

# **'How do COPD patients perceive self-management of their illness and what can physiotherapists do to facilitate this? – a qualitative research.'**

Masterthesis

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“ONDERGETEKENDE

Lise Maren Kloosterman,

bevestigt hierbij dat de onderhavige verhandeling mag worden geraadpleegd en vrij mag worden gefotokopieerd. Bij het citeren moet steeds de titel en de auteur van de verhandeling worden vermeld.”

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## **Abstract**

**Background :** In line with European public health policies, patients with Chronic Obstructive Pulmonary Disease (COPD) are being held more responsible for taking control of one's own health. However, studies have shown that the COPD population show less proactiveness and take less control in healthcare. The perception of COPD patients on self-management after newly introduced reimbursements policy have not yet been investigated.

**Aim:** To discover what the perception of COPD patients on self-management is and what physiotherapists can do to facilitate this.

**Methods:** Purposeful sampling of COPD patients and physiotherapists from physiotherapy centre 'Van Kasteel' was used. Four focus group interviews using an interview guide were conducted. Three of those were with patients and one with physiotherapists. Sessions were tape-recorded and transcribed verbatim. A constant comparison analysis strategy was used to analyse the data using ATLAS.ti.

**Results:** Patients do not seem to be able to change their behaviour and are therefore not likely to take initiative for self-management. Informed decision-making (IDM) is complicated by the fact that patients do not actively search for information, despite the fact that they seem to have a need for information. Patients are also scoring low on shared decision-making (SDM). Only a few of them make decisions together with healthcare providers. In the field of behavioural change, there is a difference between what patients deem important and what physiotherapists think is necessary to improve their quality of life. Moreover, a discrepancy exists in the perception of physiotherapists. Whereas physiotherapists see themselves as facilitators in the treatment of COPD, patients consider physiotherapists as stimulators at most.

**Conclusion and key findings:** Self-management does not seem to play a role in the life of the COPD patient. To improve patients IDM, SDM and behavioural change, physiotherapists should use an integrated approach according to the knowledge and theory of behavioural change models and focus more on communication and adequate provision of information to improve self-management in COPD patients. The results of this study could help define a new strategy on how to incentivize the desired behaviour among COPD patients to improve self-management.

**Keywords:** COPD, self-management, physiotherapist

## Introduction

Worldwide, 174.5 million people cope with the physical burdens of Chronic Obstructive Pulmonary Disease (COPD). During the past 25 years the prevalence of COPD has increased by 44.2% and is expected to increase further in the future<sup>1</sup>. In 2017 the European Union (EU) Parliament made prevention for Chronic respiratory Diseases such as COPD a priority of the public health policy<sup>2</sup>. More generally speaking, the public health policies in the EU are brought more in line with other public service policies, by putting a greater emphasis on the individual<sup>3</sup>. This trend is continuing in the public health sector, resulting in people being held more responsible for taking control of one's own health<sup>4</sup>. In line with this, the Dutch National Health Care Institute, evaluated the physiotherapeutic treatment for COPD patients and made suggestions and recommendations to improve COPD care, based on accessibility and affordability<sup>5</sup>.

Due to a recommendation of this institute, changes were made regarding the financial compensation of physiotherapeutic treatment of COPD patients<sup>6</sup>. Since 2019, the number of reimbursed treatments became dependent on the burden of the disease instead of an unlimited number of reimbursements<sup>7</sup>. When accepting the new recommendations, the new scenario would provide patients with severe cases of COPD with limited visits for physiotherapy: seventy times in the first year and three times in the second year, given that their illness has not deteriorated<sup>7</sup>. If there is no worsening of the disease in the following year, the patient retains three treatments per year. In practice, this means that the responsibility for further prevention lies with the patients.

