

ONLINE SUPPLEMENT

Patient-clinician communication about end-of-life care for patients with COPD in the Netherlands and the U.S.

Authors: Daisy J.A. Janssen,^{1,2,3} J. Randall Curtis,⁴ David H. Au,^{5,6} Martijn A. Spruit,¹
Lois Downey,⁴ Jos M.G.A. Schols,⁷ Emiel F.M. Wouters,^{1,8} Ruth A. Engelberg⁴

Affiliations:

¹ Program Development Centre, CIRO+, centre of expertise for chronic organ failure, Horn, the Netherlands

² CAPHRI, Maastricht University, Maastricht, the Netherlands

³ Proteion Thuis, Horn, the Netherlands

⁴ Division of Pulmonary & Critical Care Medicine, Department of Medicine, Harborview Medical Center, Seattle, U.S.

⁵ Health Services Research and Development, VA Puget Sound Health Care System, Seattle, U.S.

⁶ Department of Medicine, University of Washington, Seattle, U.S.

⁷ Department of General Practice, Nursing home medicine, Faculty of Health Medicine and Life sciences / CAPHRI, Maastricht University, Maastricht, the Netherlands

⁸ Department of Respiratory Medicine, Maastricht University Medical Centre+ (MUMC+), Maastricht, the Netherlands

METHODS

Ethics

The Medical Ethical Commission of the Maastricht University Medical Centre + (MUMC+), Maastricht, the Netherlands, approved the original Dutch study (MEC 07-3-054). The Institutional Review Board at the University of Washington, Seattle, U.S. approved the initial U.S. studies (HSCA#97-4700-C 10 and IRB#24803) and the secondary analysis of the existing datasets.

Preferences for Cardiopulmonary Resuscitation and Mechanical Ventilation

Preferences for Cardiopulmonary resuscitation (CPR) and Mechanical ventilation (MV) have been assessed using two validated questions, previously used in patients with COPD.[1] Response options were 'yes', 'no', or 'don't know'.

- MV:

'The first treatment is short-term mechanical ventilation. You would be in an ICU, and a tube would be placed through your mouth or nose into your lungs. This tube would be attached to a breathing machine for a few days. During that time, you would have to be continuously on the breathing machine and would be unable to talk. If you were in your current health and were unable to breathe on your own, would you want to be on a breathing machine for a few days? There would be no guarantee that you would be able to come off the breathing machine and be able to breathe on your own.'

- CPR:

'The second treatment is CPR, which consists of electric shocks to the heart, pumping on the chest, help with breathing and heart medications given through the veins. Possible side effects of CPR include broken ribs and memory loss. Because you would be unconscious, other people would need to make the

decision for you regarding your treatment. In your current health, would you want resuscitation (CPR) if your heart were to stop beating?'

Comparison of two U.S. samples

The two U.S. study samples were compared to ensure that they were similar on the primary outcome and that it was appropriate to combine these two samples. Patient characteristics of the two samples are shown in table 1. The smaller U.S. sample enrolled only patients with oxygen-dependent COPD and consequently patients in this sample had a lower mean FEV₁ and worse disease-specific health status. In addition, patients in this smaller sample were more likely to be female and less likely to have cancer as a co-morbidity.

Median (inter-quartile range) QOC end-of-life care domain scores were 1.4 (0.0-2.9) and 2.6 (0.6-4.4) for the two U.S. samples, respectively. Linear regression analysis with robust standard errors and clustering for clinician demonstrates that QOC end-of-life care domain scores were similar in these two U.S. samples after adjusting for patient characteristics ($p>0.05$). (*table 2*) Because the two U.S. samples were similar for the primary outcome variable for this study, we combined the two U.S. samples for analyses comparing the Netherlands to the U.S.

Item characteristics

We also examined the item scores for the QOC separating out the “doctor didn’t do” and reporting the proportion of item scores above and below 7 as an alternate way to examine the data. For all items of the QOC questionnaire, the proportion of patients responding “doctor didn’t do”; “don’t know” or missing; item score between zero and

seven points; and a score greater than or equal to eight is shown in table 3. This approach gives similar results to the primary analyses.

REFERENCE

1. Stapleton, R.D., Nielsen, E.L., Engelberg, R.A., et al., Association of depression and life-sustaining treatment preferences in patients with COPD. *Chest*. 2005;127:328-34.

Table 1. Demographic and clinical patient characteristics of the two US study samples

	Sample 1 (n=313)	Sample 2 (n=78)	p-value*
Age (years)	69.2 (10.0)	66.8 (9.5)	0.06
Sex (male)	303 (96.8%)	57 (73.1%)	0.00
Marital status (married / living with partner)	149 (47.6%)	39 (50.0%)	0.80
Race (Caucasian)	272 (86.9%)	67 (85.9%)	0.82
Education (high school or more)	260 (83.1%)	65 (83.3%)	1.00
Receiving treatment by chest clinician	111 (35.5%)	60 (84.5%) [#]	0.00
FEV ₁ (% predicted)	46.9 (19.9)	29.2 (14.4)	0.00
Comorbid illnesses			
Myocardial infarction	63 (20.1%)	12 (15.4%)	0.34
Congestive heart failure	48 (15.3%)	13 (16.7%)	0.91
Stomach ulcer	54 (17.3%)	6 (7.7%)	0.06
Diabetes	80 (25.6%)	14 (17.9%)	0.21
Cancer	67 (21.4%)	5 (6.4%)	0.00
Liver disease	34 (10.9%)	2 (3.6%) [†]	0.16
Self-perceived health status			
Excellent	4 (1.3%) [‡]	0 (0.0%) [§]	0.39
Very good	41 (13.1%) [‡]	5 (6.6%) [§]	
Good	102 (32.7%) [‡]	26 (34.2%) [§]	
Fair	111 (35.6%) [‡]	28 (36.8%) [§]	
Poor	54 (17.3%) [‡]	17 (22.4%) [§]	
Disease-specific health status			
SGRQ symptoms score	56.6 (23.4)	61.9 (22.7)	0.07
SGRQ activity score	66.5 (22.0)	76.6 (17.1)	0.00
SGRQ impact score	38.5 (18.4)	44.5 (16.4)	0.01
SGRQ total score	50.0 (17.9)	56.8 (14.5)	0.00

