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Am I Coughing More Than Usual? Patient Reflections and User Needs on Tracking COPD Data in a Telehealth System

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ABSTRACT

An increasing number telehealth systems continuously collect self-reported data from patients. Objective and subjective collection of health data facilitates early detection and treatment of chronic conditions, but patient needs in these telehealth contexts are poorly understood. It is for example not clear how to support patients' reflection on their daily self-reported data. Inadequate support can result in fragmented daily health monitoring and poor adherence. This paper contributes 1) a synthesis of the related but hitherto disjunct personal informatics literature on self-tracking and 2) an in-depth field study on how six people suffering chronic obstructive pulmonary disease (COPD) used a telehealth system as part of their health self-tracking. Our analysis showed that a telehealth solution which relegated patients to mere data suppliers missed out on opportunities to address user needs. We extended Li's 5-stage model to show where reflection manifested when interacting with the telehealth system.

CCS CONCEPTS

• **Human-centred computing** → **Field studies**; Ubiquitous and mobile computing systems and tools; • **Human-centered computing** → *Interaction paradigms*; *Interaction devices*; *Graphical user interfaces*;

KEYWORDS

self-tracking, quantified self, personal informatics, reflection, telehealth, telecare, patient-reported outcomes, COPD

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1 INTRODUCTION

Aging societies are facing higher health care burdens. Telehealth and multimodal sensor technologies save cost and can empower patients and help them become more active and motivated to engage in their care. Telehealth applications for chronic obstructive pulmonary disease (COPD) require objective (e.g. measured oxygen saturation measures) and subjective (e.g. self-reported shortness of breath) data known as patient reported outcomes (PRO). Patients track and submit data daily this way, to support early detection and initiation of treatment of exacerbations. COPD patients face decreased life quality and increased healthcare service use when exacerbations go undetected and untreated.

Previous studies have shown poor self-management among COPD patients, for example that patients did not act on early warning signs [3, 15, 29]. The telehealth literature provided little insight on how the user interfaces of telehealth systems concretely supported patients in their monitoring efforts, reflecting on their data, and taking appropriate actions [28]. To shape our research into concrete user needs and interaction design of COPD telehealth, we relied on insights from the personal informatics literature. We then analyzed experiences of six COPD patients with their telehealth solution through this lens and compared needs in telehealth contexts to needs in personal informatics.

This paper is a two-fold contribution: 1) We propose a telehealth-based extension to Li's 5-stage model and follow-ups [4, 9, 16]. The extension cover voluntary self-tracking behavior and reflection and identifies Our telehealth extension identifies key differences and touch points where patients reflect in the process of self-tracking. 2) We identify key sub-stages in the Collection stage of Epstein et al.'s [9] Lived Informatics Model and discuss the implications for patient reflection.

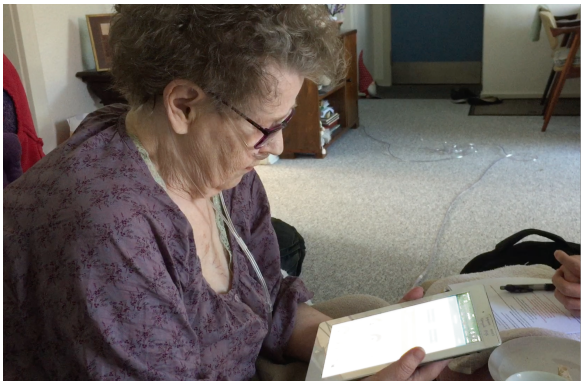

Figure 1: COPD patient using Ambuflex Telehealth System.

2 BACKGROUND

Technological advances in wearable sensor technology brought personal informatics to the wider public. People use quantified-self applications for knowledge gain and self-reflection, by tracking personally relevant information [16]. In the personal informatics 5-stage model by Li et al. [16] self-trackers transition between five stages: (1) determining variables, tools and frequency of tracking (*preparation*), (2) logging data (*collection*), (3) preparing data for reflection e.g. by aggregating and analysing data (*integration*), (4) examining data to gain self-knowledge (*reflection*) and (5) deciding what to do with said knowledge (*action*). Epstein et al. argued that collection, integration and reflection are ongoing processes of *tracking* and *acting* that can occur simultaneously [9]. Bussone et al. broke down the preparation stage into a motivational part of tracking (*intention*) and a choosing what and how to track (*identification*) [4]. Additionally, they broke the integration stage into manipulating data further (*management*) and its depiction (*representation*). From comparison of personal informatics and telehealth literature, we found differences in roles of stakeholders for each stage, illustrated in Figure 2. The telehealth scenario in Figure 2 is described in detail below [24, 29]:

- *Preparation*: In telehealth, healthcare professionals (HCP) usually mandate tracking goals, by defining what symptoms, how often and with what tool patients should track.
- *Collection*: Patients collect both objective numerical (e.g. oxygen saturation measures) and subjective binary data (e.g. yes/no answers to whether a symptom has increased).
- *Integration*: The system integrates the data and based on predefined individual "normal ranges" and flags data for follow-ups.
- *Reflection* Trained nurses or physicians review the data and decide on a course of action.
- *Action* If needed the nurses contact and advise the patient on potential initiation of treatment.

From the literature, we classified four main drivers for sustained tracking among people with a health-related condition: (1) *documentation* (e.g. to create records for their healthcare providers [1]), (2) *communication* (e.g. to communicate their condition to family members [18]), (3) *self-knowledge and advice* (e.g. to get a sense of the current state of their condition or to get advice from their healthcare-provider [1, 18]), (4) *self-improvement* (e.g. to change or maintain a behaviour in order to improve well-being or lifestyle [1, 7, 18]) and (5) *self-control* (e.g. to exert control over chronic condition and achieve self-stabilization) [19].

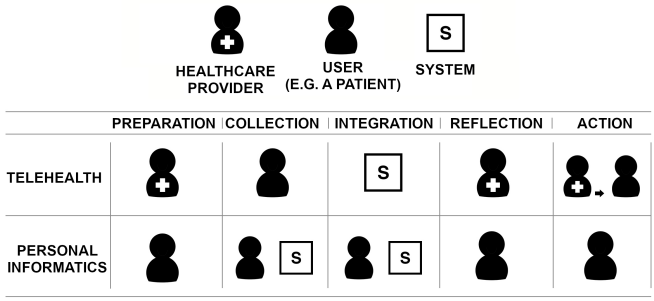

Figure 2: Involvement of users and HCPs in telehealth in comparison to Li et al.'s 5-stage model from personal informatics [16].

Barriers to motivation included strong emotional adversity to reflection on data, because it reminded people of negative aspects of their illness [1, 16], tracking the wrong data or not tracking well enough to gain benefits [6], effort [5, 23], reliability and relevance [9, 22, 29] and mismatches between subjective feeling and objective measures [1].

Rivera Pelayo et al. [25] suggested technology can support reflection through (1) *tracking* experiences (e.g. feelings or physiological data) and outcomes (gained insight or changes in behaviour). The tracked experiences and outcomes serves as basis for the reflective process, induced by (2) *triggers* to raise awareness and detect data discrepancies. The tracked data is (3) enriched with e.g. context data and data visualizations to facilitate *recall and revisit* of past experiences. In the following sections, we used Li et al.'s *5-stage model* [16] and Rivera Pelayo et al.'s framework as an analytical lens to identify user needs and barriers for self-tracking and synthesize findings from the literature.

2.1 Preparation

The *preparation* stage includes people getting motivated to track (e.g. because of a goal they have in mind), which guides the decision on, what data to track and selecting the tool to track with.

From the literature, we classified four main drivers for sustained tracking among people with a health-related condition: (1) *documentation* (e.g. to create records for their healthcare providers [1]), (2) *communication* (e.g. to communicate their condition to family members [18]), (3) *self-knowledge and advice* (e.g. to get a sense of the current state of their condition or to get advice from their healthcare-provider [1, 18]) and (4) *self-improvement* (e.g. to change or maintain a behaviour in order to improve well-being or lifestyle [1, 7, 18]). Barriers to motivation included strong emotional adversity to reflection on data, because it reminded people of negative aspects of their illness [1, 16], tracking the wrong data or not tracking well enough to gain benefits [6], effort [5, 23], reliability and relevance [9, 22, 29] and mismatches between subjective feeling and objective measures [1].

