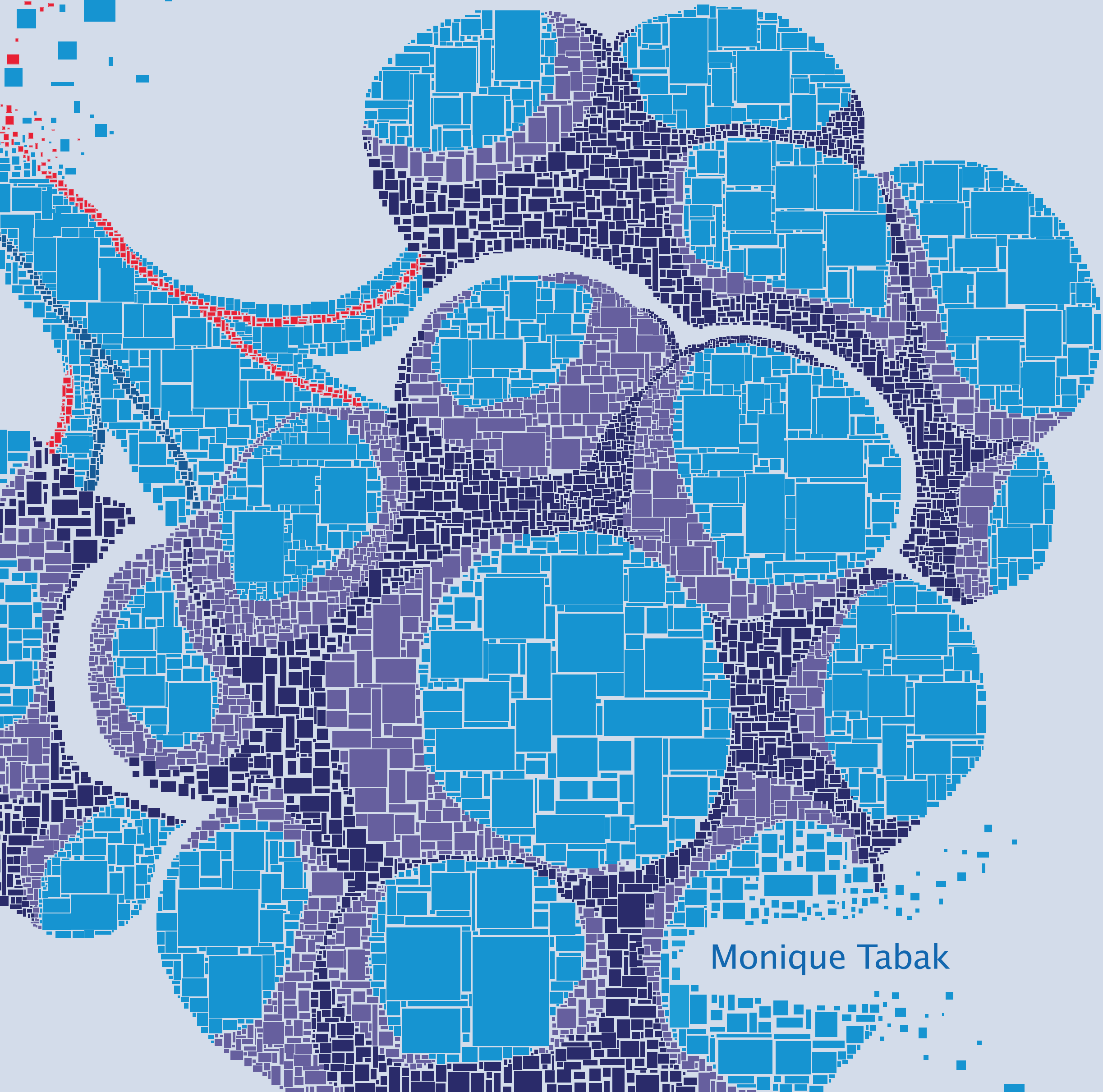
TELEMEDICINE

FOR PATIENTS WITH COPD

New treatment approaches to improve daily activity behaviour



Monique Tabak

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NEW TREATMENT APPROACHES
TO IMPROVE DAILY ACTIVITY BEHAVIOUR

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Contents

CHAPTER 1
General introduction

COPD & physical activity

Chronic Obstructive Pulmonary Disease (COPD) is a highly prevalent condition that has a large effect on physical, psychological and social functioning.[1, 2] COPD counts for 5% of all deaths globally and will become the third leading cause of death worldwide in 2030.[3] Especially the hospital admissions due to periods of acute worsening of the patient's condition – exacerbations[4] – constitute a major problem in the management of the disease due to their negative impact on prognosis and costs.[5, 6]

Chronic Obstructive Pulmonary Disease is defined as "*a common preventable and treatable disease, characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients".*[7] The chronic airflow limitation is caused by a mixture of small airways disease (obstructive bronchiolitis) and parenchymal destruction (emphysema), the relevant contributions varying from person to person. The main risk factor of COPD is smoking of tobacco products, although non-smokers may also develop COPD.[8] COPD has a progressive course, especially in patients who continue to smoke,[9] and it influences quality of life drastically, causing primarily shortness of breath (dyspnoea), chronic cough, and chronic sputum production.[10]

Patients with COPD often restrict activities due to dyspnoea (during exertion), which leads to an inactive lifestyle. This is thought to be part of a vicious circle of symptom-induced inactivity, leading to a lack of fitness and a reduced quality of life,[11] which may be accelerated by acute exacerbations.[12] Physical activity is defined as the totality of voluntary movement, produced by skeletal muscles during everyday functioning and includes exercise.[13] Regular physical activity is known to be positively associated with a reduction of the risk of hospital (re)admission,[12, 14, 15] increase of life expectancy,[16] as well as slowing the rate of decline in lung function.[17] In this thesis, daily activity behaviour is defined as the way someone acts in relation to physical activity in daily life. The importance of promoting physical activity in daily life is underlined by several studies showing the inactive behaviour of COPD patients compared to healthy individuals, e.g.[18-25] For the above-mentioned reasons, several (inter)national guidelines advise to promote physical activity in daily life.[7]

Treatment of COPD

The treatment of stable COPD is aimed at reducing symptoms (relieve symptoms, improve exercise tolerance, improve health status) and reducing risk (prevent disease progression, prevent and treat exacerbations, reduce mortality).[7] The therapeutic approach includes both pharmacological and non-pharmacological treatment, although smoking cessation is the single most effective intervention to influence the natural history of COPD. In addition, all COPD patients advantage from exercise training programmes and from regular physical activity, which should frequently be encouraged to remain active.[7] In the Netherlands, both community-based physiotherapeutic exercise programmes and pulmonary rehabilitation programmes aim to improve activity levels through exercise and teach patients to deploy a physically active lifestyle. Pulmonary rehabilitation is defined as *"a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies, which include, but are not limited to, exercise training, education and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviours".*[26] Although it is shown that strategies like exercise training can indeed improve exercise capacity, quality of life and reduce dyspnoea on exertion,[27] (post-)rehabilitation programmes do not guarantee a change in activity levels in daily life.[28-30] As such there is an emerging need for interventions that aim at sustainable lifestyle change characterized by increased physical activity and less sedentary behaviour.

There are a number of elements that could contribute to the fact that current programmes often do not improve daily activity behaviour in COPD.[28-30]

1) In current care, patients are not fully aware of their activity behaviour as objective measurements of activity in daily life are mostly lacking.[30] Patients need to be aware of their activity behaviour; otherwise treatment is unlikely to be effective.[31] The ability to understand the activity behaviour and the willingness of the patients to change is important for the success of any treatment aiming to improve daily physical activity of COPD patients.
2) For professionals, objective information on the daily activity behaviour of their patients is essential as this is used as input for feedback to the patient and to provide direction for treatment. Therefore, professionals need to be aware of the patients' individual activity behaviour. However, in current

care this insight is not available causing that the feedback is not optimally tailored to the individual patient.

3) Thirdly, patients do not receive feedback and coaching in daily life, only at regular encounters in the healthcare clinic. Once at home, the patient has to put this into practice by him/herself. However, adherence with home exercising is low[32, 33] and daily activity levels do not improve.[28-30]
4) Exercising and daily activity behaviour is complicated by exacerbations in patients with COPD. Exacerbations (and chest infections) were reported to be an important barrier to exercise in a post-rehabilitation study[34] and result in immediate and prolonged activity limitation.[35, 36] However, patients often do not report episodes of exacerbations to their healthcare provider, thereby potentially delaying treatment.[37]
5) Finally, one has to take into account that the optimal management of COPD is complex due to a heterogeneous picture of progressive deterioration as well as the great variation in symptoms, functional limitations and well-being that patients with COPD experience.[35, 38, 39] This emphasizes the need for advances towards more personalized medicine and tailor-made treatments in COPD.[40]

Interventions that ensure appropriate monitoring and treatment in daily life, in order to gain insight, provide tailored feedback to both patient and care providers, and support early detection and fast treatment of exacerbations, could potentially contribute to improving daily activity behaviour in patients with COPD. Information and communication technologies could be used to shift the intervention to the daily environment (telemedicine), to help patients manage their disease in everyday life.

Telemedicine in COPD

In contrast with the clinical setting of classical therapy, telemedicine interventions can provide objective and quantitative insight in daily life activities by using technology, like motion sensors and smartphones. The present status however is that only a small number of telemedicine interventions aim at supporting patients in daily activity or home-exercise programmes, thereby showing mixed results (Table 1: an overview of studies from 2006 to 2013).

A number of these studies used activity sensors for monitoring activity behaviour. In one study,[41] the activity data was evaluated by a physician, while in the other studies pedometer feedback was applied to increase physical activity levels within an exercise counselling intervention.[42-44] The applied pedometer feedback provided the number of steps, and in addition patients had a daily or weekly goal and received weekly reinforcement texts. However, the interventions were partly successful in increasing activity levels compared to regular care[42, 43] and the additional coaching by reinforcement texts did not seem beneficial.[44] A reason could be that the feedback was not sufficient as it did not provide insight into the activity behaviour during the day, nor did the patient receive advices on how to improve the activity behaviour real time. We expect that real-time ambulant coaching on activity behaviour could provide a more intensive treatment and could therefore have a more powerful influence on the daily activity behaviour of patients with COPD.

Some studies used technology to support specific exercises: i.e. walking exercise by way of preinstalled music tempos on a cell phone[45, 46] and high-intensity interval exercises to be performed at home by means of video.[47] Both studies showed significant improvements in the incremental shuttle walk test, and high compliance was reported by the group that used music pacing on their smartphone. Thus telemedicine applications can motivate patients to do specific exercises. Perhaps especially due to the combination of daily reminders via telephone follow-up that were provided in the first 3 months in case the exercise was not performed.[46] However, in these studies all patients received the same set of exercises. Motivation might be further increased when the exercises programmes are more individualized and tailored to the user.[29]

Nguyen et al.[48, 49] used a tailored exercise and activity plan with biweekly personalized reinforcement and feedback. However, daily activity was not monitored by activity sensors – only exercise by self-report – and the feedback was provided via emails from a nurse. The main focus of the intervention was on the self-management of dyspnoea. In self-management programmes, patients acquire the skills needed to carry out disease-specific medical regimens and to guide change in health behaviour to help control their disease and improve their well-being.[50] The programme of Nguyen et al. showed to improve self-efficacy and patients were highly satisfied with the received care. The incorporation of self-management in telemedicine interventions could thus potentially contribute to the treatment effectiveness in COPD and might be translated towards other aspects in treatment. This might especially apply to the self-management of exacerbations: previous studies, without using technology, showed that patients with COPD were well able to manage their exacerbations, which made timely treatment of exacerbations possible, thereby reducing exacerbation duration, hospitalizations and associated costs.[51, 52]

Nevertheless, dyspnoea was not significantly improved as a result of the dyspnoea self-management programme compared to regular care. A possible explanation is that patients performed more activity with the same amount of dyspnoea.[48] The authors suggest that reductions in dyspnoea may not be the best target for the intervention and physical activity is probably a better primary outcome.

Moreover, the only difference between the technology-supported programme and the face-to-face programme was the mode of delivery.[47, 48] Active involvement of a nurse was still needed for providing feedback to the patient albeit now via an email. The same can be observed in other studies that incorporated monitoring or early recognition of worsening symptoms.[41, 44] Healthcare professionals were needed for final interpretation of the monitoring data and feedback to the patient, which might slow the treatment process. Technology could partially automate this process, by using decision-support technology and automated feedback to the patient for early detection of worsening symptoms and an efficient coaching to support self-management.

Aim & outline of the thesis

The aim of this thesis was to study whether telemedicine can promote daily activity behaviour and support patients with COPD in their self-management. We expect that the application of personalized, tailored real-time feedback, provided by technology, can contribute to better activity behaviour in patients with COPD. Furthermore, we expect that the use of technology can facilitate the self-management of COPD exacerbations.

As there is limited insight in the daily activity behaviour of patients with COPD, we first performed a telemonitoring study to gain insight in the daily activity behaviour of patients with COPD, compared to healthy controls. This study is written down in *Chapter 2.*

The outcomes of the telemonitoring study served as input for the design of the feedback of an ambulant activity coach – using an accelerometer-based activity sensor and smartphone – that aims to both increase *and* balance activity behaviour of COPD patients in daily life. The feedback consists of an activity graph, showing the accumulated amount of activity in relation to the goal, and time-related motivational cues via text messages. In ***Chapter 3*** we investigated how COPD patients respond to these motivational cues that were provided by the activity coach. The activity coach was evaluated as part of a one-month telerehabilitation intervention, which also consisted of a web portal with a symptom diary for self-management of exacerbations. In ***Chapter 4*** the effects of this intervention on health status and activity level were examined within a randomized controlled pilot trial.

The results of Chapters 2-4 were used as input for the design of a new activity coach: a new sensor was integrated and the user interface on the smartphone was improved. In ***Chapter 5*** the acceptance and usability of the new activity coach was evaluated, together with an interactive game for online exercising. Consequently, the activity coach was improved by incorporating self-learning motivational cues that can automatically choose the best timing of presenting a cue to an individual patient. The activity coach application was so far never applied for a longer period of time. Therefore, in ***Chapter 6*** the new activity coach was evaluated during a period of 3 months to gain detailed insight in long-term activity behaviour in response to the activity coach on an individual level.

Chapters 2 to 6 show the feasibility of telemedicine applications for COPD to promote daily activity behaviour and support self-management of exacerbations. With these experiences we developed a multimodal telecare programme, which was applied in both primary and secondary care. This telecare programme was completely supported by technology and consisted of the activity coach, a symptom diary for self-treatment of exacerbations, an online exercise programme and teleconsultation. The use of the nine-month telecare intervention – applied as blended care – was examined in ***Chapter 7*** in a randomized controlled pilot trial and clinical changes were explored.

Finally, in ***Chapter 8*** the findings of these studies are integrated and discussed in the context of existing literature to move towards new approaches for improving daily activity behaviour in patients with COPD.

Table 1: Overview of studies that use technology to improve daily activity behaviour in patients with COPD. Studies that only provide telephone support to monitor or change behaviour, were not included in the overview.

Study	Study design	Intervention	Technology	Outcome
de Blok et al., 2006[42]	RCT: COPD patients within rehabilitation programme IG: rehab + counselling progr. (n = 10), CG: rehab (n = 11) Duration: 9 weeks	Regular rehabilitation with lifestyle physical activity counselling: o a pedometer with activity goal, for motivation and feedback o 4 individual exercise counselling sessions by therapist using motivational interviewing	Yamax Digi-Walker SW-200	IG: +1430 steps/day, CG: +455 steps/day, p = 0.11. No sign. secondary outcomes.
Hospes et al., 2008[43]	RCT: stable COPD patients IG: exercise counselling (n = 20), CG: usual care (n = 19) Duration: 12 weeks	Customized exercise programme to enhance daily physical activity: o a pedometer with activity goal, for monitoring and support o 5 exercise counselling sessions by therapist using goal setting and motivational interviewing	Yamax Digi-Walker SW-200	IG: +785 steps/day, CG: -1372 steps/day, p = 0.01. Sign. difference in fitness, QoL and intrinsic motivation.
Liu et al., 2008[46] Hung et al., 2007 (pilot)[45]	RCT: stable moderate to severe COPD patients IG: daily exercise endurance training at home with cell phone (n = 24) CG: daily exercise endurance training at home, without cell phone (n = 24) Duration: 12 months	Supervised endurance exercise training programme in a home setting: o daily walking exercise (IG: by music pacing on cell phone) o first 3 months: visit every 4 weeks, telephone reinforcement daily (IG), two-weekly (CG) o following 9 months: visit to clinic every 3 months, no telephone reinforcement o adherence and compliance on website by monitoring frequency & duration of exercise o education: home rehabilitation programme booklet and a DVD (CG&IG)	Java 2 Micro Edition software on Sony Ericsson K600i cell phone Data uploading through GPRS to a website	At 1-year: 92% (IG) and 38% (CG) performed daily exercise, p < 0.01 IG sign. improved ISWT distance, inspiratory capacity and QoL, with less exacerbations and hospitalizations.
Moore et al., 2007[47]	RCT: COPD patients before enrolment in PR programme IG: home exercise programme (n = 10), CG: usual care + educational booklet (n = 10) Duration: 6 weeks	Home exercise video programme: o 19 min video on benefits exercise, with physiotherapist o 30 min exercise-video, to be performed 4 times a week at home o exercise diary to monitor exercise frequency o educational booklet about COPD (both IG&CG)	VHS or DVD player and television for watching exercise video	IG: +45m, CG: -15m on ISWT, p = 0.013 and CRQ dyspnoea score p = 0.042. IG sign. improved for CRQ units emotion & fatigue.

Nguyen et al., 2013[48] 2008 (pilot)[49]	Randomized, repeated measures study Stable COPD patients eDSMP: internet-based (2013: n = 43, 2008: n = 26), fDSMP: face-to-face (2013: n = 41, 2008: n = 24), GHE: attention control (2013: n = 41) Duration: 12 months (2013), 6 months (2008)	Internet-based dyspnoea self-management programme (eDSMP): o dyspnoea and exercise consultation (face to face & training on website/PDA) o individual exercise programme based on meeting with nurse (web-based goal setting tool) o self-monitoring exercise and symptoms (PDA + web diary, reinforcement emails) o dyspnoea management education, skills training, peer interactions (web modules, group chat, bulletin board) o email alert to nurse for symptom and exercise data	PDA: Blackberry 680 (2008) Palm Treo 650/680/700 (2013) + electronic game Web-based application	2008: clinically sign. improvements in both groups in dyspnoea, exercise time, physical functioning and self-efficacy. 2013: no sign. differences between groups except arm endurance (p = 0.04). Self-efficacy better in DSMP groups.
Nguyen et al., 2009[44]	Randomized, repeated measures study Stable COPD patients, who completed 2-week run-in period. Mobile-C group: exercise intervention + reinforcement messages (n = 9), Mobile-SM group: exercise intervention (n = 8) Duration: 6 months	Cell-phone based exercise persistence intervention: o pedometer + individual exercise programme (booklet) o generic exacerbation action plan on signs & symptoms, strategies self-care → baseline meeting nurse o self-monitoring daily exercise and symptoms via cell phone, with audio alarm o nurse can review data from server, worsening symptoms flagged for follow-up to cell phone nurse, telephone/text follow-up by nurse (only Mobile-C) o automatic text message with summary of entered exercises, weekly reinforcement text messages by nurse (only Mobile-C) o standard weekly text after entering data (only Mobile-SM)	Omron HJ-112 digital pedometer Cell phone to enter data, sent real-time to central server	Mobile-SM sign. increased total steps/day compared to Mobile-C (p = 0.04), no differences in workload, 6MWD or QoL.
Pedone et al., 2013[41]	Randomized trial Moderate to severe COPD patients over 65 years IG: telemonitoring (n = 50), CG: standard care (n = 49) Duration: 9 months	Telemonitoring to reduces hospitalizations: o wristband automatically performs 5 measurements every 3 hours of HR, PA, temp, GSR o mean value shown to operator, data evaluated by physician daily o alert when out of range, physician contacts patient	wristband, pulse oximeter, cell phone, web-based software for monitoring	IG had lower rate of exacerbations (IRR 0.67) & hospitalizations (IRR: 0.66) compared to CG.

Abbreviations: RCT=randomized controlled trial, IG=intervention group, CG=control group, QoL=quality of life, ISWT=incremental shuttle walk test, 6MWD=6-minute walking distance, HR=heart rate, PA=physical activity, GSR=galvanic skin response, IRR=incidence rate ratio, CRQ=Chronic Respiratory Questionnaire.

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CHAPTER 2

Telemonitoring of daily activity and symptom behaviour in patients with COPD

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Abstract

Objectives: This study investigated the activity behaviour of patients with COPD in detail compared to asymptomatic controls, and the relationship between subjective and objective activities (awareness), and readiness to change activity behaviour.

Methods: Thirty-nine patients with COPD (66.0 years; FEV_1% predicted: 44.9%) and 21 healthy controls (57.0 years) participated. Objective daily activity was assessed by accelerometry and expressed as amount of activity in counts per minute (cpm). Patients' baseline subjective activity and stage of change were assessed prior to measurements.

Results: Mean daily activity in COPD patients was significantly lower compared to the healthy controls (864±277 cpm versus 1162±282 cpm, $p < 0.001$). COPD patients showed a temporary decrease in objective activities in the early afternoon. Objective and subjective activities were significantly moderately related and most patients (55.3%) were in the maintenance phase of the stages of change.

Conclusions: COPD patients show a distinctive activity decrease in the early afternoon. COPD patients are moderately aware of their daily activity but regard themselves as physically active. Therefore, future telemedicine interventions might consider creating awareness of an active lifestyle and provide feedback that aims to increase and balance activity levels.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a respiratory disease characterized by the progressive development of airflow limitation in the lungs, causing primarily shortness of breath (dyspnoea) and diminishing physical exertion capabilities.[1, 2] Symptomatic patients with COPD are dyspnoeic even when they perform normal daily activities, which leads to inactivity and, subsequently, to physical deconditioning.[1] A vicious cycle develops that greatly affects quality of life.[1, 2] Regular physical activity in COPD has been associated with a reduction of the risk of hospital (re)admission,[3-5] increase of life expectancy,[6] and slowing the rate of decline in lung function.[7] The importance of an active lifestyle is underlined by several studies that showed the inactivity of COPD patients compared to healthy individuals (for example[8-15]). This decrease in activity levels is not caused solely by airflow limitation, and other factors like dynamic hyperinflation and systemic inflammation seem to play an important role as well.[16-18]

In addition to increasing activity levels, a more equally distributed daily activity pattern is assumed to improve patients' well-being. In daily care healthcare professionals therefore advise their patients to plan their days and weeks carefully to use their energy efficiently, spreading chores and alternating heavy activities with light activities over the day, but these advices can be difficult to apply in daily life. Unbalanced activity patterns have been found in patients with chronic low back pain (CLBP) and chronic fatigue syndrome (CFS), showing reduced levels of activity in the afternoon and evening compared to healthy controls.[19, 20] Previous research already showed that telemedicine applications can positively influence the daily activity behaviour for patients with CLBP[21] and CFS.[22] These telemedicine interventions measure the activity behaviour by an activity sensor and provide personalized feedback messages with advice on how to improve the measured activity on a smartphone. Patients with COPD might also benefit from such applications, but detailed monitoring information about the activity behaviour of COPD patients during the day is not yet available. This should first be investigated in detail, before these interventions can be designed. Moreover, the information about whether symptoms influence this activity during the day is not yet available. This together makes it difficult to determine where to concentrate on in (future) treatment.

A prerequisite for treatment to change the activity behaviour—by increasing and balancing activity patterns—is awareness. Patients need to be aware of their activity behaviour; otherwise treatment is unlikely to be effective.[23, 24] The ability to understand the activity behaviour, the relationship with daily symptoms, and the willingness of the patients to change is important for the success of any treatment aiming to improve activity behaviour of COPD patients.

Therefore, this study aimed to investigate the activity behaviour of patients with moderate to severe COPD during the day in comparison with asymptomatic controls. A triaxial accelerometer was used to measure activity objectively. The second aim of this study was to investigate how symptoms change during the day and whether they are related to the amount of activity during the day. A smartphone was used to score symptoms during the day. Finally, we investigated the relationship between subjectively and objectively measured activity to assess COPD patients' awareness and their readiness to change activity behaviour based on the stages of change.[23]

Methods

Subjects

Thirty-nine patients with COPD (66.0±8 years; 23 male, 16 female) with a clinical diagnosis of stable COPD, that is, no infection or exacerbation in the 4 weeks prior to measurement, were recruited at Medisch Spectrum Twente hospital at Enschede, the Netherlands. A postbronchodilator spirometry recording using ERS standards was used to confirm patients' diagnosis, to measure the forced expiratory volume in one second percent predicted (FEV_1% predicted) and to classify the patients in one of the GOLD stages.[2] Other inclusion criteria were presence of dyspnoea, current or former smoker, ability to read and speak Dutch, and age between 40 and 80 years. Exclusion criteria were a rapidly declining clinical course, use of a wheelchair, use of long-term oxygen therapy, a history of asthma, any medical condition impairing the activities of daily life, serious psychiatric comorbidity, and participation in a COPD rehabilitation programme in the past 3 months.

In addition, 21 asymptomatic controls without (57.0±4.5 years; 8 male, 13 female) a history of asthma or COPD, or any medical condition that impairs normal daily activities, were recruited from staff, their relatives, and through advertisements. The same exclusion criteria applied for controls. All participants gave their informed consent.

Daily measures

Objective daily activity was assessed using the MTx-W sensor (Xsens Technologies B.V., P.O. Box 559, 7500 AN Enschede, the Netherlands), which measures 3D acceleration (90 × 45 × 17 mm, 77 g). The output measure is calculated following the method of Bouten et al.,[25] which is highly related to energy expenditure.[25, 26] The accelerometer data (output frequency: 100 Hz) was band-pass filtered using a 4th order Butterworth filter, with cut-off frequencies of 0.11 Hz and 20 Hz. The absolute accelerometer signals were integrated over 60 seconds and summed over the three axes, and the final output was expressed in activity counts per minute (cpm). For each measurement direction, sensitivity is set at 1000 counts/min, corresponding to an acceleration of 1 g. The sensor system communicated wirelessly with a smartphone (HTC P3600/3700) by Bluetooth, which stored the data on the storage card.

Both the activity sensor and smartphone were worn on the subject's belt (Fig. 1). Daily activity was assessed for four consecutive days from waking to 22:00 h. Previous studies have shown that two days of measurement are required to reliably (intraclass correlation coefficient > 0.8) measure physical activity in GOLD II patients[12] and three days in GOLD III patients.[27] Sundays were found to be a day of reduced activity and variability was higher in less severe COPD patients.[28] Therefore, a measurement period of four days was chosen in the present study, excluding Sundays. Participants were asked to continue the routine of their daily life during measurement.

Using the smartphone, the COPD patients answered questions at fixed time intervals (13:00 h, 17:00 h, and 20:00 h) during the day about self-perceived activity performance—to assess awareness—and dyspnoea and fatigue levels by means of visual analogue scales (VAS).

Fig. 1. Participant wearing the sensor on the belt and holding the smartphone.

Subjective activity and stage of change

The general self-perceived amount of activity of the COPD patients was measured using the Baecke Physical Activity Questionnaire (BPAQ) to assess activity awareness. The BPAQ covers questions about work activities, sports, and leisure-time activities (range: 3–15). The stage of change questionnaire was used to assess the patients' motivation to change their activity behaviour, according to the Transtheoretical model.[23] This defines five principle stages of change: precontemplation, contemplation, preparation, action, and maintenance. The questionnaires were administered before start of the measurement.

Data analysis

Mean activity per hour for each subject was calculated and line graphs were made that show the average activity per hour. Only those hours between 8:00 h and 20:00 h, for which at least 50% of the data for that particular hour was available, were included in the analysis. Data points could be missing due to the following: 1) the device was switched on/off in the middle of an hour (e.g., at waking, or when swimming/showering), or 2) connection/battery problems. Three day parts were evaluated in the analysis: morning (8:00 h to 13:00 h), afternoon (13:00 h to 17:00 h), and evening (17:00 h to 20:00 h). For the VAS questions, the mean VAS score for each subject per day part was calculated, and line graphs were made that show the average VAS scores per day part.

Statistical analysis

The Statistical Package for the Social Sciences (SPSS, 18.0) was used for statistical analyses. The results are described in terms of mean (SD) or percentage. For all parameters, the mean of the measurement days per subject was used for analysis. Data on activity was normally distributed and comparison between the two groups in mean daily activity and activity levels were performed using the independent t-test. When comparing more than two categories, analysis of variance (ANOVA) with Sidak post hoc test was used or the Kruskal-Wallis test with post hoc Mann-Whitney U tests with Holm-Bonferroni correction, as appropriate.

The Pearson product-moment correlation coefficient was calculated to evaluate the relationships of the objectively measured daily activity with continuous variables (e.g. age) or subjective daily activity (BPAQ). For comparing two categorical variables (such as gender with work status), Pearson Chi-square was used.

For the subject characteristics we investigated possible significant differences between the healthy group and the COPD group and possible significant correlations with mean daily activity. Confounding factors were controlled by using a univariate linear regression model. Effect modification of the relationship between group (COPD/healthy control) and activity was a priori suspected for age and work status. This was formally tested by including interaction terms in the regression models. In case of effect modification, data is presented in subgroups.

Results

Participants

Characteristics of the patients with COPD are listed in Table 1. The healthy control group (n = 21) had a mean age of 57.0±4.5 years and consisted of 8 males and 13 females with a mean BMI of 26.9±3.6. In this group, 52.4% were employed, and 47.6% were unemployed. There was no significant difference found for gender or BMI between the two groups. Age and work status differed significantly between the two groups (resp. $p < 0.001$ and $p = 0.006$).

Table 1. Patients' characteristics and health status.

