**Patient-clinician communication about end-of-life care
for Dutch and US patients with COPD**

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ABSTRACT

Background: Improving patient-clinician communication about end-of-life care is important to enhance quality of care for patients with COPD. Our objective was to compare quality of patient-clinician communication about end-of-life care and endorsement of barriers and facilitators to this communication in the Netherlands and US.

Methods: The present study is an analysis of survey data from 122 Dutch and 391 US outpatients with COPD. We compared quality of patient-clinician communication about end-of-life care (Quality of Communication questionnaire) and barriers and facilitators to communication about end-of-life care (Barriers and Facilitators questionnaire) between the Netherlands and the US controlling for patients' demographic and illness characteristics.

Results: Although Dutch patients in this study had worse lung function and disease-specific health status than US patients, Dutch patients reported lower quality of communication about end-of-life care (median score (inter-quartile range): 0.0 (0.0-2.0) vs. 1.4 (0.0-3.6), adjusted p<0.005). Clinicians in both countries rarely discussed life-sustaining treatment preferences, prognoses, dying processes, and spiritual issues.

Conclusions: Quality of communication about end-of-life care needs to improve in the Netherlands and the US. Future studies to improve this communication should be designed to take into account international differences and patient-specific barriers and facilitators to communication about end-of-life care.

INTRODUCTION

Because Chronic Obstructive Pulmonary Disease (COPD) is a major cause of mortality worldwide[1], the provision of high quality palliative care to these patients is an important priority. Understanding and improving patient-clinician communication about end-of-life care is one way to ensure the delivery of high quality palliative care.[2] Studies of patient-clinician communication about end-of-life care in COPD have been performed primarily in the US. These studies have identified areas for improvement in communication about end-of-life care as well as barriers and facilitators to communication about end-of-life care in COPD.[3, 4]

Important regional differences may exist in patient-clinician communication about end-of-life care.[3] Indeed, patient involvement in decisions about life-sustaining treatments differs between North America and Europe[5] and international differences exist in the provision of end-of-life care. For example, a higher proportion of US than European patients die in the ICU[6] and participation of palliative care teams in European ICUs remains uncommon, while it occurs more frequently in the US.[7, 8] Further, Dutch patients with chronic diseases are more informed about treatment options and more involved in treatment decisions than US patients.[9] Lastly, a recent report concerning the quality of death across the world ranked the Netherlands higher than the US.[10] These studies would suggest that communication about end-of-life care may be better in the Netherlands than the US.

Future efforts to improve communication about end-of-life care for patients with COPD may benefit from an understanding of international differences in quality of communication about end-of-life care and the barriers and facilitators to this communication. Based on the prior research, we hypothesized that Dutch patients with

COPD would be more involved in decision making about their care at the end of life and report higher quality of patient-clinician communication about end-of-life care.

We sought to compare the quality of patient-clinician communication about end-of-life care and the endorsement of barriers and facilitators to patient-clinician communication about end-of-life care in patients with COPD in the Netherlands and US.

MATERIAL AND METHODS

Study design

The present study is an analysis of baseline data from three studies: 1) a Dutch longitudinal observational study of self-perceived symptoms and care needs of patients with severe COPD [11, 12]; 2) a randomized controlled trial designed to improve quality of communication for patients with COPD in the US[13]; and 3) a cross-sectional observational study concerning quality of communication in patients with severe COPD in the US.[3]

Study population

The study population consisted of 513 outpatients with COPD. Diagnosis of COPD was based on airflow obstruction as defined by the Global initiative for Chronic Obstructive Lung Disease (GOLD) criteria.[14] The Dutch dataset consisted of 124 outpatients with moderate to very severe COPD.[12] Patients were recruited by their clinician specialist at one university and two general hospitals and data were collected in 2008 and 2009. The first US dataset consisted of 376 patients with COPD from the Veterans Affairs Puget Sound Health Care System, recruited between 2004 and 2007.[13] The second US dataset consisted of 115 patients with severe COPD.[3] These patients were identified through ambulatory pulmonary clinics in three hospitals (one university hospital, one university-affiliated hospital and one Veterans Affairs Medical Center) and through an oxygen delivery company between 1999 and 2002 in Seattle. The final sample included 122 Dutch and 391 US patients with COPD who had valid responses for the primary outcome measure (Quality of Communication (QOC) questionnaire) and the covariates included in the regression models at study enrollment (83.4% of the original datasets). All procedures were approved by institutional review boards at all institutions (see online supplement).

