Advance Care Planning with COPD Patients

Planificación de cuidados y tratamientos en pacientes EPOC

To the Editor:

After reading the interesting article by A. Couceiro,¹ I think it is appropriate to elaborate on it with the results of a qualitative study² that explores decision making in COPD patients in terms of their treatment, based on their knowledge of the disease, information provided by the doctor in charge, and the patient’s preferences (Research assistance from the Respira Foundation, SEPAR grants, 2002). Semi-structured interviews were carried out with 40 patients (36 men and 4 women) with a mean age of 68.82 years. Most felt well-informed and none thought the information given was incomplete or that it was being concealed from them. None had ever been spoken to by their doctor in charge about being admitted to the ICU or about mechanical ventilation (MV) as a possible treatment for a severe exacerbation, except for 2 who had previously been admitted to the ICU. After an explanation of MV as part of a the treatment for severe exacerbations, they gave their consent to the procedure if it meant they could improve and maintain their current quality of life—‘I would choose intubation if it means I can carry on living like up till now, but if I don’t improve after about six days, they can give me something to stop the suffering and that’s it…at least we tried.’

The patients interviewed had an adequate level of information about the etiology of COPD, its common symptoms, and that it is a chronic and progressive disease. Despite this, many gaps were detected in the information given regarding prognosis, knowledge of MV, and admission to the ICU as treatment options for severe exacerbations. The process of providing information is commonly seen to stop at a point, a boundary that is difficult to cross: talking about end-of-life matters. Going beyond the everyday range of topics of the medical relationship to talk about more transcendental matters and find out the possible ways to proceed when their situation is not as stable as at present is something that still needs to be looked at.

One of the reasons for this lack of information may be the doctor in charge’s fear of frustrating the patient’s hopes. Certainly, if we want the patients to collaborate effectively in the process, it is important to know what their expectations and wishes are.³ It appears that the relationship of trust is based on everything is OK, and both sides avoid talking about unpleasant matters such as serious complications or the possibility of dying of COPD.

Most patients were unaware of the possibility of putting into writing their preferences regarding health-related matters with an advance directive (AD). Furthermore, it did not occur to them that it might be of interest to them. They believed that it was aimed at people who are dying. Another possible reason for the lack of information about care planning is that the doctor in charge is convinced that they really know their patient’s preferences.⁴ Several studies have shown that this is often not the case. Even when both opinions coincide, the AD process could be of use because the doctor who has to make the decisions in severe acute situations would most likely not have prior knowledge of the patient.⁵⁶
With COPD patients there is a series of circumstances which make this type of conversations easier, for example the patient’s trust in their doctor and the numerous opportunities offered by routine consultations during stable phases of the disease. It is important to take advantage of this to find a moment and pause, to talk about the future, about the patient’s personal wishes in the event of becoming seriously ill or at times of uncertainty, in order to plan the end of their life according to their values and preferences. Health care professionals need ongoing training in end-of-life problems and advance care planning. If the model of good practice is to become more deliberative and participative, it will be necessary to improve the patients’ involvement in decision-making, which nowadays rarely happens. Therefore, the first step is to improve the quality of the information process, a basic requirement to start making decisions.

Funding

Research assistance from the Respira foundation, SEPAR GRANTS 2002.

References


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