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Long-term exercise maintenance via telerehabilitation for people with COPD

Feasibility, effectiveness, benefits and challenges

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Abbreviations

30s-STS	30 second Sit-To-Stand chair test
6MWD	6-Minutes Walking Distance
6MWT	6-Minutes Walk test
ACE	Acute COPD Exacerbation
ANOVA	Analysis of Variance
ATS	American Thoracic Society
BMI	Body Mass Index
CAT	COPD Assessment Test
CCQ	Clinical COPD Questionnaire
CHF	Chronic Heart Failure
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease
CRQ-D	Chronic Respiratory Questionnaire – Dyspnoea domain
ED	Emergency Department
EQ-5D	EuroQol 5-Dimension Questionnaire
EQ-VAS	EuroQoL Visual Analogue Scale
ERS	European Respiratory Society
ESWT	Endurance Shuttle Walk Test
FEV_1	Forced Expiratory Volume in one second
FTSST	Five Times Sit to Stand Test
FVC	Forced Vital Capacity
GOLD	Global Initiative for Chronic Obstructive Lung Disease
GP	General Practitioner
GSES	Generalised Self-Efficacy Scale
HADS	Hospital Anxiety and Depressions Scale
heiQ	Health Education Impact Questionnaire
HRQoL	Health Related Quality of Life
LIPA	Light Intensity Physical Activity
m	Meter
MAST	Model for Assessment of Telemedicine
MCID	Minimal Clinical Important Difference
MCTT	Maugeri Centre for Telehealth and Telecare
min	Minute
MLHFQ	Minnesota Living with Heart Failure Questionnaire
mMRC	modified Medical Research Council scale
MRC	Medical Research Council scale
MVPA	Moderate to Vigorous Physical Activity
PA	Physical activity
PASE	Physical Activity Profile
PGIC	Patient Global Impression of Change scale
PhD	Philosophiae Doctor
PR	Pulmonary rehabilitation
PRAISE	Pulmonary Rehabilitation Adaptive Index for Self-Efficacy
PT	Physiotherapist
QALY	Quality-Adjusted Life Year
RCT	Randomized Control Trial
SD	Standard Deviation
SF-36	Short Form 36-health survey
SGRQ	Saint George's Respiratory Questionnaire
TUG	Timed Up & Go test

List of papers

I. Zanaboni P, **Hoaas H**, Lien LA, Hjalmarsen A, and Wootton R. Long-term exercise maintenance in COPD via telerehabilitation: A two-year pilot study. J Telemed Telecare. 2016;0(0):1-9.

II. **Hoaas H**, Andreassen H, Lien L, Hjalmarsen A, and Zanaboni P. Adherence and factors affecting satisfaction in long-term telerehabilitation for patients with chronic obstructive pulmonary disease: a mixed methods study. BMC Med Inform Decis Mak. 2016;16(1):26.

III. **Hoaas H**, Morseth B, Holland AE, and Zanaboni P. Are Physical Activity and Benefits Maintained After Long-Term Telerehabilitation in COPD? International Journal of Telerehabilitation. 2016;8(2):39-48.

IV. Zanaboni P, Dinesen B, Hjalmarsen A, **Hoaas H**, Holland AE, Oliveira CC, and Wootton R. Long-term integrated telerehabilitation of COPD Patients: a multicentre randomised controlled trial (iTrain). BMC Pulm Med. 2016;16(1):126.

V. **Hoaas H**, Zanaboni P, Hjalmarsen A, Morseth B, Dinesen B, Burge A, Cox N, and Holland A. Seasonal variations in objectively assessed physical activity among patients with COPD in two Nordic countries and Australia: a cross-sectional study. International journal of chronic obstructive pulmonary disease [under revision].

Abstract

Background and aims: The availability of pulmonary rehabilitation (PR) and exercise maintenance programs for people with chronic obstructive pulmonary disease (COPD) is low, despite being beneficial and recommended. Telerehabilitation can support the delivery of such programs to patients' homes. However, there is little knowledge of its benefits for people with COPD. This thesis aimed to investigate feasibility, effectiveness, benefits and challenges of a long-term exercise maintenance program via telerehabilitation in COPD.

Methods: An innovative 2-year telerehabilitation intervention comprising of treadmill exercise at home, telemonitoring by a physiotherapist via videoconferencing, and self-management via a website was investigated in a pilot study and an international randomized control trial.

Results: No adverse events related to the intervention occurred. After one year, 6-minutes walking distance was improved. Physical capacity, lung capacity, symptom level, and quality of life were maintained over the long-term. Participants were satisfied with the intervention and found the technology user-friendly. Satisfaction was supported by experienced health benefits, increased self-efficacy and emotional safety.

Discussion and conclusions: Long-term exercise maintenance in COPD via telerehabilitation is safe and feasible. Results are encouraging and suggest that telerehabilitation can prevent deterioration in lung function, symptom burden and health-related quality of life, and maintain functional walking capacity over the long-term. Telerehabilitation can overcome geographical distance, provide specialist access in areas where this is not available, and provide regularity of follow-up by the same healthcare personnel over a longer period. Challenges included maintenance of motivation for exercise, and challenges with transport of equipment and teaching in how to use the technology in the participants' homes. Long-term telerehabilitation could be offered as an alternative or supplement to centre-based PR.

1 Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive lung disease that is characterised by airflow limitations and respiratory symptoms (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). The disease contributes significantly to morbidity and mortality worldwide (World Health Organization, 2017). Pulmonary rehabilitation and exercise training are considered core components in the management of COPD and are recommended for all people with COPD (Spruit et al., 2013b, Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018, Troosters, 2018). However, the availability of pulmonary rehabilitation and exercise maintenance programs is low and dropout rates are a high (Spruit et al., 2013b, Rochester et al., 2015, Troosters, 2018). The development of telerehabilitation interventions attempts to meet the need for increased applicability and accessibility of pulmonary rehabilitation in a cost-effective way (Vitacca and Holland, 2018, Clini et al., 2018b). Telerehabilitation is defined as the delivery of medical rehabilitation service at a distance, regardless of patients' geographical location, using electronic information and communication technologies (Rosen, 1999, International Organisation for Standardization, 2016 p.4). Telerehabilitation differs from telemonitoring, which only provides remote monitoring of patients. Telerehabilitation has the potential to deliver effective pulmonary rehabilitation and long-term exercise maintenance to people with COPD in their homes. There is still little evidence of the benefits of telerehabilitation for people with COPD (Spruit et al., 2013b). Previous studies reported promising results for telerehabilitation in COPD in regards of feasibility, safety, physical activity and health-related quality of life (Holland et al., 2013a, Tabak et al., 2014c, Burkow et al., 2013, Marquis et al., 2015, Paneroni et al., 2015). However, all interventions had a short-term duration. Long-term adherence of exercise routines are often difficult for those with COPD (Hellem et al., 2012), and new ways of extending short-term benefits of pulmonary rehabilitation are warranted (Spruit et al., 2013b). The overall aims of this thesis were to investigate and discuss feasibility, effectiveness, benefits and challenges of a long-term exercise maintenance program via telerehabilitation for people with COPD. These topics were addressed in the five papers presented in this thesis.

1.1 COPD: definition, diagnosis, and epidemiology

Chronic obstructive pulmonary disease (COPD) is a common and prevalent, not curable, yet preventable and treatable disease (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). The disease is characterized by persistent respiratory symptoms and progressive expiratory airflow limitation due to airway and/or alveolar abnormalities that is usually caused by exposure to noxious particles or gases (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). COPD is considered a complex, heterogeneous, multicomponent disease and disease severity is affected by exacerbations, extrapulmonary manifestations and comorbidities (Vanfleteren, 2018).

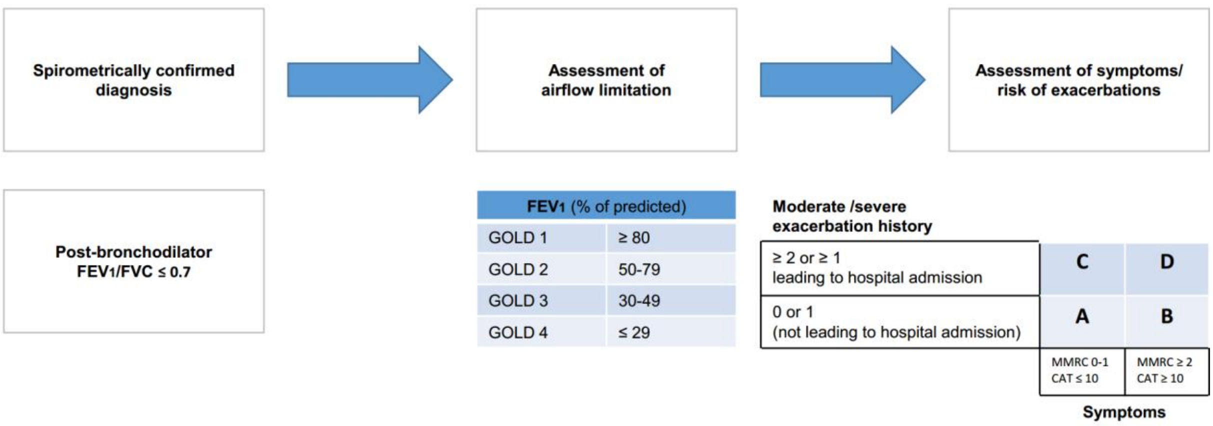
The diagnosis of COPD should be considered in any patient who experiences dyspnoea, chronic cough or sputum production, and/or a history of exposure to risk factors for the disease (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018, Celli et al., 2004). The diagnosis is confirmed by spirometry, and a presence of persistent airflow limitation is revealed with a post bronchodilator forced expiratory volume in one second (FEV_1)/forced vital capacity (FVC) ≤ 0.70. The severity of the disease increases with a reduction in FEV_1, and COPD is categorized into four stages according to the GOLD classification (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018) (Table 1).

Table 1 The GOLD classification of COPD

In patients with $FEV_1/FVC \leq 0.70$ post bronchodilator		
GOLD 1	Mild	$FEV_1 \geq 80\%$ predicted
GOLD 2	Moderate	$50\% \leq FEV_1 < 80\%$ predicted
GOLD 3	Severe	$30\% \leq FEV_1 \leq 50\%$ predicted
GOLD 4	Very severe	$FEV_1 < 30\%$ predicted

Based on increasing knowledge about COPD and its extrapulmonary effects, a new approach to the grading system was proposed with the ABCD assessment tool in 2011 (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). Disease severity was determined by combining assessment of the patient’s level of symptoms with spirometric classification and/or risk of exacerbations. However, the ABCD assessment tool was not better in predicting mortality or other important health outcomes than the spirometric grading system (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018, Franssen and Han, 2013). A further refinement of the ABCD assessment tool was presented in the 2017 GOLD Report. Spirometric grades were separated from the ABCD groups (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). In this revised version, spirometry should be used to determine the patient's severity of airflow limitation (four GOLD stages as the earlier GOLD classification). Then dyspnoea or symptoms should be assessed, using the modified Medical Research Council dyspnoea score (mMRC) or the COPD Assessment Test (CAT), respectively. In addition, history of moderate and severe exacerbations (including hospitalisations) should be recorded to evaluate future risk of exacerbation. Based on information regarding symptom burden and exacerbation risk, the patient is categorised into one of the ABCD groups. This refined approach acknowledges the limitations of spirometry alone for deciding treatment options on an individual patient level, and highlights the importance of perceived symptoms and risk of exacerbations in making treatment decisions. However, spirometry remains the main criterion for making a diagnosis of COPD (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018).

Figure 1 The ABCD assessment tool



FEV_1= Forced expiratory volume in one second. MMRC= Modified medical research council. CAT= COPD assessment test. Figure from the Global Initiative for Chronic Obstructive Lung Disease (GOLD) (2018).

Under-diagnosis of COPD is widespread and affects prevalence data (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). According to the World Health

Organization (2017), 251 million people were suffering from COPD in 2016 worldwide, and 5% of all deaths globally were estimated to be caused by COPD in 2015. However, COPD is likely underestimated as cause of death (May and Li, 2015). Estimates from population studies suggests that 8% of Norwegians aged above 40 years have COPD. This is equivalent to at least 200 000 people (Leivseth et al., 2017). However a prevalence up to 350 000 Norwegians suffering from COPD has been reported (Gulsvik et al., 2012).

The most common symptoms for COPD are chronic and progressive dyspnoea, cough and sputum production. Symptoms vary from day-to-day, and may develop years before an airflow limitation is present (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018).

People with COPD experience frequent exacerbations, between one to four per year (Miravitlles et al., 2004). Exacerbation of COPD is defined as "an acute worsening of respiratory symptoms that results in additional therapy" and can occur in all grades of COPD (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). Exacerbations are associated with a more rapid decline in lung function, particularly among those with mild COPD (Makris et al., 2007, Dransfield et al., 2017), reduced health-related quality of life (Roche et al., 2017), and increased risk of future exacerbations (Sadatsafavi et al., 2018). Exacerbations may lead to hospitalisations, but about half of the cases are unreported by patients, despite considerable encouragement to do so (Wedzicha and Donaldson, 2003). Prevention of severe exacerbations is important and has potential in modifying the disease trajectory (Sadatsafavi et al., 2018).

Systemic manifestations such as increased lung inflammation, which in turn is associated with low body mass index, skeletal muscle wasting and loss of fat free mass are common in COPD (Barnes and Celli, 2009, Sinden and Stockley, 2010). Systemic inflammation may lead to or worsen comorbidities such as ischaemic heart disease, heart failure, osteoporosis, anaemia, lung cancer, depression and diabetes (Barnes and Celli, 2009). People with COPD are prone to comorbidities (Vanfleteren et al., 2013), and have an average of seven comorbidities compared to three for other persons (Baty et al., 2013). Common comorbidities are lung cancer, cardiovascular diseases, osteoporosis, depression, anxiety, metabolic syndrome, diabetes, obstructive sleep apnoea, and gastroesophageal reflux.

Comorbidities contribute to the severity of disease in individual patients (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018).

A significant economic burden is associated with COPD (World Health Organization, 2017). Both maintenance treatment and treatment of acute exacerbations are associated with high healthcare costs (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018, May and Li, 2015). One COPD-related hospitalisation is estimated to £1807/ €2250/ NOK 20820 (Punekar et al., 2015). In the European Union, respiratory diseases are estimated to seize about 6% of the total healthcare budget, with COPD accounting for 56% of the cost of respiratory diseases (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018).

1.2 Exercise capacity limitations and effects of exercise in COPD

Reduced physical capacity, dyspnoea and (leg) fatigue are hallmarks of COPD and limits exercise capacity. Exercise capacity is reduced due to ventilatory and gas exchange limitations, cardiac and respiratory muscle dysfunction, reduced functions of skeletal muscles, or any combination of the above (Cooper and Storer, 2010, Spruit et al., 2013b). Muscle weakness in the skeletal muscles is common in COPD. This weakness is associated with reduced capillarisation and a shift from type I to type IIa fibres. Consequently, the muscles are more disposed to fatigue. Lactic acid production and metabolic acidosis is encountered at low workloads, which leads to an increase drive to breathe and dynamic hyperinflation that result in increased work of breathing (Romer, 2010). Even though the cause of exercise intolerance among those with COPD is multifactorial and related to disease severity, abnormal dynamic ventilatory mechanisms, especially dynamic hyperinflation, are believed to play a central role (Laveneziana et al., 2007, O'Donnell and Laveneziana, 2007). The term dynamic hyperinflation refers to the increase in end-expiratory lung volume and air trapping that occurs when airflow limitations prevent complete exhalation during exercise, hypoxia or anxiety. As a result, exhalation may not be completed prior to the onset of the next breath, causing progressive hyperinflation of the lungs. This air trapping causes the lungs to be slightly more inflated than normal, putting the diaphragm muscle at a mechanical disadvantage due to length-tension effect, which in turn decreases its function and increases the work of breathing. Dynamic hyperinflation is experienced as dyspnoea on exertion

(McCormack, 2017). People with COPD are less physically active than healthy age-matched controls (Pitta et al., 2005, Park et al., 2013). Inactivity leads to further physical deconditioning, increased ventilatory requirements and increased breathlessness (Cooper and Storer, 2010). Psychological conditions, such as anxiety, depression and poor motivation might also limit the ability to exercise in individuals with COPD (Spruit et al., 2013b).

Exercise can increase physical capacity, also for those affected by COPD (Cooper and Storer, 2010). Exercise does not improve lung function or gas exchange in this group of patients. The aim is rather to reverse the systemic consequences of the disease. Endurance training improves cardiovascular function through increased maximum oxygen uptake. Exercise also increases endurance (longer duration at same work load) and increases the ability to tolerate higher intensity of exercise due to reduced heart rate, lactate levels and ventilatory requirements on a given work load (Cooper and Storer, 2010, Casaburi and Zuwallack, 2009). Strength training of skeletal muscles contributes to an increase in muscle strength and endurance (Cooper and Storer, 2010). Other favourable exercise responses in the skeletal muscles are increased capillary density and type I (aerobic) muscle fibres. This increases oxygen extraction and decreases lactic acid production, thus reducing the ventilation requirements. As patients improve their physical capacity, less demands are made on the ventilation at a given work load and respiratory rate reduces, prolonging the time allowed for expiration and reducing dynamic hyperinflation, thsu reducing breathlessness (Casaburi and Zuwallack, 2009).

1.3 Pulmonary rehabilitation

1.3.1 Current concept of pulmonary rehabilitation

Definition

Pulmonary rehabilitation is an evidence-based treatment option for people with respiratory diseases and is recognised as a core component in the management of COPD (Troosters, 2018). The American Thoracic Society (ATS) and the European Respiratory Society (ERS) updated the definition of pulmonary rehabilitation in 2013 as following: *"Pulmonary rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient tailored therapies that 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."(Spruit et al., 2013b).*

For whom?

All patients with chronic respiratory disease might be eligible for pulmonary rehabilitation provided that there are clear clinical needs in terms of lack of physical capacity, symptoms or lack of physical activity (Spruit et al., 2013b, Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018, Troosters, 2018). As pulmonary rehabilitation is considered an integral part in the management of COPD, it might be offered at any stage of the disease. There is evidence that both patients with less and more severe degree of airflow limitation might benefit (Spruit et al., 2013b). According to ATS/ERS recommendations, pulmonary rehabilitation should not be initiated during hospitalisation due to a COPD exacerbation, but rather initiated within 3 weeks following hospital discharge. Pulmonary rehabilitation shortly after discharge from a COPD exacerbation is associated with a reduction in readmissions and improved quality of life. However, these are conditional recommendations with very low quality of evidence, and should be reconsidered as new evidence becomes available (Wedzicha et al., 2017).

Goals and benefits

Based on thorough initial and ongoing assessment, the pulmonary rehabilitation program itself should be individualised and fitted to the clinical needs and goals of each patient (Spruit et al., 2013b, Singh, 2018, Nici, 2009). Nevertheless, the overarching goal is to minimise symptom burden, maximise exercise performance, promote autonomy, increase participation in everyday activities, enhance health-related quality of life, and support long-term health-enhancing behaviour change (Spruit et al., 2013b).

The benefits of pulmonary rehabilitation for people with COPD are substantial. Pulmonary rehabilitation has been proven to improve dyspnoea, health status and exercise tolerance in stable patients with COPD, and graded evidence level A (Celli and Goldstein, 2018). In addition, it reduces hospitalisation in patients with recent exacerbations (≤4 weeks from prior hospitalization) (Evidence level B) (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). With an estimated cost per quality-adjusted life year (QALY) of

£2000 – £8000, pulmonary rehabilitation ranks as one of the most cost-effective treatment strategies for people with COPD (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). However, short-term benefits appear to diminish over the succeeding 6-12 months without any maintenance strategy (Spruit et al., 2013b).

Program components

Due to the complex nature of COPD, its multisystem manifestations, comorbidities, and frequent exacerbations, it is recommended that pulmonary rehabilitation is provided by a dedicated, interdisciplinary team consisting of physicians and other health professionals. The latter may include physiotherapists, respiratory therapists, nurses, psychologists, behavioural specialists, exercise physiologists, nutritionists, occupational therapists, and social workers (Spruit et al., 2013b).

Exercise and education aimed at supporting health behaviour change are the two core components of pulmonary rehabilitation (Desveaux et al., 2015, Burtin and Zuwallack, 2018). A variety of exercise training methods can be implemented to achieve improvements in cardiorespiratory endurance, strength and flexibility. These include endurance training, interval training, strength training, upper limb training, and transcutaneous neuromuscular electrical stimulation (Spruit et al., 2013b, Burtin and Zuwallack, 2018). Exercise training might be performed as outdoor walking with or without poles (Nordic walking), on a treadmill, stationary cycling, resistance training, aquatic exercises, group-based aerobic training and calisthenics. Moreover, a variety of training intensities and durations might be effective, depending on the specific patient deficits (Spruit et al., 2013a, Burtin and Zuwallack, 2018). Inspiratory muscle training may also be added to the program for motivated patients with COPD and impaired respiratory muscle function (Langer, 2018).

Pulmonary rehabilitation programs provide a good opportunity to deliver education and help people with COPD develop the skills and confidence they need to adopt a healthier lifestyle. Traditionally, education was provided as information and advice, assuming that knowledge would lead to behaviour change. However, patients often failed to adopt or maintain new behaviours. Today, it is recommended to integrate collaborative self-management skills by targeting not only knowledge, but also motivation to engage in behaviour change. Features supporting self- management include: involving the patient in decision making, assessment of the unique needs and barriers for the individual patient, agreement of goals, enhancing skills, problem solving, follow-up and support, and increasing access to resources (Bourbeau et al., 2018). Other components of the program might be nutrition, occupational therapy, guidance on disease management skills including medication management and smoking cessation, physical activity coaching, and breathing exercises and mucus clearance techniques (Spruit et al., 2013a, Clini et al., 2018a).

Organisation

Pulmonary rehabilitation programs can be organised successfully in several locations (Troosters et al., 2014, Rochester and Clini, 2018). Outpatient programs where patients visit hospital outpatient departments, community facilities or physiotherapy clinics, two to three times per week for a duration of 6 to 12 weeks, are the most common settings. Inpatient rehabilitation can be offered in hospitals or specialised rehabilitation centres where patients participate in to the program up to 6 days per week for 2 to 4 weeks (Spruit et al., 2013a, Rochester and Clini, 2018). More recently, pulmonary rehabilitation delivered in a home-based setting has shown similar effects as centre-based pulmonary rehabilitation (Holland et al., 2017). In addition, a variety of telerehabilitation interventions can be used to deliver pulmonary rehabilitation successfully. However, home-based pulmonary rehabilitation and telerehabilitation is not widely used in clinical practice and mostly been conducted in the context of clinical trials (Rochester and Clini, 2018). The updated knowledge related to telerehabilitation is extensively discussed in detail in paragraph 1.4.

1.3.2 Challenges of conventional centre-based pulmonary rehabilitation

As described in a previous paragraph, pulmonary rehabilitation has an evidence level “A” (Celli and Goldstein, 2018). Nevertheless, there are still some challenges to be met. Telerehabilitation and new technologies may be viable solutions to face some of these challenges (Donner et al., 2018, Clini et al., 2018b).

Applicability, scope and accessibility

Researchers underlines the need to increase the applicability, scope and accessibility of pulmonary rehabilitation programs in the future (Clini et al., 2018b). The number of suitable patients participating in pulmonary rehabilitation is surprisingly and strikingly low (Rochester et al., 2015, Keating et al., 2011). First, there is a large variation in referral rates to pulmonary rehabilitation, ranging from 0% to 85%. The most common barriers to referral among physicians seems to be the low knowledge of the content and benefits of pulmonary rehabilitation, and the referral process (Milner et al., 2018). Second, up to half of referred patients does not attend at all. Identified barriers for participation are disruption to established routines, travel and transportation difficulties, lack of encouragement from the participant's physician, lack of perceived benefit and inconvenient timing of the program (Keating et al., 2011). Methods and programs to increase the number of patients assessing pulmonary rehabilitation, including those living in remote areas, are encouraged (Clini et al., 2018b). Another future target is to offer pulmonary rehabilitation in a larger scale, including also those patients affected by milder disease, comorbidities, exacerbations, critical illness, and other "non-COPD" chronic respiratory diseases (Clini et al., 2018b). Available resources and availability of pulmonary rehabilitation programs vary across different healthcare settings (Spruit et al., 2013b, NHS Right Care, 2012). A Canadian study found that only 1.2% of the COPD population had access to pulmonary rehabilitation programs (Brooks et al., 2007). In Sweden, the availability of pulmonary rehabilitation programs also is reported to be low. Pulmonary rehabilitation was not available to people with COPD in 24% of all primary care centres (Arne et al., 2016). A systematic review found that less than 1.2% of individuals with COPD had access to pulmonary services on an international basis (Desveaux et al., 2015). The ATS/ERS has acknowledged the need to increase availability of pulmonary rehabilitation (Spruit et al., 2013b).

Dropout and adherence

For patients who attend pulmonary rehabilitation programs, dropout and lack of adherence to the program and to long-term health-enhancing behaviour after the program are a known challenge (Spruit et al., 2013b, Rochester et al., 2015, Hayton et al., 2013). Dropout rates vary between studies, ranging from 10-32% (Spruit et al., 2013b). A study investigating attendance and adherence among people with COPD attending pulmonary rehabilitation found that 29%

of the participants completed less than 2/3 of the sessions. The study concluded that age, smoking status, availability of social support, travel distance, and markers of disease severity, use of long-term oxygen therapy in particular, were strong predictors of attendance and adherence to pulmonary rehabilitation (Hayton et al., 2013). A qualitative study exploring perspectives related to adherence to pulmonary rehabilitation among of people with COPD suggested that adherence could be enhanced by building confidence in the patient, fostering tangible results, and recognising and responding to the patient readiness and access issues (Guo and Bruce, 2014). To improve adherence and increase benefits, a report from a recent international workshop emphasised the need for improving delivery and outcome assessment of the education component of pulmonary rehabilitation (Blackstock et al., 2018).

Maintenance of long-term benefits

Benefits of pulmonary rehabilitation appear to wean off over 6-12 months without any maintenance strategy (Spruit et al., 2013b, Spruit and Singh, 2013). The decline in health status may partially reflect disease progression or exacerbations but, at large, it is probably due to a drop-off in adherence to exercise prescription, and the optimal maintenance intervention to sustain benefits still remains unknown (Spruit and Singh, 2013, Brooks et al., 2002, Griffiths et al., 2000). Ongoing encouragement after pulmonary rehabilitation by more frequent contact with health professionals through visits to the institution and by telephone contact does not appear to be enough to avoid the decline in health status (Brooks et al., 2002). Even among those patients who initiate a formal post-rehabilitation maintenance program, the dropout rate is reported to be 36.7% one year after completing pulmonary rehabilitation (Heerema-Poelman et al., 2013).

Physical inactivity among people with COPD

People with COPD are less physically active than healthy age-matched controls (Pitta et al., 2005, Park et al., 2013), and physical inactivity and sedentary behaviour are associated with an increased risk of all-cause mortality in this group (Troosters et al., 2013, Watz et al., 2014, Waschki et al., 2011, Furlanetto et al., 2017). Inactivity is also thought to lead to a more rapid progression of the disease and the development of comorbidities in these individuals (Troosters et al., 2013, Van Remoortel et al., 2013, Watz et al., 2014, Waschki et al., 2011).

Improving physical activity levels during and after pulmonary rehabilitation is a challenge (Burtin et al., 2015, Cindy Ng et al., 2012), and studies are aiming to test behaviour-targeted interventions for improving physical activity (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018). A recent review concluded that the addition of physical activity counselling to exercise training in pulmonary rehabilitation is beneficial in increasing physical activity (Lahham et al., 2016).

Individualising and tailoring of pulmonary rehabilitation

Professionals in the field have suggested a more personalised approach to refine pulmonary rehabilitation to target the unique needs of the complex and individual patient. One size does not seem to fit all in the vast and heterogeneous population of people with COPD. (Ambrosino and Clini, 2015, Spruit et al., 2013b, Vanfleteren et al., 2017). To accomplish this, the patient should be involved in decision making, evaluation of his goals and needs, as well as making priorities for follow-up in a coordinated way (Vanfleteren et al., 2017). It is important to identify the right patient to the right rehabilitation program. A study including 2068 patients with COPD identified groups of patients with a very good, good, moderate or poor response to the pulmonary rehabilitation program. Ongoing pulmonary rehabilitation programs may need to be redesigned to better fit the poor responders (Spruit et al., 2015).

1.3.3 Pulmonary rehabilitation in Norway

There is a large variation in where and how pulmonary rehabilitation programs are organized in Norway. Most programs are offered by the specialist health service, like hospitals or private rehabilitation centres. In 2015, 75% of people with COPD receiving pulmonary rehabilitation was enrolled in a program offered by a public funded hospital. However, pulmonary rehabilitation is also offered by some primary care services, which represents a recent political goal (Leivseth et al., 2017).

Pulmonary rehabilitation is provided in form of both inpatient programs and outpatient programs. Geographical conditions often make inpatient programs the only choice for patients living in remote areas, while outpatient programs are offered mostly to patients living close to a rehabilitation centre or hospital. Group-based programs are most utilised (Hjalmarsen, 2012 p. 66).

Specialist competence and availability of pulmonary rehabilitation programs is lower in Norway than in England and the Netherlands. Often only patients with a severe degree of COPD are offered a rehabilitation program (Askvik, 2015). In 2015, about 2500 Norwegians with COPD participated in pulmonary rehabilitation (of whom, 1343 women and 1181 men). Four out of five were aged 60 years or older (Leivseth et al., 2017). There was a considerable geographical variation in the number of people enrolled in pulmonary rehabilitation across the country, and there seems to be an unwarranted variation in the service (Leivseth et al., 2017). Moreover, people with COPD does not receive enough information about pulmonary rehabilitation and its benefits (Nasjonalt servicemiljø for medisinske kvalitetsregistre, 2017).

The Norwegian Heart and Lung Association offers group-based exercise maintenance programs led by volunteers across the country (Landsforeningen for hjerte- og lungesyke). However, the availability of maintenance programs after rehabilitation is low, especially in the remote areas and Northern Norway.

1.4 Telerehabilitation

The term telerehabilitation is relative new, but is an important subdiscipline of telemedicine (Brienza and McCue, 2013). Telerehabilitation involves clinical rehabilitation through information and communication technology, regardless of the patient's geographical location (Rosen, 1999). Telerehabilitation differs from telemonitoring, which refers to monitoring of patients at a distance using information technology. Initially, the focus of telerehabilitation was to mimic real-time face-to-face interactivity in a telesetting, typically by video conferencing. However, advancements in technology now make it possible to initiate new types of interventions (Brienza and McCue, 2013). Examples are programs provided by web-based platforms, peer-group support through web-based network (Donner et al., 2018), pre-filmed videos (Burkow et al., 2015, Burkow et al., 2013), interactive group sessions (Cox et al., 2018a, Hansen et al., 2017), exergames, serious games and gamification (Brox et al., 2011, Brox et al., 2017, Tabak et al., 2015), and virtual reality (Wardini et al., 2013). Further, monitoring of health parameters and/or physical activity through direct feedback via mobile apps (Lunde et al., 2018), Internet and mobile-based interventions (Antypas and Wangberg, 2014b) or activity armbands (Tabak et al., 2014b) has the potential to foster increased physical activity in home dwelling patients. Costs may be reduced and effectiveness may be improved compared with conventional in-person rehabilitation, especially for prolonged interventions for people with chronic conditions (Brienza and McCue, 2013). In addition to increase accessibility in both remote areas and urban settings, telerehabilitation holds a potential to provide effective rehabilitation in the patient's natural environment. Brienza and McCue (2013) provided evidence that suggests that rehabilitation services can be more effective when they are provided in the natural environment where the client lives, works, and/or interacts socially and recreationally rather than in a clinical environment. Others have also advocated that telerehabilitation in the home may contribute to long-term adoption of healthy behaviours (Donner et al., 2018). Other pros for telerehabilitation suggested by a recent interdisciplinary workshop with health experts in the field of pulmonary rehabilitation are summarised in table 2.

Table 2 Pros for telerehabilitation for the individual patient

• Access to rehabilitation service regardless of location and time of the day
• Access to regularly updated standardised information and education material so the patient can learn in his own pace
• Access to specialised healthcare professionals
• Access to advice to share with partners and caregivers
• Content can be customised to individual needs

Table from Donner et al. (2018).

1.4.1 Telerehabilitation interventions for people with COPD

The knowledge base on telerehabilitation has moved forward since our research group started to plan, design and test a pilot intervention in 2011 (Zanaboni et al., 2016b), and since the start of this PhD work in February 2014. In order to provide an up-to-date state of knowledge, structured literature searches were performed during Summer 2018. The last search was performed on 29th August 2018. Literature published after this date is not discussed in this thesis. Searches were performed in PubMed, Embase, and Cochrane Central Register of Controlled Trials. Search terms were "telerehabilitation" or "internet" or "e-health" or "video conference" and "chronic obstructive pulmonary disease" and "pulmonary rehabilitation". Reference lists of the retained articles were also screened to identify studies that were not originally captured in the electronic database searches.

From the literature searches 3 systematic reviews, 1 study protocol for a systematic review (Cox et al., 2018b), 8 published randomised controlled trials (RCT), 7 intervention studies on telerehabilitation, and 3 study protocols for RCTs were found. In addition, one upcoming Danish RCT investigating the feasibility and effect of a follow-up telerehabilitation program for COPD against standard follow-up was identified from ClinicalTrials.gov (Identifier: NCT03443817). Finally, 4 qualitative or mixed-methods studies were found. Details of the study protocols, RCTs, intervention studies, mixed method studies and qualitative studies are summarised in table 3, 4, 5 and 6, respectively. Study protocols that were followed by articles reporting the main results, were not reported in table 3, but in table 4. Studies involving telemonitoring alone, self-management alone, and interventions promoting physical activity alone were not included. Studies delivering telerehabilitation in community-based centres or inpatient facilities and not in the individuals homes were also excluded. Studies whose results were only published in conference proceedings were not covered.

A systematic review by Lundell et al. (2015) showed that telemedicine may lead to increased physical activity level for people with COPD, but no beneficial effect was found on exercise capacity and dyspnoea. However, the majority of the studies included consisted of simple interventions and results should be considered with cation given a heterogeneity among the studies. Another systematic review by Chan et al. (2016) compared exercise telemonitoring and telerehabilitation with conventional cardiac and pulmonary rehabilitation. However, only one study on pulmonary rehabilitation was included in this review (Paneroni et al., 2015). Consequently, more studies comparing telerehabilitation for patients with COPD with usual care need to be conducted (Chan et al., 2016). Another systematic review by Almojaibel (2016) including seven studies provided a narrative synthesis of the use of video components to provide real-time interactive pulmonary rehabilitation at home for people with COPD. Although this review included pilot studies with small sample sizes and without a control group, findings suggested that the provision of pulmonary rehabilitation via specially designed or commercially available telecommunication equipment is feasible, well-accepted by the participants, and safe. Telerehabilitation was associated with positive clinical outcomes including improvements in exercise capacity, quality of life, dyspnoea level, and sense of social support (Almojaibel, 2016). A recent review by Bairapareddy et al. (2018), attempted to review the evidence behind telerehabilitation to inspire healthcare personnel and decisions makers in India to test telerehabilitation for people with COPD. Twelve studies with different study designs, most of them with small sample sizes and only three RCTs were included. Eight of the studies comprised supervised exercise training via video conferencing. Authors concluded that telerehabilitation was effective in improving dyspnoea, functional work capacity, and quality of life in people with COPD (Bairapareddy et al., 2018).

Table 3 Protocols on randomized controlled trials on telerehabilitation for people with COPD

Author	n	Intervention	Comparison	Timeframe	Measurement points	Outcomes
Zanaboni et al. (2016a)	120	Remotely supervised exercise training via iPad and video conferencing software, comprising treadmill training ≥30 min and strength exercises 3-5 sessions per week in the home. Intensity and mode (interval or continuous training) is adjusted individually depending in the patient's condition. Telemonitoring by pulse oximeter. Website with training diary, symptom diary, and individual goal setting. Individual follow-up.	1) Individualised unsupervised training program on a treadmill at home performed as described to the telerehabilitation group. Training sessions to be recorded on a paper-based diary. 2) Standard care.	2 years, at least one weekly follow-up in the first 8 weeks, and at least 1 monthly follow-up in the following period.	Baseline, 6 months, 1 year and 2 years.	Hospitalisations, ED presentations, mortality, time free from first event, health status, quality of life, anxiety and depression, self-efficacy, subjective impression of overall change, physical performance, level of physical activity, cost-effectiveness, and experiences in telerehabilitation.
Hansen et al. (2017)	134	Remotely supervised exercise training via web camera and computers in groups of 4-8, comprising 35 min exercise and 25 min patient education in the home.	Standard outpatient group-based PR comprising 60 min exercise 2 times/week and 60-90 min patient education 1 time/week.	10 weeks, 3 weekly follow-ups.	Baseline, end of intervention, and 3, 6 and 12 months post-intervention.	Endurance and walking capacity, lower extremity muscle strength, health status and symptoms, quality of life, anxiety and depression, level of physical activity, and health economic analysis.
Cox et al. (2018a)	142	Remotely supervised exercise training via iPad and video conferencing software in groups of 4-6, comprising 30 min stationary cycling and/or walking + strength training in the home. Telemonitoring by pulse oximeter. Individualised education and self-management training. Home exercise program 3 times/week documented in a diary. After 8 weeks: supervised exercise maintenance program.	Standard outpatient group-based PR, comprising 30 min aerobic training and strength training. Groups of 8-12. Individualised education and self-management training. Home exercise program 3/week to be documented in diary. After 8 weeks: supervised exercise maintenance program.	8 weeks, 2 weekly follow-up.	Baseline, end of intervention and 12 months post-intervention.	Change in dyspnoea score, endurance and walking capacity, level of physical activity, quality of life, self-efficacy, anxiety and depression, adherence, and health economic analysis.

PR: Pulmonary rehabilitation.

