

Patient Data Work with Consumer Self-Tracking: Exploring Affective and Temporal Dimensions in Chronic Self-Care

Tariq Osman Andersen¹, Jonas Fritsch², and Stina Matthiesen¹

¹ Dept. of Computer Science, University of Copenhagen, Denmark

² Digital Design, IT University of Copenhagen, Denmark

tariq@di.ku.dk

Abstract. Emerging studies are reporting on the implications of self-tracked data in patients' everyday life and how it influences self-care activities in chronic care. The increased uptake of consumer wearable activity trackers in healthcare contexts and the wider application of advanced analytics is changing the temporal scope from 'past-centric' to 'future-centric' personal informatics. At the same time, a stream of research is making clear that experiences of emotion are constitutive of patient data work suggesting that the micro practices of engaging with personal data has an important affective dimension. We conducted an exploratory interview study with five chronic heart patients with an implanted cardiac device to conceptualize the data work, which is involved in making sense of self-tracked data from a consumer wearable activity tracker (Fitbit Alta HR). In this paper, we contribute to understanding patient data work as seven forms of micro practices: Verifying, Questioning, Motivating, Reacting, Accepting, Distancing, and Sharing. We discuss how these practices relate to temporal and affective dimensions of engaging with self-tracked data in chronic care and point to future research.

Keywords: Self-tracking, self-care, wearable activity trackers, personal informatics, affective computing

1 Introduction

Self-care technologies in chronic care have traditionally been regarded as tools for supporting disease-related matters [1]. However, during the last two decades there has been a boom in consumer self-tracking devices, originally designed for sport, leisure, and wellness. These wearable and mobile devices are increasingly becoming part of patients' self-management practices and the line between the realms of medicalized self-care technologies and consumer self-tracking technologies is gradually being blurred [2, 3]. Along with this pervasive access to consumer health applications and wearable activity trackers, the work of *producing, gathering, interpreting* and *using*

health data is no longer a job solely upheld by healthcare professionals. Instead, individuals with chronic conditions can engage in various forms of patient health data management practices, which has been broadly described as “patient data work” [4, 5].

Outside the medical contexts, engagements with personal information and self-tracking data have been conceptualised into different stages including activities of *preparation, collection, integration, reflection* and *action*. Studies under the term “personal informatics” have given shape to a long-standing discourse and multiple contributions to understanding how people engage with new types of digital devices that allow for collection of multiple forms of personal data [6]. Moreover, studies of using wearable activity trackers in clinical care contexts have been studied in health informatics [7], often with a focus on acceptability and effect in clinical encounters like using Fitbit in cancer or cardiac care or self-tracking among patients with co-morbidity [2, 8, 9]. In Human Computer Interaction (HCI), studies have examined how participants used self-tracking technologies as intertwined with self-care practices for disease monitoring and fitness tracking in chronic care [3, 10, 11].

More recently, two streams of research have appeared, which give rise to new questions: one stream examines emotion and affect during patients’ data intensive practices [12–14]. For example, it is known that patients’ experiences in diabetes self-care practices have an important affective dimension, and that patients and relatives are bound to the emotional struggle moving between control, freedom, and anxiety [13]. Another stream of research, which is concerned with future-oriented personal informatics in health contexts [15–17], has started to examine the opportunities and implications of artificial intelligence and advanced analytics in the space of self-tracking and self-care. For example, one study found that supporting “anticipation” and engaging in prospective and proactive approaches to tracking can provide new opportunities for design, which is somehow an extension to the withstanding focus on supporting reflection on historic data.

With this paper, we wish to explore two questions that cut across these newer streams of research and connect with earlier studies of self-tracking by seeking to conceptualise the micro practices that emerge when chronic heart patients are exposed to consumer wearable activity data with a Fitbit device.

- *What forms of patient data work do chronic heart patients engage in during self-care activities when using a consumer wearable activity tracker?*
- *What are the temporal and affective dimensions of patients’ self-tracking and self-care activities?*

We conducted a qualitative interview study with five participants who all have chronic heart disease and an implanted cardiac defibrillator (ICD) which is remotely monitored at the Rigshospitalet, Copenhagen University Hospital, Denmark. The study is an extension of a previous study where 27 chronic heart patients were invited to use a Fitbit consumer device for 3-12 months and were interviewed about their experiences of self-tracking during self-care.

2 Background

2.1 Self-Tracking with Consumer Wearable Technologies in Everyday Chronic Care

People living with chronic conditions engage in self-care activities to manage their disease as part of everyday life [1]. Some activities are an extension to the medicalized part of their treatment, such as the day-to-day management of prescribed medication and self-monitoring of symptoms as well as using medical grade equipment like blood glucose monitors or home telemonitoring equipment to manage the disease [1, 18]. Other self-care activities are related more to the mundane character of living with a chronic condition such as responding to the psychological and emotional impact of the disease and undertaking lifestyle changes as well as getting support from informal caregivers, searching for information, or communicating with other patients with similar diseases.

