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To cite this article: J. Schrijver, T. Effing, M. Brusse-Keizer, J. van der Palen, P. van der Valk & A. Lenferink (2023) Facilitators and Barriers of Adherence to Multi-Disease Exacerbation Action Plans in COPD Patients – A Qualitative Study, COPD: Journal of Chronic Obstructive Pulmonary Disease, 20:1, 262-273, DOI: [10.1080/15412555.2023.2240408](https://doi.org/10.1080/15412555.2023.2240408)

To link to this article: <https://doi.org/10.1080/15412555.2023.2240408>



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Facilitators and Barriers of Adherence to Multi-Disease Exacerbation Action Plans in COPD Patients – A Qualitative Study

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ABSTRACT

Whereas exacerbation action plans to self-manage Chronic Obstructive Pulmonary Disease (COPD) significantly improve health outcomes, patients' adherence to those action plans is often poor. This study aimed to identify facilitators and barriers of adherence to tailored multi-disease exacerbation action plans. We also explored patients' perspectives toward disease management roles. Individual semi-structured interviews were conducted with a sample of COPD patients who completed a Dutch-Australian self-management intervention evaluating tailored exacerbation action plans for COPD and relevant comorbidities. Interviews were thematically analyzed using a deductive approach guided by the Capability, Opportunity and Motivation of Behavior (COM-B) model. In 2016, ten patients (5 Australian; 5 Dutch; 6 men; age 59-83 years) were interviewed at the end of their one-year follow-up. Facilitators of adherence included improved patients' comprehension of disease and treatment, positive feelings about the intervention, improved self-confidence, and professional support. Barriers included difficulties to recognize symptoms, dislike toward daily symptom monitoring, negative feelings about the intervention, negative mood state, and complexity of symptom diaries and action plans. Patients indicated three distinctive perspectives of their own and their healthcare professional's role in their disease management: 1) patients felt mainly responsible; 2) patients felt shared responsibility with their healthcare professional; and 3) patients felt not responsible as they perceived their healthcare professional to be mainly responsible. We successfully used the COM-B model as a guide to identify facilitators and barriers of patients' adherence to multi-disease exacerbation action plans. Improving patients' adherence in future self-management interventions by targeting specific facilitators or barriers should be considered.

ARTICLE HISTORY

Received 18 November 2022
Accepted 19 July 2023

KEYWORDS



Chronic Obstructive Pulmonary Disease; adherence; disease management; self-treatment; exacerbations; qualitative research


Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease characterized by persistent airflow limitation and episodes of acute deterioration, which are referred to as exacerbations [1]. Over 50% of the COPD patients have one or more comorbidities [1–9], that may have a significant impact on disease progression, morbidity and mortality [1,10–13].

Self-management is important in the treatment of COPD [14,15]. It encompasses self-monitoring and self-treatment of symptoms, lifestyle adjustment, coping with (the consequences of) the chronic disease(s), and communication with healthcare professionals, including active participation in decision-making processes about care and treatment [16]. A COPD self-management intervention is defined as

a structured, but personalized, and often multi-component intervention, with goals of motivating, engaging and supporting the patients to positively adapt their health behavior(s) and develop skills to better manage their disease [17]. Exacerbation action plans are considered a key element in COPD self-management interventions [18,19]. They aim at recognizing exacerbation symptoms early and taking appropriate and prompt action (e.g. self-initiating a course of oral corticosteroids) [18,20]. Early detection of exacerbations while using an action plan, has shown to accelerate recovery time after an exacerbation [21], improve HRQoL [20], shorten the duration of COPD exacerbations [22], lower the probability of respiratory-related hospitalizations [22], and lead to considerable cost savings [23].

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 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/15412555.2023.2240408>.

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Patients' adherence to COPD exacerbation action plans is sub-optimal, with adherence rates around 40% [21,24,25]. Adherence is generally defined as 'the extent to which a person's behavior corresponds with agreed recommendations from a healthcare professional' [26]. It is understandably an essential contributor of effective self-treatment of exacerbations [21]. If patients become more adherent, it is likely that they actually derive benefit (i.e. improved patient health outcomes) from self-management interventions. Patients' adherence can be influenced by a variety of factors on disease-related, social, and psychological level [27]. Reported factors of non-adherence to COPD self-management interventions are e.g. patients' inability to recognize exacerbations, make decisions to initiate action, and initiate actual actions to reduce symptoms [28]. Presence of comorbidities may negatively influence patients' adherence to exacerbation action plans, as the added responsibility of self-managing multiple diseases can easily become too overwhelming [29,30]. In addition, deteriorating comorbid disease symptoms may overlap with COPD symptoms. Breathlessness could for example link to either a COPD exacerbation, a heart failure or anxiety flare-up, or a combination [31–34]. This could easily lead to uncertainty of symptom recognition among patients, which could subsequently complicate patients' appropriate self-treatment decision making (e.g. resulting in incorrect or delayed treatment and thus sub-optimal patient adherence) [31]. Furthermore, patients' perspectives of disease management roles may influence patients' adherence to their exacerbation action plans [29]. Some patients tend to hold their healthcare professional responsible for monitoring and managing their health, preventing them from taking an active role in disease management themselves [29].

