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## Identifying Patients with COPD in Need for Psychosocial Care Through Screening with the HSCL-25 and the CCQ Mental State

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### ABSTRACT

High levels of psychological distress are documented in patients with COPD. This study investigates the extent to which patients with a high score on the Hopkins Symptoms Checklist-25 (HSCL-25) or with a high score on the Mental State scale of the Clinical COPD Questionnaire (CCQ) endorse a need for psychosocial care, and investigates several characteristics of patients with a need. Outpatients with COPD of the Department of Pulmonary Diseases of a University Medical Center were assessed with the HSCL-25, CCQ and a question on need for psychosocial care. For patients indicating a need, the percentage of patients with HSCL-25  $\geq 39$  was compared with the percentage of patients with CCQ Mental State  $> 2$  and tested with a Chi-square. In total 323 patients participated; 57% of them were distressed according to the HSCL-25 ( $\geq 39$ ) and 20% according to the CCQ Mental State ( $> 2$ ); 28% reported a need for psychosocial care. For patients reporting a need for psychosocial care a higher percentage was identified by the HSCL-25 than by the CCQ Mental State ( $\chi^2 = 9.41, p < .002$ ) and they were younger than patients without a need ( $t = 4.48, p < .001$ ). No differences existed for sex, FEV<sub>1</sub>, FEV<sub>1</sub>% predicted or medical comorbidities. The HSCL-25 identified more patients in need than the CCQ Mental State scale. However, not all patients with a need were identified. No relationship was found between need for psychosocial care and illness variables or comorbidities. Distress screening is questioned as the most effective way to identify patients with COPD in need for psychosocial care.

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### KEYWORDS

anxiety; distress; depression, psychology



## Introduction

Coping with a progressive disease such as COPD may induce high levels of distress. Being distressed means that a person experiences symptoms of anxiety and/or depression. Studies investigating distress in patients with COPD indeed report high levels of both anxiety and depression (1), with meta-analyses showing pooled prevalence rates as high as 40% for depressive symptoms and 36% for anxiety (2). The consequences of under-treatment of high psychological distress levels may be serious, as distress conceivably negatively affects functional status, dyspnea, exacerbation risk, quality of life, treatment adherence and even survival (1,3–7). However, under-treatment of distress in patients with COPD frequently occurs due to under identification by physicians, amongst other things (8–10), who have limited time available for their patient consultations and often are unfamiliar with symptoms of psychological distress (11,12).

In order to increase the identification of patients with COPD in need for psychological treatment, routinely screening for psychological distress by means of self-report measures has been advocated (12–16). This recommendation implies that screening leads to successfully identifying patients in need for

psychological care. However, scientific literature concerning other somatic illnesses shows that high distress levels are not by definition statistically related to a concurrent need for psychosocial care (17,18). For example, Van Scheppingen et al. (17) found that, irrespective of distress levels, only 10% of a sample of cancer patients indicated an unmet need for psychosocial care. To the best of our knowledge, no studies have looked into the association of (high) distress levels and need for psychosocial care in patients with COPD. The existence of such an association seems an important prerequisite for the decision to implement psychological distress screening in COPD care.

As the literature in this field shows that psychological distress levels are not per se related to a need for professional psychosocial care, the first aim of the present study is to examine the screening capacities of a specific distress measure (i.e. the HSCL-25 (19)) and the Mental State scale of a COPD-specific health status measure (i.e. CCQ (20)), to identify patients with a need for psychosocial care. Given the stronger focus of the HSCL-25 on psychological distress, we hypothesize that the HSCL-25 is better capable of identifying patients with a need (met or unmet) for psychosocial care than the CCQ Mental State. The second

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aim of the study is to identify several characteristics of patients who endorse a need for psychosocial care. We hypothesize that patients with COPD in poor medical health, i.e. those with worse lung function and more comorbidities, report a higher need for psychosocial care (21).

