Dear Dr. Jeff:

Many of our residents have orders to thicken their liquids to various consistencies, based on recommendations from a knowledgeable and experienced speech therapist. Verbal residents frequently complain about thickened liquids, and families bring in treats (homemade soups, coffee from the local coffee shop) that aren’t thickened but that the residents seem to enjoy. We don’t have good data confirming that all this thickener helps, but I am reluctant to oppose it since it seems indicated and is apparently the standard of care for residents with dysphagia. Are we at risk for deficiency citations for allowing outside treats? Any suggestions?

Dr. Jeff replies:

Thickened liquids are a common component of diet orders for many nursing home residents. In 2004, a large survey found that a mean of 8.3% of nursing home residents had such orders, but rates varied from 0% to 28% depending on geographic region. The prevalence of such orders has only increased since then. Typically, 60% of orders to thicken liquids are for “nectar-thick”; 33% for “honey/syrup” consistency; and 6% for “pudding/spoon” consistency. Nectar-thick liquids, like tomato juice or buttermilk, flow without individual drops; honey-thick liquids flow more slowly and should adhere to the sides of a glass; pudding-thick liquids will not pour out of the spoon at all.

Moreover, the frequency of orders for individual consistencies varies from 0% to 100% depending on the facility. Given that 40% to 60% of all nursing home residents have clinically evident dysphagia, these variations cannot reflect evidence-based quality care.

Any evaluation of the use of thickened consistency diets should weigh the benefits and harms of their use, based on best available scientific evidence and individualized to the particular patient’s condition and preferences. Episodes of choking, gagging, coughing, or wheezing after meals; chronic congestion; or recurrent pneumonias all have significant impact on the quality of a resident’s life as well as the potential to shorten it.

As with other aspects of skilled nursing care, residents and their health care agents have the right to accept or refuse dietary limitations, but this decision should be made after they have been fully informed about the intervention. Residents and families who choose to opt out of these dietary restrictions should at least understand that they are not adhering to recommended orders, and that making such a decision may place the resident at risk. There is certainly a risk for a deficiency citation or even litigation if a resident with an order for thickened liquids receives thin liquids because of a facility error or because the facility allows visitors to ignore the care plan. In the same way that the facility should ensure that visitors do not administer outside medications to a resident, it is equally responsible for potentially dangerous food that is given without a doctor’s order. But when an informed resident choice is honored, the facility is providing person-centered care.

The Science of Thickeners

Unfortunately, the evidence regarding swallowing interventions, particularly in nursing home residents, is somewhat equivocal. Although thickening orders are common, few clinicians understand what exactly is being ordered.

The National Dysphagia Diet (NDD) created definitions of terms, based on a mixture of science and clinical so-called common sense, and was designed primarily to create standards useful for research and comparative studies. Thin liquids were defined as below 50 centipoise (cP); nectar-thick as 51 to 350 cP; honey-thick as 351 to 1750 cP; and spoon- or pudding-thick was greater than 1750 cP. For those not familiar with the centipoise, it is, of course, one hundredth of a poise (a unit named in honor of the scientist Jean Poiseille). By contrast, molasses is typically near 5,000 cP. Different honeys vary in their viscosity, but one standardized value of natural honey is 2,000 cP, suggesting that honey is thicker than “honey-thick.”

Standard thickening agents are either starches — such as cornstarch — or polyacrylamide vegetable gums. Starches are frequently used as thickening agents by cooks when they thicken gravies or add potato starch to potato pancake batter. Vegetable gums appeal to commercial food processors due to their stability. Thickening products have been created specifically for the medical dysphagia market and often come in individual standard-sized packets or in canisters with measuring scoops to assist in creating desired levels of thickening. Many different factors affect the degree of viscosity created, including the temperature of the liquid being altered, the acidity of the liquid, the hand of the preparing individual, the mixing time, the product, and the time between preparation and administration of the thickened liquid. Independent studies using a viscometer to evaluate the actual viscosity of prepared thickened liquids from medical facilities show wide variations in the results produced, often far outside the prescribed ranges as defined in the NDD.

