Facilitators and barriers of adherence to multi-morbid exacerbation action plans in COPD patients with comorbidities: a qualitative study

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Abstract

Background: Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease, of which the majority of patients suffers from at least one comorbidity. Whereas the use of exacerbation action plans to self-manage COPD patients' condition significantly improves health outcomes, poor adherence is common. The presence of comorbidities, limited knowledge of symptoms and being passive towards disease management, decrease patients' abilities and motivation to be adherent self-managers. Currently, it remains unknown what factors influence adherence to action plans that take into account common comorbidities.

Objective: The aim of this study is to identify facilitators and barriers of adherence to multi-morbid exacerbation action plans in COPD patients with ischaemic heart disease, chronic heart failure, diabetes mellitus, anxiety and/or depression.

Methods: Qualitative research was performed using a subsample of Dutch and Australian patients who participated in a self-management trial (COPE-III). Individual semi-structured interviews were conducted on patients' experiences with symptom diaries and exacerbation action plans in patients with moderate to severe COPD and ≥ 1 comorbidity. A deductive-dominant content analysis approach was used to analyse the interview data, with the Capability, Opportunity, Motivation model of behaviour change as theoretical framework.

Results: Ten patients (5 Australian, 5 Dutch, 6 males, age range 59-83) were interviewed. Patients' perspectives on roles towards disease management encompassed patients feeling mainly responsible themselves, patients feeling just as responsible as they perceive the healthcare provider to be, and patients having no active role as they perceive the healthcare provider to be mainly responsible. Facilitators of adherence included the continuous availability of professional support, positive beliefs about the effectiveness of the symptom diary and action plan, and self-confidence in one's abilities to use the action plan. Barriers of adherence included patients' incapability of memorizing to use the symptom diary daily, insufficient comprehension of symptoms, the symptom diary' complexity, aversion towards medication use, and a lack of stimulation to use the diary in stable phase.

Conclusion: To optimize adherence, the number of contact hours with case managers should increase in which patients' individual barriers can be addressed and strategies to overcome these barriers can be identified. The benefits of symptom diary use should be more emphasized and patients should be coached into taking on main responsibility for disease

management and therefore improve patients' motivation to be adherent. E-health should be introduced to suit individual preferences regarding the symptom diary's ease of use to increase patients' opportunity to be adherent.

Acknowledgements

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Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a prevalent and progressive lung disease that is defined by an enhanced chronic inflammatory response in the airways and the lungs due to exposure to noxious particles or gases (Vogelmeier et al., 2017). The disease is characterized by persistent airflow limitation and episodes of acute deterioration in respiratory health symptoms, such as increased cough, wheeze, dyspnoea and sputum production, which are referred to as exacerbations (Rodriquez-Roisin, 2000; Wacker et al., 2016). According to the World Health Organization (2018), COPD is now the third leading cause of mortality worldwide.

COPD has a large impact on individual patients' well-being, as well as a social and economic impact. COPD exacerbations weaken patients' lung function, decrease physical performance and accelerate disease progression (Anzueto, 2010), whereby severe exacerbations are the main cause for hospitalization among COPD patients (Terzano et al., 2010). Exacerbating symptoms are also often accompanied by feelings of panic and fear (Miravitlles & Ribera, 2017), and throughout their daily lives, patients often deal with stressful feelings such as frustration and regret (Miravitlles & Ribera, 2017). In addition, COPD patients can experience disruptions in their social interactions, due to patients' reduced mobility, fear of symptoms or embarrassment, as patients may feel they are being held responsible for their disease (i.e. due to smoking) (Johnson, Campbell, Bowers & Nichol, 2007). Furthermore, COPD contributes to increasing healthcare utilization, showing a direct relationship between the severity of COPD and the costs of healthcare (Vestbo et al., 2013). Also, patients' loss of productivity, early retirement and reduced ability to work, contribute to the significant economic burden of COPD (Ramsey & Sullivan, 2003).

Self-management is of increasing importance in the treatment of COPD (Bourbeau & van der Palen, 2009), and refers to "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition" (Barlow et al., 2002). Self-management encompasses medical management (self-monitoring symptoms and self-treatment), lifestyle adjustment, coping with (the consequences of) the chronic disease(s) in daily life, and communication and relations with healthcare professionals, including active participation in decision-making processes about care and treatment (Heijmans et al., 2015). Self-management interventions for COPD patients are associated with increased HRQoL and overall well-being, and decreased

dyspnoea, health distress levels, and healthcare utilization (Jonkman et al., 2016; Zwerink et al., 2014). However, limited knowledge and understanding of their disease, poor health literacy, and low self-confidence often inhibits COPD patients' active engagement in self-management practices (Russell et al., 2018; Yadav et al, 2020). Additionally, part of the patient population tend to hold their healthcare provider as responsible for monitoring and managing their health, preventing them from taking on an active role in disease management themselves (Coventry et al., 2014). Moreover, patients often find coping with COPD alone demanding enough (Rijken, Jones, Heijmans & Dixon, 2008), whereas the majority of patients need to cope with at least one coexisting disease (comorbidity) as well. The added responsibility of self-managing multiple diseases can easily become too overwhelming (Coventry et al., 2014; Yadav et al., 2020).

According to Yin et al. (2017), up to 90% of COPD patients have at least one comorbidity, and according to Franssen and Rochester (2014), up to 40% of COPD patients suffer from at least two comorbid conditions. Comorbidities often contribute to impaired HRQoL, and increased mortality for increasing the burden of COPD management on health care and creating dilemma's regarding symptom treatment (Ng et al., 2007; Vestbo et al., 2013). For instance, due to the similarity of COPD symptoms and comorbid symptoms (e.g. breathlessness, fatigue, reduced physical activity), it can be difficult for patients to differentiate between these symptoms (Vestbo et al., 2013), which in turn can lead to the initiation of incorrect or delayed treatment of exacerbations.

To promote recognition and treatment of COPD exacerbations, action planning is a frequently applied technique in self-management interventions (Lenferink et al., 2017). It takes the form of personalized, multi-component exacerbation action plans, usually designed in partnership with the physician and the patient, and taking into account the patient's experience of an acute (severe) exacerbation (Decramer et al., 2008). Exacerbation action plans are aimed at instilling confidence for recognizing symptoms of an exacerbation early on, taking appropriate action on time (e.g. antibiotics and oral corticosteroids) and providing support (Effing et al., 2011; Lenferink et al., 2017). Early detection of an exacerbation while using an action plan, has been shown to accelerate recovery time after an exacerbation, decrease the acute impact of COPD exacerbations on health status, improve HRQoL, lower the probability of respiratory-related hospitalization, and lead to considerable cost savings (Bischoff et al., 2011; Fogleman, 2018; Lenferink et al., 2019; Zwerink et al., 2016).

Therefore, exacerbation action plans are considered as a key element in self-managing COPD (Effing et al., 2011).

Unfortunately, poor adherence to treatment guidelines is common in COPD patients(Pinnock et al., 2011; Bourbeau & Bartlett, 2008). Adherence is defined as 'the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a healthcare provider.' (Sabaté, 2003). For instance, Bischoff et al. (2011) found that in only 40% of COPD exacerbations patients adhere to their written action plan, whereby healthier patients showed a tendency to delay self-treatment in comparison with patients with worse disease severity (i.e. lower lung function or cardiac comorbidity), who were more likely to adhere to their action plan (Bischoff et al., 2011). Vestbo et al. (2009) argue that patients with COPD are non-adherent to approximately half of their inhaled respiratory pharmacotherapies, and suggest that this could be the result of treatment with multiple medications, since COPD patients often have comorbidities. According to Langsetmo et al. (2008) and Xu et al. (2010), approximately 50% of exacerbations is not adequately treated, as COPD patients do not report symptom deterioration to their healthcare providers.

Adherence to recommended self-management guidelines is of great importance for unburdening the patient as well as the healthcare system. Not only can active self-management diminish the impairment of patients' quality of life caused by COPD, but increasing the number of adherent self-managers can take significant pressure off healthcare systems as well (Cramm & Nieboer, 2011). As the number of people with a chronic disease increase, along with Western societies' life expectancy and financial cutbacks in healthcare, care systems are struggling to continuously meet the demands of those with long-term health conditions (Cramm & Nieboer, 2011). Increasing adherence to self-management guidelines, such as exacerbation action plans, allows patients to better maintain independent and autonomous lifestyles for longer periods of time, which in turn relieves the burden on the healthcare system, and upholds its (financial) capacity to keep delivering quality care in the future (Barlow et al., 2002; Cramm & Nieboer, 2011).

Several determinants of (non-)adherence in patients with COPD have been described so far. For exacerbation related self-management, patients must be able to recognize an exacerbation, make the decision to initiate action, and initiate the actual action to reduce symptoms (Korpershoek et al., 2016). If patients are not able to recognize exacerbations on

time or at all, patients cannot initiate timely action (Korpershoek et al., 2016). When patients do recognize exacerbations but do not feel they can exert control or feelings of fear take over, actions to reduce symptoms stay absent (Korpershoek et al., 2016). Also, in the absence of social support are COPD patients less adherent to treatment recommendations, as patients' motivation to stay alive reduced without having (the support of) family and/or friends (Cicutto, Brooks & Henderson, 2004). Furthermore, comorbid depression negatively affects adherence to medical treatment, as reduced energy and feelings of hopelessness can create more negative expectations of treatment outcomes (Sundbom & Bingefors, 2013). Schrijver et al. (2019) found that comorbid cardiac diseases increase the risk of self-treatment outside the COPD exacerbation period, as patients may have been treating overlapping symptoms (e.g. breathlessness) instead. DiMatteo et al. (2000) found contradictory effects of comorbid anxiety on adherence to treatment recommendations, and suggest that this is caused by the heterogeneity of anxiety symptoms. Anxious patients can become excessively worried about their health, leading to increased motivation to initiate treatment, or they can become afraid of developing adverse drug reactions, leading to reluctance or avoidance of medication (DiMatteo et al., 2000; Santana & Fontenelle, 2011).

Throughout the years, many COPD self-management interventions included exacerbation action plans, education and training for COPD patients to recognize symptoms earlier, accelerate the initiation of appropriate treatment and thus better control deteriorating symptoms (Lenferink et al., 2017). However, these interventions were often not adjusted to comorbidities frequently existing in COPD patients. Previous research suggests that the use of COPD-specific action plans for COPD patients with comorbidities might be less effective (Lenferink et al., 2017), or even unsafe (Fan et al., 2012; as cited in Lenferink et al., 2017) Therefore, a randomized controlled trial, the COPE-III study, was executed to improve the self-management skills of patients with COPD and comorbidities, using individualized exacerbation action plans tailored to patients' comorbidities (Lenferink et al., 2019). Its results have shown that these action plans embedded in an individualized, multi-faceted self-management intervention are effective in reducing COPD exacerbation duration and respiratory-related hospitalizations without excess all-cause mortality (Lenferink et al., 2019).

As adherence is largely determined by motivation (Coventry et al., 2014), it is important that a self-management intervention is designed to motivate the patient to keep using the exacerbation action plan. A model that provides insight in factors that influence motivation and behaviour, is the Capability, Opportunity, Motivation (COM-B) model of

behaviour change, developed by Michie, Van Stralen and West (2011). Capability refers to the individual's psychological and physical capacity to perform a behaviour, and includes reasoning, comprehension, and skills (Michie et al., 2011). This means that COPD patients need to have sufficient knowledge and skills to use the exacerbation action plan properly. Then, opportunity refers to the physical and social factors outside of the individual that inhibit behaviour or prompt it (Michie et al., 2011). This means that COPD patients need to have access to the resources necessary for them to use the exacerbation action plan without difficulties, and that it is safe and acceptable for them to do so. Finally, motivation refers to all reflective and automatic processes in the brain that directs and energize behaviour. This can be conscious reflective processes (e.g. decision-making and goal setting), and unconscious automatic processes (e.g. emotional responses and habitual processes) (Michie et al., 2011). Motivation is influenced by capability and opportunity, and all three components influence behaviour. However, performing behaviour can influence capability, opportunity and motivation as well (see figure 1.1). This means that adherence to an exacerbation action plan is highly context dependent.
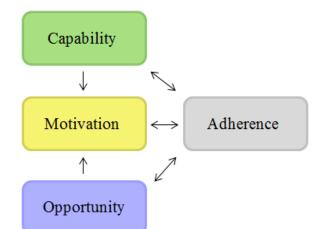
Figure 1.1 Application of the COM-B system to action plan adherence

Currently, there is a lot unknown about the extent to which capability, opportunity and motivation influence COPD patients' adherence to their individualized exacerbation action plans, and how their adherence can be improved. No previous research has investigated the context, as illustrated by the COM-B system, in which adherence to action plans specifically tailored to patients' comorbidities takes place. As adherence is essential for effective self-management (Bischoff et al., 2011), it is important to explore what facilitators and barriers of adherence to the multi-morbid exacerbation action plans exist in COPD patients with comorbidities. Subsequently, it is important to explore how this knowledge can be used to improve the exacerbation action plans, the self-management intervention in which they are embedded, patients' adherence to them, and thus patients' abilities to recognize and treat

COPD exacerbations on time. Therefore, this study aims to answer the following main research question and three associated sub questions:

1. What are facilitators and barriers of adherence to multi-morbid exacerbation action plans in COPD patients with ischaemic heart disease, chronic heart failure, diabetes mellitus, anxiety and/or depression, using the COM-B system as a theoretical framework?

a. How do patients perceive their own role and the role of their healthcare providers in managing their COPD and comorbidities?
b. What are facilitators and barriers experienced by patients regarding the usability of the symptom diaries and exacerbation action plans?
c. What are facilitators and barriers experienced by patients regarding the recognition of symptoms and initiation of actions related to their COPD and comorbidities?

