

Designing for Reflection: Chronic Obstructive Pulmonary Disease Patients as Self-Trackers in Telehealth

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ABSTRACT

Telehealth (TH) systems for early detection and treatment of chronic conditions have seen increased use. But the effects on user needs and concerns when healthcare provider continuously monitor and patients provide subjective and objective data over time is poorly understood. Personal Informatics literature informed the analysis of interview data from six Chronic Obstructive Pulmonary Disease (COPD) patients to improve understanding of user needs and concerns in the use of a state of the art TH solution. While patients generally felt taken care of, the system in many ways did not meet user needs. It included no access to previously entered data leading to difficulties assessing reliable subjective measures and provided no support on reflection and follow-up action.

Author Keywords

self-tracking; personal informatics; reflection; telehealth; chronic obstructive pulmonary disease;

INTRODUCTION

In response to ageing societies, there is an increasing need for people to take an active role in their own health and well-being. Designing technologies that support self-reflection, awareness and self-management of chronic conditions have particularly been of interest to HCI researchers to support quality of life issues. Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease in which the airways are damaged. People with chronic health conditions such as COPD occasionally experience exacerbations that, if not detected and treated early, result in an increased use of healthcare services and a decline in health-related quality of life. Previous studies have shown poor self-management among COPD patients, who do not respond to the early warning signs, because they have difficulties recognizing the onset of an exacerbation or its importance, resulting in delayed recognition and treatment of exacerbations.

Telehealth technologies where patients log and keep track of important variables and symptoms (e.g. self-reported shortness of breath or fluctuations in oxygen saturation measures) are widely used today by healthcare providers to remotely monitor patients and support early detection and initiation of treatment. We refer to the ongoing activity of logging data (objective or subjective) during concrete *episodes* over time

as *self-tracking*. Self-tracking is well-understood from literature on the Personal Informatics movement, where people voluntarily, self-initiate and successfully use technology to enhance self-awareness, self-reflection and thereby change behaviours, improve health or other aspects of life. While the health literature provides little information on, how patients are supported in their self-tracking efforts in the telehealth context, Personal Informatics literature investigates interaction design aspects of self-tracking important for the successful integration of technology in self-tracking interventions.

We synthesized findings from the disparate fields of telehealth and Personal Informatics and used it as an analytical lens for material from semi-structured interviews with COPD patients using a telehealth solution to understand, how we can support patients in their self-tracking efforts (Study 1). While patients generally felt safe, many struggled with subjective data entries that employed references to perceived baselines. The state of the art system they used provided little support on follow-up actions and reflection by excluding access to historical data.

We used findings from the literature and the study to propose design solutions through mockups, focusing on supporting self-reflection that could potentially support patients in the early detection and treatment of exacerbations. We conducted individual feedback sessions on design mockups with five COPD patients (Study 2) and found that not all patients were willing to engage in self-reflection and identified some major concerns related to the design proposals.

We redesigned and implemented a prototype to evaluate it in a real context during a two-weeks trial by six new COPD patients (Study 3). The trial informed, how four concrete design decisions affects reflection among COPD patients. This paper presents key findings on how telehealth systems in the future may be designed to support reflection, finish by drawing some key concerns for those intending to design and evaluate reflection.

BACKGROUND

In recent years, Personal Informatics or Quantified Self (QS) tools have received an increasing interest in the field of human-computer interaction with the introduction of low-cost mobile applications, wearables and advances in sensor technologies. Personal Informatics help people understand themselves through self-tracking of personally relevant in-

formation for the purpose of self-reflection and gaining self-knowledge [2].

Researchers have proposed different models for understanding, how self-trackers concretely use Personal Informatics tools over time. Li et al. proposed the cascading five-staged *Personal Informatics Model* describing, how self-trackers transition between: (1) *Preparation* (determining variables, tools and frequency of tracking), (2) *collection* (logging data), (3) *integration* (preparing data for reflection e.g. by aggregating and analysing data), (4) *reflection* (examining data to gain self-knowledge) and (5) *action* (deciding what to do with said knowledge) [2].

Little is known about self-tracking practices around telehealth systems in the health context, but we found that despite telehealth does not completely reflect the practices of Personal Informatics (because there are multiple stakeholders/users in telehealth), the above-mentioned stages still apply. We have illustrated the differences between stakeholders roles in Personal Informatics and Telehealth on Figure 1.

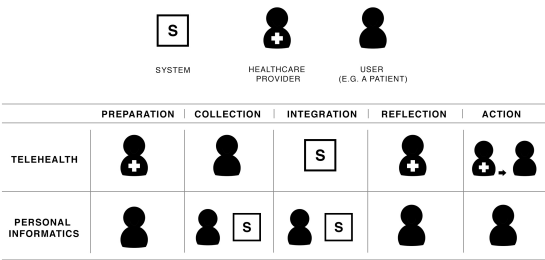


Figure 1. Stakeholders model bla bla

In telehealth, healthcare providers mandate and predefine what symptoms, how often and with what tool patients should track (*preparation*). Patients collect both objective numerical (e.g. oxygen saturation measures) and subjective binary data (e.g. yes/no answers to whether dyspnea has increased more than usual) (*collection*). The system integrates the data and based on predefined individual normal ranges flags data for follow-ups (*integration*). Trained nurses or physicians review the self-tracked data (*reflection*) in telehealth and if needed contact and advise the patient on potential initiation of treatment (*action*) [5, 3].

Epstein et al. found that *collection*, *integration* and *reflection* are ongoing processes that can occur simultaneously and integrated *lapsing* (e.g. due to an oversight, holidays, injuries or when life habits change) and *resuming* into their *Lived Informatics Model* [1, 4].

Rivera-Pelayo et al.[?] and Mller et al.[?] discuss Personal Informatics in light of reflective learning theory (or learning by reflection) based on the work of Boud et al., who describe reflection as those intellectual and affective activities in which individuals engage to explore their experiences in order to lead to new understandings and appreciations [?].

Rivera-Pelayo proposed a framework that shows three dimensions in which technology can support reflection: (1) Tracking, (2) Triggering and (3) Recalling and Revisiting.

STUDY 1

Method

Results

Discussion

STUDY 2

Method

Workbook design

Prototype design

Results

Discussion

STUDY 3

Method

Results

Discussion

CONCLUSION

FUTURE WORK

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