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Outcome measures

Quality of Communication questionnaire

The primary outcome of interest was quality of communication, assessed with the QOC questionnaire.[3, 15] The QOC questionnaire consists of 13 items that form two domains (general communication and communication about end-of-life care). Patients were asked to rate how good their doctor is at each of these items on a scale of 0 to 10, with 0 indicating "the very worst" and 10 indicating "the very best." Patients were offered two additional response options: "My doctor did not do this" and "don't know". Domain scores were the average from all endorsed items and were calculated for patients who had at least 3 valid items for the general communication domain and at least 4 valid items for the end-of-life communication domain. Scores for both domains range from 0 (worst) to 10 (best). The answer "my doctor did not do this" was replaced by a score of '0', while "don't know" was replaced by the median domain score of the valid items for the individual, as suggested by the QOC questionnaire developers.[3, 15]

Life-sustaining treatment preferences

Patients' preferences in their current health state for cardiopulmonary resuscitation (CPR) and invasive mechanical ventilation (MV) were assessed using two validated questions, previously used in patients with COPD.[16] Response options were 'yes', 'no', or 'don't know' (see online supplement for details). In addition, patients reported whether they had discussed their treatment preferences with their clinician, using a previously developed question.[15]

Barriers and Facilitators Questionnaire

Barriers and facilitators to communication about end-of-life care were assessed using the Barriers and Facilitators Questionnaire (BFQ).[4] The BFQ consists of 15 barriers

and 11 facilitators to communication about end-of-life care. For each barrier and facilitator, the respondent was asked if the item applied to his/her situation and it was scored dichotomously (0 = not applicable; 1 = applicable).[4]

Covariates

The following patient characteristics were obtained by self-report: age, sex, marital status, race, education and co-morbidities (myocardial infarction, congestive heart failure, stomach ulcer, diabetes, cancer and liver disease). We also collected the specialty of the treating clinician. All patients had spirometry performed. FEV_1 was expressed as percentage of predicted reference values.[17] Patients were asked to rate their health status on a five-point scale (excellent, very good, good, fair and poor).[18] For assessment of disease-specific health status, participants completed the St. George Respiratory Questionnaire (SGRQ).[19] SGRQ provides a total score and three domain scores (symptoms, activities and impact) ranging from 0 (=optimal) to 100 points (=worst).

Statistics

Analyses included descriptive statistics using frequencies for categorical variables and means and standard deviations (SD) or medians and inter-quartile ranges (IQR) for continuous variables depending on the variable distribution. Patient characteristics were compared using T-tests or Mann-Whitney U tests (as appropriate) for continuous variables and Chi square tests for categorical variables. Our first step was to compare the two US study samples to ensure that they were similar on the primary outcome. QOC end-of-life care domain scores were similar in these two US samples, after adjusting for patient characteristics and clustering for clinician, allowing us to combine them for analyses (see online supplement).

In order to examine the association of country with the quality of patient-clinician communication about end-of-life care, we used linear regression analysis with robust standard errors adjusting for patient's demographic and clinical characteristics. Since limited data are available on potential predictors of quality of communication about end-of-life care in COPD, models were constructed by including variables that were possible confounders, defined as a p-value ≤ 0.20. A priori, sex was included as a covariate because it was unequally represented in our comparison samples. The following variables were entered in the final regression models: age; sex; race (Caucasian and non-Caucasian); marital status (living alone or living with a partner); FEV_1; SGRQ total score; and medical history of myocardial infarction, congestive heart failure or diabetes. There were several covariates that did not confound the relationship between country and communication scores (p>0.20) and were not included in the final model, including educational level (less than high school or high school or more), speciality of the treating clinician (chest clinician or primary care clinician/geriatrician) and other comorbidities. Since clinicians could have referred more than one patient, this analysis was clustered by clinician.