Methodology

2.1 Design

For this study an exploratory qualitative approach was used to investigate the facilitators and barriers of adherence in patients with COPD and comorbidities, while using an individualized multi-morbid exacerbation action plan during a period of one year. This study was conducted with a subsample of patients who participated in a one-year international multicentre open parallel-group randomized controlled trial of the use of self-management exacerbation action plans in patients with COPD and common comorbidities: the COPE-III study (Lenferink et al., 2013; Lenferink et al., 2019). All research participants engaged in informed-consent procedures approved by Medical Ethical Committee Twente and the Southern Adelaide Clinical Human Research Ethics Committee.

2.2 Background COPE-III study

During the COPE-III study patients filled out written symptom diaries on a daily basis, based on what their usual symptoms were in a stable phase related to their COPD and comorbidities, and if these had remained the same or had increased (e.g. not more than usual, slightly more than usual, significantly more than usual) (Lenferink et al., 2019). Beforehand, these usual symptoms were written down on a 'what are my "usual" symptoms'-card' to which the patients could refer when answering the diary questions (Lenferink et al., 2019). The symptom diaries(see Appendix 1a) were colour-coded in terms of COPD and the comorbidities that were applicable to them and included the symptoms belonging to the different diseases (Lenferink et al., 2019). Subsequently, the patients used individualized exacerbation action plans(see Appendix 1b) that were based on increased symptoms as indicated in the diaries (Lenferink et al., 2019). These individualized action plans contained the same colour codes of the diaries and contained the individualized actions for COPD and each of the comorbid symptoms that applied to the patient in question (Lenferink et al., 2019). The actions that should be taken by the patient when this was indicated due to significantly increased symptom severity, related to taking appropriate medication on time, seeking help from healthcare providers and conducting relaxation exercises (for patients with comorbid anxiety and/or depression). Patients were directed step by step from the symptoms that applied to them at that particular time, to the actions that they should take in order to reduce the symptoms, such as doing breathing exercises, starting a course of prednisolone and/or antibiotics or calling the case manager for help when symptoms were not decreasing after initiating self-treatment (Lenferink et al., 2019). All patients were educated in completing the

diaries and using the action plans by trained case managers prior to using them, and received interim feedback by means of phone calls from their case manager while using them for the intervention period of one year (Lenferink et al., 2019).

2.3 Participants

Eligible patients were defined as: 1) aged >40 years; 2) a clinical diagnosis of COPD according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria (GOLD, 2011); 3) clinically stable at the time of inclusion; 4) At least one clinically relevant comorbidity (ischaemic heart disease(IHD), chronic heart failure(CHF), diabetes mellitus, anxiety and/or depression); 5) At least three COPD exacerbations or one hospitalisation for respiratory problems in the two years preceding study entry (Lenferink et al., 2013). Exclusion criteria were: 1) terminal cancer, end stage of COPD or another serious disease with low survival rate (expected survival < 12months); 2) other serious lung diseases; 3) cognitive impairment; 4) enrolment in other randomised controlled trials or intensive case management programmes (Lenferink et al., 2013). Participants were recruited from the outpatient departments of respiratory medicine of two Dutch hospitals (Medisch Spectrum Twente, Enschede; Canisius-Wilhelmina Ziekenhuis, Nijmegen) and three Australian hospitals (Repatriation General Hospital, Adelaide; Royal Adelaide Hospital, Adelaide; Flinders Medical Centre, Adelaide) (Lenferink et al., 2019). From the 201 participating patients, 102 were allocated to the self-treatment intervention group (Lenferink et al., 2019). From this intervention group, ten participants were approached for the current study through purposive sampling (Lenferink et al., 2013).

2.4 Materials & procedures

The materials used were semi-structured interviews to identify facilitators and barriers experienced by patients who used the symptom diaries and exacerbation action plans. All interviews were executed by an external interviewer (N.G.). Ten patients were invited through a phone call to participate in the interview study by researchers (T.E. and A.L.), and upon agreement they were invited to the hospital where the interview took place (The Netherlands: Medisch Spectrum Twente, Enschede; Australia: Repatriation General Hospital, Adelaide) Additionally, N.G. was trained by a health psychologist to adequately conduct the interviews. For some of the interviews an observer was present to notice non-verbal responses and conspicuous events. Also, a copy of the symptom diary and the action plan were present during the interviews. Beforehand, informed consent was obtained from all participants to record the interviews. This interview study was approved by The Southern Adelaide Clinical

Human Research Ethics Committee and the Medical Research Ethics Committee Twente as a sub-study of the COPE-III study. Furthermore, this study was approved by the Behavioural, Management and Social Sciences Ethics Committee Twente.

The interview guide, as established by N.G., A.L. and T.E., entailed six main, open-ended questions which addressed the following subjects: 1) what role patients think they and their healthcare provider have in managing patients' diseases; 2) what patients think about the usefulness of the symptom diary; 3) what patients think about the usefulness of the exacerbation action plan; 4) how patients know when deterioration of their symptoms require action; 5) what role patients think they have themselves when their symptoms require action; 6) wat patients' experience is with using the symptom diaries and exacerbation action plans and how they feel about their self-treatment of exacerbations. Furthermore, probes were asked when elaboration on the main questions was requested or when patients did not know how to answer. The use of open-ended questions prompted patients to answer with sentences and stories, which provided researchers with the opportunity to explore new insights and deeper meaning behind patients' stories, experiences, and motivations (Patton, 2014). The full interview guide can be found in Appendix 2. All interviews were recorded and transcribed clean verbatim by N.G. Furthermore, other materials used included a questionnaire measuring e.g. patient demographics, on which health literacy was measured with a 5-point Likert scale ranging from *"Extremely confident"(1)* to *"Not confident at all"(5)*.

2.5 Data analysis

The interview transcripts were stored in Microsoft Word and then transferred to Atlas.ti 8 for further analysis. The transcripts were analysed using a deductive-dominant qualitative content analysis approach, and involved three main phases: preparation, organization and reporting of the results (Elo & Kyngäs, 2008; Armat, Assaroudi, Rad, Sharifi & Heyradi, 2018). Deductive coding was conducted using the six sub components of the COM-B system as main codes (Michie, van Stralen & West, 2011). The theoretical framework COM-B was chosen, because it provides insight and understanding in factors that explain (non-)adherent behaviour to exacerbation action plans. A description of each sub component of the COM-B system can be found in table 2.1. Furthermore, inductive coding within the main codes was conducted by finding sub codes that fitted the data in more detail. Sub codes were initially inspired by two studies who had previously found factors assigned to the COM-B system (Jackson, Eliasson, Barber and Weinman, 2014; McDonagh et al., 2018), of which one study was adherence-related (Jackson et al., 2014). These sub codes were used deductively to code the data. As the

coding process progressed, the sub codes were further personalized and tailored to the data and thus inductively developed.

During the preparation phase and organization phase, a first coder (S.H.) and a second coder were involved (J.S.). During the preparation phase, a structured categorization matrix was developed with the main codes and sub codes. Based on the main research question the units of analysis were selected, which were facilitators and barriers. All ten transcripts were then globally read by S.H. to get an initial sense of the richness of the data. During the organization phase, two transcripts that seemed most rich in data were coded separately by two coders, where S.H. and J.S. coded one different transcript each according to the main codes and sub codes from the categorization matrix. The applicability of the sub codes to the content of the two coded transcripts was then examined by both coders where after the categorization matrix was revised with sub codes more tailored to the data by S.H. Consensus about the revised categorization matrix was reached with J.S., and the two coded transcripts were then exchanged and again coded separately by the two coders. During a follow-up meeting consensus was reached about the coding of the two transcripts. Then, a third transcript was coded separately by both coders and the findings were compared until consensus was reached again. The data of the remaining seven transcripts were then coded by S.H. independently. After finishing coding all ten transcripts, final consensus was reached with J.S. During the reporting phase, the final categorization matrix and the results were represented in different sections related to the COM-B sub components, supported by evidence such as multiple perspectives and quotes.

Table 2.1 Theoretical construct of categorization matrix (Michie, van Stralen & West, 2011)

Theoretical construct	Component	Subcomponent	Description
COM-B system	Capability	Psychological capability	*Capacity to engage in necessary thought processes.*
		Physical capability	*Capacity to engage in necessary physical processes.*
	Opportunity	Physical opportunity	*Physical opportunity provided by the environment.*

	Social opportunity	*Cultural milieu that dictates the way we think about things.*
Motivation	Reflective motivation	*Evaluations and plans.*
	Automatic motivation	*Emotions and impulses arising from associative learning and/or innate dispositions.*

Results

Ten patients were interviewed (Australian n=5; Dutch n=5), of which six were male, and ranging in age between 59 and 83 years old at baseline of the COPE-III study. Six COPD patients had one comorbidity. The educational level of the patients varied between low (n=4) and medium attained educational level (n=6). Approximately two-third of patients reported having little to no confidence in their ability to complete medical forms by themselves. Furthermore, approximately two-third of patients lived alone. An overview of the patient characteristics can be found in table 3.1. An individual interview took approximately 45 minutes.

In analysing the interview data, seventeen sub codes were extracted from the transcripts. One identified sub code related to patients' perception of their own role and healthcare providers' role towards disease management. Sixteen sub codes were identified as either facilitators or barriers related to the usability of the symptom diary and exacerbation action plan, and related to symptom recognition and action initiation. The sub codes that were found could be classified within all six subcomponents of the COM-B system. An overview of all identified sub codes and associated components of the COM-B system can be found in the categorization matrix, in Appendix 3. The full coding scheme containing all the results of data-analysis can be found in Appendix 4.

Table 3.1 Baseline patient characteristics

ID	Age[a]	Sex	Nationality	Comorbidity	GOLD stage[b]	Smoking status	Educational level	Health literacy confidence[c]	Living alone
P1	72	Male	Australian	IHD Depression	3	Smoker	Low	Confident	Yes
P2	64	Male	Australian	IHD	3	Ex-smoker	Middle	Confident	Yes
P3	59	Male	Australian	Anxiety Diabetes	4	Ex-smoker	Middle	Somewhat confident	Yes
P4	64	Male	Australian	IHD	3	Ex-smoker	Middle	Unconfident	Yes
P5	67	Female	Australian	CHF Depression Diabetes	3	Ex-smoker	Low	Unconfident	Yes
P6	74	Male	Dutch	CHF	2	Ex-smoker	Middle	Somewhat confident	No
P7	64	Female	Dutch	IHD Diabetes	2	Ex-smoker	Low	Unconfident	No
P8	67	Female	Dutch	CHF	2	Ex-smoker	Middle	Somewhat confident	Yes
P9	83	Male	Dutch	IHD	2	Smoker	Middle	Confident	No
P10	74	Female	Dutch	Depression	2	Ex-smoker	Low	Somewhat confident	Yes

Abbreviations: *ID,* Identification; *GOLD,* Global Initiative for Chronic Obstructive Lung Disease; *COPD,* Chronic Obstructive Pulmonary Disease; *IHD,* Ischaemic Heart Disease; *CHF*, Chronic Heart Failure

[a] Age in years

[b] COPD classification according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2011)

[c] Measured by asking patients for their confidence in completing medical forms by themselves on a 5-point Likert scale

3.1 Patients' perceived own role and perceived role of their healthcare providers in managing COPD and comorbidities

Patients had varying perspectives on what their role and their healthcare providers' role is towards the management of the patients' COPD and comorbidities, with some patients feeling greater responsibility towards self-management than others. A distinction could be made between three different roles the patients felt they have towards their disease management (see table 3.2). When it comes to the role the patients felt their healthcare providers(e.g. pulmonologist, respiratory nurse, physiotherapist) have towards the management of the patients' diseases, two distinctive roles could be identified. Based on how patients perceived their own role accompanied by how they perceived their healthcare providers' role, three role types could be identified (see table 3.2).

