EPEC-O

Education in **P**alliative and **E**nd-of-life **C**are - **O**ncology

Participant's Handbook

Module 11

Withdrawing Nutrition, Hydration

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Abstract

The withholding and withdrawing of life-sustaining therapies is ethical and medically appropriate in some circumstances. Oncologists need to develop facility with general aspects of the subject, as well as specific skills and approaches. In this module, general aspects are discussed first. Then, a specific application to artificial nutrition and hydration is presented.

Weight loss and diminished ability or interest in oral intake are common features and poor prognostic signs in cancer. In addition to attempts to cure or control the cancer, a reasonable hypothesis was that the provision of nutrients, either enterally or parenterally, would improve quality life or survival. Unfortunately, prospective randomly controlled trials have failed to demonstrate that nutritional support alone improves morbidity, mortality, or duration of hospitalization for the vast majority of cancer patients. In contrast with conventional wisdom, the scientific evidence for efficacy of artificial nutrition and hydration to sustain life and relieve symptoms is limited to very specific circumstances in a small number of patients.

Patients and families need clear communication from their oncologist that artificial nutrition, whether parenteral or enteral, does not help most cancer patients. Artificial hydration rarely improves symptoms and quality of life near the end of life. Artificial nutrition and hydration can cause symptoms and, in some circumstances, hasten death.

Discussions and decisions about the use of artificial nutrition and hydration are always challenging. The decision to not initiate (withhold), or to withdraw artificial nutrition and hydration is ethical and medically appropriate in some circumstances. A structured approach to discussing artificial hydration and nutrition is needed to address the cultural and emotional implications of decisions about artificial hydration and nutrition for the patient, family and the oncologist. To meet the need to 'do something' and demonstrate caring, alternatives to artificial nutrition and hydration must be part of the overall plan of care.

Objectives

After reviewing this module, oncologists and other members of the cancer care team will be able to:

- Discuss the principles for withholding or withdrawing therapy.
- Describe the evidence base for artificial nutrition and hydration.
- Use a 7-step approach to discussing the withholding or withdrawing of these treatments as a model for these discussions.
- Help families and professionals with their need to give care.
- Discuss hospice care.

Clinical case on trigger tape

J.P. is a 45-year-old securities trader who was diagnosed with stage IV ovarian cancer 8 months ago after feeling 'bloated.' She initially thought it was related to menopause or 'getting fat'. Her mother died at age 50 of breast cancer. She has no siblings. Exploratory laparotomy and debulking were performed. Six cycles of carboplatin and Taxotere every 3 weeks were administered. Recurrence within 1 month was treated with weekly Taxotere with a partial response. Four weeks ago, the patient developed nausea and bloating again. Evaluation showed progression with carcinomatosis and malignant ascites. Experimental therapy was instituted. There is temporal wasting and obvious loss of peripheral muscle mass. Serum albumin is 1.8 g/dl. Eastern Cooperative Oncology Group (ECOG) performance status is 3 (Karnofsky Score of 50). The patient has no appetite, though is not clinically obstructed. The patient wonders if a feeding tube or total parenteral nutrition is needed. The patient's husband and 13-year-old daughter are anxious that the patient will 'starve to death.'

Introduction

Facilitating decision making and implementing decisions about life-sustaining treatments are essential skills for oncologists. Impediments to good care include misconceptions about legal and ethical issues, as well as unfamiliarity with the practical aspects of implementation.

This module discusses approaches to determine and implement treatment preferences regarding the withholding or withdrawal of interventions. First, general principles and approaches are covered. Related discussions appear in the original *EPEC Curriculum* in Plenary 2: Legal Issues.[1] They are also in EPEC-O Module 3: Symptoms and EPEC-O Module 9: Negotiating Goals of Care. Next, the specific issues of artificial nutrition or hydration are covered in more detail. They present a frequent challenge in the routine practice of oncology, and they also provide an example of how to discuss withholding or withdrawing treatments in general.

Role of the oncologist

The oncologist plays an essential role in defining and implementing the medical plan of care, and providing continuity of care as the goals evolve and change over time. The oncologist will often take the lead in initiating discussions about life-sustaining treatment, educating patients and families, helping them deliberate, and making recommendations about the treatment plan. As part of this role, the oncologist is responsible for ensuring that the patient's wishes are documented and supported by the appropriate medical orders. Advance directives may be in place and helpful, but may not necessarily make clear how to translate general goals or treatment preferences into treatment of the present medical conditions. Consequently, it is critical that oncologists have the knowledge and

skills necessary for discussions, negotiations, and implementation of decisions related to life-sustaining treatments.

Legal perspective

All states in the United States have statutes covering issues related to withholding or withdrawing life-sustaining treatments. The Quinlan case (1976) established that artificial nutrition could be withdrawn even from a patient in a persistent vegetative state.[2] In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research found that no treatments, including artificial nutrition and hydrations, were obligatory.[3] This was confirmed in the United States Supreme Court decision on the Cruzan case (1990) which established that artificial hydration and nutrition are like other life-sustaining treatment.[4] It was upheld again in Florida courts in the case of Schiavo (2005).

It is also legal and ethical to withhold or withdraw nutrition and hydration for the patient who lacks decision-making capacity.[5] States may differ in the degree of evidence that is required if the patient lacks decision-making capacity. For example, in New York and Missouri, there must be 'clear and convincing evidence.' In the other states, substitute decision-makers can make the decision.

Institutional policies of many hospitals or other health care institutions tend to include considerations, perhaps drafted by ethics committees, to protect patient's rights and interests and considerations, perhaps crafted by risk management officers, to protect the institution from risk. Often, institutional policies are written in response to the general legal imperative to, when in doubt, provide treatment to prolong life. If the appropriate goals of care are other than 'life at all costs,' then the physician needs to write orders that are specific enough to accomplish the intended goals.

Emergency medical technicians are regulated by statute, and sometimes by city ordinance. Although requirements vary, in general emergency medical technicians are required to provide all resuscitative and life-prolonging treatments unless a physician's order is in place to the contrary.