We also compared individual QOC item scores between Dutch and US patients using the same analytic approach: linear regression analysis with robust standard errors, clustered by clinician and adjusting for the same patient characteristics identified above. Finally, because BFQ items and preferences for life-sustaining treatments were scored dichotomously, we modelled logistic regression analyses, controlling for the same patient characteristics identified for the primary QOC questionnaire analyses and clustered by clinician. SPSS 17.0. was used to develop descriptive statistics; STATA 11.1 was used for the regression analyses. A two-sided level of significance was set at p≤ 0.05.[20]

RESULTS

Patient characteristics

The current study includes 122 Dutch and 391 US patients with COPD. The majority of the patients had severe to very severe COPD (GOLD stage III or IV). Dutch patients had lower FEV_1 and worse disease-specific health status. All Dutch patients were Caucasian. Most US patients were male and a lower proportion of US patients were married or living with a partner. All patients of the Dutch sample rated care and communication from a chest clinician, as compared with 44% of the US patients; the rest of the US patients rated care and communication from geriatricians or primary care clinicians. Finally, a higher proportion of patients from the US sample reported myocardial infarction or liver disease (table 1).

Communication about end-of-life care

General communication domain scores were rated high, while communication about end-of-life care domain scores were rated low (figure 1). Dutch patients reported statistically significant lower QOC general and end-of-life care domain scores than US patients. After controlling for country, three other patient characteristics were also statistically significant predictors for higher QOC end-of-life care scores: 1) younger age; 2) worse disease-specific health status as assessed with the SGRQ; and 3) having a history of myocardial infarction (table 2). QOC end-of-life care domain scores were comparable for patients with mild to moderate COPD (GOLD Stage I-II) and patients with severe to very severe COPD (GOLD Stage III-IV) with median score (inter-quartile range) as follows: 1.1 (0.0-2.9) vs. 1.4 (0.0-3.4), respectively (p=0.42).

The QOC item analyses showed that most general communication items as well as specific end-of-life care communication items were rated lower by Dutch than US

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patients (table 3). However, the items 'talking about what dying might be like' and 'asking about spiritual or religious beliefs' were rated very low in both the Netherlands and the US. These low scores for communication about end-of-life care are mainly due to the fact that patients reported these items had not been discussed. Four specific end-of-life care items were less frequently discussed in Dutch than US patients (table 4).

Life-sustaining treatment preferences

Patients' preferences in their current health state for MV and CPR were similar in the Netherlands and the US: 70.5% of Dutch and 58.2% of US patients reported they would accept invasive MV (adjusted p=0.29) and 69.7% of Dutch and 70.2% of US patients reported they would accept CPR (adjusted p=0.18) if needed. Although conversations about life-sustaining treatments with clinicians were not frequent in either country, Dutch patients reported having these conversations significantly less often than US patients (12.3% and 17.6%, respectively, adjusted p=0.02).

Barriers and facilitators to communication about end-of-life care

Endorsed barriers and facilitators to end-of-life care communication were different for Dutch and US patients (table 5 and 6). A higher proportion of Dutch than US patients reported '*I don't know what kind of care I want if I get very sick*'; '*I'm not ready to talk about the care I want if I get very sick*', '*I don't want to make plans for the future*'; and '*I have concerns about bringing up assisted suicide*'. US patients more frequently endorsed '*I'm not sure which doctor will be taking care of me if I get very sick*'; '*My ideas about the kind of medical care I want change at different times*'; '*I have a living will and that means I don't need to talk with my doctor about the care I want if I'm too sick to speak for myself*'; and '*Doctors look down on people who developed lung/respiratory disease because of smoking*' (table 5).

In addition, a higher proportion of US than Dutch patients endorsed the following facilitators to end-of-life care communication: '*My doctor cares about me as a person*'; '*I worry that I could be a burden on my friends and family if I got very sick*'; '*I worry about the quality of my life in the future*'; '*My doctor often asks me about end-of-life care*'; '*My doctor is very good at talking about end-of-life care*'; and '*Someone other than my doctor has talked with me about the care I would want if I got too sick to speak for myself*'. None of the facilitators was more frequently endorsed by Dutch patients (table 6).

DISCUSSION

Overview of findings

Despite the fact that the Dutch patients with COPD from the current sample had more severe disease, Dutch patients reported communication about end-of-life care as occurring less frequently and rated the quality of this communication lower than US patients. However, prognosis, dying and spiritual issues were rarely discussed by clinicians in both countries. Moreover, in both countries only a minority of the outpatients with COPD had discussed life-sustaining treatment preferences with their clinician. There were also differences in endorsed barriers and facilitators to communication about end-of-life care between Dutch and US patients that may provide direction for future interventions.