Table 3.2 Overview of roles towards disease management as perceived by patients.

Role type	Perceived own role	Perceived role of healthcare provider	Number of patients (N)
1.	Responsible for managing own diseases themselves. Help from healthcare providers is required when managing symptoms feels beyond their own control.	Responsible for exacerbation recovery during /after acute exacerbation phase.	5
2.	Responsible for managing own diseases themselves. Help from healthcare providers with disease monitoring and management during stable phase is required.	Responsible for disease monitoring and management during stable phase, and exacerbation recovery during/after acute exacerbation phase.	2
3.	No active role in managing own diseases.	Responsible for disease monitoring and management during stable phase, and exacerbation recovery during/after acute exacerbation phase.	3

In role type 1, patients felt the management of their COPD and comorbidities as something they were mainly responsible for themselves. Only if increased symptoms could not be treated effectively by their own efforts, the patients indicated that they would like help from their healthcare provider. Their healthcare provider would then have to help the patients recover if their symptoms have deteriorated beyond the patients' control, during and after an acute

exacerbation phase. For instance, when self-treatment (e.g. prednisolone and/or antibiotics) would not stop symptoms from exacerbating, or when the patients would become hospitalized. In addition, if hospitalization would happen, patients indicated they would need a healthcare provider to help them improve their self-management skills after the exacerbation recovery, so another hospitalization in the future could be better prevented. *"Because I don't have major issues, I don't believe they need to do a lot anyway. If I was, let's say I got enough to have to go to the hospital, then it is a different story. My doctor would then have to really make sure that I'm doing things correctly. As I said I like to do things myself but until I get to that point where I have got to go to the hospital and then be on the oxygen for two days."* *(P1)*. It appeared that almost all patients in this role type were characterized by having the lowest educational level.

In role type 2, patients did consider the management of their COPD and comorbidities as their own responsibility as well, but indicated to require additional help and support from their healthcare provider during their stable phase, thus in between acute exacerbation periods as well. These patients monitored their own symptoms and followed the exacerbation action plan when their symptoms deteriorated. Simultaneously, from their healthcare provider it was expected to monitor the patients' individual situations as well and to advise the patients the correct medication for the treatment of their diseases. In addition, the healthcare provider was needed to help the patients distinguish between COPD symptoms overlapping with comorbid symptoms. *"If it goes wrong, to pick up the part of me that's gone wrong because I have bronchiectasis, COPD, asthma and chronic sleep apnea which makes it really hard, and they act up, my heart acts up more. So if I have problems with my heart its generally because of my lungs, so I need a professional to make sure that it's just not my heart."* *(P2)*.

In role type 3, patients did not feel they had an active role in their own disease management of COPD and comorbidities. Although improving one's lifestyle was acknowledged as something patients could do by themselves, patients generally did not know what they ought to do with regard to disease management, besides following the advices from their healthcare provider. They felt that their main responsibility was to do whatever their health care provider would decide for them. In the patients' opinion, the healthcare provider knew best what the patients needed and made the decisions with respect to treatment and management of the patients' diseases. *"My role is to, well, I suppose it's to assist any medical people and continue to do what they suggest. I don't really know what else is my role. I mean*

it's to follow suggestions of professionals and do what they say. That's about as much as I can do to improve it." (P4).

3.2 Experienced facilitators and barriers regarding the usability of the symptom diary and exacerbation action plan

Several facilitators and barriers emerged among the patients while using the symptom diary and exacerbation action plan. An overview can be found in table 3.3, and further elaboration on these facilitators and barriers is presented below.

Table 3.3 Facilitators and barriers for the usability of the symptom diary and action plan

	Sub code	Description	Component of COM-B system	Number of patients (N)
Usability of the symptom diary				
Facilitators	Professional support	*The (availability of) support from the patient's healthcare providers that facilitates the usability of the symptom diary.*	Physical Opportunity	4
	Beliefs about treatment	*Positive beliefs about the effectiveness of the symptom diary that facilitates using it.*	Reflective Motivation	3
Barriers	Executive function	*Reduced capacity to plan and execute the task of filling out the symptom diary on a daily basis.*	Psychological Capability	3
	Regimen complexity	*The complexity of the symptom diary that inhibits the patient from using it.*	Physical Opportunity	5
	Stimuli or cues for action	*The lack of stimuli for the patient to use the symptom diary when increased symptoms are not experienced.*	Automatic Motivation	4
	Beliefs about treatment	*Negative beliefs about the usefulness of the symptom diary and its applicability to one's own situation, that inhibits the patient from using it.*	Reflective Motivation	1

	Sub code	Description	Component of COM-B system	Number of patients (N)
	Mood disorder	*Mood disorder (depression) that negatively affects the patient's ability to cope with the workload of the symptom diary.*	Automatic Motivation	1
Usability of the exacerbation action plan				
	Sub code	***Description***	**Component of COM-B system**	**Number of patients (N)**
Facilitators	Professional support	*The (availability of) support from the patient's healthcare providers that facilitates the usability of the action plan.*	Physical Opportunity	5
	Beliefs about treatment	*Positive beliefs about the effectiveness of the action plan that facilitates using it.*	Reflective Motivation	7
Barriers	Cognitive function	*Reduced capacity for thinking and concentrating due to breathlessness, which inhibits the patient from using the action plan.*	Psychological Capability	1
	Perception of illness	*The perception of one's illness as uncontrollable, and further participation in the self-management intervention as unnecessary.*	Reflective Motivation	1

3.2.1 Facilitators regarding the usability of the symptom diary and exacerbation action plan.

A facilitator that emerged strongly amongst several patients, was that **support from healthcare professionals** was necessary for them to fully understand how the symptom diary and action plan had to be used, separately as well as in relation to each other. Patients called the study office, which was indicated on the action plan, to ask the study nurses their questions by phone. This happened mostly at the beginning of the intervention period. *"At first I asked questions and that cleared it up. The nurses I talked to on the phone cleared it up." (P2).* Some patients also found that the communication was fine between them and the study nurses, which had helped them continuing to use the symptom diary and action plan effectively, for instance when the 'what are my "usual" symptoms'- card needed to be changed due to a change in the patient's day-to-day symptoms. For one patient the opportunity to contact a nurse quickly was the only reason to use the action plan, as the

patient wanted confirmation by a professional first before taking any medication for significantly increased symptoms.

Positive beliefs about treatment can also be defined as an important facilitator for the continuous use of both the symptom diary and exacerbation action plan, and emerged after patients experienced its benefits. For instance, patients indicated how the symptom diary was effective in assessing patients' own situation which helped them see how there were actually doing. A patient found the purpose of the symptom diary so good, he wished to continue using it after the intervention period. Another patient found the symptom diary especially helpful in making distinctions between overlapping symptoms from COPD and from environmental allergic reactions which the patient indicated to experience frequently, and which made the patient better able to prevent becoming too sick. Regarding the action plan, patients described several times how it had helped them in treating their symptoms, and once how it had kept a patient out of the hospital. *"It's everything it was supposed to do. It kept me out of hospital, it got me to the doctor before I got too sick, especially to garden mold. because it does, even though this is for COPD, it separated the garden mold from the COPD and that does it." (P2)*. Also, the action plan was still in use by a patient after the intervention period, because it remained useful for consultation regarding breathing exercises.

3.2.2 Barriers regarding the usability of the symptom diary and exacerbation action plan.

Insufficient executive functioning can be defined as a barrier for using the symptom diary, which refers to patients' capacity for planning and executing behaviour. Patients indicated to experience difficulties with the planning and execution of filling out the diary as a daily recurring task. Patients found it difficult to implement the use of the symptom diary into their daily routine. They explained that it was not easy to think every single day about answering the diary questions, which led them to put off the task often. *"I just never had any time for it and then I thought I will do it tomorrow, and tomorrow would not be tomorrow... and also not the next week and then eventually it would become the next month." (P6)*. One patient eventually filled out the diary only once a month before it had to be sent to the study office, despite having experienced increased symptoms during the intervention period.

In addition, the **complexity of the symptom diary** appeared for several patients as a barrier for using it. Patients considered the overall amount of questions that had to be answered as too much, unnecessary, and user-unfriendly. Therefore, patients became less

inclined to use the diary every day for symptom monitoring or at all. A patient explained that because there was so much that had to be filled out, the diary was not used properly and therefore the patient could not initiate action based on the diary. *"It is not hard, it is too much work. Way too much. I have to do too many things. Because you have to fill out all of this (diary no. 1) and then all of that (diary no. 2) and then that again, and that again and then that again.. It makes me... No, stop it. And if you don't fill it out, you cannot take action either."* (P6). Also, one patient described that the amount of choice options in the diary were too many, which made it difficult to answer the questions accurately. Another patient described that the boxes were too small and therefore found it difficult to fill out the diary every day. Instead, the patient only filled out the diary when experiencing noticeable increases in symptoms (e.g. changed sputum colour, fever). *"To fill it out, I find it difficult. I never actually filled it out every day. In my agenda I did keep track of where there were any particularities were, and what these particularities were. If there are any peculiarities then I think I should just keep a close eye on it, because I think the boxes are really small."* (P8). Some patients also expressed their own, alternative ideas about effectively monitoring their symptoms. For instance, it was suggested that recording one's symptoms once a week retrospectively should be sufficient enough. Also, it was suggested that patients should only have to write down what days they experienced changes in symptoms and what medication was taken for increased symptoms. Another patient considered a telephone call from the healthcare provider to check up on the patient as more effective than using the symptom diary. *"I had filled out those forms once, but a call once a week is more effective than filling out that whole list once a month. Then you will have a more realistic view than when you fill out a form every month and where I think by myself, 'oh yeah, what was that again...'"* (P6).

Using the symptom diary only when there were significantly increased symptoms, was something other patients did as well. It was explained that as long as there were no noticeable changes in their symptoms, there were **no stimuli** that motivated these patients **to use the symptom diary** every day. Instead, the patients used the diary when they did feel noticeable changes. *"Only when there were complaints I filled it out."* (P9). They ticked the diary entries of that particular day and then filled out the boxes of the empty diary entries from previous days, because the diary had to be completed before it had to be sent to the study office. *"And then at the end of the month 'oh, that reminds me, I will send that shortly'. Because it had to be sent. And then you are ticking boxes for half an hour."* (P6).

Additionally, **negative beliefs about treatment** appeared for a patient as a barrier for using the symptom diary. The patient felt as if the symptom diary was not applicable to one's individual situation, thus **considered the diary not useful** and was therefore less inclined to use it. This was because the alterations between daily symptoms were often too slight to be able to answer the diary questions with accuracy. *"How useful? For me, not really a lot. It's not difficult, it's just not easy, you know, and doing the whole thing a lot of it didn't even feel like it had anything to do with me. It's like this waking up at night and the ankles and abdomens and all that, I mean it doesn't change, it's just the same thing every day." (P5).*

Then, **depression** emerged for a patient as a barrier to answering the diary questions properly. The patient explained having been through a traumatic time, and therefore having a hard time coping with many questions ever since. Coping with so many questions or forms in general became very frustrating and upsetting. *"I've been through a traumatic time in the last few years and a lot of questions I don't cope with. you know I find it too much and I can't fill in forms or anything anymore I get really frustrated and upset and things, I found this was very taxing for me but not even so much the questions it was just the fact it was a form and I had to fill it in and I just found it very hard to cope with." (P5).*

Furthermore, a barrier that emerged amongst a patient for using the exacerbation action plan properly, was a **reduced cognitive functioning during an exacerbation**, which refers to the patient' capacity for judgement, thinking, memory, and decision making. It was described that increased symptoms such as breathlessness, can cause the patient to concentrate less than normally. When this happened, it became more difficult for the patient to concentrate and consult the action plan. *"When you have got the problem of not breathing or something you don't concentrate like you normally would." (P1).*

Finally, **negative illness perceptions** emerged as a barrier for using the exacerbation action plan. One patient felt that besides taking maintenance medication, there was nothing else that could be done about the patient's condition anymore, including by healthcare providers. The patient's overall physical state had worsened so much over the years that motivation was lost to actively manage one's diseases. *"I don't do much about it anymore. What happens, happens and I just can't do much about that. If it wasn't for her(spouse) still being around, I would be done with it. As far as I'm concerned, it is over." (P9).* Additionally, it appeared that the patient had quit participating in the self-management intervention prematurely. The patient had lost interest in further participation after two

months, and did not consider receiving new diaries as necessary anymore. When the case manager called due to the unsent diaries, the patient confirmed not to continue with the study.