Table 4 Randomized controlled trials on telerehabilitation for people with COPD

Author	n	Intervention	Comparison	Timeframe	Results
Bernocchi et al. (2018)	112	Telemonitoring of vital signs with pulse oximeter and electrocardiograph in older patients with combined COPD and CHF. Unsupervised personalised exercise program with minimum of 45-55 min on a mini-ergometer and callisthenics 3/week + free walking 2/week. Weekly telephone call from nurse and PT.	*Standard care including medications and oxygen prescriptions, visit from GP, and in-hospital check-ups on demand.	4 months, 2 weekly follow up (once by nurse, once by PT)	Significant improvement in 6MWD, time to hospitalisation/death, MRC, PASE, Barthel, MLHFQ, CAT compared to control after 4 months of interventions * Benefits were maintained at 2 months post intervention for all outcomes.
Bourne et al. (2017)	90	6-week online program called myPR comprising educational videos and exercise videos that consisted of 10 exercises. For each week the length of each of the 10 exercises increased by 30 seconds, starting from 60 seconds the first week. Patients were instructed to access myPR at least twice and up to 5/week.	Standard outpatient group-based PR comprising educational sessions and 10 exercise stations, which were identical to the exercises carried out by the patients using myPR.	6 week, 2 weekly sessions + 3 additional weekly exercise sessions at home.	No difference was seen in 6MWD and CAT score between groups. Non-inferiority was demonstrated between the impacts of online and conventional PR on clinical scores for breathlessness or HRQoL between groups.
Vasilopoulou et al. (2017)	147	Following completion of an initial 2-month conventional PR program, a 12-month home-based maintenance telerehabilitation was provided. The program comprised an individualised action plan, exercise training (video on tablet computer demonstrating arm and leg exercises and walking drills), access to a call centre 5 days/week, psychological support, and dietary and self-management advice via weekly contact with personnel from an interdisciplinary team through phone or video conference. Telemonitoring by spirometry and pulse oximeter.	1) 12-months hospital-based outpatient maintenance rehabilitation program twice weekly including exercise training, physiotherapy, dietary and psychological advice. 96 sessions. 2) 12-months usual care treatment without initial PR.	12 months, 144 sessions in total.	Both maintenance telerehabilitation and hospital-based PR were independent predictors of a lower risk for ACE and hospitalisations. In addition, these groups improved functional work capacity and HRQoL from baseline to 12 months. Only maintenance telerehabilitation was an independent predictor of ED visits.
Chaplin et al. (2017)	103	Web-based PR program including individualised webpage with personalised action plan for managing exacerbations, goalsetting, educational content, and home exercise program consisting of daily walking and strength training to be reported	Conventional PR, 7 weeks (4 weeks supervised/3 weeks unsupervised), twice weekly, 2 hourly sessions (1 hour for exercise training consisting of walking and strength training and	6-8 weeks	Significant improvements in ESWT and CRQ-D form baseline in both groups. No significant differences between groups in any outcome. Dropout rates were higher in the web-based program (57% vs 23%).

		at website. Weekly contact by phone or email with healthcare personnel. Motivational interviewing techniques were used.	1 hour for education in topics including medication, relaxation skills, chest clearance etc.)		
Tsai et al. (2017)	37	Remotely supervised exercise training via laptop computer with an in-built camera in groups up to 4, comprising lower limb cycle ergometer, walking training for a total of 40-55 min and lower limb strengthening exercises (sit to stand and squats), 3 times/week.	Usual care consisting of usual medical management including optimal pharmacological intervention and provision of an action plan. This group did not participate in any exercise training. No education component in either groups.	8 weeks	Significant improvements in ESWT and self-efficacy, and a trend towards improvement in HRQoL when compared with control.
Paneroni et al. (2015) (Controlled clinical trial)	36	Interactive television monitor and remote control system called the IGEA-SAT platform, comprising strength exercises for 40 min, stretching/relaxation for 20 min, cycle ergometer training for 40 min 6 times/week, and an educational component. Diary to report dyspnoea, leg fatigue sensation and 02 saturation before and after exercise. Follow-up by physiotherapist by phone or video conference.	Retrospectively matched group who had undertaken centre-based conventional PR similar to the telerehabilitation program.	28 sessions (in maximum period of 40 days)	No difference in 6MWD, MRC and SGRQ compared to control. Telerehabilitation was well accepted by the participants.
Tabak et al. (2014c)	34	Physical activity coach by smart phone for ambulant activity registration and real-time feedback, complemented by a web portal with a daily symptom diary.	Usual care (no PR).	4 weeks	No difference in physical activity levels compared to control. A non-significant improvement for health status was found between groups. Activity coach was wore more than prescribed.
Tabak et al. (2014a)	29	Telerehabilitation program consisting on an activity coach for ambulant activity monitoring and real-time coaching of daily activity behaviour, web-based exercise program for home exercise (endurance and strength training, mobilisation, relaxation, breathing exercises and mucus clearance), self-management of COPD exacerbations via a triage diary on the web portal, and teleconsultations.	Usual care (contact with medical doctor as usual and attend physiotherapy sessions if this was prescribed as part of the usual care).	9 months	Participants were satisfied with the program. The self-management module was highly used, while use of the exercise module was critically low. No significant improvements in exercise capacity or HRQoL in neither groups, or in between group differences in hospitalisations.

CHF: Chronic heart failure. PT: Physiotherapist. GP: General practitioner. PR= Pulmonary rehabilitation. 6MWD: six minutes walking distance. MRC: Medical research council scale. MMRC= the modified medical research council scale PASE: physical activity profile. Barthel: The Bartel index of activities of daily living. MLHFQ: the Minnesota living with heart failure questionnaire. CAT: the COPD assessment test. HRQoL= Health related quality of life. ACE= Acute COPD exacerbations. ED= Emergency department. CRQ-D= Chronic Respiratory disease Questionnaire -Dyspnea domain. ESWT= Endurance shuttle walk test. SGRQ= the Saint George’s respiratory questionnaire. CCQ= Clinical COPD Questionnaire.

Table 5 Intervention studies on telerehabilitation for people with COPD

Author	n	Intervention	Timeframe	Results
Zanaboni et al. (2016b)	10	One weekly individual supervised exercise training via iPad and video conferencing software, comprising interval training on a treadmill ≥30 min and strength exercises in the home. Recommended unsupervised training additionally 2 times per week. Telemonitoring by pulse oximeter. Website with training- and symptom diary.	2 years	No dropouts. Improvements in 6MWD, CAT, and EQ-5D after one year. After two years, the different outcomes were in line with baseline. Patients succeeded in maintaining exercise over 2 years.
Hoaas et al. (2016b)	9	Participants participating in the study of Zanaboni et al. (2016b) described above was reassessed after 1 year post intervention. After the intervention period, participants kept all equipment for exercise training on a treadmill, self-monitoring with a pulse oximeter and access to a web-based diary for reporting symptoms and exercise training. No other maintenance strategy was provided.	1 year	Physical activity levels and adherence to registration of symptoms and training sessions in the web based diary decreased significantly. Other outcomes including health status, quality of life, anxiety and depression, self-efficacy, and healthcare utilization did not change significantly.
Marquis et al. (2015)	26	Remotely supervised exercise training via video conferencing, comprising endurance exercise on a stationary bike lasting 10-40 min 3/week and strengthening exercises with weights and rubber bands. Sessions were supervised three times during Weeks 1 and 2, two during Weeks 3–5, and one during Weeks 6–8. Telemonitoring by pulse oximeter and heart rate sensor. Self-managements education comprising written pamphlets and PowerPoint presentation on computer every week.	8 weeks	Significant improvements in 6MWD, cycle endurance test time and CRQ from baseline to post-intervention. Users were very satisfied with the program and adherence was high.
Minet et al. (2015)	50	Remotely supervised exercise training via a video conferencing system called the "Patient Briefcase" early after hospitalisation three times per week 30-45 min each time, comprising thorax mobilisation exercises, walking on the sport, seated exercises and strengthening exercises etc, and up to two sessions of supervised counselling in energy conservation	3 weeks	74% completed the program. Significant improvements in TUG, FTSST and CCQ.
Holland et al. (2013a)	8	Remotely supervised exercise training via video conference software on a stationary bicycle for 30 min twice a week in groups of 2. Telemonitoring by pulse oximeter. Informal discussions about aspects of self-management of COPD.	8 weeks	Participants attended 76% of possible sessions. No significant adverse events. Three participants did not complete the program due to exacerbation of COPD (2) and unstable diabetes (1). Clinically significant improvements in 6MWD, CRQ dyspnea and CRQ fatigue in participants completing the program.
Tousignant et al. (2012)	3	Remotely supervised exercise training via video conference on a stationary bicycle for 10-45 min and strengthening exercises, 3/week. Supervision was	8 weeks	Clinically significant improvements in 6MWD for 2 of the 3 participants. All participants improved the scores on the CRQ.

		gradually decreased to be replaced by unsupervised exercise training. Telemonitoring by pulse oximetry.		
Marquis et al. (2014)	23	Participants participating in the study of Marquis et al (2015) described above was reassessed after 24 weeks post intervention. After the intervention period, the stationary bicycle was removed from the home, but participants kept the exercise program and written pamphlets on self-management. No formal maintenance strategy was provided. Participants were simply encouraged to buy their own stationary bicycle, continue their programs.	6 months	Improvements in exercise tolerance and quality of life obtained in the previous/before going intervention, decreased significantly after 6 months without any maintenance strategy provided.

COPD= Chronic obstructive pulmonary disease. 6MWD: six minutes walking distance. CAT: the COPD assessment test. EQ-5D: EuroQol 5-Dimension Questionnaire. CRQ= Chronic respiratory disease questionnaire. TUG : Timed up & go test,. FTSST: The five times sit to stand test. CCQ: the Clinical COPD questionnaire.

Table 6 Qualitative studies or mixed method studies on patients with COPD perspective on telerehabilitation

Author	n	Intervention	Timeframe	Results
Burkow et al. (2013)	5	Multidisciplinary led group-based PR program in the home of the patients. Delivered via patients' own television connected to a computer and a remote control. Program included pre-filmed education videos and follow-along exercising videos, weekly educational sessions and supervised exercising in groups (30 min) via videoconferencing, a health diary for reporting daily symptoms and sensor data (oxygen saturation, heart beat), and weekly individual consultations.	6 weeks	Individual semi-structured interviews indicated that the home PR program were acceptable and positively received by the participants. The group setting at home gave the participants a possibility to share experience and to learn from questions raised by others. The participants valued the socially supportive environment facilitated by multiparty videoconferencing. The individual consultations were well perceived, but the need to discuss personal health issues varied among the participants.
Burkow et al. (2015)	10	Multidisciplinary led, PR program delivered via the participants TV connected to a small computer with internet connection, headset and remote control to navigate in menus and enter data. Exercise training twice each week lasting 30 min and weekly self-management education lasting 60 min in groups of 5, additional training via online follow-along exercise video, educational videos, and individual online consultations. Digital health diary for reporting daily symptoms, pulse oximetry and step counts.	9 week	Multidisciplinary PR delivered in online groups may be feasible for patients with different severity levels of COPD. The program supported learning from both healthcare personnel and peers, for group exercising and for social support. High usability of the technology. Significant improvements in HRQoL. The cost per patient of the home rehabilitation programme was lower than the reimbursement rate for outpatient rehabilitation.
Tsai et al. (2016)	19	Remotely supervised exercise training via real-time video conferencing in groups up to 4, comprising 60 min cycling on a stationary cycle ergometer, strengthening exercises for lower limbs, and ground-based walking training within their home.	8 weeks, 3 weekly sessions	Key themes emerged from semi-structured interviews (n=11) were: positive virtual interaction through technology; use of equipment; convenience; and health benefits. Participants were highly satisfied with the program. In addition, participants' partners reported a high level of satisfaction with the program.
Hoaas et al. (2016a)	10	Weekly individual supervised exercise training via video conferencing as described in Zanaboni et al. (2016b) in table 5 above. Telemonitoring via pulse oximeter, and access to web-based diary for reporting exercise performance and daily symptoms.	2 years	Participants registered 3.0 symptom reports/week and 1.7 training sessions/week in the diary. Adherence rate decreased during the second year. Four major themes regarding factors affecting satisfaction, adherence and potential improvements of the intervention emerged from two focus group interviews: (i) experienced health benefits; (ii) increased self-efficacy and independence; and (iii) emotional safety due to regular meetings and access to special competence; (iv) maintenance of motivation. Participants were highly satisfied with the technical components.

PR= Pulmonary rehabilitation. COPD= Chronic obstructive pulmonary disease.

1.5 Aims and objectives

The overall purpose of our research was to increase access to pulmonary rehabilitation and support long-term maintenance of exercise through telerehabilitation. Such needs were especially relevant for Arctic regions, characterised by remote and scattered populations, harsh winters and long travel distances to healthcare facilities. Northern Norway thus represented an attractive setting for research in telerehabilitation. Adherence to long-term regular exercise is often difficult for people with COPD (Hellem et al., 2012) and developing new ways to prolong the benefits obtained from pulmonary rehabilitation is an important goal (Spruit et al., 2013b).

The main objective of this thesis was to investigate the feasibility, clinical effects, adherence, benefits and challenges of providing long-term exercise maintenance to people with COPD in their homes via telerehabilitation. To achieve this, we evaluated the feasibility and effects of a two-year pilot study on a long-term exercise maintenance program provided via telerehabilitation. We also evaluated the adherence to this program and explored participants' perspectives. After completing this pilot study, the participants kept the equipment, but were no longer supervised via telerehabilitation. Participants were reassessed at the end of the post-intervention year to evaluate if adherence to self-management and home exercise routines would decline. An international, multicentre RCT was then designed to compare long-term telerehabilitation with unsupervised exercise training at home and with standard care. One hundred and twenty people with COPD from Norway, Denmark and Australia were randomly assigned to telerehabilitation, unsupervised treadmill exercise training at home or control, and followed up for two years. We also wanted to investigate whether there were differences in physical activity levels among the participants across the three different countries, and establish if any variations in physical activity would be attributable to seasonal variations. Understanding such variations across countries can assist the interpretation of data from international multicentre RCTs.

The specific objectives of this theses were addressed in five scientific papers.

Paper I

- To investigate feasibility, long-term exercise maintenance, clinical effects, quality of life and use of hospital resources of a two-year telerehabilitation intervention tested in a pilot study with ten people with COPD.

Paper II

- To investigate the adherence to a two-year telerehabilitation intervention tested in a pilot study with ten people with COPD.
- To identify the main factors affecting satisfaction and adherence to the long-term telerehabilitation intervention for people with COPD.
- To identify potential factors that might increase adherence.

Paper III

- To investigate if the benefits achieved after a two-year of telerehabilitation intervention for people with COPD would deteriorate in the post-intervention year with access to exercise equipment but without supervision via telerehabilitation.

Paper IV

- To compare long-term telerehabilitation comprising exercise training at home, telemonitoring, and self-management designed for people with COPD with unsupervised exercise training at home on a treadmill, and with standard care (Study protocol).

Paper V

- To investigate potential differences in physical activity levels between Norwegian, Danish and Australian people with COPD.
- To establish if potential variations in physical activity levels were attributable to seasons.

2 Materials and methods

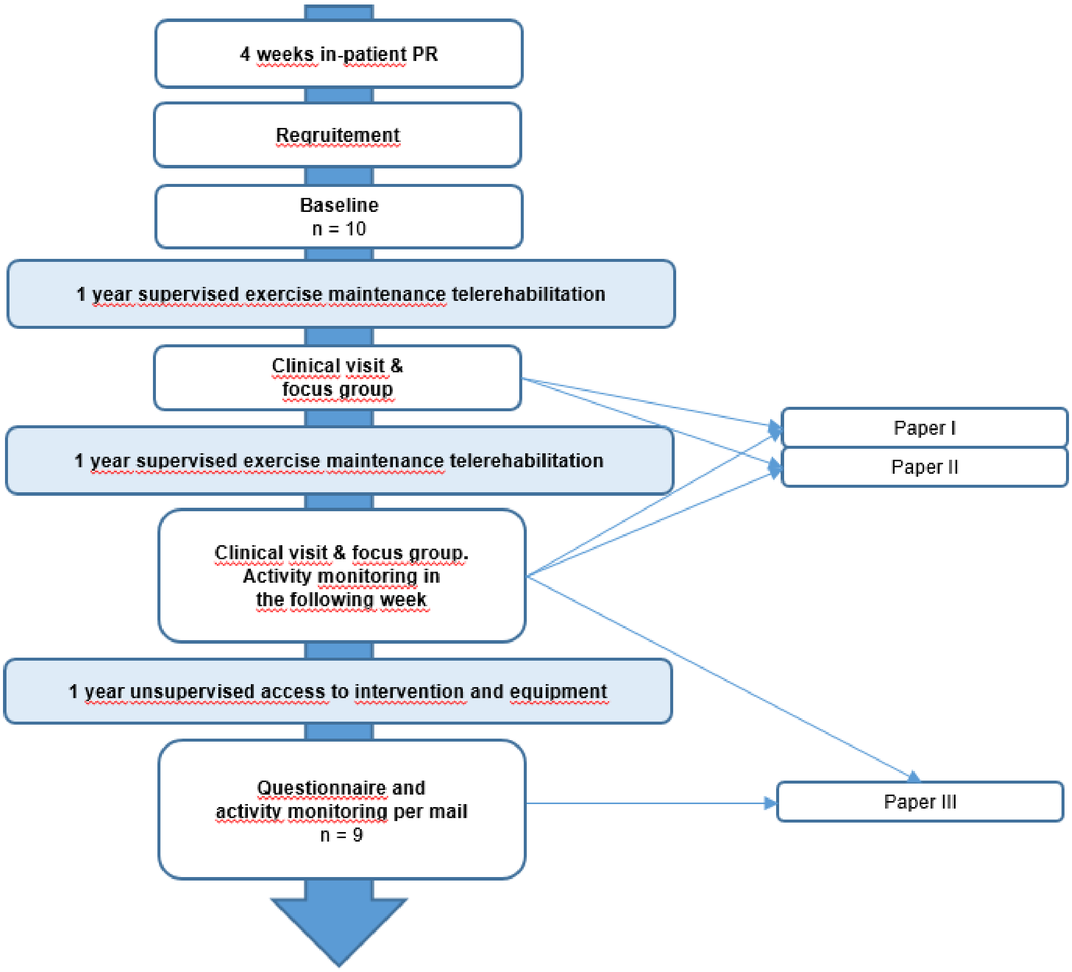
2.1 Design and study material

The five papers in this thesis included research on patients with COPD. An overview of the timeline of the two studies performed (pilot study and RCT), sample sizes, and related papers is presented in figure 2 and figure 3.

Previous studies described promising results for telerehabilitation in COPD in regards to feasibility, safety, physical activity and health-related quality of life (Holland et al., 2013a, Tabak et al., 2014c, Burkow et al., 2013, Marquis et al., 2015, Paneroni et al., 2015). However, all interventions had a short-term duration. A 10-year survival study conducted in Northern Norway found that people with very severe COPD could be favourably treated with a long-term extensive rehabilitation program in an outpatient setting (Hjalmarsen et al., 2014). Alternatives for long-term rehabilitation and maintenance programs for this patient group are lacking in Northern Norway. Long-term adherence to exercise routines is often difficult for those with COPD (Hellem et al., 2012), and new ways of extending short-term benefits of pulmonary rehabilitation are warranted (Spruit et al., 2013b). We therefore wanted to test an innovative long-term telerehabilitation intervention in a pilot study to obtain documentation on feasibility, long-term exercise maintenance and other benefits. The telerehabilitation intervention included a customised website used for self-monitoring and telemonitoring, an application for video conferencing, a treadmill, a tablet computer and a pulse oximeter. The intervention was developed and implemented in a two-year pilot study with a test-retest design. Based on the results and experience from the pilot study, a RCT was planned and implemented. When properly designed, conducted and reported, RCTs are considered the gold standard for evaluating the effect of treatments. However, it has been argued that the controlled setting of a RCT and possible patient selection bias can make it difficult to extrapolate findings to the general target population and real life situations (Pringle and Churchill, 1995, Mørch, 2010). A systematic review of reviews assessing telemedicine (Ekeland et al., 2012) concluded that larger and rigorous studies are crucial to evaluate the effectiveness of telemedicine interventions. However, summative methodologies and formative, naturalistic methodologies are also acknowledged as important to produce knowledge in the field of telemedicine. Our RCT (iTrain study) was an international multicentre trial conducted across sites in Norway, Denmark and Australia. The specific methods used in the pilot study and the iTrain study are described in detail in the following sections.

2.1.1 Study 1: the pilot study

Figure 2 Timeline pilot study



Participants

Ten participants were recruited from the rehabilitation clinic LHL-klinikkene Skibotn, about two hours driving North from Tromsø. Inclusion criteria were: confirmed diagnosis of moderate to severe COPD in accordance with the GOLD guidelines (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018), aged 40 to 75 years, Norwegian speaking and resident in Northern Norway, and completion of a 4 week inpatient pulmonary rehabilitation program during the previous six months. Their clinical status was considered stable and their physical condition optimised before enrolment in the pilot study. They were also experienced with treadmill training from the recent rehabilitation stay. Exclusion criteria were: unwillingness or inability to give informed consent, presence of comorbidity or physical condition which might interfere with performing home rehabilitation in a safe manner, or home environment not suitable for installation and use of telerehabilitation equipment (including space and Internet connection). Recruitment process was swift. All eligible patients who were approached agreed to participate.

Outcome measures

Baseline measures were collected from the participants' final assessments of their recent rehabilitation stay. Patients' characteristics, including age, gender, use of long-term oxygen treatment, distance from closest hospital, living arrangements, education level and experience with internet, were also collected at baseline. All participants attended clinical visits at LHL-klinikkene Skibotn for outcome measurements one year and two years after baseline. The clinical visits were organised as two overnight stays due to long travel distance for most participants. Focus groups were conducted at both clinical visits. Participants wore physical activity monitors in the week following the clinical visit at two years (end of intervention). At one year post-intervention, the participants wore physical activity monitors for one week and answered the study questionnaires, which were collected via mail. In addition, data on hospitalisation and outpatients visits were collected form the Norwegian Patient Registry for the two years prior to enrolment, the two years of the intervention period, and the following post-intervention year. An overview of the outcomes measured in the pilot study is provided in table 7.

The long-term exercise maintenance intervention via telerehabilitation

The intervention consisted of exercise training in the home, telemonitoring, and self-management support via video conferencing with an experienced physiotherapist.

Equipment was installed in the participant's home shortly after recruitment and included a treadmill, a pulse oximeter, a tablet computer to access a website for self-management and telemonitoring, an app to perform videoconference sessions with a physiotherapist, and a tablet holder mounted on the treadmill to allow safe use of the tablet while exercising. The equipment is showed in figure 3. A training session on the use of the equipment including a test videoconference session was conducted during a home visit.

During the study, participants were asked to fill in a daily electronic form for self-management of symptoms including oxygen saturation at rest and the breathlessness, cough and sputum scale (Leidy et al., 2003). Each participant received an individual exercise program consisting of interval training on the treadmill, recommended three times per week. The program was accessible from on the website after login. Interval training consisted of a 10-minutes warm-up, followed by three or four exercise bouts lasting between 3 to 4 minutes with a perceived exertion of 5-6 on the Borg CR10 scale (Borg and Borg, 2010), interposed by 2 to 3 minutes active recovery periods with a perceived exertion of 3-4. The training session ended by a 5 minutes cool-down. This gave a total exercise time of ≥30 minutes. Number and length of intervals were adjusted according to the individual participant's condition. Adjustments of speed and/or incline of the treadmill, and exercise duration were adjusted individually during the study. Participants were also encouraged to perform strength training exercises and other physical activity on their own. After each training sessions, participants were asked to fill in an electronic form including: training duration, perceived exertion, oxygen saturation (lowest value during exercise) and heat rate (highest value during exercise). Both the participants and the physiotherapist could access historical data for the daily diary and the training diary from the website. Participants were followed-up via videoconferences on a weekly basis for two-years. The physiotherapist supported and educated the participants in health-enhancing behaviour, focusing on motivation for exercise training, but also self-efficacy strategies were emphasised so that the participants could gain insight into their own health and management of their disease. In the beginning all participants were supervised during one weekly exercise session on the treadmill, but after a while some participants requested to talk to the physiotherapist after they had exercised to that they could have a quiet talk about the exercise and other topics without being "out of breath" during the exercise. Some also requested less frequent videoconference follow-ups as they felt they were more independent in the training and had nothing new to discuss with the physiotherapist.

Statistical analyses

Quantitative data were analysed using IBM SPSS Statistics Version 22. A value of $p \leq 0.05$ were considered statistically significant.

Descriptive analyses were reported as mean ± standard deviation (SD) and range (min-max) for continuous data, and as counts and percentages for categorical data. In addition, results in *Paper III* were also reported as mean difference with 95% confidence interval (CI). Normality were assessed by the Shapiro–Wilk test. Descriptive statistics were used to describe the study population, results for clinical effects, patient-related outcomes and for adherence to the intervention.

The specific statistical analyses related to the pilot study are presented as follows.

Paper I:

To investigate feasibility, long-term exercise maintenance, clinical effects, quality of life, and use of hospital resources during the two-year intervention an analysis of variance (ANOVA) with repeated measures was performed. A Bonferroni post hoc test was used to discover which specific means differed in case the overall ANOVA result was significant.

Paper III:

Changes in physical activity and other outcomes from the second year of telerehabilitation to the post-intervention year were tested with the paired-samples t-test.

Mixed methods and triangulation of data collection techniques

Mixed methods and triangulation of data collection techniques were also used in the pilot study and presented in *Paper II*. This study was focused on adherence and patients' experience, aiming to explore the perspectives of people with COPD participating in long-term telerehabilitation and to identify factors affecting satisfaction and potential improvements of the intervention. Four methods for data collection were utilised. Adherence to the telerehabilitation intervention was measured through the analysis of logs reporting the frequency of registrations in the daily diary and the training diary on the website. Factors affecting satisfaction and adherence, together with potential for service improvements, were explored through focus groups and individual open-ended questionnaires. User-friendliness and technical improvements were examined through standardised questionnaires and open-ended questionnaires. The conduction of focus group and related analysis will be elaborated in the following paragraph.

Focus groups and data analysis

Thoughts and reflections about use of a new intervention may be best captured by individual interviews or focus groups (Kitzinger, 2007). In focus groups, experiences are discussed openly. Different opinions and points of view can be forwarded, negotiated and new insight may be produced from the group interaction. In this way, this might be a good approach to discuss and discover alternatives for improving interventions (Flick, 2009). However, more in-depth information about each participant's experience may be lost.

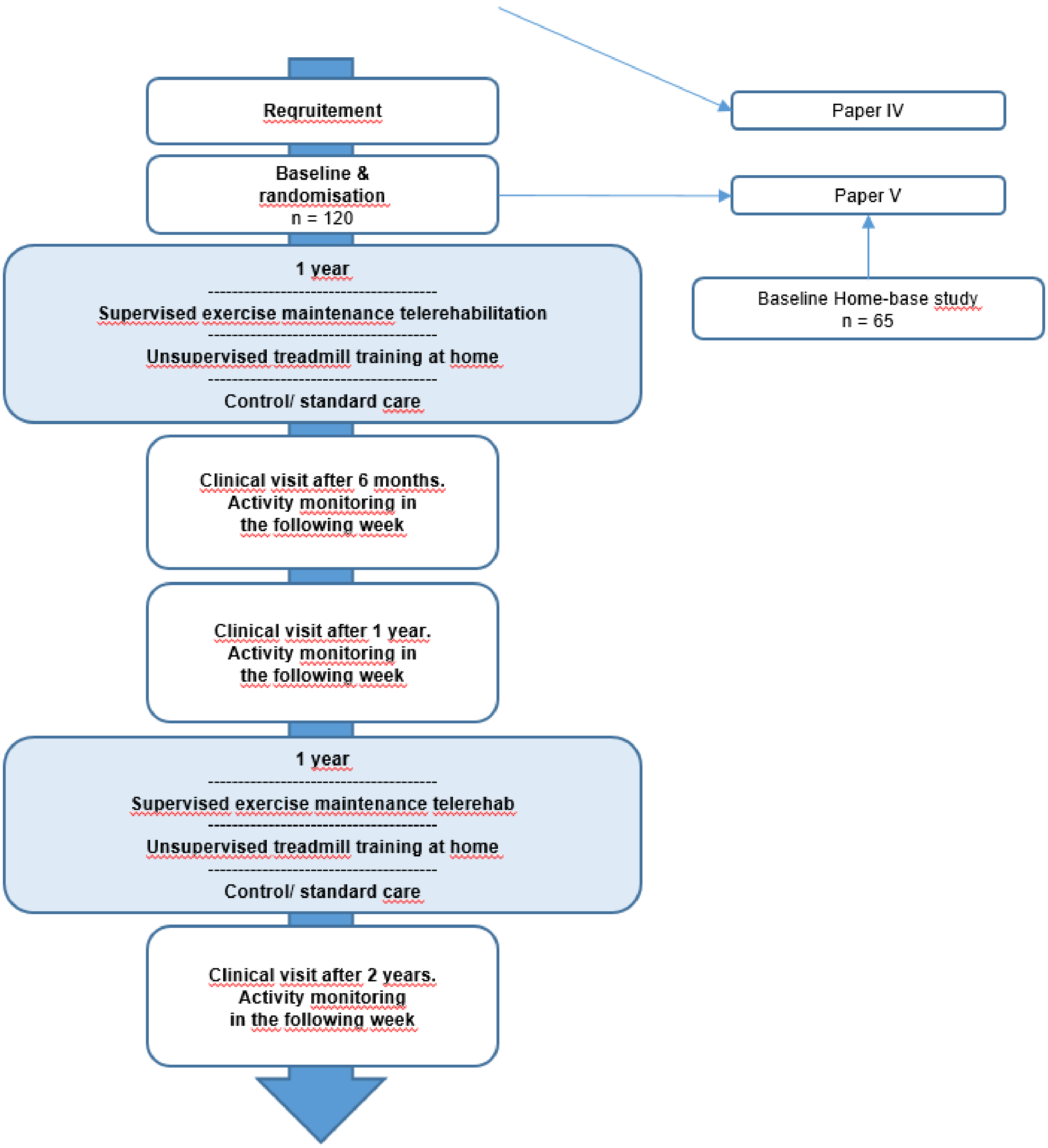
Two semi-structured focus groups were conducted during the two clinical visits after the first year of the intervention and after the second year. A semi-structured interview guide was used at both occasions. The first focus group was focused mainly on user-friendliness and experience with the technical equipment. Issues from the interview guide were: potential benefits from telerehabilitation in health and everyday life, challenges, motivation, experience with the different equipment (treadmill, pulse oximeter, iPad, website, videoconferences), and suggestions for improvements. Issues from the interview guide were: potential benefits from telerehabilitation on health and everyday life, challenges, motivation, experience with the equipment (treadmill, pulse oximeter, iPad, website, videoconferences), and suggestions for improvements. Issues covered in the second focus group included the experiences with participation, experiences with the exercise training, improvements of the equipment, webpage and videoconferences, and organisation of telerehabilitation (who should be offered this service, when, content, healthcare personnel included, groups-based vs individual-based).

Analysis of the qualitative data focused on identifying topics rather than on differences and similarities between individual respondents, thus confirming to a thematic analysis technique (Braun and Clarke, 2006). Further, the material was analysed using systematic text condensation, which is inspired by Giorgi and modified by Malterud

(Malterud, 2001, Malterud, 2011). Details on the steps of analysis in systematic text condensation with examples are available in *Paper II*.

2.1.2 Study 2: the iTrain study

Figure 3 Timeline iTrain study



Participants

The iTrain study aimed at enrolling 120 participants. Norwegian participants were recruited from the Department of Pulmonary Medicine at the University Hospital of North Norway in Tromsø and Harstad, and the Medical Department at the Finnmarkssykehuset in Kirkenes. Danish participants were recruited from the Pulmonary ward at South West Hospital and the Esbjerg Healthcare Centre in Esbjerg. Australian participants were recruited from the Alfred Health in Melbourne. Inclusion criteria were: confirmed diagnosis of moderate, severe or very severe COPD, based on a an FEV_1/FVC ratio ≤70% and an airflow limitation of FEV_1% of predicted ≤80% (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018), at least one COPD-related hospitalisation or COPD-related emergency department (ED) presentation in the prior 12 months, age between 40-80 years, and capable of providing informed written consent. Exclusion criteria were: attendance at a rehabilitation program in the 6 months prior of enrolment, participation in another clinical study that might have an impact on the primary outcome, physical incapable of performing the study procedures, presence of comorbidities that might prevent the participant to perform exercise training in the home, home environment not suitable for installation and use of telerehabilitation equipment. The second inclusion criteria was modified from the pilot study according to the primary outcome of the iTrain study, which was the combined number of hospitalisations and ED presentations. Patients with a recent history of hospital access are more likely to experience re-hospitalisations in the following period. Consequently, a change in the primary outcome can be expected in this population. The first exclusion criteria was modified from the pilot study because clinical benefits from a recent pulmonary rehabilitation program might be maintained in the first months of participation in the RCT, thus affecting the study outcomes. Potential participants were not excluded on the basis of their existing home Internet access, as this could be provided by the study. Recruitment process was challenging in all countries. We assessed 198 Norwegian patients for eligibility and approached them by mail correspondence and/or phone. Out of these, 38 did not meet the inclusion criteria, 28 did not answer, and 89 declined to participate. In the end, 43 patients were included in the study. The first Norwegian participant was enrolled in October 2014, while the last participant was enrolled two years later, in October 2016. Overall, the last participant in the whole study was enrolled in Australia in December 2016.

Randomisation

Participants were randomly assigned to three arms (telerehabilitation, treadmill or control) in a 1:1:1 ratio after baseline measures and followed up for two years. Randomisation was stratified by centre and disease severity (FEV_1 ≥50% vs. FEV_1 ≤50%). The randomisation process was web-based and concealed from the researchers by the program.

Outcome measures

Appropriately trained study personnel blinded to group performed all clinical assessments at baseline, 6 months, 1 year and 2 years.

The primary outcome was the combined number of hospitalisation and ED presentations. Differences in the rate of events between the study arms will be measured at all assessment time points. Data on hospitalisations and ED presentations, together with out-patient visits, were requested to national registries in Norway, regional systems in Denmark, and hospital records in Australia.

An overview of outcome measures used in both the pilot study and the iTrain study is given in table 7. During the planning of the iTrain study, two other questionnaires were considered. We wanted to use the Pulmonary Rehabilitation Adapted Index of Self-Efficacy (PRAISE) (Vincent et al., 2011) to investigate self-efficacy and the Health Education Impact Questionnaire (heiQ) (Osborne et al., 2007) to evaluate patient education. However, validated versions of the PRAISE tool were not available for all languages and access to the heiQ stranded on administrative delay at the university that provided the contracts to use the questionnaire. Use of these tools could have provided valuable insight in disease specific self-efficacy for those with COPD and possible benefits of our telerehabilitation intervention as a patient education program.

Most assessment tools used to evaluate the iTrain study are frequently used in pulmonary rehabilitation research, except from the Patient Global Impression of Change scale (PGIC) (Hurst and Bolton, 2004) and the Generalised Self-Efficacy Scale (GSES) (Schwarzer and Jerusalem, 1995), which we used instead of the PRAISE tool to investigate self-efficacy. The System Usability Scale (Brooke, 1996) and frequency of registrations in web-based diaries have been used in other studies on telerehabilitation for people with COPD (Burkow et al., 2015, Tabak et al., 2014c), but might be unfamiliar to most in the pulmonary rehabilitation field. Patients' characteristics, such as clinical history, age, gender, body weight status, use of long-term oxygen treatment, distance from closest health facility and living arrangements, were also collected.

Table 7 Objectives and assessment tools used in the studies

Objectives	Assessment tool	Pilot study	iTrain study
Feasibility	Completion rate	x	x
Exercise maintenance and adherence to intervention	Frequency of training sessions reported in the web-based diary	x	x
Self-management maintenance and adherence to intervention	Frequency of daily registrations reported in the web-based diary	x	x
Functional walking capacity	6-minutes walk test (6MWT) (Holland et al., 2014)	x	x
Lung capacity	Spirometry	x	x
Body weight status	Body Mass Index	x	
Symptom burden	COPD Assessment Test (CAT) (Jones et al., 2009)	x	x
Health-related quality of life	EuroQoL 5 dimensions (EQ-5D) (EuroQol Group, 1990)	x	x
Level of dyspnoea	Modified British medical research council questionnaire (Fletcher, 1960, Stenton, 2008)		x
Self-efficacy	Generalised self-efficacy scale (GSES) (Schwarzer and Jerusalem, 1995)	Post-intervention	x
Subjective impression of change	Patients Global Impression of Change scale (PGIC) (Hurst and Bolton, 2004)	After two years	After 6 months
Anxiety and depression	Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)	Post-intervention	x
Level of physical activity	Daily number of steps, minutes of moderate to vigorous physical activity and sedentary time during one week measured with the Sensewear Activity monitor	Post-intervention	x

Healthcare utilisations	Number of COPD-related hospitalisations, ED presentations and out-patient visits	x	x
Mortality and adverse events	Mortality rate and number of adverse events such as treadmill injuries		x
Time free from first event	Days to first hospitalisation		x
Cost-effectiveness	Cost-utility analysis (cost per QALY)		x
User-friendliness	System Usability Scale (Brooke, 1996)	End of first year	
Technical improvements	Individual open-ended questionnaire	x	
Motivational factors for maintaining exercise	Individual open-ended questionnaire	Post-intervention	
Experiences with telerehabilitation	Focus groups or qualitative interviews with semi-structured questions	Focus groups (end of first year and end of second year)	Individual interviews with 5-8 patients in the telerehabilitation arm at each site before telerehabilitation, after 1 year and after 2 years.

The long-term exercise maintenance intervention via telerehabilitation

The intervention used in the iTrain study was an improved version of the intervention from the pilot study. This paragraph will shortly describe the improvements and changes that were implemented for the iTrain study.

As in the pilot study, the intervention used in the iTrain study consisted of exercise training at home, telemonitoring, and self-management support via videoconferences with an experienced physiotherapist (Figure 4).

The requirement for participants to have a recent COPD-related hospitalisation implied that more severe and unstable patients were included in the iTrain study than in the pilot study. Moreover, none of the participants had attended a rehabilitation program in the period prior of enrolment. Their physical conditions were therefore not optimised and most of them were not familiar with treadmill exercise. Consequently, we needed to have an even broader exercise prescription in this study. Initial exercise training on the treadmill was individualised and adjusted based on the participants' performance on the 6-minutes walk test (6MWT) at baseline. According to patients' preference and previous experience, an exercise program with continuous or interval training was prescribed. Regardless of the exercise mode, treadmill training lasting for at least 30 minutes, three times per week, was recommended. Additionally, strength exercises were recommended with a frequency of 2-3 sessions a week. Progression in the program was made according to the patients' conditions. Details of the training prescription can be found in Appendixes.

Based on the experience from the pilot study, new functionalities were implemented in the website. As in the earlier version, participants could access their individual exercise program, fill in a daily diary and a training diary, and access their past data. In addition, they could exchange electronic messages with the physiotherapist, have an overview of the upcoming scheduled videoconferencing sessions, their individual goal setting and goal attainment. The items used in the daily diary and in the training diary were mostly the same than in the earlier version. A general wellbeing scale, based on a five-point Likert scale illustrated by emoticons, was added to the daily diary. Moreover, a field with open-ended text where participants could provide additional comments was added to both the daily diary and the training diary. The information reported by the participants was monitored and interpreted by the physiotherapist on a weekly basis. Another new functionality was the addition of a page where the physiotherapist could take electronic notes regarding the participants. This information was not accessible to the participants.

The app used to conduct videoconferences between the tablet computer provided to each participant and the physiotherapist was changed to Acano^{TM}. The frequency of contacts was modified from that used in the pilot study based on previous feedback from the participants and the physiotherapist. In the iTrain study, at least one individual videoconference session per week was scheduled during the first 8 weeks after enrolment, and at least one individual videoconference session per month was scheduled in the following period. Participants who experienced a hospital admission or exacerbation of disease were invited to continue their participation with at least one videoconference contact per week in the month after discharge as a reinforcement strategy. Physiotherapists were provided with common project guidelines for exercise prescription, theoretical background on how to support and educate participants in health-enhancing behaviour and goalsetting, and practical instructions for the conduction of videoconferences (weekly interpretation of participants' registrations on the website, topics to be discussed, writing of electronic notes, etc.). Topics discussed between the participant and the physiotherapist included individual goals, self-management education, exercise completion and progression, pursed lip breathing, and airway clearance techniques. Project guidelines are available in the Appendixes.

Figure 4 Telerehabilitation equipment used in participants' home

Photo by Jarl-Stian Olsen, Norwegian Centre for E-health Research.

Costs of the telerehabilitation equipment

Total cost of the telerehabilitation equipment for each Norwegian patient was approximately NOK 12 000 (€ 1 235). This price includes the costs for the treadmill, transportation of treadmill, the pulse oximeter, the iPad, and the iPad holder. The videoconference software Acano^{TM} and user accounts were provided for free by the Norwegian Health Network (Norsk helsenett, 2018). The Norwegian physiotherapist used approximately 20% of her work time over the study period to supervise the participants in the telerehabilitation arm and support the iTrain study.

Treadmill arm

Participants in the treadmill arm of the iTrain study were provided with a treadmill for unsupervised exercise training at home. They were recommended the same exercise training as the telerehabilitation group and taught how to progress the program themselves. Details of the training prescription can be found in Appendixes. Participants were asked to record each training session on a paper-based diary. This intervention arm allowed us to compare the effects of providing exercise equipment only, to those who were followed-up via telerehabilitation. In particular, according to the findings from the post-intervention year of the pilot study, we wanted to investigate whether the provision of exercise equipment and one-time instruction could be enough to produce clinical benefits for the patients and whether this intervention could be cost-effective.