## Materials and methods

**Participants and procedure.** Outpatients with COPD of the outpatient clinic for Pulmonary Medicine of the University Medical Center Groningen (UMCG) were approached for this study between January 2010 and July 2011. Participants in this study were recruited as part of the screening procedure for a multicenter RCT on the effectiveness of psychological treatment in individuals with COPD. Inclusion criteria were a diagnosis with COPD, according to the GOLD criteria (22) and being able to fill out questionnaires. Patients were excluded when no medical history was available. Patients were sent screening questionnaires and an informed consent form, two weeks prior to scheduled visit. A letter was enclosed in which the purpose of the screening was explained and patients were asked to bring the completed questionnaires and signed informed consent to the visit. Two days prior to the visit patients received a phone call from a research assistant, to remind them about the study. According to Dutch law, no further Institutional Review Board approval was required.

## Measures

Age, sex and recent (<6 months) spirometry data were derived from medical records for both respondents and non-respondents. In addition, medical comorbid conditions were registered from the medical records only for respondents.

**Distress** was assessed with: (1) the Dutch version of the Hopkins Symptom Check list-25 (HSCL-25 (23). Each item is scored on a 4-point scale, ranging from 1 (never) to 4 (always). A total score is calculated, with a higher score indicating more distress. A cut-off score of  $\geq 39$  was used to indicate high levels of distress (24). (2) The Dutch version of the Clinical COPD Questionnaire (CCQ) (20). This 10-item self-report measure is originally developed to assess the broad concept of health status and is widely used in clinical context. It covers three domains: Functional State, Mental State and Symptoms. All items are scored on a 7-point scale, ranging from 0 (asymptomatic/no limitation) to 6 (extremely symptomatic/totally limited). The Mental State subscale consists of two questions. In clinical practice, a Mental State score cut-off of  $> 2$  is often used as an indicator for distress (25). A higher total score indicates a worse COPD health status and a total score cut-off of  $\geq 3$  is often used as an indicator for poor COPD health status (very instable-very severe limited health status) (26).

**Need for psychosocial care** was assessed with a single question: 'Would you like to talk to a healthcare provider about any potential problem you are experiencing?' Patients who answered 'Yes', 'Maybe' or 'No, because I already receive treatment from a healthcare provider (for instance, a psychologist, psychiatrist or social worker)' were considered to have a need for professional psychosocial care. Patients who answered 'No, I don't need it' were considered to have no need for psychosocial care.

## Statistical analyses

For all analyses SPSS 20 for Windows (SPSS Inc., Chicago, Illinois) was used. First descriptive statistics (means and percentages) were used to compare respondents and non-respondents on mean age, sex and FEV<sub>1</sub>. Then, percentages of patients were calculated with high distress levels (HSCL-25  $\geq 39$  or CCQ Mental State  $> 2$ ) or a poor health status (CCQ  $\geq 3$ ) for patients with a need for psychosocial care. They were compared with a Pearson Chi-square test. Descriptive statistics (means and percentages) were calculated for patients with a need/no need for psychosocial care.

## Results

### Descriptives

The characteristics of respondents are shown in Table 1. Out of 420 eligible patients, 323 patients (77%) completed the screening questionnaires (Figure 1). Respondents and non-respondents did not differ in mean age ( $t = .06$ ,  $p = .93$ ), sex ( $\chi^2 = .00$ ,  $p = .96$ ) and FEV<sub>1</sub> ( $t = -1.52$ ,  $p = .13$ ). With respect to need for care, results show that 72% ( $n = 232$ ) reported no need for psychosocial care and 28% ( $n = 91$ ) did indicate a need for psychosocial care (i.e. 5% yes, 7% maybe, 15% I already receive treatment from a healthcare provider).

The reliability (Cronbach's  $\alpha$ ) of both the HSCL-25 and the CCQ was good in this sample (respectively  $\alpha = .94$  and  $\alpha = .90$ ). The correlation between the HSCL-25 and the CCQ Mental State was moderate ( $r = .59$ ), as well as the correlation between the HSCL-25 and the CCQ Total Score ( $r = .59$ ). As to be expected, the correlation between the CCQ Mental State and the CCQ Total Score was high ( $r = .73$ ).

