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Autonomy and dyspnea in palliative care: A case report

Introduction

Dyspnea is a complex and subjective experience, its intensity is wholly determined by the patient's sensation and how it is perceived depends on previous beliefs, emotions, values and experiences.[1,2] Several measures are employed to alleviate dyspnea, which must be acceptable to the patient. Thus, therapeutic adherence is promoted, and a good symptomatic control is achieved, as illustrated in the present case.

Case report

M.S., female, 61 years old, divorced, retired, with asthma-chronic obstructive pulmonary disease overlap syndrome (ACOS) diagnosed four years ago, and still worsening, currently under noninvasive ventilation (NIV) and long-term oxygen therapy (LTOT). She has a history of hypertensive heart disease and anxiety disorder. She is an ex-smoker (40 Units Year Package).

She was followed in outpatients clinics in General and Family Medicine and Pulmonology, suffering from irreversible respiratory insufficiency, which was potentially difficult to control due to therapeutic failure. She had had multiple admissions to acute hospitals due to the exacerbation of her pathology, ending up being referred to and admitted into a Palliative Care Unit (PCU) for symptomatic control of dyspnea and fatigue. On admission she presented with a grade 4 dyspnea (Modified Dyspnea Scale Medical Research Council) and a performance status of 4 (Eastern Cooperative Oncology Group). Her Palliative Performance Scale was 50–60%. She was prescribed montelukast 10 mg id, aminophylline 225 mg bid, tiotropium bromide 1.25 mcg 2 id inhalations, fluticasone/salmeterol 250/25 mcg 2 bid inhalations, salbutamol 100 mcg PRN inhalations, lisinopril 5 mg id, omeprazole 20 mg id, and hydroxyzine 25 mg bid.

After her admission to the PCU, therapeutic adjustments were made according to her symptoms. Prolonged-release morphine was prescribed (10 mg bid) after proper titration with immediate-release morphine (5 mg PRN), butylscopolamine 20 mg tid, prednisolone 10 mg id and laxatives (macrogol 13.7 g bid and sennosides 7.5 mg bid). Due to the patient's refusal to keep on LTOT and NIV, even after multiple adjustments, they were progressively reduced and suspended; yet symptomatic control was not compromised. Likewise, due to the patient's non-compliance with inhalation therapy, without the symptomatic relief expected, and considering her wishes, it was suspended. She used a hand fan, but because there was an air conditioner unit in the room, she preferred to turn it on. Pulse oximetry, when measured, was more than 90%. A physical rehabilitation plan was implemented with an adaptative training program.

Because she complained of pruritus, an opioid-related side-effect, morphine dose was initially reduced, and an opioid rotation to tapentadol was done.

At follow up evaluation after three weeks, through daily clinical evaluation, symptoms have been well controlled: dyspnea and fatigue are mild (self-assessment). She is fully motivated to her rehabilitation plan and shows good compliance with it.

Currently her regular medications are: escitalopram 10 mg id, pantoprazole 20 mg id, aminophylline 225 mg bid, lorazepam 1 mg id, tapentadol 50 mg bid, prednisolone 5 mg id and bisacodyl 5 mg id.

Discussion

Patients diagnosed with ACOS are over 40 years old (15–55% of them are over 50 years old) and experience frequent exacerbations, showing a quick decline in lung function and high mortality.[3]

Mrs MS frequent exacerbations and worsening of her clinical condition were considered to be due to lack of motivation to adhering to the therapeutic regimen and other inherent factors. In fact, perhaps Mrs MS did not understand the therapeutic plan, or the medications she was prescribed were not adjusted to her needs. Moreover, a lack of an effective doctor–patience communication may have led to non-compliance and therapeutic failure.

The principle of autonomy respects the ability of an individual to self-determination, allowing or enabling patients to make their own decisions about any medical interventions.[4] Consequently, the doctor-patient relationship has moved from a paternalistic and disease-centered model to a person-centered care model. Informed consent is essential to the latter process and the patient has the right to refuse any intervention that is proposed.[5]

In Portugal, according to Decree-Law no. 25/2012 (July 16th), a legally aged and capable person, who is not prohibited or disabled by psychiatric abnormality, can declare and specify the type(s) of healthcare he/she wishes to receive, or not, in case of – for any reason – he/she finds

him/herself unable to express his/her preferences, personally and autonomously, in the form of advance directives, namely in the form of a living will. This document has to record provisions relating to healthcare for serious or irreversible illnesses at an advanced stage, including appropriate symptomatic therapy.

Mrs MS had neither interest nor the will to keep to a therapeutic plan that included inhalers, masks or any other of the respiratory accessories that were proposed, which is the reason why she did not comply with them at all. With Mrs MS preferences and in her best interest in mind, pharmacological adjustments were made to her plan of care, leading to good symptomatic control and excellent therapeutic adherence.