3.3 Experienced facilitators and barriers regarding the recognition of symptoms and initiation of actions related to patients' COPD and comorbidities

Several facilitators and barriers for both symptom recognition and action initiation were identified. An overview can be found in table 3.4, and further elaboration on these facilitators and barriers is presented below.

Table 3.4 Facilitators and barriers for the recognition of symptoms and initiation of action

Recognition of symptoms				
	Sub code	*Description*	Component of COM-B system	Number of patients (N)
Facilitators	Professional support	*The (availability of) support from the patient's healthcare providers that facilitates symptom recognition.*	Physical Opportunity	1
	Goals	*The strong ambition of the patient to strive towards a desired result, that facilitates symptom recognition.*	Reflective Motivation	1
	Beliefs about symptom recognition	*Positive beliefs about the importance of symptom recognition, that facilitates recognizing symptoms that need treatment.*	Reflective Motivation	1
Barriers	Comprehension of disease and treatment	*Insufficient understanding of COPD and/or comorbidities, which inhibits the patient from recognizing (overlapping) symptoms.*	Psychological Capability	3
	Cognitive function	*Reduced capacity for thinking and concentrating, which inhibits the patient from recognizing (overlapping) symptoms.*	Psychological Capability	1
Initiation of actions				
	Sub code	*Description*	Component of COM-B system	Number of patients (N)

Facilitators	Professional support	*The (availability of) support from the patient's healthcare providers that facilitates action initiation.*	Physical Opportunity	4
	Self-efficacy	*Confidence in one's own abilities to initiate action according to the action plan.*	Reflective Motivation	3
	Beliefs about symptom recognition	*Positive beliefs about the importance of symptom recognition, that facilitates initiating action.*	Reflective Motivation	1
	Goals	*The strong ambition of the patient to strive towards a desired result, that facilitates action initiation.*	Reflective Motivation	1
Barriers	Comprehension of disease and treatment	*Insufficient understanding of one's own diseases, which inhibits the patient from initiating appropriate action..*	Psychological Capability	1
	Beliefs about treatment	*Aversive beliefs about medication, and beliefs in alternative treatment methods that inhibit the patient from initiating action according to the action plan.*	Reflective Motivation	4
	Stimuli or cues for action	*Missing the cue for taking action to prevent an upcoming exacerbation, which inhibits the patient from initiating action as indicated by the action plan.*	Automatic Motivation	1

3.3.1 Facilitators regarding the recognition of symptoms and initiation of actions related to patients' COPD and comorbidities.

Support from healthcare professionals appeared necessary and as a facilitator for several patients to recognize their symptoms and to initiate appropriate action for their symptoms. Patients explained that being able to call the telephone number from the action plan felt as having some leverage and provided feelings of security and self-confidence. A patient explained also that information provided by healthcare providers had helped to recognize an infection when looking at the sputum colour. A few other patients described how their healthcare providers had encouraged them to initiate action, when feeling hesitation towards

medication. Another patient would not take any medication without having confirmation over the phone from the study nurse. One patient did take the medication when this was indicated by the action plan, but required confirmation from the healthcare provider afterwards. *"I go on prednisolone if I make two ticks of the box and if they say go ahead. Then my doctor will tell me to either stay on it or go off it and put me on another drug for my garden mold."(P2)*.

Additionally, feeling **self-confident about one's own abilities** to take the right action for increased symptoms was for some patients a facilitating factor for initiating certain actions from the action plan. For instance, because the action plan was something that patients could always consult and refer to, they felt more confident about their ability to treat themselves and were therefore more inclined to try and use the action plan, e.g. when their symptoms required certain medication. *"Now the opportunity is there, then I just know that it (self-treatment) is possible. And having the action plan next to it I am not insecure and I will just do it. That has also to do with a certain ignorance about medication and drug use, so I want to be very sure about what I take and if it helps. Then, you will find that out very soon." (P8)*.

Furthermore, **positive beliefs about the importance of symptom recognition** appeared as a facilitator for a patient to recognize symptoms, and subsequently to initiate action. The patient expressed the significance of being able to distinguish between the symptoms that needed action and which did not, which in turn enabled the patient to respond with the appropriate course of action. *"It(symptom diary) helped me understand it a bit more, because I did this and I tick the reds and I tick this and eventually you work out when to worry because I've been to hospital a couple of times and my heart hurt and it wouldn't stop hurting, but it wasn't spasming it was just hurting. In the morning it was fine so I've learnt that sort of pain I don't worry too much about and it generally comes along with chestiness in my lungs, so my lungs are causing my heart to do it. It generally comes along with chestiness in my lungs, so my lungs are causing my heart to do it. So if I keep them clean but sometimes I can't, you know? Might be a heavy pollen day somebody might drive past with a trailer full of cuttings or I walk past a tree that's pollenating, just one sickly smelling tree that hurts" (P2)*

Finally, having **goals** as motivation to stay in good health for, emerged as a facilitator to learn about both recognizing symptoms and initiating appropriate action by means of the symptom diary and exacerbation action plan. It was explained that there is something a patient wanted to stay alive for, which worked as motivation to take better care of oneself and thus to manage COPD more carefully. The patient suspected not having been alive anymore if the

patient had continued without learning to recognize and manage symptoms. *"I won't tell what it is but it's just something I want to be around for. I am so glad I actually did this. So glad. It's probably wrong but I probably.. if I didn't do this and didn't understand what my body is going through I may be dead by now. I know its hypothetical but you don't know." (P1).*

3.3.2 Barriers regarding the recognition of symptoms and initiation of actions related to patients' COPD and comorbidities.

Insufficient comprehension of diseases can be defined as an important barrier for recognizing (overlapping) symptoms, and taking appropriate action. One patient found it particularly hard to answer the diary question about breathlessness and which box had to be ticked every day (e.g. 'slightly more than usual' or 'significantly more than usual'). One patient did not always understand if certain overlapping symptoms, such as breathlessness, were relating to anxiety or COPD. Another patient explained that it was hard to determine a 'normal standard' based on daily symptoms, despite having the 'what are my "usual" symptoms'-card' to which symptoms could be compared. The patient felt as if symptoms fluctuated every day to the extent that there was no standard that could be defined as normal. Consequently, the patient found it difficult to recognize which symptoms needed action, and to decide when it was the right time to take any medication. *"When sputum changes color, when that starts going like a green color and stuff like that, then I know I've got an infection coming, but that can be green today and tomorrow it's just a sort of yellowy color, so I can't sort of say, my sputum's this color I better start taking antibiotics, I'm better to wait a day or so." (P5).*

A patient also explained being less able to concentrate than in the past, due to the patients' depression. This made it more difficult for the patient to daily determine if symptoms had changed compared to 'usual', and to make distinctions between symptoms that were overlapping with different diseases. Therefore, **reduced cognitive functioning as a consequence of depression**, appeared as a barrier in recognizing symptoms. *"I don't concentrate very well any more. Like you've got a question here; felt dizzy or light headed? Not more than usual, more than usual. That's very hard to answer because I've also got vertigo, so you know, some days I get really dizzy and some days I can't get out of bed because it's so bad and then the breathlessness and the heart and things like this. Sometimes I've got rimtoid arthritis and osteo arthritis and all that as well, so on the bottom here for me I'm talking about is pain, pressure, heaviness, tightness in one or more of your chest, neck,*

jaw, arms, back, shoulders and all this sort. I get that all the time, so it would be quite confusing because I can fill in all of that and it's got nothing to do with my heart or anything like that." (P5).

Furthermore, **negative beliefs about treatment** for their COPD and comorbidities appeared for several patients as a barrier for initiating action according to the action plan. Some patients described feelings of **hesitation and aversion towards the use of medication**, which made them more inclined to avoid taking them for as long as possible or at all. Another patient explained not to use the depression-part of the action plan at all, because the patient already practiced alternative methods believing to be effective in managing depressive symptoms. *"No I just have a good cry and, because I'm on tablets for that, I'm on citalopram for the depression. I have a good cry, I yell at my son, and I have a good cry and, he gives me a cuddle." (P5)*

Finally, **missing the cue for taking action** for increased symptoms emerged as an important barrier for initiating actions from the action plan. A patient explained that the phase in which taking medication would be useful to stop symptoms from exacerbating, was continuously missing. Whenever the patient's symptoms slightly increased, it was never bad enough to tick the red boxes on the diary(significantly increased symptoms), but then all of a sudden the symptoms would become so bad, it would be too late for initiating self-treatment and an ambulance had to be called straight away. *"Mine(symptoms) might take three weeks to finally comes out but there's no sign of when. As I said I might sit on these line for months (points out at the diary, second boxes in the row) and then all of the sudden bang! My symptoms just coming along like, just 'bang!' but I can actually feel it coming but it's not to the point that I need it (medication). So I might just go and sit down and the next moment just... the world just crashes in on you. " (P3).*

Discussion

The goal of this study was to explore what factors are facilitators and barriers of adherence to multi-morbid exacerbation action plans in COPD patients with IHD, CHF, diabetes mellitus, anxiety and/or depression. The results show that adherence was inhibited by patients' incapability of memorizing to use the symptom diary daily, and patients' insufficient comprehension of their symptoms. Also, complexities of the current design of the symptom diary lowered patients' opportunity to use the diary. Then, adherence was inhibited by patients' lowered motivation to use the symptom diary daily, as patients were not stimulated to use the symptom diary if symptoms were not increased compared to usual. On the other hand, adherence was facilitated by the continuous availability of professional support, which increased patients' opportunity of understanding and using the symptom diary and exacerbation action plan, recognizing symptoms, and initiating appropriate action correctly. Also, feelings of self-confidence about their own abilities to initiate action according to the exacerbation action plan increased patients' motivation to use the action plan. Patients' beliefs about treatment appeared as both a barrier and a facilitator. Some patients had positive experiences with the symptom diary, which caused an increase in motivation to keep using the diary, whereas others considered the diary as not useful or harboured aversive medication beliefs, which decreased their motivation to use the diary or initiate action when necessary. Then, the results suggest that patients' perceived roles towards disease management played an important part in their adherence. The results seem to indicate that an increase in patients' feelings of personal responsibility led to an increase in motivation to use the symptom diary and action plan correctly.

Interestingly, it was found that support from healthcare professionals was an important facilitator for patients in using the symptom diary, recognizing their symptoms, using the exacerbation action plan, and the initiation of action. This suggests that patients were not completely able to use the diary and action plan as tools to self-manage their multiple diseases and interpret and respond to their deteriorating status independently, without access to ongoing case manager support. This is in line with Pinnock, Steed and Jordan (2016), who argue that the demands from different conditions can conflict or confuse COPD patients to the extent that patient-tailored, ongoing professional support is needed to help them live optimally with their conditions and, more specifically, recognize their symptoms and respond with the correct course of action. Support that is patient-tailored recognizes and treats the patient as an individual, and anticipates to how COPD and comorbidity affects the patient and how the

patients' circumstances and experiences affect their COPD, comorbidity and patients' self-management behaviour (Gardener et al., 2018). Based on this understanding, the case manager can determine the advice and support patients need to overcome their personal barriers in self-managing their condition (Gardener et al., 2018). Also, support needs to be ongoing so adaptations can be made to the change in needs of patients with COPD and comorbidity as their diseases progress and personal circumstances change over time (Pinnock et al., 2016). However, this study showed there were still personal barriers patients did not overcome, suggesting that these patients might benefit from more intensive guidance by their case manager. Hillebregt et al. (2017) argue that a higher and more regular frequency(opposed to approximately 2 times a year) of in-person healthcare provider-patient contact is required for developing mutual trust and effectively achieving behaviour change in COPD patients. It is therefore recommended to schedule additional face-to-face contact hours besides the already scheduled contact hours via telephone. Face-to-face communication is also preferred over telephone contact, as it enables the case manager to respond to patients' body language or facial expressions that might imply confusion in response to what the case manager says, or other signs of misunderstandings (Vermeir et al., 2015). Additionally, it is recommended to offer additional training sessions after patients had an exacerbation, in which patients are guided in their efforts to examine what could be done differently. This way, certain skills and/or knowledge that need improvement can be addressed. Lastly, it is recommended to explore the possibilities that lie in combining ongoing case-manager support with technology, which increases accessibility of case managers, lowers possible thresholds for patients to reach out, and positively affects exacerbation-related health outcomes (Farias et al., 2019).