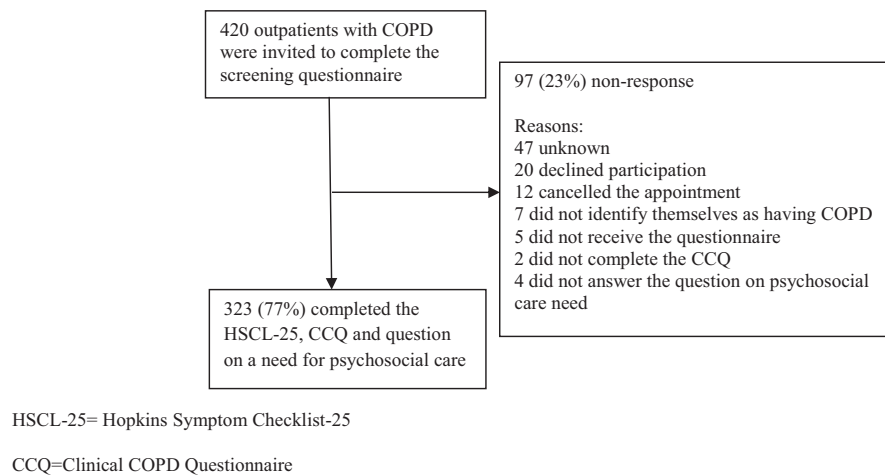
### Capacities of the HSCL-25 and the CCQ Mental State to identify those in need for psychosocial care

A total of 57% of the respondents ( $n = 184$ ) scored above the cut-off of the HSCL-25, and 20% ( $n = 63$ ) scored above the cut-off of the CCQ Mental State. Of the 91 patients who indicated a need for psychosocial care, 79% ( $n = 72$ ) were identified by the HSCL-25 ( $\geq 39$ ), 35% ( $n = 32$ ) by the CCQ Mental State ( $> 2$ ) and 41%

**Table 1.** Characteristics of respondents ( $n = 323$ ).

Variable	Mean $\pm$ SD (%)	Mean Z score *
Female Sex, $n$ (%)	140 (43)	
Age, y	65.4 $\pm$ 9.4	
FEV <sub>1</sub> , l	1.48 $\pm$ 0.66	-3.0
FEV <sub>1</sub> /%pred	51 $\pm$ 20	
FEV <sub>1</sub> /FVC	0.48 $\pm$ 0.16	-3.1
0 comorbid conditions, $n$ (%)	159 (49)	
1 comorbid condition, $n$ (%)	106 (33)	
$\geq 2$ comorbid conditions, $n$ (%)	58 (18)	
Cancer, $n$ (%)	52 (16)	
Heart disease, $n$ (%)	48 (15)	
Diabetes Mellitus, $n$ (%)	31 (10)	
Other comorbid conditions, $n$ (%)	49 (15)	
HSCL-25 $\geq 39$ , $n$ (%)	184 (57)	
CCQ Mental State $> 2$ , $n$ (%)	63 (20)	
CCQ Total Score $\geq 3$ , $n$ (%)	91 (28)	

\* Calculated with the GLI 2012 calculator of the European Respiratory Society.



**Figure 1.** Flowchart of the inclusion.

( $n = 37$ ) by the CCQ Total Score ( $\geq 3$ ). Chi-square tests showed the differences between the HSCL-25 and the CCQ Mental state ( $\chi^2 = 9.41, p < .002$ ) and between the HSCL-25 and the CCQ Total Score ( $\chi^2 = 12.47, p < .001$ ) to be statistically significant. Out of the 184 patients who scored above the HSCL-25 cut-off, 61% ( $n = 112$ ) reported no need for psychosocial care and out of the 64 patients with a high score on the CCQ Mental State 49% ( $n = 31$ ) patients reported no need for psychosocial care.