Prior research in health informatics has investigated the experiences of patients when engaging in self-tracking using consumer wearable activity trackers and smartphone applications in chronic care contexts [7, 9, 19–21]. Several studies have considered acceptability and adoption in medical care, for example research on the acceptability and attitudes towards integrating fitness tracking with a Fitbit device into clinical care of men with prostate cancer [9]. Other research examined the use of self-tracking among patients with multiple chronic illnesses and found that there are multiple purposes for tracking and that some patients consider it as work to track their own data [8]. Research also considered the implications of sharing “patient-generated” data in different types of patient-clinician interactions [20] suggesting that data produced and collected by patients, including activity and biomedical data from consumer wearables, becomes health data when used as part of the formal and the informal disease management. More recently, a study found that the effects of self-tracking with a consumer wearable device (Fitbit) in chronic care constituted ambivalent experiences i.e., both negative and positive experiences such as gaining new insights from data in one moment and data evoking doubts in another moment [2].

In HCI, studies of self-tracking have united around the term personal informatics and have focused on systems that support data intensive practices like collection and reflection upon self-tracked data [6, 22]. Early studies were mostly oriented towards the “quantified self” and domains of general health, fitness, and behaviour change i.e., non-medicalized contexts [22]. Today, HCI studies are increasingly exploring the role of self-tracked data in more medicalized contexts such as diabetes [10], irritable bowel syndrome [11], and multiple sclerosis [3] where findings include unpacking of how participants used self-tracking technologies as intertwined with self-care practices for disease monitoring and fitness tracking.

Self-reflection or just “reflection” on self-tracked data has been a prominent theme and it has been argued that designing for reflection is just as important as designing for “experience” through interaction [23]. For example, there can be different purposes of reflection such as learning, prompting action, and self-development and there are different levels of reflection such as descriptive (i.e., revisiting events), explanatory, and

transformative (i.e., a fundamental change in understanding which might ultimately lead to a change in practice). The idea of designing for reflection on self-tracked data suggests an orientation towards the past and historic moments of data collected less than a future-oriented one. However, the advent of artificial intelligence and advanced analytics has pushed the perspective in HCI and personal informatics from a mostly historically oriented perspective in self-tracking towards a more future-oriented perspective.

Emerging studies have started to explore future-centric personal informatics whereby self-tracking data are turned into prognostics and personalized predictions. Lee and others [15] explore the differences between what they call ‘past-centric’ and ‘future-centric’ and found opportunities for stress management when supporting individuals’ anticipation and engaging in prospective and proactive approaches to tracking. Similarly, Rho et al. [17] conducted an experiment on supporting people with predictive information to lose weight and found that future-oriented ‘consequence information’ had a more positive impact than traditional ‘performance information’ when self-tracking for weight loss. Others have explored opportunities in chronic self-care and experimented with personalized predictions to generate nutrition-driven, and real-time forecasts of blood glucose levels to support decision-making among diabetes type 2 patients. Desai et al. [16] developed a smartphone app called GlucOracle and evaluated its feasibility for facilitating nutritional decision-making and found that technologically savvy individuals with well-managed blood-glucose experienced forecasts to be unsurprising and rarely prompting action while individuals with limited health technology experience and knowledge of diabetes self-management found predictions to be insightful and encourage concrete changes in diet and blood glucose management. These recent studies provide a different take on self-tracked data in healthcare contexts and foreground a temporal perspective on data work as well as emphasizing the need to explore the prognostic role which consumer wearable data may have for chronic patients.

2.2 Emotion and Affect in Design of Self-Care Technologies and HCI

When looking across studies of patients’ engagement with self-tracking technologies there is a growing body of literature that has turned to investigate the role of affect and the emotional implications of patient data work [4, 5, 24, 25]. Research has investigated patients’ emotional experiences around self-monitoring, for example the ways in which blood glucose data collected by patients with diabetes and their caretakers is tightly bound to the emotional struggle moving between control, freedom, peace of mind and anxiety, and the burden of dealing with technology [13]. Similarly, it is found that data tracking for fertility self-monitoring promotes the achievement of certain positive goals but may accentuate negative emotions such as feeling burdened or abandoned [12]. Others have studied patient experiences in cardiac device telemonitoring and found that not having access to data or feedback from clinicians can create anxiety and the feeling of uncertainty as well as emotional and life-changing impact, which in turn creates doubt, guilt, and concern [26]. Positive and negative affect can therefore co-exist and

become present as emotional ambivalence, which studies have found in healthcare contexts and among quantified self-enthusiasts [2, 25, 27, 28]. Conflicting or ambivalent experiences appear constitutive of self-tracking including affective responses like “doubt, guilt, fear, shame, dismay, disappointment, and hesitation as well as joy, relief, excitement, enthusiasm, and pride” [28].

