Supplementary material Broese et al

**Table S1.** Survey items and nonresponse per item.

| # | Item | Answer options | Missing n (%) | |
| --- | --- | --- | --- | --- |
| Introduction | | | **Pulmo-**  **nologists** | **General Practitioners** |
|  | In this survey, we talk about palliative care and the palliative phase. Palliative care is an approach that improves the quality of life of patients and their relatives facing a life-threatening condition, by preventing and relieving suffering, through early detection and careful assessment and treatment of problems of a physical, psychological, social and spiritual nature. The palliative phase in patients with COPD is determined according to the guideline Palliative care for people with COPD by, among others:  • (a deterioration of) the clinical condition;  • status after intensive treatments with no (lasting) effect;  • the assessment of the need and desirability of palliative care from both patient and healthcare professional. | |  |  |
| Structure | | |  |  |
| 1 | How do you determine whether the palliative phase has started in patients with COPD? (Multiple answers possible) | * *This distinction is not made* * *On the basis of the GOLD classification* * *On the basis of clinical expertise* * *On the basis of information of/transfer by the pulmonologist\*\** * *By using the surprise question ("Would I be surprised if this patient dies within 12 months?")* * *Using the SPICT (Supportive and Palliative Indicators Tool) indicators* * *Using the RADPAC (Radboud Identification Palliative Patients) indicators* * *Using the Prolong or ProPal-COPD indicators* * *Based on the following clinical indicators* * *Different, namely* | 0 (0.0) | 0 (0.0) |
| 2 | Is there a specific protocol or are there specific appointments in your department\*/practice\*\* regarding the care of patients with COPD in the palliative phase? | *No – I don’t know – Yes. Please explain briefly* | 8 (6.2) | 4 (1.3) |
| 3 | Are there any plans for the coming year to (further) develop a specific protocol or specific agreements? | *No – I don’t know – Yes. Please explain briefly* | 11 (8.5) | 4 (1.3) |
| Experience | | |  |  |
| 4 | How much experience do you have with palliative care for patients with COPD? | *None – Little – A reasonable amount – A lot* | 6 (4.6) | 1 (0.0) |
| 5 | How many patients with COPD in the palliative phase do you treat on average per year? (an estimate is sufficient) | *…… patients per year* | 13 (10.0) | 15 (4.9) |
| *If you have not treated any patients with COPD in the palliative phase in the past year, please proceed to question 15.* | | |  |  |
| Symptom management | | |  |  |
| 6 | For the patients with COPD in the palliative phase you treated in the past year, how often did you give the treatments below? | |  |  |
|  | Morphine/opioid due to dyspnea | *Never – Rarely – Sometimes – Often – Always* | 7 (5.4) | 3 (1.0) |
|  | Non-pharmacotherapeutic treatment for dyspnea | *Never – Rarely – Sometimes – Often – Always* | 11 (8.5) | 11 (3.6) |
|  | Morphine / opioid due to pain | *Never – Rarely – Sometimes – Often – Always* | 10 (7.7) | 6 (2.0) |
|  | Pharmacotherapeutic treatment for anxiety or depression | *Never – Rarely – Sometimes – Often – Always* | 12 (9.2) | 8 (2.6) |
|  | Non-pharmacotherapeutic treatment for anxiety or depression | *Never – Rarely – Sometimes – Often – Always* | 13 (10.0) | 13 (4.3) |
| Communication | | |  |  |
| 7 | For the patients with COPD in the palliative phase you treated in the past year, how often did you discuss the following topics with the patient and/or relatives? | |  |  |
|  | Disease course and incurability | *Never – Rarely – Sometimes – Often – Always* | 13 (10.0) | 12 (3.9) |
|  | Life expectancy | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 14 (4.6) |
|  | Fear of choking | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 14 (4.6) |
|  | Fear of death / dying | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 20 (6.6) |
|  | Advantages and disadvantages of intensive life extension treatments (e.g. cardiopulmonary resuscitation) | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 19 (6.2) |
|  | Advantages and disadvantages of non-invasive ventilation (NIV) | *Never – Rarely – Sometimes – Often – Always* | 14 (10.8) | 18 (5.9) |
|  | Desirability of hospitalization in case of a future lung attack | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 16 (5.2) |
|  | Palliative treatment options for dyspnea (e.g. morphine) | *Never – Rarely – Sometimes – Often – Always* | 17 (13.1) | 17 (5.6) |
|  | Preferred place of death | *Never – Rarely – Sometimes – Often – Always* | 18 (13.8) | 16 (5.2) |
|  | Spiritual and existential needs | *Never – Rarely – Sometimes – Often – Always* | 18 (13.8) | 18 (5.9) |
|  | Caregiver burden | *Never – Rarely – Sometimes – Often – Always* | 19 (14.6) | 17 (5.6) |
|  | Goals of care | *Never – Rarely – Sometimes – Often – Always* | 20 (15.4) | 19 (6.2) |
| 8 | For the patients with COPD in the palliative phase you treated in the past year, where and when did you discuss treatment preferences with the patient and/or relatives? | |  |  |
|  | In the emergency room\*/At the patient’s home\*\* | *Never – Rarely – Sometimes – Often – Always* | 22 (16.9) | 22 (7.2) |
|  | At the outpatient clinic\*/In the general practice\*\* | *Never – Rarely – Sometimes – Often – Always* | 22 (16.9) | 27 (8.9) |
|  | During hospitalization\*/Just after hospitalization for an acute exacerbation\*\* | *Never – Rarely – Sometimes – Often – Always* | 23 (17.7) | 23 (7.5) |
|  | During a regular appointment | *Never – Rarely – Sometimes – Often – Always* | 22 (16.9) | 25 (8.2) |