Noteworthy was that patients' demonstrated an insufficient comprehension of their symptoms, which in turn led to uncertainty about which symptoms required action, and about appropriate self-initiation of actions. This suggests that, despite the training and education involving the added complexity of comorbidities these patients received, they were psychologically not sufficiently capable to monitor and appropriately respond to their symptoms by means of the diary and action plan. This is in line with Russell et al. (2018) who argue that limited understanding of disease often limits COPD patients active engagement in self-management activities. It might be possible that forgetfulness or confusion regarding learned strategies to distinguish between symptoms played a role in this over time, as a decline in memory functions can be a consequence of COPD and depression (Morris et al., 2019; Ouelette & Lavoie, 2017). Equally interesting was that these patients had relatively low

educational levels, which can be a related factor as well. Namely, Pleasants et al. (2016) found that COPD patients with lower educational levels experienced more difficulties with understanding their disease. Low educational attainment is an important indicator of low socio-economic status (SES), of which its population is disproportionally more affected by COPD than other socio-economic groups (Booker, 2015). This is because SES is associated with important risk factors such as cigarette smoking and working in dusty occupations (Kanervisto et al., 2011). It is therefore no coincidence that this study's participants have relatively low educational levels. However, Russell et al. (2018) argues that even when knowledge and understanding is limited, patients can be capable of initiating their own management strategies due to developing an understanding of their condition over time. As such case managers should aim for ongoing engagement with patients, harnessing patients' own illness perceptions and self-learned self-management strategies (Russell et al., 2018). It is therefore recommended for these patients to have recurring appointments with their case manager, in which case manager and patient attempt to identify recurring patterns of symptoms over a longer period of time, and explore how they can establish a more suitable strategy for recognizing symptoms that require initiation of action.

Another important finding was that patients experienced certain elements of the symptom diary as too complex, too much work and therefore user unfriendly. The symptom diary not being easy to use for some patients might in turn have negatively influenced their motivation to use the diary as a tool to monitor their symptoms with. This is confirmed by Walters et al. (2012), who found that paper symptom diaries are often considered burdensome by COPD patients which decreased their motivation to use the diaries consistently. This in turn can have negative associated consequences regarding action initiation, as the results show a patient who was aware of one's lack of action initiation as a consequence of not wanting to use the symptom diary daily. Oduor and Oinas-Kukkonen (2017) argue that most people are aware of their problem for which they ought to change their behaviour, but are not able to make the decision to actually change it when the immediate costs (e.g. putting in the required effort) outweigh the long-term benefits (e.g. experiencing the health benefits of being able to respond to an upcoming exacerbation in time). Reluctance to fill out the diary on a daily basis might have happened because patients perceived the immediate costs of the effort coming with filling out the diary as too high. To enhance these self-management behaviours, it is important to emphasize patients' personal benefits. This is supported by another theoretical model of behaviour, the Health Belief Model, which states that if the perceived benefits do

not outweigh the perceived barriers, the health behaviour for reducing the health threat remains absent (Janz & Becker, 1984). Based on this knowledge, it can be argued that if the benefits of using the symptom diary daily to monitor symptoms become more salient for patients, their willingness to engage in this activity increases. It is therefore recommended to increase salience of the beneficial consequences of using the diary daily, and where possible increase its benefits, and therefore increase patients' motivation to use it. In addition, solutions can lie in digitalizing the symptom diary. This way, the content can be more easily adapted to improve ease of use while taking into account individual preferences.

Lastly, it was interesting to see that patients had different roles regarding the management of their diseases, meaning that some patients had not fully adopted the responsibility of managing their diseases themselves. Kaptein et al. (2014) argue that self-management interventions in patients with COPD have been primarily associated with a health professional-centered approach focusing on teaching patients how to use a written action plan in the event of an exacerbation. It is therefore possible that the vision of self-management being patient-centered is not fully embedded in patients' vision on healthcare (Kaptein et al., 2014). In addition, Coventry et al. (2014) argue that patients with low SES and multi-morbidity often tend to hold their doctor responsible for managing and monitoring their health, preventing them from taking an active role themselves. This study's results were therefore surprising, as they show that patients with a low educational level felt more personal responsibility for disease management, while requiring less interference from healthcare providers, than their counterparts did with medium educational level. Booker (2015) argues that patients from low socio-economic backgrounds can feel 'blamed' or 'judged' in their communication with healthcare providers, since COPD is often smoking-related and surrounded by 'blame culture'. Having had certain negative patient-provider experiences and communication difficulties can negatively influence trust in healthcare providers and increase individual patients' aspiration motivation to self-manage their conditions (Booker, 2015; Coventry et al., 2014). Based on this knowledge, it can be argued that patients having a passive role towards self-management need not only be made more aware of the purpose of self-management being patient-centred, but also motivated into taking shared responsibility with the healthcare professional, instead of remaining primarily dependent on their support. It is therefore recommended to investigate patients' perceptions regarding responsibility for disease management before starting the intervention, and coach 'passive' patients into becoming active self-managers.

4.1 Strengths and limitations

A strength of this study was the use of the COM-B system for analysing the interview data, as this theoretical framework provided insight in all reported factors explaining (non)adherent behaviour regarding the exacerbation action plan. Every quote from the interview transcripts that was relevant for answering the research questions could be classified within the COM-B framework. Another strength was that all patients included in this interview study had finished their participation in the COPE-III study for no longer than three months. Therefore, recall bias related to their experiences during the intervention period was limited and thus the descriptive accuracy of the reported facilitators and barriers optimized. Additionally, due to the involvement of a second coder in analysing the data, bias due to researcher's individual perceptions was reduced. Another strength was that saturation of the interview data was reached after the ten transcripts were analysed, because no new facilitators or barriers were found in the last analysed interviews.

It is a strength that interviewing the patients and analysing the data was not done by the same researcher, as the involvement of different researcher perspectives limits bias caused by individual perceptions, however, in this study it appeared to be a limitation. Namely, it is suspected that if additional in-depth questions had been asked in response to several specific answers from patients, information could be learned about e.g., possible relations between specific sub codes, and about patients' use of words that were sometimes generic and not specific enough to draw clear conclusions from (i.e. words were used as 'my self-management skills', without specifying if these skills related to action plan use or something else). Consequently, saturation of the interview data might not be reached, as new sub codes might have arisen when additional questions had been asked, which makes it a limitation of this study as well. A third limitation was that some findings relating to patients' roles could not be concluded with certainty. The results suggest that an increase in patients' feelings of personal responsibility for self-management have led to an increase in their motivation to be adherent to the exacerbation action plan. However, the exact relationship between patient roles and motivation could not be investigated with the available data at hand.

4.2 Implications for practice

The first step was to understand what facilitators and barriers underpinned patients' behaviour regarding adherence. The second step is to consider how to influence these facilitators and barriers and therefore change the behaviour. The COM-B system is part of a larger framework aimed at characterizing and designing behaviour change interventions, the Behaviour Change

Wheel (BCW), and forms its hub (Michie et al., 2011). Around the COM-B system are positioned nine intervention functions aimed at addressing the deficits regarding patients' capability, opportunity and motivation, and can be delivered in practice by behaviour change techniques (BCT's) (Michie et al., 2011). Using the BCW, the following practical recommendations are made.

Firstly, in providing ongoing individualized case manager support the intervention function 'enablement' was already applied, and should be further expanded to tailor it more to patients' individual needs. Additional face-to-face contact hours can be scheduled in between phone calls that take place after the individual and group training sessions. The phone calls can be used to invite patients to report experienced difficulties in their exacerbation action plan-related self-management. When patients report difficulties, an appointment can be scheduled wherein case manager and patient discuss a plan of action for the problem, and necessary follow-up appointments can be agreed on. When patients do not report difficulties over the phone, at least one face-to-face appointment(in between phone call 1 and 2) can be scheduled wherein case manager and patient reflect on patients' experiences with the action plan. If the case manager can indeed not identify any barriers possibly inhibiting effective self-management, or the patient does not want a second appointment, further contact can be limited to the phone calls. Furthermore, intervention function 'training' can be expanded by offering additional training sessions to patients who have had an exacerbation and feel the need to improve their current skills and knowledge after recovery. During this additional training, elements from training sessions at the start of the intervention can be repeated until the patient's confidence to recognize and respond to an upcoming exacerbation by means of the action plan and diary is renewed.

Secondly, for improving patients' understanding of symptoms and their abilities to recognize the symptoms that require action, additional training should be held by means of recurring face-to-face appointments. Case manager and patient should identify the symptoms that are difficult to recognize, if these overlap with a comorbid condition, the extent to which these fluctuate, its consequences for patients' condition, and how often these symptoms tend to increase. Subsequent sessions can be scheduled after set time periods or each time symptoms have increased significantly, to discuss patients' observations of the symptoms, the circumstances (e.g., the weather, possible reasons for feeling anxious), the course of action taken and its effect. In doing so, patterns in symptoms may become more visible and familiar, and cues may be become recognizable for patients. Elements from training sessions at the

start of the intervention can then be rehearsed until patients' confidence to recognize and respond to the symptoms in questions is sufficient.

Thirdly, to increase user motivation for the symptom diary, BCT 'salience of consequences' can be applied, whereby the consequences of the behaviour are emphasized with the aim of making them more memorable. This can be done during an education session at the start of the intervention, by discussing patients' individual situations in a positive light, whereby desirable health outcomes are highlighted and connected to patients' personal perceptions of positive health outcomes. This can also be done by discussing patients' individual situations in a negative light, whereby undesirable consequences are highlighted. If patients motivation tend to decrease over time, BCT 'habit formation' can be applied as well, whereby patients are prompted to rehearse diary use after another daily recurring task (e.g., eating breakfast). This way, the context of eating breakfast elicits the diary use every day.

Fourthly, to motivate 'passive' patients into becoming active self-managers, healthcare professionals can use motivational interviewing (MI), which is a collaborative, person-centred and goal-oriented communication method focused on the language of change, and is intended to strengthen personal motivation for and commitment to a target behaviour change, by eliciting and exploring an individual's own arguments for change (Miller & Rollnick, 2010). Before the start of the intervention, patients should undertake a small inquiry by means of a questionnaire to obtain a clear picture of patients' individual perceptions regarding their own and their healthcare provider's responsibilities. Then, an additional, individual education session should be held wherein reasons behind patients' 'passiveness' are further explored. If patients lack knowledge about (the purpose of) self-management, providing information may be sufficient. If patients lack intrinsic motivation to adopt main responsibility for disease management, MI should be applied based on patients' readiness to change.

Finally, combining exacerbation action plan-use with technology increases opportunities for e.g., expanding ongoing case manager support and improving the symptom diary's ease of use, and takes the form of electronic health(e-health) management. E-health is "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies", and is widely used as a tool in enabling COPD patients to live as independent as possible with their disease and to manage their symptoms themselves (Eysenbach, 2001). To expand ongoing case-manager support, secured messaging options

during office hours can be made available through which patients can ask for answers to their questions in an easily accessible manner. Also, an automated tool can be made available that provides tailored self-management advice, which is based on an automated decision model built by a clinical expert panel, and available at any time of day and night (Boer et al., 2018). In addition, mini 'lectures' that rehearse content of the education and training sessions at the start of the intervention can be produced and made available, to remind patients' of what they have learned, without patients having to attend additional education and training (e.g. for increasing salience of the consequences of diary use). To improve ease of use of the symptom diary, the lay-out of an electronic version can be made adaptable to the extent that it suits individual preferences. For instance, showing one diary question at a time makes the amount of questions to be answered less overwhelming. Also, making the font size and size of the diary entries configurable enables patients to improve its visibility if necessary. Then, persuasive features can be added to the technology to increase adherence. Persuasive technology refers to computerized software designed to reinforce, change or shape attitudes and/or behaviors without using coercion or deception (Oinas-Kukkonen & Harjumaa, 2009). The Persuasive Systems Design model is a state-of-the-art approach for designing and evaluating persuasive systems, which includes four categories of software features for persuasive systems: 1) Primary task support, 2) Computer-human dialogue support, 3) System credibility support, 4) Social support (Gemert-Pijnen et al., 2018; Oinas-Kukkonen & Harjumaa, 2009). Different types of persuasive software features, grounded in psychological theories, can be implemented in order to: 1) support the users' primary activities such as personalizing the technology, 2) represent information sufficiently in the computer-human dialogue such as praising the user for "good" behaviour, 3) convey the credibility of the presented information through i.e. trustworthiness of the technology, and 4) leverage social influence through social comparison (Gemert-Pijnen et al., 2018). For instance, to increase patients' motivation to use the symptom diary daily, persuasive feature 'rewards' can be added whereby the system provides virtual rewards for patients to give credit for e.g., completing the diary for a week on time (Oinas-Kukkonen & Harjumaa, 2009). This way, benefits of symptoms diary use can be increased. Also, persuasive feature 'reminders' can be added whereby the system reminds forgetful patients to monitor their symptoms that day (Oinas-Kukkonen & Harjumaa, 2009), through e.g., push notifications.