The oncologist is the only member of the cancer care team who can write orders and ensure appropriate care, if the goals of care are other than the default mode. It is the oncologist's responsibility to ensure that the patient's wishes (or parents' if the patient is a child) are followed across care settings. In the hospital, one major study demonstrated that the majority of patients in intensive care unit settings die without attention to issues of life-sustaining treatment.[4] Many of these patients have undergone some form of invasive medical treatment against their previously stated wishes.[6]

All too often, patients are transferred to the acute-care setting where life-sustaining measures are administered because the appropriate treatment plan and physician's orders have not been completed and placed in the patient's chart. One study demonstrated that fewer than 25% of advance directive orders were carried from the nursing home to the

acute care hospital.[7] The fact that physician's orders may not transfer across settings, eg, nursing home, ambulance, acute care hospital, also exacerbates the problem.

Life-sustaining treatments

There is a wide range of life-sustaining treatments that might be considered for an individual patient and family. These include cardiopulmonary resuscitation, elective intubation and mechanical ventilation, surgery, dialysis, blood transfusions or blood products, artificial nutrition and hydration, diagnostic tests, antibiotics, other medications and treatments, and future hospital or intensive care unit admissions.

After determining the general goals of care (see EPEC-O Module 9: Negotiating Goals of Care), discuss specific treatments with your patients and families if those treatments will possibly help achieve the overall goal (see EPEC-O Module 13: Advance Care Planning). At a minimum, try to discuss an invasive and a noninvasive intervention to get a general idea of a patient's priorities for making treatment decisions. Decisions about surgery and antibiotics are often strongly predictive of other invasive and noninvasive decisions, respectively.[8]

Culture

Culture plays a role in decisions to withhold or withdraw care. For example, many studies have shown that non-white patients are less likely than white patients to agree to 'Do Not Resuscitate' (DNR) orders or to withhold or withdraw care and are less likely to have advance care directives.[9,10,11] In Asian cultures, filial piety, the obligation of children to care for their parents in gratitude for the parent's caring and sacrifice, is a central value. Making a decision to withhold or withdraw life support from a parent may be seen as unfilial.[12] If the integrity of the family as a whole is valued more than the wishes of an individual family member, even patients who would not want life support may expect their family to 'do everything possible' to prolong their life. To do otherwise would bring dishonor on the family.

Culture may have varying views of the role of suffering. Although many nurses and doctors may support withholding life support at the end of life as a compassionate act that prevents unnecessary suffering, not all patients share this value. Some cultures view suffering as redemptive, something to be endured as a test of faith, rather than avoided. The idea that only God, not doctors, knows when it is time to die may also affect how patients view the use of life-sustaining therapies. This is discussed in more detail in EPEC-O Module 12: Conflict Resolution.

Religion

Various religions have espoused specific opinions about the use of artificial hydration and nutrition. Most teach that, when death is inevitable and not due to the absence of hydration or nutrition, then withholding both can be appropriate. However, some

religious leaders teach that human beings must do all in their power to prolong life. In situations of conflict, it is wise to engage leaders or teachers of the religious faith in question.

Weight loss

Weight loss is a common feature and an independent poor prognostic sign in cancer.[13] Various mechanisms have been proposed, including decreased caloric intake, increased metabolic rate, specific nutritional or vitamin deficiencies, and disordered or futile metabolic pathways. Since cancer is frequently accompanied by a loss of appetite and diminished caloric intake, the hypothesis that provision of nutrients, either enterally or parenterally, would improve quality of life or survival has been repeatedly tested over the past 30 years.[14] Unfortunately, except in limited circumstances for clearly defined subsets of patients, the hypothesis has not been supported.[15] Since this finding contradicts popular wisdom, oncologists need to know both the evidence base as well as develop specific skills and approaches to discuss artificial nutrition and hydration with patients and families.

Clinical practice is frequently not guided by the evidence.[16] Impediments to good care include unfamiliarity with the evidence base, misconceptions about legal and ethical issues, lack of training in how to discuss the issues, reimbursement of ineffective treatment, and insufficient attention to alternative strategies to meet the needs of families and health care professionals to show they care for the patient.

Artificial nutrition

It is 'ordinary care' to provide oral nutrition to the patient who wants to eat. That includes bringing food to the mouth even if the patient is too weak to do so. For the patient who needs assistance, special attention to appearance, color, smell, and consistency may be needed to make food appetizing. However, it is unethical and illegal to force the patient to eat if the patient declines to do so.

Administration of nutrition by an alternate route is indicated if the patient is hungry and cannot eat, ie, when there is a neurological abnormality affecting swallowing or an obstructing esophageal cancer.[17] The gastrointestinal tract should always be the route of intake if it is functional.

There is no evidence that artificial nutrition alone improves functional ability, energy, relieves fatigue, improves survival or symptom control (except hunger) if it is the cancer that is responsible for the anorexia and weight loss.[18,19,20,21,22,23,24,25,26,27]

Pathophysiology of anorexia

The causes of anorexia are numerous.[28] The consequences of anorexia depend on the composition of what continues to be ingested. The patient who takes in no calories develops ketosis as fats, and proteins are metabolized to an energy source.

Anorectic ketosis, in contrast to diabetic ketoacidosis, is experienced as a mild euphoria or sense of well-being and analgesia. Supplemental carbohydrates or other foods interfere with ketosis.[29] See EPEC-O Module 3b: Symptoms - Anorexia/cachexia for more details.

Enteral nutrition

There are two common reasons for instituting enteral nutrition in cancer patients: improve fatigue or 'strength' and to avoid 'starving to death.' Patients, family, and some clinicians erroneously believe that the patient is weak because he or she is not eating. Further, they erroneously believe that if the patient does not eat, he or she will die.

In contrast with conventional wisdom, there is no evidence that enteral nutrition improves energy level or survival in the patient with progressive cancer. With the exception of patients with a mechanical reason for not being able to eat, eg, an obstructing cancer or stroke involving deglutition, cancer patients who report anorexia and cachexia do so for a number of complex reasons. These reasons are not reversible if the underlying cancer cannot be reversed.

No study has demonstrated improved outcomes over oral feeding alone. In contrast to original expectations, percutaneous endoscopic gastrostomy (PEG) tubes increase the risk for aspiration; they do not reduce it. The use of feeding tubes is associated with higher mortality than those not treated. Complications from PEG tubes reached 35%.[27,30,31] In fact, enteral feeding tubes can make matters worse. They are associated with infection, obstruction, edema, ascites, and aspiration pneumonia.

In summary, there is no evidence that enteral nutrition improves survival or improves quality of life for the general oncology patient.

There are reasons to believe that the patient with anorexia associated with advanced cancer is not suffering because of it. In most cases, it is the meaning of not eating which distresses patients and families. Finding meaning is an emotional and spiritual, not a biological, issue. While placement of a feeding tube may avert a discussion about the meaning of anorexia, it will not treat it, and only sets the patient and family up for disappointment later.