Since limited research on factors influencing adherence to exacerbation action plans has been published, underlying mechanisms of adherence are still poorly understood [24,35]. Conducting secondary analyses of qualitative data from a COPD self-management trial [36], we aimed to identify facilitators and barriers of patients' adherence to multi-disease exacerbation action plans and to explore patients' perspectives toward disease management roles in patients with COPD and comorbidities. Study findings can support further tailoring of multi-disease exacerbation action plans in order to improve patients' adherence and health outcomes in future self-management interventions.

Material and methods

Sample and setting

In this qualitative study, we included an equal number of Dutch and Australian patients that were included in the COPE-III intervention group by employing convenience and purposive sampling. Only those patients who had recently (≤ 3 months) finished the one-year COPE-III follow-up were invited for an interview in June and July 2016. No other selection criteria were used to obtain the sample frame. The COPE-III study was a large Dutch-Australian multicenter randomized controlled trial conducted between 2012 and 2016. This study explored the effectiveness of

a self-management intervention including multi-disease exacerbation action plans in patients with COPD and common comorbidities [22,36].

In the COPE-III study, patients could be included if they had a COPD diagnosis [37], were ≥ 40 years, had ≥ 3 exacerbations or ≥ 1 COPD hospitalization in the past two years prior to study entry, had ≥ 1 clinically relevant comorbidity (ischemic heart disease, chronic heart failure, diabetes mellitus, anxiety and/or depression), and were excluded when having a Mini-Mental State Examination (MMSE) score [38] < 24 [22,36]. Patients were recruited from two Dutch and three Australian hospitals [22,36]. Detailed methodologies including in- and exclusion criteria have previously been published [22,36]. The COPE-III study was approved by the Medical Ethical Committee Twente and the Southern Adelaide Clinical Human Research Ethics Committee, and written informed consent was obtained from all patients [22,36].

We presumed that we would reach data saturation when interview data of ten patients would be gathered [39,40]. Patients were invited to participate through a phone call by researchers (TE and AL). If the patient agreed to participate, they were asked for a home-visit or to visit the hospital to conduct the interview.

Self-management intervention

COPE-III study intervention group patients received two or three individual and two group self-management training sessions directed toward symptom recognition and monitoring, self-treatment of COPD exacerbations and flare-ups of comorbidities, disease knowledge, inhaler techniques, and relaxation and breathing exercises [22,36], see Figure 1. They were asked to complete tailored daily symptom diaries, including COPD and relevant comorbid symptoms for a one-year period [22,36]. Patients were directed to consult their tailored exacerbation action plans if symptoms had increased [22,36]. The action plans contained self-management instructions for patients how to act in case of COPD exacerbations or flare-ups of comorbidities, such as taking appropriate medication on time, seeking help from a healthcare professional and conducting relaxation exercises [22,36]. All patients were educated in completing the diaries and using the action plans by trained case-managers (experienced respiratory nurses), and supported by cardiac, diabetes and/or mental health diabetes nurses [22,36]. The case-managers evaluated and consolidated patients' self-management behaviors by phone at three scheduled moments during follow-up to reinforce self-management skills [22], see Figure 1. In addition, patients could contact the case-manager on their own initiative by phone if they: 1) did not feel better after treatment, with specific instructions provided in their action plans; or 2) had any doubts or questions [22]. To elicit patients' motivation, confidence and competence toward the self-management intervention, five behavior change technique (BCT) categories were incorporated (i.e. goals and planning, feedback and monitoring, social support, shaping knowledge, and repetition and substitution) [17,41,42]. More

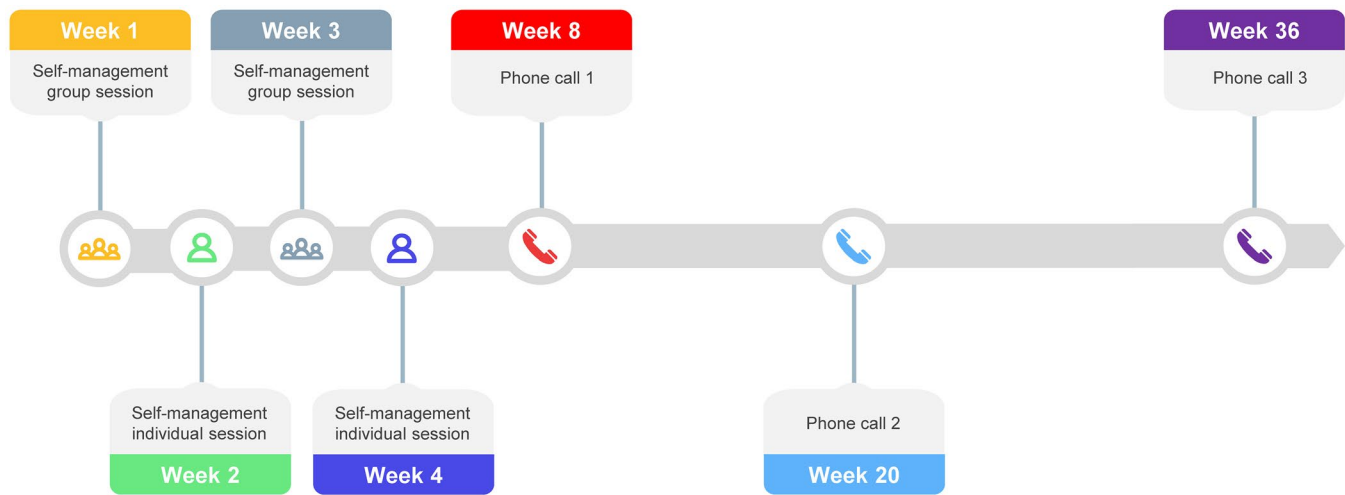


Figure 1. Brief timeline of the COPE-III study self-management intervention content.

