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A qualitative study of COPD-patients' experience of a telemedicine intervention

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ABSTRACT

Background: Clinically stable patients with chronic obstructive pulmonary disease (COPD) are often followed at regular intervals regardless of the needs. Our aim was to investigate the patient perspective on receiving telemedicine with weekly submission of readings and regular video consultations (Net-COPD) as an alternative to visits in the respiratory outpatient clinic and investigating the role of telemedicine in management of severe COPD.

Design: Descriptive design and the method is qualitative based on semistructured interviews.

Methods: Fourteen intervention patients participated from the Danish randomized clinical trial Net-COPD project. The transcribed interviews were analysed using manifest and latent content analysis.

Findings: Participants reported that Net-COPD brought enhanced wellbeing and a sense of security in knowing that nurses kept an eye on them and initiated appropriate interventions in case of changes in the patient's condition. This was experienced as a lifeline to the respiratory outpatient clinic, which could be contacted when needed. Through monitoring, moreover, patients developed increased awareness and better self-management of their disease. Patients also experienced more focused and less stressful meetings via video consultations, than in respiratory outpatient visits. Nevertheless it was important that it was the same health staff patient met in the video consultations.

Conclusion: Participation in telemedicine increased the patient empowerment primarily by the sharing of data with a permanent staff of nurses. This knowledge was used to keep control of the disease in the form of extra readings and the systematic use of learned initiatives. This gave patients and relatives a sense of security.

1. Background

There are approximately 400,000 people in Denmark with chronic obstructive pulmonary disease (COPD), of whom approximately 40,000 suffer to a severe degree [1]. Annually, roughly 18,000 patients attend outpatient clinics, on average twice, while about 25,000 are hospitalized with COPD exacerbation, of whom 14% are readmitted within 30 days [2]. With such a large patient group and consequent increased demands on the health services, initiatives are called for to involve patients, prevent occurrence and optimise resources. Telemedicine offers significant potential for contributing to the political health agenda. Thus, in 2011 the Regions of Denmark [3,4] drew up a tele medicine strategy as a solution to the dilemma arising from a growing elderly population, many with chronic disorders, a health service with an increasing number of treatment options and a society with fewer economic resources and a demand for increased effectiveness. Telemedicine is expected to give patients greater insight into and understanding of their own disease, increased possibility of participating actively in their treatment and more responsibility for their own health, in other words increased empowerment [3,5].

The Danish randomized clinical trial (RCT), the Net-COPD project (n = 281) was launched with the hope of increased effectiveness by replacing routine check-ups in respiratory outpatient clinics with video consultations, thereby creating better and more coherent patient pathways through telemedicine, counselling and treatment as well as saving the patients' time and resources by eliminating tiring travel [6]. The RCT study found no effect of telemedicine on admission rates, but a survey administered to the participants indicated that it was an attractive alternative to visits to respiratory outpatient clinics. The authors called for more studies on the role of telemedicine in follow-up of COPD patients.

Earlier studies on telemedicine for COPD-patients have shown modest but disparate results and have chiefly investigated the patient's perspective quantitatively using questionnaires focusing, for instance, on quality of life, anxiety or depression [7,8]. Cartwright et al. [7] did not find any effect on these issues in their randomized controlled study

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(n = 3230) in the UK, which, included patients with COPD, diabetes and heart failure. Unfortunately no subgroup analysis was made for COPD patients. McLean et al. [8] concluded in their systemic review of 10 RCT studies that telemedicine may have a positive effect on COPD-patients' quality of life as well on the number of hospitalizations and visits to casualty wards. However, the telemedicine was often supplemented by other interventions, such as access to a complete COPD case management programme including patient education and frequent face-to-face consultations and telephone follow-ups by the case manager. Hence, the impact of telemedicine in particular was not distinguishable. The authors recommended further qualitative studies to illuminate this issue.

The attitudes of Danish COPD-patients and their experiences of telemedicine have been only sparsely illuminated. A survey [9] in 2013 among 208 members of the Danish Lung Association with COPD found that 70% wished to make use of telemedicine solutions in their treatment. Half of the 208 believed that it would optimise the treatment, and also that telemedicine solutions offer opportunity for the more active patients.

There exist only few qualitative studies on telemedicine treatment of COPD-patients, two of them from Denmark [10,11]. In these studies the intervention was brief and directed at COPD-patients hospitalized with exacerbation in the period following their discharge. Where Sorknæs et al. [10] found that patients became more active in managing their own treatment, Ballegaard et al. [11] found in their field study on patients use of telemedicine an increased sense of security in the patients, who experienced improved skills in interpreting readings and recognising signs of exacerbation. The main goal of the two studies was not, however, to investigate the patient experience of the telemedicine solution.