Values reported as mean (SD) or n (%)

*p values based on chi square, independent sample T-test or Mann-Whitney U test

[#]n=71; [†]n=55; [‡]n=312; [§]n=76

FEV₁: Forced Expiratory Volume in the first second
SGRQ: St. Georges Respiratory Questionnaire

Table 2. QOC “Communication about end-of-life care” domain scores:

Association with US samples, using linear regression and clustered by clinician

	Beta	95% CI	p-value
Primary predictor			
U.S. sample (ref: sample 1)	0.739	-0.011-1.488	0.053
Demographics			
Age	-0.021	-0.045-0.002	0.071
Sex (ref: male)	0.058	-0.689-0.805	0.879
Marital status (ref: living alone)	0.253	-0.224-0.730	0.296
Race (ref: non-Caucasian)	-0.527	-1.275-0.222	0.166
Disease severity			
FEV ₁ (% predicted)	-0.002	-0.013-0.010	0.784
SGRQ total score	0.008	-0.005-0.022	0.229
Co-morbidities			
Myocardial infarction (ref: none)	0.831	0.171-1.492	0.014
Congestive heart failure (ref: none)	0.095	-0.711-0.901	0.817
Diabetes (ref: none)	0.284	-0.232-0.799	0.278

$n=391$, $R^2=0.074$, $p=0.002$

number of clusters: 140

CI: Confidence Interval

FEV₁: Forced Expiratory Volume in the first second

SGRQ: St. Georges Respiratory Questionnaire

ref: reference category

Table 3. QOC items: Descriptive statistics

	Doctor didn't do		Don't know or missing		Item score 0-7 points		Item score ≥8 points	
	Dutch patients (n=122)	US patients (n=391)						
General communication items								
Using words you understand	2 (1.6%)	15 (3.8%)	1 (0.8%)	9 (2.3%)	28 (23.0%)	62 (15.9%)	91 (74.6%)	305 (78.0%)
Looking you in eye	3 (2.5%)	2 (0.5%)	2 (1.6%)	14 (3.6%)	28 (23.0%)	31 (7.9%)	89 (72.9%)	344 (88.0)
Answering all questions about illness	2 (1.6%)	9 (2.3%)	0 (0%)	4 (1.0%)	31 (25.4%)	44 (11.3%)	89 (73.0)	334 (85.4%)
Listening to what you have to say	0 (0%)	2 (0.5%)	0 (0%)	7 (1.8%)	31 (25.4%)	32 (8.2%)	91 (74.6%)	350 (89.5%)
Caring about you as a person	3 (2.5%)	2 (0.5%)	23 (18.9%)	30 (7.7%)	29 (23.8%)	32 (8.2%)	67 (54.8%)	327 (83.6%)
Giving full attention	0 (0%)	1 (0.3%)	3 (2.5%)	1 (0.3%)	30 (24.6%)	27 (6.9%)	89 (72.9%)	362 (92.5%)
Communication about end-of-life care items								
Talking about your feelings about getting sicker	89 (72.9%)	208 (53.2%)	0 (0%)	16 (4.1%)	8 (6.6%)	32 (8.2%)	25 (20.5%)	135 (34.5%)
Talking about details if you got sicker	89 (72.9%)	221 (56.5%)	0 (0%)	14 (3.6%)	14 (11.5%)	28 (7.2%)	19 (15.6%)	128 (32.7%)
Involving you in treatment discussions about your care	103 (84.4%)	271 (69.3%)	1 (0.8%)	21 (5.4%)	5 (4.1%)	22 (5.6%)	13 (10.7%)	77 (19.7%)
Asking you about important things in life	98 (80.4%)	227 (58.1%)	0 (0%)	13 (3.3%)	7 (5.7%)	31 (7.9%)	17 (13.9%)	120 (30.7%)
Talking about how long you have to live	108 (88.5%)	319 (81.6%)	1 (0.8%)	14 (3.6%)	3 (2.5%)	17 (4.3%)	10 (8.2%)	41 (10.5%)
Talking about what dying might be like	108 (88.5%)	360 (92.1%)	1 (0.8%)	9 (2.3%)	6 (4.9%)	14 (3.6%)	7 (5.6%)	8 (2.0%)
Asking about spiritual, religious beliefs	111 (91.0%)	341 (87.2%)	2 (1.6%)	10 (2.6%)	6 (4.9%)	14 (3.6%)	3 (2.5%)	26 (6.6%)

Values reported as n (%)