Note: Figure adapted from Figure 1 in the paper of Lenferink 2013 [36] (page 83) and Table 1 in the paper of Lenferink 2019 (page 3) [22].

in-depth details of the self-management intervention have been published previously [22,36].

Interviews

In the collection of interview data, researcher triangulation was employed to enhance the study's rigor and ensure data reliability [43]. A semi-structured interview guide (established by AL, TE, a health psychologist, and a research assistant) was used for the interviews. The guide entailed six open-ended questions addressing the following three topics: 1) perceived patients' and healthcare professionals' role in disease management; 2) experienced usefulness of the symptom diary and action plan; and 3) recognition of symptoms and initiation of actions. For the full interview guide, including probing questions, see Table A in the [supplementary material](#).

All interviews were executed in-person by an independent interviewer (research assistant), who was trained by a health psychologist, at either the patient's home or at the hospital's outpatient clinic, depending on the patient's preference. During the first two interviews, an observer was present to notice non-verbal responses and conspicuous events. Copies of symptom diaries and action plans were provided to the patients, to point out specific sections where questions referred to. All interviews were recorded and transcribed verbatim by the research assistant.

Demographic information, educational background, health literacy confidence, motivation, and cognitive impairment assessment data (MMSE score [38]) were collected as part of the COPE-III study [22].

Analysis

The general aim of the interviews was to explore patients' overall experiences with the self-management intervention. The current qualitative analysis of these interview data involved a secondary analysis to identify specific facilitators and barriers of patients' adherence to multi-disease

exacerbation action plans and explore patients' perspectives toward disease management roles, employing researcher triangulation [43]. Content analysis of interviews was conducted using a deductive-dominant approach, involving three phases: preparation, organization and reporting of the results (Figure 2) [44,45]. Data analysis was supported by ATLAS.ti [46]. A categorization matrix was developed including components and sub-components, that were deductively obtained from the Capability, Opportunity, Motivation of Behavior (COM-B) model [47]. We applied this model to provide insight and understanding in factors explaining patients' adherence to exacerbation action plans (Figure 3). Facilitators and barriers of adherence to multi-disease exacerbation action plans were not qualitatively investigated before. Therefore, we used a suggested framework of a study that had applied the COM-B model [47] to factors associated with medication adherence [48], as a first starting point in the current study to identify facilitators and barriers of adherence. With the obtained interview data, we were unable to determine whether the revealed disease management roles impacted patients' adherence to the action plan. Disease management roles were therefore analyzed and reported separately from the COM-B model. Methodological quality of our analysis approach was discussed with a researcher specialized in qualitative research. The process of data analysis and interpretation of results was discussed in our research team.

Results

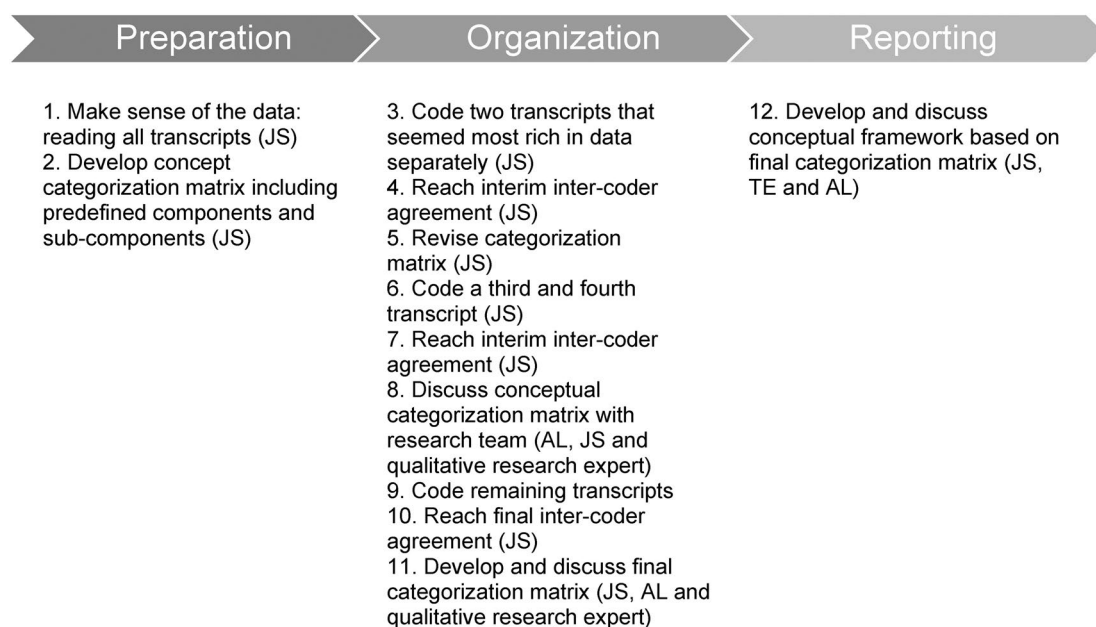
Ten COPD patients were interviewed (Australian $n=5$; Dutch $n=5$). Baseline characteristics of this COPE-III study sample are presented in Table 1. The patients' age ranged between 59 and 83 years, six patients were male, and four patients had multiple morbidities. The educational level varied between low ($n=4$) and medium ($n=6$). Seven patients reported having little to no confidence in their ability to complete medical forms by themselves, and seven patients lived alone.

