A Formative Evaluation of an eHealth Service for Patients with COPD

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Abstract. The number of people suffering from chronic conditions such as COPD is increasing globally because of demographic changes worldwide. People suffering from severe stages of COPD commonly experience exacerbations leading to hospital admissions. Telehealth solutions can be used as a means for improved healthcare delivery to this patient group with a possible impact on preventing COPD exacerbations and hospital admissions. We conducted a pilot study where patients with COPD were offered an eHealth service from the hospital for three months. The eHealth service involved the patients reporting daily on fixed health parameters, which they sent to the clinic through an eHealth tablet computer application. Nurses at the clinic received the patients' reports on a computer-based system and provided follow-up based on these reports. We here report from a formative evaluation of the pilot study, where data collection was done through workshops with patients and healthcare providers, and where participatory design approaches enabled active engagement and involvement of the users in evaluating the service and proposing future adjustments of the solution.

1 Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the leading causes of mortality and morbidity worldwide and is the fourth leading cause of death [1]. People suffering from severe stages of COPD commonly experience exacerbations leading to hospital admission; for some, this occurs several times a year [2,3]. Such hospital admissions are associated with deteriorated health status of the individual and involve considerable health care and societal costs [1,4]. One main objective in COPD management is to improve or preserve the patients' health status. Increasingly, patients with COPD are being managed at home to reduce health related costs while trying to increase their comfort [5,6]. The use of Internet based tools and eHealth solutions have increased in the last decade and

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people use these to search for information, manage their own health and illness, and communicate with peers and healthcare providers [7]. As the populations' competence in using such tools increases, people suffering from chronic diseases use these as important resources in their daily lives. It is expected that healthcare services will increasingly implement and adapt to using eHealth solutions to facilitate patients at a distance and provide quality care services in a cost-efficient manner.

Participatory design is an approach where various stakeholders are actively involved in the design process to identify, create and ensure that new solutions are according to their needs. Such approaches are randomly used in the design of eHealth services, resulting in solutions that fail to engage the end-users, and that lead to low adaptation and use. Health care is a complex domain with unforeseen incidents, changing use contexts and multiple stakeholders with specific needs, interests, roles, expectations and power. These factors are important to take into consideration when designers design and develop solutions for this specific domain.

The HelsaMi innovation project comprised of the development of an eHealth service for integrated care at home for patients with COPD. The overall project aim was to improve the efficacy and quality of the health services while improving the patients' quality of life. In the project, a new health-care service was proposed, involving eHealth follow-up of patients with COPD. We here report from a formative evaluation as part of the first pilot study in the project, where the eHealth service was implemented in a specialist healthcare clinic and offered to patients. The objective of the formative evaluation was to improve the project's design and effects, to understand which parameters influenced use and usability, and to understand internal and external factors that might influence the project.

2 Methods

The pilot study was carried out in spring 2014 and lasted for three months. The evaluation comprised of workshops with the nurses and patients that had participated in the pilot study. The Norwegian Social Science Data Services approved the study and all participants provided written informed consent at participation.

2.1 The pilot study: 'HelsaMi' (MyHealth)

The pilot study involved five patients (three men and two women) enrolled to participate and receive the eHealth service from the hospital for a period of three months. Two nurses who were specialized in respiratory nursing at the clinic were responsible for handling the received patient reports and providing follow-up to the patients. In addition, respiratory physicians were available for decision support.

The patients were included in the study when they were discharged from hospital after an incidence of COPD exacerbation. The eHealth service involved the patients sending daily health reports through a tablet computer application (app) to the clinic. The eHealth app included predefined questions about health-related parameters (e.g. respiration, expectorate, use of medications etc.) which the patients were to report on. The patients were instructed to send their health reports every working day (Monday– Friday) before noon, a timing that was set to ensure that the clinic could handle and provide follow-up to the patients during office hours. The clinic was closed during weekends; this also applied to the eHealth service.

The nurses at the clinic had the responsibility of receiving the patients' health reports, evaluating them and providing further follow-up to the patients if required. To access the patient reports, the nurses logged into a Web-based portal, which they accessed through their stationary computer at the clinic. Since the nurses were not merely stationed in the office during their working hours, they could also receive patients' reports on their mobile phone, for immediate evaluation.

2.2 Participants and data collection

Data collection involved two separate workshops with the involved stakeholders, in total five participants: one with the nurses (n=2) and the other with patients (n=3). All patients (n=5) in the pilot study were requested to participate, but two were prevented from attending. The workshops lasted 60–120 minutes, were audio-recorded and parts of the recordings were transcribed verbatim. Participatory design (PD) activities such as brainstorming sessions, sketching and plenary discussions were conducted as part of the workshops. Evaluating interface design and creating redesign proposals were also included. Two researchers facilitated each workshop, where one had the responsibility to lead the conversations and facilitate the design activities, while the other had the responsibility to make notes. The material was analyzed inductively.