Characteristics	n	Mean±SD	Frequency	Percentage (%)
Age (years)	39	66.0±8.1		
Gender	39			
Male			23	59
Female			16	41
FEV_1% predicted	39	44.9±15.5		
GOLD stage	39			
II			13	46.2
III			18	33.3
IV			8	20.5
Smoking	38			
Current smoker			10	25.6
Former smoker			28	71.8
MRC	38			
1			7	17.9
2			12	30.8
3			14	35.9
4			3	7.7
5			2	5.1
BMI (kg/m^2)	38	26.7±4.9		
Work status	39			
Employed			7	17.9
Unemployed			32	82.1

Abbreviations: FEV_1% predicted: forced expiratory volume in 1 second percent predicted, GOLD: Global Initiative for Chronic Obstructive Lung Disease, MRC: medical research council dyspnea scale, BMI: Body Mass Index.

Mean daily activity

Mean daily activity—the amount of activity per day—in COPD patients was significantly lower compared to the healthy controls, 864±277 cpm versus 1162±282 cpm, $p < 0.001$. Taking both groups together, mean daily activity was not significantly related to work status ($p = 0.067$), but significantly related to age ($r = -0.33$, $p = 0.009$). In a linear regression model using mean daily activity (in cpm) as dependent variable, and group (COPD/control) and age as independent variables, age did not significantly contribute to the model ($p = 0.356$). There also was no age-group interaction ($p = 0.617$). In the same manner, work status did not significantly contribute ($p = 0.506$) as confounder, but there was a work-group interaction ($p = 0.018$) meaning that work status does not influence the activity behaviour in the total group; however, within both groups the relationship between work status and activity behaviour differs significantly. Therefore, data will be presented separately for those with and without work, respectively.

Activity behaviour

Table 2 presents the mean activity for both the COPD group and the asymptomatic control group, by day, morning, afternoon, and evening, stratified for work status. Unemployed patients with COPD were significantly less active compared to the unemployed healthy controls over the entire day, as well as for all day parts. However, employed patients with COPD were equally active compared to the employed healthy controls over the entire day, as well as for all day parts.

For unemployed patients with COPD the difference in mean activity between day parts was significant for morning-evening ($p < 0.001$) and afternoon-evening ($p = 0.012$), and reached borderline significance for morning-afternoon ($p = 0.056$). The mean activity for the three day parts was not significantly different for employed patients with COPD ($p = 0.336$), employed controls ($p = 0.074$), and unemployed controls ($p = 0.246$).

Figure 2 shows the mean activity per hour—the daily activity pattern—for the patients with COPD and asymptomatic controls, stratified for employment status. The COPD group showed a dip of lower activity in their daily activity pattern in the early afternoon. This dip occurs in the activity pattern of COPD patients both with and without work. This dip does not occur in the control group.

Table 2. Mean daily activity in counts per minute in COPD patients (n = 39) and controls (n = 21), stratified for employment status (COPD: employed (n = 7) / unemployed (n = 32), controls: employed (n = 11) / unemployed (n = 10)).

		COPD patients	Controls	95% CI	p value
Day	Employed	1066±409	1091±187	-323; 274	p = 0.865
	Unemployed	820±225	1241±352	-611; -231	p < 0.001
Morning(8-13h)	Employed	1165±545	1087±307	-344; 501	p = 0.699
	Unemployed	958±281	1382±511	-682; -165	p = 0.002
Afternoon(13-17h)	Employed	1088±369	1235±304	-486; 192	p = 0.371
	Unemployed	804±260	1241±301	-635; -240	p < 0.001
Evening (17-20h)	Employed	830±355	911±343	-438; 275	p = 0.634
	Unemployed	615±212	1078±343	-647; -279	p < 0.001

Data is presented as mean±SD. 95% CI: 95% confidence interval of the difference.

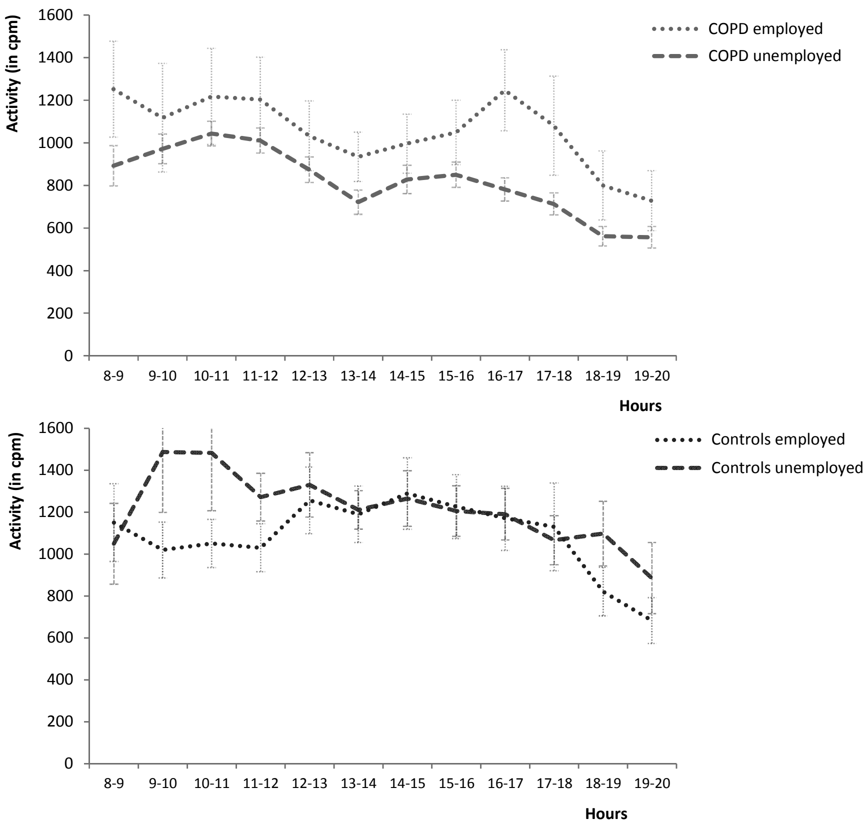

Fig. 2. The daily activity pattern in mean activity per hour (cpm) for both the COPD group and the healthy control group with standard errors of the mean.

2

Relation between physical activity and COPD symptoms during the day

Assessed by VAS questions on the smartphone, dyspnoea levels remained constant during the day (VAS morning: 2.7±1.8, afternoon: 2.9±1.6, evening: 2.9±1.8) in COPD patients. Fatigue was highest in the afternoon (VAS morning: 3.0±1.8, afternoon: 3.6±1.9, evening: 3.0±2.0), but this difference was not statistically significant.

To investigate the relation between activity and symptoms during the day, correlations of dyspnoea and fatigue with objectively measured activity per day part were investigated (Fig. 3). Both fatigue and dyspnoea levels were not significantly related to activity during the day.

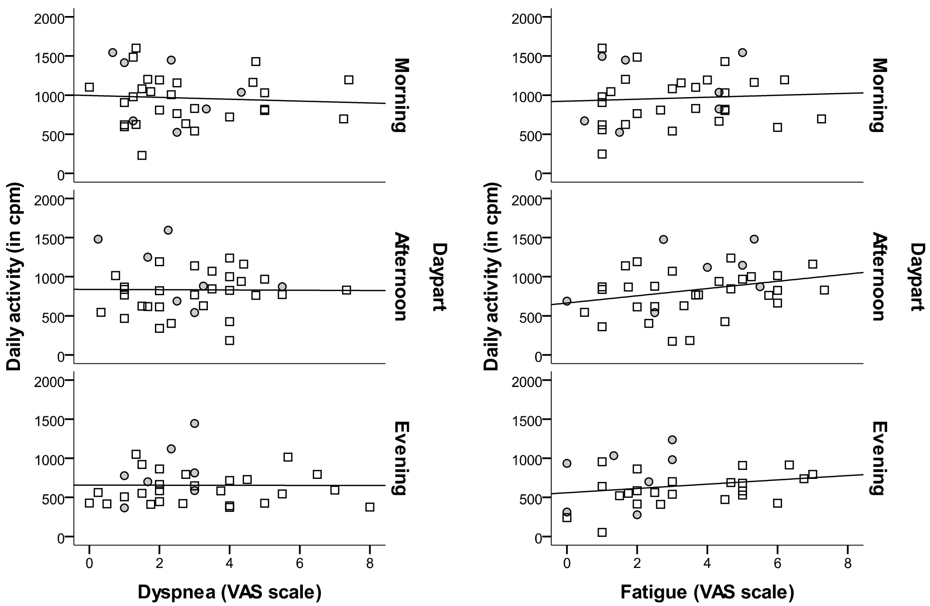

Fig. 3. Scatter plots per day part for objectively measured activity (in cpm) (y-axis) and symptom scores (VAS score, x-axis), with linear trend line. On the left this is shown per day part for dyspnoea, on the right for fatigue. Each dot represents the mean of one patient, stratified for employment.

Activity awareness and stages of change

To investigate the activity awareness of COPD patients during the day, VAS questions to rate the perceived activity were asked thrice daily. This self-perceived activity was moderately correlated to the objectively measured activity (in cpm). Morning: r = 0.54, p = 0.001; afternoon: r = 0.57, p < 0.001; evening: r = 0.56, p = 0.001.

Also, the BPAQ was measured prior to measurement, to investigate general activity awareness. COPD patients had a mean subjective activity of 6.4±1.3, which was moderately correlated to objectively measured activity: r = 0.49, p = 0.002. In Figure 4 this is shown, stratified for employment status.

With regard to physical activity, the majority (55.3%) of the COPD patients were in the maintenance phase of the stages of change model (precontemplation: n = 0, contemplation: n = 3, preparation: n = 10, action: n = 4, maintenance: n = 21, 1 missing). Using Kruskal-Wallis, the stages were not significantly related to objective activity levels (employed: p = 0.317, unemployed: p = 0.174).

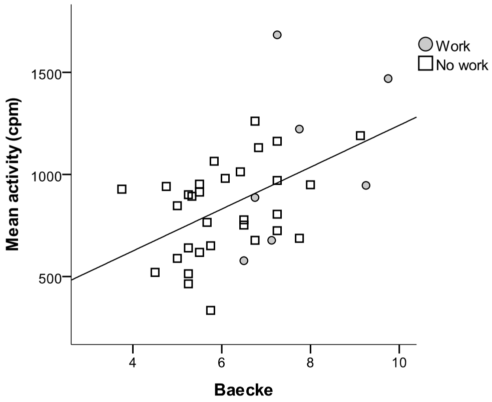

Fig. 4. Scatter plot of COPD patients for subjective activity (BPAQ) (x-axis) and objective activity (accelerometer) (y-axis), stratified for employment with linear trend line.

Discussion

The aim of this study was to investigate the activity behaviour of patients with moderate to severe COPD during the day in comparison with asymptomatic controls and the relationship with symptoms during the day. Furthermore, the goal of this study was to investigate whether COPD patients are aware of their own daily activity and ready to change their activity behaviour. This can provide a starting point for designing new telemedicine interventions that aim to improve activity behaviour for COPD patients.

The results of this study show that COPD patients are significantly less active than controls. These results correspond to findings in previous studies, showing reduced amounts of activity in COPD patients.[8, 9, 12-15] In our study, there was a large age difference reported between groups, as well as difference in employment status. However, only employment status affected activity levels in both groups, therefore results were presented in subgroups. In literature, work status of the patients was not reported,[8, 9, 13, 15] only unemployed participants were included,[12] or no relationship between work status and activity was found.[14] Based on our results, we expect that work status could importantly influence results on activity behaviour. Our study shows that unemployed COPD patients are almost 35% less active than unemployed controls, while the activity level of employed patients and employed controls is approximately the same. This could be due to the healthy worker effect; an individual must be relatively healthy to be employable in a workforce. Patients that are unemployed are not working due to their ill health; they are not able to function on an activity level needed for their job. This is emphasized by the fact that COPD patients in general have a lower socioeconomic status, and consequently more physically demanding jobs. Unemployed healthy people are not restricted anymore by their day time jobs and can now plan and do fun visits and activities, thereby being more active.

Both employed patients and unemployed patients show a temporarily decrease in activity in the early afternoon. This suggests that they perform too many activities in the morning, resulting in an activity relapse in the afternoon. Activity again increases in the late afternoon, especially in employed COPD patients. Visual inspection of the daily activity patterns of each individual patient with COPD shows that this trend observed for the average population is shown in the majority of the patients. These findings underpin the professionals' advice to their patients to use their energy efficiently during the day. Hecht et al. showed that in very severe COPD patients using LTOT a sharp decrease in activity is present in the early afternoon, but activity only shows a small recovery afterwards in the evening.[29] Telemedicine interventions could balance this activity pattern,[21] but whether a more distributed daily activity pattern indeed improves physical health status and well-being of COPD patients should be investigated in future studies.

Our results show that the amount of activity per day part of unemployed patients is significantly below that of unemployed controls for all day parts, while this is not the case for the employed. This is different from other chronic patient groups, where normal levels of activity were found in the morning, and only reduced levels of activity in the afternoon and evening.[19, 20] These studies suggested that these decreased activity levels could correspond to increased pain or fatigue intensities during the day, but this was not yet investigated. In the present study, we used a smartphone to rate symptom levels retrospectively on a visual analogue scale three times a day. Our study shows that the relationship of symptoms and activity during the day was not clearly present, and there seem to be different factors that determine patients' distinctive activity pattern. This could require further investigation in future studies.

Regarding the last research objective, we investigated the relationship between subjective and objective measured activity to assess COPD patients' awareness and their readiness to change their activity behaviour based on the stages of change. Patients should be aware of their amount of daily activity and motivated to change their behaviour, otherwise a treatment is unlikely to be effective in the long run, as indicated by the Transtheoretical model.[23] By using a subjective measurement such as the BPAQ the patient with COPD can be assessed on the awareness of his or her daily activity.[30] Our results show that the objective daily activity and subjective daily activity assessed by the BPAQ are significantly related for patients with COPD (r = 0.49), which is a bit less than reported in literature for healthy controls (r = 0.66), but higher than for chronic low back pain patients (r = −0.27).[31] In other words, patients seem fairly aware of their amount of activity, which is an important finding for treatment. This relationship between objective and subjective activity is also present for the different day parts. Furthermore, the majority of the included patients were in the maintenance phase of the stages of change model, meaning that they regard themselves as being regularly physically active for an extended period of time and think that their current activity behaviour is fine. The data indeed shows that patients in the maintenance phase were not more active compared to patients in other stages. These are very important findings; although patients seem to be aware of their daily activity, they feel fine with the current situation and do not have the intention to change their present activity behaviour. Future interventions might consider focusing on the importance of an active lifestyle, and motivating patients to change their behaviour.

We used a validated method for measuring activity behaviour; however our study had some limitations. The wireless Bluetooth connection between the sensor and smartphone was a drain on the batteries of both devices meaning that the devices would often run out of power after 12 hours of operation. Besides, charging of the sensors was experienced to be difficult, resulting in not fully charged sensors and thus less lengthy measurement days. As a consequence, the hours after 20:00 h were excluded from analysis. Further advancements in the field of wireless sensor technology and mobile devices should overcome these issues in future telemedicine treatment. Furthermore, we did not include a functional capacity measurement, such as the 6-minute walking test. This might be a useful outcome measure in the evaluation of future (telemedicine) treatments; can the use of a telemedicine system change activity behaviour and, consequently, can it improve patients' functional capacity?

Implications

Our study used telemonitoring to assess the activity and symptom behaviour during the day, using a 3D-accelerometer for activity monitoring and a smartphone for monitoring symptom levels. Telemonitoring of activity and symptoms can be a valuable tool in daily practice, for professionals and patients to monitor patients' progress and well-being, both in primary and secondary care. Moreover, telemonitoring provides new information and insights from daily life and supports evidence-based treatment. This study provides a first insight in the activity behaviour in more detail, and its relations with symptoms levels during the day. We can conclude that COPD patients, especially unemployed, have a low and imbalanced activity pattern compared to healthy controls. Therefore, we should aim to restore activity levels and it might be considered to pay special attention to the distribution of activities over the day. Furthermore, to let treatment be effective, treatment should make patients aware of their activity behaviour and the importance of an active lifestyle.

Based on the outcomes of telemonitoring studies, we can start designing new and effective treatment methods for improving activity behaviour. Also, telemonitoring can be integrated with telemedicine applications, like online exercise programmes or ambulant personalized feedback, to improve activity behaviour. This feedback could raise awareness of the activity behaviour and motivate patients to change. Previous studies already showed that pedometer feedback could be used to increase physical activity levels;[32-34] however research into effective feedback strategies is still in its infancy.[24]

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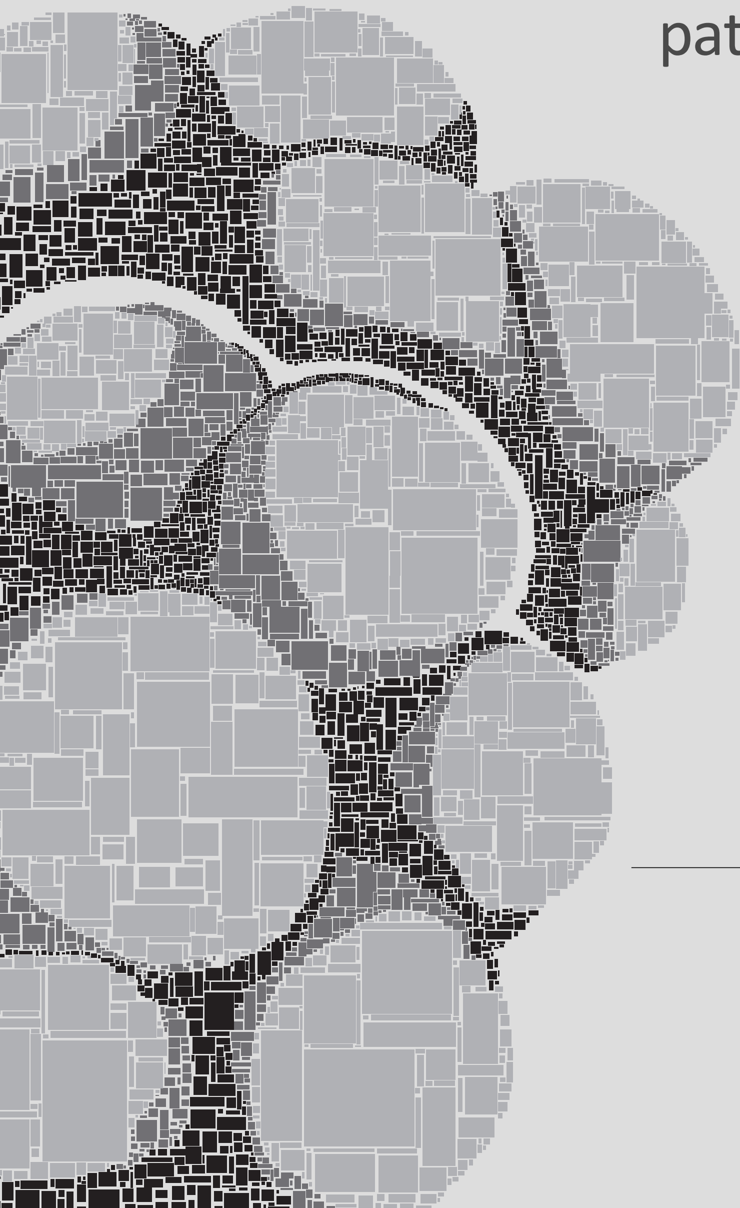
CHAPTER 3

Motivational cues as real-time feedback for changing daily activity behaviour of patients with COPD



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Abstract

Objective: To investigate how COPD patients respond to motivational cues that aim to improve activity behaviour and how these responses are related to cue- and context characteristics. In addition, to explore whether activity can be increased and better distributed over the day by providing such cues.

Methods: Fifteen COPD patients participated. Patients used an activity sensor with a smartphone for four weeks, at least four days/week. Patients received motivational cues every two hours with advice on how to improve their activity, on top of real-time visual feedback. The response was calculated by the amount of activity 30 minutes before and after a cue.

Results: In total, 1488 cues were generated. The amount of activity significantly decreased in the 30 min after a discouraging cue ($p < 0.001$) and significantly increased ($p < 0.05$) in the 10 min after an encouraging cue. The activity level increased with 13% in the intervention period compared to corrected baseline ($p = 0.008$). The activity was not more balanced over the day.

Conclusions: COPD patients significantly change their activity level in response to motivational cues, based on continuous ambulatory assessment of activity levels.

Practice implications: Motivational cues could be a valuable component of telemedicine interventions that aim to improve activity behaviour.

Introduction

Globally, six percent of deaths are attributed to physical inactivity.[1] Regular physical activity is related to better health, reduced risk of (chronic) diseases,[2, 3] and can increase active life expectancy by limiting the development and progression of chronic disease and disabling conditions.[4] The promotion of a physically activity lifestyle plays an essential role in chronic disease management, such as Chronic Obstructive Pulmonary Disease (COPD) – a respiratory disease characterized by a progressive airflow limitation of the lungs. In patients with COPD, dyspnoea (during exertion) is one of the major symptoms, which leads to lower physical activity levels. This is thought to be part of a vicious circle of symptom-induced inactivity, leading to a lack of fitness and a reduced quality of life.[5] In addition, a physically active lifestyle reduces the risk of hospital (re)admission,[6-8] increases life expectancy,[9] and slows lung function decline.[10] Previous studies demonstrated the inactive behaviour of the COPD population[11-18] with a less equally distributed activity pattern[19] compared to healthy individuals. Increasing physical participation in everyday activities is among the key goals in the treatment of COPD.[20]

Telemonitoring provides the possibility of measuring activity behaviour in daily life in an objective manner. In telemedicine treatments the challenge is to replace some or all of the face-to-face contact with technology-provided coaching. Like the feedback from the professional, ambulant feedback should create awareness about patient's own functioning, motivate and stimulate patients to positively change their activity behaviour, and eventually improve patient's functioning.[21] In contrast with the intramural setting of classical physical therapy, telemedicine can provide real-time, intensive feedback in the daily environment of the patient. We expect that feedback on the unobtrusive activity measurements can provide an intensive treatment with positive effects on daily activity behaviour, by both increasing and balancing activity patterns. However, to our knowledge, such type of intervention that automatically provides real-time feedback based on objectively measured activity data has not been realized yet for COPD patients.

The activity coach – part of a telerehabilitation intervention[22] – consists of an activity sensor and smartphone that aims to increase activity levels and to balance activities over the day. The activity coach visualizes the activity behaviour of the individual patient, and provides real-time motivational cues in the form of text messages (e.g. "You have taken more rest, please go for a walk.") on top of continuous visual feedback i.e. a graph displaying the activity. These motivational cues have been successfully used in studies on chronic fatigue syndrome[23] and chronic low back pain,[24] where 75% of chronic low back pain patients had a positive response to the motivational cues. We do not yet know how patients with COPD respond to the feedback and whether this kind of intervention can improve the activity behaviour. In addition, we would like to know what determines the response to the motivational cues, so we can tailor future telemedicine treatments that aim to improve activity behaviour.

The objective of this study was to investigate how COPD patients respond to motivational cues and whether this response is related to cue- and context characteristics (e.g. time of motivational cue, weather influences). In addition, this study aims to explore whether the daily activity behaviour can be altered by providing ambulant feedback enhanced with motivational cues via a smartphone on the activity level during the day. We hypothesize that the amount of activity will increase and that the distribution of activities throughout the day will be more balanced.

Methods

Design and participants

The intervention arm of a randomized controlled trial was studied that aimed to investigate the effect of a telerehabilitation intervention compared to usual care in patients with COPD. This study has been approved by the hospital's Medical Ethical Committee and registered in the Netherlands Clinical trial register (no. NTR2440). Thirty-four patients (22 male, 12 female) with a clinical diagnosis of COPD, were recruited from the department of pulmonary medicine of the Medisch Spectrum Twente hospital in Enschede, the Netherlands. The inclusion criteria were: a clinical diagnosis of COPD,[20] no infection or exacerbation in the 4 weeks prior to start of the study, and a current or former smoker. Exclusion criteria were disorders or progressive disease seriously influencing daily activities or causing inability to use the smartphone application, other diseases influencing bronchial symptoms and/or lung function, need for regular oxygen therapy (>16 h per day or pO_2 < 7.2 kPa), history of asthma, and recently (<6 weeks) started training with a physiotherapist. Eligible patients were randomly assigned to either the intervention or control group according to a computer-generated randomization list. Sixteen patients participated in the control group (mean age: 68 years, male/female: 11/5, mean FEV_1% predicted: 56.4%). Patients in the control group received regular care, which could consist of e.g. medication and physiotherapy. The results of the randomized controlled trial are described separately.[22] Fifteen patients started with the intervention, but one patient was lost to follow-up in the intervention group after the third week.

The activity coach intervention

The activity coach consisted of an activity sensor (MTx-W sensor, Xsens Technologies) and a smartphone (HTC P3600/3700). The activity sensor was a triaxial accelerometer, which measured 3D acceleration, expressed in counts per minute (cpm). The sensor connected wirelessly with the smartphone using Bluetooth. Both the sensor and smartphone were worn on the subject's belt. Patients used this system for four weeks from waking up until 22.00 in the evening, with a minimum of four days per week. The first week was a baseline measurement, followed by 3 weeks in which the patient received feedback to change activity behaviour. This feedback consisted of 1) visual continuous feedback in the form of a graph and 2) text-based motivational cues. This feedback aimed to increase the activity level and distribute the activity level more equally over the day.

Visual continuous feedback

The smartphone showed the measured activity cumulatively in a graph, together with the cumulative activity the patients should aim for: the reference activity line (Fig. 1, left). This reference line was developed based on a combination of social comparison (with healthy individuals) and temporal comparison (with oneself). The patient's baseline was compared to a social norm line (based on the data of 56 healthy controls) and the difference between both lines was calculated. To establish the reference line, the baseline of the patient was increased by 50% of this difference (Eq.1).

$$\boldsymbol{Reference\ line} = \textbf{baseline patient} + \mathbf{0.5} * (\boldsymbol{social\ norm\ line} - \boldsymbol{baseline\ patient}) \quad (\textbf{Eq. 1})$$

The reference line and the measured activity were displayed on the smartphone, so patients could continuously see their activity pattern in order to raise awareness. Patients were asked to try to approach the reference line as closely as possible during the day.

Motivational cues

During the intervention, the patients automatically received text-based motivational cues every two hours on the smartphone, in order to increase awareness and provide extra motivation. These cues were based on the difference between the measured activity and the reference line at the moment the cue was generated. Based on this deviation, the patient received advice to become more active, less active, or that they are doing well. The text message always consisted of 1) short summary of activity behaviour of the past two hours and 2) an advice on how to improve the activity behaviour (see Fig. 1, right). There were three types of motivational cues: encouraging cues (>10% deviation below reference line), discouraging cues (>10% deviation above reference line) and neutral cues (≤10% deviation with reference line). An encouraging cue could be for example: "you took more rest, we advise you to take a short walk" and a discouraging cue could be: "you have been very active, take some time to read a magazine". Neutral cues were provided for extra motivation when the patient was doing well, such as: "you are doing well, keep up the good work!" The last generated motivational cue could be retrieved by pressing the advice button in the graph screen.

Fig. 1. Left: continuous feedback, right: text-based motivational cue. (Translation: "You took more rest. Please go for a walk around the block".)

Measures

The objective daily activity was measured using the MTx-W sensor which measured 3D acceleration, as described previously.[19] The final output was expressed in activity counts per minute (cpm). In order to investigate the responses to the motivational cues, all the cues generated by the system were logged. The patient had to confirm reading a motivational cue by pushing a button, taking the patient back to the graph screen. This event was logged with the corresponding time stamp. In addition, cue characteristics and context variables were logged with the motivational cue retrospectively, like the outside temperature (see Table 1). General patient characteristics (age, gender, work status) were retrieved before start of the intervention.

Table 1. Overview of the cue characteristics and context variables that were logged with the motivational cues.

Cue characteristic / context variable	
Hour of day	Hour of day in which the cue was provided (between 8.00 and 22.00)
Day part	Day part in which cue was provided (morning, afternoon, evening)
Day of the week	Day of the week in which cue was provided (Monday to Sunday)
Feedback day of usage	The number of days the activity coach was used in (the intervention period) in which cue was provided
Near full hour	Whether or not the message was read within 5 minutes after the full hour (time of generation by the system).
Delayed read of cue	The number of seconds between the time of message generation and the time of reading.
Distance from reference	The deviation from the reference line (in counts per minute)
Approaching reference	Was the patient approaching the reference line in the 30 minutes before the cue was provided? (yes/no)
Motivational cue	The motivational cue that was provided (17 options)
Cue: go outside	Was the cue suggesting to be more active by going outside? (yes/no)
Cue: question	Was the cue provided as a question? (yes/no)
Cue: suggest idle	Whether or not the message suggests to perform an activity (e.g. read) or to idle (e.g. "please relax").
Temperature (min)	Minimum outside temperature of that day on which the cue was provided (in degrees Celsius)
Temperature (max)	Maximum outside temperature of that day on which the cue was provided (in degrees Celsius)
Temperature (mean)	Mean outside temperature of that day on which the cue was provided (in degrees Celsius)
Cloud scale	The cloud scale of that day on which the cue was provided (from 0: no clouds to 8: completely covered)
Precipitation sum	The total amount of precipitation of that day on which the cue was provided (in mm)
Precipitation duration	The total duration of precipitation of that day on which the cue was provided (in hours)

Data analysis

The mean activity for each patient was calculated for the baseline- and intervention period. Only those days were included in the analysis for which at least 6 hours per day were available. To investigate the response to the motivational cues, we compared the amount of activity (in cpm) 30 minutes before (act_{before}) the cue was seen by the patient with a time interval after the cue was seen (act_{after}). The time intervals are: 5-, 10-, 15-, 20-, 25-, and 30 minutes. The magnitude of the response was expressed as a percentage of change (Eq.2).

$$\boldsymbol{Response}\ (\%) = \frac{\boldsymbol{act_{after}} - \boldsymbol{act_{before}}}{\boldsymbol{act_{before}}} * \mathbf{100\%} \quad (\mathbf{Eq.2})$$

The response of an individual cue was only calculated if 90% of the data points per time interval was available. For discouraging cues we expected a decrease in activity level and for encouraging cues we expected an increase of activity. For neutral cues we expected no significant response. To investigate how the responses are related to cue- and context characteristics the time interval (between 10 and 30 minutes) was used where the largest response was found. To investigate whether the distribution of activities throughout the day would be more balanced, we calculated the absolute difference between the reference line and measured activity line for each data point (every minute). Subsequently, the line was vertically translated with a constant ***c*** to obtain the smallest difference and thus to rule out the influence of the activity level. This mean smallest cumulative deviation from the reference line was divided by the mean cumulative activity value of the reference line and expressed as a percentage (Fig. 2). In other words, when the patient's activity line follows the exact same pattern as the reference line, the percentage would be 100%.