Table 1. Baseline characteristics of interviewed COPE-III intervention patients ($n=10$).

ID	Age	Sex	Nationality	Comorbidity	Educational level*	Health literacy confidence [#]	Living alone	Motivation [§]	Cognitive impairment (MMSE [38] score) [~]
P1	72	Male	Australian	IHD Depression	Low	Confident	Yes	7	28
P2	64	Male	Australian	IHD	Middle	Confident	Yes	9	30
P3	59	Male	Australian	Anxiety Diabetes	Middle	Somewhat confident	Yes	6	30
P4	64	Male	Australian	IHD	Middle	Unconfident	Yes	10	29
P5	67	Female	Australian	CHF Depression Diabetes	Low	Unconfident	Yes	8	29
P6	74	Male	Dutch	CHF	Middle	Somewhat confident	No	7	28
P7	64	Female	Dutch	IHD Diabetes	Low	Unconfident	No	8	28
P8	67	Female	Dutch	CHF	Middle	Somewhat confident	Yes	8	25
P9	83	Male	Dutch	IHD	Middle	Confident	No	7	29
P10	74	Female	Dutch	Depression	Low	Somewhat confident	Yes	8	29

Notes: *Educational level was classified as low: no school or primary school; middle: secondary school or vocational college; or high: undergraduate or postgraduate. [#]Health literacy confidence was measured by asking patients the question "How confident are you in completing medical forms by yourself?" This was classified as follows: confident, somewhat confident or unconfident. [§]Motivation was self-reported by the question "What is your motivation to use the daily symptom diary and action plan?", in a range between 0-10 (0 = totally unmotivated and 10 totally motivated). [~]A score between 25 and 30 was considered normal, indicating no cognitive impairment [38].

Abbreviations: ID, Identification; P, Patient; IHD, Ischemic Heart Disease; CHF, Chronic Heart Failure; MMSE, Mini Mental State Examination score [38].

**Figure 2.** Phases of a deductive-dominant qualitative content analysis approach.

Note: Figure adapted from Elo 2008 [44]. A psychology student was involved in all analysis steps, except for step 12.

Facilitators and barriers of adherence

Four facilitators and five barriers of adherence to multi-disease exacerbation action plans were identified (Figure 4, Tables 2 and 3). These facilitators and barriers were mapped into the three components from the COM-B model [47], and subsequently linked to suitable sub-components of the COM-B model [47]: patients' psychological capability, patients' reflective and automatic motivation, and patients' physical opportunity (Figure 4, and categorization matrix in the [supplementary material](#) (Table B)). We found no facilitators or barriers for

patients' physical capability and patients' social opportunity, and no facilitators for patients' automatic motivation.

Facilitators of adherence included: 1) improved comprehension of disease and treatment (i.e. related to their COPD and comorbidities); 2) positive feelings about the intervention (i.e. perceived usefulness and benefits from the symptom diary and action plan); 3) improved self-confidence (i.e. strengthened feelings about patients' own abilities to initiate actions according to their exacerbation action plan); and 4) professional support (i.e. possibility to call a case-manager

