# Determinants of self-management capacity of patients with Chronic Obstructive Pulmonary Disease: A cross sectional study.

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#### INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is 'a preventable and treatable disease, characterized by airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases' (1). COPD is one of the most common chronic diseases worldwide and the fourth leading cause of mortality (1-4). Globally, the prevalence of patients with COPD was estimated to be 64 million in 2004 and is expected to increase in further decades due to continued exposure to risk factors and aging of the population (1,4,5). This will lead to increased healthcare costs. COPD is already considered to be a significant economic burden since COPD accounts for 56% of the estimated total costs of respiratory diseases, which amounts to 6% of the total healthcare budget in the European Union (1).

Key COPD symptoms are chronic dyspnea, sputum production and cough (1,6). The natural course of COPD is interrupted by exacerbations characterized by a sustained worsening of patient's baseline symptoms, which are beyond normal day-to-day variability, and may warrant medical treatment (3,7). These exacerbations have a serious negative impact on quality of life (8,9), are associated with accelerated lung function decline and increased mortality (10,11). Additionally they represent a significant economic burden due to healthcare utilization (1). Current evidence shows that COPD patients can actively influence the course of their disease (2,12). Self-management can help patients to manage their symptoms, prevent complications and to make adequate decisions on medication, exercise, breathing techniques, diet and contacting healthcare providers (2,12,13).

Self-management is one of the four essential components of the Chronic Care Model, which supports activation of patients to improve self-management (13-15). Self-management is defined as 'an individual's ability to detect and manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition' (15). The pivotal objective is to change behaviour (12), which is essential to boot up a sequence of effects on disease outcomes, quality of life and healthcare costs (16,17). Health care professionals have a major role in self-management support (2,18,19). Recent literature reviews show that self-management interventions have positive outcomes for COPD patients, like a reduction of hospital admissions and improved health status (17,20).

Although self-management interventions are nowadays commonly provided (21), a substantial proportion of COPD patients does not respond or comply with these interventions (2,17,18,22). The large variance in effectiveness between patients presumes that it is unlikely that one intervention fits all patients (18,22). Little is known about determinants associated with self-management capacity (2,18). This knowledge gap hampers identifying patients who are capable of self-management and patients who encounter difficulties in performing adequate self-

management. An initial assessment on facilitators and barriers of self-management capacity may help health care professionals to tailor intensity and content of self-management interventions. If determinants which are negatively associated with self-management capacity are identified, the intensity of self-management support should be increased to maximize its effectiveness (18). Based on a systematic review it is assumed that self-management capacity is related to patient characteristics like illness perception, dyspnea, depression, anxiety, socioeconomic status and social support (2). Additionally there are assumptions about associations with age, gender, education, disease severity, disease duration, comorbidities, health status and smoking (23-28). Based on clinical experience, body weight and exacerbations are also expected to be associated with self-management capacity.

# PROBLEM STATEMENT, AIM AND RESEARCH QUESTIONS

There is a lack of knowledge about determinants associated with self-management capacity. Previous studies have shown associations with several determinants, but these determinants together have not yet been examined in relation with self-management capacity. This may help to explain a substantial part of the variance in self-management capacity of COPD patients.

This study is a part of the TASTE-program which aims at 'systematically filling the knowledge gap in order to develop tailored interventions based on individual patient profiles and preferences of chronic disease patients' (22). This study aims at identifying key determinants of varying self-management capacity of patients with COPD. Understanding these determinants enables identifying patients at risk of inadequate engagement in self-management, which is essential to target and tailor individualized self-management interventions. In this way efficiency and cost-effectiveness of self-management interventions can be improved.

The primary research question was: Which combination of determinants is associated with self-management capacity of patients with COPD? Secondary research questions were: What is the prevalence of different levels of self-management capacity among patients with COPD? And which determinants are associated with a high risk of poor self-management capacity?

### **METHOD**

## Study design

A prospective, explorative study was performed with a cross-sectional research design. The study was conducted in one secondary and two primary care settings in the Netherlands from January 2013 until June 2013. The study has been approved by the Medical Research Ethics Committee of the University Medical Centre of Utrecht, The Netherlands. All included patients have provided written informed consent (IC).

## Study population and recruitment

A convenience sample of patients diagnosed with mild to very severe COPD was selected by the attending physician according to the following inclusion criteria: a clinical diagnosis of COPD and age above 40 years. In secondary care patients should have visited the outpatient clinic in the past six months to reduce the risk of approaching patients who are deceased or no longer under treatment. Exclusion criteria were a diagnosis of lung cancer, cognitive impairments (e.g. dementia or Alzheimer's), language or communication problems and a life expectancy of less than three months.

The sample size was calculated to allow sufficient power for a multiple linear regression analysis using fifteen variables. According to the ratio number of predictor variables to number of participants 1:10 (29,30) a sample size of at least 150 participants was required.

Patients were selected from January 2013 until April 2013 by chart review according to the inand exclusion criteria. Patients received an invitation letter from their attending physician to participate in this study. Attached, patients received a letter with study information, an IC-form, a questionnaire and a pre-addressed return envelope. To enhance recruitment rates patients received a reminder after three weeks if the IC-form was not returned. By signing the IC-form patients gave consent to consult their chart to obtain additional information.

### Data collection

The data on the main study parameter self-management capacity and on the independent determinants were collected by means of administering a questionnaire and chart review. The questionnaire was a composition of Dutch validated questionnaires and a set of questions to determine socio-demographic characteristics.

Self-management capacity was measured by the Patient Activation Measure (PAM-13) (31,32), a 13-item instrument that assesses self-reported knowledge, skills and confidence for self-management (31,33,34). Items can be scored on a five-point scale. The sum of these scores can be converted in a 0-100 point scale. Higher activation scores are positively associated with self-management behaviour (34). Based on cut-off points a person can be divided in four levels of activation (31,32) (Appendix). The PAM-13 is translated in Dutch and validated for COPD patients (34). Internal consistency was good. Item-rest correlations were moderate to strong and test-retest reliability was moderate (34).

