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Panting for breath in end-stage dementia

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What do I do now? Palliative Care Series Respiratory symptoms

Panting for breath in end-stage dementia

2000-2500 words/9-13 pages excl abstract

Times New Roman, 12 point, double-spaced

style: “include advice in the form of the kind of conversational response you might receive if you happened to buttonhole your favorite specialist, outlining their thought process and pointing out best diagnostic, diagnostic testing, and treatment option tables.”

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Abstract 100-150 words

Keywords 10-15

Abstract

When a person with advanced dementia develops respiratory symptoms, infection, pulmonary embolism, and heart failure are considerations. Pneumonia often has a high mortality rate and high symptom burden. While a decision to focus on palliative treatment is often appropriate, even with prior discussions, families may experience considerable distress. Dyspnea can usually be controlled with opioids, typically morphine. Other symptoms, such as reduced oral intake and dehydration, pain, fever and neuropsychiatric symptoms are also discussed. The need for careful symptom monitoring preferably with observation scales and swift interventions to alleviate the symptom burden is highlighted. Family support and guidance on a daily basis are important treatment foci.

Keywords

dementia; pneumonia; aspiration; dyspnea; pain; fever; dehydration; delirium; family support; observation scales

Case description

You are summoned to the bed of an 82-year-old man, who has been living in this nursing home for approximately three years. Since yesterday afternoon, he has become increasingly uncomfortable, and this morning, he began panting for breath. Walking into the room, you find a distressed family around the patient's bed and a man who is clearly experiencing respiratory distress with a respiratory rate of 33 breaths per minute. His blood pressure is 115/65 mmHg, pulse rate 88 beats per minute and his temperature is 39.2 degrees Celsius. He is somnolent but reacts to touch and speech; his breathing is audible. On auscultation, heart and abdomen show no deviant signs, lungs give soft sounds, with diminished breath sounds in the right basal field and crackles in all other fields. The glucose level measured in capillary blood is 8 mmol/l (144 mg/dl); the C-reactive protein (CRP) in capillary blood is 180 mg/l. Previously, he required support in his daily functioning in almost every domain due to his advanced Lewy Body dementia with a Barthel score of 15/100. He is incontinent of both urine and faeces. He can transfer from bed to chair but is incapable of walking, and he requires help with eating due to apraxia, and thickened liquids because of swallowing difficulties. His medical history shows a myocardial infarct 12 years prior, hypertension, an artificial hip due to a fracture 6 years ago and a tendency for obstipation. Medications include macrogol 1 sachet/day, paracetamol 1000mg three times daily, acetylsalicylic acid 80mg daily; enalapril 10mg daily, no allergies. Two months ago, the patient was successfully treated for a pneumonia with amoxicillin/clavulanic acid. The family wants you to act; they can't stand to see their father this uncomfortable. Previously, only limited advanced care planning (ACP) had been discussed: a Do Not Resuscitate status was agreed upon, but no further discussions were held on treatment wishes, hospital or hospice admissions, artificial fluids or nutrition or other end-of-life wishes.

What do I do now?

Respiratory problems in advanced dementia - clinical problem solving

The differential diagnosis of dyspnea in patients with advanced dementia is broad, including, amongst others, pneumonia, pulmonary edema due to heart failure, pulmonary embolism, hyperventilation, exacerbation of COPD, Kussmaul ventilation due to acidosis with hyperglycemia, and severe obstipation with a resulting elevated diaphragm. Also, in the nursing home setting, the available diagnostic tools are often very limited and the impact of tests on the patient's well-being must be taken into consideration. Patient medical history is not always present nor trustworthy; medical history from the nursing staff is often fragmented. Neither X-ray nor ultrasound imaging is available on site; auscultation gives limited information as the patient cannot follow instructions and breathing sounds are often very soft. A point-of-care CRP measurement can be helpful, as is a point-of-care glucose measurement. Other blood diagnostics often take over 24 hours to yield results.

Pneumonia

Given the nurses' reports and the findings of the physical examination combined with the medical history, the diagnosis of pneumonia, likely due to aspiration, is the most probable one in this case. This diagnosis in patients with advanced dementia and difficulties in swallowing carries a high mortality rate even with treatment. From Table 1, it is clear that this case is very high-risk with a predicted 14-day mortality of 75%, as all high-risk factors are present except for respiratory rate and pulse rate, which are close to the mean.

The family is in distress. Uncertainty of prognosis and seeing a loved one suffer are stressful. Identifying the diagnosis, unfolding the possible scenarios and thereby marking the palliative phase is helpful in alleviating the uncertainty and thereby feelings of distress, even though the delivered message is somber. Discussing the possible treatment options should not only include curative approaches for the pneumonia but should also include the options to treat

symptoms only. Often family members have an (unspoken) fear of suffocation or starvation for their loved ones or have witnessed a troubled death before. Asking about concerns and experiences gives room to address implicit assumptions and align both family and healthcare team to the optimal care plan.