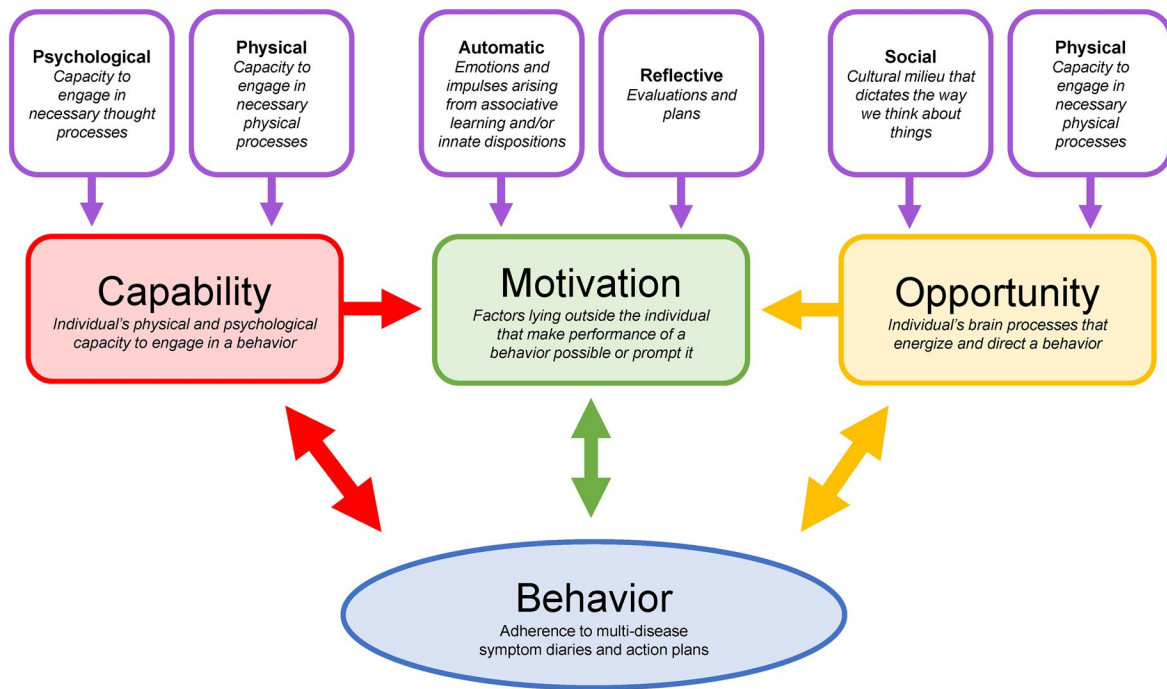


Figure 3. Application of the Capability, Opportunity, Motivation of Behavior model to patients' adherence to exacerbation action plans. Note: This is an adapted version of Figure 1 in the paper of Michie 2011 [47] (page 4). Descriptions in italic refer to definitions reported by Michie 2011 [47] (pages 3-5).

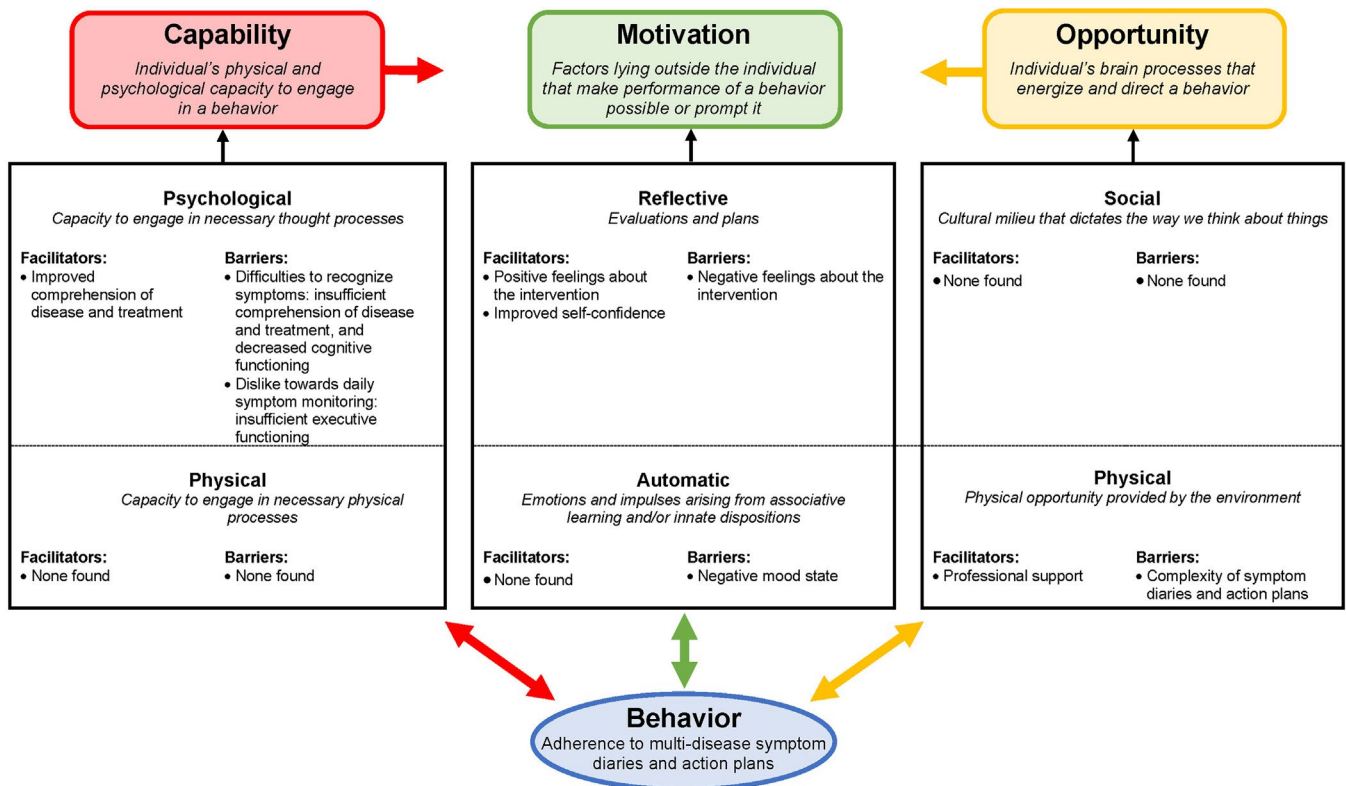


Figure 4. Facilitators and barriers of patients' adherence to exacerbation action plans mapped into the Capability, Opportunity, motivation of behavior model. Note: This is an adapted version of Figure 1 in the paper of Michie 2011 [47] (page 4). Descriptions in italic refer to definitions reported by Michie 2011 [47] (pages 3-5).

that helped patients to recognize their symptoms and subsequently to initiate actions).

