
‘The issue with *that* sort of data...’: Clinicians’ accountability concerns around COPD self-monitoring tools

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ABSTRACT

There is an increasing interest in CSCW to understand how technology can be used for the monitoring of chronic conditions, and how collaboration for care planning can occur between clinicians and patients through its use. Many studies in this area have focussed on the *patients’* experience of using such technology. We report findings from a small-scale study, where a smartphone app for monitoring Chronic Obstructive Pulmonary Disease symptoms was introduced into a community care respiratory service for patients’ use. Our findings provide three key insights into the *clinicians’* experiences in receiving the patient reported data and supporting the patients’ use of the app as part of their service.

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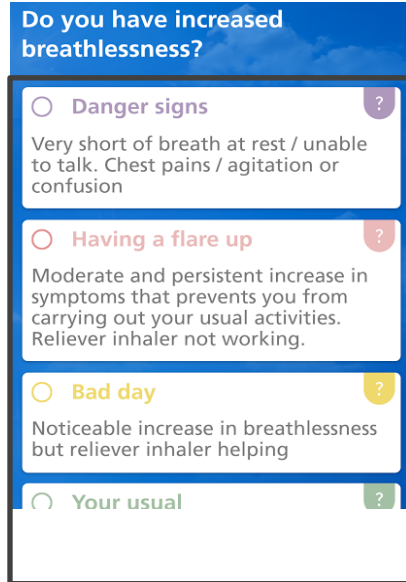
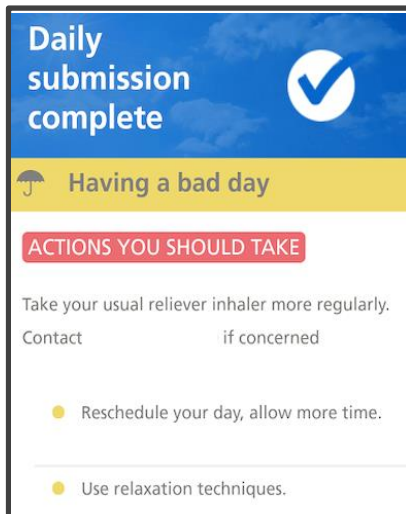


Figure 1. One of the daily questions asked by the app



INTRODUCTION

Effective self-management of chronic conditions can help to improve a patient’s quality of life, while also reducing demand on overstretched healthcare services. Digital health technology can enable people with chronic conditions to self-monitor and track their symptoms for care planning, while keeping their healthcare professional connected in the process. Understanding how clinicians can incorporate self-monitoring technology into their service is important for CSCW research. This helps to gain insight on the broader context of how patients and clinicians can collaborate in this self-monitoring process.

Past work has shown that patients believe that sharing their self-tracking data with their clinicians can help to create personalized self-management plans [1, 2] and can help them to seek help when they are struggling to manage [5]. However, for clinicians, many challenges can arise when engaging with patient generated data and patient monitoring technology. For example, concerns about being liable for checking the content of patients’ digital notes [3], the accuracy of the self-reported data [4] and feeling overwhelmed by masses of patient generated data presented in the clinic [1] or received remotely [9]. Through conducting a user study with clinicians and patients, we further explore the challenges clinicians face in supporting patients’ use of self-monitoring technology. This adds to insight into how such technology can effectively integrate into practice and improve support provision for patients.

In this paper, we report on findings from a four-week user study involving eight participants (four patients with Chronic Obstructive Pulmonary Disease (COPD) and four community respiratory clinicians). COPD is an umbrella term describing a set of chronic lung conditions, including emphysema, and chronic asthma [8]. People with COPD may experience fatigue, breathlessness, and frequent severe chest infections. Effective self-management can help to improve patients’ quality of life by better recognising, understanding and managing symptoms.

During the study, patients used a smartphone app for daily monitoring of their COPD symptoms (described in the following section). The four clinicians (**Table 1**) were part of community respiratory care team, which provides community-level care and support to respiratory patients across a certain locality. For example, they conduct daily telephone calls, home visits, and education classes to patients to support them in managing their respiratory condition. As a service, they were interested in exploring new ways to support and educate COPD patients to better understand and self-manage their symptoms. Throughout the study the clinicians supported patients’ use of the app and received weekly reports of the patients’ symptom data. We captured *both* patients’ and clinicians’ experiences on the study. However, here, we focus on the *clinicians’* experiences in supporting the patients’ use of the app and remotely receiving weekly reports of their symptom data.

THE SMARTPHONE APP

The study utilised an off-the-shelf app that had been commissioned by various respiratory services across the North West of England [10]. It had been designed based on pre-existing paper diaries that were developed by clinicians for COPD self-management in community care settings. The clinicians

Figure 2. An example daily recommendation to the patient

Table 1: Clinical study participants

<i>Identifier</i>	<i>Job Role</i>
CLIN1	Lead Physiotherapist
CLIN2	Lead COPD Nurse
CLIN3	Assistant Practitioner
CLIN4	Assistant Practitioner

in this study were interested to see how it could support their goals around improving the ways in which they assist their patients to better manage their COPD.

The app required users to fill out a short survey daily, which consisted of five symptom related questions (**Fig. 1**). This included asking the user if they had taken any respiratory medication on the prior day or contacted their health team, then proceeded to ask about potential increases in cough, sputum (phlegm) production, breathlessness, and change in sputum colour. At the end of the survey, the app labelled the ‘type’ of day that the user was having and suggested a management action (**Fig. 2**). There were four different day types: ‘no symptoms’, ‘bad day’, ‘flare up’, and ‘danger day’. In the event of a ‘bad day’, the app would recommend the user to increase their inhaler use. Whereas in the event of a ‘danger day’, the app would recommend the user to call emergency services. The users’ day types were sent digitally to the clinicians at their respiratory care service.