|  | During a specially scheduled appointment for this purpose | *Never – Rarely – Sometimes – Often – Always* | 21 (16.2) | 23 (7.5) |
| 9 | How often in the past year did you have a conversation about the palliative phase, palliative treatment options and/or treatment preferences with only the next of kin, without the presence of the patient with COPD? | *Never – Rarely – Sometimes – Often – Always* | 21 (16.2) | 21 (6.9) |
| Collaboration | | |  |  |
| 10 | How satisfied are you with the exchange of information from the primary to the secondary care\*/from the secondary to the primary care\*\* in patients with COPD in the palliative phase? | *Very dissatisfied – Somewhat dissatisfied Neutral – Somewhat satisfied – Very satisfied* | 13 (10.0) | 15 (4.9) |
| 11 | How satisfied are you with the collaboration with general practitioners\*/pulmonologists\*\* in the care of patients with COPD in the palliative phase? | *Very dissatisfied – Somewhat dissatisfied Neutral – Somewhat satisfied – Very satisfied* | 15 (11.5) | 15 (4.9) |
| 12 | For the patients with COPD in the palliative phase that you treated in the past year, how often did you collaborate with the following healthcare providers in the care of these patients? | |  |  |
|  | general practitioner\*/pulmonologist\*\* | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 26 (8.5) |
|  | palliative care nurse in primary care | *Never – Rarely – Sometimes – Often – Always* | 15 (11.5) | 25 (8.2) |
|  | specialized COPD-nurse in primary care | *Never – Rarely – Sometimes – Often – Always* | 17 (13.1) | 27 (8.9) |
|  | practice nurse | *Never – Rarely – Sometimes – Often – Always* | 21 (16.2) | 27 (8.9) |
|  | specialized COPD-nurse or advanced nurse practitioner in hospital | *Never – Rarely – Sometimes – Often – Always* | 20 (15.4) | 27 (8.9) |
|  | district nurse | *Never – Rarely – Sometimes – Often – Always* | 20 (15.4) | 27 (8.9) |
| 13 | For the patients with COPD in the palliative phase that you treated in the past year, how often did you consult or refer to the following healthcare providers? | |  |  |
|  | palliative care consultant in hospital | *Never – Rarely – Sometimes – Often – Always* | 21 (16.2) | 21 (6.9) |
|  | physiotherapist | *Never – Rarely – Sometimes – Often – Always* | 21 (16.2) | 16 (5.2) |
|  | occupational therapist | *Never – Rarely – Sometimes – Often – Always* | 22 (16.9) | 20 (6.6) |
|  | speech therapist | *Never – Rarely – Sometimes – Often – Always* | 23 (17.7) | 22 (7.2) |
|  | psychologist | *Never – Rarely – Sometimes – Often – Always* | 21 (16.2) | 22 (7.2) |
|  | dietician | *Never – Rarely – Sometimes – Often – Always* | 23 (17.7) | 24 (7.9) |
|  | spiritual caregiver | *Never – Rarely – Sometimes – Often – Always* | 22 (16.9) | 24 (7.9) |
|  | social worker | *Never – Rarely – Sometimes – Often – Always* | 23 (17.7) | 25 (8.2) |
| Bereavement care | | |  |  |
| 14 | Of your patients with COPD who died in the past year, how often did you provide aftercare (care/support) to the relatives? | *Never – Rarely – Sometimes – Often – Always* | 26 (20.0) | 27 (8.9) |
| Barriers | | |  |  |
| 15 | In your opinion, what are the most important reasons that there is little or no discussion about the palliative phase, palliative treatment options and/or treatment preferences with a patient with COPD? (Multiple answer options possible) | * *The difficulty of predicting the disease course of COPD* * *The lack of a clear definition of the palliative phase in COPD* * *Healthcare professionals find it difficult to discuss this topic with COPD patients* * *Insufficient knowledge about treatment options in the palliative phase* * *The fear of losing the patient's hope* * *Patients do not want to discuss this topic* * *Patients have insufficient insight in and knowledge of their disease* * *Relatives do not want to discuss this topic* * *Patients have difficulty specifying what future care/treatment they want if their situation deteriorates* * *Patients' care/treatment wishes change over time* * *Suboptimal information exchange between primary and secondary care* * *No clear agreements between healthcare professionals on who is in the lead to discuss palliative care issues with the patient* * *Insufficient financial compensation* * *Lack of time* * *Different, namely:* | 17 (13.1) | 14 (4.6) |
| Demographics & education | | |  |  |
| 16 | What is your age? | *……year* | 18 (13.8) | 20 (6.6) |
| 17 | What is your gender? | *Male – Female* | 7 (5.4) | 20 (6.6) |
| 18\* | What is your position?\* | *Pulmonologist – Pulmonologist in training – Non-practicing pulmonologist* | 19 (14.6) | N/A |
| 18\*\* | Do you work as an attending or permanent general practitioner?\*\* | *Attending GP – Permanent GP* | N/A | 24 (7.9) |
| 19 | How many years of experience do you have as a pulmonologist (i.t.)\*/general practitioner\*\*? | *……years* | 18 (13.8) | 20 (6.6) |
| 20\* | What type of hospital do you work in?\* | *General hospital – Top clinical hospital – University medical center* | 17 (13.2) | N/A |
| 20\*\* | Where do you work (first part of postal code)\*\* |  | N/A | 24 (7.9) |
| 21\* | How many pulmonologists are working in your department?\* | *…… pulmonologists* | 21 (16.2) | N/A |
| 21\*\* | Have you followed the post graduate course in asthma/COPD?\*\* | *No – Yes* | N/A | 23 (7.5) |
| 22 | Have you received education and/or training in palliative care? | * *No.* * *Yes, the Dutch postgraduate course palliative care (2 years) or Cardiff Palliative Medicine Course (post graduate)* * *Yes, 8-day palliative care course for medical specialists\** * *Yes, 2-day course palliative care of KNMG\*\** * *Yes, different namely:* | 18 (13.8) | 28 (9.2) |