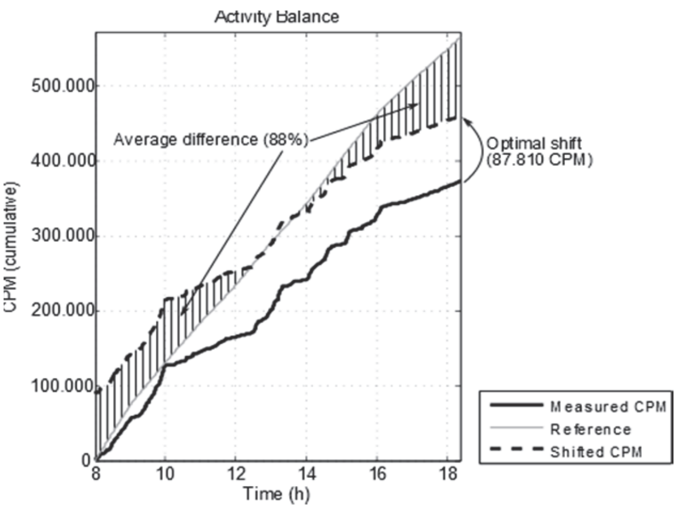

Fig. 2. Illustration on how the activity balance was calculated. The absolute difference between the reference line and measured activity line for each data point was calculated. Subsequently, the line was vertically translated with a constant ***c*** to obtain the smallest difference. This mean smallest cumulative deviation from the reference line is divided by the mean cumulative activity value of the reference line and expressed as a percentage.

To investigate whether the patient increased the activity level, we calculated the mean activity level during baseline and during intervention. In our study, which was part of a telerehabilitation intervention,[22] patients wore a pedometer in addition to the activity sensor. They recorded their steps/day during the whole study period in a paper diary. Literature shows that recording your steps in a diary already causes a substantial increase in activity level in the first measurement week compared to a blinded baseline activity measurement.[25] As such, Clemes and Parker advised the first three days of a baseline measurement to be treated as a familiarization period. These results were confirmed by our pedometer findings from the RCT.[22] Therefore, we corrected for this effect by a lowering of the entire baseline period by 13.21% based on the results found by Clemes and Parker.[25] Both the original and the corrected data were displayed in the results.

Statistical analysis

The results were described in terms of mean (SD), counts or percentage. The Statistical Package for the Social Sciences (SPSS, 19.0) was used for statistical analyses, and the alpha was set at 0.05. P values ≤ 0.20 were shown; p values > 0.20 were shown as non-significant (ns). The analyses were performed separately for encouraging, discouraging and when applicable, neutral cues.

The response to the motivational cues was tested using a paired t-test, comparing the 30 minute activity interval before the cue, with the activity level after the cue in increasing time intervals, to be able to observe the possible difference between a faster or slower response. All cues were used for calculating the overall response on a group level. Similarly, the change in amount of activity and balance was tested using a paired t-test, comparing the baseline period with the feedback period.

To investigate the relation of the response to the motivational cues, the following tests were performed. When comparing two categories the independent Student's t-test was used, and when comparing more than two categories analysis of variance (ANOVA) with the Bonferroni post hoc test was used. The Pearson product-moment correlation coefficient (r) or Spearman's rank correlation coefficient (r_s) was calculated to evaluate the relationships of the response with continuous variables, as appropriate.

Results

Characteristics

Fifteen patients were included in the intervention. Table 2 shows the patients' characteristics.

Table 2. Patient characteristics, expressed as mean±SD or counts.

	COPD patients (n = 15)
Age (years)	66±9.2
Gender (male/female)	9/6
FEV_1% predicted	47.7±16.6
GOLD stage (II/III/IV)	5/8/2
BMI (kg/m^2)	28.1±7.5
Current smoker (yes/no)	1/14
Work status (employed/unemployed)	4/11

COPD, chronic obstructive pulmonary disease; FEV_1% predicted, forced expiratory volume in 1 second percent predicted; GOLD, Global Initiative for Chronic Obstructive Lung Disease; BMI, Body Mass Index.

Response to motivational cues

In total, 1488 motivational cues were generated. One patient did not have sufficient sensor data and was excluded from analysis. One patient was lost to follow-up in the third week, but the results are included in the analysis of the response to motivational cues. For the analysis (n = 14), 809 motivational cues were used of which 250 (31%) encouraging, 421 (52%) neutral, and 138 (17%) discouraging cues.

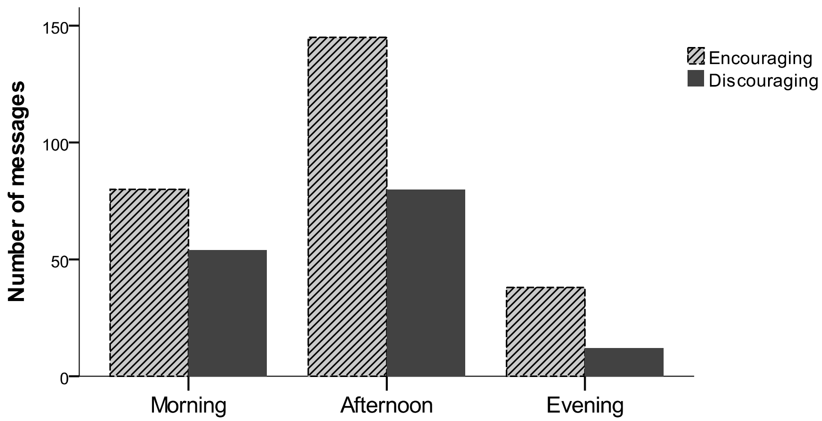

Fig. 3. Number of motivational cues per day part, subdivided into encouraging cues and discouraging cues.

Others were excluded because either they did not have 90% of the data points available in all time intervals, either due to a gap in the sensor data, or due to partly overlapping responses when 2 cues were viewed in too rapid succession. Figure 3 shows the distribution of encouraging and discouraging cues per day part. The patients received a different set of motivational cues: 5 patients received mostly encouraging cues, 7 patients mostly neutral cues, 1 patient mostly discouraging cues and 1 patient received encouraging and neutral cues equally. Of this group, there were 3 patients that did not receive any discouraging cues.

Table 3 shows the response to the motivational cues on a group level. Patients respond significantly to discouraging cues for all time intervals, with the largest response for the 30 minute interval. Patients also significantly respond to encouraging cues, although mainly in the first 5 to 10 minutes. There was no significant response found for the neutral cues, which corresponds to our expectancies. Due to these findings, the rest of our analysis of discouraging cues will employ the 30 minute interval after the cue, and for encouraging cues the 10 minute interval is used.

Relation with response to motivational cues

The relationships between the response to motivational cues and cue characteristics are shown in Table 4. For encouraging cues, a significant relation was found for the `approaching reference' parameter. When a person was approaching the reference line in the half hour before the cue, the mean response to the cue was -10±66%, while when a person was not approaching the reference line, the response was 194±410%. For discouraging cues this was respectively +10±90% and -27±84%. In other words, when patients are not already improving their activity behaviour the 30 minutes before the cue, they respond better to the cue. In addition, patients respond significantly different to the different encouraging cues. The highest responses were found for: “Is there something to clean in your house?” and “Go for a nice walk!”, while a negative response was found for “Do you need something out of town?” After this cue, patients became less active. The response to discouraging cues significantly related to the hour of day and the amount of precipitation, and showed a trend with the minimum temperature.

Table 3. Response to the motivational cues (n = 809). The table shows the total number of motivational cues, subdivided into encouraging, neutral and discouraging cues and the response to these cues. The response is shown for different time intervals, to be able to observe the possible difference between a faster or slower response.

Cue type	N	t = 5	t = 10	t = 15	t = 20	t = 25	t = 30
Discouraging	138	-25% $p < 0.001^{¥}$	-25% $p < 0.001^{¥}$	-25% $p < 0.001^{¥}$	-26% $p < 0.001^{¥}$	-27% $p < 0.001^{¥}$	-29% $p < 0.001^{¥}$
Encouraging	250	+23% $p = 0.005^{‡}$	+15% p = 0.017*	+11% p = 0.076	+10% p = 0.100	+11% p = 0.090	+10% p = 0.115
Neutral	421	-3% ns	-6% p = 0.109	-6% p = 0.137	-5% p = 0.158	-6% ns	-5% p = 0.116

* $p \leq 0.05$, ‡ $p \leq 0.01$, $^{¥}$ $p \leq 0.001$

Table 4. Relations with the response to the motivational cues, and cue characteristics and context variables. The correlations are shown separately for encouraging and discouraging motivational cues.

	Encouraging	Discouraging
Hour of day	ns	r = 0.168, p = 0.043*
Day part	ns	ns
Day of the week	ns	ns
Feedback day of usage	r = 0.097, p = 0.118	r = -0.109, p = 0.189
Near full hour	ns	ns
Delayed read of cue	ns	ns
Distance from reference	ns	ns
Approaching reference (yes/no)	$p < 0.001^{¥}$ (CI: -279, -130)	$p = 0.014^{‡}$ (CI: 7.4, 65.5)
Motivational cue (17 options)	p = 0.021* [a]	ns
Cue: go outside (yes/no)	p = 0.102 (CI: -198, 17.9)	n/a
Cue: question (yes/no)	ns	ns
Cue: suggest idle (yes/no)	n/a	ns
Temperature (min)	ns	r = 0.159, p = 0.055
Temperature (max)	ns	ns
Temperature (mean)	ns	r = 0.126, p = 0.131
Cloud scale (1 to 8)	ns	ns
Precipitation sum	ns	r = 0.232, p = 0.005 ‡
Precipitation duration	ns	r = 0.156, p = 0.060

[a] Bonferroni post-hoc test, mean response (%) is -14±75 and 271±404, for respectively “Do you need something out of town?” and “Is there something to clean in your house?” (p = 0.045). * $p \leq 0.05$, ‡ $p \leq 0.01$, $^{¥}$ $p \leq 0.001$.

Activity behaviour

In total, there were 254 measurement days of which 186 feedback days with >6 hours measured. One patient dropped out due to technical problems in the third week and three patients were excluded from the data analysis because of insufficient data in the baseline period. Therefore, 11 COPD patients were included in the data analysis.

Table 5 shows the measured activity levels at baseline and at the intervention period, per patient and for the total group. In addition, this table shows whether the patients increase and balance their activity level. On a group level, no significant changes were found in activity level or balance. The table also shows the activity data corrected for reactivity (based on [25]). After this correction, the activity level significantly improved on a group level. The response to the encouraging motivational cues was significantly related to the percentage change in activity level ($r_s = 0.66$, $p = 0.026$), but not to balance. The response to discouraging motivational cues showed no significant relationships with activity level or balance.

Discussion and Conclusion

Discussion

This study aimed to investigate how COPD patients respond to motivational cues, whether this response is related to cue- and context characteristics and in addition, to explore whether the daily activity can be altered by providing these cues. This study showed that COPD patients significantly change their activity level on a short-term notice in response to motivational cues on a smartphone. On a group level, the activity level increased with 13% in the intervention period compared to corrected baseline, but was not more balanced. Patients responded significantly to discouraging cues, with the largest response for the 30 minute interval. In response to the encouraging cues, people became increasingly active for at least 10 minutes. This corresponds to the ACSM guidelines, which indicate that the recommended amount of physical activity can be reached by engaging in several short periods of activity lasting at least 10 minutes to accumulate the desired amount of daily activity. Patients with COPD often show sedentary activity behaviour, and in this group, also accumulation of shorter sessions of physical activity (<10 min) may result in fitness and health benefits as long as the total energy expended is similar.[26] When sedentary activities are broken up by short periods of physical activity or standing, this can decrease the damaging effects of sedentary behaviour.[27] Therefore, text-

Table 5. Original activity data and balance data, and the corrected activity, per patient and for the group (n = 11). We corrected for the reactivity effect by a lowering of the baseline period by 13.21%.

No.	T	Activity (cpm)	Balance (%)	Corr. activity (cpm)
1	Baseline	851±117	94.7±1.2	738±101
	Intervention	928±135	93.3±2.4	914±125
	Difference	+9%, ns	-1%, ns	+24%, p = 0.051
2	Baseline	1072±178	93.0±2.2	930±155
	Intervention	1104±187	92.9±5.6	1104±187
	Difference	+3%, ns	-0%, ns	+19%, p = 0.134
3	Baseline	556±106	85.7±7.6	483±92
	Intervention	549±80	87.9±5.9	549±80
	Difference	-1%, ns	+3%, ns	+14%, ns
4	Baseline	990±203	91.8±2.2	859±176
	Intervention	1008±196	91.5±3.6	1008±196
	Difference	+2%, ns	-0%, ns	+17%, ns
5	Baseline	1047±142	86.6±6.3	908±123
	Intervention	1006±78	94.3±2.3	1006±78
	Difference	-4%, ns	+9%, p = 0.003‡	+11%, p = 0.074
6	Baseline	1102±154	92.8±1.3	957±134
	Intervention	849±139	90.2±4.0	849±139
	Difference	-23%, p = 0.005‡	-3%, p = 0.174	-11%, p = 0.165
7	Baseline	763±106	89.6±9.6	663±92
	Intervention	681±169	85.4±9.0	681±169
	Difference	-11%, ns	-5%, ns	+3%, ns
8	Baseline	875±126	94.8±2.5	759±110
	Intervention	917±53	95.8±1.0	917±53
	Difference	+5%, ns	+1%, ns	+21%, p = 0.002‡
9	Baseline	945±61	94.0±2.4	820±53
	Intervention	829±41	92.8±2.1	829±41
	Difference	-12%, p = 0.020*	-1%, ns	+1%, ns
10	Baseline	332±48	78.0±4.8	288±42
	Intervention	573±153	90.4±7.3	569±158
	Difference	+73%, p = 0.003‡	+16%, p = 0.003‡	+98%, p = 0.001‡
11	Baseline	1593±616	88.6±9.3	1382±535
	Intervention	1507±460	88.0±8.5	1507±460
	Difference	-5%, ns	-1%, ns	+9%, ns
T	Baseline	920±323	89.9±5.1	799±280
O	Intervention	904±268	91.1±3.1	903±269
T	Difference	-2%, ns	+1%, ns	+13%, p = 0.008‡

* $p \leq 0.05$, ‡ $p \leq 0.01$

based motivational cues provided on a smartphone seem feasible to use for activity interventions in COPD. Nguyen et al. used weekly reinforcement text messages in a cell-phone based exercise intervention for COPD, but did not find a significant contribution of these messages to the end results of their exploratory study.[28] This could very likely be caused by the low frequency of the messages provided. Text messaging on mobile devices are shown to be an effective manner for influencing physical activity behaviour in several user groups.[29] Although the results were positive, these interventions neither provided messages automatically, nor in real-time. Dekker-van Weering et al. did provide time-based text messages to patients with chronic low back pain, and found significant responses to both encouraging and discouraging messages.[24]

Patients received a mixture of encouraging, discouraging and neutral cues, whose distribution differed considerably between patients. Most encouraging cues were provided in the afternoon, which could be expected as the activity pattern of COPD patients show a decrease in activity level in the afternoon.[19] The responses to the motivational cues, especially to encouraging cues, were not clearly related to the cue- or context variables. Only when a patient was approaching the reference line in the 30 minutes before the cue was provided, the response was lower than when the patient was not approaching the reference line. Other variables, like the influence of the time and weather were only weakly related to the response. From our study results, we can therefore not provide a general recommendation for the motivational cues – describing the best type of cue, under what kind of conditions they should be provided or at what moment – applicable to the general COPD population. COPD is a systemic disease, influenced by comorbidities, and patients exhibit great variation in their degree of activity behaviour.[30] Together with the different responses found among the patients to the motivational cues, this suggests that the response and compliance would be better when the system would be able to adapt to its individual user, which underlines the recommendation towards more personalized medicine and tailor-made treatments in COPD.[30, 31] Such a personalized system should be able to learn to predict the optimum content and timing by analysing the responses on previously given cues and learning when a patient is likely to respond well to a given cue by relating relevant context factors to patient compliance and content.[32] In addition, investigating the influence of patient characteristics and behavioural parameters, such as the stages of change,[33] on the response to motivational cues would be an additional potential improvement to gain more insight in these relationships.

This study showed that the activity level significantly increased compared to corrected baseline, but was not more balanced, which partly confirmed our hypothesis. This increase in activity level was significantly related to the response to the encouraging motivational cues. In other words, the motivational cues seem to contribute to an improvement in activity level. Clinical guidelines indicate that self-monitoring – using e.g. activity sensors – has been the behaviour modification strategy that has produced the most consistent effects in increasing participation in physical activities in daily life.[34] However, providing an activity sensor could be an intervention on its own, and an important factor for baseline measurements or monitoring studies.[25] In the present study, we corrected for this effect by lowering the measured values of the entire baseline period. For future studies, a blinded activity sensor is recommended, and a longer baseline period, to obtain the least influence of reactivity. The activity level was not more balanced over the day, and motivational cues had no direct influence on the activity balance. A balanced daily activity pattern is often assumed to be beneficial in regular care to improve patient's well-being, as the energy is more efficiently spread over the day. This is not directly mentioned in the guidelines and more research is needed, on how we can improve this balance and whether this can indeed improve patient's quality of life. A potential limitation of the current study is that we applied personal feedback within a telerehabilitation programme of four weeks, which is very short to establish changes in behaviour. More research is needed to investigate the effects of the activity coach and whether it can motivate patients in the long term to establish sustainable behaviour change.

Conclusion

This study was to our knowledge the first intervention that provides motivational cues as real-time feedback to promote a change in activity behaviour in COPD. It shows that using motivational cues provided on a smartphone seems feasible and can positively change activity behaviour. More research into optimization of the feedback strategy and a more adaptive generation of feedback may result in an innovative approach to promote an active healthy behaviour, which is beneficial for patients with COPD.

Practice implications

This first study shows that motivational cues could be a valuable component of telemedicine interventions that aim to improve activity behaviour. Providing feedback to the patient about the physical activity behaviour is important to stimulate self-management. The activity coach could support patients in enabling a more active and healthy lifestyle through active participation in their healthcare.

Conflict of interest

None declared.

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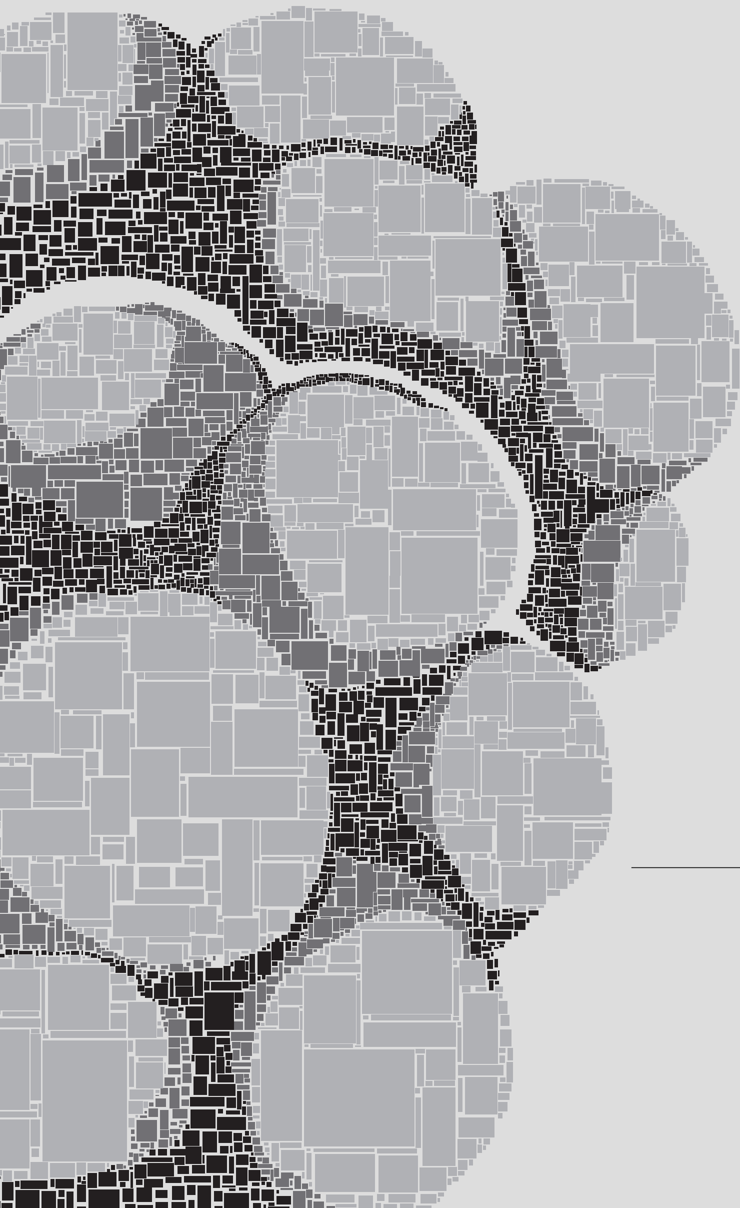
CHAPTER 4

A telerehabilitation intervention for patients with COPD: a randomized controlled pilot trial



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Abstract

Objective: First, to investigate the effects of a telerehabilitation intervention on health status and activity level of patients with Chronic Obstructive Pulmonary Disease (COPD), compared to usual care. Second, to investigate how patients comply with the intervention and whether compliance is related to treatment outcomes.

Design: a randomized controlled pilot trial

Subjects: Thirty-four patients diagnosed with COPD.

Intervention: The telerehabilitation application consists of an activity coach (3D-accelerometer with smartphone) for ambulant activity registration and real-time feedback, complemented by a web portal with a symptom diary for self-treatment of exacerbations. The intervention group used the application for 4 weeks. The control group received usual care.

Main measures: Activity level measured by a pedometer (in steps/day), health status by the Clinical COPD Questionnaire at baseline and after intervention. Compliance was expressed as the time the activity coach was worn.

Results: Fourteen intervention and 16 control patients completed the study. Activity level (steps/day) was not significantly affected by the intervention over time. There was a non-significant difference in improvement in health status between the intervention (-0.34 ± 0.55) and control group (0.02 ± 0.57, $p = 0.10$). Health status significantly improved within the intervention group ($p = 0.05$). The activity coach was used more than prescribed (108%) and compliance was related to the increase in activity level for the first two feedback weeks ($r = 0.62$, $p = 0.03$).

Conclusions: This pilot study shows the potential of the telerehabilitation intervention: compliance with the activity coach was high, which directly related to an improvement in activity levels.

Introduction

The promotion of physical activity in daily life is a key aspect in the treatment of patients with Chronic Obstructive Pulmonary Disease, a respiratory disease characterized by a chronic airflow limitation that is not fully reversible.[1] Patients with Chronic Obstructive Pulmonary Disease have decreased exercise capacity and experience substantial limitations in their daily activities,[2] which results in an inactive lifestyle compared with healthy individuals.[3-6] In current treatment, regular exercise training sessions and pulmonary rehabilitation programmes aim to improve activity levels through exercise, and patients are educated on the importance of an active lifestyle. Indeed, a meta-analysis by Lacasse et al.[7] showed that pulmonary rehabilitation benefits patients in terms of symptoms, emotional function, and control over their condition, but these programmes do not necessarily lead to a change in activity levels in daily life.[8-10]

Interventions that facilitate self-monitoring of behaviour change in daily life are recommended to improve activity behaviour.[11-13] Activity monitoring makes patients aware of their activity, which is likely needed for successful treatment effects.[14] Feedback on these activity measurements can be provided face to face by the professional, but could also be provided in the daily environment of the patient for optimal awareness and coaching.[15] For example, some studies successfully applied pedometer feedback to increase physical activity levels.[16-18] Although overall results published in stimulating activity behaviour in daily life seem positive, the effectiveness of telerehabilitation interventions in general for patients with Chronic Obstructive Pulmonary Disease is not yet proven.[19] Besides, the applied (pedometer) feedback is limited to providing the number of steps, and setting a daily or weekly goal. This is probably not sufficient as it does not provide insight into the activity behaviour during the day, nor does the patient receive advice on how to improve the activity behaviour real time.

In this article, we describe a telerehabilitation intervention with an ambulant activity coach for promotion of an active lifestyle, complemented by a web portal for monitoring symptom levels by a triage diary. The latter enables self-treatment of exacerbations and raises awareness about the patient's health status. The activity coach monitors activity behaviour with a triaxial accelerometer, and provides real-time patient-specific feedback based on the measured activity. The activity coach visualizes the activity behaviour of the individual user in a graph, and provides motivational cues in the form of text messages (e.g. "You have taken more rest, please go for a walk."). We expect that real-time ambulant coaching on activity behaviour could provide a more intensive treatment and could therefore have a more powerful influence on the activity behaviour and health status, compared with regular care. Besides, we would like more in-depth research in whether our activity coach can indeed increase activity levels, and whether this relates to improved health status. Previous research suggests that physical benefits are related to consistent compliance with an intervention.[20] However, we know little about treatment compliance and its relationships with clinical benefits, especially in telemedicine.[21]

Therefore, we performed a pilot randomized controlled trial that compared the telerehabilitation intervention to usual care. The objective was to investigate the effects of this intervention on activity level and health status. In addition, we investigated how patients complied with the intervention and whether this treatment compliance was related to treatment outcomes.

Methods

Patients with a clinical diagnosis of Chronic Obstructive Pulmonary Disease were recruited by a chest physician or nurse practitioner. Inclusion criteria were: no infection or exacerbation in the four weeks prior to measurement; current or former smoker; able to read and speak Dutch; and internet access at home. Exclusion criteria were: impaired hand function causing inability to use the application; disorders or progressive disease seriously influencing daily activities (e.g. amputation); other diseases influencing bronchial symptoms and/or lung function (e.g. sarcoidosis); need for regular oxygen therapy (>16 hours per day or $pO_2 < 7.2$ kPa); a history of asthma, and less than six weeks ago started training with a physiotherapist. The study was approved by the Medical Ethical Committee Twente and registered in the Netherlands Clinical Trial Register (no. NTR2440). The trial took place between October 2010 and April 2011.

This pilot randomized controlled trial aimed to examine the effect of a telerehabilitation intervention compared with usual care in patients with Chronic Obstructive Pulmonary Disease. A sample size of 32 participants was expected to be feasible (16 participants in each group) owing to the limited availability of the activity coach. Eligible participants were randomly assigned to either the intervention or control group according to a computer-generated randomization list (programme: Block Stratified Randomization V5; Steven Piantadosi), where blocked randomization was applied in blocks of four, stratified for gender. Participants were allocated in order of inclusion following the randomization list. Recruitment, randomization, and allocation were performed by different persons. The data collection was not blinded to the data collector.

The application consisted of two modules: 1) activity coach for ambulant activity registration and feedback and 2) web portal with a symptom diary for self-treatment of exacerbations and an overview of the measured activity levels. The activity coach consisted of a three-dimensional-accelerometer (MTx-W sensor, Xsens Technologies, Enschede, the Netherlands) and a smartphone (HTC P3600/3700). The sensor had a wireless connection with the smartphone by Bluetooth. Both the activity sensor and smartphone were worn on the subject's belt. The smartphone showed the measured activity cumulatively in a graph, together with the cumulative activity the users should aim for: the reference activity line (see photograph available online). The reference activity is the line between the mean baseline of the participant and a social norm line (based on the data of 56 healthy controls). Participants were asked to try to be active in such a way during the day that the displayed reference line is closely approached. In addition, the users automatically received feedback text messages, for awareness and extra motivation. These messages were based on the difference between the measured activity and the reference line and always consist of 1) a short summary of activity behaviour and 2) advice on how to improve or maintain the activity behaviour. The participant's measured activity levels were also displayed on the web portal. Every day, participants were asked to fill in the diary on the web portal, which is the digital version of the diary used by Effing et al.[22] A decision-support system automatically forms an advice to start medication in case of an exacerbation. Before using this diary, participants had to attend two 90-minute self-management sessions given by a nurse practitioner, to learn how to complete the daily diary, how to recognize symptoms of an impending exacerbation, and how to deal with the exacerbation.

The intervention group received usual care and in addition, the telerehabilitation intervention. Participants in the intervention group used the activity coach for four weeks from waking till 22:00 h, for a minimum of four days per week. The first week was a baseline measurement to establish the reference line, followed by three weeks in which the participant received feedback to change activity behaviour. Participants were asked to continue the routine of their daily life during baseline measurement. Participants in the control group only received usual care, which could consist of, for example medication and physiotherapy. The latter mostly included weekly (group) training sessions at the local physiotherapy practices. In case of an exacerbation, the participants had to contact their medical doctor. The primary outcome parameter was activity level, assessed by measuring the number of steps per day with a pedometer (Yamax Digi-Walker 200) in both groups. The choice for the pedometer to assess outcome was made because of the limited availability of the three-dimensional-accelerometers. Age, gender, work status, and physiotherapy use were retrieved at baseline for every participant. The Clinical COPD Questionnaire (CCQ) was used to measure health status of the patients.[23] A change of 0.4 represents the minimal important difference for an individual patient.[24] The Medical Research Council Dyspnoea Scale (MRC) was used to grade the effect of dyspnoea on daily activity.[25] The Multidimensional Fatigue Inventory (MFI-20) was used to assess subjective fatigue.[26] The MFI-20 is divided in five individual dimensions: general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue. In the intervention group, use of the system was expressed in the number of visits to the web portal and the time the activity sensor was worn. Only those days were included where at least 50% of the day was measured, for all day parts. Compliance was calculated by dividing the number of days the activity sensor was worn by the minimal number of days that was prescribed (i.e. ≥ four days/week). In addition, compliance for the triage diary was calculated by dividing the number of diary fill-outs by the number of days that was prescribed (every day).