Quality of communication about end-of-life care

The present study shows that quality of patient-clinician communication about end-of-life care was rated low in both the Netherlands and the US. However, Dutch patients rated quality of communication about end-of-life care even lower than US patients. In contrast to our hypothesis, we found that patients with COPD in the Netherlands were less involved in decision making about end-of-life care. Interestingly, this was different from what Schoen and colleagues reported concerning involvement in general decision making.[9] Although reasons for these differences are not clear, previous authors have described differences in the role of autonomy in decision-making between the US and Europe.[5, 7, 21] A more prominent role for autonomy in decision-making may increase the need for or perceived value of timely conversations about life-sustaining treatments in the US.

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Our study confirms the need for enhancing the quality of communication about end-of-life care in the US and supports this as an even more pressing need for patients with COPD in the Netherlands. Patients with COPD report that clinician communication skills are an important predictor of quality of care.[13] Patients with advanced COPD also report that avoidance of prolonged or unwanted life support is an important element of palliative care.[22] Among patients with cancer, communication about end-of-life care has been associated with improved quality of life at the end of life and reduced intensity of care without any evidence of increased anxiety or depression.[23] In addition, communication about end-of-life care is also associated with higher ratings of the quality of dying as assessed by bereaved relatives.[24] Finally, a recent randomized trial showed that advance care planning improved satisfaction of patients and families with their care and reduced stress, anxiety, and depression in families of deceased patients.[25] Our study, in the context of these prior studies, suggests that communication about end-of-life care is an important target for improving quality of care for patients with COPD.

Barriers and facilitators to communication about end-of-life care

Barriers and facilitators to communication about end-of-life care may provide direction for future interventions. We found a number of differences between the Netherlands and US in barriers and facilitators endorsed by patients with COPD. Even though our Dutch sample had more severe disease, a considerably higher proportion of Dutch patients reported that they were not ready to talk about care they want if they got very sick. This may reflect a difference in patients' preferences for communication about prognosis and should be considered in future studies and efforts to improve communication about end-of-life care. One potential approach for discussing prognosis and end-of-life care with patients who are uncomfortable talking about end-of-life care is an indirect approach to

the discussion of prognosis.[26] Conversations directed to self-efficacy around disease management as well as quality of life concerns may also enable patients uncomfortable with end-of-life care discussions to find a way to participate and plan for treatments that might be needed if they were to become very ill.[27-29] Furthermore, the barrier '*I don't know what kind of care I want if I get very sick*' was more frequently endorsed by Dutch patients. This latter barrier has been associated with a lower occurrence of discussions about end-of-life care [4] and therefore may be particularly important to address in designing interventions to increase the occurrence of communication about end-of-life care. Finally, prior research has shown that media coverage can influence treatment preferences for patients with COPD and may also be related to some of the regional differences in attitudes about discussing end-of-life care.[30]

We found that a higher proportion of US patients reported as a barrier that they are not sure which doctor would be taking care of them if they got very sick. Slatore and colleagues found that 55% of patients with COPD who received care from the same clinician for more than five years reported receiving the best possible care, while only 37% of the patients who had the same clinician for less than two years reported receiving the best possible care (p=0.02).[13] Therefore, continuity of care may be an important factor in enhancing quality of patient-clinician communication in the US. We also found that US patients more frequently endorsed '*Doctors look down on people who developed lung/respiratory disease because of smoking*'. Recently, a qualitative study illuminated the challenge for clinicians to combine health advice on smoking cessation with non-blaming support throughout the course of COPD.[31] Attention to this issue may be relatively more important in US interventions.

End-of-life care discussions occur more frequently if patients perceive that their clinician is good at talking about end-of-life issues.[4] Although US patients report this more frequently than Dutch patients, in both countries only a minority of patients endorsed this facilitator. Previous studies have shown that communication skills-building workshops for clinicians working in oncology can improve communication skills about end-of-life care.[32, 33] Therefore, this may be a useful intervention to improve communication about end-of-life care in the Netherlands and the US.