Parenteral nutrition

The weight of scientific evidence has shown no general benefit for parenteral nutrition in patients with cancer.[14,32] This has even turned out to be the case in the surgical and intensive care settings. Parenteral nutrition has been shown to be of benefit in the limited circumstances where the gastrointestinal tract suffers prolonged toxicity, eg, bone marrow transplant, or in the perioperative setting where there is preexisting malnutrition. In fact, even in the setting of bone marrow transplant, there only appears to be a role when there is prolonged, demonstrable inability to eat.[22] This surprising conclusion is drawn from studies performed over the past 30 years. In other words, the null hypothesis has proved to be true: parenteral hydration does not improve survival or symptoms in

patients with cancer. In fact, meta-analysis suggests that patients with cancer who receive parenteral nutrition die faster than patients not so treated.[32]

Artificial hydration

One of the commonest treatments associated with medical care is an intravenous infusion of fluids. The indication is the maintenance of fluid and electrolyte balance when the patient is temporarily unable to drink adequate volumes. The administration of isotonic fluids subcutaneously (hypodermoclysis) is an underutilized, equally efficacious way to administer fluids without the risk of intravenous access (infection, clot, bleeding) or the skills needed to locate a vein.

The commonest inappropriate reason to consider intravenous fluids in the setting of symptom control is to prevent or treat thirst and to prevent 'dehydrating to death.'

Pathophysiology of dehydration

The conventional evidence base for dehydration comes from the study of normal individuals and those with reversible conditions causing the dehydration. It is divided into hyponatremic dehydration (where salt loss exceeds water loss), hypernatremic dehydration (where water loss exceeds salt loss), and mixed dehydration, where salt and water loss are balanced. Diuretics, vomiting, diarrhea, osmotic diuresis, adrenal insufficiency, edema, ascites, fever, laxatives, and postobstructive diuresis may all contribute to dehydration. Patients dying of cancer without a confounding etiology usually have a mixed pattern.

Symptoms of dehydration differ between those who are ambulatory and those who are bed-bound. Whereas an otherwise healthy person will experience reversal of severe thirst, fatigue or malaise with rehydration, a seriously ill patient will not. There is no evidence that IV fluids relieve thirst in the patient with advanced cancer. The same is true for fluids given via an enteral feeding tube. In contrast, stopping medications with anticholinergic side effects and good lip and mouth care will relieve thirst.[33,34,35,36,37]

Dehydration appears to be associated with endorphin release and associated improved mood.

Common concerns

There are several common concerns that impact decisions about life-sustaining treatments in general and withdrawal of hydration and nutrition in particular.[3]

Are oncologists legally required to provide all life-sustaining measures possible? No. Physicians are required to provide care that will accomplish treatment goals within the bounds of accepted medical practice. No physician is required to provide care that is futile, eg, total parenteral nutrition for a dying patient. Conversely, even when a treatment

might prolong life, eg, intravenous antibiotics for pneumonia, patients have a right to refuse, and the physician has an obligation not to provide or coerce.

Is withdrawal or withholding of artificial hydration and nutrition euthanasia? After decades of discussion in society, there is strong general consensus that withdrawal or withholding of artificial hydration and nutrition is a decision/action that allows the cancer to progress on its natural course. It is not a decision/action actively to seek death and end life. By contrast, euthanasia actively seeks to end the patient's life.

Can the treatment of symptoms associated with withdrawal of hydration and nutrition constitute euthanasia? The intent of the oncologist and the means used to accomplish the intent are important. Opioids for pain, sedatives for restlessness, and other treatments to control symptoms are not euthanasia when accepted dosing guidelines are used. Avoid the rationale that says, "death is the treatment." Symptom treatment alleviates symptoms; it does not intentionally cause death.

Is it illegal to prescribe large doses of opioids to relieve symptoms of pain, breathlessness, or other symptoms after artificial hydration and nutrition have been withdrawn? Even very large doses of opioids or other drugs are both permitted and appropriate, if the intent and doses given are titrated to the patient's needs.

7-step protocol to discuss treatment preferences

To guide the discussion of treatment preferences, particularly when considering withholding or withdrawing a life-sustaining therapy, use the following modification of the 6-step protocol, SPIKES,[38,39] for communicating bad news (see EPEC-O Module 7: Communicating Effectively).

SPIKES+	7-step protocol to discuss treatment preferences
Setting. Getting started.	1. Be familiar with pertinent policies and statutes. Establish the right setting for the discussion.
Perception. What does the patient know?	2. Ask patient and family what they understand.
Invitation. How much does the patient want to know?	3. Determine/reconfirm goals of care.
Knowledge. Sharing the information.	4. Establish the context of the discussion. Discuss artificial nutrition and hydration.
Emotion. Responding to the patient and family feelings.	5. Respond to emotions.

Subsequent. Planning and follow-up.	6. Establish a plan and follow-up.
+ Review. Reassess and revise periodically.	7. Reassess and revise periodically.

Module 7: Communicating Effectively presents guidelines on how to conduct discussions related to communicating bad news. Module 9: Negotiating Goals of Care presents an approach to determining the general goals of care. Module 13: Advance Care Planning presents a general approach to the discussion of advance care planning. This module integrates the principles from these modules to the discussion of specific treatment preferences, particularly to discussion about withholding or withdrawing therapy.

Reasonable physicians may disagree about the extent to which specific treatment preferences ought to be discussed, if such treatment will not help achieve the overall goals. It is well established that, if a treatment has no chance of achieving its intended benefit, eg, performing cardiopulmonary resuscitation on a body whose head has been severed as a result of trauma, it need not be offered. However, since chance for benefit is rarely absolutely zero, and since discussion of treatment decisions is favored by patients and builds trust, an approach to discussing these decisions is part of the skills set of the oncologist. In approaching all discussions of withholding or withdrawing treatment, discuss general goals of care first. Then discuss specific treatment preferences in light of whether they are likely to help achieve the overall goal.

Physicians usually conduct discussions of treatment preferences. Other appropriate members of the cancer care team may enhance the discussion and prevent subsequent conflict within the team. They will have additional time to carry on the dialogue with the patient and family. The team will also be able to provide valuable emotional support to the patient, family, and each other.

Even though other members of the health care team participate and/or conduct the discussion, implementation of any decision requires a physician's order. The attending physician must sign the documentation and assume full responsibility for its accuracy.