Healthcare providers may give little support on what symptoms to track and how to track (e.g. frequency of tracking) [23]. This becomes problematic in conditions that involve many symptoms which may arise unexpectedly [7, 23]. People who track used tools, such as notebooks, health diaries and specific applications to do additional tracking or sometimes developed tools themselves that were cumbersome and incomplete [23]. This later affected the *integration* and *reflection* stages, where healthcare providers struggled with interpreting data sets with additional and not always relevant information [6, 7].

2.2 Collection

The *collection* stage deals with logging data. Logging constitutes a prerequisite for triggering and supporting *reflection* requiring an unobtrusive a method to avoid tracking fatigue [5, 23] while being

sufficiently reliable [21]. Manual logging requires responsibility and motivation that has to be kept over time and can therefore be burdensome compared to automatic logging [16, 21]. Some self-trackers found manual logging time consuming and requiring effort [1], hampering incorporation of tracking into daily routines, e.g. when resting before taking physiological measures was required [30]. Data granularity can impede logging when overthinking how to rate on a scale from 0 to 10 [22]. People with chronic conditions needed a baseline to compare with when self-reporting on severity of symptoms [29]. While reducing effort, automatic logging creates challenges in terms of filtering and aggregating large data amounts [21] and can reduce awareness and self-reflection [5, 17].

2.3 Integration

The *integration* stage can be more or less apparent to the tracker depending on whether integration is automatically done by the system, requiring less effort from the self-tracker [16]. Previous studies show that self-trackers sometimes postponed data exploration, when integration did not happen automatically, since it involved tedious tasks, such as cleaning up data, formatting and running statistical tests [5, 6, 16].

Systems that require manual integration expect the user to be able to analyse the data and ascertain the best way of creating a representation. Whooley et al. found that this is of interest to curiosity-driven self-trackers that want to integrate data manually and explore the novel insights that data can offer them. In contrast, self-trackers with a goal, knew what they were looking for in the data and strived at using automatic integration systems, allowing them to concentrate on reflection. The manual integration process is an iterative process of moving back and forth between representation creation and reflection [31].

2.4 Reflection

While previous research pointed towards many different definitions of reflection, we found little on how to measure or evaluate reflection. Fleck & Fitzpatrick distinguished between five different 'levels of reflection' (R0-R4) that indicate what types of activities and behaviours can be associated with reflection [10]. Levels consist of (R0) describing or stating without being reflective (*description*), (R1) describing with explanations in a reportive or descriptive way (*reflective description*), (R2) seeing things from different perspectives and trying to identify relationships (*dialogic reflection*), (R3) changing original point of view due to gained knowledge (*transformative reflection*) and (R4) seeing the wider perspective beyond the immediate context (*critical reflection*). While higher level indicates being more reflective, lower levels are prerequisites for becoming more reflective. Bussone et al. distinguished between three different strategies for reflection that depended on which stakeholders were involved in the process: only the person tracking (*solo reflection*, summarizing and requesting comments from others (*reflection through their community*) or healthcare professionals (*reflection through their healthcare professional*) [4].

To engage in reflection, people should be open-minded and willing to reflect. Reflection requires critical analysis and evaluation skills [2, 26], which people develop with time and the right support [10]. People often need a reason (e.g. a purpose) or at least an encouragement to reflect [10, 20]. Another condition for reflection is creating and allowing for time to reflect [10]. Li et al. distinguished between short-term reflection, where the self-tracking person reflects immediately after logging the data and long-term reflection that might occur several days or weeks after [16]. When people use long-term reflection, they reach higher levels of reflection (at least R2). Long-term reflection enables people to compare logged data between different times and explore trends and patterns, not available during short-term reflection.

In psychology, Festinger's cognitive dissonance theory describes, how a mismatch (psychological discomfort or dissonance) between an individual's attitude and behaviour can lead to rethinking one's attitude and behaviour [25]. Systems can actively trigger dissonance by directing user's attention visually to a mismatch). Dissonance may occur due to comparison between current level and a recommended level, "normal ranges", or goal, but some might prefer such comparison in response to oneself [1].

