BACKGROUND

For patients and caregivers, the topic of nutrition at the end-of-life is emotional and complex. Food and nutrition are a culturally meaningful part of life, signifying love and care and marking traditions or milestones. Reduced food and fluid intake in a dying patient can be difficult for families to accept, even when the patient has lost interest in eating or is no longer capable of oral intake due to diminishing levels of consciousness (1,2). Many clinicians have experienced some version of the comment, “[My loved one] is starving to death or dying of thirst,” or the question, “How are we going to feed or give fluids to [my loved one]?” This Fast Fact discusses communication about nutrition at end of life and offers suggested language to use. This Fast Fact focuses on patients who are imminently dying (in their final days to weeks of life), for whom medically administered nutrition and hydration does not improve longevity or quality of life (4,5,6). It does not address stopping medically administered nutrition and hydration (MANH) in patients already receiving those treatments. See Fast Facts #84,133, 313 regarding enteral feeding, non-oral hydration, and thirst.

ADDRESSING PRACTICAL CONCERNS

Assess what the family is concerned about. Sometimes statements of concern about nutrition are fundamentally statements of grief and loss about a patient’s impending death and do not require any response from the clinician beyond empathetic understanding. Many families desire their dying loved one be encouraged to eat or drink because they fear physical discomfort or suffering from hunger or thirst. Clinicians should normalize the care and concern of the family while normalizing the loss of oral intake as a universal part of the dying process and offering reassurance about symptom burden (Table). Smaller studies have shown that dying patients do not typically experience hunger or thirst if provided with adequate mouth care (3). Families should be encouraged to help the dying patient eat and drink what the patient is interested in and capable of comfortably taking (without distressing coughing or gagging), even if it is minimal. If comfortable, they should be taught how to provide oral care, as this can be a meaningful caregiving activity.

ADDRESSING REQUESTS TO INITIATE MANH

Given how frequently MANH is utilized in healthcare, it can be difficult for families to understand why this intervention is not being recommended for the dying patient who has minimal oral intake. When asked to begin MANH in the dying patient, clinicians should share their worry about causing harm, including worsening gastrointestinal discomfort, nausea, vomiting, loose stooling (which could lead to skin breakdown), increased aspiration risk, or volume overload symptoms such as dyspnea. There is a lack of evidence to support the use of MANH in the final days of life, with the few reported uncontrolled studies focusing on patients with prognoses of “months” rather than “days” and highlighting frequent complications (4-7).

ADDRESSING EMOTION

Given the cultural and emotional significance of food, these discussions can trigger strong emotions. Family members may feel helpless, guilty, or even complicit in the patient’s death if they cannot get their loved one to eat or do not advocate for MANH. Seemingly cognitive questions may in fact be emotional responses. Clinicians should consider that the underlying cause of persistent requests for MANH are often coming from a place of grief and helplessness (to stop someone from dying), and specifically attempt to address that. In many situations, this is more helpful for grieving loved ones than supplying research data about MANH outcomes. Acknowledging the underlying emotional distress can help families feel heard and supported (8). See Table for example language (9).

ADDRESS RELIGIOUS OR SPIRITUAL CONCERNS

Some patients and loved ones may cite religious or spiritual beliefs and concerns when making decisions about nutrition at the end of life. Exploring these and acknowledging their concerns are important first steps. It can be important to reframe for families that the patient is dying from a terminal illness which is leading to diminished oral intake, but that the diminished oral intake is not the cause of the patient’s terminal condition. Involving spiritual care providers such as a chaplain or community spiritual resources may be beneficial in these situations.
The importance of language and phrasing

The Table below reviews suggested language when communicating with family members or other care partners about nutrition at end of life (9).

<table>
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<th>Family concern</th>
<th>Example Response</th>
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| “Is my loved one starving to death?”  
“What if they’re hungry?”                                                   | “Tell me more about your concerns.”  
“I’m worried that forcing them to eat or giving non-oral nutrition will not help them feel better and may make them feel worse. At this stage, most people don’t experience hunger the way that we’re used to. As the body slows down, it often rejects food.” |
| “Our religion says we must give them nutrition somehow. Aren’t we causing their death by not feeding them?” | “Tell me more about your beliefs and concerns.”  
“The [stroke, cancer, etc.] is what is causing their death.”                                                                                     |
| “Aren’t they suffering?”                                                       | “I can tell how much you care about them. We can provide a lot of comfort with good mouth care and sips or swabs of liquids. This is something you can help us with if you wish.” |
| “I can’t watch them waste away.”                                                | “This is difficult. I can only imagine it might feel helpless, since food is often how we show our love and concern for people when they are sick.”     |

References


Authors’ Affiliations: Medical College of Wisconsin, Milwaukee, WI (KT, CG, AZ); John Peter Smith Hospital, Fort Worth, TX (JPF)

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