In order to meet the EU's public health policy and the resulting recommendation by the Dutch National Health Care institute, COPD patients will need to take control over a great deal of their treatment. However, COPD patients tend to be older, lower educated and have lower incomes than the general patient population<sup>8</sup>. Studies have shown that populations with these characteristics shows less proactiveness in behavioural change, a complex process for which behavioural change models such as Health Believe Model should be taken into account<sup>9,10</sup>. In addition, COPD patients take less control in healthcare<sup>10</sup>. Several studies have been conducted to understand the experienced barriers in behavioural change and self-management in COPD patients<sup>11-14</sup>. Amongst others, a low level of experienced burden, dealing with social problems, motivation, fear, physical impairments, psychological difficulties and the wish of not to be confronted with the disease, have been found as obstructions to successful self-management<sup>13,14</sup>. Despite the current knowledge about the perceived barriers in self-management, the perception of COPD patients on self-management after newly introduced reimbursements policy have not yet been investigated.

Gaining insight in the perception of COPD patients on self-management could prove to be a fruitful foundation for new strategies on how to incentivize the desired behaviour among COPD patients (and patients of diseases with similar population characteristics) in the EU. Moreover, it gives physiotherapists the opportunity to prepare themselves for a new role and a different approach in the treatment of COPD patients and this could also contribute to more efficient care for COPD. This leads to the following research question: What is the perception of COPD patients on self-management and what can physiotherapists do to facilitate self-management amongst COPD patients?

## **Methods**

This report was written according to the items of the Consolidated criteria for reporting qualitative research (COREQ)<sup>15</sup>.

### ***Study population***

A purposive sample of COPD patients and physiotherapists was used. Patients with COPD Global Initiative for Chronic Obstructive Lung Disease grades II-IV were included in this study<sup>16</sup>. Physiotherapists were included on the basis of experience in the treatment of COPD patients. Patients and physiotherapists had to live or work in a maximal radius of 15 kilometres from the community Midden-Groningen. Non-native Dutch speakers were excluded from participation.

### ***Procedure***

Patients and physiotherapist were recruited from physiotherapy centre 'Van Kasteel' in a period of two weeks during regular patients visits or during their regular working days. Participants were informed about the study by a poster and by the researcher, who is a physiotherapist working at 'Van Kasteel'. This initial contact took place face-to-face. If participants were interested they were checked for suitability and whether they could provide rich information on the subject. The participants that were compatible with both the inclusion and exclusion criteria and were willing to participate were asked to sign the informed consent form.

### ***Data collection***

Three focus groups interviews with patients and one with physiotherapists were conducted in February 2020. Patients were randomly assigned to the focus groups. The focus group method was considered appropriate because of group interaction and how this interaction affects perception<sup>17</sup>. The focus groups were led by a Clinical Health Science Master student (LMK), who is also involved in the treatment of the majority of these patients. All focus groups were conducted at physiotherapy centre 'Van Kasteel' and were tape-recorded and transcribed with permission of the participants. The focus group interview guide (addendum I) was tested in a group of chronically ill people without COPD, after which adjustments were made to improve the questions. The focus of the interview guide was on informed decision-making, shared decision-making and behavioural change. These factors are important for adequate self-management<sup>9,18,19</sup>.

All meetings followed the structure according to figure 1. Before the focus groups interviews, patients were asked to fill in the COPD Assessment Test(CAT) questionnaire and a form with socio-demographic questions about gender, age, educational level,

comorbidities, exacerbations, smoke status and amount of physiotherapy visits<sup>20</sup>. The CAT-questionnaire is a questionnaire assessing the impact of COPD on health status ranging from 0-40. A higher score corresponds to a higher disease burden. Physiotherapists only filled in their specialization in the field of physiotherapy and their experience as physiotherapist. An independent assistant moderator made field notes, encouraged participants to share perceptions and recorded and supervised the sessions<sup>21,22</sup>. The average duration of the patient focus groups was one-and-a-half hour while the physiotherapist group was interviewed for one hour and a quarter.

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1. Filling in questionnaires;
  2. Explaining ground rules and make participants feel at ease;
  3. Introduction on the concept of self-management;
  4. Starting question: 'Where are you currently looking for information related to your health?'
- 

**Figure 1** Flowchart protocol focus groups

Both focus groups, with patients and physiotherapists, were asked the same questions. In the patient groups the emphasis was mainly on the experience of patients with regard to self-management. In the group with physiotherapists, the focus was on the answers that the physiotherapists expected from patients. Data collection was continued until the saturation point was reached. Saturation was achieved when a focus group did not generate new themes<sup>23</sup>.