The following determinants were selected based on findings of previous research. Health status was measured by the Short Form-12 Health Survey (SF-12), a short version of the Short Form-36 (SF-36) (35,36). The 12-item SF-12 measures physical and mental health (37). Item scores are summed and transformed to a 0-100 point scale. Higher scores are related to a better health

status. The SF-36 is validated in a Dutch chronic disease population and proven both valid and reliable (36). Results showed almost complete overlap between the SF-12 and SF-36 (37).

Presence of anxiety or depression was measured by the Hospital Anxiety and Depression Scale (HADS) (38,39). The HADS includes two 7-item subscales (anxiety and depression) both with a score range of 0-21 (39). Higher rating indicates a higher state of anxiety or depression, with cut-off points above 8 indicating a depression or anxiety disorder. The HADS is validated in different groups of Dutch patients. Internal consistency and test-retest reliability of the subscales and the total scale were good (39).

The Brief Illness Perception Questionnaire (B-IPQ) was used to measure illness perception (40). The B-IPQ consists of eight items that can be scored on a scale from 1-10. Higher scores indicate a more negative illness-perception. Assessment of reproducibility was performed with Dutch COPD patients. Face and content validity were acceptable. Reproducibility showed moderate to good reliability (40).

Social support was measured by the 12-item Multidimensional Scale of Perceived Social Support (MSPSS) (41). Items can be scored on a 7-point scale. Higher scores indicate higher perceived support (42,43). Validity and reliability were confirmed by Dutch cardiac patients and their partners. Internal consistency was good (41).

Socio-demographic characteristics included age, gender, body mass index (BMI), ethnicity, living situation, educational level, financial situation, working status, smoking habits and current exacerbations. Operationalization of these determinants is shown in Table 1.

Chart review was conducted to determine disease severity, COPD duration and comorbidities. Severity of COPD was classified into four GOLD stages (1), which were determined using FEV1/FVC and FEV1% predicted data. When these data were missing GOLD stage as reported by the physician was used. To complement FEV1% predicted in the classification of COPD severity, dyspnea was measured by the five-point Medical Research Council (MRC) scale. This is a valid instrument to categorize COPD patients in terms of their disability. A higher score indicates a higher degree of perceived breathlessness (44). COPD duration was determined by number of years since diagnosis. Furthermore comorbidities were assessed by number of comorbidities besides COPD.

## Data analysis

Statistical analysis was performed using SPSS 21.0 (45). Descriptive statistics were used to describe baseline characteristics. Means and standard deviations were used to describe continuous variables whereas frequencies and percentages were used for categorical variables. Univariate linear regression analysis was used to analyse the association between single determinants and self-management capacity. First assumptions of linearity, normal distribution and homoscedasticity were checked.

A backward multiple linear regression analysis was performed in order to identify the explanatory variables, comparing the relative influence of each determinant on self-management capacity, rather than as a predictive model. First bivariate correlations were generated to detect multicollinearity problems (R>0.8). Variables were included in the initial model when they showed a univariate association with self-management capacity at a 20% significance level (46). Dummy variables were entered in blocks. Then variables were excluded in order of the highest P-value when significance was above 0.1, resulting in a model that includes the explanatory variables.

Furthermore a univariate logistic regression analysis was performed to explore determinants associated with poor self-management capacity. Therefore self-management capacity was dichotomised distinguishing poor self-managers (first level PAM-13) from other participants.

Missing data were handled according to instructions of the questionnaires. An available case analysis was performed since only 2.6% of the values was missing (47). Cases were excluded listwise.

# **RESULTS**

In total 607 eligible COPD patients were invited in this study, of which 315 patients (51.9%) agreed to participate. The response rate was higher in secondary care compared to primary care (63.3% versus 47.6%). A total of 36 patients were excluded during the process of recruitment. In total 296 participants were eligible for analysis (Figure 1).

#### Figure 1

Participants had a mean age of 67.3 and male/female ratio was 62.7/37.3. The majority of participants were natives (93.5%), married (65.9%), not working (82.8%) and not smoking (68.6%). The average participant had a moderate health status, moderate illness perception, moderate perceived social support and no presence of a depression or anxiety disorder.

Most participants had a moderate COPD severity since mean FEV1% predicted was 63.5 (GOLD stage two). A minority of 35.7% of the participants had a MRC score equal to three or higher. Only 58.4% of the population was aware of their COPD duration. Comorbidities were common since 69.6% was diagnosed with one or more comorbidities.

Differences were observed between participants recruited from primary and secondary care. In secondary care the proportion of male participants was larger and the mean age was higher. The average participant was higher educated, was smoking less, had a lower health status, a more negative illness perception and more severe COPD (Table 1).

# Table 1

### Prevalence of different levels of self-management capacity

The prevalence of different levels of self-management capacity among the study population was almost equally spread in level two and three. Poor self-management capacity (level one) was observed by 22.9% of the participants. A minority of 14.6% of the participants scored on level four (Figure 2).

# Figure 2

## Determinants associated with self-management capacity

The association between single determinants and self-management capacity is presented in Table 2. Health status, anxiety, depression, illness perception, BMI, educational level, current working and dyspnea were significantly associated with self-management capacity (P<0.05). A multiple linear regression analysis revealed four explanatory determinants of self-management capacity: illness perception, depression, BMI and age (Table 2). A more negative illness perception, increased level of depression, increased BMI and increased age were associated with a decrease in self-management capacity (P<0.1). R squared was equal to 0.143. High correlations were observed between anxiety and depression (R=0.7), B-IPQ, anxiety, depression and SF-12 (R=0.6) and B-IPQ and depression (R=0.6).