Research into emotion in HCI research is, however, not new. In particular, the notion of affect has played a prominent role in HCI and design since Picard’s pioneering work on Affective Computing [29]. Initially, it was argued that Affective Computing would be “computing that relates to, arises from, or deliberately influences emotion or other affective phenomena” (ibid.). Nonetheless, the main agenda of Affective Computing has been formulated as making computers recognize or express emotions [30, 31]. This has led to critique within HCI and interaction design where it has been argued that this definition of emotion as a kind of transferable “information” is reductionist and does not fully encompass the complexity of the human emotional experience [31]. Instead, it was argued that an “interactional” approach to affect that lets people reflect on their emotional richness was needed [32]. Within this interactional approach, Höök has suggested the term ‘affective loop’ pointing to the way that affect and emotion can emerge and be supported through interactions with technology and data involving both body and mind [33]. Lately, the concept of “affective health” has been coined by Sanches et al. [14], to encompass the stream of HCI studies related to affective disorders such as depression, anxiety, and bipolar health issues. In this paper, we follow this turn towards continued engagement with affective interactions and the role of emotions as interactive properties of technology design [34]. We further advance recent research that points to a holistic and encompassing engagement with how affective interactions on a micro-level can lead to relational changes on a macro-level [35]. Here, affect is conceptualised as constitutive for human experience, and not only in affective disorders. We built on this approach to explore affective dimensions of self-tracking technologies that come to have an intimate role in e.g., chronic self-care. We also consider the temporal i.e., historic versus future-oriented engagement with self-tracked data to explore the implications of patient data work in a time where application of predictive analytics is emerging.

3 Study Design and Method

This study explores patient data work and the micro practices chronic heart patients engage in with various information sources including but not limited to their bodily sensations, communication with health professionals, and wearable activity data using a Fitbit Alta HR device. The study is an extension of a former study where 27 ICD patients were invited to use a Fitbit wearable activity tracker for 3-12 months and share their experiences through three semi-structured interviews [2]. Five patients were recruited from the original study and the selection was carried out using purposive sampling. Our criteria for inclusion were based on having a mix of participants who had different illness severities and diverse uses and experiences of the Fitbit device. The

original study received formal ethical approval by the Capital Region of Denmark's Committee for Health Research Ethics (no. H-19029475) and patients provided informed consent and were carefully instructed about their participation in the extension of the project, which had no intervention component. Five semi-structured interviews were conducted using an interview guide with four themes, which revolved around the patients' day-to-day prognostic (i.e., future-oriented) work and their use of activity data, their emotional labor, and their informational needs. In addition, the study added speculative considerations of the usefulness of predictions based on artificial intelligence of severe heart arrhythmia in a smartphone app. Two interviews were carried out in-person and three interviews were carried out over Zoom due to Covid-19. The duration of the interviews was between 43 minutes and 131 minutes. All interviews were transcribed verbatim. Data analysis was carried out collaboratively using an inductive qualitative approach based on constructing grounded theory [36] supported by the qualitative data analysis software NVivo 12 (QSR International, Melbourne, Australia).

4 Findings: Patient Data Work

We identified seven forms of patient data work that describe the micro practices that participants engaged in by relating their lived, bodily experiences with consumer self-tracking data. We explored how these data work practices were characterised by having an emotional dimension as well as a temporal dimension ranging from the here and now (situational) to the reflective (historic) and prospective (future-oriented).

4.1 Verifying

The most prevalent patient data work practice with Fitbit was verifying bodily felt symptoms. Several of the participants reported how they began using heart rate data and activity data to confirm or check for the alignment with their heart related symptom experiences. All the participants explained how they had already developed a sensitivity towards particular bodily sensations for recognizing emergent severe heart arrhythmia. Previous experiences had taught them how certain symptoms were anticipatory of upcoming events and how these symptoms functioned as cues for taking action. P4 explained that when he experienced severe "chest cramps" he knew "automatically" that severe heart arrhythmia was underway, and it is due time for calling an ambulance and P1 told several stories of how he learned that "dizziness" and "near fainting" were clear signs of severe arrhythmias: *"I'm 110% sure of VT [severe heart arrhythmia] because when I get the VTs I feel badly uncomfortable. I almost faint, they are very clear"*.

Despite having developed a form of bodily awareness about sensations and symptoms, several of the participants began to use wearable data during everyday situations to check their heart condition and thereby verifying their symptom experiences. One participant explained that severe heart arrhythmia can feel a bit different from time to time and that he has begun to use heart rate data to become more certain: *"I can see that the curve is even for a normal high heart rate - it is the same all the way. But the curve is, definitely, not even when you have VT. I use the watch to be absolutely sure"*

because it does not always feel the same” (P3). In this way, Fitbit data became a tool for verifying experiences of symptoms and bodily sensations “here and now” and supported a form of patient self-diagnosing. By keeping a personal log and using his smartwatch to verify bodily sensations of severe heart arrhythmia, P3 expressed how he had become more aware of emergent arrhythmia by turning to the combination of data and symptoms: “I am becoming more and more aware of it. I experience it every time I get confirmed when it shows that it is exactly as I have felt it [by combining Fitbit data and personal log data]”.

Similarly, P1 described how he used Fitbit to verify his symptoms of atrial fibrillation (AT), another type of severe heart arrhythmia: *“It is AT when the heart spins with a pulse from 110-140. This is the area where things start to get critical and then it is time. I’ve started to keep an eye on my pulse when I begin to sweat, and I can feel it on my breathing” (P1).* He gave an example of waking up in the middle of the night feeling uncomfortable, sweating, and having difficulties breathing, and explained how he turned to the Fitbit device to verify his symptom experiences: *“The times I have woken up with it at night, I could see from the intervals [in the Fitbit data] that I had been lying with a high pulse for a very long time.”* For him, the combination of symptom experiences and Fitbit data enabled him to verify bodily sensations but moreover supported his decision on what action to take: *“When I had those episodes during the night, I could knock them down with an extra beta blocker [prescribed heart medicine], right, and if the pulse does not calm down then I have to call 112 or 1813 [emergency telephone number].*