**Data-analysis**

After each focus group the collected data was transcribed verbatim in Microsoft Word by LMK. The data was analysed by LMK using ATLAS.ti<sup>24</sup>. After full analysis, the results were shared with an independent researcher (ELP) and the assistant moderator (WWV). To become familiar with the data, the researcher went through multiple steps. A constant comparison analysis strategy was used to analyse the data (figure 2)<sup>22</sup>.

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- |                     |                                                                             |
|---------------------|-----------------------------------------------------------------------------|
| 1. Open coding      | Initial codes identified; Field notes linked to the corresponding sections. |
| 2. Axial coding     | Initial codes reduced into categories.                                      |
| 3. Selective coding | Categories reduced into themes.                                             |
- 

**Figure 2** Flowchart constant comparison analysis

**Reliability**

A number of measures have been taken to enhance the reliability of this study<sup>25</sup>. To enhance credibility and confirmability of the data, reflexivity had a role throughout the research process and researcher triangulation was used. WWV was involved during the focus groups to reduce the risk of researcher bias<sup>26</sup>. The coding process and the analysis in the study were peer reviewed by ELP and WWV to break through blind spots of the



researcher. Furthermore, the focus group interviews were transcribed verbatim to reduce the chance for bias. Additionally, memos were taken during all phases of the study to reflect on the feelings of the researcher, to record the initial themes, to describe the context and striking features of the focus groups. In addition, intercoder agreement was reached between LMK, ELP and WWV in a consensus meeting<sup>27</sup>. To guarantee transferability, thick description is used. Thick description is applied by thoroughly describing the characteristics of the participants and the results<sup>25,26</sup>.

## Results

Nineteen patients and five physiotherapists were included in the study. The characteristics of the patient focus groups are shown in table 1. Of the COPD patients in the study the majority was female and the overall level of education in the population was low. In the physiotherapist focus group, four participants were female with an average age of 30 years and 7.1 years of working experience. The physiotherapists were specialized in geriatric physiotherapy, lymphedema therapy, health coaching or dry-needling treatment. All physiotherapists treated about the same number of COPD patients.

**Table 1** Characteristics patients per focus group

FG	Age	Gender	Smokers	Comorb	Exa <sup>a</sup>	Education <sup>b</sup>	PT visits last year	CAT-score
1	66.7	66.6% F	Current: 16.6% Former: 83.3%	1.5	2.2	50% low 50% med 0% high	0-20 0% 20-40 16.7% 40-60 33.3% 60-80 16.7% >80 33.3%	16.8
2	67.7	71.4% F	Current: 28.6% Former: 57.1% Never: 14.3%	1.7	1.9	42.9% low 42.9% med 14.3% high	0-20 28.6% 20-40 14.3% 40-60 14.3% 60-80 14.3% >80 28.6%	20.1
3	60.2	66.6% F	Current: 0% Former: 100%	1.2	1.5	33.3% low 50% med 16.7% high	0-20 0% 20-40 33.3% 40-60 33.3% 60-80 0% >80 33.3%	21.2
Total								
	65	68.4% F	Current 15.8% Former: 78.9% Never 5.3%	1.5	1.8	42.1% low 47.4% med 10,5% high	0-20 10.5% 20-40 21.1% 40-60 26.3% 60-80 10.5% >80 31.6%	19.4

CAT, COPD Assessment Test; Comorb, number of comorbidities per person; Exa, exacerbation; F, female; FG, focus group; med, medium; PT, physiotherapy.

<sup>a</sup> number of exacerbations last year;

<sup>b</sup> low = primary school, med = secondary school, high = college or university degree<sup>28</sup>

Themes emerging during analysis are discussed below in a successive order: patients' perceptions on the change in reimbursement, informed decision-making, shared decision-making, behavioural change, and the role of the physiotherapist.