# Table 2

#### Determinants associated with poor self-management capacity

Univariate associations between determinants and poor self-management capacity are presented in Table 3. Increased odd of poor self-management capacity was significantly related to a decrease in health status, social support and educational level (P<0.05). A positive association was found with anxiety, depression, BMI, illness perception and financial situation (P<0.05). Identifying explanatory variables of poor self-management capacity by a multiple logistic regression analysis was not allowed based on study sample size (48).

#### Table 3

#### DISCUSSION

This study has examined the association of multiple determinants and self-management capacity of COPD patients. The main finding was that illness perception, depression, BMI and age were key determinants of varying self-management capacity. It is important to note that anxiety and health status were highly correlated with respectively depression and illness perception and therefore may also be important explanatory determinants. Furthermore this study has provided insight in the prevalence of different levels of self-management capacity among COPD patients and made a first step in exploring determinants associated with poor self-management capacity.

Self-management capacity of the study population, represented by the mean activation score, was lower compared to previous studies (32,34). In this study only a minority of participants had adopted new behaviours towards self-management (level four). Slightly more than half of the participants scored on level two and three and nearly a quarter was considered to be a poor self-manager (level one). However, a previous study showed that most patients scored on level three and four (34). This contrast may be explained by the fact that those results were based on patients with different chronic diseases and that the mean age of patients was lower compared to this study (58.7 years versus 67.3). Furthermore, depression might be more common for COPD patients than for patients with other chronic diseases (2,26,49), and may have negatively affected the level of self-management capacity.

Based on a systematic review dyspnea, anxiety, depression, social support, illness perception and socio-economic status were expected to be associated with varying self-management capacity (2). This study partly confirmed this expectation. Financial situation was not related to varying self-management capacity, which may be due to different measurements of socio-economic status. Moreover, no association was found with social support.

Univariate associations with education level, health status, dyspnea, anxiety and working status are in accordance with previous studies (23,25-28). In contrast, no univariate associations were found with gender, age, disease severity (GOLD-stage), comorbidities, ethnicity, living situation and current smoking (23-25,27,28). Striking was that age emerged as a key determinant of self-management capacity while no significant univariate association was found (P<0.05). Furthermore BMI was a key determinant while this was not expected based on previous studies. Unfortunately COPD duration appeared to be inconsistently registered in charts and many self-reported data of duration were missing. Since the origin of COPD was difficult to determine this variable was omitted.

The identified key determinants of varying self-management capacity could only explain the variance to a limited extent. The explained variance was only 14%, which is lower compared to previous studies on explanatory variables of self-management (31 - 35%) (25,27). This may be

explained by other types of determinants influencing self-management capacity, for example selfefficacy or received care from health care professionals.

In contrast to determinants associated with varying self-management capacity, social support and financial situation were associated with a high risk of poor self-management capacity and no associations were found with age, current working and dyspnea. Although many similarities were observed, this implies that other determinants may be relevant for patients with a high risk of poor self-management capacity.

Important strengths of this study are the fact that many different variables were included and that the response rate was higher than the expected rate of 40% (28,50). Furthermore validated questionnaires were used, which contributes to the study's internal validity.

A limitation of this study was that patients were not selected based on a primary diagnosis of COPD. Patients were not excluded based on comorbidities so that patients enrolled with another primary disease and mild COPD. Although participants were explicitly instructed to fill in the questionnaire based on managing COPD, presence of other diseases may have biased the results of self-management capacity.

Another limitation arises as patients were recruited by different physicians in different settings, which may have resulted in selection bias. Physicians considered a few patients eligible while lung function data were missing, probably due to recruiting patients from primary care who were treated for their COPD in secondary care, or when the data did not exactly meet the criteria for diagnosis. Those participants were included in the analysis when a diagnosis of COPD was explicitly listed in the chart and patients received active treatment for their COPD.

Furthermore internal validity may be negatively affected since the results were not corrected for exposure to self-management interventions prior to this study. Finally, assessment of disease severity was not based on the recently updated GOLD guidelines, which may reflect complexity of COPD in a better way (51).

The large study population contributes to the external validity of the study. Including patients from both primary and secondary care had a positive impact on the generalizability of the results since this maximizes variation in COPD severity. However, the difference in response rates between settings may have biased the results. For example, the proportion of male participants (62.7%) seemed over-represented in the study population since 73.8% of the participants in secondary care were male (31).

Although response rates were relatively high, still a non-response of 48% was observed. Based on data of the Dutch population a larger proportion of immigrants was expected in the study population (52). In addition, a higher degree of dyspnea was expected (31). Unfortunately the

unknown baseline characteristics of the non-responders makes it difficult to draw conclusions regarding the effect of non-response to representativeness of the study population.

The knowledge on key determinants of self-management capacity is important for all health care professionals supporting COPD patients in self-management, as it allows them to make a risk assessment of inadequate engagement in self-management based on an individual patient profile. Based on the study results more special attention should be paid to relatively older patients, with a relatively high weight, a more negative illness perception and a relatively high state of depression. For these patients intensifying self-management support seems important to increase the likelihood of improvement in self-management capacity. With respect to poor self-management capacity it also seems important to have attention for patients with poor social support and a poor financial situation. This knowledge may help health care professionals to make a first step in targeting and tailoring self-management interventions.

#### CONCLUSION

This study identified illness perception, depression, BMI and age as key determinants of varying self-management capacity of patients with COPD. This knowledge contributes to identification of patients at risk of inadequate engagement in self-management, which is essential to target and tailor individualized self-management interventions. It is likely that different determinants are relevant for poor self-management capacity compared to determinants associated with varying self-management capacity. This study showed that only a minority of COPD patients is capable of self-management, which implies that there is a large potential for improvements in self-management capacity and subsequently in health outcomes.

## **RECOMMENDATIONS**

More knowledge is needed on barriers and facilitators of self-management capacity of COPD patients. Future research should focus on identifying causal relationships between determinants and self-management capacity. A longitudinal study is required to determine key determinants of change in self-management capacity. This knowledge is essential to eliminate barriers of self-management capacity and will contribute to targeting and tailoring of self-management interventions based on individual patient profiles. Thereby it is recommended to investigate associations with other determinants than patient characteristics and self-management capacity. Finally, for future development of self-management interventions it is important to identify whether determinants of self-management capacity are generic or disease specific.

