Comfort Care for Terminally Ill Patients

The Appropriate Use of Nutrition and Hydration

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Objective.—To determine the frequency of symptoms of hunger and thirst in a group of terminally ill patients and determine whether these symptoms could be palliated without forced feeding, forced hydration, or parenteral alimentation. Design.—Prospective evaluation of consecutively admitted terminally ill patients treated in a comfort care unit. Setting.—Ten-bed comfort care unit in a 471-bed long-term care facility. Participants.—Mentally aware, competent patients with terminal illnesses monitored from time of admission to time of death while residing in the comfort care unit. Main Outcome Measures.—Symptoms of hunger, thirst, and dry mouth were recorded, and the amounts and types of food and fluids necessary to relieve these symptoms were documented. The subjective level of comfort was assessed longitudinally in all patients. Results.—Of the 32 patients monitored during the 12 months of study, 20 patients (63%) never experienced any hunger, while 11 patients (34%) had symptoms only initially. Similarly, 20 patients (62%) experienced either no thirst or thirst only initially during their terminal illness. In all patients, symptoms of hunger, thirst, and dry mouth could be alleviated, usually with small amounts of food, fluids, and/or by the application of ice chips and lubrication to the lips. Comfort care included use of narcotics for relief of pain or shortness of breath in 94% of patients. Conclusions.—In this series, patients terminally ill with cancer generally did not experience hunger and those who did needed only small amounts of food for alleviation. Complaints of thirst and dry mouth were relieved with mouth care and sips of liquids far less than that needed to prevent dehydration. Food and fluid administration beyond the specific requests of patients may play a minimal role in providing comfort to terminally ill patients.

METHODS
Setting
The study was carried out in a comfort care unit at St John's Home, a 471-bed, community-based long-term care facility in Rochester, NY, from April 1990 to April 1991. Patients were eligible for admission to the 10-bed comfort care unit if they were certified by their primary care physician as terminally ill, which implies a life expectancy of 3 months or less, and if they wished comfort care. The patient's pertinent medical history was reviewed before admission by a staff physician to verify that the patient had a terminal illness and was functionally in need of skilled nursing care. All patients had specific care guidelines outlined based on their wishes with specific reference made to cardiopulmonary resuscitation, artificial nutrition and hydration, and the use of antibiotics.
The majority of eligible patients had diagnoses of cancer or stroke. Patients were admitted from hospital units and home. Although no strict age limit was defined, most patients were older than 60 years.

Patient Care
Patients admitted to the unit were cared for by a multidisciplinary team consisting of a nurse, physician, social worker, dietitian, recreational therapist, and chaplain. When requested, patients were also evaluated by physical and occupational therapists. The team met formally on a weekly basis and also frequently communicated during the week in the routine care of the patients admitted to the unit.
The multidisciplinary team assessed each patient to develop a care plan aimed at maximizing physical and psychological comfort. Nursing and dietary staff ascertained food preferences and recorded food consumption. Most dietary restrictions were eliminated at this stage, and patients were offered whatever food they felt they could eat. Food was offered if necessary fed to patients but was never forced. All patients received meticulous mouth care that included combinations of cleaning, various swabs, ice chips, hard candy, and lubricants. Narcotics were used for most of the patients to treat symptoms of pain and shortness of breath when present. The dose of narcotics was titrated to provide pain relief while avoiding sedation. When the win-

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food and fluids calculated to be greater than 75% of his daily requirement.

**Impact on the Physical and Emotional Well-being of Patients**

All of the patients died in the comfort care unit. Twenty-seven patients were considered to have been comfortable during their stay and subsequent death (Table 3). Four patients (13%) were thought to have experienced "some discomfort" during their stay. Of these patients, one had a significant amount of bony pain from multiple myeloma in the initial part of his stay but eventually had relief from most of that pain. An 83-year-old woman with lung cancer and chronic obstructive pulmonary disease experienced shortness of breath and anxiety during much of her stay, which was only partially relieved with medications, treatments, and emotional support. Two other patients experienced discomfort from metastases of cancer to bone and liver, which was only partially relieved with medications.

An 83-year-old man with prostate cancer and a length of stay of 104 days experienced an acute confusional state a few days before death, and it was impossible to assess his level of discomfort at that time. He initially experienced hunger and thirst relieved with small amounts of nourishment but became more narcotics-like and stopped eating and drinking 2 weeks before his death. He had been comfortable before his acute confusional state. It is possible that his delirium may have been related to his cessation of food and fluid intake.

**COMMENT**

While much attention has been focused on the rights of patients to refuse medical interventions, little has been written about the benefits that competent terminally ill patients may experience by exercising this right, particularly in regard to artificial feeding. We found that patients with terminal illness can experience comfort despite minimal if any intake of food or fluids. This is consistent with the experience that others have had in caring for dying patients.14-16 Using a patient-centered team approach, we were able to direct our efforts toward each patient's particular needs. Those patients able to communicate consistently reaffirmed our hypothesis that lack of food and fluids sufficient to replete losses did not cause them suffering, as long as mouth care was provided and thirst alleviated with sips of water. In fact, in nine instances, patients experienced abdominal discomfort and nausea when they ate to please their families.

Our study had several limitations, the most important being lack of a randomized controlled trial. Because we had no comparison group of artificially fed patients, we cannot definitively state that artificial feeding would not have added some benefit to their care. However, in this population of patients, our goals were to provide comfort and avoid some of the well-described complications of artificial feeding, such as infection, aspiration, fluid overload, and self-extubation, often resulting in the patient being restrained.17,18 These complications almost certainly increase patient suffering and lead to the staff's time being consumed artificially feeding patients and treating complications. We feel that available time is better spent talking with the patients, assisting them in their activities of daily living, and providing effective pain control, good positioning, and skin care. Few of our patients had evidence of fluid overload resulting in congestive heart failure, edema, and excessive secretions, likely because most patients were relatively dehydrated.

A second limitation was that our team's individual assessments were not strictly blinded as to what kind of food ingestion a patient had when determining comfort levels and may have led to bias. However, by having multiple interviewers of a multidisciplinary team ask patients similar questions, an accurate assessment likely was obtained.

A third limitation is that levels of comfort and suffering are difficult to grade. We relied mostly on the statements of patients and their families to determine the level of comfort. These statements along with observations of the team were used to grade levels of comfort. A more objective measure of comfort would be useful as a research tool.

Fourth, narcotic use may have influenced symptoms in a variety of ways. Narcotics can cause dry mouth even in well-hydrated patients, but there was no ethical way to assess the impact of narcotics by stopping them, since they were one of the cornerstones of pain management. Ice chips, sips of liquid, hard candies, and mouth care (cleaning, swabbing, and application of lip moisturizers) provided relief of dry mouth and thirst for varying periods of time. Some patients experienced relief for an hour while others remained symptom free for many hours. As stated in the "Results" section, there was much intrapatient and interpatient variability in the length of time these interventions were effective in relieving symptoms. There was no clear relation to the amount of food or fluids a patient would consume and the duration of relief of symptoms from the interventions mentioned herein.

The known physiology of starvation in humans with and without terminal illness may provide a physiological explanation for the relative comfort our patients exhibited despite severe protein-calorie malnutrition and eventual dehydration. In previous studies of individuals without terminal illness who have voluntarily fasted, the long-term adaptation to starvation is that body fuel sources appear to be increasingly derived from fat metabolism.19-21 This lipolysis ultimately leads to increased ketone production, which serves as an energy source for both peripheral tissues and for the central nervous system. The net result of