Limitations

The current project has a number of important limitations. Perhaps most importantly, the difference between the Dutch and US samples could be due to differences other than regional variability. For example, female patients were underrepresented in the US sample, while the Dutch sample consisted only of Caucasian patients. Although we used regression analyses to adjust for known differences in patient characteristics, other differences may have been present which were not assessed in the current study, like differences in religion or psychological symptoms. Perception of quality of communication may be influenced by the presence of depression.[3] However, Slatore and colleagues have shown that QOC scores were not related to the presence of depression symptoms (measured by the MHI5 instrument) or previous self-reported physician diagnosis of depression.[13] Data for the US samples were collected between 1999 and 2002 and between 2004 and 2007, while the data for the Dutch sample were collected in 2008 and 2009. Because data were collected at three different time points, it is possible that effects may be due to secular trends rather than country differences. Given the absence of any overlap in time among the three samples, it is impossible to assess the extent to which observed differences were primarily functions of sample rather than functions of time. In addition, all Dutch patients were recruited by their chest

clinician and rated quality of communication with their chest clinician, while some of the US patients rated quality of communication with the primary care clinician or geriatrician. Although we did not include Dutch primary care physicians, Dutch patients in our sample reported visiting their chest clinicians more frequently than their primary care clinicians. Furthermore, in our study, quality of communication about end-of-life care was not associated with clinician specialty and therefore seems unlikely to be an important confounder. Nevertheless, clinician specialty has been suggested to be related to willingness to discuss end-of-life care issues[34] and it remains unknown whether results would have been comparable if Dutch patients rated quality of communication with their primary care clinician.

There are several other important limitations. First, participants in these studies were volunteers and we do not know whether their views are representative of all patients with COPD. This is an inherent limitation of such research, but should be considered in interpreting the results. Second, the present study is based on the patients' perception of quality of communication and does not include objective measures of quality of communication. However, we believe that the patients' perception of the quality of communication about end-of-life care is an important construct. Third, the current project compared communication about end-of-life care between the Netherlands and the US and it is unknown whether the current Dutch findings are applicable to other European countries. The Netherlands is unique in having legalized euthanasia and it is difficult to determine what effect this has on communication about end-of-life care.[35] Furthermore, Cartwright and colleagues have shown that Dutch clinicians were more likely to discuss purpose of treatment and palliative care compared with clinicians from other European countries.[34] Further research is necessary to study whether and to what extent quality of communication about end-of-life care is comparable between

European countries. Finally, US patients have mainly been recruited in one region in the US and it is unknown if results are comparable with other regions in the US.

Conclusions and future directions

There is increasing realization of the importance of communication to the provision of high quality end-of-life care. Our results suggest that improvements in communication about end-of-life care are needed in both the Netherlands and the US. We found that conversations about advance care planning occurred for only a minority of outpatients with moderate or severe COPD. Therefore, clinicians caring for patients with COPD in both countries need to pay more attention to communication about end-of-life care. International differences were also notable, with communication about end-of-life care rated lower by Dutch than US patients. It will be important for future studies to collect data concurrently in the two countries in order to produce definitive comparisons of the two locales. Future studies are needed to develop interventions to improve patient-clinician communication about end-of-life care for patients with COPD. These interventions should take into account regional differences in barriers and facilitators to communication about end-of-life care.

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Legend figure 1

Median (inter-quartile range, minimum and maximum) Quality of Communication (QOC) questionnaire scores for the domain 'general communication' (left panel) and the domain 'communication about end-of-life care' (right panel) reported by Dutch (n=122) and US (n=391) patients with COPD.

p-values are based on linear regression analysis clustered by clinician (156 clusters), adjusted for age, sex, race, marital status, FEV_1, SGRQ total score, medical history of myocardial infarction, congestive heart failure and diabetes.
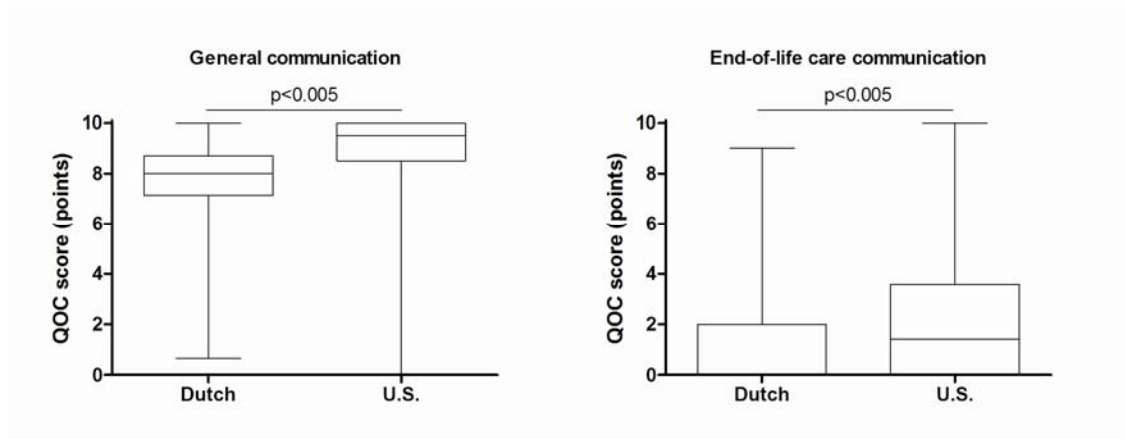
Table 1. Demographic and clinical patient characteristics

