shared emotional experience of self-tracking connects community members.

These findings enrich our understanding of what factors influence the emotional experience of personal informatics tools in several ways.

The first major finding, that individuals seek out the data experiences of others in order to *better understand the details of their own surprising experiences*, demonstrates how talking about their data with others can provide benefits beyond clearly defined information goals. Seeking information resources for health concerns in online communities is a common motivator for people [36, 43, 93]. However, existing evidence in the context of self-tracking and information-seeking has been focused around people's search for facts and ideas (like a new way to talk to your doctor or a research article to read) [19, 36] rather than focusing on how they are impacted by the rich details of others' internal, emotional experiences. When facing uncertainty, these community members seek out the detailed firsthand experiences of others to imagine new possibilities and broaden their perspective of possible outcomes rather than absolute solutions.

A richer understanding of how users find value in the experiences of others beyond just similar, directly applicable experiences and knowledge can inform future design approaches. For example, existing technologies for connecting self-tracking users describe using connection criteria based on similarities [49]. But, users in our study appeared to find the most value in how the details of their experiences differed from others and the consequences of these differences on the outcome they care about. Systems for making these connections should also consider connecting users that *differ* on variables of interest. Perhaps users could search for others whose personal data fall within certain ranges or within certain contextual factors so they can connect with others based on the degree of difference/similarity they are comfortable with or most interested in.

Self-tracking systems not being flexible and individualized enough for all the kinds of data people think is actually relevant to record is a common complaint [29, 76, 91]. Design suggestions to make these technologies more personalized and customizable [76] have mostly focused on the relationship between the individual and the interface. However, our findings suggest that facilitating ties with other people in the interface could support this personalization work. For example, people sought out the experiences of others to better understand and articulate what phenomena they were experiencing, including emotions. If the actual tracking app let users describe a symptom(s) or feeling(s), share it with others, and then develop their own tracking metrics or variables based also on the details others have shared that resonate with them, users would benefit from more accurate data recording and social support.

Additionally, the finding that users progress through three stages when sharing their data experiences with the community (initiating connection, identifying similar narratives, generating plausible explanations) expands upon existing models of self-reflection and sense-making [71] by demonstrating how collective sense-making reflects the process imagined in individuals. Seeking out support is triggered by surprise or uncertainty, just as in existing models of what triggers the initial stages of sense-making [4, 25, 81, 86]. But rather than just sharing after they have everything figured out, *thinking about* and *socializing about* their data appear to operate in tandem to allow users to reach their goals.

Next, the findings related to tensions surrounding hope demonstrate that the role of motivation and optimism is more complex than just serving as a positive predictor of sustained self-tracking engagement. These findings demonstrate that hope, can also increase users' distress and depression. The emotional repercussions of feeling hopeful makes hope something that is risky and always at risk of collapse. These findings challenge existing narratives suggesting that sustained motivation and related experiences like optimism [41] are the key to sustained tracking and positive tracking outcomes. While hope has been recognized as potentially damaging [34, 35], we argue that our study innovates by examining *how users make decisions about hope socially* and what *described impact this has on their own self-tracking experiences*. Incorporating systems that validate and support

feelings of hopelessness and feeling unmotivated warrant further investigation for their potential to better support tracking habit-formation and interest. In particular, incorporating features that allow people to connect with others to receive validation and support for the feelings of guilt and failure that often accompany thoughts of non-use may be a valuable approach.

Additionally, in this community, tracking exists outside the binary of use vs. non-use [11]. The degree at which tracking takes place, what devices are used, and when they are used varies widely across individual circumstances over time, with an apparent influence of emotional state on whether tracking happens or not. Further investigation in to what specific types of emotional experiences spark what types of fluctuations in tracking rate could inform the design of future tracking support technologies.

The findings related to doubting the validity and efficacy of self-tracking altogether also expand on existing calls for more transparency [27, 33, 37, 49] represented in aggregate data predictions. Users repeatedly described the stress and doubt sparked by predictions based on their personal data that they could not logically connect to the *why* of the prediction. While it is widely recognized that infertility technologies specifically are not particularly accurate predictors and often fail at helping people plan pregnancy [27, 37], we argue that our findings demonstrate the importance of data *feeling* accurate to the individual in how people use the data. Transparency and clear visualizations centered around individuals' specific treatment goals are important for tracking success [33, 76]. But how does the value of transparency intersect with the emotional experiences of participants? Tools to adjust the mode and level of transparency afforded to an individual based on their emotional state or the stage of their treatment could potentially better meet the needs of users while minimizing exposure to unwanted, irrelevant information.