Apply 7-steps to discuss nutrition and hydration

Oncologists frequently perceive the discussion about whether or not to use or continue artificial feeding and/or hydration to be difficult. Successful approaches are not customarily demonstrated during medical training.[3] Food and water are widely held symbols of caring, so withholding of artificial nutrition and hydration may be easily misperceived as neglect by the patient, family, or other professional and volunteer caregivers.

Step 1: Become familiar with pertinent policies and statutes.

Be familiar with the policies of the institution and pertinent statutes where they practice**.** Unfortunately, many oncologists presume that, because their institution has a specific policy, eg, all patients who cannot eat will have a percutaneous enteroscopic gastrostomy tube, this practice reflects state or federal law. In fact, no state requires artificial nutrition and hydration when the cancer patient cannot eat. Most states leave specific treatment decisions to be decided between patient and physician.

Step 2: Ask the patient and family what they understand

Listen for how they make sense of the relationship between the disease and eating and drinking patterns. For example, if someone says, "If only she'd eat, she'd get stronger" may show the need to review why it is the doctor thinks the patient is weak. Similarly, "I don't want her to dehydrate to death" may show the need to explain how normal dying occurs.

Step 3: Determine/reconfirm goals of care

Determine or reconfirm the general goals of care. Examples are:

- Can we review our overall goals for your care?
- Let me tell you what I understand you want as we plan your care.

Talk about the general medical condition. For example, if the patient has advanced cancer, establish an understanding of the overall situation. What is the expected course of the cancer? Is anything reversible?

Once the general goals of care have been confirmed, specific life-sustaining treatment preferences can be discussed.

Step 4: Establish the context of the discussion

Be sure to establish the context in which or for which artificial nutrition or hydration is being discussed. The classic misstatement on the part of well-meaning physicians is, "Do you want us to do everything?" This highly euphemistic and misleading question fails to acknowledge context, "When are we talking about?" (Today, when the patient is recovering from an infection or the side effects of chemotherapy, or when the patient is dying despite maximal medical therapy.) 'Everything' is much too broad and is easily misinterpreted by families, especially when they feel 'everything' has not, in fact, been done.

Discuss artificial nutrition and hydration

Explore how artificial hydration and nutrition will contribute to the overall goals of care, or improve the situation. If the patient and family hope to see improved energy, weight,

and strength, then artificial fluid and nutrition are unlikely to accomplish those goals. Help the patient and family to understand the goals for which artificial nutrition and hydration would be appropriate (see EPEC-O Module 9: Negotiating Goals of Care).

Discuss specific treatment preferences. Use language that the patient will understand. If the patient is not fluent in English, use a translator, preferably someone trained in these skills. Give information in small pieces. Reinforce the context in which the decisions will apply. Stop frequently to check for reactions, to ask for questions, and to clarify misunderstandings.

Reasonable physicians may argue that it is unnecessary and potentially confusing to patients and families to ask them to decide about specific treatment preferences. Patients and families may be ill served if physicians regard the principle of autonomy as meaning that physicians must offer all possible therapies from which patients and families choose, as though they were choosing items from a menu in a restaurant. Nonetheless, it is often useful to discuss and recommend withholding or withdrawing artificial nutrition and hydration in light of the general or overall goals that have previously been established.

Aspects of informed consent

Informed consent is a fundamental ethical principle that underlies contemporary medical care. Patients deserve a clear, complete understanding of all therapies that are being proposed for them. Some will want to know all the details. Others will prefer not to know anything.

Be prepared to describe in simple, neutral terms the aspects of artificial nutrition and hydration in a manner that conforms to the principles of informed consent:

- The problem the treatment would address.
- What is involved in the treatment or procedure.
- What is likely to happen if the patient decides not to have the treatment.
- The benefits of the treatment.
- The burden created by the treatment.

Information that could be provided to patients and families who are making decisions regarding artificial feeding and hydration is provided in the Appendix.

Address misperceptions

Listen for cues like:

- I don’t want her to starve to death.
- Dehydration is a miserable way to die.
- We can’t just let her die.

These statements often express goals for the family as much or more than they express goals for the patient. These statements suggest the patient and family have misperceptions about the underlying situation, or the meaning of signs and symptoms. They may believe that lack of appetite and diminished oral intake of fluids is causing the patient's level of disability. Most then make the assumption that, if only the patient got more fluids and nutrition, he or she would be stronger. Use clear, simple language to help the family focus on the true causes of the situation, for example:

- The cancer is taking all of your strength.
- The fact that your heart is so weak is what is causing you to lose your appetite and feel so fatigued.
- I can understand why you might think that, but she's dying of cancer, not starvation.

If the patient is close to dying, make sure the family knows that a dry mouth may not improve with intravenous fluids. Relief is much more likely with attention to mouth care and oral lubricants (see EPEC-O Module 6: Last Hours of Living).

In some patients, delirium may be related to dehydration, so a clinical trial of intravenous fluids may be warranted. However, before starting, ensure that everyone is aware that there are other causes of delirium that may not respond to fluids, and there is a risk that fluids will only increase other physical symptoms, eg, edema, breathlessness, without relieving the delirium.

Urine output normally declines in the patient who is dying; it is not just an indicator of hydration. Urine output in the range of 300 to 500 ml/day is adequate. The large volumes (2 to 3 l/day) that physicians and other health care professionals associate with hospitalized patients are usually the result of over-vigorous intravenous infusions in patients with normal renal function and oncotic pressure and do not reflect usual output with oral hydration. Both high-volume infusions and excessive urination may be a source of discomfort to the patient (see EPEC-O Module 3: Symptoms and EPEC-O Module 6: Last Hours of Living).

Step 5: Respond to emotions

During these discussions, respond to patient and family anxiety, and acknowledge emotional content. Empathic silence, and acknowledging the situation with a phrase like, "I wish things were different," may be all that is needed. Parents, if the patient is a child, are likely to be very emotional and need support from the physician and other members of the health care team. Patients, families, and surrogates may be profoundly disturbed by the subject matter being discussed. If a physician finds that emotions are too challenging, ask other colleagues and/or members of the cancer care team to assist.

Step 6: Establish a plan

Establish and implement a plan that is well articulated and understood. The next steps may be as simple as planning to discuss the subject again at the next visit, or convening a family meeting to further discuss the proposed treatment plan. They may be as complex as organizing nursing, social work, and chaplaincy intervention, or assuring that a key family member living out of town is notified.