### *Change in reimbursement of the treatment*

The change in the reimbursement structure did not lead to stimulation of self-management in these patients. Patients do not seem ready to change their behaviour and find change of behaviour difficult. Patients are therefore not likely to take initiative for self-management. Reimbursement will probably not be enough to encourage patients to self-manage their disease. Patients responded mostly with anger and disappointment when asking them about the changes(Q1). An important finding was that the majority of them wanted to stick to the current situation. They compensated the lost reimbursed treatments by better insuring themselves for physiotherapy or to take a gym subscription within the same physiotherapy practice(Q2-3). This finding was anticipated by the physiotherapists as it matched their expectation of the patients' answers(Q4). Another group of patients did not seem to be worried about the upcoming changes. Reasons that were provided were: they already received unlimited compensation due to comorbidity, the limited visits were sufficient, or people were already exercising independently prior to the change(Q5). Only two patients made the change to exercising more. These patients were no longer reimbursed for physiotherapeutic treatments and independently started looking for an alternative. In contrast, two patients said they would stop exercising and not to look for an alternative if the limited number of treatments would turn out to be insufficient(Q6).

**Table 2** Quotes change in reimbursement of the treatment

Quote	Theme	Participant ID (educational level, age) or (working experience in years)	
Q1	Change in reimbursement	1.6 (low, 72)	"Well, that means you are limited in your limitation."
Q2	Change reimbursement: maintaining current situation	1.3 (low, 65)	"I want to keep working out anyway. Whether it is reimbursed or not."
Q3	Change reimbursement: maintaining current situation	1.4 (med, 62)	"..and if I have to purchase a sports subscription myself, well, I will take it."
Q4	Change reimbursement: maintaining current situation	4.2 (11 years)	"I think they went to the doctor to get a referral for 50 or 70 times physical therapy. But I am afraid the rest has not changed much."
Q5	Change reimbursement: no change triggered	3.3 (low, 41)	"It does not apply to me. I have got that muscle disease. I can go five times a week if I want."
Q6	Change reimbursement: demotivation.	1.6 (low, 72)	"No, I am just going to get on with my life. If I am not allowed to come and train those other times, well then I do not and I will see what happens."

Med, medium; Q, quote.

### *Informed decision-making (IDM)*

Many participants do not actively seek for information. Two reasons emerged. Firstly, patients said to know enough about their illness and therefore have no need for more information, while others avoid the search for additional information through fear of what

they will read(Q7). Despite this, the responses of the patients revealed a need for information, but they did not take any action to collect this information(Q8). This corresponds to the experience of the physiotherapists. Patients do not actively ask for information from their physiotherapist, even though it appears that they do have a need for information(Q9). Physiotherapists recognize this and suspect this is because patients think it is part of the disease, they feel embarrassed or it is automatic behaviour.

**Table 3** Quotes informed decision-making

Quote	Theme	Participant ID (educational level, age) or (working experience in years)	
Q7	Info: fear	3.4 (med, 64)	"I am definitely not going to browse the Internet. No, I have looked at it once and when I see all that, it does not make me any better. I am just going to worry about it more and then you will only feel worse."
Q8	Info: barrier	2.3 (med, 75)	"Yeah, I got the problems mixed up. I never know why I am so tired, whether it is from the sugar, or whether it is because of my lungs."
Q9	Info: barrier	4.1 (8 years)	"One patient said: 'I am having trouble with this'. But did not ask any further. You can pick up on that and that is what I often do."

Info, information; med, medium; Q, quote.

#### *Shared decision-making(SDM)*

Almost all patients said to be in control of their own treatment choices, but responses show that only a few of them actually make decisions together with their health care professional(HCP). Many patients were critical of their prescribed treatment but did not seem to discuss this with the HCP(Q10). Patients said they did not want to interfere with the professional. For the minority of patients, patient and HCP jointly determine what treatment to follow(Q11). A few patients said they decided independently about their health(Q12). In two cases, the HCP decided on patient's treatment completely independently. (Q13).

Physiotherapists did not expect their patients to decide on a treatment in cooperation with HCP's(Q14). In line with this the majority of the physiotherapists stated that there is also no SDM in their treatment with this population. They discussed the content of the treatment with their patient, but this was actually always a one-way discussion. They notice that patients trust that the physiotherapist will know(Q15). The minority of the physiotherapists said that they consulted with their patients about the content of the treatment(Q16).