The Statistical Package for the Social Sciences (SPSS, v19) was used for statistical analyses. The results were described in terms of mean±SD, counts, or percentage. The level of significance was set at $p < 0.05$ and a trend was defined as $p < 0.10$. To investigate the effect of the feedback on the activity levels, a mixed model analysis for repeated measures was performed. Time of measurement (baseline, feedback week 1, 2, and 3) was used as a within-subjects factor and group (control or intervention) as a between-subjects factor. Post hoc comparisons were made when required and the method of Sidak was used to correct for multiple comparisons. Questionnaires to assess clinical parameters (health status, dyspnoea, fatigue) were administered at baseline and after the intervention. The difference between these two time points was calculated (‘change’) for each clinical parameter. The differences between groups were analysed using the unpaired t-test and within groups were analysed using the paired t-test. For the health status, the percentage of subjects with a clinically relevant improvement (≥0.4) was assessed.[24] The Pearson product-moment correlation coefficient was calculated to evaluate the relationships between continuous variables (e.g. activity level and compliance). For comparing two categorical variables (such as gender with group), Pearson Chi-square was used.

Results

Figure 1 shows the progression through the study. Eighteen patients were allocated to the intervention group, and 16 to the control group. In the intervention group, three patients did not receive the intervention and one patient was lost to follow-up in the intervention group after feedback week 2. The intervention and control group were similar in age, gender, lung function, smoke status, dyspnoea level, body mass index, and employment status (all $p > 0.05$) (Table 1).

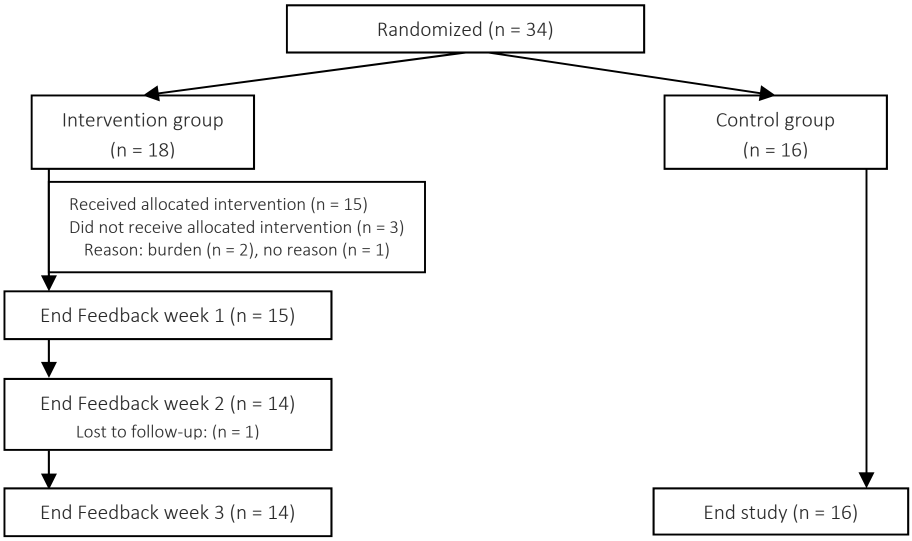

Fig. 1. Flow diagram of participants in the study.

Mixed-model analysis for repeated measures showed that the activity level measured by the pedometer was not significantly affected by the intervention over time: $p = 0.482$; effect intervention: $p = 0.382$ (Table 2). The intervention group showed a non-significant increase in the number of steps/day in feedback week 1 (+340 steps) and 2 (+505 steps), and a decrease in the last feedback week (–162 steps) compared with baseline. The control group showed a non-significant decrease compared with baseline for all weeks (resp. –403 steps, –666 steps, and –639 steps).

Table 1. Patients' characteristics at baseline.

Characteristics	Intervention group	Control group
Age (years)	65.2±9.0	67.9±5.7
Men/women	8/6	11/5
FEV_1% predicted	48.7±16.7	56.4±10.6
Current smoker (yes/no)	1/13	3/13
MRC	2.0±0.9	2.3±1.4
BMI (kg/m^2)	28.4±7.8	29.2±4.7
Work (employed/unemployed)	4/10	3/13
Physiotherapy (yes/no)	11/3	13/3

Abbreviations: FEV_1% predicted: forced expiratory volume in 1 second percent predicted, GOLD: Global Initiative for Chronic Obstructive Lung Disease, MRC: medical research council dyspnea scale, BMI: Body Mass Index. No significant differences between groups were found. Intervention group n = 14 & control group n = 16.

Table 2. Mean activity levels (steps/day) for the intervention group and the control group with standard error of the mean, obtained from the repeated measures analysis.

Activity (steps/day)	Intervention group	Control group
Baseline	5766±965	5256±865
FB week 1	6106±965	4853±865
FB week 2	6271±959	4590±865
FB week 3	5603±964	4617±865

FB: feedback, Intervention group n = 13 & control group n = 16.

Table 3 shows the baseline scores and changes for health status, dyspnoea, and fatigue. A non-significant improvement was found for health status between groups (mean difference: intervention group −0.34±0.55; control group: 0.02±0.57, 95% confidence interval (CI): −0.08 to 0.80, p = 0.104). Health status significantly improved within the intervention group (CCQ change: −0.3, p = 0.046), but not in the control group (p = 0.89). A minimal clinical important improvement in health status of ≥0.4 was found in five patients in the intervention group (n = 13), and one patient significantly decreased health status. In the control group (n = 15), three patients showed a clinical improvement and three patients showed a clinical significant worsening of the health status. Within groups, reduced motivation showed a trend for improvement in the intervention group (p = 0.073) and significantly improved the control group (p = 0.023), meaning that both groups seemed more motivated to start any activity.

Table 3. Mean±SD at baseline and mean changes±SD from baseline to after one month intervention for symptom levels and health status. A lower score means a better health status (CCQ), a lower dyspnoea level (MRC) and a lower fatigue level (MFI).

	Intervention group		**Control group**	
	Baseline	Change	Baseline	Change
CCQ score[a]	2.0±0.8	-0.3±0.5*	1.8±1.0	0.0±0.6
MRC score	2.0±0.9	-0.3±0.7	2.3±1.4	-0.2±0.9
MFI score				
General fatigue	12.5±4.0	-0.9±2.7	11.6±4.4	-0.3±2.6
Physical fatigue	13.1±3.7	-1.1±3.8	11.6±3.5	-0.4±2.7
Reduced activity	9.9±3.7	-1.4±2.7	9.9±4.0	-0.2±3.6
Reduced motivation	9.0±3.8	-0.6±2.2**	9.3±3.4	-1.1±1.6***
Mental fatigue	6.8±3.2	-0.5±3.5	6.6±3.8	-0.6±3.7

Paired t-test for changes within groups and unpaired t-test for differences between groups (intervention group n = 14 & control group n = 15). P values are marked for p < 0.15. [a] CCQ change between groups: p = 0.104, *within group CCQ p = 0.046, **within group MFI reduced motivation: p = 0.073, ***within group MFI reduced motivation: p = 0.023. Abbreviations: MRC: medical research council dyspnea scale, CCQ: clinical COPD questionnaire, MFI: multidimensional fatigue inventory.

Table 4 shows the use and compliance of the intervention. The activity coach was worn more than prescribed: for 17.5±2.2 days on average, which is 109% of prescribed. Only two patients used the system for less than the prescribed 16 days (13 and 14 days). In other words, 86% of the patients complied with the activity coach. The average duration per day was almost 10 hours (588±101 minutes). The diary was filled in 242 times, 17.3±7.8 times on average per patient, which is 58% of prescribed. Only one patient complied with the intervention and filled in the diary every day. Two patients had a very low compliance regarding the diary: one patient did not use the web portal at all and one other patient only for four days.

Table 4. Use and compliance of the activity sensor and web portal Intervention group n = 14.

	Total use	**Mean±SD per patient**	**Percentage prescribed**
Activity sensor			
Days	245 days	17.5±2.2 days	109.4±14.0%
Minutes	145161 min	588±101 min/day	n/a
Web portal	322 sessions in 271 days	23.0±10.3 sessions	n/a
Diary fill-outs	242 times	17.3±7.8 times	57.6±0.26%

In the intervention group, compliance with the activity sensor was significantly correlated to the change in activity level from baseline to feedback week 1 (r =

0.617, p = 0.033) and from baseline to feedback week 2 (r = 0.621, p = 0.031). The change from baseline to feedback week 3 was not significantly related to compliance with the sensor (r = 0.512, p = 0.107). The clinical parameters were obtained at baseline and after feedback week 3. The change in activity level from baseline to feedback week 3 showed a trend with the change in health status (CCQ, r = 0.606, p = 0.064) and general fatigue (MFI-20 general fatigue, r = 0.553, p = 0.078). There was no significant relationship found for the compliance with the diary and health status (p = 0.3).

Discussion

This pilot randomized controlled trial shows the potential of a new four-week telerehabilitation intervention for Chronic Obstructive Pulmonary Disease. The telerehabilitation intervention consisted of an ambulant activity coach for promotion of an active lifestyle, complemented by a web portal for self-treatment of exacerbations. As expected, the intervention did not result in significant differences in activity level or health status when compared with the control group, and as such the findings of this pilot study should be interpreted with caution. Within the intervention group, a significant improvement in health status was found from baseline till after the intervention. The compliance with the activity coach was high and a higher usage of the activity coach was significantly associated with an improvement in activity levels.

The Dutch standard for healthy physical activity[27] recommends at least 30 minutes of moderate intensity physical activity per day, at least five days a week, which corresponds to 10,000 steps/day.[28] At baseline, the patients in our study were far below this recommendation; their activity corresponds to that of the chronically ill (3500–5500 step/day).[28] This again underlines the necessity of an intervention that stimulates an active lifestyle for patients with Chronic Obstructive Pulmonary Disease. After two weeks treatment, the intervention group showed an increased activity level towards 6300 steps/day, which corresponds to the general activity level of healthy elderly.[28] The telerehabilitation intervention could have potential, just as has been found in other patients groups, i.e. chronic low back pain[29] and chronic fatigue syndrome.[30]

The control group on the other hand, showed a decrease in activity level compared with baseline. This decline was also observed in the study of Hospes et al.,[17] who used pedometer feedback combined with individually tailored exercise-counselling sessions. These decreases in activity level are not expected in a control setting, as patients did not receive an intervention. Research by Clemes and Deans[31] showed that the activity level can substantially increase as a result of wearing an unsealed pedometer, compared with a blinded activity measurement. They also indicated that in the absence of an intervention, step counts return to normal levels during the second measurement week. We would therefore expect larger differences between groups when blinded sensing would be applied.

A very high compliance was found using the activity coach and a higher usage of the system appeared to be significantly associated with an improvement in activity levels. Apparently, patients are willing to wear such a device in daily life to improve their activity behaviour. Previous research regarding telerehabilitation in chronic pain patients already showed that the more compliant subjects were, the more they benefited from the intervention.[21] Compliance with the diary for self-treatment of exacerbations was around 58%, which is lower compared with the activity coach compliance. This might be owing to the different treatment protocol: the activity sensor had to be worn four days/week, while the diary had to be filled out every day, and as such asks higher effort of the patients.

The effect on exacerbations was not evaluated in this trial as we would not expect changes in exacerbations during a four-week follow-up period. Previous research that used the paper version of the triage diary showed that self-treatment of exacerbations makes timely intervention possible, leading to less exacerbation days.[22] Moreover, studies showed that telemonitoring of symptoms significantly decreases hospital admission rates, the total number of exacerbations,[32] and healthcare costs.[33] Therefore, longer interventions are recommended with a group of patients with regular exacerbations, to obtain insight in the use of this web-based triage diary.

The small sample size and insufficient power represent considerable limitations of this pilot randomized controlled trial. The largest difference between the intervention and control group, of 1171 steps/day, was measured in feedback week 2. Taking into account our SD of 3300 steps/day, we would need 126 patients in each group to make this difference significant. In the first place this underlines a clear limitation of the present study, and a main cause of obtaining trends and no significant effects on some main outcome variables. Second, with respect to the use of activity level as an outcome parameter, the minimal clinical important difference might be more meaningful to evaluate instead of the significant difference.

However, the minimal clinical important difference for daily activity is so far not yet established.[10] As an alternative one could think of exercise capacity as a major outcome parameter.

Another aspect for future research is the finding of this study that changes in activity level seem to diminish after a few weeks of treatment. A review by Bravata et al.[34] already showed that physical activity can be significantly improved on a short-term, but whether these changes are durable in the long term is undetermined. As such, establishing sustainable changes in activity seems to be a challenging aspect in (tele)treatment. In a recent article, Effing et al.[35] noted that in Chronic Obstructive Pulmonary Disease the optimal maintenance could be achieved by a combination of exercise training and self-management interventions aimed to stimulate and maintain behavioural change. In addition, as long-term behavioural change is furthermore complicated by heterogeneity in activity behaviour,[36] fluctuations of symptoms,[37] disease progression, and exacerbations,[38] developments towards personalized medicine and tailor-made treatments are becoming increasingly important.[39] For future research, we would therefore recommend a telemedicine intervention that is applied for a longer period of time, and that includes exercise training and individual tailoring, in which the patient is guided to achieve and maintain an active lifestyle.

This is the first study that applied a telerehabilitation intervention in patients with Chronic Obstructive Pulmonary Disease that consists of a real-time ambulant activity coach and a webportal for self-treatment of exacerbations. An ambulant activity coach offers the possibility of measuring activity behaviour in daily life – insight which is often not available in current care. Moreover, the advantage of our telerehabilitation intervention is the possibility to receive feedback on activity levels with a higher frequency compared with normal care. Despite inherent limitations of the study, an important finding is that the intervention has a positive potential use: compliance with the activity coach was high and was directly related to an improvement in activity levels. However, in this pilot trial no significant effects have been established between groups. Four weeks is quite short for establishing changes in activity behaviour or to detect exacerbations, and it would be interesting to investigate the response and compliance to the intervention for a longer intervention period. Therefore, future studies are recommended with a larger sample size, which investigate treatment effects and compliance on both the short- and long-term.

Conflict of interest

The author declares that there is no conflict of interest.

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Clinical messages

- A four-week telerehabilitation intervention for patients with Chronic Obstructive Pulmonary Disease seems feasible. Future studies are needed to determine (clinical) effectiveness.
- A high compliance with an ambulant activity coach is positively related to improvement in activity levels in patients with Chronic Obstructive Pulmonary Disease.

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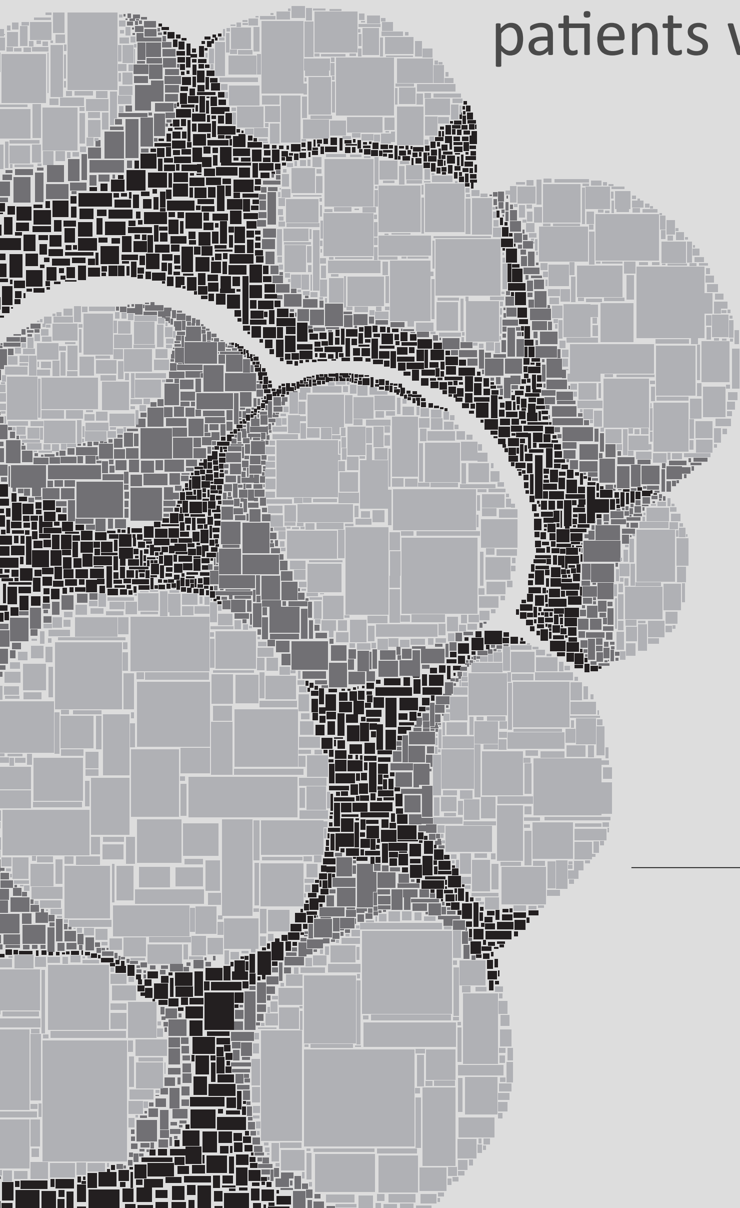
Figure on web: activity coach showing the activity graph.

CHAPTER 5

Acceptance and usability of technology-supported interventions for motivating patients with COPD to be physically active



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Abstract

In chronic care, technology can play an important role to increase the quality and efficiency of healthcare. But to be successful, healthcare technology needs to be acceptable, usable, and easily integrated into daily life. As a consequence, end-users need to be actively involved in the design process. In the European IS-ACTIVE project, we developed technology-supported interventions that promote physical activity in patients with COPD, by using an ambulant activity coach and an interactive game. In this paper, we elaborate on the design, involving the end-users, to develop interventions that are highly usable and well accepted.

Introduction

Regular physical activity plays an essential role in chronic disease management, such as for Chronic Obstructive Pulmonary Disease (COPD), a respiratory disease characterized by the progressive development of airflow limitation that is not fully reversible.[1] Providing face-to-face care to stimulate patients in regaining activity levels is difficult as care professionals lack insight in the patient's activity behaviour in daily life. Besides, the adherence with exercise programmes is low[2, 3] and they do not necessarily lead to improved daily activity behaviour.[4] The growing pressure on healthcare resources and costs and the increase in the number of patients,[5] argues for the need to find inventive ways to care for these patients. Healthcare technology seeks to respond to these pressures by assisting healthcare professionals in delivering high-quality patient care, and empower patients in self-care and disease management. Although numerous ICT-based healthcare applications have been designed and investigated, very few are eventually implemented in daily healthcare.[6] User acceptance of the technology is an important barrier to successful implementation in healthcare,[7] which emphasizes the need for involving users in the design process. In addition, the usability of an application seems to be a key aspect for success,[7] and should be evaluated in designing healthcare technologies.[8]

In this paper, two of the technology-supported interventions developed in the European IS-ACTIVE project (www.is-active.eu) are described and evaluated. These interventions aim to improve the physical activity of COPD patients from two perspectives: 1) daily monitoring and feedback using an ambulant activity coach and 2) supporting exercise using an interactive game. These interventions were developed from a user-centred perspective, in an iterative manner (see Fig. 1), where requirements were elicited from scenarios based on the PACT approach (People Activities Context Technology).[9] Both user needs and the state of the art in physical activity interventions for chronic conditions (e.g. [10, 11]) were used as input. Different stakeholders took part from the early stages of the design process, to meet the needs and wishes of the potential users, to improve usability, to increase the chance of user acceptance and consequently, adoption of the product being developed. The prototypes were first evaluated regarding technical feasibility. Subsequently, users need to work with the applications to obtain early user feedback. Therefore, this paper describes the small-scale evaluation of the technology-supported interventions. In future large-scale trials, the interventions –

with a fixed design – will be investigated in terms of clinical and cost-effectiveness to work towards implementation in health care.

The aim of this study was to determine the acceptance and usability of the interventions and to gain knowledge for further improvement, e.g. to explore how patients would like to receive feedback. The paper describes 1) the activity coach, 2) the interactive game, 3) the methodology for the evaluation study, and subsequently 4) the results. Finally, the findings of the evaluation are integrated and discussed to move towards next steps for improving physical activity in patients with COPD.

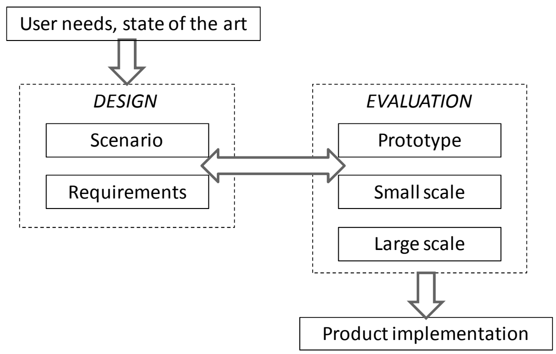

Fig. 1. Methodology for the development of the technology-supported interventions.

The activity coach

The promotion of physical activity in daily life is one of the key treatment goals for patients with COPD.[1] Patients with COPD often restrict activities due to dyspnoea (during exertion), which leads to an inactive lifestyle and consequently a lack of fitness.[12] Previous studies showed reduced amounts of daily activity in patients with COPD compared to healthy controls, and a distinctive activity decrease in the early afternoon.[13] Besides, COPD patients were moderately aware of their daily activity and do not have the intention to change their present daily activity. According to behaviour change theories, like the Transtheoretical model, patients need to be aware of their activity behaviour, otherwise treatment is unlikely to be effective.[14] Telemonitoring can provide the possibility of measuring the activity behaviour in daily life in an objective manner and thus create awareness. Similar to the feedback from the professional, ambulant technology-provided feedback should create awareness about patient's own functioning, motivate and stimulate patients to positively change their activity behaviour, and eventually improve patient's functioning.[15] In technology-supported interventions, the feedback can be intensified and provided in real-time, within the daily environment of the patient.

The activity coach aims to coach and motivate patients with COPD to obtain and maintain a physically active healthy lifestyle. The treatment goal is twofold: to increase activity levels and to distribute the activity level more equally over the day. The activity coach consists of a smartphone (HTC Desire S) and a sensor node with an on-board 3D-accelerometer (Promove-3D, Inertia Technology B.V., Enschede, the Netherlands) that measures the daily activity, referred to as the IMA value.[16] Both the accelerometer and the smartphone are worn on the subject's hip, measuring the 3D-bodily movement to estimate energy expenditure.[16] The sensor connects with the smartphone using Bluetooth. The smartphone shows the measured activity cumulatively in a graph, together with the cumulative activity the patients should aim for: the reference activity line (Fig. 2). Patients are asked to try to approach the reference line as closely as possible during the day. In addition, the patients receive text-based motivational cues on the smartphone. These messages are based on the difference between the measured activity and the reference line at the moment the message is generated. There are three types of motivational cues: encouraging (>10% deviation below reference line), discouraging (>10% deviation above reference line) and neutral messages (≤10% deviation with reference line). Besides, the user can answer questions on the smartphone about self-perceived activity performance and dyspnoea and fatigue levels.

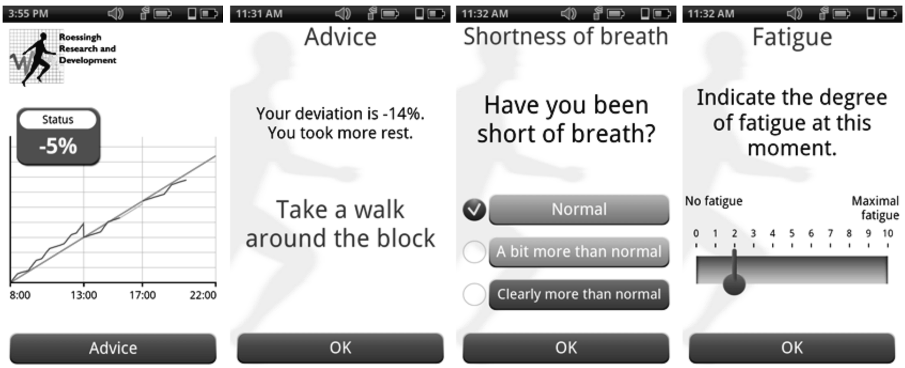

Fig. 2. Shows from left to right: 1) the main screen with a graph of daily activity, 2) a motivational cue, 3) a multiple choice question and 4) a Visual Analogue Scale (VAS) question. The top bar in each of the device screenshots shows a list of icons from the application that gives an indication of the application's current status, from left to right: sound on/off, wireless sensor connection, wireless sensor battery status, smartphone battery status.

Interactive game

All patients with COPD benefit from exercise training programmes and from regular physical activity[1] yet adherence with home exercising is low.[2, 3] Gaming technologies are believed to provide a variation or addition to the regular therapy, which can have a positive effect on motivation[17] without additional burden on neither formal, nor informal health care. Furthermore, games can increase the treatment intensity as players would like to beat their high score. However, very few of the available games today specifically target the elderly population[18] or aim at exercise for patients with a (chronic) condition.[19]

The orange submarine game aims to support and motivate patients with COPD to exercise. In this game, a submarine moves at a constant speed across an underwater landscape with hills at regular intervals. Air bubbles appear in a sinusoidal arrangement. This pattern can be adapted to the exercise the patient has to perform. The goal of the game is to catch as many air bubbles as possible, by directing the submarine through them. During the game, real-time feedback is given about the score, pulse rate, and oxygen saturation for motivation and controlled exercising (Fig. 3). Thresholds for heart rate and saturation could be entered before game play and when the patient crosses these thresholds, the game stops and displays a warning message. This warning message urges the patient to take a break.

Fig. 3. Right: screenshot of the orange submarine game, top left: the dumbbell (exploded view, showing the accelerometer and pulseoximeter integrated), bottom left: person playing the game.

A sensor node with an on-board 3D-accelerometer (ProMove-3D, Inertia Technology, Enschede, the Netherlands) is used to control the orange submarine in the game. By moving the sensor node up or down, the orange submarine moves in the corresponding direction. The node transmits the sensor data at 250 kbps through a 2.4 GHz wireless radio to a gateway, which in turn is connected through USB 2.0 to a computer. The oxygen saturation and the heart rate are measured with a Nonin WristOx2 3150 sensor, which is connected to the computer through a secure wireless Bluetooth 2.0 connection. For upper extremities exercising, a special dumbbell is used where the sensor node and the pulseoximeter are integrated in one single device (see Fig. 3). For lower extremities exercises the sensor node is attached to the hip and the saturation is measured using a separate finger clip sensor.

Methods

The purpose of the small-scale evaluation studies was to gain early user feedback. Patients with a clinical diagnosis of stable COPD, age above 40 years, and ability to read and speak the local language, were recruited from physiotherapy practices and (rehabilitation) hospitals in the Netherlands, Norway and Romania. All participants gave their informed consent prior to participation.

The test with the activity coach was performed in a lab setting and was designed to simulate daily use of the activity coach application and to simulate daily activities while using the application. At measurement start, the researcher tells a scenario to the patient to describe the patient why and how the activity coach can be used in daily life: *"You are diagnosed with COPD and you regularly exercise with your physiotherapist. You often feel short of breath, which causes you to be less active. This influences your daily routines and activities, and weakens your physical condition. A vicious circle develops that greatly affects your quality of life. To prevent physical deconditioning, an active lifestyle is very important. To do so, you follow physiotherapy and home exercises, which are intensive for you, but also demanding for your physiotherapist. Therefore, the physiotherapist gave you a new device, so you can be treated at home, using technology. This is the activity coach. The activity coach consists of an activity sensor and a smartphone. The activity sensor measures your daily activities during the day. The sensor can be attached to your belt and the smartphone can be put in your pocket or purse. You wear the activity coach during the day, at home and outdoors. The smartphone shows your activity in a graph. You* *receive messages with advice about how you can change your activity, in order to keep an active lifestyle and promoting a more uniform spread of activities during the day. You use the activity coach at least 4 days per week. You keep following your regular physiotherapy sessions, and you can discuss your progress with the physiotherapist. The idea is that, when you follow the advice of the activity coach, your physical condition will improve."* Subsequently, the patient uses the application while performing a number of daily life tasks, such as standing up from a chair and walking.

For testing the orange submarine game, an easy-to-perform exercise was chosen for the lower extremities: squatting. This exercise is suited for use in a home-based environment and is often part of the regular treatment. Beforehand, a short demonstration was given of the orange submarine game to familiarize the patients with the game. Patients first performed a measurement at rest to obtain a mean baseline score for pulse rate and saturation. A notebook was positioned in front of the patients and they were asked to stand next to or in front of a chair. If able, the patients were asked to play the game a total of three times.

In both evaluations, patients were asked to fill out the following questionnaires afterwards:

- The System Usability Scale (SUS) was selected to obtain a general and high-level view on usability The SUS is a simple scale with 10 statements covering a variety of aspects of system usability, such as the need for support, training, and complexity.[20]
- The Unified Theory of Acceptance and Use of Technology (UTAUT)[21] is a technology acceptance model that aims to explain user intentions to use an information system and subsequent usage behaviour. As this was a first user evaluation study, the technology aspects of the UTAUT model were assessed (i.e. performance expectancy and effort expectancy) and in addition, intention to use. Example statements include: "Using the system will improve my physical condition" and "I believe the system is easy to use". The questionnaire consisted of statements with a 5-point (activity coach) or 7-point (game) Likert scale ranging from "strongly agree" to "strongly disagree". The percentage of respondents that provided a positive (score coach: 4/5, score game: 6/7), negative (score: 1/2) and neutral answer (score coach: 3, score game: 3/4/5) were evaluated for each question.

- Additional questions were asked to obtain feedback about the game and activity coach using statements on a 7-point Likert scale. Example statements include: “The meaning of the graph is not clear to me” or “I find it difficult to follow the air bubbles on the screen”.

Results

In total, 39 patients with COPD participated in the evaluation of the technology-supported interventions. Twenty-one patients contributed in the evaluation of the activity coach: 7 males and 14 females, with a mean age of 63.5±9.6 years. Eighteen patients with COPD participated in the evaluation of the game: 5 males and 13 females, with a mean age of 58.6±7.1 years.

The average SUS score was 75.6 (range: 27.5-97.5) for the activity coach. Lowest scores were found for the learnability aspects: patients need some time learning how to operate the application, and expect they need help using it. The mean SUS score for the game was 85.0 (range: 50-100) with the lowest scores found for the question on the integration of various functions within the game.