Antibiotics or no antibiotics

Mortality in patients with lower respiratory tract infection and advanced dementia is substantial despite antibiotics or hospital care. Antibiotic treatment, if given, may prolong life only for a few days or even with recovery for a few months. A helpful question about any treatment in this setting is whether treatment is prolonging living or prolonging the dying process. There is also uncertainty as to whether antibiotics play a significant role in the maintenance of comfort. Decisions to prescribe or not to prescribe or whether to hospitalise (an option frequently considered in the US) should take into consideration the risks and benefits of assessing and treating infections, the uncertainty regarding any significant benefits of treatment for patient comfort or prolonging life, and should align such considerations with goals and burden of care and treatment preferences as appropriate. If treatment is considered, amoxicillin three times daily 500mg (or in severe penicillin allergy, doxycycline 200 mg on day 1 then 100 mg daily thereafter, or clarithromycin 2 times daily 500mg) represents a suitable treatment option, with treatment duration of five days. Oral administration in this case may require syrup/liquid or orodispersible formulations due to dysphagia. An alternative option to oral administration is intramuscular or subcutaneous ceftriaxone (1-2g daily).

Food and fluids

Intake is problematic; swallowing dysfunction is already present, and the somnolent state of the patient is contributing to further risk of aspiration. Feeding tubes have not shown benefits in patients with advanced dementia in terms of preventing malnutrition, preventing complications and prolonging life; this is mostly due to the fact that there is still risk of

aspiration with a feeding tube and the underlying cachexia is only partly caused by malnutrition. In terms of reducing symptom burden, tubes are often considered uncomfortable, both when being inserted and when in-situ. Moreover, physical restraint might be needed to prevent the patient from pulling the tube out. Therefore, in our case, the use of a feeding tube for food intake is not considered a viable option.

Dehydration in this situation will most probably be of an isotonic nature resulting in a relative low symptom burden. Correlation between thirst sensations and volume depletion are, at most, modest. The most cumbersome symptom is a dry mouth, particularly in the presence of oral respiration, which can be treated with frequent oral cleaning and the application of artificial saliva-gel. If artificial hydration is considered, via tube, through subcutaneous boluses or intravenously, it should be taken into account that hydration might prolong the dying process by several days, with an increased symptom burden due to increased sputum production. It is acknowledged that there are different attitudes and beliefs concerning artificial hydration therapy worldwide based on culture and medical education and the evidence is not conclusive. However, experts agree that it is appropriate in the palliative phase not to start artificial rehydration. Comfort feeding by hand, if the patient shows a need for intake and exhibits an adequate swallowing reflex, would be an option. Consulting a speech and language therapist to assess the risks might be considered. Hand feeding by the family or otherwise oral cleaning and applying artificial saliva or applying fat to the lips to prevent dehydration might reduce the sense of powerlessness in the family present at the bedside.

Symptoms observation and treatment

Dying from pneumonia generally has a higher symptom burden than dying from other causes. Dyspnea, delirium and anxiety, pain and general discomfort should be closely monitored so that palliative measures can be implemented in a timely and appropriate manner. Various

symptom scales are available and should be considered for use by nursing staff, depending on their level of training.

Dyspnea

Dyspnea is the sensation of not getting enough breath. It can be classified in patients who cannot adequately communicate their symptom burden by use of, for instance, the Respiratory Distress Observation Scale (RDOS). Dyspnea is considered a symptom that involves a high burden of discomfort and should be treated where possible.

Non-pharmaceutical interventions are relevant and include a seated bed position and the use of a fan. The use of oxygen is debatable as the sensation of dyspnea is often not directly linked to the oxygen level; a trial of oxygen administration can be evaluated for effects on the level of dyspnea, taking into account the possible discomfort caused by the noise and the mouth drying effect of the oxygen flow.

Suction of mucus is not advisable as the intervention itself causes discomfort and its effect is short-lived. Further, the act of suction stimulates the production of more mucus. The primary pharmaceutical intervention is the administration of morphine. Other opioids are being considered but so far have shown equivocal effects on dyspnea. As oral intake in this case is compromised, morphine can be applied subcutaneously, either continuously via a pump or as a bolus with injections via a subcutaneous entrance port. The starting dosage of morphine for dyspnea is much lower than the dosage indicated for pain. If only dyspnea is being treated, the starting dose should be around 0.5-1.0ml/hr. or 2.5mg every 4 hours. An alternative to subcutaneous administration is the use of morphine concentrates of 20mg/ml sublingually; as oral morphine has a potency of 1/3 of the parenteral route the starting dose would generally be 5-10 mg sublingual every 1 hour as needed with increases as needed until adequate symptom relief is obtained. Usually, the use of an opioid necessitates concomitant laxative use; however, in this palliative phase, with a short life expectancy and difficulties

with oral intake, this is not appropriate. Sometimes the use of bronchodilators such as inhaled salbutamol can reduce the symptom burden. Again, the discomfort of the use of a nebulizer should be evaluated against the achieved symptom relief.