\* Item for pulmonologists only. \*\* Item for general practitioners only.

**Table S2.** Symptom management in patients with COPD in the palliative phase by physicians with (T) and without (NT) any training in palliative care.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | **Never** | **Rarely** | **Sometimes** | **Often** | **Always** | ***p* valuea** |
| Dyspnea using opioids | Pulmonologists | T | 0 (0.0) | 2 (5.1) | 3 (7.7) | 31 (79.5) | 3 (7.7) | .891 |
|  | NT | 0 (0.0) | 1 (1.4) | 14 (20.0) | 45 (64.3) | 10 (14.3) |  |
|  | GPs | T | 1 (1.3) | 1 (1.3) | 15 (20.0) | 38 (50.7) | 20 (26.7) | .636 |
|  |  | NT | 4 (2.2) | 2 (1.4) | 24 (17.1) | 67 (47.9) | 43 (30.7) |  |
| Dyspnea using non-pharmacological treatment | Pulmonologists | T | 0 (0.0) | 3 (7.7) | 8 (20.5) | 23 (59.0) | 5 (12.8) | .051 |
|  | NT | 0 (0.0) | 6 (9.0) | 26 (38.8) | 31 (46.3) | 4 (6.0) |  |
|  | GPs | T | 1 (1.4) | 5 (6.8) | 26 (35.6) | 31 (42.5) | 10 (13.7) | .078 |
|  |  | NT | 10 (7.4) | 18 (13.3) | 43 (31.9) | 49 (36.3) | 15 (11.1) |  |
| Pain using opioids | Pulmonologists | T | 2 (5.3) | 6 (15.8) | 20 (52.6) | 8 (21.1) | 2 (5.3) | .663 |
|  | NT | 4 (5.8) | 17 (24.6) | 28 (40.6) | 17 (24.6) | 3 (4.3) |  |
|  | GPs | T | 4 (5.5) | 14 (19.2) | 29 (39.7) | 22 (30.1) | 4 (5.5) | **.048** |
|  |  | NT | 14 (10.1) | 36 (25.9) | 54 (38.8) | 30 (21.6) | 5 (3.6) |  |
| Anxiety/depression using pharmacological treatment | Pulmonologists | T | 2 (5.3) | 5 (13.2) | 20 (52.6) | 10 (26.3) | 1 (2.6) | .237 |
|  | NT | 6 (8.7) | 17 (24.6) | 28 (40.6) | 17 (24.6) | 1 (1.4) |  |
|  | GPs | T | 2 (2.8) | 9 (12.5) | 31 (43.1) | 28 (38.9) | 2 (2.8) | .196 |
|  |  | NT | 11 (8.0) | 18 (13.0) | 62 (44.9) | 43 (31.2) | 4 (2.9) |  |
| Anxiety/depression using non-pharmacological treatment | Pulmonologists | T | 1 (2.8) | 6 (16.7) | 12 (33.3) | 16 (44.4) | 1 (2.8) | **.030** |
|  | NT | 4 (5.7) | 17 (24.3) | 32 (45.7) | 16 (22.9) | 1 (1.4) |  |
|  | GPs | T | 0 (0.0) | 7 (10.3) | 35 (51.5) | 22 (32.4) | 4 (5.9) | **.011** |
|  |  | NT | 14 (10.1) | 27 (19.6) | 56 (40.6) | 34 (24.6) | 7 (5.1) |  |