Like P4 and P1, P2 began to use Fitbit in relation to her heart condition. She developed a daily routine of checking in to see that everything is okay: *“(…) a couple of times a day I go in and check what my heart rhythm is, if it is higher” (P2).* Similarly, P2 also began to consult her heart rate data to confirm or disconfirm her symptom experiences: *“If I feel that my heart has been throbbing a little, I can go in and check to see, okay, is there anything behind this, or not.”* She explained how she used the wearable data to calm her when in doubt about her heart condition while being outside and on the go: *“At the same time it [FitBit] can also calm you. During a winter holiday in Thy I was out walking. We were four and two of them were walking really fast. I felt I could walk fast but I could feel that I could not keep up with this, but in reality, I could see on my app that I could do it without problems. So, in this way you could say that it calms you down” (P2).*

While alike in comparing symptoms and data for verification purposes, these examples point to quite different temporalities of use. The real-time verification of bodily felt symptoms was supportive in the situation, but moreover worked as cues for potential upcoming events by knowing what action to take. This is different from the retrospective verification work of P3, but both forms of verification were afforded by the data-body loop. Besides appropriating the use of the wellness-fitness tracker towards a disease diagnostic device, we also found that some participants used verification for providing reassurance and emotional comfort, which underlines the importance of the affective dimension of patient data work with consumer wearable data.

4.2 Questioning

Another type of patient data work that emerged was using self-tracking data to explore or seek answers to disease related questions. One participant, P1, described how he began to use Fitbit for exploring associations between behaviour change and his heart. He was concerned about exploring the effects that smoking may have on his severe heart arrhythmias. By experiment, he found that his average heart rate clearly decreased when no longer smoking: *“From the day I stopped and ten days onwards my average heart rate dropped by one per day”* (P1). From this active questioning along with his use of self-tracking, he reasoned that it was the “tangibility” of his heart rate data and the visualization that enabled his discovery: *“This tells me that smoking, along with several other factors, can push me to a place where I can get some abnormal and irregular heart rhythms. If I had not had this [Fitbit], then I wouldn’t have been able to get these answers. I could, perhaps, feel that I had gotten it a little better, but it is the tangible and visual, that makes it happen for me”* (P1).

Consumer self-tracking data can, in turn, generate prompts for new questions that lead to individual discoveries. Led by curiosity, some participants engaged in keeping track of their wearable activity data on a daily basis. One participant explained how she used Fitbit a couple of times a day to look for abnormal patterns. By actively questioning the relation between her behaviour, bodily sensations, and past experiences, she discovered that there may be a connection between increased heart rate and normal activity: *“I can see if the heart rate is in the red area, and I know that I have not been out for a walk then I think: “I need to be a little bit careful”. But, if I know I have been out for a long brisk walk, then there is an explanation, and everything is fine, and I won’t expect any events will come unannounced”* (P2).

Likewise, P1 discovered that just before arrhythmias occur, there is a traceable disconnect between not being active and data showing an abnormally high heart rate. This led to increased concerns and made P1 take action and contact the hospital: *“I think my heart rate was relatively high when I was in the normal range of activity, right? And that made me contact the hospital where I said: “we will have to get this under control: either there is something wrong with my medication, it does not work, or I would like to have a responsible doctor to take a closer look”* (P1).

In this way, participants engaged in micro practices of continuously exploring and reflecting upon self-tracking data to seek unanticipated discoveries or generate some form of answers to pertinent questions that may support their self-care practices. While the work of questioning typically has a retrospective orientation, patients may be affected emotionally in the situation of discovery and decide to take action. Moreover, the participants’ discoveries could turn in to patient knowledge that the participants would use for purposes of verifying bodily felt symptoms.

4.3 Motivating

Motivating relates to the ways in which the wearable activity data became integrated with exercising, which the participants, like most other people, considered as good for their heart and overall health condition. For some of the participants, engagement with

steps and heart rate data was linked to a desire to stay in control of their health condition and afforded positive affect. For P2 who had never experienced a shock from her ICD, the Fitbit data encouraged her to ensure that the activities she engaged in were good for her. She described how she was motivated to go from walking 10.000 to 15.000 steps and how FitBit had gradually motivated her to improve her exercise behavior: “[I]n the beginning it was just the steps and then it was like the steps and number of days in a week where I get enough exercise – and then it became interesting with that heart rate or need for sleep[...].” (P2).

Similarly, for P1, the visual cues of exercising more and improving behavior like eating healthier, decreasing stress or quitting smoking, motivated and provided reasons for changing his behavior: “These visual things they make me happy it seems that it’s actually working that you’re doing this. To me it’s reinforcing the situation you’re in, well okay it’s motivating to continue. Because when I feel better maybe I can do more. I can visually see the effects [...]” (P1). Just like verifying emergent symptoms with activity data became a routine activity, several participants explained how checking heart rate, number of steps, and stress levels was motivation for keeping a positive outlook and encouraged being more active: “I look at it every day. I can get all the information I want so yes, I use it a lot. It gives me all the information I really want. In relation to my number of steps, my heart and stress” (P5).