Time-limited trials

In some circumstances, a time-limited trial of artificial nutrition and hydration may be warranted when it is unclear whether these treatments will achieve a specific goal. For example, a Dobhoff tube may be placed during a hospitalization for evaluation of new onset fatigue and anorexia. It should be clearly stated at the outset what the measures of success will be. 'Tolerating' the feeding is not a very satisfying endpoint. Reasonable endpoints are if the patient feels stronger or is able to resume eating after 2 weeks.

Document and disseminate the plan

Discuss treatment plans with other health care professionals so that the plans may be carried out in a straightforward and organized fashion. In health care institutions, this involves discussing the plan with nursing and house staff, at a minimum. Write the appropriate orders, document the discussion in the medical record, and talk about the plan with other members of the health care team.

Step 7: Review and revise periodically

People change their goals of care and treatment priorities periodically. Once presented with a situation and information, eg, that fluids and nutrition are not helping and may be harmful, patients and families may take some time to decide to change the plan of care. Even after stopping a therapy, review the goals of care and treatment priorities periodically to ensure that the patient's choice is durable. It is always comforting to know that the plan can change at any time.

Help family and professionals with their need to give care

Family members and health care professionals frequently feel helpless in the face of cancer.[40] Their advocacy for artificial nutrition or hydration may be a response to the feeling. The advocacy may come from a misunderstanding of the situation, eg, she'll be stronger if only she eats more, he won't die if he eats, her mouth won't be so dry if she has an IV, or as an emotional response, eg, its important to fight back. 'Doing something' may be an important motivation for the professional; for example, associating large urine output as can only be obtained with an intravenous infusion as being equivalent to providing good medical care.

As part of the discussion, identify the emotional need that providing food and water meets, particularly for families and other health professionals. Don't just address issues of artificial hydration and nutrition. Help the family find ways to demonstrate their caring in the face of 'letting nature take its course', and teach them the skills they need to be effective. A major goal is to permit the family and professionals to feel helpful rather than helpless. Examples include:

- Eat for pleasure.
- Plan social interactions that don't center on meals.
- Read or watch movies together.
- Look at photo albums together.
- Participate in mouth care.
- Massage the extremities or feet with unscented oil.
- Do chores such as housecleaning, gardening.
- Reminisce and tell stories.

Normal dying

Loss of appetite and diminished fluid intake are a part of normal dying. Trying to counteract the natural trends may lead to more discomfort for the family without affecting the outcome.

Near the end of life, patients and families may be concerned that there will be suffering from thirst or hunger if the patient is not taking any fluids or nutrition. Help the patient and caregiving family to understand that dehydration is a natural part of the dying process. It does not affect the dying patient in the same way as a healthy person who feels thirsty on a hot day or becomes dizzy on standing.

Let family members know that if the patient is not hungry, artificial fluids and hydration will not help him or her feel better. Badgering the patient to eat or drink more will only increase tensions and may cause the patient to become angry, depressed, or withdrawn, if he or she cannot comply.

In addition, make sure that family members and caregivers know that artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia.

Ensure that family and caregivers know that a state of dehydration in a patient who is bed-bound and imminently dying may have some benefits. Pulmonary secretions, vomiting, and urinary incontinence may be less. Dehydration may actually stimulate the production of endorphins and other anesthetic compounds that help to contribute to a peaceful, comfortable death for many patients.

Practical approaches to managing specific symptoms are covered in EPEC-O Module 3: Symptoms and EPEC-O Module 6: Last Hours of Living.

Discussing hospice care

A referral for hospice care is frequently perceived as challenging. It becomes easier if the idea for hospice care is presented as a response to need rather than something to do when there is nothing left to do.[41]

Elicit the patient and families understanding of the current situation before discussing hospice care. If there is an understanding that the main focus should be on comfort, quality of life, emotional and practical support, hospice care can be introduced as a way for the physician to provide additional resources to care for the patient and family at this time. Patients frequently identify the family as needing the most help. Family members identify the need for a group that will help manage the case and coordinate numerous caregivers and services. Hospice programs are an effective way to provide this.

About 10-15% of all patients referred for hospice care are disenrolled (graduate) because they get better with the intensive care and support. There is no penalty for disenrolling and becoming involved later, if needed.

Summary

Withholding and withdrawing artificial hydration and nutrition therapy challenge oncologists to be excellent communicators with patients and families. When oncologists establish the overall goals first, then evaluate whether artificial hydration or nutrition will achieve those goals, patients and families understand the limits of modern medical help and can focus on the role they can play in the best oncological care of their loved one.

Key take-home points

1. Patients have the right to refuse any medical treatment, even artificial nutrition and hydration.
2. Withdrawal or withholding of treatment is a decision/action that allows the disease to progress on its natural course. It is not a decision/action intended to cause death.
3. In rare circumstances, opioids and other drugs are rapidly titrated to treat physical symptoms following accepted dosing guidelines. They might be perceived to contribute to death. Provided the intent was genuinely to treat the symptoms, then such use is not euthanasia.
4. Physicians must familiarize themselves with the policies of the institution and pertinent statutes where they practice.

5. Impediments to good care include misconceptions about legal and ethical issues, as well as unfamiliarity with the practical aspects of withholding or withdrawing treatment.
6. Patients may be transferred to the acute care setting where life-sustaining measures are administered because the appropriate treatment plan and physician's orders have not been completed and placed in the patient's chart, or physician's orders may not transfer across settings.

Nutrition/hydration

7. If the patient and family hope to see improved energy, weight, and strength, artificial fluid and nutrition may not help accomplish those goals.
8. If the patient is close to dying, make sure the family knows that a dry mouth may not improve with intravenous fluids. Relief is much more likely with attention to mouth care and oral lubricants.
9. Dehydration is a natural part of the dying process. Artificial fluids and hydration will not help the patient feel better.
10. Artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia.

Pearls

1. Discuss overall goals before discussing specific treatments.
2. Acknowledge emotional components of decisions.
3. Dehydration may stimulate the production of endorphins and other anesthetic compounds that help to contribute to a peaceful, comfortable death for many patients.

Pitfalls

1. Avoid loaded slogans like 'do everything,' 'starve to death.'
2. Institutional policies may be written in response to the general legal imperative to err of the side of prolonging life in cases of uncertainty or in emergencies.