Fever

Fever in itself is not a symptom that should be treated per se, unless it causes discomfort in the patient. A cool environment, and thin cotton clothing and bedsheets may be sufficient. If not, antipyretics can be considered, which will also yield some pain reduction, but in this case, this would require turning the patient in bed to administer via the rectal route.

Pain

Pain is an indirect effect of the respiratory infection. It is often caused by lengthy immobility in the same bed position and overall malaise. In non-responsive patients such as ours, the use of a monitoring scale is strongly advised. There are several available; in this instance the PAINAD (Pain Assessment in Advanced Dementia) is applicable and sufficiently easy to use without training. Pain is often recognized rather late and it might prove a challenge to distinguish it and/or anxiety from dyspnea. Nevertheless, it is advisable to immediately start using a pain scale when the diagnosis of pneumonia has been made, so as to detect pain promptly and not delay the use of appropriate pain medication. Non-pharmaceutical interventions, which also serve as prevention measures, involving changing of bed position on a regular basis and the use of an appropriate bedding for the prevention of pressure ulcers. Pharmaceutically, opioids are the most logical choice, due to their effects on dyspnea, with a dosage also suitable to alleviate pain. The use of subcutaneous morphine is preferable over transdermal opioids as titration against symptom burden is easier and faster, which can reduce the time in discomfort.

Neuropsychiatric symptoms

Neuropsychiatric symptoms should be expected, including anxiety due to dyspnea and restlessness with pain, but also delirium resulting in agitation and/or apathy. Patients with dementia have a much higher risk of developing delirium. A Delirium Observation Screening (DOS) scale should be considered to monitor this. Pain, dyspnea, urine retention or a full rectum or fecaloma should be treated. A trusted environment (the patient's own bedroom) with trusted faces (family and staff); short calm and friendly instructions and validations, and promoting a diurnal rhythm by opening curtains during daytime and promoting an adequate night rest are helpful. Delirium can be treated with antipsychotic medication although there is increasing research that its effect might be limited or even negative. Haloperidol is in general the agent of choice, however in Parkinson's Disease Dementia or Lewy Body dementia it is contra-indicated. The most commonly used antipsychotics would be quetiapine or clozapine. However, oral administration is difficult in our case which would suggest either clozapine 1dd 12.5mg orally or in buccal form or olanzapine 5mg orally, intramuscular or via orodispersible tablets as an alternative for quetiapine. The use of a benzodiazepine, such as lorazepam or midazolam should also be considered.

Medication review: what is still needed and what can be withdrawn

Medication should be reviewed. In our case the enalapril and acetylsalicylic acid can be stopped as the indications for preventive measures are no longer applicable. Macrogol and acetaminophen are still indicated; macrogol to prevent obstipation associated with opioid use and acetaminophen to combat pain and fever. Both should be stopped due to compromised oral intake; acetaminophen might be switched to rectal administration. Newly added medications will be subcutaneous or oral morphine, artificial saliva, possible salbutamol and oxygen, and clonazepam and/or midazolam in the event of delirium developing.

Family guidance

In this phase, daily conversations with the family are recommended. The process will often take anywhere between a couple of days and a week, and these days can prove very long for the next of kin. Reiteration of the care plan, unfolding of possible scenarios, advising possible actions they might perform (mouth care, possible comfort feeding, creating a calm and reassuring environment, familiar music in the background, hand touch) and in a later stage, predicting Cheyne-Stokes breathing patterns or explaining death rattle in advance, all contribute towards anxiety relief in the family. Moreover, it shows them that their loved one is still receiving optimal appropriate medical care, despite cure no longer being the aim.

Key points to remember

- The family requires daily support where there is room for reiterating the care plan and the scenario unfolding, but also for carefully listening to their (often implicit) concerns.
- Pneumonia in advanced dementia carries a high mortality rate but also a high symptom burden. The use of observation scales is highly recommended to detect possible symptoms promptly.
- Changes in the severity of symptoms or the onset of symptoms should be quickly acted upon.
- Non-pharmaceutical interventions should not be overlooked, they can bring relief and also help family members feel less powerless.

Further reading

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Table 1, Risk factors for 14-day mortality (www.evidencio.com for algorithm)

Risk factor for 14-day mortality	Present case	PneuMonitor study (Rauh et al.; van der Maaden et al.)
Male gender	present	43%
Respiratory rate, breaths/minute	33	mean 25 (SD 8)
Respiratory difficulty	present	56%
Pulse rate, beats per minute	88	mean 91 (SD 17)
Decreased alertness	present	30%
Insufficient fluid intake	present	51%
Dehydration	present	30%
Eating dependency independent requires assistance fully dependent	fully dependent	21% 36% 43%
Increase in eating dependency during the 2 weeks before diagnosis	present	34%
Bowel incontinence	present	62%
Cardiovascular history	present	49%
14-day mortality		
with antibiotic treatment	predicted 75%	14% overall in study population