While some patients, like P4, did not find the data useful for motivating exercise due to inaccuracy of the data that “don’t make sense”, several of the participants used Fitbit and the self-tracking data as a motivational device, which in general supported positive affective loops such as feeling motivated or seeing that efforts led to positive health outcomes such as a lower average heart rate and thus, lower risk of heart arrhythmia.

4.4 Reacting

Reacting was another form of patient data work, which was triggered when patients were prompted with information about heart arrhythmia episodes or other information signifying certain changes in their heart condition. For example, P2 explained that one time she received a phone call from the ICD remote monitoring clinic where they told her that several severe heart episodes were detected. P2 reacted by looking into her calendar to understand the circumstances and the possible reasons for having the heart arrhythmia: “When the hospital called me and said you had an episode at that and that time then I went back to my calendar and found that it happened during a tough meeting at work, possibly when I was fired. So, there have been some pinpoints like that where I have had a mentally hard time. It’s my belief that when I’m under hard psychic pressure it can trigger heart fibrillation”. In this way, external prompts with clinical information spurs certain considerations that can involve reasoning between past events and possible cues for actions. For P2, being prompted with information about certain heart episodes, initiated reflections, and reasoning, which resulted in increased awareness about how psychic stress may induce problematic episodes.

Reacting became particularly present in conversations with participants about opportunities of forecasting the risk of future arrhythmic heart episodes using the wearable and implantable data. The participants engaged in speculating about what it would

mean to be notified and technology-prompted about increased risk of upcoming arrhythmic episodes. P3 considered being notified in due time would enable him to react and take appropriate action: *“Getting notified a few hours in advance would mean that I can react and do something”* (P3). Similarly, P2 speculated how a prompt with short-term prediction of upcoming arrhythmia could enable her to be in secure surroundings: *“Well, I would not drive a car and be behind the wheels. If I was in the danger zone for the next 48 hours, to get a shock, then I would make sure I was not alone but with someone who could help me”* (P2). P1 speculated that he would react by considering the forecast against his bodily feeling and take appropriate action, somehow reversely verifying the data induced forecast: *“I think I would hold such a risk forecast up against how I feel right now, to see if it might go in that direction”* (P1).

While some data work practices were mostly patient-initiated e.g. verifying and questioning, we found reacting to be a distinct type of activity, alluded by prompts with external informational cues and imposing upon the patient some form of actualization of the disease. Reacting to data-induced forecasts could – in best cases – support self-care by enabling the participants to take appropriate action, but the accompanied emotional labor could overshadow the opportunity and lead to a worsened situation.

4.5 Accepting

While wearable activity data and data from the participant’s implanted cardiac device could afford a positive outlook, we also found that coping with negative data could be seen as an active process of accepting. For some participants, accepting was integral to using self-tracking data and could set negative as well as positive affective loops in motion: *“If there are days where I have not moved enough. Then I got a bad conscience because then I kind of got reminded of it”* (P3). In this way biometrics and activity data are not “just” data that can lead to a bad consciousness. Instead, it is more pertinent what is at stake with inactivity for some chronic patients: *“Yes, but it is important to keep going. It is whether you are a heart patient or not. I feel it’s even more important that I keep in shape. Especially because I know my illnesses. Whichever way it goes, there is no standby, that is, at some point, I will have to be transplanted. Then, as far as possible, I want to be in good shape or whatever I can now”* (P3). As the quote demonstrates, self-tracking data carries along emotional labor and managing concerns in relation to the current health condition and the clinical prognosis. Activity data from consumer devices can, when incorporated into self-care, act as reminders of how well or how poorly you manage, not only your daily goals for exercise or lifestyle change, but moreover the prognostic outlook your chronic heart condition.

4.6 Distancing

Most of the participants had a positive attitude toward accepting their heart condition and welcoming “good” and “bad” news emerging from implant and wearable data. Yet, some of the participants also emphasized ‘distancing’ as a strategy to cope with their disease. P4 only experienced severe heart arrhythmia a few times and for him it has been a meaningful strategy to think less of his heart disease in his everyday life and only

consider it when severe heart arrhythmia emerges: *“Well, I did have a lot of concerns about it when I was diagnosed with the heart disease. But, I have the heart that I have, and the psyche that I have. It’s just my life condition and it’s not something I go and fill my head with”*. Similarly, for P5, who has struggled with longer periods of being in a depressive state and crying a lot, now prefers to distance himself from reflecting too much on his heart condition: *“So you start with asking questions all the time like “why did it happen” and “what can we do to make you feel better”. I believe that the worrying makes most people more sick than it makes them healthy. We are sick already, there is no reason to make us sicker”*.

P4 and P5, also considered the critical and negative emotional effects that short term predictions with activity data could generate. P5 speculated about the consequences it would have had for a recent trip to IKEA where he experienced a cardiac arrest. He explained that he preferred his bodily sensing and his personal know-how over relying on data and technology to verify his symptoms: *“If you can sense it and if you can feel that now it’s on its way to something. And if you can handle it – well then you don’t need to know it before it comes” (P5)*. He believes that arrhythmia risk predictions based on data of upcoming severe heart arrhythmia could lead to increased worrying: *“Personally, I would probably be skeptical: is it necessary for me to know? For me, I would not care. I think it would give more concerns than it would give me joy to know” (P5)*. Similarly, P4 speculated that his reaction to technology-based prompts of risk prognosis would lead to more worrying and ultimately trigger arrhythmic episodes: *“I think, if I found out that in 14 days “you can count on getting an event” then it would in itself lead to more worrying or the anxiety itself would provoke a heart attack”*. As such, some participants prefer – in some situations – to distance themselves from data-initiated actualization of their disease. For them, it is the experience that negative affective loops emerge from engaging too much with data that can infer something about their developments in their disease state.