	Dutch patients (n=122)	US patients (n=391)	p-value*
Age (years)	66.7 (9.3)	68.7 (10.0)	**0.05**
Sex (male)	75 (61.5%)	360 (92.1%)	**0.00**
Marital status (married / living with partner)	88 (72.1%)	188 (48.1%)	**0.00**
Race (Caucasian)	122 (100%)	339 (86.7%)	**0.00**
Education (high school or more)	93 (76.2%)	325 (83.1%)	0.12
Receiving treatment by chest clinician	122 (100%)	171 (44.5%)[#]	**0.00**
FEV_1 (% predicted)	37.8 (15.5)	43.3 (20.2)	**0.00**
GOLD stage			
GOLD stage I	1 (0.8%)	20 (5.1%)	**0.04**
GOLD stage II	24 (19.7%)	105 (26.8%)	
GOLD stage III	50 (41.0%)	150 (38.4%)	
GOLD stage IV	47 (38.5%)	116 (29.7%)	
Comorbid illnesses			
Myocardial infarction	13 (10.7%)	75 (19.2%)	**0.04**
Congestive heart failure	12 (9.8%)	61 (15.6%)	0.15
Stomach ulcer	14 (11.5%)	60 (15.3%)	0.36
Diabetes	28 (23.0%)	94 (24.0%)	0.90
Cancer	23 (18.9%)	72 (18.4%)	1.00
Liver disease	3 (2.5%)	36 (9.8%)[†]	**0.02**
Self-perceived health status			
Excellent	0 (0%)	4 (1.0%)[‡]	**0.00**
Very good	2 (1.6%)	46 (11.9%)[‡]	
Good	21 (17.2%)	128 (33.0%)[‡]	
Fair	80 (65.6%)	139 (35.8%)[‡]	
Poor	19 (15.6%)	71 (18.3%)[‡]	
Disease-specific health status			
SGRQ symptoms score	58.6 (22.6)	57.6 (23.4)	0.68
SGRQ activity score	72.9 (22.9)	68.5 (21.5)	0.06
SGRQ impact score	43.8 (19.1)	39.7 (18.1)	**0.03**
SGRQ total score	55.1 (17.7)	51.4 (17.5)	**0.04**

Values reported as mean (SD) or n (%)
*p-values based on chi square or independent sample T-test
[#]n=384; [†]n=368; [‡]n=388
FEV_1: Forced Expiratory Volume in the first second
GOLD: Global initiative for chronic Obstructive Lung Disease
SGRQ: St. Georges Respiratory Questionnaire

Table 2. QOC "Communication about end-of-life care" domain score: Association

with country using linear regression and clustered by clinician

	Beta	95% CI	p-value
Primary predictor			
Country (ref: the Netherlands)	**1.03**	**0.54-1.52**	**0.00**
Demographics			
Age	**-0.02**	**-0.05- -0.00**	**0.03**
Sex (ref: male)	0.13	-0.34-0.60	0.58
Marital status (ref: living alone)	0.37	-0.03-0.76	0.07
Race (ref: non-Caucasian)	-0.52	-1.25-0.21	0.16
Disease severity			
FEV_1 (% predicted)	-0.01	-0.02-0.00	0.31
SGRQ total score	**0.02**	**0.00-0.03**	**0.02**
Co-morbidities			
Myocardial infarction (ref: none)	**0.63**	**0.01-1.25**	**0.05**
Congestive heart failure (ref: none)	0.26	-0.46-0.97	0.48
Diabetes (ref: none)	0.27	-0.16-0.70	0.21

n=513, R^2=0.096, p<0.00005
number of clusters: 156

CI: Confidence Interval
FEV_1: Forced Expiratory Volume in the first second
SGRQ: St. Georges Respiratory Questionnaire
ref: reference category