Data are expressed as absolute values and percentages.

a*P*-values based on Mann-Whitney *U*-test.

**Table S3.** Frequency of topics discussed by physicians, with (T) and without any training in palliative care (NT), in the previous year.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | **Never** | **Rarely** | **Sometimes** | **Often** | **Always** | ***p* valuea** |
| Disease course and incurability | Pulmonologists | T | 0 (0.0) | 1 (2.8) | 2 (5.6) | 20 (55.6) | 13 (36.1) | .130 |
|  | NT | 0 (0.0) | 1 (1.4) | 9 (12.9) | 44 (62.9) | 16 (22.9) |  |
|  | GPs | T | 0 (0.0) | 1 (1.4) | 6 (8.6) | 28 (40.0) | 35 (50.0) | .314 |
|  |  | NT | 2 (1.4) | 1 (0.7) | 16 (11.6) | 59 (42.8) | 60 (43.5) |  |
| Life expectancy | Pulmonologists | T | 0 (0.0) | 5 (14.3) | 11 (31.4) | 13 (37.1) | 6 (17.1) | .780 |
|  | NT | 0 (0.0) | 7 (10.1) | 29 (42.0) | 22 (31.9) | 11 (15.9) |  |
|  | GPs | T | 3 (4.3) | 5 (7.1) | 16 (22.9) | 33 (47.1) | 13 (18.6) | .737 |
|  |  | NT | 5 (3.7) | 10 (7.4) | 34 (25.0) | 54 (39.7) | 33 (24.3) |  |
| Fear of choking | Pulmonologists | T | 0 (0.0) | 0 (0.0) | 3 (8.8) | 20 (58.8) | 11 (32.4) | **.015** |
|  | NT | 0 (0.0) | 2 (2.9) | 15 (21.4) | 42 (60.0) | 11 (15.7) |  |
|  | GPs | T | 0 (0.0) | 1 (1.4) | 11 (15.7) | 37 (52.9) | 21 (30.0) | .406 |
|  |  | NT | 1 (0.7) | 6 (4.4) | 18 (13.2) | 57 (41.9) | 54 (39.7) |  |
| Fear of death/dying | Pulmonologists | T | 0 (0.0) | 1 (2.9) | 9 (25.7) | 15 (42.9) | 10 (28.6) | **.025** |
|  | NT | 1 (1.4) | 6 (8.7) | 25 (36.2) | 28 (40.6) | 9 (13.0) |  |
|  | GPs | T | 0 (0.0) | 2 (3.0) | 10 (14.9) | 32 (47.8) | 23 (34.3) | .440 |
|  |  | NT | 2 (1.5) | 4 (2.9) | 14 (10.3) | 62 (45.6) | 54 (39.7) |  |
| Advantages and disadvantages of life sustaining treatments | Pulmonologists | T | 0 (0.0) | 0 (0.0) | 4 (11.4) | 12 (34.3) | 19 (54.3) | .119 |
|  | NT | 0 (0.0) | 1 (1.4) | 4 (5.8) | 41 (59.4) | 23 (33.3) |  |
| GPs | T | 0 (0.0) | 0 (0.0) | 8 (11.9) | 28 (41.8) | 31 (46.3) | .987 |
|  |  | NT | 0 (0.0) | 6 (4.4) | 11 (8.1) | 55 (40.4) | 64 (47.1) |  |
| Advantages and disadvantages of non-invasive ventilation | Pulmonologists | T | 0 (0.0) | 2 (5.7) | 7 (20.0) | 18 (51.4) | 8 (22.9) | .479 |
|  | NT | 0 (0.0) | 2 (2.9) | 18 (25.7) | 40 (57.1) | 10 (14.3) |  |