Figure 4 shows the results of the UTAUT questionnaire for performance expectancy, effort expectancy and intention to use. Performance expectancy relates to the degree that a patient believes the use of the technology intervention would improve health outcome. 60% responded positively for the coach and 44% for the game. For the latter, the majority of patients answered ‘somewhat agree’ to the different questions, so they are not convinced that the game can improve their performance. For both interventions the questionnaire showed that patients believe the system is useful but they do not all believe that their complaints will actually improve (game: 5.2 out of 7, coach: 3.2 out of 5). Effort expectancy relates to the degree of ease that a patient associates with the use of the technology-supported intervention. 76% responded positively for the coach and 67% for the game i.e. patients do not think it will require a lot of effort to use the interventions. Patients generally believed the game is easy to use and that interaction is clear in most cases. Lastly, 65% of the patients have the intention to use the activity coach or game in the future. This was also specifically asked in a multiple choice question: “How long would you like to use the activity coach in the future?” 45% of the patients indicate ‘always’, 15% ‘one year’, 5% ‘3 months’, 15%, ‘1 month’, 15% ‘1-2 weeks’, and 5% ‘never’.

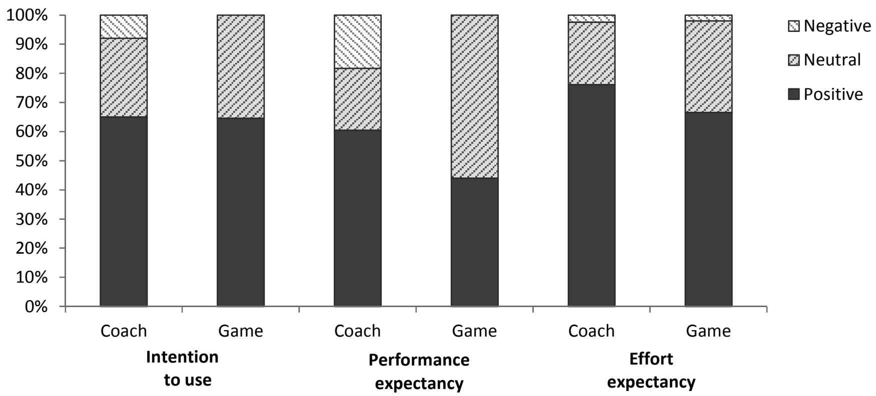

Fig. 4. Results from the UTAUT questionnaires for performance expectancy, effort expectancy and intention to use, for both the activity coach (n = 21) and the interactive game evaluation (n = 17).

The additional questions showed where the effort was expected by. Regarding the activity coach, patients scored lowest (score: 3.3) for that the smartphone was not light-weight enough. Also specific questions were asked for both feedback modalities of the activity coach: the activity graph and motivational cues. For the activity graph the mean score was 5.4, which includes a lower score on the question that the meaning of the graph was not always clear (score: 4.7), while the colours used were most highly appreciated (score: 6.3). The motivational cues questions had a mean score of 5.5; the cues were considered readable and motivating. The majority of all patients preferred both graphs and messages as feedback modality and preferred to receive their feedback whenever needed. Also, the patients in Romania considered the application useful for getting more information regarding heart rate and oxygen saturation in daily life to increase their confidence being active. Regarding the game, the additional questions showed that patients found it difficult to follow the bubble pattern of the game (score 3.3). Patients would like to get better in the game (score 5.9) and believe they are able to play the game at home by themselves (score: 6.3).

Discussion

Lessons learned

This study aimed to investigate the usability and acceptance of two technology-supported interventions that aim to improve physical activity in patients with COPD.

The small-scale evaluation showed a SUS score of 75.6 for the activity coach and of 85.0 for the game, which means that the technology-supported interventions have a good to excellent usability.[22] This is an important finding, as previous research showed that for example ease of use is an important factor of adherence to telecare systems.[23] The scores were well above the average of 68 found in literature.[20] For example, an exergame for physical rehabilitation of chronic pain patients had a usability score of 79.[24] In that study, patients with chronic pain had to play a game as part of their rehabilitation treatment. In our study the game was tested in a lab setting. Although lower scores were given for the integration of functions within the game, usability scored high, which could mean that the patients see past the flaws in this version of the game and recognize the potential for future use. This is also shown in the response to the squatting exercise which was well received, despite the fact that most patients were unable to follow the bubbles with the submarine properly by squatting. In a next phase, we should evaluate the actual user experience as part of regular treatment.

Patients regard the interventions as useful, believe their use does not require lots of effort, but remain a bit more doubting whether it could increase their performance, especially in relation to their complaints. Both interventions are indeed primarily aimed to improve activity behaviour, but we expect that its use will consequently lead to improved symptoms and quality of life. Symptoms cause patients to avoid activities, inactivity limits physical exertion capabilities, this decreases physical condition, and consequently, symptoms worsen and a negative circle ensues.[12] In this phase, it is unclear whether the daily coaching can improve daily activity behaviour and whether the gaming exercise is a valuable addition to COPD treatment. This should be a research aim of future investigations.

Literature also shows that performance expectancy can be influenced by worries concerning the quality of feedback, the possibility of fellow patient's contact and the feeling of alienation.[25] Therefore, when providing the activity coach or game to the patient in the future, the patient should be well informed about why he/she should use the application, how the feedback works and how it can improve the health status. This is also confirmed by literature; education is important for introducing new applications.[7] Patients can be provided a manual, or can receive a short training within the smartphone or game to familiarize (e.g. [26]). Professionals are also important to help patients understand the nature of the disease, the potential benefits of treatment, and to encourage development of self-management skills.[27] As such their attitude towards the technology-supported interventions can greatly influence the perception and adherence of the patients.

Patients generally showed a positive intention to use the interventions in the future. The majority of the patients would like to use the activity coach for more than a year or always. Moreover, the patients found the exercise of the game easy to perform, they expect to be able to play the game in their home environments and they would like to get better at the exercise. In a recent study, a virtual game system (Nintendo Wii) was used within a 3- to 4-week inpatient pulmonary rehabilitation programme.[28] The patients with COPD enjoyed the programme and would recommend it to others. As such we would expect that the orange submarine game – which is dedicated to the target group – could be a motivational tool for performing physical activity for patients with COPD either at home or in a care setting.

The strength of this study is that it provides a very early insight in the usability and acceptance of newly designed technology-supported interventions aimed to improve daily activity, so we can easily integrate the feedback in the upcoming iterations. In addition, the evaluations were performed with the future target group of the interventions, which is not always common practice.[29] A limitation of this study is that, although based on the same framework, the UTAUT and evaluation questionnaires differed for the coach and the game, and that these questionnaires were not validated. Another limitation of the current study is that the evaluation tests were not performed as part of the daily lives of the patients. For the activity coach, some activities were resembled in the lab and for the game we tested only one exercise. Future evaluations should incorporate more exercises including for the upper extremity, and gain insight in the use and experience in the daily environment and regular healthcare. For these upcoming studies, the other UTAUT constructs, i.e. facilitating conditions and social influence, should be investigated too, in order to obtain a complete picture of the acceptance and subsequently, usage behaviour. This would preferably be combined with qualitative data, such as the number of hours the activity coach was worn to obtain adherence.

Next steps

The evaluation provided us with concrete points for improvement. For the activity coach this has already resulted in a number of development steps. First of all, the feedback (i.e. the graph and motivational cues) has been optimized. The cues were provided at fixed time intervals (time based), but patients pointed out that the cues should be given when necessary. This affirmed our work on developing an intelligent coach that is tailored to the individual user in terms of its timing and content. This coach is able to learn to predict the optimum timing by analysing previously given cues and learning when a patient is likely to respond well to a given message by relating relevant context factors to patient compliance and content.[30] We expect that the tailored feedback will increase user acceptance of the activity coach, and that this will also increase the motivational aspect. The latter remains a challenging factor in this – mainly elderly – patient group; how can we ensure that people will keep using the activity coach? Therefore, we are investigating motivational terms, e.g. the possibility to add weekly messages that display the progress of the patient.

Based upon the requests of especially the Romanian users, it was decided to integrate oxygen saturation measurement (Nonin Medical) with the activity coach. The pulseoximeter values are transmitted to the smartphone along with the information from the activity sensor, and the patient can see these values on the screen of the smartphone, besides the activity graph. The saturation values are presented in coloured, traffic light boxes, indicating the saturation level and its potential risk. This enables the user to gain insight into the health status, and enables a safe training environment in daily life. This is expected to give the user more self-confidence and impulse to become more physically active, following the feedback from the smartphone.

Training and learning how to use the device were important aspects that resulted from the small-scale evaluation. We therefore made a clear, short manual for the patients, which describes the different aspects of the application and its use. To enable different kinds of future uses of the activity coach, three versions are available. These are containing the activity graph, and in addition: 1) motivational cues with self-adapting content and timing, 2) time-related motivational cues or 3) pulseoximeter values. In the future, the weight of the smartphone could be addressed by providing the activity coach as an app on the patient's own phone.

For the game a number of adjustments should be made before it can be evaluated in regular care. First, the controls of the game should be improved to move the submarine up and down by squatting with the sensor attached to the hip, for example by incorporating the gyroscope and magnetometer information. Second, the current version only consisted of one level and one (squatting) exercise. Although previous research showed that one simple exercise provided by a smartphone and telephone follow-up can effectively improve activity and have good adherence,[31] an increase of the number of levels and exercises would be desirable. With these adjustments incorporated, the game can be applied in healthcare and the effectiveness can be investigated. The current study can therefore be used as a stepping stone towards 1) further development of the orange submarine game, introducing compatibility with different physiotherapeutic exercises and testing in the patient's home environment, and 2) evaluation of a training effect when using a physiotherapeutic exercise in combination with the orange submarine game.

Besides, little is known what motivates elderly users such as COPD patients to engage in (ambulant) gaming and what games elderly would like to play.[18] Therefore, we started to investigate preferred motivation strategies and effective gamification feedback strategies in elderly (patient) groups by combining a user-centred design approach with experimental work based on theoretical models related to player motivation strategies and behavioural change. With this knowledge, combined with the further development of the game, gaming can be better tailored towards the treatment goals of the individual patient and might effectively improve daily activity in the future.

Towards implementation in COPD care

Before the activity coach can be implemented in COPD care, more insight is needed in the (long-term) use and acceptance, in the real-life care setting. Therefore, we are now heading towards small to medium field trials with the activity coach following the same methodology as the small-scale study, by evaluation of the usability (SUS) and usage behaviour (UTAUT and quantitative data) in field trials. In Romania, a longitudinal study has been executed in which the activity coach with the pulseoximeter addition was used for one month in daily life. In the Netherlands, the tailored activity coach with self-adapted timing is used for 3 months in a longitudinal study, to investigate the changes in COPD activity behaviour in a long term. Besides, in the Netherlands a randomized controlled trial has been executed where the time-based activity coach is part of a telehealth programme. These studies are the last phase before the interventions are investigated in terms of clinical and cost-effectiveness to eventually work towards final application in health care.

We envision several options of applying the activity coach in the future. First of all, as a standalone application that supports mild, stable COPD patients in keeping an active lifestyle without supervision, who do not follow physiotherapy sessions on a regular basis, but want to work on their activity behaviour. For this, strong motivational strategies are needed to support long-term use and obtain sustainable changes in daily activity. Second, as an application for mild to severe COPD patients, in addition to – or as partial replacement of – physiotherapy sessions, e.g. in a rehabilitation clinic. Using the activity coach in daily life provides insight in the activity behaviour of the patient, and by showing the activity on a webportal both patient and physiotherapist can monitor the progress. Third, as a part of a self-management programme for (very) severe COPD patients, in which patients not only work on self-management of their activity behaviour, but also on self-management of their exacerbations. Another possibility is to use the activity coach in exacerbation treatment, to prevent activity level decline during the exacerbation, and consequently have better health outcomes after exacerbation. Or lastly, as a post-treatment after completion of a rehabilitation programme to maintain the built physical capacities and prevent a relapse into an inactive lifestyle.

The game supports specific exercises of patients with COPD and can provide a fun and motivating manner to promote exercise, at home or in the healthcare clinic. The use of the game could provide valuable information on treatment adherence, or can monitor the patient's progress. In this way, the professional can better align treatment to the individual patient and the patients can exercise in a fun way with higher intensity. Further developments are needed for application in healthcare.

Conclusions

In this study, technology-supported interventions that aim to promote daily activity have been developed by means of a user-centred design approach. The activity coach aims to improve activity behaviour of patients with COPD by applying real-time feedback based on measured activity levels, while the interactive game aims to motivate exercising by means of a game. This small-scale evaluation study showed good usability and acceptance of these interventions in the target group. For the activity coach both the continuous feedback (by an activity graph) and motivational cues were preferred as feedback modality, and patients would like to receive the motivational cues whenever needed. We are now heading towards small to medium field trials with the activity coach. The game was positively received by the patients and could provide a new fun way for performing exercises, either at home or as part of the regular treatment. The game is not ready for implementation, but prospects are promising as the patients found the game usable and intent to use the game if available in the future.

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CHAPTER 6

Improving long-term activity behaviour of individual patients with COPD using an ambulant activity coach

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Submitted

Abstract

This study investigated whether an ambulant activity coach could positively influence the long-term daily activity behaviour, exercise capacity, and health status of patients with COPD. Patients with COPD (n = 8) completed a 3-month programme using the activity coach. Patients received self-adapting motivational cues on top of personal real-time visual feedback to get insight in their activity behaviour and guidance for behaviour change. For this highly individualized intervention, a single-case experiment was performed. A total of 464 measurement days were analysed. Five patients showed an improvement in activity level, and four patients improved their activity balance from baseline to the end of the intervention. Exercise capacity and health status showed a clinical improvement in respectively three and five patients. The activity coach can be effectively applied in individuals with COPD, but not to everyone. Future developments focus on personalization and selection criteria for participation to optimize the intervention.

Introduction

Physical inactivity has been identified as the fourth leading risk factor for global mortality causing an estimated 3.2 million deaths globally.[1] Regular physical activity is related to better health and lower mortality, and could reduce the risk of (chronic) diseases like coronary heart disease, type II diabetes and some cancers.[2, 3] However, two thirds of the adult populations of European countries are insufficiently active to support physically healthy living.[4] Reviews show that programmes that aim to reduce inactive behaviour and increase physical activity in adults are only marginally effective.[5, 6] This might be due to the distraction by embedded daily routines from the action plans to change activity behaviour[7] and the lack of support to change behaviour in a daily life setting.

Recent advances include the effective use of mobile technologies, e.g. smartphones and activity sensors, to promote a physically active lifestyle.[8] Text messaging is the primary technology utilized, for which short-term benefits are reported that could be clinically significant if sustained in the long term.[9] Behaviour change theories, like the Transtheoretical model, indicate that for effective behaviour change people should first be aware of their behaviour.[10] Activity sensors can quantify activity behaviour, create awareness, and provide feedback to change behaviour based on e.g. pedometer counts. Indeed, the use of pedometers is associated with significant increases in physical activity although whether these changes are durable in the long term is undetermined.[11] Also, the feedback is limited to showing the number of steps and/or setting a daily or weekly goal. People use mobile technologies, such as their phone, during the day, wherever they go. These applications can thus be especially suitable to provide real-time support, and keep intentions to change behaviour active, throughout the day.

The concept of real-time feedback, with motivational cues, is upcoming and has recently been investigated among different groups of users, such as chronic low back pain (CLBP)[12] chronic fatigue syndrome (CFS)[13] and Chronic Obstructive Pulmonary Disease (COPD).[14] Results show that users significantly respond to the motivational cues, but still not sufficiently effective as compliance to this feedback decreases over time[13] and changes in activity behaviour seem to diminish after few weeks use.[15] Individual tailoring with personalized activity goals,[16] professional guidance and on-going support,[5] and periodic prompts and reminders[17] are reported to potentially be more effective. We might successfully improve long-term activity behaviour by incorporating these elements in a technology-supported approach: by applying highly personalized real-time feedback and motivational reminders to coach patients in reaching their personal activity goal.

In this paper, we describe an ambulant activity coach that provides real-time feedback with self-adapting motivational cues. The activity coach visualizes the activity behaviour of the individual user in a graph, and provides motivational cues in the form of text messages (e.g. "You have taken more rest, please go for a walk."). The activity coach is personalized in the sense that it is able to learn to predict the optimal timing of the motivational cue by analysing the responses on previously given cues and learning when a patient is likely to respond well to a given cue by relating relevant context factors to patient compliance and content.[18] This type of technology intervention, which is tailored to the user, is new and information regarding individual responses and changes in activity behaviour over time is not yet available.

To investigate the changes in activity behaviour by using the activity coach, we applied the intervention in a small group of patients with Chronic Obstructive Pulmonary Disease for 3 months. For such a highly individualized intervention, a traditional control-group comparison for investigating treatment effects is considered less appropriate[19] as information on individual variability would disappear, causing information about each individual's process in treatment to get lost in the analysis. Single-case experimental design (SCED) is better suited for studies in which understanding and changing patient behaviour and functional status are primary goals.[19]

In the present study, we tried to enhance daily activity behaviour in patients with COPD by using the ambulant activity coach for 3 months and investigate the change in activity behaviour on an individual level. This effect was investigated in terms of amount of activity, activity balance, as well as in relation to exercise capacity and health status. The following research questions were addressed:

- Is the intervention effective? I.e. has the individual increased his/her activity behaviour and is the activity behaviour more balanced from the pre-intervention baseline condition to the end of the 3-month intervention?
- Is this maintained at 3-month follow-up?
- Is there a meaningful change in the patient's exercise capacity and health status from baseline to the end of the intervention, and is this maintained at 3-month follow-up?

Methods

Design

A single-case experimental design was used, to investigate the changes in long-term activity behaviour. The main outcome parameter was objectively measured activity behaviour; which was measured for one week before the intervention (A1: baseline phase), during the 3-month intervention (B: intervention phase), and for one week three months after the intervention (A2: follow-up phase). The study was approved by the Medical Ethical Committee Twente and registered in the Netherlands Clinical trial register (no. NTR3245).

Participants

Ten patients (6 male, 4 female) with a clinical diagnosis of COPD, were recruited from a rehabilitation centre in the Netherlands. Other inclusion criteria were: no infection or exacerbation in the 4 weeks prior to measurement; current or former smoker; age > 40 years; able to read and speak Dutch; and internet access at home. Exclusion criteria were: other diseases with low survival rate; other diseases influencing bronchial symptoms and/or lung function (e.g. cardiac insufficiency, sarcoidosis); severe psychiatric illness; need for regular oxygen therapy (>16 h per day or pO_2 < 7.2 kPa); known $alpha_1$-antitrypsine deficiency; disorders or progressive disease seriously influencing daily activities (e.g. amputation, paralysis, progressive muscle disease); and impaired hand function causing inability to use the application. All patients finished the lung rehabilitation programme at least 3 months before start of the study.

Activity coach

The activity coach was developed within the European IS-ACTIVE project and consists of a smartphone (HTC Desire S) and a 3D-accelerometer (Inertia Technology B.V., Enschede, the Netherlands) that measures the activity behaviour. Activity was expressed as the Integral of the Modulus of body Accelerations (IMA) which is a reliable estimation of energy expenditure.[20] The sensor connects with the smartphone using Bluetooth. The smartphone was used for data storage and providing feedback to the patient. The sensor was worn on the subject's hip. Patients wore this system for three months from waking till 22:00 h, with a minimum of four days per week. The first week was a baseline measurement, followed by 3 months in which the patient received feedback to change activity behaviour. This feedback consisted of 1) visual continuous feedback in the form of a graph and 2) text-based motivational cues.

Visual continuous feedback

The smartphone showed the total cumulative measured activity in a graph, together with the cumulative activity the patients should aim for: the reference activity line (Fig. 1). Patients were asked to try to approach the reference line as closely as possible during the day. The reference activity was calculated as follows:

- Patients performed a baseline measurement in the first week (minimum of 4 days).
- The mean daily activity level was calculated and distributed per day part according to the distribution of daily activities in healthy individuals: 40% in the morning, 30% in the afternoon and 30% in the evening.[21]
- Every week, the reference line was increased with 10% above the mean of the past measurement weeks.

In this way, the activity goal was adapted to every patient's abilities, and was changed based on the previous performance of the patients.

Fig. 1. Left: the main screen with a graph of daily activity, right: example of motivational cue. The top bar in each of the device screenshots shows a list of icons from the application that gives an indication of the application's current status, from left to right: sound on/off, wireless sensor connection, wireless sensor battery status, smartphone battery status.

Motivational cues

In addition, the patients received text-based motivational cues on the smartphone (Fig. 1). These messages were based on the difference between the measured activity and the reference line at the moment the message was generated. It consisted of 1) a short summary of activity behaviour and 2) an advice on how to improve the activity behaviour. An encouraging message could be for example: “You took more rest, we advise you to take a short walk”. There were three types of motivational cues: encouraging (>10% deviation below reference line), discouraging (>10% deviation above reference line) and neutral messages (≤10% deviation with reference line). The activity coach predicts the optimal timing of the cue, by analysing previously given cues and learning when a patient is likely to respond well to a given message by relating relevant context factors to patient compliance and content.[18]

Webportal

Patients could log on to a webportal, via a personal, password protected log in. On the web portal patients could see the measured activity level, per day, per week, and per month.

Measures

The daily activity behaviour was measured using the ProMove-3D sensor which measures 3D acceleration, expressed in IMA.[20] A change of ≥0.5 SD of the intervention period was defined as the minimal important difference (MID).[22] The following measurements were taken at baseline (A1), after the intervention period (B) and at 3-month follow-up (A2):

- The 6-minute walking test (6MWT) was performed to estimate exercise capacity, using a rectangular course of 25 meters, following standardized guidelines.[23] The MID was set at 25 meters.[24]
- The Clinical COPD Questionnaire (CCQ) was used to measure health status of COPD patients. Patients were asked to record their experiences of the last week. A change of 0.4 represented the minimal important difference for an individual patient.[25]
- The general self-perceived amount of activity of the COPD patients was measured using the Baecke Physical Activity Questionnaire (BPAQ) to assess activity awareness. The BPAQ covers questions about work activities, sports, and leisure-time activities (range: 3–15).
- The Medical Research Dyspnoea Council (MRC) scale was used to grade the effect of dyspnoea on daily activity at T0.

Data analysis

- Activity level: The mean activity per day was calculated for each patient. Only those days were included in the analysis for which at least 6 hours per day were available. Daily activity behaviour is displayed graphically per individual, per phase, to enable visual inspection. The means per phase were also displayed to investigate changes in activity level.

- Activity goal: We calculated whether the patient reached the personal activity goal. The measured cumulative activity of the patient at the end of the day is divided by the personal activity goal (i.e. the end of the cumulative reference line of that day) and expressed as a percentage.
- Activity goal compliance: The number of days in which the final cumulative activity was between 90% and 110% of the defined goal was calculated and expressed as the percentage of the total number of measurement days in the intervention.
- Balance goal: To investigate whether the distribution of activities throughout the day would be more balanced, we calculated the absolute difference between the reference line and measured activity line for each data point (every minute). Subsequently, the line was vertically translated to obtain the smallest difference and thus to rule out the influence of the activity level. This mean smallest cumulative deviation from the reference line was divided by the mean cumulative activity value of the reference line and expressed as a percentage (see [14]).
- Balance compliance: Per individual, the number of days in which the balance goal was reached (>90%) was calculated, and expressed as the percentage of the total number of measurement days in the intervention.

Results

Ten patients were included. One patient dropped out after 4 weeks due to personal issues, which lost him the motivation for continuing the investigation (pt. 9) and one patient had to stop participation after 6 weeks because of non-COPD related medical reasons (pt. 3). One patient stopped wearing the activity sensor after 2 months intervention because of technical problems, but did perform the follow-up measurements (pt. 8) therefore the results of this patient were included.

In total, 464 measurement days were analysed. Figure 2 shows the variability over time for activity level per phase: baseline (A1), intervention (B), 3-month follow-up (A2) per individual patient (n = 8). Figure 3 shows the variability over time for balance for the three phases per individual patient. Below, the individual responses are presented per patient.

Patient 1

Patient 1 (Table 1) is a 61-year old male with severe COPD and a BMI of 19.5 who becomes short of breath when walking uphill (MRC score of 2). He is unable to work any longer. Patient 1 shows an increase in activity level in the intervention period, especially in the first month. After 30 measurement days, the activity level decreases but is still above the activity level in the baseline period. The activity goal compliance was 23.1%. The mean balance improved from 77±11% at baseline to 82±11% during the intervention. The balance compliance was only 20.5%. The improvements in activity level and balance were not maintained at follow-up. There were no changes observed in subjective activity and exercise capacity, which means that this patient did not perceive large changes in his activity behaviour, nor did the use of the activity coach improve his exercise capacity. This patient showed a clinically significant worsening of the health status from baseline to the end of the intervention period, which is maintained at follow-up. Patient 1 was treated for an exacerbation at home after 1 month, which is clearly seen as a decline in activity level and low balance. After 2 months, this patient was hospitalized for an exacerbation and the activity coach was not used temporarily.

Table 1. Changes in activity behaviour, exercise capacity and health status for patient 1.

Patient 1	Baseline	Intervention	Follow-up
Activity level (IMA)	401±237	565±159*	295±66*
Balance (%)	77±11	82±11	69±5
Subjective activity (Baecke)	6.25	6.0	6.0
Exercise capacity (6MWT, meters)	531	510	530
Health status (CCQ)	0.9	1.9*	1.7*

* MID compared to baseline

Patient 2

Patient 2 (Table 2) is a 60-year old female with severe COPD, although she never experiences shortness of breath (MRC score of 1). She has a BMI of 22.0 and retired shortly after the intervention period. There were no changes observed in activity level between the baseline and intervention period. During the intervention, the activity compliance was 46.2%. The balance improved from 89% at baseline to 92% during the intervention period. The balance compliance – the number of days in which the balance goal was reached – was 76.9%. The subjective activity level increased with 0.9 points; patient 2 perceived an increase in activity level during the intervention. The exercise capacity and health status showed a minimal important difference (MID) at the end of the intervention period. The improvement in exercise capacity was even more increased at follow-up, but the health status worsened. In the last days of the intervention period, this patient was treated with antibiotics for a non-COPD related infection.

Table 2. Changes in activity behaviour, exercise capacity and health status for patient 2.

Patient 2	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	695±86	661±79	662±64
Balance (%)	89±9	92±3*	91±1*
Subjective activity (Baecke)	8.63	9.5	6.75
Exercise capacity (6MWT, meters)	495	525*	548*
Health status (CCQ)	1.5	1.1*	2.1*

* MID compared to baseline

Patient 4

Patient 4 (Table 3) is a 64-year old male with moderate COPD and a BMI of 26.1. He experiences shortness of breath when walking uphill (MRC score of 2). He is not working. The graph with the activity level shows a long baseline period, due to a wrong setting of the device (later start of intervention). The activity level shows an increase after about 4 weeks intervention, with an activity compliance of 40.0%. The mean balance was also improved from 82% at baseline to 87% during the intervention period, with a balance compliance of 32.5%. The subjective activity level increased at the end of the intervention period, and this was maintained at follow-up. The patient perceived an increased activity level at follow-up, which was not objectively measured. There were no minimal important differences observed for exercise capacity and health status from baseline to intervention, although there was a clinically significant worsening of the health status at follow-up. This patient was prescribed prednisolone 6 weeks after measurement start, which was followed by the flu (2 weeks). In week 10, this patient injured himself, causing knee problems and difficulties walking.

Table 3. Changes in activity behaviour, exercise capacity and health status for patient 4.

Patient 4	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	507±66	702±140*	630±97
Balance (%)	82±4	87±6*	88±5*
Subjective activity (Baecke)	6.0	7.75	7.5
Exercise capacity (6MWT, meters)	549	540	559
Health status (CCQ)	2.6	2.5	3.2*

* MID compared to baseline

Patient 5

Patient 5 (Table 4) is a 59-year old male with severe COPD and a BMI of 22.1, who experiences shortness of breath when walking uphill (MRC score of 2). He is currently employed. Immediately at the start of the intervention, the activity level increases and remains higher during the whole intervention period compared to baseline. During the intervention, the activity compliance was 54.1%. The mean balance also improved; a balance compliance of 85.3% was reached. The improvements in activity level and balance were not maintained at follow-up. The subjective activity was increased by 1.4 points after the intervention; this patient perceived an increase in activity level, which was not maintained at follow-up. Health status showed an MID at the end of the intervention period compared to baseline, and although health status was worsened at follow-up, this was still clinically improved compared to baseline. Exercise capacity also showed an MID at follow-up compared to baseline. At the end of the second month, the GP prescribed prednisone and antibiotics, and one month later, antibiotics.

Table 4. Changes in activity behaviour, exercise capacity and health status for patient 5.

Patient 5	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	576±148	661±93*	543±123
Balance (%)	87±7	93±3*	85±5
Subjective activity (Baecke)	8.13	9.5	8.5
Exercise capacity (6MWT, meters)	558	582	621*
Health status (CCQ)	3.5	1.8*	2.5*

* MID compared to baseline

Patient 6

Patient 6 (Table 5) is a 64-year old male with severe COPD, but he is rarely short of breath (MRC score of 1). He has an active job and has a BMI of 28.3. The mean activity level has significantly increased in the intervention period, with an activity goal compliance of 43.9%. The balance does not show improvements. During the intervention, the balance compliance was 52.3%. In the third month, there is a large temporary decrease visible in both the activity level and balance graphs. In that week, this patient had an arthroscopy of the knee. Patient 6 did perceive a slight decrease in activity level (decrease of 0.75) after the intervention period and a clinically significant worsening of the health status. There were no changes observed for exercise capacity.

Table 5. Changes in activity behaviour, exercise capacity and health status for patient 6.

Patient 6	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	772±139	1009±221*	790±229
Balance (%)	91±3	89±6	87±3*
Subjective activity (Baecke)	10.5	9.75	9.75
Exercise capacity (6MWT, meters)	547	538	548
Health status (CCQ)	1.1	1.6*	1.0

* MID compared to baseline

Patient 7

Patient 7 (Table 6) is a 49-year old female with severe COPD and a BMI of 24.9, who experiences more shortness of breath compared to her peers (MRC score of 3). She has a job. No significant change in activity level was observed in the intervention period compared to baseline. The activity compliance during the intervention was 39.7%. In the balance graph, some downward peaks can be observed and variability seems high. During the intervention, the balance compliance was 67.2%. At follow-up, both the activity level and balance are lower compared to the baseline and intervention period. The patient perceived an increase in activity level during intervention, and even more at follow-up. There was an MCID observed of 36 meters in exercise capacity from baseline to intervention, but this was not maintained at follow-up. Health status was clinically worsened at follow-up compared to baseline. In month 2, this patient received antibiotics (2x) and prednisolone, afterwards she continued again with her maintenance antibiotics.