Table 3. QOC items: Descriptive statistics and association with country using

linear regression

	Dutch patients (n=122)	US patients (n=391)	Beta[#]	Adjusted p-value*
General communication items				
Using words you understand	8.0 (7.8-9.0)	9.0 (8.0-10.0)	0.57	**0.01**
Looking you in eye	8.0 (7.0-9.0)	10.0 (9.0-10.0)	1.43	**0.00**
Answering all questions about illness	8.0 (7.0-9.0)	10.0 (8.0-10.0)	1.09	**0.00**
Listening to what you have to say	8.0 (7.0-9.0)	10.0 (9.0-10.0)	1.05	**0.00**
Caring about you as a person	8.0 (7.0-9.0)	10.0 (9.0-10.0)	1.23	**0.00**
Giving full attention	8.0 (7.8-9.0)	10.0 (9.0-10.0)	1.12	**0.00**
Communication about end-of-life care items				
Talking about your feelings about getting sicker	0.0 (0.0-3.8)	0.0 (0.0-9.0)	1.64	**0.00**
Talking about details if you got sicker	0.0 (0.0-3.5)	0.0 (0.0-9.0)	1.73	**0.00**
Talking about how long you have to live	0.0 (0.0-0.0)	0.0 (0.0-0.0)	0.67	**0.05**
Involving you in treatment discussions about your care	0.0 (0.0-0.0)	0.0 (0.0-3.0)	1.11	**0.00**
Asking you about important things in life	0.0 (0.0-0.0)	0.0 (0.0-8.0)	2.00	**0.00**
Talking about what dying might be like	0.0 (0.0-0.0)	0.0 (0.0-0.0)	-0.20	0.35
Asking about spiritual, religious beliefs	0.0 (0.0-0.0)	0.0 (0.0-0.0)	0.26	0.27

Values reported as median (inter-quartile range)

*p-values based on linear regression analysis clustered by clinician (156 clusters), adjusted for age, sex, race, marital status, FEV_1, SGRQ total score, medical history of myocardial infarction, congestive heart failure and diabetes

[#]*reference category: Dutch patients*

Table 4. QOC "Communication about end-of-life care" items not discussed by clinicians: Descriptive statistics and

association with country using logistic regression

End-of-life care items	Dutch patients (n=122)	US patients (n=391)	Odds Ratio*	95% CI*
Talking about your feelings about getting sicker	**89 (73.0%)**	**208 (53.2%)**	**0.37**	**0.21-0.65**
Talking about details if you got sicker	**89 (73.0%)**	**221 (56.5%)**	**0.38**	**0.24-0.60**
Involving you in treatment discussions about your care	**103 (84.4%)**	**271 (69.3%)**	**0.35**	**0.19-0.66**
Asking you about important things in life	**98 (80.3%)**	**227 (58.1%)**	**0.30**	**0.16-0.54**
Talking about how long you have to live	108 (88.5%)	319 (81.6%)	0.46	0.21-1.00
Talking about what dying might be like	108 (88.5%)	360 (92.1%)	1.24	0.60-2.54
Asking about spiritual, religious beliefs	111 (91.0%)	341 (87.2%)	0.79	0.35-1.77

Values reported as n (%) answering 'doctor didn't do'

*Odds ratio and 95% confidence interval (95% CI) based on logistic regression analysis clustered by clinician (156 clusters), adjusted for age, sex, race, marital status, FEV_1, SGRQ total score, medical history of myocardial infarction, congestive heart failure and diabetes; reference category: Dutch patients

Table 5. Endorsed barriers to communication about end-of-life care: Descriptive statistics and association with country using logistic regression

