End of Life Care and Artificial Nutrition

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Palliative Care, as defined by the Canadian peer-reviewed referenced resource *The Pallium Palliative Pocketbook*, is “a philosophy of care that aims to relieve suffering and improve the quality of living and dying in those patients diagnosed with progressive incurable illness,” (Pereira, 1-1). This includes addressing the physical, psychological, social and spiritual needs of both the patient and their family. “It involves optimizing living as fully as possible in the time remaining while preparing for dying,” (Pereira, 1-1). As this author explains, Palliative Care is not an exclusive entity but an approach that can complement treatment used to control disease such as chemotherapy, surgery, parental nutrition and tube feeds. This article will identify the areas of concern over parental nutrition and tube feeds, examining quality of life for the patient as well as the benefits and burdens of this treatment during the last stages of their illness.

The questions that our consultation team at the Royal University Hospital often asks when reviewing a patient and their family unit are:

1. What potential benefits and burdens are known to the present treatment plan?
2. Are any of the burdens of the treatment leading to discomfort or distress to the patient?
3. How does the present treatment plan affect quality of life?
4. Are we able to recommend/modify the plan to meet the patient’s and family’s physical, psychological, social and spiritual needs?

A number of our consultations involve individuals diagnosed in the late stages of cancer and often the first symptom that these patients experience is weight loss. This weight loss is “chronic, progressive and involuntary,” (Bozzetti, p. 445). This condition is called cachexia and is also present in late stage congestive heart failure as well as renal failure. It is accompanied by “anorexia (loss of appetite), early satiety, fatigue or weakness, chronic nausea, decreased performance status, and psychological distress from changes in body image,” (Macdonald, p. 76). Cachexia is the result of numerous metabolic derangements and is defined by a negative protein and energy balance resulting in the loss of skeletal muscle mass.

Cachexia associated with late stage cancer or other non-malignant diseases CANNOT be fully reversed by conventional nutritional support. It is often unclear to the clinician as to the timeline to stop nutritional support in the terminally ill patients and the use of tube feeds or parental nutrition in these patients has long been an area of controversy for our population. At the very end stages of life however, the use of nutritional interventions may no longer support the treatment goal of providing energy and weight gain. At this point, the risk is that the intervention of nutritional support may weigh heavily on the side of burden, contributing to the patient’s suffering due to increased nausea, vomiting, edema, pulmonary congestion and/or aspiration.

How do we provide a smooth transition for those patients where parental nutrition or tube feeds have gone from benefit to potential burden?

Firstly, as Patricia Fuhrman states, "the difficulty lies in the patient's desires. Conversations about end-of-life issues should be initiated early in the diagnostic and treatment stages rather than waiting until the dying process has begun," (p. 70). Special circumstances such as the wish to be present for a birth or anniversary must be considered if life can at all be extended using parental nutrition. The patient and family require clear communication both about realistic goals of care and the body's response to the dying process. As well, Fuhrman indicates that an advanced care directive should be filled out and reviewed often to ensure it is current and up-to-date.

Secondly, day-to-day evaluation by staff of the patient's functional status and lab work, including albumin, will indicate indirectly if the process of providing nutrition in this manner remains effective. If there is evidence that this therapy has become ineffective or harmful, information again must be shared between the medical staff and the patient or Medical Proxy. Comfort care should be offered in order to maximize quality of life for the patient. Ideally, at this point nutritional support can be withdrawn and the process of comfort care for end of life may begin.

Family members often worry that the patient will experience distress once all nutritional support and fluids are discontinued. In reality, most patients at the end of life do not experience hunger or thirst. In fact, the lack of food and fluids can lead to a mild euphoria, a sense of wellbeing and even analgesia due to an increased release of endogenous opiates. Parental nutrition, tube feeds and intravenous fluids can make edema, ascites, pulmonary and other secretions, as well as dyspnea worse. Discontinuation of medications with anticholinergic side effects and the administration of good oral care has shown to relieve any sense of a dry mouth. Ultimately, withholding hydration and artificial feeding at the end of life reduces the chances of fluid overload and leads us closer to providing a more comfortable death.

We can encourage families to participate in the care of the patient during last days. Suggestions for the family include: Allow the patient to eat what they want when they want if the patient is not at high risk of aspiration. Plan interactions that do not center around meals. Read, listen to music or watch TV together. Reminisce. Massage and/or cuddle. Lastly, if they are comfortable, allow the family to participate in some of the physical care such as mouth care.

In conclusion, discontinuation of artificial feeding can be a hard decision for patients, families or the Medical Proxy to consider. We must consider the patient's wishes balanced with a review of where the patient is in the trajectory of the disease in addition to a review of the benefits and burdens of treatment. Nurses can facilitate the change in goals of care by providing alternatives in family interactions that place less significance on food. Dying in a natural state can be a comfortable experience for the patient and avoids the burdens of fluid overload at the end of life.

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