It is important to take into account user-adoption issues, as e-health initiatives tend to struggle with technology adoption (van Gemert-Pijnen et al., 2018). All stakeholders,

including patients and clinicians must be involved in an iterative development process (van Gemert-Pijnen et al., 2018). To optimize adoption amongst the COPD patient population , e-health interventions should consume as little time as possible and offer community-based support to ease the adoption process (Slevin et al., 2019). Also, COPD patients prefer personalized education focused on improving digital literacy, reflecting the clinical and psychosocial factors of their condition, and ongoing education and supervision as their digital competencies develop (Slevin et al., 2019).

4.3 Implications for future research

Further research is needed to gain insight in ways alternative to the symptom diary that patients' may prefer for monitoring their symptoms, as several patients mentioned having other preferences (e.g. receiving a phone call from their healthcare provider once in a while, rather than filling out the symptom diary every day). It would be interesting to see if this information can be used to personalize ongoing case manager support further to increase these patients' adherence to the exacerbation action plan. In addition, further research is needed to investigate the effects of digitalization the symptom diary, and ongoing patient-tailored case manager support regarding the use of the (electronic) symptom diary and exacerbation action plan. It would be interesting to see if patients' consider the electronic diary as more easy to use opposed to paper diaries and if actual adherence to the diary and the exacerbation action plan increases. Consequently, it would be interesting to investigate if patients prefer a digitalized version of the multi-morbid exacerbation action plan as well. Furthermore, it would be interesting to see to what extent patients prefer online contact with the case manager, as it can be useful to investigate if ongoing support, such as recurring education and training sessions can also be offered by means of video contact over time. Then, it is important to further investigate patients' self-efficacy regarding the use of digitalized case manager support, the symptom diary and action plan, and if there are other user-adoption issues that must be taking into account for COPD patients with comorbidities. Finally, more research is needed to gain more certainty about the extent to which patients' roles towards self-management impacts adherence, and if an increased sense of personal responsibility indeed increases adherence to multi-morbid exacerbation action plans in COPD patients with comorbidities.

Conclusion

It can be concluded that the COM-B system provided a good overview of facilitators and barriers of adherence to multi-morbid exacerbation action plans in COPD patients with comorbidities. The BCW can be used to expand on the already existent intervention functions training and education, and to identify BCT's useful for increasing adherence to the exacerbation action plan. To optimize adherence, ongoing case-manager support should be further tailored to patients' individual needs by scheduling a higher frequency of face-to-face contact hours in which personal barriers can be addressed and training elements can be rehearsed to improve patients current skills and knowledge. Daily engagement with the symptom diary can be increased if more emphasis is placed on the beneficial consequences of its use. To further improve adherence, patients should be coached and motivated into becoming active self-managers and adopt full responsibility for managing their diseases. E-health can be introduced to improve the symptom diary more easy to use, and improve the accessibility and range of options for patient-tailored case manager support. Future research is needed to gain insight in patients preferences for alternative ways of symptom monitoring, in the effectiveness of using digitalized symptom diaries, action plans and case manager support, and in the extent to which patients' sense of responsibility increases

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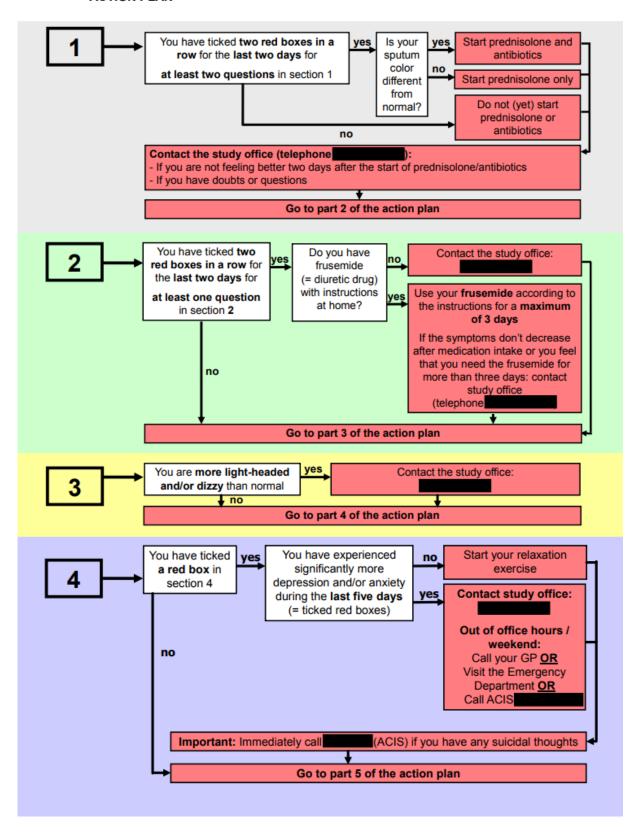
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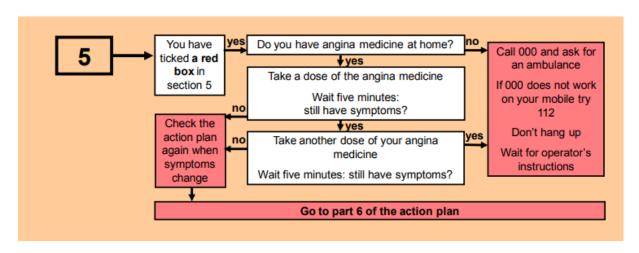
DAILY SYMPTOM DIARY

Month: ....

Day: 1 2 3 4 5 6 7   8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
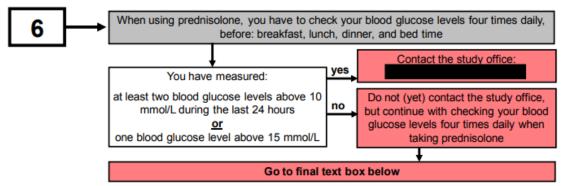
Did you have more symptoms than usual during the last 24 hours?
(If yes, complete the section below and check the action plan)

No   No
Yes   Yes

Please indicate which symptoms have changed during the last 24 hours by ticking a box for every symptom:

Day: 1 2 3 4 5 6 7   8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

1

A. Sputum production
- Not more than usual
- Slightly more than usual
- Significantly more than usual

B. Sputum colour
- Usual for me
- Different from usual

C. Breathlessness
- Not more than usual
- Slightly more than usual
- Significantly more than usual

D. Did you have a **fever** (more than 38.5°C) or did you experience a **significant change** in **coughing and/or wheezing** in the last 24 hours?
- No
- Yes

2

E. Weight
- Not more than usual
- Slightly more than usual
- Significantly more than usual (= at least 1 kg in 24 hrs)

F. Swelling of ankles or abdomen
- Not more than usual
- Slightly more than usual
- Significantly more than usual

G. Waking up at night short of breath
- Not more than usual
- Slightly more than usual
- Significantly more than usual

3

H. Felt light headed or dizzy
- Not more than usual
- More than usual

4

I. Felt depressed
- Not more than usual
- Slightly more than usual
- Significantly more than usual

J. Felt anxious
- Not more than usual
- Slightly more than usual
- Significantly more than usual

5

K. Did you experience:
A <u>change</u> in: pain – pressure – heaviness – tightness In one or more of your: chest – neck – jaw – arm(s) – back – shoulders **OR** a <u>sudden change</u> in your breathing resulting in severe shortness of breath **OR** black-outs
- No
- Yes

ACTION PLAN

1 → You have ticked **two red boxes in a row** for the **last two days** for **at least two questions** in section 1

— yes → Is your sputum color different from normal?

— yes → Start prednisolone and antibiotics

— no → Start prednisolone only

— no → Do not (yet) start prednisolone or antibiotics

Contact the study office (telephone ▮▮▮▮):
- If you are not feeling better two days after the start of prednisolone/antibiotics
- If you have doubts or questions

Go to part 2 of the action plan

2 → You have ticked **two red boxes in a row** for the **last two days** for **at least one question** in section **2**

— yes → Do you have frusemide (= diuretic drug) with instructions at home?

— no → Contact the study office: ▮▮▮▮

— yes → Use your **frusemide** according to the instructions for a **maximum of 3 days**

If the symptoms don't decrease after medication intake or you feel that you need the frusemide for more than three days: contact study office (telephone ▮▮▮▮)

— no →

Go to part 3 of the action plan

3 → You are **more light-headed and/or dizzy** than normal

— yes → Contact the study office: ▮▮▮▮

— no →

Go to part 4 of the action plan

4 → You have ticked **a red box** in section 4

— yes → You have experienced significantly more depression and/or anxiety during the **last five days** (= ticked red boxes)

— no → Start your relaxation exercise

— yes → **Contact study office:** ▮▮▮▮

Out of office hours / weekend:
Call your GP **OR**
Visit the Emergency Department **OR**
Call ACIS ▮▮▮▮

— no →

Important: Immediately call ▮▮▮▮ (ACIS) if you have any suicidal thoughts

Go to part 5 of the action plan

5 → You have ticked **a red box** in section 5 — yes → Do you have angina medicine at home? — no → Call 000 and ask for an ambulance

If 000 does not work on your mobile try 112

Don't hang up

Wait for operator's instructions

yes ↓

Take a dose of the angina medicine

Wait five minutes: still have symptoms?

no ← / ↓ yes

Take another dose of your angina medicine

Wait five minutes: still have symptoms? — yes → (Call 000 box)

no ←

Check the action plan again when symptoms change

Go to part 6 of the action plan

---

6 → When using prednisolone, you have to check your blood glucose levels four times daily, before: breakfast, lunch, dinner, and bed time

↓

You have measured:

at least two blood glucose levels above 10 mmol/L during the last 24 hours

or

one blood glucose level above 15 mmol/L

— yes → Contact the study office: ▮▮▮▮▮▮▮▮

— no → Do not (yet) contact the study office, but continue with checking your blood glucose levels four times daily when taking prednisolone

↓

Go to final text box below

FINAL PART OF THE ACTION PLAN:

If you are not feeling better two days after the start of prednisolone/antibiotics
→ **Contact the study office**

If you have had a **fever** (more than 38.5°C) for **at least two days in a row** but you **did not** tick any red boxes for other symptoms
→ **Contact your GP**

PLEASE CHECK THE ACTION PLAN TOMORROW AGAIN

And remember: you can always contact the study office if you have any doubts or questions ▮▮▮▮▮▮

Description of the interview	
Main questions	**Examples of follow-up questions / probes**
1. In managing your COPD and other diseases, what role do you think you should have and what should be the role of your healthcare provider?	• What do you think is your responsibility? • What do you think is the responsibility of your doctors and/or other health professionals?
2. Please comment on the usefulness of the daily symptom diary for your COPD and other diseases?	• Which parts of the diary did you find easy to complete? • Which parts of the diary were difficult to complete? • Which parts of the diary were helpful in managing your COPD and other diseases?
(Explaining what exacerbations are) 3. Please comment on the usefulness of the action plan for the self-treatment of exacerbations of COPD and other diseases?	• Which parts of the action plan did you find easy to follow? • Which parts of the action plan were difficult to follow? • Which parts of the action plan were helpful with your self-treatment of exacerbations of COPD and other diseases?
4. How do you know when symptoms of your COPD or other diseases require action?	• What has helped you to make this judgement? Is there anything that makes this judgement difficult to make? • What has helped you to take an action when required according to the action plan? • What gets in the way of you taking action when required according to the action plan?
5. What role do you have when the symptoms of your COPD or related problems require action?	• What has helped you to carry out this role? • What gets in the way of you carrying out this role?

6. How would you describe your self-treatment of exacerbations of COPD and other diseases?	What do you think are important components of self-treatment?
	Prompts confidence: • What has helped you to gain more confidence in self-treatment of your COPD and other diseases? • What gets in the way of your confidence in self-treatment of your COPD and other diseases? *Prompts competence/ability:* • What has helped you to carry out self-treatment of your COPD and other diseases? • What gets in the way of you carrying out self-treatment of your COPD and other diseases? *Prompts satisfaction:* • Which parts of the self-treatment of your COPD and other diseases are you satisfied with? • Which parts of the self-treatment of your COPD and other diseases are you unsatisfied with?