Table 2: Example questions asked in the initial focus group.

In what ways can the introduction of a self-monitoring app for COPD benefit your patients?
In what ways can the introduction a self-monitoring app for COPD can benefit your service and your staff?
Does the introduction of a self-monitoring app for COPD support your organizational goals?

METHODS

We first conducted a focus group to understand the lead clinicians’ (CLIN1 and CLIN2) motivations to introduce a COPD self-monitoring app in their service (**Table 2**). Next, four COPD patients from their service were enrolled onto the study and used the app for four weeks to monitor their symptoms. After this four-week period, we ran follow up interviews with all the clinicians (**Table 1**) to learn about their experiences supporting patients’ use of the app and receiving patient generated data. Both the focus group and interviews were audio recorded and transcribed. We used a thematic analysis approach by hand to analyse both datasets, which involved coding transcripts at a sentence level then comparing

Table 3: Quotes from the follow up interviews with the clinicians.

<p>CLIN1a: <i>“Patients’ perceptions of their condition can be very different, so in terms of perception of breathlessness ... it’s quite subjective.”</i></p>
<p>CLIN1b: <i>“It’s about how it [the app] applies to the local area that you are using it in ... patients were getting advice that didn’t match with what we had told them ... there are lots of national guidelines but within that there are local differences.”</i></p>
<p>CLIN2: <i>“Because we were getting the data, there’s almost a sort of professional obligation to act.”</i></p>
<p>CLIN3: <i>“They started ringing us for advice are you then doubling</i></p>

codes to build themes. The insights from the focus group data prompted the questions for the follow up interviews, scoping whether clinicians’ initial expectations had been met.

FINDINGS

Our findings revealed three key accountability concerns that clinicians faced when supporting patients’ use of the self-monitoring app as part of their service during the study.

Concerns Around Failure to Act

Simply receiving patient generated data around daily symptoms created a feeling of an “*obligation to act*” for the clinicians (Table 3, CLIN2). They had perceived themselves as accountable for taking immediate action based on the reported data. This arose from concerns that patients may depend on them to immediately detect and subsequently act on any signs of health decline surfacing from the data. Usually, if a patient experienced an unexpected worsening of their symptoms, they would be expected to initiate contact with the service. Yet, through the introduction of a shared view of patients’ symptom data, clinicians felt there was an onus on them to actively check and detect any decline in health. This was challenging, as their current workflow could not support constant monitoring of the data to meet these potential expectations. This raised concerns about potential *failure to act* in any critical situations.

Concerns Around Overreacting

Clinicians voiced how consistent symptom monitoring through subjective measurements could lead to both themselves and patients *overreacting* to the data. For example, clinicians highlighted that breathlessness was rated by the patient without any objective rating, such as a pulse oximeter reading. Clinicians noted that it is not uncommon for COPD patients to mistake feelings of breathlessness as a flare up of their condition. For example, patients may perceive breathlessness caused by anxiety or tiredness as a worsening of their COPD symptoms (Table 3, CLIN1a). When this occurred in regular practice, the clinicians would coach the patients over the phone to better recognize the root cause of their breathlessness and reassure them that they are not becoming unwell. However, the app relied on the patients’ subjective measure of breathlessness and labelled the day type accordingly. This caused clinicians to feel that the labels could lead to themselves *and* patients believing they are worsening, thus clinicians felt accountable to immediately follow up with the patient.

The Need to Verify Daily Recommendations

Clinicians felt the daily recommendations that were generated by the app did not align with the procedures in their local practice. They noted how the app provided generic advice to patients, when their approach was to “*individualize care*” (CLIN2) depending on patients’ lifestyle, condition stage, and national guidelines. For example, inhalers and their dosages varied per patient. While referring to one of the recommendations to ‘increase inhaler use’ (Fig. 2), CLIN1 argued “*you can’t give standard advice, even about that*” and that such advice required background knowledge of the patient, paired

with clinical judgement. As recommendations did not always align with the advice they had previously given to the patient (**Table 3**, CLIN1b) clinicians felt distrustful, and received telephone calls from confused patients asking for clarification on the advice (**Table 3**, CLIN3). This added to the daily workload around supporting the app's use, as they became accountable to verify the recommendations.

DISCUSSION AND CONCLUSION

Our findings have unearthed how the introduction of patient generated data into the community respiratory service created accountability concerns for the clinicians. This created unforeseen strains on the clinicians' daily work, as they had to correct or clarify aspects of the patient generated data and the daily recommendations with the patient. This resonates with previous work that suggested decreasing clinicians' perceived liability and responsibility for patient generated data can maximize their acceptance of patient monitoring technologies [3, 14]. Moreover, accountability concerns around patient data have been explored by Murphy and Reddy [6] in the context of hospital staff addressing patient related information problems, such as inaccuracies in patient records. Our work extends this notion of accountability by showing how it occurs when clinicians receive patient generated data.

Hartswood et al. [7] discussed how users' perceptions of the reliability of evidence that is generated by decision aids affects their trust around its use. We saw how clinicians distrusted the recommendations provided by the app due to its standardized nature, which contrasted with their individualized and localized approach to patient care. As clinicians could not rely on these recommendations being appropriate, they became accountable to correct them. Our findings further the demand to recognise such contextual differences when designing self-monitoring technologies for chronic conditions [11, 12, 13]. We have identified how accountability concerns arise when clinicians support patients' use of self-monitoring technology. We are continuing to explore how such technology and patient reported data can be best used by both patients and clinicians to enhance COPD care.

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