#### REFERENCE LIST

- (1) Global Initiative for Chronic Obstructive Lung Disease (GOLD). Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. Update. Available at: <a href="http://www.goldcopd.org/uploads/users/files/GOLD\_Report\_2011\_Feb21.pdf">http://www.goldcopd.org/uploads/users/files/GOLD\_Report\_2011\_Feb21.pdf</a>. Accessed 08/25, 2012.
- (2) Disler RT, Gallagher RD, Davidson PM. Factors influencing self-management in chronic obstructive pulmonary disease: an integrative review. Int J Nurs Stud 2012; 49(2):230-242.
- (3) Bourbeau J. Self-management interventions to improve outcomes in patients suffering from COPD. Expert Rev Pharmacoecon Outcomes Res 2004; 4(1):71-77.
- (4) World Health Organisation. The global burden of disease. Update 2004. Available at: <a href="http://www.who.int/healthinfo/global\_burden\_disease/GBD\_report\_2004update\_full.pdf">http://www.who.int/healthinfo/global\_burden\_disease/GBD\_report\_2004update\_full.pdf</a>. Accessed 09/04, 2012.
- (5) World Health Organisation. Causes of COPD. Available at: <a href="http://www.who.int/respiratory/copd/causes/en/index.html">http://www.who.int/respiratory/copd/causes/en/index.html</a>. Accessed 09/04, 2012.
- (6) World Health Organisation. Diagnoses of COPD. Available at: <a href="http://www.who.int/respiratory/copd/diagnosis/en/index.html">http://www.who.int/respiratory/copd/diagnosis/en/index.html</a>. Accessed 09/05, 2012.
- (7) Burge S, Wedzicha JA. COPD exacerbations: definitions and classifications. Eur Respir J Suppl 2003; 41:46s-53s.
- (8) Miravitlles M, Ferrer M, Pont A, Zalacain R, Alvarez-Sala JL, Masa F, et al. Effect of exacerbations on quality of life in patients with chronic obstructive pulmonary disease: a 2 year follow up study. Thorax 2004; 59(5):387-395.
- (9) Seemungal TA, Donaldson GC, Paul EA, Bestall JC, Jeffries DJ, Wedzicha JA. Effect of exacerbation on quality of life in patients with chronic obstructive pulmonary disease. Am J Respir Crit Care Med 1998; 157(5 Pt 1):1418-1422.
- (10) Soler-Cataluna JJ, Martinez-Garcia MA, Roman Sanchez P, Salcedo E, Navarro M, Ochando R. Severe acute exacerbations and mortality in patients with chronic obstructive pulmonary disease. Thorax 2005; 60(11):925-931.

- (11) Donaldson GC, Seemungal TA, Bhowmik A, Wedzicha JA. Relationship between exacerbation frequency and lung function decline in chronic obstructive pulmonary disease. Thorax 2002; 57(10):847-852.
- (12) Bourbeau J, van der Palen J. Promoting effective self-management programmes to improve COPD. Eur Respir J 2009; 33(3):461-463.
- (13) Bourbeau J, Nault D. Self-management strategies in chronic obstructive pulmonary disease. Clin Chest Med 2007; 28(3):617-28, vii.
- (14) Bodenheimer T. Helping patients improve their health-related behaviors: what system changes do we need? Dis Manag 2005; 8(5):319-330.
- (15) Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns 2002; 48(2):177-187.
- (16) Adams SG, Smith PK, Allan PF, Anzueto A, Pugh JA, Cornell JE. Systematic review of the chronic care model in chronic obstructive pulmonary disease prevention and management. Arch Intern Med 2007 26; 167(6):551-561.
- (17) Effing T, Monninkhof EM, van der Valk PD, van der Palen J, van Herwaarden CL, Partidge MR, et al. Self-management education for patients with chronic obstructive pulmonary disease. Cochrane Database Syst Rev 2007 17;(4)(4):CD002990.
- (18) Effing TW, Bourbeau J, Vercoulen J, Apter AJ, Coultas D, Meek P, et al. Self-management programmes for COPD: moving forward. Chron Respir Dis 2012; 9(1):27-35.
- (19) Heijmans M, Spreeuwenberg P, Rijken M editor. Ontwikkelingen in de zorg voor chronisch zieken. Rapportage 2010. Utrecht: NIVEL; 2010.
- (20) Bourbeau J, Julien M, Maltais F, Rouleau M, Beaupre A, Begin R, et al. Reduction of hospital utilization in patients with chronic obstructive pulmonary disease: a disease-specific self-management intervention. Arch Intern Med 2003 10;163(5):585-591.
- (21) Long Alliantie Nederland (LAN). Zorgstandaard 2012. Available at: <a href="http://www.longalliantie.nl/images/library/pdf/LAN%20Zorgstandaard%20COPD-8.pdf">http://www.longalliantie.nl/images/library/pdf/LAN%20Zorgstandaard%20COPD-8.pdf</a>. Accessed 21/06, 2013.
- (22) Trappenburg J, Jonkman N, Jaarsma T, van Os-Medendorp H, Kort H, de Wit N, et al. Self-management: One size does not fit all. Patient Educ Couns 2013; 92 (1):134-7.