Appendix 3
Categorization matrix

Component	Sub component	Sub code	Description
Capability	Psychological capability	Cognitive function	Capacity for judgement, thinking, memory, and decision making.
		Comprehension of disease and treatment	Knowledge and understanding about disease, treatment, desirable and undesirable behaviour.
		Executive function	Capacity for planning and executing behaviour.
	Physical capability	Physical function	The physical skills and abilities needed to engage in behaviour and for adapting to lifestyle changes.
Opportunity	Physical opportunity	Professional support	Support availability from the patient's healthcare providers that facilitates or inhibits initiation of action.
		Regimen complexity	The extent to which treatment regimen is easy or difficult to adhere to.
		Access	Availability of medication and other facilities that enable desired action taking.
	Social opportunity	Social influence/ pressure	The direct influence on the patient by peers.
Motivation	Reflective motivation	Perception of illness	Perception about controllability, curability, necessity of treating, cause, seriousness of own condition.
		Beliefs about treatment	Beliefs about efficacy, necessity or importance of treatment, concerns about current or future adverse

			events, general aversion to taking medicines.
		Beliefs about symptom recognition	Beliefs about the importance of recognizing symptoms of one's own diseases.
		Identity	What the patient characterizes as an individual.
		Self-efficacy	Beliefs about one's own capabilities to engage in a behaviour.
		Outcome expectancies	Anticipated consequences (positive of negative) as a result of engaging in a behaviour.
		Roles	The role patients think they and/or their healthcare providers have regarding the management of their diseases.
		Goals	The ambition of the patient to strive towards a desired result .
	Automatic motivation	Stimuli or cues for action	Intrinsic or extrinsic stimuli / cues that trigger, or making patients more inclined to (not) perform certain behaviour.
		Mood state/ disorder	Emotions or mood disorders (depression, anxiety) affecting thought processes and actions.

Participants' perceived own role				
Component	**Sub component**	**Sub code**	**Description**	**Quotes**
Motivation	Reflective motivation	Roles	*The role patients think they have regarding the management of their diseases.*	I manage mine purely because I have done the uh.. well I have done two courses now. The one I did here was brilliant. It thought me to look at symptoms. Which I do now. My responsibility, I to try to look after myself. And make sure that I do. [1]
				Everything yeah. Medication, my therapy's like doing my exercise and my breathing things. It's all mine until that point where I can't do it anymore. [5]
				Making sure that it goes away a bit, making sure that I will take the medication right and that I give serious thought to what I do. And when it is getting too bad, call in the doctor. [7]
				Taking the medication on time. That is the most important. Calling the docter. If it (increased symptoms) doesn't go away, if it doesn't get better. If I don't sound the alarm, then nothing will happen. They (healthcare providers) can't do anything then. [10]
				My role is to, well I suppose it's to assist any medical people and continue to do what they suggest. I don't know what else really is my role. I mean it's to follow the suggestions and, of professionals and do what they say. That's about as much as I can do to improve it. [4]
				What I have to do… no idea! I do what they (healthcare providers) tell me to do and that's about it. And what they say is what my physiotherapist says. Because he coaches me. And he says "you have to do these excercises for COPD", but the other symptoms I have those are because of my heart attack that I had. That I have to do some excercises for those symptoms too, for my balance and what else, but that is all I have. [6]
				I do very little about it anymore. What happens, happens, and I just can't do much about it. It has been enough for me. I take my medicines and I just accept it. I have to accept that I have it (COPD) and there's nothing more I can do about it. [9]

			I follow that (action plan). Do what my specialist said because that covers the COPD and the garden mold isn't part of it (action plan) so that's something I have to do on the outside. [2]
			My role is: in the first place I'm a patient and I'm coached by the doctor and recently also by a respiratory nurse. My responsibility is to keep an eye on my own situation very closely and taking the prescribed medicines. [8]
			I don't really have a role. I just go with the flow and if I feel crook... cause mine.. mine come on just like that (snaps fingers). What is my role? Well phone up for an ambulance. Because I was always told by one guy. He said if you are feeling crook just phone. Whether there is anything wrong or not.. just phone. But I do know when I need one. [3]
	Identity	*What the patient characterizes as an individual.*	But I'm independent. It took me three busses to get here today but I don't care, you know. [1]

Participants' perceived role of their healthcare providers				
Component	Sub component	Sub code	*Description*	Quotes
Motivation	Reflective motivation	Roles	*The role patients think their healthcare providers have regarding the management of patients' diseases.*	Because I don't have any major issues I don't believe they need to do a lot anyway. If I was let say I got sick enough to have to go to hospital, then it is a different story. My doctor would then have to really make sure that I'm doing things correctly. As I said I like to do things myself but until I get to that point where I have got to go to hospital and then be on the oxygen for two days... [1]

That they monitor it(overall condition) as well. [7]

I think that the doctors have their own responsibility towards their patients. Their responsibility is that they just monitor my well-being and just that they also prescribe the appropriate medication. [8]

Well the role of the professionals and the doctors is to assess the individual's situation, work out what they require, and deliver it as best they can. [4]

What their responsibility is? Well in my mind they try and help you through. They won't say what's right and what's wrong. It's my choice on whether I take in any other word for it and 99 times out 100 I would. [3]

To me, well if it goes wrong, to pick up the part of me that's gone wrong because I have bronchiectasis, COPD, asthma and chronic sleep apnea which makes it really hard, and they act up, my heart acts up more. So if I have problems with my heart its generally because of my lungs, so I need a professional to make sure that it's just not my heart. [2]

The doctors can't do anything about that as well. I've always been helped very well, only once with an operation of a vein in my chest, something went wrong, but otherwise I have always been helped fine. The doctors can't do anything about it (illness). [9] |

Facilitators of usability symptom diaries and exacerbation action plans				
Component	**Sub component**	**Sub code**	**Description**	**Quotes**
Capability	Cognitive capability	Cognitive function	*Capacity for judgement, thinking, memory, and decision making.*	**Symptom diary:** I didn't have got any problems with doing that because of doing it every day. As you go through each questions you look.. okay.. yep.. fine.. fine.. fine.. fine.. (ticks of boxes). It's very simple, straight forward. It is actually very easy to use. [1] It's easy, this is easy to follow. [2] I found it all easy. Because it's very straight forward. It just writes down how you actually feel. So if you feel good in one part but you don't feel good the other. [3] No it didn't cost me any effort. [7] For me it was, yes. I also didn't think about it much. It was more like, I just take it and I fill it out. [8] Yes rather easy. There were no difficulties, no. [9] It is easy to fill out. [10] **Exacerbation action plan:** I didn't find any of it difficult. [2] Pretty easily yes. As I said I haven't had to do it very often, but this one is certainly nothing. I've never had to worry about that one. So as I said its only that top one I ever have to worry about. [4] That was also rather clear, yes. [6] Well, you just have yes and no and that's what you follow. Yes, that works really well. [6] Well I just find it easy. If I read it then I just know what to do. You read the questions and then it works

				itself out. [7]
				With this it is the same like, I use it as it is and I haven't necessarily experienced obstacles of which I would say that should change. I understand what it says and I fill it out. It was always rather clear. [8]
				I find it rather easy. [10]
		Comprehension of disease and treatment	*Knowledge and understanding about disease, treatment, desirable and undesirable behaviour etc.*	**Exacerbation action plan:** That has also to do with a certain ignorance about medication and drug use, so I want to be very sure about what I take and if it helps. Then, you will find that out very soon. [8]
Opportunity	Physical opportunity	Professional support	*Support availability from the patients' healthcare providers that facilitates or inhibits initiation of action.*	**Exacerbation action plan:** After I got shown what what was, how to use this (diary) in relation to this (action plan) it then became a lot easier. And I knew exactly which one if I mark two (on diary) then I went to two (on action plan). Then it was simple. It all fell in the place. Very logical. [1] At first I asked questions and that cleared it up. The nurses I talked to on the phone cleared it up. [2] If I read it then I also just know what to do and if you do something wrong then you can call as well. [7] I find it a really good idea. Because the lead is shorter. I need it, I feel bad, is it responsible that I take it? Then I can have an answer right away, like, yes or no, and then I can take it. [6] So I got it changed. and that was a good thing about the communication in between me and you guys, that it worked both ways. [1] I am actually rather satisfied about it all. Also that conversation where you had to go to with, what's her name, that nurse. Lovely woman. I really had fun when I was there. Pleasant conversations. I had to go there every three months and in between she called as well. [7]
Motivation	Reflective	Beliefs	*Beliefs about*	**Symptom diary:**

motivation	about treatment	*amount of work, necessity, efficacy, concerns about current or future adverse events, general aversion to taking medicines*	I actually found it very good. Very very good. As I said I wish I was still using it. In some respects, I wish I was still using it. Because I had marked two red ones on the bottom and about three red ones on this one and two on the following day. And I knew then that I have got to take it.. And that's what I meant. this is brilliant! [1]
			Good. Its bloody good. Yea yea yea.. no.. mine.. mine sat (laughs) more or less than I.. the yes.. it more or sat for the whole month.. but it wouldn't quite hit the red.. came close.. but this is very very good. Very good. [3]
			It's useful, it allows me to see how I'm going, asses myself. I haven't had a lot of feedback on it, so... it's useful but all it is... it's useful as far as being able to see what the trends and how your managing and how you're going. And it's incredible how up and down it goes, that some days are really good and others aren't so good and even some weeks are good and some aren't so good so you see. As far as that's concerned its useful. [4]
			Exacerbation action plan: I am so glad I actually did this. So glad. It's probably wrong but I probably... if I didn't do this and didn't understand what my body is going through I may be dead by now. I know its hypothetical but you don't know. [1]
			It's everything it was supposed to do. It kept me out of hospital, it got me to the doctor before I got too sick, especially to garden mold. because it does, even though this is for COPD, it separated the garden mold from the COPD and that does it. [2]
			I think the action plan and the study is fine. I wish I didn't have to do it but you know, I can't think of anything better then something like this. [4]
			I found that was very useful for me because I was very slack with the prednisolone and the antibiotics, because I don't like taking either one of them and I would put it off and I learnt with this not to do that. That if I followed the action plan with the boxes that I actually got it to get it started before I got too bad, so I found that was very good. [5]
			Oh I find that rather good. I find it a very good idea. That one time I used it I was very happy with it. [6]

		I still go through it some times, and I do the excercises from this thing (action plan). Sometimes I still do those breathing excercises so I do that as well that is on the paper. So uh, I think to myself 'hey, I still need to do that'. No I still take a look at it rather often. [7] For sure, yes. There was also a good period. [10]

Barriers of usability symptom diaries and exacerbation action plans				
Component	**Sub component**	**Sub Code**	**Description**	**Quotes**
Capability	Cognitive capability	Cognitive function	*Capacity for judgement, thinking, memory, and decision making.*	**Exacerbation action plan:** When you have got the problem of not breathing or something you don't concentrate like you normally would. [1]
		Executive function	*Capacity for planning.*	**Symptom diary:** I just never had any time for it and then I thought I will do it tomorrow, and tomorrow would not be tomorrow... and also not the next week and then eventually it would become the next month.[6] Yes, you have to use it every day, it is not easy. It is a task you have to do every day over again, and you have to think about it every day. Because, for example, I thought by myself late in the evening like "oh, I still have to fill out my diary today" [7] I'm sorry, I just forgot (laughs). I forgot to do it every now and then. [9]
	Physical capability	Physical function	*The physical skills and abilities needed to engage in behaviour and for adapting to lifestyle changes.*	**Symptom diary:** Once or twice I've sent it, and then I became ill and I didn't fill it out anymore. [9]
Opportunity	Physical opportunity	Regimen complexity	*The extent to which treatment regimen is easy or difficult to adhere to.*	**Symptom diary:** I think probably not quite so many choices would be... I'm not senile, I'm not, I haven't got altziemers or anything like that but I've been through a traumatic time in the last few years and a lot of questions I don't cope with. [5]

			To fill it out, I find it difficult. I never actually filled it out every day. In my agenda I did keep track of where there were any particularities were, and what these particularities were. If there are any peculiarities then I think I should just keep a close eye on it, because I think the boxes are really small. [8]
	Environmental context	*Situational cues outside the control of the patient that inhibit or prompt the initiation of action.*	**Symptom diary:** I believe that I have used it for two months. Well then I came back from the hospital and my daughter was with me. I said "where did that(symptom diaries) go?" "Oh" she says, "I thought it was not really that important, so I threw it out." I said "if only you had asked me first". I thought oh well, never mind then. [9]
	Access	*Availability of medication, materials, and other facilities that enable taking the desired action.*	**Symptom diary:** I believe that I have used it for two months. Well then I came back from the hospital and my daughter was with me. I said "where did that(symptom diaries) go?" "Oh" she says, "I thought it was not really that important, so I threw it out." I said "if only you had asked me first". I thought oh well, never mind then. [9]
Social opportunity	Social influence or pressure	*The direct influence on the patient by peers.*	**Symptom diary:** From experience I also know, because I have spoken to others about it, that they just have be filled out at the end of the month, when they need to be sent. [6]

| Motivation | Reflective motivation | Beliefs about treatment | *Beliefs about amount of work, necessity, efficacy, concerns about current or future adverse events, general aversion to taking medicines.* | **Symptom diary:**
It is not hard, it is too much work. Way too much. I have to do too many things. Because you have to fill out all of this (diary no. 1) and then all of that (diary no. 2) and then that again, and that again and then that again.. It makes me... No, stop it. And if you don't fill it out, you cannot take action either. [6]