3 Results

The analysis revealed four main themes: (1) the healthcare professionals mapping of the patients' health status and needs; (2) the importance of the professionals' qualification and competence regarding facilitating patients through such an eHealth service; (3) the patients' experience that the eHealth service is safeguarding; (4) usability and the requirement for added features of the eHealth system.

3.1 Mapping the patients' health status and needs

The patients sent their health reports based on a subjective evaluation of their health status by answering a set of predefined questions. The nurses reported that the information they acquired about the patients through the app was minimal for being able to do a sufficient evaluation of the patients' health condition. In cases when a patient reported that his/her health condition was as normal or as usual, the nurses did not conduct any further actions. If a patient reported on symptoms of change in health status, the nurses required additional information to get a sufficient understanding about the patient's condition. In these cases, the nurses would contact the patient by phone to obtain further information:

> *"We ask about much more, because if they have heavy breathing; we check or ask if they have chest pain; if their feet are swollen; and find out if it can be something else." (nurse)*

The nurses conveyed that the phone call provided valuable non-verbal information about the patients that they did not capture in any way other than by talking to the person; by listening to the patient's tone of voice, the respiration (breathing) and coughing, the nurses acquired additional information that was relevant to attain a sufficient understanding about the patient's situation. When asked if additional questions could be included in the technical solution in the app to elucidate these aspects, the professionals did not consider it necessary. They elaborated that they would prefer to contact the patients by phone for a further investigation anyway: *"no, those questions do not need to be in the app"* (nurse).

Patients suffering from COPD commonly have several comorbidities. This was also the case for those participating in this study. The patients expressed that they found it difficult to merely report on one disease, as they had several illnesses which might affect the other and thus cause a change in health status and illness deterioration: *"It* *feels awkward to merely report on COPD […] One thing affects the other"* (patient). As a result, the patients would prefer to report on more general parameters or questions about their health, and not merely be limited to COPD related parameters/symptoms. Further, the patients conveyed that a COPD exacerbation could occur in various ways for the individual, with a great specter of individual variations, not always appearing with the standard symptoms of such exacerbations. Due to this fact, the nurses underlined the need for acquiring more information, thus having a telephone conversation with the patients to identify the cause of the reported health deterioration and symptoms. The combination of information from the app together with a follow-up phone call became the standard procedure to map the patients' situation sufficiently.

Hvordan er dagsformen?

○ God

● Dårlig

○ Veldig dårlig

Fig. 1: Illustration of the graphical interface of the tablet application used in the pilot study.

3.2 Professionals' qualifications and competence

The nurses that were responsible for managing the patient reports were specialized in respiratory nursing. Being able to consider various factors that could influence the patients' situation by the professionals was crucial to be able to evaluate the patients' health condition. If a patient had reported on illness deterioration or on symptoms of worsened health condition, the nurses would use the subsequent telephone conversation as an additional source to map the person's condition:

> *"The one that talks with them (patients) needs to be*

> *experienced, that you both listen… it is good to hear when they talk, if they are breathing heavily, hear if they cough… […] and I check what medications they have taken, what kind of inhalations, perhaps they haven't taken it at all… different things*." (nurse)

Their personal experience of working with this patient group would influence the way the nurses would conduct the telephone conversation with the patient:

> *"We start [the phone call] with repeating what they have registered, [I say] that I see that you have reported that you are like this and that… how are you actually? And then they explain from that. And then we ask the additional questions. The first thing is to check according to the differential diagnosis*." (nurse)

However, in cases where the patients had reported on illness symptoms, the nurses reported that they needed decision support in quite a few cases and stated a need for decision support from the pulmonary physician in about 50% of instances during the study period. They elaborated that the need for decision support was primarily in cases concerning initiating or dose adjustments of medications.

The patients on the other hand, expressed that they very much appreciated the way they were approached and handled by the professionals. They reported having full confidence that their needs were addressed and that the decisions made would be correct.