4.7 Sharing

The participants reported that sharing their disease-related concerns prompted by data from the implanted and wearable devices with partners was an important part of their data work and self-care practices. P2 explained that sharing concerns about arrhythmic episodes with her husband, for example, happened last time they called from the clinic: *“After the clinic called in December, I quickly told it to my husband and my mother. I was like - whoops, I need to take care of myself”*. Similarly, for P5 it is critical for self-care to involve close relatives in coping with the heart disease whenever arrhythmic episodes emerge: *“It will always, always be a good idea to also involve your relatives in one way or another”*. For P3, his wife supports him when severe episodes arise and becomes a close partner for detecting and coping with severe arrhythmic events: *“Just after the fainting on Saturday, it still sits in me. Because when I fainted and woke up again, I actually didn’t know if I got a shock from the ICD. But then my wife was next to me and could tell me that I did not.”*

Sharing concerns about data becomes particularly pertinent when there are opportunities for taking counter measures and managing emergent episodes with heart arrhythmia. When engaging the participants in discussing the use of self-tracking data for arrhythmia risk prediction, several of the participants speculated that they would share it with their partners, like P5 explained: *“It will make really good sense, because then you are two who can act”*. P2 considered involving her husband, daughter, or others nearby to co-manage the critical situation: *“If I had known that I was in dangerous risk then I might have told my husband ‘you’ll have go with me’ or one of the riding girls down at the stable ‘could you please go with me and help out’ or tell my daughter on the road ‘try to listen here, it’s not so good’”*. Similarly, P1 speculated about contacting his girlfriend if he learned about increased risk: *“I would maybe contact my girlfriend if I was not near her, and then say: ‘Well the forecast looks kind of bad, I just have to do something’”*. These examples describe that patient data work is not only individual but is oftentimes connected with care activities where partners, relatives and informal caregivers take part. It suggests a move beyond the individual relation to the coupling between the bodily-lived and self-tracking and implant data to a wider social sphere, most commonly consisting of the person and the person’s partner.

5 Discussion

While the patients in this study are all proactive and engaged users of self-tracking technologies, the ways in which these patients interpret and use their data vary. Some patients log and use their data to critically question and follow the medical treatment they receive. Other patients use their data exploratorily to constantly test the ways in which they can optimize or improve their health condition. However, one thing that the patients have in common is that they engage in data work practices of verifying, questioning, motivating, reacting, accepting, sharing, and distancing in relation to coping and living with a chronic illness.

Looking at the findings, we can identify several temporal dimensions regarding the patients’ use of their self-tracked Fitbit data. In particular, we can distinguish between practices related to collecting and reflecting on data to 1) understand *past* developments of e.g. your heart rate when doing exercises or when trying to make sense of events in the past as seen during activities of questioning or by being prompted by past events as in the examples of reacting, 2) in cases where the patients explore connections between in the *present* moments as in many of the verification examples, e.g. when trying to figure out whether a severe heart arrhythmia is coming within the next few minutes and 3) when concerned about *future* actions as e.g. in the motivational practices. Naturally, we see crossovers e.g., when looking at past data to better envision future actions, as in the case of P2 when verifying arrhythmias and considering the action to take. We also see that these temporalities are often strongly related to making sense and taking action, whether by building an understanding of past patterns, by navigating a difficult situation in the moment, or by developing future strategies of coping and improving quality of life and avoid severe arrhythmic episodes.

A strong current underlying many of the presented data work practices has to do with the affective and emotional aspects of living with a disease that can be potentially life threatening, and which has often been initiated by a traumatic event. Examples from the questioning practices also suggest a relation between positive and negative affect and the ability to take action in everyday life. Here, we see different ways in which some patients use self-tracking data from consumer wearables to explore pertinent questions to generate answers that support their self-care practices. Related to this, we can also see that the reacting practices carry negative affect since they are often initiated by the health professionals or prompted by self-tracked data, rather than the patients themselves and can hence come as a surprise or in the form of unwanted news. The distancing practices show how patients sometimes feel the need to “escape” their condition, or data that reinforce negative aspects of their condition – even though this practice is not always tenable in the long run. Accepting practices are in a different state; here, we see how the negative affect sometimes surrounding the physical condition and bodily data is always in process – and that it is also possible to turn negative data into positive affect if you find a way to act upon it. Importantly, we see that patients developed very different affective attachments to the interplay between bodily symptoms, their wellbeing, and data, which can lead to reifying affective loops; if you get motivated, knowing that you are continuously doing better will be a positive factor. However, if you are constantly experiencing the data as a reminder that you are not doing enough or that you are in fact losing your health, it can become a reinforcing negative spiral. This calls for a very personalized strategy for understanding the different parameters and ways of presenting data to best suit the patients’ needs.