- (23) Connelly CE. An empirical study of a model of self-care in chronic illness. Clin Nurse Spec 1993; 7(5):247-253.
- (24) Agh T, Inotai A, Meszaros A. Factors associated with medication adherence in patients with chronic obstructive pulmonary disease. Respiration 2011; 82(4):328-334.
- (25) Wang KY, Sung PY, Yang ST, Chiang CH, Perng WC. Influence of family caregiver caring behavior on COPD patients' self-care behavior in Taiwan. Respir Care 2012; 57(2):263-272.
- (26) Dowson CA, Town GI, Frampton C, Mulder RT. Psychopathology and illness beliefs influence COPD self-management. J Psychosom Res 2004; 56(3):333-340.
- (27) Warwick M, Gallagher R, Chenoweth L, Stein-Parbury J. Self-management and symptom monitoring among older adults with chronic obstructive pulmonary disease. J Adv Nurs 2010; 66(4):784-793.
- (28) Cramm JM, Nieboer AP. Self-management abilities, physical health and depressive symptoms among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. Patient Educ Couns 2012; 87(3):411-415.
- (29) Harrell FE. Regression Modeling Strategies. With applications to lineair models, logistic regression and survival analysis. First ed. New York: Springer-Verlag; 2001.
- (30) Kline RB. Principles and practice of structural equation modeling. First ed. New York: Guilford Press.; 1998.
- (31) Baan D, Heijmans M, Spreeuwenberg P, Rijken M. Zelfmanagement vanuit het perspectief van mensen met astma of COPD. Available at: <a href="http://www.nivel.nl/sites/default/files/bestanden/Rapport-Zelfmanagement-mensen-met-COPD-of-Astma.pdf">http://www.nivel.nl/sites/default/files/bestanden/Rapport-Zelfmanagement-mensen-met-COPD-of-Astma.pdf</a>. Accessed 09/03, 2012.
- (32) Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res 2005; 40(6 Pt 1):1918-1930.
- (33) Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res 2004; 39(4 Pt 1):1005-1026.

- (34) Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). BMC Public Health 2012 31;12(1):577.
- (35) Ware J,Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care 1996; 34(3):220-233.
- (36) Aaronson NK, Muller M, Cohen PD, Essink-Bot ML, Fekkes M, Sanderman R, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol 1998; 51(11):1055-1068.
- (37) Mols F, Pelle AJ, Kupper N. Normative data of the SF-12 health survey with validation using postmyocardial infarction patients in the Dutch population. Qual Life Res 2009; 18(4):403-414.
- (38) Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983; 67(6):361-370.
- (39) Spinhoven P, Ormel J, Sloekers PP, Kempen GI, Speckens AE, Van Hemert AM. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. Psychol Med 1997; 27(2):363-370.
- (40) De Raaij EJ, Schroder C, Maissan FJ, Pool JJ, Wittink H. Cross-cultural adaptation and measurement properties of the Brief Illness Perception Questionnaire-Dutch Language Version. Man Ther 2012; 17(4):330-335.
- (41) Pedersen SS, Spinder H, Erdman RA, Denollet J. Poor perceived social support in implantable cardioverter defibrillator (ICD) patients and their partners: cross-validation of the multidimensional scale of perceived social support. Psychosomatics 2009; 50(5):461-467.
- (42) Zimet GD, Dahlem NW, Zimet S.G, Farley GK. The Multidimensional Scale of Perceived Social Support. Journal of personality assessment 1988; (52): 30-41.
- (43) Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. J Pers Assess 1990; 55(3-4):610-617.
- (44) Bestall JC, Paul EA, Garrod R, Garnham R, Jones PW, Wedzicha JA. Usefulness of the Medical Research Council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. Thorax 1999; 54(7):581-586.

- (45) IBM Corp. IBM SPSS Statistics for Windows. Armonk, NY: IBM Corp Released 2012.;Version 21.0.
- (46) Grobbee DE, Hoes AW. Clinical epidemiology. Principles, methods, and Applications for clinical research. first ed. Sudbury, Massachusetts: Jones and Bartlett Publishers, Inc.; 2009.
- (47) Heitjan DF. Annotation: what can be done about missing data? Approaches to imputation. Am J Public Health 1997; 87(4):548-550.
- (48) Peduzzi P, Concato J, Kemper E, Holford TR, Feinstein AR. A simulation study of the number of events per variable in logistic regression analysis. J Clin Epidemiol 1996; 49(12):1373-1379.
- (49) Wingate BJ, Hansen-Flaschen J. Anxiety and depression in advanced lung disease. Clin Chest Med 1997; 18(3):495-505.
- (50) Jansen DL, Bloemendal E, Rademakers J. CQ-index astma en COPD: meetinstrumentontwikkeling en onderzoek naar het discriminerend vermogen. 2010; Available at: <a href="http://www.nivel.nl/sites/default/files/bestanden/CQ-index-astma-COPD-2010.pdf">http://www.nivel.nl/sites/default/files/bestanden/CQ-index-astma-COPD-2010.pdf</a>. Accessed 11/05, 2012.
- (51) Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease (Updated 2013). Available at: <a href="http://www.goldcopd.org/uploads/users/files/GOLD\_Report\_2013\_Feb20.pdf">http://www.goldcopd.org/uploads/users/files/GOLD\_Report\_2013\_Feb20.pdf</a>. Accessed 06/23, 2013.
- (52) Sanderse C, Verweij A, Beer de J. Etniciteit: Wat is de huidige situatie? 2012; Available at: <a href="http://www.nationaalkompas.nl/bevolking/etniciteit/huidig/">http://www.nationaalkompas.nl/bevolking/etniciteit/huidig/</a>. Accessed 05/30, 2013.