How useful? For me, not really a lot. It's not difficult, it's just not easy, you know, and doing the whole thing a lot of it didn't even feel like it had anything to do with me. It's like this waking up at night and the ankles and abdomens and all that, I mean it doesn't change, it's just the same thing every day. [5]

Then I won't have that administrative hassle and I can reduce it to what is really necessary. [8]

I had filled out those forms once, but a call once a week is more effective than filling out that whole list once a month. Then you will have a more realistic view than when you fill out a form every month and where I think by myself, "oh yeah, what was that again...". [6]

I would find it better if it was weekly. That you have to do it once a week. That you have to think about it more. Filling out the diary. Instead of every day, do it once a week, then you look at the week retrospectively and then you fill it in. So you will think about it more. [7]

If I had to compose it myself, I would just say that uh, like, just indicate on what days you had complaints and what medication have taken. [8]

Exacerbation action plan:
I knew everything was there, I knew I had my care plan, I've had that for years and years. I'm not saying that I don't follow that plan(COPE-III), what I'm saying is that, I know what to do. Because I've been doing it for years, so I don't have to get this(action plan) out and look at it and say, well I'm going to have to follow that plan because I know to relax, and I do breathing and relaxation and all that sort of thing and I get over it. [5] |
| | | Perception of illness | *Patient's perception about controllability,* | **Exacerbation action plan:**
I don't do much about it anymore. What happens, happens and I just can't do much about that. If it wasn't for her(spouse) still being around, I would be done with it. As far as I'm concerned, it is |

		curability, necessity of treating, cause, seriousness of own condition.	over. [9]
Automatic motivation	Stimuli or cues for action	*Includes extrinsic cues and intrinsic cues, and extrinsic motivation and intrinsic and motivation.*	**Symptom diary:** Only when there were complaints I filled it out. [9] I have to admist that I have filled it out a few days later. But that happened during the period in which I feel good. [10] And then at the end of the month 'oh, that reminds me, I will send that shortly'. Because it had to be sent. And then you are ticking boxes for half an hour. [6]
	Mood state or disorder	*Emotions or mood disorders (depression, anxiety) affecting thought processes and actions.*	**Symptom diary:** I've been through a traumatic time in the last few years and a lot of questions I don't cope with. you know I find it too much and I can't fill in forms or anything anymore I get really frustrated and upset and things, I found this was very taxing for me but not even so much the questions it was just the fact it was a form and I had to fill it in and I just found it very hard to cope with. [5]

Facilitators of symptom recognition and initiating action				
Component	**Sub component**	**Sub code**	**Description**	**Quotes**
Capability	Cognitive capability	Cognitive function	*Capacity for judgement, thinking, memory, and decision making.*	**Symptom recognition:** Not at all. I'm sitting in the morning drinking a cup of coffee. How much does it take to read that? Read that. Read that (goes though diary). Not a lot at all! [1] **Action initiation:** Because this told me like.. because I was filling it out every day I sort of.. okay yesterday I didn't breathe properly so was it really bad or was it a little bit worse than normal. Then I have got to think 'ah okay'. I wish I was still using it. Because then I could go.. As I said to you, it took three days to realise that I needed prednisolone where as if I was doing this, if I had 2 reds in 2 days (clicks finger). I would have known on the 2nd day.. okay shit, I got to do this now. [1]. I look at this, then I answer all the questions I went on a prednisolone a couple of times. Then I had to go on my insulin because the prednisolone alone sent my insulin crazy. It went up 21-22 and I was still doing the same test the same way. I didn't find any of it confusing, I just followed it. Do I have angina medicine at home? Yes. If I got too worried about it, I'd take it and generally that all I had to do. [2]
		Comprehension of disease and treatment	*Knowledge and understanding about disease, treatment, desirable and undesirable behaviour etc.*	**Action initiation:** I think I've left it too long when it gets to that point so now I know not to leave it until I get that pain. [5] Well I have once used the insulin syringe, because my levels were on a certain height. Because I was taking prednisolone. I didn't know that actually of the glucose, I didn't know exactly what I had to do when my glucose levels were too high. I know that now as well thanks to this. [7] You have to read it, you have to fill it out. You will also take a moment to think about it. I think it is positive, because then you can do something about it, right? [10] Yes, things like that you know more about it. That you know a little better how you ought to behave.

				[9]
Opportunity	Physical opportunity	Professional support	*Support availability from the patients' healthcare providers that facilitates or inhibits initiation of action.*	**Symptom recognition:** When it's green(sputum) there is an infection. Normally I get unwell, but I also know that from the doctors. [7] **Action initiation:** I go on prednisolone if I make two ticks of the box and if they say go ahead. Then my doctor will tell me to either stay on it or go off it and put me on another drug for my garden mold.[2] I also felt more secure because I could call. I wasn't only more secure, I found it more pleasant as well, that you know like, I always have a back-up. [6] I'm doing medical fitness, for the chronically ill. Oh they are such... If you are short of breath they say do you raise the alarm early enough? Yes, you don't have to worry about that. [7] That is something that the doctor told me, like, "don't dread it and just take the medication, because everyday the symptoms progress will make it worse for you." So that tells me like, to just do it. [8]
		Access	*Availability of medication, materials, and other facilities that enable taking the desired action.*	**Action initiation:** I find it a very good idea. Because the lead is shorter. Then you know that you always have something as a back-up. If it gets out of hand, I can always rely on that. [6] Based on the action plan to to take a look at it, to check what you have to do, or you go to the general practitioner. Well than this is rather convenient. Because I have this. That saves me a drive of 10 kilometers. That is convenient. Then I won't have to drive 10 kilometers and I won't have to go to the pharmacy seperately, because I have courses of prednisolone and antibiotics right at home. [8] I find it a pleasant idea to always have the medication in your house and you can start. I found it a lovely idea that I had it. That I had it all. That I could rely on it. You are sick, you don't exaggerate because you are not well. [10]
Motivation	Reflective motivation	Outcome expectancies	*Anticipated consequences*	**Action initiation:** The more I ignore it the worse it gets. And as I said I worked that one out, it was three days were I, I

		(positive of negative) as a result of engaging in a behaviour.	felt like, I felt terrible. And if I had to start taking them after two days I may have felt better earlier. [1] I follow the action plan because I know the repercussions from growing up with it and I've had a couple of angry doctors that told me, that I should've gone and seen them and I didn't and I ended up with pneumonia: I ended up with, I was walking around with an epi pen because it took that long to get it under management. [2] I was very slack with the prednisolone and the antibiotics, because I don't like taking either one of them and I would put it off and I learnt with this not to do that. That if I followed the action plan with the boxes that I actually got it to get it started before I got too bad. [5] It is a drastic remedy, because eventually your glucose level rises because of it, so therefore I have to be extra alert to it, but prednisolone in itself is working for me. [7] And if you keep carrying it (increased symptoms) around I get the feeling that you will get pneumonia again. [9]
	Self-efficacy	*Beliefs about one's capabilities to engage in a behaviour.*	**Action initiation:** Now the opportunity is there, then I just know that it (self-treatment) is possible. And having the action plan next to it I am not insecure and I will just do it. That has also to do with a certain ignorance about medication and drug use, so I want to be very sure about what I take and if it helps. Then, you will find that out very soon. [8] I might get it wrong, that's the risk but think I've been doing better with it then before. Because it's something I can refer to, because sometimes you get tired and you get worries and this is sort of your conscience. You can read it in yourself, I know I haven't got that, I've got that but don't have that, oh it's not too much. It does give you the confidence. [2] Because you feel that it's there, you see that it's there. It's right in front of you.., the tools [10]
	Goals	*The ambition or effort of the patient to strive towards a desired*	**Action initiation:** All I know trying to do was made me think about what I am doing and now I do. I actually do. I have a goal. and I hope that I get to do it actually. that why I'm doing what I'm doing now. I have a goal. I won't tell what it is but it's just something I want to be around for. [1]

		result .	
Automatic motivation	Stimuli or cues for action	*Includes extrinsic cues and intrinsic cues, and extrinsic motivation and intrinsic and motivation.*	**Action initiation:** Check out how many red ones are marked per day. and if it was two days in a row then I go straight on to here (action plan). [1] The temperature, or my breathing so bad I can't walk. My walking is my gauge and then I came to this (holds diary) and I mark, read the questions and mark which is significant. If it goes to two boxes, then I look at here (pointing in diary). Then I follow this and if I get worse I go to my doctors. There is always that, but go on this first. [2] So it's pretty straight forward that when you, you've ticked that bottom box, then you look over there as to when you need to, to do things a little bit different. [4] I get a pain, I've started the antibiotics because, to help get rid of the muck and you know off my chest, but you see, when I start the steroids when I get a pain in my ribs, I mean in my lung, it's in my left lung, I'll get pain and then I'll know it's time to get onto the steroids because they tend to mess me up a little bit with my diabetes and that. [5] If I cough heavily, and I am really tight in the chest, and I also have a fever, then I just know what to do and that I cannot wait too long with it. [8]

Barriers of symptom recognition and initiating action

Component	Sub component	Sub code	Description	Quotes
Capability	Cognitive capability	Cognitive function	*Capacity for judgement, thinking, memory, and decision making.*	**Symptom recognition:** I don't concentrate very well any more. Like you've got a question here; felt dizzy or light headed? Not more than usual, more than usual. That's very hard to answer because I've also got vertigo, so you know, some days I get really dizzy and somedays I can't get out of bed because it's so bad and then the breathlessness and the heart and things like this. Sometimes I've got rimtoid arthritis and osteo arthritis and all that as well, so on the bottom here for me I'm talking about is pain, pressure, heaviness, tightness in one or more of your chest, neck, jaw, arms, back, shoulders and all this sort. I get that all the time, so it would be quite confusing because I can fill in all of that and it's got nothing to do with my heart or anything like that. [5]
		Comprehension of disease and treatment	*Knowledge and understanding about disease, treatment, desirable and undesirable behaviour etc.*	**Symptom recognition:** No, no, no, no. Because I am not sure whether because I do what I have been told to do. So because it is also anxiety brings it on. right? As far as I am concerned. Anxiety will bring on the hard bit to breathe but if you control the anxiety side it sorts of goes away. I am weird (laughs). [3] The hardest one is to work out where you're at if you're not feeling the best is this one here, is to which particular area you find that you are, you know, which one suits how you feel. I've never had to, these have always been the same, never a problem, this is the only one that really has… B, C, D, E were never a problem. A is the one that I have to think about. [4] Now first question is breathlessness, say today, not more than usual, slightly more than usual, significantly more than usual. Yeah what am I doing (confused) breathlessness yeah slightly significantly, sputum production, not that much. At the moment I don't seem to have a real normal, for me you know. It's not difficult, it's just not easy, you know. [5] **Action initiation:** When sputum changes color, when that starts going like a green color and stuff like that, then I know I've got an infection coming, but that can be green today and tomorrow it's just a sort of yellowy color, so I can't sort of say, my sputum's this color I better start taking antibiotics, I'm better to wait a day or so. [5]

	Physical capability	Physical function	*The physical skills and abilities needed to engage in behaviour and for adapting to lifestyle changes.*	**Symptom recognition:** The only thing I don't do that is says to do is to weight yourself every day, I don't do that, I do the ankles and I do the fluid with the pressure and things like that because when I'm, I try to get my weight my boobs get in the way. I can't see the thing, so we do it that way. [5]
Motivation	Reflective motivation	Beliefs about treatment	*Beliefs about amount of work, necessity, efficacy, concerns about current or future adverse events, general aversion to taking medicines.*	**Action initiation:** And I don't like taking the steroids. I try to avoid them. But I had to take them. [1] I'm nervous but I'm satisfied because I'm not a doctor, and there is always the worry that when, everything goes off the rails at the same time, that's a worry, but that always going to be a worry and it does happen every now and then. [2] Yes, I find it... To take medication just like that, I always find that a risk, so therefore I always make a quick call about it. [6] What bothers me is that, in principle I dislike an amount of medicines and certainly when it comes to prednisolone and antibiotics. So that is what's in the way, that I will think twice if I take it or if I won't take it. [8] No I just have a good cry and, because I'm on tablets for that, I'm on citalopram for the depression. I have a good cry, I yell at my son, and I have a good cry and, he gives me a cuddle. [5]
	Automatic motivation	Stimuli or cues for action	*Includes extrinsic cues and intrinsic cues, and extrinsic motivation*	**Action initiation:** My symptoms just coming along like, just 'bang!' but I can actually feel it coming but it's not to the point that I need it (medication). So I might just go and sit down and the next moment just... the world just crashes in on you. [3]

		and intrinsic and motivation.