However, even if a standardized viscosity could be achieved overcoming all these physical and chemical challenges to the delivery of desired viscosity, biology also presents barriers to achieving reproducible degrees of thickening. First, the body produces unpredictable amounts of saliva. Salivary flows vary among individuals and from hour to hour. Attractive food (rarely an issue with pureed diets) increases the flow of saliva — thus, the adjective “mouth-watering.” Medications may increase or decrease the production of saliva. A spoonful of “honey-thick” liquid may be nectar-thick or even unthickened when diluted in the mouth. Moreover, the amylase produced in the salivary glands enzymatically cleaves starch-based thickener into sugars with dramatically decreased viscosity. The literature provided by food service companies charged with producing meals that are within the required cP parameters reflects the difficulties inherent in the production of diets as ordered.

Interventions that are difficult to standardize are also difficult to evaluate. In 2008, a controversial and somewhat contentious review argued that dysphagia diets are ineffective. This review understandably produced a vigorous response from the then-president of the American Speech and Hearing Association. There is unmistakable evidence that, for some residents, thickening the consistency of liquids decreases or eliminates aspiration during videoclycopically observed swallowing. What is less clear is whether this improvement carries over into significant clinical long-term improvement in rates of aspiration pneumonia or longevity. Patients who do not benefit from these maneuvers on examination would appear to have little or no long-term benefit. Of course, the absence of well-conducted randomized trials does not disprove the efficacy of thickened liquids.

Thicker Risks

Much more is known about the risks associated with the use of thickeners, although this knowledge has generally not carried over to the clinicians who order them. These risks include issues regarding medication bioavailability, impaired hydration, decreased caloric intake, and negative effects on quality of life.

Increased viscosity decreases the bioavailability of many, but not all, medications. Medicines with film coatings may have their dissolution decreased to 30% after an hour when delivered with a viscous solution. Some medications, such as prednisolone and penicillin, have been documented to demonstrate markedly decreased availability. Others, such as digoxin, have been documented to be relatively unaffected. Useful data are not available for the majority of medications commonly prescribed for the elderly.

Negatively charged thickeners, such as guar gum, may impede dissolution more than neutrally charged thickeners such as xanthan gum. Thickeners may increase the exposure of medications to the oral and buccal mucosa, decrease exposure to the stomach and small intestine, and increase exposure to the colon. Thus, absorption effects may vary significantly with highly variable implications among medications. Because thickeners significantly delay gastric emptying, the stomach may not be empty 2 hours after a meal, when medication is being administered on a so-called empty stomach. Consultant pharmacists should review medication regimens whenever a significant change in dietary viscosity is ordered.

Clinically, the most significant risk relates to decreased intake of food and fluids with significant risk of undesired weight loss and dehydration. Dysphagia patients often have underlying conditions such as dementia that already place them at risk for these conditions. Thickening the presented diet may induce satiety with less caloric intake, a combined effect of prolonged oral transit times, gastric “stretch” from semi-solid food, and persistent adhesion of food to oral and gastric surfaces. The sensation of fullness may be increased when large industrial mixers also significantly aerate the thickened product. Healthy volunteers consume less and desire less liquid when administered a thickened diet. All residents on thickened liquid regimens require close monitoring for dehydration.

These physiologic effects, which should give pause to the interdisciplinary team, are rarely discussed with patients and families. The sticking point for them is usually the effect on quality of life. Thickening liquids alters their flavor, generally for the worse. Starch thickeners are never completely tasteless. Have you experienced the honey-thick coffee your facility is offering? It is truly nasty tasting. Many clinicians who care for the frail elderly have taken the so-called “Thickened Liquid Challenge” with videos available on YouTube from many leaders of the Society and the American Geriatrics

DEAR DR. JEFF
Jeffrey Nichols, MD, CMD

Sometimes Treatment Is Hard To Swallow

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Rosacea Linked to Increased Risk of Dementia

Carey Cowles

Patients with rosacea, particularly those older than 60, have an increased risk of being diagnosed with dementia and Alzheimer’s disease, according to Alexander Egeberg, MD, PhD, and his associates. Their findings are published in the Annals of Neurology.

“We hypothesized that patients with rosacea may have increased risk of AD, because we have clinically observed a familial overrepresentation of AD in patients with rosacea, and because of the overlap of proinflammatory mediators between rosacea and AD,” wrote Dr. Egeberg, of the National Allergy Research Center at the University of Copenhagen.

Rosacea is a common chronic inflammatory skin disorder involving upregulation of matrix metalloproteinases (MMPs) and antimicrobial peptides (AMPs), according to the study. Similarly, “inflammation, MMPs, and AMPs are also involved in the etiopathogenesis of neurodegenerative disorders including certain forms of dementia such as Alzheimer’s disease,” the authors wrote [Ann Neurol April 28. doi: 10.1002/ana.24645].