#### **TABLES & FIGURES**

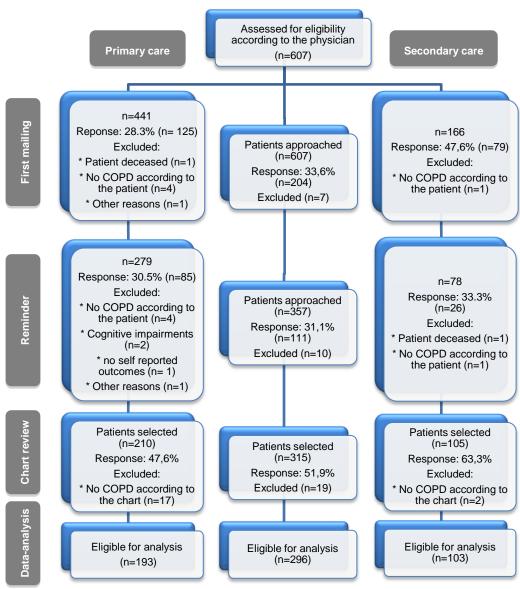


Figure 1 Flow chart of recruitment

Table 1 Baseline characteristics of the study population

Sociodemographic characteristics (available cases)	Primary care (n=193)	Secondary care (n=103)	Total (n=296)	
Gender (n=295)				
Male	109 (56.8)	76 (73.8)	185 (62.7)	
Female	83 (43.2)	27 (26.2)	110 (37.3)	
Age (years) (n=295)	65.7 ± 10.4	70.1 ± 9.7	67.3 ± 10.4	
BMI (kg/m²) (n=283)	26.7 ± 4.6	25.8 ± 4.8	26.4 ± 4.7	
Marital status (n=296)*	100 (00 0)	22 (24 1)	10= (0= 0)	
Married	129 (66.8)	66 (64.1)	195 (65.9)	
Other	64 (33.2)	37 (35.9)	101 (34.1)	
Living situation (n=292) Alone	43 (22.8)	32 (31.1)	75 (25.7)	
Together	146 (77.2)	71 (68.9)	217 (74.3)	
Educational level (n=289)	( /	(55.6)	()	
Lower secondary or less	85 (45.2)	44 (43.6)	129 (44.6)	
Higher secondary	76 (40.4)	37 (36.6)	113 (39.1)	
College/university	27 (14.4)	20 (19.8)	47 (16.3)	
Current working (n=291)	4.4.400	o /= o:	<b>50</b> (1 <b>5</b> 5)	
Yes	44 (23.4)	6 (5.8)	50 (17.2)	
No Ethnicity (p. 202)	144 (76.6)	97 (94.2)	241 (82.8)	
Ethnicity (n=292)	177 (02 7)	06 (03 3)	272 (02 5)	
Native Immigrant	177 (93.7)	96 (93.2) 7 (6.8)	273 (93.5) 19 (6.5)	
Immigrant Self-reported financial situation (n=289)	12 (6.3)	1 (0.6)	19 (6.5)	
Good	78 (41.9)	46 (44.7)	124 (42.9)	
Average	89 (47.8)	43 (41.7)	132 (45.7)	
Poor	19 (10.2)	14 (13.6)	33 (11.4)	
Smoking habits (n=293)	,	,	,	
Non smoker	22 (11.6)	5 (4.9)	27 (9.2)	
Former smoker	91 (47.9)	83 (80.6)	174 (59.4)	
Current smoker	77 (40.5)	15 (14.6)	92 (31.4)	
Average smoking (pack-years) (n=257)	36.2 ± 24.5	36.7 ± 24.8	$36.4 \pm 24.6$	
Self-management capacity (PAM-13) (n=288)	55.6 (10.5)	53.3 (10.1)	54.8 (10.4)	
Health status (SF-12) (n=293)	59.2 (23.7)	42.5 ± 21.2	53.5 ± 24.0	
Anxiety (HADS) (n=292)	5.5 (4.1)	$6.0 \pm 4.7$	$5.6 \pm 4.3$	
Depression (HADS) (n=293)	5.1 (4.1)	$6.4 \pm 4.3$	$5.6 \pm 4.2$	
Illness perception (B-IPQ) (n=293)	37.4 (12.3)	44.3 ± 10.6	39.8 ± 12.2	
Social support (MSPSS) (n=295)	61.8 (17.6)	59.7 ± 17.5	61.1 ± 17.6	
Clinical characteristics				
Self-reported COPD duration (years) (n=173)	13.3 (19.2)	23.4 (20.1)	17.4 (20.1)	
FEV1% predicted (n=241)	70.9 (14.7)	52.7 (19.7)	63.5 (19.1)	
GOLD stage (n=273)**				
I (mild)	78 (45.9)	13 (12.6)	91 (33.3)	
II (moderate)	87 (51.2)	41 (39.8)	128 (46.9)	
III (severe)	5 (2.9)	35 (34.0)	40 (14.7)	
IV (very severe)	=	14 (13.6)	14 (5.1)	
MRC score (n=294)	155 (90.2)	3/ (22.7)	180 (64.2)	
<3 ≥3	155 (80.3) 38 (19.7)	34 (33.7) 67 (66.3)	189 (64.3) 105 (35.7)	
Comorbidities (n=296)***	JU (18.7)	01 (00.3)	100 (33.1)	
0	56 (29.0)	34 (33.0)	90 (30.4)	
1	88 (45.6)	39 (37.9)	127 (42.9)	
≥2	49 (25.4)	30 (29.1)	79 (26.7)	
Current exacerbation (prednisone/antibiotics) (n=290)	, /	( - )	, ,	
No cure	162 (85.6)	67 (65.0)	228 (78.4)	
Cure in past three months	26 (13.8)	36 (35.0)	62 (21.3)	

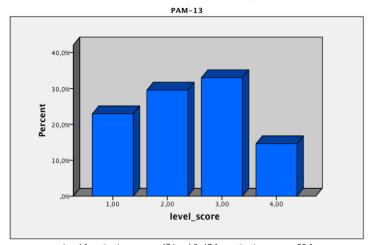
Data presented as mean ± SD or n (%)

\* Marital status: Married, widow, divorced or unmarried people were included.

\*\*\*GOLD stage: I (FEV1 ≥ 80%), II (50% ≤ FEV1 ≤ 80%), III (30% ≤ FEV1 ≤ 50%), IV FEV1 ≤ 30%.