**Table 4** Quotes shared decision-making

Quote	Theme	Participant ID (educational level, age) or (working experience in years)	
Q10	SDM: critical	1.1 (med, 67)	"Then I said to him, I am terribly distressed. But then I get prednisone right away and I say, is that normal? Yes he says, you really need it."
Q11	SDM	2.2 (med, 68)	"No, but I can discuss things with the pulmonologist. If I have any questions, I call the nurse. And I can discuss that very well with her. Look, that is how I do it myself. I come up with proposals and ideas. With the pulmonologist, with the nurse as well as with the dietician."
Q12	SDM	3.1 (med, 55)	"I always have a course of antibiotics in the house and if I need a new one I just order one and I do not go to a doctor for it. I can feel that myself."
Q13	SDM: HCP determines	1.2 (low, 61)	"The antibiotics will make me sick, but he says you just need it. Well then, I will take it."
Q14	SDM	4.2 (11 years)	"Yeah, I think most of the long-term clients in particular, they have said no, I am the one who decides."
Q15	SDM: HCP determines	4.2 (2 years)	"They just think that is protocol, it is been proven, so let's do it."
Q16	SDM	4.4 (12 years)	"The goal is always important. What do they want and what are their ideas? So what do you think we should do? And then see if the goal you have in mind matches what the patient wants. And then you get back together to decide if the patient likes the therapy."

HCP, healthcare provider; med, medium; Q, quote.

### *Behavioural change*

When asked about what behaviour they would like to change in order to improve their quality of life, patients responded that they were mainly interested in learning to cope with COPD rather than changing behaviour. Consequently, acceptance of their disease was the most common statement. Acceptance could be subdivided into adjusting pace and handing over things to others. In focus group one it was specifically described as handing over(Q17), while adjusting pace was addressed in all groups(Q18). Eating healthy and maintaining a healthy weight also emerged as changeable behaviour in all focus groups. Only one patient mentioned exercising more(Q19). Contrary to the patients' answers, the physiotherapists expected primarily that patients would want to change behaviour in terms of activities such as exercising and doing more fun things. They expected behaviours such as illness acceptance and learning about boundaries would be mentioned less by the patients.

Patients explained several facilitators to behavioural change. Social support was the most frequently mentioned facilitator. Especially partners and children are important for mental support, stimulation to be active, help with illness acceptance or to take things out of the patients' hands(Q20). Being able to share their story with fellow patients, knowing you are not the only one and sharing tips is also important. In addition, feeling good after achieving a goal or doing an activity is frequently stated as facilitator to stay physically active(Q21). Another facilitator for behavioural change is positive thinking. Patients

indicated that they find this difficult, but when they succeed it helps them to show desired behaviour and to look at what you can do instead of what you cannot(Q22). Finally, patients reported that ultimately, intrinsic motivation makes it possible to change behaviour.

The most commonly stated barrier in trying to change the mentioned behaviour are the symptoms associated with COPD. Patients experience a vicious cycle in which the symptoms associated with COPD, mainly dyspnoea, limits them to become physically more active(Q23). They felt that activities of daily living are already enough of a burden. Another barrier is the lack of knowledge about what they can and cannot do(Q24). Finally, the patients indicated that their limited financial resources are hampering them. Other less frequently mentioned barriers are lack of internal motivation and the continual relapse after exacerbations.

