Author's response to reviews

Title: End-of-life care in a COPD patient awaiting lung transplantation: a case report

Authors:

Daisy J.A. Janssen (daisyjanssen@proteion.nl)
Martijn A. Spruit (martijnstrup@proteion.nl)
Joan D. Does (joandoes@proteion.nl)
Jos M.G.A. Schols (jos.schols@hag.unimaas.nl)
Emiel F.M. Wouters (e.wouters@mumc.nl)

Version: 2 Date: 1 March 2010

Author's response to reviews: see over
Dear Editor in Chief,

We thank you for the opportunity to submit the thoroughly revised manuscript entitled "End-of-life care in a COPD patient awaiting lung transplantation: a case report" (manuscript number: MS: 3381378843158628) and a point-by-point reply concerning the reviewers’ reports. May we respectfully ask you to take the revised version of our manuscript into consideration for publication for BMC Palliative Care?

Sincerely,

Daisy J.A. Janssen, MD
Martijn A. Spruit, PhD
Joan D. Does, MD
Prof. Jos M.G.A. Schols, PhD MD
Prof. Emiel F.M. Wouters, PhD MD

Financial disclosure: none
Point-by-point reply - Reviewer 1

Major points

C1. There is no clear description the rational behind why the patient was admitted to the nursing home. Was it to get a nursing care or palliative care or social care?

R1. The aim of admission to the specialized nursing home unit was providing nursing care and interdisciplinary care to improve her functional status. This has been added to page 4, line 16-17, of the revised version of the manuscript.

C2. The history of the patient requires more information in terms of Pa Co2 and the duration and dosage of oxygen therapy she was receiving when the patient was considered for lung transplantation.

R2. Since 2001 she used long-term oxygen therapy. (page 4, line 13 of the original submission). Since 2005 the patient was listed for lung transplantation (page 4, line 16 of the original submission). At that moment she needed two liters oxygen per minute for 24 hours a day. Her arterial carbon dioxide tension (PaCO₂) was 6.2 kPa. This has been added to page 4, line 26-28 of the revised manuscript.

C3. The life expectancy for a patient with FEV1 < 15% of predicted values (life expectancy? 2 years) necessitate the patient to be in the high priority list in 2005. Why this has not been done for this patient?

R3. Despite the FEV₁ of 15% of predicted values at admission to the nursing home, in 2006 she did not fulfil the criteria for the high priority list for COPD patients. However, in June 2007 she did fulfil the criteria and was accepted for the high priority list (page 5, line 7-8 of the original submission). According to our currently available knowledge FEV₁ is in Europe not one the criteria for high priority list for COPD patients.

C4. I wonder whether the authors able to explain the reasons behind why other forms of surgical procedures were not considered for this patient.

R4. Other surgical procedures were considered, like lung volume reduction surgery, but were not possible because of homogeneous distribution of her emphysema on High Resolution Computed Tomography (HRCT). This has been clarified on page 5, line 1-2 of the revised manuscript.
C5. How long was the patient-centred management programme?
R5. She was offered the patient-centred management programme from admission to the nursing home until she died.

C6. How was anxiety measured for this patient? Was the patient suffering clinically anxiety or anxiety symptoms? “She was treated by the psychosocial team”. What kind of treatment do they provide?
R6. She was suffering from clinically relevant symptoms of anxiety measured with the Hospital Anxiety and Depression Scale (HADS), a validated and reliable measurement instrument used widely in medically ill patients. (Zigmond and Snaith 1983) Therefore, she was treated by the psychosocial team with psychological individual counselling and art therapy. This has been added to page 5, line 18-22 of the revised manuscript.

C7. In September 2008 when the patient was housebound and receiving high dosages of corticosteroids and the morphine level was increased to 40 mg. I wonder why the team did not consider referring the patient for the palliative care treatment.
R7. In September 2008 the possibilities of palliative care were discussed with the patient and her family and in October she agreed with palliative treatment (page 6, line 11-20 of the original submission).

C8. There is confusion between the ‘curative-restorative care’ and ‘palliative care’. The potential benefits (advantages and disadvantages) providing both cares simultaneously for this patient should be explained in the text.
R8. The following part has been added to page 3, line 28 to page 4, line 3 of the revised manuscript: “Recently has been described the need for a model of care in which comprehensive palliative care approaches are embedded within curative-restorative care. (Lanken, Terry et al. 2008; Goodridge, Marciniuk et al. 2009) However, goals of palliative care and curative-restorative care may be conflicting. For example, life-prolonging interventions may interfere with quality of life. (Pochard, Lanore et al. 1995)”

C9. The manuscript requires rigorous editing for grammatical and syntax errors and repetitions to improve the message of the paper
R9. The manuscript has been edited and thoroughly revised.
C10. It would be helpful to state the main key findings of this case report.
R10. Key findings have been added to page 8, line 2 of the revised manuscript.