\*\*\*\* Comorbidities categorised by cardiovascular diseases, respiratory diseases, diabetes, kidney diseases, liver diseases, cancer, connective tissue disorders, paraplegia, osteoporosis and arthrosis, gastro intestinal disorders, anxiety and depression, Parkinson's disease and multiple sclerosis, eczema, dementia and HIV.

# Prevalence of different levels of self-management capacity



Level 1: activation score  $\leq$  47 Level 2: 47.1  $\leq$  activation score  $\leq$  55.1 Level 3: 55.2  $\leq$  activation score  $\leq$  67.0 Level 4: activation score  $\geq$  67.1

Figure 2 Prevalence of different levels of self-management capacity

Table 2 Univariate linear regression and multiple linear regression to analyze the association between multiple determinants and self-management capacity.

Determinants association with self- management capacity (PAM-13)	Univariate linear regression			M	Multiple linear regression §		
	β *	95% CI **	P-value t	β*	95% CI**	P-value t	
Health status (SF-12) (n=286)	0.12	0.07 / 0.17	.00		NA		
Anxiety (HADS) (n=284)	-0.55	-0.83 / -0.27	.00		NA		
Depression (HADS) (n=285)	-0.69	-0.98 / -0.41	.00	-0.36	-0.71 / -0.01	.04	
Illness perception (B-IPQ) (n=285)	-0.26	-0.36 / -0.16	.00	-0.18	-0.31 / -0.06	.00	
Social support (MSPSS) (n=287)	0.06	-0.01 / 0.12	.12		NA		
Age (years) (n=287)	-0.11	-0.23 / 0.01	.07	-0.12	-0.24 / -0.01	.04	
Gender (male or female) (n=287)	0.19	-2.34 / 2.72	.88		NA		
BMI (kg/m²) (n=275)	-0.38	-0.65 / -0.12	.01	-0.35	-0.61 / -0.10	.01	
Ethnicity (native or immigrant) (n=285)	-4.04	-8.92 / 0.83	.10		NA		
Living situation (alone or together) (n=284)	-1.36	-4.16 / 1.45	.34		NA		
Education level (n=281) Lower secondary vs. higher secondary	2.57 4.96	-0.05 / 5.19 1.48 / 8.44	.01 ∞ .06 .01		NA		
Lower secondary vs. college/university Financial situation (n=281) Good vs moderate	-0.65	-3.23 / 1.93	.62 ∞ .62		NA		
Good vs low Current working (yes or no) (n=283)	-1.95 -3.80	-5.97 / 2.08 -7.07 / -0.53	.34 .02		NA		
Current smoking (yes or no) (n=285)	-0.77	-3.40 / 1.87	.57		NA		
MRC (<3 of ≥3) (n=286)	-3.81	-6.29 / -1.33	.00		NA		
GOLD (n=266) GOLD 1 vs. GOLD2 GOLD 1 vs. GOLD3 GOLD 1 vs. GOLD4	-3.12 -4.20 -3.56	-5.79 / -0.46 -7.99 / -0.40 -9.34 / 2.23	.06 ∞ .02 .03 .23		NA		
Current exacerbation (yes or no) (n=282)	2.52	-0.47 / 5.51	.10				
Comorbidity (n=288)  No comorbidities vs. 1 comorbidity  No comorbidities vs. ≥2 comorbidity	-1.17 -1.36	-4.05 / 1.72 -4.60 / 1.89	.65 ∞ .43 .41		NA		

<sup>§</sup> Model statistics F test 10.97 df =  $4 P < 0.000 R^2 = 0.143 (n=269)$ 

**Table 3** Univariate logistic regression to analyze the association between determinants and poor self-management capacity.

Determinants association with self- management capacity (PAM-13)	Univariate logistic regression			
	OR*	95% CI **	P-value	
Health status (SF-12) (n=286)	0.98	0.96 / 0.98	.00	
Anxiety (HADS) (n=284)	1.14	1.07 / 1.21	.00	
Depression (HADS) (n=285)	1.20	1.12 / 1.28	.00	
Illness perception (B-IPQ) (n=285)	1.05	1.02 / 1.08	.00	
Social support (MSPSS) (n=287)	0.98	0.96 / 0.99	.01	
Age (years) (n=287)	0.99	0.96 / 1.02	.54	
Gender (male or female) (n=287)	1.13	0.64 / 2.00	.67	
BMI (kg/m²) (n=275)	1.10	1.04 / 1.17	.00	
Ethnicity (native or immigrant) (n=285)	1.62	0.59 / 4.44	.35	
Living situation (alone or together) (n=284)	1.02	0.54 / 1.95	.94	
Education level (n=281) Lower secondary vs. higher secondary	0.79	0.43 / 1.43	.05 .43	
Lower secondary vs. college/university Financial situation (n=281) Good vs. moderate	0.26 1.32	0.09 / 0.77 0.70 / 2.48	.02 .01 .39	
Good vs. low Current working (yes or no) (n=283)	3.47 1.82	1.50 / 8.01 0.77 / 4.29	.00 .17	
Current smoking (yes or no) (n=285)	0.91	0.50 / 1.65	.76	
MRC (<3 of ≥3) (n=286)	1.61	0.92 / 2.82	.09	
GOLD (n=266) GOLD 1 vs. GOLD2 GOLD 1 vs. GOLD3 GOLD 1 vs. GOLD4	2.02 1.85 1.46	1.01 / 4.05 0.74 / 4.63 0.36 / 5.92	.25 .05 .19 .60	
Current exacerbation (yes or no) (n=282)	0.93	0.47 / 1.83	.84	
Comorbidity (n=288) No comorbidities vs. 1 comorbidity No comorbidities vs. ≥2 comorbidity	0.94 1.02	0.49 / 1.81 0.50 / 2.12	.97 .86 .95	

<sup>\*</sup> Odds Ratio \*\* 95% confidence interval for odds ratio

#### **DUTCH SUMMARY**

**Titel:** Determinanten van zelfmanagement capaciteit bij patiënten met Chronic Obstructive Pulmonary Disease: Een cross-sectionele studie.