Reflective questions or prompts can trigger reflections. For example, asking people to provide justification or explanation for events or actions can trigger *reflective descriptions* (R1) [10]. The presence of another person can encourage reflection, especially in a dialogue among two "uneven partners" (i.e. two people not sharing the same understanding or experience), where one takes the leading role of asking questions. Standard systems can take this role, too, by posing an initial reflective question but fail to provide a dialogue [20]. Intelligent system could support further reflection through follow-up questions or by prompting questions triggered by automatically logged context data [10]. Viewing data not usually visible encourages people to see things from another perspective and can lead to looking for relationships and patterns (R2) [10].

While looking at data does not constitute reflection in Fleck & Fitzpatricks' levels, representations are a prerequisite to support higher reflective levels [10] and taking readings and reflecting emerged as a prominent self-management technique in Tendedez et al's. study on people with chronic respiratory conditions [28]. Interactive visualisations of data can support exploration and gaining insights [5, 16] if built with health numeracy and storytelling taken into account [12]. Design of such visualisations should consider time and effort expected from the user, skills, self-awareness and purpose for reflection [8, 11, 21]. Li et al. identified six types of questions people ask about self-tracked data [17]: getting to know (1) status (what is current status?), (2) history (what has status been in the past?), (3) goals (what goal is appropriate to pursue?), (4) discrepancies (how does current status compare to goal?), (5) context (what affects current status?), (6) factors (how are different variables related?). Depending on the conditions, supporting both simple (e.g. status charts) and detailed visualisations (e.g. of time series) can be important [8, 21].

Often people want to obtain answers to their question (e.g. status) without spending too much time or effort, which can be done on a simplified dashboard representation that allows for a quick overview [8]. People used status charts to quickly get an overview of their data and used it as a starting point for exploration and requested comparison charts to benchmark against other people in the sense-making process and to assess success [21]. But some prefer that benchmarking is comparison to oneself [1]. Visualisations of time series data can support revisiting and analysing past

experiences (history) and trigger storytelling about experiences behind data [21, 25] based on single or multiple time series [8]. They can foster reflection on global (e.g. upward and downward) trends or deviations from a historical normal (suggesting a problem) [25] and how multiple variables are related but do not facilitate exploring temporal patterns [8]. Calendar heatmaps pose an alternative representations to indicate variable values [8]. Time series visualisations can be combined with discrete events [27] to support reflective description (R1). Barriers for reflection include lack of simple visualisations of data or more complex features (e.g. filtering data to focus on a subset of data, zooming out to get an overview or comparing multiple variables) [17, 18]. While reflection is an internal process, it can occur when trying to externalize thoughts and feelings e.g. in diaries or during reflective writing [20]. These activities are often descriptive or emotional (R1). Recording reflection outcomes for later revisiting and reflection on gained insights has been proposed as another way to support reflection [13, 21].

2.5 Action

People decide what *action* to take based on the findings from the *reflection* stage. Trackers sometimes lacked the knowledge necessary to identify the appropriate actions to take, in order to regulate their progress towards their behaviour change goal. This happened either because of irrelevant data [5, 6] (e.g. food and symptoms, instead of ingredients that triggered the symptoms) or because they needed actionable (expert) advice [16, 22, 30] missing from most Personal Informatics systems [6, 16, 30].

In summary, previous research has shown user needs and concerns in self-tracking activities but little is known about self-tracking behavior in telehealth systems. As long as patient needs in telehealth are unarticulated, it becomes difficult to design telehealth systems which can empower patient action through self-reflection.

3 STUDY

We designed a study to explore self-tracking needs and concerns in a telehealth context using COPD patients as our case.

The participants used two telehealth systems: AmbuFlex and Tunstall described in Table 1 and shown in Figure 4. Patients could access AmbuFlex via mobile devices or computers. Tunstall consisted of a monitoring box installed in the patient's home. In both systems, users submitted objective and subjective data items three times a week. After a start screen (Figure 4, left), patients needed to authenticate themselves to AmbuFlex by typing in their national security ID through a keypad (with mouse) or keyboard. AmbuFlex collected data through a series of forms (one per item). These consisted for all binary measures of a question (e.g. "Are you coughing more than usual?"), a yes/no radio button, and a button to proceed to the next screen (Figure 4, middle). The most complex form was that for the three objective measurements and it included the possibility of leaving a text comment (Figure 4, right). On the final page AmbuFlex provided confirmation of submission but no option for reviewing previous data. Patients received follow-up calls when healthcare providers monitoring the data needed additional information. Hospital staff made follow-up calls to patients to discuss deviations and/or advise patients' to initiate medication or validate measurements.