There are three qualitative foreign studies [12–14] which, however, did not include video consultations. Patients in these studies sent in a daily symptom score questionnaire and weekly readings.

In conclusion, the patient perspective of telemedicine has been sparsely investigated for COPD patients, and that mainly in quantitative studies or in studies focusing on short-term use of technology immediately after discharge from hospital in relation to exacerbations. However, to understand fully the barriers for acceptance and use of technology, and the patients wishes and capabilities for participation in self-management of COPD by the use of technology, insight is needed into the patient experience of telemedicine use over time and in stable periods.

2. Objective

The aim of this study was to illuminate stable COPD patients‘ experience of participating in a 6 month telemedicine intervention substituting visits to the outpatient clinic.

3. Methods

The design is descriptive and the method is qualitative based on semi-structured interviews [15].

3.1. Participants

Participants in our study were recruited from the intervention group of a larger RCT study, the Net-COPD project (n = 281) [6].

3.1.1. The Net-COPD project

The RCT study (n = 281) [6] included patients from four university hospitals with specialised pulmonary wards. Eligible patients were stable ones from the outpatient clinic with severe and very severe COPD and at high risk of exacerbation. Patient with an episode of exacerbation requiring a change in medication three weeks prior to enrolment were excluded. Patients were divided into three groups before randomization: 1) Hospital admission for COPD in the previous year; 2) Hospital admission for COPD in the previous 3 years, 3) long-term oxygen therapy (LTOT) regardless of the number of admissions.

Nurses from the outpatient clinic identified patients with stable COPD followed regularly at the outpatient clinic and telephoned to ask if they would participate. They made an appointment where patients who agreed to participate were informed about the Net-COPD study. They were randomized to either the intervention group or usual care and the intervention group was introduced to the equipment.

Each patient was given a tablet computer with a web camera, a microphone and measurement equipment (a spirometer, a pulse oximeter and scales) and were instructed in submitting readings of saturation, pulse, weight, and changes in dyspnoea, cough and sputum colour and purulence three times a week during the first month and thereafter once a week. As an alternative to regular scheduled visits to respiratory outpatient clinics, video consultations, including measuring spirometry, was performed three times a week during the first month and once a month after that. The readings were transferred to a call centre at the patients local hospital and automatically categorized and prioritized (green-yellow-red coded). In case of one red or two yellow codes the patient was contacted by the respiratory nurse, and following a single red code or consecutive yellow codes the nurse could, if she deemed it necessary, consult a respiratory medicine specialist. The call centre was open weekdays between 9am to 3pm and staffed by a specially trained respiratory nurse.

Patients were free to take additional readings or phone the call centre in opening hours, if they deemed it necessary. The readings were recorded in a secured database to which the patient, their General Practitioner (GP) and the municipaĺs social and health workers had access.

After completion of the project patients in the intervention group had the option of continuing with telemedicine.

The present study was not included in the original Net-COPD design. It was carried out to investigate the patient perspective of the intervention, an idea originating from the nurses in one of the outpatient clinics participating in the RCT.

3.1.2. Sampling strategy for the present study

A total of 14 patients were included in the study and were selected purposefully on a principle of maximum variation with reference to sex, age, forced expiratory volume in one second (FEV1), Medical Research Council (MRC) dyspnoea scale, low/high Body Mass Index (BMI), smoker/non-smoker, exacerbations or none in the project period and LTOT/not LTOT. The participants were selected from all four hospitals participating in the Net-COPD project (2 from Amager Hospital, 3 from Herlev Hospital, 4 from Hvidovre Hospital and 5 from Bispebjerg Hospital),and they were selected in collaboration with respiratory nurse specialists in those hospitals. Inclusion continued until saturation was achieved.

The 14 participating patients in the interview study represented the three groups in the Net-COPD project. The sample consisted of eight women and six men with a mean age of 69.5 years (range 55–83) and is further described in Table 1.

The interviews were conducted in the period 30.01.2015 – 12.03.2015.

3.2. Collection of data

The 12 participants who still had the telemedicine equipment were interviewed via a video link on their tablets. This was done to lead the participants' thoughts to the advantages and disadvantages of telemedicine and to obtain an insight into their experience with participation in telemedicine. The remaining two were interviewed in their own homes as they had ceased receiving telemedicine. All interviews were conducted by first author on the basis of an interview guide, to ensure that relevant fields were covered. The interview guide covered