Control arm

Participants in the control arm were offered standard care. Any participant in the study could undertake a conventional pulmonary rehabilitation program at any time during the 2-year study period if their usual healthcare personnel considered this necessary. All participants were provided brochures containing information about pulmonary rehabilitation, physical activity and exercise, diet, self-management, motivation and lifestyle changes, smoking cessation, and oxygen therapy.

Sample size calculation

The sample size requirements for this study were intended to provide adequate power for the analysis of the primary outcome, which was the combined number of hospitalisations and ED presentations. We calculated that a sample size of 65 person-years per group would allow a power of 95% to detect an incidence rate ratio of 0.60, with a type-I error (α) of 0.05. Assuming that up to 20% of participants could drop out uniformly over the intervention period, we aimed at enrolling 40 patients (corresponding to 80 person-year) per each of the three arms for the 2-year study duration. In total, we aimed at enrolling 120 patients (corresponding to 240 person-years).

Statistical analyses

The statistical analyses related to the iTrain study are reported in *Paper IV.* Descriptive statistics at baseline will be reported as means ± SD for normally distributed continuous variables, or medians with 25–75th percentiles in the case of skewed distribution. Normality of distribution will be tested by means of the nonparametric Kolmogorov-Smirnov test. An intention-to-treat analysis will be performed on all randomised subjects to provide unbiased comparisons among groups and avoid the effects of dropout. The primary outcome and related secondary outcomes will be measured through the Incidence Density, defined as the number of events in a group divided by the total person-time accumulated during the study in that group. Differences between study arms will be tested by the Comparison of Incidence Rates. A two-sided test and a significance level of $\alpha = 0.05$ will be used. All events from the day after randomisation to patient exit/death will be included. Other secondary outcomes will be measured as changes from baseline to all assessment time points. Changes of the secondary outcomes will be tested by use of linear mixed models. A p-value <0.05 will be considered significant for all tests. All statistical analyses will be performed by using IBM SPSS Statistics. Preliminary results for the patients enrolled in the telerehabilitation arm were analysed and summarised with descriptive statistics.

The statistical analyses related to the cross-sectional study are reported in *Paper V.* To investigate whether there were differences in physical activity levels between Norwegian, Danish and Australian people with COPD and to establish if any variation in physical activity levels was attributable to seasons (winter, spring, summer, autumn) an one-way ANOVA was performed. A Tukey post-hoc test was used to discover which specific means differed where the overall ANOVA result was significant. Between country differences were also adjusted for disease severity (FEV_1 %) using one-way ANCOVA. The combined effect of seasons and countries on physical activity was analysed with two-way ANOVA. Log transformation (used for energy expenditure) and cubic root transformation (used for steps, LIPA and MVPA time) were applied to the physical activity variables with a non-parametric distribution in order to obtain normally distributed data so that parametric methods for statistical analyses could be performed. No transformation nor statistical analyses were applied to time in MVPA bouts due to the high number of zero values.

2.1.3 The cross-sectional study

During my PhD, I submitted an application to the ERS for a Short-term research fellowship, which was approved and successfully funded in 2016. This fellowship project was conducted at La Trobe University in Melbourne, supervised by Anne Holland. The fellowship work plan included an introduction to research projects in home-based pulmonary rehabilitation and telemedicine conducted at the university, appropriate training on extracting and analysing data on physical activity from the iTrain study across the three sites (Norway, Denmark, Australia), and preparation of a joint publication. By the time I was in Australia, not all the baseline visits of the iTrain study were conducted. Supervised by Holland, a cross-sectional study was conducted to explore seasonal variations in objectively assessed physical activity among people with COPD in two Nordic countries and Australia. Available data from the iTrain study were merged together with data from COPD patients with similar characteristics enrolled in the Homebase study (Holland et al., 2013b, Holland et al., 2017) performed at Alfred Health in Melbourne, Australia. Results was reported in *Paper V*, which was submitted in November 2018 and is currently under review.

Minimal clinically important differences

Minimal clinically important differences (MCID) are patient derived scores that reflect changes in a clinical outcome variable that is perceived as useful and important for the patient in his everyday life (Cook, 2008). Some findings presented in this thesis were interpreted in light of the MCID in addition of the statistical significance. The rationale for this was that even though studies might not show statistical significant changes in some outcomes, the changes might be of larger clinical significance. For those with COPD, perceived improvements in physical capacity, physical activity, and quality of life might feel useful in everyday life hence be of clinical significance. The MCID for these three outcome measures are provided below.

We have used the 6MWT (Holland et al., 2014) to evaluate physical capacity. In the past, the MCID for the 6MWT was considered 54 meters (Carlin et al., 2010 p. 387, American Thoracic Society, 2002). In the most recent guideline on field walking tests from the ERS/ATS, a MCID of 30 meters in the 6MWT was suggested for adult patients with chronic respiratory disease (Holland et al., 2014). The MCID for the 6MWT was reported and interpreted in *Paper I*.

Daily step count was used as a main outcome measure when evaluating physical activity. An increase between 600 and 1100 steps/day is considered a MCID in daily step count after pulmonary rehabilitation (Demeyer et al., 2016). The MCID for daily step count was reported and interpreted in *Paper III and Paper V*.

The CAT was used to evaluate symptom burden and health-related quality of life. Recently, a new MCID for the CAT ranging between -3.0 and -2.0 points was proposed (Smid et al., 2017) and was used as a criterion for a positive change in this thesis. It is also reported and interpreted in *Paper I and Paper III.*

2.2 Ethical aspects

All patients participating in the studies reported in this thesis were given written and oral information when invited to participate in accordance with the Declaration of Helsinki. They were informed that participation was voluntary and that they could withdraw from the study without giving any reason at any time of the follow-up period. All participants signed a written informed consent to participate. The pilot study was approved by the Regional Committee for Medical and Health Research Ethics (2011/2154 REK nord). The iTrain study received approval from the Regional Committee for Medical and Health Research Ethics in Norway (2014/676 REK nord), the Alfred Hospital Human Research Ethics Committee (289/14), and the North Denmark Region Committee on Health Research Ethics (N-20140038).

The pilot study was funded by the Northern Norway Regional Health Authority (grant number HST1014-11). The iTrain study was funded by the Research Council of Norway (Project Grant 228919/H10) and the Northern Norway Regional Health Authority (Project Grants HST1117-13, HST118-13 and HNF1384-17).

3 Results

This section summarises and repeats the results presented in *Papers I, II, III, IV* and *V*. In addition, some unpublished preliminary descriptive results from the iTrain study are presented. A publication including the results on the primary and secondary outcomes from the first year is expected in the beginning of 2019. Where appropriate, results from the different papers are grouped into common topics. Details can be found in the attached papers.

3.1 Feasibility

On average, the ten patients enrolled the pilot study participated to the intervention for 740 ± 26 days. They experienced voluntarily and non-voluntarily relapses due to holidays, travelling, sickness, or hospital admissions. However, they all rejoined the program after these breaks, and no dropout occurred *(Paper I).*

In total, 120 participants were enrolled in the iTrain study. Forty-three of these were enrolled from Norway. For the whole iTrain study, the dropout rate was 7.5% after one year. Three of the five Norwegian participants who dropped out during the first year were enrolled in the telerehabilitation group of the study. The other two who dropped out, were enrolled the control group. Both reported a dissatisfaction with randomisation to control as the reason for dropping out, reflecting their frustration since the current offer is very limited and they missed the chance of receiving some kind of support. Such dissatisfaction was also expressed at randomisation by many of those enrolled into the control group, reflecting their desire for this type of interventions. No adverse events (deaths, injury or other events) specifically related to the provision of the telerehabilitation intervention or treadmill exercise training at home occurred. However, some participants experienced exacerbations of COPD or other comorbid diseases that contributed to dropouts or deaths *(Unpublished results).*

Due to the low number of dropouts and adverse events specifically related to the intervention, long-term exercise maintenance via telerehabilitation is considered feasible and safe.

3.2 Clinical effects

Ten people with COPD took part in the pilot study. They were on average aged 55.2 ± 6.1 years. The mean FEV1 (% of predicted) was 49.1 ± 20.9).

After one year of telerehabilitation, the 6 minutes walking distance (6MWD) improved with a mean of 40 meters compared to baseline (post-pulmonary rehabilitation). After two years, 6MWD decreased to a value in line with baseline. Mean FEV_1 % of predicted, mean total score for the CAT, mean utility score from the EQ-5D and mean EQ-VAS followed the same pattern, with improvements after one year and values in line with baseline measurements after two years (Table 7). Statistical analyses of these outcomes with a repeated measures ANOVA did not show any statistical significant differences between time points. Nevertheless, long-term exercise maintenance via telerehabilitation succeeded in maintaining clinical effects like functional walking capacity, lung function, level of symptoms, and quality of life over a two-year period *(Paper I).*

Table 8 Results for clinical effects in the pilot study

Outcomes	Baseline	1 year	2 years
6MWD, m	493 ± 106	533 ± 124	473 ± 108
FEV_1 % of predicted	49.1 ± 20.9	54.9 ± 28.8	45.2 ± 20.6
Total CAT score	21.5 ± 6.3	17.7 ± 5.5	20.3 ± 6.7
EQ-5D, utility score	0.624 ± 0.218	0.660 ± 0.210	0.557 ± 0.211
EQ-VAS	48.6 ± 21.9	64.2 ± 20.4	52.3 ± 23.9
BMI, kg/m^2	27.9 ± 7.3	26.7 ± 5.5	26.4 ± 5.3

Data are mean ± standard deviation. 6MWD: 6-minute walking distance, m: metres, FEV_1 % of predicted: forced expiratory volume in 1 second, percentage, CAT: COPD Assessment Test, EQ-5D: EuroQoL 5 dimensions, EQ-VAS: EuroQoL visual analogue scale, BMI: body mass index.

Results from the iTrain study are not published at the time of completion of this thesis. However, some preliminary results on the secondary outcome measures for the telerehabilitation group only are provided in table 8. This allows to provide a comparison with the results from the pilot study. Forty participants of the iTrain study were randomised to the telerehabilitation group. The mean age was 64.9 ± 7.1 years, mean FEV_1 % of predicted was 40.4 ± 16.5, 30% were had severe to very severe COPD, 57.5% were men, 30% used long-term oxygen treatment, mean body mass index was 27.0 ± 5.6, and mean number of comorbidities were 2.6 ± 1.2.

The telerehabilitation group improved their walking capacity with a mean of 53 meters from baseline to 6 months. This improvement was maintained until the 1-year follow-up. Values for FEV_1 % of predicted, total score for the CAT, utility score from the EQ-5D and EQ-VAS at 6 months and 1 year were in line with baseline measurements (Table 8). Statistical analyses of these outcomes are not computed yet. Nevertheless, long-term exercise maintenance via telerehabilitation improved functional walking capacity, and succeeded in maintaining lung function, level of symptoms, and quality of life over a period of one year *(Unpublished results).*

Table 9 Preliminary results for clinical effects in the telerehabilitation group of the iTrain study

Outcomes	Baseline	6 months	1 year
6MWD, m	367 ± 125	420 ± 126	415 ± 146
FEV_1 % of predicted	40.4 ± 16.5	44.5 ± 18.4	40.1 ± 19.4
Total CAT score	19.6 ± 6.2	18.2 ± 6.9	18.6 ± 7.0
EQ-5D, utility score	0.739 ± 0.110	0.733 ± 0.149	0.688 ± 0.197
EQ-VAS	51.9 ± 21.0	58.4 ± 16.6	56.8 ± 18.8

Data are mean ± standard deviation. 6MWD: 6-minute walking distance, m: metres, FEV_1 % of predicted: forced expiratory volume in 1 second, percentage, CAT: chronic obstructive pulmonary disease assessment test, EQ-5D: EuroQoL 5 dimensions, EQ-VAS: EuroQoL visual analogue scale, BMI: body mass index.

3.3 Adherence to the telerehabilitation intervention

On average, the participants in the pilot study reported 3.0 diary registrations/week and 1.7 training sessions/week via the website during the whole period of the two-year intervention. This corresponds to an average adherence rate of 43.3% and 56.2%, respectively. On average, participants had 3.4 diary registrations/week during the first year, while adherence decreased to 2.6 diary registrations/week during the second year. Adherence to training sessions was maintained at an average of 2.1 training sessions/week during the first year, before it decreased to 1.2 sessions/week during the second year *(Paper II).*

The participants reported fewer training sessions and diary registrations during December (Christmas) and July/August (summer holidays). During holiday periods, they did not receive video conference follow-up by the tele-physiotherapist and were also encouraged to take some time-off *(Paper II).*

Individual adherence rates to self-management via daily diary for the ten participants in the pilot study ranged from 8.2% to 98.3%, while individual adherence rates to exercise ranged from 16.3% to 99.1% *(Paper II).*

3.4 Participants perspectives

Four major themes regarding factors affecting satisfaction and adherence, and potential for service improvement emerged from the analysis of the data collected from two focus group interviews with the participants in the pilot study: i) experienced health benefits; ii) increased self-efficacy and independence; iii) emotional safety due to regular meetings and access to specialist competence; and iv) maintenance of motivation *(Paper II).*

Themes emerged are elaborated in the paragraphs below. More elaboration and quotes that illustrates the themes can be found in *Paper II*.

3.4.1 Experienced health benefits

All participants in the pilot study mentioned a positive change in perceived level of health throughout the two-year intervention period. Experienced health benefits were interpreted as one of the main factors affecting satisfaction. Despite having a chronic disease, the participants felt in good health most of the time. They described a broad perspective of health and health benefits consequent to their participation in the study, including physical, psychological, and social achievements *(Paper II).*

3.4.2 Increased self-efficacy and independence

The participants proudly described an increased competence in a variety of different fields. These mastery experiences seemed to have created a higher degree of self-efficacy and confidence in self-management of their exercise regime, everyday life, and disease.

More independence was also described in the relationship with the therapist. Participants reflected on how the technology made it easier for them to withdraw themselves without confrontation from the collaboration with the tele-physiotherapist if the follow-up did not “fit” their goals, mood or values, or if the relationship felt too challenging *(Paper II).*

3.4.3 Emotional safety due to regular meetings and access to specialist competence

Participants expressed that they felt safe and well taken care of in the pilot study. They valued especially their relationship with the tele-physiotherapist and the regularity of the videoconferences *(Paper II).*

3.4.4 Maintenance of motivation during the intervention

Motivation for exercise training declined for most participants in the pilot study over the two-year period. Consequently, maintenance of motivation was interpreted as a challenge. How physical performance developed during the intervention period represented one of the main factors affecting motivation.

When searching for motivational strategies in the focus group interviews, we found that participants used both a promotion and a prevention focus. There was no connection between high adherence and a specific motivational strategy *(Paper II).*

3.4.5 Motivational factors for maintaining exercise post intervention

After the two-year intervention, participants were recommended to continue exercising on the treadmill without supervision. Two themes affecting motivation for maintaining exercise were identified in the open-ended questionnaires collected at one year post-intervention: i) experiences of health improvements and ii) regularity, feedback and affiliation. Most participants described previous or current experiences of health improvements related to exercising as reasons why they continued to exercise *(Paper III).*

3.4.6 User-friendliness and technical improvements

Participants in the pilot study had an average score of the System Usability Scale of 83.5 (min 32.5, max 100). This indicates that they were highly satisfied with the telerehabilitation intervention and considered it user-friendly. Participants' main complaint was the stability of the videoconference connection. They also had different suggestions for technical improvements of the intervention *(Paper II).* These suggestions were improved and implemented to some extent in the iTrain study.

Further, four key factors of potential improvements in long-term telerehabilitation were identified: i) adherence to different components of the telerehabilitation intervention is dependent on the level of focus provided by the health personnel involved; ii) the potential for regularity that lies within the technology should be exploited to avoid relapses after vacation; iii) motivation might be increased by tailoring individual consultations to support experiences of good health and meet individual goals and motivational strategies; iv) interactive functionalities or gaming tools might provide peer-support, peer-modelling and enhance motivation *(Paper II).*

3.4.7 Patients global impression of change

The average score from the PGIC questionnaire (Hurst and Bolton, 2004) reported in the pilot study after two years was 5.5±1.2. Nine out of 10 participants expressed a change-score ≥ 5, which is considered a significant and favourable change in their conditions, including activity, limitations, symptoms, emotions, and overall quality of life *(Paper I).*

In the iTrain study, the PGIC questionnaire was collected only after six months. Fifty-three % of the telerehabilitation group reported a change-score ≥5, while 24% and 13% in the treadmill and the control group reported a such a significant positive change score *(Unpublished results).*

3.5 Healthcare utilisation and cost-effectiveness

Overall, healthcare utilisation during the two years of the pilot study was reduced by 32% compared to the two years prior to enrolment. However, only two participants had a history of hospitalisation at baseline. Most participants were therefore not classified at high risk of hospitalisations or readmissions *(Paper I).*

There was no statistical significant difference in healthcare utilisation between the second year of the intervention in the pilot study and the following post-intervention year. However, the average number of COPD-related hospitalisations per patient doubled during the post-intervention year compared with the previous year when the participants were still in the intervention. The average number of COPD-related outpatient visits almost tripled during the year following the intervention. Hence, the estimated COPD-related hospital costs also increased *(Paper III).*

Per December 2018, data on hospital accesses were requested to the national registries in Norway, Denmark and Australia *(Paper IV)* but not yet delivered. A publication reporting the results on the primary outcomes is expected in early 2019.

3.6 Maintenance of physical activity after the intervention

Physical activity data were available for 7 out of 9 participants at one year from completion of the two-year pilot study. On average, total energy expenditure decreased from 9451 kJ per day at the end of the intervention to 8270 kJ per day one year post intervention ($p=0.011$). The number of steps decreased from an average of 3806 steps/day to 2817 steps/day ($p=0.039$). There was a 21% decline in time spent in light physical activity ($p=0.009$). On average, total time spent in moderate to vigorous physical activity dropped by 51% between time points, from 88 ± 66 minutes per day to 43 ± 34 minutes per day, although this was not statistically significant. Time spent in bouts of moderate to vigorous physical activity decreased by 53% ($p=0.110$). At the end of the intervention, 6 of the 7 participants had ≥150 weekly minutes of bouts of moderate to vigorous physical activity, whereas only two participants maintained that level one year after the intervention. Adherence to registration of symptoms and training sessions decreased significantly without supervision *(Paper III).*

3.7 Seasonal variations and physical activity levels among people with COPD in two Nordic countries and Australia

In total, 168 subjects with moderate to severe COPD from Norway, Denmark and Australia were included in the cross-sectional study. Demographics for the three groups were generally similar, although the percentage of participants in GOLD stage 3 and 4 (severe and very severe airflow limitation) was higher among Danish participants. Australian participants had the highest number of comorbidities and Danish participants had a lower functional walking capacity.

After controlling for disease severity, awake sedentary time was greater in Danish participants compared to the other countries (median 784 min/day [660-952] vs 775 min/day [626-877] for Norwegians vs 703 min/day [613-802] for Australians, p=0.013). Time spent in moderate to vigorous physical activity was lower for the Danish participants (median 21 min/day [4-73] vs 30 min/day [7-93] for Norwegians vs 48 min/day [19-98] for Australians, p=0.024). Participants tended to walk more during summer (median 3502 [1253-5407] steps/day) than in spring (median 2698 [1613-5207] steps/day), winter (median 2373 [1145-4206] steps/day) and autumn (median 1603 [738-4040] steps/day), regardless of geography. The median difference between summer and other seasons exceeded the minimal clinically important difference of 600 steps/day. However, the differences were not statistically significant (p=0.101) *(Paper V).*

4 Discussion

We designed an innovative two-year telerehabilitation intervention bringing pulmonary rehabilitation into the patients' homes, thus allowing remote supervision at distance. To our knowledge, this is the first telerehabilitation interventions with such a long-term follow-up.

Despite the evidence and knowledge still is limited, this thesis has showed that long-term exercise maintenance via telerehabilitation for people with COPD is safe and feasible.

Deterioration in the disease is expected over time (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2018, Hjalmarsen et al., 2014). Results from our studies are encouraging and suggest that telerehabilitation can prevent deterioration in lung function, symptom burden and health-related quality of life in addition to improve and maintain functional walking capacity over the long-term. Other RCTs on short-term telerehabilitation programs (Bernocchi et al., 2018, Bourne et al., 2017, Chaplin et al., 2017, Tsai et al., 2017, Paneroni et al., 2015) have reported effectiveness in a variety of outcome measures including functional walking capacity, dyspnoea, symptom burden, health-related quality of life, self-efficacy, physical activity profile, and time to first hospitalisation and mortality. In addition, one RCT investigating a 12-months home-based maintenance telerehabilitation program following an initial 2-month conventional pulmonary rehabilitation program (Vasilopoulou et al., 2017) reported improved functional walking capacity, higher health-related quality of life, and lower risk of acute COPD exacerbations and hospitalisations. The evidence of cost-effectiveness of telerehabilitation interventions is still limited. In addition, real-life experience of full-size routine programs is also very limited.

The advantage of long-term telerehabilitation over the existing offer of exercise maintenance programs after conventional pulmonary rehabilitation in Norway is threefold. Telerehabilitation has the ability to overcome geographical distance, provide specialist access in areas where this is not available, and provide regularity of follow-up by the same healthcare personnel over a long period. Our research has also revealed some factors that are important for successful use and acceptance of telerehabilitation interventions. Satisfaction was supported by experienced health benefits, increased self-efficacy and emotional safety. We identified four key factors of potential improvements in long-term maintenance telerehabilitation: i) adherence to different components of the telerehabilitation intervention is dependent on the level of focus provided by the health personnel involved; ii) the potential for regularity that lies within the technology should be exploited to avoid relapses after vacation; iii) motivation might be increased by tailoring individual consultation to support experiences of good health and meet individual goals and motivational strategies; iv) interactive functionalities or gaming tools might provide peer-support, peer-modelling and enhance motivation.

Challenges included motivation for exercise over the long-term especially without supervision from healthcare personnel. Our experience from running the pilot study and the iTrain study also revealed challenges with transport of equipment and teaching in how to use the technology in the participants' homes, mostly due to long travel distances and limited time available for us since we were not located in the same area than all participants. Local health personnel seems vital in implementing full-scale programs outside urban settings, especially if these include the use of training equipment such as treadmills or bicycles in the participants' homes.

4.1 Feasibility of the intervention

Findings reported in this thesis and its related papers showed that long-term exercise maintenance via telerehabilitation comprising supervised treadmill exercises in the participants' homes via individual real-time videoconferencing was feasible and safe for people with COPD. The equipment, technology and supervision model used was acceptable for participants with moderate to severe COPD.

Participants in the pilot study expressed that the program provided emotional safety due to regular meetings and access to specialist competence. A study comprising a model for supervision and monitoring during exercise training similar to ours suggested that the monitoring provided via pulse oximetry and an experienced physiotherapist was sufficient to allow safe and effective exercise training for people with COPD at home (Holland et al., 2013a). Moreover, no important adverse events related to the program or exercise training itself occurred during our studies. However, two of the Norwegian participants that dropped out from the telerehabilitation group experienced cognitive or psychological comorbid diseases causing them to withdraw from video conference follow-up during the first year of the intervention. The third participant from Norway that dropped out during the first year died after a COPD exacerbation. All participants recruited in the iTrain study had a history of at least one COPD-related hospitalisation prior to enrolment, hence being at high risk of future exacerbations of the disease (Sadatsafavi et al., 2018). Re-hospitalisation and death rates one year after a COPD-related hospitalisation are reported as high as 25% and 21%, respectively. After five years, re-hospitalisation and death rates are 44% and 55%, respectively (McGhan et al., 2007). More recently, a study on 35 994 individuals with COPD reported that the first severe exacerbation during an average follow-up of 3.21 years was associated with a 75% increase in the risk of future severe exacerbations, which was reduced to 11% for the fourth severe exacerbation (Sadatsafavi et al., 2018). Furthermore, researchers have suggested that there is substantial heterogeneity in the rate of severe COPD exacerbations among individual patients so that the rate of exacerbations may vary from year to year (Han et al., 2017, Sadatsafavi et al., 2018). When conducting research on such frail individuals with a progressive chronic disease as those included in the iTrain study, one could expect some deterioration of symptoms and disease severity despite the long-term intervention provided. With this, our findings regarding adverse events are not surprising.

4.1.1 Patients are ready to use telerehabilitation interventions

During the randomisation process in the iTrain study, we identified a desire for telerehabilitation interventions among the volunteer participants as many expressed dissatisfaction with being randomised to the control group, and some even dropped out from the study due to their disappointment. A recent survey (Seidman et al., 2017) among people attending conventional pulmonary rehabilitation supports our observation, as the majority of patients expressed a substantial technology engagement, access to devices and willingness to use telerehabilitation, especially those younger than 70 years and regular users of technology. However, despite many had access to technology and rated their computer and Internet skills as adequate, few did actually use technology to search health information online (Seidman et al., 2017). Interestingly, in our studies, previous computer skills did not seem to be a barrier for use of the telerehabilitation program when face-to face education and a written education manual was provided, as participants with low computer literacy also managed to use the intervention intuitively.

To sum up, our findings related to feasibility of long-term exercise maintenance via telerehabilitation in COPD are in tandem with other short-term intervention studies on telerehabilitation for those with COPD (Burkow et al., 2015, Burkow et al., 2013, Holland et al., 2013a, Marquis et al., 2015, Minet et al., 2015, Tsai et al., 2016) and one other long-term maintenance telerehabilitation program (Vasilopoulou et al., 2017).

4.2 Effects of the intervention

4.2.1 Clinical effects

In the absence of any maintenance strategy, benefits of pulmonary rehabilitation seems to diminish after 6 to 12 months (Spruit et al., 2013b). The reason for this decline includes decrease in adherence to therapy, especially long-term regular exercise, progression of underlying disease and comorbidities, and exacerbations (Carr et al., 2007). Our telerehabilitation intervention aimed to support patients with COPD in maintaining exercise routines over a two-year period. The findings described in this thesis and related papers revealed that functional walking capacity, lung capacity, health status, symptom burden and quality of life were all maintained over the long term.

Both participants in the pilot study and participants in the telerehabilitation group of the iTrain study improved their walking distance with more than 30 meters after the first year of telerehabilitation, which is considered to be a clinically important difference (Holland et al., 2014). A study investigating longitudinal change in 6MWT on a Norwegian cohort of patients with COPD found that walking distance was maintained after 1 year, but decreased significantly after 3 years. The decrease over time was only evident for patients with severe and very severe COPD. Furthermore, participation in pulmonary rehabilitation, self-reported vigorous physical activity and an increase in FEV_1 were significant predictors of a positive change in walking distance (Frisk et al., 2014).

A surprising difference in the results between our two studies was that participants in the pilot study, despite considered optimised in health status after the recent pulmonary rehabilitation program, seemed to improve more in lung capacity, symptom burden and health-related quality of life after one year than their counterparts in the iTrain study. One explanation might be that the attendance to a conventional inpatient pulmonary rehabilitation program before enrolment made it easier for the tele-physiotherapist to support participants in self-management strategies and health enhancing behaviour. Participants in the iTrain study were older, had a more severe disease, and were not educated in self-management and health enhancing behaviour. Even though the tele-physiotherapists provided a dialogue on self-management routines and individual goal attainment, the focus was oriented towards exercise routines and the participants did not receive the full interdisciplinary education which is common and highly recommended in conventional centre-based programs (Blackstock et al., 2018). The effects of our telerehabilitation intervention might have been larger if it had been provided by an interdisciplinary team as piloted in other studies (Burkow et al., 2015, Burkow et al., 2013, Vasilopoulou et al., 2017). However, physiotherapists are an important member of the pulmonary rehabilitation team and are present in most programs (Desveaux et al., 2015). One easy way to provide a more formal education in telerehabilitation interventions is to use pre-filmed educational videos. One study showed that education via pre-filmed videos were acceptable to patients participating in a pulmonary rehabilitation program and were as effective in improving patients' knowledge of COPD as spoken talk (Ward et al., 2018).

To date, only eight RCTs evaluating telerehabilitation against conventional pulmonary rehabilitation or standard care have been published. The evidence base of the clinical effects of telerehabilitation in COPD still is limited. However, the published studies yield positive benefits in regards of functional walking capacity, dyspnoea, symptom burden, health-related quality of life, self-efficacy, physical activity profile, lower risk of acute COPD exacerbations and hospitalisations, and time to first hospitalisation and death (Bernocchi et al., 2018, Bourne et al., 2017, Chaplin et al., 2017, Tsai et al., 2017, Paneroni et al., 2015, Vasilopoulou et al., 2017). The optimal telerehabilitation intervention for people with COPD has not been identified yet, and may vary across settings (Vitacca and Holland, 2018).

4.2.2 Healthcare utilisation and cost-effectiveness

Exacerbations and re-hospitalisations are expected to increase along the disease trajectory. Results from the pilot study were encouraging and suggested that telerehabilitation could maintain benefits over time, prevent deterioration and limit the use of hospital resources. Results from the iTrain study on the primary outcomes (hospitalisations and ED admissions) and on cost-effectiveness (cost-utility analysis) will represent new knowledge. However, these data have not been analysed yet. More RCTs providing evidence of cost-effectiveness are needed.

4.2.3 Adherence

Program effectiveness depends on adherence (Sabaté, 2003). Adherence was used in this thesis to describe the degree to which a participant correctly followed the recommended use of the website for self-management and conduction of their prescribed exercise regime. According to the World Health Organization, only about 50% of patients with chronic diseases follows their treatment recommendations (Sabaté, 2003).

In the pilot study, the average adherence rate for diary registrations and training sessions was 43.3% and 56.2%, respectively. Compared to a nine-month intervention consisting of a web-based home exercise program, an activity coach for ambulant activity registrations and feedback, self-management via a web-based triage diary, and teleconsultations (Tabak et al., 2014c), adherence in the current study was higher for the training sessions, but lower for the web-based diary. Reasons might be that our intervention had a stronger focus on exercise rather than on monitoring symptoms and early recognition of exacerbations. A more active education on the recognition of early symptoms of exacerbation and the importance of treatment together with a provision of a straightforward treatment regimen might support participants' adherence to fill in the diary. On the other hand, the patients in our pilot study were in a quite stable condition of their disease, and registering symptoms every other day (50% adherence) throughout a period of two years might be enough to detect early changes in symptoms and start treating exacerbations as soon as possible. An average adherence rate of 56.2% for the training sessions equals to 1.7 training sessions per week. Compared to recommendations of 3 training sessions per week, this rate is probably too low to maintain the experienced health benefits and increased physical performance. Even though the average adherence rate was kept lower than recommended, we consider the intervention successful as all participants maintained their exercise and self-management routines for the 2-year period. No other studies have succeeded in such a result. However, we believe that while a lower adherence for the diary registrations does not have any negative impact, it is important to focus on patient's compliance to exercise, which is the key feature of conventional centre-based pulmonary rehabilitation programs as well as of the current telerehabilitation intervention.

Adherence rate for training sessions increased during the first three months of the pilot study to a level close to the recommendation. This could be due to a learning effect or an increase in motivation. Adherence was also affected by seasonality. The participants were encouraged to take time-off and did not receive follow-up via videoconferencing from the tele-physiotherapist during holidays. This influenced the lower adherence in these periods. As the participants appreciated the regularity of the telerehabilitation intervention and found it difficult to start exercising again after holidays, we would recommend to exploit the potential for regularity that lies within the technology. Future long-term telerehabilitation interventions could benefit from prescheduled peer-group meetings or exercise sessions via videoconferencing, mobile text message reminders aimed to motivate individual training, online follow-along exercise videos or other gaming elements for exercise training during holidays to avoid relapses.

The wide range of individual adherence rates in the pilot study (from 99.1% to 16.3% for the training sessions) shows that, as for conventional pulmonary rehabilitation programs, one size does not fit all.

4.3 Benefits and potential improvements

Findings from our mixed methods study suggest that the potential of long-term telerehabilitation over the existing offer of exercise maintenance programs after conventional pulmonary rehabilitation in Norway is threefold. Telerehabilitation has the ability to overcome geographical distance. A travel time to a rehabilitation facility greater than 30 minutes is a known barrier to attending pulmonary rehabilitation and exercise programs for patients with COPD (Rochester et al., 2015). Another advantage of long-term telerehabilitation lies in the specialist access and the potential regularity of follow-up by the same health personnel over a long period.

Participants perceived the exercise and monitoring equipment and the technology used in our interventions as user-friendly. Their main complaint was the stability of the videoconference connection. Access to an adequate data network might be a major challenge especially for remote places where such services might not be fully developed. Others have also emphasised that the effective delivery of telerehabilitation requires an adequate data network (Holland et al., 2013a). However, the quality and speed of many broadband suppliers have improved during the last few years, even in Northern Norway. Yet, more than an adequate data network is required for an effective telerehabilitation intervention. As few telerehabilitation interventions have evolved beyond the pilot phase, understanding the determinants of success is key to design better interventions. We received feedback on functionality in the focus groups during the pilot study, and made changes to the webpage used for the iTrain study so that it was better suitable to the needs of the participants and physiotherapists involved. Through this work and related research, we identified four key factors related to potential improvements for future telerehabilitation interventions: i) adherence to different components of the telerehabilitation intervention is dependent on the level of focus provided by the health personnel involved; ii) the potential for regularity that lies within the technology should be exploited to avoid relapses after vacation; iii) motivation might be increased by tailoring individual consultations to support experiences of good health and meet individual goals and motivational strategies; iv) interactive functionalities or gaming tools might provide peer-support, peer-modelling and enhance motivation. Only one group of healthcare personnel, namely physiotherapists, provided our telerehabilitation intervention. This represents a limitation to our intervention. To adhere stronger to the definition of pulmonary rehabilitation, we recommend that future telerehabilitation programs should be patient-tailored and provided by an interdisciplinary team of engaged healthcare personnel. Tailoring could be provided by visualisation of individual goals and goal attainment or maintenance of exercise-, self-management or physical activity routines (Froisland et al., 2012), by including motivational messages (Higgins, 1998, Antypas and Wangberg, 2014a), by providing social support via group exercises (Burkow et al., 2015), by online gaming tools (Tabak et al., 2015), chat rooms or discussion forums (Antypas and Wangberg, 2014b). Persuasive technology designs may also enhance adherence and provide tailored elements (Blackstock et al., 2016, Oinas-Kukkonen and Harjumaa, 2009). Persuasive technology is computer software or information systems designed to reinforce, change or shape attitudes and/or behaviours without using coercion or deception (Oinas-Kukkonen and Harjumaa, 2009). Such technology designs can reduce complex behaviour into simple tasks that help users to perform the target behaviour and visualise the benefit/cost ratio of a behaviour. People have a tendency to become more motivated to change behaviour if the effort to make the change complies with what we gain. For example, a website for smoking cessation can provide calculations on how much money a user could save by quitting. Furthermore, persuasive technology can guide users through a learning process by offering self-reflection questions or suggestions for actions based on results from a quiz. Visualisation of the users' performance or status can support them in achieving goals. Systems that offer reminders, praise, and rewards might also have the capability to persuade their users (Oinas-Kukkonen and Harjumaa, 2009).

Individual interviews conducted with Norwegian participants in the iTrain study supported that the changes we made to the intervention were beneficial as all interviewees described the website and the technology used as user-friendly *(Unpublished results).* Technological improvements are further elaborated in *Paper III*.

We gained a lot of insight through the conduction of two focus groups where the feasibility of the intervention was discussed with the participants. To support future implementation of telerehabilitation interventions and ensure that such interventions are a viable option for all partners involved, we recommend involving all users (both patients and healthcare personnel) at an early stage of development.

4.3.1 Participants perspectives on factors affecting satisfaction and adherence

In the pilot study, participants highlighted health benefits, experienced in terms of increased physical performance and self-management, as the main factor affecting satisfaction. Despite having a chronic disease, the participants gave an optimistic and varied picture of their definitions of good health. It seems important to foster these positive perspectives of health in long-term telerehabilitation interventions. Good health is often seen as medicine's main goal (Nordenfelt, 2007). If individual experiences of good health represent a primary objective in long-term telerehabilitation services for patients with COPD, health professionals cannot rely on following up all patients in the same manner. It becomes important to find out what corresponds to the patients' "own peak" and what good health is for the individual patient. This corresponds well to recent holistic views of health and theories of health promotion (Tones and Tilford, 2001, Huber et al., 2011, Antonovsky, 1996, Nordenfelt, 2007, Walseth and Malterud, 2004). It has been argued that telerehabilitation might contribute to more individualised treatment processes and flexibility in the patients everyday life (Thorup, 2017). To fulfil this prophesy, it is important to consider how the technology can be tailored to the individual patient. A pilot study (Yan and Or, 2017) on acceptance of a computer-based self-monitoring system for diabetes mellitus and/or hypertension found that participants were more likely to form positive feelings and intentions towards the use of the e-health technology if they perceived the technology as useful for their disease self-management. Yan and Or, headlights the importance of performing careful studies on the participants' needs, preferences and expectations to provide information about what functions to incorporate in the technology (Yan and Or, 2017).

Participants in our pilot study expressed an increase in self-worth and acceptance of their condition. They became more aware of their own needs and how they could fend for themselves. Despite feeling vulnerable, patients with COPD often come to an acceptance of their situation, which lead them to be able to adapt to their physical limitations and make the most out of their situation (Hellem et al., 2012). Their condition is perceived as a "way of life" rather than an illness, where symptoms and health problems become the normality. This "passive acceptance" might hinder patients to address healthcare needs (Pinnock et al., 2011). In contrast, the participants in the pilot study developed a newfound control over their own health situation and a renewed interest in their own health. When taking actions in terms of exercising, they felt they could cope with the vulnerability and stigma from having a chronic and often self-inflicted disease. Increased awareness and interest in once own health after using telemedicine interventions have been reported in a systematic review (Morton et al., 2017).

Conventional pulmonary rehabilitation is patient-tailored, and core generic strategies such as goal setting, goal assessment, problem solving and decision-making are important elements in self-management for patients with COPD (Spruit et al., 2013b). Patients' goals and resources are often assessed against their specific context and opportunities in the environment (Solli, 2011). The pilot study did not have a formal functionality for goal setting and goal attainment included in the website. Maintenance of motivation was perceived by participants as a main challenge. They were motivated to exercise as long as they experienced progress in physical capacity and the exercise program could be progressed. However, motivation decreased once their threshold for progress in physical capacity was reached. This happened for most of the participants after the first year of follow-up. Adherence might benefit if patients with COPD are involved in their own rehabilitation process. An agreement of goals and methods between the patient and the helper is seen as an important key to the change process (Bordin, 1979). Further, patients with COPD might need support to define visible results and appraise their newly acquired competences to be able to implement them in everyday life (Guo and Bruce, 2014, Mousing and Lomborg, 2012). To have a stronger focus on long-term maintenance of motivation, a template for goal setting and goal attainment was added to the website used in the iTrain study.

A previous qualitative study revealed that patients with COPD expressed and alternated between four attitudes towards telerehabilitation: indifference, learning as part of situations in everyday life, feeling of security, and motivation to perform physical exercise (Dinesen et al., 2013). These experiences with telerehabilitation are to some extent congruent with our findings. In the aforementioned study, indifference was related to measuring stable values (of blood pressure, pulse, weight, spirometry and oxygen saturation). This implied that stable patients with COPD would not benefit as much from telerehabilitation as patients with more unstable conditions. Pulmonary rehabilitation is recommended for all patients with COPD, even patients in earlier stages (Spruit et al., 2013b). Patients in earlier stages are often medically stable, but they would still benefit from rehabilitation in terms of enhanced mastery of everyday life and increased physical performance. Visualisation and documentation of tangible signs of improvements and maintenance might reduce the feeling of indifference and make long-term telerehabilitation suitable and beneficial for patients in stable conditions as well. Future telerehabilitation services, particularly in chronic diseases, should therefore also be patient-tailored, focusing on documentation and evaluation of goals, progress and maintenance. Likewise, it is important to assess individual interpretations of good health and preferences in motivational strategies so that every participant can be followed up according to his or her own needs and values.

4.4 Challenges of telerehabilitation

A recent review of the literature evaluating telemonitoring for people with COPD performed by Vitacca et al. (2018) revealed several barriers and challenges to telemedicine development which may be relevant for telerehabilitation implementation as well. These include a variety of difficulties related to work organisation, cultural barriers and technical concerns (Table

8)(Vitacca et al., 2018). Challenges considered relevant for telerehabilitation are elaborated below. Some challenges are also described as suggestions for future research.