Appendix

Appendix 1: Case for role play

Doctor

D.W. is an 82-year-old widowed retired secretary with advanced colon cancer. She is cared for in the home of her married daughter, who is her power of attorney for health affairs. She requires assistance in all her domestic activities of bathing, feeding, toileting,

ambulation, etc. She spends most of the day in bed, or lying on the sofa. She is still able to express her wishes. She has recently stopped eating almost everything, saying she doesn't have an appetite. She takes a few bites of what is put before her, then stops. Her daughter is irritable, and works hard to make the 'things her mother likes.' She urges her mother to 'keep trying.' The relationship between the two is strained. The possibility of a feeding tube has been raised. You are discussing this with the daughter in the office.

Daughter

You have been caring for your 82-year-old mother with advanced colon cancer in your home. You are married, an only child, and you are your mother's power of attorney for health affairs. Your mother requires assistance in all her domestic activities of bathing, feeding, toileting, ambulation, etc. She now spends most of the day in bed, or lying on the sofa. She is still able to express her wishes. She has recently stopped eating almost everything, saying she doesn't have an appetite. She takes a few bites of what is put before her, then stops. You find this maddening—you want your mother to try, and feel inadequate when she only takes a few bites of what you have made. You would say you have always been close with your mother, but can see that your relationship is strained. You wonder whether a feeding tube would help her be stronger. You know she is dying, but you don't want her to 'starve to death.'

Appendix 2: Information for patients/families re: artificial nutrition and fluids

When is artificial feeding and nutrition most appropriate?

If you have a temporary condition that prevents swallowing, artificial fluids and nutrition can be provided until you recover.

What is involved in the procedure?

An intravenous catheter may be placed in a vein in the skin for fluids, or sometimes nutrition.

Alternatively, a plastic tube called a nasogastric tube (NG tube) may be placed through the nose, down the throat, and into the stomach. It is approximately 1/8 inch in diameter. This can only be left temporarily.

If feeding by this route, a more permanent feeding tube may be placed into the wall of the stomach (PEG tube or G tube).

What happens if it is not administered?

If a person is unable to take any food or fluids due to illness, he or she will eventually fall into a state much like a deep sleep. This process will take 1 to 3 weeks.

Before entering the deep sleep, he or she will normally not experience any hunger or thirst after the first several days.

For a person who has an advanced illness, giving artificial hydration and nutrition may not prolong life.

What are the benefits?

A feeding tube may reduce hunger in someone who is hungry, but cannot swallow.

Intravenous fluids may reduce some symptoms, such as delirium.

What are the burdens?

All feeding tubes are associated with significant risk. Around 30% of patients have signs of the liquid entering the lungs. This aspiration of fluid can cause coughing, pneumonia, and shortness of breath.

Feeding tubes may feel uncomfortable. They can block the stomach, causing pain, nausea, and vomiting.

Tubes for food and fluids may become infected.

Physical restraints are occasionally needed so the patient won't remove the tube.

Appendix 3: reprinted documents

Physician Orders for Life Sustaining Treatment (POLST Form), reprinted by permission of the Center for Ethics in Health Care, Oregon Health Sciences University, Portland, Oregon, USA.[42]

References

[1] Plenary 2: Legal Issues. In: Emanuel LL, von Gunten CF, Ferris FD. The education in palliative and end-of-life care (EPEC) curriculum. American Medical Association, Chicago, IL, 1999. Available at http://www.epeconline.net/EPEC/Webpages/ph.cfm. Accessed March 20, 2005.

[2] In re Quinlan, 70 NJ 10, 355 A2d 647, cert denied 429 US 922, 97 SCt 319, 50 LEd 2d 289 (1976).

[3] 1983 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

This recommends that no program of compensation for injured research subjects be instituted.

[4] Cruzan v Director of Missouri Department of Health 109 SCt 3240 (1990).

[5] Council on Ethical and Judicial Affairs. Decisions to forgo life-sustaining treatment for incompetent patients. In: Council on Ethical and Judicial Affairs Reports on End-of-Life Care. Chicago, IL: *American Medical Association.* 1998:30-40.

[6] The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA.* 1995;274:1591-1598.

A total of 9105 adults over 2 years in 5 academic medical centers hospitalized with one or more of nine life-threatening diagnoses had an overall 6-month mortality rate of 47%. The phase I observation documented shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death. The phase II intervention phase produced no improvement in patient-physician

communication (eg, 37% of control patients and 40% of intervention patients discussed CPR preferences) or in the five targeted outcomes.

[7] Morrison RS, Olson E, Mertz KR, Meier DE. The inaccessibility of advance directives on transfer from ambulatory to acute care settings. *JAMA*. 1995;274:478-482.

The medical records of 180 admissions showed only 26 percent of patients who had previously executed advance directives had their directives recognized during their hospitalization. When the advance directive was recognized, it appeared to influence treatment decisions in 12 (86%) of 14 cases.

[8] Fischer GS, Alpert HR, Stoeckle JD, Emanuel LL. Can goals of care be used to predict intervention preferences in an advance directive? *Arch Int Med*. 1997;157:801-807. PMID: 9125014.

This study showed among patients who completed an advance care document as part of a survey, their selected goals predicted intervention choices. Further, decline of noninvasive interventions predicted decline of invasive interventions and desire for invasive interventions predicted desire for noninvasive interventions.

[9] Caralis PV, Davis B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments and euthanasia. *J Clin Ethics*. 1993;4:155-165. PMID: 8334279.

This study analyzes the influence of race and ethnicity on the knowledge and attitudes of patients concerning advance directives and life-prologing therapy.

[10] Blackhall LJ, Grank G, Murphy S, Michel V, Palmer JM, Azen S. Ethnicity and attitudes toward life sustaining technology. *Soc Sci Med.* 1999;48:1779-1789. Full Text

A survey of 200 respondents from each of four ethnic groups: European-American, African-American, Korean-American and Mexican-American (800 total), followed by in-depth ethnographic interviews with 80 respondents was conduced. European-Americans were the least likely to both accept and want life-support ($p < 0.001$). Mexican-Americans were generally more positive about the use of life-support and were more likely to personally want such treatments ($p < 0.001$). Ethnographic interviews revealed that this was due to their belief that life-support would not be suggested if a case was truly hopeless. Compared to European-Americans, Korean-Americans were very positive regarding life-support (RR = 6.7, $p < 0.0001$); however, they did not want such technology personally (RR = 1.2, $p = 0.45$). Ethnographic interviews revealed that the decision of life support would be made by their family. Compared to European-Americans, African-Americans felt that it was generally acceptable to withhold or withdraw life-support (RR = 1.6, $p = 0.06$), but were the most likely to want to be kept alive on life-support (RR = 2.1, $p = 0.002$). Ethnographic interviews documented a deep distrust towards the health care system and a fear that health care was based on one's ability to pay.