6 Conclusion

In this paper, we have explored patient data work among chronic heart patients with an ICD using a consumer wearable activity tracker (Fitbit Alta HR). We found seven micro practices: Verifying, Questioning, Motivating, Reacting, Accepting, Distancing, and Sharing. As we demonstrated in our findings, patients living with a chronic illness are already emotionally burdened and their health conditions entail that even mundane activities such as driving a car or going to IKEA is not worry-free. As part of coping with their health condition, the patients have developed different practices of relating their bodily cues with their self-tracked data. The ways in which the patients speculate about their reaction to and use of short-term predictions might also open a path for exploring how the use of predictive health technologies may support everyday planning, which may also be easier to speculate about in contradiction to emotional reactions toward being told by an app that you are in high risk of a severe arrhythmic heart event. However, our results also showed that the effect of such predictive health results might differ from patient to patient; it can potentially introduce feelings of reassurance for some patients, while for other patients they risk prompting (unnecessary) concern.

References

1. Nunes, F., Verdezoto, N., Fitzpatrick, G., Kyng, M., Grönvall, E., Storni, C.: Self-care technologies in HCI: Trends, tensions, and opportunities. In: *ACM Transactions on Computer-Human Interaction, TOCHI*. Vol 22(6), pp. 1-45. ACM, New York, NY, USA (2015).
2. Andersen, T.O., Langstrup, H., Lomborg, S.: Experiences with wearable activity data during self-care by chronic heart patients: qualitative study. *Journal of Medical Internet Research* (7), e15873 (2020)
3. Ayobi, A., Marshall, P., Cox, A.L., Chen, Y.: Quantifying the body and caring for the mind: self-tracking in multiple sclerosis. In: *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pp. 6889-690. ACM, New York, NY, USA (2017).
4. Bossen, C., Pine, K.H., Cabitza, F., Ellingsen, G., Piras, E.M.: Data work in healthcare: An Introduction. *Health Informatics Journal* 25(3), 465-74 (2019).
5. Torenholt, R., Saltbæk, L., Langstrup, H.: Patient data work: filtering and sensing patient-reported outcomes. *Sociology of Health & Illness* 42(6), 1379-93 (2020)
6. Epstein, D.A., Caldeira, C., Figueiredo, M.C., Lu, X., Silva, L.M., Williams, L., Lee, J.H., Li, Q., Ahuja, S., Chen, Q., Dowlatyari, P.: Mapping and taking stock of the personal informatics literature. In: *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*. Vol 4(4), pp. 1-38. ACM, New York, NY, USA (2020).
7. Shin, G., Jarrahi, M.H., Fei, Y., Karami, A., Gafinowitz, N., Byun, A., Lu, X.: Wearable activity trackers, accuracy, adoption, acceptance and health impact: A systematic literature review. *Journal of biomedical informatics* 93(1), 103153 (2019).
8. Ancker, J.S., Witteman, H.O., Hafeez, B., Provencher, T., Van de Graaf, M., Wei, E.: "You get reminded you're a sick person": personal data tracking and patients with multiple chronic conditions. *Journal of medical Internet research* 17(8), e4209 (2015).
9. Rosenberg, D., Kadokura, E.A., Bouldin, E.D., Miyawaki, C.E., Higano, C.S., Hartzler, A.L.: Acceptability of Fitbit for physical activity tracking within clinical care among men with prostate cancer. In: *AMIA Annual Symposium Proceedings Vol. 2016*, pp. 1050. American Medical Informatics Association, Bethesda, MD, USA (2016).
10. Mamykina, L., Mynatt, E., Davidson, P., Greenblatt, D.: MAHI: investigation of social scaffolding for reflective thinking in diabetes management. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, pp. 477-486. ACM, New York, NY, USA (2008).
11. Chung, C.F., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J.A., Munson, S.A.: Boundary negotiating artifacts in personal informatics: patient-provider collaboration with patient-generated data. In: *Proceedings of the 19th ACM conference on computer-supported cooperative work & social computing*, pp. 770-786. ACM, New York, NY, USA (2016).
12. Figueiredo, M.C., Caldeira, C., Reynolds, T.L., Victory, S., Zheng, K., Chen, Y.: Self-tracking for fertility care: collaborative support for a highly personalized problem. In: *Proceedings of the ACM on Human-Computer Interaction*, pp. 1-21. ACM, New York, NY, USA (2017).
13. Kaziunas, E., Ackerman, M.S., Lindtner, S., Lee, J.M.: Caring through Data: Attending to the Social and Emotional Experiences of Health Datafication. In: *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, pp. 2260-2272. ACM, New York, NY, USA (2017).
14. Sanches, P., Janson, A., Karpashevich, P., Nadal, C., Qu, C., Daudén Roquet, C., Umair, M., Windlin, C., Doherty, G., Höök, K., Sas, C.: HCI and Affective Health: Taking stock of a decade of studies and charting future research directions. In: *Proceedings of the 2019 CHI*