Table 10 Barriers and challenges to telemedicine development

Work organisation	**Cultural barriers**	**Technical concerns**
Short-term funding	Low level of interest	Face-to-face visits are preferred
Sustainability	Technology not being user-friendly and support the needs of the users	Follow-up plan customized to each patient
Integration of new technologies into routine service	Low acceptance	Complexity of the system
Time limitations	Individuals illness and health literacy	Many different software, hardware and telecommunication options
Requirements for technical competence	Too much responsibility for patients with chronic disease	Poor specification design for each condition
Lack of standardisation of best practice	Poor knowledge and culture for use of technology	Legal/confidentiality problems between subjects involved (poor standard of care, manipulation of data, poor protection of data)
Lack of interoperability among different solutions	Lack of knowledge of e-health among patients, citizens and healthcare personnel	The network may show difficulty to ascertain responsibilities and potential obligations of healthcare personnel
Limited evidence of cost-effectiveness	Scepticism from doctors	High start-up costs
		Absence of reimbursements

Table from Vitacca et al. (2018).

4.4.1 Practical challenges in the iTrain study

Recruitment and home visits were rather time consuming. Recruitment in Harstad required a 3-hours boat ride one way, and travelling to Kirkenes took 30 minutes on a plane. These trips often included an overnight stay. Paolo Zanaboni and I who delivered and provided the initial teaching on the equipment to participants in the iTrain study in Norway travelled more than 8 000 kilometres, using plane, ferry, speedboat, shuttle boat, bus and car. This corresponds to a travel distance from Tromsø to Rome, and back, by car. In some cases, the treadmills were delivered by a transport bureau, but sometimes we brought them with us in a van when conducting the home visit. If we needed to carry the treadmill up or down one or two floors, we were both present, otherwise only one person was sufficient to deliver the equipment. We calculated every visit to be at least one hour, but we often stayed longer. Some participants needed to be visited more than one time.

There were also some problems with the technical equipment. The Norwegian IT-support consultant and our technical support consultant in the iTrain study had 34 requests from physiotherapists and participants regarding technical problems or updates on the software related to the videoconference system or iPad *(Unpublished results).*

4.4.2 Legal issues: data security and confidentiality

Telerehabilitation systems might be rather complex, involving data transmittance, real-time video interactions between patients and healthcare personnel, and storage of data in archives or clouds. Some systems also utilise hardware and software provided by international companies (Donner et al., 2018). Legal principles applying to centre-based rehabilitation services are equally valid for telerehabilitation (Vitacca and Holland, 2018). Healthcare personnel providing rehabilitation services are either ways bound by the duty of confidentiality and are not allowed to disclosure medical information without the patients' consent (The Norwegian Directorate of Health, 2015, Præstegaard, 2017). However, telerehabilitation holds unique legal challenges related to use of technology compared to centre-based rehabilitation. These includes possible failure to provide an acceptable standard of care, failure to equipment and software, electronic data can be manipulated, risks related to data protection (poor confidentiality, authenticity, data report, procedure certification, security and privacy), misunderstanding among patient, family and healthcare personnel, and not clarified responsibilities among healthcare personnel (Donner et al., 2018, Vitacca and Holland, 2018). Electronic telerehabilitation equipment connected to the Internet used in private homes is more exposed to unauthorised access. One way to limit potential risk of unauthorised use is to implement log-on identification and automatic log-out mechanisms after a period without interaction between user and system (Henriksen et al., 2013). Other measures to increase security in telerehabilitation interventions are: encrypted storage of sensitive user data and encrypted transfer of data, messages, and videoconferences (Henriksen et al., 2013). Education in secure behaviour and awareness about privacy risks among users may decrease unwarranted incidents and threats related to confidentiality risks (Henriksen et al., 2013). In Norway, e-health services require a Security Level 4 to be used in clinical practice. Some telerehabilitation programs are group-based and participants might be able to hear and see other participants during a videoconference session. Such interventions require confidentiality not only between patient and healthcare provider, but also among all the participants. An agreement on not to disclose medical or personal information about other participants might be signed by enrolment to the program (Præstegaard, 2017). Enrolment of patients to telerehabilitation program should be governed by “informed consent”. This allows patients to be adequately informed about content of the service, how confidentiality is ensured, potential risks and how to reduce them (Vitacca and Holland, 2018). Careful considerations about data security and patient confidentiality are paramount for properly use of telerehabilitation services.

All participants in our research were thoroughly informed about what the interventions implied and provided signed written consent to participation. In our interventions, communication was performed with Advanced Encryption Standard encryption. This minimized the risk of videoconferences being hacked by others. Access to the website and videoconference system was anonymised by use of study identification numbers (e.g. no001), and the contact information of the study participants was only available to designated study personnel. Confidentiality is also better secured in individual videoconferences than in group videoconferences where participants’ relatives or other visitors might be listening in on the conversation in the group. All data collected in our studies were anonymised before publication in journals.

4.4.3 Economic considerations

The cost-effectiveness of telerehabilitation interventions is not fully evaluated yet. To evaluate the real cost-effectiveness it is important to understand and reveal all costs related to conventional centre-based rehabilitation and standard care, as well as describing the costs of the new intervention, as “standard care” might vary among European countries and even within each country (Vitacca et al., 2018).

To set up a telerehabilitation system in the homes of a patient, transportation of equipment and an initial home visit are often required. Funding and reimbursement for this and to the healthcare professionals providing the telerehabilitation service may not be well established in many countries (Vitacca and Holland, 2018).

4.4.4 Comorbidities and health limitations

Comorbidities are not a sufficient reason to exclude patients from pulmonary rehabilitation, exercise (Burtin and Zuwallack, 2018) or telerehabilitation. However, every comorbidity in the individual patient must be taken into account when prescribing exercise and other components of rehabilitation provided via centre-based programs or telerehabilitation. In the iTrain study, participants reported having on average 2.6±1.2 comorbidities. Of the 29 Norwegian participants enrolled in either, the telerehabilitation group or the treadmill group 38% experienced comorbidities or COPD exacerbations that hindered them to exercise on the treadmill for a shorter or longer period within the first year. Moreover, health limitations such as impaired cognition, sight and hearing impairment could impact on how the participant will be able to use a telerehabilitation intervention (Donner et al., 2018).

4.4.5 Health literacy and computer literacy

Health literacy is the degree to which an individual is able to obtain, process, communicate and understand basic health information and health services to make appropriate decisions regarding one’s own health (Institute of Medicine, 2004). Low levels of health literacy is common in patients with COPD and is linked to impaired self-management behaviour (Kale et al., 2015). It can also moderate the learning process in pulmonary rehabilitation (Blackstock et al., 2018). How level of health literacy affects the ability to use e-health technology is not clear and further research is needed (Emtekær Hæsum et al., 2016). One systematic review synthesising users’ experience of digitalised self-management interventions for chronic health conditions found that the intervention enhanced health literacy by helping the participants to be more aware of their condition, by making them more capable to take decisions about their own health, and by enabling participants to engage in discussions as an equal with the healthcare personnel (Morton et al., 2017). Participants in our pilot study also had this experience.

The participants' familiarisation with technologies may be a barrier to use telerehabilitation. A survey performed in 2010 showed that American adults with chronic diseases are significant less likely to have access to the Internet than healthy adults (62% versus 81%, respectively). People affected by multiple diseases are even less likely to have Internet access, as only 52% reports to go online (Fox and Purcell, 2010). However, telerehabilitation studies reported that participants perceived the equipment as easy to use (Tsai et al., 2016, Burkow et al., 2015, Holland et al., 2013a). Participants in our pilot study shared this opinion, even though they sometimes experienced problems with the network and website.

Successful use of e-health technology is also depended on the healthcare personnel's knowledge on how to use the equipment. Yet perhaps more important, is their reflections on how technology affects work practices in telerehabilitation. Implementing new technologies might influence professionalism, collaborative relationships, core tasks and how healthcare personnel prioritises and acts towards the patients (Esbensen and Nickelsen, 2017). This is elaborated in the following paragraph.

4.4.6 A new meeting arena between patient and healthcare personnel

Traditionally, rehabilitation has required the patient and healthcare personnel to be located at the same place, at the same time. With telerehabilitation, this requirement is no longer needed as the patient can access educational content and exercise programs on his own and complete a telerehabilitation program in his own pace where he wants. How does this change the interaction between patient and healthcare personnel? What can be gained and what can be lost on this digitalised pathway? A qualitative meta-synthesis (Andreassen et al., 2018) explored digitally mediated patient-healthcare personnel interactions and identified four key concepts that point at structural processes of change: respatialisation, reconnection, reaction and reconfiguration. Respatialisation referred to healthcare being relocated in space and time, and that this changed the meaning and experience of patients' homes (and the primary health space). Respatialisation comes with relational consequences, which might lead to instrumental, emotional and contested reconnections. Paradoxically, technology may empower patients to act autonomously, but it also may lead to new dependencies. The synthesis suggested that use of technology alters social identities and interaction chains.

Patients’ reactions to these altered states can be found on a continuum between domestication and resistance. Some patients adapts well to technology, some resigns and others refuses to use the it. Health work and labour processes are reconfigured through e-health. E-health can redefine professional roles and create new ways of working. Which in turn can lead to negotiations and conflict on who does what, what healthcare work consists of, and what it means to be a competent healthcare professional. E-health can create new forms of labour process that includes patients and sometimes their family as well. Use of technology can also reconfigure how patients and their relatives think and act related to the disease and influence relational practices in the families (Andreassen et al., 2018).

Similarly to the previous synthesis, a systematic review and meta-synthesis (Brunton et al., 2015) of qualitative studies exploring the experience of both patients, their carer and healthcare personnel with a variety of telehealth interventions in COPD identified conflicting consequences of telehealth. Findings revealed three overarching themes that may either hinder or promote positive user experience with telehealth: i) telehealth influence on the moral dilemmas of help seeking (which may enable dependency or self-care); ii) telehealth transform interactions (which may increase risk or reassurance); and iii) telehealth reconfigures work practices (which may cause burden or empowerment) (Brunton et al., 2015). Comprehensive monitoring and self-reporting of symptoms may, instead of promoting independence foster patient dependency on healthcare personnel for feedback and assessment among those with COPD (Goldstein and O'Hoski, 2014, Donner et al., 2018). In our pilot study, participants described how the technology could make it easier for them to withdraw themselves without confrontation from the collaboration with the physiotherapist. If the follow-up did not fit their goals, mood or values, or the relationship felt too challenging, they could become “unavailable” by “loosing network access”. Participants in our pilot study also perceived that monitoring via telerehabilitation contributed to emotional safety. Others have experienced monitoring as violation of privacy (Thorup, 2017).

When we are not communicating face-to-face, the non-verbal communication might be limited and the contextual relationship weakened. With this, the risk is that healthcare personnel fails to observe symptoms, signs or personal interests in the patient (Præstegaard, 2017) that might contribute to increased health and/or motivation to health enhancing behaviour. Other concerns are that telerehabilitation might contribute to increased loneliness as patients meet their therapists through the screen and remain isolated in their homes (Præstegaard, 2017).

4.4.7 Implementation into routine healthcare

Policy makers in Norway have shown a strong interest in offering e-health solutions and welfare technologies to the population to reduce the demand of expensive hospital admission whilst helping people to live independently for longer. Despite the current e-health strategy, few telemedicine solutions have been successfully integrated into routine healthcare and, to our knowledge, none for people with COPD (The Norwegian Directorate of E-health, 2018). A telemonitoring service for patients with COPD have been used in routine practices locally in one hospital (Knarvik et al., 2014, Zanaboni et al., 2014, Linjord, 2015), but no telemonitoring or telerehabilitation services have been implemented into routine healthcare at national level.

At the Maugeri Centre for Telehealth and Telecare (MCTT) (Scalvini et al., 2018) in Italy, multidisciplinary e-health services have been successfully implemented into routine healthcare after hospital discharge for people with COPD, chronic respiratory insufficiency, amyotrophic lateral sclerosis, neuromuscular diseases, chronic heart failure, post-stroke and post-cardiac surgery patients. People with COPD and chronic heart failure account for 80% of the patients treated. The content of the e-health service vary depending on the underlying chronic disease. Key elements are a structured physician-directed and nurse-managed telephone support and telemonitoring service provided to the patients' homes. The service also involves several disease-specific educational sessions before discharge, aimed to educate patients in self-management of their disease and early recognition of signs and symptoms of exacerbations. Patients are contacted weekly after discharge to reinforce adherence to self-management routines and counsel the patient on weight management, physical activity, smoking cessation, dietary changes, stress management and other specific targets set for the individual patient. Patients can contact the staff through a 24h/day open call centre out of the scheduled weekly contacts if they have any enquiries. An individually tailored exercise program is prescribed and supervised by a physiotherapist via home visits, scheduled videoconferences and/or telephone appointments. Videoconferences are also used to deliver an educational program and for counselling by the nurse. Patients are supplied with telemonitoring equipment depending on disease-specific clinical requirements. This equipment transmits data instantly to the MCTT via a secure data connection. Results from a series of studies demonstrated that the e-health service provided by MCTT to people with COPD is feasible, more effective in reducing re-hospitalisations (-36%), acute exacerbations (-71%) and urgent calls to general practitioners (-65%) than a control group. Improvements in quality of life were also observed among people with COPD enrolled to the e-health program (Scalvini et al., 2018). Another example of routine practice is a 6-month telemonitoring service for patients with COPD called the Nuovi Reti Sanitarie (New Healthcare Network) in the Lombardy region in Italy (Luzzi et al., 2017).

Despite optimistic evidence on the efficacy and benefits of telerehabilitation, there seem to be some barriers to the implementation of such services in routine healthcare (See also table 8). One main barrier is related to policies and economic incentives. Such services must be institutionalised, recognised, defined in respect to requirements and quality assurance, and have proper economic incentive in form of reimbursements.

Other barriers for implementation of telerehabilitation in routine healthcare include the availability of equipment and functional procedures on how to deliver equipment and to teach how to use it (Donner et al., 2018). Challenges related to the delivery of equipment was also faced in our studies, as participants were spread over Northern Norway and cooperation with local helpers were not established. For those with respiratory diseases located away from urban settings, another barrier is how to conduct a thorough initial assessment of lung function and physical capacity. Rural dwelling patients might find it difficult to travel long distances to a specialised health facility to conduct these assessments. During the recruitment process in the iTrain study, five of the 89 who declined to participate specified long travel distance as main reason for not participating in the study. It could have been possible to cooperate with local general practitioners' offices and physiotherapists, but this would have added a high degree of complexity to establish contacts and routines for exchange of sensitive personal health information with numerous local healthcare services in the different communities.

4.5 Variations in physical activity across countries and seasons

The cross-sectional study aimed at investigating whether there were differences in physical activity levels between Norwegian, Danish and Australian people with COPD. Results revealed some differences across countries after controlling for disease severity. Danish participants, who spent significantly longer periods of the day in sedentary activities and less time walking at higher intensities, had significantly lower functional walking capacity (indicated by 6MWD) than participants from other countries. There is a strong association between physical activity and physical capacity (Pitta et al., 2005). Participants from Norway and Australia had a median walking distance of >400 meters on the 6MWD and achieved ≥30 minutes of moderate-to-vigorous activity, whereas Danish participants walked <400 meters and did not meet the value of ≥30 minutes of moderate activity which is recommended by the American College of Sports Medicine (Haskell et al., 2007). Such relationship between physical capacity and intensity of physical activity has been observed by Pitta et al (Pitta et al., 2005). However, high physical capacity does not always translate into higher levels of physical activity, as physical activity is also influenced by psychological factors like habit, self-efficacy and health beliefs (Thorpe et al., 2014, Burtin et al., 2015). Strategies to reduce sedentary time may be clinically relevant in COPD (Lahham et al., 2016), for example via reduction of cardiovascular risk (Maclay et al., 2007, Wilmot et al., 2012) and improvement of physical functioning (Gibbs et al., 2017). Strategies that target sedentary behaviour might have a potential for increasing overall physical activity. The cross-sectional study could not answer why Danish participants with COPD were more inactive than the other groups, except that their disease severity was greater and physical capacity poorer. In addition, they wore the activity monitor for longer each day and, by this, they might have recorded longer time in sedentary activities than their counterparts.

The cross-sectional study aimed also at establishing whether variations in physical activity levels were attributable to seasons. Although it did not reach statistical significance, there was a trend for the participants to walk more and with higher intensity during summer compared to spring, winter and autumn, regardless of geography. Climate and variations in weather conditions following the different seasons may influence levels of daily physical activity in COPD (Watz et al., 2014). Studies have reported lower number of steps during rainy and colder days, in winter and during extreme summer heat (Togo et al., 2005, Sewell et al., 2010, Alahmari et al., 2015, Balish et al., 2017). A change in daily step count has also been observed during transition between different seasons (Wan et al., 2017). Results did not reach statistical significance due to the modest sample size in each group. However, the overall difference between summer (3502 steps/day) and winter (2373 steps/day) exceeded the minimal clinically important difference (between 600 and 1100 steps/day) in daily step count after pulmonary rehabilitation (Demeyer et al., 2016). An improvement of more than 600 steps/day after pulmonary rehabilitation is also reported to reduce the risk of hospitalisation in patients with COPD (Demeyer et al., 2016). We therefore considered the difference of 1129 daily steps between summer and winter to be of clinical relevance. Weather conditions and seasonal variations may influence outcomes in clinical trials and health registries measuring physical activity over time, irrespective of the interventions delivered, and should be taken into account when interpreting results.

4.6 Methodological considerations

4.6.1 Study designs, study populations and transferability

Results and discussions in this thesis are primarily based on two studies: 1) a pilot study investigating the feasibility of a long-term telerehabilitation intervention, the usability of the technology, and exploring participants' experience with the intervention, and 2) a RCT comparing the clinical effects and cost-utility of a long-term telerehabilitation intervention against a unsupervised exercise training at home and standard care. The Model for Assessment of Telemedicine (MAST) is a recognised model to evaluate the effects of empirical studies on telemedicine. According to the MAST model, it is necessary to conduct formative evaluation studies (e.g. participatory design-studies, usability studies or feasibility studies) before multidisciplinary effect studies (e.g. RCT) are performed. This is particularly important if the technology in question is still in a developmental phase and not tested on patients or personnel before (Kidholm and Dinesen, 2017). With this, our choice of conducting a pilot study was appropriate as such long-term telerehabilitation intervention had never been trialled before. The next step in the MAST model is to conduct a multidisciplinary evaluation of the effects of the intervention compared with one or more comparators in relation to seven different domains. These include description of the users health problem and the intervention, safety, clinical effects, patients perspective, economic aspects, organisational aspects, and socio-cultural, ethical and legal aspects (Kidholm et al., 2012). How our research complies with the MAST model is described in table 11.

Table 11 Evaluation of the pilot study and iTrain study based on the MAST model

Domain	**Data collection method and outcome measures used**
Health problem and intervention	The main health problem is the current need for increased accessibility and applicability of pulmonary rehabilitation in patients with COPD. The description of the telerehabilitation intervention we evaluated, together with a thorough description of the characteristics of COPD in general and the patients enrolled in the studies, are provided in this thesis and the related papers.
Safety	Safety in form of dropout rates and adverse events are registered. Technical reliability of the technology and equipment used is registered and also described as a challenge in qualitative focus groups.
Clinical effects	Valid and reliable outcome measures commonly used to evaluate clinical effects in this patient group were used in the evaluation of the telerehabilitation intervention (table 7). Internal validity of the studies are discussed below.
Patients perspective	Qualitative focus groups with ten participants in the pilot study and individual interviews with 5-8 participants from each site in the telerehabilitation arm were performed in the iTrain study.
Economical aspects	Changes in use of healthcare utilisation (combined number of hospitalisations and ED presentations) is the primary outcome of the iTrain study. A cost-utility analysis will be performed as a secondary outcome to verify whether the telerehabilitation and the treadmill interventions are cost-effective.
Organisational aspects	Assessment of the resources that need to be mobilised and organised before implementation of our intervention in routine healthcare, and potential changes or consequences this might imply, were not evaluated.
Socio-cultural, ethical and legal aspects	This thesis discusses and reflects over how socio-cultural aspects and relations might change between patients and healthcare personnel through telerehabilitation. Ethical and legal issues were considered before starting the study and described in *Paper IV*.

The third step in the MAST model is assessment of transferability. Transferability of results of studies investigating e-health interventions from one setting to another is a general problem (Kidholm et al., 2012). One reason is that organisation of healthcare services and technical infrastructure might vary between countries, and this can create substantial differences in applicability and cost per patient by introducing the same service into different countries (Kidholm et al., 2012). A strength related to transferability in our studies was that the iTrain study was an international study conducted in three countries. Our intervention was tested for both stable patients familiar to pulmonary rehabilitation (pilot study) and for patients more recently affected by exacerbations, most of whom non-familiar with rehabilitation (iTrain study). By this, our intervention was tested in a heterogeneous group, representative for a larger population of patients with COPD. The broad patient selection supports the external validity of our research and the implementation of such interventions in a real-life setting. Limitations that might affect transferability were the low sample size in the pilot study and the problems encountered with recruiting patients in the iTrain study. However, eventually, the iTrain study enrolled 120 participants with a dropout rate of 7.5% after the first year. This is within our initial sample size calculations for allowing a power of 95% to detect an incidence rate ratio of 0.60 on hospitalisation which were the main outcome in the iTrain study, with a type-I error (α) of 0.05.

4.6.2 Internal validity

Internal validity refers to what degree the study is free from systematic errors (bias). Randomisation to intervention and control groups in traditional RCTs is considered the best way to control threats to the internal validity. Likewise, it is important to ensure that the intervention groups receive the intervention as designed and that control groups not inadvertently receive components of the intervention. Furthermore, an accurate, reliable and preferably blinded collection of data is an important way of controlling the internal validity (Domholdt, 2005). Participants in the iTrain study were stratified by centre and disease severity before randomisation to preserve homogeneity between arms. Randomisation was web-based and the randomisation sequence was concealed from the research team. To ensure that the intervention was delivered correctly and equally by each site, the physiotherapists conducting the individual videoconferences and follow-ups of participants were provided with common project guidelines for exercise prescription, goalsetting, and practical instructions regarding the videoconferences. They were all experienced in pulmonary rehabilitation. However, individual differences in the way participants were followed up might have occurred. This also represents an issue in conventional pulmonary rehabilitation. Furthermore, the internal validity of our research was supported by use of external research assessors blinded to group allocation to perform the study follow-ups. Participants might have received other forms of medical or rehabilitation follow-up during the intervention period that might have influenced the results. However, to ensure that no participants was denied access to the best healthcare practice, any participant in the trial could undertake a conventional pulmonary rehabilitation programme at any time during the two-year study period if it was considered clinically indicated by their usual treating team.

4.6.3 Reliability

Reliability is the extent to which measurements are repeatable and free from errors (Domholdt, 2005). Common, validated and standardised tests and outcome measures were used to evaluate the telerehabilitation intervention. Threats to the reliability were multiple and different research assessors conducting the spirometry and 6MWT at each site. We also suspect that the number of comorbidities was underreported in the iTrain study among Danish participants, as they had registered fewer comorbidities despite having a more progressed and severe disease *(Paper V).*

4.6.4 Methodological considerations regarding the mixed method study

As most of the results in the mixed method study implemented in the pilot study *(Paper II)* were based on qualitative data, strengths and weaknesses were assessed against the four criteria for trustworthiness in qualitative research proposed by Guba and discussed by Shenton: credibility; transferability; dependability; and confirmability (Shenton, 2004). All participants were given the opportunity to express their experiences and reflections regarding attendance in the study through a triangulation of methods in a familiar atmosphere. Authors' immediate understanding of the participants' answers were summarised consecutively during the focus groups, so that participants' interpretations were confirmed, thus increasing credibility. We conducted a pilot study with a small number of patients with COPD. Results might therefore not necessarily be transferred to other settings or patient groups. Nevertheless, the findings are somewhat congruent with the existing body of evidence. In terms of dependability, an effort was made to transparently describe the research process and the analysis procedure. The conduction of the two focus groups and the analysis of the material were made by more than one of the authors, thus increasing confirmability. On the other hand, the physiotherapist conducting the videoconferences was also present during the focus groups. The participants might therefore have held back some personal thoughts. However, our overall impression is that triangulation of data collection allowed the participants to provide their critical views as well, thus reducing the effect of investigator bias. Despite being conscious of our preconceptions and theoretical background during data collection and analysis process, these might have affected our interpretations.

4.7 Suggestions for future research

Now that the feasibility of telerehabilitation for people with COPD has been established, future research should focus on providing more evidence of the efficacy, cost-effectiveness and long-term effects. Then the next step would be to understand how to deliver such programs optimally. Questions that still remain are discussed below.

4.7.1 Standardisation of best practice

Future challenges include standardising best practice of telerehabilitation to allow meaningful comparison of outcomes across studies and further allow a consistent implementation in routine healthcare. As described in this thesis, there is a large heterogeneity among telerehabilitation studies in terms of technology used, healthcare personnel involved, disease severity of patients enrolled, exercise modes and equipment, content of the educational component, degree of supervision, and program length. In addition, there is a large variability among outcome measures used in telerehabilitation studies. These findings stress the importance of future agreement on performance metrics and outcome measures to evaluate telerehabilitation interventions, to be able to provide quality healthcare via telerehabilitation, start international benchmarking, and provide recommendations for international standards based on evidence and best practice (Huynh and Stickland, 2016). In addition, achieving consensus on the content and costs of “standard” pulmonary rehabilitation is important so that potential benefits and cost-effectiveness of telerehabilitation can be better quantified (Vitacca et al., 2018).

All content components from conventional pulmonary rehabilitation are not always provided in telerehabilitation interventions. For example, education and social support are important components of pulmonary rehabilitation, and telemedicine holds an opportunity to deliver these components in a new way (Blackstock et al., 2018). However, their effectiveness when delivered via telerehabilitation has not been thoroughly evaluated.

We found that physical activity and other outcomes obtained after participation in the two-year pilot study were not maintained in the following year without supervision from the tele-physiotherapist, even though the participants kept the exercise equipment. More studies on long-term outcomes of telerehabilitation compared with conventional pulmonary rehabilitation (and usual care) are needed.

More research is also warranted on the security and confidentiality of patient data related to telerehabilitation services in general (Vitacca et al., 2018).

Broadening the scope of pulmonary rehabilitation with features from telerehabilitation

Different functionalities from telerehabilitation such as pre-filmed educational videos, exercise videos, and virtual game systems as described by Wardini et al. (2013), might have the potential to prepare people with COPD for conventional centre-based rehabilitation, as extra sessions during program delivery, as home exercises, or as a maintenance program after centre-based rehabilitation programs. The effectiveness of such approaches warrants future research.

4.7.2 Selection of the best candidates for telerehabilitation

So far, we do not know if there are subgroups of patients who benefit more, or could be harmed, by participating to telerehabilitation programs, or when telerehabilitation should be offered (e.g. disease severity, acute vs stable disease) (Vitacca et al., 2018). In our two studies, we experienced that it was easier to recruit stable COPD patients who were familiar with rehabilitation and exercising than more fragile and severe patients with a recent hospitalisation due to exacerbation. Suggestions for selecting candidates from other studies are conflicting. A qualitative study exploring patients' perspectives in an intervention comprising telemonitoring and unsupervised home exercises found that a small number of patients experienced indifference towards the telemonitoring measurements as it did not make sense for them to measure stable values (e.g. blood pressure, pulse, weight, spirometry and oxygen saturation) over time (Dinesen et al., 2013). This implied that stable patients with

COPD would not benefit as much from telerehabilitation as patients with more unstable conditions. Rochester and Clini (2018) suggested that individuals with less disease severity, fewer comorbidities, lower levels of disability and lower risk of adverse medical events are more likely to be better suited to telerehabilitation.

No association between motivational strategies and adherence rate was found in the pilot study. Consequently, we were not able to make conclusions regarding the process of selecting the best candidates for telerehabilitation. However, our findings were based on a small sample size and better results could be obtained if testing the intervention on a bigger target population.

A preference-based randomised control trial enrolling patients with COPD to telerehabilitation or conventional pulmonary rehabilitation based on the individuals' preference might produce knowledge on which patients prefer telerehabilitation and if preference can guide selection to telerehabilitation. Alternatively, if those choosing telerehabilitation have other characteristics than those choosing a face-to-face service? The latter question could be answered through a survey that also collected characteristics of the respondents. For our research group, the next research step might be to do a study on responders versus non-responders in the telerehabilitation intervention group of the iTrain study using multidimensional response profiling as described by Spruit et al. (2015).

Further, little is known about the feasibility and effectiveness of telerehabilitation for patients with other respiratory diseases.

4.7.3 Health economic benefits

The literature search described in paragraph 1.4.1 detected three published RCTs (Bernocchi et al., 2018, Vasilopoulou et al., 2017, Tabak et al., 2014a) and three upcoming RCTs (Zanaboni et al., 2016a, Hansen et al., 2017, Cox et al., 2018a) evaluating health economic benefits related to telerehabilitation. Nevertheless, more research is needed to articulate and conclude of the cost-effectiveness of telerehabilitation.

4.7.4 Patients perspective

Some research has already described the perspectives of those with COPD in e-health technology (Vatnøy et al., 2017, Brunton et al., 2015) and in telerehabilitation (Hoaas et al., 2016a, Burkow et al., 2015, Burkow et al., 2013, Tsai et al., 2016). However, future research should further address needs, preferences, attitudes and knowledge of the target population. Such knowledge might guide innovation of the technology, content and implementation of service in a way that can support adherence and long-term health enhancing behaviour.

4.7.5 Healthcare professionals perspectives

A successful implementation process of new health interventions is dependent not only on the patients, but also on the health professionals involved. To date, few studies (Brunton et al., 2015, Horton, 2008, Fairbrother et al., 2013, Fairbrother et al., 2012, Mair et al., 2008, Hibbert et al., 2004, Ure et al., 2011) have described the perspectives of healthcare professionals involved in e-health interventions for people with COPD. Only one study has explored healthcare professionals' experience with telerehabilitation for people with COPD (Damhus et al., 2018). It is important to address the needs, preferences, attitudes and potential barrier to adaptation and acceptance of telerehabilitation from the views of the service providers to be able to innovate and implement an effective and beneficial telerehabilitation service.

4.7.6 Implementation of routine service

For those who consider implementing a telerehabilitation component in their current pulmonary rehabilitation program, the evidence is promising, although additional research is needed (Huynh and Stickland, 2016). Before widespread implementation occurs, more research is required on organisational aspects of the delivery of telerehabilitation services. Other aspects to be considered include purchase and maintenance of equipment (e.g. should equipment be bought by patients vs equipment offered by healthcare providers), reimbursements and how to provide competence and training to the healthcare personnel involved. Moreover, it is important to describe, organise and clarify the needs for cooperation and shared responsibilities between specialist care services and primary care services, which is vital before a full-scale implementation.

5 Conclusions

The innovative two-year exercise maintenance telerehabilitation intervention investigated in this thesis and related papers is the first telerehabilitation intervention with such long-term follow-up.

Long-term exercise maintenance via telerehabilitation for people with COPD is safe and feasible. Findings from our pilot study and preliminary results for the telerehabilitation group of the iTrain study, are encouraging and suggest that long-term telerehabilitation can prevent deterioration in lung function, symptom burden and health-related quality of life, in addition, it can improve and maintain functional walking capacity over a longer period. This adds to the growing evidence that short-term telerehabilitation can achieve meaningful clinical benefits for this group of patients. Moreover, benefits similar to those of standard rehabilitation can be expected by a telerehabilitation program.

The advantage of long-term telerehabilitation over the existing offer of exercise maintenance programs after conventional pulmonary rehabilitation in Norway was threefold. Telerehabilitation has the ability to overcome geographical distance, provide specialist access in areas where this is not available, and provide regularity of follow-up by the same health personnel over a longer period. People with COPD were satisfied with the long-term follow-up and found the technology user-friendly. Satisfaction was supported by experienced health benefits, increased self-efficacy and emotional safety.

Long-term adherence to exercise routines was possible with telerehabilitation. However, maintenance of motivation for exercising was still a challenge despite regular supervision via telerehabilitation. Barriers for implementing telerehabilitation in routine healthcare are related to policies and economic incentives. In addition, practical concerns such as availability of equipment, functional procedures on how to deliver equipment and to teach how to use it might be other barriers. Other challenges to consider before routine implementation of telerehabilitation include difficulties related to work organisation and cultural barriers.

The findings in this thesis support the suggestion that long-term telerehabilitation for people with COPD is an alternative or supplement to conventional centre-based pulmonary rehabilitation. Centre-based programmes is still considered the best practice for pulmonary rehabilitation. However, telerehabilitation holds a great potential to expand the availability of pulmonary rehabilitation programs to a greater number of people who would benefit both in Northern Norway and worldwide.

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Long-term exercise maintenance in COPD via telerehabilitation: a two-year pilot study

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Abstract

Introduction: Pulmonary rehabilitation (PR) is an integral part of the management of chronic obstructive pulmonary disease (COPD). However, many patients do not access or complete PR, and long-term exercise maintenance has been difficult to achieve after PR. This study aimed to investigate feasibility, long-term exercise maintenance, clinical effects, quality of life and use of hospital resources of a telerehabilitation intervention.

Methods: Ten patients with COPD were offered a two-year follow-up via telerehabilitation after attending PR. The intervention consisted of home exercise, telemonitoring and self-management via a webpage combined with weekly videoconferencing sessions. Equipment included a treadmill, a pulse oximeter and a tablet. Data collected at baseline, one year and two years were six-minute walking distance (6MWD), COPD assessment test (CAT), EuroQol 5 dimensions (EQ-5D), hospitalisations and outpatient visits.

Results: No dropout occurred. Physical performance, lung capacity, health status and quality of life were all maintained at two years. At one year, 6MWD improved by a mean of 40 metres from baseline, CAT decreased by four points and EQ visual analogue scale (EQ VAS) improved by 15.6 points.

Discussion: Long-term exercise maintenance in COPD via telerehabilitation is feasible. Results are encouraging and suggest that telerehabilitation can prevent deterioration and improve physical performance, health status and quality of life.

Keywords

COPD, pulmonary rehabilitation, telemedicine, exercise, home monitoring

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Introduction

Pulmonary rehabilitation (PR) is an evidence-based component of the disease management of chronic obstructive pulmonary disease (COPD).[1–3] The main goal of PR is to improve the patient's conditions, both physically and psychologically, and to promote long-term adherence of health-enhancing behaviours.[4] PR improves dyspnoea, physical performance and quality of life in COPD.[4] However, benefits diminish over the succeeding 12 months without any maintenance strategy,[5] and long-term exercise maintenance has been difficult to achieve after short-term treatment.[6] Supervised post-rehabilitation exercise programmes appear to be effective in preserving exercise capacity in the medium term.[7] Nevertheless, the optimal maintenance intervention to sustain benefits of PR over the long term remains still unknown.[5,6,8] Regular exercise for patients with COPD is difficult for many reasons, including variation in day to-day condition, exacerbations, hospital admissions, transportation problems and lack of support and follow-up programmes.[9] Developing new ways to maintain regular exercise, thus extending the effects of PR, is an important goal in COPD management.

Telemedicine has the potential to support disease management of COPD. Telerehabilitation refers to the use of information and communication technologies to provide rehabilitation services to people remotely in their homes or other environments.[10] The primary aim is to provide equitable access to rehabilitation.[11] This is especially important to people living in rural areas. In contrast to traditional centre-based PR programmes, undertaking PR within the home environment may promote more effective

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integration of exercise routines into daily life over the longer term.[12]

Evidence of the use of telemedicine in PR is still scarce.[4] A recent review showed that telemedicine may lead to increased physical activity levels in patients with COPD, but no effect was found on exercise capacity or dyspnoea.[13] Other studies showed promising results for telerehabilitation in COPD in regards to feasibility, safety, exercise capacity, physical activity and health-related quality of life.[14–19] However, all interventions had a short-term duration. So far, no telerehabilitation intervention was conducted to support exercise maintenance and long-term effects.

We conducted a pilot study where a long-term telerehabilitation intervention for patients with COPD was offered over a two-year period. The aim was to investigate feasibility, long-term exercise maintenance, clinical effects, quality of life and use of hospital resources.

Methods

Study design

A two-year pilot study was conducted to test long-term exercise maintenance in COPD via telerehabilitation. The study was conducted by the Norwegian Centre for Integrated Care and Telemedicine (NST), University Hospital of North Norway (UNN) and the rehabilitation centre LHL-klinikkene Skibotn. Participants were 10 patients with moderate to severe COPD, who were recruited after attending a four-week inpatient PR. Their clinical status was therefore stable and their physical conditions optimised. Inclusion and exclusion criteria are described in detail in Table 1. The study was approved by the Regional Committee for Medical and Health Research Ethics.

Objectives

The primary objective was to determine whether long-term telerehabilitation in COPD was feasible and could promote exercise maintenance and self-management. Feasibility was assessed in terms of completion rate, measured as the number of completers divided by the number of participants. Completers were defined as those participants actively undertaking the study procedures until the end of the intervention, while dropouts where those who ceased participation before the end of the intervention.[21] Frequency of training sessions was calculated to measure how active patients were in maintaining exercise. Frequency of registrations of daily symptoms was used to assess maintenance of self-management routines. Other study objectives included impact on patients' physical performance, lung capacity, body weight status, health status, quality of life and subjective impression of change (Table 2). All data were collected at baseline, one year and two years. The study also tested whether long-term telerehabilitation was associated with a change in healthcare resources utilisation. Data on hospitalisations and outpatient visits were collected from the Norwegian Patient Registry for the two years of follow-up and for the two years prior to enrolment.

The telerehabilitation intervention

Telerehabilitation was designed as a comprehensive intervention consisting of home exercise, telemonitoring and

Table 2. Study objectives.

Objectives	Measure
Feasibility	Completion rate
Exercise maintenance	Frequency of training sessions
Self-management maintenance	Frequency of daily registrations
Physical performance	6MWD
Lung capacity	FEV_1 (% of predicted)
Body weight status	BMI
Health status	CAT
Quality of life	EQ-5D
Subjective impression of overall change	PGIC
Healthcare utilisation	COPD-related hospitalisations and outpatient visits

6MWD: six-minute walking distance; FEV_1 (% of predicted): forced expiratory volume in 1 second percentage; BMI: body mass index; CAT: chronic obstructive pulmonary disease assessment test; EQ-5D: EuroQol 5 dimensions; PGIC: patient global impression of change scale; COPD: chronic obstructive pulmonary disease.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Moderate/severe diagnosis of COPD in accordance with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines[20]	Unwillingness or inability to give informed consent
Completion of a rehabilitation programme during the previous 6 months	Presence of comorbidities or physical conditions which might interfere with home rehabilitation
Aged 40–75 years	Home environment not suitable for installation and use of training and monitoring equipment (e.g. space, internet connection, family needs)
Resident in northern Norway	
Norwegian-speaking	

COPD: chronic obstructive pulmonary disease.

self-management. The service was offered as two-year follow-up to patients with COPD. The two-year duration was proposed since there have been almost no previous reports of studies lasting longer than 12 months. After attending a PR programme, participants were supplied with equipment for home exercise and videoconferencing so that they could be supervised by a physiotherapist. Equipment for home exercise consisted of a treadmill installed in the patient's home. Folding treadmills were chosen since they are ideal for in-home use, where space is a concern, and are less expensive. Treadmills supported speeds up to 16 km/h and incline up to 10%. A pulse oximeter (Nonin GO2 LED) was provided to monitor oxygen saturation at rest and while exercising. A tablet computer (Apple iPad 2) was used to perform weekly videoconferencing sessions with a physiotherapist and to access a web-based self-management platform. A tablet holder mounted on the treadmill allowed safe use of the tablet while exercising (Figure 1). A mobile application for videoconferencing (LifeSize, ClearSea) could connect the participant's tablet to videoconferencing protocol H.323 and Session Initiation Protocol (SIP) standards-based systems, desktop computers or mobile clients. Communication was performed with Advanced Encryption Standard (AES) encryption. Videoconferencing was initiated from a rehabilitation centre and performed through the

Figure 1. Home telemedicine unit, including treadmill, pulse oximeter, iPad and holder.