**Table 5** Quotes behavioural change

Quote	Theme	Participant ID (educational level, age) or (working experience in years)	
Q17	Behavioural change: handing over	1.2 (low, 61)	"I have a housekeeper now. One hour a week. I am only 60 and I need a housekeeper because I cannot do it by myself."
Q18	Behavioural change: adjusting pace	3.3 (low, 41)	"I just need to move more slowly. I am someone who does everything in fourth gear. Now I have to shift down to first or second gear.'
Q19	Behavioural change: stay active	2.6 (high, 72)	"I mean moving slowly all day long. You do not have to run a marathon, but you do have to keep moving."
Q20	Facilitator: social support	2.3 (med, 75)	"What important to me is my situation at home, how me and my partner sort things out. What I cannot do he does, and what he cannot do I do. And together you will get on like this."
Q21	Facilitator: feeling good after an activity	2.6 (high, 72)	"The reason I do that is because it makes me feel much better. I keep doing that because I want to, I do not want to go back."
Q22	Facilitator: positive thinking	2.2 (med, 68)	"Well at a certain point I became quite depressed. I have a disabled child, and then I said to myself. I say to my child: you can still look at the trees, the flowers ect. Look at what you can do. And there's a button turned so that what I teach her counts for me as well. That's how I started to think positive at a certain point."
Q23	Barrier: symptoms of COPD	3.2 (high, 60)	"This chronic fatigue, apparently related to COPD, is a hard thing for me to get over. This is a barrier for me to do extra things like taking an extra walk."
Q24	Barrier: fear	1.6 (low, 72)	"I am alone so something could happen to me. I could collapse or I could hyperventilate because of the COPD."

COPD, chronic obstructive pulmonary disease; med, medium; Q, quote.

### *Role physiotherapist*

The most common response was that the physiotherapist had a stimulating role to tell them what to do(Q25). According to patients it is especially important to have a helping hand, someone who knows what is good for them and helps them define their boundaries. Patients also stated a need for confidence and assurance(Q26). Other less reported roles for physiotherapists according to the patients are providing information and being a point of contact(Q27). In focus group three, patients stated that there is no role for the physiotherapist in self-management(Q28). They said that people have to do this themselves and the physiotherapist has no effect on that. Within this group, the majority did not have to make any adjustment as a result of the change in reimbursement. Four of them still have enough reimbursements and two of them already had a gym subscription before the change took effect.

Physiotherapists expected patients to see them as an external motivator. Information provision is the main role in self-management they attribute to themselves. In addition, by means of motivational interviewing, they expect to give patients insight into their own motivation and awareness of one's own abilities. By mid-term evaluation physiotherapist expected to facilitate patients in showing desired behaviour and self-management(Q29). The physiotherapists also indicated that they see themselves act case managers in the care of the COPD patients. This because they notice that their patients feel more comfortable with them in comparison to other HCP(Q30).

**Table 6** Quotes role physiotherapist

Quote	Theme	Participant ID (educational level, age) or (working experience in years)	
Q25	Role PT: stimulation	1.4 (med, 62)	"If I did not go here now and I would agree to walk for an hour every day. Well the first couple of days I would, but the third day it rains. Well, never mind. I will go a quarter of an hour longer tomorrow."
Q26	Role PT: confidence	1.2 (low, 61)	"If I know what I need to do, it takes away some of the uncertainty."
Q27	Role PT: contact	2.6 (high, 72)	"How do you feel? What is the problem? But also the patient has to indicate what the problems are. So it is a mutual dialogue. How can I help you and what are your problems? Only when you understand those problems as a physiotherapist you can help."
Q28	Role PT: no role	3.2 (high, 60)	"I do not think a physiotherapist has much of a role to play."
Q29	Role PT: facilitator	4.4 (12 years)	"I think we should use mid-term evaluations. So they see that they have made an improvement. That is encouraging. Than they can see for themselves that they do not deteriorate in health when they keep exercising."
Q30	Role PT: case manager	4.3 (2 years)	"So they tell quite a lot of things pretty soon. Some patients you see once or twice a week. They do not see other care providers that often."

Med, medium; PT, physiotherapist; Q, quote.

## Discussion

### *Main findings*

In this study the perception of COPD patients on self-management after newly introduced reimbursement policy and what physiotherapists can do to facilitate this was explored. The findings of this study show that self-management hardly plays a role in the lives of the studied patients. In the areas of IDM, SDM and behavioural change there are shortcomings. Patients do not seem to be able to change their behaviour and are therefore not likely to take initiative for self-management. IDM is complicated by the fact that patients do not actively search for information, despite the fact that they seem to have a need for information. In addition, patients are lacking in SDM. Only a few of them make decisions together with HCP. This is confirmed by the physiotherapists who indicate that there is no SDM in their treatment with this population. When it comes to behavioural change, there is a discrepancy between what patients deem important and what physiotherapists think is necessary to improve their quality of life. In addition, patients and physiotherapists differ in opinion about the role of the physiotherapist in self-management.