Table 6. Changes in activity behaviour, exercise capacity and health status for patient 7.

Patient 7	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	634±54	611±75	557±103*
Balance (%)	92±4	91±5	84±7*
Subjective activity (Baecke)	8.8	9.25	9.63
Exercise capacity (6MWT, meters)	448	484*	450
Health status (CCQ)	1.6	1.8	3.1*

* MID compared to baseline

Patient 8

Patient 8 (Table 7) is a 64-year old female with very severe COPD and a BMI of 23.1. She experiences shortness of breath when walking 100 meters (MRC score of 4). She is not employed. The graph with the activity level shows a long baseline period, due to a wrong setting of the device (later start of intervention). The activity level does not show major changes during the intervention period, in which the activity compliance was 58.8%. The mean balance on the other hand, was greatly improved from 80% at baseline to 92% during the intervention period, with a compliance of 70.6%. The subjective activity level did not change; the patient did not perceive a change in activity level. There was an MID observed of 42 meters in exercise capacity from baseline to intervention and of 61 meters from baseline to follow-up. There was a clinically significant improvement in health status from baseline to intervention, which was not maintained at follow-up. This patient was hospitalized for an exacerbation in the second month. She stopped wearing the activity coach after 2 months intervention, because of technical problems with the device.

Table 7. Changes in activity behaviour, exercise capacity and health status for patient 8.

Patient 8	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	390±67	370±52	320±51
Balance (%)	80±5	92±4*	75±6
Subjective activity (Baecke)	5.5	5.25	5.5
Exercise capacity (6MWT, meters)	295	337*	356*
Health status (CCQ)	2.8	1.8*	2.8

* MID compared to baseline

Patient 10

Patient 10 (Table 8) is a 63-year old female, with moderate COPD who rarely experiences shortness of breath (MRC score of 1). She is employed and has a BMI of 24.2. The activity level is slightly higher during intervention. The activity compliance was 26.7% during intervention. There were no improvements in balance observed and during the intervention; the balance compliance was 33.3%. This patient showed low adherence with the intervention as there are only 30 measurement days in the intervention period. There were no changes observed for subjective activity and exercise capacity from baseline to the end of the intervention. There was a clinically significant improvement of 1.0 in health status from baseline to after the intervention. At follow-up, activity, balance, subjective activity and health status were lower compared to baseline. In the third month, the patient fell, causing pain and difficulties walking. Therefore, a new reference line was made in week 10.

Table 8. Changes in activity behaviour, exercise capacity and health status for patient 10.

Patient 10	Baseline	Intervention	Follow-up
Activity level (accelerometer, IMA)	532±177	588±97*	476±63*
Balance (%)	85±6	86±12	80±2
Subjective activity (Baecke)	8.3	8.13	6.63
Exercise capacity (6MWT, meters)	475	457	460
Health status (CCQ)	1.5	0.5*	2.5*

* MID compared to baseline

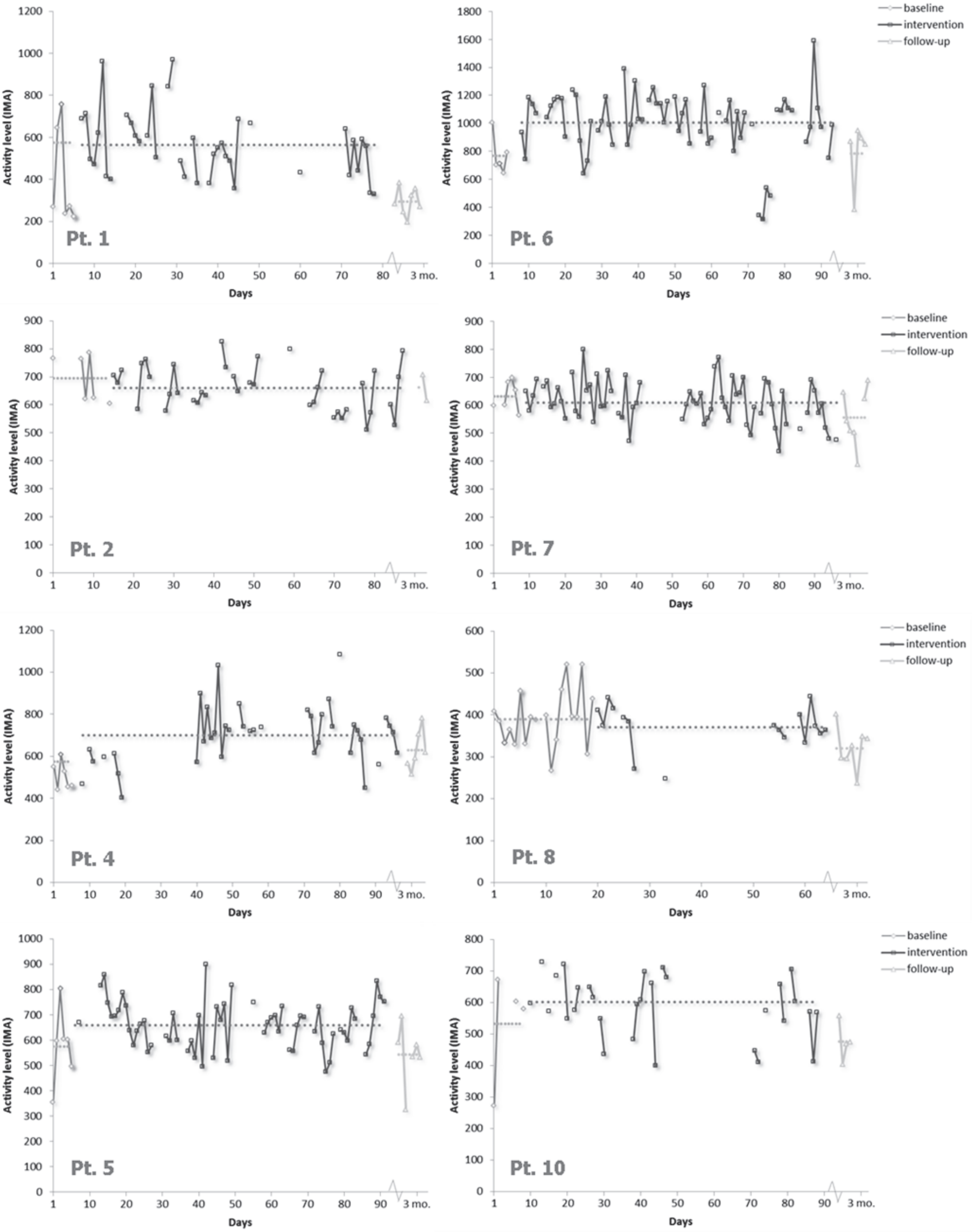

Fig. 2. Variability over time in activity level shown per phase: baseline (A1), intervention (B), 3-month follow-up (A2), per individual patient.

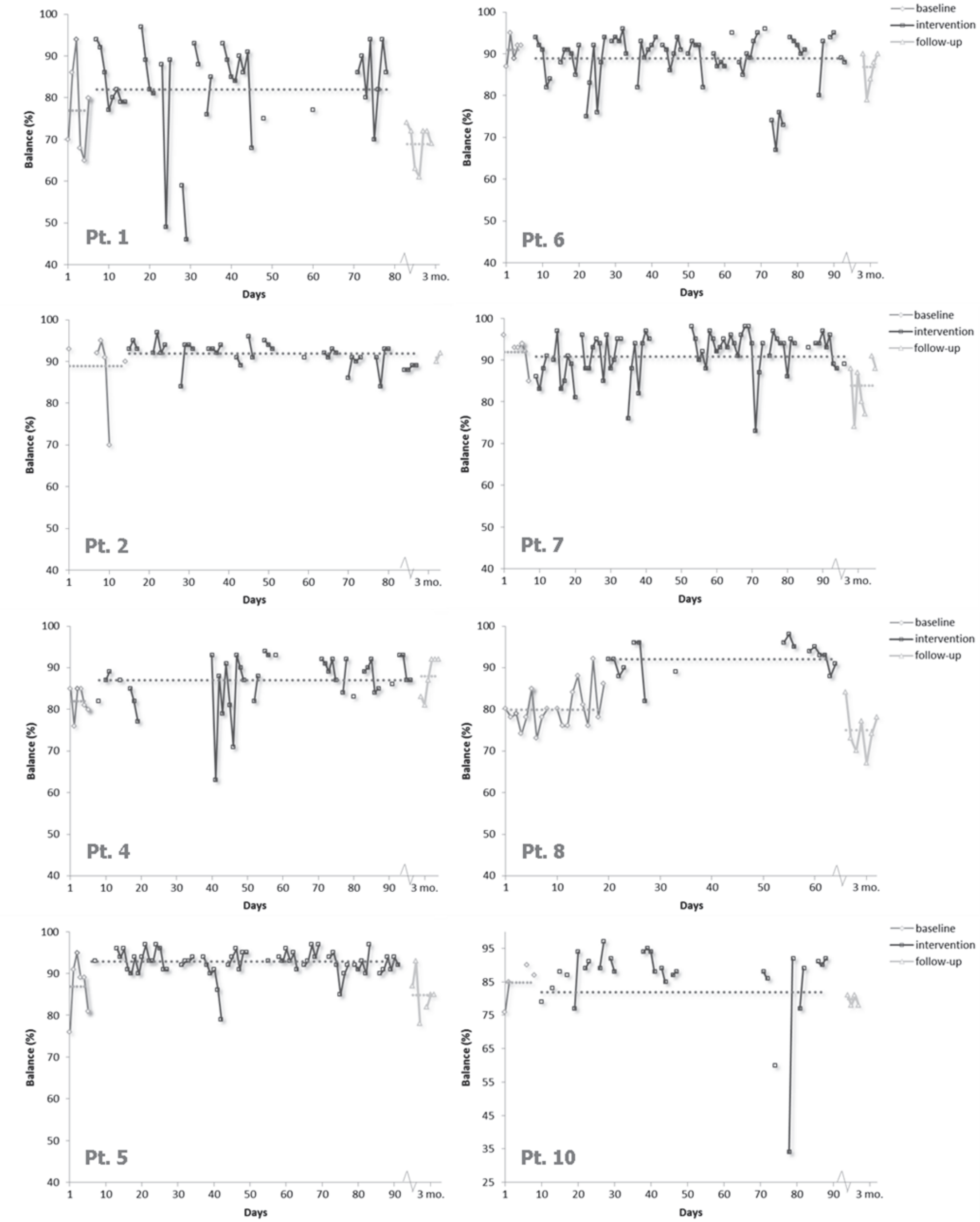

Fig. 3. Variability over time in balance shown per phase: baseline (A1), intervention (B), 3-month follow-up (A2) per individual patient.

Compliance, exercise capacity and health status

Figure 4 shows the changes in exercise capacity (top) and health status (bottom) together with the activity compliance (left) and the balance compliance (right). Three patients improved their exercise capacity by at least 25 meters (MID) and one patient with 24 meters. Regarding balance, there is a notable difference in relation to exercise capacity. The individuals with the higher balance score (>65%) show positive improvements in exercise capacity. Compliance with the activity level shows a less clear distinction in relation to exercise capacity.

Five patients show a clinically significant improvement (decrease of at least 0.4) in health status. There is no clear distinction observed between individuals that show improvements in health status and the individuals with no or negative changes in health status in relation to activity compliance or balance compliance. Patients 2 and 8 improve both in exercise capacity and health status.

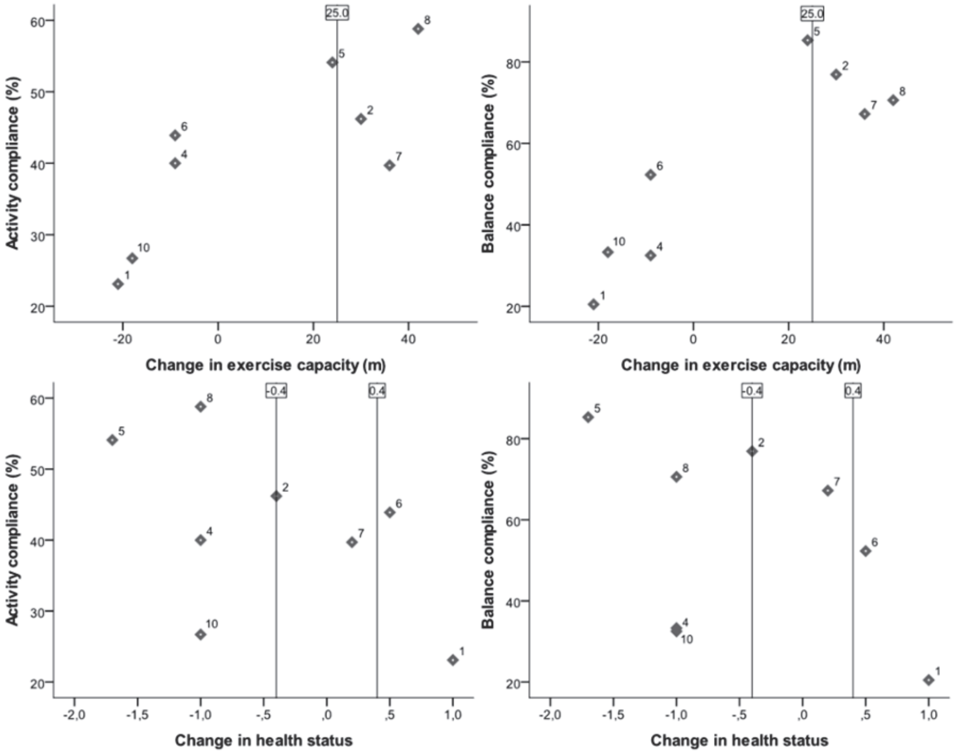

Fig. 4. Changes in exercise capacity (top) and health status (bottom) in relation to the compliance in terms of activity level (left) and activity balance (right). Each dot is one individual patient. The vertical lines represent the MIDs.

Discussion

This paper investigates individual changes in activity behaviour in response to an ambulant activity coach with self-learning motivational cues. Our results show that the intervention is (clinically) effective for some patients, but not for all.

The intervention is effective in 5 patients in terms of increasing activity levels and 4 patients of improving activity balance from the pre-intervention baseline condition to the end of the 3-month intervention. In a previous study, a small significant average increase in activity level of COPD patients was observed in response to using an activity coach during three weeks, while no significant improvement was observed for activity balance.[14] The same study showed that only a minority of the patients (2 out of 11) had a significant individual response for activity level or balance. The motivational cues in this earlier study were provided at fixed time intervals, and the reference line was partly based on the activity levels of healthy individuals. This suggests that the tailoring we applied — self-adapting cues and a more personalized reference line — might contribute to better treatment effectiveness. This should be investigated in future studies.

Three patients had a clinically significant improvement in exercise capacity of >25 meters after the intervention period, and one patient of 24 meters. Well-balanced activity behaviour seems to be important for the improvement of exercise capacity, which is an interesting finding, as so far, no evidence is present that a balanced activity pattern would improve clinical outcomes. This is something for further exploration in clinical studies.

Our study showed that the increased activity levels of the individuals were not maintained at follow-up and only two patients maintained their improved activity balance. This suggests that the patients were not able to maintain their change in activity behaviour after the intervention ended. According to the stages of changes, people move through stages of increasing readiness to follow recommendations as they develop the motivation and skills required to change their behaviour.[10] In our study, the intervention was prescribed to a group of COPD patients, who were not selected based on the need to change activity behaviour (e.g. after an exacerbation) nor readiness to change activity behaviour. For future research, we would therefore recommend to include behavioural features like the readiness to change behaviour, so we can better predict for which individuals this intervention is most likely to be successful. With this information, we can further tailor the activity coach intervention on an individual level.

For the case of COPD patients specifically, an option would be to use the activity coach as an integrated part of a COPD self-management programme in a clinical setting. Such programmes aim at structural behaviour change to sustain treatment effects after the programme is finished. Patients learn to cope with the complexity of their disease, including self-management of exacerbations and activity behaviour. Effing et al. mention that these programmes should include techniques aimed at behavioural change, be individually tailored, and should vary with the development of the patient's disease.[26] The self-learning activity coach can thus play an important role to help patients develop their self-regulatory skills required for achieving and maintaining an active lifestyle. For other less complex user groups, who only need to target their activity behaviour, we expect that the activity coach can be used more effectively as a standalone intervention.

Differences were observed between and within individual patients: in activity level, balance, patient characteristics as well as in the response to the intervention. E.g. not all patients that improved their activity behaviour (level or balance) also improved in exercise capacity or health status, and vice versa. Also the average compliance — the percentage of days in which the goal was reached during the intervention period — varied greatly between patients: from 23% to 59% for the activity level and from 21% to 85% for balance. Previous studies have shown that patients exhibit considerable variability in their degree of activity behaviour,[27] but also in fluctuations of COPD symptoms.[28] Moreover, health status does not solely depend on physical activity and is influenced by several factors, like symptom severity, social influence and emotional well-being.[29, 30] Many co-occurring conditions were present during our study (e.g. exacerbations, injuries), which are clearly visible in the activity graphs, reflecting their direct impact on the outcome of the intervention. Besides, not only personal events, but also e.g. environmental factors such as the weather can influence the ability and motivation to change activity behaviour.[31]

The heterogeneous baseline characteristics, varying responses to the intervention and co-occurring conditions emphasizes the need for advances towards more personalized medicine and tailor-made treatments in COPD,[32] in which the intervention is adapted to the individual activity behaviour, the patient’s everyday functional and emotional well-being[29] and changes in the environment. Such tailoring of the activity coach could be achieved by adapting the provided feedback to the patient's stage and readiness of change, and adapt its feedback accordingly. Furthermore, self-learning motivational cues could be used in terms of timing and content, and should also incorporate the (daily) fluctuations in symptom levels and patients well-being.

In conclusion, this study has provided us detailed insight in the activity behaviour of individuals with COPD in response to using an ambulant activity coach. The cases reflect clearly the large variability between individual patients, well-known in daily clinical practice. We would recommend 1) investigating the (behavioural) characteristics of individuals for which this intervention is suitable and 2) improving the tailoring of the activity coach to the user, by optimizing timing and content of the messages, and incorporation of how the patient feels. The activity coach intervention was investigated in the case of COPD but this intervention can be applied more broadly — not only in other chronic diseases but to anyone who would like to improve activity behaviour.[25]

Acknowledgements
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CHAPTER 7

A telehealth programme for self-management of COPD exacerbations and promotion of an active lifestyle: a pilot randomized controlled trial

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Submitted

Abstract

The objective was to investigate the use of and satisfaction with a telehealth programme and to explore clinical changes compared to usual care. The programme was implemented in primary and secondary care and consisted of four modules: 1) activity coach for ambulant activity monitoring and real-time coaching of daily activity behaviour, 2) web-based exercise programme for home exercising, 3) self-management of COPD exacerbations via a triage diary on the web portal, and 4) teleconsultation. Twenty-nine COPD patients were randomly assigned to either the intervention group (telehealth programme for 9 months) or the control group (usual care). Page hits on the web portal showed the use of the programme, the Client Satisfaction Questionnaire showed satisfaction with received care. Clinical changes were explored by exacerbations, hospitalizations, exercise tolerance, health status, activity, fatigue and quality of life. The telehealth programme was accessed 86% of the treatment days, especially the diary. Adherence with the exercise schedule was low (21%). Median hospitalization was 5.5 (IQR: 4.8-6.3) days for the telehealth group and 7.0 (IQR: 6.0-7.0) days for the control group. These results show that the telehealth programme has potential but future studies are needed to determine clinical- and cost effectiveness.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is characterized by a chronic airflow limitation of the airways and has a large effect on physical, psychological and social functioning.[1, 2] Periods of acute worsening of the patient's condition – exacerbations[3] – accelerate the decline of lung function,[4] have a serious negative impact on patients' quality of life[5] and result in prolonged activity limitation.[6, 7] Especially hospital admissions due to exacerbations constitute a major problem in the management of COPD as they represent more than two thirds of all costs.[8] Given the growing number of patients and the increasing burden on healthcare resources and costs,[9] the challenge to provide quality care in the future is becoming increasingly important.

The optimal management of COPD is complex due to a heterogeneous picture of progressive deterioration as well as the great variation in symptoms, functional limitations and well-being that patients with COPD experience.[6, 10, 11] Multidisciplinary, integrated programmes have shown to be able to optimize quality of life and exercise tolerance,[12] especially when containing an exercise programme.[13] However, these programmes are advised to be more individually tailored and accessible by the patient when they need it most.[14, 15] The recent technological advances in healthcare could supply this need by monitoring symptoms in daily life and support self-management of exacerbations. For example, Nguyen et al. incorporated technology to their dyspnoea self-management programme, to support early recognition of worsening symptoms through real-time monitoring, quick feedback, and access to information and support.[16] In the study of Jensen et al., a telehealth monitor collected and transmitted data about the patient to a web-based portal or electronic healthcare record, while professionals could monitor progress and training inputs and provide advice to the patient.[17] In telemonitoring, active involvement of a case manager is needed for final interpretation of monitoring data or feedback to the patient, which might slow the care process. We would assume that by using decision-support technology and automated feedback to the patient, telehealth interventions can contribute to more effective and efficient, quality health care.

The potential of telehealth regarding healthcare utilization and costs, acceptability, or clinical characteristics is the starting point for development of interventions. However, the overall benefits are not yet proven[18, 19] and limited evidence has been reported for their value in chronic disease management.[19] One reason for this might be that most telehealth studies in COPD use technology for one of the aspects of integrated care programmes, which mostly consists of monitoring symptoms for self-management of exacerbations.[16, 17, 20-24] Multimodal telehealth programmes that monitor patient behaviour and symptoms in daily life, deliver intensive personal automated feedback to improve activity behaviour, facilitate home exercising, and empower patients in self-care and disease management are not yet investigated.

In this paper, we describe a technology-supported care programme that supports the treatment of COPD patients through self-treatment of exacerbations, and promotion of an active lifestyle by real-time coaching and home exercising via a webportal. This programme was applied as blended care, i.e. implemented within the usual care – primary and secondary – to explore the potential for daily health care practice. Understanding the use of and compliance with such an intervention is essential for creating a standard for future telemedicine interventions.[25] Therefore, the objective of this study was to gain insight in the use of the telehealth programme that was applied for 9 months, and explore the experienced satisfaction with received care. The secondary aim of this study was to explore the clinical changes of the telehealth programme compared to usual care in terms of hospitalizations, health status, exercise capacity, symptoms, activity level and quality of life.

Methods

In this pilot randomized controlled trial the following conditions were compared: 1) regular treatment and 2) telehealth programme. Patients were recruited by a chest physician or nurse practitioner. Patients were eligible for inclusion if they fulfilled the following criteria (COPE II study criteria[26]): a clinical diagnosis of COPD according to the GOLD criteria, no exacerbation in the month prior to enrolment, ≥3 exacerbations or one hospitalization for respiratory problems in the two years preceding study entry, (ex)smoker, ≥40 years of age, post-bronchodilator FEV_1 25-80% of predicted, able to understand and read Dutch. Besides these inclusion criteria, patients should also have internet access at home.

Patients were excluded if they had: serious other disease with a low survival rate, other diseases influencing bronchial symptoms and/or lung function (e.g. sarcoidosis), severe psychiatric illness, uncontrolled diabetes mellitus during a COPD exacerbation in the past or a hospitalization for diabetes mellitus in the two year preceding the study, need for regular oxygen therapy (>16 h per day or pO_2 < 7.2

kPa), maintenance therapy with antibiotics, known $alpha_1$-antitrypsine deficiency, disorders or progressive disease seriously influencing daily activities (e.g. amputation), or impaired hand function causing inability to use the application. The study took place in Medisch Spectrum Twente Hospital and primary care physiotherapy practices in Enschede, the Netherlands, between December 2011 and July 2013. The study was approved by the Medical Ethical Committee Twente and registered in the Netherlands Clinical trial register (no. NTR3072).

No power analysis was completed as this was a pilot trial to examine the use of the programme; exploring clinical changes between groups were a secondary aim. Sample size was based upon the estimated number of patients that could be included within the recruitment period and availability of technology. Patients were randomized using a computer-generated randomization list (programme: Blocked Stratified Randomization V5; Steven Piantadosi), where randomization was applied in random blocks of two and four. Participants were allocated by a data manager in order of inclusion following the randomization list, placed in a sealed envelope.

Intervention group: telehealth programme

The framework for the technology-supported care programme, called the Condition Coach (CoCo) was provided by previous work on self-management programmes,[26] home exercise programmes,[27] changing activity behaviour,[28, 29] and telemedicine interventions.[30, 31] CoCo is a telehealth programme for self-management of COPD exacerbations and for promotion of an active lifestyle. CoCo consists of four modules (Fig. 1):

1. A web-based exercise programme on the webportal, originating from the COPE II & Pulmofit studies.[27, 32] This included breathing exercises, relaxation, mobilization, resistance and endurance training, and mucus clearance. For every individual patient, exercise schemes were made by the patient’s physiotherapist via the webportal. Every exercise consists of a text description and movie. The patient is able to login at home, follow the exercise scheme, execute the exercises and provide feedback to the physiotherapist. Apart from the exercise scheme patients can perform an extra exercise by the ‘additional exercises’ option.
2. Activity coach for ambulant activity registration and real-time feedback to improve daily activity. The activity coach consists of an accelerometer-based activity sensor (Inertia technology, Enschede, the Netherlands) and a smartphone (HTC Desire S). The smartphone shows the measured activity cumulatively in a graph, together with the cumulative activity the users

should aim for: the reference activity line. In addition, the users received motivational cues during the day for awareness and extra motivation. These messages were based on the activity of the last 2 hours and of the day so far. Each cue provided a summary of the activity behaviour and an advice on how to continue the activity behaviour, for example: “You have been very active today, but took some rest now. Keep on going like this, and keep in mind your activity balance.” At the end of the day the patient received a summary of their activity behaviour (e.g. “You were clearly less active today. Discuss this with your physiotherapist”). The participant’s measured activity levels were also displayed on the web portal.

3. A self-management module on the webportal for self-treatment of COPD exacerbations. Every day, participants were asked to fill in the diary on the web portal, which is the digital version of the diary used by Effing et al.[26] The decision tree of the diary was translated into a decision-support system that automatically forms an advice to start medication in case of worsening of the clinical condition.
4. Teleconsultation module for asking questions to the patient’s primary care physiotherapist, via the webportal.

The webportal was accessible for the patient and the involved primary and secondary care professionals. Before start of the programme, participants had to attend two 90 min self-management teaching sessions given by a nurse practitioner, to learn completing the daily diary.[26] Patients were also educated in early recognition of exacerbations and in starting standardized treatment in case of an exacerbation. Furthermore, they got instructions by the primary care physiotherapist explaining the webportal and for performing baseline measures. There was no standardized exercise treatment protocol: the physiotherapist determined per individual patient how and when the activity coach module was used. Likewise, the reference activity line could be completed on the webportal, without restrictions, although the physiotherapist could use activity monitoring data of the patient as starting point. The physiotherapist could freely select the exercises per patient for the online exercise programme. This exercise programme could be adapted during the intervention period following the progress of the patient at the discretion of the therapist. Both primary and secondary care professionals could supervise the patient at a distance by checking progress on the webportal.

Fig. 1. The telehealth programme modules.

Control group: regular treatment

Participants in the control group only received usual care. In case of an exacerbation, the participants had to contact their medical doctor.

Outcome measures

Questionnaires were administered at T0 (inclusion), T1 (1 month), T2 (3 months), T3 (6 months) and T4 (9 months). For the intervention group, use of the application was registered by the system between the T0 measurement and the T4 measurement. Use of the application was calculated for all patients, including drop-outs. Adherence to the online diary was calculated by dividing the number of diary fill-outs by the number of treatment days. Adherence to the exercise schedule was calculated by dividing the number of schedules that were prescribed by the number of schedules performed. Satisfaction with received care was measured by the Client Satisfaction Questionnaire (CSQ-8) in both groups. The total score scale range is 8–32 and a higher score indicates a higher degree of client satisfaction. Exacerbation types were defined according to Anthonisen[33] and the decision-support diary automatically identified exacerbations following previously described criteria.[26] In addition, the number of hospitalizations, length of stay, and emergency department visits were registered during the 9-month follow-up period. The activity sensor of the activity coach was used for registration of activity levels in both groups expressed in IMA.[34] A measurement day should consist of 6 or more hours. The

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Baecke Physical Activity Questionnaire (BPAQ) was used for assessing self-perceived activity levels. Additional outcome measures to evaluate the clinical changes were: exercise tolerance (6-minute walking test: 6MWT), fatigue (Multidimensional Fatigue Inventory: MFI-20), health status (Clinical COPD Questionnaire: CCQ), dyspnoea (Medical Research Dyspnoea Council scale: MRC) and quality of life (EQ-5D). Questionnaires were administered from T0 to T4; 6MWT was not performed at T1.

Statistical methods

A standard package was used (Statistical Package for Social Sciences, IBM SPSS 19.0). The alpha was set at 0.05 and a trend was defined as $p \leq 0.10$. To explore the effect of the telehealth programme a mixed model analysis for repeated measures was performed (intention-to-treat). Time of measurement (T0 to T2) was used as a within-subjects factor and group (telehealth or usual care) as a between-subjects factor. Differences in continuous variables (e.g. activity level) between the two groups were compared using the independent t-test or Wilcoxon rank-sum test as appropriate. Differences within the groups were analysed using the paired t-test (in case of normal distribution) or related-samples Wilcoxon signed-rank test. For comparing two categorical variables, Pearson's chi-squared or Fisher's exact test was used.

Results

Twenty-nine patients of the 101 patients (29%) that fulfilled the inclusion criteria were willing to participate and randomized in one of the two groups. An important reason for not participating was that patients did not have a computer or internet-access at home. Figure 2 shows the progression of the participants through the study. There was a high drop-out rate: intervention group 33% and control group 86%. Although some patients in the intervention group quit the physiotherapy modules (exercising and activity coach) due to weak (n = 1, <T1) or unstable condition (n = 1, <T2) and personal circumstances (n = 2, <T4), they persisted in using the webportal and triage diary till T4.