3.1 Participants

Six COPD patients (P1-P6) participated in the study; Two male patients (P1, P2) between 64 and 65 years (M: 64.5) and four female patients between 54 and 74 years (M: 66.8). We established contact with patients through a regional hospital. All patients had severe COPD and multiple other health-related conditions (diabetes, heart disease, pulmonary oedema, asthma, bronchitis, osteoporosis and sleep apnea). Three of the patients used supplemental oxygen (P3, P5, P6). All of them lived in their own homes with a spouse, except P3 who lived alone. P6's spouse (P6S) took responsibility for her and was her spokesman, as she had a speech disorder. All participants had used AmbuFlex for 3-24 months. Two patients had previously used the Tunstall HealthCare solution for 3 months.

3.2 Method

We conducted semi-structured interviews in the participants' home. The interviews covered demographic information, COPD-related information, the patients experience with self-management of COPD. The patients demonstrated the use of the web-based telehealth system 'AmbuFlex' and discussed their experiences and motivation in relation to using it. From the patients' reports, we coded the field notes and audio recordings using an open-coding method. The thematic analysis of COPD patients self-tracking needs used Li et al.'s 5-stage model as a lens.

Name	System Type	Data Collection
Ambuflex (P1-P6)	Web-based (Mobile / PC)	Oxygen Saturation Pulse Weight Multiple Choice Free-form Text
Tunstall (P2 & P5)	Monitor Box	Oxygen Saturation Pulse Lung Function Weight Multiple Choice Free-form Text

Table 1: COPD Telehealth System Characteristics.

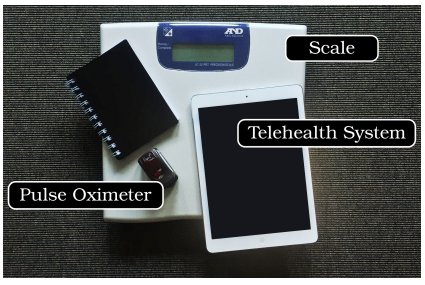

Figure 3: The Ambuflex telehealth kit & a patient notebook.

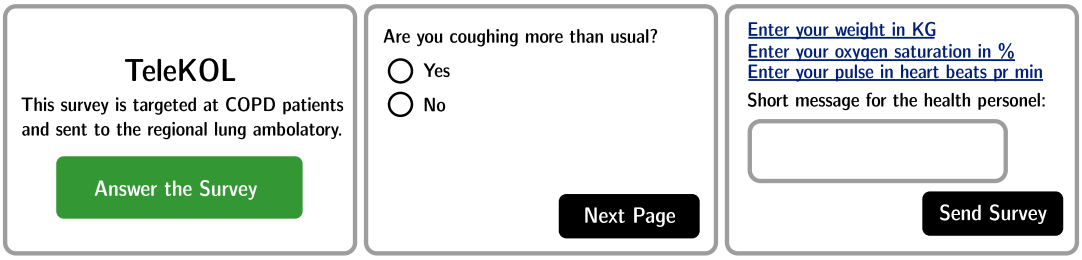

Figure 4: Ambuflex menu (Left), 4 multiple choice questions (Middle) & measurements with opt-in text to hospital (Right).

4 RESULTS

4.1 Preparation

The majority of participants (P1-P5) found the sense of security from healthcare providers monitoring their data motivating. "*(...) it gives you a huge sense of security that you are not gonna lay at home ill*" (P2). P4 felt obligated to take measurements due to the presence of a healthcare provider. Two patients tracked additional data on paper (P5, P6S). P5 used the additional data as documentation, e.g. when being admitted to the hospital to discuss it with healthcare providers. P6S' spouse mentioned curiosity, self-satisfaction, and sense of agency as motivations for tracking on paper.