### *Findings compared with existing literature*

The results of this study show that problems arise in the field IDM, because patients do not go looking for information despite a need for information. The two reasons mentioned in this study correspond to the findings of Hillebregt et al.(2016): wishing not to be confronted with COPD and a low level of experienced burden of the disease<sup>13</sup>. Joseph et al.(2013) conducted a systematic review on SDM and they found patient characteristics such as poor health, low level of education, having a chronic disorder and patients having no desire to be involved as important barriers to SDM<sup>29</sup>. The limited SDM in this study population and the differences within the focus groups can be explained by these barriers. The overall level of education in the studied population was low compared to the general population<sup>30</sup> and the studied patients who use more SDM are on average higher educated and are healthier. In addition, the patients in this study seem to like being told what to do. This corresponds to the role they assign to the physiotherapist, which is mainly stimulating. The difficulties these patients experience regarding behavioural change can be explained using the The Health Believe Model (HBM). According to the HBM a number of factors are necessary to bring about a change in behaviour: perceived severity, perceived benefits, perceived barriers and self-efficacy<sup>9</sup>. Findings from this study suggest that all these factors appear low in this COPD population and therefore behavioural change is not likely to occur. Firstly, the perceived severity is low. There seems to be a difference between what patients consider to be important changeable behaviours for the highest possible quality of life and what the current evidence supports. Patients seem to be primarily interested in



being able to accept living with COPD better, while physiotherapists believe that optimizing exercise capacity ensures an optimal quality of life<sup>31</sup>. Additionally, the perceived benefits and barriers are low. For many patients within this study, it seems there is little reason to compensate the lost number of physiotherapeutic treatments. The two patients who were able to do this had a below-average disease burden and had not experienced exacerbation in the past year. For the others it appears that the advantages of keeping active are not perceived large enough to compensate for the disadvantages of losing the physical therapist's stimulus. The barriers found in this study then seem to make the patients incapable to overcome these and therefore being unable to act which hampers self-efficacy.

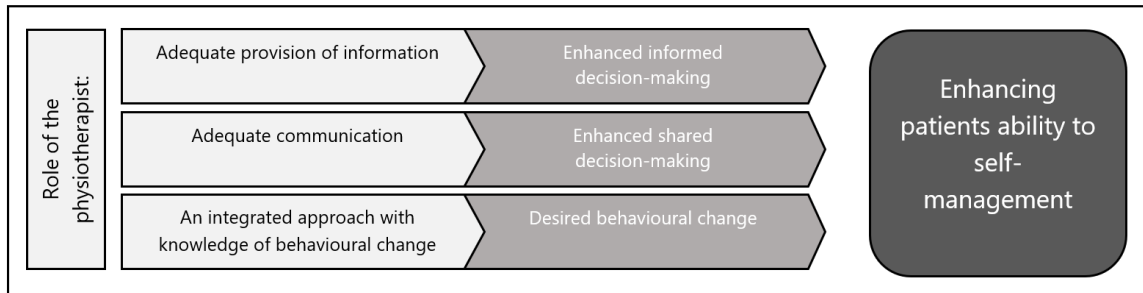
### *Strengths and limitations*

A strength of this study is the focus on perspectives of both patients and the physiotherapists. Mirroring the differences in perspectives of the patients with that of the physiotherapists provides insight into the extent to which the current physiotherapeutic policy fits the needs of the patient. In addition, qualitative research offers the opportunity to describe motivations in depth and detail by asking about underlying mechanisms. A limitation of this study is the chance of researcher bias. The researcher is involved in the treatment of the majority of the patients, which could jeopardise the objectivity of the researcher or there is a risk that participants will give socially desirable answers. However, the researcher has a relationship of trust with the participants which makes the participants more likely to share and therefore provide more useful information<sup>26</sup>. Additionally, the recruitment from one physiotherapy practice with regard to patients and physiotherapists limited the generalizability of this study. Although, they reflect on a general COPD population and other populations with chronic illnesses with regard to educational level and age, which contribute to the transferability of the study<sup>32</sup>.