Finally, these findings reveal that data accuracy, a positive predictor of user engagement with self-tracking technology [1, 39, 90], was only one of many factors that appeared to influence user engagement with their self-tracking data. Users openly criticized how Fertility Friend and other technologies represented their experiences and bodies. But, users still described motivation to use and trust these technologies because of the emotional reassurance they provided. Additionally, the frustrations of using these tools reflected their frustrations with the experience of infertility generally, offering a point of connection and commiseration with community members. These findings demonstrate the value of further considering how even data perceived as inaccurate can still be meaningful and motivational to users. Understanding why people abandon self-tracking tools so often [5] could be supported by examining these other potential motivators, including emotions surrounding humor, frustration, and empathy.

## 6 CONCLUSION

With the proliferation of self-monitoring technologies, people have easy access to record details of their day-to-day thoughts, behaviors, and experiences. But, the complex, highly personal nature of these tools can create new challenges with data interpretation, sharing the data with others, and using the data effectively to achieve personal goals. Emerging evidence suggests that personal sensations that are *emotional* in nature influence how people understand their data both by themselves and in tandem with others. To better understand the role of emotional reactions to data in data sharing and collective sense-making, we examined discussions centered on self-tracking in two online communities on Reddit.com. We found three major emotional tensions drove community discussion of self-tracking. When users were faced with uncertainty and other negative feelings, they grounded their sense-making efforts in the perspectives and experiences of other community members. Even when adverse feelings were generated by the self-tracking itself, these negative emotions became a catalyst for communication, commiseration, and intellectual exploration that supported individual's decision-making about using and collecting their data.

Whether self-tracking technologies support their users or not has consequences beyond just being useful or not. How these technologies represent the personal data they collect can have life-or-death consequences for users, ranging from physical to mental health outcomes. Emotions color our experience of the world around us, and this holds true for self-tracking. Feeling good or bad about these data outcomes can better support positive outcomes or damage self-esteem and tracking motivation altogether. Whether self-tracking tools serve as beacons of hope or catalysts for despair is determined in large part by the connections they can facilitate with supportive social ties. Scholars and designers in CSCW can better support self-tracking technology users by continuing to understand how emotional reactions to data mediate the role data plays in people's lives.

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## A APPENDIX

### A.1 Table 1

<i>AF</i>	Aunt Flo	Slang for a period; AF arriving indicates that an individual has not gotten pregnant during that menstrual cycle
<i>BFN</i>	Big Fat Negative	Slang that refers to a negative result on a home pregnancy test
<i>CP</i>	Chemical Pregnancy	A type of miscarriage. An individual becomes pregnant, but loses the pregnancy so soon afterwards that it is difficult to detect the pregnancy at all except on hormone tests
<i>DH</i>	Dear Husband	Slang used to refer to the partner of the individual attempting to get pregnant
<i>DPO</i>	Days Past Ovulation	The number of days since ovulation used to identify when a possible pregnancy may show up on a pregnancy test
<i>FF</i>	Fertility Friend	Software used to chart a user's menstrual cycle. Users input their symptoms, test results, and other measurements. Makes predictions about fertility and ovulation.
<i>FRER</i>	First Response Early Result	A commonly used brand of home pregnancy test often considered to be more expensive and accurate than other brands or types of tests
<i>MC</i>	Miscarriage	Any time an individual becomes pregnant but due to various factors loses the pregnancy.
<i>OPK</i>	Ovulation Prediction Kit	Often paper strips that are urinated on. These give users an indication of hormone levels that can help them determine when they are ovulating
<i>PMS</i>	Pre-Menstrual Syndrome	A cluster of emotional and physical symptoms that occur one to two weeks before an individual's period whose presence or intensity are used to speculate about pregnancy.
	Temp Drop	FitBit style wearable that measures body temperature
<i>TTC</i>	Trying to Conceive	Slang referring to anyone who is trying to become pregnant, whether or not they are experiencing medical infertility
<i>TW</i>	Trigger Warning	Slang used to inform readers that the content they are about to say may contain upsetting and/or traumatic information

Table 1. The communities studied here employ frequent use of slang, acronyms and medical terminology. Quotes are provided as originally written; we define a number of the more common acronyms here to aid in interpreting the quotes. During our analysis, we built a much larger dictionary of acronyms and medical terms to help us understand the conversations.

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