**Inleiding:** Zelfmanagement is belangrijk in de zorg voor COPD patiënten, maar een substantieel aantal patiënten reageert niet op zelfmanagement interventies. Er is weinig bekend over determinanten die geassocieerd zijn met zelfmanagement capaciteit.

**Doel en onderzoeksvragen:** Inzicht krijgen in determinanten van zelfmanagement capaciteit om patiënten die moeite hebben met zelfmanagement te kunnen signaleren, zodat zelfmanagement interventies op maat kunnen worden toegepast. Onderzoeksvragen waren: Welke combinatie van determinanten is geassocieerd met zelfmanagement capaciteit? Wat is de prevalentie van verschillende niveaus van zelfmanagement capaciteit? En welke determinanten zijn geassocieerd met een hoog risico op slechte zelfmanagement capaciteit?

**Methode:** Een exploratieve, cross-sectionele studie werd uitgevoerd in zowel de eerste- als tweedelijns zorg van januari 2013 tot en met juni 2013. Bij COPD patiënten ouder dan 40 jaar werd een vragenlijst afgenomen om determinanten en zelfmanagement capaciteit te meten. Enkelvoudige en meervoudige lineaire regressie analyses werden uitgevoerd.

**Resultaten:** In totaal waren er 296 participanten, waarvan slechts 14% in staat bleek tot zelfmanagement. Zelfmanagement capaciteit was geassocieerd met gezondheidsstatus, angst, depressie, ziekteperceptie, body mass index (BMI), opleidingsniveau, werkstatus en dyspneu (P<0.05). Bij slechte zelfmanagement capaciteit waren er ook associaties met andere determinanten. Er werden vier verklarende variabelen van zelfmanagement capaciteit gevonden: ziekteperceptie, depressie, BMI en leeftijd (P<0.1).

**Conclusie:** Ziekteperceptie, depressie, BMI en leeftijd zijn verklarende determinanten van zelfmanagement capaciteit. Deze kennis helpt zorgprofessionals om patiënten die moeite hebben met zelfmanagement te identificeren, waardoor een eerste stap kan worden gemaakt in het toepassen van zelfmanagement interventies op maat. Er is nog veel ruimte voor verbetering in zelfmanagement capaciteit van COPD patiënten.

**Aanbevelingen:** Toekomstig onderzoek is nodig naar oorzakelijke verbanden tussen determinanten en zelfmanagement capaciteit. Deze kennis is essentieel om barrières van zelfmanagement capaciteit te kunnen elimineren en zal bijdragen aan het toepassen van zelfmanagement interventies op maat.

**Trefwoorden:** Zelfmanagement, Chronic Obstructive Pulmonary Disease, Determinanten.

#### **ENGLISH ABSTRACT**

**Title:** Determinants of self-management capacity of patients with Chronic Obstructive Pulmonary Disease: A cross sectional study.

**Background:** Self-management is a pivotal element in COPD management, but a substantial proportion of COPD patients does not respond to self-management interventions. Little is known about determinants associated with self-management capacity.

Aim and research questions: Understanding key determinants of self-management capacity to be able to identify patients at risk of inadequate engagement in self-management, which is essential to target and tailor self-management interventions. Research questions were: Which combination of determinants is associated with self-management capacity? What is the prevalence of different levels of self-management capacity? And which determinants are associated with a high risk of poor self-management capacity?

**Method:** An explorative, cross-sectional study was conducted in primary and secondary care from January 2013 until June 2013. COPD patients above 40 years were recruited to answer a questionnaire measuring determinants and self-management capacity. Univariate and multiple linear regression analyses were performed.

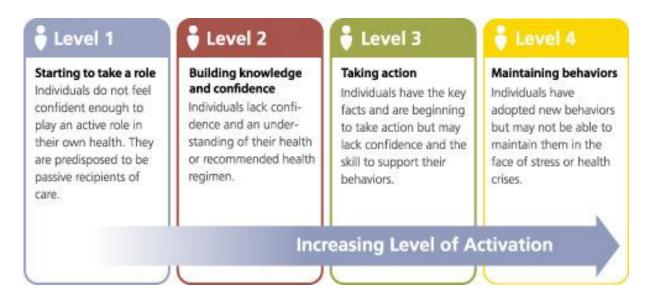
**Results:** A total of 296 COPD patients were included. Only 14% of the participants was capable of self-management. Self-management capacity was associated with health status, anxiety, depression, illness perception, Body Mass Index (BMI), educational level, current working and dyspnea (P<0.05). Determinants associated with poor self-management capacity were partly different. Four explanatory determinants of self-management capacity were revealed: illness perception, depression, BMI and age (P<0.1).

**Conclusion:** Illness perception, depression, BMI and age are key determinants of self-management capacity. This knowledge may help health care professionals to identify of patients at risk of inadequate engagement in self-management, which is essential to make a first step in targeting and tailoring of self-management interventions. There is a large potential for improvements in self-management capacity of COPD patients.

**Recommendations:** Future research is needed to identify causal relationships between determinants and self-management capacity. This knowledge is essential to eliminate barriers of self-management capacity and will contribute to targeting and tailoring of self-management interventions.

Keywords: Self-management, Chronic Obstructive Pulmonary Disease, Determinants.

#### **APPENDIX**



**LEVEL 1: May not yet believe that the patient role is important** (Having a PAM score of 47.0 or lower, 11.8%)

**LEVEL 2: Lacks confidence and knowledge to take action** (Having a PAM score of 47.1 to 55.1, 29.3%)

**LEVEL 3: Beginning to take action** (Having a PAM score of 55.2 to 67.0, 36.5%)

**LEVEL 4: Has difficulty maintaining behaviors over time** (Having a PAM score of 67.1 or above, 22.3%)

Insignia Health. Four levels of activation. 2012; Available at: http://www.insigniahealth.com/solutions/patient-activation-measure. Accessed 10/18, 2012.