4.2 Collection

All patients remembered to take their measurements consistently and routinely in the morning themselves. They found data collection easy, not requiring expert computer skills, and not taking too much effort or time. P5 stressed the importance of fast collection, "*it must not take ten or fifteen minutes to do it everyday (...)*". "*This [AmbuFlex] is really simple (...) you can add some more to it*" (P6S). Patient mentioned currently spending between 1-2 minutes and 15-20 minutes on AmbuFlex.

Several patients found answering subjective questions difficult when it required comparisons with the 'usual' (e.g. "*Are you coughing more than usual?*") baseline. "*What is usual? Isn't that also how I felt yesterday? Otherwise, I have misunderstood the question*" (P4).

Patients sought higher than binary granularity to answer some items, "*When they ask if you have more dyspnea than usual, then we say yes .. but how much is it? They [healthcare providers] cannot see*" (P6S). As a result, some patients under-reported baseline deviations and only answered "yes" in large or extreme deviations, "*if it's just a little different, I do not mention it*" (P2), "*I would have to be coughing a lot and feel very ill, if I answer yes to that question (...)*" (P4). P2 asked for a scale instead "*(..) why don't they make a scale instead for example from 1 to 5 or 1 to 10? One day I could perhaps say it's 5, the next day 6 and the day after I can go back to 5*". P5 used the comment box to make small deviations go on record, "*(...) to me it is important that we take every small nuance*".

P4 was unsure when to collect data like oxygen saturation measure and pulse, because it depended on her level of activity. She wondered why the system did not take into account external factors related to her condition, "*Do you feel more breathless today? But it does not say anything about the fog outside*" (P4).

4.3 Reflection

Several patients mentioned that an exacerbation comes within a few hours or even minutes, and that they were not able to recognize an onset by using AmbuFlex. P1, P2, P3 and P5 measured oxygen saturation several times a day more often than AmbuFlex required. P2 and P5 explained this served to verify their subjective feeling of well-being or lack thereof. None of the patients felt they learned anything about their disease from their use of AmbuFlex. *I can feel it [an exacerbation], even if I did not have the monitoring device*" (P3).

Patients did not express concerns waiting for a (potential) call. Most of them had identified the hours of the reviewers at the hospital and several had a mental model of when a call would ensue. "*They usually do it [reviewing the data] before noon*" (P3). "*I already know when there is going to be a call (..) when the oxygen saturation is too low, the pulse is high, and your measures fluctuate, they react*" (P2). P6S found benefits in tracking data on paper, to understand his wife's baseline and identify deviations from it. "*You can see how stable it is .. (..) Let's say she loses weight, then I become alert that something is wrong*" (P6S). Patients had not been informed by their healthcare providers about their "normal area" (recommended level) and the AmbuFlex interface did not communicate it either. Half the patients wanted to know these in numbers. Some of the patients had identified their own "normal area" of oxygen saturation that mapped to not feeling well (usually below 90).

4.4 Action

All patients had received education in self-management of their condition (e.g. breathing techniques). When breathing techniques did not work, patients sought additional actionable advice from their interactions with AmbuFlex. P2 and P5 added questions to the comment box. P2 wanted to know additional methods to increase oxygen saturation. P6 wanted recommendations on duration for supplemental oxygen use based on her oxygen saturation measures. P6 felt that variables such as the weather could influence her symptoms and sought information about other influencing variables. P3 and P4 used their oxygen saturation measures to adjust their supplemental oxygen. However, P3 preferred not to initiate treatment before consulting a healthcare provider, unless in extreme cases of symptoms or unavailability of staff. "*I might do it [initiate medication treatment] if it [sputum color] was very green, if it was a Tuesday [a day not monitored by healthcare providers], otherwise I wouldn't*". P2 acted on the basis of his oxygen saturation measures, "*when it is lower than 93, you do not feel fine (...) then I walk a little slower and take it a bit more easy*".

5 DISCUSSION

The patients in this study were highly motivated to track potentially due to the active role of the healthcare provider that provided them with a sense of security not present in previous studies [1, 6, 16]. One patient relied on the monitoring to such an extent that she sometimes delayed treatment, waiting for confirmation from the healthcare provider.

None of the patients described the tracking activity requiring too much effort or time (approximately two-three minutes). A few patients expressed willingness to spend more time interacting with a telehealth system, but not more than ten to fifteen minutes.