[11] Crawley L, Payne R, Bolden J. Payne T, Washington P, Williams S. Palliative and end-of-life care in the African-American community. *JAMA.* 2000;284:1518-1521. Full Text

African Americans and other minorities underuse palliative and hospice care, even when they have access to this care.

[12] Frank G, Blackhall LJ, Mechel V, Murphy ST, Azen SP, Park K. A discourse of relationships in bioethics: patient autonomy and end-of-life decision making among elderly Korean Americans. *Med Anthro Quart.* 1998;12:403-423.

This article reports on an interview with a 79-year-old typical Korean American respondent to explain contradiction in survey data. Expectations among elderly Korean Americans include protecting family

members with a life-threatening illness from being informed of their diagnosis and prognosis, and doing everything to keep them alive.

[13] Dewys WD, Begg C, Lavin PT, et al. Prognostic effect of weight loss prior to chemotherapy in cancer patients. *Am J Med.* 1980;69:491-497.

The prognostic effect of weight loss prior to chemotherapy was analyzed using data from 3,047 patients enrolled in 12 chemotherapy protocols of the Eastern Cooperative Oncology Group. Chemotherapy response rates were lower in the patients with weight loss, but only in patients with breast cancer was this difference significant. These observations emphasize the prognostic effect of weight loss, especially in patients with a favorable performance status or a limited anatomic involvement with tumor.

[14] Koretz RL. Parenteral nutrition: is it oncologically logical? *J Clin Oncol.* 1984;5:534-538. PMID 6427418.

[15] Shike M. Nutrition therapy for the cancer patient. *Hematol Oncol Clin North Am*. 1996;10:221-234. PMID: 8821569.

Weight loss is a poor prognostic factor in cancer. Enteral feeding is only effective when patients are unable to ingest food because of neurological disorders or structural abnormalities of the upper GI tract. Enteral therapy has not been shown to be an effective adjuvant for anti-cancer therapy. Total parenteral nutrition has only been shown to be of benefit in cases of prolonged GI tract toxicity such as in bone marrow transplant.

[16] Mercadante S. Parenteral versus enteral nutrition in cancer patients: indications and practice. *Support Care Cancer*. 1998;6:85-93. Full Text

Prospective randomly controlled trials have failed to demonstrate the clinical efficacy of providing nutritional support to most cancer patients in terms of morbidity, mortality, and duration of hospitalization. Although retrospective studies of parenteral nutrition suggested a benefit for patients with cancer who are undergoing surgery, radiation, or chemotherapy, carefully designed, prospective studies have not shown benefit. Routine use of parenteral nutrition should be discouraged.

[17] Brody H. Evidence-based medicine, nutritional support and terminal suffering. *Am J Med*. 2000;109:740-741. FullText

[18] Schattner M. Enteral nutritional support of the patient with cancer: route and role. Enteral nutritional support of the patient with cancer: route and role. *J Clin Gastroenterol*. 2003;36(4):297-302. PMID: 12642734.

Enteral nutrition has proven efficacy in patients receiving radiation to the head and neck, those with persistent dysphagia, and critically ill patients with impaired gastric emptying. Specialized formulas designed to enhance immune function may decrease infectious complications but do not improve survival.

[19] American College of Physicians. Parenteral nutrition in patients receiving cancer chemotherapy: Consensus Statement. *Ann Int Med*. 1989;110:734-736.

Parenteral nutritional therapy is associated with net harm, no conditions could be defined in which such treatment appeared to be of benefit. In regard to survival, those treated with TPN had a best estimate odds ration of 0.81. ($p = 0.05$). For those with short-term survival (3 months) the best estimate odds ration is 0.74. For tumor response rates, the best odds ratio is 0.68. These data have been summarized as the TPN 'feeds the tumor' and not the patient.

[20] McCann RM, Hall WJ Groth-Juncker A. Comfort care for terminally ill patients: the appropriate use of nutrition and hydration. *JAMA.* 1994:272:1263-1266. Full Text

Prospective evaluation of 31 dying cancer patients. No parenteral hydration or nutrition. 20 patients (63%) no hunger. In 11 patients (34%) hunger, thirst and dry mouth alleviated with small amounts food, fluids, ice chips and lubrication.

[21] Heys S. Walker L, Smith I, Eremin O. Enteral nutrition supplementation with key nutrients in patients with critical illness and cancer: a meta-analysis of randomized controlled clinical trials. *Ann Surg*. 1999;229:467-477. Full Text

11 prospective, randomized controlled trials evaluating 1009 patients treated with combinations of key nutrients were evaluated. There were no differences between patient groups for either pneumonia or death.

[22] Clamon GH, Feld R, Evans WK, et al. Effect of adjuvant central IV hyperalimentation on the survival and response to treatment of patients with small cell lung cancer: a randomized trial. *Cancer Treat Rep.* 1985:167-177.

119 evaluable patients. Median survival for patients with limited disease was 18 months; median survival for patients with extensive disease was 11 months. Patients randomized to receive IVH did not have a better response rate (P = 0.97) or survival (P = 0.78) than control patients.

[23] Bozzetti F, Amadori D, Bruera E et al. Guidelines on artificial nutrition versus hydration in terminal cancer patients. *Nutrition.* 1996;12:163-167.

We propose a three-step process: Step 1: define the eight key elements necessary to reach a decision; Step II: make the decision; and Step III: reevaluate the patient and the proposed treatment at specified intervals.

[24] Roberts S, Miller J, Pineiro L, Jennings L. Total parenteral nutrition vs. oral diet in autologous hematopoietic cell transplant recipients. *Bone Marrow Transplant.* 2003;32:715-721. Full Text

55 patients randomized to TPN vs oral diet. 50% on oral diet given TPN later due to poor oral intake. No difference in length of stay or survival between 2 groups.

