

Swallowing difficulties

A prognostic signpost

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Yolanda, an 88-year-old woman, is transferred from her residential care home to acute care for management of confusion and a reduced level of consciousness. She has a history of dementia, non-insulin-dependent diabetes, osteoporosis with compression fractures, mild chronic renal failure, and hypertension. On admission she is diagnosed with aspiration pneumonia in the right lower lobe and is treated with intravenous then oral antibiotics.

Yolanda's family is told that the cause of the pneumonia is aspiration secondary to swallowing problems. The family reports that the amount of food eaten by their mother has steadily declined and they are concerned about the staff in her residence not having the time to feed her.

In residential care facilities the estimated prevalence of dysphagia is 50% to 75%, with half of those patients aspirating their food and one-third developing pneumonia as a complication.¹ In patients with advanced dementia who develop pneumonia the 6-month mortality rate is 46.7%.² The same study showed that those families who had an understanding of the prognosis and the expected course of the illness were less likely to agree to burdensome interventions in the last 3 months of life.

Dysphagia contributes to reduced intake of food, but there is also a known reduction in the appetite of patients with dementia, likely owing to reduced caloric needs secondary to inactivity and lower basal metabolic rate.³ The swallowing difficulties and lower appetite are natural indicators of the progression of the disease. Families will experience less distress and have a greater understanding of the progression of the disease if they are prepared for these events in advance.

Swallowing assessment

Six months before admission to acute care, Yolanda had a swallowing assessment done by the occupational therapist at her facility, which showed decreased awareness of food in her mouth and a delay in initiating swallowing. The instructions for helping Yolanda with her eating had been adjusted, and the family was informed that Yolanda must be sitting up, awake, and swallowing 1 mouthful of food before another was offered.

Several days after her admission to acute care, Yolanda has improved with fluid and antibiotics. Her

acute delirium secondary to the infection is improving and she is more awake and aware. Her estimated glomerular filtration rate has stabilized at 45 mL/min, and her electrolyte levels show that she is now hydrated adequately.

The occupational therapist in acute care uses a bedside water test in which she asks Yolanda to swallow and watches for coughing, choking, and voice alterations, and checks for oxygen desaturation. On swallowing water Yolanda appears to choke and cough, her voice alters slightly, and she shows a desaturation of almost 10% after choking.

Swallowing involves a complex set of sensory and motor nerves, the cerebral cortex, the brainstem and cerebellum, and more than 40 muscles.⁴ Any dysfunction in the system from chewing to making a bolus of food or liquid and passing it into the pharynx and past the larynx can result in dysphagia.

The complications of dysphagia include choking, laryngospasm, aspiration pneumonia, and lung abscess.

There are 3 categories of dysphagia.⁵ Oropharyngeal dysphagia is when there is difficulty forming and swallowing the bolus and moving it from the oral cavity into the pharynx. This mechanism is the most common in patients with Alzheimer-type dementia in which the patient has difficulty in recognizing food in the mouth and initiating a swallow.⁶ Vascular dementias tend to have a pattern consistent with difficulties chewing the food and actually coordinating the swallow because of the multiple infarcts in the corticobulbar tracts.

Esophageal dysphagia is diminished ability to move food through the esophagus, resulting in esophageal spasm and regurgitation. Other comorbidities contributing to dysphagia are gastroesophageal reflux, diabetes, and aging, as well as esophageal varices.

The third category of dysphagia is "silent aspiration," in which ingested materials end up in the lungs without any symptoms of swallowing difficulties or coughing. This is most often due to weakness in the muscles of the mouth or throat and can occur in 2% to 25% of acute stroke patients.⁷

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Occupational therapists are trained to do in-depth swallowing assessments; however, it always helps physicians to know some bedside screening checks. A systematic review comparing bedside tests for dysphagia with videofluoroscopy of fiberoptic endoscopic evaluation of swallowing showed that a test of swallowing water with coughing, choking, and voice alteration as end points, in addition to checking for oxygen desaturation of greater than 2% during the swallow, gave the best sensitivity and specificity.⁸

Feeding tubes

As part of the assessment, the admitting physician reviews Yolanda's records from residential care, which show that her score on the Mini-Mental State Examination 3 months ago was 14 out of 30. She is also dependent on others for her mobility and feeding. The acute care team asks the palliative care team to assist them with supporting the family to understand Yolanda's poor prognosis.