### Characteristics of patients with a perceived need for psychosocial care

Patients with a need for psychosocial care were about five years younger than patients without a need for psychosocial care ( $t = 4.48, p < .001$ ). No differences were found with respect to sex, FEV<sub>1</sub>, FEV<sub>1</sub>%predicted, FEV<sub>1</sub>/FVC or medical comorbidities (Table 2).

### Discussion

In line with our hypothesis, the HSCL-25 identified more patients with COPD in need for psychosocial care than the CCQ

Mental State (and Total Score). A need for psychosocial care was indicated by almost a third of all patients and they were somewhat younger than patients without a need for psychosocial care. Contrary to expected, patients with a poor medical health, i.e. those with worse lung function and more comorbidities were not significantly more often in need of psychosocial care than those with relatively better medical health.

Since the HSCL-25 was specifically designed to detect psychological distress, it is not surprising this instrument is better capable of detecting patients in need for psychosocial care than the CCQ subscale Mental State, which consists of only two questions. However, one-fifth of the patients who reported a need for psychosocial care were not highly distressed (according to their score on the HSCL-25) and the majority of the highly distressed patients reported no need for psychosocial care. These findings indicate that, similar to what has been found in other chronically ill populations (17,18), high psychological distress levels are not by definition related to a need for psychosocial care in COPD patients. The HSCL-25 and other distress instruments should therefore be treated with caution when it comes to their capabilities to screen which patients with COPD are in need for psychosocial care. Specific reasons for the presence/absence of a need for psychosocial care in highly distressed patients were not investigated in this study: future research should focus on mediators or moderators between distress questionnaires outcomes and need for psychosocial care. For instance, a low perception of symptoms or alexithymia (a difficulty in expressing psychological symptoms) might influence the expression of a need for psychosocial care (27). In Asthma literature, a relationship between alexithymia and the perception of symptoms is reported, as well as a relationship between alexithymia and coping styles (28).

In this study, more than half of the patients with a need for psychosocial care were already receiving such treatment. Apparently, those patients find ways to meet psychosocial care needs within the Dutch healthcare system. However, under-treatment still occurs, as some patients with high distress levels do not express a need for psychosocial care, and therefore do not receive treatment. As indicated in the introduction of this article, consequences may be serious.

Currently it is suggested to ask all patients with COPD to complete a self-report screening questionnaire (29), but it

**Table 2.** Characteristics of patients with a need for psychosocial care (unmet or met) vs. no need.

Variable	Need ( $N = 91$ )	No need ( $N = 232$ )	Significance
Female Sex, $N$ (%)	44 (48%)	96 (41%)	$\chi^2 = 1.29, p = .26$
Age, $y$	$61.75 \pm 9.58$	$66.82 \pm 8.98$	$t = 4.48, p < .001$
FEV <sub>1</sub> , l	$1.45 \pm 0.66$	$1.5 \pm 0.67$	$t = .46, p = .65$
FEV <sub>1</sub> %pred	$54 \pm 25$	$54 \pm 21$	$t = .03, p = .98$
FEV <sub>1</sub> /FVC	$0.49 \pm 0.17$	$0.48 \pm 0.17$	$t = .11, p = .91$
Comorbidities present, $N$ (%)	39 (43%)	125 (54%)	$\chi^2 = 3.18, p = .08$
Cancer, $N$ (%)	12 (12%)	41 (18%)	$\chi^2 = 1.51, p = .22$
Heart disease, $N$ (%)	11 (12%)	37 (16%)	$\chi^2 = .77, p = .38$
Diabetes Mellitus, $N$ (%)	6 (7%)	25 (11%)	$\chi^2 = 1.32, p = .25$
Other comorbid conditions, $N$ (%)	12 (12%)	37 (16%)	$\chi^2 = .39, p = .53$
HSCL-25 $\geq 39$ , $N$ (%)	72 (79%)	112 (48%)	
CCQ Mental State $> 2$ , $N$ (%)	32 (35%)	31 (13%)	
CCQ Total score $\geq 3$ , $N$ (%)	37 (41%)	54 (23%)	