Figure 2. Videoconferencing between physiotherapist and patient.

application running on the participant's tablet (Figure 2). Participants used the web-based platform to access an individual training programme, to fill in a daily diary and a training diary and to access historical data. The information was also accessible to the physiotherapist and used for discussion with the patients.

Statistical analyses

Data from baseline (post-PR), one-year and two-year visits for all subjects were evaluated with descriptive statistics and analysis of variance (ANOVA) with repeated measures. Continuous variables are reported as mean ± standard deviation (min–max). Categorical variables are reported as counts and percentages. Normality of distribution was tested by means of the Shapiro–Wilk test. Effects of the long-term telerehabilitation were evaluated with an ANOVA with repeated measures. A value of $P < 0.05$ was considered significant. A Bonferroni post hoc test was used to discover which specific means differed in case the overall ANOVA result was significant. All statistical analyses were performed with IBM SPSS Statistics Version 22.

Study procedures

Participants were enrolled by a lung specialist and a trained physiotherapist during a baseline visit to the rehabilitation centre. A clinical assessment included conduction of spirometry and six-minute walking test, measurement of bodyweight and height and collection of the study questionnaires. After enrolment, the equipment was installed at the participant's home. A training session on the use of the equipment was performed. A test videoconferencing session between the participant and the physiotherapist at the rehabilitation centre was also conducted.

During the study participants were asked to fill in a daily electronic form for self-management of symptoms including oxygen saturation (at rest) and the breathlessness, cough and sputum scale (BCSS).[22] Each participant received an individual exercise programme consisting of interval training on the treadmill, recommended three times a week. This was accessible from the web-based platform. Participants were also encouraged to perform strength training exercises consisting mainly of squats and calf raises (three sets of 10 reps) and to do any physical activity on their own. Interval training consisted of a 10-minute warm-up, followed by three or four exercise bouts lasting between three and four minutes with a perceived exertion of 5–6 on the Borg CR10 scale,[23] interposed by two- to three-minute active recovery periods with a perceived exertion of 3–4. The training session ended with a five-minute cool-down. This gave a total exercise time $\geqslant$30 minutes.[4] The number and length of intervals were adjusted to the participant's condition. Speed and/or incline of the treadmill were adjusted individually during the study to reach the desired perceived exertion. After each training session, participants were asked to fill in an electronic form including: programme completion (duration); perceived exertion; oxygen saturation (lowest value during exercise) and heart rate (highest value during exercise).

Participants had weekly individual videoconferencing sessions with the physiotherapist, who was able to supervise them remotely while the participants were exercising. The physiotherapist supported and educated the patients in health-enhancing behaviour, focusing on increasing their motivation for exercise training and other physical activities. Self-efficacy strategies were emphasised so that the patients could gain insight into their own health and skills to optimally manage their illness and everyday life.

Participants had follow-up visits at the rehabilitation centre after one year and two years. During these visits spirometry, 6MWD, bodyweight and height were measured and the same baseline questionnaires were collected. At study exit, the patient global impression of change (PGIC) questionnaire was also collected.[24] During the study, participants received standard care, with their general practitioner as main contact, and attended the hospital for specialised care when needed.

Results

Study timelines and population

Ten participants were enrolled from January 2012 to May 2012. The baseline characteristics of the participants are shown in Table 3. Follow-up visits were held in June 2013 and May 2014.

Table 3. Patients' characteristics at baseline.

Demographics	Measure
Age, years	55.2 ± 6.1 [48–67]
Sex	
Males	5 (50%)
Females	5 (50%)
Patients on LTOT	3 (30%)
Distance from closest hospital, km	99 ± 76 [3–218]
Travel time to closest hospital, minutes	101 ± 69 [5–198]
Patients living alone	5 (50%)
Patients working	2 (20%)
Higher educational level	
Secondary school	1 (10%)
High school	7 (70%)
University / university college	2 (20%)
Internet use	
Never	1 (10%)
Every month	1 (10%)
Every week	5 (50%)
Every day	3 (30%)

LTOT: long-term oxygen therapy.

Feasibility and exercise maintenance

On average, patients participated in the study for 740 ± 26 days. All patients attended the baseline, one-year and two-year visits and data were collected at all time points. No dropout occurred during the study. The completion rate was therefore 100%. Patients experienced voluntarily and non-voluntarily relapses due to holidays, travelling, sickness or hospital admissions. However, all patients rejoined the programme after each break. On average, patients registered 1.7 training sessions/week via the webpage during the two-year intervention period. Frequency decreased from the first to the second year, but all the patients maintained exercise until the end of the study. Patients registered on average 3.0 daily measurements/week, thus also maintaining their self-management routines.

Clinical status

After one year, 6MWD improved by a mean of 40 metres compared to baseline (post-PR) (Table 4). This exceeded the minimal important difference (MID) in COPD, corresponding to 30 metres.[25] After two years, 6MWD decreased to a value in line with baseline, but still higher than the pre-PR measurement (464 ± 108). Mean forced expiratory volume in 1 second percentage (FEV_1) (% of predicted) increased after one year, while it declined during the second year. Body mass index (BMI) showed a slight reduction over the two years. Mostly, patients who were overweight reduced their weight, reaching a BMI closer to 25. A repeated measures ANOVA did not show any statistically significant difference between time points. Long-term telerehabilitation succeeded in maintaining clinical effects over a two-year period.

Health status and quality of life

After one year, the total score for the COPD assessment test (CAT) decreased by a mean of four points (Table 5). This exceeded the MID, estimated as two points.[26] After two years, the mean score was in line with baseline value. Patients experienced statistically significant changes between time points in breathlessness ($F = 4.729$, $P = 0.022$) and energy ($F = 4.534$, $P = 0.025$). The impact level of the CAT showed an increase of patients with a low–medium score (0–20) after one year, thus experiencing a lower burden of symptoms.

After one year, the utility score calculated from the EuroQol 5 dimensions (EQ-5D) and the EQ visual analogue scale (EQ VAS) increased by 0.036 and 15.6 points, respectively. Both measures declined during the second year. A repeated measures ANOVA did not show any statistically significant difference between time points for the EQ-5D states, the EQ VAS or any of the five dimensions. Overall, patients perceived an improvement of symptoms and quality of life during the first year, while during the second year they experienced a decline, with results in line with those at baseline.

Table 4. Results from the clinical status.

Outcomes	Baseline	1 year	2 years
6MWD, m	493 ± 106	533 ± 124	473 ± 108
FEV_1 (% of predicted)	49.1 ± 20.9	54.9 ± 28.8	45.2 ± 20.6
BMI, kg/m^2	27.9 ± 7.3	26.7 ± 5.5	26.4 ± 5.3

6MWD: 6-minute walking distance; m: metres; FEV_1 (% of predicted): forced expiratory volume in 1 second percentage; BMI: body mass index.

Table 5. Results from the health status and quality of life.

CAT	Baseline	1 year	2 years
Total score	21.5 ± 6.3	17.7 ± 5.5	20.3 ± 6.7
Cough	2.2 ± 1.0	2.0 ± 0.8	2.2 ± 1.1
Mucus	2.8 ± 1.0	2.2 ± 1.1	2.1 ± 1.4
Chest tightening	2.4 ± 1.1	2.2 ± 1.2	2.1 ± 1.0
Breathlessness	3.6 ± 1.3	3.0 ± 1.1	3.5 ± 1.0 *
Daily activities	3.4 ± 1.3	3.0 ± 0.8	3.0 ± 1.2
Confidence	1.5 ± 1.2	1.5 ± 1.3	1.8 ± 1.4
Sleep	2.6 ± 1.5	1.7 ± 1.6	2.8 ± 2.0
Energy	3.0 ± 1.2	2.1 ± 1.1	2.8 ± 0.9 *
Impact level			
Low (CAT < 10)	1 (10%)	1 (10%)	0 (0%)
Medium (CAT 10–20)	3 (30%)	5 (50%)	4 (40%)
High (CAT 21–30)	6 (60%)	4 (40%)	6 (60%)
Very high (CAT 31–40)	0 (0%)	0 (0%)	0 (0%)
EQ-5D	**Baseline**	**1 year**	**2 years**
Utility score	0.624 ± 0.218	0.660 ± 0.210	0.557 ± 0.211
Mobility	1.6 ± 0.5	1.5 ± 0.5	1.6 ± 0.5
Personal care	1.3 ± 0.5	1.1 ± 0.3	1.1 ± 0.3
Usual activities	1.8 ± 0.6	1.9 ± 0.6	2.0 ± 0.7
Pain/discomfort	1.7 ± 0.7	1.7 ± 0.7	1.9 ± 0.6
Anxiety/depression	1.6 ± 0.5	1.5 ± 0.5	1.7 ± 0.7
VAS	48.6 ± 21.9	64.2 ± 20.4	52.3 ± 23.9

CAT: chronic obstructive pulmonary disease assessment test; EQ-5D: EuroQol 5 dimensions; VAS: visual analogue scale.
* $P < 0.05$.

The average score from the PGIC questionnaire was 5.5 ± 1.2. Nine out of 10 patients expressed a change-score ⩾ 5, which is considered a significant and favourable change of their conditions, including activity, limitations, symptoms, emotions and overall quality of life.[24] Only one patient reported a little improvement (score 3), but without a noticeable change. It is worth noting that this patient had an exacerbation while attending the two-year visit.

Healthcare utilisation

Overall, healthcare utilisation during the two years of follow-up was reduced by 32% compared to the two years prior to enrolment. Specifically, 11 COPD-related hospitalisations and 38 COPD-related outpatients visits occurred during the follow-up, while five and 67 respectively occurred during the previous period. Only two patients had a history of hospitalisation during the previous two years. Patients were thus not characterised by a high risk for hospitalisation and readmission. Average hospital length-of-stay was 4.6 days before the intervention and 5.3 days during the follow-up.

Discussion

We conducted a pilot study where telerehabilitation was offered to patients with COPD for two years. This intervention is innovative and brings PR into the patient's home, thus allowing remote supervision at distance. To our knowledge, this is the first telerehabilitation intervention with such a long-term follow-up. Ten patients were recruited after attending a PR programme and participated actively in the intervention, maintaining their exercise and self-management routines for the duration of the study. No dropout occurred. In other long-term studies in PR, dropout rates ranged from 21%[27] to 41%.[28] Long-term telerehabilitation is a feasible intervention and represents an effective strategy for long-term exercise maintenance and self-management.

For people living in rural areas it can be difficult to participate in traditional centre-based PR programmes. In Norway, PR is offered either as a six- to eight-week outpatient programme or as a four-week inpatient programme. Practical barriers include harsh weather conditions, long travelling distances and lack of follow-up programmes locally. Home-based programmes have the potential to overcome these barriers and improve access to PR in underserved areas.[16] Telerehabilitation can also increase access to PR in urban areas, where PR programmes are limited. Telerehabilitation might represent an innovative and efficient strategy to provide both short-term PR programmes and long-term maintenance strategies. Any individual could potentially perform PR at home while remotely supervised by health personnel.

In the absence of any maintenance strategy, benefits of PR appear to diminish after six to12 months.[5,29] The reasons for this decline include decrease in adherence to therapy, especially long-term regular exercise, progression of underlying disease and comorbidities, and exacerbations.[30] The telerehabilitation intervention trialled in this study aimed to support patients with COPD in maintaining benefits of PR in the long term. Results showed that physical performance, lung capacity, health status and quality of life were all maintained at two years after completion of PR. Moreover, patients' 6MWD, FEV_1 and CAT scores improved considerably at one year compared to baseline. Statistically significant improvements were detected at one year for breathlessness and energy levels, which may explain the increase in lung capacity and functional exercise capacity, respectively. Similarly, patients reported a higher quality of life after one year. Since this study did not have a control group, comparison of outcomes is possible only with similar populations from other studies with follow-up longer than 12 months. Figure 3 shows the results of the 6MWD for the patients undergoing long-term telerehabilitation compared to a control group of patients with moderate to severe COPD and similar baseline characteristics followed up for two years after PR.[6] While in Ries et al.[6] there is an

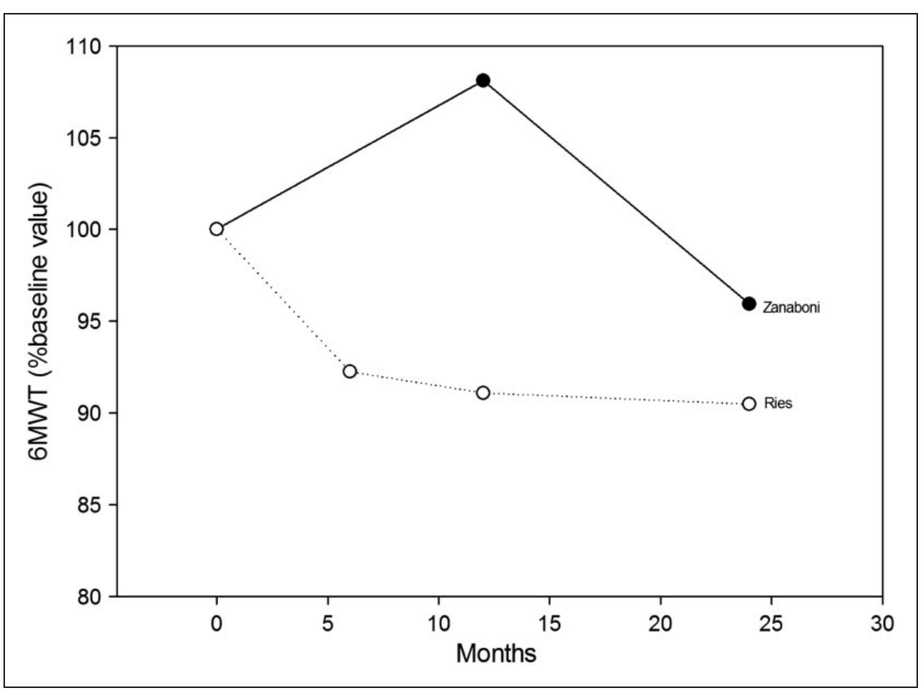

Figure 3. Six-minute walking distance (6MWD) for patients undertaking telerehabilitation compared with a control population from Ries et al.[6]

overall decline of 10% over the period, patients participating in telerehabilitation experienced only a 4% reduction from baseline.

To date, there is limited evidence of the use of telerehabilitation in COPD. In a recent review, telemedicine interventions were promoted through phone calls, websites or mobile phones, often combined with education and/or exercise training.[13] However, no study specifically delivered telerehabilitation. A few studies have shown promising results for short-term telerehabilitation in COPD,[14–19] but none addressed long-term effects.

Other studies evaluated longer-term benefits of maintenance exercise programmes for patients with COPD with limited results. A 12-month maintenance programme of weekly telephone contacts plus monthly supervised reinforcement sessions for patients with moderate to severe COPD was only modestly successful in maintaining health outcomes after PR.[6] In another study, six months of daily rehabilitation followed by six months of weekly supervised maintenance showed improvements in exercise tolerance, dyspnoea and quality of life compared with a control group of subjects with moderate to severe COPD, but benefits diminished over the second year of follow-up.[27] Weekly maintenance training for 12 months after PR in moderate to severe COPD improved walking time but had no influence on quality of life or hospital admissions, compared with unsupervised daily training at home.[31] In a 12-month follow-up study, both weekly, supervised, outpatient-based exercise plus unsupervised home exercise and standard care of unsupervised home exercise successfully maintained 6MWD and quality of life in subjects with moderate COPD.[32] Participation in regular walking after completing PR was associated with slower declines in quality of life and walking self-efficacy as well as less progression of dyspnoea for patients with moderate to severe COPD.[33] Despite some positive results, no study had succeeded in maintaining the benefits of PR for a period longer than one year. In our pilot study, all outcomes at two years were still in line with baseline values.

The optimal combination of maintenance interventions after completion of a PR programme remains unknown.[3] Telemedicine may represent a cost-effective alternative for the follow-up of patients with COPD. In stable, optimised COPD patients who completed PR, telemonitoring reduced primary care chest contacts.[34] We believe that long-term telerehabilitation is an innovative intervention which might also limit the use of hospital resources.

Limitations

This study primarily aimed to investigate the feasibility of telerehabilitation on long-term exercise maintenance in COPD. Due to the innovative nature of the intervention, the study did not have any control group. However, its findings are unique. A multicentre randomised controlled trial (RCT) is currently ongoing to test clinical and cost-effectiveness of this long-term telerehabilitation.

Most of the existing studies have focused on attendance of short-term PR programmes,[35] where participants are required to undertake at least 70% of planned sessions.[36] The challenges of long-term adherence to exercise in COPD are not addressed.[37] In absence of reliable published data, and due to the two-year follow-up during which interruptions were expected, we did not have any a priori definition of completion rate. The average adherence rate for registrations of daily measurements and training sessions was 43% and 56%, respectively. These results appear to be in line with adherence to long-term therapy in chronic diseases, which averages to 50%.[38]

Due to the small sample, one physiotherapist was responsible for supervising the 10 participants during the two-year period. Another physiotherapist was substituted during holiday, absence or sick leave. The high completion rate and exercise maintenance might have been influenced by the presence of one motivated physiotherapist. Use of telerehabilitation in real settings should take into account variations due to supervision by different physiotherapists. Moreover, the study was conducted with voluntary participants willing to attend telerehabilitation. This might also have represented a selection bias and positively influenced the results.

Patients with COPD often experience repeated exacerbations which can lead to a worsening of their health condition and to hospital admissions.[39] Most expenditures for COPD are for hospitalisations and emergency department visits, which account for over 70% of healthcare costs.[40] Long-term telerehabilitation, thanks to the benefits maintained over time, has the potential to prevent exacerbations in COPD and limit healthcare utilisation, which is expected to increase along with disease progression. A systematic cost analysis taking into account differential costs and savings was out of the scope of this study. Moreover, the participants had a low risk for readmission. Equipment costs included NOK 12,000 per patient for the two-year period for treadmill, pulse oximeter, tablet and holder, plus NOK 2000 per patient per year for videoconferencing. These were covered by project funding. The participants kept the equipment after the study end. Assuming a four-year equipment life expectancy, and two-hour monthly follow-up per patient, yearly costs per patient would be approximately NOK 5500 and NOK 6500 for equipment and a physiotherapist's time, respectively. As a means of comparison, the average cost of a COPD-related hospitalisation and a COPD-related outpatient visit was NOK 60,000 and NOK 2000, respectively. We believe that telerehabilitation might represent a cost-effective strategy and a valuable supplement to PR programmes and maintenance programmes. This hypothesis has to be tested with a proper RCT comparing long-term telerehabilitation to usual care.

Conclusion

Long-term exercise maintenance in COPD via telerehabilitation is feasible and patients succeeded in maintaining exercise over two years. Deterioration in the disease is expected over time.[29,30] Results from this pilot study are encouraging and suggest that telerehabilitation can prevent deterioration, improve physical performance, health status and quality of life and limit hospital accesses.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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RESEARCH ARTICLE Open Access

Adherence and factors affecting satisfaction in long-term telerehabilitation for patients with chronic obstructive pulmonary disease: a mixed methods study

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Abstract

Background: Telemedicine may increase accessibility to pulmonary rehabilitation in chronic obstructive pulmonary disease (COPD), thus enhancing long-term exercise maintenance. We aimed to explore COPD patients' adherence and experiences in long-term telerehabilitation to understand factors affecting satisfaction and potential for service improvements.

Methods: A two-year pilot study with 10 patients with COPD was conducted. The intervention included treadmill exercise training at home and a webpage for telemonitoring and self-management combined with weekly videoconferencing sessions with a physiotherapist. We conducted four separate series of data collection. Adherence was measured in terms of frequency of registrations on the webpage. Factors affecting satisfaction and adherence, together with potential for service improvements, were explored through two semi-structured focus groups and an individual open-ended questionnaire. Qualitative data were analysed by systematic text condensation. User friendliness was measured by the means of a usability questionnaire.

Results: On average, participants registered 3.0 symptom reports/week in a web-based diary and 1.7 training sessions/week. Adherence rate decreased during the second year. Four major themes regarding factors affecting satisfaction, adherence and potential improvements of the intervention emerged: (i) experienced health benefits; (ii) increased self-efficacy and independence; and (iii) emotional safety due to regular meetings and access to special competence; (iv) maintenance of motivation. Participants were generally highly satisfied with the technical components of the telerehabilitation intervention.

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Conclusions: Long-term adherence to telerehabilitation in COPD was maintained for a two-year period. Satisfaction was supported by experienced health benefits, self-efficacy, and emotional safety. Maintenance of motivation was a challenge and might have affected long-term adherence. Four key factors of potential improvements in long-term telerehabilitation were identified: (i) adherence to different components of the telerehabilitation intervention is dependent on the level of focus provided by the health personnel involved; (ii) the potential for regularity that lies within the technology should be exploited to avoid relapses after vacation; (iii) motivation might be increased by tailoring individual consultations to support experiences of good health and meet individual goals and motivational strategies; (iv) interactive functionalities or gaming tools might provide peer-support, peer-modelling and enhance motivation.

Keywords: Adherence, Chronic obstructive pulmonary disease, Exercise, Pulmonary rehabilitation, Self-management, Telemedicine, Telerehabilitation

Background

Pulmonary rehabilitation (PR) is a well-documented component in the management of chronic obstructive pulmonary disease (COPD) [1]. The main goal of PR is to improve the patient's overall condition, both physically and psychologically, and to promote long-term adherence of health-enhancing behaviour [2]. PR has proven effective in reducing dyspnoea and improving functional exercise capacity and quality of life [1, 2]. PR is a comprehensive intervention, which includes patient assessment, patient-tailored therapies, such as education, behaviour change, and self-management support [2]. Exercise training is a cornerstone of a PR program [2, 3]. Without any maintenance strategy, benefits after PR usually diminish after 6–12 months. Quality of life is reported better maintained than exercise capacity [2].

Available resources for PR vary among different health care settings and might affect attendance and adherence [2, 4]. Patients living in rural areas especially suffer from poor availability of PR programs [5, 6]. In Norway, specialist competence in PR in community settings is lower than in England and the Netherlands [7], and even fewer exercise maintenance programs are available for patients with COPD, especially in rural areas like Northern Norway. Attendance rate to PR is also negatively affected, as up to 50 % of those patients who are offered PR decide not to attend [2]. Barriers, which prevent patients from attending PR, include disruption of their everyday routine, travel or transportation difficulties, inconvenient timing of the program, lack of perceived benefit, lack of social support, low self-confidence, and fear of being breathless or exacerbating existing medical problems [2, 8–10]. High dropout rates are an additional challenge in PR. Dropout rates vary between studies, ranging from 10 % to 32 % [2]. A study investigating attendance and adherence by COPD patients to PR programs found that 29.1 % of the patients attending PR participated in less than 63 % of the sessions, and were categorised as "non-adherers". The study concluded that age, smoking status, availability of social support, travel distance, and markers of disease severity, in particular use of long-term oxygen therapy, were strong predictors of attendance and adherence to PR [11]. A qualitative study exploring the perspectives of patients with COPD on adherence to PR suggested that adherence could be enhanced by building confidence in the patient, fostering tangible results, and recognising and responding to the patient readiness and access issues [12].

Development of telemedicine-based rehabilitation interventions for patients with COPD attempts to meet the need for increased applicability and accessibility of PR. Telerehabilitation is defined as the delivery of medical rehabilitation service at a distance, regardless of the patients' geographical location, using electronic information and communication technologies [13]. This often implies two-way video communication between the provider and the patient [13]. In contrast to conventional PR, which is often offered as shorter, intensive programs, telerehabilitation has the potential to provide long-term follow-up in the patients' homes. Telerehabilitation for patients with COPD often includes exercise and/or self-management education [14–17]. In addition, a telemonitoring component, which focuses on disease management and monitoring of symptoms, for example after an exacerbation or hospitalisation, may be included [18].

There is still little evidence of the benefits of telemedicine in PR [2]. A recent review showed that telerehabilitation may lead to increased physical activity level, but no effect was detected on exercise capacity and dyspnoea [19]. Other studies have shown promising results for telerehabilitation for patients with COPD in terms of feasibility, safety, exercise capacity, physical activity, health-related quality of life, and reduced hospital admissions [14–16, 20–22]. Dropout rates vary greatly between these studies, ranging from 0 % to 45 % [14–16, 19–22]. Information about adherence to telerehabilitation for patients with COPD is limited. A pilot study of 4-week telerehabilitation intervention showed good adherence by patients to wear a device for ambulant activity monitoring and real-time coaching of daily activity behaviour and to fill in a web-based diary (median use was 109 % and 58 % of the recommended times, respectively) [15]. In another 9-month pilot study, the median use of a web-based triage diary was 82.8 % and the median adherence to prescribed exercises was 21.0 % [16]. Adherence seems to vary just as much between patients as between different telerehabilitation interventions. To our knowledge, no criteria for stratification of patients with COPD who would benefit from telerehabilitation have been developed yet.

Program effectiveness depends on adherence. Adherence to conventional rehabilitation programs and telemedicine interventions may be influenced by patients' satisfaction [19, 23]. Thus, it is important to understand factors affecting satisfaction when planning and developing new telerehabilitation interventions. Together with other patient-related outcomes, patients' satisfaction, perceived usability of the technology, and adherence represent crucial factors to consider when implementing telerehabilitation interventions in routine use for patients with COPD. However, patients' perspectives in telerehabilitation are sparsely documented. We have found only one recent study exploring in depth the attitudes of patients with COPD towards telerehabilitation [24]. Others reported that patients were generally satisfied with telerehabilitation solutions, but experienced some technological usability problems [15, 16].

We conducted a two-year pilot study on telerehabilitation in COPD. Clinical and other patient-reported outcomes have been reported elsewhere [14, 25]. The aim of the current study was to explore the patients' perspectives in long-term telerehabilitation in COPD. We focused our study on adherence and patients' experiences, aiming to identify factors affecting satisfaction and potential for improvements that might increase adherence. Our research questions were: i) How well do participants adhere to telerehabilitation in COPD? ii) Which are the main factors affecting satisfaction and adherence to long-term telerehabilitation program for patients with COPD? iii) Which are the potential improvements that might increase adherence?

Theoretical framework

The theoretical background used in this study was based on selected theories that are suited to highlight patients' perspectives and address the study objectives.

Our work was empirically based, but the analysis was theoretically informed. Theories of health promotion and self-efficacy provided some key concepts [26, 27]. Further, our analysis was based on a view of health as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" [28]. This dynamic view of health emphasises the individual's resilience or capacity to cope, maintain or restore one's integrity, equilibrium, and sense of wellbeing as one face the many challenges of life. This view of health is also in line with Antonovsky's salutogenic theory [29]. Interpretations were informed by Bordin's definition of therapeutic alliance, which consists of three elements: an agreement on the goals of the treatment, agreement on the tasks and methods, and the development of a personal bond between the person seeking change and the helper (therapist) [30]. Motivational strategies were analysed in the light of regulatory focus theory. According to the regulatory focus theory, motivational strategies can be guided by a promotion or a prevention focus [31]. A promotion focus aims to accomplish positive outcomes, while a prevention focus aims to avoid negative outcomes. Individuals with a promotion focus will therefore tend to get motivated by accomplishments, hopes, and aspirations, while individuals with a prevention focus are more likely to get motivated by safety, responsibilities, and obligations [31].

Methods

Study description and intervention

We conducted a pilot study of a two-year telerehabilitation intervention for patients with COPD [14, 25]. Telerehabilitation consisted of three components: exercise training at home, telemonitoring and self-management. Exercise training was performed by participants on a treadmill at home. Participants received an individually tailored interval-training program, consisting of a warm-up period followed by 4 bouts up to 4 min of walking at a higher intensity alternated by bouts of lower intensity or full stop. The program ended in a cool-down period. Training was recommended three times a week, and the duration of each session was ≥30 min. Perceived intensity to be aimed for during interval bouts was 6 on the Borg CR10 scale, corresponding to a strenuous exercise level [32, 33]. Participants were provided with a tablet computer (Apple iPad 2) and a pulse oximeter used for telemonitoring. Videoconferencing sessions up to 30 min between participant and tele-physiotherapist were performed weekly. The tablet computer was also used to access a webpage for self-management which included: an individual training program, a daily diary for reporting symptoms and oxygen saturation at rest, a training diary for reporting exercise duration, perceived exertion, oxygen saturation and heart rate during exercise, and historical data. Data were also accessible to the tele-physiotherapist and used for discussion with the patients.

The Regional Committee for Medical and Health Research Ethics, North Norway, approved the study, and all participants signed a written consent form for the study.

Participants

Among patients completing a four-week inpatient pulmonary rehabilitation program, the physician in charge selected eligible patients with COPD in a stable health condition and deemed physically capable to perform safely exercise at home. Patients were then invited to take part to the study, and participation was on a voluntary basis. Ten patients with moderate to severe COPD were recruited for the pilot study. The average age of participants was 55.2 years. Eight participants were retired. Five lived with their spouses or other family members. Half of the participants were women. Three used long-term oxygen therapy. Average travel distance to the closest hospital was 99 ± 76 km (range 3–218 km). Eight participants used the Internet daily or nearly every day before the intervention, while two were inexperienced computer users.

Triangulation of data collection techniques

A mixed methods approach and a triangulation of data collection techniques were selected to address the study objectives. Four methods for data collection were utilised to explore our research questions. Adherence to the telerehabilitation intervention was measured through the analysis of logs on the webpage. Factors affecting satisfaction and adherence, together with potential for service improvements, were explored through focus groups and individual open-ended questionnaires. User-friendliness and technical improvements were examined through a standardised questionnaire and open-ended questionnaires.

Analysis of logs

Adherence to the telerehabilitation intervention was assessed by the dropout rate and adherence rate. A dropout was defined as a participant failing to participate to the intervention as required by the study protocol. The dropout rate was therefore calculated by the percentage of participants who did not attend the final visit and were no longer active. Adherence was defined in relation to what extent the participants used the intervention compared to the recommendations [34]. Logs on the webpage were extracted to measure, for each participant, the average number of daily diary registrations per week and the average number of training sessions per week. Recommendation regarding daily diary registrations and training sessions was 7 times per week and 3 times per week, respectively. The adherence rate for the daily diary was measured by the number of registrations entered divided by the number of those recommended (7 times per week). The adherence rate for the training diary was measured by the number of training sessions performed divided by the number of those recommended (3 times per week). Descriptive statistics were summarised for the whole study period and stratified for the first and the second year of follow-up. Diary registrations and training sessions were also analysed by 3-month intervals to show the trend from baseline to study end. Since the 10 participants started at different times, the average use for each month of the year was also computed to detect whether there was any seasonality. Finally, the average for each participant was summarised to show individual differences in adherence.

Focus groups

We relied our study of satisfaction and potential improvements on focus groups because we wanted to open the analysis for new angles and connections to everyday life from the participants' view. Focus groups are used to benefit from the group interaction to produce data and insight [35]. We used the focus groups to explore the participants' experiences with the intervention and technology and to facilitate a creative process between the participants and the research team. The goal was to explore factors affecting satisfaction and discover potential improvements which might affect adherence.

Two semi-structured focus groups took place during a two-day meeting in June 2013 and May 2014 at the rehabilitation centre where the participants were recruited. All 10 participants took part in at least one of the two focus groups. One moderator (P.Z.) and one co-moderator (L.A.L.) led the first focus group. This was focused mainly on user-friendliness and experiences with the technological equipment. The second focus group, led by one moderator (H.H.) and two co-moderators (L.A.L. and P.Z.), focused on experiences with participating in a long-term telerehabilitation intervention and potential for service improvements. H.H. knew some of the participants from a previous work relationship at the rehabilitation centre. L.A.L. was the physiotherapist supervising the participants via telemedicine. P.Z. did not have any relationship with the participants beforehand. A semi-structured interview guide was used. The moderators presented topics using open-ended questions, facilitated the dialogue among the participants and followed up with further questions in an informal and open atmosphere. The participants allowed themselves to discuss relatively freely about their experiences. They mirrored each other, discussed different opinions, and presented new topics. The moderators sought to summarise discussions around the various topics consecutively, so that interpretations of the informants' answers were verified directly. Both focus groups lasted for 1.5 h and were recorded. Recordings were transcribed verbatim in Norwegian. Quotes used in this paper were later translated into English.

Open-ended questionnaires

An individual open-ended questionnaire focused on personal experiences, benefits and challenges in participating in long-term telerehabilitation was collected and analysed together with the transcripts from the focus groups. The questionnaires were collected for all patients after the first and the second year of participation, just before the focus groups.

User-friendliness questionnaire

The System Usability Scale (SUS) is a questionnaire used to grade the usability of systems [36]. SUS is considered a valid and reliable tool for evaluation of a wide variety of products and services, including mobile devices and webpages [37]. It consists of a 10-item questionnaire with five response options (5-point Likert scale with anchors for Strongly agree and Strongly disagree). SUS results yield a score between 0 and 100, with 100 indicating best usability. In the current study, SUS was used to measure user-friendliness of the telerehabilitation intervention [36], and was completed by the participants at the end of the first year, before conduction of the first focus group.

Data analysis

Analysis of the qualitative data focused on identifying topics rather than on differences and similarities between individual respondents, thus confirming to a thematic analysis technique [38]. Further, the material was analysed using systematic text condensation, which is inspired by Giorgi and modified by Malterud [39, 40]. In the current study, three of the authors read the material separately to get an overall impression, which was later discussed. Secondly, the text was analysed individually in search for meaning units that could represent the participants' experiences and adherence to the intervention. Then these meaning units were discussed, condensed and coded under themes. In the end, findings were summarised and constructed into major themes that could represent factors affecting satisfaction and adherence, or potential for service improvement (Fig. 1).

Results

Adherence

On average, the participants were in the study for 740 days. No dropout occurred. They all participated actively during the two-year period and attended all planned visits at baseline, 1 year and 2 years. The participants experienced some relapses due to different reasons, including holidays, traveling, sickness, or hospital admissions. However, they all rejoined the program after these breaks. One participant stopped registering in the daily diary and training sessions two months before the study end, but still maintained regular contacts with the tele-physiotherapist during this period.

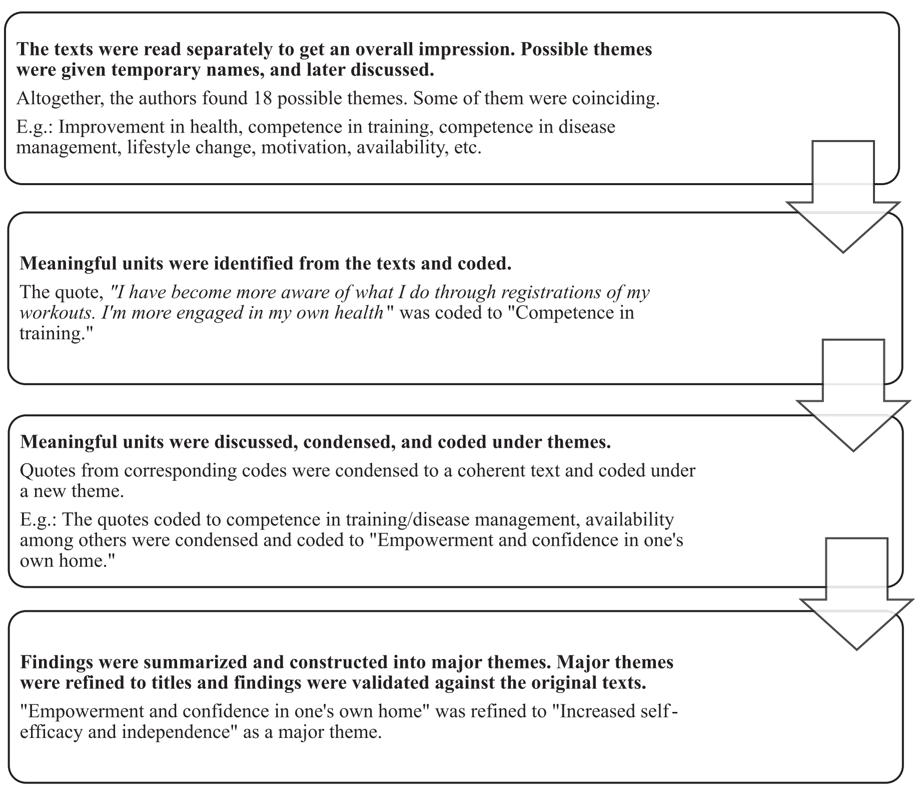

Fig. 1 The steps of analysis in systematic text condensation with examples

On average, participants registered 3.0 diary registrations/week and 1.7 training sessions/week via the webpage during the whole study period. This corresponds to an average adherence rate of 43.3 % and 56.2 %, respectively (Table 1). Use and adherence decreased from the first to the second year. On average, participants had 3.4 diary registrations/week and 2.1 training sessions/week in the first year, and 2.6 diary registrations/week and 1.2 training sessions/week in the second year.

Adherence rate for training sessions increased during the first three months of the study to a level close to the recommendation (Fig. 2). Adherence was then maintained during the first year, while it decreased from the second year until the study end. Adherence rate for diary registrations showed a similar trend, but with lower variations over the two-year period (Fig. 2).

Figure 3 shows the seasonality of training sessions and diary registrations. There were some negative troughs during December (Christmas) and July-August (summer holidays) during which participants performed fewer training sessions. The tele-physiotherapist encouraged the participants to take time-off during holidays, underpinning exercise as an ordinary job. Diary registrations appear to be affected by the same seasonality as training sessions (Fig. 3).

Table 2 summarises the individual adherence rates for the ten participants for the two-year period. Adherence to the daily diary ranged from 8.2 % to 98.3 %, while adherence to training session ranged from 16.3 % to 99.1 %.

Factors affecting satisfaction and adherence

Four major themes regarding factors affecting satisfaction and adherence, and potential for service improvement emerged from the analysis of the data collected: (i) experienced health benefits; (ii) increased self-efficacy and independence; (iii) emotional safety due to regular meetings and access to special competence; and (iv) maintenance of motivation. Quotes from the participants used to highlight the themes, are marked with participant number and sex (F for female and M for male).

Experienced health benefits

A positive change in experienced level of health throughout the two-year period was mentioned by all the participants. Experienced health benefits were interpreted as one of the main factors affecting satisfaction. The second focus group started with the question: "What do you think about participating in the study?" The first reply was as follows:

> *Gold and green forests… in terms of my health… compared to before. It has been effective, even though you are plagued with pneumonia and all that, which drags you down, but after a while, you get back on your feet again, up, on your own peak. It is not much, but I have to call it my own peak* (M10).

Despite having a chronic disease, the participants felt in good health most of the time. They described a broad perspective of health and health benefits consequent to their participation in the study, including physical, psychological, and social achievements. They also valued these benefits in relation with their everyday life. Some of the most colourful and descriptive statements regarding experienced health benefits appeared on the individual open-ended questionnaires after the first year:

> *The study gave me better health and immune defence. Now it is easier to cope with problems that are there almost all the time when you have COPD and just 30 % of your lung capacity left. The spark of life is increasing. This means that you meet your days easier from morning to night* (M10).

> *I can tag along with my family on trips, and go fishing with my grandchildren* (M4).

> *My couch is less worn down than it would be without this project* (M3).

Increased self-efficacy and independence

The participants proudly described an increased competence in a variety of different fields. These mastery experiences seemed to have created a higher degree of self-efficacy and confidence in self-management of their exercise regime, everyday life, and disease.