AmbuFlex did not meet the needs of users in terms of (1) scope, (2) reliability, (3) validity, and (4) actionable advice. AmbuFlex's scope was limited to submitting variables directly related to the condition at time of entry. Two patients logged additional data on paper (*c.f.* [4, 7, 23]) as having access to their previous data made them feel in control.

Patients felt unsure whether they were collecting data under the right conditions which affected data reliability. Answering subjective questions with a baseline comparison proved difficult for two reasons. Patients had insufficient access to their usual subjective feelings and tried to remember previous events. They wanted to establish their 'usual' baseline (*c.f.* [29]), but AmbuFlex provided no access to historical data. Even if AmbuFlex provided access to previous data this might prove difficult due to the low granularity. The binary answer options reduced the validity of data as patients under-reported significant increases from the baseline. One patient specifically asked for rating on a scale instead. The literature on PRO (see King's [14] overview of methods and below concepts) labels the smallest difference in score that patients perceive as important and would lead the clinician to consider a change in the patient's management as the *minimal important differences* (MID). AmbuFlex, however, presumably employed what is referred to as *clinically significant change* - a difference score (from an anchor), which is large enough to have an implication for the patient's treatment.

Due to the absence of data access, patients did not interact with the data they had collected. None of the interviewed patients expressed having learnt anything from the telehealth system and its use. Several patients mentioned not being able to recognize the onset of an exacerbation. Many self-management tools provide data access, and try to help patients identify triggers for exacerbations, but even then there are underpinning behavioral challenges, which inhibit patient reflection [28] (e.g. exhaustion, immobility, anxiety.).

Patients did not know their provider-recommended "normal area". Instead they used their own identified "normal area" in management of their condition using the pulse oximeter. Some patients wanted to know the provider-recommended "normal area" to become more empowered, while others were not interested. One reason for that could be that patients get reminded about the negative aspects of their health when reviewing data or that they rely more on their subjective feeling than on quantities (c.f. [1].

Apart from support during subjective data entry, patients sought two types of support, (1) confirmation from healthcare providers to act (e.g. initiation of medication) and (2) actionable advice on self-management strategies (e.g. coping with breathlessness) (*c.f.* [6, 16]). We believe that one of the barriers to action was the lack of support for reflection during entry and review of data - a prerequisite to action according to Li et al. [16]. Based on our findings and synthesis of personal informatics literature, we revised the Data Collection stage from the Lived Informatics Model [9] (see Figure 5). We broke down a data collection episode into:

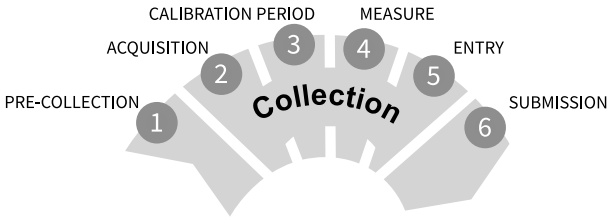

Figure 5: Our extension to the "Collection" Phase of Epstein's Lived Informatics model [9].

- *Pre-collection*: Deciding on whether to log or skip
- *Acquisition*: Preparing required artifacts
- *Calibration period*: Satisfying guidelines for tracking
- *Measure*: Taking measure using artifact
- *Entry*: Entering measurements from the artifact, providing scale based ratings (absolute or relative to baseline) or providing qualitative comments
- *Submission*: Submitting data

The patients reflected during multiple stages of collection before entering both subjective and objective measures. For example, asking people to provide justification or explanation for events or actions can trigger *reflective descriptions* (R1) [10]. The presence of another person can encourage reflection, especially in a dialogue among two "uneven partners" (i.e. two people not sharing the same understanding or experience), where one takes the leading role of asking questions.

6 CONCLUSION

Self-tracking can be sustained by having healthcare providers continuously monitor data, but patients have equivalent monitoring needs. The patients in our case study expressed difficulties rating their symptoms relative to their usual baseline and uncertainty in terms of which conditions to measure in. Telehealth systems without data review facilitation, risk reduced reliability of patient reported data. Without access to historical data, patients are hindered in entering reliable subjective measurements, reflection, and taking actions. Based on our findings, we revisited the Lived Informatics Model and extended 5-stage model to make the models better applicable for designing telehealth systems.

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