Table 1 shows the baseline characteristics for both the intervention and control group. There was a significant difference found for baseline dyspnoea levels between groups ($p = 0.03$), and a trending difference for health status ($p = 0.079$) and exercise capacity ($p = 0.065$), showing better clinical measures in the telehealth group.

Table 1. Baseline demographics and clinical characteristics.

Variable	n	Telehealth	n	Usual care	95%CI	p
Age (years)	12	64.1±9.0	12	62.8±7.4	-5.7; -8.2	0.71
Male/female	12	6/6	12	6/6		1.0
^FEV_1% predicted	12	50.0 (33.3-61.5)	12	36.0 (26.0-53.5)		0.25
BMI (kg/m^2)	12	25.3±4.2	12	28.2±4.6	-6.6; -0.9	0.126
Exercise capacity (6MWT, m)	11	409.5±111.6	7	313.0±79.4	-6.8; -199.7	0.065
^Dyspnoea (MRC)	10	3.0 (2.0-3.3)	11	4.0 (3.0-4.0)		0.032*
Health status (CCQ)	11	2.0±1.0	11	2.7±0.8	-1.5; -0.1	0.079
^Fatigue (MFI)	11	12.0 (10.0-16.0)	11	16.0 (11.0-20.0)		0.26
Quality of life (EQ-5D)						
VAS	11	64.1±15.9	11	65.0±12.0	-13.5; -11.7	0.88
Index	11	0.75±0.09	9	0.69±0.14	-0.05; -0.17	0.28
Subjective activity (BPAQ)	10	7.1±1.4	10	6.2±1.3	-0.34; 2.25	0.139
Smoker/no smoker	11	4/7	12	4/8		1.0
Employed /unemployed	12	5/7	11	2/9		0.371

* $p < 0.05$, ^non-parametric test, showing the median and interquartile range. Abbreviations: FEV_1%: Forced Expiratory Volume in 1 second % predicted, BMI: Body Mass Index (in kg/m^2), 6MWT: 6-minute walking test, MRC: medical research council dyspnoea scale, CCQ: clinical COPD questionnaire, MFI: multidimensional fatigue inventory (general fatigue scale), EQ-5D: EuroQol, BPAQ: Baecke Physical Activity Questionnaire.

Use and satisfaction

Figure 3 shows the percentage of treatment days in which patients visited the webportal, per intervention month. The webportal was highly used over time and no large changes were observed between months (Fig. 3).

Table 2 shows in more detail the specific use of the web portal per patient. In a number of patients, the intervention period (T0-T4) lasted more than nine months. The webportal was used in 86.4% of the days during the intervention, in which the triage diary was the mostly used module (median 82.8%). In total, 569 exercise schemes were subscribed to the patients, of which 127 schemes were completely performed (22.3%) and 17 schemes partly (3.0%). A total of 1110 exercises were prescribed to the patients within the exercise schemes. Additionally, 543 exercises were performed independently (‘additional exercises’ option). Four patients apparently did not receive an exercise scheme from their physiotherapist, although one patient did perform exercises independently. Patients 9, 18, 19 and 24 were the ones that stopped using the exercise and activity modules, but continued using the diary.

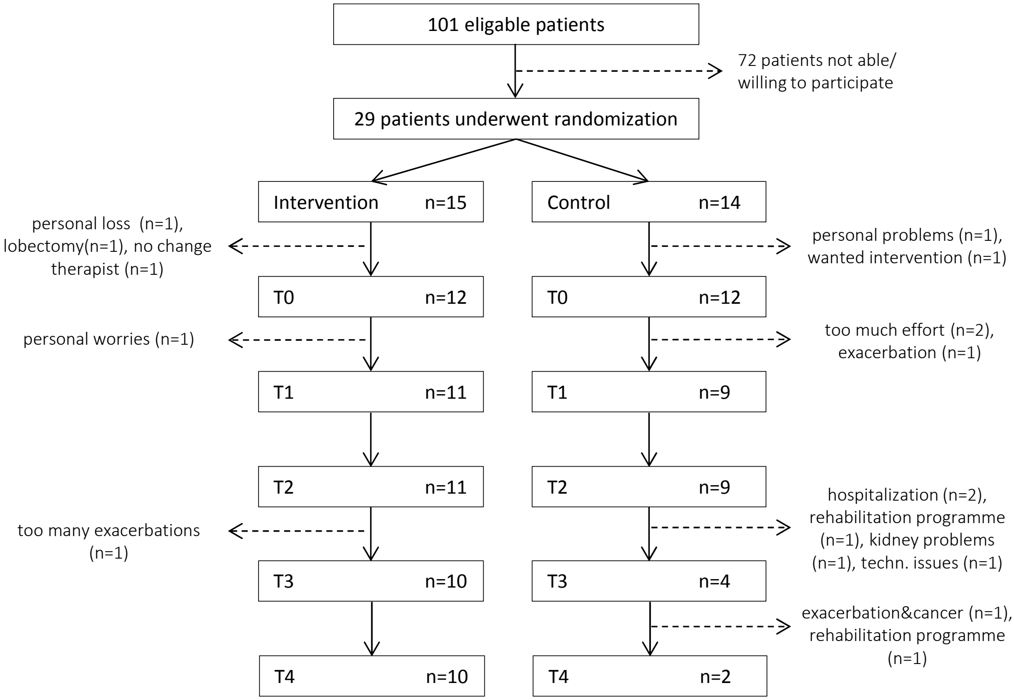

Fig. 2. Flowchart for recruitment, randomization and drop-out.

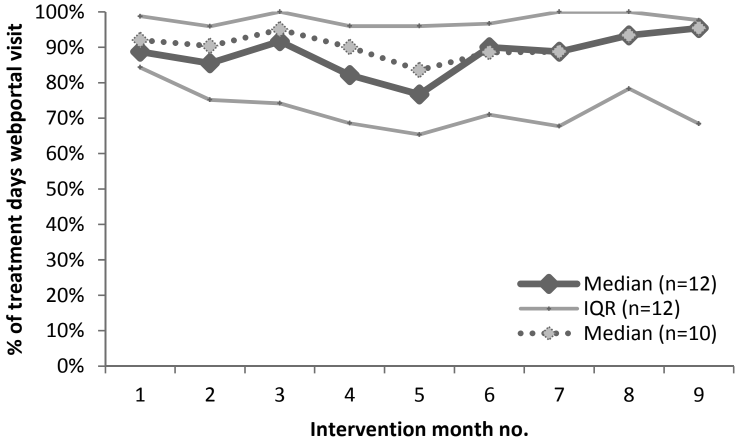

Fig. 3. Median number of days (with interquartile range) in which the web portal was visited. Dotted line: patients that completed the intervention (n = 10).

Table 2. Use of the intervention by the telehealth group (n = 12).

No.	Treat-ment days	% of days visited	Diary			Exercise				Activity Coach		No. com-ments
			fill-outs	checks	compl.	perf.	not perf.	compl.	add. ex.	visits port.	days use activity coach (monitor / feedback)	
1	92	67,4%	61	13	66,3%	-	-	-	0	11	5 (5/0)	0
2	347	94,2%	321	54	92,5%	48	72	40,0%	123	29	30 (8/22)	2
3	336	65,5%	212	16	63,1%	33	128	20,5%	71	5	30 (7/23)	95
4	265	86,8%	227	61	85,7%	-	-	-	0	21	28 (13/15)	0
5	316	94,9%	299	34	94,6%	-	33	0,0%	15	1	30 (9/21)	0
6	253	93,7%	234	154	92,5%	-	-	-	21	27	27 (20/7)	0
7	259	79,5%	202	162	78,0%	10	31	24,4%	30	16	33 (21/12)	0
8	255	85,9%	204	28	80,0%	30	89	25,2%	283	19	38 (14/24)	0
9	250	95,6%	234	186	93,6%	-	-	-	0	0	7 (7/0)	0
10	296	59,5%	174	133	58,8%	-	27	0,0%	0	15	39 (8/31)	0
11	144	47,2%	64	37	44,4%	6	22	21,4%	0	2	6 (6/0)	2
12	254	87,0%	218	180	85,8%	-	23	0,0%	0	4	26 (14/12)	0
Median	*257*	*86.4%*	*215*	*58*	*82.8%*	*30*	*32*	*21.0%*	*8*	*13*	*29 (9/14)*	*0*
Sum	*3067*		*245*	*1058*		*127*	*425*		*543*	*150*	*299 (132/167)*	*99*

Abbreviations: compl: compliance, perf: performed, add ex: additional exercises, port: portal, no: number.

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In the intervention group, the activity coach module was used for 299 days in total, of which 132 days were in the monitoring mode, and 167 days were in the feedback mode. Although both monitoring and feedback modes were used, the activity coach was rarely used outside of the measurement weeks (T0-T4). The use of the webportal differed greatly between patients; some used the diary almost every day, other only half of the days. Some performed regular additional exercises, while others did not use the exercise module at all.

Figure 4 shows the number of patients who received exercise schemes from their physiotherapist over time. Eight out of twelve patients received an exercise schedule from the therapist and the number of prescribed schedules declined over time. The average number of schemes prescribed by the physiotherapists to an individual patient tends to increase in the first half year. In the first month, only one patient received an exercise scheme.

Satisfaction with received care as obtained by repeated measures (mean(SE)) was 26.4(1.3) for the telehealth group and 30.4(1.5) for the usual care group at T1. At T2 this was 26.3(1.3) for the telehealth group and 29.9(1.4) for the usual care group. No statistical tests could be performed due to limited data so only descriptive data is presented.

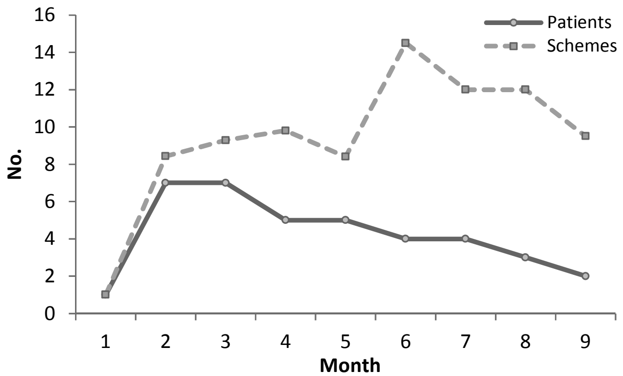

Fig. 4. Number (no.) of patients who received exercise schemes from their physiotherapist (solid line) and the average number of schemes that were prescribed to these patients (dotted line) per month.

Clinical changes

Table 3 describes the number and duration of hospitalizations, emergency room visits and number of exacerbations. For the telehealth group, the decision-support diary identified exacerbations as described previously.[26] The telehealth group reported a total of 33 exacerbations (median: 2.0, IQR: 1.0-3.0) for which medication was required; of which one patient had 11 exacerbations according to the COPE criteria.[26] A number of these exacerbations occurred within 28 days of the previous exacerbation. The telehealth group had 4 hospitalizations for COPD with a mean duration of 5.5 days, while the control group had 5 hospitalizations for COPD with a mean duration of 7.2 days.

Table 4 shows the clinical changes as obtained from the repeated measures. Because of the small numbers, data in Table 4 are descriptive only and present T0 to T2. No statistical tests have been performed.

Table 3. Number of hospitalizations, ED visits, exacerbations and length of stay for the telehealth and usual groups in the study period.

	Telehealth (n = 12)	Usual care (n = 12)
Total no. exacerbations/relapses	33	n/a
Total no. advices to start medication	35	n/a
Total no. hospitalizations COPD	4	5
Total no. hospitalizations other	4	2
Total length of stay hospitalization COPD	22 days	36 days
Median length of hospital stay COPD days	5.5 (4.8-6.3)	7.0 (6.0-7.0)
Total no. ER visits COPD	5	5

Discussion

In this study a telehealth programme was investigated within the usual primary and secondary care to explore the potential for daily health care practice. We aimed to gain insight in the use of the telehealth programme, investigate experienced satisfaction and explore clinical changes by use of the programme compared to usual care. The study showed that the telehealth programme has potential since a part of it was highly used during the 9-month intervention period and patients were satisfied. Larger-scale trials are needed for investigating clinical- and cost-effectiveness.

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Satisfaction with received care was high in both groups with scores of 26.3 for the telehealth group and 29.9 for the usual care group (max: 32, at T2). For the usual care group this is in comparison with previous findings. Hynninen et al. (2012) found high satisfaction with a cognitive behavioural therapy (CBT) in COPD (mean score of 28.8).[35] However, the satisfaction with our telehealth programme was higher compared to literature as internet-based therapy in other patient groups scored remarkably lower (e.g. 20.6±4.8 in online psychotherapy[36] to 24.5±4.8[37] and 22.8±4.6[36] for online CBT). The slightly lower satisfaction score for the telehealth group compared to usual care might be attributed to the frustrations some patients experienced with the activity coach. For example, some patients found it frustrating that it did not properly assess cycling. This also has been reported earlier: Koff et al. (2009) found low satisfaction scores for their activity sensor due to unreliable detection of slow walking, but high satisfaction for the telehealth programme.[38]

Table 4. Clinical changes obtained from repeated measures, with standard error of the mean.

	Telehealth			**Usual care**		
	T0	T1	T2	T0	T1	T2
Exercise capacity (6MWT, m)	409.5(29.5)	n/a	412(38.7)	300.1(33.6)	n/a	312.4(44.0)
Health status (CCQ)	2.0(0.26)	1.9(0.17)	1.8(0.24)	2.7(0.27)	2.3(0.21)	2.3(0.26)
Fatigue (MFI)						
General fatigue	12.3(1.4)	11.0(1.1)	10.4(1.3)	15.0(1.4)	13.6(1.3)	13.8(1.5)
Physical fatigue	12.2(3.2)	11.9(3.2)	11.0(3.3)	16.5(3.2)	14.4(3.2)	14.4(3.3)
Reduced activity	8.3(1.2)	9.3(0.9)	8.2(1.2)	12.5(1.3)	11.7(1.1)	10.5(1.3)
Reduced motivation	9.3(1.1)	7.4(0.9)	7.5(1.2)	9.4(1.2)	8.2(1.0)	8.8(1.3)
Mental fatigue	8.5(1.1)	9.9(1.4)	6.6(0.9)	7.0(1.2)	8.0(1.7)	7.3(1.1)
Quality of life (EQ-5D)						
VAS	64.7(4.4)	73.1(4.0)	72.3(3.1)	65.0(4.5)	69.3(4.9)	62.4(3.5)
Index	0.76(0.03)	0.81(0.03)	0.78(0.08)	0.70(0.04)	0.72(0.03)	0.61(0.09)
Subjective activity (BPAQ)	7.1(0.4)	6.5(0.4)	7.2(0.4)	6.1(0.4)	6.7(0.4)	6.2(0.4)
Objective activity (IMA)	536.3(42.6)	556.7(43.4)	511.0 (44.1)	360.5(44.7)	381(45.1)	335.2(46.3)

Abbreviations: FEV_1%: Forced Expiratory Volume in 1 second % predicted, BMI: Body Mass Index (in kg/m^2), 6MWT: 6-minute walking test, CCQ: clinical COPD questionnaire, MFI: multidimensional fatigue inventory (general fatigue scale), EQ-5D: EuroQol, BPAQ: Baecke Physical Activity Questionnaire.

Besides, interviews with patients after finishing the programme showed that it is very important to manage the expectations of the patient regarding such a new intervention and how (often) this webportal is used by the healthcare professionals. For example: how often will the professional look into the data on the webportal and when will the professional take action? When the patients' expectations are in line with the received care, the satisfaction is expected to increase too.

The intervention group used the webportal 86% of the treatment days and this remained stable over the intervention period. This is a very high compliance, as according to the WHO, adherence to long-term therapy in chronic diseases averages 50%.[39] The diary was the most frequent used module: 82% of the treatment days. This is considerably higher than found previously (58%),[30] in a pilot study of 4 weeks with stable COPD patients. Previous research with the same inclusion- and exclusion criteria that used the paper version of this diary, showed an 85% completion rate (unpublished data:[26]) comparable to our study. In that study, patients were asked to return their completed diary by pre-paid mail to the research office at the end of each month, and in case of incorrect completion the patient was contacted by phone. To even further increase adherence to filling in the online diary, an option would be to apply the diary on a smartphone, where the patient automatically receives a message to fill in the diary.

In contrast to the self-management module, the use of the exercise module and the activity coach was critically low. It is however very important to increase the use of these modules, since a higher usage of the activity coach has been shown to be significantly associated with an improvement in activity levels.[30] Besides, the use of online exercise programmes with teleconsultation in COPD patients have shown to be as effective as regular rehabilitation.[40] As such it is very important to get insight in the results and to find out which steps are needed to overcome this low usage. From the experience gained in this study several reasons can be given.

Firstly, the self-management module was instructed to the patients as part of a standard self-management training course before using the module, organized by the chest department of the hospital. The module incorporated influential factors for good adherence:[41] the patient was actively involved in the treatment process, in which they were educated in how to recognize their symptoms, but also in the importance of treatment. In addition, the self-management course was provided by their healthcare professional in an interactive real-life group-setting with fellow patients and the treatment regimen was simple and straight-forward. This self-management programme seems to be a successful aspect in treatment of COPD exacerbations.[26] The other modules, i.e. the exercise module and the activity coach, were offered by the primary care physiotherapists, and the patient had an individual appointment where the modules were explained (non-standardized). These modules showed as well low adherence of the patients, as low use by the physiotherapists. They did not regularly prescribe exercise schemes to the patients or incorporate the activity coach in the treatment programme. This underlines the very important role of the healthcare professional in the adoption of the intervention by patients.[42]

Adherence might be increased by integrating the exercise and activity coach modules in a self-management programme targeting both (post-)exacerbation strategies and activity behaviour.[43] In this way, the intervention would also target exercise self-efficacy and expected benefits from regular exercise, which are predictors of exercise adherence.[41] Professionals are important to help patients understand the nature of the disease, potential benefits of treatment, and encouraging development of self-management skills.[41] As such their attitude towards the telehealth treatment can greatly influence the perception and adherence of the patients. In literature, a reported problem regarding the use of telehealth by professionals is distrust in the technology due to problems and reliability of the measurements.[44, 45] Another issue is that only a few patients of the involved healthcare professionals took part in the telehealth study, thereby causing that the telehealth was not a part of their regular routine. Full-scale implementation in health care is needed in the future in which use and acceptance of all the users, including the healthcare professionals, should be investigated.

Secondly, the low adherence to the exercise module by the patients could be explained by the fact that the technology was not sufficiently motivating or stimulating for doing exercises at home. The exercises were already familiar for the patients as these are also used in regular care, and the schemes do not change very much over time. Providing these exercises online via a webportal might therefore not trigger patients enough to exercise. An alternative could be to incorporate motivational strategies, for example by the use of gaming technologies, which can have a positive effect on motivation.[46]

Regarding the clinical changes, the results are promising. Patients in the intervention group seem to have a shorter hospital length of stay compared to the control group, and the same number of ED visits. These trends are in line with results of Effing et al.

who showed that self-treatment of exacerbations can reduce exacerbation duration, hospitalizations and associated costs.[26] However, due to the limited number of patients, differences in clinical changes between groups could not be statistically tested and this needs further research. This research should be directed towards the effectiveness as well as cost-benefits of this integrated programme.

Next to the small sample size there are some other limitations of this study. Only 29% of the eligible patients wanted to participate, which might be because of worries about the technology beforehand[47] or because of the strict in- and exclusion criteria with a focus on patients with regular exacerbations. Also, a high number of drop-outs were reported, especially in the control group who had in general a poorer health status. A review of Beauchamp[48] addressed this issue in supervised exercise programmes after rehabilitation where acute exacerbations and disease progression contributed to the high dropout rate, which also is shown in our study. The drop-outs resulted in missing measurements, although this was also influenced by a temporarily unavailability of one physiotherapy practice to perform the measurements. The missing measurements limited the statistical evaluation of our study and cancelled the report on the number of exacerbations in the control group, who had to fill in paper diaries for monitoring symptom levels.

In conclusion, this is the first study that applied an integrated telehealth intervention as blended care in patients with COPD that consists of a real-time ambulant activity coach, a webportal for self-treatment of exacerbations, an online exercise programme and teleconsultation. The telehealth programme with decision-support was feasible to use in patients with COPD but large-scale studies are needed to determine clinical- and cost-effectiveness. Satisfaction was high and parts of the intervention were highly used. Healthcare providers seem to play an important role in the patients' adherence to telehealth in usual care. For future research, we would recommend 1) to integrate all the modules in a standardized self-management programme, in which management of patient expectations is addressed and 2) to investigate technological advances, like gaming, to increase adherence.

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CHAPTER 8

General discussion

Chronic Obstructive Pulmonary Disease (COPD) is a highly prevalent condition that has a large effect on physical, psychological and social functioning.[1, 2] As physical activity is low in patients with COPD and inactivity is associated with poor prognosis, several (inter)national guidelines advise to promote physical activity in daily life.[3] Physical activity is defined as the totality of voluntary movement, produced by skeletal muscles during everyday functioning and includes exercise.[4] In this thesis we have defined daily activity behaviour as the way in which a person acts in relation to physical activity in daily life.

Interventions like exercise training can improve exercise capacity,[5] but these programs do not necessarily lead to a change in daily activity behaviour.[6, 7] It can be argued that current treatment programs are not tailored enough, due to a limited insight in the daily activity behaviour and the heterogeneous picture of COPD.[8-10] Also the fact that current treatments are not employed in the daily environment of the patient is expected to contribute to the limited effectiveness. In addition, the nature of the disease with exacerbations often results in immediate relapses and prolonged limitations in active behaviour.[10, 11] Based on this, it is hypothesized that interventions that ensure appropriate monitoring in daily life, to gain insight and provide tailored feedback to both patient and care providers, and that support in early detection and fast treatment of exacerbations, could potentially be effective in improving daily activity behaviour in patients with COPD. The current state-of-the-art information and communication technology enables the realization of such interventions for healthcare in daily life, so called telemedicine.

The aim of this thesis was to study whether telemedicine can promote daily activity behaviour and support patients with COPD in self-management of exacerbations. As there was limited insight in the daily activity behaviour of patients with COPD, we first performed a telemonitoring study (Chapter 2) by investigating the daily activity behaviour and investigate its relationship with daily symptoms. The outcomes of the telemonitoring study served as input for the design of an ambulant activity coach – using an activity sensor and smartphone – that aims to both increase *and* balance activity behaviour of COPD patients in daily life. In Chapter 3 and Chapter 4, we investigated the potential of this activity coach. Chapter 3 focused on investigating the personalized feedback part by studying the response to motivational cues. In Chapter 4 we investigated whether the use of the activity coach could effectively change daily activity levels. The results of Chapters 2-4 were subsequently used as input for the design of a new activity coach: a new sensor was integrated and the user interface on the smartphone was improved. Chapter 5 describes two interventions that aim to improve the physical activity of COPD patients from two perspectives: 1) daily monitoring and feedback using the new ambulant activity coach and 2) supporting exercise using an interactive game. These technology-supported interventions were evaluated in terms of acceptance, together with an interactive game for online exercising (Chapter 5). The activity coach was again further improved by incorporating self-learning mechanisms for the motivational cues that are able to choose the best timing for presenting a cue to an individual patient. The self-learning activity coach was evaluated during a period of 3 months to gain detailed insight in long-term activity behaviour of patients with COPD (Chapter 6). Finally, the activity coach was integrated in a multimodal telecare programme for promoting daily activity behaviour and self-management of exacerbations that, besides the time-based activity coach, consists of a web-based exercise programme for home exercising, self-management of COPD exacerbations via a triage diary on a web portal, and teleconsultation. This programme was applied as blended care for a period of 9 months and was evaluated in terms of use, satisfaction, and clinical outcomes (Chapter 7). In this final chapter the findings of these studies are integrated and discussed in the context of existing literature and a move towards future approaches for improving daily activity behaviour in patients with COPD is being described.

Insight in daily activity behaviour

The results of the study described in Chapter 2 show that COPD patients, especially unemployed, have a low and imbalanced daily activity behaviour compared to healthy controls. These results correspond to findings in previous studies, showing reduced amounts of activity in COPD patients.[12-17] The imbalanced activity behaviour was expressed as a temporarily decrease in activity in the early afternoon. Hecht et al. (2009) also found a sharp decrease in that period of the day, but in a more severe COPD population.[18] This decrease in the early afternoon is hypothesized to represent an imbalance in activity pattern caused by a too high activity load in the morning and consequently, insufficient capacity to maintain the activity level in the afternoon.

The results of this study show no clear relationship between symptoms and activity during the day. This is unexpected as dyspnoea is thought to play an important role in the inactive behaviour of patients with COPD.[19] In our study, we measured the absolute level of dyspnoea at fixed moments in time during the day. However, symptoms are subjective and always present, and as such it might be better to monitor and relate the daily activities to changes in dyspnoea beyond ‘normal’ (i.e. individual level of symptoms at stable state).[20] Another possibility is to investigate the relationship of symptoms *during* activities, as in that case, dynamic hyperinflation could greatly induce dyspnoea levels and thereby limiting daily activity behaviour.

Changing daily activity behaviour is a process that occurs over time and is hypothesized to be a process that evolves via stages, like explained in the stages of changes model. This model describes that people move through five stages of change: precontemplation, contemplation, preparation, action and maintenance.[21] A first step in changing behaviour when someone is in the precontemplation phase (i.e. not considering changing physical activity) is to increase the awareness and understanding about physical activity. In our study we found that objective and subjective activity levels were only moderately related. The majority of the patients consider themselves being regularly physically active whereas the objectively measured data show low levels of daily activity. However, they do not have the intention to change their present activity behaviour. An important first step in treatment is therefore assumed to be the monitoring of daily activity behaviour and providing feedback on this to the patients, with the aim to increase their awareness.[22, 23]

Development of the activity coach

The activity coach monitors the daily activity behaviour of patients with COPD by means of an activity sensor and provides feedback on a smartphone. The aim is to create awareness as a first step, and in addition, to further increase and better balance the daily activity behaviour. During the course of this thesis the activity coach underwent several developments to move towards an activity coach that is adaptive to the patient’s activity behaviour.

The first generation of the activity coach for COPD consists of a wireless 3D-accelerometer (XSens MTx-w) and an HTC smartphone (3600/3700) (Chapter 3, 4). The accelerometer connects wirelessly via Bluetooth to the smartphone. The smartphone shows the measured activity cumulatively in a graph, together with the cumulative activity the patient should aim for: the reference activity line. In this version of the activity coach, the reference activity is the line *between* the mean baseline of the patient and a social norm line (based on the data of healthy controls). The reason for doing this was the fact that the reference line setting of healthy controls alone was experienced as unreachable by patients with chronic fatigue syndrome and small improvements in activities were not awarded sufficiently.[24] In addition, the patients automatically receive time-based motivational cues, for awareness and extra motivation. These cues were based on the difference between the measured activity and the reference line and consist of 1) a short summary of activity behaviour and 2) an advice on how to improve or maintain the activity behaviour.

Further advancements in the field of wireless sensor technology and mobile devices led to an extra cycle of design and development and a new version of the activity coach (Chapter 5, 6, 7). This activity coach now uses the ProMove-3D wireless sensor (Inertia Technology) – with improved performance, computational and storage resources, wireless capabilities, and form factor. A smartphone (HTC desire S) is used for displaying feedback to the patient with a new user interface.

In this improved activity coach, the reference line settings and feedback was used in two different ways. The reason for this was to focus the feedback more to the individual capacities of the patient. In the CoCo study (Chapter 7) the reference activity line is adapted by the primary care physiotherapist via a webportal. For this, the physiotherapist can see the patient's monitored activity behaviour, select the days which should be used as input, and a mean activity monitoring line is calculated. Subsequently, the physiotherapist can increase or change the activity line into a reference line that is most suitable for the patient's treatment goals. In addition, the patient receives motivational cues which are based on the measured activity of the last 2 hours and of the day so far and specifically highlight the activity balance. Each cue provides a summary of the activity behaviour and an advice on how to continue the activity behaviour, for example: *"You have been very active today, but took some rest now. Keep on going like this, and keep in mind your activity balance."* At the end of the day the patient receives a summary of their activity behaviour (e.g. "You were clearly less active today. Discuss this with your physiotherapist").

The other approach was optimized towards a more tailored activity coach (Chapter 6). The reference line is automatically adapted to every patient's abilities and is changed based on the previous performance of the patients as follows: 1) patients perform a baseline measurement, 2) the mean daily activity level is calculated and distributed per day part according to the distribution of daily activities in healthy individuals: 40% in the morning, 30% in the afternoon and 30% in the evening,[25] 3) every week, the reference line is increased with 10% above the mean of the past measurement weeks. In addition, the patient receives motivational cues automatically at the most opportune moment.[26] For this, the smartphone application uses machine learning to classify situations as providing suitable moments for delivery of motivational cues.

Improving daily activity behaviour

Increasing the activity level

The results from Chapter 2 show that patients with COPD are significantly less active compared to healthy controls. As inactivity is associated with poor prospects, increasing activity levels is important. However, regular interventions do not necessarily lead to a change in activity levels in daily life.[6, 7]

Results of Chapter 3 and 4 show that the time-based activity coach can positively contribute to increasing activity levels. We found that COPD patients significantly change their activity level on a short-term notice in response to both encouraging and discouraging time-based cues (Chapter 3). In addition, a higher usage of the coach is significantly associated with an improvement in activity levels (Chapter 4). However, on a group level no significant differences in activity behaviour could yet be established in a 4-week treatment period. Only a minority of the patients (2 out of 11) showed a significant improvement in activity level in response to the intervention (Chapter 3).

These findings are in line with previous studies showing the potential of motivational cues in patients with chronic low back pain[27] and chronic fatigue syndrome.[24] In COPD, only Nguyen et al. used weekly reinforcement text messages in a cell-phone based exercise intervention for COPD, but they did not find a significant contribution of these messages to the end results of their exploratory study.[28] This could very likely be caused by the low frequency of the messages they provided as it is known that receiving reminders about the commitment to be physically active is important, especially when patients are in preparation to change their physical activity.[21] In line with this, results of Chapter 6 show that the self-learning activity coach in terms of timing seems beneficial as it effectively increased the activity level in 5 (out of 8) patients from the pre-intervention baseline condition to the end of the 3-month intervention (Chapter 6). This further underlines the importance for tailoring to enable better treatment outcome.