Yolanda's family attends a meeting with the staff. The team emphasizes that the dysphagia and resulting pneumonia are caused by the underlying dementia, which is in an advanced stage. Her other comorbidities are also explained to the family. Inquiries about advance care planning reveal that this had never been discussed with Yolanda when she was capable.

Yolanda's family members are very worried about her reduced weight and appetite and inquire about a feeding tube, as they are concerned about her being hungry and yet unable to eat enough to be as well as possible.

Percutaneous endoscopic gastrostomy tubes for feeding in advanced dementia have always been controversial. While a systematic review of the evidence concludes that the use of feeding tubes when compared with hand feeding does not prolong survival for patients with advanced dementia,⁹ the evidence is limited by the observational design of the trials and a lack of randomized controlled studies.¹⁰ It is important to note that percutaneous endoscopic gastrostomy tubes do not reduce the incidence of aspiration pneumonia and have a considerable complication rate.¹¹ However, this might not be what concerns family members, as they might be worried about starvation or might have their own ideas about why their loved ones are not eating.

Pain relief

A staff member of the palliative care team asks Yolanda's family members about their understanding of why she is not able to eat. They express concerns that she is sad and upset with them because she is in a facility rather than at home. They also note that she is often drowsy during meals and believe that her pain medication is causing sedation, and this is a reason why she is unable to eat.

Yolanda's medications include 1 mg of hydromorphone 4 times daily for chronic back pain secondary to osteoporosis and loxapine as needed if she is agitated at night. Staff members have noticed periods of drowsiness during the day and that she is often taking the as-needed loxapine at night for restlessness.

The undertreatment of pain, as well as side effects from medications, can contribute to poor appetite through reduced level of consciousness.¹² Because the pain medication was given 4 times daily, the drug was only administered during the time Yolanda was awake. Poor pain control at night might lead to agitation, resulting in the use of loxapine causing oversedation the next day. The ideal drug for long-term chronic pain management is a long-acting opioid titrated to the best pain relief with the fewest side effects.¹³ This will give round-the-clock pain relief and might result in better sleep and less use of neuroleptics. If the drowsiness persists, especially in frail older adults and those with renal failure, opioids with no active metabolites are the best choice.¹⁴ Other causes of poor oral intake should also be addressed.¹⁵

Conclusion

The palliative care team educates the family on the natural history of dementia and how this condition affects the whole functioning of the person, including swallowing. They connect what is happening on a daily basis with Yolanda to the natural progression of her disease and that she is nearing the end of her life. Yolanda returns to her facility.

Knowing that this is a terminal illness and that food is an important part of the quality of life for Yolanda, the team in the facility works with the family to modify the diet and texture of her food to minimize the risk of aspiration pneumonia. The occupational therapist ensures proper seating and positioning for feeding and encourages the family to visit at mealtimes to help with feeding. Yolanda eats smaller, more frequent meals, and she has good oral hygiene after each meal.

Yolanda's pain medication is changed to half of a 12-µg fentanyl patch every 3 days, with hydromorphone used for breakthrough pain only. The loxapine is changed to 12.5 mg of trazodone as needed.

The team in the facility reaffirms the family members' decision to have Yolanda cared for in a facility because they can no longer manage at home. The team continues to prepare the family for further decline and decisions¹⁶ about whether intravenous antibiotics will be beneficial for Yolanda's next episode of aspiration pneumonia. 🌿

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Competing interests
None declared

BOTTOM LINE

• Swallowing problems leading to food aspiration and aspiration pneumonia are common in residential care facilities.

• In persons with advanced dementia who develop aspiration pneumonia the 6-month mortality is very high (46.7%).

• Although occupational therapists are trained to do in-depth swallowing assessments, the simple bedside maneuver of asking the person to drink water and checking for coughing, choking, and voice alterations, as well as for a decline in oxygen saturation of greater than 2% during swallowing, is reliable and can be done by a physician.

• Modifying the diet and the texture of the food, ensuring proper seating and positioning at meals, and having the patient's family help with feeding reduce the risk of aspiration.

• Percutaneous endoscopic gastrostomy tubes for feeding in advanced dementia do not reduce the risk of aspiration pneumonia and have a high complication rate.

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