Barriers of adherence included: 1) difficulties to recognize symptoms (i.e. recognition of deteriorated symptoms and symptom recognition due to concentration problems); 2)

dislike toward daily symptom monitoring (filling out the symptom diary as a daily recurring task); 3) negative feelings about the intervention (i.e. dislike toward medication use for the self-treatment of exacerbations); 4) negative mood state; and 5) complexity of symptom diaries and

Table 2. Facilitators of patients' adherence to multi-disease symptom diaries and action plans.

Components	Sub-components	Facilitators	Definition	Quotes
Capability	Psychological	Improved comprehension of disease and treatment	Knowledge and understanding about disease, treatment, desirable and undesirable behavior	Q1: "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 [action plan]" (P7). Q2: "Yes, things like that you know more about it. That you know a little better how you ought to behave." (P9).
Motivation	Reflective	Positive feelings about the intervention	Feelings about efficacy, necessity or importance of intervention and treatment, concerns about current or future adverse events, general aversion to taking medicines	Q3: "I actually found it [symptom diary and action plan] 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 [self-treatment]. And that's what I meant. This is brilliant!" (P1) Q4: "It's [symptom diary] useful, it allows me to see how I'm going, assess 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 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." (P4). Q5: "It [symptom diary] helped me understand it [symptom recognition] 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 pollinating, just one sickly smelling tree that hurts" (P2).
Opportunity	Physical	Professional support	Beliefs about one's own capabilities to engage in a behavior	Q6: "It's [symptom diary and action plan] 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). Q7: "Because it's [symptom diary and action plan] 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." (P2). Q8: "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). Q9: "At first I asked questions and that cleared it up. The nurses I talked to on the phone cleared it up." (P2). Q10: "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). Q11: "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." (P6). Q12: "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.'" (P8).

Abbreviations: P, Patient; Q, quote.

Table 3. Barriers of patients' adherence to multi-disease symptom diaries and action plans.

Components	Sub-components	Barriers	Definition	Quotes
Capability	Psychological	Difficulties to recognize symptoms: insufficient comprehension of disease and treatment	Knowledge and understanding about disease, treatment, desirable and undesirable behavior	<p>Q13: "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." (P5).</p> <p>Q14: "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 is this color, I better start taking antibiotics, I'm better to wait a day or so." (P5).</p> <p>Q15: "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).</p> <p>Q16: "When you have got the problem of not breathing or something you don't concentrate like you normally would." (P1).</p> <p>Q17: "I don't concentrate very well any more. Like you've got a question herefelt 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 rheumatoid arthritis and osteoarthritis 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).</p> <p>Q18: "I just never had any time for it [completing symptom diary] 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).</p> <p>Q19: "Yes, you have to use it [symptom diary] 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 [completing symptom diary] every day. Because, for example, I thought by myself late in the evening like, oh, I still have to fill out my diary today." (P7).</p> <p>Q20: "Only when there were complaints I filled it [symptom diary] out. (...) I'm sorry, I just forgot [laughs]. I forgot to do it [completing symptom diary] every now and then." (P9).</p> <p>Q21: "And then at the end of the month 'oh, that reminds me, I will send that [symptom diary] shortly'. Because it had to be sent. And then you are ticking boxes for half an hour. (...) Laziness. (...) Too much work." (P6).</p> <p>Q22: "And I don't like taking the steroids. I try to avoid them. But I had to take them." (P1).</p> <p>Q23: "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." (P8).</p> <p>Q24: "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)</p>
Motivation	Reflective	Negative feelings about intervention	Negative feelings about efficacy, necessity or importance of intervention and treatment, concerns about current or future adverse events, general aversion to taking medicines	<p>Q25: "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).</p> <p>Q26: "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 [symptom diary] 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).</p> <p>Q27: "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 number 1] and then all of that [diary number 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).</p> <p>Q28: "To fill it [symptom diary] 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).</p> <p>Q29: "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).</p>
Opportunity	Physical	Complexity of symptom diaries and action plans	The extent to which intervention tools are difficult to adhere to	

Abbreviations: P, Patient; Q, quote.

Table 4. Overview of patients' perspectives of roles toward disease management (n=10).