### *Implications for the physiotherapeutic treatment*

The results of this study could help define a new strategy on how to incentivize the desired behaviour among COPD patients. Stimulation to self-management seems to require more than a change in reimbursement for these patients and because of the change in reimbursement, the role of the physiotherapist will change. Physiotherapists need to be aware of the fact that role expectations are formed on the basis of experiences that individuals have with interaction with others<sup>33</sup>. They need to adjust the approach of the interaction so that the patient's role expectation about the physiotherapist changes. Through adequate information provision, adequate communication and an integrated approach with knowledge of behavioural change, the physiotherapist can play a role in

improving IDM, SDM and behavioural change to enhance patients ability to self-management(figure 3)<sup>9,18,19</sup>.



**Figure 3** Schematic representation of the important results and clinical implications

Using an integrated approach, physiotherapist should focus on all aspects of the HBM in order to stimulate behavioural change. The physiotherapists in this study focus mainly on finding the intrinsic motivation of the patient through information and communication. However, behavioural change is more complex than that. They have to adapt their treatment to affect patients perceived severity, benefits, barriers, and self-efficacy. Especially the most important barrier in these patients, the vicious cycle of breathlessness<sup>34</sup>, should be broken to entice behavioural change. The facilitators found in this study should also be included in the treatment.

#### *Implications for further research*

For future research it is relevant to reconfirm the findings of this study in the future, because many patients have had little reason to change behaviour as result of the change in reimbursement. The expectation is that more patients will have to make adjustments in their behaviour to enhance self-management in the coming years. Additionally, future research should focus on the implementation and effect of the new physiotherapeutic approach on behavioural change and self-management.

## **Conclusion**

Despite the change in physiotherapeutic reimbursements, self-management does not seem to play a role in the life of the COPD patient. Patients do not appear to make the link between the change in reimbursement and what is expected from them. Also, the perceptions and visions of patients and physiotherapists do not always match. To improve patients IDM, SDM and behavioural change, physiotherapists should use a more integrated approach according to the knowledge and theory of behavioural change and focus more on communication and adequate provision of information to enhance self-management in COPD patients.

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## Addendum I Focus group interview guides

Informed decision-making	Welcome Explaining ground rules Introduction on self-management 1) Where are you currently looking for information related to your health to have the best possible quality of life? 2) Can you find the information you need?
Behavioural change	3) Do you find its it difficult sometimes to find the right information? 4) What behaviour could you change to maintain the best possible quality of life? 5) How do you manage to change this behaviour?
Shared decision-making	6) Why is it difficult to change behaviour? What are barriers? 7) To what extent do you and your healthcare provider determine the policy that best suits you?
Cause	8) Did the arrival of the reimbursement change, in which self-management takes a larger role, stimulate and motivate you to self-management?
Role physiotherapist	9) How can a physiotherapist help you with self-management?

**Figure 4** Patient focus group guide

Informed decision-making	Welcome Explaining ground rules Introduction on self-management What do you think patients answered on the following two questions? 1) Where are you currently looking for information related to your health to have the best possible quality of life? 2) Are you able to find the information you need? 3) What information should we provide as a physiotherapist?
Behavioural change	What do you think patients answered on the following questions? 4) What behaviour could you change to maintain the best possible quality of life? 5) How do you manage to change this behaviour? 6) Why is it difficult to change behaviour? What are barriers? 7) What do we have to do as a physiotherapist in regard to this?
Shared decision-making	8) To what extent do you and your healthcare provider determine the policy that best suits you? 9) To what extent do you yourselves make joint decisions with patients?
Cause	What do you think patients answered on the following question? 10) Did the reimbursement change, in which self-management takes a larger role, stimulate and motivate you to self-management?
Role physiotherapist	What do you think patients answered on the following question? 11) How can a physiotherapist help you with self-management? 12) As a physiotherapist, how can you contribute to self-management? 13) Does self-management play a role in your treatment at all?

**Figure 5** Physiotherapist focus group guide