- Conference on Human Factors in Computing Systems. ACM, New York, NY, USA pp. 1-17. (2019).
15. Lee, K., Cho, H., Toshnazarov, K., Narziev, N., Rhim, S.Y., Han, K., Noh, Y., Hong, H.: Toward Future-Centric Personal Informatics: Expecting Stressful Events and Preparing Personalized Interventions in Stress Management. In: Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems, pp. 1-13. ACM, New York, NY, USA (2020).
 16. Desai, P.M., Mitchell, E.G., Hwang, M.L., Levine, M.E., Albers, D.J., Mamykina, L.: Personal health oracle: Explorations of personalized predictions in diabetes self-management. In: Cui, W., Zheng, J., Lewis, B., Vogel, D., Bi, X. (eds.) Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems, pp. 1-13. ACM, New York, NY, USA (2019).
 17. Rho, S., Lee, I., Kim, H., Jung, J., Kim, H., Jun, B.G., Lim, Y.K.: FutureSelf: What Happens When We Forecast Self-Trackers' Future Health Statuses? In: Editor, Marshall, j., Tennet, P. (eds.) Proceedings of the 2017 Conference on Designing Interactive Systems, pp. 637-648. ACM, New York, NY, USA (2017).
 18. Piras, E.M., Miele, F.: Clinical self-tracking and monitoring technologies: negotiations in the ICT-mediated patient-provider relationship. *Health Sociology Review* 26(1), 38-53 (2017).
 19. Mercer, K., Giangregorio, L., Schneider, E., Chilana, P., Li, M., Grindrod, K.: Acceptance of commercially available wearable activity trackers among adults aged over 50 and with chronic illness: a mixed-methods evaluation. *JMIR mHealth and uHealth* 4(1), e4225 (2016).
 20. Zhu, H., Colgan, J., Reddy, M., Choe, E.K.: Sharing patient-generated data in clinical practices: an interview study. In: AMIA Annual Symposium Proceedings, Vol. 2016, pp. 1303. American Medical Informatics Association, Bethesda, MD, USA (2016).
 21. Ancker, J.S., Witteman, H.O., Hafeez, B., Provencher, T., Van de Graaf, M., Wei, E.: The invisible work of personal health information management among people with multiple chronic conditions: qualitative interview study among patients and providers. *Journal of medical Internet research* 17(6), e4381 (2015).
 22. Li, I., Dey, A., Forlizzi, J.: A stage-based model of personal informatics systems. In: Proceedings of the SIGCHI conference on human factors in computing systems, pp. 557-566. ACM, New York, NY, USA (2010).
 23. Fleck, R., Fitzpatrick, G.: Reflecting on reflection: framing a design landscape. In: Viller, SA., Kraal, B. (eds.) Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction, pp. 216-223. ACM, New York, NY, USA (2010).
 24. Piras, E.M.: Beyond self-tracking: Exploring and unpacking four emerging labels of patient data work. *Health informatics journal* 25(3), 598-607 (2019).
 25. Ruckenstein, M., Schüll, N.D.: The datafication of health. *Annual review of anthropology* 46(1), 261-278 (2017).
 26. Andersen, T.O., Andersen, P.R., Kornum, A.C., Larsen, T.M.: Understanding patient experience: a deployment study in cardiac remote monitoring. In: Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare, pp. 221-230. ACM, New York, NY, USA (2017).
 27. Marent, B., Henwood, F., Darking, M.: Ambivalence in digital health: Co-designing an mHealth platform for HIV care. *Social Science & Medicine* 215(1), 133-141 (2018).
 28. Salmela, T., Valtonen, A., Lupton, D.: The affective circle of harassment and enchantment: reflections on the ÖURA Ring as an intimate research device. *Qualitative Inquiry* 25(3), 260-270 (2019).

29. Picard, R.W.: *Affective Computing*. MIT Press, Cambridge, MA, USA (1997).
30. Aboulafia, A., Bannon, L.J.: Understanding affect in design: an outline conceptual framework. *Theoretical issues in ergonomics science* 5(1), 4-15 (2004).
31. Sengers, P., Liesendahi, R., Magar, W., Seibert, C., Müller, B., Joachims, T., Geng, W., Mårtensson, P., Höök, K.: The enigmatics of affect. In: *Proceedings of the 4th conference on Designing interactive systems: processes, practices, methods, and techniques*, pp. 87-98. ACM, New York, NY, USA (2002).
32. Boehner, K., DePaula, R., Dourish, P., Sengers, P.: Affect: from information to interaction. In: *Proceedings of the 4th decennial conference on Critical computing: between sense and sensibility*, pp. 59-68. ACM, New York, NY, USA (2005).
33. Höök, K.: Affective Loop Experiences – What Are They? In: Oinas-Kukkonen, H., Hasle, P., Harjumaa, M., Segerståhl, K., Øhrstrøm, P. (eds) *Persuasive Technology*, *Lecture Notes in Computer Science*, pp. 1-12. Springer, Berlin, Heidelberg (2008).
34. Lottridge, D., Chignell, M., Jovicic, A.: Affective interaction: understanding, evaluating, and designing for human emotion. *Reviews of Human Factors and Ergonomics* 7(1), 197-217 (2011).
35. Fritsch, J. *Affective Interaction Design at the End of the World*. In *Proceedings of DRS 2018: Catalyst* (pp. 896-908). Design Research Society (2018).
36. Charmaz K. *Constructing grounded theory: A practical guide through qualitative analysis (Introducing Qualitative Methods Series)*, (2006).