An increased competence and reflection on how they best can adjust and perform their exercise regime can be exemplified in the following quotations:

> *There are many different elements that might affect how you complete the exercise and what you think about it* (M4). *-Yes, like the temperature in the room,*

Table 1 Average adherence to the daily diary and training sessions during the study

N = 10	Averageyear 1	Adherenceyear 1	Averageyear 2	Adherenceyear 2	Averagetotal	Adherencetotal
Daily diary registrations	3.4/week	48.5 %	2.6/week	37.0 %	3.0/week	43.3 %
Training sessions	2.1/week	69.1 %	1.2/week	40.5 %	1.7/week	56.2 %

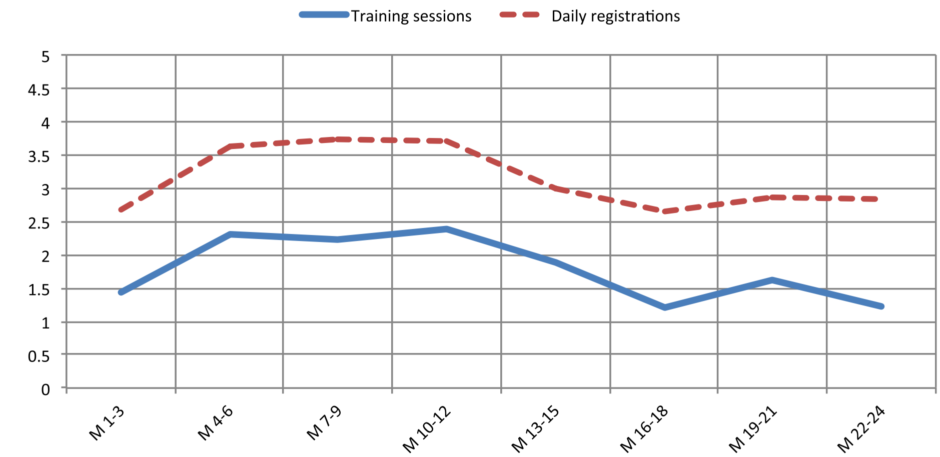

Fig. 2 Monthly adherence rate for training sessions and diary registrations with three-month intervals

which other activities you have been doing that day, if you exercise in the morning or in the evening (M6).

Mastery experiences in training influenced also their independence and self-efficacy in other areas of their everyday life:

I have become stronger mentally. When I managed something physically, I somehow got stronger mentally as well. I felt: Yes! I managed to do the housework, and then I dared to go to the grocery store as well (F1).

Curiosity, access to a pulse oximeter and a mastery experience from the everyday life improved one of the participants' self-management of her disease:

I saw the light one day. I was using the oximeter while cleaning the house, and I discovered that I was sooo low. I didn't use the oxygen while doing housework before, but I do now (F8).

For many of the participants, self-efficacy seemed somehow connected to acceptance and control of their disease. In one section of the second focus group, they talked about the shame and stigma they might feel while being out in the society:

I felt ashamed to ask the woman at the cashier for help… I felt shame, but then I thought: Why bother with the shame?! If you need help, you need help. That's a done deal. Then I felt better. Now I can ignore

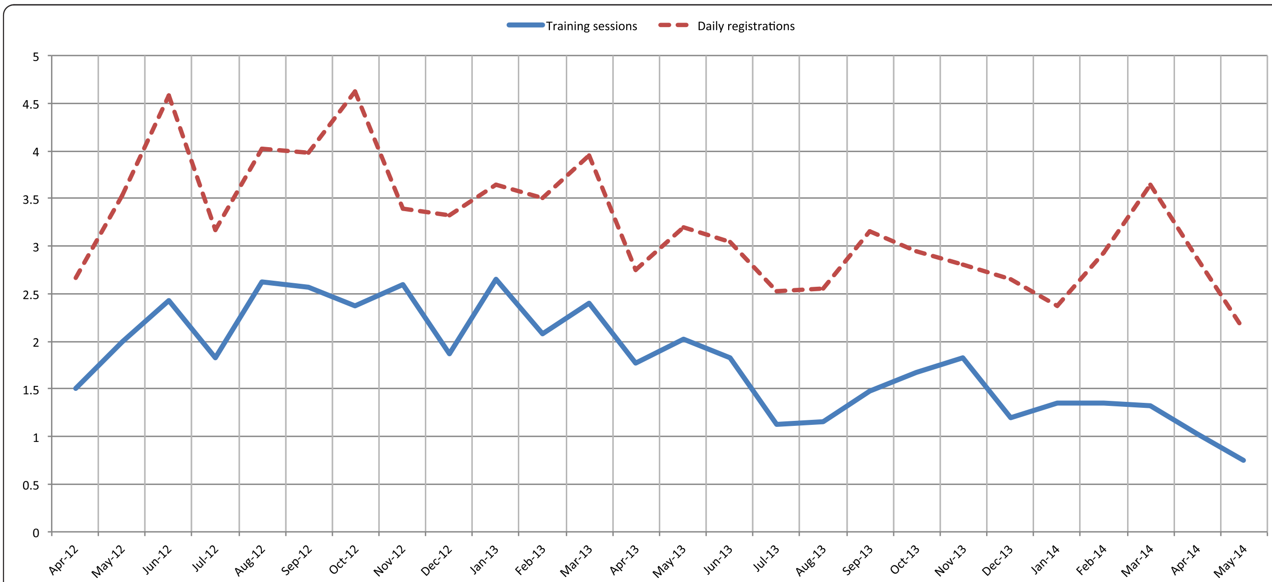

Fig. 3 Seasonality of adherence rate for training sessions and diary registrations

Table 2 Adherence, diary registrations and training sessions per participant during the study

Participant n = 10	Treatment days	# Diary registrations	# Training sessions	Diary reg/ week	Training/ week	Adherence to diary registrations in %	Adherence to training sessions in %
F 1	780	593	329	5.3	3.0	76.0	98.4
M 2	765	752	325	6.9	3.0	98.3	99.1
M 3	704	540	124	5.4	1.2	76.7	41.1
M 4	753	133	128	1.2	1.2	17.7	39.7
F 5	752	185	83	1.7	0.8	24.6	25.8
M 6	752	218	219	2.0	2.0	29.0	68.0
F 7	743	61	52	0.6	0.5	8.2	16.3
F 8	704	275	171	2.7	1.7	39.1	56.7
F 9	709	189	109	1.9	1.1	26.7	35.9
M 10	738	273	258	2.6	2.4	37.0	81.6
Average	740	321.9	179.8	3.0	1.7	43.3	56.2

M = Male. F = Female. Recommendations for diary registrations and training sessions were respectively 7 and 3 times/week

> *other people. I have to focus on myself to be able to go through the shopping mall* (M2).

> *You have to accept your disease. When you have done everything you can to be at your best health, when you have exercised as much as you can, and things cannot get better, then you do not feel as ashamed any more. You actually do make an effort to keep on your own feet* (M8).

All participants were satisfied with the opportunity to exercise independently at home. In Northern Norway, where the study was conducted, there can be long travel distances to training facilities and harsh weather conditions, especially during winter. The availability of a treadmill at home appeared as a solution to these barriers and participants valued the broadened accessibility and availability: *You can register at any time of the day and we have even talked when I was in Turkey* (F8). In addition, the participants appreciated the possibility to exercise effectively at home thus avoiding the stigma of being observed while exercising:

> *If I want to go to the gym, it is a 60 km drive from my house. Moreover, I would have felt weak in front of others. They would have looked at me, and thought: He cannot do anything. Then I would have felt it myself as well. I think I would have quit sooner* (M2). *–Kind of the opposite experience, but I got a lot of positive, but for me, unpleasant attention at the gym, especially since I got this oxygen tube in my nose. I heard like thirty times in one session: You are doing sooo good! Too much attention, well meant, but for me it was negative* (F8). *-I really enjoy going to the basement at home to exercise. There I can be alone, listen to music, and just walk. Then I actually can relax* (M2).

More independence was also described in the relationship with the therapist. With laughter, the participants reflected on how the technology made it easier for them to withdraw themselves without confrontation from the collaboration with the tele-physiotherapist. Through onomatopoeic words and statements like: *Bang!* (Referred to slamming the iPad cover together to break contact) and *Tut tut tut tut! No longer online…*, they described how they could become "unavailable" or "lose network access" if the follow-up did not “fit” their goals, mood or values, or if the relationship felt too challenging.

The nature of the telerehabilitation intervention, which encouraged daily registrations of symptoms and training sessions on the webpage, gave some of the participants increased control over their own health:

> *I have become more aware of what I do through registrations of my workouts. I am more engaged in my own health* (F1).

Participants highlighted also that the intervention helped them establish *regular routines for exercising (M2 & M3).* However, one participant reported difficulties in performing regularly all the required activities: *I exercise, but I always forget to report the sessions (F7).*

Emotional safety due to regular meetings and access to special competence

The participants expressed that they felt safe and well taken care of in the study:

It was comforting that the physio was there [over videoconferencing] when I started. She confirmed that I was doing it right. I think it is important that you do not go there by yourself and exercise in the wrong way. Then you knew you were on safe ground at least (M6).

The tele-physiotherapists' competence and experience with pulmonary diseases available via videoconferencing was particularly appreciated:

My physio at home does not have the special knowledge about COPD. Pulmonary diseases are not her specialty field (F8).

Participants valued their relationship with the tele-physiotherapist and the regularity of the videoconferences. These were seen as important factors for exercise maintenance:

If the health personnel do not have knowledge about the disease, then it is a problem. However, they also have to know the person who has it (M2).

One of the best things with the project has been to meet the [tele-]physiotherapist once a week, and get to ask questions about everything that is on your mind (F1).

Maintenance of motivation

After the first year, only two participants reported that their motivation was declining. Four participants described themselves as still highly motivated. The others described their motivation for exercising as good. The description of their level of motivation was more nuanced at the end of the second year. The participants felt that it was more difficult to start exercising again after periods of vacation and sickness. Seven of the participants stated that they had several periods with pneumonia or exacerbations during the second year. Two participants expressed lack of motivation and depression as reasons for not exercising or registering in the diary. Only one participant claimed to be highly motivated throughout the two years. Hence, maintenance of motivation was seen as a highly relevant challenge in this long-term telerehabilitation intervention. One of the participants described the increasing lack of motivation as follows:

Everything went well during the first six months. I felt I increased my capacity every week. Then it stopped. Actually, I felt that my capacity started to decrease, and exercise became tougher to complete. I felt pleasure by the improvements. However, when it worsened, I struggled. I postponed and postponed, to the end of the day. This "upward feeling" is important, at least for me (M6).

An increase in physical performance seemed to represent one of the main factors affecting motivation. However, this group of patients cannot increase their physical capacity infinitely. One of the participants, who adhered very well to the study, was able to set new goals when the "upward feeling" was lost:

I could not run faster, but I could increase the duration and walk for a longer time. Then I felt an accomplishment (F1)!

During the study period, the exercise program was progressed or changed by the tele-physiotherapist according to the participants' registrations of the Borg CR10 scale for perceived exertion [32, 33], heart frequency, and oxygen saturation during interval peaks. The previous programs were not saved in the system. The participants experienced self-reported changes in physical capacity, especially related to better management of everyday life. However, they missed a more objective measure of exercise progress. As one stated and others supported:

I would like to try the first exercise program I got. I remember how I struggled. I would like to try this now to see if there is any improvement (F1).

Objective reports from graphs of the training diary and the daily diary that tracked changes in symptoms and exercise performance, seemed to be appreciated by the participants. Participants considered these graphs as motivational factors and learning opportunities.

In the first focus group, the participants mentioned how being part of a research study motivated them. Affiliation, being part of a "bigger" context and a sense of doing something for other patients with COPD, were motivational factors.

During the second year, the participants seemed to have entered a maintenance phase. They expressed that they were generally satisfied with life and had accepted their condition. They coped well with everyday life according to the varying symptoms of the disease:

*I organise my life in a different way now. I know my limitations and my physical capacity better (*M3).

When we searched the material for motivational strategies, we found that the participants used both a promotion and a prevention focus. Most of the participants distinctly reported a promotion focus related to motivation:

> *Suddenly I could walk outside for 3 km quite fast without any stops. I also got comments on how good I looked. I have lost 10 kg* (F1).

However, we also find 2–3 participants using a prevention focus for describing their motivational strategy:

> *My father had COPD. He just sat there, crying for the entire day, feeling sorry for himself. I can see him before me, and then I want to exercise. I don't want to be like him! I don't want to sit like that. What horror! This motivates me* (M2).

There was no connection between high adherence and a specific motivational strategy. The two participants with the highest degree of adherence expressed different motivational focuses.

User-friendliness and technical improvements

The average score in the SUS was 83.5 (min 32.5, max 100). This indicates that the participants were highly satisfied with the equipment and considered it user-friendly.

The experience with the computer technology ranged from:

> *After two years, I'm still not fluent with the iPad* (M4) to *In the beginning, I almost didn't dare to touch the iPad, but now it is absolutely essential for me* (F1), and, *I had no experience with computers, but if I can learn this, everybody else can* (M2).

The participants had different suggestions for technical improvements of the intervention. Their main complaint was the stability of the videoconference connection. Technology that does not function the way it is supposed to is experienced as stressful. As one participant stated:

> *I had many difficulties during videoconference with the physiotherapist. Sometimes we saw each other, but could not speak. Sometimes we could speak, but we could not see each other. It has been a slight nightmare at times* (M3).

Other suggestions for improvements were: more flexible exercise programs that could take into account "good days and bad days," bigger buttons in the webpage, more training in the use of the tablet and the webpage, including interpretations of the diary and exercise registrations. The reliability of the measurements from the pulse oximeter was brought forward as important for completing and keep up with the registrations. Finally, participants would have preferred to meet face to face more often to discuss experiences and challenges. Some saw a potential in meeting in a group videoconference, but the strongest opinion was that they would benefit more from a physical meeting.

Discussion

As few telerehabilitation interventions have evolved beyond the pilot phase, understanding the determinants of success is key to design better interventions. This paper explored adherence and factors affecting satisfaction in long-term telerehabilitation for patients with COPD from the participants' perspectives. First, the results suggest that the potential in long-term telerehabilitation over the existing offer of exercise maintenance programs after conventional PR is threefold. Telerehabilitation has the ability to overcome geographical distance. A travel time greater than 30 min is a known barrier for attending PR and exercise programs for patients with COPD [41]. Another advantage of telerehabilitation lies in the specialist access and the potential regularity of follow-up by the same health personnel over a long term. Second, the results identified four key factors to be considered when designing and delivering future telerehabilitation interventions for patients with COPD in order to increase adherence and satisfaction. These key factors are: (i) adherence to different components of the telerehabilitation intervention is dependent on the level of focus provided by the health personnel involved; (ii) the potential for regularity that lies within the technology should be exploited to avoid relapses after vacation; (iii) motivation might be increased by tailoring individual consultations to support experiences of good health and meet individual goals and motivational strategies; (iv) interactive functionalities or gaming tools might provide peer-support, peer-modelling and enhance motivation.

Adherence

According to the WHO, adherence to long-term therapy in chronic diseases averages to 50 % [34]. In our two-year study, the average adherence rate for diary registrations and training sessions was 43.3 % and 56.2 % respectively. Compared to a nine-month intervention consisting of a web-based home exercise program, an activity coach for ambulant activity registrations and feedback, self-management via a web-based triage diary, and teleconsultations, adherence in the current study was higher for the training sessions, but lower for the web-based diary [16]. Reasons might be that our intervention had a stronger focus on exercise rather than monitoring symptoms and early recognition of exacerbations. A more active education on the recognition of early symptoms of exacerbation and the importance of treatment together with a provision of a straightforward treatment regimen might support the participants' adherence to fill in the diary. On the other hand, the patients in our study were in a quite stable condition of their disease, and registering symptoms every other day (50 % adherence) throughout a period of two years might be enough to detect early changes in symptoms and start treating exacerbations as soon as possible. An average adherence rate of 56.2 % for the training sessions equals to 1.7 training sessions per week. Compared to recommendations of 3 training sessions per week, this rate is probably too low to maintain the experienced health benefits and increased physical performance. Even though the average adherence rate was kept lower than recommended, we consider the intervention successful as all participants maintained their exercise and self-management routines for the 2-year period. No other studies have succeeded in such a result. However, we believe that while a lower adherence for the diary registrations does not have any negative impact, it is important to focus on patient's compliance to exercise, which is the key feature of traditional PR programs as well as of the current telerehabilitation intervention.

Adherence rate for training sessions increased during the first three months of the study to a level close to the recommendation. This could be due to a learning effect or an increase in motivation. Adherence was also affected by seasonality. The participants were encouraged to take time-off and did not receive follow-up via videoconferencing from the tele-physiotherapist during holidays. This influenced the lower adherence in these periods. As the participants appreciated the regularity of the telerehabilitation intervention and found it difficult to start exercising again after holidays, we would recommend to exploit the potential for regularity that lies within the technology. Future telerehabilitation interventions could benefit from prescheduled peer-group meetings or exercise sessions via videoconferencing, mobile text message reminders aimed to motivate individual training, online follow-along exercise videos or other gaming elements for exercise training during holidays to avoid relapses.

Factors affecting satisfaction and adherence, and potential service improvements

Health benefits, experienced in terms of increased physical performance and self-management, were highlighted by the participants as the main factor affecting satisfaction. Despite having a chronic disease, the participants gave an optimistic and varied picture of their definitions of good health. It seems important to foster these positive perspectives of health in long-term telerehabilitation interventions. Good health is often seen as medicine's main goal [42]. If individual experiences of good health represent a primary objective in long-term telerehabilitation services for patients with COPD, health professionals cannot rely on following up all patients in the same manner. It becomes important to find out what corresponds to the patients' "own peak" and what good health is for the individual patient. This corresponds well to recent holistic views of health and theories of health promotion [27–29, 42, 43].

During the two-year participation in the pilot study, participants expressed an increase in self-worth and acceptance of their condition. They became more aware of their own needs and how they could fend for themselves. Despite feeling vulnerable, patients with COPD often come to an acceptance of their situation, which lead them to be able to adapt to their physical limitations and make the most out of their situation [44]. Their condition is perceived as a "way of life" rather than an illness, where symptoms and health problems becomes the normality. This "passive acceptance" might hinder patients to address healthcare needs [45]. In contrast, the participants in our study developed a newfound control over their own health situation and a renewed interest in their own health. When taking actions in terms of exercising, they felt they could cope with the vulnerability and stigma from having a chronic and often self-inflicted disease.

Conventional PR is patient-tailored, and core generic strategies such as goal setting, goal assessment, problem solving and decision-making are important elements in self-management for patients with COPD [2]. Patients' goals and resources are often assessed against their specific context and opportunities in the environment [46]. In our long-term telerehabilitation intervention, there was no formal functionality for goal setting and goal attainment included in the webpage. Maintenance of motivation was perceived by participants as a main challenge. They were motivated to exercise as long as they experienced progress in physical capacity and the exercise program could be progressed. However, motivation decreased once their threshold for progress in physical capacity was reached. This happened for most of the participants after the first year of follow-up. Adherence might benefit if patients with COPD are involved in their own rehabilitation process. An agreement of goals and methods between the patient and the helper is seen as an important key to the change process [30]. Further, patients with COPD might need support to define visible results and appraise their newly acquired competences to be able to implement them in everyday life [12, 47]. A previous qualitative study revealed that patients with COPD expressed and alternated between four attitudes towards telerehabilitation: indifference, learning as part of situations in everyday life, feeling of security, and motivation to perform physical exercise [24]. These experiences with telerehabilitation are to some extent congruent with our findings. In the aforementioned study, indifference was related to measuring stable values (of blood pressure, pulse, weight, spirometry and oxygen saturation). This implied that stable patients with COPD would not benefit as much from telerehabilitation as patients with more unstable conditions. Conventional PR is recommended for all patients with COPD, even patients in earlier stages [2]. Patients in earlier stages are often medically stable, but they would still benefit from rehabilitation in terms of enhanced mastery of everyday life and increased physical performance. Visualisation and documentation of tangible signs of improvements and maintenance might reduce the feeling of indifference and make long-term telerehabilitation suitable and beneficial for patients in stable conditions as well. Future telerehabilitation services, particularly in chronic diseases, should therefore also be patient-tailored, focusing on documentation and evaluation of goals, progress and maintenance. Likewise, it is important to assess individual interpretations of good health and preferences in motivational strategies so that every participant can be followed up according to his or her own needs and values.

Potential for technological improvements

We have already suggested exploiting the potential for regularity that lies within the technology. Motivational strategy seemed to differ among the participants with adherence above 70 %. We see a potential in using the technology to include tailored motivational messages based on the individuals' promotion or prevention-goal orientation on the webpage or via mobile text messages [31, 48].

Increased self-efficacy and independence were among the factors affecting satisfaction. Together with increased physical capacity, increased self-efficacy helped the participants in regaining energy to enjoy and participate in social activities, including family life. One of the best ways to increase self-efficacy is through mastery experiences [26]. By provision of equipment for effective exercise training, self-monitoring and supervision in the home environment, the participants seemed to have experienced many positive mastery experiences. In this study, a treadmill and pulse oximeter formed the foundation for new mastery experiences. The best way to provide mastery experiences via telemedicine is not known. Other studies piloted different activity monitors [15, 16].

Self-efficacy can also be created and strengthened through peer-modelling processes or vicarious experiences provided by social models. Seeing people similar to oneself succeed by sustained effort raises the observers' beliefs that they too can be able to master the opposing challenge [26, 49]. Telemedicine can easily support peer-modelling processes through interactive interaction or gaming tools [15]. Online group exercise sessions for patients with COPD have been piloted successfully [50]. Telemedicine can also facilitate peer-support and regular exchange of experiences that our participants have missed [51]. Group exercise sessions or self-scheduled meetings between the participants supported by videoconferencing or gaming tools might be provided in future telerehabilitation interventions. Peer-support can also be provided through chat rooms or discussion forums where participants can share their experiences [52]. It is known that social support from a group contributes to increased motivation for exercise and exercise maintenance in COPD [44].

Limitations

As most of the results in this study is based on qualitative data, strengths and weaknesses are assessed against the four criteria for trustworthiness in qualitative research proposed by Guba and discussed by Shenton: credibility; transferability; dependability; and confirmability [53]. All participants were given the opportunity to express their experiences and reflections regarding attendance in the study through a triangulation of methods in a familiar atmosphere. Authors' immediate understanding of the participants' answers were summarised consecutively during the focus groups, so that participants' interpretations were confirmed, thus increasing credibility. We conducted a pilot study with a small number of patients with COPD. Results might therefore not necessarily be transferred to other settings or patient groups. Nevertheless, the findings are somewhat congruent with the existing body of evidence. In terms of dependability, an effort was made to transparently describe the research process and the analysis procedure. The conduction of the two focus groups and the analysis of the material were made by more than one of the authors, thus increasing confirmability. On the other hand, the physiotherapist conducting the videoconferences was also present during the focus groups. The participants might therefore have held back some personal thoughts. However, our overall impression is that triangulation of data collection allowed the participants to provide their critical views as well, thus reducing the effect of investigator bias. Despite being conscious of our hypothesis and theoretical background during data collection and analysis process, these might have affected our interpretations.

During the first year, participants recognised affiliation to the research study as a motivational factor. Hence, adherence and positive experiences perceived during the first year might have been affected by the Hawthorne effect. Being observed might change research participants' behaviour or answers to what they think is expected [54]. However, only few studies on this concept have demonstrated the Hawthorne effect beyond a 6-months period [54].

No individual interviews were conducted in this study. This is considered a limitation. However, focus groups were chosen to facilitate a creative process among the participants and to open for a thematic analysis of new angles on long-term telerehabilitation from the participants' view. Individual feedback and experiences were provided by individual open-ended questionnaires.

Implications for research

The adherence rate differed widely among the participants in this pilot study. Our research was not designed to investigate which personal characteristics influence adherence to telerehabilitation. Future studies should implement telerehabilitation interventions on a large-scale and explore how adherence differs among patients, thus producing useful knowledge to develop stratification tools for telerehabilitation interventions.

Conclusions

No other studies have focused on long-term exercise maintenance via telerehabilitation. The current study suggests that long-term exercise maintenance is feasible and that patients with COPD successfully adhered to the intervention for the long-term duration of 2 years. Our findings revealed some factors that are important for the successful use and acceptance of the intervention. Satisfaction was supported by experienced health benefits, increased self-efficacy and emotional safety. Maintenance of motivation was a challenge and might have affected long-term adherence. Four key factors of potential improvements in long-term telerehabilitation were identified: (i) adherence to different components of the telerehabilitation intervention is dependent on the level of focus provided by the health personnel involved; (ii) the potential for regularity that lies within the technology should be exploited to avoid relapses after vacation; (iii) motivation might be increased by tailoring individual consultations to support experiences of good health and meet individual goals and motivational strategies; (iv) interactive functionalities or gaming tools might provide peer-support, peer-modelling and enhance motivation.

Abbreviations

COPD: Chronic obstructive pulmonary disease; PR: Pulmonary rehabilitation; SUS: The System Usability Scale.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

H.H. contributed to acquisition of data, analysis and interpretation of data, drafting and revision of the manuscript. H.K.A. contributed to the interpretation of data and revision of the manuscript. L.A.L. contributed to the conception and design of the study, acquisition of data, analysis of data and revision of the manuscript. A.H. contributed to the conception and design of the study, patient selection and revision of the manuscript. P.Z. contributed to the conception and design of the study, acquisition of data, analysis and interpretation of data, drafting and revision of the manuscript. All authors read and approved the final manuscript.

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ARE PHYSICAL ACTIVITY AND BENEFITS MAINTAINED AFTER LONG-TERM TELEREHABILITATION IN COPD?

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ABSTRACT

This study investigated whether physical activity levels and other outcomes were maintained at 1-year from completion of a 2-year telerehabilitation intervention in COPD. During the post-intervention year, nine patients with COPD (FEV_1 % of pred. 42.4±19.8%; age 58.1±6 years) were encouraged to exercise on a treadmill at home and monitor daily symptoms and training sessions on a webpage as during the intervention. Participants were not provided supervision or motivational support. Physical activity levels decreased from 3,806 steps/day to 2,817 steps/day (p= 0.039). There was a decline in time spent on light physical activity (p=0.009), but not on moderate-to-vigorous activity (p=0.053). Adherence to registration of symptoms and training sessions decreased significantly. Other outcomes including health status, quality of life, anxiety and depression, self-efficacy, and healthcare utilization did not change significantly. In conclusion, provision of equipment for self-management and unsupervised home exercise might not be enough to maintain physical activity levels.

Keywords*: COPD, Maintenance, Physical activity, Pulmonary rehabilitation, Quality of life, Telemedicine, Telerehabilitation*

Patients with Chronic Obstructive Pulmonary Disease (COPD) suffer from a persistent airflow limitation which, together with commonly experienced extrapulmonary effects and comorbidities, is associated with physical inactivity (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2016; Suissa, Dell'Aniello, & Ernst, 2012; Watz et al., 2014). An inactive lifestyle might in turn lead to a more rapid progression of the disease and worsening of health status (Troosters et al., 2013). Inactivity is also associated with a higher risk of COPD-related hospital admissions (Garcia-Aymerich, Lange, Benet, Schnohr, & Antó, 2006). Pulmonary rehabilitation (PR) is highly recommended for all patients with COPD, and is effective in reducing dyspnea, improving functional exercise capacity, and quality of life (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2016; Spruit et al., 2013). However, PR shows only modest effects in enhancing daily physical activity in patients with COPD (Burtin et al., 2015; Watz et al., 2014). Benefits of PR seem to diminish after 6-12 months without any maintenance strategy. Low adherence to long-term regular exercise might be one of the main reasons (Spruit et al., 2013). The optimal maintenance intervention to extend benefits of PR and enhance or prevent loss of physical activity over the long-term still remains unknown (Brooks, Krip, Mangovski-Alzamora, & Goldstein, 2002; Ries, Kaplan, Myers, & Prewitt, 2003; Spruit & Singh, 2013; Watz et al., 2014). However, continuity in follow-up programs and access to regular support and supervision is reported to support long-term exercise maintenance in COPD (Hellem, Bruusgaard, & Bergland, 2012). Telemedicine-based interventions promoted through phone calls, websites, or mobile phones have showed promising results in increasing physical activity levels in COPD (Lundell, Holmner, Rehn, Nyberg, & Wadell, 2015). Nevertheless, few studies have been conducted on the effects of telerehabilitation in COPD, and there is little knowledge about the long-term effects. Eight weeks of telerehabilitation comprising bicycle exercise remotely supervised via videoconferencing and self-management education provided on a computer resulted in significant improvements in exercise tolerance and quality of life (Marquis, Larivée, Dubois, & Tousignant, 2014). However, participants did not keep the exercise equipment after the intervention ended and improvements were not maintained after 6 months.

We conducted a pilot study on a 2-year telerehabilitation intervention for patients with COPD (Zanaboni, Lien, Hjalmarsen, & Wootton, 2013). This study demonstrated positive outcomes in terms of exercise maintenance, functional walking capacity, health status, and quality of life (Zanaboni, Hoaas, Lien, Hjalmarsen, & Wootton, 2016). Importantly, factors affecting satisfaction with the intervention from the participants' view included experienced health benefits, increased self-efficacy and independence, emotional safety due to regular meetings, and access to specialist competence. Maintenance of motivation was a challenge and might have affected long-term adherence to the intervention (Hoaas, Andreassen, Lien, Hjalmarsen, & Zanaboni, 2016). After completing the study, participants kept the equipment and were reassessed at the end of the post-intervention year. Our hypothesis was that adherence to self-management and home exercise routines would decline without supervision and that patients therefore would not maintain physical activity and patient-reported outcomes like health status, quality of life, self-efficacy, and anxiety and depression in the post-intervention year, with more frequent COPD-related hospitalizations.

METHODS

STUDY DESCRIPTION AND INTERVENTION

A 2-year pilot study was conducted to test the benefits of a long-term telerehabilitation intervention for patients with COPD (Zanaboni et al., 2016). Equipment included a treadmill, a pulse oximeter, and a tablet computer. Participants were recommended to perform home-based exercise three times per week. They also had access to a webpage for self-management, which included an individually tailored interval training program, a daily diary for reporting symptoms and oxygen saturation at rest, and a training diary for reporting exercise duration, perceived exertion, oxygen saturation, and heart rate during exercise. A physiotherapist supervised the participants remotely via videoconferencing on a weekly basis. Details on the intervention and the exercise program are described elsewhere (Zanaboni et al., 2016).

At the end of the 2-year intervention period, participants kept the equipment and were encouraged to continue performing home-based exercise on the treadmill on their own and to record daily symptoms and training sessions on the webpage. However, during the post-intervention year they no longer received any supervision, motivational, or self-management support from the physiotherapist via videoconferencing. That is, they only kept the tools to perform unsupervised exercise at home and self-management.

The primary outcome of this study was change in physical activity level. Secondary outcomes included adherence to daily registrations and training sessions, health status, quality of life, self-efficacy, anxiety and depression, subjective impression of change, and healthcare resource utilization. We also wanted to explore motivational factors affecting maintenance to unsupervised home exercise.

A one-group pretest-posttest design was used. Data were collected both along the 2-year intervention period (at baseline (T0), one year (T1), two years (T2)), and at the end of the post-intervention year (T3). The current study focuses on comparing the post-intervention year (T3) with the last intervention year (T2). The study was approved by the Regional Committee for Medical and Health Research Ethics, North Norway. All participants gave written informed consent.

DATA COLLECTION AND ANALYSIS

Baseline patients' characteristics in terms of age, gender, body mass index [BMI], lung function (forced expiratory volume in 1 second as percentage of predicted values [FEV_1 (% of pred.]), functional walking capacity (six-minute walk distance [6MWD]), and residential status were collected at T2 only. All study outcomes were collected at T2 (May 2014) and T3 (May 2015). Data at T2 were collected during an in-clinic visit, whilst data at T3 were collected by mail correspondence. All study objectives and time points for data collection are given in Table 1.

Table 1. Study Objectives and Time Points for Data Collection

Objectives	Measure	End of telerehabilitation, T2	End of post-intervention year, T3
Age	Year	X	
Lunge capacity	FEV_1 (% of pred)	X	
Use of LTOT	Yes/no	X	
Body weight status	BMI	X	
Functional walking capacity	6 MWD	X	
Residential status	Living alone or not	X	
Physical activity levels	Activity monitor	X	X
Adherence to intervention	Logs on webpage during one year	X	X
Health status	CAT	X	X
Health-related quality of life	EQ-5D	X	X
Anxiety and depression	HADS	X	X
Self-efficacy	GSES	X	X
Subjective impression of change	PGIC	X	X
Healthcare utilization	COPD-related hospitalizations and outpatient visits	X	X
Motivational factors for maintaining exercise	Open-ended questionnaire		X

FEV_1(% of pred)= Forced expiratory volume in 1 second, percentage. LTOT= Long-term oxygen treatment. BMI= Body Mass Index. 6MWD= 6 minute walk distance. CAT= the COPD Assessment Test. EQ-5D= the EQ-5D questionnaire. HADS= the Hospital Anxiety and Depression Scale. GSES= the General Self-Efficacy Scale. PGIC= the Patient Global Impression of Change

Physical activity levels were objectively measured by an activity monitor validated for people with COPD (Bodymedia SenseWear Armband) at T2 and T3 (Patel, Benzo, Slivka, & Sciurba, 2007). Participants were asked to wear the activity monitor for 7 consecutive days, day and night, except for a 1-hour break daily, normally for personal hygiene. The minute-by-minute output from the activity monitor was exported for further analysis using SenseWear Professional, version 8.0 software. The first and the last day of recording were excluded from analysis due to incomplete measurements which could introduce a bias. Hence, the minimum required measurement period was 5 days with wear time ≥10 hours, including at least one weekend day. Measurements for four weekdays of ≥8-10 hours wear time during waking hours are considered sufficient to obtain reliable data on physical activity in patients with COPD (Byrom & Rowe, 2016; Demeyer et al., 2014). Physical activity outcomes were measured energy expenditure in kilojoules (kJ) per day, total number of steps per day, minutes of awake sedentary time per day, total minutes of light physical activity per day (LIPA), total minutes of moderate-to-vigorous activity per day (MVPA), and total minutes in ≥10 minutes bouts of moderate-to-vigorous activity (MVPA bouts). Awake sedentary time is here defined as activity where the metabolic equivalent is between 0<1.5 METs, and measured sleep, as registered by the SenseWear armband, is excluded (Byrom & Rowe, 2016). Non-wear time is not included in measurement of sedentary behavior. By definition, LIPA refers to any activity between 1.5<3 METs (Norton, Norton, & Sadgrove, 2010). Any activity ≥3 METs was considered MVPA (Norton et al., 2010).

Use of the equipment and adherence were measured through the analysis of logs on the webpage during the last year of the telerehabilitation intervention and the post-intervention year. The average number of diary registrations per week and the average number of training sessions per week were computed for each participant. The adherence rate was calculated according to the recommendation of regular daily diary registrations and three training sessions per week, which were the same as in the telerehabilitation intervention. Details reported in the commentary field of the diaries during the intervention and the post-intervention year were also analyzed. In addition, use of the equipment and the webpage was assessed with a 5-point categorical scale (never, seldom, monthly, weekly and daily).

Patient-reported outcomes collected at T2 and T3 included health status and health-related quality of life, measured through the COPD Assessment Test [CAT] and the EQ-5D questionnaire, respectively. The minimal important difference (MID) for CAT is estimated as two points (Kon et al., 2014). Assessment of self-efficacy along with anxiety and depression were measured through the General Self-Efficacy Scale [GSES] and the Hospital Anxiety and Depression Scale [HADS], respectively. In addition, subjective impression of change was expressed by the Patients' Global Impression of Change [PGIC]. A change-score ≥5 is considered a favorable change in their condition, including activity, limitations, symptoms, emotions, and overall quality of life (Hurst & Bolton, 2004). Moreover, a 2-point change from the last reported score is considered clinically significant (Hurst & Bolton, 2004).

The study also investigated changes in healthcare resource utilization between the last year of the telerehabilitation intervention (T2) and the post-intervention year (T3). Data on hospitalizations and outpatient visits were collected from the Norwegian Patient Registry. Costs were calculated from the diagnosis-related group (DRG) points specifically attributed to hospitalizations and outpatient visits and the public tariff per DRG point offered by the healthcare authority.

Motivational factors for maintaining exercise during the post-intervention year were explored using open-ended questionnaires at T3. The questionnaire consisted of three questions: (i) If you have missed the follow-up by telerehabilitation, which specific features have you missed? (ii) If you have exercised on your own, what has motivated you to continue exercising? (iii) Do you have anything else to tell us? A thematic analysis technique was used to identify topics in the written material (Braun & Clarke, 2006). One author structured the material, and three authors analyzed it individually before a mutual consensus was agreed upon.

STATISTICAL ANALYSES

Descriptive data were reported as mean and standard deviation for continuous variables, and counts for categorical variables. Normality of distribution was tested by the Shapiro-Wilk Test. Subjects with missing data on one outcome measure were excluded from the analysis for that particular outcome measure. Multiple imputation was not performed due to the small sample. Changes in physical activity and other outcomes from the second year of telerehabilitation to the post-intervention year were tested with the paired-samples t-test. Results were reported as mean, standard deviation and mean difference with 95% confidence interval (CI). A value of $p<0.05$ was considered statistically significant. All statistical analyses were performed with IBM SPSS Statistics Version 22.

RESULTS

STUDY POPULATION

Nine patients with moderate to severe COPD who participated in long-term telerehabilitation were followed-up during the post-intervention year. Patients' characteristics at T2 are shown in Table 2.

Table 2. Patients' Characteristics at the End of the Telerehabilitation Intervention, T2

Variable	End of telerehabilitation, T2
Sex, males/females	5/4
Age, year	58.1 ± 6
FEV_1, % of predicted	42.4 % ± 19.8
Use of LTOT, yes/no	4/5
BMI	25.7 ± 4.6
6MWD, meters	467.7 ± 106.7
Living alone, yes/no	5/4

FEV_1, % of predicted= Forced expiratory volume in 1 second, percentage. LTOT= Long-term oxygen treatment. 6MWD= 6 minute walk distance.

PHYSICAL ACTIVITY

Physical activity data were available for 7 out of 9 participants. One participant had missing data from T2 due to an ongoing and prolonged exacerbation at the end of the telerehabilitation intervention. Another participant had missing data at T3 due to an allergic reaction to the armband experienced at the end of the post-intervention year. On average, participants had valid measurements from six days with recording of ≥22 hours on both occasions.

One year post intervention, average energy expenditure decreased from 9451 kJ per day to 8270 kJ per day (p=0.011, Table 3). Physical activity decreased from an average of 3806 steps/day to 2817 steps/day. This decline between time points was statistically significant (p=0.039). On average, the time spent in awake sedentary activity differed with one minute between time points (p=0.973). There was a 21% decline in time spent in LIPA (p=0.009). On average, total time spent in MVPA dropped by 51% between time points, from 88±66 minutes per day to 43±34 minutes per day, although this was not statistically significant (p=0.053). Time spent in MVPA bouts decreased by 53% (p=0.110). At the end of the intervention, 6 of the 7 participants had ≥150 weekly minutes of MVPA bouts, whereas only two participants maintained that level one year after the intervention.

Table 3. Physical Activity (Second Year of the Telerehabilitation vs. Post-intervention Year)

Physical activity	Intervention year 2 (n=7)	Post-intervention year (n=7)	Mean difference (95%CI)	P-value
Wear time, min/day	1342 ± 68	1329 ± 79	-13 (-81, 55)	0.653
Measured energy expenditure, kJ/day	9451 ± 2635	8270 ± 1846	-1181 (-1981, -381)	0.011
Steps, number/day	3806 ± 1596	2817 ± 1968	-989 (-1914, -66)	0.039
Awake sedentary time, min/day	654 ± 86	653 ± 124	-1 (-112, 109)	0.973
Total LIPA, min/day	187 ± 48	147 ± 67	-40 (-67, -14)	0.009
Total MVPA, min/day	88 ± 66	43 ± 34	-45 (-91, 1)	0.053
Time in MVPA bouts, min/day	49 ± 46	22 ± 27	-26 (-61, 8)	0.110

LIPA= Light physical activity. MVPA= Moderate-to-vigorous physical activity.