Perceived own role	Perceived role of healthcare professionals	Quotes
Patient feels mainly responsible for their own disease management. Help from HCPs is required when symptom management feels beyond their own control (n=4).	Patient feels the HCP to be responsible for disease management during and after acute exacerbation phase.	Q30: "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).Q31: "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." (P5). Q32: "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." (P7). Q33: "Taking the medication on time. That is the most important. Calling the doctor. 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 professionals] can't do anything then." (P10).
Patient feels responsible for disease management but help from HCPs is required with disease monitoring and management during stable phase (n=2).	Patient feels the HCP assistive in disease monitoring and management during stable phase, and exacerbation recovery during and after acute exacerbation phase.	Q34: "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 it's generally because of my lungs, so I need a professional to make sure that it's just not my heart." (P2). Q35: "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. (...) I think that the doctors have their own responsibility toward their patients. Their responsibility is that they just monitor my well-being and just that they also prescribe the appropriate medication." (P8).
Patient feels not responsible for their own disease management (n=4).	Patient feels the HCP to be mainly responsible for disease monitoring and management during stable phase and during and after acute exacerbation phase. The HCP is the expert and should decide what patients need.	Q36: "I don't really have a role. I just go with the flow and if I feel crook. Cause 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." (P3). Q37: "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). Q38: "What I have to do. No idea! I do what they [healthcare professionals] 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 exercises for COPD", but the other symptoms I have those are because of my heart attack that I had. That I have to do some exercises for those symptoms too, for my balance and what else, but that is all I have." (P6). Q39: "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." (P9).

Abbreviations: P, Patient; HCP, healthcare professional; Q, quote.

action plans (e.g. too many questions in case of multiple morbidities, unnecessary questions not applicable to one's individual situation, user-unfriendly lay-out of diaries and action plans (e.g. too small boxes to indicate if symptoms changed during past 24 hours)).

Roles toward disease management

Three perspectives were revealed by patients on their own role and their healthcare professionals' (e.g. pulmonologist, respiratory nurse) role toward disease management of COPD and comorbidities (Table 4). An overview of extracted interview quotes related to patients' perspectives of the three identified roles toward disease management can be found in Table 4.

The first role suggests patients feeling mainly responsible. "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, Q30).

The second role indicates patients feeling as responsible as the healthcare professional. "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. (...) I think that the doctors have their own responsibility toward their patients. Their responsibility is that they just monitor my well-being and just that they also prescribe the appropriate medication." (P8, Q35).

Finally, the third role points out patients feeling the healthcare professional to be mainly responsible. "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, Q37).

Discussion

In this qualitative study, facilitators and barriers of COPD patients' adherence to multi-disease exacerbation action plans were identified. Whether patients considered factors to be a facilitator or a barrier to their adherence appeared to be personal. For instance, some patients stated that positive feelings (e.g. perceived usefulness and benefits) about the self-management intervention improved their adherence, while other patients indicated that negative feelings (e.g. dislike toward medication use for the self-treatment of exacerbations) impeded their adherence. Furthermore, our study revealed three patient perspectives of their own and their healthcare professional's role in their disease management.

Patients' adherence was facilitated by their improved self-confidence. Previous research also reported that low self-confidence often impedes COPD patients' active engagement in self-management practices [27,49]. Furthermore, in line with previous qualitative research [50], the availability of support from healthcare professionals that helped patients to recognize symptoms and subsequently to initiate actions, was indicated by patients as an important facilitator of adherence. Professional support during the self-management intervention has been observed in previous studies as crucial for achieving safe and effective COPD self-management, and to stimulate and maintain patients' behavior change [51–53]. However, it is still unknown what essential professional support strategies in self-management interventions should be in place and should be explored in future studies.

Consistent with previous research, patients' adherence was inhibited by patients' difficulties to recognize symptoms, in particular when symptoms deteriorated [28,54]. Also, decreased concentration during an exacerbation was mentioned to further limit patients' adherence. A recent study reported that lack of oxygen in the brains of patients with an exacerbation may negatively impact on their concentration and usual abilities [55]. During self-management training sessions, it should be standard to discuss and evaluate whether the patient would benefit from (professional) support with symptom recognition and the use of the exacerbation action plan. Especially during exacerbations, support may be helpful or even necessary for appropriate decision making. Another barrier described was 'a dislike toward daily symptom monitoring'. This has not been described before and suggests that the patient may, at that moment, not be fully ready to use the symptom diary and action plan due to e.g. unawareness of its purpose and/or beneficial consequences [19,56]. As a result, resistance and non-adherence of patients may be a consequence [19,57]. Assessment of patients' level of readiness before the self-management training is therefore advisable, to adopt an appropriate strategy (e.g. motivational interviewing [57,58]) that facilitates patients' readiness to change [19]. Another barrier of

adherence was the dislike toward medication use for the self-treatment of exacerbations, due to e.g. side effects of oral corticosteroids or (poly)pharmacotherapy regimens, which has been discussed in previous studies [28,54,59]. Moreover, the complexity of the current lay-out of the (multi-disease) symptom diary and action plan (i.e. too many and unnecessary questions, user-unfriendly) was identified as a barrier for patients being adherent, and may therefore not be suitable for all COPD patients.