Minor points

C11. Clarify the points you are referring to spiritual symptoms.
R11. The sentence “In addition, pastoral care supported her with her existential questions concerning her disease and dying.” has been added to page 7, line 15-16 of the revised version of this manuscript.

Point-by-point reply - Reviewer 2

C1. It would be helpful to specifically describe competing/conflicting goals of care in the background section and the confusion that can be engendered for patients, families and clinicians.
R1. The following part has been added to page 3, line 28 to page 4, line 3 of the revised version of the manuscript: “Recently has been described the need for a model of care in which comprehensive palliative care approaches are embedded within curative-restorative care. However, goals of palliative care and curative-restorative care may be conflicting. For example, curative-restorative interventions may interfere with quality of life.”

C2. I think a short discussion of supportive care and how it is similar/different from conventional palliative care would also be useful.
R2. This comment is not clear to the present authors. The broad WHO definition of palliative care, used in the present case report, has been provided on page 3, line 21-25 of the original submission. In our opinion the term supportive care can be used instead of palliative care. However, the term palliative care is used more often in the currently available literature and better defined.

C3. p. 7 A more complete discussion of whether this patient met all of the transplant criteria as she became more ill would be helpful. Were these criteria re-visited?
**R3.** The transplant criteria were regularly re-visited. For example, she was admitted to the transplant centre in June 2008 to evaluate if she was still an appropriate candidate for lung transplantation. (page 5, line 19-20 of the original submission).

**C4.** What are the implications to the patient and family of taking them off of the list? Incorporating a discussion of ethical principles and values would strengthen the discussion.

**R4.** The following part has been added to the revised manuscript (page 8, line 11-19): “Since this patient was listed for lung transplantation she showed a progressive decline. The transplant criteria were regularly re-visited and several times she was temporarily de-listed, which had significant consequences for the patient and her loved ones. Nevertheless, the persistent scarcity of donor lungs asks for a careful selection of lung transplant candidates.(De Meester, Smits et al. 2001) Although the success rate of lung transplantation has gradually improved, morbidity and mortality rate immediately post-transplant remain considerably high.(De Meester, Smits et al. 2001) Minimizing the chance of dying while on the waiting list is justified from the equity perspective, but wasting of donor lungs need to be avoided by de-listing of patients without a significant chance for successful transplantation.(De Meester, Smits et al. 2001; Glanville 2006)”.

**C5.** There is a significant body of literature related to treatment decision making that should be incorporated into the discussion.

**R5.** The following part has been added to the revised version of the manuscript (page 9, line 11-13): “COPD patients may be confronted with acute life-threatening exacerbations. Therefore, timely advance care planning before such a crisis occurs, is necessary to guide treatment at the end of life.(Goodridge 2006)”

**C6.** The clarity of the manuscript will be greatly improved if the following editorial comments relating to grammar are incorporated:

a) Abstract:To prevent that eol care needs of COPD patients dying ...are not optimally addressed.

**R6.** This sentence has been changed in: “Discussing the possibilities of palliative care and the patient’s treatment preferences is necessary to prevent that end-of-life care needs of COPD patients dying while listed for lung transplantation are not optimally addressed.” (page 2, line 11-14 of the revised manuscript)
C7. b) Abstract: The patient's end-of-life care preferences may ask for a clear distinction....

R7. This sentence has been changed in: “The patient's end-of-life care preferences may ask for a clear distinction between the period in which palliative and curative-restorative care are offered concurrently and the end-of-life care period.” (page 2, line 14-16 of the revised manuscript)

C8. c) The background is one long paragraph and will read much better if it is made into several paragraphs. The writing here is quite choppy.

R8. The background is divided in several paragraphs.

C9. d) p. 3 survival benefit of lung transplantation remains debated (debatable?)

R9. ‘Debated’ has been changed in “debatable” (page 3, line 18 of the revised manuscript).

C10. e) Case Report: This section would benefit from general editing to improve flow and again the use of more paragraphs to mark changes in topic.

R10. The section ‘case report’ has been edited and has been divided in paragraphs.