	Dutch patients (n=122)*	US patients (n=391)*	Odds ratio[#]	95% CI[#]
Barriers more common in the Netherlands				
I don't know what kind of care I want if I get very sick.	92/122 (75.4%)	193/374 (51.6%)	**0.28**	**0.16-0.48**
I'm not ready to talk about the care I want if I get very sick.	86/122 (70.5%)	110/376 (29.3%)	**0.14**	**0.08-0.25**
I don't want to make plans for the future.	62/122 (50.8%)	75/382 (19.6%)	**0.20**	**0.11-0.37**
I have concerns about bringing up assisted suicide.	35/121 (28.9%)	50/371 (13.5%)	**0.38**	**0.20-0.72**
Barriers more common in the US				
I'm not sure which doctor will be taking care of me if I get very sick.	75/122 (61.5%)	287/378 (75.9%)	**2.01**	**1.21-3.36**
My ideas about the kind of medical care I want change at different times.	15/122 (12.3%)	160/375 (42.7%)	**5.12**	**2.48-10.58**
I have a living will, and that means I don't need to talk with my doctor about the care I want if I'm too sick to speak for myself.	16/121 (13.2%)	133/381 (34.9%)	**3.37**	**1.87-6.07**
Doctors look down on people who developed lung/respiratory disease because of smoking.	20/121 (16.5%)	121/355 (34.1%)	**2.96**	**1.43-6.14**
Barriers similar in the Netherlands and the US				
I don't like to talk about getting very sick.	58/122 (47.5%)	165/384 (43.0%)	0.85	0.57-1.25
My doctor doesn't like to talk about me getting very sick.	15/117 (12.8%)	44/271 (16.2%)	1.07	0.46-2.48
My doctor never seems to have the time to talk about issues like end-of-life care.	9/121(7.4%)	44/307 (14.3%)	2.12	0.73-6.16
I would rather concentrate on staying alive than talk about death.	95/122 (77.9%)	295/376 (78.5%)	1.50	0.78-2.89
I feel that talking about death can bring death closer.	20/122 (16.4%)	58/381 (15.2%)	0.94	0.48-1.82
I worry that talking about getting sick is too depressing for my doctor.	2/122 (1.6%)	13/368 (3.5%)	2.55	0.29-22.41
I have not been very sick.	44/122 (36.1%)	167/379 (44.1%)	1.22	0.67-2.21

Values reported as n (%)
*n is variable per item because of response 'don't know' or missing responses

[#]Odds ratio and 95% confidence interval (95% CI) based on logistic regression analysis clustered by clinician (156 clusters), adjusted for age, sex, race, marital status, FEV_1, SGRQ total score, medical history of myocardial infarction, congestive heart failure and diabetes; reference category: Dutch patients

Table 6. Endorsed facilitators to communication about end-of-life care: Descriptive statistics and association with country using logistic regression

	Dutch patients (n=122)*	US patients (n=391)*	Odds ratio[#]	95% CI[#]
Facilitators more common in the US				
My doctor cares about me as a person.	87/119 (73.1%)	336/358 (93.9%)	**5.25**	**2.28-12.06**
I worry that I could be a burden on my friends and family if I got very sick.	59/121 (48.8%)	286/384 (74.5%)	**5.19**	**3.13-8.61**
I worry about the quality of my life in the future.	47/122 (38.5%)	201/385 (52.2%)	**2.56**	**1.58-4.15**
My doctor often asks me about end of life care.	1/122 (0.8%)	17/376 (4.5%)	**9.99**	**1.37-72.97**
My doctor is very good at talking about end-of-life care.	8/118 (6.8%)	47/290 (16.2%)	**4.87**	**2.09-11.36**
Someone other than my doctor has talked with me about the care I would want if I got too sick to speak for myself (like a nurse, home health worker, chaplain or clergy, social worker).	12/121 (9.9%)	150/383 (39.2%)	**7.42**	**3.93-14.01**
Facilitators similar in the Netherlands and the US				
I <u>have</u> been very sick.	75/122 (61.5%)	228/387 (58.9%)	1.13	0.61-2.09
I have had family or friends who have died.	115/122 (94.3%)	373/389 (95.6%)	1.15	0.50-2.67
I trust my doctor.	115/122 (94.3%)	363/378 (96.0%)	1.02	0.36-2.88
My doctor is very good at taking care of lung/respiratory disease.	111/120 (92.5%)	292/319 (91.5%)	0.68	0.29-1.59
I feel sure that my doctor will be there for me if I get very sick.	106/122 (86.9%)	300/366 (82.0%)	0.65	0.32-1.29

Values reported as n (%)
*n is variable per item because of response 'don't know' or missing responses

[#]*Odds ratio and 95% confidence interval (95% CI) based on logistic regression analysis clustered by clinician (156 clusters), adjusted for age, sex, race, marital status, FEV_1, SGRQ total score, medical history of myocardial infarction, congestive heart failure and diabetes; reference category: Dutch patients*