

Chronic Lung Allograft Dysfunction (CLAD): a collaborative approach with palliative care

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Introduction

CLAD is the leading cause of late mortality following lung transplantation. The two main components of CLAD are the bronchiolitis obliterans syndrome (BOS) and the restrictive allograft syndrome (RAS), first described in 2011 [1]. Most CLAD patients develop an obstructive disease, but 28 % develop a restrictive disease with a worse survival than BOS. Studies show a 26-32% survival at 5 years after developing CLAD [2].

In the Lausanne-Geneva lung transplantation program about 3-5 patients a year die of CLAD. Our experience shows that patients with CLAD suffer not only from physical symptoms but also from psychological, social and spiritual distress related to their specific medical history.

This is why we made the hypothesis that the quality of life of these patients can be improved by incorporating palliative care early in the management of CLAD. As in the literature there are no reports about CLAD/palliative care and in order to improve the care of the patients we have to explore their needs through a qualitative study.

Objectives

- To identify the patients' needs (physical, psychological, social, existential)
- To identify their wishes about care planning
- To identify the needs of the family

Methods: mixed approach qualitative/quantitative

We make interviews, during 9 months of follow up by patient/relative, which are recorded and analyzed through a framework approach [3].

Patients:

a) qualitative:

- 4 depth-interviews of 1.5 hours are conducted by a nurse specialized in qualitative study.
- The interviews are recorded and transcribed.
- The interviews are analyzed using the framework approach.

b) quantitative:

- Evaluations of the symptoms by the Edmonton Symptom Assessment System (ESAS) [4] and quality of life by the SF36 questionnaire [5].

Relatives:

a) qualitative:

- 2 depth-interviews of 1.5 hours are conducted by the same nurse (at the beginning and at the end of the study), recorded, transcribed and analyzed.

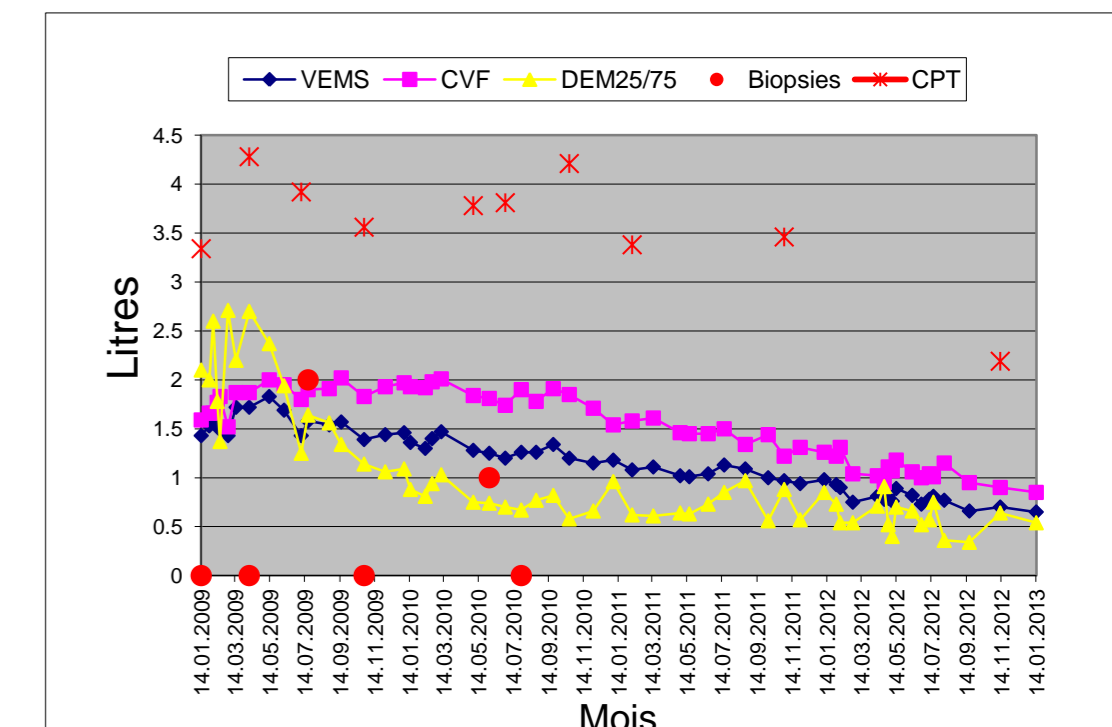
About one case

This is a representative case of this ongoing study:

Woman, 58 years old, RAS diagnosed in 2011

Confronted to the diagnosis of CLAD the woman reacted with denial until mid 2012. We began in August 2012 a collaborative approach with the palliative care unit every two-three weeks. During these sessions, the patient could explain physical, psychosocial and existential suffering:

- anorexia evaluated as 7/10 with ESAS,
- asthenia : 3/10,
- depression: 5/10,
- fears about suffering, about inappropriate care at moment of dying, and leaving her children alone: 5/10.



During the following six months, we help the patient to identify her values and priorities with a "Go Whish" game. After this work, the patient was able to write advance directives. She gradually became more peaceful. In February 2013, the anxiety and the depression were evaluated as 2/10. She was able to speak of her death and to express wishes about her end of life to her children and medical staff.

In March, she was hospitalized because of terminal respiratory failure due to RAS and lung infection. Her advance directives were very helpful to organize palliative care the way she expected. She was accompanied by her children, severe dyspnea could be controlled by morphine and midazolam. She died peacefully 3 days after admission.

This patient taught us much how to support patient with CLAD, to consider not only somatic dimensions but also psychosocial and existential needs.

Conclusions

Palliative care is not common practice in the field of solid organ transplantation

However, we believe that this early collaborative approach may substantially improve the global management of the patient.

We hope that our study will be helpful not only for lung transplanted patients but also for others with Chronic Allograft Dysfunction (heart, liver, kidney).

References

- 1: Sato, M., et al., *Restrictive allograft syndrome (RAS): a novel form of chronic lung allograft dysfunction*. J Heart Lung Transplant, 2011. **30**(7): p. 735-42.
- 2: Verleden, G.M., et al., *Survival determinants in lung transplant patients with chronic allograft dysfunction*. Transplantation, 2011. **92**(6): p. 703-8.
- 3: Elkington, H., et al., *The last year of life of COPD: a qualitative study of symptoms and services*. Respir Med, 2004. **98**(5): p. 439-45
- 4: Bruera, E., et al., *The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients*. J Palliat Care, 1991. **7**(2): p. 6-9
- 5: Gandek, B., et al., *Tests of data quality, scaling assumptions, and reliability of the SF-36 in eleven countries: results from the IQOLA Project. International Quality of Life Assessment*. J Clin Epidemiol, 1998. **51**(11): p. 1149-58