In palliative care (PC), in advanced respiratory diseases, symptomatic relief of dyspnea is of capital importance. Pharmacologic palliation of dyspnea involves the use of opioids, oxygen, and/or benzodiazepines.[6] Systematic opioids therapy are the mainstay of palliative pharmacologic management of severe dyspnea and their effectiveness has been demonstrated in numerous clinical trials.[6–8] However, a recent systematic review suggests that some of the evidence that shows benefit from their use is of low quality.[9] In many studies that have used opioids for the relief of dyspnea, it has been stated that the initial dose for a specific patient is to be defined according to the intensity of dyspnea reported, preferably through self-assessment; and after the titration phase the dose should be readjusted.[10,11] The ideal therapeutic dose is the minimum dose that promotes, from the patient's perspective, both good symptomatic control and tolerable/acceptable side effects. The opioid prescription should happen according to the patient's functional status and in agreement with previous opioid use.

Often, anxiety is a factor to take in consideration, as it contributes to symptomatic exacerbations, therefore therapy should be adjusted accordingly. The effect of morphine and its analogs is amplified when used in combination with benzodiazepines.[1,12]

Mrs MS's weaning from oxygen therapy may be considered controversial – since this therapy is often used in the end-of-life as a first-line strategy in the management of dyspnea. However, Mrs MS had demanded the weaning to proceed. The indications for oxygen therapy in advanced disease are partial, with no evidence of improved survival.[1]

The use of a low-dose systemic corticosteroid treatment has been advocated. In PC, the prescription of corticosteroids in a low-dose/short duration scheme has been described, without great evidence about its benefits. Corticosteroids are pluripotent drugs that can be used in pain control (as adjuvant analgesics), nausea/vomit control, appetite and lethargy management (syndrome of anorexia-cachexia), etc.[13]

NVI is an extremely important measure, usually well accepted by patients, unlike what happened to this patient probably due to her anxiety.[14] It would be considered effective if it improves dyspnea without causing other troubling consequences.[15] Other non-pharmacological interventions are also used to control dyspnea, such as appropriate room environment, adequate body positioning, breathing, physiotherapy techniques and acupuncture.[16,17] Several studies have demonstrated inadequate symptom management in patients with advanced respiratory disease, the discomfort of physicians in prescribing opioids is one of the contributors to this.[18] Although there is a growing awareness about the need for PC in end-stage non-neoplastic respiratory diseases, there are some accessibility and clinical issues that prevent patients being referred to PC services. Sometimes, physicians' reluctance and/or difficulties to define ''a palliative care status'' may contribute to that.[19]

The present case reflects: (a) the respect for each patient's preferences and autonomy in clinical practice; (b) the prescription of less common treatments for dyspnea control, such as opioids, corticosteroids and benzodiazepines in PC; (c) the importance of shared decision-making in clinical management of patients with advanced disease.

Conflicts of interest

The author has no conflicts of interest to declare.

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Catathrenia resolved with the lowest CPAP pressure settings

Introduction

Catathrenia is a rare sleep disorder first described by Roeck et al.[1] Originally classified as a parasomnia, it is currently included within the group of respiratory sleep disorders. Its incidence, prevalence, and physiopathology are unknown, and its onset is more frequent in adolescents and young adults of average weight. Bed partners are the ones who commonly report strange sounds while breathing during sleep, as affected individuals are unaware of their problem.

Catathrenia usually occurs during REM sleep, though it may be also present in other stages. A catathenia event is characterized by a repeated groaning or moaning sound during prolonged expiration preceded by a deep inhalation and accompanied by a breathing pattern marked by bradypnea of variable duration. Its clinical relevance remains uncertain; catathrenia is considered a self-limited benign condition causing no negative effects beyond significant social nuisance. Although still debated, a significant proportion of patients with catathrenia do report disrupted sleep and some sleepiness or tiredness as in our current case.[2] There is little documented experience in treating the condition, but some studies have shown resolution of events with continuous positive airway pressure (CPAP). Here we describe a patient with substantial clinical repercussions due to sleep fragmentation, responding favorably to CPAP without a need for treatment at high-pressure levels.

Abbreviations: CPAP, continuous positive airway pressure; SDB, sleep-disordered breathing; REM, rapid eye movement sleep; PSG, polysomnography; AHI, Apnea/hypopnea index; RDI, respiratory disturbance index.

Case report

A 22-year-old average-weight (BMI 24) woman with no relevant medical history who did not smoke or drink complained of nocturnal groaning and arousals due to the noise which caused sleep fragmentation, low quality of sleep, daytime tiredness, and headache predominantly in the morning hours. An examination was performed on the patient, including neurologic and otolaryngology assessment and pulmonary function examination, revealing no pathological findings that could explain the clinical symptoms.

A polysomnography (PSG) was carried out showing apnea/hypopnea index (AHI) of 4.8e/h, desaturation index of 0e/h, and respiratory disturbance index (RDI) of 14e/h. The PSG revealed 18 cathathrenia events, most of which occurred from REM sleep. These events were characterized by prolonged expiration with acute sound during bradypnea without oxygen desaturation, lack of effort in the chest and abdomen, and sleep fragmentation related to the electroencephalographic arousals secondary to these events (Fig. 1). The results of the study confirmed the diagnosis of catathrenia. Based on the clinical impact, CPAP treatment was administered at a pressure of 4 cmH_2O.

To confirm treatment results, a respiratory polygraphy test with a microphone was performed on 2 consecutive nights. We conducted a baseline polygraphy test (Fig. 2) which detected catathrenia noise with the typical signs in flow/effort bands without desaturation. In the following polygraphy with a low CPAP pressure setting (4 cmH_2O) minimal residual events were observed.