ADHERENCE AND USE OF THE EQUIPMENT

Adherence to registration of daily symptoms decreased from 39.3% during the second year of telerehabilitation to 15.6% during the post-intervention year (Table 4). Adherence to registration of home-based training sessions decreased from 42.9% to 13.9%. There was a statistically significant reduction in the use of both the daily diary (p=0.010) and training sessions (p=0.004). Only two of the participants actively used the webpage during the post-intervention year, with adherence to registration of daily symptoms and training sessions of 68.7% and 58.8%, respectively. During the intervention year, these two participants had an adherence rate of 87.2% to registrations in the daily diary and 98.8% for the training sessions. Both participants started reporting other forms of exercise and physical activity than home-based treadmill training (e.g. stationary bicycling, outdoor walking, snow shoveling, lawn mowing) in the post-intervention year. For these activities, they reported perceived exertion, lowest oxygen saturation, highest heart frequency, and duration as for treadmill training. One of the participants kept reporting in the daily diary detailed comments regarding everyday life, travels, sickness, and use of medication for 1.5 years after the end of the intervention.

On the questionnaire regarding use of the equipment, six participants answered they had used the treadmill and the pulse oximeter monthly or more. Four also reported using the webpage monthly or more.

Table 4. Adherence (Second Year of the Telerehabilitation vs. Post-intervention Year)

Adherence	Intervention year 2 (n=9)	Post-intervention year (n=9)	Mean difference (95%CI)	P-value
Diary registrations per week	2.8 ± 2.2	1.1 ± 2.2	-1.7 (-2.8, -0.5)	0.010
Training sessions per week	1.3 ± 0.7	0.4 ± 1.0	-0.9 (-1.4, -0.3)	0.005
Diary registration % recommended	39.3 ± 31.1	15.6 ± 32.0	-23.8 (-40.0, -7.5)	0.010
Training sessions % recommended	42.9 ± 24.3	13.9 ± 31.7	-29.0 (-46.1, -11.9)	0.004

Recommendations for diary registrations and training sessions were 7 and 3 times/week, respectively.

HEALTH STATUS AND QUALITY OF LIFE

There was no clinically or statistically significant change in the CAT score at the end of the post-intervention year (p=0.388, Table 5). The utility score calculated from the EQ-5D and the EQ Visual Analogue Scale (EQ VAS) were also not statistically significant different (p=0.070 and p=0.718, respectively).

ANXIETY AND DEPRESSION

Data on anxiety and depression were available for all 9 participants. There was no statistically significant change in the average score for anxiety and depression measured with the HADS (Table 5).

SELF-EFFICACY AND SUBJECTIVE IMPRESSION OF CHANGE

There was no difference in scores for self-efficacy and subjective impression of change between the end of the second intervention year and the end of the post-intervention year (Table 5). At the end of the post-intervention year, two participants reported an unfavorable change-score of 1 and 2 for the PGIC.

Table 5. Patient-related Outcomes (Second Year of the Telerehabilitation vs. Post-intervention Year)

Patient-related outcomes	Intervention year 2 (n=9)	Post-intervention year (n=9)	Mean difference (95%CI)	P-value
CAT, total score	20.9 ± 6.8	19.1 ± 5.2	-1.8 (-6.3, 2.7)	0.388
EQ-5D, utility score	0.575 ± .215	0.715 ± .146	0.140 (0.014, 0.293)	0.070
EQ-5D, VAS scale	47 ± 24	51 ± 26	4 (-21, 29)	0.718
HADS, anxiety	6.67 ± 3.6	6.78 ± 3.1	0.11 (-1.90, 2.13)	0.902
HADS, depression	4.22 ± 2.3	4.78 ± 2.5	0.56 (-1.13, 2.24)	0.468
HADS, total score	10.89 ± 5.1	11.56 ± 3.6	0.67 (-2.73, 4.06)	0.663
GSES, total score	30.6 ± 4.9	30.0 ± 5.3	-0.6 (-2.8, 1,7)	0.584
PGIC score	5.4 ± 1.2	5 ± 2.1	-0.4 (-2.0, 1.1)	0.537

CAT= the COPD Assessment Test. EQ-5D= the EQ-5D questionnaire. HADS= the Hospital Anxiety and Depression Scale. GSES= the General Self-Efficacy Scale. PGIC= the Patient Global Impression of Change

HEALTHCARE UTILIZATION

There was no statistically significant difference in healthcare utilization between the second intervention year and the following post-intervention year. However, the average number of COPD-related hospitalizations per patient per year doubled during the post-intervention year compared to the previous year when the patients were still participating in the intervention. The number of yearly COPD-related outpatient visits almost tripled during the year following the intervention (Table 6). Hence, the estimated COPD-related hospital costs also increased.

Table 6. Healthcare Utilization (Second Year of the Telerehabilitation vs. Post-intervention Year)

Healthcare utilization	Intervention year 2 (n=9)	Post-intervention year (n=9)	Mean difference (95%CI)	P-value
COPD-related hospitalisations, number	0.44 ± 0.73	0.89 ± 1.27	0.45 (-0.11, 1.00)	0.104
COPD-related outpatient visits, number	1.22 ± 0.83	3.55 ± 7.00	2.33 (-3.12, 7.78)	0.352
COPD-related hospital costs, NOK	27,376 ± 45,661	54,816 ± 60,036	27,439 (-7,784, 62,663)	0.110

MOTIVATIONAL FACTORS

Two themes regarding motivational factors for maintaining exercise were identified in the open-ended questionnaires collected at T3: (i) experiences of health improvements and (ii) regularity, feedback and affiliation.

EXPERIENCES OF HEALTH IMPROVEMENTS

Most participants described previous or current experiences of health improvements related to exercising as reasons why they continued to exercise:

- *I have certainly experienced that I benefit from physical activity and interval training* (P8).
- *I keep good health when I exercise and I recover faster after a flu. I get a lot of positive feedbacks from others. People who have not seen me for a while can hardly recognize me, and they say that I look healthy* (P1).

One participant stated that his motivation for exercise was *a wish for not getting worse* (P6).

REGULARITY, FEEDBACK AND AFFILIATION

Most of the participants expressed they missed the regularity and the feedback that the telerehabilitation intervention provided them during the pilot study:

- *I have missed the "pressure" to exercise weekly that came with the follow-up* (P3).

However, some participants did not miss the telerehabilitation follow-up:

- *I do not really miss the follow-up. However, I have not been diligent with my training (P4).*

The affiliation to the project and the group during the intervention seemed to have made an impression on the participants, and they *liked to be a part of the project* (P8) and after the intervention ended they *miss getting together to share experiences* (P2). Participants also highlighted *the training instruction and feedback* (P1), and *the conversations and being motivated by the physiotherapist* (P7) as something that they missed during the post-intervention period.

DISCUSSION

Physical inactivity is associated with increased risk of all-cause mortality in COPD, and might also influence the clinical evolution of COPD (Van Remoortel et al., 2013; Waschki et al., 2011; Watz et al., 2014). Physical activity is reduced even from the early stages of the disease, in terms of both quantity and movement intensity (Van Remoortel et al., 2013; Watz et al., 2014). The American College of Sports Medicine recommends that adults engage in moderate physical activity for a total of ≥150 minutes per week (Garber et al., 2011). It is not known to what extent these recommendations apply to patients with COPD (Watz et al., 2014). Nevertheless, most patients with COPD do not meet these recommendations (Watz et al., 2014). In our study, the average time spent in MVPA bouts at the end of the post-intervention year was halved from that at the end of the intervention. This was still just above the recommendation of 150 minutes per week. However, analyzing the time spent in MVPA bouts individually, only two participants met the recommendations at the end of the post intervention year. The number of steps per day at the end of the telerehabilitation intervention was low and decreased even more and significantly at the end of the post-intervention year. The expected average value amongst free-living patients with COPD was estimated at 2237 steps per day (Tudor-Locke, Washington, & Hart, 2009). In our study, the average number of steps per day was just above this value at the end of the post-intervention year. However, we consider the difference between time points to be clinically important, as the MID after PR is estimated between 600 and 1100 steps per day (Demeyer et al., 2016). Further, there seems to be a discrepancy between the number of steps obtained and the time spent in MVPA bouts in our data. Thirty minutes spent in MVPA bouts would in healthy subjects translate to 7000-8000 steps per day (Tudor-Locke et al., 2011), whereas participants in our study had on average only 3806 ± 1596 steps from 49 ± 46 minutes in MVPA bouts (end of intervention). One reason for the discrepancy might be that accelerometers like the SenseWear activity monitor is worn on the upper arm unlike pedometers, which often are positioned at the hip and therefore gives more accurate measures of steps (Andersson, Janson, & Emtner, 2014). However, the SenseWear might be better in measuring MVPA due to its several heat-related sensors, which provide a good indication of the intensity of activity performed (Andersson et al., 2014; Cavalheri et al., 2011). Rollator use is known to influence the number of steps detected by the SenseWear (Andersson et al., 2014). Holding on to the handrails while walking on the treadmill might also influence the number of steps detected. The number of steps might have therefore been underestimated in this study. Nevertheless, the level of physical activity that the participants performed one-year post intervention seems not to be enough to maintain or achieve additional health benefits.

Maintenance of physical activity after PR is generally difficult (Spruit et al., 2013; Watz et al., 2014). Factors supporting maintenance of physical activity after PR from the patients' view include reconciliation with the disease, professional support, adaption of intensity of the exercise program, feeling of mastery, social support from peers, and access to appropriate exercise facilities with regular supervision (Hellem et al., 2012). Most of the participants in our study stopped using the webpage for self-monitoring during the post-intervention year without any supervision provided by the physiotherapist via telerehabilitation. Adherence to training sessions also declined. This may have contributed to the significant decrease in physical activity levels compared to the previous telerehabilitation period. Only two participants continued using the webpage during the post-intervention year. They also had the highest adherence to telerehabilitation. These participants seemed to have effectively integrated exercise and self-management routines into their everyday life over the long term. Moreover, during the year following telerehabilitation, they started reporting more detailed and varied descriptions of their activities on the webpage, including other forms of physical activity besides treadmill training. There have been some, albeit few studies reporting telemedicine interventions for self-management support and exercise maintenance delivered without supervision or input from health personnel. Interventions seemed likely to be successful if they were individually tailored to fit the patients' needs and skills, thus better integrated in everyday life and health care routines (Vassilev et al., 2015). It appears that the unsupervised version of the telerehabilitation intervention fit the needs of only two participants. The rest of the participants stopped adhering to the intervention as the professional support and regular supervision ceased.

Besides tailoring the intervention to fit the participants, development of relationships is recognized as a key component for successful telemedicine interventions (Vassilev et al., 2015). Results from the open-ended questionnaires on motivational factors for maintaining exercise during the post-intervention year support the importance of established relationships. These findings also confirm the results from focus groups conducted during the telerehabilitation intervention (Hoaas et al., 2016). Motivation for maintaining exercise was supported by experienced health benefits. In addition, some of the participants missed the regularity of feedback, motivational support and the specialized and individualized follow-up from a physiotherapist. Visibility of symptoms and exercise sessions through telemonitoring on the webpage and regular contact with the physiotherapist during the intervention period might have worked as a reinforcement or incentive as it encouraged accountability and a mild "pressure" to exercise (Vassilev et al., 2015). Therefore, increased attention seemed to be a key motivational factor for exercise maintenance. However, according to quotations from the open-ended questionnaires, this does not necessarily need to be provided by health personnel via telerehabilitation. Positive feedback and attention from other people might also be sufficient to continue exercising.

LIMITATIONS

In our study, health status, health-related quality of life and other patient-related outcomes like anxiety and depression, self-efficacy, and subjective impression of change remained unchanged during the post-intervention year. However, it must be acknowledged that our small study may have been underpowered to detect changes in these outcomes. Quality of life is often maintained better than physical activity and exercise capacity in the long term after conventional pulmonary rehabilitation (Spruit et al., 2013). For the one study identified assessing long-term benefits of telerehabilitation for patients with COPD, improvements measured in quality of life during the intervention were not present 24 weeks later (Marquis et al., 2014).

In addition to the personal burden of having COPD, the disease poses a substantial economic burden on the public health system (García-Polo et al., 2012). In our study, there was no statistically significant change in COPD-related healthcare utilization between the time points. Participants might have been able to maintain their self-management routines during the post-intervention year after withdrawal of the supervision from the physiotherapist. However, the clear increase in the average number of hospitalizations and outpatient visits makes it difficult to be certain of this. COPD is a progressive disease. This might have influenced the tendency for more frequent hospitalization that we see in the average numbers. Since lung function was not measured at the end of the post-intervention year, we do not know whether participants had experienced a progression of the disease. A control group was not included for comparison. These are clearly limitations to the study. However, participants had reduced physical activity level and this is also known to influence the risk of hospitalization (Garcia-Aymerich et al., 2006; García-Polo et al., 2012; Watz et al., 2014).

Although this study is unique due to the long-term duration of the intervention and the additional reassessment one-year post intervention, generalization of results is hampered by the small sample size and uncontrolled nature of the study. Further, it is difficult to draw conclusions regarding which specific patients' characteristics in terms of gender, residential status, disease severity, and BMI are related to maintenance of physical activity. Also, in the questionnaire regarding the use of the equipment, six participants answered they had used the treadmill and the pulse oximeter monthly or more often. This means that some participants might have exercised on the treadmill without registering the training sessions on the webpage, as this was voluntary during the post-intervention year. Adherence to training might therefore have been underestimated by the analysis of the logs from the webpage. Four participants also reported using the webpage monthly or more often. However, this is not reflected by the logs on the webpage. Self-reported data on patient questionnaires often overestimate objectively measured data. As a consequence, the logs on adherence to daily self-management registrations are more accurate.

CONCLUSIONS

This paper examined whether physical activity and other outcomes obtained after participation in a two-year telerehabilitation intervention for COPD patients could be maintained over the following year without any supervision provided by a physiotherapist via telerehabilitation. We conclude that provision of equipment for self-management and home exercise might not be enough to maintain long-term effects on physical activity levels. Maintenance strategies including regular supervision, feedback or input by health professionals might better support long-term maintenance of physical activity and adherence. However, the cost-effectiveness of such interventions remains unknown.

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

H.H. and P.Z. contributed to the conception and design of the study, acquisition of data, analysis and interpretation of data, drafting and revision of the manuscript. B.M. and A.E.H. contributed to the manuscript. All authors read and approved the final manuscript.

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STUDY PROTOCOL

Open Access

Long-term integrated telerehabilitation of COPD Patients: a multicentre randomised controlled trial (iTrain)

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Abstract

Background: Pulmonary rehabilitation (PR) is an effective intervention for the management of people with chronic obstructive pulmonary disease (COPD). However, available resources are often limited, and many patients bear with poor availability of programmes. Sustaining PR benefits and regular exercise over the long term is difficult without any exercise maintenance strategy. In contrast to traditional centre-based PR programmes, telerehabilitation may promote more effective integration of exercise routines into daily life over the longer term and broaden its applicability and availability. A few studies showed promising results for telerehabilitation, but mostly with short-term interventions. The aim of this study is to compare long-term telerehabilitation with unsupervised exercise training at home and with standard care.

Methods/Design: An international multicentre randomised controlled trial conducted across sites in three countries will recruit 120 patients with COPD. Participants will be randomly assigned to telerehabilitation, treadmill and control, and followed up for 2 years. The telerehabilitation intervention consists of individualised exercise training at home on a treadmill, telemonitoring by a physiotherapist via videoconferencing using a tablet computer, and self-management via a customised website. Patients in the treadmill arm are provided with a treadmill only to perform unsupervised exercise training at home. Patients in the control arm are offered standard care. The primary outcome is the combined number of hospitalisations and emergency department presentations. Secondary outcomes include changes in health status, quality of life, anxiety and depression, self-efficacy, subjective impression of change, physical performance, level of physical activity, and personal experiences in telerehabilitation.

Discussion: This trial will provide evidence on whether long-term telerehabilitation represents a cost-effective strategy for the follow-up of patients with COPD. The delivery of telerehabilitation services will also broaden the availability of PR and maintenance strategies, especially to those living in remote areas and with no access to centre-based exercise programmes.

Trial registration: ClinicalTrials.gov: NCT02258646.

Keywords: COPD, Pulmonary rehabilitation, Telemedicine, Exercise, Home monitoring, Telerehabilitation

Abbreviations: 6MWD, 6-minute walking distance; AES, Advanced encryption standard; BCSS, Breathlessness, cough, and sputum scale; CAT, COPD Assessment test; COPD, Chronic obstructive pulmonary disease; ED, Emergency department; GSES, Generalised self-efficacy scale; HAD, Hospital anxiety and depression scale; PGIC, Patient global impression of change scale; PR, Pulmonary rehabilitation; RCT, Randomised controlled trial; SIP, Session initiation protocol

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Background

Chronic obstructive pulmonary disease (COPD) is characterised by a persistent airflow limitation that is usually progressive [1]. Patients experience frequent acute exacerbations, characterised by worsening of respiratory symptoms [2] which may lead, in the worst cases, to a hospital admission [3]. COPD poses a substantial burden on healthcare budgets. The largest part of the health service expenditure is for hospitalisations and emergency department (ED) presentations, which commonly occur in the latter stages of the disease [4]. Moreover, prior hospitalisations represent a risk factor for rehospitalisation in patients discharged after a severe exacerbation [5]. Hospital admissions for exacerbations do not only represent a burden for the healthcare system, but have also a negative impact on patients, who experience reduced physical activity, decreased exercise performance [6], and impaired quality of life, even in mild stages of the disease [7]. Dyspnoea, the most commonly reported symptom during acute events, is associated with anxiety and depression [8]. Importantly, reduced physical activity is the strongest predictor of mortality in patients with COPD [9].

Pulmonary rehabilitation (PR) is an evidence-based, multidisciplinary, and comprehensive intervention for the management of COPD [10–12]. The main goal is to improve the physical and psychological condition and to promote long-term adherence of health-enhancing behaviours [13]. Exercise training is the cornerstone of PR, aiming to improve physical capacity and ability to perform activities of daily living. Other components include patient assessment, behavioural change, education on self-management, and psychosocial support [13]. PR improves dyspnoea, physical performance, quality of life [10], and is effective in reducing use of healthcare resources [14]. However, the short-term benefits diminish over the succeeding 12 months without an effective maintenance strategy [15]. Sustaining long-term adherence to exercise training is difficult due to variation in day to-day condition, exacerbations, hospital admissions, and transportation problems [16]. Key factors which promote exercise maintenance include professional support, review of exercise intensity, goal setting, social support, positive personal attributes, and the availability of exercise programmes with regular supervision [16]. Only a few investigators have explored maintenance strategies to sustain the benefits of PR over the long term, with inconsistent results [17–20].

Telemedicine has the potential to improve access to PR and support long-term exercise maintenance strategies. Telerehabilitation is the use of information and communication technologies to provide rehabilitation services remotely to people in their homes or other environments [21]. In contrast to traditional centre-based programmes, undertaking PR within the home environment may promote more effective integration of exercise routines into daily life over the longer term [22]. Evidence of the use of telemedicine in PR is still limited [13]. A recent review showed that telemedicine was effective in increasing physical activity levels in patients with COPD [23]. A few studies, most of which uncontrolled, showed promising results for short-term telerehabilitation interventions in regards to feasibility, safety, exercise capacity, and health-related quality of life [24–29]. However, only one uncontrolled pilot study trialled a long-term telerehabilitation intervention for patients with COPD [30]. This study demonstrated positive outcomes in terms of exercise maintenance, physical performance, health status and quality of life [31]. Importantly, long-term adherence was supported by experienced health benefits, self-efficacy, emotional safety, and maintenance of motivation [32]. Larger controlled trials are needed to explore the long-term effects of telerehabilitation in COPD.

Developing new cost-effective ways to sustain regular exercise over the long term and broaden the applicability and availability of PR is an important goal in the COPD management. The aim of this study is to compare long-term telerehabilitation of COPD patients consisting of exercise training at home, telemonitoring, and self-management, with unsupervised exercise training at home and with standard care. We hypothesised that long-term telerehabilitation will reduce the number of hospital readmissions and improve patient's level of physical activity, health status and quality of life. The results from this study will provide decision makers, as well as practitioners, evidence on whether telerehabilitation interventions might be added to the current offer of traditional PR programmes and maintenance strategies.

Methods/Design

Design

An international multicentre randomised controlled trial (RCT) conducted across sites in three countries (Norway, Australia, and Denmark), where 120 patients with COPD are randomly assigned to three arms (telerehabilitation, treadmill, control) in a 1:1:1 ratio and followed up for 2 years. The trial is restricted to patients who have volunteered and provided written informed consent in accordance with the Declaration of Helsinki. The trial received approval from the Regional Committee for Medical and Health Research Ethics in Norway (2014/676/REK nord), the Alfred Hospital Human Research Ethics Committee (289/14), and the North Denmark Region Committee on Health Research Ethics (N-20140038). The protocol of this RCT fulfils the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines (Additional file 1).

Eligibility criteria

To be eligible for enrolment, participants must have the following inclusion criteria: 1) a diagnosis of COPD, based on an FEV_1/FVC ratio < 70 % [33], 2) moderate, severe or very severe airflow limitation, with forced expiratory volume in 1 s percentage (FEV_1 % of predicted) < 80 %, 3) at least one COPD-related hospitalisation or COPD-related ED presentation in the 12 months prior to enrolment, 4) aged between 40 and 80 years, and 5) capable of providing signed written informed consent.

Participants are excluded if they have at least one of the following criteria: 1) attendance at a rehabilitation programme in the 6 months prior to enrolment; 2) participation in another clinical study that may have an impact on the primary outcome, 3) deemed by the healthcare team to be physically incapable of performing the study procedures, 4) presence of comorbidities which, in the opinion of the healthcare team, might prevent patients from safely undertaking an exercise programme at home (for example severe orthopaedic or neurological impairments, severe cognitive impairment), and 5) home environment not suitable for installation and use of rehabilitation and monitoring equipment. Potential participants are not excluded on the basis of their existing home Internet access, as this can be provided by the study.

Randomisation

Randomisation is stratified by centre and disease severity ($FEV_1 < 50$ % vs. $FEV_1 \geq 50$ %) to preserve homogeneity between arms with regard to severity of clinical status. Randomisation is web-based and performed via the WebCRF program developed by the Unit for Applied Clinical Research at the Norwegian University of Science and Technology in Trondheim. The tool uses a computerised block randomisation, and the size of the first, smallest and largest blocks is established based on the total number of patients expected to be included in the study. The randomisation sequence generated is concealed from the study team by the program. The same WebCRF program is used to fill out electronic case report forms (CRFs). This allows patient data from several centres to be entered into the same database.

Interventions

Telerehabilitation arm

Patients in the telerehabilitation arm are offered an integrated intervention consisting of exercise training at home, telemonitoring, and self-management. The equipment includes: a) a treadmill (Sportsmaster T2 in Norway, Sportsmaster T3i in Denmark, Reebok ZRK1 in Australia), b) a pulse oximeter (Nonin 9570/9571), c) a tablet computer (Apple iPad Air), and d) a holder for the tablet computer (RAM) (Fig. 1). The feasibility of using such equipment was tested in a previous pilot study [30]. Videoconferencing is performed through Acano™ due to its ability to connect the participant's tablet to videoconferencing protocol H.323 and Session Initiation Protocol (SIP) standards-based systems, desktop computers or mobile clients. Communication is performed with Advanced Encryption Standard (AES) encryption and features multiconferencing.

The exercise intervention consists of an individualised training programme of regular exercise of continuous or interval training on the treadmill and strength training exercises according to current guidelines [13]. The treadmill exercise programme lasts for at least 30 min. Depending on the patient's condition, a programme of continuous training (moderate intensity - Borg scale [34] ratings up to 4) or interval training (high intensity - Borg scale ratings up to 6) is conducted. The frequency prescribed is 3–5 times/week for continuous training and 3 times/week for interval training. For interval training, up to 4 interval bouts of high intensity lasting from 1 to 4 min could be prescribed. Progression is made by increasing speed and incline first. Then the patient is encouraged to increase duration. Patients are permitted to take short rests if intolerable symptoms occur, but rest time does not count towards training duration. The exercise programme can be modified by the physiotherapist or the patients themselves according to their conditions. Strength training is prescribed for a frequency of 2–3 sessions per week. Each session includes at least two lower limb exercises (6–12 repetitions, 3 sets) and two upper limb exercises (6–12 repetitions, 1–3 sets). The patients can choose between sit-to-stand, squat, step-up, lunge, calf raise, biceps curl, shoulder press, wall push up, bench press, standing row, seated row, lateral pull down, triceps press. Bottles filled with sand/water or elastic bands/free weights can be used for upper limb exercises if already available in the patient's home.

A customised website is used to access the individual training programme, fill in a daily diary and a training diary, review historical data, exchange electronic messages, schedule videoconferencing sessions, and assess individual goal settings and goal attainment. Patients are asked, every evening, to use their pulse oximeter at rest and to fill the daily electronic diary on the website including: a) oxygen saturation, b) heart rate, c) Breathlessness, Cough, and Sputum Scale (BCSS) [35], d) general wellbeing (qualitative self-score on a five-point Likert scale), and e) additional comments. During an exercise session on the treadmill, patients are required to self-monitor their oxygen saturation and heart rate. After each exercise session, patients are asked to fill in the electronic training diary on the website including: a) programme completion, b) Borg CR10 scale - Rating of

Fig. 1 Telerehabilitation in a participant's home

Perceived Exertion for leg (highest value during exercise), c) Borg CR10 scale - Rating of Perceived Dyspnoea (highest value during exercise), d) oxygen saturation (lowest value during exercise), e) heart rate (highest value during exercise), and f) additional comments. The information sent through the electronic forms is monitored and interpreted weekly by a physiotherapist, who also checks for any out-of-range value. The physiotherapist can provide feedback to the patients via the website, or use this information in the upcoming videoconference. Patients are also informed on the presence of signs and symptoms to ensure that they do not exercise if not recommended.

Patients have scheduled videoconferencing sessions with the physiotherapist. During videoconferencing, patients are encouraged to set specific goals for their ongoing programme and their daily life activities. Self-management education and training are provided to promote adherence to health-enhancing behaviours. During disease exacerbations, strength training exercises might be encouraged until the patient gets well enough to exercise on the treadmill. If the patient reports changes on sputum aspect, guidance on airway clearance techniques is offered (e.g. active cycle of breathing). The physiotherapist can take electronic notes using the same website. The frequency of contacts consists of at least 1 individual videoconferencing session/week in the first 8 weeks after enrolment, and at least 1 individual videoconferencing session/month in the following period. Participants who experience a hospital admission during the study period are invited to continue their participation after discharge. In these cases, at least 1 individual videoconferencing session/week will be applied in the month after discharge as a reinforcement strategy. Additional peer-group exercise sessions supervised by the physiotherapist can be organised.

Treadmill arm

Patients in the treadmill arm are provided with a treadmill only to perform unsupervised exercise training at home. The exercise intervention consists of an individualised unsupervised training programme performed as prescribed to the participants in the telerehabilitation arm, without regular review or progression of the program. Participants are asked to record each training session on a paper-based diary. This intervention arm allows comparing the effects of providing training equipment only to those using telerehabilitation.

Control arm

Patients in the control arm are offered standard care. To ensure that no participants are denied access to the best health care practice, any participant in the trial can undertake a traditional PR programme at any time during the 2-year study period if it is considered clinically indicated by their usual treating team.

Recruitment and study procedures

At enrolment, a clinical assessment is performed for all the patients by appropriately trained study personnel blinded to group allocation. Participants are asked to perform spirometry, the 6-min walking test [36] and complete the study questionnaires (Table 1). Participants are also provided brochures containing information about PR, physical activity and training, diet, self-management, motivation and lifestyle changes, smoking cessation and oxygen therapy.

After enrolment, patients in the telerehabilitation and the treadmill arms undergo a supervised session on the treadmill with an experienced research physiotherapist to learn how to safely exercise at home, receive information on how to make progress in the programme and are given the opportunity to clarify any questions related to equipment management. Patients in the telerehabilitation arm also receive training on the use of the study website. A test videoconferencing session is also performed by the local research team to guarantee proper equipment functioning. Patients can always contact the research team in case of technical issues.

At 6-month, 1-year and 2-year, patients undergo a clinical reassessment and are asked to complete the study questionnaires (Table 1). During data collection patients are encouraged to continue participating in the study. Patients are discharged from the trial after 2 years, those in the telerehabilitation and the treadmill arms can keep the equipment at the end of the study.

Table 1 Data collected at baseline and follow-up visits

Data collected	Baseline	6-month	1-year	2-year
Clinical history and patient's characteristics	X			
Pharmacological treatment	X			
Spirometry	X	X	X	X
6-min walking test	X	X	X	X
MMRC Dyspnoea Scale	X	X	X	X
COPD Assessment Test	X	X	X	X
EQ-5D Health Questionnaire	X	X	X	X
Generalised Self-Efficacy Scale	X	X	X	X
Hospital Anxiety and Depression Scale	X	X	X	X
Level of physical activity	X	X	X	X
Healthcare utilisation		X	X	X
Patient Global Impression of Change		X		

Outcome measures

The primary outcome is the combined number of hospitalisations and ED presentations. Differences in the rate of events between the study arms will be measured at all assessment time points (Table 2). Data on hospitalisations and ED presentations, together with outpatient visits, will be collected from hospitals records (in Australia), regional systems (in Denmark) and national registries (in Norway). Details will include institution, date of admission, date of discharge, diagnosis-related group (DRG), diagnoses, procedures and associated cost. In addition, use of hospital resources will be recorded during the follow-up visits. Hospitalisations and ED presentations will be also analysed separately as secondary outcomes. Mortality will be monitored along the study together with dropouts.

Health status will be measured with the COPD Assessment Test (CAT) [37]. Health-related quality of life will be measured with the EQ-5D questionnaire [38]. Levels of anxiety and depression will be measured with the Hospital Anxiety and Depression Scale (HAD) [39]. Self-efficacy will be measured with the Generalised Self-Efficacy Scale (GSES) [40]. Subjective impression of overall change will be measured with the Patient global impression of change scale (PGIC) [41]. The study questionnaires, available in English, Norwegian and Danish with validated versions, will be collected along the study at different time points (Table 1).

Functional exercise capacity will be measured with the 6-min walking distance (6MWD). The 6-min walking

Table 2 Primary and secondary outcomes and related measures

Outcome	Measure
Primary outcome	
• Combined number of hospitalisations and ED presentations	• Incidence Density
Secondary outcomes	
• Hospitalisations	• Incidence Density
• ED presentations	• Incidence Density
• Mortality	• Mortality rate
• Time free from first event	• Days to first hospitalisation or ED presentation
• Health status	• COPD Assessment Test
• Quality of life	• EQ-5D
• Anxiety and depression	• Hospital Anxiety and Depression Scale (HAD)
• Self-efficacy	• Generalised Self-Efficacy Scale (GSES)
• Subjective impression of overall change	• Patient global impression of change scale (PGIC)
• Physical performance	• 6-min walking distance (6MWD)
• Level of physical activity	• Daily number of steps, minutes of moderate to vigorous physical activity and sedentary time during 1-week
• Cost-effectiveness	• Cost-utility analysis (cost-per-QALY)
• Experiences in telerehabilitation	• Qualitative interviews with semi-structured questions

test will be performed twice according to guidelines, and the furthest distance recorded [36].

Objective physical activity assessment will be undertaken using the SenseWear Armband (SWA; BodyMedia, Pittsburgh, USA; professional software version 7.0). The SWA will be positioned on the participant's left upper arm according to manufacturer instructions. Participants will be instructed to wear the SWA for 1 week, only removing it for bathing or water-based activities. The first and last days of data will be excluded from analysis upon data retrieval. A day of data (midnight to 23:59) will be included for analysis if there is at least 10 h of data within the 24-h period. A minimum of four valid days of data will be required per participant at each assessment time point [42], inclusive of at least 1 weekend day. The proprietary algorithm provides a range of variables for each minute of wear time, including energy expenditure and number of steps. The intensity of physical activity is described according to metabolic equivalents (1 MET = 1 kcal/kg/h). Each minute of wear time will be allocated to a category of physical activity on the basis of MET classification (sedentary ≤ 1.5 METs, moderate and vigorous ≥ 3 METs). The amount of time spent in moderate to vigorous physical activity, and time spent sedentary, will be calculated.

A cost-utility analysis will be performed to verify whether the telerehabilitation and the treadmill interventions are cost-effective. The perspective of the healthcare authority will be adopted with respect to costs. The following cost components will be included in the analysis: a) hospital resources, b) delivery of the telerehabilitation intervention, and c) equipment. Hospital resources will include hospitalisations, ED presentations, outpatient visits, and rehabilitation. Unit cost for each resource will be based on the specific public tariffs from the national DRG system. Delivery of the telerehabilitation intervention will include the time used by the project team to install the equipment in the patient's home and provide training, and the time used by the physiotherapist to supervise the patients. Equipment costs for the telerehabilitation arm and the intervention arm will be calculated based on a 5-year amortisation period. All costs will be expressed in Euros (€). Utility will be measured in terms of quality adjusted life years (QALYs), based on the answers of the EQ-5D questionnaires at baseline, 6 month, 1–2 years. Utility values will be calculated using the European EQ-net VAS set, and only if all the five dimensions are answered. The incremental cost-effectiveness ratio will be computed as differential costs and differential QALYs.

Patients' perspectives in participating in long-term telerehabilitation will be explored through qualitative interviews with semi-structured questions. Interviews will be conducted before telerehabilitation, after 1 year and after 2 years, with 5–8 patients in the telerehabilitation arm at each site. Interviews will be recorded on audio digital file, transcribed verbatim and analysed via Nvivo 10.0 upon the theoretical frame of the learning theory [43].

Adverse events and dropouts

Adverse events, including deaths, treadmill injuries and other unspecified reasons, will be recorded in the WebCRF program. Technical problems will be recorded by each participating centre into a separate database. Dropouts will occur if patients notify the research team that they do not want to participate any longer to the study and therefore withdraw their consent. In this case the project team might collect the equipment upon request. Patients who do not participate actively in the intervention will still be included in the study, and analysed according to the intention-to-treat approach. They will keep the project equipment as long as they want.

Statistical analysis

Descriptive statistics at baseline will be reported as means ± SD for normally distributed continuous variables, or medians with 25–75th percentiles in the case of skewed distribution. Normality of distribution will be tested by means of the nonparametric Kolmogorov-Smirnov test. An intention-to-treat analysis will be performed on all randomised subjects to provide unbiased comparisons among groups and avoid the effects of dropout. The primary outcome and related secondary outcomes will be measured through the Incidence Density, defined as the number of events in a group divided by the total person-time accumulated during the study in that group [44]. Differences between study arms will be tested by the Comparison of Incidence Rates. A two-sided test and a significance level of $\alpha = 0.05$ will be used. All events from the day after randomisation to patient exit/death will be included. Other secondary outcomes will be measured as changes from baseline to all assessment time points. Changes of the secondary outcomes will be tested by use of linear mixed models, which allow accounting for repeated measures collected in a longitudinal design. Moreover, linear mixed models deal better with dropouts that other methods used for repeated measures, and use of imputation techniques for missing data is not necessary. A p-value <0.05 will be considered significant for all tests. All statistical analyses will be performed by using IBM SPSS Statistics.

Sample size

The sample size requirements for this study were intended to provide adequate power for the analysis of the primary outcome. From studies with patients with similar characteristics [45–48], we estimated an incidence density used as a null hypothesis of 2 events per person-year, and a 40 % relative reduction in the primary outcome. In a major study of a management programme including home exercises for COPD patients after acute exacerbations [46] the mean number of hospital admissions per patient was reduced from 1.6 to 0.9 in the year following a hospital admission. We calculated that a sample size of 65 person-years per group would allow a power of 95 % to detect an incidence rate ratio of 0.60, with a type-I error (α) of 0.05. Assuming that up to 20 % of patients may drop out uniformly over the intervention period, 40 patients (corresponding to 80 person-years) will be enrolled per each of the three arms for the 2-year study duration. In total, 120 patients (corresponding to 240 person-years) will therefore be enrolled in the study. Recruitment is expected to be concluded by the end of 2016.

Discussion

This study protocol described the methods used in this first RCT investigating the effects of long-term telerehabilitation in COPD. Patients with COPD often experience repeated exacerbations which lead to a worsening of their health condition and to hospital admissions [3]. Moreover, hospital readmissions are more likely to occur in patients with prior history of hospitalisations [5]. There is an increasing need for cost-effective treatment strategies for patients with COPD [22]. PR is a low-cost, integral component of COPD management [12]. PR is traditionally centre-based and offered either as a 6–12-week outpatient programme or as a 4-week inpatient programme. Available resources for PR are often limited, and patients living in rural areas especially suffer from poor availability of PR programmes [49]. Maintenance strategies are needed to sustain the benefits of PR over the long term [15]. However, these are scarcely documented, and the optimal combination of maintenance interventions after completion of a PR programme remains unknown [12]. Long-term telerehabilitation is an innovative intervention which might reduce hospital readmissions in COPD and thus limit healthcare utilisation. The results of this study will provide evidence on whether long-term telerehabilitation represents a cost-effective strategy for the follow-up of patients with COPD. The delivery of telerehabilitation services will also broaden the availability of PR and maintenance strategies, especially to those living in remote areas and with no access to centre-based exercise programmes.

Significant improvements in outcomes can be obtained with both supervised and unsupervised home exercise [50]. However, sustaining long-term exercise is generally difficult [17] for many reasons, including professional support, regular supervision [16], emotional safety, and maintenance of motivation [32]. We expect that standard care and unsupervised home exercise will be less beneficial than a telerehabilitation intervention where patients are supervised regularly by a physiotherapist via videoconferencing. The study was designed as a three-armed RCT to isolate the effects of placing training equipment in the patient's home from those of telemonitoring.

Trial status

Patient recruitment commenced in October 2014 and is continuing.

Additional file

Additional file 1: SPIRIT checklist. (DOC 121 kb)

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Availability of data and materials
The data supporting the results of this study will be available upon request.

Authors' contributions
PZ, BD, AEH and RW designed the study protocol. PZ, BD, AEH, AH, and RW procured the study funding. PZ, HH, AEH and RW drafted the manuscript and BD, AH, and CCO contributed to the manuscript. All authors read and approved the final manuscript.

Competing interests
The authors declare that they have no competing interests.

Consent for publication
Consent to publish the image of the telerehabilitation in a participant's home was sought and obtained from that person.

Ethics approval and consent to participate
The trial is restricted to patients who have volunteered and provided written informed consent in accordance with the Declaration of Helsinki. The trial received approval from the Regional Committee for Medical and Health Research Ethics in Norway (2014/676/REK nord), the Alfred Hospital Human Research Ethics Committee (289/14), and the North Denmark Region Committee on Health Research Ethics (N-20140038). Any important modifications to the protocol which may impact on the conduct of the study will require a formal amendment to the ethics committees.

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ORIGINAL RESEARCH

Seasonal variations in objectively assessed physical activity among people with COPD in two Nordic countries and Australia: a cross-sectional study

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Abstract

Purpose:

Seasons and weather conditions might influence participation in physical activity and contribute to differences between countries. This study aimed at investigating whether there were differences in physical activity levels between Norwegian, Danish and Australian people with chronic obstructive pulmonary disease (COPD), and establishing if any variations in physical activity were attributable to seasons.

Patients and methods:

Study subjects were people with COPD who participated in two separate clinical trials: the iTrain study (Norway, Denmark, and Australia) and the HomeBase study (Australia). Physical activity was objectively assessed with an activity monitor; variables were total energy expenditure, number of daily steps, awake sedentary time, light, and moderate-to-vigorous intensity physical activity. Differences in physical activity between countries and seasons were compared, with adjustment for disease severity.

Results:

In total, 168 participants were included. After controlling for disease severity, awake sedentary time was greater in Danish participants compared to the other countries (median 784 min/day [660-952] vs 775 min/day [626-877] for Norwegians vs 703 min/day [613-802] for Australians, p=0.013), whilst time spent in moderate to vigorous physical activity was lower (median 21 min/day [4-73] vs 30 min/day [7-93] for Norwegians vs 48 min/day [19-98] for Australians, p=0.024). Participants tended to walk more during summer (median 3502 [1253-5407] steps/day) than in spring (median 2698 [1613-5207] steps/day), winter (median 2373 [1145-4206] steps/day) and autumn (median 1603 [738-4040] steps/day), regardless of geography. The median difference between summer and other seasons exceeded the minimal clinically important difference of 600 steps/day. However, the differences were not statistically significant (p=0.101).

