

Advanced respiratory disease care. Psychological and emotional needs of patients and caregivers.

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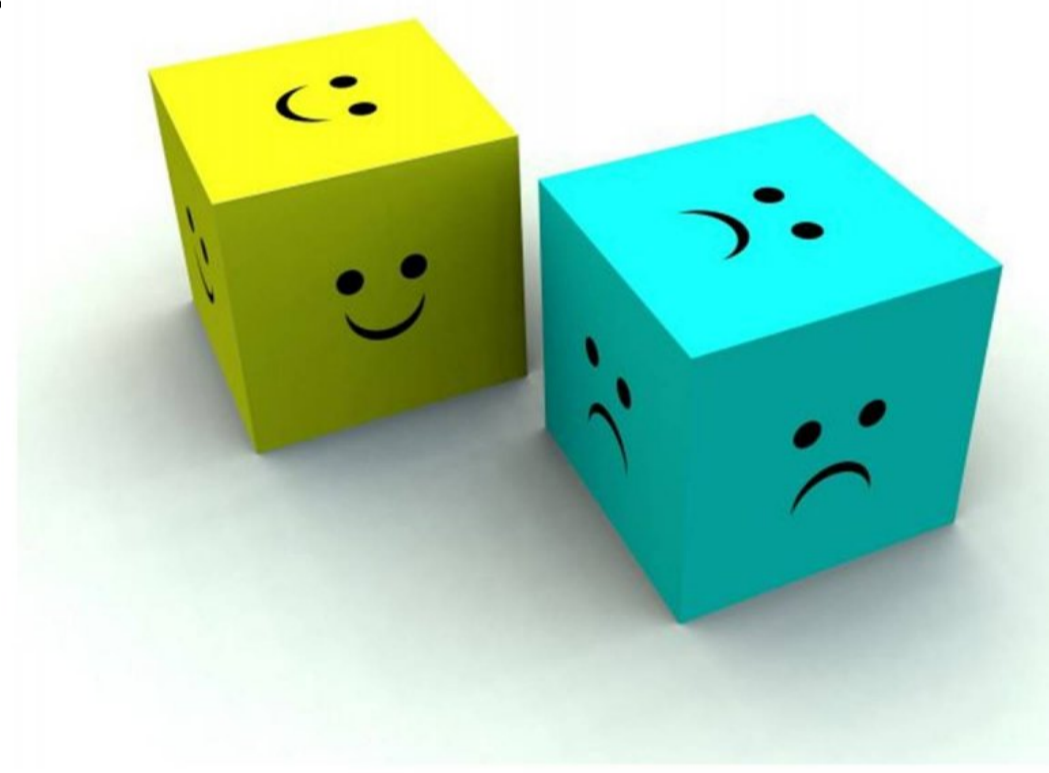
Project abstract

Care for people with advanced chronic respiratory disease often focuses on clinical management aspects to control severe symptoms that impact on their lives and their caregivers. This common practice reduces the management time that professionals could devote to other kind of latent needs such as psychological and emotional needs.



Methodology / Materials

- **Objective:** To determine the profile of psychological and emotional needs of people with advanced chronic lung disease from the perspective of patients, carers and the professionals responsible for their care.
- **Design:** Qualitative study. Grounded Theory approach. Semi-structured and in-depth interviews with patients, caregivers and primary care professionals (47 interviews). The interviews were recorded on audiotape and literally transcribed for their subsequent analysis of the issues and the discourse (software Atlas.ti).
- **Participants:** 10 patients, 10 caregivers and 19 primary care professionals (doctors and nurses), 2 Respiratory Specialists, 2 Palliative Care Specialists (PADES) involved in their care and Clinical Psychologist 1 (expert). The patients of the sample were randomly recruited from primary care patients with advanced respiratory disease and no evidence of significant cognitive impairment.
- **Location:** County of Osona.
- **Period:** 2013-2014.



Conclusions

The emotional impact of the disease on advanced chronic respiratory patients and caregivers is a prevalent element that causes great suffering, little expressed and with low demand of help. However this emotional impact were identified as a latent need that should be covered by a comprehensive approach by professionals from a general and specialized perspective.



Findings / Research update

- **Patients:** their characteristics (age, gender, life expectations, history of the disease) influence in the psychological impact and the degree of adaptation to the limitation that causes the disease. The fluctuations of their mood or emotional state and intensity of psychological symptoms (anxiety, fear, anger and depression) are mediated by basal dyspnea and its exacerbation in the crisis and the limitations that it causes. Fear of death is a latent feeling that emerges when increasing dyspnea in the crisis. The acceptance and adaptation to losses caused by disease and dependence are essential to minimize the emotional impact.
- **Caregivers:** their mood or emotional state and the presence of psychological symptoms (anxiety, fear, depression) is parallel to the clinical condition of patients. The emotional overload is added to the physical overload (support in Activities of Daily Living) and disease management patient entails a state of permanent alert. The severe crisis episodes cause an anticipation of mourning for the loss of patients who care.
- **Primary Care Professionals:** they detect the emotional impact on patients and caregivers but the implemented support measures usually reduces to pharmacological actions. Often, this lack of intervention is justified by the absence of explicit demand from patients and caregivers. The emotional impact on the caregiver is often underestimated and furthermore is considered a sign of weakness. The professionals recognize training gaps to make this approach.

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