The activity coach could not successfully establish a sustainable change in daily activity levels in the long term as activity levels are not maintained at 3-month follow up with the self-learning activity coach. A review by Bravata et al.[29] also showed that durable long-term changes in activity levels are not yet established. It is expected that long-term behavioural change is complicated by heterogeneity in activity behaviour,[30] fluctuations of symptoms,[9] disease progression, and exacerbations.[10] These findings suggest that a more personalized approach is needed[31] that can be tailored to the characteristics and progress of the individual patient. In addition, due to the large individual variability found in our studies and in literature, individual goal setting, based on the patient's capabilities is considered important.

Changes in activity balance

The results from Chapter 2 indicated, next to a decrease activity level, an imbalanced distribution of daily activity during the day, showing as a temporarily decrease in activity in the early afternoon.

The activity coach as being studied as a 4-week intervention with the time-based motivational cues did not significantly contribute to a better balance (Chapter 3). A possible reason could be that patients do not become sufficiently aware of their activity balance as the representation in a cumulative graph might be too difficult to distinguish. Also, the motivational cues are not highlighting tips and advices for the activity balance.

This explanation is supported by the results that the self-learning activity coach shows an improved balance in 4 (out of 8) patients after a 3-month treatment period (Chapter 6). The importance of reaching a better balance is further underlined by the result that only the individuals with the higher balance score (>65%) show positive improvements in exercise capacity. Rationally we could reason that a balanced daily activity pattern is favourable to improve patient's well-being, as the energy is more efficiently spread over the day. For example, by doing fewer activities in the morning and doing more activities in the early afternoon and evening. Coherently we could argue that patients can do more with the same amount of energy. Although this is advised to patients in regular healthcare, these findings are not yet evidence based. Therefore, more research is needed 1) to have consistent evidence about unbalanced activity behaviour in patients with COPD and 2) whether this can indeed improve patient's well-being.

Feedback strategies

In this thesis, three different feedback strategies were used to change daily activity behaviour. In the first studies (Chapter 3, 4), a reference line was used that was partly based on the mean activity line of healthy elderly. Chapter 2 already showed the large and significant difference in activity levels between healthy persons and patients with COPD. The goal might therefore be too difficult to reach and a more individual goal setting that resembles the capacities of the individual patient would probably fit better. Besides, the responses of the patients to the motivational cues were not clearly related to the cue- or context variables such as the contents of the cue. We could thus not recommend an approach for providing motivational cues to the general COPD population as the patients seem to respond very differently to the cues. This suggests that the response and compliance could be better when the activity coach is more tailored to its individual user.

This individual goal setting was done in two ways: by the therapist or by the technology. In Chapter 7, the reference line was set by the therapist based on what a patient can and wants to achieve. The motivational cues were time-based and also emphasized balancing activity behaviour. In Chapter 6, the reference line was increased based on previously measured activity behaviour of the patient. The intervention was more tailored by the self-learning motivational cues with regard to the timing of the cues.

We would expect that these more tailored feedback strategies would have the best effects when compared to the reference line that was partly based on the activity of healthy persons, as these strategies take the individual capacity of the patient as a starting point. In this thesis, the two more tailored feedback strategies were evaluated in terms of changes in daily activity behaviour. An interesting next step would be to investigate how these strategies differ with respect to each other. For example, which of the feedback strategies show the best adherence to the motivational cues? In addition, as it is thought that patients change behaviour following the stages of change it would be interesting to investigate whether the response to the motivational cues is different between the stages of change. With this information we can further optimize the feedback strategies in the future.

A next level of intelligence

From our studies and previous literature it became apparent that daily activity behaviour is complex, influenced by e.g. behavioural and personal characteristics, exercise-associated symptoms, mood, past behaviours and environmental factors.[32, 33] This suggests that the response and compliance would be better when the activity coach would be more tailored to its individual user, not only in relation to the timing of the cues, but also in terms of (behavioural) characteristics, and changes in well-being and surroundings. As such we envision an activity coach that can provide even more smart and tailored feedback that takes these characteristics into account, and is automatically adapting on these changes. The proposed building blocks[34] of this new system are shown in Figure 1.

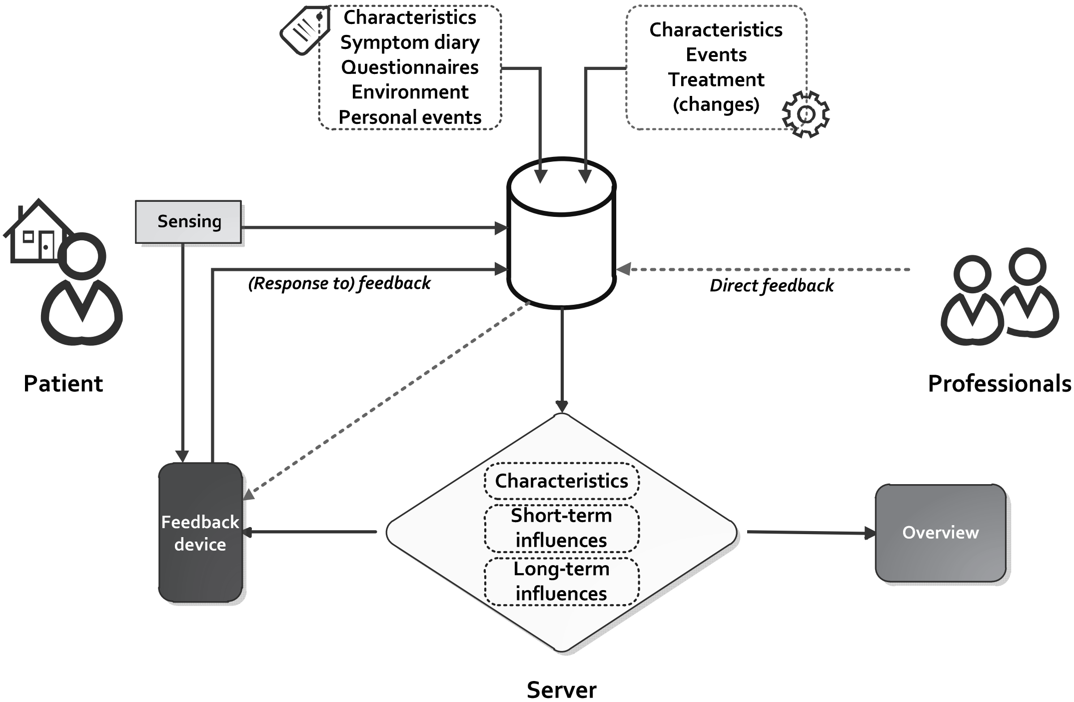

Fig. 1. Building blocks for the future activity coach. Left: the patient side that receives feedback and provides input by e.g. sensors or diaries. Input can also be automatically gathered from e.g. the internet. Middle: the server with the database and decision support to determine the most suitable feedback to the patient and support the professional in decision making by highlighting important changes in the data. Right: the professional side that can provide input e.g. a change in lung function for the decision support. Feedback can also be provided directly to the patient's feedback device bypassing the decision support.

On the patient side (left, Fig. 1), sensors enable the acquisition of activity behaviour continuously, but can also provide momentarily measurements such as pulseoximetry during specific exercises. Context information can be obtained by environmental sensors (e.g. temperature) and from external data sources (e.g. weather information from internet). Automated location tracking can automatically determine working hours, travel time and time spent at home. Also, the patient can provide information using their feedback device, like symptom information in an online diary.

On the server side (middle, Fig. 1), the data is wirelessly and securely transferred to a central server system. A decision-support system continuously monitors the incoming data, extracts features from it and compares it in an intelligent way to specific references to enable real-time decision support and generate tailored feedback. The decision support has 3 elements for determining the optimal feedback to the patient:

1) *Characteristics:* these include general characteristics of the patient, from medical, personal and behavioural points of view, and they do not change greatly over time. These include characteristics like: GOLD stadium, stage of change, work status, exercise preferences, or having a dog.
2) *Short-term influences*: these include influencing factors from the patient or the environment, which can change on a minute-to-minute basis. These include how a patient feels today, the current weather, or the patient's agenda.
3) *Long-term influences:* these include influencing factors in relation to the progress of the patient, which can change slowly over time. These include improvement in activity levels over time, disease progression, or detection of exacerbations.

On the professional side (right, Fig. 1), professionals can provide input for the feedback provided to the patient. This can be used as input for the decision support (e.g. GOLD stadium), but the professional can also overrule the decision support and apply feedback directly to the device of the patient (dashed line in Fig. 1), for example by setting a daily activity goal. The professional can securely access the data via a web service in either a live mode or at a later point in time to allow access and interpretation of the data. For this, the decision support can support the professional in highlighting important changes of the patients. Outside these building blocks, there is face-to-face communication between the health care professional and the patient, for example to discuss treatment progress.

Towards an integrated approach

The use of the activity coach as a stand-alone application might not be sufficient for improving daily activity behaviour. Home exercising to obtain sufficient physical fitness might support deployment of daily activities. Self-management of COPD exacerbations could shorten exacerbation duration and hospitalizations, and might prevent immediate and prolonged activity limitation.[10, 11] As such the activity coach was an integrated part within a 9-month technology-supported care programme. Besides the time-based activity coach with special attention for balancing daily activity, this programme contains 1) a web-based exercise programme for home exercising, 2) self-management of exacerbations via a triage diary on the webportal and 3) teleconsultation.

Results of this thesis (Chapter 7) show that such an integrated programme indeed has potential. Patients are satisfied with the received care and parts of the programme are highly used during the 9-month intervention period. In addition, promising changes in clinical outcomes are shown as patients in the intervention group seem to have a shorter hospital length of stay compared to the control group. Due to the pilot character of the study, no significant effects could be established. Future research should focus on full-scale implementation in health care to investigate effects and adoption by all the users.

The high usage of the intervention especially applies to the self-management module, which already has shown to be a successful aspect in treatment of COPD exacerbations.[35] The exercise module and activity coach show a low usage within the programme. This was not expected, as our previous studies showed good usability and high patient compliance (Chapter 3, 5, 6). One reason for the low usage is that the physiotherapists did not regularly prescribe exercise schemes to the patients or incorporate the activity coach in the treatment programme. A reported problem regarding the use of telehealth by professionals is distrust in the technology due to problems and reliability of the measurements,[36, 37] but another reason could be that the telehealth was not sufficiently imbedded in the daily care of the professional.

The low adherence to the exercise module by the patients could also be explained by the fact that the technology is not sufficiently motivating or stimulating for doing exercises at home. An alternative could be to incorporate motivational strategies, for example by the use of gaming technologies, which can have a positive effect on motivation.[38] The small-scale evaluation of the orange submarine game shows that the game has an excellent usability and can provide a fun and motivating way to exercise (Chapter 5). Gaming could also be used to include more fun elements into the feedback strategy of the activity coach, to develop a game for daily use anywhere, anytime. However, the application of gaming to change behaviour is still in its infancy and further research is needed.

A subsequent step could be to use the activity coach with a next level of intelligence and apply this activity coach, with the other modules, within a self-management programme targeting both (post-)exacerbation strategies and activity behaviour.[39] By applying self-management in improving activity behaviour, the intervention would also target exercise self-efficacy and expected benefits from regular exercise, which are predictors of exercise adherence.[40] In this programme, the activity coach can support both patients and professionals by providing insight in daily activity behaviour and providing the tools for changing activity behaviour in daily life.

Conclusions

In this thesis we made a step forward towards new treatment approaches that can improve daily activity behaviour in patients with COPD and support self-management. From the studies presented in this thesis it can be concluded that telemedicine – using activity monitoring, real-time feedback and motivational cues – has potential to promote daily activity behaviour in patients with COPD.

Challenges lie ahead in terms of technology and implementation of telemedicine in COPD healthcare. Decision-support technology should provide highly individualized and intelligent feedback approaches, while gamification strategies could increase motivation. Next to that, implementing the telemedicine applications within a self-management module for the patient and as true blended care for the professional is considered to be of most potential.

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Summary

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Summary

Chronic Obstructive Pulmonary Disease (COPD) is a highly prevalent condition that has a large effect on physical, psychological and social functioning. In patients with COPD, dyspnoea (during exertion) is one of the major symptoms, which leads to an inactive lifestyle. This is thought to be part of a vicious circle of symptom-induced inactivity, leading to a lack of fitness and a reduced quality of life, which may be accelerated by acute exacerbations. The promotion of physical activity in daily life is thus an important aspect in the treatment of COPD. Current treatment programs show a limited effectiveness in improving daily activity behaviour. It can be argued that these interventions are not tailored enough, due to a limited insight in the daily activity behaviour and the heterogeneous picture of COPD. Also the fact that current treatments are not employed in the daily environment of the patient is expected to contribute to the limited success. Interventions that ensure appropriate monitoring and treatment in daily life, provide tailored feedback to both patient and care providers, and support early detection and fast treatment of exacerbations, could potentially improve daily activity behaviour in patients with COPD. Information and communication technologies enable the realization of such interventions for healthcare in daily life. Such technologies are commonly referred to as *telemedicine*. The aim of this thesis was to study whether telemedicine can promote daily activity behaviour and support patients with COPD in self-management of exacerbations.

Chapter 2 describes a telemonitoring study about the daily activity behaviour of patients with COPD and its relationship with daily symptoms. The daily activity behaviour was assessed for 4 days by an accelerometer-based activity sensor. The study shows that COPD patients were significantly less active compared to healthy controls. COPD patients also show activity behaviour that was less evenly distributed over the day. This imbalance was expressed as a temporarily decrease in activity in the early afternoon. A relationship of symptoms and activity during the day was not clearly present. The results also show that objective and subjective activity levels were only moderately related. The majority of the patients consider themselves being regularly physically active whereas the objectively measured data show low levels of daily activity. A prerequisite for changing behaviour is the awareness and understanding about physical activity. An important first step in treatment should therefore be the monitoring of daily activity behaviour and providing feedback on this to the patients, to increase their awareness.

An ambulant activity coach – consisting of an activity sensor and smartphone – was designed that aims to both increase and balance activity behaviour of COPD patients in daily life (Chapter 3, 4). The feedback consisted of an activity graph, showing the accumulated amount of activity in relation to the activity goal: the reference line. In addition, the patients received time-related motivational cues via text messages. These cues were based on the difference between the measured activity and the reference line and consisted of 1) a short summary of the activity behaviour and 2) an advice on how to improve or maintain the activity behaviour. This activity coach was evaluated in terms of increasing activity levels and balancing activity behaviour. Chapters 3 and 4 describe the evaluation of the activity coach as part of a one-month telerehabilitation intervention, which also involved a web portal with a symptom diary for self-management of exacerbations. The evaluation shows that the time-based activity coach can positively contribute to increasing activity levels: 1) COPD patients significantly change their activity level on a short-term notice in response to time-based cues and 2) a higher usage of the activity coach is significantly associated with an improvement in activity levels. The intervention has potential, although on a group level significant effects have not yet been established in the randomized controlled pilot trial. Concerning the balance of the activity behaviour, the results show that the activity was not more distributed over the day, and motivational cues have no direct influence on this activity balance. A possible reason could be that patients did not become sufficiently aware of their activity balance in the current feedback representation.

Advancements in the field of wireless sensor technology and mobile devices led to an extra cycle of design and development, resulting in a new version of the activity coach (Chapter 5, 6, 7). A small-scale evaluation study (Chapter 5) shows that the new sensor and smartphone with a new user interface, show good usability and acceptance. Besides, the feedback was more adapted to the individual capacities of the patient. This individual goal setting was done in two ways: by the therapist or by the technology. By technology, the reference line was increased based on previously measured activity behaviour of the patient (Chapter 6). In addition, the smartphone application uses machine learning to provide motivational cues automatically at the most suitable moment to the patient. This self-learning activity coach – in terms of timing – was evaluated during a period of 3 months in order to gain detailed insight in the long-term activity behaviour. The results show that the self-learning activity coach seems beneficial as it effectively increases the activity level in 5 out of 8 patients. The activity coach could not successfully establish a sustainable change in the long term as activity levels were not maintained at 3-month follow-up. Both our results and findings in literature suggest that long-term behavioural change is complicated by heterogeneity in e.g. activity behaviour, patient characteristics and exacerbations. A more personalized feedback approach that can be tailored to the characteristics and progress of the individual patient would therefore be recommended. The results also show that the new, self-learning activity coach could effectively balance activity behaviour in individuals with COPD, but not for everyone. The importance of reaching a better balance is emphasized by the result that only the individuals with the higher balance score show improvements in exercise capacity. However, more research is needed to have consistent evidence about (im)balanced activity behaviour and whether this can indeed improve patients' well-being.

On the other hand, the reference line could also be set by the therapist based on what a patient can and wants to achieve (Chapter 7). Here, the motivational cues were time-based and also emphasized the balance of the activity behaviour. This activity coach was integrated in a multimodal telehealth programme for promoting daily activity and self-management of exacerbations. This programme integrated the new time-based activity coach, a web-based exercise programme for home exercising, self-management of COPD exacerbations via a triage diary on a web portal, and teleconsultation. The use of the nine-month telehealth intervention – applied as blended care – was examined in a randomized controlled pilot trial. The results show promising changes in clinical outcomes, for example in hospital length of stay in case of exacerbation. Due to the pilot character of the study, no significant effects could be established. The results also show that patients were satisfied with the received care and that the self-management module was highly used during the 9-month intervention period. On the other hand, the exercise module and activity coach show a low usage within the programme. A possible reason could be that that the technology was not sufficiently motivating or stimulating for doing exercises at home. Also, the physiotherapists did not regularly prescribe exercise schemes to the patients or incorporate the activity coach in the treatment programme. The telehealth programme might in this way still not be sufficiently imbedded in the daily care of the professional. Future research should also include this aspect and should focus on all stakeholders involved in a full-scale implementation.

As motivation is considered a very important element in changing activity behaviour, a motivating alternative to conventional exercising was developed in addition: the orange submarine game. The game aims to support and motivate patients with

COPD to exercise. In this game, a submarine moves across an underwater landscape which is controlled by an activity sensor on the hip or in a dumbbell. During the game, real-time feedback was given regarding the game score, pulse rate, and oxygen saturation for motivation and controlled exercising. A small-scale evaluation study (Chapter 5) shows that the game has an excellent usability and can provide a fun and motivating way to exercise.

In Chapter 8, the findings of all studies are integrated and discussed in the context of existing literature, to move towards future approaches for improving daily activity behaviour in patients with COPD. Results of this thesis suggest that telemedicine – using activity monitoring, real-time feedback and motivational cues – has the potential to promote daily activity behaviour in patients with COPD. Future challenges lie in developing intelligent (decision-support) technology and full implementation of telemedicine in COPD healthcare.

Samenvatting

Chronisch Obstructieve Longziekte (COPD) is een veel voorkomende aandoening met een groot effect op fysiek, mentaal en sociaal functioneren. Kortademigheid is één van de belangrijkste symptomen van COPD, waardoor patiënten fysieke activiteit zoveel mogelijk vermijden. Er ontstaat een inactieve levensstijl gevolgd door een afname in fysieke capaciteit en deconditionering. Deze negatieve spiraal heeft een grote invloed op de kwaliteit van leven en wordt verergerd door exacerbaties. Het stimuleren van fysieke activiteit in het dagelijks leven is daarom een belangrijk aspect in de behandeling van COPD. Huidige behandelmethoden slagen er niet in het dagelijkse activiteitengedrag effectief te verbeteren. Mogelijk zijn deze interventies niet voldoende toegespitst op het individu, vanwege onvoldoende inzicht in de dagelijkse activiteiten van de patiënt en het heterogene beeld van COPD. Ook het feit dat huidige behandelmethoden niet worden toegepast in de dagelijkse omgeving van de patiënt kan bijdragen aan de beperkte effectiviteit. Interventies die door monitoring en behandeling in het dagelijks leven inzicht kunnen bieden in het activiteitengedrag, gerichte feedback kunnen geven aan zowel de patiënt als de zorgprofessional en exacerbaties vroeg kunnen detecteren en behandelen, kunnen mogelijk bijdragen aan een effectieve verbetering van het dagelijks activiteitengedrag bij patiënten met COPD. Informatie en communicatie-technologieën maken dergelijke interventies in het dagelijks leven mogelijk, ook wel *telemedicine* genoemd. Het doel van dit promotieonderzoek was om te onderzoeken of telemedicine kan bijdragen aan het bevorderen van het dagelijkse activiteitengedrag en het ondersteunen van zelfmanagement van exacerbaties bij patiënten met COPD.

In Hoofdstuk 2 wordt een telemonitoringstudie beschreven, die was uitgevoerd om inzicht te krijgen in het dagelijkse activiteitengedrag van patiënten met COPD en de relatie met dagelijkse symptomen. Dagelijkse activiteit werd gedurende 4 dagen gemeten met een activiteitensensor. Uit deze studie komt naar voren dat patiënten met COPD significant minder actief zijn in vergelijking met gezonde personen. Daarnaast laten patiënten met COPD een activiteitenpatroon zien dat minder gelijkmatig over de dag is verdeeld. Deze onbalans uit zich als een tijdelijke afname in activiteit aan het begin van de middag. De studie laat geen relatie zien tussen dagelijkse symptomen en activiteit. Daarnaast geven de resultaten weer dat de objectieve en subjectieve activiteit matig gerelateerd zijn. De meerderheid van de patiënten vond zichzelf regelmatig fysiek actief terwijl de objectieve activiteitendata

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lage activiteitenniveaus lieten zien. Een voorwaarde voor het verbeteren van het activiteitengedrag is bewustwording en begrip van fysieke activiteit. Het monitoren van activiteitengedrag en het geven van feedback op basis van dit gedrag, zou daarom een belangrijke eerste stap moeten zijn in de behandeling om de bewustwording van de patiënt te vergroten.

Vervolgens was de activiteitencoach ontwikkeld – bestaande uit een activiteitensensor en een smartphone – met als doel het verhogen en balanceren van het dagelijkse activiteitengedrag (Hoofdstuk 3, 4). De patiënt ontvangt feedback bestaande uit een activiteitengrafiek met daarin de gemeten activiteit en de streefactiviteit (de referentielijn). Daarnaast ontvangt de patiënt motiverende aanwijzingen in de vorm van tekstberichten. Deze berichten zijn gebaseerd op het verschil tussen de gemeten activiteit en de referentielijn. De berichten bestaan altijd uit 1) een korte samenvatting van het activiteitengedrag en 2) een tip om de streefactiviteit te behalen. Deze activiteitencoach is geëvalueerd in termen van verhoging van het activiteitenniveau en verbetering van de balans van het activiteitengedrag. In Hoofdstukken 3 en 4 wordt de evaluatie van de activiteitencoach beschreven als onderdeel van een telerevalidatie-interventie van 4 weken. Deze interventie bevatte ook een webportaal met een symptoomdagboek voor zelfmanagement van exacerbaties. De evaluatie laat zien dat de activiteitencoach positief kan bijdragen aan een verbetering van het activiteitenniveau: 1) COPD patiënten laten een significante verandering zien in hun activiteit als reactie op een motiverende aanwijzing en 2) een frequent gebruik van de activiteitencoach is significant gerelateerd aan een verbetering van het activiteitenniveau. De inzet van een dergelijke interventie is veelbelovend, maar op groepsniveau zijn er nog geen significante effecten aangetoond in deze pilot gerandomiseerde gecontroleerde studie. Betreffende de balans van het activiteitengedrag, laat de evaluatie zien dat de activiteit niet beter over de dag werd verdeeld en dat de motiverende aanwijzingen hier geen directe invloed op hadden. Mogelijk maakte de feedback de patiënten nog niet voldoende bewust van de verdeling van hun activiteit over de dag.

Ontwikkelingen op het gebied van draadloze sensortechnologie en mobiele apparatuur hebben geleid tot de ontwikkeling van een nieuwe versie van de activiteitencoach (Hoofdstuk 5, 6, 7). Een kleinschalig evaluatieonderzoek (Hoofdstuk 5) laat zien dat deze nieuwe sensor en smartphone, met een nieuwe interface, een goede bruikbaarheid en acceptatie hebben. Daarnaast was de feedback meer aangepast aan de individuele capaciteiten van de patiënt. Deze individuele 'goal setting' werd op twee verschillende manieren uitgevoerd: door de technologie of door de therapeut. Middels de technologie, werd de referentielijn opgehoogd op basis van de gemeten activiteit van de patiënt (Hoofdstuk 6). De smartphone-applicatie was zelflerend door de toepassing van 'machine learning'. Dit houdt in dat de applicatie leert op welke momenten de patiënt beter reageert op de tekstberichten. Het tijdstip voor toekomstige berichten wordt hier automatisch op aangepast. Deze zelflerende activiteitencoach was gedurende 3 maanden ingezet om gedetailleerd inzicht te krijgen in de veranderingen van het activiteitengedrag (Hoofdstuk 6). De resultaten laten zien dat de zelflerende activiteitencoach het activiteitenniveau effectief kan verhogen bij 5 van de 8 patiënten. De activiteitencoach kon geen blijvende gedragsverandering bewerkstelligen, aangezien het activiteitengedrag niet werd gehandhaafd bij 3-maanden follow-up. Zowel onze resultaten als bevindingen uit de literatuur suggereren dat blijvende gedragsverandering naar verwachting wordt bemoeilijkt door de heterogeniteit in onder andere: activiteitengedrag, patiënteigenschappen en exacerbaties. Daarom is een gepersonaliseerde feedback aanpak aan te bevelen, welke is toegespitst op de eigenschappen en voortgang van het individu. De resultaten laten ook zien dat de zelflerende activiteitencoach de balans van activiteiten effectief kan verbeteren, maar niet bij iedereen. Het belang van een goede balans van activiteitengedrag wordt benadrukt door het resultaat dat alleen de mensen met een betere balans een verbetering van de inspanningscapaciteit laten zien. Er is echter meer onderzoek nodig om bewijs te verzamelen over (on)gebalanceerd activiteitengedrag bij patiënten met COPD en of dit inderdaad kan bijdragen aan een verbetering van het welzijn van de patiënt.

De referentielijn kon ook worden ingesteld door de therapeut, op basis van wat een patiënt kan en wil bereiken (Hoofdstuk 7). Hier werden de motiverende aanwijzingen gegeven op vaste tijdstippen en werd specifiek aandacht geschonken aan de balans van het activiteitengedrag. Deze vernieuwde activiteitencoach met berichten op vaste tijdstippen was geïntegreerd in een technologie-ondersteunend zorgprogramma, met als doel verbetering van dagelijkse activiteit en zelfmanagement van exacerbaties. Het programma integreerde deze activiteitencoach, een online oefenprogramma, zelfmanagement van exacerbaties via een triage dagboek op het webportaal en teleconsultatie. Het gebruik van de 9-maanden durende interventie – toegepast als gecombineerde zorg – werd onderzocht in een gerandomiseerde gecontroleerde studie. De resultaten laten veelbelovende veranderingen zien in klinische uitkomstmaten, waaronder de opnameduur na een exacerbatie. Vanwege het pilotkarakter van de studie konden er echter geen significante effecten worden aangetoond. De resultaten laten ook zien dat de patiënten tevreden waren met de ontvangen zorg en dat de zelfmanagementmodule intensief werd gebruikt gedurende de 9 maanden. Het online oefenprogramma en de activiteitencoach werden weinig gebruikt. Mogelijk was de technologie niet voldoende motiverend voor de patiënt om te gaan bewegen. Ook schreven de fysiotherapeuten weinig oefenschema's voor via het webportaal en werd de activiteitencoach weinig in de behandeling toegepast. Het telehealthprogramma is dus op deze manier wellicht nog niet voldoende ingebed in de dagelijkse praktijk van de zorgprofessional. Toekomstige studies moeten zich dan ook richten op dit aspect en op alle gebruikers die betrokken zijn bij een volledige implementatie.

Aangezien motivatie een belangrijk onderdeel is in de verandering van het activiteitengedrag, is er ook een alternatief ontwikkeld om patiënten te motiveren tot beweging: de 'orange submarine game'. Dit spel had als doel patiënten te motiveren en ondersteunen tijdens het oefenen. In het spel beweegt een onderzeeboot in een onderwateromgeving, welke aangestuurd wordt door een activiteitensensor op de heup of in een halter. Tijdens het spel ontvangt de patiënt feedback over de score van het spel, hartslag en zuurstofsaturatie. De kleinschalige evaluatiestudie (Hoofdstuk 5) laat zien dat het spel een uitstekende bruikbaarheid heeft en een leuk en motiverend alternatief is om te bewegen.

In Hoofdstuk 8 werden de bevindingen van alle studies geïntegreerd en bediscussieerd in het kader van bestaande literatuur en werd er een stap gemaakt naar toekomstige mogelijkheden voor het verbeteren van het activiteitengedrag van patiënten met COPD. De resultaten van dit proefschrift laten zien dat telemedicine – met activiteitenmonitoring, real-time feedback en motiverende aanwijzingen – positief kan bijdragen aan verbetering van het dagelijks activiteitengedrag van patiënten met COPD. De uitdagingen liggen in de verdere ontwikkeling van intelligente (decision-support-)technologie en de volledige implementatie van telemedicine in de COPD zorg.

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Curriculum vitae

Monique Tabak was born in Amstelveen, the Netherlands, in 1984. She started Biomedical Engineering at the University of Twente, Enschede, in 2003. She performed her internship at the University of Buenos Aires in 2008. The research for her MSc thesis was on monitoring physical activity, oxygen saturation and pulse rate in daily life in patients with COPD and healthy elderly, at the Roessingh Research and Development and Medisch Spectrum Twente in Enschede. She graduated (Cum Laude) in 2009.

After her graduation she was subsequently employed as a PhD student at Roessingh Research and Development, where she has been working on the development and evaluation of ambulant feedback applications and telemedicine programmes for patients with COPD. She was involved in the projects COPDdotCOM (ZonMW), IS-ACTIVE (AAL) and Condition Coach (NL Agency). This thesis presents her PhD research within these projects. Besides, she was involved in projects in the area of navigation i.e.: HealthNavigator (Euregio) and NavMem (AAL) and trusted healthcare: THeCs (COMMIT).

Currently, Monique is employed as a post-doctoral researcher at Roessingh Research and Development and the University of Twente where she is investigating motivational strategies to promote healthy behaviour by means of technology, e.g. ambulant monitoring and feedback, intelligent navigation support, and gamification.

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