|  | GPs | T | 12 (17.6) | 14 (20.6) | 24 (35.3) | 11 (16.2) | 7 (10.3) | .064 |
|  |  | NT | 39 (28.7) | 33 (24.3) | 34 (25.0) | 20 (14.7) | 10 (7.4) |  |
| Desirability of hospitalization for acute exacerbation | Pulmonologists | T | 0 (0.0) | 2 (5.7) | 12 (34.3) | 17 (48.6) | 4 (11.4) | .214 |
|  | NT | 1 (1.4) | 8 (11.6) | 24 (34.8) | 33 (47.8) | 3 (4.3) |  |
|  | GPs | T | 0 (0.0) | 1 (1.4) | 10 (14.5) | 32 (46.4) | 26 (37.7) | .597 |
|  |  | NT | 2 (1.5) | 2 (1.5) | 14 (10.2) | 63 (46.0) | 56 (40.9) |  |
| Palliative treatment options for dyspnea (e.g. morphine) | Pulmonologists | T | 0 (0.0) | 0 (0.0) | 1 (2.9) | 24 (70.6) | 9 (26.5) | .283 |
|  | NT | 0 (0.0) | 0 (0.0) | 8 (11.8) | 45 (66.2) | 15 (22.1) |  |
|  | GPs | T | 0 (0.0) | 0 (0.0) | 4 (5.8) | 28 (40.6) | 37 (53.6) | .893 |
|  |  | NT | 0 (0.0) | 1 (0.7) | 8 (5.9) | 52 (38.2) | 75 (55.1) |  |
| Preferred place of death | Pulmonologists | T | 0 (0.0) | 3 (9.1) | 10 (30.3) | 15 (45.5) | 5 (15.2) | **.005** |
|  | NT | 5 (7.4) | 15 (22.1) | 25 (36.8) | 17 (25.0) | 6 (8.8) |  |
|  | GPs | T | 0 (0.0) | 2 (2.9) | 6 (8.7) | 30 (43.5) | 31 (44.9) | .638 |
|  |  | NT | 1 (0.7) | 4 (2.9) | 17 (12.4) | 44 (32.1) | 71 (51.8) |  |
| Spiritual and existential needs | Pulmonologists | T | 3 (8.8) | 7 (20.6) | 17 (50.0) | 5 (14.7) | 2 (5.9) | **.007** |
|  | NT | 11 (16.4) | 30 (44.8) | 18 (26.9) | 7 (10.4) | 1 (1.5) |  |
|  | GPs | T | 1 (1.5) | 6 (8.8) | 29 (42.6) | 22 (32.4) | 10 (14.7) | .257 |
|  |  | NT | 9 (6.6) | 20 (14.7) | 48 (35.3) | 40 (29.4) | 19 (14.0) |  |
| Caregiver burden | Pulmonologists | T | 0 (0.0) | 2 (5.7) | 16 (45.7) | 15 (42.9) | 2 (5.7) | **.003** |
|  | NT | 1 (1.5) | 15 (23.1) | 34 (52.3) | 13 (20.0) | 2 (3.1) |  |
|  | GPs | T | 1 (1.5) | 0 (0.0) | 13 (19.1) | 37 (54.4) | 17 (25.0) | .641 |
|  |  | NT | 1 (0.7) | 4 (2.9) | 29 (21.2) | 69 (50.4) | 34 (24.8) |  |
| Goals of care | Pulmonologists | T | 0 (0.0) | 0 (0.0) | 15 (42.9) | 15 (42.9) | 5 (14.3) | **.020** |
|  | NT | 0 (0.0) | 11 (17.2) | 28 (43.8) | 20 (31.3) | 5 (7.8) |  |
|  | GPs | T | 4 (6.0) | 8 (11.9) | 23 (34.3) | 23 (34.3) | 9 (13.4) | .302 |
|  |  | NT | 16 (11.8) | 15 (11.0) | 51 (37.5) | 35 (25.7) | 19 (14.0) |  |

Data are expressed as absolute values and percentages.

a*P*-values based on Mann-Whitney U test.