Adaptations to the multi-disease symptom diaries and exacerbation action plans should be considered. First, the content should be tailored to patients' comprehension of diseases and symptoms, and simplified as much as possible, e.g. by incrementally and partially offering the (simplified) symptom diary and action plan, sending verbal, written or digital reminders, and offering tailored feedback [19]. In addition, the delivery of the intervention tools could be improved by tailoring them to patients' needs, preferences (e.g. using digital symptom diaries and/or action plans [60]) to make them more suitable for the individual patient [19]. In the majority of the interviewed COPE-III study patients, health literacy confidence was reported as 'having somewhat or no confidence in their ability to complete medical forms by themselves', which could be one of the inhibiting factors of using the intervention tools appropriately. A recent systematic review concluded that COPD self-management interventions with focus on patients' health literacy led to improved COPD knowledge [61]. This indicates that multi-disease exacerbation action plans also should consider patients' health literacy level, e.g. by making adaptations to the intervention tools for the individual patient (e.g. by using pictograms and videos) [19,62,63].

The COM-B model [47] makes it easier to identify appropriate patient-tailored BCTs [41] as suggested by Michie et al. 2011 [47]. Although the COPE-III study intervention incorporated BCTs that might have impacted patients' adherence to multi-disease exacerbation action plans [22, 36,42], alternative BCTs may have been more effective, depending on the individual. The combination of our findings on barriers of adherence with the COM-B model [47], can guide the selection of potentially useful BCTs [41]. In practice, these techniques can be applied in COPD self-management interventions including multi-disease exacerbation action plans to overcome potential individual barriers of patients' adherence (see Table C in the [supplementary material](#)) [41,47]. For example, psychological capability can be improved through techniques such as shaping knowledge, and problem solving [41,47]. This may help to conquer patients' difficulties to recognize symptoms. More research is however warranted on the use of effective BCTs while addressing different COPD self-management intervention characteristics.

Three distinctive perspectives of patients on their own role and their healthcare professionals' role toward disease management were revealed, ranging from a main responsibility for only the patient or the healthcare professional up to a shared responsibility for disease management. To date, little is known about the effects of different disease management roles on adherence and health outcomes of patients participated in COPD self-management interventions. When

a patient's capacity to manage the disease decreases (e.g. by increased disease severity or co-existing morbidities), the disease management by the healthcare professionals will increase and vice versa [15]. Responsibility of patients for maintaining their own health could be influenced by the patients' activation. Patient activation is defined as the individual's knowledge, skills, and confidence in managing their own health and care, and has shown to play a central role in COPD self-management behaviors [64,65]. Patients who assume a passive role toward self-management need not only be made more aware of the purpose of self-management being patient-centered, but also motivated into taking shared responsibility with the healthcare professional, instead of remaining primarily dependent on their support. In clinical practice, we therefore recommend assessing patients' perceptions toward disease management during the self-management training, to enhance patients' responsibility, and to coach 'passive' patients into becoming 'active' self-managers.

Our qualitative study had several strengths. First, interviews were conducted and analyzed by independent researchers who were not involved in the COPE-III study, which reduced investigator bias. Second, by employing a combination of convenience and purposive sampling, we selected a diverse sample of Dutch and Australian patients who had finished their one-year follow-up in the COPE-III study recently. This combined approach facilitated easy access to patients, strengthened patients' memorization regarding their experiences with the self-management intervention, and ensured representation from both countries to capture potential cultural variations. Furthermore, it allowed us to capture a rich and diverse range of perspectives, that ultimately led to the recruitment of information-rich cases. Third, validity of our study findings was enhanced by the use of researcher triangulation during all study phases [43]. Our study also had some limitations. First, we aimed to provide insight in aspects of the interview data (i.e. disease management roles and patients' adherence) that were only partially addressed in the primary interview purpose. As interview questions were initially not developed to identify facilitators and barriers of adherence, this may have affected the completeness of our study findings. Second, we used patient interviews that were conducted in 2016. It would not have been possible in this study to recruit additional patients for extra interviews in case data saturation was not reached. However, data saturation was achieved with ten patient interviews as no new facilitators and barriers were identified in the last two interviews. Third, our sample was primarily designed to provide insights into the experiences and perceptions of patients who participated in the self-management intervention. The representation of patients and their voices may have been limited as we did not sample any patients of the intervention group who withdrew from the study (16.7%) [22].

Conclusion

This study provided insight into facilitators and barriers of patients' adherence to multi-disease exacerbation action plans and patients' perspectives toward disease management

roles. The COM-B model [47] was successfully used as a guide in our analyzes to identify facilitators and barriers. Future development of self-management interventions should consider targeting specific facilitators or barriers identified by this study to improve patients' adherence to multi-disease exacerbation action plans.

Acknowledgements

We thank all patients who participated in the interviews for sharing their time and experiences toward the COPE-III study participation. Furthermore, we thank Nina van Gameren (research assistant), Paul Cafarella (health psychologist), Suzanne Hoftijzer (student Master of Health Psychology and Technology at the University of Twente), and Annemarie Braakman-Jansen (researcher and assistant professor Psychology, Health and Technology at the University of Twente) for their valuable contribution to this study.

Disclosure statement

The authors report no conflicts of interest in this work.

Funding

This study was supported by the Stichting Astma Bestrijding, Lung Foundation Netherlands (grant number 3.4.11.061), Lung Foundation Australia (Australian Lung Foundation Boehringer Ingelheim COPD Research Fellowship), and Repat Foundation, GlaxoSmithKline (unrestricted grant).

Data availability statement

Data that support the findings of this study are available upon reasonable request (corresponding author, J. Schrijver).

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