[25] Ripamonti C, Twycross R, Baines M, et al. Clinical-practice recommendations for the management of bowel obstruction in patients with end-stage cancer. *Support Care Cancer.* 2001;9:223-233. Full Text

Surgery should not be undertaken routinely in patients with poor prognostic criteria, such as intra-abdominal carcinomatosis, poor performance status and massive ascites. A nasogastric tube should be used only as a temporary measure. Medical measures such as analgesics, anti-secretory drugs and anti-emetics should be used alone or in combination to relieve symptoms. A venting gastrostomy should be considered if drugs fail to reduce vomiting to an acceptable level. TPN should be considered only for patients who may die of starvation rather than from tumour spread. Parenteral hydration is sometimes indicated to correct nausea, whereas regular mouth care is the treatment of choice for dry mouth.

[26] Brennan MF, Pisters PW, Posner M, Quesada O, Shike M. A prospective randomized trial of total parenteral nutrition alter major pancreatic resection for malignancy. *Ann Surg.* 1994;220:436-441.

No benefit of TPN demonstrated. Complications were significantly greater in the TPN group, primarily associated with infection.

[27] Chlebowski RT. Nutritional support of the medical oncology patient. *Hematol Oncol Clin North Am.* 1991;5:147-160.

Nutrient provision has not been successfully demonstrated to influence survival or quality of life.

[28] Jatoi A, Loprinzi, CL. Current management of cancer-associated anorexia and weight loss. *Oncology.* 2001;15:497-508.

Most patients with advanced cancer, anorexia, and/or weight loss do not appear to benefit from nutritional supplementation.

[29] Veech RL. The therapeutic implications of ketone bodies: the effects of ketone bodies in pathological conditions: ketosis, ketogenic diet, redox states, insulin resistance, and mitochondrial metabolism Ketosis Prostaglandins Leukot Essent Fatty Acids. March 2004;70(3):309-319.

The effects of ketone body metabolism suggests that mild ketosis may offer therapeutic potential in a variety of different common and rare disease states.

[30] Persson CR, Johansson BB, Sjoden PO, Glimelius BL. A randomized study of nutritional support in patients with colorectal and gastric cancer. *Nutr Cancer*. 2002;42:48-58.

[31] Kaw M, Sekas G. Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Dig Dis Scie*. 1995:40:920-921.

46 nursing home patients with PEG tubes were studied. 48% were completely functionally impaired. There was no functional improvement and high mortality (50% at 12 months, 60% at 18 months). 35% had PEG-related complications.

In a retrospective study of 7,369 VA patients, 23.5% had a PEG placed during the admission and died. Median survival after PEG was 7.5 months.

[32] American College of Physicians. Parenteral nutrition in patients receiving cancer chemotherapy: Consensus Statement. *Ann Int Med*. 1989;110:734-736.

Parenteral nutritional therapy is associated with net harm, no conditions could be defined in which such treatment appeared to be of benefit. In regard to survival, those treated with TPN had a best estimate odds ration of 0.81. ($p = 0.05$). For those with short-term survival (3 months) the best estimate odds ration is 0.74. For tumor response rates, the best odds ratio is 0.68. These data have been summarized as the TPN 'feeds the tumor' and not the patient.

[33] Huang ZB, Ahronheim JC. Nutrition and hydration in terminally ill patients: an update. *Clin Geriat Med*. 2000;16:313-325.

82 hospice patients with decreased oral intake. Serum sodium checked 1-5 days before death. Despite many patients having normal chemistrities, 87% had thirst, 83% dry mouth. 91% of patients received drugs that may cause dry mouth.

32 alert, terminally ill patients were studies re symptoms of hunger, thirst, dry mouth. The were offered food, fluid, ice chips, lubricants and opioids. 1/3 had no thirst or dry mouth. 1/3 had thirst, dry mouth only initially. 1/3 had thirst and drymouth present until death.

31 dying patients were observed for spontaneous fluid intake. 60% drank < 500 cc/day. 19% drank >500 cc/day up until 3 days before death. Most common symptom, dry mouth, easily controlled.

Agitated delirium Rx with hypodermoclysis, decrease incidence to 10-30%. May have been due to opioid rotation or the use of less sedating agents.

[34] Andrews M, Bell ER, Smith SA, Tischler JF, Veglia JM. Dehydration in terminally ill patients. Is it appropriate palliative care? *Postgrad Med*. 1993;201-203.

The authors discuss possible physiologic explanations for observed dehydration-related phenomena and offer guidelines for determining when it is appropriate to decrease or discontinue nutritional support and hydration by artificial means.

[35] Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Sympt Manage.* 1995;10:192-197. Full Text

Prospective evaluation of 82 dying cancer patients. No parenteral hydration. Serum osmolality measured. No correlation between level of hydration and symptoms of dry mouth.

[36] Musgrave CF, Bartal N, Opstad J. The sensation of thirst in dying patients receiving IV hydration. *J Palliat Care*.1995;17-21.

Prospective assessment of 30 cancer patients dying with IV hydration. 19 able to give reports. Six reported mild thirst, 8 moderate thirst, four severe thirst. No relationship between level of thirst and amount of IV fluids received, BUN or serum sodium.

[37] Klein S. Clinical efficacy of nutritional support in patients with cancer. *Oncology* 1993;7(11) Supplement:87-92.

This reviews the published data regarding the use of nutritional support in patients with cancer. Total parenteral nutrition has shown no benefits in patients being treated with standard-dose chemotherapy or radiation.

[38] Buckman R. *How to Break Bad News: A Guide for Health Care Professionals.* Baltimore, MD: The Johns Hopkins University Press; 1992:65-97.

[39] Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5:302-311. PMID: 10964998. Full Text

A protocol for disclosing unfavorable information-"breaking bad news"-to cancer patients about their illness is described.

[40] McClement SE, Degner LF, Harlos MS. Family beliefs regarding the nutritional care of a terminally ill relative: a qualitative study. *J Palliat Med*. 2003;6:737-748. Full Text

Qualitative study of 47 participants. Open-ended, face-to-face interviews with 13 cancer patients, 13 family members, 11 health care providers and 10 bereaved family members. 'Fighting back' vs 'Letting nature take its course' captured variability. Patients were distressed by family and staff 'pushing food and drink' if it was unwanted, even though they could understand its origin.

[41] von Gunten CF. Discussing hospice care. *J Clin Oncol*. 2003 May 1;21(9 Suppl):31-36. PMID: 12743186. Full Text

[42] POLST: Physician Orders for Life Sustaining Treatment. Center for Ethics in Health Care, Oregon Health Sciences University, Portland, Oregon, USA. Available at http://www.ohsu.edu/ethics/polst/index.shtml. Accessed March 20, 2005.