Conclusion:

Seasonal variations may influence physical activity outcomes over time, irrespective of any interventions delivered. Understanding differences in physical activity patterns and seasonal variations across countries will assist in interpreting data from multi-national trials as well as health registries where physical activity is an outcome.

Keywords: Chronic obstructive pulmonary disease; activity monitoring; population comparison; seasons; weather

Introduction

Physical inactivity contributes significantly to morbidity and mortality worldwide.[1] People with chronic obstructive pulmonary disease (COPD) are less physically active than healthy age-matched controls,[2,3] and physical inactivity and sedentary behavior are associated with an increased risk of all-cause mortality in this group.[4-7] Inactivity is also thought to lead to a more rapid progression of COPD and the development of comorbidities in these individuals.[4-6,8] Conversely, disease progression and comorbidities may also lead to decreased physical activity. Given the interplay between physical activity and health in this group,[9] a physically active lifestyle is recommended for all individuals with COPD.[10]

In healthy people, physical inactivity varies between countries, with populations from high-income countries being the most inactive.[11] Socio-economic factors may also have some influence on physical activity among people with COPD. In a study comparing physical activity levels among people with COPD with different socio-economic and ethnic characteristics, the percentage of Austrians performing less than 30 minutes of moderate to vigorous physical activity per day was 48% compared with 23% in a disease severity-matched Brazilian group.[12]

Seasonal variations in terms of duration of daylight time and weather conditions might also affect physical activity levels and could be a confounder when investigating physical activity in COPD.[13-16] Winter months with cold temperatures have an impact on lung function and the risk of exacerbations.[17,18] In a study of 190 people with COPD in Canada, temperature was positively related to the number of steps per day, while precipitation was negatively related.[16] However, extremes of hot weather have also been linked to increased morbidity among those with COPD.[18]

The objectives of this study were: 1) to investigate whether there were differences in physical activity levels between Norwegian, Danish and Australian people with COPD and 2) to establish if any variation in physical activity levels was attributable to seasons (winter, spring, summer, autumn). Understanding differences in physical activity patterns and seasonal variations in physical activity across countries will assist in interpreting data from multi-national trials as well as health registries where physical activity is an outcome.

Material and methods

Study subjects and design

Study subjects were participants in two separate clinical trials, the iTrain study and the HomeBase study. Baseline data were used for this analysis. The iTrain study was an international multi-center randomized controlled trial on telerehabilitation for people with COPD in Norway, Denmark and Australia.[19] The HomeBase study was a randomized controlled trial investigating home-based pulmonary rehabilitation for people with COPD in Australia.[20] Common inclusion criteria for both trials were a confirmed diagnosis of COPD (forced expiratory volume in 1 second over forced vital capacity ratio/ forced vital capacity (FEV_1/FVC) ≤ 0.70) and age between 40 and 80 years. Participants in these trials were recruited during all seasons. Participants in the HomeBase study were recruited between March 2013 to March 2014. Physical activity was measured in a subgroup of participants recruited from the time when additional funding became available until the end of the trial. The iTrain study recruited from October 2014 to December 2016. The current study included physical activity data in a subgroup of participants recruited from the beginning of the trial to August 2016 when data analysis was initiated.

Settings

The Tromsø area where the Norwegian participants lived has a humid subarctic continental climate with cool summers and snowy winters. The temperature typically varies from -7°C to 15°C over the course of a year, and is rarely below -13°C or above 21°C. The warm season lasts from June 14 to September 3 with an average daily high temperature above 12°C. The warmest month of the year is July. The cold season lasts from November 16 to March 31 with an average daily high temperature below 1°C. The coldest month of the year is February.[21]

The Danish participants lived in the area near Esbjerg, which has a mild humid temperate climate characterized by warm summers. Over the course of a year, the temperature typically varies from -2°C to 21°C and is rarely below -8°C or above 26°C. The warm season lasts from May 27 to September 10 with an average daily high temperature above 18°C. The warmest month of the year is

July. The cold season lasts from December 4 to March 5 with an average daily high temperature below 6°C. The coldest month of the year is February.[22]

The area around Melbourne, where the Australian participants were situated, also has a mild humid temperate climate with warm summers and no dry season. The temperature typically varies from 6°C to 26°C over the course of a year and is rarely below 3°C or above 34°C. The warm season lasts from December 20 to March 14 with an average daily high temperature above 24°C. The warmest month of the year is January. The cold season lasts from May 22 to September 3 with an average daily high temperature below 15°C. The coldest month of the year is July.[23]

Data collection and analysis

Data on participant characteristics included nationality, gender, age, body mass index (BMI), number of comorbidities, smoking history, lung function measured by spirometry, disease severity (I to IV) according to the former staging system of the Global Initiative for Chronic Obstructive Lung Disease (GOLD),[10] use of long-term oxygen therapy (LTOT), dyspnea measured with the modified Medical Research Council dyspnea scale (MMRC),[24] and functional walking capacity measured by the 6-minute walk distance (6MWD).[25]

Physical activity levels were objectively assessed at baseline, prior to any implementation of interventions, with an activity monitor (SenseWear Armband, BodyMedia, Pittsburgh USA). Participants were asked to wear the activity monitor continuously for seven consecutive days, except for personal hygiene or other water-based activities. Minute-by-minute output was exported using SenseWear Professional version 8.0 software (BodyMedia, Inc). The first and the last day of recording were excluded from analysis to avoid incomplete measurements which could introduce a bias. Samples without at least one weekend day or without 5 valid days with wear time ≥12 hours days were excluded.[13,26] All valid days were included in the analysis. Physical activity outcomes were measured total energy expenditure in kilojoules (kJ) per day, total number of steps per day, minutes of awake sedentary time per day, total minutes of light intensity physical activity per day (LIPA), total minutes of moderate-to-vigorous physical activity (MVPA) per day, and total minutes in ≥10 minutes bouts of moderate-to-vigorous physical activity (MVPA bouts). Awake sedentary time was defined as activity where the metabolic equivalent was ≤1.5 METs, and measured sleep was excluded.[26] Non-wear time was not included in measurement of sedentary behavior. Any activity between 1.5 and 3 METs was defined as LIPA, and activity measured to ≥3 METs was considered MVPA.[27]

Differences in physical activity levels were compared across the three countries (Norway, Denmark and Australia). Seasonal variations were defined according to the meteorological seasons in the Northern Hemisphere and the Southern Hemisphere. The four seasons were defined as follows: winter (from December 1 to February 28 in Norway and Denmark, from June 1 to August 31 in Australia), spring (from March 1 to May 31 in Norway and Denmark, from September 1 to November 30 in Australia), summer (from June 1 to August 31 in Norway and Denmark, from December 1 to February 28 in Australia), and autumn (from September 1 to November 30 in Norway and Denmark, from March 1 to May 31 in Australia).

Statistical analyses

Descriptive data were reported as median and interquartile range (IQR) for continuous variables, and counts and percentages for categorical variables. Normality of distribution was tested with the Kolmogorov-Smirnov test. Differences in participant characteristics between the three countries were compared with Kruskal-Wallis test for continuous variables and chi-squared test for categorical variables. A Mann-Whitney test was used as a post-hoc test to discover which specific means differed when the overall Kruskal-Wallis result was significant. Log transformation (used for energy expenditure) and cubic root transformation (used for steps, LIPA and MVPA time) were applied to the physical activity variables with a non-parametric distribution in order to obtain normally distributed data so that parametric methods for statistical analyses could be performed. No transformation nor statistical analyses were applied to time in MVPA bouts due to the high number of zero values. Values reported in tables are original median and IQR values. Differences in physical activity variables between countries and seasons were compared with one-way ANOVA. A Tukey post-hoc test was used to discover which specific means differed where the overall ANOVA result was significant. Between country differences were also adjusted for disease severity (FEV_1 %) using one-way ANCOVA. The combined effect of seasons and countries on physical activity was analyzed with two-way ANOVA. A p-value <0.05 was considered significant for all tests. All statistical analyses were performed with IBM SPSS Statistics Version 25.

Results

Participant characteristics

In total, 168 participants with moderate to severe COPD from Norway, Denmark and Australia were included (Table 1). The Australian sample consisted of 61 participants from the HomeBase study and 33 participants from the iTrain study, while samples for Norway (n=38) and Denmark (n=36) consisted only of participants from the iTrain study. Demographics for the three groups were generally similar, although the percentage of participants in GOLD stage III and IV (severe and very severe airflow limitation) was higher among the Danish participants. Australian participants had the highest number of comorbidities and Danish participants had a lower functional walking capacity.

Table 1 Characteristics of participants with COPD from Norway, Denmark and Australia

	Norway (n=38)	**Denmark (n=36)**	**Australia (n=94)**	**p-value**	**Post-hoc***
Sex,					
male	24 (63%)	20 (55%)	52 (55%)	0.696	
Age, year	66 [63-72]	63 [61-68]	66 [60-73]	0.211	
BMI, kg/m^2	28.4 [24.0-33.1]	25.6 [22.9-28.0]	26.0 [22.0-30.5]	0.066	
Comorbidities, number	2 [1-3]	2 [0-2]	3 [2-4]	<0.001	A vs N = 0.009
					D vs A = 0.001
Smoking status				0.085	
Current smoker	14 (37%)	13 (36%)	18 (19%)		
Ex smoker	24 (63%)	23 (64%)	73 (78%)		
Never smoked	0 (0%)	0 (0%)	3 (3%)		
Smoking, pack years	24 [15-40]	40 [25-46]	45 [31-56]	<0.001	D vs N = 0.003
					A vs N = 0.001
FEV_1/FVC	52.8 [44.0-59.0]	51.5 [43.0-62.5]	43.5 [34.0-56.0]	0.002	A vs N = 0.008
					D vs A = 0.002
FEV_1, liters	1.32 [0.97-1.82]	0.92 [0.69-1.11]	1.13 [0.86-1.50]	<0.001	D vs N = 0.001
					D vs A = 0.002
FEV_1, % predicted	50.7 [38.7-63.8]	32.5 [25.0-41.0]	44.0 [32.0-62.0]	<0.001	D vs N = 0.001
					D vs A = 0.001

FVC, % predicted	74.7 [67.0-90.0]	65.5 [48.5-78.0]	74.0 [62.0-90.0]	0.011	D vs N = 0.013 D vs A = 0.004
Disease severity					
GOLD II	20 (53%)	3 (8%)	40 (43%)	<0.001	
GOLD IIII	11 (29%)	15 (42%)	38 (40%)		
GOLD IV	7 (18%)	18 (50%)	16 (17%)		
Use of LTOT, yes	5 (13%)	9 (25%)	12 (13%)	0.204	
MMRC				0.642	
Score 0	2 (5%)	2 (6%)	1 (1%)		
Score 1	11 (29%)	10 (28%)	40 (43%)		
Score 2	12 (32%)	13 (36%)	27 (29%)		
Score 3	11 (29%)	10 (28%)	23 (24%)		
Score 4	2 (5%)	1 (3%)	3 (3%)		
6MWD, meters	416 [350-480]	318 [193-383]	427 [358-480]	<0.001	D vs N = 0.001 D vs A = 0.001
Lowest SpO2 during 6MWD, %	90 [86-93]	90 [86-92]	90 [86-93]	0.978	
Max HR during 6MWD, beat per minute	112 [99-127]	115 [106-122]	113 [102-122]	0.889	
SOB end of 6MWD, Borg CR-10 scale	5 [4-7]	3 [2-3]	4 [3-5]	<0.001	D vs N = 0.001 D vs A = 0.002
RPE end of 6MWD, Borg CR-10 scale**	4 [2-6]	3 [2-4]	3 [2-5]	0.432	
Gait aid, yes	2 (5%)	6 (17%)	8 (9%)	0.218	

Data are median [interquartile range] for continuous variables, counts and percentages for categorical variables. BMI = body mass index; FEV_1 = Forced expiratory volume in the first second; FVC = Forced vital capacity; LTOT= long-term oxygen therapy; MMRC = Modified version of the Medical Research Council Scale; 6MWD = 6-minutes walking distance; SpO2 = Peripheral capillary oxygen saturation; HR = Heart rate; SOB = Rating of perceived shortness of breath; RPE = Rating of perceived exertion for leg fatigue.

*=Only significant comparisons are listed.

**= For the Australian participants, this variable was only calculated for the 33 participants in the iTrain study.

Differences in physical activity levels across countries

All subjects had valid physical activity measurements from 5 days including 1 weekend day with recordings of ≥12 hours per day. There was a statistically significant difference in wear time between all countries (p=0.001). Danish participants wore the activity monitor the most. Physical activity levels were higher for Norwegian and Australian participants compared to Danish participants (Table 2). Danish participants had a lower number of daily steps, less time spent in MVPA, and more awake sedentary time compared to the Australians (p=0.025, 0.014 and 0.007, respectively). After controlling for FEV_1, differences in time spent in MVPA and awake sedentary time across countries persisted (p=0.024 and 0.013, respectively), while the difference for daily number of steps was no longer statistically significant.

Table 2 Physical activity among participants from Norway, Denmark and Australia

	Norway (n=38)	**Denmark (n=36)**	**Australia (n=94)**	**p-value**	**Post-hoc**	**p-value after controlling for FEV_1**
Wear time, min/day	1361 [1340-1414]	1429 [1408-1437]	1418 [1401-1429]	0.001	D vs N&A N vs A	
Energy expenditure, kJ/day	9790 [8237-11754]	8439 [7772-9641]	8320 [7569-10843]	0.266		0.288
Steps, number/day	1672 [1020-3839]	1534 [778-3194]	2916 [1316-4986]	0.025	D vs A	0.133
Awake sedentary time, min/day	775 [626-877]	784 [660-952]	703 [613-802]	0.010	D vs A	0.013
Total LIPA, min/day *	158 [81-219]	178 [124-234]	208 [132-249]	0.388		0.422
Total MVPA, min/day	30 [7-93]	21 [4-73]	48 [19-98]	0.014	D vs A	0.024
Time in MVPA bouts, min/day	8 [0-30]	4 [0-26]	7 [0-24]	n.a		n.a

Data are median [interquartile range]. kJ = Kilojoules; LIPA= Light-intensity physical activity; MVPA= Moderate-to-vigorous physical activity; min= minutes. n.a= non applicable. D vs N&A, N vs A and D vs A = p-value ≤0.050, only significant comparisons are listed.
* LIPA for the Australian sample was available for the 33 participants in the iTrain study only.

Effect of seasonal variations on physical activity levels

The median (IQR) number of steps for all patients tended to be highest in summer (3502 [1253-5407] steps/day) with lower levels in spring (2698 [1613-5207] steps/day), winter (2373 [1145-4206] steps/day) and autumn (1603 [738-4040] steps/day). The difference between summer and other seasons exceeded the minimal clinically important difference of 600 steps/day.[28] However, there was no statistically significant difference among seasons (p=0.101). The same tendency described for steps could be seen for the total MVPA time. Nevertheless, there were no statistically significant difference among seasons for any of the physical activity variables (Table 3).

Table 3 Physical activity in the different seasons

	Winter n=50 (NO=12;DK=8; AU=30)	**Spring n=40** (NO=11;DK=8; AU=21)	**Summer n=22** (NO=0;DK=4; AU=18)	**Autumn n=56** (NO=15;DK=16; AU=25)	**p-value**
Energy expenditure, kJ/day	9075 [7796-10297]	8571 [7748-11783]	8491 [7642-11164]	8442 [7261-10314]	0.181
Steps, number/day	2373 [1145-4206]	2698 [1613-5207]	3502 [1253-5407]	1603 [738-4040]	0.101
Awake sedentary time, min/day	721 [608-868]	755 [635-901]	700 [617-801]	735 [620-824]	0.796
Sleep time, min/day	410 [316-463]	362 [316-451]	365 [317-481]	401 [314-463]	0.982
Total LIPA, min/day *	160 [102-237]	197 [150-255]	159 [99-251]	177 [106-230]	0.487
Total MVPA, min/day	39 [15-88]	38 [20-100]	62 [11-108]	27 [8-90]	0.326
Time in MVPA bouts, min/day	9 [0-23]	7 [0-34]	7 [2-25]	5 [0-25]	n.a

Data are median [interquartile range]. kJ = Kilojoules; LIPA= Light-intensity physical activity; MVPA= Moderate-to-vigorous physical activity; min= minutes; n.a= non applicable; NO= Norway; DK= Denmark; AU= Australia.
* LIPA for the Australian sample was available for the 33 participants in the iTrain study only.

Results from the two-way ANOVA showed that there was no significant effect for the interaction between country and seasons on the number of steps (p=0.432), with no significant main effect for season (p=0.273), but a significant main effect for nationality was confirmed (p=0.018). The interaction effect between seasons and nationality on awake sedentary time was not statistically significant (p=0.774). There was no significant main effect for season (p=0.936), but a significant main effect for nationality was confirmed (p=0.044). The interaction effect between seasons and nationality on MVPA time was not statistically significant (p=0.801). There was no significant main effect for season (p=0.633), but a significant main effect for nationality (p=0.042).

Discussion

This study aimed at investigating whether there were differences in physical activity levels between Norwegian, Danish and Australian people with COPD. The results revealed some differences across countries after controlling for disease severity. Danish participants spent more time in an awake sedentary state and less time in MVPA. The study aimed also at establishing whether variations in physical activity levels were attributable to seasons. Although it did not reach statistical significance, there was a trend for the participants to walk more and with higher intensity during summer when compared to spring, winter and autumn, regardless of geography.

Differences in physical activity levels across countries, as seen in this study, has been observed before. A study on participation in physical activity among Austrian and Brazilian people with COPD, suggested that Brazilian participants, due to lower socio-economic status, may ambulate more for daily activities and to access public transportation than the Austrians who more often had access to their own cars.[12] In our study, the countries involved have similar prosperity indexes and socio-economic standards,[29] while there were differences in disease severity among participants. Disease severity has been shown to have a weak-to-moderate positive association with reduced physical activity in patients with COPD.[5,30] This partially explained the differences in physical activity in the current study, as the Danish participants, who had higher sedentary time and lower MVPA time, also had more severe COPD than their counterparts in Norway and Australia. As disease severity may influence physical activity, it is important to take this into account in clinical studies, and ensure that participants are properly stratified to achieve similarity between groups in multi-center and multi-national trials.

For the healthy population, nationality seems to influence self-reported physical activity more than in people with COPD. According to the Global Observatory for Physical Activity, 53% of the Norwegian population and 76% of the Danish population report being physical active compared with only 43% of the Australian population.[31] However, these findings are based on self-reported data and may not be as accurate as our objectively measured data as large variations between self-reported and accelerometer-measured physical activity and sedentary time have been reported.[32]

In our study, the difference in awake sedentary time and time spent in MVPA persisted across countries after controlling for disease severity. Danish participants, who spent significantly longer periods of the day in sedentary activities and less time walking at higher intensities, had significantly lower functional walking capacity (indicated by 6MWD) than participants from other countries. There is a moderate association between physical activity and physical capacity.[5] In the current study, participants from Norway and Australia had a median walking distance of >400 meters on the 6MWD and achieved ≥30 minutes of MVPA, whereas Danish participants walked a median of <400 meters and did not meet the value of ≥30 minutes of MVPA which is recommended by the American College of Sports Medicine.[33] Such correlation between physical capacity and intensity of physical activity has previous been observed by Pitta et al.[2] However, high physical capacity does not always translate into higher levels of physical activity, as physical activity is also influenced by psychological factors like habit, self-efficacy and health beliefs.[34,35] In addition to individual factors, social and physical environment such as urban planning, transport systems, and parks and trails may explain why some people are more physically active than others.[36] A qualitative study identified barriers and enablers for participation in physical activity among COPD patients after hospital admission due to a disease exacerbation. The main barriers were health-related (comorbidities, COPD symptoms, injury and illness), self-related (advancing age and experience of previous physical activity) and environment-related (weather, transport and finance).[34] Main enablers were identified as access to health professionals and equipment, social support, routine and hobbies, personal goals and motivation, and the feeling of getting better when being more active.[34]

Reducing sedentary time can decrease cardiovascular risk in other patient groups.[37] As many patients with COPD have cardiovascular comorbidities,[38] strategies to reduce sedentary time may be clinically relevant in COPD.[39] Targeting sedentary behavior can also be effective in improving the ability to stand up from a seated position among older adults, thus improving physical functioning.[40] A recent review suggests that future trials should examine sedentary time as an outcome when assessing physical activity interventions as this may have clinical benefits for people with COPD.[39] In the current study, variations in step count across the year were not offset by changes in awake sedentary time, as sedentary time was unchanged all year. Strategies that target sedentary behavior might have a potential for increasing overall physical activity.

Climate and variations in weather conditions following the different seasons may influence levels of daily physical activity in COPD.[5] Studies have reported lower number of steps during rainy and colder days, in winter and during extreme summer heat.[14,16,41,42] A recent study of people with COPD residing in Canada reported that an increase in daytime temperature of 10°C translated into 316 more daily steps (6.6% of mean steps/day) whereas rainfall of 10 mm had a negative effect of 175 less daily steps (3.6% of mean steps/day).[16] The current study was conducted in three countries with climate zones spanning from Arctic climate with cold summers and cold winters to tropical influenced climate with hot summers and mild winters. Participants with COPD tended to walk more during summer than during spring, winter and autumn, regardless of location. Results did not reach statistical significance due to the modest sample size in each group. However, the overall difference between summer (3502 steps/day) and winter (2373 steps/day) exceeded the minimal clinical important difference (between 600 and 1100 steps/day) in daily step count after pulmonary rehabilitation.[28] An improvement of more than 600 steps/day after pulmonary rehabilitation is also reported to reduce the risk of hospitalization in patients with COPD.[28] We therefore consider the difference of 1129 daily steps between summer and winter to be of clinical relevance.

Seasonal differences have implications for clinical trials that measure physical activity over time, as the season in which the measurement is taken may influence outcomes irrespective of any intervention delivered. The effect of temperature and season on daily steps has recently been reported in a 3-months physical activity intervention trial on people with COPD.[43] An increase in daily steps was found in subgroup analysis of both a group receiving a pedometer and web-based support and a group receiving a pedometer intervention alone during the transition from spring to summer. During the transition from summer to autumn, the group with web-based support experienced an increase in daily step count from baseline, while the group using only pedometer had a significant decline.[43] The influence of seasonal variations on physical activity habits may be relevant for both selected patient groups, such as COPD, as well as for the healthy population. Results from multi-national trials as well as health registries where physical activity is an outcome should take into account differences in physical activity patterns due to seasonal variations both if the trial is performed across countries or within one country.

Study strengths and limitations

This study included a total of 168 participants from three countries. Study subjects were participants enrolled in two separate trials using common inclusion criteria, methods and algorithms for objectively measurements of physical activity. This allowed us to investigate differences in physical activity across countries based on a larger sample than that from a single trial. Differences in disease severity between participants in the different countries were found, and as a consequence controlled for. Danish participants wore the activity monitor for longer each day, and by this, they might have recorded longer time in sedentary activities than their counterparts might. The lower number of Nordic patients with physical activity data collected during summer may have influenced the results on seasonal variations. Recruitment during summer was low due to summer holiday for both healthcare personnel supporting the recruitment procedures and potential participants. We recommend that future studies investigating seasonal variation will be attentive to include enough participants in each season. The majority of the physical activity variables in the dataset were characterized by a non-normal distribution. We therefore transformed those variables to achieve normal distribution and use parametric tests. However, similar results were achieved by use of non-parametric tests. These data represent cross sectional observations rather than assessment of the longitudinal impact of seasons on a given individual. Further studies taking into account seasonal effects on changes in physical activity over time are required.

Conclusion

In this study, Norwegian, Danish and Australian people with COPD differed in terms of time spent in awake sedentary and moderate-to-vigorous physical activity after controlling for disease severity. There was a tendency for participants to walk more and with higher intensity during summer than during spring, winter and autumn, regardless of geography. Weather conditions and seasonal variations may influence outcomes in clinical trials and health registries measuring physical activity over time, irrespective any interventions delivered, and should be taken into account when interpreting results.

Abbreviations

BMI = body mass index
COPD = chronic obstructive pulmonary disease
FEV1 = forced expiratory volume in the first second
FVC = forced vital capacity
GOLD = Global initiative for chronic obstructive lung disease
HR = heart rate

kJ = kilojoules
LIPA = light-intensity physical activity
LTOT = long-term oxygen treatment
METs = metabolic equivalent
min = minutes
MMRC = modified Medical Research Council dyspnea scale
MVPA = moderate-to-vigorous intensity physical activity
MVPA bouts = 10 minutes bouts of moderate-to-vigorous intensity physical activity
RPE = rating of perceived exertion for leg fatigue
SOB = rating of perceived shortness of breath
SpO2 = peripheral capillary oxygen saturation
6MWD = 6-minute walk distance

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Disclosure

Ethics approval and informed consent

Only patients who had volunteered and provided written informed consent in accordance with the Declaration of Helsinki were included in this study. The iTrain study was approved by the Regional Committee for Medical and Health Research Ethics in Norway (2014/676/REK nord), the North Denmark Region Committee on Health Research Ethics (N-20140038), and the Alfred Hospital Human Research Ethics Committee (289/14). The HomeBase study was approved by the Alfred Hospital Human Research Ethics Committee (261/11), Austin Health Human Ethics Committee (H2011/04364) and La Trobe University Faculty of Health Sciences Human Ethics Committee (11-134). Approval to combine data from the HomeBase study with the iTrain study has been received. Trial registration: Clinical Trials registry NO.: NCT02258646 and NCT01423227.

Consent for publication

Not applicable.

Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Competing interests

The authors declare that they have no competing interests.

Authors' contributions

P.Z., A.H., B.D, and A.E.H. are responsible for the iTrain study protocol. A.E.H. is responsible for the HomeBase study protocol. H.H., P.Z. and A.E.H. contributed to the conception and design of the current study. H.H., P.Z., B.D., A.T.B., N.S.C., and A.E.H. contributed to the acquisition of data and analysis of data. H.H., P.Z., A.H., A.T.B., N.S.C., A.E.H. contributed to the interpretation of data. H.H., P.Z., A.H., and A.E.H. contributed to drafting the manuscript, and all other authors contributed to revision of the manuscript. All authors read and approved the final manuscript.

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APPENDICES

APPENDIX 1

iTrain: Treadmill exercise prescription, continuous training

- **Treadmill walking speed**

  Initial walking speed: 80% of average 6MWT walking speed (based on the best of the two 6MWTs)

  Example:
  If the patient walked 300 m in the 6MWT, then:
  300 x 10 ÷ 1000 = 3.0 km / hr.
  80% of 3.0 km / hr = 2.4 km / hr.
  Therefore, the initial treadmill speed would be set at 2.4 km / hr. The treadmill may start at approximately 2 km/hr to account for the patient being unfamiliar with treadmill walking.

  Beside this, a Borg dyspnea or leg fatigue score of 4 (moderate to severe) is considered a target training intensity.

- **Duration**
  A total minimum duration of 30 minutes should be achieved. This can be in 2 sets of 15 mins if required. Some patients may need to start with an exercise duration of 2 x 10 mins, but this should be built up to a total duration of 30 mins by the second week of the program.

  Participants are permitted to take short rests in the event of intolerable symptoms, or if oxygen saturation decreases ≤ 88 %, but rest time does not count towards training duration.

- **Frequency**
  A frequency of 3-5 times per week is prescribed.

- **Treadmill training progression**
  Treadmill walking speed:
  - Increase walking speed as tolerated each week by 0.25 km/hr if initial walking speed is <3 km/hr; increase 0.5 km/hr if initial speed is >3 km/hr (this can be increased more quickly if the Dyspnoea or RPE scores are below 3)
  - Once walk speed reaches 5 km/hr, reduce speed to 4.5 km/hr and add gradient of 1-2%. Then increase gradient 1-2% weekly
  - If unable to reach 5 km/hr due to leg length, gradient can be introduced a little earlier

Duration:

- Training duration up to 60 minutes can be tolerated after some weeks of training, depending on the patient's condition. Longer duration could affect the frequency, but a minimum frequency of 3 times per week should always be targeted.

Reference:
http://www.pulmonaryrehab.com.au/index.asp?page=49

Spruit et al. An Official American Thoracic Society/European Respiratory Society Statement: Key Concepts and Advances in Pulmonary Rehabilitation *American Journal of Respiratory and Critical Care Medicine* 2013;188:e13-64

iTrain: Treadmill exercise prescription, interval training

- **Treadmill walking speed**

Warm up:
Choose one of 4 levels of initial speeds based of the patients' condition.

Level	Initial speed	Increase gradually to (if tolerated)	Borg ratings Dyspnea/leg fatigue	Time
# 1.	1,6 km/hr	2,4 km/hr	3-4	10 min or more, include breaks if needed *
# 2.	2,4 km/hr	3,6 km/hr	3-4	10 min or more, include breaks if needed *
# 3	3,6 km/hr	4,8 km/hr	3-4	10 min or more
# 4.	4,8 km/hr	5,4 km/hr	3-4	10 min or more

*Rest time does not count towards duration of warm up

Intervals:
Choose length of high intensity interval peaks based on the patients' level of function and GOLD stadium. You might choose a longer interval for the patient than prescribed for his GOLD stadium and rather base your decision of his actual level of function. Make account for experience of training, lung function, desaturation, ventilator limitations/dynamic hyperinflation, weight etc.

GOLD stadium	Length of interval	Number of interval	Progression
I-II	2-4 min	3-4	Increased incline/speed
III- IV	1 min	4	Longer duration of interval

Intervals of 1 min x 4 times:
From warm up speed, increase speed as tolerated until Borg ratings of 5-6 for dyspnea or leg fatigue.

Intervals of 2 min x 4 times:
From warm up speed, increase incline or speed as tolerated until Borg ratings of 5-6 for dyspnea or leg fatigue.

Intervals of 3 min x 3-4 times:
From warm up speed, increase incline and speed until Borg ratings of 5-6 for dyspnea or leg fatigue.

Intervals of 4 min x 3-4 times:
From warm up speed, increase incline and speed until Borg ratings of 5-6 for dyspnea or leg fatigue.

Beware that the SpO2 always should be above 88 %. If desaturation, decrease length of interval peak or incline/speed. Full stops might be needed instead of active breaks.

Active rests:
Between the interval peaks there should be active rests or full stops depending on the patients' condition. The active rests/stops could last from 2- 4 minutes. Dyspnea or leg fatigue ratings of 3-4 are desired. Reduce gradient, and then speed if needed.

Cool down:
Choose the same level as initial speed and reverse the speed prescription (e.g. 3,6 km/hr → 2,4 km/hr.) Minimum 5-10 minutes of low to moderate intensity. Borg ratings of 3-4.

- **Duration**
  A total minimum duration of 30 minutes should be achieved. Participants are permitted to take full stops in the event of intolerable symptoms, or if oxygen saturation decreases ≤ 88 %, but rest time does not count towards training duration.

- **Frequency**
  For interval training a frequency of 3 times per week is prescribed.

- **Interval training progression**
  If the patient reports lower dyspnea or leg fatigue ratings than prescribed, progression should be made. Try to make progression 3, 6 and 9 weeks into the program as followed:

  If starting interval peaks of 1 min x 4 times:
  Make progression by increasing duration of peaks to 2 min, and later on increase duration to 3 min. When 3 min duration is reached, you could make further progression by increasing incline and/or speed or duration up to 4 min if tolerated.

Intervals of 2 min x 4 times:
Make progression by increasing duration of peaks to 3 min. When 3 min duration is reached, you could make further progression by increasing incline and/or speed or duration up to 4 min if tolerated.

Intervals of 3 min x 3-4 times:
Make progression by increasing duration of peaks to 4 min. You could also make progression by increasing incline and/or speed.

Intervals of 4 min x 3-4 times:
Make progression by increasing incline and/or speed.

Progression can also be made by adding active breaks if full stops between interval peaks has been prescribed earlier in the program.

- If patient reports higher dyspnea or leg fatigue ratings than prescribed, reduction to the program must be made. Continuous training could be an option, or gradient/speed should be reduced.

- Duration:
  Total training duration up to 60 minutes can be tolerated after some weeks of training, depending on the patient's condition.

The minimum exercise prescription for both exercise modes:

Frequency: 3 times per week.
Intensity: Dyspnea ratings of leg fatigue at 4 on Borg CR 10. Might use 3 for warm up and cool down under interval training.
Type: Treadmill
Time: ≥ 30 minutes

A combination of modes can be used.

References:

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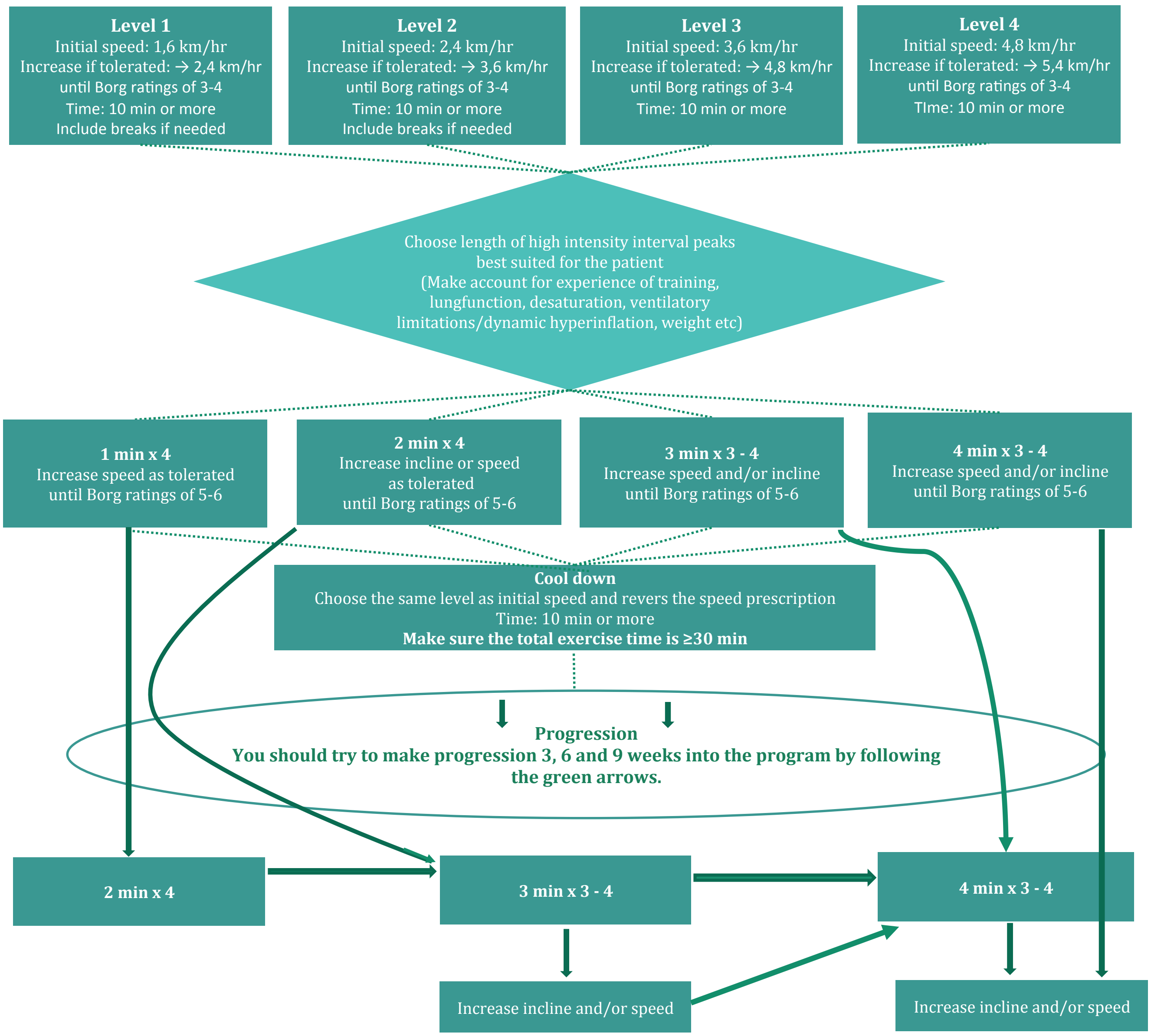
APPENDIX 2

iTrain: Prescription of interval training

Choose level of initial speed for warm up and follow suggested path way



APPENDIX 3

iTrain: Practical conduction of the video conferences

Before the first meeting with the patient:

- Make sure you have all the information about the patient that you need. You should be given a copy of the spirometry, 6 MWT and the exercise program if someone else has done the first prescription of the program.

First meeting via videoconferencing, 60 minutes

- Getting to know each other (Clinical history, experience with exercising and computers and other information you would like to know about the patient).
- Goal setting and expectations regarding participation in the project. Post the goals you agree up on in the patient web page.
- Explain the project and functions of the web page if needed.
- Try out the exercise program, and post it at the patient webpage if this have not been done.
- Schedule the next meeting and post it as an upcoming event.

Weekly interpretation of data and before the videoconference:

- Go through the patient' webpage, daily measurements, training diary, comments and messages if there are any.
- Assess the whole picture. Has the patient exercised according to the plan? Are adjustments to the exercise program needed? Do health conditions seem stable?

You should go through the patient' web page on a weekly basis, even though you haven't scheduled a videoconference. Answer questions or write comments if needed.

Videoconference, 20 – 30 minutes (Might need more time for the first couple of meetings)

- Clarify whether the patient wants to use this session to exercise or just discuss exercise, goals, daily measurements etc. You could do a bit of both if there is time available, but do not expect the patient to have a whole conversation with you while walking. The patient needs his breath for exercising.
- Discuss last week's/last month's exercising:
    - Accomplishments? New experiences? Changes?
    - Deviation from the plan? Why? Need to make adjustments?
    - Coping with dyspnea during exercise?
    - Exercising during illness and convalescence.
    - A major goal with this discussion is to make the patients understand how exercise influences their body, to provide knowledge and experience in how they can adjust their training according to their daily conditions and make progressions.
    - Motivation.

- Dialogue regarding daily measurements:
  - Educate the patient in early recognition and treatment of COPD exacerbations. The warning signals are:
    - More wheezy or breathless than normal
    - More coughing than normal
    - Less energy for usual activities
    - Loss of appetite or sleep
    - Change in amount or color of sputum (yellow-green or brown)
    - Need for an inhaler or nebulizer more often than usual.
    - Signs of fever or the first signs of a cold.
    - Increased heart rate, resting saturation and BCSS score might also predict upcoming exacerbation (5).

  Treatment:

    - Encourage the patient to get a plan for increasing medication/ dosage for rescue medication for early treatment of exacerbations from his physician if he does not have one yet, and guide him to use this additional medication when needed.
    - Reduce activity level and rest frequently.
    - Clear sputum with techniques for airway clearance (Active cycle and huffing).
    - Use of breathing- and relaxation techniques.
    - Eat small amounts of nourishing food, often.
    - Drink extra fluids.

  Advice patient to get in touch with a physician if they seem to have a more severe chest infection and are unable to perform normal activities (e.g. dressing, bathing, eating), have fever or chills, increased swelling of ankles or extremely shortness of breath. Note that the project-patients should use all the health services as other COPD patients (e.g. standard care) during the two-year period.

- Goal and goal attainment, regularly.
    - To keep focus on the goals and the progress these questions among others could be asked:
      - What have been different in regard of your goal this week?
      - Have you discovered any small signs of change in regard to your goal this week?
      - What do you need to change to get closer to your goal?
      - Why do these things seem different?
      - What have you done that seems to work?

- Other discussion topics:
    - Need of more knowledge about COPD and living with COPD?
    - What to do to stay well and healthy (Plan activities and pace yourself, listen to your body, nutrition, social activities, smoking cessation if needed, avoid allergens and things that make symptoms worse, take medication and use oxygen as prescribed etc)

After the videoconference:

- Make notes for future references in the electronic journal.
- Adjust the exercise program on the patient’s webpage if not previously done while talking. The different versions of the exercise program will be saved.