The researchers studied a cohort of 5,591,718 Danish citizens 18 years and older from Jan. 1, 1997, to Dec. 31, 2012. Overall, 82,439 individuals had rosacea, and 29,193 of patients were diagnosed with AD. Patients with rosacea had a 7% increased risk of dementia and a 25% increased risk of AD compared with individuals without rosacea, the researchers reported. Stratified by sex, women had a 28% increased risk of AD and men had a 16% increased risk if they had rosacea.

When results were stratified by age at baseline, only individuals older than 60 years had a significantly increased risk (20%) of AD.

“Indeed, emerging evidence suggests that rosacea may be linked with neurological disorders including Parkinson’s disease and now also Alzheimer’s disease,” the researchers wrote. “There are certain mechanistic overlaps between rosacea and Alzheimer’s disease that may explain the observed association, albeit the pathogenic links between these conditions are still unclear.”

Future research should focus on symptoms of cognitive dysfunction in patients with rosacea, they wrote.

FDA Approves First Drug To Treat Parkinson’s Psychosis

The Food and Drug Administration has approved pimavanserin for the indication of hallucinations and delusions associated with psychosis in Parkinson’s disease.

Pimavanserin became the first drug to receive approval from the FDA for this indication. It is also the only drug approved by the FDA that preferentially targets 5-HT2A receptors. These receptors are thought to play an important role in Parkinson’s disease psychosis.

The unique pharmacology of pimavanserin establishes a new class of drug — selective serotonin inverse agonists (SSIA) — by not only preferentially targeting 5-HT2A receptors, but also avoiding activity at dopamine and other receptors commonly targeted by antipsychotics.

Typical Parkinson’s disease therapy consists of drugs that stimulate dopamine to treat patients’ motor symptoms such as tremor, muscle rigidity, and difficulty with walking. Pimavanserin does not interfere with patients’ dopaminergic therapy, and therefore does not impair their motor function.

The approval of pimavanserin represents a new direction in the treatment of Parkinson’s disease psychosis, according to Michael S. Okun, MD, medical director of The National Parkinson Foundation. “Through its novel and selective mechanism of action, [pimavanserin] is a breakthrough treatment that works in a whole new way — treating hallucinations and delusions without blocking dopamine receptors and, therefore, not impairing motor function in Parkinson’s psychosis patients,” he said in a press statement.

The FDA approval of the drug, to be marketed under the brand name Nuplazid (Acadia Pharmaceuticals), was based largely on data from a phase III study, in which pimavanserin was shown in a 6-week clinical trial of 199 participants to significantly reduce the frequency and severity of psychotic symptoms compared with placebo on the Scale for Assessment of Positive Symptoms – Parkinson’s Disease (SAPS-PD). (Lancet 2014;383[9916]:533–40). This benefit was achieved without impairing motor function. The most common adverse reactions in this study were peripheral edema (7% pimavanserin vs. 3% placebo) and confusional state (6% pimavanserin vs. 3% placebo).

The FDA gave pimavanserin a Boxed Warning due to the increased risk of death associated with the use of atypical antipsychotic drugs to treat older people with dementia-related psychosis.

“Hallucinations and delusions can be profoundly disturbing and disabling,” said Mitchell Mathis, MD, director of the Division of Psychiatry Products in the FDA’s Center for Drug Evaluation and Research. “[Pimavanserin] represents an important treatment for people with Parkinson’s disease who experience these symptoms.”

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Society, including Karl Steinberg, MD, CMD, HMDC, editor in chief of Caring and one of his dogs (https://youtu.be/BGrKsQfMInk), drinking anywhere from 8 ounces of thickened liquids to consuming them exclusively for 12 hours. Experiencing even the lesser challenge will certainly increase one’s understanding of the experience of so many of our residents. For them, the challenge is not for 12 hours but for the rest of their lives.

As with any intervention that truly affects quality of life, it is important to allow our residents and their families to make informed, person-centered decisions. Because eating is one of the few pleasures that many nursing home residents still enjoy, the imposition of a thickened liquid diet should be evaluated as with any invasive procedure. It is no small matter.

Dr. Nichols is president of the New York Medical Directors Association and a member of the Caring for the Ages Editorial Advisory Board.