Mean  $\pm$  SD.

would be potentially more cost-effective to specifically direct a screening procedure at those patients most likely to be in need of psychosocial care (30). However, a need for psychosocial care seems not to be related to objective illness variables; we found no statistical significant differences between patients with a need versus no need for psychosocial care, with respect to FEV<sub>1</sub>, FEV<sub>1</sub>% predicted or medical comorbidities. Possibly COPD patients with (more) medical comorbidities are not more likely to express a need for psychosocial care than patients without, or with less comorbidities because the burden of COPD in itself is already high, and having a comorbid disease does not add significantly to this burden, in terms of experiencing a need for psychosocial care. The only specific characteristic we found was that patients with a need for psychosocial care were younger, compared to patients with no need for care; a finding consistent with research in cancer patients (17). More research is needed to understand what characterizes the subgroup of patients with COPD and a need for psychosocial care or patients with COPD who report high psychological distress levels, but report no need for professional psychosocial care. Potentially, concrete stressful illness related events that have a major impact on daily life (such as hospitalization with an exacerbation) may create a need for psychosocial care. At the other hand, it may be that the urge to survive acute physical problems concerning COPD overrules eventual needs for psychosocial care. We suggest that future research on psychosocial care needs in patients with COPD monitors patients over a longer period of time and screens right after (illness related) stressful events have happened.

Regarding our findings, the following should be taken into account. We relied on a single question in our questionnaire with regard to patients' need for psychosocial care ('Would you like to talk to a healthcare provider about any potential problem you are experiencing?'), it may be that interviewing COPD patients on their need for psychosocial care would have led to more reliable results. The sensitivity of the question used needs to be formally tested, before it may be considered a "golden standard." Furthermore, we did not assess anxiety and depressive symptoms separately. Possibly, a need for psychosocial care is different for patients with symptoms of an anxiety disorder compared to patients with a depressive disorder. Because of apparent reliability- and validity-problems with the cross-cultural use of the Hospital Anxiety and Depression Scale (31) (HADS; a questionnaire frequently used in COPD research), this well-known scale was not used in this study. We did not collect data on important clinical variables, such as exacerbations, in our retrospective study. In future prospective work, data on clinical variables will be collected. Recently, the usage of new normal values and z-scores have been proposed and became more familiar (GLI-2012 (32)), in particular with regard to FEV<sub>1</sub>/FVC as diagnostic criterion for COPD. In our sample of 323 subjects, roughly 10% of the patients had a z-score for FEV<sub>1</sub>/FVC > minus 2 and may therefore nowadays be classified as non-obstructive disease, such as chronic bronchitis or emphysema without obstruction. We compared the group with FEV<sub>1</sub>/FVC z-score < 2 with that with z-score ≥ 2 and found no differences in age, sex and levels of distress. Therefore, we feel certain that the results in our sample apply to other outpatient populations of COPD.

## Conclusions

The HSCL-25 identified more patients with COPD who endorse a need for psychosocial care than the CCQ Mental State or Total Score did, and no relationship was found between a need for psychosocial care and objective illness variables or comorbidities. A substantial part of the patients with COPD reported a need for psychosocial care. Interestingly, about half of them already received such care. This study raises questions about the effectiveness of screening for distress in patients with COPD, as a means to identify patients in need for psychosocial care. Alternative ways to identify those patients should therefore be evaluated. However, distress measurements in patients with COPD should not be abandoned, for instance to investigate the influence of distress for a particular patient with COPD and treat distress if necessary.

## Declaration of interest

All authors have no conflicts of interest to disclose. The work was funded by the Lung Foundation Netherlands. The sponsor had no role in the study design, data collection, data analysis, writing and reviewing of the article.

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