3.3 The eHealth service as safeguarding

The new eHealth service involved increased accessibility to healthcare professionals and specialist healthcare that was valued by the patients. One of the nurses experienced this in her daily work: "*We have our office phone (cell phone) with us all the time, so they can call us. And they do call*" (nurse). The patients experienced that this service made them feel safe. This was emphasized as safeguarding because of the way the service was designed, with the health professionals making contact with the patient if s/he had reported feeling ill through the tablet application. One of the participants expressed: "*Because of my health condition, the app is my safety in my daily life*' (patient). The service was particularly appreciated by those who lived alone and who did not have a shared household with anyone. All the patients conveyed that they experienced it as reassuring that someone else knew how s/he was coping, which made them feel safe and catered for. The nurses occasionally experienced not receiving the patient report before noon, if so, they would contact the patient by phone to check that everything was okay:

> *"It depends, the same day at least, but they are supposed to report before noon or one o'clock. It says that in our protocol. So, we follow that, so I call, I consider… half past one, or one o'clock. I call in sufficient time before the working day is over. To check, give them a chance to…" (nurse)*

The patients experienced that it was reassuring to be contacted by phone if they had not reported through the tablet application. The nurses reported that they had experienced that patients had not been able to deliver their daily report through the tablet app because they were in bad shape. In other instances, the users had just forgotten to report. All the patients described being sincerely satisfied with the follow-up and care they attained during the pilot study period.

3.4 Usability and added features

The patients reported that the app was easy to use and time efficient, as one participant said: "*I think it is good as it is. Honestly*" (patient). However, when going into details about the app and when presented with alternatives for how questions could be visualized, the participants reported that they would prefer more graphical illustrations and not merely text based questions. The patients could be categorized as novice users, with limited experience with the Internet, applications and online solutions. Therefore, they had low expectations and little to compare with considering what to expect. However, both patients and professionals remarked that the text used in the app could be improved to avoid misunderstandings. Further, they reported that some of the questions about medication were imprecise and could lead to misunderstandings; they were to report if they had taken their 'standard medication', but what each individual considered this to be differed from person to person. The participants created sketches of suggested app features, such as exercise and information videos, and social networking features. The nurses informed of several technical challenges, some more critical than others, which had been identified during the pilot study. These had been adjusted continuously but needed further improvements. The graphical user interface (GUI) of the receiving system in the clinic was easy to use, but required improvements for increased usability. Particularly, the GUI of the patient reports on the recipients' cellphones needed improvement. The cell phones appeared to be a crucial working tool for the nurses due to their mobile working situation: "*It is important that we receive [the patient reports] on the cell* *phone. We are not stationed here all the time*" (nurse). They considered the GUI of their stationary (pc) access to the patient reports as satisfying, as one of the nurses expressed: "*I don't use it much, NN [the other nurse] checks every day, so I only do it the few days she is not here. And so… if I can manage to use it, then it is quite good.*"

4 Discussion

The findings from this formative evaluation revealed some important aspects concerning both interaction design and service design of the HelsaMi-solution for patients suffering from COPD. By using PD approaches as part of the workshops we could identify the participants' experiences and improvement suggestions of importance. By using a combination of individual brainstorming activities and plenary discussions, we allowed the participants express their experiences and perspectives that otherwise might not have come to the surface. Commonly in such workshops some participants are more verbal and engaged than others, taking more attention on behalf of those who are more silent and shy. Considering small-scale pilots in healthcare, such as the one described in this project, presupposes acquiring the views and voices of the participants to evaluate and give directions for the next phase. Using PD approaches are useful but require consideration for those involved. We observed that some participants had difficulties participating in the more creative tasks, such as drawing suggestions for a redesign of the app, but were easier to engage after being presented with some suggestions that could trigger their creativity and discussions. This implies that the use of various techniques is important to accomplish the planned PD-activities. This understanding complements previous experiences of using PD-techniques with patients [8].

Our results revealed the need for improvements of the GUI of the patient application and the receiving system at the clinic. These requirements were of both aesthetical and functional character. Such need for improvements could have been identified by usability testing of the eHealth solution earlier in the development process, and thus prevented technical hustle during the pilot study. This finding underlines the importance of structured usability testing early in a project. The fact that the nurses required additional information from the patients by phone, supplementing the received info through the eHealth app, emphasizes the need to plan sufficient resources and time to conduct essential activities that result from introducing new tools such as eHealth solutions in clinical care. Considering the nurses' high need for decision support reveals the necessity of having qualified personnel that have the competence to identify specific illness symptoms, and thus enable decision support to implement interventions. This implies the requirement of having qualified personnel to receive and handle such patient data and information, but also the importance of having qualified decision support available. The tested eHealth solution was based on self-reported patient data, but for further studies, it would also be interesting to add objective data measures from the patients, such as pulse oximetry, body temperature etc. to supplement the patient self- reported data. These could act as mediators for the professionals to facilitate decision support. The service was considered valuable and important for the participating patients, and indicates that an eHealth solution for COPD management and follow-up has potential for positive outcomes, particularly regarding feeling safe and concerning quality of life for this patient group. This study is limited to its qualitative approach and the results cannot be generalized. Nevertheless, the study provides some implications about using PD - approaches as important means to reveal users' experiences, perspectives and demands that are important for system and service design of eHealth solutions in COPD management. Further studies are needed to explore the potential and impact of using eHealth solutions in integrated health services for people with COPD.

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